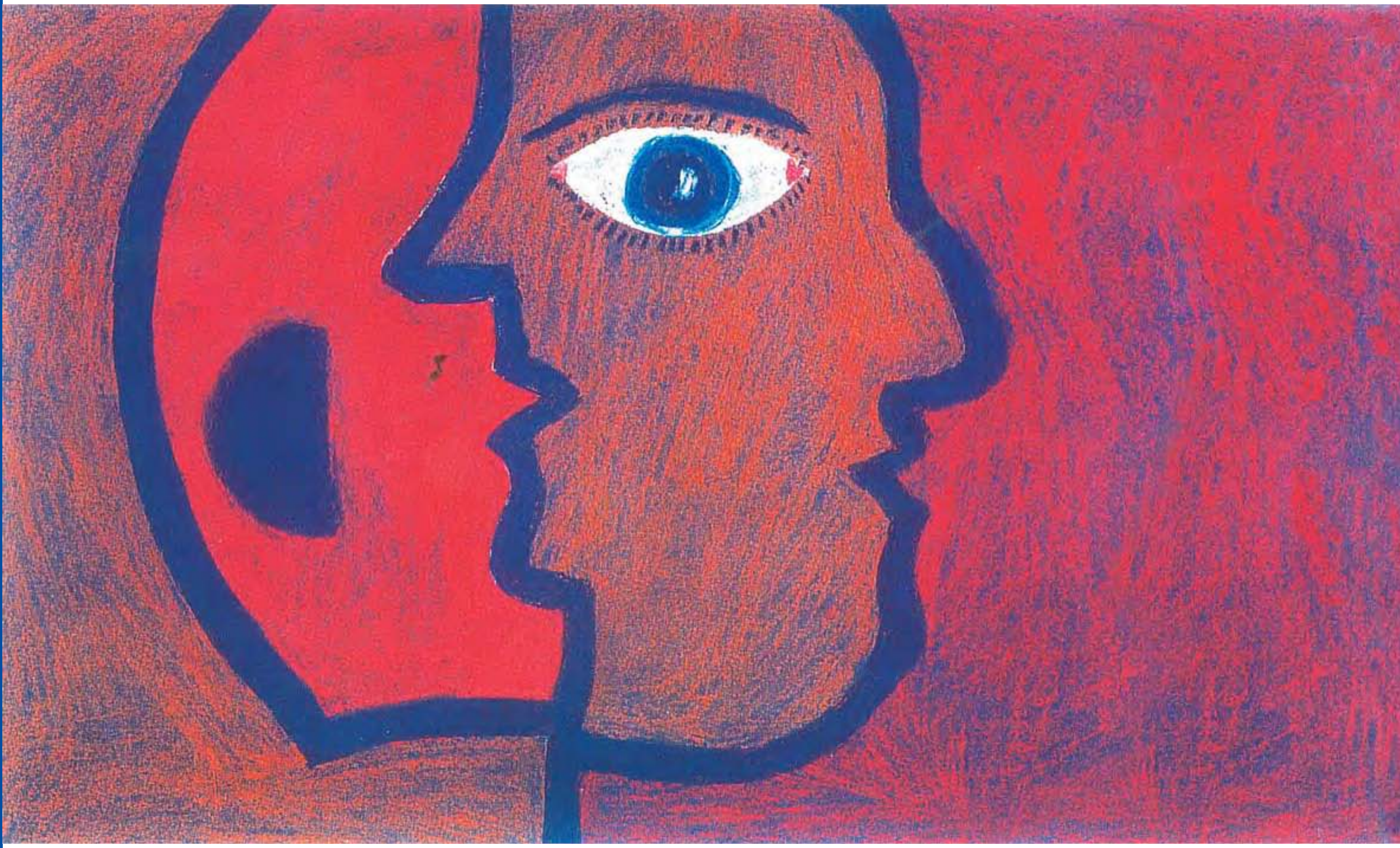
The Specific Risks of Discrimination
Against Persons in Situation of Major Dependence or with Complex Needs



Report of a European Study

Volume 3: Country Reports and Stakeholder Interviews

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The Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs
Report of a European Study

Volume 3: Country Reports and Stakeholder Interviews

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Summary

The Study on the Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs financed by the European Commission has produced a series of twelve Country Reports detailing the risk of discrimination against people with complex needs in Belgium, the Czech Republic, France, Germany, Italy, Lithuania, the Netherlands, Poland, Romania, Spain, Sweden and the United Kingdom. Authored by the National Research Experts of the study, the Country Reports compiled in Volume 3 of the project report provide a comprehensive overview. They are complemented by a selection of stakeholder interviews with policy makers, disabled peoples organisations and service providers from each country.

According to the life-course orientation adopted by the project methodology, each Country Report has been divided into 14 areas of analysis:

- Pre-Natal Diagnosis and Counselling
- Early Childhood
- Childhood: Education and Care
- Childhood and Youth: School
- Childhood and Youth: Housing and Family Support Services
- Childhood and Youth: Leisure Time
- Youth and Young Adults: Vocational Training
- Children and Adults: Social Security and Health Care
- Adults: Work and Employment
- Adults: Housing
- Adults: Education and Leisure Time
- Adults: Partnerships and Parenting
- Adults: Exercising Civil Rights
- Adults: Ageing and End of Life

This approach allowed the research team to compare discrimination risks systematically according to each life phase and to pay special attention also to the risks associated with the transition between the different life phases. The results of these comparisons have been presented in a series of five Synoptical Papers in Volume 2 of the Project Report.

Although each National Research Expert conducted interviews with at least two policy makers, two disabled peoples organisations and two service providers, space restrictions made it necessary to present in this volume only a selection of these interviews. They provide useful commentaries and additional insights into the national situation of people with severe disabilities and/or with complex needs.

Résumé

L’étude sur les risques spécifiques de discrimination des personnes en situation de grande dépendance ou ayant des besoins complexes, financée par la Commission européenne, a produit une série de douze rapports nationaux qui analysent en détail les risques de discrimination de ces personnes en Belgique, en République tchèque, en France, en Allemagne, en Italie, en Lituanie, aux Pays-Bas, en Pologne, en Roumanie, en Espagne, en Suède et au Royaume-Uni. Réalisés par des experts et chercheurs nationaux, les rapports nationaux rassemblés dans ce volume 3 offrent un panorama complet de la situation dans ces pays. Ils sont complétés par des entretiens avec des décideurs politiques, des représentants d’organisation de personnes handicapées et de prestataires de services de chacun des pays.

Pour respecter la méthodologie du projet adoptée, qui suit le cycle de la vie, chaque rapport national est divisé en 14 domaines d’analyse :

- Diagnostic prénatal et conseil aux familles
- Petite enfance
- Enfance : éducation et santé
- Enfance et jeunesse : scolarisation
- Enfance et jeunesse : logement et services d’aide aux familles
- Enfance et jeunesse : loisirs
- Jeunesse et jeunes adultes : formation professionnelle
- Enfants et adultes : sécurité sociale et soins de santé
- Adultes : travail et emploi
- Adultes : logement
- Adultes : formation et loisirs
- Adultes : vie affective et sexuelle, parentalité
- Adultes : exercice des droits civiques
- Adultes : vieillissement et fin de vie.

Cette approche a permis à l’équipe de recherche de comparer de manière systématique les risques de discrimination au cours des différentes phases de la vie, et plus particulièrement de se pencher spécialement sur les risques associés aux transitions entre deux phases. Les résultats de cette comparaison sont présentés dans une série de cinq synoptiques dans le volume 2 de l’étude.

Bien que chaque experts national ait interviewé au moins deux décideurs politiques, deux représentants d’organisations de personnes handicapées et deux prestataires de services, pour des raisons de place, nous ne présentons dans ce rapport qu’une sélection de ces entretiens. Ils apportent des commentaires utiles et des renseignements supplémentaires sur la situation des personnes ayant des besoins complexes et/ou en situation de grande dépendance dans les pays concernés.

Study on the Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs

www.non-discrimination.eu

Country Report Belgium

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Tender on Behalf of the European Commission
D.G. Employment, Social Affairs and Equal Opportunities
Integration of People with Disabilities - Unit G3

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Selected Stakeholder Interviews

1. Summary

The present Country Report on Belgium comes to the following six main conclusions:

1) In Belgium there is no comprehensive consensus on exactly how to specifically identify people with complex support needs. There is neither definition nor reference statistics on high dependence. The handicap sector is moving in that direction and collects as much information as possible about target public.
2) Belgium has some interesting and new national legislation like the euthanasia law, abortion law, anti-discrimination law, or the provisory administration law. However a practical transfer is slow because of ethical questions arisen and the weakness of available means.
3) People with severe disabilities or complex needs' care policies in Belgium suffer from the dispersion of competences at multiple levels of powers (federal, regional, communities) and the lack of coordination. On the other hand, we can notice a clear lack of transversality between the different concerned sectors with the target group (social aid, health, social security, education…).
4) There is a clear difference between Flanders and Wallonia. Flanders seems to be more advanced for the implementation of some dispositive: personal budget, autonomy insurance. In term of resources for services, all three regions are not equal. It is urgent to create more services, with better geographical distribution, more diversified and offering home care and temporary care to relieve the parents.
5) Belgium is particularly behind regarding some issues: accessibility (public places, transport, housing, leisure), education (need of a new thinking of the actual system), family cares' status (Belgium has not yet developed a real policy of help for informal carers).
6) People with multiple impairments, with autism, with behaviour troubles and with cerebral lesion meet most difficulties to find adapted answers to their needs.

Due to lack of space, references could mostly not be added in this paper but are part of the annotated bibliography.

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Een dwarslopend lezen van het Belgische verslag brengt zes belangrijke punten naar voren :

1) In België bestaat er geen overeenstemming aangaande de manier waarmee men personen met complexe behoeften vaststelt. Er bestaan noch definitie, noch verwijzingsstatistieken over de grote afhankelijkheid. De sector van de handicap ontwikkelt zich in die zin en concentreert tegenwoordig meer informatie over het publiek waarvan sprake.
2) België beschikt over sommige interessante en soms baanbrekende nationale wetgevingen zoals de wet over euthanasie, de wet over abortus, de wet tegen discriminatie en de wet over tijdelijke administratie. De praktijken ontwikkelen zich echter langzamer omdat ze ethische vragen oproepen en omdat de middelen die ter beschikking worden gesteld te gering zijn.
3) De hulppolitiek aan personen met zware tekortkomingen en met complexe behoeften lijdt in België onder de splitsing van bevoegdheden tussen de federale, regionale en

communautaire machtniveaus en hun gebrek aan coördinatie. Aan de andere zijde bestaat ook een schreiend gebrek aan coördinatie tussen de verschillende sectoren die zich met dit publiek bezig houden (sociale hulp, gezondheid, zorgverzekering, onderwijs…)

4) Er bestaat een duidelijk verschil tussen Vlaanderen en Wallonië. Vlaanderen blijkt vooruitgang te boeken in de plaatstelling van sommige voorschriften : persoonlijke assistantiebudget en zorgverzekering. Wat de hulpbronnen van de diensten betreft, zijn de drie regio's ook niet op hetzelfde niveau. Het is dringend om talrijke diensten in te stellen die op geografisch gebied beter verdeeld zouden zijn en die ook meer veelvuldig zouden zijn om huishulp en tijdelijk onderhouden te bezorgen en zo de ouders te ontlasten.
5) België is bijzonder achteruit op het gebied van sommige probleemstellingen : toegang (openbare ruimtes en gebouwen, transport, huisvesting), onderwijs (het systeem moet helemaal herzien worden), mantelzorgerstatuut (België heeft nog geen werkelijke hulppolitiek voor informele zorgers).
6) De polygehandikapte personen en de autisten met gedragsstoornissen en ook de personen met hersenletsels hebben de meeste moeilijkheden om aangepaste antwoorden op hun behoeften te verkrijgen.

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Le présent rapport sur la Belgique permet de dégager six points importants :

1. En Belgique, il n'y a pas de consensus global sur une identification des personnes présentant des besoins complexes. Il n'y a ni définition ni statistique de référence sur la grande dépendance. Le secteur du handicap essaie actuellement de collecter le plus d'information possible sur le public cible.
2. La Belgique dispose de certaines lois intéressantes et nouvelles comme la loi sur l'euthanasie, la loi sur l'avortement, la loi anti-discrimination, la loi sur l'administration provisoire. Leur mise en pratique est cependant lente à cause des questions éthiques qu'elles soulèvent et de la faiblesse des moyens mis à disposition.
3. La politique d'aide aux personnes avec déficiences sévères et/ou besoins complexes souffre en Belgique de la division des compétences à différents échelons de pouvoir (fédéral, régional, communautaire) et du manque de coordination. D'autre part on constate clairement un manque de transversalité entre les différents secteurs concernés (aide sociale, santé, sécurité sociale, éducation…).
4. Il existe une différence nette entre la Flandre et la Wallonie. La Flandre semble plus avancée dans la mise en place de certains dispositifs : budget personnel et assurance-dépendance. En termes de ressources au niveau des services, les trois régions ne sont pas non plus à égalité. Il est urgent de créer des services plus nombreux, mieux répartis géographiquement, plus diversifiés et offrant aides à domicile et prises en charge temporaires pour le répit des parents.
5. La Belgique est particulièrement « à la traîne » dans certains domaines : l'accessibilité (lieux publics, transports, logement, loisirs), l'éducation (il faut repenser complètement le système), statut d'aidant familial (la Belgique n'a pas encore développé de véritable politique d'aide aux aidants informels).

6. Les personnes polyhandicapées, autistes, avec des troubles du comportement, ainsi que les personnes cérébro-lésées sont celles qui rencontrent le plus de difficultés pour trouver des réponses adaptées à leurs besoins.

Par manque d’espace, la plupart des références ne peuvent pas figurer ici, mais elles figurent dans la bibliographie annotée

2. Introduction

2.1. National approaches to identify the group of people with complex needs

In Belgium there is no comprehensive consensus on exactly how to specifically identify people with complex support needs.

- **In Wallonia**

In Wallonia, the target public could be identified starting with the disability criteria used by AWIPH (Wallonia regional structure for disabled people's integration). There are 16 categories of disabilities. Those categories were defined in a law (Royal Order of 10 November 1967 creating a fund for medical, social and pedagogic care for handicapped persons). In its article #3, a list of 16 disabilities is established to allow the admission of beneficiaries in approved and subsidized services. In 1993, federal competences were transferred to Communities and Regions, but categories remained the same. The 16 categories of disabilities used today are: motor system disorders; cerebral paralysis; respiratory disorders; cardiac malformations; dysmélia; poliomyelitis; serious disorders of the sight and hearing; multiple sclerosis; spinabifida or myopathy; epilepsy; mental disability (light, moderate, severe, profound); malformation of the skeleton or body; polyhandicap; emotional disturbance, presenting a neurotic or pre-psychotic state (only for children); autism; congenital or acquired cerebral lesion.

Those categories of disabilities do not allow measuring the degree of dependence. There is another classification in 3 categories (A, B and C), used for adults which allows to measure dependence. This classification was defined by the regional law of the Walloon's government of October 9th 1997. Those are the administrative categories for subventions.

Nursing criteria involve the following questions:
i. Bedridden invalid state.
ii. Necessity of a non-stop and active presence of a third person.
iii. Severe disability of comportment.
iv. Assistance of a third person to be fed.
v. To be washed completely by another person each day.
vi. Assistance of a third person to move.
vii. Day and night incontinence.
viii. Un-stabilized epilepsy.
ix. Medical care because of a somatic chronic severe affection.

Category C: Physical, sensitive or intellectual severe or profound disabilities + 4 criteria with at least one among the 3 first.

Category B: Intellectual profound disabilities or physical, sensitive or intellectual severe disability + 3 criteria.

Category A: Light, moderate or severe intellectual disabilities or sensitive or physical disabilities.

This scale of measurement of autonomy is the only one in Wallonia pretending to the identification of the target public (high dependence, complex support needs): this public will be mainly in the category C. Unfortunately, this classification is not accurate enough and concerns only people under 65 and registered with AWIPH.

AWIPH uses disability and autonomy criteria but did not define yet what "high dependence" is. The only definition of high dependence in Wallonia is in the "White book" edited by the parents of the group GAMP (Group for lack of places). They took over the "High dependence" definition of Mr. Ennuyer (*« Les malentendus de la grande dépendance; de l'incapacité au lien social »* Paris, Dunod, 2002*)*: "*Every person who needs someone else to achieve simple acts of daily life to ensure his/her survival and/or who needs someone else in any life project is considered as severely dependent*". According to those parents, it concerns persons with multiple impairments, autistic persons, persons with a moderate to profound mental handicap, persons with acquired cerebral lesion and any other persons in situation of high dependence (total physical dependence or cumulating several handicaps) due to various causes as genetic diseases, degenerative diseases... A sole definition of high dependence does not exist as a reference today in Wallonia.

- **In the Brussels Region**

On basis of an initiative of the ministerial cabinet in charge of policies of assistance to the French-speaking handicapped persons of the Brussels' region, a coordination "high dependence" was created in 2007 in order to identify and count handicapped persons in situation of high dependence (French speaking) in the Brussels-Capital region whose requests of assistance are on waiting list. The selected definition takes into account the A, B and C categories of the AWIPH and also the "nursing" criteria. This census of population was made only for handicapped persons in situation of high dependence waiting for an adapted answer and not for the whole population. No definition is still made concerning high dependence up to now except for this approach following AWIPH's criteria.

- **In Flanders**

In Flanders, in addition of the classification allowing to determine administrative categories of subsidizing of the services of the VAPH (Vlaams structure for disabled people's integration), the Flemish Community identify the public in situation of high dependence with the "zorgverzekering" (autonomia insurance). The article #2 of the decree of the Flemish government of March 30th 1999 on the organization of the "zorgverzekering" defines the concept of "autonomy": "*by autonomy, we must understand: the decisions taken and the actions achieved by a physical person in his/her daily life in order to provide basis needs as well as social activities, a way to open out and to orient in time and space*". "*A reduced autonomy means a reduction of the possibilities to take care of yourself*". Whether the person in situation of dependence is a child, an adult, or an elderly and according to his/her place of living, the tool to measure the dependence will be different.

- **Federal level**

At a Federal level, we can find the measures of dependence in the calculus of the amount of allocations realized by the social security federal public service (DGPH): majored family allocations, integration allocations, replacement of incomes allocations.

For children, the procedure to define the amount of the majored family allocations counts among its classification's tools scales to measures autonomy. Since 2003 the scale of measure is more accurate and includes a calculus of:

- The percentage of incapacity.
- The activities and the participation of the child.
- Impact of the child's pathology on the family life.

To benefit from those majored family allocations, the child must have 66% of incapacity (BOBI's scale: list of infantile pathologies) and present a loss of autonomy on a scale graduated with categories from 1 to 6.

For adults,

- To benefit from a replacement of incomes allocation, the adult must prove that according to his/her physical or psychic state, his/her capacity of income is reduced of a third or less compared to what a valid person can earn by having a job on the general market of work (excluded protected employment).

- To benefit from an integration allocation, a lack or loss of autonomy has to be established. During the evaluation of the degree of autonomy, the following fields are taken into account: mobility, food, clothing, domestic tasks, security, communication and social relationships. For each functions, the doctor notes the level of difficulty met by the person. Points obtained for each functions are added and results are classified in 5 decreasing categories of autonomy.

2.2. Available data on people with complex needs

For the moment there are no reliable or accurate enough statistic estimations on population that could be defined as in situation of high dependence. Census and epidemiologic studies are scarce and partial.

At a regional level, the AWIPH's data are related to the application of the legislation. Those are categories of disabilities that don't allow measuring the degree of dependence. The AWIPH has information on people hosted in institutions and on those who introduce a request and received a principle decision. This does not allow measuring the handicap in its familial environment. Neither those data don't allow to quantify the number of persons with complex needs who did not introduce an assistance request by the AWIPH. All families having a high dependence problem are not necessarily asked for lodging.

At a federal level, the annual report of activities of the DGPH supplies statistics on beneficiaries of allocations for handicapped persons. But this system does not care much of dependence, a lot less in fact than the criteria of the regional administrations.

In order to reach the percentage of the population with complex needs, it is interesting to see the data from a health survey[1] made every 4 years by the Scientific Institute of Public Health and whose last one was made in 2004 (sample representative of the Belgian population, 12.650 persons).

The health survey provides information on health as health is seen by the population itself. The "handicap" module of the health survey is interested in functional limitations in the population. Rather than insisting on the disability, the handicap or the disease, the survey focuses on the consequences brought by those in terms of limitations in activities of daily life. The word "handicapped" must be understood as "people having limitations because of long term diseases, long terms affections or handicaps".

Belgium: percentage of the population with limitations because of long term diseases, long term affections or handicaps – results proposed by regions (table's data are only from people who answered to the questions).

	Walloon Region	**Flanders Region**	**Brussels' Region**	**Belgium**
Severe limitation	4	3	5,3	3,6
Moderate limitation	9,8	4,7	6	6,5
Weak limitation	7,3	6	5,7	6,4
Impaired, but no limitation	6,8	6,8	6,7	6,8
No impairment	72,1	79,5	76,3	76,8
TOTAL	**100**	**100**	**100**	**100**

2.3. Classification systems, procedures and identification-practices

- **Federal level**

At a federal level, every person with complex needs may request financial support from social security: allocations and insurances. In order to request this financial support, the person must first check that his/her situation is in line with the criteria of age, residence, nationality and income. If his/her situation is fine, the person can introduce a request with the proper form to the appropriate administration. When the request is recorded, an administrative examination of the file is made and if necessary a medical expertise.

For the expertise, the person is invited to a medical examination at the medical service of the appropriate administration. If the person can not get there, he/she will be examined at home. Results of this expertise allow the appropriate administration to decide the granting and the amount of the allocation or insurance. The decision is notified by post to the concerned person.

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[1] « Health Survey made by interviews, Belgium, 2004 » Scientific Institute of Public Health, http://www.iph.fgov.be/epidemio/

- **Regional level**

At a regional and a community level, all persons with complex needs may request a status of handicapped person and consequently for financial helps for his/her social and professional integration by registration to the agency for handicapped person of his/her region (Flemish, French, German or Brussels).

There is a limitation of age at that level: this registration must be made before 65 years old. All persons developing problems with autonomy after 65 will not be able to request for the status of a ‘handicapped’ person. Administrative procedures to follow are quite the same that those described in the Federal level section.

3. Pre-Natal Diagnosis and Counselling

Through the extended possibilities for family planning, parenthood in modern societies has increasingly become a question of individual decision-making. Prenatal diagnostics and reproduction technologies permit the inclusion of characteristics of the fetus in this decision. This extended knowledge brings individuals into difficult situations when they have to make decisions regarding children. These individual decisions are affected by social values, attitudes, anxieties and knowledge of disabilities. They are also influenced by the quality of the counseling process if professional support is available and used. It is important that individual decisions are accepted by the social environment of people concerned. How is this achieved?

3.1. Description of the National Situation

Prenatal medicine and the medical follow up of the pregnancy are in evolution since several years. In the case of pre-natal diagnostic, there are two situations, on the one hand, there are predictive genetic tests and diagnostics (family diseases with genetic transmission) and on the other hand a general tracking for all pregnant women.

In the first case, there is a difference between knowing that there was a risk before conception and knowing during the pregnancy that there was a risk. Couples knowing that they have a risk before conception learn about their own risk and may decide then not to procreate or procreate with recourse to an ante-natal diagnostic and therapeutic interruption of pregnancy in case of problem with the foetus.

Today several techniques allow establishing a diagnostic during pregnancy, for example echography allows diagnostic of foetal malformations or amniocentesis which allows establishing a foetal chromosomic chart and then the diagnostic of Down Syndrome. There are also techniques allowing the tracking of pregnancy with increased risk of anomalies as the triple test or the measure of the foetal neck per echography. In those last type of tracking, it is necessary to define the limit of risk from which it is to considered that this one is sufficiently increased to justify a diagnostic test as amniocentesis (because it presents a death risk for the baby).

In some cases, the problem will be treated medically or surgically, but most of the time, the only solution is the interruption of pregnancy.

When the problem is recognized as “severe and incurable at the time of diagnostic”, the parents may request a medical interruption (or therapeutic) of pregnancy. This interruption remains possible until the birth. The Belgian legislation requires that the child to be born has those types of diseases. This ante-natal selection is authorized by law in very specific conditions and with full information’s duty for the doctor. Today there is no list with genetic conditions allowing such an intervention: problems are dealt individually with the gynaecologist, the genetic council or the local ethic committee of the hospital.

The genetic adviser will help the parents to understand the risks and consequences. He/she can also reassure and support the parents in their decision, whatever it is.

3.2. Specific Risks of Discrimination

The development of foetal medicine questions ethics of such tracking practices: who benefits from such a medicine: The foetus or the mother? The family or society? Is the objective of the medicine changed? Did we move from a medicine that eliminates diseases to a medicine that eliminates sick people? Finally, does medicine remain scientific when interruption of pregnancy decisions occurs when we do not know about the spontaneous evolution of the detected anomaly? Up to now, foetal medicine is essentially made by the obstetrician and his/her multidisciplinary team. Unfortunately doctors are sometimes not prepared enough for that difficult task, not formed to difficulties related to communication and to reflexions on ethical issues. Bioethics, as a new discipline, is trying to support those doctors.

From a strictly therapeutic point of view, there are often few actions to take in order to help the future child to go over his/her problem. That’s why we underline frequently that diagnostic possibilities of ante-natal genetic tests are way over and probably for a long time their therapeutic possibilities. It is one of the major objections often made against ante-natal tests.

4. Early Childhood

For most families, having a baby creates a situation of uncertainty and a need for direction and guidance. Living with a baby or a young child with a severe disability or with severe developmental problems brings parents into a situation with specific and difficult challenges and dependencies. Psychological stress in their daily lives often makes it difficult to cope with their parental responsibilities. When dealing with educational tasks or when specific therapeutical or medical treatment is necessary, parents cannot refer to their own educational experiences, but are dependent on professional support of various kinds. Having access to good medical care, self-help groups and early intervention services from a very early age of the child are decisive factors both for the personal development of the child and for the successful adjustment and coping process of the parents. How is this achieved?

4.1. Description of the National Situation

To be or to become a parent of a handicapped child brings a lot of questions. When the child’s difficulties start, parents are surrounded by professionals of the medical sector. They are often specialists. Parents take note of all advises and are oriented to new therapists. Soon or later, they keep on working with therapists who answer the best the child’s needs. To allow a proper answer to the families’ needs of coordination between those different therapies, regional authorities have approved and subsidized starting in the 80’s early childhood services. Those services were created for children from 0 to 7 years old and their families.

Those services' general mission is to bring an educative, a social and a psychological help through individual interventions, principally at home, with children with an acquired mental, physical or sensitive disability. Possible actions from early childhood services are: talking with doctors, coordinate care, find re-educ, advise games, talk about development, food, future, psychological difficulties. In order to welcome the children properly, schools and cribs will also benefit from information and advices. Early childhood can supply this assistance in collaboration with PMS centre (psycho-medico-social centre) and with all concerned persons. They develop collective actions or community work aiming to inform or form the parents and the different actions in the child's development (cribs, schools, etc.). A third axis of work concerns the promotion of prevention and tracking of all kinds of handicap before, during and after pregnancy (collaboration with other services).

Those services' teams are often small and composed of a psychologist and paramedical people (kinesitherapist, logo, psychomotricians, etc.). There are no accurate statistics about the number of children with severe disabilities benefiting from those services. There are only partial figures. For example, in the Walloon's Region, in 2005, the 19 early childhood services answered requests from 1654 children with disabilities.

4.2. Specific Risks of Discrimination

Establishment and announcement of diagnostics appear to be chaotic, what we can easily understand with the difficulties related to some type of handicap (either it is autism or multiple impairment). But hesitations, repeated re-orientations, lack of information make the parents think they are sent from one professional to another without having a defined professional of reference. On basis of some surveys, we note that some families are oriented to adapted and specialized services after a very long time. This late orientation penalizes sometimes badly the handicapped persons and their families.

Early childhood services bring a very important support to the families and their work of coordination is very important for the development of the child. In spite of this mitigated report shared with public authorities, those services are not enough (all approved and subsidized services processed more cases than the number they are subsidized for) and are not known of doctors and hospitals.

5. Childhood: Education and Care

Preschool institutions like inclusive or special kindergartens offer care and education for younger children. They prepare children for school and give them the opportunity to interact with peers. Young girls and boys can broaden their experiences in life and enhance their social skills.

Children with severe disabilities have the same need to interact with peers, to make friends outside the family and to view themselves as a part of a social group. But young children with complex needs are dependent on additional support to participate in preschool education, such as barrier-free access or well-trained educators with specific skills and the intention to cooperate with other professionals. How is this achieved?

5.1. Description of the National Situation

Before the obligation to attend school (6 years old), a child not presenting handicap goes generally to a crib until the age of 2,5 when he/she can go to kindergarten. Children with severe disabilities are most of the time refused in those structures because there are too many assistance care and this scares working teams. Some cribs develop integration projects for handicapped children but those are isolated cases. Some ordinary teaching schools accept the integration of one handicapped child per class but often with the condition to have the help of an extra person (nursery or parents).

Beside specialized schools, day services or specialized residential services can answer to the specific needs of the children in terms of education and health. They are approved and subsidized by regional public authorities. Those are day services for youth (SAJJ) that welcome handicapped children during the day out of school time; day services for youth unable to attend school (SAJJNS) that welcome children all day long; and residential services for youth (SRJ) organising a permanent care, days and nights. Those different hosting and housing services answer the different needs of the families and the child. Needs going from the organisation of day activities, educative support, therapeutic or psychological support if necessary to full support of a child, 24 hours a day.

Those services are the former IMP (medico-pedagogic institutes). Transportations from services to home are managed by public authorities.

SAJJNS are in some ways the replacement schools for the children attending those but with its own organisation and often an adapted paramedical and therapeutic follow-up thanks to a close collaboration with Functional re-adaptation centres (CRF). Those services satisfy the parents because they take a global care of the children and social services take also care of administrative steps for allocations and health care insurance. The quality of those services depends on 4 factors: human tasks, space, material means and time. Because of the important need of assistance care for those children with severe disabilities, the educative projects of those services cannot avoid to give an important place to those cares. The well-being and the health of children will hang on those cares. That’s why quality services’ projects are founded on the basis of 2 pedagogic principles: 1) a caring pedagogy and 2) an integration pedagogy.

5.2. Specific Risks of Discrimination

The quality of care is important for the parents when they choose a service for their child. For minor, the heaviness of the handicap is a factor taking into account properly. Places remain expensive because scarce.

Children with severe disabilities are oriented to SRJ because of 2 linked elements: assistance and health care are too difficult to manage at the family home and services are too far from home to make the journey daily.

The solution of the residential service is often a compromise between therapeutic necessities and quality of life within the family but it is never a conviction choice. Families would rather keep their child at home.

In those various institutions, parents do not feel involved enough in their child’s educative project. Communication is difficult from time to time between parents and professionals. There is often a lack of communication. Professionals need specialized and adapted formations for the public they are taking care of.

6. Childhood and Youth: School

Schools are responsible for a child's education and the teaching of knowledge of varying subjects. Furthermore, school proves to be an important part of young peoples' socialization process by offering the chance to enhance social skills and deepen social contacts with peers.
Children with severe disabilities also need high quality education and access to public schools. Pupils with complex needs are dependent on additional support in order to participate in school education, such as barrier-free access or well-trained teachers with the intention of cooperating with other professionals.
But especially pertaining to them, schools often exercise a kind of segregation. How do children with complex needs find their place in the school system, in which way are their special needs considered and how do professionals cooperate together?

6.1. Description of the National Situation

In Belgium, attendance at school is compulsory and free of charge for all children, including those with severe learning disabilities, between 6 and 18 years old. In Belgium, education is a Community competence (French = French speaking part; Flemish = Flemish speaking part). Communities subsidized schools but do not organised all education structures. There are two main education networks for organisations of kindergartens, primary and secondary schools: independent education system and official education system. The official education system is organised by public authorities (Communities, provinces and communes). Independent education system is organised by associations, dioceses or religious congregations which are confessional (catholic) or not confessional.

Specialized education for children with learning disabilities exists in Belgium since the 70’s. Each network has developed a specialized education system for children with learning difficulties in parallel of its ordinary education system to ensure a right to education to every children and teenagers. There are 8 types of education systems, each type is for a specific public: 1) light intellectual disabilities, 2) moderate or severe intellectual disabilities, 3) comportment and/or personality disorders, 4) physical disabilities, 5) sick children in hospitals or at home, 6) Visual disabilities, 7) hearing disabilities, 8) instrumental disorders. Specialized fundamental education is organised in 4 maturity degrees and not in cycles of years as in ordinary education system. Going from one degree of maturity to another is linked to the acquisition of determined competences and it can occur at all time during the school year. Specialized secondary education system is organised in 4 ways in order to take into account the personal project of each pupil: 1) social adaptation education; 2) professional and social adaptation education; 3) professional education; 4) ordinary secondary education with adapted means (school integration). Specialized education offers additional means for the adaptation to the rhythm and o the specific needs of each pupil: specific care norms (with additional paramedical, psychological and social teams) allow the individualisation of education (individual training plan). Transport is organized by the specialized school and is free of charge. School integration of handicapped children in ordinary school is possible. In the French Community, 1400 handicapped children are integrated in ordinary schools, 80% in fundamental education and 20% in secondary education. PMS centre is a structure independent from the school but collaborating with it and the families for school orientation.

6.2. Specific Risks of Discrimination

All children are not equal facing education and this is a reality in Belgium, in specialized school but also in ordinary schools. There are inequality situations from one family to another, according to the pathologies or the child or teenager's handicaps, according to resources' persons, according to the schools. The right to education is denied in some cases. Access to schools is refused to some child (judged unable to attend school by PMS centres) and children are excluded because of a lack of possible adapted care. Because of a non-homogenous geographical distribution of the specialized schools, many children with severe disabilities must cope daily with long distance transports to school and back home. In some specialized schools, pupils with severe disabilities and high dependence are grouped in special classes called "experimental" for more than 15 years. This is related to the trend that they are taught by educational or care staff not being fully trained as specialized teachers and accompaniment's norms are calculated on the number of children and not on the charge of assistance care needed. Integration in ordinary schools is a daily challenge for the parents. Other parents fear a levelling down which is possible in primary school but not anymore in secondary schools because of the complex organisations of the schedules and teams.

7. Childhood and Youth: Housing and Family Support Services

Due to the variety of modern family life, all children grow up in different environments. These environments can be understood as a social network including all sorts of relationships to individuals or institutions. The family's living conditions during childhood are very important for social inclusion of the young person in society. The family has a strong impact on his/her primary socialization and influences the access to certain social institutions.

Family support services offer community-based professional support and services for families. Some children and young people live in a foster family, others in foster homes. Are such support systems available? In which way are children with severe disabilities or complex needs and their families involved in these support systems?

7.1. Description of the National Situation

When a person is in a situation of mental handicap and when he/she can't represent himself/herself, we can't deny the place of the family. Multiple or complex handicapped persons' families associations are important to defend the interests of those persons. Those associations are also an important support for guidance and advices to face multiple administrative steps and choices to make in the path of their children or relative. Associations play an essential role in the family support through the organisation of group talk, etc.

Day services and residential services foresee to give a place to the families (participation council, administration council, users council, individualized projects meetings...). Those consultative instances are places where they should be able to say what they think and make proposals about questions concerning the management of the service and the quality of the handicapped person's care.

Parents need to be recognized in their competences, to be supported and valorised. The families of handicapped persons in situation of high dependence want to keep a dominating place in their child's education and to privilege a family life (at home) as long as possible. So those parents assume a daily care of their child but claim to be able to rest, to have a break or just take some vacations as every parents. In Walloon's Region, there is only one home care service for people with multiple handicaps. For holydays, parents choose short stays in residential services.

Brothers and sisters are also affected by a sense of duty toward the person who needs their care. Groups talk reserved to those brothers and sisters are being developed locally.

7.2. Specific Risks of Discrimination

There is an inequality of relationship between families and heads of institutions because of the lack of vacancies. Some directors do not hesitate to remind to "difficult" families this penury situation and take advantage of that situation. Parents feel locked. If at the very beginning they look for an institution whose project fits to their values, the small number of vacancies force them to be happy with what they find, it's a non-choice situation. The service found is not necessarily appropriate nor satisfactory. Parents do not always dare to express their needs and expectations to professionals who are sometimes no prepared to a partnership approach. So we note communication difficulties as well as differences of quality between what professionals think they offer and the quality received by the families. Existing communication tools with professionals are not enough according to the families.

Families with a child with severe disabilities and health disorders do not have access to general care services. Therefore they can only contact specialized services and associations but requests are a lot larger than the offer. It is urgent to create more services, with a better geographical distribution, more diversified and offering home assistance and temporary cares to relieve the parents.

Too many parents of handicapped children in situation of high dependence are discriminated by association to their child's handicap. The huge amount of time necessary for the care of high dependence makes the parents, mainly the mothers, quit their jobs. This situation has for consequence a global decrease of the family's incomes and a financial situation close to precariousness because of the high costs of those persons' care. The high dependence cannot continue to rely on affective links. Families wish a recognition of a status of close carers with professional adaptations and compensatory income; all families expect a better awakening of their situation by the political leaders. Finally the parents need reference centres, sole counters for a better information.

8. Childhood and Youth: Leisure Time

Young people use their leisure time to do enjoyable and amusing activities and to get free from daily routines. Often free time activities are organized in clubs or in various forms of sportive or cultural associations. But youngsters also spend their free time with peers without adults. Many experiences among young people of the same age are made spending leisure time together, e.g. discovering new social roles, social spaces, friendship or falling in love. Youngsters with severe disabilities or complex needs have the same leisure time needs as *their non-disabled peers, but are dependent on additional support to participate in mainstream leisure time activities. How is this achieved?*

8.1. Description of the National Situation

The ONE (National Office for Childhood) is in charge to ensure the approval, the subsidy, the organisation, the accompaniment, the control and the evaluation of the hosting of children under 12 years old outside school and family. The ONE takes care of the application of decrees on “hosting during free time” (ATL) and on “holyday centres”. ATL involves activities and educative, cultural and sport animations before and after school, mainly during the week but also during week-ends and holydays for children aged from 2,5 to 12 years old. Holyday centres are hosting services for children by a qualified animation staff, residential or not. Those centres include holydays’ playgrounds, boy scouting, holyday’s camps. Compared to the ATL decree, the holyday centres decree has very clear disposals concerning the care of handicapped children. They are no clear figures on the amount of operators that welcome handicapped children, but integration projects remain scarce. A general movement of opening to integration seems to start in the sector, wills are existing for more adaptations of places, staffs, as well as more formations for animators but means are not always following.

Integration help services subsidized by regional agencies for the integration of the handicapped persons as well as specialized association and mutual insurance are very active in the development and organisations of leisure adapted activities for handicapped children and teenagers.

8.2. Specific Risks of Discrimination

There is a cruel lack of hosting structures for extra-school care of children with handicap. Children with a very severe handicap and comportment disorders have a lot of difficulties to find vacancies.

Parents need to be informed of what kind of hosting places exist for their children with specific needs. Parents’ request is a request of integration for their children in an ordinary leisure environment. They look for handicap-formed teams and a satisfactory care in terms of quality and quantity.

For ATL and holyday centres, additional financing granted by communities to the hosting structures integrating a child with specific needs does not allow to cover additional care norms required by the decrees. The risks of such norms are that they become an obstacle rather than a help. There should be more flexibility in categories and those categories should take into account the needs rather than the types of disorders. Finally subsidizing of each integrated child should be a lot higher to allow a real financing of this specific care. We can’t ask operators to obey very strict rules without giving them the means to do so.

Finally those integration projects are too often individual initiatives, they do not emerge from a global and engaged public politic issue.

9. Youth and Young Adults: Vocational Training

A successful transition from school to the employment system is usually related to vocational training. After finishing school young people need to find a job according to their interests and abilities with which they can earn a living. Vocational training prepares for the access to the employment system and is an important step into adult life. Youngsters and young adults with severe disabilities are dependent on adapted training courses, assisting technologies, other individual support and barrier free infrastructure to enable their access. How is this achieved?

9.1. Description of the National Situation

A handicapped person wishing to have a formation beside the mandatory school circuit can activate two public networks: the network of formations' organisms for general population and the network of specialized organisms for weakened public (people without superior secondary school's diploma, people with a handicap, foreigners, etc...)

General organisms integrating handicapped persons in their formation circuit can activate bonus for employers welcoming a person presenting difficulties for a training: training contracts, training conventions, formation-insertion plans etc. People with disabilities may also request a pedagogic accompaniment in order to attend normally a university cursus, superior non-university cursus or in a general public organism of formation. It is for example an accompaniment by a translator in signs' language for a deaf person.

Regional public authorities in charge of the integration's policies for handicapped persons have created two formation measures with financial incentives for employers in the private sector: formation in company with a professional adaptation contract (fiscal bonus for the employer + follow-up of the trainee by a professional integration agent), professional formations centres (respect of the learning rhythm, individualized formations in function of the needs and potentialities). Persons who have a qualification when finishing specialized schools can access those measures. Formations through work's companies and sociol-professional organisms welcome weakened persons (long-term unemployed people, foreigners, people with few diplomas or competences). People presenting disabilities can access those formations.

Like in other sectors, there are differences of offers according the regions. For example, the German region propose a training convention in companies to people with a moderate intellectual disability. They integrate a company for the realisation of "help" tasks. This convention guarantee a gratification of 1 EUR/hour for the trainee who can keep his/her replacement of income allocation if the income does not exceed 185 EUR/month

9.2. Specific Risks of Discrimination

The different support for integration in the ordinary adult training programmes targets principally people with a motor and sensory disability. People with multiple handicaps or with intellectual disability have no access to those general training programme despite the available support.

In the training programmes adapted to handicapped people, once again people with multiple handicaps or with a moderate to severe intellectual disability will not access those offers, despite the available support, because they are judged “not employable” or because they quit on their own because they just can’t make it.

Regions are not equal in their subsidizing available for handicapped persons’ integration and are unequal in their offers of training for people with severe disabilities and complex needs. According to the place of living of the handicapped person, he/she will be able to access those training possibilities.

10. Children and Adults: Social Security and Health Care

Modern societies are shaped by an enlargement of welfare systems and an increasing dependence on social security institutions. It is a challenge for all citizens to clarify their entitlements and to find access to services. The need for basic social security and to have access to health care services if necessary is important for all people.

In most cases having complex needs leads to an increase of dependence on social benefits and requires special support and services granted by welfare administration boards. Bureaucratic procedures of application approval create special risks of stigmatization. Allowances, benefits and services can improve the possibilities of individual participation, but can also initiate processes of social exclusion. How is this achieved?

10.1. Description of the National Situation

Persons in situation of high dependence have generally a need of medical and paramedical care. Those cares are given in the cadre of health care and are refunded by INAMI. As everyone, the person with severe disabilities or complex needs subscribed to a mandatory invalidity/disease insurance of social security (INAMI, federal) by being registered to a mutual insurance of his/her choice.

The Flemish region added a mandatory insurance to cover complementary expenses linked to the loss of autonomy (zorgverzekering) through the Flemish fund for cares (Vlaams zorgfonds). Only people living in the Flemish Community benefits from this regime. Steps are facultative for people living in Brussels capital’s region. French speaking and German speaking do not have that regime in Walloon’s region.

Every person unable to work and therefore to have an income will also contact social security to benefit from allowances and compensatory allocations. Moreover, social security contains regimes known as waste being part of social aid. This social aid leads to allocations to handicapped persons. Finally, according to whether the person has been able to work before being in situation of dependence or whether he/she did never worked and he/she has been recognized “inapt”, he/she will benefit from a type of allocation from social security rather than another. Every allocation given to handicapped persons is preceded by a medical expertise and an investigation on the person’s financial resources. It’s a key moment and not always easy to live for persons with severe disabilities or complex needs and their families. The system is often qualified of bureaucratic and de-humanized.

Finally people under the regional regime of integration of the handicapped person have at some point some difficulties when their situations request also an intervention of federal health institutions because of the lack of coordination and transversal dispositives between those two levels of power and competence. For example, for nursing cares in institutions for handicapped persons in the Walloon's region, the double agreement do not always allows the clarification of the roles between INAMI and AWIPH's teams. An other example concerns all handicapped persons hosted in psychiatric institutes. Who is responsible of those persons? Both levels of competences contest the responsibility. It's the quality of assistance cares that is levelling down for the dependent person.

10.2. Specific Risks of Discrimination

Even if Belgium can propose its large social protection dispositive, there are still many situations of social inequality because of several factors: 1) The complexity of the Belgium system with its different levels of power and competence: people the best informed will get what they legally deserve. Lack of cooperation, of coordination and of transversality between those different levels of power and consequently a diminution of the quality of care. 2) Reference to the persons incomes and family to calculate the amount of financial help: it is better to live alone when severely handicapped (?!). 3) the different of social security's regimes between employed workers and independent workers: it is better to be employed if you become severely handicapped. 4) Place of living of the person: people in Flanders and Wallonia does not get the same fiscal advantages: it is better to live in Flanders when severely handicapped.

11. Adults: Work and Employment

Having work or a day occupation is, for financial and other reasons, a very important indicator of social inclusion and quality of life. Going to work not only structures peoples' days and weeks, but also has an important impact on the development of a person's identity. It also provides access to the social security system and is an important basis for participation. For people with severe disabilities, transitional situations from school or vocational training into the employment system must often be systematically planned and organized, because they are dependent on adapted work places or assistive technologies and other individual support like a barrier-free infrastructure to enable their access. How is this achieved?

11.1. Description of the National Situation

Having a remunerated job is considered as a principal way of integration in society. However, according to a survey on work forces made in 2002 by the National Institute of Statistics, about 60% of people with handicap are unemployed. It would be the case of 80% of the handicapped persons recognized by public authorities.

When we talk about working in Belgium for handicapped persons, we can consider two options: protected work sector and regular work sector with some additional help if necessary. Regional public authorities have the competence of professional integration of handicapped persons.

The Walloon Government 's decree of November 5th 1998 (modified by the WGD of 18.05.2000 – Belgian Monitor 6.06.2000) aiming to promote equality of chances of handicapped persons on the employment market, implements a series of inciting measures (organisational and financial) for either employers or handicapped persons themselves with the objective to eradicate several obstacles to working in ordinary environment (companies' tutors; integration bonus; compensation bonus; financial interventions for the installation of a handicapped person’s working place; etc.) job coaches and professional insertion agents have an accompaniment role of the handicapped person in his/her project of professional insertion. They also have the mission to arise interest among employers. In reality those measures principally concern physical or sensorial handicapped persons.

When someone can’t work because of physical, psychological, intellectual or mental very invalidating disorders, he/she can request a replacement income to social security (federal). A doctor will then calculate the loss of earnings’ capacity of the person, under a bottom limit, the person is judged “inapt” to work. An inaptitude degree of 33% means that the person looses a third of his/her earnings’ capacity in comparison to a person of the same condition and with the same cursus. Different legislations see that bottom limit of 33% as a critical limit (unemployment, INAMI, social aid).

Only protected employment remains open to those people under the 33% of incapacity’s limit. Adapted work companies (ETA) were created for people with a handicap unable to work in usual conditions.

In its activity report of 2005, AWIPH mentions 58 approved and subsidized ETA in Walloon’s region for 6372 handicapped remunerated workers.

11.2. Specific Risks of Discrimination

People with complex support needs and/or severe disabilities rarely have a chance to find employment on the regular employment, either on the protected employment market. In protected work crafts, profitability is a more and more important aspect because of the market’s competition. Part time jobs do not exist even if they would be adapted for many people with cognitive and attention disorders.

Legal measures inciting public sector to hire 5% of handicapped persons are not efficient because of the absence of amends to sanction services that don’t reach that figure.

The private sector is not concerned by those measures. The longer a handicapped person gets a replacement of income allocation from the competent federal public authority in terms of handicap, the most difficult it will be for him/her to find a remunerated job. The handicapped person’s allocation is a stable income even if modest. So if the person starts a job then looses it, he/she risks to be for several months (from 9 to 12 months) without income, the time to realize administrative steps to clarify his/her situation.

12. Adults: Housing

Becoming an adult also means making up your mind about how you would like to live: stay in the natural family for a while, live alone, with a partner or family, with a friend, etc. Having privacy, a place to go to, feeling safe and comfortable there, realizing one’s own ideas on how to live, are all very important for people in our societies. For people with complex needs it is a big challenge to find their own way to living. They have restricted alternatives for housing because they need barrier-free environments and life-long support. People with severe disabilities do not only need good support services but also counseling to realise their ideas and style of private living. How is this achieved?

12.1. Description of the National Situation

In order to achieve a high quality of life, people with complex needs are strongly dependent on assistance in their individual social network, usually from their birth family (and their mother). Outside of the family, people with complex needs mostly live in residential services for people with disability or nursing homes or hospitals. Those with a serious mental health and/or mental retardation problem with behaviour trouble in some case live in psychiatric hospitals.

People with complex needs get benefits from the federal social security public service. People in situation of high dependence get replacement of incomes allocations and integration allocations which amounts is calculated on bases of their degree of autonomy but also on the basis of incomes of people living with the handicapped person. If they can't manage to pay everything (housing, care, medications, etc.) they can call on social security. Walloon's region subsidizes more than 6300 day hosting centres and residential services for adults with a handicap. The moratorium on the creation of such places plus the general lack of vacancies and adapted structures do not allow to satisfy all requests. For many families, it is not bearable anymore to live with a person in situation of high dependence. So the regions started with legal criteria to define emergencies situations and have created a priority persons' list. The creation of emergencies desks and those priority lists as well as nominative conventions allowed to answer requests partially. Nevertheless hundreds of persons in situation of high dependence have to live in family despite placement requests.

Subsidizing authority keeps on promoting the autonomy of handicapped people thanks to adapted housing and a series of essential services to the everyday life (everyday life help services). Those series are accessible to adult persons with a locomotors disability. For people living at home, public authority grant them with help bonus to adapt the housing. Ergotherapists have for mission to help families to evaluate necessary helps and to estimate refundable costs by the subsidizing authority.

Personal budget aim to encourage the autonomy of handicapped people and their families through a financing model and services focus on the person who shall evaluate himself/herself his/her own needs and who will choose his/her way of life. More than 1000 persons use PB in Flanders against 19 in Wallonia.

12.2. Specific Risks of Discrimination

Quality of life is not equal according to the age, the heaviness of the handicap and the place of living of the person in situation of high dependence. Quality of life within an institution depends on competent human resources and in a sufficient number what is not enough recognized everywhere by public authorities especially in hosting and housing services for adults.

Lack of vacancies, in spite of all what has been realized during the past 35 years remains a problem everywhere and mainly in Brussels. Families register their handicapped child on several waiting lists to be sure to get a place in an institution once the child is an adult. "The" place that they will get will be a chance to catch. This will not be a choice on institution's project but a spite solution and most of the time, the service is far from the parents' home.

The most frequent and dramatic exclusions concerns autistic persons and people with a mental disability and severe comportment disorders. People with cerebral lesions cannot find easily adapted structures. High dependence should be seen by all actors and deciders so it's integrated in a global vision of each concerned person, vision which includes the person's life project and his/her relatives. Separated sectors, mistrust and budgetary frilosity often wins against necessity and will to work in a transversal way by encouraging collaborations unifying and respecting each concerned person's project.

13. Adults: Education and Leisure Time

Leisure time comprises all the time out of work to either relax or find a balance in contrast to every-day-life. Activities can be done on one's own, organized in clubs or in various forms of cultural or other social facilities. In their leisure time, people in our societies are supposed to act with less formal restrictions and try to achieve a high degree of satisfaction and self-determination in their activities.

Adult education – taking the idea of life-long learning as postulate – can be seen as part of the individual's leisure time, sometimes connected to work or the expectation that a certain course promotes one's professional career. Sometimes people participate in adult education courses for the sake of their personal well-being, health or general personal development. For people with severe disabilities the participation in organized leisure time activities or adult education courses very often must be systematically planned and organized, because they are dependent on adapted courses, assistive technologies and other individual support, and barrier free infrastructure to enable their access. How is this achieved?

13.1. Description of the National Situation

In fact people with disabilities spend most of their leisure time with activities at home and in peer groups. At the beginning of specialized accompaniment services, handicapped person's families associations, mutual insurances, there was a widespread offer of clubs, holiday trips, self-help groups and sport groups especially for people with disabilities and chronic health troubles. Poly-handicapped adult persons with comportment disorders remain those having the most difficulties to find a place ready to welcome them.

Home care services start to develop to answer most dependent persons' needs in order to propose a specialized services for poly-handicapped persons, autistic persons or Alzheimer disease persons, bring over basis nursing acts, leisure activities or adapted well-being activities and are wide opened to the "outside" world. In the day host services and residential services, educators and paramedical staff organize leisure activities with handicapped persons. Hydrotherapy, hippotherapy and snoezelen approaches are developed a lot with persons with severe disabilities in a perspective of well-being and blooming. Integration within the society is also more and more developed. Educators and parents go with the handicapped persons in publics shops, museums, swimming pools, movie theatres, concert halls, parks and gardens, etc... There is an evolution in manners, people are more and more in the ordinary society but mainly in groups of peers or individually but with professionals. Families have tough times with the others' look, it remains a fight and a challenge to go out with their severely handicapped child.

In terms of education, in parallel of adult formations (cfr. supra chapter), there are a lot of initiatives from groups talk for people with intellectual disabilities. They are places with a professional animation aiming the development of auto-determinations' capacities of mental handicapped persons. Adapted tools allow to work on identity's construction, emotion's communication, sexual life and relationship education, etc... Families associations and specialized hosting, housing and accompanying services organize those type of educative meetings for young adults and adults. Families and handicapped persons themselves have lots of benefits: it is an undeniable psychological support for each.

13.2. Specific Risks of Discrimination

In all spheres of leisure time activities people with complex support needs face problem with the accessibility (ex.: movie theatres). It starts with mobility problems and non barrier-free environment and comes to problems of exclusion out of common activities. The antidiscrimination approach leads to a better consideration of barrier-free environments for example in the sector of tourism.

In spite of specialized services’ offers and associations’ offers, we note a lack of valorising, adapted and useful activities for people with severe disability or with complex needs. This is a quantitative problem: their number and diversity are not enough. There is also an inadequacies toward specificity of handicaps, professionals are not formed enough to the problematic of the population they are responsible of and consequently cannot propose an adapted care.

14. Adults: Partnerships and Parenting

According to social trends and changes, the decision of having one’s own family is not as easy as it used to be. More and more the decision to get married or to have children is a conscious one based on emotions, being aware of the changes that these decisions will mean.
Not too long ago the idea of people with (intellectual) disabilities getting married or having children was regarded as impossible. People with complex needs who wish to marry or have a child often have to face prejudices. After all, in their parenting they are dependent on special support. Professionals from different services and service sectors have to cooperate to prevent exclusion and discrimination. How is this achieved?

14.1. Description of the National Situation

Time is over when it was considered that people with mental disabilities would go without any transition from childhood to elderly because of a short life and a early ageing. They escaped from the adult age which is also the age of sexuality. It is a new fact that we consider the actual population of persons with a mental disability needs relationships and sexual relations and access to love life.

Relationships are respected and a path is made to the acceptance of a couple life for two persons with an intellectual disability (common room, common apartment). If the person is under prolonged minority, we cannot forbid him/her to have a companion, to have affective relations but we can forbid him/her to have sexual relations in a protection purpose. Services and parents have a duty of information for contraceptive techniques and all what concerns transmission of sexual diseases.

Since several years, professionals and families took conscience of the importance of a sexual and affective life for handicapped persons. In Belgium, any mandatory or generalized sterilization of persons with disabilities is forbidden. Sterilization cannot be made without the approval of the person. Nevertheless we note that in practice the person with a disability do not always understand the consequences of sterilization and that he/she is influenced by the judgments of his/her surroundings.

There are lightly intellectually disabled parents who manage the education and care of their children very well thanks to accompaniment services. There are also difficult situations in which the child does not receive sufficient care and the justice services intervene to place the children in homes or in host families. Handicapped persons under goods' administration can get a parental authority as well as he/she can make a wedding contract.

Among services, the respect of the affective and sexual life if the handicapped person is written down in a values' charter. Ethic committees exist in services in order to talk about those situations where practices evolve faster than mentalities. Finally they are a lot of formations available for professionals. A services' direction will is however mandatory so thinking and modifying practices in institutions concerning relational, affective and sexual life of users become an institution's project, if not it remains isolated initiatives, the theme remains "taboo" and practices do not evolve. There are publications and legal aspects by regional authorities in charge of policies for handicapped persons.

For families, their representations are disturbed too, they need to talk about it and to be reassured that their child is making a choice in total freedom and knowing all consequences of his/her act.

14.2. Specific Risks of Discrimination

Society must recognized the desire of becoming parents of persons with mental disability but also develop prevention programs to protect the child. A listening work and identification of motivations to be parents is essential.

15. Adults: Exercising Civil Rights

According to social trends and changes, the decision of having one's own family is not as easy as it used to be. More and more the decision to get married or to have children is a conscious one based on emotions, being aware of the changes that these decisions will mean.
Not too long ago the idea of people with (intellectual) disabilities getting married or having children was regarded as impossible. People with complex needs who wish to marry or have a child often have to face prejudices. After all, in their parenting they are dependent on special support. Professionals from different services and service sectors have to cooperate to prevent exclusion and discrimination. How is this achieved?

15.1. Description of the National Situation

At 18 years of age, all Belgians are supposed to be able to exercise all acts of civil life. However everyone may be, and sometimes starting at his/her birth, unable, permanently or temporarily, to express his/her will after a medical affection. Consequently, law proposes assistance, representation, or even privative measures according to the needs. In reality, handicapped persons are most of the time placed under one of the following status: prolonged minority (art. 487bis and next from civil code) or provisory administration (art.488bis and next from civil code). Those regulations are federal competences (federal public service justice).

The status of prolonged minority is described in the law of June 29th 1973. This law stipulates that this status is given to people presenting a minor or major mental severe disorder. Every person under this status is considered like a minor of under 15 for any issues concerning himself/herself and his/her goods and remains under parental authority which can be replaced by a tutor. We can't forbid to a person under the prolonged status to have a companion or an affective life however interdiction of sexual life is possible to protect him/her.

Provisory administration of goods is a protection regime which is often applied to handicapped persons. This regulation has for object to protect major persons recognized totally or partially, temporarily or permanently, unable to assume the management of their goods because of their physical or mental state. This protection regime was totally re-made in the law of May 3rd 2003. The provisory administrator, who can be the companion, a close parent or a third person has a mission, of inheritance management. According to what a judge (Peace justice) decides, he will assist or represent the protected person in legal acts and he/she will conserve capacity for acts relative to the state of the person: voting, wedding, divorce, adoption, parental authority, etc...

Status or not, sexual offence or not, a person who commit a crime or an offence and who is in a state of insanity or presenting severe mental disorders making him/her unable to control his/her acts can benefit from a measure of internment (jail), decided by the "Council Chamber" or a correctional court (Law of social defence of July 1st 1964). In this case he/she avoids all penal sanctions. However length of internment is not determined.

15.2.Specific Risks of Discrimination

Before the law of 1991 on provisory administration, families requested the measure of prolonged minority to protect their handicapped child. The result is that today, many adults presenting a light to moderate intellectual disability are assimilated to minors of under 15 years old. In some situations, there is a real gap between the person's aspirations for his/her life and what his/her status let him/her realize legally.

The law on provisory administration of 1991 came to fulfil a legal lack but the prolonged minority remains nevertheless a good law, at the condition that it is strictly applied to the appropriate persons. Some new issues are on process to enforce those laws.

In spite of these legal measures of protection, persons in situation of high dependence remain a weak public and may risk to see their fundamental rights denied because they can't defend themselves. They are still often victims of abuses and not defended appropriately.

Finally, too many times forgotten, mental handicapped prisoners are more and more in Belgium. Procedure of internment is questionable concerning long waiting periods and placement not taking into account the specific problematic of the person. Solutions must be find for their re-insertion and for the defence of their rights.

16. Adults: Ageing and End of Life

Ageing contains a lot of new challenges: Retiring, organizing one's day in a new way, coping with the loss of abilities and coming to terms with it and with one's life. Regularly, more support is needed in day-to-day life and thus social dependencies are increasing. Often this means that familiar life settings must be changed because care needs cannot be covered anymore by the given arrangement. Most people don't want to leave their familiar setting even when their care needs are becoming extensive and complicated. They prefer arrangements which are based on home care services that are reliable and flexible. When people reflect upon the end of their life there is also a wish to die in dignity.
How is this achieved?

16.1. Description of the National Situation

In Belgium, 15% of the population is over 65 years old so 1 700 000 persons. 5664 adults among whom 59% presents a moderate or severe disability are welcomed in day host services in Walloon's region. On those 5664 adults, 43% are aged between 40 and 65 years old and 2% are over 65 years old. If nothing changes, in 2012, more then 62% will be over 40 years old.

Conjunctions between phenomena's of early ageing with handicapped persons and the demographic ageing make that there will be more an more persons requesting adapted cares. We have in Belgium two networks of care for ageing persons presenting severe disabilities: geriatric medical sector and social sector for handicapped persons' care. Elderly people of more than 65 years old who become handicapped cannot request the status of handicapped person so they directly go to geriatric sector. On the other hand, ageing handicapped persons can remain in the handicap sector but can also be re-oriented - if no adapted medical care - to care retirement home in the geriatric sector. The handicap sector works principally with educative staffs. The medical care is sometimes not sufficient enough. Insanity becomes also a more and more important reality. Professionals and parents must decide what kind of adaptations should be made. There is not yet a consensus of the best practices, each one creating what is possible at an organisational level in his/her structure.

1) Which place of living? Several orientations are envisaged practically: existing residential structures' adaptations, creation of specific structures, orientation to care and retirement homes (medical-geriatric) or living at home with the parents (with family assistance and paramedical cares).
2) What kind of activities? Adaptations of the nature of the activities, of their rhythm, and material environmental conditions (extra or intra muros?)
3) What kind of professionals? Many paramedical staff are hired to accompany ageing people. Multi-fields work is mainly practiced. Educators question themselves about their professional identity.
4) What kind of care? Assistance cares, palliatives cares, end of life cares. Ethical questions arise, euthanasia and handicap is a touchy issue. Finally, the need of a double accompaniment: medication and psychological accompaniment. (mourning)

For families and relatives, a question arises for the future: how can we guarantee to the dependent person a good follow-up of his/her situation when parents won't be there anymore? We are facing the first generation of handicapped people surviving to their parents. Services exist to prepare the after-parents (convention between the handicapped person, his/her parents and the approved association to carry out this mission) and watch for a proper care after the parents' death.

16.2.Specific Risks of Discrimination

The law according euthanasia in some cases is still young (2002). Event if it is positive up to now, public opinion and professionals are not unanimous. That law may get larger and concern insane persons and persons with cerebral lesion. This step is far from being made because of the necessity to debate on that issue and have a better integration of the actual law within the medical lobby. Then a very small step will remain before moving from persons with cerebral lesion to mental handicapped persons. We must be very cautious in order to guarantee security for the weakest.

Country : Belgium

Date : 21/09/07
Policy-Makers Representative : Mrs Muriel Gerkens
Federal Deputy (ECOLO) – House of Representatives of Belgium.

- **Could you comment on the description of the situation of people with severe disabilities in our national report?**

- Access to places is catastrophic in Belgium. A person with a reduced mobility does not have access to all public places.
- Education is an overdrawn sector too in terms of assistance, re-education, teachers' formation so it has the capacity to welcome anyone. Specialized schools have been created for kids with different needs but we didn't give them sufficient means to elaborate interesting pedagogies and directives. Financial collaborations between regions and communities were started under the past government to encourage insertion of kids with multiple needs in school but this measure has not been used enough nor encouraged practically.
- We must help the sector of early assistance and pre-birth: to offer formations to doctors, bet on resources of the early assistance which is at the basis of everything.

- **In your opinion: What are the main risks of discrimination against persons with severe disabilities in your country?**

Why regarding the place he/she's living, the handicapped Belgian citizen will or will not find answers to his/her specific needs. Since Belgium was, two trends co-exist: public service took care of all kind of needs and, in parallel, the associative movement issued at that time out of the Christian population who developed itself a lot to bring complementary answers. From this sharing of influences and roles results the fact that Belgian federal power in all its components decided not to take care financially of all citizens' needs because associative structures are co-existing. This division between public services and catholic associations is going through all federal and federated entities in Belgium even if different political orientations are added to this. That is the choice of correspondent regional governments. In conclusion, regarding handicap matters, they are no Belgian citizens but Walloons or Flemish citizens. From one region to another, means are different, as well as in some regions, means are not distributed in an homogen way. The budgetary component is always called in Belgium to explain the lack in terms of social care dispositives. Files' treatments are slow because there is not enough budget. The reality is that handicapped people must go down in the streets to get the budget! It sounds like it's not "in" enough in politics to care for handicapped people. Finally when a new budget is unlocked, it's not enough to answer to the needs of all concerned persons. Therefore a characteristic of Belgium is its incapacity to move! The Belgian social state built itself on a "pilarisation system" (there is not a unique network for health, social care and education for example) more particularly on the development of the two pillars (catholic and socialist). A politic that would fancy to meet handicapped people in their project of life and would say "we are working the same way everywhere to answer your needs" is impossible in Belgium because those two pillars block. There is a resistance to change because public structures in place or catholic institutions have an interest to keep their operational systems and not to change them. It's just like there was a tacit agreement that budget repartition will not change. All innovating initiative not coming from those two networks will have difficulties to take place and to be encouraged in its innovating aspects. This might explain the Belgian difficulty to develop a BAP, because if we want such a disposition to work, we will have to take into account the project of life of the person and his/her environment, we cannot say in advance how the person will use this budget (to do so, with such partners), this implies a huge amount of possibilities. To step out of the traditional practices requires an other lecture, an other way of getting involved and this is scary.

- **In your opinion: What are the perspectives of anti-discrimination policies for people with severe disabilities in your country and in the EU?**

The movement that places the project of life of the person as a central concept is interesting because in that perspective, the person who is in situation of high dependence for a determined time or for life, benefits from individual answers to his/her needs. A personalized budget allows to set what a person needs to realize his/her life as he/she wishes. This implies a diversity of actors, a possibility of choice, and to take into account what it takes financially to that person to live like everybody does.

Independently from a pre-determined and normative evaluation of his/her needs and a financing of structures that can bring answers and can vary in time. The grid of reading becomes the project of life. We can pre-determine, pre-suppose what the person needs and how he/she must live. We cannot avoid the network practice in this perspective: the interactivity between persons with different characteristics will create something.

- **Are there policy programmes/legislation, which have intended or un-intended effects on persons with severe disabilities ?**

1. <u>Legislation on allocations to a third person</u> (social security – federal measure) has beneficial effects. Everyone who needs the assistance of a third person receive this allocation as long as she/he needs it and only if her/his incomes are not over a certain amount.
2. <u>Legislation on integration allocation </u>(General Direction for handicapped people – federal measure) which is on the first place interesting but has some perverse effects related to the criteria to calculate the amount: capacity level + income. The more the handicapped person will take part to a social life, the less his/her integration allocation will be. If the handicapped person lives with someone with an income, his/her integration allocation will go down. Consequences are as follow: to keep his/her integration allocation, 1) you don't have to make too much progress or not show it too much, 2) you don't want to live with someone (= the price of love). The maximum amounts have been increased recently but it's still illogical that those amounts are still calculated in regard to the incomes of your companion or other people living with you. It's the income of your companion that will be used partly to get what you need to live like everybody, like a spouse without this dependence. Every handicapped person that cannot afford the fact of living and who needs allocation to achieve it should benefit from this allocation independently of his/her income and independently of his/her companion's income. What a person receive in connexion with his/her dependence is something related to that dependence.
3. It's the same logic for the <u>host families' system</u>: every families receiving replacement incomes (unemployment, social security...) and is welcoming an handicapped adult will loose that replacement income. In conclusion, financially, such a citizen engagement is penalized by this legislation. Money is used to cover supplementary expenses and should not be considered as a wage. INAMI took some dispositions (incapacity income) so the welcomer is not penalized. To go over that discrimination, we have to take into account every kind of replacement incomes with their specific legislation and make a proposal of law for every specific situations. So it is quite a tough job.

4. Legislation on work is discriminative towards families with someone in permanent high dependence situation. There are no measures to encourage a professional life AND the assistance of someone (supplementary special vacations, flexible schedules). A good follow up of a person in situation of high dependence by a member of his/her family will hang of the capacity of his/her family to have sufficient incomes so they can live on only one wage rather than two or having someone with a liberal profession with a flexible schedule. It appears that most of the time women quit their jobs to take care of the dependent person even if we must avoid such discriminations. Law proposals could stop such situations but it is too difficult to find the appropriate formula of law's proposal that will give those people something necessary but that will not put them in a situation in which their capacity to find a job will be reduced.
5. In Belgium, the "family carers" status does not exist and the natural carer is often the woman.
6. There is also a discrimination in terms of amount of majored family benefits because the amount is based on the status of worker of the parents and not only on the needs of the kids. Measures are coming to try to change that difference in treatment between employed persons and independent.

- **In which political field is the life situation of people with severe disabilities currently on the political agenda at national level ?**

By the handicap sector: regions, communities and federal. There is almost no consideration for handicap issues in the general politics except the anti-discrimination law which is transversal.

- **Who are the most important actors in the national policy field for persons with severe disabilities ?**

At a national level and on the ground with handicapped people is the General Direction for Handicapped Person (former ministry of social precaution (rue de la Vierge Noire) + Health care (INAMI + Mutuelles) + Social Security on a global way.

- **What are the key issues in national policy field for persons with severe disabilities?**

In situations of high dependence (and mainly in those situations), people must have the right to build a project of life, benefit from material and human help sufficiently to reach that objective. Therefore, key issues are: do we want to accept to individualize answers to those persons' needs? Do we want that all sectors take part and are part of those answers? This implies that work legislation has to be reviewed for the members of the families for example and not only for politicians working in the ministry in charge of handicap matters.

- **Are there specific policy programmes for persons with severe disabilities that already exist ?**

The only program set up to take care of the dependence of someone, whatever the handicap is, is the Flemish program set up by the high dependence insurance.

- **Are there specific policy programmes for persons with severe disabilities in preparation ?**

7. It would be appropriate to review the mechanism of allocation at a federal level: integration allocations, replacement of income allocations, personalized assistance budget.
8. It would be important that the autonomy insurance mechanism was taken in charge by the federal state, via a interdependent contributions system. This health care insurance would then be accessible to anyone who is in situation of high dependence and who needs care and help in daily life. Flemish set it up but it costs a lot.
9. We must re-think the care system to elderly people having a dependence after 65. Currently, the legislations exclude any person who wishes to make recognize his/her handicap after 65 years.
10. We must step out the bulk-headings at a federal level. We should quit this notion of handicap (you have to prove that you are the real true handicapped person) because situations of dependence a multiple. It would be interesting to work with a budget more wide opened. We must split budgets and step out of that logic “only for real handicapped people”.
11. We should also review the way of financing institutions: one part of the financing would come from a global operation, collective; an other part of the financing would come from the person. But the repartition of the competences and the way of working in Belgium make it impossible.

Country : Belgium
Date : October 12th 2007
Interviewee : Mr Jean-Pierre Martin, director of a day center for 40 children with multiple impairments, in Namur.

In your opinion: What are the main risks of discrimination against persons with severe disabilities in your country?

Risks of discrimination against those people are, according to Mr Martin, occurring in the following cases:

- Recognition of their specific and heavy needs of cares: medical care, paramedical care, assistance care.
- Vacancies in places where material and human environments allow a quality life.
- Accessibility to public places, to a social life.
- Recognition of specific needs and the right to a have a social life for close carers.
- Unequal treatments of those people according to their age, the place where they live in Belgium and the information that is actually given to them.

In your opinion: What are the perspectives of anti-discrimination policies for people with severe disabilities in your country and in the EU?

According to Mr Martin, the organisation of a “dependence” insurance in Belgium and in the EU should allow a decrease of those discriminations. If politic authorities make of this insurance their priorities and their main axe toward concerned persons, this insurance will present risks of inappropriate situations that will have to be managed:

- The first risk concerns the width of the insurance’s coverture; the fields and budget must be sufficient enough to meet all needs related to that dependence.
- The second one concerns the social participation of the dependent persons. It’s important to avoid that the “dependence” insurance stigmatise the concerned persons and lock them in a recognition procedure of their dependence that would take over their legitimate aspirations essential to an activity, a social participation, a relative autonomy, to a personal blooming in a project of life that belongs to them and for which assistance is essential and has to be financed.

What can you say about the difficulties of people with severe disabilities having access to support from professional services ?

Two difficulties must be underlined according to Mr Martin :

- If the person in situation of major dependence is welcomed in a day centre, the first difficulty concerns the quality of the care and that quality depends on a competent human professional team which has to be composed of enough members what is not always accepted by all public authorities especially in host services and residential services for adults.

- If the person is not hosted in a day centre but is benefiting from any care from professional services, close carers remain in difficulty for unsatisfied break-time needs as well as professional and social aspirations.

How many and what kind of people are excluded from all or certain services and get only support from their families ?

Most frequent and dramatic exclusions concern:

- Poly-handicapped persons.
- Autistic persons.
- Persons with a mental handicap and important comportment troubles.

In which areas of the support system do you see problems of avaibility or bad quality ?

In spite of all what have been made during the last 35 years, lack of vacancies is still noted everywhere. And regarding the quality it occurs that it is not at a same level regarding the age, the level of the handicap and the place of living of the person in situation of major dependence.

Are there differences in quality of services for people with mild, profound and severe disabilities ?

For minors, the heaviness of the handicap is taken into account properly. It is not the same situation concerning adults for who the recognition of the weight of some assistance by the public authorities remains symbolic...

Which structural problems do you see in the service system an in service providing ?

Systems of the oldest and most important services are too structured and are not flexible enough. This implies inertias, heaviness and too many defensive reflexes among all actors, either organizers of the services, professionals and parents...

Which problems do you see in intersectoral co-operation, in service planning an delivery ?

The 3 strong sectors (health, social care and education) depend from authorities too far from each others. The first one depends from federal authorities, the second one from regional authorities and the last one from community authorities. Separated competences, mistrust and budget frigidity break often the necessity and will to work in a transversal way by supporting collaborations that will unify and respect the project of each concerned persons.

What are the main concepts for the support of people with severe disabilities in your country ? Are there differences between provider groups ? Are there ‘taken for granted assumptions’ in this field that foster discrimination ?

Major dependence appears to be a concept that “health’s world” seized. On the other hand, concerning close carers, it seems that awakening arise from the social sector. Major dependence should be looked at by all sectors and responsible in order to integrate it in a global vision of each concerned persons, vision that will include the project of life of that person and his/her close environment.

What are the biggest challenges for the development in service providing for persons with severe disabilities ?

- Recognition of rights related to that major dependence.
- The implementation of projects and resources to meet those rights. Projects and resources to be integrated in the assistance network already developed.

What experience have the service providers with personalised service delivery and personal budgets ?

Individualization of services is on march, in an advanced way in declarations and more modestly in practices being impregnated of too collective inherited logics. On the other hand, personal budgets are variously and much criticized among services suppliers, often in an univocal way, without knowing the subject. There is a huge information and listening work to realize by each others and if not, evaluations of new projects may risk to be univocal and lead to decisions either disappointing or imprudent.

Country: Belgium

Date: 24th August 2007

NGO representative: Mr. Jacques LODOMEZ is Chairman of the association "AP3 : Association of Parents and Professionals for People with multiple impairments" since 1990. This association was founded in 1988 by parents and professionals. This association is located in Brussels (www.ap3.be).
Mr Lodomez is also vice-chairman of COFACE- Handicap (founded in 1998 by a Confederation of family organisations in the European Union, www.coface-eu.org).
Mr. LODOMEZ is a parent of a thirty years old woman with multiple impairments.

Could you comment on the description of the situation of people with severe disabilities in our national report?
Mr LODOMEZ wishes to remind that multiple impairments people are persons, with rights as any other persons. He confirms that Belgian distribution of competences between federal and regional powers related to handicap matters is a discrimination source for many families. He adds that Brussels is living a dramatically situation. Brussels' commission in charge of handicap matters (COCOF) is particularly poor and is not able to finance the creation of specialized structures for multiple impairments adults: 280 adults with multiple impairments are waiting for vacancies in such institutions in the Brussels' area.
An other problem is that bilateral agreements exist between all regions and communities except for Flemish region and Brussels' region. The consequence is that a family living in Brussels will never get a subsidized place for a handicapped child in a Flemish institution nor a French speaking handicapped adult living in Vlanderen will never get a subsidized place in a Brussels' institution.
As well, Mr LODOMEZ would like to draw our attention on problems occurring during the announcement of the handicap to the parents. Too many times, mothers are alone when doctors inform about the handicap. This moment is decisive for the parents but also for the couple. He observed that those difficulties in couples start at that important period of time. Doctors should always announce their diagnostic to both parents and at the same time.
Finally, it's important not to forget about single-parent families (most of the time a single mother). They are alone to face all difficulties related to their child with severe impairments. They do not have enough opportunities to take a break. Those who quitted their jobs live in precariousness knowing that the handicap is a source of higher expenses than ordinary families.

In your opinion: What are the main risks of discrimination against persons with severe disabilities in your country?
The quality of life of those people and their families is far from being satisfactory. In spite of differences of situation in terms of income, education, career, housing, most parents feel alone and share the feeling to be regularly smashed and exhausted by the assistance of their child in a situation of high dependence, financially and personally. Those parents need a break, they need flexibility in their professional life and adapted services to the high dependence of their child, they need psychological support, material and financial assistance, accurate information, appropriate formations and recognition as *family carers*. The assistance of high dependant persons takes loads of time and even more, it's for life.

In your opinion: What are the perspectives of anti-discrimination policies for people with severe disabilities in your country and in the EU?
More advanced formations for professionals and a better public information. More assistance services with more efficiency. Specific and accurate information for parents so they can face difficulties related to their child's handicap. Financial means. An organisation adapted to their needs. To solve the urgent problem of vacancies in institutions by programming the creation of new structures, short term and long term. Create services to solve emergencies situations. Create references centres (a database of information daily updated). Adapt the services-cheques system to high dependence handicap. Create more flexible services of nursing and home assistance with professionals formed to matters related to high dependence handicap and give those professionals a valorised income. Form the social services of hospitals to a quality assistance of a sick disabled person. Insure a follow-up after school (or day centres), during the week, holidays and bank holidays.

What are the most important issues to articulate for people with severe disabilities in interest groups rsp. lobby work?
Mr LODOMEZ is fighting so priorities are given to :

- Accessibility of services: disabled persons and their families have a right to benefit from all general services even if there is a risk of constitutional discrimination. They also need specific services: 1) diversified in order to answer several needs (leisure, health, education, home assistance, short holidays...). 2) Geographically close to their home. 3) Plurals in order to be able to make a choice related to the needs and valour. 4) With qualified professionals, well formed, able to propose a multidisciplinary assistance, from birth to adult age.
- Research: stimulate research in the handicap field, create references centres specialized in high dependence handicap.

What are the key issues in the field of participation of people with severe disabilities?
Create public spaces adapted and opened to severe disabled persons (movie theatres, playgrounds, theatres...) and develop holiday centres adapted to that public (adapted sport equipments, adapted rooms, available material as individual lifter...).

What are the key issues in the field of discrimination against people with severe disabilities?
Discrimination per association: the assistance of people with severe disabilities needs a lot of time that often leads a member of the family (the mother in most case) to quit his/her job. This situation leads to the following consequences: financial lack, social life is affected, it affects also the psychological resources, couple's life and the family life itself. For those who keep working, professional responsibilities and requirements related to the assistance is too much stress.

Are there people with severe disability who work within NGO´s or self-advocacy organizations?
No.

How do you co-operate with special interest groups of people with severe disabilities?
On the national plan, the AP3 works with all associations and lobbies working for the defence of people with high dependence by proposing a better daily life (Famisol, Afrahm, Apepa,

Apem-T21, Aide aux Aidants, Ligue des familles, Gamp, Sapham, Réseau inter-institutionnel bruxellois).

On the European plan, Mr LODOMEZ is involved in the COFACE-handicap. He is the representative of that confederation in meetings at European Community. Themes of those meetings are: lack of room in institutions, lack of formations and information for parents and professionals, lack of services answering the need of respite for the families. Recognition of a status of *“family carers”* (specific adaptation of the part time job system, of career pauses, retirement allocations, income for home assistance of disabled people related jobs...).

What are your experiences to articulate the special needs and interests of people with severe disabilities in public discussions at regional and national level?

Websites of both associations AP3 and COFACE are giving and allow the exchange of a lot of information. Sitting in many meetings of competent institutions for handicap at regional level is also important to communicate our claims.

Study on the Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs

www.non-discrimination.eu

Country Report Czech Republic

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Tender on Behalf of the European Commission
D.G. Employment, Social Affairs and Equal Opportunities
Integration of People with Disabilities - Unit G3

Table of Contents

Selected Stakeholder Interviews

1. Summary

This paper contains information on the specific risks of discrimination of people with severe disabilities and complex needs in the Czech Republic.

An introductory part presents general aspects of categorization approaches, availability of data, eligibility procedures and key human rights and legal documents. Following a life-course systematic, the main part of the paper consists of 14 sections with a nearly identical structure. Firstly, it is described what the general developmental tasks for all people in modern societies in a given phase of life are. As people with severe disabilities are depending on specific arrangements or support to cope with life challenges especially in periods of transition, the availability of support services or barrier-free conditions are crucial for social participation. Secondly, for each phase of life or dimension the characteristics of the support system and other relevant information are presented in a very concise form. On that basis, thirdly, specific risks of discrimination for people with severe disabilities or complex needs are formulated as essential for a given life phase. Due to lack of space, references have mostly not been added in this paper but are part of the annotated bibliography.

The Czech Republic is party to most major human rights instruments, including those pertaining to the rights of people with disabilities. The Czech Republic does not have a comprehensive anti-discrimination framework. The Charter of Fundamental Rights and Freedoms, an instrument of the constitutional order, provides guarantees of fundamental rights and freedoms. However, the Charter is solely a framework; the rights and freedoms found in the Charter must be specified in implementing legislation to be enforceable.

Several new laws concerning persons with severe disabilities entered into force since 2004 – the Education Act, the Employment Act, and the Social Services Act. Despite progress towards social inclusion of persons with severe disabilities, the current situation is far from satisfactory. Access to mainstream education and to community-based residential services were identified in particular.

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Předložený dokument obsahuje informace o rizikových oblastech diskriminace osob s těžkým nebo kombinovaným postižením v České republice.

Úvodní kapitola se zabývá obecnou problematikou klasifikace postižení, dostupnosti statistických dat a základními dokumenty lidských práv a stěžejními právními předpisy. Následujících čtrnáct kapitol má jednotnou strukturu založenou na systematicky členěném běhu života. Nejprve jsou popsány obecné úkoly, které lidé řeší v běžné společnosti v dané fázi svého života. Protože lidé s těžkým postižením jsou při plnění těchto výzev závislí na zvláštní podpoře a to zejména v přechodových obdobích, dostupnost podpůrných služeb či bezbariérové prostředí jsou podmínkou pro jejich účast na životě společnosti. Za druhé, u každé životní etapy je souhrnně popsána stávající situace v poskytované podpoře. Za třetí u každé životní etapy jsou formulována rizika diskriminace osob s těžkým nebo kombinovaným postižením. Z důvodu nedostatku místa nejsou vysvětlivky uvedeny pod textem, ale jsou součástí závěrečné bibliografie

Česká republika přijala většinu hlavních dokumentů lidských práv včetně těch, které se dotýkají práv lidí s postižením. Česká republika však postrádá jednotný anti-diskriminační rámec. Listina (dále Listina) základních práv a svobod, jež je součástí Ústavy České republiky, zaručuje základní lidská práva a svobody. Přesto jsou tato lidská práva a svobody vymahatelné pouze tehdy, jsou-li implementovány do zákonných norem.

Několik zákonů týkajících se osob s těžkým nebo kombinovaným postižením vešlo v platnost od roku 2004 – školský zákon, zákon o zaměstnanosti a zákon o sociálních službách. Přestože došlo k výraznému posunu směrem k sociálnímu začleňování osob s postižením, současná situace je stále neuspokojivá. Zejména se jedná o dostupnost vzdělávání těchto osob v hlavním vzdělávacím proudu a dostupnost komunitních služeb residenčního typu.

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Ce document contient des informations sur les risques spécifiques de discrimination des personnes avec des handicaps sévères et des besoins complexes en République tchèque.

L'introduction donne des généralités sur la classification des handicaps, la disponibilité de données, les procédures d'éligibilité, des documents–clés en matière juridique et de droits de l'homme. Le corps de ce rapport, qui suit les phases de la vie, se compose de 14 sections structurées de façon presque identique. D'abord, il décrit le développement de l'individu dans les sociétés modernes pour une phase donnée de la vie. Les personnes avec des handicaps sévères étant dépendantes d'un accompagnement spécifique pour affronter les défis de la vie, particulièrement pendant les périodes de transition, la disponibilité des services nécessaires ou l'absence de barrières sont cruciales pour elles. Ensuite, les caractéristiques des services nécessaires à cette période ainsi que d'autres informations importantes sont présentées sous une forme très condensée. Enfin, il en ressort les risques importants de discrimination pour cette période de la vie. En raison du manque d'espace, les sources ne sont pas reprises dans le document mais uniquement dans la bibliographie.

La République tchèque a signé la plupart des instruments importants relatifs aux droits de l'homme, y compris ceux concernant les droits des personnes handicapées.

La République tchèque n'a pas un cadre législatif complet de lutte contre les discriminations. La Charte des Droits Fondamentaux et des Libertés, instrument d'ordre constitutionnel, assure la garantie des droits fondamentaux et des libertés. Mais la Charte n'est qu'un cadre et les droits et les libertés qui y sont inscrits nécessitent une loi pour être opposables.

Depuis 2004, plusieurs nouvelles lois concernant les personnes avec des handicaps sévères sont entrées en vigueur - la Loi sur l'Education, sur l'Emploi, sur les Services Sociaux. Malgré des progrès vers plus de participation sociale, la situation actuelle est loin d'être satisfaisante. Notamment, l'accès à l'éducation ordinaire, à des services résidentiels de proximité ont été identifiés comme problématiques.

2. Introduction

Social exclusion, very limited self-determination of parents of children with disabilities and service users, no quality assurance of public services were main weaknesses of the Czech social policy in last two decades. To date, the deinstitutionalisation process in the Czech Republic has been still unsatisfactory and the number of people with disabilities in residential care has only slightly decreased in recent years. The continuing high level of institutionalisation can be partly explained by the lack of community-based services for care of people complex needs or severe disabilities at home.

However, central governmental bodies together with NGO´s for persons with disabilities and with support from EU have developed a new legislative framework based on social inclusion and equal opportunities. Several key laws, affecting persons with complex needs and/or severe disabilities entered into force since 2004 – the Law on Education, the Law on Employment and the Law on Social Services.

At present, there is no unified definition of “disability” or “severe disability” in the Czech legislation. Classification and assessment of disability differentiate according to their purposes. There are different assessment procedures for the diagnosis of severe disabilities:

- for educational purposes (for children)
- for employment purposes
- for access to disability pension, state social support, social assistant benefits and personal budget (direct payment) for social services, and
- for guardianship hearings (for adults).

Section 16 of the Education Act provides the following definition: “(1) A child, pupil or student having special educational needs shall be a disabled person, or a person disadvantaged in terms of health condition or social position. (2) For the purpose of this Act, disability shall mean mental, physical, visual or auditory disability, language deficiency concurrent with more deficiencies, autism and development deficiency in learning or behaviour. (3) For the purpose of this Act a health disadvantage shall mean a serious health defect, long-term disease or modest health defect resulting in problems in learning and behaviour which must be taken into account in education. […]”.

In general, statistical data on people with severe disabilities in the Czech Republic is of limited accuracy and is not collected across all relevant sectors. Questions on disability are not included in national population censuses. Precise data on the number of people with severe disabilities is not available; however, there are statistical data in selected spheres, for example the number of children with severe disabilities of compulsory school age. At present, there are no comprehensive data on social services and quality analyses are not being performed. The collection of quantitative data was performed until December 2006 only in respect to those facilities that were embedded in the existing legislation (the new Law on Social Services came into force in January 2007). Data on services provided by non-governmental non-profit organisations were not being systematically collected. The absence of an uniform methodology allowing for the elaboration of a survey showing the scope of social services provided and the cost of their provision was one of the reasons behind the launch of the social service reform with the new Law on Social Services, 2007. New laws delegated responsibility for education and social services in particular to regional governments.

The new law on social services entered into force on 1 January 2007 with the aim to satisfy basic needs which can not be satisfied by other persons and prevent social exclusion of persons. The new law is based on three principles: quality, accessibility and security. The new law contains three categories of social services – services of social care, services of social prevention and social counselling. Housing services – services of social care have following main characteristics: service user makes a contract with service provider; the service is funded from personal budget to which a person is entitled. There are four grades of personal budgets based on the level of the so called “dependency” of a person. Contracting the service between service provider and person with complex needs is also included in the new legislation.

The new law also obliges service providers to registration. Quality of social services shall be inspected by regional departments. Inspections are expected to disseminate quality of service particularly from users´ perspective via interviews.

The Law on Employment 2004 provides a definition of “people with disabilities” (*osoba se zdravotním postižením*), essentially establishing a new target group of employment services, which includes people with full and partial disability (as determined by the Social Security Authority). The new law is perhaps of most benefit to people declared fully disabled under Paragraph 39, Article 1(a) of the Law on Pension Insurance who, because they are now classified as “people with disabilities”, are subsequently eligible for the full range of employment services offered by labour offices. Under the Law on Employment 2004, people with full disability now have access to services such as vocational rehabilitation, special re-qualification courses, theoretical and practical training, and subsidies for sheltered employment vacancies, sheltered workshops, and other financial support for the employment of people with disabilities—but not to preferential treatment in public works or socially useful job opportunities. Importantly, they are now also eligible for employment under the quota system.

The State provides two types of disability pensions: partial and full. Full disability pensions are intended for citizens with disabilities who have been assessed as *unable* to earn income through gainful employment,[1] while partial disability pensions are intended for those at a *disadvantage* in securing gainful employment. (In 2003, there were a total of 329,140 recipients of the full disability pension and 170,642 recipients of the partial disability pension.[2] Therefore, of a total population of a little more than 10 million[3], approximately five per cent (or seven per cent of those of productive age) received a disability pension in 2003).

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[1] Law on Social Insurance, No. 100/1988 Coll., §73. The disability pension is defined by the Law on Pension Insurance, No. 155/1995 Coll. and implementing Edict No. 284/1995 Coll.

[2] The Czech Social Security Administration (*Česká správa sociálního zabezpečení*), Statistics on Disability Pensions, available at www.cssz.cz/statistiky/duchodova_2004_0103.asp (accessed 30 April 2004).

[3] For 2005, the CIA World Fact Book estimates a total population of 10,241,138 for the Czech Republic. See the country profiles at http://www.cia.gov/cia/publications/factbook.

3. Pre-Natal Diagnosis and Counselling

Through the extended possibilities for family planning, parenthood in modern societies has increasingly become a question of individual decision-making. Prenatal diagnostics and reproduction technologies permit the inclusion of characteristics of the foetus in this decision. This extended knowledge brings individuals into difficult situations when they have to make decisions regarding children. These individual decisions are affected by social values, attitudes, anxieties and knowledge of disabilities. They are also influenced by the quality of the counselling process if professional support is available and used. It is important that individual decisions are accepted by the social environment of people concerned. How is this achieved?

3.1. Description of the National Situation

Pregnant women are entitled to pregnancy care through their health insurance. Basic prenatal diagnostics that should signalize possible defects of foetus is applied to every pregnant woman, in context of regular medical check-ups. Specialized genetic diagnostics and counselling is assumed to be necessary in case of previous defects with genetic connection or disability present in the family. For genetic diagnostics are also highly recommended pregnant women over 35 for whom the risk of Down syndrome of the child is rapidly increasing comparing to younger women.

As it is presented by the medical side, its main objective is to give the pregnant woman the highest assurance of health baby to be born. The fact, that no prenatal diagnostics can give 100% assurance of perfect health of the baby and that the results of the tests can be false negative of false positive is usually treated by the woman’s consent before the tests. She confirms with her signature that the investigations can not reveal all the congenital developmental defects. The doctors try to protect themselves against the possibility of being sued in case of the defect not being recognized.

Considering a possibility of abortion, woman has a right to decide about her pregnancy in her own until the 12 week of gravidity. After this time-limit abortion is possible only from medical reasons (defect of foetus, life danger for mother). It is often a recommended solution in expected disability of the child when the prenatal diagnostics reveals a high risk of congenital defect of foetus. The tendency is to transfer the diagnostics to the earliest stadium of gravidity. In this case abortion is possible considering the wish of pregnant women in any time of gravidity. According to official statistics by Czech Statistics Yearbook 2004, the rate of born children with congenital defect is about 400 per 10.000 of new born children. Infant mortality 3, 7 attained the historical minimum and is one of the lowest values worldwide; the number is effected by high standard and professionalism of paediatric care as well as by the fact, which infants with life-incompatible defects do not born as a result of abortions.

Prenatal genetic diagnostics opens many questions combining ethics and legacy. Abortion indicated from severe developmental defects of foetus is nowadays accepted in Czech society for different reasons; its role plays i.e. high atheism in our society.

3.2. Specific Risks of Discrimination

Although an abortion is a matter of woman’s decision, a woman who doesn’t decide for abortion in high risk of severe disability of foetus must often search long for medical facility where they would accept her decision and support her in pregnancy. As the aim of genetic consultants as a part of prenatal diagnostics is to reduce the number of children born with disability, women can face the pressure of one-sided information. The emotional stress caused through the genetic diagnostics is hardly ever considered, although the current studies point out its high importance during pregnancy and maternity.

Medical attitude empowering the growth of genetic diagnostics is also criticized for ethical conflict against the advanced human-right society that promotes the respect to minorities and support for its weak members. Their point is that genetic diagnosis turned to be a test of quality of the child-to- be-born where those who failed due to a probable defect are refused as “wasters”.

There are a few consulting centers and organizations (mostly of midwifes) supporting the women in this difficult life situation, promote the controversial questions connected with genetic diagnostics to the wide society. Not every women though has a possibility to be informed otherwise then from the medical point of view.

4. Early Childhood

For most families, having a baby creates a situation of uncertainty and a need for direction and guidance. Living with a baby or a young child with a severe disability or with severe developmental problems brings parents into a situation with specific and difficult challenges and dependencies. Psychological stress in their daily lives often makes it difficult to cope with their parental responsibilities. When dealing with educational tasks or when specific therapeutical or medical treatment is necessary, parents cannot refer to their own educational experiences, but are dependent on professional support of various kinds. Having access to good medical care, self-help groups and early intervention services from a very early age of the child are decisive factors both for the personal development of the child and for the successful adjustment and coping process of the parents. How is this achieved?

4.1. Description of the National Situation

A born of child with complex needs or severe disability is often considered as a problem in the family, from the perspective of the parents as well as the doctors. Many of these children are placed immediately in the Infant institutions as their parents do not want to care for them from different reasons; one of them is a lack of support from the medical and social care professionals that they face in the unexpected life-situation and that they can not handle on their own.

Early Intervention Service is a new type of service that is officially introduced in the new law on social services, even though these counselling centers started to develop already during the 90´. The objective is to return or maintain the parents' competence to raise the child and create suitable conditions for the child's development. It considers also the situation of parents and children with complex needs/severe disability– it is provided up to the age of 7 of the child. The centers specialize according to the type of disability; children with complex support need are usually included in the care of intellectual or physical disability. In the case of physical disability presence, rehabilitation methods like Vojta’s or Bobath’s are offered under the health care facilities.

Early intervention service includes the use of educational, social and health care measures. The ambulatory services are provided in the household and specialized day care institutions, usually free of charge. The centers of early intervention promote information about their activities by the pediatrist practice that sends the families with child with disability to their care. Many parents look up the Early Intervention Service by their own when they suspect the disability of their child. A specialized program Portage is offered to few children with complex needs and their parents; it is accessible mainly in the capital and the places are very restricted due to a low number of professionals working with it and high demands on the time-frame of the interventions. There are practically no other supporting services for the families available, helping them in their extraordinary demanding life-situation with household, nursing the child, providing respite care, etc.

4.2. Specific Risks of Discrimination

The network of Early Intervention Services is still very weak and these centers are mostly seated in big cities. The families in the remote regions can not get the sufficient support they need or they must travel far from their residence for this care. Also the diagnoses process of the child’s disability can take a very long time that could be crucial for early intervention and rehabilitation in the psychomotoric development of the child and the child can therefore not use all his potentials for development in time.

The awareness of demanding situation in the family with a child with complex needs/severe disability is still very low. Therefore these families are seriously threatened by divorce of stressed parents, unemployment and poverty as the financial support is not sufficient compare to higher expenses due to the disability of the child. The parents with these children are also poorly informed since their child is born about the possibilities of support. The children with complex needs or severe disabilities are threatened to be abundant and neglected and as a result of their disability to be placed in an institution instead of growing in family environment.

5. Childhood: Education and Care

Preschool institutions like inclusive or special kindergartens offer care and education for younger children. They prepare children for school and give them the opportunity to interact with peers. Young girls and boys can broaden their experiences in life and enhance their social skills.

Children with severe disabilities have the same need to interact with peers, to make friends outside the family and to view themselves as a part of a social group. But young children with complex needs are dependent on additional support to participate in preschool education, such as barrier-free access or well-trained educators with specific skills and the intention to cooperate with other professionals. How is this achieved?

5.1. Description of the National Situation

Preschool education for children between 3 and 6 (7) is also available in various forms for children with complex needs/severe disabilities. The possibilities can often vary according to the local offers and environment. In big cities the situation seems to offer more options then in the small towns. There are special kindergartens, integrative kindergartens (often classes in common kindergartens) or the child can attend a mainstream kindergarten on the base of inclusion. The parents have to participate on funding of the kindergarten stay.

Cases when mother stays at home with child with complex needs or severe disability until the age of 7 are also not rare, particularly if mother cares for child with complex needs or severe disabilities. Also parents in small towns can have problem to find a kindergarten that would accept their child with disability from different reason such are not barrier-free environment in the school, lack of pedagogues with special education training, too many children on one pedagogue and no assistance for the child with disability, etc.

The special kindergartens are often opened for children with similar type of disability, who are considered to be difficult to support in the integrative classes. The advantage of these classes are small number of children on one pedagogue, usually special education trained staff, given space for individual tempo of each child and for his developmental needs; opposite the main disadvantage is very early exclusion of the child from the environment where s/he would naturally belong to and often from the community, because parents might travel far to the special kindergarten. Some of these kindergartens even offer week stays in boarding homes, but nowadays they try to minimize these cases. Some day-care centers for children with complex needs also provide classes of kindergarten for children from the age of three.

Integrative kindergartens are usually mainstream kindergartens that offer a class with setting for small number of children with various difficulties and disabilities (not more then 10 children). Pedagogues have usually special education training and sometimes also an assistant is available. Children from this class might have some activities together with the other children in the kindergarten. Another possibility is to integrate a child with disability in ordinary kindergarten with a support of an assistant. This option is the closest to inclusion but as the practise shows, children with complex needs or severe disabilities do not reach it very often yet.

5.2. Specific Risks of Discrimination

Accessing the kindergarten for a child with complex needs/severe disability, parents can experience a lack of good will from the directors of the facilities; placing such a child in the class is often seen as complications from the mainstream point of view. Mothers and children with complex needs/severe disability might stay at home because not finding suitable kindergarten. This situation multiplies other disadvantages; a possibility for mother loosing her job and social contacts, exclusion from the usual social life, more dependency on the social allowances, lack of natural contact of the child with other peers, etc.

The special facilities and classes only arranged for children with disability have also a main disadvantage of segregating from natural friendship of children of same age.

6. Childhood and Youth: School

Schools are responsible for a child's education and the teaching of knowledge of varying subjects. Furthermore, school proves to be an important part of young peoples' socialization process by offering the chance to enhance social skills and deepen social contacts with peers.
Children with severe disabilities also need high quality education and access to public schools. Pupils with complex needs are dependent on additional support in order to participate in school education, such as barrier-free access or well-trained teachers with the intention of cooperating with other professionals.

But especially pertaining to them, schools often exercise a kind of segregation. How do children with complex needs find their place in the school system, in which way are their special needs considered and how do professionals cooperate together?

6.1. Description of the National Situation

The Charter of Fundamental Rights and Freedoms guarantees the right to education to every citizen. The Draft General Law on Equal Treatment contains a prohibition against discrimination in education specifically on the ground of disability, but the presentation of the law to Parliament has been postponed several times and it is not clear if and when the law will be passed. At present, no such prohibition is in effect.

The Czech Republic only recently adopted new legislation on education that entered into force on 1st January 2005, replacing all prior legislation at all levels of education. The two main laws on education are now:

- Act no. 561 on Pre-school, Basic, Secondary, Tertiary Professional and Other Education[1] (hereafter, the Education Act)
- Act no. 563 on Pedagogical Staff and their Career Development (hereafter, the Act on Pedagogical Staff.

The Education Act is now the main legislation on education. The act provides a framework of education with special educational needs. It stipulates that:

> *Children, pupils or students with special educational needs shall be entitled to an education the content, form and methods of which correspond to their educational needs and possibilities, on the creation of necessary conditions enabling such education and on the advisory assistance of the school and the school advisory facility [i.e. counselling centres].*

The Education Act is a significant improvement for people with severe disabilities and for those who do not communicate orally. The act provides this group of people with the right to an education by alternative means of communication, at no additional expense to the student or his or her family.

For students with disabilities, the act provides the possibility for mainstream schools to establish “classrooms, departments or study groups” with adapted educational programmes. This provision goes on to state that “pupils suffering from serious mental disability, pupils with several learning disabilities, and autistic pupils shall be entitled to be educated at a special basic school (formally called “auxiliary schools”) if they are not thus educated otherwise”.

The act allows both mainstream and special schools, with the consent of the regional educational authorities, to establish the position of assistant teacher. For students with disabilities, the appointment of an assistant teacher requires an opinion from a counselling centre (Educational-Psychological Counselling Bureaus or Special Education Centres).[1] The Ministry of Education is to set out the conditions for establishing the position of assistant teacher and his/her duties in implementing regulations. *The Education Act fails to identify a source of funding specifically for assistant teachers.*

For a child “suffering from serious mental disability”, regional educational authorities determine the “manner of education corresponding to the mental and physical capabilities” of the child. The decision on the manner of education must be taken with the consent of the child’s legal representative and supported by the recommendation of a medical specialist and counselling centre. Regional educational authorities must “ensure adequate assistance” in educating a child with severe intellectual disabilities, particularly with respect to “pedagogical and methodological help”.

The Education Act aims to allow schools more flexibility in the development of curricula. The Ministry of Education developed a National Education Programme, and “framework educational programmes” for different educational areas or subjects, in consultation with other ministries and a wide range of stakeholders. Schools are then to develop their own “school educational programmes” in accordance with the requirements set down in the national and framework educational programmes.

6.2. Specific Risks of Discrimination

The Education Act fails to identify a source of funding specifically for assistant teachers. Together with a poor pedagogical competence of an assistant teacher, lack of additional individual support in a classroom and after school can cause a withdrawal of a pupil with special educational needs from mainstream school.

Furthermore, responsibility for transportation of children with severe disabilities or complex needs to school is not clearly delegated.

It is also recommended to establish a comprehensive system of support services for children with special educational needs in mainstream schools. This should include such services as transportation to school; the right to a personal assistant and/or a assistant teacher; and social and health care services.

7. Childhood and Youth: Housing and Family Support Services

Due to the variety of modern family life, all children grow up in different environments. These environments can be understood as a social network including all sorts of relationships to individuals or institutions. The family’s living conditions during childhood are very important for social inclusion of the young person in society. The family has a strong impact on his/her primary socialization and influences the access to certain social institutions.

Family support services offer community-based professional support and services for families. Some children and young people live in a foster family, others in foster homes. Are such support systems available? In which way are children with severe disabilities or complex needs and their families involved in these support systems?

7.1. Description of the National Situation

Some children with complex needs and/or severe disabilities stay in their school age with their family; some of them live in social care institutions. Those children between 6 and 18, who live with their parents, usually attend special schools (mainly children with severe disabilities) or day-care centers, according to their abilities. Some of these facilities offer to the pupils accommodation on week basis (typical example are special boarding school).

Nowadays the priority promoted by special education policy is to keep children in their natural environment – family and lower the capacity of boarding homes. Also nowadays there is the possibility of integration in mainstream schools, although it is applied for children with complex needs/severe disabilities still very rarely.

Children who live in infant institutions and their parents disclaimed the parental rights, can be adopted or put into foster care. Unfortunately for children with complex needs/severe disabilities these options are approachable rather sporadically, and if it happens so then more often in the form of foster care. From the age of 3 to 26 they are placed in the social care institution. Special schools are usually allocated to the facilities. Some children living in the social care institutions have contact with their parents on weekend basis or few times a week. The stay in the residential facilities is always partly financed by the users, usually from the social allowances.

Since 2007 when the new law on social services came into force, respite care is recognized as type of social service. Nowadays respite services to relieve the strain on the families are available and accessible only by some residential facilities. They usually provide a short stays up to one week. So called rehabilitation stays or summer camps when children cared for by the professionals outside home and meanwhile their parents can use that time for their own needs are more usual. These stays are organized by self-help associations, social service providers or schools. The aim of these stays is also to support independence and autonomy of children with disabilities out of their well-known family systems.

Special education centers are consulting centers often allocated to the special schools. Their aim is to support the development of the child basically in all life areas as well as to help the parents with their concerns about the child. In some regions (mainly in bigger cities) the self-help groups and associations of parents are very important for providing necessary support to the families with similar life story; from these groups also many initiatives have risen that improved and changed radically the local possibilities for their children with complex needs or severe disabilities.

7.2. Specific Risks of Discrimination

Families with a child with complex needs/severe disability have still very little offer of respite care services. The mobile respite care services do not practically exist yet in Czech Republic. As the respite care is provided only by few residential facilities or day care centers, this service can not be accessible widely for all parents around the country. The tradition of using and demanding such a service is not very long and some parents may not even know yet about such a possibility. Some parents and their children with complex needs/severe disability live in a very tight relationship that enables the child to gain the life-experiences in his own. Through the respite care parents and children can be supported in less depended relationships and it can give the child the experience of the world outside the family. If the families are not sufficiently supported, the places in the big institutions can not decrease soon.

8. Childhood and Youth: Leisure Time

Young people use their leisure time to do enjoyable and amusing activities and to get free from daily routines. Often free time activities are organized in clubs or in various forms of sportive or cultural associations. But youngsters also spend their free time with peers without adults. Many experiences among young people of the same age are made spending leisure time together, e.g. discovering new social roles, social spaces, friendship or falling in love. Youngsters with severe disabilities or complex needs have the same leisure time needs as their non-disabled peers, but are dependent on additional support to participate in mainstream leisure time activities. How is this achieved?

8.1. Description of the National Situation

Children and young people with complex needs and/or severe disabilities often attend a special school in this age and live in a social care institution or with their families. Their leisure time activities are therefore organized mostly by clubs at schools or residential facilities so they stay in this time mainly among their peers with the same type of disability. Some of the activities are also organized by NGOs or charities providing disability services as free-time activities outside the school or residential facilities but those children who attend them still stay mainly in their peer groups. Among these activities there are sports, computers, handicraft and art creative activities, expressive therapies, trip making, etc. Their choice is similar to mainstream leisure time activities for all youngsters. The activities can be also integrative – opened for children and young without disability – but this possibility is probably not widely used. More often the integration is successful in the sense of participation of families and some members of community. The trips or rehabilitation stays are often considered as a respite care for families of the child with complex need or severe disability.

Persons with complex needs are not excluded from leisure activities per se. Theatres, cinemas, clubs, relegate places often became to be accessible for persons on wheelchairs in particular. However awareness of personnel working in such places about needs of persons with disabilities remains often low. Staff should be trained about to serve also persons with disabilities.

Local as well as national authorities offer financial grants supporting integration in spending leisure time and these finances are often used by activities of service providers (especially NGOs and charities) or self-help groups, but the integration effect is not as broad as it would be assumed in the grant setting. The public is rather distant and reserved towards persons with disability, especially with complex needs or severe disability. More usual are events like beneficial concerts to support funds and organizations providing services for groups of people with disability with public attitude of sorry and pity towards these “poor” people. There is no regulation that would support accessibility of mainstream activities for children and young people with disability. The only regulation on barrier-free buildings says that the access should be changed to be suitable for persons with disability in case of reconstruction of an old building. Some cultural facilities (theatres, cinemas) promote their barrier-free accessibility.

8.2. Specific Risks of Discrimination

Children and young people with complex needs and/or severe disability have not often the access to the mainstream cultural and leisure time activities, due to the barriers in the environment that unable them to participate. Then there is definitely a lack of conceptual and organizational readiness to include persons with complex needs/severe disability into the concrete mainstream leisure time programs.

The public attitudes towards them are often reserved and rather excluding them from the mainstream according to the different prejudice, fears and feelings of pity. Some cultural events can even support this relation of the public towards children and people with severe and/or complex disability. The leisure time activities among the peers of young people with disabilities in paradox support their possible exclusion from the mainstream society, on the other hand they contribute to the family and community inclusion.

9. Youth and Young Adults: Vocational Training

A successful transition from school to the employment system is usually related to vocational training. After finishing school young people need to find a job according to their interests and abilities with which they can earn a living. Vocational training prepares for the access to the employment system and is an important step into adult life. Youngsters and young adults with severe disabilities are dependent on adapted training courses, assisting technologies, other individual support and barrier free infrastructure to enable their access. How is this achieved?

9.1. Description of the National Situation

Vocational training as part of school education
For people with severe disabilities even those with vocational training from special schools employment opportunities on the open labour market are extremely rare. People with severe disabilities would be better situated to secure employment on the open labour market if provided with opportunities to gain work experience in inclusive employment settings.

However, the schools report their difficulties to find and negotiate vocational training opportunities for theirs students amongst mainstream employers and companies. Vocational training is therefore often not related to real employment practices; it often takes place in segregated provision and it is not usually oriented towards complex professions. Therefore strategies for establishing contact with employers and companies need to be developed and implemented. There are also still problems related to physical accessibility to work places, as well as access to personal and technical support to employers.

Vocational training as part of support in employment
The law on Employment no. 435/2004 Coll., brought several models for supporting persons with complex needs/and or severe disabilities in finding and retain employment. The law introduced a definition of “vocational rehabilitation” as a “continuation of employment services that aim to find and retain employment for people with disabilities”. Moreover, it provides state financing of vocational rehabilitation services following an obligatory “individual plan of vocational rehabilitation” contracted between a labour office and a provider of vocational rehabilitation services (for example, a supported employment agency).

So called training for a job is another model introduced by the law on Employment. Training for a job or initial training of an individual with a disability for a suitable job based upon an agreement with the Labour Office. The training for a job may be performed with an assistant's support. The training lasts for a maximum of 24 months. However, question remains how these models are flexible to meet complex needs persons with severe disabilities.

9.2. Specific Risks of Discrimination

At present, most of persons with severe disabilities do not receive the vocational training and work experience they need to later access employment on the open labour market. The Law on Employment 2004 in particular does not adequately address the problem of transition. Effective transitional programmes would require cross-sectoral collaboration between the Ministry of Education, Youth and Sport and the Ministry of Labour and Social Affairs, which traditionally has been in the Czech Republic extremely limited.

10. Children and Adults: Social Security and Health Care

Modern societies are shaped by an enlargement of welfare systems and an increasing dependence on social security institutions. It is a challenge for all citizens to clarify their entitlements and to find access to services. The need for basic social security and to have access to health care services if necessary is important for all people.

In most cases having complex needs leads to an increase of dependence on social benefits and requires special support and services granted by welfare administration boards. Bureaucratic procedures of application approval create special risks of stigmatization. Allowances, benefits and services can improve the possibilities of individual participation, but can also initiate processes of social exclusion. How is this achieved?

10.1. Description of the National Situation

The social security system in the Czech Republic is closely related to the status of being an employee. The social insurance is paid partly by the employee and by employer and its aim is to cover the social care costs in cases such as illness, accident, disability, nursing care, retirement, unemployment. People with disability have granted access to the benefits and supports on the base of social solidarity; however they are often disadvantaged in the social security system by receiving minimal benefits when they do not participate on the system as employees. The unemployment among people with complex needs or severe disabilities is very high and it is one of the most discussed topics concerning disability in the national level, although there are official incentives for employees to support employment of these people i.e. financial benefits, lower tax payments, etc.

For the purposes of social security the assessment of health state is made by doctors of the district social security administrations and it can qualify the person with complex needs/severe disability for a full (partial) disability pension. Other types of social support are benefits based on unfavorable health state that are mostly one-off obligatory benefits (i.e. allowance for flat modification, for individual transport or for motor vehicle purchase, for technical aids and equipment). Transport privileged card entitles the person with severe disability and the assistant to the 50% discount on transport expenses.

The system of health care is funded from the state budget through public health insurance. It is mandatory for all citizens to participate in this system by regular financial contributions. People with complex needs/severe disabilities are also included into health care system through the principal of social solidarity. In the Czech Republic, basically all health care has been provided free of charge, but this will change since 2008 for a system of patient’s partial participation on financing medical services.

10.2. Specific Risks of Discrimination

The accessibility of the social benefits can be difficult for persons with disability. The help of a professional (social worker or consultant) is usually necessary, because information on the social support benefits (especially on one-off benefits) are not promoted enough by the respective local administrative, so the person in situation of its need can not reach them. The role of social welfare consulting provided usually by NGO’s is very important but the network is not widespread throughout the country.

In the change of payments for health care there is also a potential risk of discrimination of people with complex needs/severe disabilities because they are threatened by too high expenses for medical care and medicine that is necessary for their life and the current reform of financing is not considering their needs and financial possibilities enough. The attitude of medical staff towards persons with severe disability and complex needs is often not respecting their privacy and their right for decision because of lack of communication skills and existing prejudice against them.

Generally the question of accessibility of public places (barrier-free environment) where social and health care is provided is not satisfying.

11. Adults: Work and Employment

Having work or a day occupation is, for financial and other reasons, a very important indicator of social inclusion and quality of life. Going to work not only structures peoples’ days and weeks, but also has an important impact on the development of a person’s identity. It also provides access to the social security system and is an important basis for participation. For people with severe disabilities, transitional situations from school or vocational training into the employment system must often be systematically planned and organized, because they are dependent on adapted work places or assistive technologies and other individual support like a barrier-free infrastructure to enable their access. How is this achieved?

11.1. Description of the National Situation

The Charter of Fundamental Rights and Freedoms includes a guarantee of the right to work and provides a number of additional protections to people with disabilities in the area of employment. Article 26 contains a right to “choose freely […] a profession and the training for such profession” and the right to acquire “the means of livelihood […] by work”, and where the latter is not possible, the State shall provide “appropriate material security”. Article 29 states that “handicapped persons are entitled to increased protection of their health at work and to special working conditions”. It also states that “handicapped persons are entitled to special protection in labour relations and to assistance in vocational training”.

Anti-discrimination legislation

Amendments to the Labour Code introduced in 2004 bring the Czech Republic into compliance with the requirements of the Employment Directive and Race Equality Directive in the area of employment.

Czech employment legislation offers significant protection for people with disabilities against discrimination in the area of employment. However, it does not include a prohibition against discrimination *explicitly* on the ground of disability, and also fails to provide a definition of disability.

The Labour Code 2004 provides definitions for both direct and indirect discrimination. However, according to a report commissioned by the European Commission, “the definition of indirect discrimination does not appear to meet the standards set by the directives”. Nonetheless, the precise description of discriminatory characteristics and its systematisation in the Labour Code 2004 should provide the necessary grounds for people with disabilities to exercise the principal of equal treatment in practice. The Labour Code 2004 also provides a definition of harassment (*obtěžování*) that is applicable to the ground of disability (or “state of health”).

The Labour Code 2004 also provides the first definition of “mobbing”, which is defined as any behaviour perceived by the employee concerned as unwanted, unsuitable or offensive, and which could affect personal dignity or create a humiliating or unpleasant work environment. The Law on Employment 2004 entered into force in October 1 2004 with a section devoted specifically to people with disabilities, this law is the most important legislation concerning the employment of people with disabilities,

The Law on Employment 2004 introduces a number of important changes to employment services for people with disabilities, and indicates a positive shift in Government policy towards the social inclusion of people with disabilities. It elaborates new employment services, programmes and policy instruments. Importantly, it also provides for State financial support for the employment of people with disabilities on the open labour market, and not only in sheltered workshops.

The full disability pension does not preclude employment. If employed, they continue to receive the full disability pension, but the social authorities may decide to challenge the entitlement to the full disability pension, order a re-assessment and eventually withdraw the pension. Under previous employment legislation, recipients of full disability pensions could not register at labour offices; however with the new Law on Employment 2004, although still not permitted to register as job applicants at labour offices, they may register as “interested persons”, which entitles them to use the employment services offered by the labour offices. This provision of the new law is still discriminatory in that the status of “interested persons” does not entitle recipients of full disability pensions to preferential treatment in public works or socially useful job opportunities.

There is no discrete statistical data available on the number of people with respective categories disabilities employed in sheltered workplaces. The majority of people employed in sheltered workplaces have physical disabilities, rather than complex needs. Within sheltered workplaces, Czech legislation does not clearly distinguish between employment and unpaid vocational therapy. The various sources of funding for sheltered workshops are also poorly coordinated.

Employment and persons under guardianship
People under guardianship are not restricted in their right to employment by any legislation, nor does *partial* or *plenary* guardianship place any legal restriction on a person's right to choose a profession or type of employment. Guardians are responsible, to the extent possible, for assisting wards to make their own decisions relating to employment. However, individuals under *plenary* guardianship cannot enter into contracts without a guardian's signature.

In practice, people under guardianship are often unable to exercise their right to employment. This is mostly due to their dependence on the agreement of their legal representative or guardian to be able to enter into employment.

11.2. Specific Risks of Discrimination

People with complex needs are mainly (if at all) employed in sheltered workplaces established by NGOs, which are more focused on social and vocational rehabilitation than on income generation. However, employees often do not have an employment contract and do not receive a wage; in some cases, they may even need to pay a fee to attend. A second type of sheltered workplace is operated by large for-profit enterprises, which receive funding from labor offices. People in these workshops mainly receive the minimum wage and have an employment contract. However, people with complex needs are generally excluded. The third type of workplace is that established in residential institutions/homes for people with disabilities. However, the conditions under which residents within institutions/homes work are poorly regulated, and opportunities exist for exploitation of residents.

Residents of institutions are not sufficiently protected from exploitation in work or employment and appropriate working conditions (with paid holidays) and appropriate compensation for any work performed within the residential institution, including vocational activities are not fully guaranteed.

12. Adults: Housing

Becoming an adult also means making up your mind about how you would like to live: stay in the natural family for a while, live alone, with a partner or family, with a friend, etc. Having privacy, a place to go to, feeling safe and comfortable there, realizing one's own ideas on how to live, are all very important for people in our societies. For people with complex needs it is a big challenge to find their own way to living. They have restricted alternatives for housing because they need barrier-free environments and life-long support. People with severe disabilities do not only need good support services but also counselling to realise their ideas and style of private living. How is this achieved?

12.1. Description of the National Situation

People with complex needs and/or severe disabilities usually live in their adult period in their core family or very often in a residential facility with 24 hour available assistance. The most common type of residential facilities is social care institutions that were during the 20th century the only facility option for people with disabilities. During the communist era in Czech Republic (1948-1989), people with disability were excluded from the public sight and segregated in old, unsuitable buildings in remote parts of the country. The institutional system started to change since the 90´s, but nowadays the “old” attitudes towards people with complex needs are still residual and most of the institutions still exist even though they try to renovate the environment and improve a bit the atmosphere in the facility.

Since 2007, a new law on social services came into force with regulations on housing services. Housing services – services of social care have following main characteristics: service user makes a contract with service provider, the service is funded from personal budget, and quality of social services is inspected by regional departments.

During the last two decades, the new types of housing facilities have appeared – sheltered and supported housing based on community principles. In general these new facilities provide only few tens of places compare to couple of thousands places in social care institutions, and their providers, often NGO’s or charities, have to struggle many administrative and financing obstacles.

When staying to live in their families, people with complex needs/severe disability are again practically excluded from the society. It is usually extremely demanding on the family system to provide care for a member with such a type of disability and the parents are the only assistant of their child with disability for the entire life. For people with severe disabilities it is usually a bit easier to find a support of a professional personal assistant especially for travelling and contact with offices than it is for people with complex needs combined with severe intellectual disability; they are usually able to express more clearly and communicate their needs. The exclusion is also deteriorated by bad accessibility of the environment. Though there is an official regulation on barrier-free environment, only those parts of the building designated for the public have to be accessible.

12.2.Specific Risks of Discrimination

However the issue of contracting the service between service provider and a person with complex needs who has difficulties to communicate personal needs and wishes has not been addressed. There is thus a danger that housing facility will be contracting in interest of a service provider rather a service user.

Adult people with complex needs/severe disability are put into situations of high dependency on the caring person, whom are often parents. Due to the low nursing-benefits, service of personal assistance is often not affordable. Living in the social care institution, the privacy, participation and individual choices for people with complex needs are often threatened.

People with disabilities, and also with complex support needs are still very limited in accessibility of places and in free mobility in the environment. In individual housing there is a lack of barrier-free flats all over the country.

13. Adults: Education and Leisure Time

Leisure time comprises all the time out of work to either relax or find a balance in contrast to every-day-life. Activities can be done on one's own, organized in clubs or in various forms of cultural or other social facilities. In their leisure time, people in our societies are supposed to act with less formal restrictions and try to achieve a high degree of satisfaction and self-determination in their activities.

Adult education – taking the idea of life-long learning as postulate – can be seen as part of the individual's leisure time, sometimes connected to work or the expectation that a certain course promotes one's professional career. Sometimes people participate in adult education courses for the sake of their personal well-being, health or general personal development. For people with severe disabilities the participation in organized leisure time activities or adult education courses very often must be systematically planned and organized, because they are dependent on adapted courses, assistive technologies and other individual support, and barrier free infrastructure to enable their access. How is this achieved?

13.1. Description of the National Situation

The *White Book* includes as an aim the establishment of a system of lifelong learning. However, at present Czech legislation does not make a specific reference to the concept of lifelong learning. Lifelong learning has special significance for adults with severe disabilities. People with severe disabilities generally have difficulty retaining skills and knowledge over time and benefit from regular refresher courses. Lifelong learning also provides opportunities to develop new skills and spend time in a more meaningful way. Moreover, adult learning opportunities may also complement earlier education (whether in a mainstream or special school), or in cases where a person with intellectual disabilities did not complete school, allow them to finish their compulsory education. In the past a significant number of children with severe disabilities were denied access to education, due to the widespread application of a provision exempting students with severe disability from compulsory education. The exclusion was applied without diagnosis or possibility of appeal, although parents (or guardians) had to give their consent. In the 1990s, controls on the use of the exemption were strengthened and instructions were issued requesting (the instructions are not binding) regional governments to ensure that people with severe disabilities exempted through the provision are given the opportunity to complete their compulsory education.

The Methodical Instructions for Complementing Education, established by the Ministry of Education to correct inequalities in access to education for people with severe disabilities aimed to provide educational programmes that complement the curricula taught at mainstream primary, specific or auxiliary schools (according new Education Act – practical and special schools).

The concept of lifelong learning also covers courses that do not lead to State certificates, but which are nonetheless important for people with disabilities. The Czech NGOs play a significant role in providing educational services to people with disabilities. NGOs offer courses on dancing, photography, computing, foreign languages, and social skills development.

Local and regional members of Inclusion Czech Republic also provide educational services on various educational topics such as art, photography or video production. Some local member organisations of Inclusion Czech Republic (in Prague and Olomouc) also support self-advocacy groups. Nevertheless, the majority of lifelong learning opportunities for people with intellectual disabilities is centred in Prague or other cities. Adults with severe disabilities living in cities other than Prague and in rural areas are in urgent need of similar learning opportunities.

13.2. Specific Risks of Discrimination

Instructions to provide opportunities to complete compulsory education are not legally binding. Thus, regional educational authorities may but may not provide such courses. Educational opportunities are limited particularly in remote regions.

14. Adults: Partnerships and Parenting

According to social trends and changes, the decision of having one's own family is not as easy as it used to be. More and more the decision to get married or to have children is a conscious one based on emotions, being aware of the changes that these decisions will mean.
Not too long ago the idea of people with (intellectual) disabilities getting married or having children was regarded as impossible. People with complex needs who wish to marry or have a child often have to face prejudices. After all, in their parenting they are dependent on special support. Professionals from different services and service sectors have to cooperate to prevent exclusion and discrimination. How is this achieved?

14.1. Description of the National Situation

Deprivation or limitation of legal capacity has substantial legal consequences on the adult's right to respect for family life. Family Act (No. 94/1963 Coll.), art. 14 (1). These include parental rights and the legal capacity to marry. An adult totally deprived of legal capacity may not get married. Ibid. art. 14 (2, 3)

An adult with restricted legal capacity may enter into marriage only with an approval of a court. Marriage is further prohibited when 'a person suffers from a mental disorder which is of such an effect that this person would be deprived of his/her legal capacity or his/her legal capacity would be limited'. A marriage will be ex officio proclaimed null and void when one of the adults was fully deprived of legal capacity or 'suffers from a mental disorder which is of such an effect that this person would be deprived of his/her legal capacity'.

Adults under guardianship – whether plenary or partial – may not exercise parental responsibility. Parental responsibility is switched to the other (legally capable) parent. If the other parent is not available, the child may be taken into state care. Such adults may not adopt children. Family Act (No. 94/1963 Coll.), art. 34(2), art. 64(2).

Opportunities to partnership of persons with complex needs or severe disabilities depend also on attitude of personnel working in residential facilities in particular. The new law on social services established an obligation to service providers to meet needs and wishes of individual residents. Some facilities respect wishes of the residents in partnership and sexual life. In contrary in other institutions sexuality of persons with severe disabilities or complex needs remains taboo. Right of person with complex needs or severe disability having a child is not even discussed.

Training of the staff working in residential facilities in partnership and sexuality needs to be provided on regular bases.

14.2. Specific Risks of Discrimination

Severe limitations concerning the respect of family life and the foundation of a family exist for adults both under partial and plenary guardianships.

This is an absurd situation that adults with full legal capacity may be deprived of their right to marriage if in a particular scenario under purely speculative circumstances; they would be deprived of legal capacity. Law also stipulates that the court may allow the marriage of an adult 'whose legal capacity would be limited' if the health condition of the adult is compatible with purpose of marriage.

These provisions are absurd, unnecessary and unworkable and thus in urgent need of reform. Especially persons living in large residential facilities are in danger of deprivation in their opportunities to partnership and sexuality.

15. Adults: Exercising Civil Rights

One developmental task of adulthood is to know and to exercise one's rights. This comprises the rights that a state confers to its people in order to secure protection and political participation, e.g. basic human rights and voting.
For people with severe (intellectual) disabilities, civil rights still cannot be exercised in every case. Additional support is needed to exercise democratic rights like voting. It is also a commonly held belief that people with severe disabilities or complex needs are in capable of serving in political positions. How can people with severe disabilities exercise their rights as citizens?

15.1. Description of the National Situation

The Czech Republic is party to most major human rights instruments, including those pertaining to the rights of people with disabilities, but has yet to ratify the Revised European Social Charter of 1996, and Protocol No. 12 to the European Convention on Human Rights and Fundamental Freedoms (ECHR).

The Charter of Fundamental Rights and Freedoms[1] (hereafter, Charter), an instrument of the constitutional order[1], provides guarantees of fundamental rights and freedoms. However, the Charter solely provides a framework; the rights and freedoms found in the Charter must be specified in implementing legislation to be enforceable.[1] Article 3 of the Charter guarantees equal access to fundamental human rights and freedoms and provides a non-exhaustive list of grounds upon which discrimination is prohibited: “irrespective of sex, race, colour of skin, language, faith, religion, political or other conviction, ethnic or social origin, membership in a national or ethnic minority, property, birth, or other status”. NGOs representing people with disabilities have long advocated for the inclusion of disability as an explicit ground for non-discrimination in the Charter.

The Czech Republic does not have a comprehensive legislative framework to ensure protection from discrimination. The General Law on Equal Treatment and Protection against

Discrimination, which is currently still under preparation, is intended to bring Czech legislation in line with the EU directives.

The “National Plan on Integration of Persons with Disabilities” and “Mid-term Conception of the State Policy towards Persons with Disabilities” are the most important policy documents in the area of disability. Many of the plan’s goals are highly relevant to people with intellectual disabilities, including with respect to access to education and employment. However, implementation of the plan has been slow to date and the deadline for fulfilment of some goals has now been extended.

Guardianship

In accordance with the Civil Code, an individual acquires full legal capacity (“capacity to legal acts”) at the age of 18 years old.[1] However, in the case of an adult with complex needs, the courts may decide to *deprive* the individual of his or her legal capacity (equivalent to *plenary* guardianship), or to *restrict* his or her legal capacity (equivalent to *partial* guardianship). In both cases, a guardian is appointed to represent the individual under law.[1] Courts usually word their decisions on *partial* guardianship in the negative, in terms of what a person cannot do.

In accordance with the Civil Code, an individual acquires full legal capacity (“capacity to legal acts”) at the age of 18 years old. However, in the case of an adult with complex needs, the courts may decide to *deprive* the individual of his or her legal capacity (equivalent to *plenary* guardianship), or to *restrict* his or her legal capacity (equivalent to *partial* guardianship). In both cases, a guardian is appointed to represent the individual under law. Courts usually word their decisions on *partial* guardianship in the negative, in terms of what a person cannot do.

Guardianship procedures

Medical assessments ordered by the court in incapacity hearings do not take into account the fact that people with intellectual disabilities have the potential for skills development. In their medical judgements, court experts (usually psychiatrists) do not assess the extent of a person’s capacity for independent living, such as his or her ability to manage personal finances.

Parents and other potential guardians are screened for suitability. Parents are not automatically assigned as guardians, and only one parent may act as a guardian for a son or daughter. In accordance with the Civil Code, if a suitable family member is not appointed as guardian, then the courts appoints a local authority or a director of an institution for social care.[4]

15.2.Specific Risks of Discrimination

Legislation deprives people with no capacity of their political rights in the following areas: the right to vote in parliamentary elections, the right to be elected to both parliamentary chambers, and similarly both the right to vote and the right to be elected to municipality

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[4] MDAC: Guardianship and Human Rights in the Czech Republic, Budapest 2007

councils, regional councils, and vote in local referenda. These rights are denied to all people under plenary guardianship, regardless of their actual, individual level of functional ability.

Directors of residential institutions/homes used to be often appointed as guardians for a number of residents, and depending on the exact case, court officers and local authorities may be appointed. It is still not uncommon for a single individual to act as a guardian for several or many different wards. Under such conditions, and in the absence of any monitoring, it is difficult to imagine guardians having the time or energy to look after the interest of each individual ward. Moreover, it is a conflict of interest for a director or staff member of a residential institution/home to act as a guardian for a resident.

16. Adults: Ageing and End of Life

Ageing contains a lot of new challenges: Retiring, organizing one's day in a new way, coping with the loss of abilities and coming to terms with it and with one's life. Regularly, more support is needed in day-to-day life and thus social dependencies are increasing. Often this means that familiar life settings must be changed because care needs cannot be covered anymore by the given arrangement. Most people don't want to leave their familiar setting even when their care needs are becoming extensive and complicated. They prefer arrangements which are based on home care services that are reliable and flexible. When people reflect upon the end of their life there is also a wish to die in dignity.
How is this achieved?

16.1. Description of the National Situation

The demographic evolution of Czech population is characterized by further intensification of demographic ageing, like in most other European countries. Life expectancy is 72, 5 for men and 79 for women. The trend of decreasing mortality (which prolonged the life expectancy at birth) and decreasing natality appeared in Czech Republic after the fall of communism with the overall social transformation.

Mainly improvement in medical care has a result in prolonging the life-expectancy in population in general, as well as for people with complex needs/severe disabilities. The increasing number of elderly people will need a wider network of elderly care. This general fact is a serious matter of discussions in creating social policy of the state, but still it has not been fully mirrored in conception of social service system for people with disabilities. This topic is expected to draw the attention of policy as well interest groups of people with disability.

Most of the people end their life in the hospitals and in the nursing homes. The trend of home care supporting the dying person and his family in the natural conditions is increasing very slowly; there are the first hospice facilities and also home-hospice services, but their full capacity can cover only a very little part of the need. There are no special facilities or services for elderly people with severe disabilities/complex needs. Also the distinction between a person with disability and geriatric patient in the hospital or nursing home disappears due to possible physical and mental deterioration caused by polymorbidity in old age.

Active euthanasia is prohibited in Czech Republic and this regulation does not seem to change soon, it is not among the “hot topics” of our politics. The public surveys show ambivalent attitudes of public towards this topic.

16.2.Specific Risks of Discrimination

The topic of social dimensions of ageing and especially improving life-quality in that period has a tendency to be reduced on the economical questions of social care for elderly persons. Ageing connected with death and severe disability connected serious and complex defects are both excluded from the sight of “modern” market-centered society; care for dying and severely disabled persons is considered as the last one, after the care and services for less dependent seniors and people with moderate disability. There are voices by intellectuals and social field people warning against this perception split of the human life, from the ethical, moral and psychological point of view.

Comparing the high standard of health care in the beginning of the life, seniors often experience the lack of respectful attitude from the medical and nursing staff in the facilities. As the needs of elderly people with complex disabilities are not recognized and detected, there is a high risk of neglecting and discrimination of them, unfortunately based on real situations in elderly care.

Interview with NGO Representative

Country: Czech Republic

Interviewee: Mr Dr Jan Hutař
The Czech National Disability Council
Director of the Legislative Section
Lawyer

***The Czech National Disability Council** is an umbrella organization that associates 101 member organizations of people with different disabilities. The Czech National Disability Council is the main advisory partner of the Government Board for People with Disabilities.*

Interviewer: Ms Jana Vránová
Charles University, Faculty of Education
Prague
Supervision: Dr. Jan Šiška

Date: September 24th 2007

The interview was made personally during approximately two hours.

Could you comment on the situation of people with severe disabilities in Czech Republic (CR)?
The situation is relatively satisfactory in the social welfare field. Through the social security system people with severe disabilities can be supported by disability pension, by social allowances and benefits (f.e. for flat conversion, purchase of a car, special utilities, etc.). People with full disability pension (this is a group of people with severe disabilities) can work without limit of their income and they would not loose the pension. Employers are stimulated by financial support to create places for these people. The problem is the attitude towards these people that is wide-spread and residual from the former times. It is difficult to change the conviction that disability is a problem of the person, not of the society. Nowadays, Czech Republic is heading for the conception of the human rights that are accessible for all. To implement this idea to the practice, it is a legislative problem (CR has not adopt any complete antidiscrimination law as some other counties, f.e. the United Kingdom and Poland) but then also a financial problem. The situation is improving, step by step is increasing the public transportation without barriers or new buildings according to the conception “design for all”.

In your opinion: What are the main risks of discrimination against persons with severe disabilities in your country?
The main risks exist in the field of employment, access to education and mobility (transport and accessibility of the buildings). Till 1989, people with disabilities were segregated in all these areas: they attended special schools, then worked in special workshops for handicapped and lived in the institutions. The only advantage was that people with disabilities had “their place”. This has changed. Considering the employment, people with disabilities are often discriminated (openly or implicitly) and they do not complain at the court because they are afraid. The unemployment was very high among these people, for one place there were about 60 applicants, but in the last time it has been improving.. Across the disability spectra, people with intellectual disability are in the highest risk of discrimination.

In your opinion: What are the perspectives of anti-discrimination policies for people with severe disabilities in your country and in the EU?
EU is stimulating the members to adopt an antidiscrimination law. In the present situation in Czech Republic, there is a draft bill that was discussed in Parliament. After this procedure, there are many adjustments and restrictions of the text; so the question is: does it still fulfill the purpose? In my opinion, the draft bill turns to be more declarative then having a real content. I think, the antidiscrimination law should contain definition of disability and consider also reasonable accommodation, because the exercise of the rights is subject to some accommodation of the outer conditions. On the international level, the United Nation's "Convention on the Rights of Persons with Disabilities" starts being ratified in the member countries; in the Czech Republic it has not been discussed yet.

What are the most important issues to articulate for people with severe disabilities in interest groups rsp. lobby work?
The issues vary in the particular interest groups; there exist many specific issues according to the type of the disability and the age.

What are the key issues in the field of participation of people with severe disabilities?
This is a wide laid question. In general the participation of people with severe disabilities starts to grow – it is not rare to meet them on different occasions. They can be seen in the higher politics and even more often in the local politics; they participate on the cultural life, in sports, etc. The fundamental question is the barriers and the adaptation of the environment - this is a legislative as well as a financial problem.

What are the key issues in the field of discrimination against people with severe disabilities?
The crucial problem is that in many cases the discrimination is not recognised. Often there is the general attitude: "It is his/her pity that he/she has a disability".

Are there people with severe disability who work within NGO's or self-advocacy organizations?
Yes, there are people with severe disability in these organisations. Unfortunately, according to the new Law on social services that went into force recently, people who work as consultants and giving advices within the organisations must have only a certain type of education (social work-law) and there are many people with disabilities who do not fulfil this formal demand. The formal education is overrated and valued more than a personal experience that qualifies these people by the principle.

How do you co-operate with special interest groups of people with severe disabilities?
The Council as an umbrella organization and has more than 90 member organizations. On the national level we cooperate with the Government Board for People with Disabilities on the preparation and evaluation of the National Plans of Actions for the Handicapped Persons. We gather suggestions from the organizations and we stand for them in the Board. On the national level, inter alia, in Czech National Disability Council we create remarks to legal regulation prepared by Government or Parliament and co-operate in their creating with the organizations. We help to propose the international initiatives to our organizations through regional level of the Council.

What are your experiences to articulate the special needs and interests of people with severe disabilities in public discussions at regional and national level?
We have a good experience on the national level, with our participation on the National Plans, taking part in creating them and revising their fulfilment. On the regional level, it depends very much on the particular representatives of the Regional Disability Councils and of the regional governments. To point out the disability issues, a person from the whole country who is active in working on disability field is awarded a “Bridge” prize every year.

Interview with Policy Maker

Country: Czech Republic

Policy-maker: Dr. Pavel Ptáčník
Government Board for People with Disabilities
Lawyer of the Board
Head of the Secretariat

Government Board for People with Disabilities *was established in 1991 by the resolution of the Czech Government. The Board is a coordinating and advisory body for the Government*

Interviewer: Ms Jana Vránová **Date:** September 18th 2007
Supervision: Dr. Jan Šiška

The interview was made personally during approximately one hour.

Could you comment on the situation of people with severe disabilities in the Czech Republic (CR)?
In general, the situation has improved very much after the fall of communism (1989) till nowadays. The change has two levels: the social welfare level and the integration level. On the social welfare level, CR can be compared to other European countries with a long history of higher standards in providing material (financial) support to people with disabilities. Nowadays, it is a social state support, social benefits and disability pension. With the economical differentiation of the Czech population as a result of the growth of national economy, the task is to be solicitous about a possible poverty of people with disabilities.
The integration level is tightly connected with fulfilling the human rights of people with severe disabilities in practice. The problems in this area existed in the past and they have been present will now. There is no general Disability Act in CR as it is f.e. in Anglo-American legislation. Considering the legislation structure and its historical development, the antidiscrimination thesis must be implemented in the individual laws (on education, transport, building, etc.). To achieve the objective (that it would also change in reality), it takes a lot of financial resources and also a long period of time.

In your opinion: What are the main risks of discrimination against persons with severe disabilities in your country?
The main risks are in the individual approach towards these people. The public is still not used to get in touch with disability; they do not know it and they are scared. For example, the employers rather avoid employing a person with disability, because they do not have experience with such a person, they might not believe in his skills, they might expect the employment to be very demanding, etc. The discrimination is not expressed openly, but implicitly. This attitude has its roots in our history of institutions hidden from the sight in the remote regions. The NGOs and also the ministries have to contribute to raising public awareness about disability and severe disability in particular.

In your opinion: What are the perspectives of anti-discrimination policies for people with severe disabilities in your country and in the EU?

The main task in CR would be to guarantee the equal access to the opportunities for this group of people. It should be done by adding an antidiscrimination provision as a part of the constitution, to the List of Fundamental Rights and Freedoms. A particular time frame, when the adding happens, is not known yet, the question of implementations in the List is too complex.
The EU task in this field is to unify its members in anti-discrimination policy.

Are there policy programmes/legislation, which have intended or un-intended effects on persons with severe disabilities?
The Government Board for People with Disabilities was established in 1991 by the Resolution of the Czech Government as its coordinating and advisory body for the Government. The main task of the Board is to highlight the respective problems and to suggest their solutions. The principal programme document of the Board is the “National Plan of Actions for the Handicapped Persons”. Over the years the plan has been updated several times, all versions are approved by the Government resolutions and the Government monitors and revises its implementation in each ministry resort every year. Also regional governments are beginning to create their own “Regional Plans”.

In which political field is the life situation of people with severe disabilities currently on the political agenda at national level?
This topic is discussed on the highest – governmental – level. The Government Board consists of representatives of the government (prime minister and respective ministers) and representatives of associations of persons with disabilities. This topic belongs in the priorities of national politics, even though it is not in the front as it used to be, because of other specialized groups carrying through their topics.

Who are the most important actors in the national policy field for persons with severe disabilities?
The Government Board plays an important role there as well as the National Board for Persons with Disabilities, which gathers representatives of all disability groups. The Board co-operates with the public administration authorities as well as with the non governmental sphere. The NGOs have strengthened their lobbying position in the Parliament and in the Government Board; this depends a lot on the particular personalities who represent them, on their charisma and knowledge.

What are the key issues in national policy field for person with severe disabilities?
The main key issue in the national policy field for persons with severe disabilities is employment or rather unemployment of these persons (totally there were 76,000 people with disability unemployed in 2006). This happens despite of different provisions to support employment. The main reasons for it are stronger economy, low education of these people (mainly the older ones) and psychosocial barriers on the side of employers. Another key issue is accessibility of the public transport and buildings. All buildings before 1994 were constructed without any obligatory barrier-free access. The accessibility of the transport is a question of lack of money, especially in small municipalities. Quite a new issue is access to the information (PC, internet, compensating instruments). In general often there is respective legislation but there are problems with its implementation.

Are there specific policy programmes for persons with severe disabilities that already exist or are in preparation?

Nowadays the “National Plan for the Support and Integration of Persons with Disabilities 2006 - 2009" is valid. Other programmes of the Government Board are the “Middle term Concept of the Governmental Policy towards Persons with Disabilities”, the “National Plan on Equalization of Opportunities for Persons with Disabilities” and the “National Development Programme Mobility for All”. These plans are evaluated and the new plans are based on the report of the fulfilment and implementation of the previous ones.

Interview with a Representative of Service Providers

Country: Czech Republic

Interviewee: Mr Dr. Jaroslav Šturma
Organization ***Paprsek****, provider of services for children with complex needs and their families*
Widely known expert and disability activist
Psychologist

Interviewer: Ms Jana Vránová **Date:** September 25th 2007

Supervision: Dr. Jan Šiška

The interview was made personally during approximately one and a half hour.

Could you comment on the situation of people with severe disabilities in Czech Republic (CR)?
In my opinion looking at the situation of people with severe disabilities it is noticeable that they are the weaker side of the system. So called "humanization" progresses in the centric circles first, including persons with mild disabilities and "more hopeful" ones, and only then turning towards persons with complex needs. This is possible to demonstrate on example of social and support services. In the boom after the Velvet revolution in 1989 the civic organisations and NGOs supporting people with mild disabilities began their activities, and later the first organisations started to provide care for people with severe or complex disabilities. The situation in general has improved. However, it is still important to follow up the rule - more people miss, more it is necessary to add from outside. More complex disability of a person is - more complex care he/she needs.

In your opinion: What are the main risks of discrimination against persons with severe disabilities in your country?
Discrimination is that there is a small range of services – services are not accessible for all people with severe disabilities. Because of that their human rights are in risk. For example families with a severely disabled child are in risk of being overcharged (the number of divorces in these families is higher then the country's average). Children are in risk of being placed in institutions for infants or at least not being able to develop fully their potentials.

In your opinion: What are the perspectives of anti-discrimination policies for people with severe disabilities in your country and in the EU?
There is a tendency to focus on the human rights of people with all types of disability. With adoption of human rights, responsibility relates tightly. We must make concrete steps towards fulfilling the right in practice. Arising of social solidarity is necessary for it. It depends on the fact, how much people are willing to do something for the others. We are on our way improving in this field, and so do the other European countries.

What can you say about the difficulties of people with severe disabilities having access to support from professional services?
First, the prejudice persists that more disabled person is, less support services he/she needs. The opposite fact is true. And second corresponding with first, there is a lack of number and variety of services for severely disabled people. There are specialists who would work in this field but there are no budgets for paying them. The potential providers are not stimulated to open new services, because running them is too expensive. Awareness of needs and neediness in this area is very low.

How many and what kind of people are excluded from all or certain services and get only support from their families?
Considering there are about six percent of people with disability within the population rough estimation would be that a quarter of them are more or less excluded from the services. In this quarter most of them are people with severe disabilities and with complex needs; the rest three quarters with more possibilities are often people with only one disability or with a moderate disability. The exclusion depends not only on the service system but also on the families; some families with a severely disabled member would find it stigmatizing to show this person in community and they feel ashamed to ask for help.

In which areas of the support system do you see problems of availability or bad quality?
There is a lack of comprehensive services for supporting families, starting with respite care and finishing with family services (housekeeping, laundry, etc.). Parents have no time for their own life. Also enough professional services for people with severe disability are missing.
Another problem is building and transport accessibility as a necessary condition for the accessibility of the services.

Are there differences in quality of services for people with mild, profound and severe disabilities?
The differences are mainly in availability and accessibility – for people with mild disabilities the services are more accessible, there is a wider range of them, they are more differentiated (also because there are more people with moderate disabilities in the population). The support of them is easier, while taking care for a person with a severe disability is more complicated and demanding.

Which structural problems do you see in the service system and in service providing?
The service system has to deal with structural problems of divided competences according to departments (health care, social care, education). People with severe disabilities though need a complete care that requires interdisciplinary cooperation among these three departments.

Which problems do you see in intersectoral co-operation, in service planning and delivery?
Problem is that each department would like to have leadership in influencing the services (to determine the provision of the services), but then they do not put as much finances into the system as it would need.

Study on the Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs

www.non-discrimination.eu

Country Report France

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Tender on Behalf of the European Commission
D.G. Employment, Social Affairs and Equal Opportunities
Integration of People with Disabilities - Unit G3

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Selected Stakeholder Interviews

1. Summary

Our report proposes a synthesis of the specific risks of discrimination against persons in situation of major dependence or with complex needs in France.

According to the general methodology adopted, we dedicate an introduction to the general questions relating to the definitions, to the statistics, to the processes of recognition and assessment of disability and its degree of severity. We include some main results of the national population survey on disability, limitations activity and dependence, which was realized in France (Handicap, Incapacité et Dépendance -HID, 1998, 1999, 2000, 2001). We explain also the main process and tools actually implemented by the new Local Disability Houses created by the law of 11 February 2005 on equal rights and opportunities, participation and citizenship for people with disabilities.

In the following, we present the essential points about the situation of severely disabled people and the risks of discrimination against them which in our opinion may be retained for the 14 fields approached in this study : Prenatal diagnosis and counselling; Early Childhood, Childhood: Education and Care; Childhood and youth: School; Childhood and youth: Housing/Network, Family Support Services ; Childhood and youth: Leisure time; Youth and young adults: Vocational training; Children and Adults: Social security/health care; Adults: Work ; Housing ; Education and leisure time ; Partnership and parenting; Exercising Civil Rights ; Ageing/End of life.

The text on each of these 14 domains leans on the list of legislation and policies which was also produced within the framework of this study. It presents, when it is feasible, statistical data which demonstrate the situation of severely disabled persons or persons having complex needs. It integrates ideas expressed during the interviews that granted us policy makers, representatives of the NGO and services providers. The text takes into account the essential factors which appeared in case studies and analyses of good practices.

Whatever is the considered domain, the risks of discrimination against persons in situation of major dependence or with complex needs are important. They result from a lack of accessibility (physical, psychological and cultural) and from an insufficient individualized compensation of the limitations of activity and restrictions of participation. This can be observed at all ages of life and in all social spaces, school or leisure centres, work or built environment as well. The way of being parent or citizen is also concerned.

True inclusion implies not only a wide opening of all the social spaces to the disabled persons but also a consideration of all their individual needs of care, material and human support and specialized accompaniments. It requires an optimal mobilization of all the partners and new means. A deep change of the mentalities and an excellent cooperation of all the sectors are necessary to reduce in a significant way the risks of discrimination.

Due to lack of space, references were mostly not included in this paper but are part of the annotated bibliography.

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Résumé

Notre rapport propose une synthèse des risques spécifiques de discrimination des personnes dans une situation de grande dépendance ou avec des besoins complexes, en France.

Selon la méthodologie générale adoptée, nous consacrons une introduction aux questions générales de définitions, de statistiques, de processus de reconnaissance et d'évaluation du handicap et de son degré de sévérité. Nous exposons certains des principaux résultats du recensement national concernant le handicap, les limitations d'activité et la dépendance, qui a été réalisée en France, (Handicap, Incapacité et Dépendance - HID, 1998, 1999, 2000, 2001). Nous présentons également le processus et les outils principaux actuellement mis en oeuvre par les Maisons Départementales pour les Personnes Handicapées, structures nouvelles créées par la loi du 11 février 2005 sur les droits et l'égalité des chances, la participation et la citoyenneté des personnes handicapées.

Ensuite, nous présentons les points essentiels sur la situation des personnes avec des handicaps sévères et les risques de discrimination qui, à notre avis, peuvent être retenus pour les 14 domaines approchés dans cette étude : Diagnostic et conseil prénataux ; Petite enfance, enfance : Education et soins; Enfance et jeunesse: scolarisation ; Enfance et jeunesse : logement/relations, aide aux familles; Enfance et jeunesse : loisirs; Ados et jeunes adultes : formation professionnelle ; Enfants et adultes : sécurité sociale/soins de santé ; Adultes : travail, logement, éducation et loisirs ; Trouver un partenaire et parentalité; Exercice des droits civils ; Vieillissement/fin de vie.

Le texte proposé pour chacun des domaines s’appuie sur la liste des lois et politiques produite pour cette étude. Il présente les données statistiques existantes illustrant la situation des personnes avec des handicaps sévères ou des besoins complexes. Il intègre des idées exprimées lors des entrevues avec des décideurs politiques, des représentants d’ONG et des prestataires de services. Le texte rend compte des points essentiels apparus lors des études de cas et des analyses de bonnes pratiques.

Quel que soit le domaine considéré, les risques de discrimination encourus par ces personnes sont importants. Ils résultent d'un manque d'accessibilité (physique, psychologique et culturelle) et d'une compensation individuelle insuffisante des limitations d’activités et restrictions de participation. Cela peut être observé à tous les âges de la vie et dans les tous les espaces sociaux, école ou centres de loisir, au travail mais aussi dans l’environnement bâti. La manière d'être parent ou citoyen est également concernée.

La véritable inclusion implique non seulement une large ouverture de tous les espaces sociaux mais aussi une prise en compte de tous leurs besoins de soins, aides matérielles et humaines et accompagnements spécialisés. Elle exige une mobilisation optimale de tous les partenaires et de nouveaux moyens. Un changement profond des mentalités et une excellente coopération de tous les secteurs sont nécessaires pour réduire de manière significative les risques de discrimination.

2. Introduction

Definitions and Data on persons with complex needs:

- **National Approaches to identify the group of people with complex needs**

In France, there is no global and specific approach of the group of people with complex needs. Any person with disability, mild or severe, simple or complex, is covered by the law of 11 February 2005 on equal rights and opportunities, participation and citizenship for people with disabilities.

However, several groups of people with specific disabilities and complex needs have been studied in the last years: autistics, people with multiple disabilities, cranial traumatised people and people with psychiatric disability. The purpose was to define specific programs for these groups. With the same intention, another group has also been identified: the group of people in situation of almost total dependence in the area of daily activities and with very severe disabilities.

- **Available data of people with complex needs**

In France, as the group of people with complex needs is not defined, there are no specific statistical data concerning it. However, a national population survey on disability, limitations activity and dependence, was realized in France, (Handicap, Incapacité et Dépendance -HID, 1998, 1999, 2000, 2001). This survey was about all people with disabilities, mild or severe, simple or complex, at any age.

According to the survey HID and the evaluation grid to measure autonomy (Colvez), there are 1 417 000 dependent persons of 60 and more years old among whom 628 000 classified at the levels 1 and 2 considered as being affected by high dependence needs. Among these persons, 405 000 live in their personal place of residence, 217 000 in residential institutions for old persons and 6 000 in the other institutions (institutions for disabled adults, psychiatric institutions).

In 1999, approximately 31 million persons from 20 to 59 years old lived in common place of residence in metropolitan France. Among them, 7,6% (2,4 M) have an impairment without activity limitation, 21,5% (6,7M) have an activity limitation, 8,3% (2,6M) have a moderate activity limitation and 3,4% (1,05 M) have a severe activity limitation. The severe limitation of activity appears mainly in four big groups of impairments: the group of people who have mental and physical impairments, the group of people who have mental impairments, the group of people who have several physical impairments, and the group of people who have mobility impairments. Prevalence of the severe disability is respectively for each of these 4 groups of: 27,6 %, 8,8 %, 8,3 % and 4,1 %.

Among a population of 31 million persons from 20 to 59 years old, 2,6 million people (that is to say approximately 8% of this population) experienced at least three restrictions of participation in the social life among the five following ones: absence of extra-family social relations, absence of emotional relations, poverty, absence of external leisure, involuntary not-access to employment. These 2,6 million persons consisted of 1,5 million disabled persons and 1,1 million not disabled persons. So, severe restrictions of participation were more frequent (14%) for disabled people than for not disabled people (5,4%). They were especially more frequent for severely disabled people (28,6%).

The population of young people of less than 20 years was, in 1999 of 14,77 millions. According to the survey HID, young people with impairment or having a difficulty in their everyday life because of a problem of health were 3, 86 millions (26, 2 %). However, severe disability is much less frequent. So, for 2006, the national statistics indicate a number of 160 000 beneficiaries of the educational allowance (allocation) which can be attributed(awarded) to the disabled children whose rate of incapacity is at least 50 %.

These statistical data give some landmarks onto prevalence of people with severe disabilities in France. But they do not allow identifying the population that is of interest for the present study. This last one constitutes certainly a subset of the previous one. But it would have been necessary to define it more precisely to try to delimit it better quantitatively.

- **Classification systems, procedures and identification-practises**

From the adoption of the law of February 11, 2005 on equal rights and opportunities, participation and citizenship for people with disabilities, people with disabilities who have simple or complex needs have to contact the Local Disability House (Maison départementale des personnes handicapées (MDPH)). A multidisciplinary team estimates the disability, the needs and the person’s rights in every area of life and elaborates with the person its plan of compensation. This plan is then submitted to the acceptance of the Disabled person's rights and independent living Commission (Commission des droits et de l’autonomie des personnes handicapées (CDAPH)) of the Local Disability House (MDPH)).

The assessment of the person’s disability situation is made with the “GEVA” tool. (Guide of multidimensional evaluation). The conception of this tool is made on reference to the "ICF". It approaches all the domains of human functioning, activities and participation. It allows to investigate the needs of assistance and aspiration of the disabled person. It is aimed to facilitate the elaboration of the plan of compensation. But this is not the only tool. The multidisciplinary team uses two other tools: *“the table of impairments and disability "* used to examine the eligibility of disabled person to the allowances which existed already before the new law. The *"functional referential"* used to examine the eligibility of disabled person to a new allowance of compensation.

According to the referential, the new allowance is attributed if the person has one or several cognitive or psychic, physical, sensorial, mental functions impairments and has total difficulty to perform an activity or heavy difficulties to perform two activities. The activities taken into account are: 1. Mobility: waking up, transfers, walk, gripping ability…; 2. Personal maintenance: to wash, to assure the elimination, to get dressed, to take meals…; 3. Communication: to speak, to hear, to see, to use communication devices …; 4. General tasks and requirements: relation with others, orientation in time, in space, to manage safety, to master one’s behaviour in the relations with others…

For dependent persons of more than 60 years, other multidisciplinary teams use the evaluation grid “AGGIR” (to assess the degree of the individual’s loss of independence of elderly people) for the attribution of allowances to finance human assistants: the “APA”. The decision of attribution of the “APA” is taken by the president of the County Council on proposition of a Commission specially created in every county.

3. Pre-Natal Diagnosis and Counselling

Through the extended possibilities for family planning, parenthood in modern societies has increasingly become a question of individual decision-making. Prenatal diagnostics and reproduction technologies permit the inclusion of characteristics of the fetus in this decision. This extended knowledge brings individuals into difficult situations when they have to make decisions regarding children. These individual decisions are affected by social values, attitudes, anxieties and knowledge of disabilities. They are also influenced by the quality of the counseling process if professional support is available and used. It is important that individual decisions are accepted by the social environment of people concerned. How is this achieved?

3.1. Description of the National Situation

Prenatal screening of severe congenital anomalies is very active in France. Women realize generally three or four echographies by pregnancy. The screening of infections as the toxoplasmosis or the rubella, is systematic. The blood screening for Down's syndrome is systematically proposed and it is widely practised today. The amniocentesis which is paid off only at the women presenting a higher risk (generally beyond 38 years) is used on 11 % of pregnant women.
The prenatal diagnosis only concerns pregnancies where some risks of very serious or incurable diseases are diagnosed. This may lead to a medical termination of pregnancy only if the pregnant woman does ask for it, after being duly informed and after receiving the opinion of a multidisciplinary centre for prenatal diagnosis (Law on Bio-ethic, August 6 2004).
In France, the law says that voluntary termination should be carried out up to 12 weeks of pregnancy. But, the interruption of a pregnancy can be carried out up to 9 months of pregnancy if two doctors give evidence, after examination and discussion, that the pursuit of the pregnancy puts in great danger the health of the woman or if there is a strong probability that the unborn baby is affected by an affection of a particular gravity recognized as incurable at the time of the diagnosis (Art. L. 162-12, Code of the Public Health).

The rate of abortions for 100 births, if we take into account sub-statements (sub-declarations) (1 out of three), is about 30 % (between 200 000 and 220 000 a year according to figures of the DREES and the INED). Abortions for medical reason represent approximately 2 % of all abortions (assessments of the multidisciplinary centres of prenatal diagnosis). Most of the abortions for medical reason (approximately 6000 a year) are connected to a risk for the foetus (approximately 98 %). A small number are connected to a risk for the mother (2 %). Nowadays, a prenatal diagnosis of Down's syndrome leads almost systematically to a termination of pregnancy.

Disadvantaged families benefit less from prenatal diagnosis for some pathology, for example Down's syndrome, compared to other families. Besides, prenatal diagnosis does have some positive aspects. It allows to anticipate aids towards families. Centres for prenatal diagnosis are beginning to ask for intervention from the CAMSP, including intervention before the birth of the child to support the family.

3.2. Specific Risks of Discrimination

The practices of screening and prenatal diagnosis aim at informing the parents during a reproduction of the risk which they incur to have a disabled child. However, the decision will belong to them, if the risk is confirmed, to ask or not for termination of the pregnancy. According to the defenders of the prevention of disability by birth, the fact that the decision is personal, distinguishes the prevention from eugenics (which applies in a collective way without personal choice).

For the National Committee of Ethics, the social solidarity should be guaranteed so that the mother who knows the risk of giving birth of a disabled child makes a decision only based on her own appraising of the situation and on her responsibility toward the child, in particular her possible suffering, and not on possible material difficulties to take care of the child. Another position statement of the Committee is in opposition with some practices of foetus discrimination based on seriousness criteria: No adoption of normative criteria that would define, without any link to the mother's feelings, a threshold of seriousness that could justify eliminating abnormal foetus, would be acceptable from an ethic point of view based on the freedom of responsible and worthy persons' choice.

But, there is a huge gap between the principles that are set down by the National Ethical Committee and clinical practices. Almost all parents to whom a risk of severe and complex disability is announced are taken in a spiral that sets aside any decision of refusing the medical interruption of pregnancy. Moreover, as the text mentions, it would be highly desirable that moral and psychological support proposed to future mothers becomes much stronger than it is presently. Discrimination risks come from the way medical doctors are trained, not for the scientific part but rather for the human part and in particular on how to announce a risk of highly serious disease to parents without making them to feel guilty. Parents should be seen together as much as possible, without isolating the mother.

4. Early Childhood

For most families, having a baby creates a situation of uncertainty and a need for direction and guidance. Living with a baby or a young child with a severe disability or with severe developmental problems brings parents into a situation with specific and difficult challenges and dependencies. Psychological stress in their daily lives often makes it difficult to cope with their parental responsibilities. When dealing with educational tasks or when specific therapeutical or medical treatment is necessary, parents cannot refer to their own educational experiences, but are dependent on professional support of various kinds. Having access to good medical care, self-help groups and early intervention services from a very early age of the child are decisive factors both for the personal development of the child and for the successful adjustment and coping process of the parents. How is this achieved?

4.1. Description of the National Situation

For 0 to 6-year-old-children who have sensorial, motor, mental, severe or complex impairments, actions of early detection, prevention, treatment and rehabilitation may be undertaken by multidisciplinary teams of the early medico-social action centres ("CAMSP").

These centres raised in-between the numerous ordinary settings (maternity hospitals, child and maternal welfare (PMI), day-care centres, nursery schools) and specialised settings (SESSAD (services of specialized education and care at home), specialised courses). These centres propose their support (one-to-one interviews with a psychologist or group therapy) to families. They also bring support by facilitating inclusion or orientation in specialised settings. They are financially supported by Health Insurance (80%) and by regional councils (20%). There are more than 200 "CAMSP" in the country.

When the severity of the disability increases, the quality of service supply is less important. There are also disparities in service structures. Some represent real places of reference for severe or complex disability issues and are composed of well-trained professionals. Most of the time, these places are related to a sector of research. Other places function in the routine. Decision-makers and associations should impulse dynamics to develop reflections, exchanges, studies and research in the field of quality of service. Professionals should train at universities other professionals interested in disability issues so that they could work in the field of disability, including that of severe disability.

4.2. Specific Risks of Discrimination

Neonatalogists are not sufficiently involved in disability networks. They ignore the diagnosed disease's consequences in terms of disabilities. There is a huge gap between the diagnosis and what it may represent for the children and their families. The services of early intervention take care of children with severe disabilities as much as other children but too often are they overcrowded.

Not all families are guided towards the CAMSP. Besides, there are not enough places for all children. However, the degree of the disability is not a criterion of exclusion. In the case of multiple impairments, doctors do guide children with disabilities towards the CAMSP or the CESAP (centre of studies and care for people with disabilities). The observation of the premature baby does not fit to given standards. Guidance in case of after-effect is usually late. Though, it should be made within some months of a year.

The early social and medical action centres (CAMSP) are examples of good practice for the whole world of disabled children. But nearly all these CAMSP are meant for general cases and they may be powerless in front of atypical and complex cases; so are the services devoted to care and education intervening either at home or in schools (SESSAD). These services should thus be linked with resources centres, especially those devoted to rare disabilities. When children have complex needs or severe disabilities, particularly mental impairment, services of early intervention should rely on reinforced multidisciplinary teams. Children should benefit from more important care.

5. Childhood: Education and Care

Preschool institutions like inclusive or special kindergartens offer care and education for younger children. They prepare children for school and give them the opportunity to interact with peers. Young girls and boys can broaden their experiences in life and enhance their social skills.
Children with severe disabilities have the same need to interact with peers, to make friends outside the family and to view themselves as a part of a social group. But young children with complex needs are dependent on additional support to participate in preschool education, such as barrier-free access or well-trained educators with specific skills and the intention to cooperate with other professionals. How is this achieved?

5.1. Description of the National Situation

In France, according to a survey of the DREES (2003), the types of childcare services are very much diversified. For children before 3 years, the main type of childcare over a week from Monday to Friday is parents (64 %), nursery assistants (18 %), day-nurseries(cribs) (8 %), grandparents (4 %), other services (4 %, including nursery schools, day-care centres), and diverse individual services (2 %). For 3-6 years, in the week (except Wednesday), the main type of childcare is nursery school (78 %), parents (15 %), nursery assistants (4 %), other services (2 %), and grandparents (1 %). Individual service by nursery assistant is three times more important than collective service. All the collective facilities for early childhood (without counting the nursery school) offers 317 000 places while the number of children of less than 6 years is approximately 5 millions among which 2,5 millions of less than 3 years.

These modes of childcare may also affect disabled children but they are badly known before the age of admittance in nursery school (2 or 3 years). The frequency of the acceptance of the young disabled children by nursery assistants, day-nurseries, and day-care centres, is not known.

Legally, since a decree published in August 2000, the admission of disabled children is part of the missions of day-nurseries (age: 2 months-3 years) and day-care centres (age: 2 months: 6 years), except if the child has health problems which require specialized care. In this last case, its admission is however possible in a sanitary nursery. But all these structures offer an insufficient number of places and these are badly distributed on the whole national territory. Besides, from the testimonies of families, it is likely that they welcome proportionally less the disabled children than the other children. The possibilities of admission are even more reduced in the case of severe disability.

A child does have to go to school at the age of 6. Under 6 years, young children with disabilities as other young children may be registered at a nursery school. In 2006, 35 500 disabled children of less than 6 years were schooled to the common nursery school (19 800 : 17 600 in ordinary classroom and 2200 in specialized classroom) or in specialized services (15 700). For severely disabled children, the schooling in common ordinary nursery schools remains still very complicated.

A plan "early childhood" was adopted by authorities in November, 2006. Its objective is to offer a place in childcare services to all the children of less than 6 years.

5.2. Specific Risks of Discrimination

The French child who is under 6 years old does not have effective right to be accepted in child care centres or nursery schools, because of the lack of equipments. Since there is no financial means, this is pure illusion to think that an adapted solution could be proposed for each child. As regard to early childhood plan, real results are expected from the childcare structures.

The parents of severely disabled children often consider that childcare facilities have not the necessary number of professionals to assume correctly their children. The admission teams often fears the fact that they cannot do they job properly when facing the situation of children with multiple impairments. So they tend to avoid that situation.

Attending special institution does not necessarily mean having a place. The child admission is based on a real process of hospitality towards the parents in order to ease their fears, to make them feel that their child is not a burden and to plan with them a support arrangement.

A lot of information and training action are necessary to improve the admission in childcare centres, kindergarten and nursery school. After child health care centres and kindergarten, the child should attend nursery school without any transition.

6. Childhood and Youth: School

Schools are responsible for a child's education and the teaching of knowledge of varying subjects. Furthermore, school proves to be an important part of young peoples' socialization process by offering the chance to enhance social skills and deepen social contacts with peers.
Children with severe disabilities also need high quality education and access to public schools. Pupils with complex needs are dependent on additional support in order to participate in school education, such as barrier- free access or well-trained teachers with the intention of cooperating with other professionals.
But especially pertaining to them, schools often exercise a kind of segregation. How do children with complex needs find their place in the school system, in which way are their special needs considered and how do professionals cooperate together?

6.1. Description of the National Situation

The new law (February 11th 2005) states as a principle the registration of any child in an ordinary school, even if the child has severe or complex disabilities. This means that every disabled child or young should be provided with schooling in the school (school of reference) that is the closest to his/her home. When a child has specific needs that may not be covered by his/her school of reference, his/her schooling may take place in another ordinary or adapted setting. Hence the ordinary school system is completed by services and settings of the medico-social field. Though, the link with the school of reference is maintained (inactive registration). The Disabled person's rights and independent living Commission together with the parents of a child with disability and after assessment, take the decision of school guidance either towards mainstreaming school or specialized institution. The training life course of the student should take place in ordinary settings with priority. The types of schooling development are specified in a personal schooling project: it allows making links between pedagogical, psychological, educative, social, medical and paramedical actions.
According to a study of the DREES (in March, 2007), 235 000 pupils with disabilities were schooled in France during the school year 2005-2006, what represents approximately 2 % of the whole total population of the children in school age. These pupils were welcomed in the schools of the Department of Education (159 100) or in specialized institutions (76 300). In the schools of the Department of Education, the individual integration concerned 104 000 pupils and the collective integration 47 600. Since 1999, the individual integration doubled. During the school year 2005-2006, among the pupils schooled individually 9 % of the first degree and 13 % of the second degree were helped by a specialized teacher. Pupils may also be helped by assistants of school life (help for writing, the installation of material, during the meals, the breaks, the school outings, etc.). The assistant can help a single pupil or the whole class. During the school year 2005-2006, 19 000 pupils were helped by an individual assistant and 22 300 by a collective assistant. The children who benefit from help are generally the ones who have the most severe deficiencies or complex needs. But the children and the teenagers who are severely disabled are more often attending specialized institutions, especially after primary education. Others, among them, do not find a place at school or in an establishment and are not schooled. Approximately 20000 disabled children and teenagers are not schooled. A majority of them have severe impairments or complex needs.

6.2. Specific Risks of Discrimination

In nursing schools, progress is meaningful. Many children with severe disabilities could go to the first level of ordinary school. But, the education of children with severe disabilities generally will become difficult after they are 6 years old. As learning activities become much more problematic, it is essential to have specialized assistants for children with severe disabilities. It is impossible to face the needs of children in terms of Braille, sign language, learning instrumental written language, real psychotherapeutic treatment with the help of assistants who have received a 60-hour training.

Systematic registration to an ordinary school of a child with disability including the ones with severe disabilities is a very positive factor because it gives to the child a social recognition and a social status. However, some parents suffer from this situation because even if they really know their child is registered in his local school, they are not sure he can attend it. The conception of the system is based on a way of thinking that skips over disability complexity. The child is registered in a school but we are unaware of the reality and the concrete difficulties. Children with complex needs may be ill-treated in ordinary school.

The personal schooling project (PPS) should not be elaborated without a representative of the special sector. The coordination and the follow up of these interventions are much more difficult to realize than in healthcare structures. In improving school condition for children with mental impairment and particularly when their disability is severe and their needs complex, the National education and the medico-social services should be fully complementary. As long as this will not be well organized and effective, the education of children with disabilities will be very difficult.

7. Childhood and Youth: Housing and Family Support Services

Due to the variety of modern family life, all children grow up in different environments. These environments can be understood as a social network including all sorts of relationships to individuals or institutions. The family's living conditions during childhood are very important for social inclusion of the young person in society. The family has a strong impact on his/her primary socialization and influences the access to certain social institutions.
Family support services offer community-based professional support and services for families. Some children and young people live in a foster family, others in foster homes. Are such support systems available? In which way are children with severe disabilities or complex needs and their families involved in these support systems?

7.1. Description of the National Situation

In France, disabled children live mostly with their parents (approximately 200 000). They may also live in specialized institutions (approximately 40 000). They may also live in foster family (no statistical data).
Allowances are given to parents who are living with their disabled child to cover the additional costs linked to the disability such as human assistance, technical helps, transport and housing adaptations. The parents, who are in charge of a child with disability under 20, are eligible to the allowance for a child with disability (AEEH) if his permanent disability rate is at least of 80% (or between 50% and 80% with specific conditions of follow-up). This allowance is attributed by the Disabled person's rights and independent living Commission of the Local Disability House. In 2006, it was attributed to 160 000 children. Its amount was 119.72 € per month since January 1st 2007. Children with severe disabilities may be eligible to a complementary allowance, also

attributed by the Commission. There are 6 categories of complementary allowances that may be classified depending on the extra cost induced from the disability of the child, the degree to which this extra cost reduces the professional activity of the parents and the need to have a third support person as. On January 1st 2007, the 1st category of complementary allowance was about 89.79 € and the sixth one about 999.83 €. Single parent families may benefit from an additional charge starting from the 2nd category of complementary allowance (48.64 €) to the sixth (400.31 €).

Any person who is in charge of the allowance for a child with disabilities (AEEH)) may also ask for the new disability compensatory benefit since the February 11, 2005 law. It allows taking in charge other elements such as housing improvements or extra cost for transportation. The daily allowance for parental presence (AJPP) may be attributed to any person who is in charge of a child who is less than 20 whose disease or disability requires a sustained presence and constraining care. On January 1st 2007, it was 39.58 € for one person living in couple and 47.02 € for one single mother or father. If there are important charges, families may have a monthly complementary allowance (101.22 €) if their income do not go beyond some thresholds depending of the number of children they are in charge of.

The life of the severely disabled children in the place of residence of their parents is also facilitated by the possibility of resorting to certain services such as the educational and home help specialized services.

Specialized institutions can also welcome, in boarding school, severely disabled children. There are diverse types of specialized institutions according to the impairment: IME for the mental impairment, ITEP for the behavioural problems, IEM for the very severe mobility impairment. Certain institutions are specialized in the admission of children with multiple disabilities. There are also educational institutions for sensory impairment (visual or hearing).

7.2. Specific Risks of Discrimination

The access to allowances is very complex with administrative files that are very long to fill in and the places of decision are too remote.

When children with severe disabilities live in their families, it is important that parents could benefit from breathing spaces. This implies the introduction of a new dimension in the organisation of services which intervention can occur at certain time and also in the organisation of structures which the children can attend at some periods.

The local disability house (MDPH) will not give aids when the diagnosis of the child is not clear, or when severe disability is suspected, even though these aids will be necessary for families. Specialized units should be set up within the MDPH in order to treat properly issues on the recognition of disability.

Maintaining or helping people with complex dependency to come back home supposes enough highly qualified staff who must be supported by resources centres. It would be also necessary to set up a program of assistance to family caregivers in order to avoid the current exclusion of too many of them (especially mothers or wives/husbands) from professional or social life. It requires setting up a network of respite solutions.

8. Childhood and Youth: Leisure Time

Young people use their leisure time to do enjoyable and amusing activities and to get free from daily routines. Often free time activities are organized in clubs or in various forms of sportive or cultural associations. But youngsters also spend their free time with peers without adults. Many experiences among young people of the same age are made spending leisure time together, e.g. discovering new social roles, social spaces, friendship or falling in love. Youngsters with severe disabilities or complex needs have the same leisure time needs as their non-disabled peers, but are dependent on additional support to participate in mainstream leisure time activities. How is this achieved?

8.1. Description of the National Situation

There is not special law for leisure time but consent on the principle of full accessibility and non discrimination (law of February 11, 2005) and volunteered action from the State.

Holidays and leisure centres collectively accommodate children and young people from 2 to 18 years old for educational activities and relaxation. They are organized around specific educational and teaching projects. The admission is regulated by the State (especially by the ministry for youth, sports and community life) and framed by a qualified team. Holidays centres welcome groups of at least 12 children and\or teenagers for a period superior to 5 nights during the school holidays. They also welcome without lodging groups of 8 to 300 children or teenagers. The centres function at least 15 days a year.

Today, more and more leisure centres organizers provide activities for disabled children and teenagers with complex needs within a group firstly made up of children without disabilities. The directors of the centres as well as the working team are informed before the stay of the particularity of the child disability in order to adapt the activities and the organization of the day.

An ethical charter on the admission of disabled young people and adults in holidays and leisure centres that are not specialized in disability accommodation was elaborated since 1997. This charter underlines the interest for integration of disabled people in holidays' centres and leisure activities. It also underlines the necessity to offer an admission of quality to disabled people. However, for severely disabled children and teenagers, integration in ordinary holidays or leisure centres remains very complicated. Today they attend specialized centres to be sure that their specific needs will be properly met.

8.2. Specific Risks of Discrimination

Holidays and leisure centres do not easily welcome young kids with severe disabilities. Some association such as “Loisirs-Pluriel” receives both children with disabilities even with complex needs and children without disabilities and offers specific supervision.
But parents of severe disabled children fear the lack of means, of access, of human assistants and the lack of specialized health care professionals.

Behaviours and attitudes from other children without disabilities are still perceived as a potential obstacle to the integration of severely disabled children. They may not be ready to accept a severely disabled child and to share activities with him. Educative and pedagogic actions towards general public are still required.

9. Youth and Young Adults: Vocational Training

A successful transition from school to the employment system is usually related to vocational training. After finishing school young people need to find a job according to their interests and abilities with which they can earn a living. Vocational training prepares for the access to the employment system and is an important step into adult life. Youngsters and young adults with severe disabilities are dependent on adapted training courses, assisting technologies, other individual support and barrier free infrastructure to enable their access. How is this achieved?

9.1. Description of the National Situation

People with disabilities have access to the whole vocational training programmes of common rights mean to all workers and job seekers. Disabled persons who are eligible to the status of disabled worker can also have access to particular vocational programmes and benefit from specific arrangements as far as wages are concerned. The status of disabled worker must be recognized by Disabled person's rights and independent living Commission (CDAPH) acting in the local disability house (MDPH).

Since January 12, 2006 vocational training agencies in regular workplace or sheltered environment, also responsible for life-long vocational training (State, local authorities services, public and private institutions, job placement institutions, trade unions) had to take any measure to facilitate part time work in order to adapt vocational training duration, and to find way to validate vocational training certificates for disabled persons.

Specific actions for vocational training are:

- 8 to 12 weeks of pre-guidance job placement to define a work project or to adapt vocational project to meet the needs or the capacities of disabled worker;
- long term job placement rehabilitation in vocational rehabilitation centres (CRP);
- vocational rehabilitation contract.

People experiencing decline in their upper body functions due to severe impairments are more in job placement assessment and guidance than in work guidance and in job rehabilitation centres. This stresses the specific difficulties professionals meet in the vocational training field according to a study on trainees by Ladapt, an organization for social and professional inclusion of people with disabilities

Centres of vocational rehabilitation are medical and social institutions, financed by the health insurance, which aim is to favour vocational training of disabled people. The centres welcome especially people whose disability requires a personalized pedagogy or a medical and social support. The duration of the training is from 10 to 30 months. On the whole territory, there are hundred centres for approximately 10000 disabled people. The mainstream training agency (AFPA) welcomes few disabled persons (approximately 5000 a year).

9.2. Specific Risks of Discrimination

The professional training sector is less open to people with severe disabilities, particularly when the origin of their impairments is not link with a work accident.

Vocational training should also be organised for severely mental impaired persons in the special medico professional institutions (IMPro).

Vocational training centres cannot indeed satisfy the needs for training of disabled people and especially of severely disabled persons:

- they often offer unsuitable trainings for the open labour market;
- they have insufficient accommodation facilities, which lead to endless waiting lists;
- their geographical distribution remains very uneven;

There is a big variability of forms to assess the capacities and vocational guidance of people with severe disabilities. It mostly depends on service supplies rather than on their capacities, their needs and aspirations.

10. Children and Adults: Social Security and Health Care

Modern societies are shaped by an enlargement of welfare systems and an increasing dependence on social security institutions. It is a challenge for all citizens to clarify their entitlements and to find access to services. The need for basic social security and to have access to health care services if necessary is important for all people.
In most cases having complex needs leads to an increase of dependence on social benefits and requires special support and services granted by welfare administration boards. Bureaucratic procedures of application approval create special risks of stigmatization. Allowances, benefits and services can improve the possibilities of individual participation, but can also initiate processes of social exclusion. How is this achieved?

10.1. Description of the National Situation

People with disabilities especially those who experience severe disabilities meet serious obstacles in their access to basic health care, to cure for complicated impairments as well as to therapy innovations. These difficulties are mainly linked to the fact that health care buildings are not accessible and also to the fact that health care professionals are still not sufficiently trained to meet the specific needs of disabled persons.

The new legislative provisions aim to reduce those difficulties.

The law states that all health care professionals must receive special training on the one hand on the evolution of knowledge related to diseases that are the cause of a disability and knowledge on therapies, technologies, learning, support of people with disabilities as well as special training for hospital accommodation and on the other hand on the announcement of the disability..

People with disabilities are eligible to extra medical prevention checks for medical expertise according to the evolution of innovation therapies and technologies to reduce their incapacities.

The disabled person and his or her assistant firstly receive from the health care professional basic adapted health education to acquire basic knowledge on medical gestures practice as far as the care is concerned.

Access to health care means financial possibilities. The Social security is usually responsible for that as well as health insurances. People with disabilities are usually eligible to the Social security as ordinary members or automatically as affiliated members due to the recognition of their disability. Mostly, being affiliated to Health insurance depends on one's needs and one's financial resources.

A specific additional healthcare insurance called « Intégrance » was created to meet the needs of people with disabilities including those with severe disabilities and high dependency needs.

10.2. Specific Risks of Discrimination

France suffers from a lack of doctors, physiatrists and physiotherapists. Today you do find plenty of psychomotor therapists but they are not trained to deal with complex disabilities apart from the case of autism.

As far as their health is concerned, young children with disabilities are well treated in hospital and liberal services as well. But when the disability is severe, some healthcare structures target on particular population, regardless the CAMSP. Acting like that, they completely exclude socially children with complex needs.

The recognition of health problems (teeth and gynaecological problems in particular) of severely mental disabled persons is not easy. We should be vigilant because these persons are unable to express what they feel properly. This implies to prepare doctors to deal with disability issues.

11. Adults: Work and Employment

Having work or a day occupation is, for financial and other reasons, a very important indicator of social inclusion and quality of life. Going to work not only structures peoples' days and weeks, but also has an important impact on the development of a person's identity. It also provides access to the social security system and is an important basis for participation. For people with severe disabilities, transitional situations from school or vocational training into the employment system must often be systematically planned and organized, because they are dependent on adapted work places or assistive technologies and other individual support like a barrier-free infrastructure to enable their access. How is this achieved?

11.1. Description of the National Situation

Before the new law, the active disabled population was 900 000 of whom 527 000 had a job in regular workplaces and a third was seeking employment (2004 data). The activities for people with severe disabilities remain particularly low (29,9 % when they experienced two severe impairments compared to 66.1 % when they experienced a single severe impairment according to HID 99 survey).

The law of February 11, 2005 aims to favour employment for disabled persons in the mainstream labour market while stressing the importance of sheltered environments. The new law brings France into line with the November 2000 European directive on equal treatment in employment and at work. The right of non discrimination is reaffirmed by the Charter of fundamental rights built into the European Union's draft Constitutional treaty. Thus, the employer's duty to take "appropriate measures" is incorporated into the non discrimination chapter of the French Labour Code. The legislation establishes and reaffirms the principle of non discrimination in the hiring of people with disabilities. The hiring quota for disabled people is accompanied by financial supports to adapt the working settings and its access. The national association for the management of the funds for the participation in employment of disabled people (Agefiph), set up in 1987 in private sector to collect financial contribution from companies of 20 employees, has more than failed to meet the hiring quota of 6 % disabled workers. The new law reinforces the financial penalties raising them from 600 times the legal minimum hourly average to 1 500 times for companies that have not employed any disabled worker for more than three years. On the other hand, firms that have invested in integration measures will be able to deduct these costs from their Agefiph charge. Agefiph also campaigns for action by business to promote the employment of people with disabilities and helps finance dedicated job placements structures. One of the innovations of the new law is the creation of a public sector fund similar to Agefiph and called FIPH - vocational integration funds for people with disabilities in public sector.

The adapted companies (previously sheltered workshops) are now part of the mainstream labour market. They allow people with complex needs to fulfil an individual vocational tailored work and to be paid on the basis of the legal minimum income wage (SMIC). Those adapted companies receive from the State a fixed financial support by any provision of job. The disabled worker is considered as a full worker with a common right employee status. He can be employed with a fixed term contract or a permanent contract along with full rights. He is automatically eligible to Social security allowances. About 20 000 disabled workers are employed there. People, who cannot properly work in the mainstream environments because they are severely disabled, can be guided towards aid through work centres now called work support services (Etablissements ou services d’aide par le travail -ESAT). In 2004, 114 811 disabled people worked in 1400 ESAT. They provide vocational activities and individual supports (social, sanitary education, sanitary and psychology). They also favour social inclusion in healthy common life environments. Since January 2007, the guaranteed wages allowed to disabled workers was comprised between 55 % and 110 % of the legal minimum wage. The guaranteed wage is financed partly from the State, partly from work support services. It is possible for disabled workers to cumulate both the Adult Disability Allowance (AAH) and a guaranteed wage up to 100 % the national minimum wage.

At the end of 2006, the active disabled population was 715 000, of whom 610 000 had a job in regular working places and 105 000 in sheltered environments. 175 0000 people with disabilities had a job in public services and 35 000 are self-employed according to “Agefiph” final report 2006.

11.2.Specific Risks of Discrimination

The required 6 % rate of jobs for people with disabilities is not achieved. A takeover by force is necessary. This can be explained by the need for companies to employ people with disabilities and particularly those with severe disabilities actually in the training environment. The proportion of people with severe disabilities who may integrate the open labour market is very weak. Some severely disabled persons may integrate the market anyway thanks to the progress in the field of e-communication and technical aids. The need for output and competitiveness impedes very often the workshops to integrate persons with severe disabilities.

Barriers are opaque. Everybody prefers to pay rather than to be next to someone who is not as the others. Services mediators are needed to break psychological obstacles. In employment sector, the less viable people with severe disabilities are most of the time exposed to exclusion. Support services for employment should exist as well as in social life. Protected work is developing but the problem remains transportation.

Access to job through workshops (aid through work centre-CAT now called work support centre-ESAT) is possible for people with severe intellectual disabilities. When vocational integration in ordinary labour market sounds like a failure, the possibility to return to work in workshops remains.

12. Adults: Housing

Becoming an adult also means making up your mind about how you would like to live: stay in the natural family for a while, live alone, with a partner or family, with a friend, etc. Having privacy, a place to go to, feeling safe and comfortable there, realizing one's own ideas on how to live, are all very important for people in our societies. For people with complex needs it is a big challenge to find their own way to living. They have restricted alternatives for housing because they need barrier-free environments and life-long support. People with severe disabilities do not only need good support services but also counseling to realise their ideas and style of private living. How is this achieved?

12.1. Description of the National Situation

People with disabilities usually live at home or in special institutions or in intermediary environments. For those who have severe or complex needs, living at home often remains impossible due to many obstacles: problems of accessibility, adaptations of a dwelling, problems of financial resources, personal assistance, medical follow up and risk of social isolation.
The law of February 11, 2005 favours the policies of accessibility and housing adaptations, built environment and transportation accessibility, the improvement of financial resources and the granting of a compensation allowance to finance individual living environment adjustments, technical and human aids as well if required.
Disabled people are eligible to Resource Guaranteed (GRPH) when they are unable to work. It is composed of the Adult Disability Allowance (AAH) and of a new complementary allowance, the amount of which corresponds to 80 % of the national minimum wage. By January 1st, 2007, the amount was 621, 27 € per month and the amount of the complementary allowance was 179, 31 € per month.
The new right to compensation leads to the creation of a Compensatory Benefit. Are eligible, persons who suffer from an alteration of one or more physical, sensorial, learning and mental functions and who face difficulties to perform an activity or who experience severe difficulties in performing two activities out of four in the domains of Mobility, Private Care, Communication, General competences (space guidance, security management, mastering one's behaviour in social relation). The disability compensation allowance can be used to pay or to compensate personal family assistance or to pay one or more personal workers or services providers.

When diversifying service offers and concentrating on the needs of disabled people, the 2002 law should also favour their life at home and more particularly the life of those who have severe disabilities or complex needs. Combined allowances such as human aids, social and health support will help to alleviate the consequences of a disability through technical or human assistance. The aim of the French disability policies is to guarantee to disabled people a real choice between living at home, living in intermediary environments or in more traditional special institutions (accommodation centres, vocational and accommodation centres, medical accommodation centres or special accommodation houses) with a capacity of 100 000 places.

Disabled adults are also eligible to Nursing services at home (SSIAD). Services of assistance and support at home (SAAD) have been regulated. Multipurpose services of assistance and care at home have been created (SPASAD). They combine nursing services at home and human aids from the SAAD for elderly dependent and disabled adults as well. A legal definition is given to the 400 social life support services (SAVS) which are under the responsible of general councils. Services of health and social support have also been legally defined for adults disabled (SAMSAH), a kind of “medical SAVS”. These double price services correspond to a real alternative between medical accommodation centres. The health care price packages are the responsibility of the Social security which depends from both general councils and local authorities.

12.2. Specific Risks of Discrimination

Accessibility actions parameters must address the needs of severely disabled people. Besides, this should interest and comfort everybody. But this condition is not sufficient.

Maintaining or helping people with complex dependency to live in their places of residence always supposes networks of assistants. It requires also setting up networks of respite solutions.

Some experts and representatives fear the “all housing” logic saying this cannot be applied to all the people with severe disabilities because of their very big loneliness. Some others say “What we have to know for severely mental impaired persons, if whether they will attend a medical accommodation centre (FAM) or a special accommodation house (MAS)”.

13. Adults: Education and Leisure Time

Leisure time comprises all the time out of work to either relax or find a balance in contrast to every-day-life. Activities can be done on one’s own, organized in clubs or in various forms of cultural or other social facilities. In their leisure time, people in our societies are supposed to act with less formal restrictions and try to achieve a high degree of satisfaction and self-determination in their activities.

Adult education – taking the idea of life-long learning as postulate – can be seen as part of the individual’s leisure time, sometimes connected to work or the expectation that a certain course promotes one’s professional career. Sometimes people participate in adult education courses for the sake of their personal well-being, health or general personal development. For people with severe disabilities the participation in organized leisure time activities or adult education courses very often must be systematically planned and organized, because they are dependent on adapted courses, assistive technologies and other individual support, and barrier free infrastructure to enable their access. How is this achieved?

13.1. Description of the National Situation

According to the HID survey, the proportion of population from 20 to 59 years, living in residence which, regularly, practices at least one sport, attends a spectacle (at least once per quarter) or takes part in an association is of 82,5% concerning people without impairment, of 67,3% concerning people having declared an impairment at least and of 54% concerning people with moderate incapacities as for those with severe incapacities. As regards to holidays, the existence of impairment with moderate or severe incapacities clearly limits the access to holidays: 74% of the adults without impairment go on holiday at intervals at least annual. It is the case only for 58% of people having declared at least one deficiency, for 51% of those which belong to the group of people with moderate limitations of their activities and for 39% of those who belong to the group of people with severe limitations of their activities.

The ministry of culture and communication set up a national Commission on culture and disability issues with associations of people with disabilities. The aim of the Commission is to facilitate access to culture for people with disabilities, whatever the nature of their impairment so that they can fully participate in cultural life. The Commission makes propositions in any area, such as access to facilities, art practice, and training in order to get jobs in the cultural field.

The State Secretary responsible for Consumer Affairs and Tourism engages an action which aim is to strengthen operations in the field of accommodation and access to leisure, to culture and to holidays for disabled people whose integration into a traditional service of consumers represents both a social and an economic challenge.

The action engaged leads to the following main points:

- awareness and mobilisation of the whole tourism professionals in private and public sector for the accommodation of disabled people in their holidays, their leisure and cultural places through the national campaign “Tourism and disability”, as well as through conferences and exhibitions on accessibility issue.
- Consideration of the needs and wishes of disabled people for accessibility areas along with the creation and implementation of the national label “Tourism and disability” in local area in order to identify accessible holidays places and leisure activities that are accessible.

In order to prevent some abuses towards disabled people, some outdoors activities have been defined as excursions specially adapted for disabled population. The activities are intended for five days or more, with access for a group of three disabled adults or more. These excursions have to be recognized by local authorities for the quality of their services and security.

13.2.Specific Risks of Discrimination

Access to facilities should favour all people particularly those with severe disabilities and complex needs. But behaviours and attitudes from other people are still perceived as an obstacle. Physical appearance and absence of verbal communication makes the access to culture very difficult. The real problem is the fear people often feel toward people with severe disabilities. Educative and pedagogical actions for the public are necessary.

Non discrimination in the field of leisure activities sets out the question of accessibility and social supports of persons with severe disabilities. For example, information in museum should be accessible to them. UNAPEI together with AFNOR (French industrial standards authority) have elaborated a pictogram for the access of people with mental impairment. The question of holiday centres also needs to be put forward. The accommodation condition should also meet the needs of people without disabilities (no more than 3 to 4 persons in a room) and the activities should be organised according to the person's age.

Vacation stays for people with very severe disabilities need a much more important organisation than what is currently available. Such organisation is expensive. In everyday life, people with severe disabilities participate very seldom in sport activities. On the other hand cultural and artistic activities can be developed according to the capacities of the persons which vary to a great extent.

14. Adults: Partnerships and Parenting

According to social trends and changes, the decision of having one’s own family is not as easy as it used to be. More and more the decision to get married or to have children is a conscious one based on emotions, being aware of the changes that these decisions will mean.

Not too long ago the idea of people with (intellectual) disabilities getting married or having children was regarded as impossible. People with complex needs who wish to marry or have a child often have to face prejudices. After all, in their parenting they are dependent on special support. Professionals from different services and service sectors have to cooperate to prevent exclusion and discrimination. How is this achieved?

14.1. Description of the National Situation

According to the HID survey, in France, 72,9 % of the population from 20 to 59 years, living at home without disability, lives in couple. This proportion is a little weaker for people who have moderate activity limitations (71 %) and very sharply lower for people who have severe activity limitations (61,5%) (CTNERHI, 2004). In institutions, more than 90 % of the disabled persons don’t live in couple and three quarter, approximately, don’t have socio-emotional partner (HID).

People with severe disabilities experience serious difficulties in their socio affective relations and particularly in starting a family and have children. The law of February 11, 2005 for equal rights and opportunities, participation and citizenship for people with disabilities allows today a grant to compensate overspending due to the disability but disabled parents are not always in a position to get human aid for their child.

A study, undertaken by UNAPEI and controlled by a group of parents, concerned 500 families (all degrees of intellectual deficiencies). It shows that 60% of the children resulting from couples, of which one or two parents are disabled, are unscathed of any disability.

Another investigation, carried out by UNAPEI in about 200 families, shows that 65% of them preserve their right to keep their child and to organize freely their family life. That implies the responsibility to supervise, to defend, to take care of the child education, health, safety and morality. 20% of these families benefit from individual, family and community assistances and 80% receive assistance from associations facilitated by support services.

Professionals of support services are more and more confronted with the wish of people with mental disabilities, to have a child. People with mental disabilities accompanied by these services, express the will to live with and like other persons: to take public transportation, to work and to earn money, to have their own house, to go on holidays, to receive friends, to have a lover, possibly to get married and have a child...

The affective and sexual life of people with mental impairment remains a taboo subject even if it benefits of the support of special services. This consideration demands an important attention and awareness to the issues of responsibility and ethics. This means that any perspective of parenthood needs to be deeply studied step by step.

14.2. Specific Risks of Discrimination

Socio-affective relationship and sexual life constitute a right for all disabled people including the one with severe disabilities. We should behave responsibly in that sensitive field and any service creation should be made with the elaboration of a deontology of total authority**.** We have to think of the reactions of people with disabilities to any answer that has to be given to them.

The right to get a family life and a sexual life is fallow. It is based on the legitimacy of desire and the respect of people. We have to go beyond the denial, to train and to inform families and professional and to conceive external services of specific aids.

These two dimensions should be considered step by step. Parenting possibilities are limited. The child to be born could also think: who is going to bring him up?

People with severe disabilities, including those living in specialised dwellings, should have access to emotional life like other citizens, but this access has to take into account that their situation may differ from one person to the other. The co-existence of men and women in the same houses must be organised in a way that really respects the dignity and the freedom of each person. In France, as well as in the rest of Europe, the very great concern relates to the respect of the body integrity. Too many people with severe disabilities undergo sterilization without consent. An overall reflection is in progress in multidisciplinary professional teams but this reflexion should be thoroughly led in connection with families and legal representatives.

15. Adults: Exercising Civil Rights

One developmental task of adulthood is to know and to exercise one’s rights. This comprises the rights that a state confers to its people in order to secure protection and political participation, e.g. basic human rights and voting.

For people with severe (intellectual) disabilities, civil rights still cannot be exercised in every case. Additional support is needed to exercise democratic rights like voting. It is also a commonly held belief that people with severe disabilities or complex needs are in capable of serving in political positions. How can people with severe disabilities exercise their rights as citizens?

15.1. Description of the National Situation

In France, a disabled person living at home or living in special institution has the same civil rights as any other person. However his or her rights can be restricted in the case he or she is unable to assume them because of a very severe intellectual impairment or mental disorders.

In 1998, according to the HID survey, 519 872 persons were under legal protection, that means about 1 % of the population. 36 % of these persons were in institution and 64 % were living at home. Among the population in institutions, 28 % were under legal protection. The rate of legal protection by type of special institutions was 11 % in institutions for children and teenagers, 71 % in institutions for adult’s persons, 18 % in institutions for old people, 29 % in long stay hospitals, and 49 % in psychiatric institutions.

Today, approximately 700 000 persons are placed under a regime of legal protection. This number could be rose up to 800 000 or one million in 2010, according to diverse demographic projections. For that reason, the previous legal protection legislation is replaced by a recent law (law of March 5th, 2007). The regimes of legal protection are from now on applicable only to persons whose disabilities have been medically diagnosed. Persons whose impairment is the results of social or economic difficulties (and who is previously under a regime of legal protection) will be provided with adapted services and support services.

The new law allows any person to choose in advance a third party who will be in charge of controlling his or her interests and his or her person if because of age or disease the person requires protection. Parents with a disabled child can as well organize his legal protection in advance for when they will disappear or will not be able any more to take care of him. The protected persons will set, as far as their state allows it, the personal decisions concerning their health or their housing. The guardian will have to inform, to support and to explain them the decisions which he or she has to take. The guardian will also try to associate them in any decision with the management of their interests, as far as their capacities will allow it. The main measures of the law will come into effect on January 1st, 2009.

The law of February 11, 2005 on equal rights and opportunities, participation and citizenship for people with disabilities, also arouses the question of civil rights. It states that people under guardianship are allowed to vote. According to the law, polling stations and voting device should be accessible to disabled voters whatever their disability is physical, sensorial, intellectual or mental. The law also says that adjustments will be made in communication systems for hearing, visual or aphasic impaired people, to avoid action before the Court.

15.2.Specific Risks of Discrimination

Progress have been made in France concerning the possibility given to persons under guardianship to vote but the International Convention on the right of people with disabilities stresses more seriously this point.

Many people with severe disabilities should have the right to vote provided they are able to express their own choices and are free from any manipulation.

Civic education should prepare them early to democracy. For all people, severely disabled people, disabled people, or non disabled people, access to civil rights is fundamental and all the barriers must be eliminated.

16. Adults: Ageing and End of Life

Ageing contains a lot of new challenges: Retiring, organizing one’s day in a new way, coping with the loss of abilities and coming to terms with it and with one’s life. Regularly, more support is needed in day-to-day life and thus social dependencies are increasing. Often this means that familiar life settings must be changed because care needs cannot be covered anymore by the given arrangement. Most people don’t want to leave their familiar setting even when their care needs are becoming extensive and complicated. They prefer arrangements which are based on home care services that are reliable and flexible. When people reflect upon the end of their life there is also a wish to die in dignity.
How is this achieved?

16.1.Description of the National Situation

In France, three main types of problems worry traditionally the partners concerned by the ageing of severely disabled persons:

- the reduction of the capacities of disabled people which can increase their need of assistance and therefore lead to a modification of their way of life;
- the barrier of 60 years which constitutes generally a limit to obtain certain services, allowances, accommodations or supports;
- the future of ageing disabled people and the disappearance of their parents who are often their main carers.

These problems become more important because of a greater longevity of disabled people. In 20 years, the median age of disabled people who live in institutions will win approximately 10 years (DREES, on 2004). In the diverse residential institutions more than a quarter of disabled persons had in 2001, more than 43 years old. According to the HID survey, from 600 000 to 800 000 disabled persons of more than 40 years old who had a deficiency and an incapacity before they got 20 years old lived at home.

With The law of February 11, 2005 for equal rights and opportunities, participation and citizenship for people with disabilities, identified problems must be treated by the generalization of access to all social spaces, individualized compensation and through the raising of the administrative and institutional age barrier of 60 years.

The new social policy on full accessibility is for all people with disabilities whatever age he or she has. The Policy of accessibility which already covered housing in collective buildings, public buildings and workplaces is widened to individual houses and systems of transport. It has to include also all the spaces of the social life: cultural activities, leisure activities, holidays etc.

The individualized compensation is fundamental, especially for severely disabled persons. Every disabled person with severe disability has the possibility to seek the visit of a multidisciplinary team in the local disability house (MDPH) in order to elaborate a global plan of compensation. This plan covers all the aspects of the situation of the person to meet his needs in all the domains (environment, transport, training, employment, resources, technical aids, human helps, etc.). It can be revised on the request of the person according to the evolution of his or her disability in the environment.

Now the new law on Disability Compensation firstly dedicated to disabled people whose disability situation occurred before they are 60 years old, should now be applied to any disabled people without a barrier of age by 2010.

16.2.Specific Risks of Discrimination

The evolution of the situation of every severely disabled person can require fast adaptations of its environment and diverse systems of helps and supports. The answers are often too partial and too slow. They should always be conceived with the person by a multidisciplinary team of his or her nearness.

The rigidity of the institutions may induce breaks of care for persons whose situation is changing. This is often the case for people with severe disability. The criteria of admission in institutions can pull their exclusion.

Ageing disabled people are going to share the same living place with elderly people with disabilities. But these persons certainly possess a degree of self-dependency tradition and social living conditions different from the first ones. So, it will be necessary to avoid making a melting pot of every situation and to diversify the answers according to the needs of everyone.

Retirement houses for all should accommodate people with severe mental impairments by making some adaptations to the admission possibilities.

Special retirement houses also need to be created.

Interviews with Service Providers
Country: France

Dr Elisabeth Zucman

President of honour of Groupe Polyhandicap France (GPF), medical doctor founder of the centre of studies and care for people severe disabilities (CESAP), former researcher at the CTNERHI (National Technical Centre of Studies and Research on Disabilities and Inadaptations), professor emeritus at the CNEFEI, now that National Superior Institute of training and research for the education of children and youth with disabilities and for specialised teaching (INS HEA), member of the scientific and pedagogic council of the association for adults and youth with disabilities (APAJH).

Practitioner within settings and services for people with disabilities and in particular people with severe disabilities, Dr Elisabeth Zucman also developed research works and training activities about the analysis of the needs and the answers to be given to these persons.

General questions

- Could you comment the situation of people with complex needs and/or severe disabilities, sector by sector ?

Before commenting the table sector by sector, Dr Elisabeth Zucman underlines how interesting it is to define the population of this study as it is done, without focusing on a specific diagnosis nor any particular impairment but considering a whole of possible situations of high dependence, regardless their origins. She thinks this approach allows not to enclose reflection in restrictive categories and to favour a global treatment of difficulties, without useless segmentation of practices.

Here are the principal remarks of Dr Zucman for the different sectors:

Prenatal diagnosis: discrimination risks come from the way medical doctors will be trained, not for the scientific part but rather for the human part and in particular on how to announce the risk of highly serious disease to parents without making them to feel guilty. Parents should be seen together as much as possible, without isolating the mother.

Early intervention: neonatalogists are too lonely. They ignore the diagnosed disease's consequences in terms of disabilities. There is a huge gap between the diagnosis and what they may represent for the children and their families. The services of early intervention take care of children with severe disabilities as much as other children but too often are they swamped.

Childhood: the early childhood plan remains a mechanical petition. Since there is no financial means, this is pure illusion to think an adapted solution could be proposed for each child.

Education / School: the schooling difficulties encountered by children with disabilities reveal the lack of means of the National education and then the state of a nation. The conception of the system is based on a way of thinking that skips over disability complexity. The child is registered to a school but we are unaware of the reality and the concrete difficulties. Each child must have one referent but Elisabeth Zucman does know some referents who are supposed to be in charge of 400 (four hundred) children, so it naturally reduces the significance of their task. According to Dr Zucman, the new positions of school assistant (auxiliaire de vie scolaire, AVS) are precarious jobs that are not equal to the announced ambitions.

France is one of the rare countries that have a splitted approach of children with disabilities. An approach in terms of “particular needs of education” that concerns all the children who have some difficulties would be better.

Housing and family support: the access to allowances is too complex with administrative dossier that are very long to complete and the places of decision are too remote.
Professional training: the professional training sector is less open to people with severe disabilities, particularly when impairments' origin is not linked with a work accident.
Health care and social security: France suffers from a lack of doctors, from a disappearance of physiatrists and physiotherapists. Today you do find plenty of psychomotor therapists but they are not trained to deal with complex disabilities apart from the case of autism.
Employment: Barriers are opaque. Everybody prefers to pay rather than to be next to someone who is not as the others. So some mediator services are necessary in order to break the psychological obstacles. In the vocational employment district, people with severe disabilities who are the less viable are those who are the most exposed to exclusion.
Housing / Independent living: Elisabeth Zucman fears the "all housing" logic saying this can not be applied to all the people with severe disabilities because of their very big loneliness.
Leisure: Physical appearance and absence of verbal communication makes the access to culture very difficult. The real problem is the fear people often feel toward people with severe disabilities.
Partnership / parenting: The right to get a family life and a sexual life is fallow. It is based on the legitimacy of desire and the respect of people. We have to go beyond the denial, to train and to inform families and professional and to conceive external services of specific aids.
Civil rights: people who are under the care of a guardian should vote, if they are prepared to democracy early.
Ageing / End of life: Great variability of ageing as for every individual.

- According to you, what are the principal risks of discrimination towards people with severe disabilities, in France?

First of all, France is late on physical accessibility: transportation, airports, etc. But the psychological inaccessibilities and racism remain in spite of efforts. There is the fear toward serious behavioural disorders. Other problem: answers for the persons are too far. The departmental level for the administration is too far from people. The local level would be much more relevant. Moreover, we may fear the merchandizing of these answers, which would lead to propose brand new offices but without enough employees.

- According to you, what are the prospects for the policies against discrimination toward these persons, in France and in the European Union?

Right now, there is no minister or secretary of state in charge of disabilities. There should be one, joined to the health sector, in order for the partners to have one important national correspondent, in a global approach of disabilities and exclusion. The most important works' perspectives are: organization of answers at the local level; training of the professionals who work in each sector; information of people and families; development of accompaniment and mediation. "Human force" should be favoured and supported.
Another important point: including the ICF culture and especially the approach of the positive side of the resources, capacity and performance of each person.

Specific questions for representatives of service providers

- What can you say about the difficulties of people with severe disabilities having access to support from professional services?

These difficulties come from a breaking up of human aids they need and from the settings and services’ rigidity.

- How many and what kind of people are excluded from all or certain services and get only support from their families?

Exclusion concerns mainly people with serious behavioural disorders whatever their age is.

- In which areas of the support system do you see problems of availability or bad quality?

A huge gap exists between the announcement of the diagnosis and the first undertaking. The aids for daily living are not enough available and the breakings of the undertaking are too frequent.

- Are there differences in quality of services for people with mild, profound and severe disabilities?

The difference lies in the density of aids for daily living which is not sufficient for people with profound and severe disabilities. They also experience more difficulties in order to be healed.

- Which structural problems do you see in the service system and in service providing?

Structural problems are the settings and services’ rigidity, the fact that the answers are too far from the people and the cumbersomeness of the administration. Moreover the financial means are not certain for the near future.

- Which problems do you see in inter-sectoral co-operation, in service planning and delivery?

Cooperation is often difficult between the sector in charge of care and the sector in charge of education.

- What are the main concepts for the support of people with severe disabilities in your country? Are there differences between provider groups? Are there ‘taken for granted assumptions’ in this field that foster discrimination?

In France, we must decrease the impact of the diagnosis and think in terms of situation and understanding of the persons and their aspiration. Generally, the conception of the actions would be better if thought more pragmatically.

- What are the biggest challenges for the development in service providing for persons with severe disabilities?

The most important challenge is to develop the density of the employees in every domain (daily living, care, education, accompaniment, mediation …), to reinforce their support and their initial and life-long training.

- What experience have the service providers with personalised service delivery and personal budgets?

No personal experience in this field.

Interviews with DPOs

Country: France

Mrs Michèle Ducroizet
Assistant President of the federation of organisations for parents and friends of mentally disabled persons (UNAPEI)

General questions

a) Could you comment the situation of people with complex needs and/or severe disabilities, sector by sector?

Mrs Ducroizet agrees with the whole presentation of the legislation and policies related to the situation of people with severe disabilities in France. Her following remarks sector by sector stress her view.
Prenatal diagnosis: Parents may be subject to discrimination. Actually, they are not welcome the same way according to the person they deal with and the information they expect to receive.
Early intervention: When children have complex needs or severe disabilities, particularly mental impairment, the services of early intervention should rely on reinforced multidisciplinary teams. Children should benefit from more important care.
Childhood: The reception of a child should be possible in nursery school, in child care centre and in day nursery. But this is not always the case because the structures are subject to the availability of places (particularly in child care centre and day nursery).Even then, if the child can not attend these structures due to the lack of places, parents are usually obliged to cease any professional activities. Therefore, they are also victim of discrimination.
Education / School: The principle of registration of any child with a disability to his or her local primary or secondary school is a very good one, but this should not be just an illusion. Some parents suffer from this situation because even if they really know their child is registered in his local school, they are not sure he can attend it. According to Mrs Ducroizet, in improving school condition for children with mental impairment and particularly when their disability is severe and their needs complex, the National education and the medico-social services should be fully complementary. As long as this will not be well organized and effective, the education of children with disabilities will be very difficult. The setting up of school assistants is actually a positive action but school attendance for some children should not be refused under the pretext that there is no school assistant left ! Paradoxically a measure which is set up to facilitate the reception of the child can also be a ground for discrimination only because it doesn't function properly.
Housing and family support: When children with severe disabilities live in they families, it is important that parents could benefit from breathing spaces. This implies the introduction of a new dimension in the organisation of services which intervention can occurs at certain time and also in the organisation of structures children can attend at some periods.
Leisure: Non discrimination in the field of leisure activities sets out the question of accessibility and social supports of persons with severe disabilities. For example, information in museum should be accessible to them. UNAPEI together with AFNOR (French industrial standards

authority) have elaborated a pictogram on the access of people with mental impairment. The question of holiday centres also needs to be put forward. Their accommodation condition should satisfy people without disabilities (no more 3 to 4 persons in a room) and their activities should be organised according to the person's age.

Professional training: a vocational training must be organised for the severely mental impaired persons in special medico professional institution (IMPro). It will be admitted that they could have access to professional training sector, but Mrs Ducroizet recognizes that training is more difficult to find for them.

Employment: Access to job through workshops (aid through work centre-CAT now called work support centre- ESAT).is possible for severely mental disabled persons. When vocational integration in ordinary market sounds like a failure, the person should have the possibility to return to work in workshops. For people with severe disabilities, there is no illusion: the possibilities left to get a job are very weak even in the adapted companies.

Health care and social security: the recognition of health problems (teeth and gynaecological problems in particular) of severely mental disabled persons is not easy. We should be vigilant because these persons are unable to express what they feel properly. This implies to prepare doctors to deal with disability issues. Mrs Ducroizet underlines the existence of a specific supplementary health insurance called « integrance » created to meet the needs of people with disabilities included those with severe disabilities and great dependency.

Housing / Independent living: what we have to know for severely mental impaired persons, if whether they will attend a medical accommodation centre (FAM) or a special accommodation house (MAS) .

Financial resources: disabled persons with independent housing are the only one eligible to complementary allowances of the Adult Disability Allowance (AAH). People with severe disabilities are less granted. The new Disability allowance compensation (PCH) provides an interesting potential benefit to finance technical aids, facilities in current environment and human aids. But can the PCH cover and meet the needs of severely mental impaired persons perfectly ?.

Partnership / parenting: these two dimensions should be considered step by step. Parenting possibilities are limited. The child to be born must also be think of : who is going to bring him up ?

Civil rights: yes, social and civil rights are necessary but mind interference

Ageing / End of life: retirement houses for all should accommodate severely mental impaired persons by making some adaptation to the reception. Special retirement houses are also to be created.

- In your opinion: What are the main risks of discrimination against person with severe disabilities in your country?

We must avoid the fact that under the pretext of non discrimination, we fail to meet the needs of these persons. This represents the first risk of discrimination. Another important risk: Broadly speaking is the problem of accessibility including environmental, technical and cultural accessibility dimension in all the area of social life. The lack of real answers to face the reception of these persons in special institution; the lack of financial means to assure and to make public policy effective.

- In your opinion: What are the perspectives of anti-discrimination policies for people with severe disabilities in your country and in the EU ?

Home special services supplies such as social life assistant services and supports services including leisure activities should be developed. But special institutions for ageing people with severe disabilities should be created. We need to be sure there is no breaking off in social supports.

Specific questions for NGO and/or self-advocacy representatives

- <u>What are the most important issues to articulate for people with severe disabilities in interest groups rsp. lobby work?</u>
We have to improve the negative image of severely mental impaired persons. There is also the problem of taking into account the person own expression of his needs, aspirations and life choice.

-What are the key issues in the field of participation of persons with severe disabilities ?
The essential question is that of the development of adapted communication tools. This should appear not only in ordinary environment but also in specialized areas where sometimes people come to sign up important documents without being informed about the content with any adapted tool. Those tools do exist but they are not been developed by lack of means. Another essential question is the necessity to develop human supports for severely mental impaired persons and enable them to participate to social activities.

-What are the key issues in the area of discrimination against people with severe disabilities ?
Besides the issues mentioned before, Mrs Ducroizet underlines here the main problem that occurs by lack of equity at the level of the whole nation. National policy is different from a department to another in spite of the regulations wished for by the National independent-living support funds (CNSA).

<u>- Are there people with severe disability who work within NGO’s or self-advocacy organizations?</u>
People with mental impairment, whatever the importance of their disability may be, can as a rule, become member of our association and participate to our activities.

<u>- How do you co-operate with special interest groups of people with severe disabilities?</u>
We have created an association called « Nous aussi » (We too) which members are only people with disabilities. It is an active association that takes part in international meetings and represents persons with severe disabilities as well. Besides, we work with other associations of persons with severe disabilities within the framework of a Board of agreement.

- <u>What are your experiences to articulate the special needs and interests of people with severe disabilities in public discussions at regional and national level?</u>
We have contributed to the elaboration of the disability law of 2005 and its decrees. We have encountered some difficulties to make certain ideas pass in force, particularly the one of the removal of the upper limit to the necessary volume allowed for human aids and that of the care taking for the security of people with severe disabilities. Another difficult idea to be passed in force is the importance of guardianship for more liberty in so far as it assures a form of protection.

Interviews with Policy-Makers

Country: France

Patrick Gohet
Inter-ministerial delegate for people with disabilities (DIPH)
Former Director-General of the federation of organizations for parents and friends of mentally disabled persons (UNAPEI)
Former President of the Mutual Insurance Company for people with disabilities and their family

General questions

- In your opinion: What are the main risks of discrimination against person with severe disabilities in your country?

First of all, the main causes are cultural and people with complex needs are first exposed to. A society culture is inspired by the way disability is considered in it and this is true as far as severe disabilities are concerned. Disability creates anguish and anxiety. It is both a state and a situation society refuse to face. In France we have that reputation which consists to sort out special solutions only when severe disability is concerned. This is just exaggerated. In fact, our system is very diversify. Hence, since 30 years and more precisely 5 years, our policies have been oriented towards an open society for people with particularly severe disabilities. Our disability policy aims to favour the autonomy and insertion of people with disabilities whatever the degree of their disability. As far as discrimination is concerned, we have to make out a difference between “a light discrimination” and “a hard discrimination”. The first one consists of revealing the differences and characteristics of the so called disabled or people in a disability situation in order to define answers, assistance and supports which in fact are intended to avoid “a hard discrimination” which can be seen in fact in individual or collective behaviour of exclusion. All that corresponds in daily living to diverse answers that are not necessary related to the characteristics, the needs and the aspirations of the disabled. This situation also constitutes a source of discrimination. In the case of severe disability, two groups have to be considered : the one in which people have severe disabilities and are able to lead they own life and the one in which people need some supports and assistant. The answers given should take into account the needs and the diverse possibilities of the two groups. Discrimination also comes from an idea deeply rooted in the great public’s belief such educators, employers who think that there will be a linear relation between the severity of disability and the capacity to learn, to get a job and to live in society capacity. I think that this can not be not true for one can suffer from a very severe disability and have success in education, a good professional career and a comfortable social level.

- In your opinion: What are the perspectives of anti-discrimination policies for people with severe disabilities in your country and in the EU?

The European Union have created a tool to fight discrimination in work place. The NGO are in favour of a directive on discrimination in every domain. EU's decision will depend on the assessment of her own initiative in the field of employment and on the apprehension her own prerogatives. In France we project to elaborate a very expected law that will integrate severe disability issue into disability policies’ objectives and various measures. The emergence of a lobby group among people with severe disabilities have contributed to create collective awareness. They have reinforced the action of another lobby group in multiple impairments with mental disorder. Today, richness in the questions and prospects from people with severe disabilities who are able to make free choice exist.

Anyway, the question of the social cost should not to be denied. Meeting the needs of people with severe disabilities represents a lot of money and this situation may bring along arguments and hesitation.

1. Could you comment the situation of people with complex needs and/or severe disabilities, sector by sector according to the table on the French policy and legislation ?

Before commenting the table sector by sector, Mr Patrick Gohet underlines the fact that it shows clearly the legislation and policy on the situation of people with disabilities in France.

His following remarks on the different sectors underpin his view of disability policies in France

- <u>Prenatal diagnosis</u>: According to Mr Patrick Gohet, there are two fundamental principles: full information and total free choice for both parents.
- <u>Announcement</u>: Vocational training should be developped
- <u>Early interventions</u>: they don’t have the importance required in the disability policies. We should increase those device.
- <u>Education/School</u>: in nursing school, progress are meaningful. Even with this important progress, attention focused on the necessity of the needs under the form of interventions of school assistants to the detriment of various pedagogical and educative answers and also on the necessity of professional of specialized sectors’ assistance.
- <u>Employment:</u> The required 6 % rate of jobs for people with disabilities is not achieved. A takeover by force is necessary. This can be explained by the need for companies to employ people with disabilities and particularly those with severe disabilities actually in the training environment
- <u>Accessibility:</u> Accessibility actions parameters must address the needs of the severely disabled. Besides, this should interest and comfort everybody
- <u>Leisure</u>: access to facilities should favour any people particularly those with severe disabilities and complex needs. But behaviours and attitudes from other people are still perceived as an obstacle. An educative and pedagogical actions of the public are necessary
- <u>Partnership and parenthood</u>: Socio-affective relationship and sexual life constitute a right for any disabled included the one with severe disability. We should behave responsibly in that sensitive field and any service creation should be made with the elaboration of a deontology of total authority**.** We have to think of the reactions of people with disabilities to any answer that has to be given to in that direction.
- <u>Civil rights:</u> Progress have been made in France as for the possibility given to persons under guardianship to vote but the International Convention on the right of people with disabilities stresses more seriously this point.
- <u>Ageing:</u> the ageing disabled persons are going to share the same living place with elderly persons with disabilities. But these persons certainly possess a degree of self-dependency tradition and a social living condition different from the former. So, it will be necessary to avoid

making a melting pot of every situation and to diversify the answers according to the needs of everyone.

Specific questions for policy-makers

- Are there policy programmes/legislation, which have intended or un-intended effects on persons with severe disabilities?

First of all, people with disabilities and whatever the severity of their impairments will be, are under the responsibility of the High authority against discrimination and for equality (HALDE) which has been set up to fight discrimination and to promote equal opportunities. Secondly specific legislations take into account the aspirations of the severely disabled.

- In which political field is the life situation of people with severe disabilities currently on the political agenda at national level?

The institutional device has been changed. There is today a Minister at the level of the ministry of Work, social relations and solidarity who treats the action and there is a transversal device which is under the control of the inter-ministerial delegate.

- Who are the most important actors in the national policy field for persons with severe disabilities?

The organization representative of people with disabilities are the most important because they are the one who give the warning sign very early. They act before any really political action particularly as far as severe disability is concerned.

- What are the key issues in national policy field for person with severe disabilities?

The two fundamental elements we need to progress are :

- equal treatment
- identification of specific needs

- Are there specific policy programmes for persons with severe disabilities that already exist?

Many action plans are set out to be elaborated : the multiple impairments plan, the rare disability plan, the autism plan, the mental health plan.

- Are there specific policy programmes for persons with severe disabilities in preparation?

The multiple impairments plan and the rare disability plan are presently going to be restored.

List of abbreviations

AAH	Allocation aux adultes handicapés *(Adult Disability Allowance)*
AEEH	Allocation d'éducation de l'enfant handicapé *(Allowance for a child with disability)*
AFNOR	Association française de normalisation *(French industrial standards authority)*
AFPA	Association nationale pour la formation professionnelle des adultes *(National mainstream training agency for adults)*
Agefiph	Association pour la gestion des fonds pour l'insertion professionnelle des personnes handicapées *(National association for the management of the funds for the participation in employment of disabled people)*
AGGIR	Autonomie Gérontologique - Groupes Iso-Ressources *(Tool for the evaluation of dependency needs of elderly people)*
AJPP	Allocation journalière de présence parentale *(Daily allowance for parental presence)*
APA	Allocation personnalisée d'autonomie *(Allowance for autonomy for elderly people)*
CAMSP	Centre d'Action Médico-Sociale Précoce *(Early medico-social action centres)*
CDAPH	Commission des droits et de l'autonomie des personnes handicapées *(Disabled person's rights and independent living Commission)*
CESAP	Comité d'Etude et de Soins Aux Polyhandicapés *(Centre of studies and care for people with multiple disabilities)*
CRP	Centres de réadaptation porfessionnelle *(Vocational rehabilitation centres)*
DREES	Direction de la Recherche, des Etudes, de l'Evaluation et des Statistiques *(Direction for research, studies, evaluation and statistics)*
ESAT	Etablissements ou services d'aide par le travail *(Work support services)*
FAM	Foyers d'accueil médicalisé *(Medical accommodation centre)*
GRPH	Garantie de ressources des personnes handicapées *(Resource Guaranteed for people with disabilities)*
IMPro	Institut Médico-Professionnel *(Special medico-professional institute)*
INED	Institut national d'Etudes démographiques *(National institute for demographic studies)*
MAS	Maisons d'accueil spécialisées *(Specialized accommodation house)*
MDPH	Maison départementale des personnes handicapées (*Local Disability House*)
PPS	Projet personnel de scolarisation *(Personal schooling project)*
SESSAD	Service d'Education Spécialisée et de Soins A Domicile *(Services of specialized education and care at home)*
SAAD	Service d'Aide et d'Accompagnement à Domicile *(Services of assistance and support at home)*
SAMSAH	Services d'accompagnement médico social pour personnes adultes handicapées *(Services of health and social support for adults disabled)*
SAVS	Services d'Accompagnement à la Vie Sociale *(Social life support services)*
SMIC	Salaire minimum interprofessionnel de croissance *(Legal minimum income wage)*
SPASAD	Service de soins infirmiers à domicile et service polyvalent de soins et d'aide à domicile *(Multipurpose services of assistance and care at home).*
SSIAD	Services de Soins Infirmiers A Domicile *(Nursing services at home).*
UNAPEI	Union nationale des associations de parents, de personnes handicapées mentales et de leurs amis *(Federation of organisations for parents and friends of mentally disabled persons)*

Study on the Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs

www.non-discrimination.eu

Country Report Germany

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Tender on Behalf of the European Commission
D.G. Employment, Social Affairs and Equal Opportunities
Integration of People with Disabilities - Unit G3

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1. Summary

This paper contains information on the specific risks of discrimination of people with severe disabilities and complex needs in Germany.

An introductory part presents general aspects of categorization approaches, availability of data and eligibility procedures. According to, disability statistics around 2.5 % of the population are categorized as ‘severely disabled’, but as there is no uniform categorization system in rehabilitation, available data does not represent prevalence adequately. Following a life-course systematic, the main part of the paper consists of 14 sections with a nearly identical structure. As people with severe disabilities are depending on specific arrangements or support to cope with life challenges especially in periods of transition, the availability of support services or barrier-free conditions are crucial for social participation in relation to discrimination. Secondly, for each phase of life or dimension the characteristics of the support system and other relevant information are presented in a very dense form. On that basis, thirdly, specific risks of discrimination for people with severe disabilities or complex needs are formulated as essential for a given life phase. Due to lack of space, references were mostly not added in this paper but are part of the annotated bibliography.

The German Basic Law prohibits discrimination due to a citizen’s disability and the Social Code Book IX provides a common framework for legislation and policy in the field of rehabilitation and social care for disabled people. Despite an increasing sensitivity towards civil rights, people with severe disabilities and/or complex needs are under high risk of discrimination especially as far as their social rights are concerned. Material and immaterial barriers, taken-for-granted assumptions, restrictive institutional traditions and partly also lack of resources, often constraint and harm possibilities of personal growth of people with severe disabilities, seen generally as incapable for a ‘normal’ life course.

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Der vorliegende Länderbericht beinhaltet Informationen über die spezifischen Risiken der Diskriminierung von Menschen mit schweren Behinderungen oder komplexem Hilfebedarf.

Das einführende Kapitel beinhaltet eine begriffliche Annäherung, informiert über vorliegende Statistiken und erläutert die Verfahren zur Feststellung einer Behinderung und zur Klärung von Anspruchsberechtigung.

Entsprechend der Schwerbehindertenstatistik gelten in Deutschland etwa 8,2 % der Bevölkerung als „schwerbehindert“; eine zuverlässige Aussage darüber, wie viele Menschen mit komplexem Hilfebedarf jedoch in Deutschland leben, lässt sich daraus jedoch schwer ableiten.

Einer Orientierung entlang des Lebenslaufs folgend werden im Weiteren 14 verschiedene Lebensbereiche/- Phasen in einer fast identischen Struktur präsentiert: Da Menschen mit komplexem Hilfebedarf oder schweren Behinderungen in Situationen des Übergangs auf eine Anpassung ihres Hilfesystems angewiesen sind, und diese mit erheblichen Risiken des Ausschlusses verbunden sind, ist vor allem die Verfügbarkeit adäquater Hilfen und

Unterstützungssysteme bedeutsam, wenn es um Möglichkeiten zur Teilhabe und Partizipation resp. die erfolgreiche Bewältigung von Übergängen geht. So werden dann auch für jede Lebensphase charakteristische Merkmale - unter anderem des Unterstützungssystems - benannt, ebenso aber spezifische Risiken der Diskriminierung identifiziert.

Insgesamt sind einige positive Entwicklungen zu beobachten: Das deutsche Grundgesetz untersagt Diskriminierung aufgrund von Behinderung und das Neunte Sozialgesetzbuch stellt eine gesetzliche Grundlage zur Sozialen Sicherung und Teilhabe – Eingliederung – von behinderten Menschen dar. Im öffentlichen Bewusstsein tritt eine Sensibilisierung im Bereich der Verwirklichung von Bürgerrechten ein. Dennoch: Schwer behinderte Menschen sind vor allem dann von Diskriminierung bedroht, wenn es um ihre Rechte und Partizipation geht. Materielle und immaterielle Barrieren, scheinbar selbstverständliche Annahmen, einschränkende institutionelle Praktiken und teilweise auch ein Mangel an Ressourcen schränken die Möglichkeiten zur individuellen Entfaltung von Menschen mit komplexem Hilfebedarf ein und bedrohen diese – vor allem dann, wenn mit der Zuschreibung einer schweren Behinderung die Möglichkeiten zur Orientierung am „normalen“ Lebenslauf erschwert werden.

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Ce document contient des informations sur les risques spécifiques de discrimination des personnes avec des handicaps sévères et des besoins complexes en Allemagne.

L’introduction présente des généralités sur les approches de classification, la disponibilité des données et les procédures d'éligibilité. Selon les statistiques, environ 2,5% de la population sont répertoriées comme «sévèrement handicapés », mais le secteur n’ayant pas de définition uniforme, les données ne représentent pas correctement la prévalence. Suivant les cycles de la vie, le corps de ce rapport se compose de 14 sections présentant une structure presque identique. D’abord, il décrit le développement de l’individu dans les sociétés modernes pour une phase donnée de vie. Les personnes avec handicaps sévères étant dépendantes d’un accompagnement spécifique pour affronter les défis de la vie particulièrement pendant les périodes de transition, la disponibilité des services ou l’absence de barrières sont cruciales pour elles. Ensuite, pour chaque phase de vie, les caractéristiques des services nécessaires à cette période ainsi que toute autre information appropriée sont présentées sous une forme très condensée. Enfin, il en ressort les risques importants de discrimination pour cette période de la vie. En raison du manque d’espace, les sources ne sont pas reprises mais figurent dans la bibliographie.

La Loi Fondamentale Allemande interdit la discrimination sur la base du handicap et le Code Social Livre IX fournit un cadre commun à la législation et la politique dans le domaine de la réadaptation et des services sociaux pour les personnes handicapées. Malgré une sensibilité croissante aux droits civils, les personnes avec des handicaps sévères et/ou des besoins complexes ont un risque élevé de discrimination, particulièrement en ce qui concerne leurs droits sociaux. Des obstacles matériels et immatériels, des « a priori», des traditions institutionnelles restrictives de droits et, pour partie aussi, le manque de ressources restreignent et nuisent aux possibilités de développement de ces personnes, généralement considérées comme incapables d’avoir une vie «normale».

2. Introduction

National Approaches to identify the group of people with complex needs

According to different traditions in various parts of the rehabilitation field, in Germany there is no comprehensive consensus on the definition of disability. Existing definitions are related to the context of their use and validity. Therefore, there can be also no uniform definition of people with severe disabilities and complex support needs.

Recently, however, some standardization has being set by legal regulations pertaining to social rights of people with disabilities. A new overall approach in the rehabilitation field was started by the definition in Social Code Book IX (§ 2) in 2001. Influenced by the International Classification of Functioning (ICF), disability is considered to be a restriction of the ability to participate in social life, as a cause to the deviant condition of the person. In this sense 'disability' is defined as being a permanent deviance of physical functions, mental abilities or of the mental health, based on a comparison to „the typical condition of their age group"(§ 2 SGB IX). This definition was literally adopted in the Social Code Book X II (SGB XII), where entitlements for 'integration assistance' for disabled people are regulated (§§ 53 SGB XIIpp.). Access to 'integration assistance' have persons with a 'considerable' disability (*Wesentliche Behinderung'*), what is defined according to the 'integration assistance regulation' (*Eingliederungshilfeverordnung).* According to this regulation there are groups of people who have a considerable disability 'by law' (e.g. deaf, blind, deafblind), as far as people with physical, intellectual or mental health related disabilities are concerned, an individual assessment has to be made. As the regulation uses undefined terms of law to describe disabilities, there is room for administrative interpretation in assessment procedures whether a disability is 'considerable' or not.

This new understanding of disability as restricted participation has so far had no influence in another system of rehabilitation, namely the procedure for formal statutory recognition of the disability status that gives access to a wide range of compensations for disadvantages. This procedure is still limited to the diagnosis of a deviant status of an individual. Using an official 'guideline for medical assessment', physicians in charge examine the reduction of the individual's performance or capacity to earn a living. The extent of disability is measured in 10 grades (10 – 100 % Grad der Behinderung, GdB). In this system, a person with a score of at least 50% is considered to be 'severely disabled'. This score can be achieved through a single impairment or by the additive consideration of different impairments. People with severe disabilities and complex needs would very probably get a disability score of 100 %.

The official guidelines followed by the assessing doctors often bases on the traditional distinctions of mild, intermediate and severe impairments. As described, the procedure results in the statement of a score, it does not make any statements regarding intensity or extend of support needs. Thus, it is not compatible with the concept of understanding disability being related with support needs..

In the area of 'Long-term Nursing Care Insurance' an approach to care needs connected with central activities-of-daily-life was developed. It refers to four types of activities: personal hygiene, food, mobility and house-keeping. The following categories were formed:

1. *Care Level I* classifies a *considerable need of care*. Persons on this level need help at least once a day with personal hygiene, food, or mobility, with a minimum of two activities from one or more these areas. They also need help several times a week with household chores. Persons need an average of at least 90 minutes every day of the week for basic care and help with household chores. A caregiver must spend more than 45 minutes of this time providing basic care.
2. *Care Level II* classifies a *severe need of care*. Persons on this level need help at least three times a day with personal hygiene, eating or getting around. In addition, they need help several times a week with household chores. People designated as level II need help for an average of at least three hours a day, with at least two of these hours being devoted to basic care
3. *Care Level III* classifies an *very severe need of care*. Persons on this level need 24-hours care every day. They need help with personal hygiene, food or mobility, as well as help several times a week with household chores. Care requirements at Level III add up to at least five hours a day, with at least four of these hours being spent on basic care.
4. Housekeeping is defined as shopping, cooking, cleaning, dishwashing, changing and washing linen and clothing, and maintaining an appropriate temperature in the home. This approach is limited incompatible with concepts that consider disability as needing special support, but it is limited to nursing care.

Since the term of ‘severe disability’ (*Schwerbehinderung*) is already used in the legal recognition procedure, in the field of education or social services terms like ‘most severe disability’ or ‘multiple disabilities’ are also in use, in order to describe persons with high and complex support needs. Clear criteria for the use of the terms are missing however. As an example the parent association of Lebenshilfe defined the group characteristics as being people with intellectual disabilities with high or very high support needs in essential areas of life, combined with one or several of the following characteristics:

- substantial additional impairments (e.g. physical handicaps, impairment of the senses, epilepsy, hyperactivity, psychological and organic illnesses)
- specific behavioral expressions/manifestations (e.g. auto-agressive or agressive behavior, a state of anxiety, crying, stereotypes, contact defense, passivity, retreat, autistic symptoms)
- specific reduced communicatory behavior (predominantly nonverbal)
- frequently very unstable, sometimes life-threatening state of health.

Within in all fields of the disability policy we find an intensive discussion about the philosophy and the classification system of the ICF. So far this has not yet lead, however, to a new and concisive classification approach to disability. This produces a situation where especially people with severe disabilities and complex needs have to respond to various classification procedures and criteria, when they want to apply and realize their legal entitlements.

Available data on people with complex needs

There are two important statistics which allow for conclusions on the number of people with complex support needs and/or severe disabilities in Germany.

1. Statistics on the Severely Disabled (*Schwerbehindertenstatistik)*
Every two years a statistic regarding severely disabled persons is published by the Federal Statistical Office. This statistic only includes persons who apply for a ‘disability card’ and who are officially approved as ‘severely disabled’. According to the official statistic, as of the 31st of December 2005 6,8 Mill. persons were recognized as severely disabled. This corresponded to approximately 8.2 % of the total population. For approx. 1,7 Mill. of these persons the GdB is 100. Additional information gathered from the severely disabled card permits better insight into the extent of support needs rather than the GdB conclusions. The ‘severely disabled card’ can be marked with an ‘H’ (for helpless). Persons with ‘H’ on the severely disability card are identified as needing high support, especially in day-to-day activities (e.g. dressing themselves, eating, hygiene, etc.). The frequency of the ‘H’ classification is not reported in the official severely disabled statistics. Using the largest German federal state, North Rhine-Westphalia, as an example, it can be assumed that approximately 11 % of severely disabled people are recognized as "helpless". Thus approx. 750,000 persons or 0.9% of the population may be regarded as the minimum estimation of the persons with very high and complex support needs in the Federal Republic of Germany.

2. Statistics on long-term nursing care (*Pflegestatistik)*
The statistics on long-term nursing care are also published every two years. Altogether, approx. 2,1 million persons (approx. 2.5% of the population) received benefits of the nursing care insurance at the end of 2005. Approx. 1.1 Mill. people received benefits from care level I, approx. 800,000 persons received care level II benefits, and approx. 300,000 persons from the care level III benefits.

Classification systems, procedures and identification-practises
The classification systems in use orient themselves with the contexts of disability in their respective usage. So, the procedure to obtain the severely disabled card is characterized by the necessity of making a clear decision about entitlements for benefits. Using an official manual physicians usually make their decision on the basis of submitted appraisals from the personal doctors. The procedure orients itself with medically diagnosable conditions.

Also the procedure to assess entitlements for nursing care services is oriented to make such a decision. Usually the procedure is done by physicians who work for an independent assessment service (medical service of the health insurance). The physicians visit the applicants in their own household or in an institution. Using checklists they assess the extent of care needs.

Due to the fact that these assessment procedures do not allow for conclusions on support needs, in many different areas of rehabilitation there are additional procedures and instruments in practice to identify support needs and consequently administer entitlements/benefits. Since some years in the realm of integration assistance, procedures for ‘individual service planning’ have been established in most parts of Germany. The procedures are, however, set up very differently. The need to improve these procedures and to come to a more obligatory and standardized form is growing, especially for people who receive benefits as direct payments. For them it is necessary that assessments are made to determine the amount of the budget.

3. Pre-Natal Diagnosis and Counselling

Through the extended possibilities for family planning, parenthood in modern societies has increasingly become a question of individual decision-making. Prenatal diagnostics and reproduction technologies permit the inclusion of characteristics of the fetus in this decision. This extended knowledge brings individuals into difficult situations when they have to make decisions regarding children. These individual decisions are affected by social values, attitudes, anxieties and knowledge of disabilities. They are also influenced by the quality of the counseling process if professional support is available and used. It is important that individual decisions are accepted by the social environment of people concerned. How is this achieved?

3.1. Description of the National Situation

Prenatal Diagnostics have developed into a routine procedure in the realm of pregnancy care in Germany. Women are entitled to pregnancy care through their health insurance. The organizations of physicians and health insurances negotiate the extent and content of this entitlement and put it into an official guideline. According to this guideline, the care also covers the information of genetic risks and prenatal diagnostics. In the context of regular medical examination, the differences between health care in pregnancy and prenatal diagnostics without therapeutic use disappears. The legal entitlement of pregnancy care, however, should not be equated with the informed consent of prenatal diagnostics.

The abortion of an impaired foetus, confirmed by medical indicators, is permitted until birth if there is a danger to the life of or a danger of serious impairment of the physical or mental state of health of the pregnant women (§ 218 a StGB). In contrast to other abortions, a consultation independent of the medical examination and to rethink the planned abortion are not laid down by law. Services for pregnancy counselling, self-help groups and other voluntary organisations offer independent counselling. In a few regions only there is a systematic co-operation between medical services and counselling services.

According to official statistics, the number of abortions in 2006 based on medical indication was 3,046. This corresponds in total to 2.5 abortions per 10,000 women between 15 and 45 years. Since 1996 the statistics easily show that the numbers are declining. It is not known how many cases of abortions there are because of an impairment of the foetus.

A special problem is late abortion after the 22nd week of pregnancy, which is permitted with a medical indication. In the case of a live birth after an attempted abortion, physicians are required to attempt to preserve the child’s life. The official statistics list a total of 183 abortions for 2006 starting from the 23rd week of pregnancy, but a high number of unreported cases is estimated. There are reports that some children with severe impairments don’t get appropriate treatment and support after birth. For such children there is a higher risk of death immediately after birth. In the political sector there is an argument to limit the exemption from punishment for abortions strictly up to the 22nd week of pregnancy.

In public discussions there is a high sensitivity regarding the spreading of eugenic tendencies in the society. An important organisation in the field of disability (Aktion Mensch) started a campaign for an open discussion of bioethical issues in society a few years ago. Many people in Germany have considerable reservations about pre-implementation diagnosis and genetic research. Whether this has effects on the individual use of Prenatal Diagnosis remains unproved.

3.2. Specific Risks of Discrimination of People in Situations of Major Dependence or with Complex Needs

Through the definition of the medical indication and the legal entitlement for prenatal diagnosis in routine treatments of pregnancy care the balance between maintaining the right of life of disabled persons and the desire for a healthy baby is solved one-sided. The focus is laid on the definition of an impairment of the foetus as a health risk. The significance of genetic aberrations as cause for an impairment is overestimated. Especially dramatic descriptions of the lives of people with genetic aberrations are used to question the right of life and the quality of life of people with high support needs and severe disabilities. Diagnosis and counselling procedures of impaired foetuses support a medical perspective on disabilities. Jurisdiction stating that an insufficient consultation about genetic risks is grounds for seeking punitive damage against physicians have lead to an expansion of prenatal diagnosis. Without intention but de facto, this encourages a constrained medical view of disability and a devaluation of people with complex support needs and severe disabilities.

4. Early Childhood

For most families, having a baby creates a situation of uncertainty and a need for direction and guidance. Living with a baby or a young child with a severe disability or with severe developmental problems brings parents into a situation with specific and difficult challenges and dependencies. Psychological stress in their daily lives often makes it difficult to cope with their parental responsibilities. When dealing with educational tasks or when specific therapeutical or medical treatment is necessary, parents cannot refer to their own educational experiences, but are dependent on professional support of various kinds. Having access to good medical care, self-help groups and early intervention services from a very early age of the child are decisive factors both for the personal development of the child and for the successful adjustment and coping process of the parents. How is this achieved?

4.1. Description of the National Situation

Living situations in early childhood in Germany are traditionally characterized by a comprehensive family responsibility, which is realized in the form of a pattern for mothers. Traditional role orientations come increasingly in conflict with new demands and role models.

Initiated by a government report in 1973, a comprehensive system of interdisciplinary Early Childhood Intervention Services (ECI) has been developed in Germany. It varies from one federal state to another with different structures and systems of financing and facilities in operation. Families can access ECI support free of charge, but many services have waiting lists. Parents and their child can be referred to the services by the family paediatric doctor, by social services or through self-referral. Initial assessment of need is the basis of an application procedure in which the local social administration and the health insurance are involved. Early diagnosis is regarded as an important task. A rehabilitation plan is to be worked out that can include weekly treatment or other support (e.g. counselling for parents). Mobile services can work with the child at home or parents can bring their child to the ECI centre for therapeutic or other treatment. ECI services can also function as a link between the family and kindergarten or school to facilitate a successful transition. ECI services in this sense have a "gate-keeping" function. It can very much depend on their conceptual orientation whether integrated or separated education settings are realised for the future of the disabled child. Existing models of ECI services have either a more pedagogical-psychological orientation (‘Heilpädagogische Frühförderstelle’) or a medico-diagnostic orientation (‘Sozialpädiatrisches Zentrum’).

The German Federal Government (2004) counted more than 1000 facilities offering ECI for children with disabilities from 0 to 7 years. These centres are mainly run by the welfare organisations Lebenshilfe, Caritas and Diakonie. There are no federal statistics on the number of children with severe disabilities receiving support from early intervention services, also because there is no agreed classification system in Germany. In Bavaria, it is estimated that 4% of children up to the age of 3 use various forms of early support with one-third having severe cognitive or physical disabilities. Ca. 14% of all children receiving ECI services are estimated to have an immigrant background.

4.2. Specific Risks of Discrimination of People in Situations of Major Dependence or with Complex Needs

Children with severe disabilities and their families depend very much on adequate support. There are clear legal entitlements and treatments are free of charge. In rural parts of the country, access to early diagnosis and regular treatment is especially difficult. Often parents report difficulties when they apply for assistive tools for children with disabilities from health insurances.

Children and parents depend also heavily on the conceptual orientation of their local rsp. regional ECI service system. If this is embedded in a traditional chain of rehabilitation and special education there is a high risk of routine placement of the disabled child in special kindergarten and schools. As a consequence this could initiate the starting of a traditional career of a ‘disabled person’ structured by segregating institutions. Access to information and gaining experience with inclusive education for children with severe disabilities is then difficult for parents. Even if there is a general inclusive orientation, the risk for severely disabled children to be placed in the separated setting of a special kindergarten is comparatively high.

5. Childhood: Education and Care

Preschool institutions like inclusive or special kindergartens offer care and education for younger children. They prepare children for school and give them the opportunity to interact with peers. Young girls and boys can broaden their experiences in life and enhance their social skills.
Children with severe disabilities have the same need to interact with peers, to make friends outside the family and to view themselves as a part of a social group. But young children with complex needs are dependent on additional support to participate in preschool education, such as barrier-free access or well-trained educators with specific skills and the intention to cooperate with other professionals. How is this achieved?

5.1. Description of the National Situation

In Germany children ages 3 to 6 years have a legal right to visit a kindergarten, and nearly all children do so. Recently, access for all younger children to ‘nursery schools’ (Kinderkrippen), which are at the moment only available for ca. 15% of all children under 3, is in high demand. Nearly all children with severe disabilities attend a kindergarten, some already at the age of 2. Since the mid-eighties there have been intensive efforts to substitute or change traditional forms of ‘special’ kindergarten into integrative settings. Between 1998 and 2002 the number of children with disabilities in inclusive kindergartens has increased about 30%. The development in the federal states varies: in some federal states like Hessia, Hamburg and Bremen, the ‘special kindergarten’ has been totally replaced by integrative settings, while in Bavaria many special kindergartens continue to exist. In practice, two main forms of integrative settings have developed: The so-called ‘integrative kindergartens’ in which there are usually five children with disabilities and 10 children without disabilities learn together in one group as well as the integrative education of children with disabilities in mainstream facilities (‘Einzelintegration’) in their residential area. Unlike the mainstream education model, ‘Integrative Kindergartens’ are free of charge and transport is organized. They are more centralized, but because of the continuity in educating children with disabilities, the staff as a rule has more experience and better qualification for inclusive education. Therapy takes place in the kindergarten and better networks with specialists in the local field exist. Nevertheless inclusive education in ‘mainstream’ kindergartens is becoming more and more important, in order to facilitate social contacts and friendships between the children and their families in their residential area. There are no federal statistics on the number of children with severe disabilities and/or complex support needs in kindergarten education, so quality statement based on different service types are difficult. But there is good reason to suppose that the more severe the degree of disability, the more segregating the educational setting will be.

5.2. Specific Risks of Discrimination of People in Situations of Major Dependence or with Complex Needs

The development towards integrative pre-school education in Germany has led to remarkable changes in service structures. But still in some regions there are no alternatives for children with severe disabilities to special kindergartens exclusively serving disabled children. In the conceptual debate, inclusive education for children with severe disabilities in mainstream pre-school facilities is seen as generally more supportive as ‘integrated kindergartens’. But access is often difficult because of conceptual deficits, and/or organisational barriers in regular kindergartens and often lack of counselling support for educators. Due to problems of coordination between the youth welfare sector and the social welfare sector, inclusive education in mainstream kindergarten is for parents a problem of a financial and organisational nature, i.e. kindergarten fees or transport problems.

6. Childhood and Youth: School

Schools are responsible for a child's education and the teaching of knowledge of varying subjects. Furthermore, school proves to be an important part of young peoples' socialization process by offering the chance to enhance social skills and deepen social contacts with peers.
Children with severe disabilities <u>*also*</u> *need high quality education and access to public schools. Pupils with complex needs are dependent on additional support in order to participate in school education, such as barrier-free access or well-trained teachers with the intention of cooperating with other professionals.*
But especially pertaining to them, schools often exercise a kind of segregation. How do children with complex needs find their place in the school system, in which way are their special needs considered and how do professionals cooperate together?

6.1. Description of the National Situation

In Germany, attendance at school is compulsory and free of charge for all children, including those with severe learning disabilities, until the age of 18. In Germany, each federal state has the autonomy to develop and implement its own school policies. Because of this there is a certain variety in school systems; which is also reflected in the special school systems. The dominant type of school for nearly all children with severe disabilities is the special school for intellectually disabled children (Schule mit Förderschwerpunkt 'Geistige Entwicklung') and the special school for physically disabled children (Schule mit Förderschwerpunkt 'motorische Entwicklung'). These types of special schools are available all over Germany. Education programs in special schools are orientated towards cognitive, linguistic, sensory, psychomotor, emotional and social area development. As well as having classes in the morning, a program is available in the afternoon designed to foster social competence and independence. In many special schools, children with severe and complex disabilities are grouped in special classes with fully qualified special teachers, but mostly other staffs teach and care for them. Transport is organised by the special school and free of charge.

As a result of a long lasting political debate starting in the 1980s, children with disabilities can in principle attend school in an integrative form. The Federal Government states that additional support should be made available to facilitate integrative school education of children with disabilities. The most frequent form of school integration is the 'integrative class' with 2 – 4 disabled children in a classroom of 15 children, with individualised teaching programs and additional staffing. In 2004 there were 14% of all children with classified special educational needs participating in school integration programs. These were mostly pupils with mild disabilities or slow-learners. Except some very few model programs, children with severe disabilities haven't had nor currently have access to inclusive school integration in Germany. Routinely and often without trying out other alternatives of training and supported employment at the end of the school period, special schools pass their pupils on to 'Workshops for People with Disabilities' (Werkstatt für behinderte Menschen').

6.2. Specific Risks of Discrimination of People in Situations of Major Dependence or with Complex Needs

Even though it has become a part of national disability policy that children with disabilities should have the chance to attend mainstream educational facilities instead of having the solitary option of special education in a special school, access to inclusive education is for children with severe disabilities nearly impossible.

Since special schools are centralised, many children with severe disabilities must cope daily with relatively long-distance transport periods to school and back home. In many special schools, pupils with severe disabilities and high dependencies are grouped in special classes. This is related with the tendency that they are taught by educational or care staff that is not fully trained as special school teachers. By routine special schools pass their pupils on to the system of 'Workshops for People with Disabilities', other potentially options of training and employment are not systematically considered.

7. Childhood and Youth: Housing and Family Support Services

Due to the variety of modern family life, all children grow up in different environments. These environments can be understood as a social network including all sorts of relationships to individuals or institutions. The family's living conditions during childhood are very important for social inclusion of the young person in society. The family has a strong impact on his/her primary socialization and influences the access to certain social institutions.

Family support services offer community-based professional support and services for families. Some children and young people live in a foster family, others in foster homes. Are such support systems available? In which way are children with severe disabilities or complex needs and their families involved in these support systems?

7.1. Description of the National Situation

Around 90 % of children with severe disabilities grow up with their families. There are ca. 170 residential homes in Germany providing places for about 5400 children and young people with disabilities. The largest group of children in residential care are those between 6 and 15 years. They are mostly coming from families who are unable to cope with caring for them at home because of the severity of the disability and social background/social problems, but no specific data exists.

There are no data on national level on how many children with severe disabilities live in foster families, even though this form of support is becoming increasingly important. Most of the residential homes have special schools organisationally related to them.

Respite services to support family carers as well as the people with disabilities' process of becoming independent from their families were mainly developed in the 1980s by the national parents' organisation for people with intellectual disabilities, 'Lebenshilfe'. Respite care facilitates offer chances for the main carers to pursue recreational opportunities and to participate in social, cultural and political life. Spending time away from home and from parents is also crucial for children and young people alike as short term care can positively influence the growth of autonomy and independence. Recipients of care can learn how to rely and deal with non-family members as assistants, e.g. how to effectively articulate and control specific needs and support.

Family respite care services are mostly conceptualised as mobile services, offering hour-wise, day-wise or a couple of days support in the family home or outside in the service's facilities. These services exist in nearly all German districts. Facilities that offer short-term care for children with severe disabilities for longer periods (i.e. 2 or more weeks) are much less established, and especially during school holiday periods very difficult to access. When the person's yearly budget from the long-term care insurance act for short-term care is spent, the coverage of costs has to be applied for at the social welfare administration.

Parents of children with severe disabilities and complex needs often are confronted with a varieties of challenges, e.g. concerning educational problems, problems of feeding, the management of behavioural difficulties, physical exhaustion through continuing care work as well, need for assistive tools or high cost for various care or therapy related expenses. Professional counseling services in the mainstream sector of family support mostly don't perceive themselves as competent and responsible and specific counseling services are rather rare. Self-help groups for parents are very important but don't exist in all regions.

7.2. Specific Risks of Discrimination of People in Situations of Major Dependence or with Complex Needs

As there is no clear legal basis for funding of respite care in Social Code Book XII, families with children with severe disabilities very often cannot use respite care services according to their specific needs. The professional counselling services in the mainstream sector generally don’t perceive themselves as competent and responsible for educational and/or other problems of parents and siblings of children with severe disabilities. Even though, self help groups are not able to provide sufficient counseling, often parents are left alone with important problems and are not informed enough to realize their entitlements.

8. Childhood and Youth: Leisure Time

Young people use their leisure time to do enjoyable and amusing activities and to get free from daily routines. Often free time activities are organized in clubs or in various forms of sportive or cultural associations. But youngsters also spend their free time with peers without adults. Many experiences among young people of the same age are made spending leisure time together, e.g. discovering new social roles, social spaces, friendship or falling in love. Youngsters with severe disabilities or complex needs have the same leisure time needs as their non-disabled peers, but are dependent on additional support to participate in mainstream leisure time activities. How is this achieved?

8.1. Description of the National Situation

In Germany there is a widespread system of youth clubs and non-school education programmes for youngsters but of course many youngsters spend most of their leisure time with private activities in peer groups. Youth clubs are either run by the local communities or by private, mostly religious organisations. By definition most of these mainstream facilities are also open for youngsters with severe disabilities and complex needs. According to non-discrimination legislation there must be no architectural barriers in the building that impede physical access to the facilities. But there is no data on the extent e.g. on which mainstream youth clubs are actually used by severely disabled youngsters; probably there are only very small numbers. There is also no evidence on whether the structures of programmes and leisure time activities offered in the youth clubs are also reflecting specific needs and interests of youngsters with severe disabilities. Nevertheless in some places there are pro-active efforts performed by committed youth workers to offer and promote the inclusion of severely disabled youngsters in the programmes of their mainstream youth club. These efforts are mostly based on good co-operation between (special) schools, disability services and the youth club, in order to facilitate the solving of technical or conceptual problems (e.g. transport, physical care, communication). In some regions such efforts are strongly backed by local disability policies.

Quantitatively more important are leisure time programmes that are organised by self-help organisations or providers of disability services and are partly funded on voluntary basis by local communities. They offer regular leisure time events (e.g. disco, trips), mostly on the week-ends. Some of these leisure time services also offer holiday trips for groups of people with disabilities. Sometimes this is seen as a part of respite-care and is financed on this basis. To a certain limit costs for transport are financed by local communities. Even though quite a few of these leisure time services follow an integrated approach and are explicitly open also for non-disabled youngsters, this can only be partially realised, and participating disabled youngsters in these clubs are mostly among themselves.

Other leisure time facilities see themselves without much reflection as a part of the ‘disability provision chain’ and co-operate closely not only with other disability services.

There is good reason to assume that aspects of inclusion in leisure time activities have so far not got the attention in service development discourse they deserve.

A more systematically conceptualised approach of ‘supported leisure’ in an ‘inclusive local culture’ that is based on intensive co-operation between disability services, mainstream youth work and the social administration could probably open up more possibilities for meaningful leisure time activities of severely disabled youngsters.

8.2. Specific Risks of Discrimination of People in Situations of Major Dependence or with Complex Needs

The access to mainstream youth clubs and programs for youngsters with severe disabilities is de facto very often not given. Reasons are organisational and conceptual barriers or insufficient reflection of professionals from the mainstream and from the disability sector. Not always inclusive youth work is an explicit objective in local communities’ youth policy, and financing for corresponding activities is not sufficient.

Due to lack of reflection or conceptual orientation some services provide leisure time activities in a segregated concept.

In some places youngsters with disabilities have no access to organized leisure time activities at all and depend fully on their families’ activities, which can led to very monotonous life situations.

9. Youth and Young Adults: Vocational Training

A successful transition from school to the employment system is usually related to vocational training. After finishing school young people need to find a job according to their interests and abilities with which they can earn a living. Vocational training prepares for the access to the employment system and is an important step into adult life. Youngsters and young adults with severe disabilities are dependent on adapted training courses, assisting technologies, other individual support and barrier free infrastructure to enable their access. How is this achieved?

9.1. Description of the National Situation

In Germany access to professional labour market is structured by the ‘dual system’ – characterised by cooperation between schools and private or public employers – or academic training.

For young people with disabilities there are a variety of incentives and support programmes for the vocational training or job-placement in the regular labour market. All of these incentives and programs have a general priority of supporting vocational training in the regular framework of ‘normal’ enterprises or agencies. By law, in each district of the Federal Agency of Labour a specific ‘integration service’ (‘Integrationsfachdienst’) has to be provided supporting labour market integration of people with disabilities no matter what kind or degree of dependency. Not by law but by practice, people with severe disabilities including intellectual disabilities are usually not included in these mainstream programmes.

Special schools for intellectually disabled or physically disabled pupils have usually no co-operation ties with regular professional schools (‘Berufsschulen’) that in the German ‘dual system of vocational training’ are of central importance. Closer relations in the transition process exist to ‘workshops for people with disabilities’ and ‘vocational training centres’.

There is a nationwide system of ‘vocational training centres’ for young people with disabilities from 16 – 28 years (‘Berufsbildungswerke’) that offer courses for vocational training, basic education and formal qualification in legally recognised administrative, technical or industrial professions. Especially for severely disabled young people also e-learning and blended learning courses are in use qualifying pupils e.g. for clerks with a specialisation on ‘tele-working’. Vocational training centres are mostly well equipped training facilities that also provide residential services and a leisure time programme for their clients. Many vocational training centres give no access to people with intellectual disabilities.

For vocational training or occupation mostly young people with severe disabilities including intellectual disabilities are referred to the nationwide system of ‘workshops for disabled people’ (Werkstätten für behinderte Menschen, WfbM). All ‘workshops’ provide an ‘entrance and training unit’ (‘Eingangs- und Trainingsbereich’) where clients get prepared and trained for further occupation in the workshops’ ‘production unit’. Some workshops also offer recognised professional training measures. There is a specific application procedure, in which a so-called ‘professional committee’ (‘Fachausschuss’) consisting of representatives from the labour administration, social administration and the service providers has a gate-keeping function. Because of their degree of dependency rsp. low level of work performance people with severe disabilities can be excluded from the workshop’s programme.

9.2. Specific Risks of Discrimination of People in Situations of Major Dependence or with Complex Needs

People with severe disabilities, including intellectual disabilities, are usually not included in programs of the Federal Agency for Labour to support vocational training in the regular framework of ‘normal’ enterprises or agencies.

Many ‘vocational training centres’ exclude explicitly or implicitly people with intellectual disabilities from their programs.

For people with severe disabilities and high dependencies there is a risk to be excluded from the vocational training programme of ‘workshops for people with disabilities’.

10. Children and Adults: Social Security and Health Care

Modern societies are shaped by an enlargement of welfare systems and an increasing dependence on social security institutions. It is a challenge for all citizens to clarify their entitlements and to find access to services. The need for basic social security and to have access to health care services if necessary is important for all people.

In most cases having complex needs leads to an increase of dependence on social benefits and requires special support and services granted by welfare administration boards. Bureaucratic procedures of application approval create special risks of stigmatization. Allowances, benefits and services can improve the possibilities of individual participation, but can also initiate processes of social exclusion. How is this achieved?

10.1. Description of the National Situation

The social security system in Germany received its strongest influences from the social insurance system introduced in the 1880s which has been developed and expanded since this time. In its beginnings the goal of providing insurance coverage for a minimal group of employees against the potential risk of work disability has continually broadened to include coverage of other benefits such as illness, accident, old age, unemployment and nursing care. Although the regular membership is connected to the status as employee, most disabled persons are however granted coverage under the social insurance system. In cases where no sufficient entitlements concerning social insurance exist, people can apply tax-based benefits from the local welfare administration.

Nevertheless, people with complex support needs are disadvantaged in systems of social security and health care. As a result of the labour market mechanisms they receive no or only a very small pension. Most people with complex needs and/or severe disabilities live only on a basic income from the local welfare administration and find themselves in a precarious financial situation.

Health care is in many cases insufficient for people with severe disabilities and complex support needs. In the past, disability institutions offered their users an own health-therapeutic supply network. In community services these special offers have to be newly organised. Many medical and therapeutically services do not fit the criteria of a barrier-free environment and are not sufficiently able to adapt treatment to people with severe disabilities. Reports of people with high support needs criticize the quality of care in hospitals due to shortages of manpower. Specific problems are known since a number of years e.g. in the field of dental care. The increasing financial pressure on statutory health care insurance has led to co-payments of users and a restriction in choices of available treatments and remedies.

An important problem for people with disabilities is the fragmentation of the social security system. Therefore the Rehabilitation Code Book (SGB IX) states that rehabilitation funding bodies must establish joint counselling centres (*Service- und Beratungsstellen*). These local service centres should offer comprehensive help and advice independent of any specific fund or provider. In reality, the service centres have so far not been able to fully realize the original intention of the legislator.

In addition to entitlements in the regular social security system, people with disabilities can apply for a severe disability card on the basis of rehabilitation law. This card allows to claim special disability benefits (e.g. tax reduction, free public transport, special car parking allowance, etc.), admission).

10.2. Specific Risks of Discrimination of People in Situations of Major Dependence or with Complex Needs

The decreasing social security resulting from the restructuring of the German welfare state especially tends to weaken the social protection status of people with complex support needs. In most cases they are not able to replace statutory resources for social security by private means. Therefore direct effects on the quality of life are noticeable.

In the health care system which is more and more shaped by market rules, persons with high and complex need are not regarded as “attractive customers”. Thus only a few incentives exist for the breaking down of barriers regarding better access to health services. In the process of treatments people with complex needs are frequently excluded on account of their disabilities from the decisions concerning medical treatments they get.

There is little sensitivity to the stigmatizing effects of labelling persons as disabled. Thus the advantages of a disability status are frequently connected with serious disadvantages, e.g. access in the labour market.

11. Adults: Work and Employment

Having work or a day occupation is, for financial and other reasons, a very important indicator of social inclusion and quality of life. Going to work not only structures peoples’ days and weeks, but also has an important impact on the development of a person’s identity. It also provides access to the social security system and is an important basis for participation. For people with severe disabilities, transitional situations from school or vocational training into the employment system must often be systematically planned and organized, because they are dependent on adapted work places or assistive technologies and other individual support like a barrier-free infrastructure to enable their access. How is this achieved?

11.1. Description of the National Situation

In general the labour market statistics show that the employment situation for people with disabilities is very difficult in Germany. The labour force participation rate was approximately 34% in 2005 (compared with approximately 74% to all employable persons). With 18.1%, the unemployment rate in 2005 was twice as high as in the total population. People with complex support needs and/or severe disabilities rarely have a chance to find employment on the regular labour market. They are excluded from earning a living as being “unemployable” or are unable to access a new job, although employment of disabled persons is an obligation of the employers. The improvement of the accessibility to the regular labour market is task of the employment office and the offices for integration, which cooperate intensively with enterprises and special services.

People with intellectual and developmental disabilities have the right to visit a Workshop for Persons with Disabilities, if they can produce a minimum of economically viable work. Workshops for Persons with Disabilities are also visited to an increasing degree by persons with chronic mental illness. An occupation in a ‘Workshop for People with Disabilities’ does not justify regular conditions of employment. It is a programme for social integration financed by the welfare administration. The number of the available places in such workshops rises continuously. At the end of 2005 there were approx. 257,000 places (i.e. 0.6% of population between 15 to 65 years).

An important goal of the support in a Workshop for Persons with Disabilities (vocational training and training on the job) is to improve the possibility of finding a job on the regular job market. The successful cross-over rate is however only approximately 0.3% per year. Persons with complex support needs who do not fulfil the criteria for working in a Workshop often visit a day care centre.

Although the instruments for labour market integration were substantially improved and made more flexible in the last years, people with complex support needs and/or severe disabilities do not profit from the benefits of these efforts. Policy programs are aimed at higher transition rates to the regular labour market by employment in subsidized enterprises (integration projects), by support of professional assistants and by incentives like direct payments for regular occupation.

People with disabilities can articulate their interests in larger enterprises and in public enterprises in special interest groups that are prescribed by law (Schwerbehindertenvertretung). They find thereby support by the offices for integration. Persons employed in Workshops organize themselves in ‘workshop user councils’.

11.2. Specific Risks of Discrimination of People in Situations of Major Dependence or with Complex Needs

People with disabilities are stigmatized and disadvantaged in application procedures and they are not very well protected against exclusion from labour market. People with complex support needs and/or severe disability do not belong to the main target groups of the employment offices and the offices for integration. That is the result of the status as incapable of earning a living. People with complex support needs are considered primarily as clients in the social care system. Because of denying the right and the possibilities to participate in the labour market, people with complex support needs and/or severe disabilities are excluded from meaningful and respected positions in the society to a large extent. As a recent development it is reported that in some federal states the social welfare administrations tend to question their funding for day care centres.

12. Adults: Housing

Becoming an adult also means making up your mind about how you would like to live: stay in the natural family for a while, live alone, with a partner or family, with a friend, etc. Having privacy, a place to go to, feeling safe and comfortable there, realizing one’s own ideas on how to live, are all very important for people in our societies. For people with complex needs it is a big challenge to find their own way to living. They have restricted alternatives for housing because they need barrier-free environments and life-long support. People with severe disabilities do not only need good support services but also counseling to realise their ideas and style of private living. How is this achieved?

12.1. Description of the National Situation

In order to achieve a high quality of life, people with complex needs are strongly dependent on assistance from persons of their social network, usually members of their birth family. For many people with complex needs there is only support from family members. Outside of the family, people with complex needs mostly live in residential services (residential services for people with disability or nursing homes).

People with complex needs get benefits from the contribution-financed nursing care insurance (SGB IX), which are different in relation to the extent of the respective support-needs. The scale for benefits is limited and does not cover the costs of professional support for persons with high support-needs. To cover the expenses users have to spend their own income and capital. If this is not sufficient, the tax-financed social welfare administration (SGB XII) takes over the costs. The social welfare administration is also responsible for other support (not nursing care) in housing.

Support outside of the family is provided primarily by private providers, which offer different types of smaller and larger residential care facilities. The number of services for supported living is increasing, but is still far from being the dominant model of care. In some cases people with a chronic mental health problem and/or severe intellectual disabilities still live in psychiatric hospitals or in residential homes close to hospitals. Everyday life support in their own dwelling is often impossible because of the insufficient infrastructure of the support system and a non barrier-free environment.

Traditionally services for people with disabilities are not well integrated in the community. Since the 1980s, people with disabilities, their family members and professionals have engaged in the development of community based services. Political discussions focus on the right to obtain sufficient assistance in private homes. Great expectations regarding the improvement of self-determination accompany the introduction of direct payment schemes, which will be available 2008 as a regular form of benefit. In residential homes the participation of users is regulated in a special ‘Home Law’ (Heimgesetz). Anti-Discrimination legislation has lead to a more systematic consideration of criteria for barrier-free planning in private homes and public environments.

12.2. Specific Risks of Discrimination of People in Situations of Major Dependence or with Complex Needs

The limitation of benefits of the contribution-financed nursing care insurance disadvantages persons with high support-needs, since the necessary assistance cannot be financed. The social welfare administration also makes a cost caveat for assistance in their place of residence. This is a serious disadvantage for persons with complex needs.

Since there is obligation of support for a disabled person on the part of service providers and there is no obligation in regional planning, we find regionally a very different situation of support systems in Germany. People with complex needs often have to look for a good service for a long time. Frequently they find a service far away from their place of residence.

In residential homes often privacy is reduced by institutional restriction , e.g. multi-bed rooms, enforces group settings, the lack of possibilities to live in partnership or family and institutional routines. Nursing homes are orientated towards the overall concept of the elderly with support needs. People with complex needs in residential homes live in situations of major dependence because they cannot attend activities outside the institution.

Claiming the right of individual assistance in a private flat is only possible for a small group of people with predominantly physical handicaps. No instruments are so far available for the participation of people with strong cognitive impairments and non-lingual communication in evaluation and quality assurance programs of services.

13. Adults: Education and Leisure Time

Leisure time comprises all the time out of work to either relax or find a balance in contrast to every-day-life. Activities can be done on one's own, organized in clubs or in various forms of cultural or other social facilities. In their leisure time, people in our societies are supposed to act with less formal restrictions and try to achieve a high degree of satisfaction and self-determination in their activities.

Adult education – taking the idea of life-long learning as postulate – can be seen as part of the individual's leisure time, sometimes connected to work or the expectation that a certain course promotes one's professional career. Sometimes people participate in adult education courses for the sake of their personal well-being, health or general personal development. For people with severe disabilities the participation in organized leisure time activities or adult education courses very often must be systematically planned and organized, because they are dependent on adapted courses, assistive technologies and other individual support, and barrier free infrastructure to enable their access. How is this achieved?

13.1. Description of the National Situation

Nowadays adults in Germany have more leisure time than ever before – on average around six hours a day. A great part of leisure time is shaped be mobility, activity and often connected with high expenses. There are different trends in using leisure time. For most people the membership in sport clubs or other social or cultural associations are very important. On the other side one can observe a rising trend to more individualistic ways to spend leisure time.

The boundary between work and leisure time is not always distinct. For example there is a general agreement, that concepts of 'life-long learning' cause a close link between informal learning in leisure time, visiting voluntary adult education programs and further education for ones job. Adult education in Germany is regulated by the state to a lesser degree than other areas of education. The most prominent and visible institution of adult education, available everywhere in Germany, is the community-based, non-profit institution 'Volkshochschule'.

In all spheres of leisure time activities people with complex support needs face problems of accessibility caused by mobility problems due to non barrier-free environment, exclusive forms of mainstream communication, lack of adaption of programmes or open or not open prejudices. Nevertheless, the anti-discrimination approach and demographic changes have lead to a better consideration of barrier free environments. Good practice can be found e.g. in the sector of tourism and in the sector of public adult education ('Volkshochschulen'). But even there facilities often don't fully comply with the criteria of barrier-free environment. Some of them offer specially designed courses for the target group of people with learning difficulties, partly in cooperation with providers from the disability field.

The disability movement in Germany has created new offers in adult education for people with disabilities in own centres for adult education. Favourite issues are self advocacy, disability studies and other themes to empower people with disabilities.

In fact, people with disabilities spent most of their leisure time with activities at home and in peer groups. There is a wide range of clubs, self-help groups and sport groups especially for people with disabilities. People living in residential care facilities or working in sheltered workshops spend most of their leisure time activities included adult education and holiday trips in the excluding framework of disability services. The focus of adult education for people with disabilities has changed. More and more providers offer training courses to improve independence in activities of daily life, courses for self-advocacy and courses or literacy. Other issues are also sexuality, partnership and parenting.

13.2. Specific Risks of Discrimination of People in Situations of Major Dependence or with Complex Needs

The access to mainstream leisure time activities and adult education for people with complex support needs is very often not given. Due to lack of accessibility people with severe disability are excluded from common leisure time activities and from important part of adult education system. Accessibility and participation to leisure time activities and adult education is not considered as a main topic in the mainstreaming discourse of modernizing disability services. So, many people with severe disabilities have to spend their leisure time at home and in special leisure time groups. In this setting they are often excluded from possibilities to learn important skills in the rapidly changing knowledge based recent society.

14. Adults: Partnerships and Parenting

According to social trends and changes, the decision of having one’s own family is not as easy as it used to be. More and more the decision to get married or to have children is a conscious one based on emotions, being aware of the changes that these decisions will mean.
Not too long ago the idea of people with (intellectual) disabilities getting married or having children was regarded as impossible. People with complex needs who wish to marry or have a child often have to face prejudices. After all, in their parenting they are dependent on special support. Professionals from different services and service sectors have to cooperate to prevent exclusion and discrimination. How is this achieved?

14.1. Description of the National Situation

Figures on marital status in the Federal Republic of Germany from 2005 indicate that disabled persons in the age of 25 to 65 years are more frequently single or divorced as the rest of the population. About a quarter of the severely disabled people live in one-person households. Women with disabilities are significantly overrepresented in the groups of independent singles and divorced people. Statistics show also that adults with severely disabilities live more rarely in households with children. The statistic gives no information about differences between persons with a lifelong or later-emerging impairment.

These figures can be understood as reflecting the exclusion of people with disabilities from social contexts and forums of ordinary life(e.g. youth culture, sport and leisure activities) Life situations characterized by exclusion make it difficult to find a partner). The figures also reflect that people with severe disabilities are mainly considered to be people with support needs and not simply as peers. This perspective has been supported by social security system in the Federal Republic of Germany shaped through the idea of subsidiarity, i.e. support for people with disability is mainly conceived as an obligation of families and relatives.

Parenting of people with severe disability has been tabooed until recently. There are reports that many women with intellectual difficulties are pushed to sterilization. In the areas of family planning, childbirth preparation and education counseling, the needs of parents with disabilities do not receive sufficient attention. Furthermore, relatives, professionals, courts and the media cast doubt on the ability of people with disability to raise children, even with support. In practice most children of people with complex needs don’t grow up in their birth family .

In response to criticisms of custody extraction (e.g. the decision of the European Court of Justice) and a growing general sensitivity relating to the rights of people with disabilities, the situation is slowly changing. The administrative separation between the youth welfare sector and the disability sector with disabilities creates difficulties for efforts to fix a helpful arrangement for families with disabled parents. Generally spoken, the child and youth care sector focuses on the child’s needs and is not sensitive enough to the needs of their disabled parents. The social welfare sector, i.e. disability services focus on individual rehabilitation and is not sensitive enough to the situation of families and the problems of raising children. Reports show, that problems of intersectoral co-operation very often cannot be solved adequately in these situations.

With the Social Code Book IX in 2001 the legislator made the needs of disabled parents visible. The law prescribes that public welfare agencies must explicitly respect and support disabled parents in their daily activities. But it is not possible to claim benefits on the basis of these regulations. Apart from some model projects, there is only a small number of schemes for specific support for disabled parents, such as supported parenting.

14.2. Specific Risks of Discrimination of People in Situations of Major Dependence or with Complex Needs

In the area of partnership and family life in particular people with complex support need experience exclusion very personally. They frequently remain dependent on the support of their family. In their parents perspective but also in the view of many professionals they are often life-long perceived in the pattern of the ’eternal child’.

Professional support cannot replace the backing found in partnerships and primary networks, which is based on emotional affection. This creates behavior patterns that often foster dependence and impede personal developments for autonomy, which can become possible in the process of transition into adult life.

As far as the general reaction to the desire of people with complex needs to have children is concerned, a strong discrimination is apparent. In opposition to the efforts towards increasing the birth rate and reducing abortions, the desire to have children of people with complex support needs often is nearly not supported. Implicitly dominant, is a strict prevention practice, including facilitated abortion.

15. Adults: Exercising Civil Rights

One developmental task of adulthood is to know and to exercise one's rights. This comprises the rights that a state confers to its people in order to secure protection and political participation, e.g. basic human rights and voting.
For people with severe (intellectual) disabilities, civil rights still cannot be exercised in every case. Additional support is needed to exercise democratic rights like voting. It is also a commonly held belief that people with severe disabilities or complex needs are in capable of serving in political positions. How can people with severe disabilities exercise their rights as citizens?

15.1. Description of the National Situation

For a long time, the status as recipient of welfare benefits was closely connected with loss of civil rights directly or implicitly by legal regulations. Persons living in an institution especially were lacking most of their civil rights. Since the early 1990s, the citizen status of people with disabilities has been remarkably strengthened. This improvement is characterized by two different developments:

The first was the replacement of the Law of Guardianship by the Caregiving Act (Betreuungsgesetz, BtG) in 1992. The Caregiving Act gives guardianship courts and legally appointed caregivers a relatively high degree flexibility in attaining the required levels of care to meet the needs of an individual with intellectual disabilities. It also makes clear, however, that the appointment of a caregiver should have no restrictive effects on the individual's rights per se (all "necessary" restrictions must be reviewed and approved by the guardianship court). The consequence of the Caretaking Act was that the sensitivity towards civil rights of people with disabilities matured. Nearly all persons with disabilities can make use of their civil right to vote as well as to marry.

The other development is marked by a long and intensive anti-discrimination campaign run by a broad alliance of organizations supporting people with disabilities. In 1994, the sentence “no one may be disadvantaged due to his or her disability” was adopted in Article 3 paragraph 3 of the German Basic Law (Grundgesetz). With respect to EU anti-discrimination policies, the Equal Opportunities for People with Disabilities Act (Bundesgleichstellungsgesetz) was passed by the national parliament in 2002 and led to the implementation of anti-discrimination laws in all federal states. In 2006 the EU-guidelines against discrimination were transferred in the General Equality Act (Allgemeines Gleichstellungsgesetz) in 2006. This provides protection against discrimination in private contracts for people with disabilities and other groups with a high risk of discrimination. Nevertheless, intensive political conflicts about the General Equality Act show that there is no of the extent and impact of discrimination is not in most parts of the German society. Consequently, anti-discrimination provisions are not viewed from the perspective of the support system or as an overall approach in disability policy. Tension remains between a perspective of civil rights and a traditional welfare approach.

Important drives to improve civil rights are set by the ‘Commissioners for the Interests of the Disabled’ and by ‘disability advisory committees’ on the different political levels. The position, tasks and competences of the national Commissioner for the Interests of the Disabled were established in 2002 by the Act for Equality for People with Disabilities. Comparable commissioners are in all federal states now. Their tasks are often regulated by laws. On the local level, an emergence of these types of laws representing the interests of disabled people is visible.

The intensive discussion about the new UN-Convention on the Rights of Persons with Disabilities is leading to a consolidation of the civil right perspective in the disability field.

15.2. Specific Risks of Discrimination of People in Situations of Major Dependence or with Complex Needs

The legal status and the civil rights of person is not determined by his or her disability. People with complex support needs are in practice exercising their civil rights in important parts of their lives. Living in an institution, not freely chosen but for absence of alternatives, restricts civil rights. In other areas, dependency on support and accessibility restricts the exercising of civil rights, because services are mostly not really individualized.

People with disabilities who need a legal guardian have problems finding someone who can represent their interests. In many cases, a parent is their legal guardian in adulthood. Professional legal guardians often have high case loads so they tend to delegate their responsibility to services expecting them to act in the interest of their clients.

16. Adults: Ageing and End of Life

Ageing contains a lot of new challenges: Retiring, organizing one’s day in a new way, coping with the loss of abilities and coming to terms with it and with one’s life. Regularly, more support is needed in day-to-day life and thus social dependencies are increasing. Often this means that familiar life settings must be changed because care needs cannot be covered anymore by the given arrangement. Most people don’t want to leave their familiar setting even when their care needs are becoming extensive and complicated. They prefer arrangements which are based on home care services that are reliable and flexible. When people reflect upon the end of their life there is also a wish to die in dignity.
How is this achieved?

16.1. Description of the National Situation

The number of elderly persons with complex support needs and/or severe disabilities continues to increase gradually. This is a result of growing life expectancy like in other developed nations. In the case of people with long-life disabilities in Germany this is also a result of the euthanasia crimes against people with disabilities in the time of National Socialism between 1939 and 1945. Gradually, the age structure of people with disabilities is adjusting to the age structure of the general population.

The structure of the care system is marked by a strict distinction between geriatric care and care for disabled people. There are different predominant fundings (long-term nursing care insurance in contrast to integration assistance), different predominant professions (nurses in contrast to pedagogues) and different providers. In the field of disability politics and services ageing is an issue of growing importance. On the one hand there is a lack of provided support for elderly people in the disability field (support for the transition into retirement, day structure, nursing care) and on the other there is a reservation of relevant actors directed towards long-life disabled people in the field of geriatric welfare. There is also an ongoing conflict that the social assistance administration is interested in transforming as many institutions as possible into pure nursing homes, where only the long-term care insurance scheme would have to provide the financial contribution.

Ageing is one of the top issues on the political agenda in Germany. Experts anticipate the German population becoming simultaneously smaller and older. They expect that in 2050 more than a third of the population will be older than 65 and they foresee an enormous increase of people who need nursing care. As a result drastic and effective changes in the field of social care are regarded as necessarily. Experts and politicians demand new solutions in supporting structures that also contain more cooperation between different service fields and policy sectors. It is not possible to manage the challenges within separated systems of institutional care and private family care. A new mix of care is needed, which is orientated towards individual support arrangements. Both, organisations of the elderly and organisations of disabled people strive for a community care system as an alternative to institutional care.

Growing life expectancies create a political debate of quality of life and self-determination at the end of life. Many people don't want to spend their end-of-life-time in a hospital and they are afraid of living in a nursing home. Many people want to refuse consent for medical treatments which only extend the process of dying. While there is a political debate on medical treatments during the process of dying, the debate of active euthanasia remains taboo in politics, due to lingering sentiment against National Socialist policies and practices.

16.2. Specific Risks of Discrimination of People in Situations of Major Dependence or with Complex Needs

The discussion of problems with demographic change tends to simplify the arguments and attribute ageing and high support needs merely negatively as a problem. This creates the real risk of neglecting the quality of life and the dignity of those affected.

Processes of ageing and especially the situation at the end of life are often connected with a situation of major dependence that is well known for people with disabilities. There is a lack of protection against the dynamics of institutions for disabled persons in this situation.

There is a high risk that people associate their fears of ageing with people with high support needs and want to avoid them and exclude them from social life.

Country: Germany

Service providers representative: Dachverband Gemeindepsychiatrie: This umbrella organization for community psychiatry promotes psychiatric reforms. So this interview is focused on the situation of persons with chronic mental health problems.

Interviewee: Mr. Christian Zechert, Managing Director

Date: October, 13th in 2007

In your opinion: What are the main risks of discrimination against persons with severe disabilities in Germany?
There are certain manners of behaviour which provoke discrimination. These can be counteracted through support, education, and communication. The label "mentally ill" already causes discrimination regarding inclusion in social groups.
People with high support needs are discriminated against when it comes to accessing support care. People who do not have the necessary competencies to articulate their support needs cannot navigate a field of social care made up of complicated application processes.
The organization and financing of care for people with chronic psychological illnesses shows a critical discrimination, because they are excluded from support by the performance of the health care system. This contributes to stigmatization.

What are the perspectives on anti-discrimination policies for people with severe disabilities in Germany and in the EU?
Anti-stigma campaigns are (only) especially meaningful if they are carried out primarily by those affected, contribute to their own emancipation and give them a chance to portray themselves openly in public. These campaigns must focus on positive aspects.
Professionals must seriously reflect on how they contribute to the stigmatization and discrimination of people with psychological problems.

What can you say about the difficulties that people with severe disabilities having access to support from professional services?
There are people with psychological illnesses who have virtually no access to community psychiatric care. These are the ones who refuse cooperation, display strong behavioural disorders and have complex problems in different areas. Thus certain people are not deemed "heimfähig" (“capable of living in a residential home”) because they disagree with rules prescribed by an institution, such as abstinence or medication compliance. These types of people frequently get accepted into clinics and, after being released, end up in homeless shelters.

How many and what kind of people are excluded from certain services?
The size of the group which either temporarily or permanently cannot access community psychiatric care is estimated to be around 10% of those who are chronically ill. It depends immensely on the conceptions of the offerer, whether or not the offer of help reaches these people.

In which areas of the support system do you see problems of availability or bad quality?
The support system is developed regionally very differently, quantitatively and qualitatively. Clinical care is however strongly regionalized and widely available throughout Germany. Other offers are more available in the area of cities and their development varies widely. National, central offers for people with very complex support needs have developed in some areas from a lack of alternatives.

Are there any differences in the quality of services for people with mild, profound and severe disabilities?
It's extremely important to develop individual assistance for those with high support needs. It's also important to (periodically) make considerable resources available in order to enable different types of access. This is not untypical for psychiatric care but it often fails with community psychiatric help due to the resources which are made available to them.

Which structural problems do you see in the service system and in service providing?
The main problem is in the coordination of help. Only hospitals have a binding obligation to care for people with mental illnesses. Attempts to implement such a commitment in complimentary areas of community psychiatric care have had limited success because the majority of the care providers make their decisions autonomously. In order to counteract this, "community psychiatric associations" are established and trained to take on an obligation of care specifically for this group of people.

Which problems do you see in intersectoral co-operation, (in) service planning and delivery?
A regionally binding obligation of care which isn't based solely on a single service or direction could find strong, individual solutions. For example, protection from apartment evictions could be combined with medical and social support. There are proposals of cooperation in all regions, but frequently these do not capture the essence of obligation and commitment. This makes a systematic planning of offers more difficult. Intersector cooperation problems arise from the involvement of different professions and different financial rules. Common regional work associations improve cooperation.

What are the main concepts concerning the support of people with severe disabilities in your country? Are there any differences among provider groups? Are there any “taken for granted assumptions” in this field that foster discrimination?
A variety of small and regionally-anchored carriers with different manners of work and technical direction have developed in association with de-hospitalization and deinstitutionalization. Many people are convinced that all actors must orient themselves with a binding association of medical care. On the other hand, autonomy is frequently referenced by the carriers regarding the design of care, referring back sooner to informal structures of cooperation. In conjunction with de-hospitalization, many believe that you must begin the development of community-integrated care with those who are the weakest, i.e. with those who need individual support the most. This orientation is still not a guiding action in everyday usage. It has, however, led to the expansion of the group of people who receive community psychiatric offers. Presently, a tendency to standardize and budgetize benefits can be seen in the health care system as well as in other areas of social care. This is not done to the benefit of people with complex support needs.

What are the biggest challenges for the development in service providing for persons with severe disabilities?

The activities of community psychiatry must be more readily recognized as treatments in the rehabilitation and the health care system if the group with high support needs is going to be effectively assisted. This includes for example social-therapy treatments, out-patient (ambulant) psychiatric care, integrated medical care and occupational therapy. Doctors with private practices must also be more effectively integrated into the care of people with complex support needs.

Preventative care must be developed in the area of community psychiatry.

What experience do service providers have with personalised service delivery and personal budgets?

There is little experience with personal budgets. It is essential that, through personal budgets, the relationship between those eligible for benefits and professionals changes. For people with high, complex and frequently changing support needs, the possibility of utilizing benefits is difficult, but can also lead to an improvement by changing their condition.

Country: Germany

Statement from the office of Karin Evers-Meyer, Bundesbehindertenbeauftragte (Federal Representative for Disabled People)

To me discrimination and exclusion are a vicious circle. People with disabilities depend on support and assistance. In the past, we met their need for support by providing comprehensive welfare services. Special homes, schools and workshops were set up to pool professional welfare arrangements. This has created separate worlds which produce social exclusion. People with and without disabilities are strangers to each other.

Disabled people resented the separate worlds and started to fight against their exclusion. Under the influence of the principle "nothing about us, without us", the paradigms of German disability policy have changed over the past years. Modern disability policy is primarily characterised by its focus on disabled people's self-determination and their active inclusion in the different levels of decision-making processes. Various new pieces of legislation such as the Act on Equal Opportunities for Disabled Persons, Book IX of the Social Code and now also the General Equal Treatment Act are the cornerstones of the new disability policy.

Our society had and has many barriers that people with disabilities have to overcome. These are architectural and geographic barriers, communication barriers and also legal barriers to access of benefits and services by the public and private sector. With the involvement of those affected many of these barriers could be removed which made life easier for disabled citizens.

Large institutions, special schools and sheltered workshops have no future; the future is living and working in the community. This means that we must encourage and support school inclusion of children with disabilities so as to foster inclusion at large. The inclusive approach became broader. Systematic inclusion from the start – not only in working life. The former Federal President von Weizäcker once said: "If we do not separate in the first place, we spare ourselves the work to integrate" I think this is an adequate description of the situation in Germany.

With special incentives for various forms of out-patient services and statutory tools such as the personal budgets, the structure of disability assistance is gradually changing. The focus is on people and their specific needs. People are to be given the support they need at the time and at the place of their choice. "Help me do it myself" is a frequent statement in this context. This means: help towards self-help, empowerment of people with disabilities rather than the extensive welfare approach that has dominated the scene in Germany for many decades. We must stop creating separate worlds. Integration starts in nursery schools and must be systematically pursued. Inclusive schools, community living and adequate assistance for people with disabilities according to the principle "help me do it myself" are the central instruments for combating exclusion. An inclusive education system is the necessary prerequisite for a comprehensive integration of people with disabilities and there is no alternative to it. A company's personnel manager who never saw a fellow student with disabilities during his entire education has natural reservations. He is totally unaware of the capabilities of disabled people and their willingness to work hard. And you can hardly blame him. With its programmes "Jobs Without Barriers" and "Job4000", the German government wishes to show that an employee with disabilities is not a burden on the employer, but an asset for any company. Individual approaches are needed. The Federal Government provides support to employers and employees alike.

The Social Code Book IX above all provides a genuinely modern basis for a participatory disability policy. The compensation levy system acts as an incentive for employers to give jobs to people with disabilities. Manifold forms of support make it attractive for employers to recruit people with disabilities. For instance, expenses for the required technical appliances and for the adaptation of the workplace are refunded – so that there are no additional costs to be met by the employer.

The statutory and the material conditions for a paradigm shift have been created. Society increasingly realises the significance of integration. A long overdue discussion has started. But a problem, in my view, is the implementation or the use of the support options in place. Even those who should provide assistance in the community are often ignorant of the variety of existing services. And many of the advice and support schemes are not sufficiently known either. Therefore disabled people should make concrete demands and be insistent so that all the parties finally acknowledge the existence of legislation.

The process we embarked upon is by no means easy. It is often lengthy and occasionally unwieldy. Procedures have to be readjusted or changed. Often people, too, have to adjust and to change their habits. As so often, there are difficulties and obstacles in the details. It certainly requires a great deal of effort and commitment from all parties to fully establish the paradigm change in our country.

At the EU level, too, many things started to move fostering the paradigm change in disability policy in Germany. The European Year of People with Disabilities and the Year of Equal Opportunities for All, for instance, have helped to alter the public's perception of people with disabilities; they are no longer seen as people dependent on support, but as human beings with justified rights entitled to a fair place in society.

Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation gave important momentum to this area. The General Equal Opportunities Act transposed the Directive into national law. What I would like to see is the adoption of another EU directive providing extensive protection of people with disabilities in all sphere of life.

Country: Germany

Maren Müller-Erichsen and Dr. Bernhard Conrads, Bundesvereinigung Lebenshilfe

Response to questions regarding the EU-study on specific risks of discrimination for people with complex needs and with special situational dependencies

As the federal director of Lebenshilfe and one of the six federal German stakeholders, I will comment on the catalogue of questions mentioned above. The response itself will be divided into two parts: the first part focuses on facts and examples of discrimination apparent to Lebenshilfe in the everyday practice of services and facilities, by rudimentarily moving through different stages of life. The second part highlights socio-political and civil rights aspects dealing with the recognition of people with disabilities, regardless of the severity of the disability.

If one examines the living situation of people in Germany with mental disabilities it is apparent, when viewing the levels of action and decision, that the "often quoted paradigm shift from supportive care to participation-based care does not necessarily include people with high support needs, considered to have significant mental disabilities. This is a fact which violates fundamental rights and stands in opposition to the basic, internationally recognized principles of care for people with disabilities laid out in the Standard Rules of the United Nations as well as in the International Classification of Functioning, Disability, and Health – the ICF of world health organizations." (Seifert, Monika: Teilhabe von Menschen mit schweren Behinderungen – ein Bürgerrecht, in: Schwere Behinderung – eine Aufgabe für die Gesellschaft! Reader mit Beiträgen vom Kongress der Lebenshilfe „Wir gehören dazu!". Marburg, 2006. S. 303).

On the contrary: the implementation of the professed goal here, to "promote a comprehensive personal development in order to make participation in society easier and to enable the most self-reliant and self-determining control of life possible" (§ 4(1)4 SGB IX), is becoming more difficult due to the politics of saving common with public funds. With this background information, the following risks of discrimination are especially important to mention:

Part I

Family:

Parents of a child with high supervision, support, and care needs feel ostracized when their child is reduced to a "cost factor". Securing support which covers individual care needs is an increasingly complicated undertaking. In Germany, many parents feel like "applicants" and not people exercising legitimate legal claims. The behavior of funding agencies seems to be a broad societal reflex of crumbling solidarity in current times of difficult "distribution battles" for available funds.

Parents who live with a child with severe disabilities rely especially on everyday-oriented, flexible, and dependable help, so that *every* family member is allowed the right of personal development. For just under 25 years, support services for families which alleviate care burdens as well as a wide range of professional services of Offene Hilfen (Open Help) have been offering such support. In spite of intensive efforts, the placement of the core business of “familiar everyday-support” in SGB IX/SGB XII has not been achieved. The claiming of benefits from SGB XI currently dominates and restricts possible participation opportunities.

Childhood/Youth

The consolidation of an inclusive system of early care for *all* children with support needs as well as their families has not been structurally achieved in Germany. What is urgently needed is a networking of the medical complex, youth care, and social care working together as integrational support organizations.

In the area of *academic education*, a “reserve of resources” for the enabling of integrative education for children with disabilities is generally laid out in state school codes.
As a result of a gradual worsening of personnel standards in day cares and schools, children and teens with high support needs are especially vulnerable to ostracization. While the basic idea of a common and shared life and education for children with severe disabilities asserts itself well conceptually and practically in day care institutions, this idea is not (yet) achieved in school systems. The report of a UN-special emissary about ostracization in German schools has fortunately set the ball rolling towards the goal of “school for everyone”.

Adults/Elderly:

Adults with severe disabilities – especially elderly people with mental disabilities and additional support needs – in (stationary) communal, integration-centered homes are increasingly at risk of being placed into a nursing home in accordance with SGB XII. According to SGB XI, the current structures and conceptual requirements of care institutions do not guarantee supervision for this group of people in line with professional requirements. Because this is the case, Lifehelp has continually demanded the securing of lifelong stays in integrational institutions for this demographic of people with severe disabilities.

It’s also important to question whether or not the policy of “ambulatory before stationary” also applies to people with severe mental disabilities in communal living arrangements. This alternative choice must be available to these people as well. Disabilities and high support needs should not automatically exclude a self-determining living arrangement with other people, for example in the form of ambulatory support.

It’s clear that when considering the realm of occupational work, those with severe disabilities are divided into those who are able to work and those who are unable to. The right to have a regular work status for people with disabilities must be demanded.

It should also be kept in mind that people with mental disabilities and high support needs receive offers for specific services and institutions according to the “new environments principle”. This also applies to different areas of life like accommodation, work/employment, and free time.

Free Time:

Free time is an area of life which is still insufficiently developed for people with mental disabilities and high support needs. This is primarily due to an unsure financial situation. Offerers of free time for people with disabilities must rely on a “financial patch work” to finance their work. This makes it extremely difficult to make offers to people with severe mental disabilities, because one-on-one supervision is generally a requirement. This is not financed by the current socio-political conditions. A definite discrimination exists here.

Education

Discrimination also appears, for example, in the inavailability of specific educational offers for people with mental disabilities and high support needs.

Self-Representation/Self-determination:

The demand for political self-representation for people with mental disabilities is still very new. It will most likely remain in the the public eye for a long time to come before the concepts and models and demands of political self-representation become a priority of the public.

The current state of laws regarding self-determination and social participation have indeed improved over the last few years, but people with high support needs must still vehemently defend their rights and demand their existing rights. There is a clear imbalance between legal claims and the actual realization of self-determined participation for people with high support needs.

Freedom From Barriers:

The creation of barrier free environments in public life is often geared toward mildly disabled people. For example, the trains of the Deutsche Bahn, which have devices designed to help passengers in wheel chairs enter, but which are too narrow for people with severe disabilities in an electric wheel chair.

Part II

There has been remarkable progress in legal and social politics for all people with disabilities towards their recognition as equal citizens. This progress is most notable in the ban on discrimination in Article 3 Abs. 3 GG in SGB IX, in the *Behindertengleichstellungsgesetz* (BGB, the Law of Equal Treatment for People with Disabilities) and in the general *Gleichbehandlungsgesetz* (AGG, Equal Treatment Law). It is additionally laid out in the German Basic Law that the Federal Republic of Germany is a social *Rechtsstaat* (Article 20 Abs. 1, 28 Abs. 1 Basic Law). The laws formed from the notion of social rights are a manifestation of the principle of a social state found in Germany. This principle contains the general responsibility of providing a legitimate social order. Above all, Social justice requires equal care for people unable to exercise the freedom provided for in our basic rights. This means protecting the weak and enabling an existence with dignity (cf. Article 1 Basic Law). Indeed, the social state principle is an organizational assignment which empowers and binds lawmakers to the establishment of social justice. This assignment stands, however, under a set of double reservations: the reservations of the *potential*, namely of those who can be financed, and the reservations of the *wanted,* implying the lawmakers and their organizational freedom.

It is clear from looking at the equal distribution of chances for people with severe disabilities, that the social laws in Germany keep benefit claims ready for people with disabilities under the conditions of respective benefit laws, which do not differentiate between people with severe disabilities and people with less severe disabilities. Many law-based provisions can de facto have detrimental consequences towards the realization of participation rights for people with severe disabilities. Examples of this – with no claim to completeness - will consequently be listed here.

1. The *preference of ambulatory over stationary service* is arranged in § 13 SGB XII. According to line 3 of the code, the preference of ambulatory service however does not apply "if a service for an applicable stationary institution is reasonable, while an ambulatory service is bound up with disproportional extra expenses." Social care providers thus regularly refuse to authorize ambulatory service and care on the basis of this regulation if the determined service needs are *not less* than stationary service needs. As a result, the feasibility of personal desires for people with high support needs who want ambulatory care are largely confined, in their own apartment for example, if the scope and the expenditure of the required care and support is greater than the cost of stationary care.

2. The *Forms of Service of the Personal Budget,* § 17 Abs. 3 Satz 3 SGB IX, works in much the same way. The amount of the personal budget may not exceed the costs of all hitherto individually determined services separate from the personal budget. This is often tied to descrimination of people with severe disabilities. There is a danger that their possible choices will be limited in favor of a switch from stationary care to an ambulatory care with an intensive support requirement..

3. A significant portion of *participation services* for people with high support needs are arranged in SGB XII. These are subjected in varying degrees to reservations stemming from social-care law about the usage of one's own income and financies, as well as the usage of subsistence allowences. Participation possibilities are consequently restricted as long as the allotted services are not sufficient and the personal (additional) care needs cannot be covered under one's own financial means.

4. The current notion of *"need for care"* demonstrates discrimination to the extent that people with severe disabilities and high supervision and care expenses are partially excluded from insurance services because their needs are not equally accounted for, for example with domestic help. Consequently, people who require 24-hour care and supervision may only be recognized as care level 1 because they do not fulfill the criteria of higher-level disability recognition found in the legally-recognized requirements.

5. According to *Krankenversicherungsrecht*, health insurance companies are required to submit liability offers for the so-called basic care. For more and more auxiliary services, citizens have the option of individual claims. In spite of the regulation found in § 20 Abs. 2

AGG which says that insurance companies are permitted to practice varying degrees of treatment for a disability simply on the basis of principles of mathematical risk calculations, people with severe disabilities are frequently removed from agreements of auxiliary service, due to the fact that they do not possess the financial means to pay the risk premiums.

6. The *Betreuungsrecht* in § 1901 Abs. 2 u. 3 BGB calls for the preference of the right to self-determination for people under supervision, so that they may have the chance to organize their lives - within the scope of their own abilities - according to their own ideas and desires. A lawful care giver should correspond to the desires of the person being cared for with two considerations: that the fulfillment of the desires be within the ability of the care giver and that the desires themselves do not jeopardize the health of the person being cared for. Professional care givers in particular have, however, a very limited amount of time and lack the required intensity to evaluate and judge the personal wishes of their patients. This is due to flat-rate pay according to the "Compensation Law of Care Givers and Guardians". In practical, law-based support care experience, this results in descrimination for people with severe disabilities.

In the face of the aforementioned risks of discrimination, Lebenshilfe, the biggest self-help organization for the interests of people with mental disabilities in Germany, sees itself as having a special obligation. Lebenshilfe arranged, for example, the much observed congress "Wir gehören dazu! Teilhabe von Menschen mit schwerer Behinderung als Herausforderung für Praxis, Wissenschaft und Politik" („We're a part of it too! The Participation of people with severe disabilities as a challenge to practices, economics, and politics"). At the end of this congress – in the sense of an collective self-obligation - the passage of the *"Magdeburger Appell"* (The Appeal of Magdeburg) occurred which, among a catalogue of other concrete steps of action taken (Seifert, a.a.O., Seite 304), functioned as our response and opinion.

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Study on the Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs

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Country Report Italy

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Tender on Behalf of the European Commission
D.G. Employment, Social Affairs and Equal Opportunities
Integration of People with Disabilities - Unit G3

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Selected Stakeholder Interviews

1. Summary

Italian legislation is sufficient in relation to the protection of persons in situations of major dependence or with complex needs. Areas that have received particular attention and development are schooling, employment and social security benefits. Major areas of concern include participation in mainstream social life and, for adults with severe intellectual disabilities, quality residential care and access to essential specialised care services.

Service provision is highly differentiated geographically. Devolution to Regional governments for policy, administration and financial provision of healthcare, to Provincial government for employment and to local Municipalities for social services, produces conflict over competencies and budget/cost allocation. At a bureaucratic level, the support system is complex to access. Access is hindered further by fragmentated services and general lack of communication between services and towards the user.

The Italian tradition of care-giving by the unpaid, unrecognised informal care sector (familial and social networks) is recognised and promoted by legislation, in policies and in relation to monetary benefits. This influences formal provision, facilities, services, specialised staff and does not recognise the heavy burden on informal care givers and the influence this has on their life opportunities.

The associations movement has had a fundamental role in bringing the situation of persons with disabilities to the attention of the government and actively promotes a rights-based approach in policy making.

Due to lack of space, the references of this Country Report could mostly not be added in this paper but are part of the annotated bibliography.

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In relazione alla protezione di persone in situazioni di grande dipendenza o con bisogni complessi, la legislazione italiana risulta adeguata. L’istruzione, il lavoro e la sicurezza sociale sono le aree che hanno ricevuto più attenzione ed elaborazione. Invece, le aree da sviluppare comprendono la partecipazione nella vita sociale e, per gli adulti con disabilità intellettiva, la residenzialità di qualità e l’accesso a servizi basilari specializzati.

L’offerta dei servizi si differenzia geograficamente. La devoluzione alle amministrazioni regionali per le politiche sociali, e per l’amministrazione e il finanziamento del servizio sanitario, alle amministrazioni provinciali per il lavoro, e ai comuni per i servizi sociali genera conflitti rispetto alle competenze e la ripartizione dei costi. A livello burocratico, è difficile accedere al sistema di supporto per via della sua complessità. L’accessibilità è ulteriormente ostacolata dalla frammentazione dei servizi e da una generale mancanza di comunicazione, sia tra i servizi stessi che verso l’utente.

La tradizione italiana di presa in carico e cura della persona con disabilità da parte del settore non-istituzionale (le reti familiare e sociale), non rimunerato e non riconosciuto, viene ammessa e promossa dalla legislazione, nelle politiche sociali e nella erogazione di benefici monetari. Ciò influisce sull’offerta istituzionale: i mezzi, i servizi e il personale specializzato.

Inoltre, non riconosce il pesante onere supportato da chi ha in carico la cura della persona e l'effetto che questa responsabilità ha sulla loro qualità di vita quotidiana.

Il movimento delle associazioni ha avuto un ruolo fondamentale nel portare all'attenzione del governo la situazione delle persone con disabilità, e nel promuove, nella redazione delle politiche sanitarie e sociali, un approccio basato sui diritti umani.

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La législation italienne est suffisante pour la protection des personnes en situation de grande dépendance ou avec des besoins complexes. L'éducation, l'emploi et les allocations de la sécurité sociale ont fait l'objet d'une attention et d'un développement particuliers. Les domaines posant le plus de problèmes sont la participation à la vie sociale ordinaire et, pour les adultes avec des handicaps mentaux sévères, l'accès à un logement accompagné de qualité et aux services de soins spécialisés essentiels.

Les prestations de service varient considérablement d'une région à l'autre. La décentralisation à l'échelon régional de la politique, de l'administration et du financement des soins de santé, à l'échelon provincial pour ce qui est de l'emploi et à l'échelon local municipal pour les services sociaux entraîne des conflits de compétences et de financement. L'accès au système d'aide est complexe au plan administratif. Il est de plus gêné par la fragmentation des services et le manque de communication entre services et envers les usagers.

La tradition italienne d'accompagnement informel bénévole (réseaux familiaux et sociaux) est reconnue et favorisée par la législation, dans la politique et sur le plan des allocations. Cela joue sur la prestation formelle, les équipements, les services, le personnel spécialisé et ne reconnaît pas le lourd fardeau des aidants informels et les conséquences sur leur propre vie.

Les associations ont joué un rôle fondamental en portant à l'attention du gouvernement la situation des personnes handicapées et en promouvant activement en matière de politique une approche basée sur les droits.

Par manque d'espace, les références n'ont pas pu être ajoutées dans ce résumé mais font partie de la bibliographie.

2. Introduction

National Approaches to identify the group of people with complex needs

Italian Law n° 104/92 "Framework law for the care, social integration and rights of persons with disabilities" , Art. 3 (3) defines persons with severe disabilities as follows: " *Accounting for age, if the impairment, whether single or multiple, has reduced a person's independence to such an extent as to require permanent, continuous and total care in the personal or the social sphere, the situation is defined as severe. Situations recognized as severe shall be given priority in the programmes and actions of the public services."*

ISTAT, the National Institute of Statistics, is the main provider of official statistical information in Italy and is responsible for the web site 'Disabilitincifre', a coordinated and integrated Statistical Data Bank on Disability the aim of which is to provide a means for programming intervention on the basis of complete and reliable data.

ISTAT adopts the definition of disability proposed by the World Health Organisation in the International Classification of Impairments, Disabilities and Handicaps (1980). The focal point of the Classification is the sequence of definitions of impairment, disability and handicap:

- Impairment is "a loss or abnormality of psychological, physiological or anatomical function (WHO, 1980, p. 27)", occurring at the level of the body;
- Disability is "any restriction or lack of ability to perform an activity in the manner considered to be normal for a human being (function (WHO, 1980, p. 28) in relation to an impairment and occurs at the level of the person;
- Handicap is " a disadvantage for a given individual from an impairment or a disability that limits or prevents the fulfilment of a role that is normal for that individual (WHO, 1980, p. 29)". Six survival roles were identified in the area of handicap by the ICIDH: orientation, physical independence, mobility, occupation, social integration and economic self-sufficiency. The idea behind these was to identify functions central to social existence, where limitations in performance result in disadvantage. Handicap occurs at the level of the society. The condition of handicap is strictly subjective and depends on life expectations and the needs of the person with a disability.

Since December 1998, the task of revising and promoting the use of the International Classification of Functioning (ICF) has been carried out by the DIN (Italian Disability Network), an informal Italian network of 25 centres throughout Italy, coordinated by the Regional Health Agency of Friuli Venezia Giulia, responsible for the Special Programme for the development of collaboration with the WHO and in particular for the semantic assessment of the then new classification ICIDH-2. The ICF philosophy is now generally accepted in all fields of disability policy but its practical application, as a new approach to identifying disabled people with complex needs, has not yet been realised.

Available data of people with complex needs

On the basis of estimates obtained in the ISTAT survey – Health Conditions and Access to Health Services (ISTAT 2004-05) and based on persons living in a family and a restrictive definition of disability (a disabled person is a person who declared a total absence of autonomy in one activity of daily living) there are 2 million 600 thousand persons with disabilities in Italy, equal to 4.8% of the total population of over 6 years of age living in a family. If great difficulty is considered then the percentage increases to 13% (similar estimate to other industrialized countries). The total number of disabled persons rises to 2 million 800 thousand if the 190,134 persons living in residential care are taken into account.

From the same survey, it is possible to identify 4 types of disability:

- Individual confinement (confined to a bed, wheelchair or house): 2.1%;
- Functional Disability (difficulty in dressing, washing self, bathing, eating): 3%
- Mobility: (difficulties in deambulation, climbing stairs, bending, getting into bed, sitting): 2.3%
- Sensorial Disabilities (difficulties in hearing, sight and speech): 1.1%

Mental disabilities are much more difficult to identify in respect to physical disabilities owing to the presence of resistance and cultural prejudice which makes the person directly concerned or their families avoid contact with the sectorial public services or not respond appropriately to research and survey questions. There is also the added difficulty of finding adequate statistical instruments to identify mental disabilities in respect to other disabilities.

Furthermore, due to the definition of disability used in this survey, it is not possible to include children under 6 years of age. This problem cannot be resolved by counting, as an institutional source, the certifications of children with disabilities attending school since this figure would not include preschool children for whom attendance in kindergarten is not compulsory. Estimates of children certified as disabled in the 3-5 age range is therefore a underestimate of real figures.

Another valuable source of data to estimate the number of persons with disabilities in Italy could be found in the certification of handicap as provided for by L.104/92, art. 4. Special commissions exist in each Local Health Unit for the issuing of various kinds of certification for the assessment of invalidity, status of handicap, functional diagnosis for school children with disabilities, for the definition of support interventions, the determination of residual work capacity. However, to date no standardised data collection criteria or registration instruments have been put in place. Data is not always entered into existing electronic databases, nor is data collection foreseen at a national level. Therefore, this source of data is currently not utilizable. The situation has been brought to the attention of the Ministries involved .

Classification systems, procedures and identification-practises

‘Disability’ and ‘invalidity’ are different concepts: the former refers to the capacity of a person to carry out the fundamental activities of daily living (also with the use of aids) autonomously and is traceable to L. 104/92 while the latter refers to the entitlement to an economic benefit as a consequence of a biological injury and is traceable to L.118/71.

Legal eligibility for monetary or other social security benefits is recognised through 3 different certification procedures:

i) Recognition of Civil Invalidity, as a consequence of biological injury (L.118/71) by the Medical Commission of the Local Healthcare Unit (ASL). According to the level of invalidity assessed (on a thermometric scale of 0-100) this certificate gives the right to claim accompanying allowance, attendance allowance for minors in school, vocational training courses, rehabilitation, health aids, additional points towards allocation of social housing, invalidity allowance or incapacity pension (with >74% invalidity).

ii) Assessment of Handicap, i.e. the ability to perform the basic activities of daily living (L.104/92) by a special Medical Commission of the Local Healthcare Unit (ASL) comprising 3 doctors, a social worker and a specialist in the disability in question. A situation of severe disability indicates the necessity for permanent, continuous, global care and this certificate is indispensable in order to claim fiscal deductions on tax returns, paid leave from work (requests by the person with a disability or family carer must be made directly to the employer), a support teacher in school (through the paediatrician, or Child and Adolescence Neuropsychiatry and Psychology Unit of the local healthcare unit) and, where provided for in Regional law, support aids, contributions for the elimination of architectonical barriers, the purchase and adaptation of motor vehicles and road tax exemption. Assessment of civil invalidity, even as a percentage near or equal to 100%, does not necessarily indicate a condition of severe disability. For this reason, it may be necessary to carry out two distinct health assessments, contextually where possible.

iii) Assessment of Disability for Work Placements (L. 68/99) on the basis of an evaluation of the person’s work skills. The person with a disability must possess an Assessment of Handicap Certificate, a functional diagnosis of his/her work skills and be registered in the Provincial Disabled Persons Work Placement Register. This certification concerns persons with a physical, psychic or sensorial impairment and/or intellectual disability and a reduction of work capacity exceeding 45%, work invalids or persons with sight and hearing impairments.

Steps have been taken to simplify, accelerate and unify certification procedures (L.80/2006, Art.6), while the Ministerial Decree of 2 August 2007 identifies the pathologies, including total sight and hearing impairments, mental disorders in children and adolescents, severe neuropsychiatric and relational disorders in adults for which recurrent controls for certification relating to the permanence of the disability have been eliminated.

New regulations in relation to statements for the identification of the status of disability for children entering primary school have been issued. Statements will be based on the ICF system (International Classification of Functioning) and issued by a joint medical commission. Provisions for implementation must still be agreed between the Regions and the National Health Service and will involve pupils with disabilities enrolling for the first time in primary school. This statement of disability does not replace certification of handicap, necessary to receive social security benefits.

3. Pre-Natal Diagnosis and Counselling

Through the extended possibilities for family planning, parenthood in modern societies has increasingly become a question of individual decision-making. Prenatal diagnostics and reproduction technologies permit the inclusion of characteristics of the fetus in this decision. This extended knowledge brings individuals into difficult situations when they have to make decisions regarding children. These individual decisions are affected by social values, attitudes, anxieties and knowledge of disabilities. They are also influenced by the quality of the *counseling process if professional support is available and used. It is important that individual decisions are accepted by the social environment of people concerned. How is this achieved?*

3.1. Description of the National Situation

Much attention is given to the role of the Family Counselling Clinics of Local Healthcare Units in protecting motherhood. Psychological, social, gynaecological and pregnancy counselling are offered along with psychological counselling and support services for women who have interrupted a pregnancy.

The National Health Service provides routine check ups during pregnancy once a month and more frequently from the 8th month. Three free scans are foreseen during pregnancy, by the 13th week, and between the 19th-23rd week and 28th-32nd, during which foetal anomalies can be detected, pathologies related to growth and the quantity of amniotic fluid assessed.

Invasive and non-invasive prenatal genetic screening may be carried out in order to evaluate whether the foetus has a chromosome anomaly and whether to proceed with amniocentesis or villocentesis. Current accepted medical practice proposes routine invasive prenatal screening for women over 35 years of age (amniocentesis is not mandatory but is provided free of charge by the National Health Service to women over 35 years of age).This practice is motivated by the fact that the increased risk in relation to age of having a foetus with chromosome anomalies (approx. 1/270) is counterbalanced by the risk of abortion related to the procedure (approx. 1/200).

Voluntary interruption of pregnancy (Law n. 194/1978) is possible within the first 90 days of pregnancy. Therapeutic interruption of pregnancy is possible up to the 24th week if the life of the mother is in serious danger or if ascertained anomalies or impairments in the unborn child determine a serious risk for the mother’s physical or mental health. The woman’s condition has to be certified by a doctor. In all events, doctors are legally obliged to examine all other possible solutions together with the woman, ensure she is aware of her rights if she decides to continue the pregnancy, and talk with her partner if the woman so wishes. At the end of the interview, the doctor is also obliged to invite her to reflect for at least 7 days and issues a certificate stating that the interview has taken place. In many Family Counselling Clinics a social worker or psychologist is also available during the interview but this is not mandatory. Of all abortions (138,123) carried out in 2004, 2.6% were therapeutic abortions.

In the case of interdicted women with mental disorders, the last word rests with the judge, while taking into account the wishes of the woman and those of her husband or guardian.

3.2. Specific Risks of Discrimination

Healthcare professionals who conscientiously object to the interruption of pregnancy must declare so and are not obliged to participate in procedures. The final decision rests with the woman concerned and must be an informed, self-determined decision. However, doctors can influence a pregnant woman’s decision to interrupt a pregnancy by their attitude and the way they communicate the results of diagnostic screening. Bias may therefore be an issue here.

L.194/78 ‘*recognises the social value of motherhood and protects human life from its beginning’* and is fundamentally ‘pro-life’. New screening techniques and testing raise moral and legal debates as to the whether the therapeutic interruption of pregnancy, provided for by this law, might not become ‘selective abortion’.

Any decrease in the number of persons with disabilities means a reduction in health and social care costs but does not answer fundamental ethical questions pertaining to the sphere of the person’s legitimate right to life.

4. Early Childhood

For most families, having a baby creates a situation of uncertainty and a need for direction and guidance. Living with a baby or a young child with a severe disability or with severe developmental problems brings parents into a situation with specific and difficult challenges and dependencies. Psychological stress in their daily lives often makes it difficult to cope with their parental responsibilities. When dealing with educational tasks or when specific therapeutical or medical treatment is necessary, parents cannot refer to their own educational experiences, but are dependent on professional support of various kinds. Having access to good medical care, self-help groups and early intervention services from a very early age of the child are decisive factors both for the personal development of the child and for the successful adjustment and coping process of the parents. How is this achieved?

4.1. Description of the National Situation

Before being discharged from the maternity hospital, an interview is arranged for the family and the child’s paediatrician in order to inform the parents of the child’s disorder and necessary therapy. According to the needs of the case, the appropriate service or services are informed. The following description is applicable for children with disabilities in the age range 0 to 18 years.

Family Counselling Clinics of Local Healthcare Units have a general paediatrics sector which provides information and assistance for new parents in relation to general caring for the newborn and in particular regarding growth parameters, nutrition and hygiene.

Services of reference for children with disabilities are a private paediatrician chosen by the parents, National Health Unit paediatrician, family doctor (children between 6-14 years) and Child and Adolescent Neuropsychiatry and Psychology Unit (NPI), which is responsible for the child’s personalized rehabilitation or maintenance programme from 0 to adulthood at 18 years of age.

A typical Child and Adolescent Neuropsychiatry Unit has 2 doctors, 1 physical therapist, 1 speech therapist and 3 psychomotricity therapists. Through these services, the family can arrange the healthcare and social care programmes their child requires but the amount of information and assistance received differs from region to region. Some controversy exists concerning the sharing of responsibilities and costs between the local health units (ASL) and municipalities in relation to social and healthcare service provision. Definitions and criteria are clarified in DPCM 14/2/01.

Many families are unaware of the steps needed to ensure the best care for their disabled children. A continuous and positive advocacy relationship with the Local Healthcare Unit is essential but best care also depends on the commitment of the individual health professional who has the disabled person in charge. The ongoing commitment of the family is crucial in order to enhance the awareness of the disabled child's needs and to influence all the decisions concerning her/his care.

4.2. Specific Risks of Discrimination

"The family is the fundamental point of reference for persons with a disability and support is provided mainly by a close relative very often a female relative" (ISTAT, 2003).

The burden of care is generally born by the mother, also in relation to the high percentage of divorce among parents with children with severe disabilities.

The family is often at risk due to economic problems, since one of parents must often leave *their place of work to take care of their disabled child, and organizational difficulties due to fragmentated, decentralized services and incomplete or inadequate information.*
The bureaucratic complexity of the system is a principle barrier and the fragmentation of information, competencies and services means it is difficult to obtain an integrated response to the child's needs. This makes caring for the child time-consuming and emotionally and economically problematic. There is generally no centralised point of reference for information and services, and the concept of 'care manager' has not yet evolved.
The Italian tradition of care-giving by the unpaid, unrecognised informal care sector (familial and social networks) is recognised and promoted by legislation, in policies and in relation to monetary benefits. This influences formal provision, facilities, services, specialised staff and does not recognise the heavy burden on informal care givers and the influence this has on their life opportunities.

5. Childhood: Education and Care

Preschool institutions like inclusive or special kindergartens offer care and education for younger children. They prepare children for school and give them the opportunity to interact with peers. Young girls and boys can broaden their experiences in life and enhance their social skills.
Children with severe disabilities have the same need to interact with peers, to make friends outside the family and to view themselves as a part of a social group. But young children with complex needs are dependent on additional support to participate in preschool education, such as barrier-free access or well-trained educators with specific skills and the intention to cooperate with other professionals. How is this achieved?

5.1. Description of the National Situation

The Child and Adolescent Neuropsychiatry and Psychology Unit (NPI) which has the child in charge programs and activates social processes to favour the inclusion of disabled children in kindergartens and mainstream schools.

Italy has a long tradition in kindergarten education and this is perceived as an important site for socialization, the development of personality and independence, and preparation for primary school.

Mainstream kindergartens are inclusive and available for all children, including children with disabilities, from 3 to 6 years of age. Attendance of kindergarten is not compulsory but is guaranteed, as a right, for children with disabilities by L.104/92 art. 12 (1), art. 13 (2) and art. 40. (This right also applies to nurseries (0-3 years of age)).

Kindergartens may be run by the local Municipality or the State, or be private kindergartens. Given the fact that now most parents work, there is a high demand for places in kindergartens and children with disabilities and socially disadvantaged families have priority placements.

In kindergartens, children with disabilities are allocated a support teacher on a similar basis as in mainstream schools.

(see below: 'Education/School)

5.2. Specific Risks of Discrimination

(see below: 'Education/School)

6. Childhood and Youth: School

Schools are responsible for a child's education and the teaching of knowledge of varying subjects. Furthermore, school proves to be an important part of young peoples' socialization process by offering the chance to enhance social skills and deepen social contacts with peers.
Children with severe disabilities also need high quality education and access to public schools. Pupils with complex needs are dependent on additional support in order to participate in school education, such as barrier-free access or well-trained teachers with the intention of cooperating with other professionals.
But especially pertaining to them, schools often exercise a kind of segregation. How do children with complex needs find their place in the school system, in which way are their special needs considered and how do professionals cooperate together?

6.1. Description of the National Situation

There is no separate education system in Italy for pupils with disabilities. All children with disabilities have the legal right to an education in ordinary classes of mainstream education for at least 12 years or up to 18 years of age. Access to, integration in, and continuity of education is supported by measures at a local level divided between the State, local authorities and the National Health Service. The right to an education is also guaranteed during hospitalisation or full-time rehabilitation.

The Ministry for Education is responsible for providing support teachers, funding projects and activities promoting inclusion, numbers of teachers, staff training at all levels and a national Observatory.

At a local level, inclusion is achieved through the GLIP (Provincial Inter-institutional Work Groups), with representatives of the Local Authorities, local health units and disability associations, and within the schools, through the GLH (Work Groups for the Integration of

Pupils with Disabilities) composed of the head teacher, teachers of pupils with a disability, parents and health staff, who also collaborate in the elaboration of the pupil's individual educational programmes (PEI), on the basis of a functional diagnosis issued by the local healthcare unit.

Classes including a pupil with a disability must have a maximum of 20 pupils. A support teacher is allocated for a certain number of hours a day. The hours allocated are determined by the type and severity of the disability and decided by the local healthcare unit. There is generally no substitute in the event the support teacher is absent from school and parents are generally asked to take their child home.

A constant increase of pupils with disabilities in the state school system has determined an increase in the number of exceptional cases. The parameters and criteria for the definition of support teachers are now under review. In the school year 2005-2006, students with a disability in mainstream schooling (state and non-state) were 178,220, equal to 2% of all students. Of these, 165,291 (98% of all students with a disability) attended state schools (SIMPI, 2005-2006), In the school year 2004-2005, support teachers in mainstream state schools were 78,622, (48% with long-term work contracts), an increase of 41% in respect to supply teachers in 1997-1998 (SIMPI, 2004-2005),

Parents of children with disabilities do not generally incur any costs for teaching materials, school meals and transport (costs covered by the Municipality).

6.2. Specific Risks of Discrimination

Despite the fact that legislation requires schools to be ‘schools for all’, mainstream schools generally conceive the inclusion of a child with a disability as integration into an existing ‘regular’ system and not as a global effort by the school to create an inclusive environment and culture.

There appears to be a lack of awareness and specific training for both class teachers and support teachers in the education of pupils with different disabilities and in disability issues in general.

Support teachers are provided as support to the class teacher and not to the individual. They are not normally specialized in specific disabilities, turn over is high and continuity cannot be guaranteed. The expectations for children with severe disabilities are low and the pupils are not given the knowledge and tools they need to develop.

Moreover, support teachers are often the target of national cost-cutting. Attempts by schools to reduce the numbers of hours of a child's support for financial or other reasons are not upheld in a court of law, as Italian case law illustrates.

7. Childhood and Youth: Housing and Family Support Services

Due to the variety of modern family life, all children grow up in different environments. These environments can be understood as a social network including all sorts of relationships to individuals or institutions. The family's living conditions during childhood are very important for social inclusion of the young person in society. The family has a strong impact on his/her primary socialization and influences the access to certain social institutions.

Family support services offer community-based professional support and services for families. Some children and young people live in a foster family, others in foster homes. Are such support systems available? In which way are children with severe disabilities or complex needs and their families involved in these support systems?

7.1. Description of the National Situation

The majority of children with severe disabilities lives in a family and grows up with their family. Residential care or fostering is provided by Municipalities for children with disabilities without a family, or as a temporary measure for families who are unable to cope in the short term or are unable to perform their parenting role.

According to the survey on “Residential Care in Italy” (ISTAT 2007) carried out by ISTAT for 2004, there were 1619 children (0-18 years) in residential care. Of these, 427 had multiple disabilities.

Respite services for children with severe disabilities are not well established in Italy. Families often need to rely on the availability of other family members for respite. Some disability associations have set up this type of service for their membership. Otherwise, it may be offered, along with holidays, by other private associations. These services are not free of charge and availability differs from region to region.

The family can apply to municipal social services for domiciliary support and applications are evaluated according to the individual situation, the presence or otherwise of relatives and on income. The quantity and quality of domiciliary support depends on the financial means available to the Municipality and is generally provided by a “social cooperative”, It is not guaranteed and provision varies from Municipality to Municipality. The Disability Units of Social Services in some Municipalities organise holidays and summer camps for children with disabilities. These services also depend basically on the financial resources of the Municipality. Some support to families is also possible through local voluntary associations.

Paid leave for the working mother or father of children with a severe disability is provided for by L.104/1992, art. 33: extension of optional maternity/paternity leave until the 3rd birthday of the child or alternatively, 2 hours paid leave/day; subsequently, 3 days/month plus 5 days/year in the case of illness. Parents of children with severe disabilities can also take advantage of L. 388/2000, which provides for up to 2 years' paid leave.

Parents/carers of dependent persons receive an accompanying allowance (no age limit), in the region of €400/month from the Social Security and Pensions Office. A monthly attendance allowance is granted to persons under the age of 18 who attend rehabilitation courses or school classes.

Family support is normally provided from within the same family and by their social network. Generally, families are also the owners of their own problems in relation to the management of their child's needs and education, finding information regarding his/her disability, their rights, services, fiscal and other benefits. Disability associations have an important support role in this regard.

7.2. Specific Risks of Discrimination

(See the section on 'Early Childhood' in relation to informal care and the Italian tradition in care-giving)

8. Childhood and Youth: Leisure Time

Young people use their leisure time to do enjoyable and amusing activities and to get free from daily routines. Often free time activities are organized in clubs or in various forms of sportive or cultural associations. But youngsters also spend their free time with peers without adults. Many experiences among young people of the same age are made spending leisure time together, e.g. discovering new social roles, social spaces, friendship or falling in love. Youngsters with severe disabilities or complex needs have the same leisure time needs as their non-disabled peers, but are dependent on additional support to participate in mainstream leisure time activities. How is this achieved?

8.1. Description of the National Situation

Children with disabilities, like all other children, take part in their family's habitual leisure time activities. The variety and extent of these activities will therefore often depend on their families' interests and economic possibilities.

According to the Region of residence, children and young people with disabilities can enjoy reserved seating arrangements and concessions on entrance tickets for mainstream sports events and entertainment such as cinemas, theatres, exhibitions and theme parks. In accordance with legislation, architectural barriers that impede physical access to public places must be eliminated but, in practice, this is not always the case.

Some parish youth clubs promote the inclusion of children with disabilities in their activities but this depends on local initiatives.

Higher functioning children with mild/moderate disabilities or children with physical disabilities have more opportunities to participate in mainstream activities. This depends on the organizational and specialized support needed for children with more complex needs but also on a general lack of an inclusive culture.

Leisure, cultural activities and sports are programmed at municipality level within the local Disability Plan. Provision therefore varies from one region to another and is normally realized through the private sector.

Social cooperatives and associations may also provide paid leisure time activities or play groups specifically for children with disabilities, against payment. However, neither of these possibilities encourages inclusion in mainstream activities but, on the contrary, can be interpreted as a form of segregation.

The Disability Units of Social Services in some Municipalities organise holidays and summer camps for children with disabilities. These services depend basically on the financial resources of the Municipality.

8.2. Specific Risks of Discrimination

Children and young persons with severe disabilities must often spend many hours per week in therapy sessions. There is therefore often little time left for ‘play time’ and valuable opportunities for development and enjoyment are therefore lost.

Leisure time activities for children and young people with severe disabilities are not a priority for policy makers and service providers, who tend to focus their attention on health and social care for this age group.

Inclusive practices in mainstream provision do not appear to be well-developed both from a conceptual and organizational perspective. In a certain sense, this situation is aggravated by the number of activities provided exclusively for children and young people with disabilities, leading to separation rather than collaboration.

(See also the section on ‘Early Childhood’ in relation to informal care and the Italian tradition in care-giving)

9. Youth and Young Adults: Vocational Training

A successful transition from school to the employment system is usually related to vocational training. After finishing school young people need to find a job according to their interests and abilities with which they can earn a living. Vocational training prepares for the access to the employment system and is an important step into adult life. Youngsters and young adults with severe disabilities are dependent on adapted training courses, assisting technologies, other individual support and barrier free infrastructure to enable their access. How is this achieved?

9.1. Description of the National Situation

Compulsory schooling terminates at 15 years of age with the attainment of the Middle School leaving certificate. However, attendance in education must be guaranteed for a total of 12 years or until 18 years of age. After Middle School, Students can attend a High School, Technical College or regional vocational training course. Students with severe disabilities have the legal right to attend any of these, according to their abilities and personal preferences.

Regional government provides vocational training courses with a high practical content and experiential work placements are also available (L. 845/75). Specific ‘pre-work’ courses are available for young people with moderate or moderate to severe intellectual disabilities and residual work capacity. Further training courses or work placements can follow on successful conclusion of basic courses.

Provincial Administration is responsible for Employment Services (information and advice) vocational training and employment. In a perspective of equal opportunities and inclusion in work and social life, vocational training for youth and young adults is provided through tenders to private accredited agencies as FLAD courses (Vocational Training for the Disabled), who must submit a project for approval.

The courses have a duration of one or two years and are available for two age groups:

- Vocational Training Courses for adolescents and youth with a disability of both sexes: open to persons with a disability with a Middle School leaving certificate, or of 15 years of age, supported by documentation from their Local Healthcare Unit.
- Vocational Training Courses for young adults and adults with a disability: Open to persons of 18 years of age or over, who have never worked or are unemployed, in possession of a civil invalidity pension and enrolled in the Special Disability Work Placement Register of the Province,.

The aim, in both cases, is to support inclusion in work and social life through the acquiring of basic work skills. Work placements may be possible in the sectors of hotel and collective catering, maintenance of public parks and ornamental green urban areas, the cultivation of small fruits and herbs, computers using programmes and software packages for persons with disabilities, and multipurpose tasks in the building industry and thermo-hydraulic plants.

As an alternative to the period of experiential work placements, persons with severe disabilities may attend simulation workshops and/or small group reinforcement activities with a tutor for cognitive skills and personal autonomy. According to Law 68/1999, a person with a disability had to be hired on termination of vocational training. With the Biagi Law (L.30/2003) on employment and the work market, this hiring clause is eliminated.

New apprenticeship schemes were also introduced with the Biagi Law, to provide formal teaching and practical work experience over a 4-year period. Agreement between the Regions and social parties has not yet been reached in relation to application of this law. In the meantime, reference is made to L. 196/97 (short-term work contracts).

9.2. Specific Risks of Discrimination

According to Law 104/92, vocational training should be compatible with the abilities and personal interests of the person with a disability and with the opportunities offered by the work market.

Greater focus on the demands of the work market and less attention to personal abilities precludes the creative development of work opportunities for persons with disabilities, and in particular persons with complex needs.

In the case of intellectual disability, courses often provide for mild/moderate disability but do not provide for persons with severe intellectual disability. Moreover, the fact that persons with severe intellectual disability often do not terminate compulsory education before the age of 18 automatically precludes them from more basic vocational training courses.
(see also the section on Employment)

10. Children and Adults: Social Security and Health Care

Modern societies are shaped by an enlargement of welfare systems and an increasing dependence on social security institutions. It is a challenge for all citizens to clarify their entitlements and to find access to services. The need for basic social security and to have access to health care services if necessary is important for all people.

In most cases having complex needs leads to an increase of dependence on social benefits and requires special support and services granted by welfare administration boards. Bureaucratic procedures of application approval create special risks of stigmatization. Allowances, benefits and services can improve the possibilities of individual participation, but can also initiate processes of social exclusion. How is this achieved?

10.1. Description of the National Situation

Healthcare System

The Italian National Health Service provides universal coverage, free of charge at the point of service. The State can be defined as a conservative welfare state operating social security schemes to manage eligibility for and access to services. Regional governments are responsible for regulating, planning and organising health care delivery through Local Health Units (ASL) and public and accredited private hospitals. The certification/statementing of the status of disability is also a regional responsibility and is assessed through the special medical commissions of local heath units (ASL). Certification is necessary to obtain access to the programmes available through the Local Healthcare Units and social security benefits, concessions, disability pensions, tax exemptions and deductions.

Social Security

- An accompanying allowance for anyone fully incapacitated, dependent or for persons with limited mobility (no age limit)
- A monthly attendance allowance for persons under the age of 18 who attend rehabilitation courses or school classes.
- For persons with sight, speech and hearing impairments: special schemes and benefits based on the person’s physical characteristics.
- invalidity pension (adults) - on 31 Decembre 2004, just over 4 million 800 thousand persons were receiving invalidity pensions (ISTAT, 2004).
- Paid leave for the working mother or father of children with a severe disability is provided for by L.104/1992, art. 33: extension of optional maternity/paternity leave until the 3rd birthday of the child or alternatively, 2 hours paid leave/day; subsequently, 3 days/month plus 5 days/year in the case of illness. Parents of children with severe disabilities can also take advantage of L. 388/2000, which provides for up to 2 years paid leave. Concessions also apply once adulthood is reached, provided that the adult lives with the parent or the parent is the sole care-giver. On the death of the parents, a sibling living with the person with a severe disability is entitled to 2 years paid leave. According to a decision of the Constitutional Court (8 June2005, n. 233) siblings are entitled even if the parents are still alive, provided that the parents are themselves totally disabled. It is not sufficient for the parents to be ‘only’ old or ‘only’ partially disabled. A further decision of the Constitutional Court (n.158/2007) extends entitlement of 2 years optional leave to the spouse of a person with a severe disability.
- VAT reductions and tax concessions for persons with disabilities and the families of dependent persons with disabilities. Tax concessions vary according to the type of

disability and can be a percentage or total deduction from tax returns .Tax concessions cover the purchase of cars, adaptations, special accessories and extraordinary repairs; technical and technological aids; elimination of architectural barriers; medical expenses and special assistance of a general nature in the case of hospitalisation and residential care; prostheses and equipment on local healthcare service lists (after prescription, authorisation, supply and inspection); general and specialist medical visits, surgery and hospitalisation, medicines; interpreting services for the speech and hearing impaired; national insurance contributions for personal assistants and cleaners; purchase and care of guide dogs for the blind.

10.2. Specific Risks of Discrimination

Despite guidelines to improve the coordination and integration of health and social care, provision is hampered by the presence of two different providers – Regional government for health services, through the local healthcare units (ASL), and municipalities for the provision of social care and community care. Often the person with a disability does not know which professional services exist and who to refer to. There is a lack of communication between the service provider and the user, and little communication and collaboration between the services themselves. Therefore, the user does not receive the information s/he needs and other services remain ‘invisible’. Occasionally, for cultural and communication problems, the user demonstrates mistrust in the services and the responses they can provide.

(See also the section on ‘Early Childhood’ in relation to informal care and the Italian tradition in care-giving)

11. Adults: Work and Employment

Having work or a day occupation is, for financial and other reasons, a very important indicator of social inclusion and quality of life. Going to work not only structures peoples’ days and weeks, but also has an important impact on the development of a person’s identity. It also provides access to the social security system and is an important basis for participation. For people with severe disabilities, transitional situations from school or vocational training into the employment system must often be systematically planned and organized, because they are dependent on adapted work places or assistive technologies and other individual support like a barrier-free infrastructure to enable their access. How is this achieved?

11.1. Description of the National Situation

The Regions decide the financial measures for access to employment and selective work placements, establish fiscal reductions for employers and agreements with social cooperatives for the placement of people with disabilities.

The objective of Law 68/1999 is to promote the placement and integration in the work place of persons with physical, intellectual or sensorial disabilities with a reduced capacity greater than 45% through selective work placements. Special employment registers are managed at a provincial level and a quota system implemented according to which employers are obliged to hire persons with disabilities in relation to the total number of their work force (determined in 1 person with a disability for 15-35 employees, 2 for 36-50 employees, 7% of the work force for over 50 employees).

The ‘Work Integration Service’ (SIL) within local healthcare units acts as intermediary between persons with disabilities and potential employers by giving assistance and support to match the work placement to the abilities and potentialities of the person with a disability and by drawing up agreements with public and private employers for work placement programmes.

Work placements would appear to favour persons with a physical disability or mild/moderate intellectual disability, since accommodation requires the elimination of architectural barriers and adaptations to the work setting and limited additional support.

Work placements in social cooperatives are possible for persons with disabilities with particular characteristics and difficulties in finding work placements in ordinary work environments, including flexible and short-term employment. It allows social cooperatives to employ persons with disabilities (and other vulnerable groups) through work orders assigned by companies/firms.

11.2.Specific Risks of Discrimination

The principle of inclusion exists through the disability employment register but in practice this is not so efficient.

In order to meet the obligations of the quota system but hire persons with disabilities who can easily be integrated into the work force, employers recruit directly and do not go through the special employment registers. This means that persons with a higher degree of disability or greater support needs remain unemployed. This would indicate a cultural conception that perceives diversity as a handicap.

The mainstream training and employment of persons with severe intellectual disabilities is neglected, on an apparent preconception that these persons do not have the capacity to work. This attitude precludes a person’s opportunities to reach some degree of independence and personal autonomy, improve self esteem and quality of life. In addition, it may also conceal a cost factor, due to the fact that these people require specialized support in a sheltered environment.

Social cooperatives have been criticized for exclusionary practices in so far as they tend to group together persons with disabilities who are therefore not included in society. On the other hand, for persons with more severe forms of disability, this may be their only possibility to work and earn a wage.

On the basis that anyone and everyone can ‘work’, a reconsideration of the definition of work in relation to persons with severe disabilities, and in particular persons with intellectual disabilities, could contribute to a different conceptualization of work and reveal a number of possible, creative work alternatives, proportionate to the abilities of the persons concerned and the effort put into the tasks they carry out.

12. Adults: Housing

Becoming an adult also means making up your mind about how you would like to live: stay in the natural family for a while, live alone, with a partner or family, with a friend, etc. Having privacy, a place to go to, feeling safe and comfortable there, realizing one's own ideas on how to live, are all very important for people in our societies. For people with complex needs it is a big challenge to find their own way to living. They have restricted alternatives for housing because they need barrier-free environments and life-long support. People with severe disabilities do not only need good support services but also counseling to realise their ideas and style of private living. How is this achieved?

12.1. Description of the National Situation

On becoming an adult and having finished compulsory schooling (18 years of age), persons with disabilities traditionally remain at home in the care of their families. They can be included in a waiting list for a day-care centre. In the meantime, the family can apply to municipal social services for domiciliary support, that is an educator or assistant to assist the person at home: The quantity (hours/week) and quality (educator or assistant) of domiciliary support depends on the financial means available to the Municipality. The domiciliary support service is generally not provided directly by the municipality, but by “social cooperatives”, which apply to run domiciliary services for disabled persons on the basis of a public call for tender. The criterion to assign the running of domiciliary support services is essentially based on the cost for the Municipality: the lower the cost to run the service, the higher the possibility of winning the tender. However, domiciliary support is not ensured to all disabled persons in need and provision varies from region to region.

Again, depending on the region, the types of day-care centres for adults with disabilities available are: i) social-education centres, paid for by social services on the budget of the municipalities. These generally receive lower daily rates, provide lower quality programmes but in theory are permanent facilities for all disabled persons, regardless of the severity of their disability; ii) rehabilitation centres, paid by the local healthcare unit on the regional budget. In the case of intellectual disabilities, they provide special education programmes and are accessible to severely disabled persons on the basis of their individual needs and programmes. These services receive higher daily rates, must ensure more qualified staff (staff qualification and number are stated in the regional regulation) and generally provide more adapted educational programmes. However they can last a maximum of 10 years. After this period, the disabled person is supposedly “rehabilitated” and must move to employment in the mainstream, or to a social-education day centre or to a residential service, depending on individual outcomes and circumstances and according to the decision of the disability unit of the local healthcare unit.

Funding for independent living projects can be applied for through the Disability Unit of the local Healthcare Unit (ASL) and are an option for persons with disabilities who are capable of self-determination and have a high level of personal autonomy. Renewal of funding must be applied for annually. Costs are shared between the person, the ASL and the Municipality and, again, an important criterion is cost. Persons with complex needs are more likely to be referred to a residential service, for which the unitary cost is apparently lower.

12.2. Specific Risks of Discrimination

Legislation promotes the family environment as the preferred environment, often to the detriment of the independent life of the adult with a disability, who remains confined within the home. (also of relevance, the section on ‘Early Childhood’ in relation to informal care and the Italian tradition in care-giving).

There is no national policy guidance from government that relates specifically to persons with intellectual disability. Therefore general proposals for health and welfare have an important impact on this group. Only 4 regions Tuscany, Lazio, Umbria, Basilicata include intellectual disability as a specific objective in their Regional Health Plans (PSR).

Policies support school integration in childhood but segregation in adult life, especially for adults with severe intellectual disability, who are referred to institutional provision in the form of generic residential services or residential services for the disabled, without regard for their age group or the service’s competency in the specific needs of this group. Alternative solutions (family homes, small-scale community homes) are normally allocated to persons with mild/moderate intellectual disability and/or physical disability.

Under national legislation there are no binding social rights. This means that a Municipality can refuse to pay its contribution to any service on the basis of its budget. Moreover, there are indications that costs are becoming a priority criterion for the implementation and maintaining of services. In practice, this means provision of lower quality services and less qualified staff to the detriment of quality and user requirements.

Residential care services enjoy permanent funding while day-care services do not. Consequently, day-care services can close down, usually due to economic difficulties in the day-to-day management of the service.

Independent Living projects are also precarious since funding must be applied for on an annual basis.

Social inclusion and the development of quality life opportunities for certain groups of adults would appear to take second place to local budget considerations.

13. Adults: Education and Leisure Time

Leisure time comprises all the time out of work to either relax or find a balance in contrast to every-day-life. Activities can be done on one’s own, organized in clubs or in various forms of cultural or other social facilities. In their leisure time, people in our societies are supposed to act with less formal restrictions and try to achieve a high degree of satisfaction and self-determination in their activities.
Adult education – taking the idea of life-long learning as postulate – can be seen as part of the individual’s leisure time, sometimes connected to work or the expectation that a certain course promotes one’s professional career. Sometimes people participate in adult education courses for the sake of their personal well-being, health or general personal development. For people with severe disabilities the participation in organized leisure time activities or adult education courses very often must be systematically planned and organized, because they are dependent on adapted courses, assistive technologies and other individual support, and barrier free infrastructure to enable their access. How is this achieved?

13.1.Description of the National Situation

Specific leisure, cultural activities and sports are programmed at a local level within the local Disability Plan. Provision therefore varies from one region to another and from service to service and is normally realized within the private sector.

Activities may be organized within day-care centres for adults with disabilities and rehabilitation centres provide special educational programmes for adults with intellectual disabilities.

The type of leisure, cultural and sports activities, as well as holidays organised within community homes and residential care centres depends on internal provision.

According to the Region of residence, adults with a disability, like children, can enjoy reserved seating arrangements and concessions on entrance tickets for sports events and entertainment such as cinemas, theatres and exhibitions. In accordance with legislation, architectural barriers that impede physical access to public places must be eliminated but, in practice, this is not always the case. For the same reason, mainstream adult education is open to all but not readily accessible to adults with complex needs and centres do not generally have specialized staff to support this group.

There is a growing trend in enrolment of students with disabilities in state universities. From the academic year 2000-01 to that of 2004-05, the number of students with a disability enrolled rose from 4.813 to 9.134 (MIUR-CINECA, 2005). Students with physical disabilities represented the majority (30.8%) in the academic year 2004-05, while the minority was composed of students with mental difficulties (3.2%) and dyslexia (0.7%) (MIUR-CINECA, 2005).

Universities must have a Disability Help Desk that provides services for students with disabilities. The services offered differ from university to university and may include Specific services become operational on the specific request of the student and within the limits of available resources. Services may include accompaniment and transport, support for students with hearing disabilities, individual tutoring, international transfers, post-degree careers advice, and library services. University students with a disability over 60% may also benefit from tax exemptions, scholarships and accommodation.

13.2.Specific Risks of Discrimination

For a person with a disability, quality of life is measured in leisure time and social relations. Leisure time is not seen as a priority by policy makers and services, who tend to invest in healthcare and employment.

Inclusive practices in mainstream provision do not appear to be well-developed both from a conceptual and organizational perspective.

Furthermore, there appears to be little opportunity for self-determination in community homes and residential care settings.

Adults with a disability living with their families, depend on familial support and for opportunities to develop and maintain leisure activities. As with children, the variety and extent of these activities will therefore often depend on their families' interests and economic possibilities.

14. Adults: Partnerships and Parenting

According to social trends and changes, the decision of having one's own family is not as easy as it used to be. More and more the decision to get married or to have children is a conscious one based on emotions, being aware of the changes that these decisions will mean.
Not too long ago the idea of people with (intellectual) disabilities getting married or having children was regarded as impossible. People with complex needs who wish to marry or have a child often have to face prejudices. After all, in their parenting they are dependent on special support. Professionals from different services and service sectors have to cooperate to prevent exclusion and discrimination. How is this achieved?

14.1. Description of the National Situation

Partnership and parenting for persons with severe disabilities and/or complex needs are practically absent from the political agenda. Disability associations and in particular women's disability associations attempt to promote greater awareness of their emotional and relational needs in relation to these issues. In fact, as an exceptional event, the establishment of partnerships among persons with disabilities (with Down's Syndrome or sight impairments, for example) is likely to receive much national mass media publicity.

In everyday society, arguments regarding sexuality and parenting for persons with a disability are still considered cultural and social 'taboos' and a woman with a disability expressing the wish to have a child tend to be considered irresponsible and physical (access), psychological (feelings of inadequacy, lack of specialized support) and social (preconceptions) limit her possibilities.

No specific law exists for the protection of disabled mothers. Framework Law 104/92 protects disabled persons and in particular the parents of disabled children but states nothing in relation to motherhood and disabled women.

Cases within examples of good practice have seen the establishment of couples and of marriage. These cases usually refer to higher functioning persons with mental disorders or intellectual disability who are able to manage, albeit with professional support, the emotional relationship and problems that living together normally generates.

14.2. Specific Risks of Discrimination

Adults with severe intellectual disabilities or complex needs often live with their families and are dependent on them for social relations in general. The tendency to continue to treat them as children excludes any possibility of their establishing significant relationships with their peers.

Residential care is organized so as to avoid 'problems' arising from the sexuality of its residents.

Partnerships and parenting for low-functioning adults with intellectual disability or mental disorders is not a principle consideration and their emotional and relational needs are generally neglected.

A primary basic need for this group is the security of stable, empathetic environment and care, in which to experience positive relationships of a more general nature in everyday living contexts.

15. Adults: Exercising Civil Rights

One developmental task of adulthood is to know and to exercise one's rights. This comprises the rights that a state confers to its people in order to secure protection and political participation, e.g. basic human rights and voting.
For people with severe (intellectual) disabilities, civil rights still cannot be exercised in every case. Additional support is needed to exercise democratic rights like voting. It is also a commonly held belief that people with severe disabilities or complex needs are in capable of serving in political positions. How can people with severe disabilities exercise their rights as citizens?

15.1. Description of the National Situation

Various forms of legal protection of the rights of persons with severe intellectual disabilities exist in Italy through the appointment of a legal representative. One such form of legal representation is the appointment of a 'caretaker' to legally protect those people who are partially or totally unable to carry out the activities of daily living, make decisions that are in their own best interest or handle their assets, but for whom interdiction or incapacitation is inappropriate. In other cases, a legal guardian is appointed by the tutelary judge. A person's legal representative can be another family member (normally a brother or sister) or another tutor outside her family. This is a person identified and named by the disabled person's parents or by the "tutelary judge", in the event parents did not appoint a legal representative or there are no available relatives. Advocacy parent associations are not entitled to exert legal representation of individuals before the law. However, the process to ensure legal protection through a legal representative outside the family requires to be actively started by the disabled person's parents at the local court. Many families do not do that. In this case, a legal representative is named by the court. This person could be a family member but also an extraneous person.

In theory, the right to vote is provided for all persons with a disability. A new norm foresees, for the first time, domiciliary voting for persons with serious illnesses who cannot be moved from their homes and who are dependent on life support machines. This provision does not apply to persons with severe disabilities who might wish to vote, are confined to their homes but are not dependent on life support machines.

The non-discrimination law on the judicial caretaking of persons with disabilities victims of discrimination (L. 67/2006) fully implemented the principles of equal treatment and equal opportunities, and in cases of discrimination relative to access to work and at the workplace against persons with disabilities. For the first time, the Ministerial Decree of 21 June 2007 provides for the legitimacy on the part of recognized associations and organizations to act on behalf of an individual or group, victim of discrimination.

Italian associations of disabled persons and their representatives have long been active in promoting a civil rights approach to disability and the new UN-Convention on the Rights of Persons with Disabilities has brought this perspective to the fore in political discussion.

15.2. Specific Risks of Discrimination

The necessity to advocate for persons with severe disabilities who are not capable of self - determination is essential in order to uphold their civil rights. The system is very complex and many families are unaware of the steps needed to ensure the best care for their disabled relatives, or of the need to provide them with a supportive legal representation after their death.

Professional or voluntary legal representatives, whether caretakers or legal guardians, may be unaware of the needs of the disabled person or poorly motivated to advocate for her/his wellbeing.

In relation to the right to vote, blind persons can be accompanied in a polling booth to vote; persons with intellectual disabilities cannot. Persons with severe disabilities confined to their homes are unable to vote, unless in the condition described above.

16. Adults: Ageing and End of Life

Ageing contains a lot of new challenges: Retiring, organizing one's day in a new way, coping with the loss of abilities and coming to terms with it and with one's life. Regularly, more support is needed in day-to-day life and thus social dependencies are increasing. Often this means that familiar life settings must be changed because care needs cannot be covered anymore by the given arrangement. Most people don't want to leave their familiar setting even when their care needs are becoming extensive and complicated. They prefer arrangements which are based on home care services that are reliable and flexible. When people reflect upon the end of their life there is also a wish to die in dignity.
How is this achieved?

16.1. Description of the National Situation

(see also all sections on Adults)

Italy has a large population of persons aged 65 and over. Persons with disabilities and non-self-sufficient elderly persons (no longer independent due to permanent infirmity or chronic disease that reduces personal freedom till requiring support in activities of daily living) constitute one category on reaching 65 years of age. The expectancy of a life free from disability at 65 years of age is 16.1 years for women and 14,9 years for men (ISTAT, 2004-2005). 32% of persons with a disability, mainly older people and widows, live alone, The average age is 76 years for men and 80 for women (ISTAT, 2004-2005). Older people with disabilities who can count on the presence of their children, have children living nearby in 89% of cases and in 87% of cases have children who visit them at least once a week

(ISTAT, 2003). Domiciliary support may be provided by the Municipality in the form of home helps, meals, accompanying the person outside the home. This service is charged to private agencies, voluntary organisations and civil community service and the level of support varies. Rather than recover an elderly person in a nursing home, domiciliary support is sought from non-specialised carers (badante), paid by the elderly person or their children.

There are 32,336 adults with disabilities and 156,175 elderly non-self-sufficient people living in residential care ISTAT, 2003). Provision varies greatly from one region to another and according to geographic location.

Nursing homes are the main non-hospital facilities and services for elderly people but also provide for persons with disabilities. There is a general lack of provision for non-self-sufficient elderly people. Institutional provision in residential care services run by religious or other organisations is the norm for adults with severe intellectual disabilities. Their needs are recognised as different from those of mental health, but they are often isolated with limited social networks, have a higher prevalence of additional disabilities, sensory impairments, epilepsy, autism etc. making care more complex. 50-90% have communication problems and a higher risk of mental health problems.

If the person has no family or legal representative, access to facilities is decided by the disability unit according to local resources in terms of availability and costs of the existing facilities. Disabled persons and their families cannot make their own decisions on the service of their choice. Nevertheless, the location of the service in the same area covered by the disability unit is considered a priority, even if local services are not the most adapted to meet the person’s needs. A disabled person should first be served by a local, less adapted facility before obtaining the authorisation to move to a more adapted facility that is located in another area. To do that, they, their family or legal representative must demonstrate that the local facility is unable to meet the person’s needs.

16.2.Specific Risks of Discrimination

Residential care for adults is an open issue, in particular in relation to adults with disabilities who require lifelong support, have ageing parents or who lack familial support (‘Durante di noi’ and ‘Dopo di noi’). Discussion revolves around the question of institutional care versus forms of independent living

Residential service provision for adults with intellectual disability is not developed in Italy. Person-centred planning is infrequent, as are forms of independent living provision. There is little integration of health and social care services and definitions and the harmonization nationwide of the Essential Levels of Care (LEA) has not yet been achieved.

In relation to people with intellectual disabilities and mental health problems, cultural and social barriers exist for which the medical model conception of care is still present in various regional situations.

Country: ITALY
NGO representative and Interviewee:
DONATA PAGETTI,
President of Autismo Italia onlus[1], Milano, Italy

Date: 3 June 2007

This was a vis-à-vis interview, lasting approximately 45 minutes.

1 - In your opinion: What are the main risks of discrimination against persons with severe disabilities in your country?

As the representative of Autismo Italia, I can speak for persons with autism. As persons in situations of major dependence with complex needs, I can say that the general situation of this group is characteristic of the situation of all persons with severe disabilities in Italy.
The main risks of discrimination can be found at the level of access and in particular access to habilitation, life-long learning, vocational training and work. Since the needs of these people are complex, care and support are also complex, multifaceted and long-term. They require high investments in terms of continuous human and financial resources. In this context, access may be only partially available, a surrogate for the real thing or inexistent.

2 - In your opinion: What are the perspectives of anti-discrimination policies for people with severe disabilities in your country and in the EU?

A transversal non-discrimination Directive for persons with disabilities is necessary at European level. Persons with disabilities cannot be defined as a particular group or confined to that group if they are really to be included in society.

At national level, we are working with the Government to establish the general 'Essential Levels of Care' (Livelli Essenziali di Assistenza - LEA) that must be applied nationwide and the guidelines for the regional application of the LEA in relation to persons with severe disabilities. Since regional government is responsible for the provision of health services, discrimination occurs at this level, despite national legislation. The LEA should state the minimum level of care the regional governments must respect.

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[1] ***Autismo Italia onlus** is a national non-profit association representing persons with autism and their families and local autism associations. It is a member of the Italian Disability Council (CND), the Italian Federation for Overcoming Disability (FISH) and the international organisation Autisme Europe. It contributes to the diffusion of reliable information on the nature of autism and organises conferences, seminars and training courses for professionals, service providers and families. Autismo Italia works with IACAPAP (International Association for Child and Adolescent Psychiatry and Allied Professions) to promote scientific research, the diffusion of reliable autism information and to raise awareness within the WHO regarding the problems of people with autism and their families.*

3 - What are the most important issues to articulate for people with severe disabilities in interest groups rsp. lobby work?

The word ‘lobby’ does not exist in the Italian language and in Italy. There is no structured, legally recognised form of lobbying, as perceived in Anglo-Saxon countries. On the contrary, the English word “lobby” in Italy assumes a negative meaning of undue pressure to obtain particular benefits in favour of a group against the general interest.

However, the most important issues that need articulating for people with severe disabilities are to guarantee lifelong support and the quality of the support provided. With the increase in life expectancy, another important issue is the inclusion of persons with severe disabilities in suitable small community houses that they can consider as ‘home’ before they lose the support of their families through incidental circumstances, old age or death.

4 - What are the key issues in the field of participation of people with severe disabilities?

In order to participate in society, people with severe disabilities must be supported through habilitation and education in order to develop communication skills and capacity to choose. This is a lifelong process starting from a very early age. That is why we use the term habilitation and not rehabilitation. Educational programmes are reductive and fail to consider education as a lifelong experience. They are inadequate both in terms of quantity and quality and do not support or encourage a person’s powers of self-determination or capacity to choose.

5 - What are the key issues in the field of discrimination against people with severe disabilities?

I believe a key issue is the approach to severe disability. This approach puts the “burden” these persons represent on their families and society at large. As a consequence, support and services, if any, are aimed at providing these people with the least expensive assistance and “places” in which only their everyday survival needs are met. Policy decision makers, public administration and society at large do not see complex dependency needs disabilities as a rights issue, but persist in a charity approach. As a consequence, people with complex dependency needs are discriminated against in terms of full enjoyment of equal opportunities and of their human and fundamental rights to education, health and habilitation, This happens because the accommodations and positive actions needed to ensure these people effective equal opportunities and fundamental rights are considered too expensive in relation to their benefits.

The situation of adults with severe disabilities in Italy is particularly distressing - or they are completely dependent on their families or they are placed in non-specialised care homes, often residential nursing homes for old people, regardless of their age. They receive a minimum of support that, more often than not, is provided by unqualified staff who, because of internal trade union agreements, have the freedom to exercise physical and/or pharmacological containment on residents as they deem fit.

6 - Are there people with severe disability who work within NGO´s or self-advocacy organizations?

There are persons with severe physical disabilities working within NGOs (known as ONLUS in Italy) but not persons with multiple or severe intellectual disabilities.
Persons with multiple or intellectual disabilities who are unable to represent themselves, are represented through their advocate associations - Autismo Italia is an example.

7 - How do you co-operate with special interest groups of people with severe disabilities?

Autismo Italia is a member of the FISH network, the Italian Federation for Overcoming Handicap (FISH - Federazione Italiano per il Superamento dell' Handicap) which acts as a voice for persons with disabilities and their families with Government, Parliament and the institutions. The FISH is consulted periodically by the Ministries of Health, Education and Welfare. Together with the Italian National Disability Council (CND - Consiglio Nazionale Disabilità), of which it is a member, it also plays a part in aligning national policy to European policy.

8 - What are your experiences to articulate the special needs and interests of people with severe disabilities in public discussions at regional and national level?

In Italy, self-advocacy and advocacy groups are ignored or at best barely regarded at all levels.
At a national level, Autismo Italia, as a member of FISH, has just recently been called on to work with the Ministry of Health who have set up a round table specifically on autism.
On the other hand, at a regional level, it depends on the region and the contacts the regional representative for persons with disabilities has and is able to maintain with the regional bodies.

Country: ITALY

POLICY MAKER Interviewee:

OMBRETTA FORTUNATI[2]
Councillor of the Province of Milan,
Responsible for Participation and Protection of the Rights of Persons with Disabilities

Date: 10 October 2007

This was a telephone interview, lasting approximately 40 minutes.

(In your opinion) What are the main risks of discrimination against person with severe disabilities in your country?

Fundamental risks are the isolation and loneliness of persons with disabilities and their families and in particular, the way in which they live their condition of disability due to the partial or imprecise information the family or adult with a disability receive on initial diagnosis (at birth, as a result of a genetic illness or following an accident) and throughout the course of their lives. This lack of precision completely disorientates the family who do not know which procedures they must follow, either initially or subsequently. Their disorientation is further complicated by the fragmentation of services that are unable to give integrated responses. As a consequence, on the one hand, there are persons with disabilities with all-inclusive rights and health and care needs; on the other, an excessive separation between healthcare and social care.

Another important issue is employment, which for persons with a disability means independence and self-assertion. Work is a possibility even for persons with a 100% disability. The problem lies in maintaining the work placement, something made more difficult by a cultural conception that perceives diversity as a handicap. Persons with a disability therefore need the support of a tutor or personal assistant.

The cultural aspect also prevails for women with a disability, who find themselves in an even more difficult situation, at work, in their social and relational life, and in their sexuality. One should not also forget that much of the onus of a disability is born by women. As well as their traditional care role within the family, they often remain the sole carer of a child with a disability since in this situation fathers sometimes abandon their families. Moreover, legislation promotes the family environment as the preferred environment often to the detriment of the independent life of the person with a disability, who remains confined within the home.

An autonomous and independent life is fundamental for a person with a disability but a condition far removed from reality. The planning of a self-determined independent life, according to an individual's possibilities, should be included in individual plans from birth.

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[2] Ombretta Fortunati: Elected in the Provincial Elections 2004, delegated responsible for Participation and Protection of the Rights of Persons with Disabilities, with the objective of promoting cultural and social policies encouraging inclusion and full realization of rights through specific projects that, within the sphere of provincial competencies and in synergy with the Provincial offices of reference, establish good practices in order to overcome multiple discrimination and architectural, cultural and social barriers still present in the community.
In accordance with her institutional role, she is a member of the Subcommittee for Employment of People with Disabilities, the Sports Council for Persons with Disabilities, the Executive Coordination Committee of the sectors involved in disability issues.

(In your opinion) What are the perspectives of anti-discrimination policies for people with severe disabilities in your country and in the EU?

The Italian associations movement strongly promotes independent living. In Italy, efficient laws exist which favour the inclusion of persons with disabilities. These laws regard inclusion in mainstream schools, the elimination of architectural barriers, the right to work, judicial guardianship, Law 104/92 (Framework Law regulating all aspects of disability) and the Law on Non Self-sufficiency which is being prepared by the Ministry for Social Solidarity (Welfare) and will also involve other Ministries. The Ministry is also working on the redefinition of the Essential Levels of Care (LEA - Livelli Essenziali di Assistenza) in order to standardise care nation-wide, and on the ratification of the recent UN Convention for Persons with Disabilities.

Although there are many laws in Italy in favour of persons with disabilities and their social inclusion, these go adrift because of non-funding and cultural perceptions, fundamental for them to be respected.

Are there policy programmes/legislation, which have intended or un-intended effects on persons with severe disabilities?

Political programming is also necessary in relation to competencies. There are Municipal competencies and also Provincial competencies such as sensorial disability and inclusion at work through work placement centres. A remarkable tool in this regard are the District Plans (piani di zona) (L.328/2000: Framework Law for the realization of an integrated system of intervention and social care services), the objective of which is to develop and qualify social care services in order to make them flexible and adapted to the needs of the population. This objective is realisable through the joint programming of all health and social care actions by the social actors in the territory: the Municipalities, local Healthcare units (ASL) and the private sector, under the coordination of the Province. At the moment however, programming of these actions is still only partial.

In which political field is the life situation of people with severe disabilities currently on the political agenda at national level?

At a political level, as conveyed by national government, the task of the Province is to provide as integrated a response as possible. The coordination among the various Provincial departments and sectors that we are currently putting in place goes against the trend of fragmentation of services. There is now greater awareness towards persons with disabilities and active policies within Provincial Government. The recent revision of the Guide to Services is an example. In the near future, the departments of Provincial Government will meet to discuss how the Province can respond to the UN Convention for Persons with Disabilities.

Who are the most important actors in the national policy field for persons with severe disabilities?

According to the principle ‘Nothing about us without us’, we believe in the active participation of associations who, together with the political competencies of the Region, Province and Municipalities, can create operational synergy in peer and participatory actions of universities, associations and the territory.

From the viewpoint of an administration open to the needs of its citizens, a participatory model has been adopted through the testimony, comparison/planning and collaboration of associations and persons with disabilities. Together, priorities have been established as the basis on which the department can act and the modes of intervention identified, among which the theme of independent living in its various aspects.

Together, the Province and local associations have established a process which began with a seminar, followed by a conference and has now seen the creation of a Round Table on Residential Care which foresees the participation of the directors of local planning offices and local associations as well as the directors of the Provincial sectors involved.

What are the key issues in national policy field for person with severe disabilities?

Substantially, the problems are those identified in the first question, in a vision of citizenship and respect for the uniqueness of the person and in contrast with the fragmentation of responses that persons receive from one office/service or another. Generally speaking, an office/service never surpasses its own competencies or bureaucratic procedure. The Department for Social Affairs of the Province of Milan is responsible for sensorial disability but this also involves guardianship, for example. A conference is being organised on this theme in collaboration with the Ministry of Social Solidarity and cultural events are being promoted to raise awareness among the general public, within the logic of inclusive diversity (one unique ‘normality’ does not exist).

Are there specific policy programmes for persons with severe disabilities that already exist? And in preparation?

As well as the programmes mentioned above concerning the new UN Convention, the Province in collaboration with local associations is also preparing a course for care workers associations and families on specific themes: mobility, employment and independent living. From the point of view of ‘during our life’ (‘durante di noi’) rather than ‘after we have gone’ (‘dopo di noi’) (the provision of residential care before a person with a disability remains without family support), an Internet site with an inclusive residential care services database has been created which gives people the possibility to know what is available and choose a specific residential option. A much-appreciated awareness booklet has been published for families of children aged 0-12 with the collaboration of the Department for Social Affairs of the Province and further programmes for families are in preparation.

Country: ITALY

Service Provider:
AIAS[3]
National Association of Support to Persons with Spastic Cerebral Palsy
Via Cipro 4/H., Roma
http://www.aiasnazionale.it/page.asp

Interviewee:
Gabriele Favagrossa,
Coordinator Leisure Time for People with Disabilities Information Desk, AIAS Milano
on behalf of the President, Nunzio Bonaccorso

Date: 18 October 2007

This was a telephone interview lasting 45 minutes

(In your opinion) What are the main risks of discrimination against person with severe disabilities in your country?
There are risks at various levels:
- in management of leisure time: if you ask a person with a disability, quality of life is measured in leisure time and social relations. Leisure time is not seen as a priority by policy makers and services, that tend to invest in healthcare and employment;
- in work placements: the principle of inclusion exists through the disability employment register but in practice this is so efficient;
- in education: legislation requires schools to be ‘schools for all’ but the right to education cannot be guaranteed and there is a risk of non-inclusion because of a lack of resources, information and trained personnel;
- cuts in social spending: this trend means continuously reduced economic resources, support and services. Therefore, fewer funds and services means greater discrimination at all levels.

(In your opinion) What are the perspectives of anti-discrimination policies for people with severe disabilities in your country and in the EU?
- equal opportunities for persons with disabilities for which Italy is in line with EU conceptions;
- social inclusion and citizenship;
- “Nothing about us without us”, decisions and policies are made in consultation with persons with disabilities;

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[3] L’A.I.A.S. (Associazione Italiana Assistenza Spastici) founded in 1954, safeguards and promotes the right of persons with disabilities to rehabilitation, health, education, vocational training and social inclusion, in order to achieve the valid prevention of disability. It operates nationwide through its 120 branches.
A.I.A.S. Milano was founded in 1959 to support the needs of children and adults disabled by the effects of infantile cerebral palsy. AIAS Milano now operates within a global vision of the life problems of persons with disabilities providing numerous services for families, including health and social care services in collaboration with the local health units, the Milano Municipality and all the hinterland to the south of Milano, the Provincial and Regional governments. Throughout the years, AIAS Milano has sustained the needs of persons with disabilities at local and national government level.

- mainstreaming with the organisation of an inclusive system at all levels, and for all types of support.

What can you say about the difficulties of people with severe disabilities having access to support from professional services?
Often the person with a disability does not know which professional services exist and who to refer to. There is a lack of communication between the service provider and the user, and little communication and collaboration between the services themselves. Therefore, the user does not receive the information s/he needs and other services remain 'invisible'. Occasionally, for cultural and communication problems, the user demonstrates mistrust in the services and the responses they can provide.

How many and what kind of people are excluded from all or certain services and get only support from their families?
It is much easier for a person with a physical disability to find adequate responses than, for example, a person with a psychiatric disorder, who requires complex responses at different levels.

In which areas of the support system do you see problems of availability or bad quality?
Fewer economic resources mean fewer services and lower quality. Residential care is an open question, in particular in relation to persons with disabilities lacking familial support ('Durante di noi' and 'Dopo di noi'). Discussion revolves around the question of institutional care or independent living and greater independence from their families.

Are there differences in quality of services for people with mild, profound and severe disabilities?
This depends on the individual service. We have noticed that paradoxically, persons with slight disabilities have greater difficulty in finding the services adapted to their needs. Diagnosis and follow-up of persons with severe disabilities is more thorough and they are more easily collocated than persons with slight disabilities.

Which problems do you see in inter-sectorial co-operation, in service planning and delivery?
Fewer resources mean greater management problems in some sectors of the system. In order to function well services need to network and know what other services can offer and not enough is invested in this area. A lack of communication means resources are wasted in overlapping services when it would be better to differentiate, new services repeat the same errors as previous services and certain services do not exist at all.

Which structural problems do you see in the service system and in service providing?
As was mentioned above, cooperation and joint planning.

What are the main concepts for the support of people with severe disabilities in your country? Are there differences between provider groups? Are there 'taken for granted assumptions' in this field that foster discrimination?
An outline of support concepts was given above. There are good and bad services in both the public and private sectors and it is not possible to distinguish. Prejudices still exist but great

progress is being made in respect to the past when persons with disabilities were perceived as unable to do anything and unintelligent, even if in a wheelchair. An equality principle is evolving even if not always put into practice.

What are the biggest challenges for the development in service provision for persons with severe disabilities?

One of the greatest challenges is to place the person at the centre, according to the logic of inclusive programming with the person with a disability. At the moment the person with a disability is asked for his/her opinion at the end of a project, when it is often too late instead of being part of the monitoring team. In order to be an inclusive society, s/he must be included with full rights. The objective, therefore, is mainstreaming and inclusion at all levels and in all sectors. For example, it is not enough to remove barriers to make tourism accessible. Tourism operators must have specific training both at school and university.

What experience do the service providers have with personalised service delivery and personal budgets?

Personalised service delivery and personal budgets are decided at a regional level. Each regional AIAS provides rehabilitation, leisure time, school inclusion and employment and family support services and is funded through the region and local municipality.

Study on the Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs

www.non-discrimination.eu

Country Report Lithuania

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Tender on Behalf of the European Commission
D.G. Employment, Social Affairs and Equal Opportunities
Integration of People with Disabilities - Unit G3

Table of Contents

Selected Stakeholder Interviews

1. Summary

This paper is an overview of the specific risks of discrimination of people with severe disabilities and complex needs in Lithuania. An introductory part presents general aspects of categorization approaches, availability of data and assessment procedures of the disability level.

People with the most severe disability comprise 14% of the total number of disabled people. 36% of disabled people are people of retirement age. People of working age with a disability comprise about 58% and disabled children about 6% of the total number of disabled people.

Following a life-course approach and various needs emerging, the main part of the document consists of 14 sections, starting with prenatal diagnosis and right to be born and ending with ageing and dying in dignity. Every section contains general information on legislation, available statistics on the specific issue and an overview of the support system. The sections are concluded with an analysis of main risks that a disabled person may experience in each stage of his/her life. Due to lack of space, references could mainly not be added in this paper but are part of the annotated bibliography.

The document concludes that despite of many legal provisions, services and benefits, the Lithuanian system of care for persons with severe disability is highly discriminating. Absence of social and psychological support leads to uninformed decisions in favour of abortion in case of an impairment of the foetus. Disabled children in rural areas have less choice of proper medical treatment, pre-school and school education according to their special needs. The support system for families is not sufficient to prevent the placement of a disabled child in an institution. Speaking about adult life there are also many obstacles to a proper participation in society: vocational training rarely leads to integration in the mainstream labour market, a disabled person can hardly choose his or her living arrangement, social security and health care systems are segregating and exclude people from mainstream services. Persons with a severe disability cannot establish a family and have children.

The life of a disabled person is followed by various stigmatizing labels, fear, intolerance and usually ends in a residential care institution together with several hundreds persons of the same fate.

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Šalies ataskaitoje apžvelgiama itin sunkią negalią turinčių asmenų patiriama diskriminacija Lietuvoje.

Įvadinėje jo dalyje pristatomi pagrindiniai įstatymai, išskiriantys ir apibrėžiantys šią socialinę grupę, statistiniai duomenys ir neįgalumo lygio nustatymo procedūros.

Itin sunkią negalią turintys asmenys sudaro 14% visų neįgaliųjų. 36% neįgaliųjų yra pensinio amžiaus, 58% - darbingo amžiaus, vaikai sudaro apie 6% neįgaliųjų.

Šis dokumentas sudarytas iš 14 dalių, atspindinčių įvairius negalią turinčio asmens gyvenimo laikotarpius ir jų metu iškylančius poreikius: nuo negalią nustatančių genetinių tyrimų, kurie itin dažnai užkerta kelią gimti neįgaliam vaikui, iki orios senatvės ir mirties.

Kiekvienoje dalyje pristatoma konkrečią sritį reglamentuojanti įstatyminė bazė, esama statistika ir apžvelgiama esama paramos sistema. Kiekviena dalis apibendrinama apžvelgiant pagrindines rizikas, kurias gali patirti itin sunkią negalią turintis asmuo kiekvienu savo gyvenimo laikotarpiu.

Šalies ataskaitoje teigiama, jog nepaisant esamos įstatyminės bazės, paslaugų ir išmokų sistemos, Lietuvoje itin sunkią negalią turinčių asmenų globos sistema veikia diskriminuojančiai. Nesant socialinės ir psichologinės pagalbos šeimos dažniausiai apsisprendžia nutraukti gyvybę, jei genetiniai tyrimai rodo vaisiaus apsigimimą; neįgalūs vaikai kaimo vietovėse turi mažesnes galimybes gauti efektyvią medicininę pagalbą bei specialius jų poreikius atitinkantį priešmokyklinį ir mokyklinį ugdymą; šeimos paramos sistema dažnai veiksmingai neužkerta kelio neįgalaus vaiko priežiūrai specializuotoje institucijoje. Kalbant apie suaugusius neįgalius asmenis, jie taip pat patiria nemažai kliūčių sėkmingai integruotis į visuomenę: darbinis mokymas retai užsibaigia sėkminga integracija į bendrą darbo rinką, neįgalus asmuo retai gali pasirinkti kur, kaip su kuo gyventi, socialinės apsaugos ir sveikatos sistema segreguoja ir diskriminuoja. Itin sunkią negalią turintis asmuo negali kurti šeimos ir turėti vaikų. Jei neįgalusis mėgina kovoti už šią savo teisę, pasitelkiamos teisinės priemonės – neveiksnumo institutas, siekiant užkirsti kelią šeimos kūrimui.

Itin sunkią negalią turinčio asmens gyvenimas, lydimas stigmos, baimių ir netolerancijos paprastai pasibaigia stacionarioje globos įstaigoje, kur dar gyvena keli šimtai jo likimo draugų.

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Ce document est un aperçu des risques spécifiques de discrimination que rencontrent les personnes avec des handicaps sévères et des besoins complexes en Lituanie. L'introduction présente des généralités sur les approches de classification, la disponibilité de données ainsi que l'existence de procédures d'évaluation du niveau du handicap.

Les personnes avec les handicaps les plus sévères représentent 14% des personnes handicapées. 36% des personnes handicapées ont atteint l'âge de la retraite, celles en âge de travailler représentent environ 58% et les enfants handicapés environ 6%.

Le corps du document est composé de 14 sections qui suivent le cycle de vie et les divers besoins qui se font jour, en commençant par le diagnostic prénatal et le droit à naître handicapé et terminant avec le vieillissement et une fin de vie dans la dignité.

Chaque section contient des informations générales sur la législation, les statistiques disponibles , un aperçu du système de soutien et se termine avec l'analyse des risques principaux qu'une personne peut rencontrer à cette étape de sa vie.

Le document conclut que malgré de nombreuses dispositions de la loi, services et allocations, le système lituanien pour les personnes avec un handicap sévère est fortement discriminatoire. L'absence d'aide sociale et psychologique, d’information, mène à une décision d’avortement en cas de fœtus avec handicap. En zone rurale, les enfants ont moins de choix pour un traitement médical approprié et une éducation préscolaire et scolaire répondant à leurs besoins particuliers. Le système d’aide aux familles est insuffisant pour empêcher le placement de l'enfant dans une institution. Concernant la vie adulte, de nombreux obstacles existent à une réelle participation dans la société: la formation professionnelle mène rarement à l’emploi ordinaire, la personne handicapée peut difficilement choisir sa résidence, le fonctionnement du système de sécurité sociale et de santé est séparé des services ordinaires. La personne avec un handicap sévère ne peut pas fonder une famille et avoir des enfants. Si elle exprime un souhait fort, des mesures juridiques (institution de l’incapacité juridique) peuvent être prises pour l'en empêcher.

La vie de la personne handicapée, accompagnée par différentes étiquettes stigmatisantes, des peurs, de l’intolérance, se termine généralement dans une institution résidentielle, groupant plusieurs centaines de personnes partageant le même destin.

2. Introduction

National Approaches to identify the group of people with complex needs

There is no national approach to identify the group of persons with complex needs or severe disability. There is no specific and separate legislation regulating services, benefits and care for this social group. However, the definition of “a person with severe disability” exists in Lithuanian legislation and in statistics on medical data, social and educational service provision for people with severe disability.

The following main laws identify the group of persons with complex needs: Law on Social Services, 2006; Law on Social Integration of disabled people, 2005; and the Joint order of the Minister of Health, Minister of Education and Science and Minister of Labour an Social Affairs Regarding Criteria of Disability Level, 2005.

The Law on Social Services divides the understanding of a “Person with a severe disability” into three categories based on age criteria:

1) a child with a severe disability – a person who has been diagnosed at a level of complete dependency under this Law and has been assigned a level of severe disability under the Law on Social Integration of disabled people;
2) an adult with a severe disability – a person who has been diagnosed at a level of complete dependency under this Law and has been rated as incapable to work under the Law on Social Integration of disabled people;
3) a person with a severe disability who has attained the pension age – a person who has attained the pension age and who has been assigned a level of complete dependency under this Law.

The Law on Social Integration of disabled people identifies and describes three disability levels:

1) severe,
2) medium and
3) mild.

According to this law, the disability level is set after a complex evaluation of the person’s health condition, daily skills, educational abilities, influence of environmental factors and other important aspects.

The Joint order of the Minister of Health, Minister of Education and Science and Minister of Labour an Social Affairs regarding Criteria of Disability Level foresees that ***severe disability*** *is a person‘s condition influenced by disease, trauma, inborn and acquired health impairments, negative influence of environmental factors diminishing his/her capacities to be educated, participate and placing him/her in constant need of care, nursing and support.*

The State Medical Social Expertise Commission under the Ministry of Social Security and Labour is responsible for ensuring a high-quality assessment of the level of capacity to work and of the disability level as well as for the settlement of disputes concerning the disability level and capacity for work level.

The Service decides on matters concerning:

- the level, cause, time of appearance and period of disability;
- the level, cause, time of appearance and period of capacity to work;
- the need for professional rehabilitation services for individuals under 18 who are (were) covered by state social insurance and individuals over 18;
- the nature and conditions for work of disabled people;
- general initial determination of special needs of disabled people.

In 2005, there were 248,260 people in Lithuania receiving pensions or benefits for incapacity to work (disability) related to disability and about 2,000 people not entitled to any pension for incapacity to work (disability), i.e. about 7% of the population of Lithuania are recognised as disabled.

The highest portion of disabled people comprises people with a level of 30–40% of capacity to work or a medium disability level (148,586). These people comprise 60% of the total number of disabled people. People with most severe disabilities, i.e. with the 0–25% capacity to work level comprise 14% of the total number of disabled people. In 2005, there were 50,035 disabled people with the 45–55% capacity to work level or the mild disability level. They comprised 20% of the total number of disabled people. There were 16,002 disabled children under 18, or 6% of the total number.

36% of disabled people are people of retirement age. People of working age with a disability group comprised about 58% and disabled children about 6% of the total number of disabled people. An analysis of the increase in the number of disabled people shows that the lowest growth of disabled people was in 2005, i.e. only an annual increase of 1.9%, while the increase during 2004 was 6,2% compared to 2003[1].

3. Pre-Natal Diagnosis and Counselling

Through the extended possibilities for family planning, parenthood in modern societies has increasingly become a question of individual decision-making. Prenatal diagnostics and reproduction technologies permit the inclusion of characteristics of the fetus in this decision. This extended knowledge brings individuals into difficult situations when they have to make decisions regarding children. These individual decisions are affected by social values, attitudes, anxieties and knowledge of disabilities. They are also influenced by the quality of the counseling process if professional support is available and used. It is important that individual decisions are accepted by the social environment of people concerned. How is this achieved?

3.1. Description of the National Situation

Social and psychological aspects of prenatal diagnosis and counselling are outdated compared to the medical developments in this field. The Lithuanian Centre for Medical Genetics (LCMG) provides sophisticated and modern researches on foetus impairment. The Genetics centre offers examination using ultrasound examination, invasive procedures and blood examination.

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[1] Source: the official website of the Ministry of Labor and Social Affairs (www.socmin.lt).

About 6000 genetic consultations per year are performed in the LCMG. Out of those, about 1500 include laboratory testing performed in the laboratories of the CMG as well as non-invasive, like ultrasound examination and invasive, like amniocentesis, sampling procedures for prenatal diagnosis. 500–600 cases of congenital anomalies are being registered annually in Lithuania.

According to the national law, an abortion may be performed on request up to 12 weeks of pregnancy. An abortion may be performed up to 22 weeks of pregnancy on the following grounds:

1) risk to life;
2) risk to physical health;
3) risk to mental health;
4) risk of foetal deformation.

An abortion must be performed by a physician in a medical institution. It is required that before termination of pregnancy the doctor should explain about the damage of an abortion to the woman's physical and mental health and the possible moral damage to the both parents. This information should be provided by a midwife – gynaecologist; the presence of a psychologist is also desirable.

If pregnancy endangers the health of the mother it can be terminated irrespective of the age of the foetus. Lithuania finances only abortions performed for medical reasons with public funds.

3.2. Specific Risks of Discrimination

Even if responsible medical professionals explain about the possible consequences of an abortion, there are no proper psychological and social consultations provided if there is an impairment of the foetus. Furthermore, if initial tests show a higher risk, doctors prescribe additional examinations like invasive procedures. There is no peer counselling, mutual support groups or other alternatives offered in addition to the medical opinion.

The Lithuanian situation of prenatal diagnosis and the absence of proper social and psychological counselling violate the main and primary right of disabled people: the right to be born irrespective of an impairment. Every family desires to have a perfect baby; therefore genetic counselling becomes very popular also among parents who are not at risk. If the medical examination of the foetus indicates a Down Syndrome, almost all families decide for an abortion. Thus there is a very high risk of a disabled person to be discriminated before he/she takes the very first breath.

The Lithuanian Welfare Society for Intellectually Disabled Persons "Viltis" raises the question of the worth of an unborn disabled person but these ideas have little acceptance in the Lithuanian society. The genetic screening of pregnant women takes away the right of choice and stresses that the "healthy" part of the society understands disabled persons as a burden. Efforts are being made on how to eliminate disabled people instead of looking for ways of teaching families and society how to live with a disability.

4. Early Childhood

For most families, having a baby creates a situation of uncertainty and a need for direction and guidance. Living with a baby or a young child with a severe disability or with severe developmental problems brings parents into a situation with specific and difficult challenges and dependencies. Psychological stress in their daily lives often makes it difficult to cope with their parental responsibilities. When dealing with educational tasks or when specific therapeutical or medical treatment is necessary, parents cannot refer to their own educational experiences, but are dependent on professional support of various kinds. Having access to good medical care, self-help groups and early intervention services from a very early age of the child are decisive factors both for the personal development of the child and for the successful adjustment and coping process of the parents. How is this achieved?

4.1. Description of the National Situation

Children with severe disabilities have entitlements for early diagnosis and early intervention. The primary responsibility for diagnosis and treatment have paediatricians, nurses and family doctors in the primary outpatient centres. If a multidisciplinary involvement and more professional care is needed, the child and its family are transferred to the Republican Child Development Centre or its regional branches. In the centre, a multidisciplinary team comprising social paediatrician, psychologists, social workers, physiotherapists, special educators, speech therapists and social pedagogues provides services to the child and its family. It is a state funded institution and a big part of its services are free of charge for children with developmental problems. The centre accepts children with behaviour, emotional and developmental problems.

The centre provides outpatient services (psychiatrist, neurological counselling, individual psychotherapy, group psychotherapy), inpatient services (the Department of early intervention accepts children under 7 years for complex evaluation and treatment and the Child psychiatry department treats children from 3 to 18 years having emotional and psychosocial disorders).

However, some important services like family counselling, individual and group psychological counselling, social work counselling, structured individual and group trainings, as well as individual speech therapy are provided on a paid basis. These services are not reimbursed by State Patient Fund and families have to cover costs for these services themselves. All over Lithuania there are more than 20 centres providing early diagnosis, rehabilitation and habilitation services.

Every Lithuanian Municipality (60 administrative territorial units) has a family support centre providing peer support, self help groups, individual counselling and other psychological and social services for parents raising disabled children of every age. These services are established by the welfare society “Viltis”.

4.2. Specific Risks of Discrimination

Since disabled children depend very much on their parents, main risks of their discrimination are closely connected to the family situation. Satisfaction of their needs very much depends on the will, abilities and capacities of their parents or carers. The following obstacles could be identified as the main risks for a disabled child to be discriminated in early childhood:

1) territorial obstacles: families living in rural areas have difficulties reaching medical services, kindergarten, or family support centres;
2) financial problems: financially less well off families cannot afford expensive medication or additional services; they also have to pay for travel costs which arise reaching special service institutions;
3) poverty: quite a usual situation is a single mother alone raising a disabled child. She has to earn money and at the same time to take care of the child with special needs. She cannot provide proper attention and care, not to speak of satisfaction of the child's special needs;
4) discrimination because of structural problems: lack of cooperation among professionals of various institutions, sharing responsibility and information. Families have to fill in the existing gaps by investing their own time, energy and financial resources.

5. Childhood: Education and Care

Preschool institutions like inclusive or special kindergartens offer care and education for younger children. They prepare children for school and give them the opportunity to interact with peers. Young girls and boys can broaden their experiences in life and enhance their social skills.

Children with severe disabilities have the same need to interact with peers, to make friends outside the family and to view themselves as a part of a social group. But young children with complex needs are dependent on additional support to participate in preschool education, such as barrier-free access or well-trained educators with specific skills and the intention to cooperate with other professionals. How is this achieved?

5.1. Description of the National Situation

The Lithuanian Law on Education foresees that pre-school education is provided to children from the age of 1 to 5 (or 6). The pre-school curriculum is implemented by nurseries, nursery-kindergartens, kindergartens, kindergarten-schools and other schools, freelance teachers or other education providers. The law entitles this right to every child irrespective of its disability level. According to the statistical data available to the Welfare Society “Viltis” there are around 60 integrated or special kindergartens all over Lithuania for disabled children. Mainly they provide day time services; some of them also provide accommodation according to the need of the family. Some of them are specialized on disabled children, another part of them tries to provide pre-school education services both for disabled and non-disabled children. Successful integration of disabled children to the regular system of kindergartens has many advantages:

1) children develop social skills of communication, can be trained and educated;
2) at the same time non-disabled children and their families are educated by getting used to disabled peers;
3) parents of disabled children can be active on the labour market.

This system is still developing and therefore many problems arise: professionals are not prepared to provide special attention for children with special needs. They lack knowledge, training, sometimes the group is too big to work both with disabled and non-disabled children. Consequently, the needs of disabled children are not properly satisfied. They can become aggressive, may refuse to cooperate and the administration of the kindergarten comes under pressure to remove the child from the group of non-disabled children.

Usually, professionals like speech therapists, psychologists, social workers, special and social pedagogues are concentrated in special kindergartens while mainstream kindergartens lack them. Thus specialized institutions provide better and more professional services for children with severe disability. Unfortunately, attending a special pre-school institution usually is the beginning of a disability career which further continues in other special institutions and never leads to mainstream education or to the labour market.

5.2. Specific Risks of Discrimination

Main risks for children with severe disabilities or complex needs to experience discrimination at pre-school age:

1. Territorial obstacles: rural children with health disorders, physical or mental disability, have less possibilities to attend a special kindergarten or a general kindergarten with special groups. Unlike in towns and cities, in the rural areas there are too few rehabilitation pre-school establishments. Urban children have better possibilities to develop their skills in specialized kindergarten groups; they receive better medical care and more attention from psychologists, social workers, speech therapists, etc…
2. Intolerance and pressure to leave the mainstream pre-school education, caused by structural and organizational problems, lack of professionalism and intolerant attitudes of the society.

6. Childhood and Youth: School

Schools are responsible for a child's education and the teaching of knowledge of varying subjects. Furthermore, school proves to be an important part of young peoples' socialization process by offering the chance to enhance social skills and deepen social contacts with peers.

Children with severe disabilities also need high quality education and access to public schools. Pupils with complex needs are dependent on additional support in order to participate in school education, such as barrier-free access or well-trained teachers with the intention of cooperating with other professionals.

But especially pertaining to them, schools often exercise a kind of segregation. How do children with complex needs find their place in the school system, in which way are their special needs considered and how do professionals cooperate together?

6.1. Description of the National Situation

The right of all children to education is guaranteed by the Lithuanian Constitution and Law on Education. According to those documents, the following rights to education are guaranteed: education until the age of 16 is compulsory; with respect to a child’s age and educational level parents or carers have right to choose school, form and methods of learning according to the child‘s mental and physical capacities and abilities. The decision should also be made in consideration of the child‘s preference.

According to statistics, there are around 580 thousand pupils in Lithuania. 10% of them have special needs of various levels. More than 15.000 have a severe disability and complex needs. According to data of the Ministry of Education, around 90% of pupils with special needs attend mainstream schools, 1,4 % attend specialized classes in general schools and around 10% are educated in special schools. Almost every Lithuanian municipality has at least one special school. 37 of them provide education for children with intellectual disability, three for pupils with visual impairments, five for children with hearing impairments, two for pupils with physical impairments, and one for those with speech impairments. Fifteen of them serve as special education centres.

According to the law, children and young people with the following disabilities may be educated in special education institutions:

1) complex disorders, i.e. various combinations of intellectual disorders and physical or motion disorders, impaired vision, hearing, or speech and speaking disorders, emotional or behaviour disorders;
2) intellectual disorders, i.e. profound, severe, moderate or mild intellectual disability.

Children with the diagnosis of mild mental retardation are admitted into special education institutions (special groups or classes) only after their unsuccessful attempt to study in the general education system in the form of full integration, upon the approval of pedagogic psychological service.

6.2. Specific Risks of Discrimination

The Laws regulating special education contains contradictory regulations. On one hand, the laws regulate that a child with special educational needs has a right to be educated as close as possible to its place of residence in order to avoid social isolation; and that the educational environment should be adapted to the needs of the child. On the other hand, the laws declare that disabled children shall have a choice between general school education and special school. Usually, families opt for the school that meets the needs of the child in a better way, i.e. the special school. Under this option, however, the child is removed from its immediate environment, its social isolation increases. Special educational institutions have been created under the ideology that children with special needs have to be educated separately from other children. According to modern concepts, the fact that the child has special needs does not mean that it must be separated from the society. In reality, however, most of the children with severe disability are educated in the special schools. A child placed in such a school finds itself far from home, since parents often leave these children at school for the entire week. Despite of the notion that children with special needs should be integrated into general education, in reality children with complex needs do not get access to the general education system since most of the specialists are concentrated in the specialized institutions. In socially weaker families, the disability of the child and the option of a residential institution become the main reasons for choosing specialized boarding schools. According to NGOs working in the field of intellectual disability, parents need an exceptional motivation to send the child with severe disability to a general education school close to home.

7. Childhood and Youth: Housing and Family Support Services

Due to the variety of modern family life, all children grow up in different environments. These environments can be understood as a social network including all sorts of relationships to individuals or institutions. The family's living conditions during childhood are very important for social inclusion of the young person in society. The family has a strong impact on his/her primary socialization and influences the access to certain social institutions.

Family support services offer community-based professional support and services for families. Some children and young people live in a foster family, others in foster homes. Are such support systems available? In which way are children with severe disabilities or complex needs and their families involved in these support systems?

7.1. Description of the National Situation

The general social policy objective is to raise disabled children in the family and these families can benefit from the family benefit system:

1) A grant for repayment of some of their housing loan is given to borrowers who are families raising a disabled child; they receive a reimbursement of 20 percent of the (remaining) amount of the loan;
2) A family raising a disabled child and living in premises rented from the municipality with a living area per family member of less than 10 or 14 m² is entitled to improvement of social housing conditions;
3) Employees who have disabled children may not be appointed to work overtime or sent to business trips against their will;
4) Employees raising a disabled child have one additional free day per month (or a shortened working time by 2 hours per week), for which salaries are paid by companies, institutions, or organizations;
5) Single employees who raise a disabled child are entitled to an annual leave of 35 calendar days. They are also entitled to choose the period for their annual leave after a period of six months of uninterrupted work for a company. At the employee's request, employees raising a disabled child under 18 are entitled to the unpaid leave of up to 30 calendar days.

These means are not successful in preventing a child’s placement in an institution if the situation of the family is difficult and presents severe social, psychological, or financial problems. Although it is understood as a last means, the process of a child’s separation from the family in Lithuania is very simple and smooth, whereas its return to the family usually is a very difficult process. Institutional child care is the result of the failure in Lithuania’s child rights protection system, which indicates that there was not enough effort made in providing support to the family. The fact that a large number of children from socially weak families are placed in residential care institutions and most of them leave them only when reaching legal age, demonstrates serious gaps in the Lithuanian family support system.

7.2. Specific Risks of Discrimination

It is especially difficult for parents to raise a child with a complex disability at home and find a community based care alternative to institutional care. Such a child needs continuous care and nursing, whereas there are no proper conditions in the community. For this reason, children with a complex disability are usually placed in child care boarding houses for continuous care. Chances are high, that under the foregoing decision of parents the child will remain in institutional care for its whole life, and will be placed in a residential care home for adults, when the child reaches legal age.

8. Childhood and Youth: Leisure Time

Young people use their leisure time to do enjoyable and amusing activities and to get free from daily routines. Often free time activities are organized in clubs or in various forms of sportive or cultural associations. But youngsters also spend their free time with peers without adults. Many experiences among young people of the same age are made spending leisure time together, e.g. discovering new social roles, social spaces, friendship or falling in love. Youngsters with severe disabilities or complex needs have the same leisure time needs as their non-disabled peers, but are dependent on additional support to participate in mainstream leisure time activities. How is this achieved?

8.1. Description of the National Situation

The Lithuanian Law on the Protection of Children’s Rights ensures that every child has a right to leisure time according to its age, health and needs. State and local municipalities have the responsibility of establishing and supporting clubs for sports of children, creativeness, leisure time and health, summer camps, family leisure centres, sanatoriums and providing children with opportunities to use privileges of social insurance.

There are many children clubs, centres which provide a big choice of various leisure time options: sports, arts, handicrafts, additional lessons and other after-school activities. However, most of the leisure time activities for children have to be paid for and only a small part of families can afford a large diversity of them.

Some NGOs receive funding from the Government or from local municipalities and organize free of charge leisure time activities for children from socially weak families or disabled children, but they are also mainly concentrated in bigger cities or towns.

Most leisure time activities for disabled children are provided by educational institutions for disabled children. All educational institutions for children with complex disability provide many extracurricular leisure time activities. Therefore, the day of a disabled child at a specialized centre comprise a combination of lessons and leisure activities. Many leisure time activities for children with disabilities are also organized by NGOs.

8.2. Specific Risks of Discrimination

If a disabled child attends a school or another educational institution, there is no doubt that its leisure time will be organized. Most likely it will happen in the same institution and will be organized by the same professionals. Probably the child will receive even more attention from the specialists during its leisure time than its non-disabled peers.

However, a disabled child will definitely experience discrimination in the field of leisure time as well:

1) Disabled children have little or no access to the mainstream children leisure centers as these centers are not properly equipped and professionals are not prepared to work with children with special needs. There will also be little acceptance from the side of other visitors and their parents

2) Spending their leisure time in the same institution where they are also educated, disabled children have little or no choice to spend their time according to their preferences. If a disabled boy prefers sports and there is no sports trainer in the centre, most probably he will have to choose singing or painting.

9. Youth and Young Adults: Vocational Training

A successful transition from school to the employment system is usually related to vocational training. After finishing school young people need to find a job according to their interests and abilities with which they can earn a living. Vocational training prepares for the access to the employment system and is an important step into adult life. Youngsters and young adults with severe disabilities are dependent on adapted training courses, assisting technologies, other individual support and barrier free infrastructure to enable their access. How is this achieved?

9.1. Description of the National Situation

The Law on Children Rights Protection states that Governmental and municipal institutions must provide necessary conditions for the education, vocational training and employment of young people with disabilities. Conditions should be created according to their health, special needs and abilities.

Vocational training in the regions is organized by Labor market training centers and the specialized training centre “Mes esame” which is adjusted to the special needs of persons with complex disabilities. Vocational rehabilitation services are provided by professional rehabilitation centres which combine medical services and vocational training. The government finances transport to the professional rehabilitation centre, accommodation during the period of rehabilitation, and pays a professional rehabilitation benefit.

The number of persons attending a professional rehabilitation programme is increasing. In the year 2005, only 12 persons took part at the programme. In the year 2006, 252 persons applied for professional rehabilitation and 69 of them successfully accomplished the programme. In 2007 (January – September), 285 persons applied for professional rehabilitation and 264 of them have already accomplished the programme.

Although there are several legal regulations foreseeing vocational training for disabled persons, this activity is still under experimentation and testing. Various state institutions (e.g. the Lithuanian Labour Exchange, the Lithuanian Labour Market Training Authority, centres for professional qualification, most vocational schools, vocational training centres established by local municipalities, etc.) and many NGOs implement a number of national and international programs, projects with the goal of vocational training of disabled people and their integration in the labour market.

9.2. Specific Risks of Discrimination

Vocational training for disabled people in Lithuania is still quite segregated from mainstream vocational training. Disabled persons have separate training centres or special classes in mainstream vocational training schools. The same tradition of segregation continues also in the labour market.

Despite of many initiatives, people with severe disabilities and complex needs have difficulties finding a job even after accomplishing vocational training in an educational institution.

10. Children and Adults: Social Security and Health Care

Modern societies are shaped by an enlargement of welfare systems and an increasing dependence on social security institutions. It is a challenge for all citizens to clarify their entitlements and to find access to services. The need for basic social security and to have access to health care services if necessary is important for all people.

In most cases having complex needs leads to an increase of dependence on social benefits and requires special support and services granted by welfare administration boards. Bureaucratic procedures of application approval create special risks of stigmatization. Allowances, benefits and services can improve the possibilities of individual participation, but can also initiate processes of social exclusion. How is this achieved?

10.1. Description of the National Situation

The Constitution of the Republic of Lithuania guarantees to citizens the right to receive old age and disability pensions as well as social assistance in the event of unemployment, sickness, loss of the marital partner, loss of the family’s wage earner, and in other cases provided for by law. The Law on Social Integration of disabled people states that the social integration system for disabled people comprises provision of medical, professional and social rehabilitation services, provision for special needs using special assistance tools, support to employment of disabled people, social assistance, award and payment of pensions and benefits of the State Social Insurance Fund, award and payment of benefits of the Compulsory Health Insurance Fund, provision of education services, ensuring equal opportunities to participate in cultural, sports and other areas of public life. The social integration system for disabled people is funded by the national budget, municipal budgets, the State Social Insurance Fund, the Compulsory Health Insurance Fund, the Employment Fund, Structural Funds of the European Union, and other legitimate financial resources.

The Law on Social Integration of disabled people requires that, in order to assure equal opportunities of disabled people, health care services are provided at the same level using the same system as for the rest of the society. Preventive means are foreseen in order to avoid complications and a decline in employment abilities.

The following special privileges are foreseen for disabled people in the field of the health care sector:

1) Depending on the disability group, the working capacity level and the level of special needs, 50-100% of the basic price of medicines can be reimbursed.
2) 100 % reimbursement of the basic price for medical rehabilitation for people sent for completion of treatment after a serious disease or injury that is included in a list approved by the Ministry of Health.
3) In cases of disease or injury, employed persons receiving the state social disability insurance pension receive a benefit for temporary incapacity for work for 90 days once during a calendar year.

10.2. Specific Risks of Discrimination

Although social security and health care systems foresee a number of means which are supposed to allow the integration of disabled people in society, they are not sufficient for many persons with complex disabilities. Especially vulnerable are disabled people living in residential care institutions. The main goal of the social security system in Lithuania is the integration of persons with social problems into society, but practically all residents of social care homes spend their entire lives in an institution. Commonly, no individual rehabilitation plans are drawn up for residents and no techniques to enhance social skills are employed. Although legal documents assure equal rights of disabled people to medical treatment, there are cases when somatic hospitals refuse to treat a person with complex disability, although the illness is somatic. Certain care facilities have entirely eliminated preventive medical examinations. In certain cases, the residents are forced to wait too long for adequate medical treatment, sometimes up to a few months.

The main form of treatment in residential care institutions is medication. In cases when the resident is admitted directly to the facility, there is a tendency to start immediate treatment with medications instead of observing the patient’s condition and seeking alternative methods. As a rule, ordinary medication is prescribed but modern neuroleptica and other medicines can also be given. In addition, medicines with a prolonged effect are given to residents, which can cause problems in cases when the effect of the medication must be terminated immediately. Residents are deprived of the opportunity to control their own right to adequate treatment. They usually have only as much information about their medicines as the doctor in charge believes they should have. Furthermore, the lack of psychiatrists in rural areas makes it impossible for residents to receive an external evaluation of their mental condition or alternative consultation by someone outside the facility.

11. Adults: Work and Employment

Having work or a day occupation is, for financial and other reasons, a very important indicator of social inclusion and quality of life. Going to work not only structures peoples’ days and weeks, but also has an important impact on the development of a person’s identity. It also provides access to the social security system and is an important basis for participation. For people with severe disabilities, transitional situations from school or vocational training into the employment system must often be systematically planned and organized, because they are dependent on adapted work places or assistive technologies and other individual support like a barrier-free infrastructure to enable their access. How is this achieved?

11.1. Description of the National Situation

Statistics shows the importance of employment of disabled people as people of working age with a disability group comprise more than a half (about 58%) of the total number of disabled people in Lithuania.

The Constitution of the Republic of Lithuania states that each human being may freely choose a job or business, and shall have the right to have proper, safe and healthy conditions at work, to receive fair pay for work. According to the Law on Support for

Employment, the following groups of persons are additionally supported in the labour market:

1) disabled people whose capacity to work is rated at 20-40% (..) or disabled people for whom a moderate disability has been established;
2) disabled people whose capacity to work is rated at 45-55% (..) or disabled people for whom a mild disability has been established;
3) a mother (adoptive mother) or a father (adoptive father), a guardian or a custodian who actually raises a disabled child under 18 years of age

Additional support on the labour market is provided to the unemployed who have levels of 20–40% or 45–55% of capacity to work. Employers who hire people with a 45–55% capacity to work level receive subsidies for salaries for up to 12 months. Employers who hire people with a 20–40% capacity to work level receive monthly payments for every employed person throughout the whole employment period. People with a 20–40% capacity to work level who start their own business receive assistance for job creation. A vacation of 35 calendar days and unpaid leave of 30 calendar days is available for disabled people.

There are many provisions foreseen enabling the integration of disabled people in the labour market. However, there is a lack of a coordinated, all-embracing system of employment of disabled persons.

11.2.Specific Risks of Discrimination

Research shows that less than 50% of persons with a mild disability successfully work after accomplishment of vocational training. The rest becomes long-term unemployed. Successful integration in the labour market of a person with a severe disability is regarded as an extraordinary achievement. Less than 10% of all disabled people receive a salary as a main source of income.

Despite of many efforts and regulations provided by Government and by the Parliament, integration of disabled people in the labour market is still slow. This can be explained by complex reasons:

1) The society is highly intolerant and will not use services provided by disabled persons.
2) Employers are afraid to employ disabled people because of various fears and stigmata: “They are unpredictable, aggressive, irresponsible…”
3) Disabled persons (and their family members) do not trust themselves. Furthermore, they are afraid to loose social guarantees if they are employed.

12. Adults: Housing

Becoming an adult also means making up your mind about how you would like to live: stay in the natural family for a while, live alone, with a partner or family, with a friend, etc. Having privacy, a place to go to, feeling safe and comfortable there, realizing one's own ideas on how to live, are all very important for people in our societies. For people with complex needs it is a big challenge to find their own way to living. They have restricted alternatives for housing because they need barrier-free environments and life-long support. People with severe disabilities do not only need good support services but also counseling to realise their ideas and style of private living. How is this achieved?

12.1. Description of the National Situation

The Constitution of the Republic of Lithuania states that citizens may move and choose their place of residence in Lithuania freely. However, the citizen's right to move and choose their place of residence in Lithuania freely is quite strongly limited for people with a complex disability. Before Lithuanian independence most of persons with complex disability used to live in social care institutions or at home cared for by their parents, however, in both cases they were fully isolated from society. The welfare society "Viltis" started taking care of intellectually disabled persons and now every region in Lithuania has a variety of community-based social services for disabled persons.

Municipalities are responsible for adaptation of the housing environment for disabled people living in their territory. This service is 100% reimbursed for persons with very evident physical impairments (80% of the cost of the service is covered by the national budget and 20% by the municipal budget). Adaptation of the housing environment for persons with average physical and self-service problems is reimbursed up to 70% (municipalities cover 20% and the state covers 50% of the service).

Less than 20% of all applications for the adjustment of the living environment are met per year: in 2001, while the need for an adjusted living environment was expressed by 1.711 disabled persons, the service was provided only to 242 persons; in 2002, 271 of 1.728 received it, in 2003, 290 of 1.595, in 2004, 249 of 1.264, and in 2005, 262 of 1.310 applicants.

Services at home are provided for 100 - 200 disabled children and 2.500 – 4.000 adults per year. Cash for care is paid to around 200 disabled adults per year (most of them living on the country side). Out of 800 - 900 applications for placement in residential care homes for adults, around 60% are satisfied per year.

12.2. Specific Risks of Discrimination

Since community living can be an expensive service, there are very few independent living homes in Lithuania. Care services at home also do not properly cover the need for care of persons with complex needs. Therefore, large residential care institutions still are very popular. A system of residential social care institutions prevails in Lithuania and big numbers of persons with complex disabilities live in social care homes, which do not correspond to modern standards of social care. According to Tobis (2001), the following are key barriers to maintain closed residential care institutions: financial and organizational pressure; absence of alternative community care services; public acceptance of isolation of persons with serious mental health problems; lack of systematic monitoring and absence of proper legislation focusing on protection human rights of vulnerable persons in care.

The main discrimination of severely disabled persons in the field of housing is an absolute absence of choice, although the decision about living arrangements is very important for every human being. The opinion of disabled individuals is never asked. Even if he/she expresses preferences, they are hardly considered. The main decision-makers about the housing issue are family members and other carers. The easiest solution is the placement in residential care institutions, which solves the question of care and the family does not need to provide any help and support any more.

Decisions on housing also depend on services in the community: the presence or absence of supported housing, possibilities to apply for adaptation of the housing environment, services at home, day care options, etc. As these services are usually hard to arrange properly, in the case of severe disability the most common solution is the person's placement in residential care institutions, although the disabled persons usually do not want to leave their homes, their social networks and be placed in institutions which have a bad reputation in the society.

13. Adults: Education and Leisure Time

Leisure time comprises all the time out of work to either relax or find a balance in contrast to every-day-life. Activities can be done on one's own, organized in clubs or in various forms of cultural or other social facilities. In their leisure time, people in our societies are supposed to act with less formal restrictions and try to achieve a high degree of satisfaction and self-determination in their activities.

Adult education – taking the idea of life-long learning as postulate – can be seen as part of the individual's leisure time, sometimes connected to work or the expectation that a certain course promotes one's professional career. Sometimes people participate in adult education courses for the sake of their personal well-being, health or general personal development. For people with severe disabilities the participation in organized leisure time activities or adult education courses very often must be systematically planned and organized, because they are dependent on adapted courses, assistive technologies and other individual support, and barrier free infrastructure to enable their access. How is this achieved?

13.1. Description of the National Situation

The Constitution of the Republic of Lithuania foresees that everyone shall have an equal opportunity to attain education according to their individual abilities. The Law on Education states that the educational system is based on the principle of equal opportunities: the educational system is fair, it ensures equality for individuals irrespective of gender, race, nationality, language, origin, social position, religion, beliefs or convictions. It assures each individual access to education, the opportunity for attainment of a general education level and of a primary qualification and creates conditions for in-service education or gaining a new qualification.

Very few persons with severe disabilities are studying or have graduated from an educational institution specialising in the training of people with special needs. Certain training courses, for example in every day living skill or computer skills, are conducted in some of the care facilities, but this is the exception rather than the rule. Leisure programmes (sports, dance, singing, etc.) are generally perceived as educational activities.

Persons with severe disabilities who accomplished a secondary school, high school or university are rare exceptions and their achievements are results of a big motivation and of the hard work done by themselves or their families.

Leisure time activities for disabled adults are organized mainly by day care centres, established by municipalities or NGOs. Their main goal is the provision of occupational services for disabled persons, which mainly includes leisure time activities and occupational therapy. Although these services are provided by well trained professionals, the leisure time of disabled persons is mainly spent in the presence of other disabled people, segregated from the rest of the society. Special concerts, festivals, sports events are also organized by disabled organizations entirely for disabled people and their family members.

About 5.000 disabled persons per year attend various sports events. 1.043 disabled persons attended events organized by the Sports Federation of Blind persons, 1.118 disabled persons attended sports events organized by the Sports Federation of the Deaf, 1.482 persons attended sports events organized by the Lithuanian Paralympics Committee, 8.255 persons attended sports events organized by the Disabled Sports Federation.

13.2. Specific Risks of Discrimination

The right for education and meaningful leisure time is quite restricted for persons with complex disabilities living in closed residential care institutions. The right to education is rarely upheld since care facilities rather prefer to promote the regression of the patients' autonomy. Residents are not encouraged to study and the staff does not support the initiatives of those wanting to study and do not search for opportunities to realise these initiatives.

Co-operation with educational institutions (for example, schools) in the nearby townships is limited to certain recreational activities, such as the use of a school swimming pool. However no opportunities are sought for young residents to attend courses at these schools.

Summing up, residential care institutions are usually regarded as the final stop in the "disability career" and no one sees any sense in the education of disabled persons who already reached this stage.

14. Adults: Partnerships and Parenting

According to social trends and changes, the decision of having one's own family is not as easy as it used to be. More and more the decision to get married or to have children is a conscious one based on emotions, being aware of the changes that these decisions will mean.
Not too long ago the idea of people with (intellectual) disabilities getting married or having children was regarded as impossible. People with complex needs who wish to marry or have a child often have to face prejudices. After all, in their parenting they are dependent on special support. Professionals from different services and service sectors have to cooperate to prevent exclusion and discrimination. How is this achieved?

14.1. Description of the National Situation

The Constitution of the Republic of Lithuania pays much attention to family issues. According to the constitution, the family shall be the basis of society and of the State. Family, motherhood, fatherhood and childhood shall be under the protection and care of the State. The right and duty of parents is to bring up their children to be honest people and faithful citizens and to support them until they come of age. The State shall take care of families who raise and bring up children at home, and shall render them support according to the procedure established by law.

Benefits of 20% of the Minimum Subsistence Level are paid to disabled people persons who raise children under 18 (full time students at general education schools, vocational, high or higher schools under 24) if they are recognized as incapable to work and if there are no other family members capable to work. If a family has two or more disabled members incapable to work, the benefit is paid to one of the disabled members irrespective of the fact if any member of the family is capable to work. Besides financial benefits, disabled parents receive some privileges and NGOs support them with humanitarian aid. However, these means are rather fragments than a rule.

There is no statistical data available on the parenting of disabled people. The only information is about children’s placement in care homes because of a parent’s illness (around 70 children per year) and because of a parent’s legal incapacity (around 60 children per year).

Generally speaking, disability and parenting sounds contradictory for Lithuanian society. If a disabled person decides to have a child mainly he/she can rely on the natural network of support. Disabled person also have to accept the fact that society will not understand and support this decision.

14.2. Specific Risks of Discrimination

Persons with severe disability in Lithuania very rarely can exercise their right to establish a family, even if they are not recognized as incapable. Irrespective of the form of care and of the carers (parents, professionals in independent living homes or in residential care institutions), the intimate life of a disabled person is constantly under control. Parenting is understood as a big additional trouble for the family or for an institution and therefore all possible legal and illegal instruments are used to prevent it. If a disabled person expresses a strong wish to get married and to have children, he or she might be declared as incapable and legally unable to get married. Abortion is one of the most severe violations of human rights of persons with severe disability. Pregnancies are always aborted in care facilities, except in cases when the woman is at the end of the second trimester. Usually, the residents are subjected to various measures ranging from persuasion to psychological pressure, deception or even outright coercion to get them to undergo an abortion. Even if a child is born it can never stay with his parents (mother) in the institution. Usually, children born in institutions for adults are placed in child care homes and can rarely meet their parents. The frequency of their meetings depends on decisions of third persons: administrations of social care homes or carers of the child, and sometimes on financial means if the child lives a long distance away from the parent’s care home.

15. Adults: Exercising Civil Rights

One developmental task of adulthood is to know and to exercise one's rights. This comprises the rights that a state confers to its people in order to secure protection and political participation, e.g. basic human rights and voting.
For people with severe (intellectual) disabilities, civil rights still cannot be exercised in every case. Additional support is needed to exercise democratic rights like voting. It is also a commonly held belief that people with severe disabilities or complex needs are in capable of serving in political positions. How can people with severe disabilities exercise their rights as citizens?

15.1. Description of the National Situation

The Constitution of the Republic of Lithuania states that all persons shall be equal before the law, the court, and other State institutions and officials. The Law on Equal Treatment ensures the implementation of human rights laid down in the Constitution of the Republic of Lithuania and prohibits any direct or indirect discrimination based upon age, sexual orientation, disability, racial or ethnic origin, religion or beliefs.

The legislation of the Republic of Lithuania guarantees equal rights for everyone to defend their rights and interests in court. However there are no existing special procedures for cases of discrimination in Lithuanian law. In these cases, victims can only rely on the general procedures established by the Constitution and laws.

The right to participation for disabled persons is limited. Society frequently perceives them as “receivers” and “dependents”, not as equal members of the society or equal service users. Critics of services received or negative attitudes are mostly misunderstood, as disabled persons are perceived as not-contributing to the common wealth of society.

Although law foresees the functioning of a Residents' Council in each social care home, this institution is rather artificial than an effective means to participate, protect rights and interests of residents. Its suggestions, questions and critics are never taken seriously by the administration and by the staff.

The Civil Code of the Republic of Lithuania foresees that custody is established in order to implement, protect and defend the rights and interests of an incapable natural person. If a person determined as incapable recovers, or if his/her health condition substantially improves, the Court can recognise him/her as legally capable. After the Court decision enters into effect, the custody in respect of this person is annulled.

15.2. Specific Risks of Discrimination

Persons with severe disabilities are at constant risk of losing their civil rights, which is quite a simple legal process in Lithuania. As society understands them as depending on the system of social support, preferences of persons with severe disability are rarely considered and they cannot take decisions about their life.

The legal incapacity status in Lithuania means the “civil death” of a person and the process of declaring a person legally incapable is very smooth and does not correspond to the basic human rights standards. Lithuania does not have the institution of limited legal capacity in the case of people with intellectual disability or mental illness and thus imposes equal and severe restrictions of civil and political rights to persons with different disability levels. Persons who once have been determined as being legally incapable, lose all civil and political rights: they cannot vote, get married, work, and make any decision of any important aspect of their life, including the right to an effective judicial defence in order to recover their legal capacity. The reconstruction of the legal capacity of a person is a rare exception

16. Adults: Ageing and End of Life

Ageing contains a lot of new challenges: Retiring, organizing one's day in a new way, coping with the loss of abilities and coming to terms with it and with one's life. Regularly, more support is needed in day-to-day life and thus social dependencies are increasing. Often this means that familiar life settings must be changed because care needs cannot be covered anymore by the given arrangement. Most people don't want to leave their familiar setting even when their care needs are becoming extensive and complicated. They prefer arrangements which are based on home care services that are reliable and flexible. When people reflect upon the end of their life there is also a wish to die in dignity.
How is this achieved?

16.1. Description of the National Situation

Aging and end of life of disabled persons is an important issue as about one third of all disabled people (36%) in Lithuania are people of the retirement age. The Law On Social Services stipulates that social services shall be provided to elderly persons by creating conditions for them to live at home, in their family and to independently manage their households as long as possible and by organizing the assistance coordinated with employment, personal health care and special assistance measures, helping to maintain social relationships with the family, relatives and society.

There is no special legislation regulating specific services for elderly disabled persons in Lithuania. However, the life expectancy of disabled persons becomes longer because of improving medical and social assistance and issue of special services for elderly disabled becomes a problem. Today, elderly disabled people usually live in residential institutions as their parents (carers) are dead or too old to take care of them.

Euthanasia is not allowed in Lithuania, although from time to time there is public discussion on this issue. The professional code of ethics of Lithuanian medical doctors does not foresee anything regarding euthanasia.

16.2. Specific Risks of Discrimination

Elderly persons having a severe disability are one of the most vulnerable groups in Lithuanian society because of several reasons. First of all, they usually have no more contacts to their families (parents are dead and contacts to other relatives were lost during their long stay in care institutions). Hence, there is no one to support their rights, interests, to take special attention of their needs and preferences. Secondly, elderly disabled persons belong to the generation of disabled people which were treated under the ideology of the Soviet "defectology" science. Usually they were placed in an institution at a very early age and underwent a long and unsuccessful medical treatment. They were perceived as un-educable, professionals never tried developing their social and daily living skills.

According to the experts, very few elderly disabled people received proper services in their childhood. Consequently, today they are not able to attend day care centers, their skills can hardly be developed and improved. They have never or rarely been outside their home or care institution, they do not know how to behave in the street, they have no social skills, no motivation. Experts think that his situation will continue for the next 20 years.

Country: Lithuania
NGO representative: Mrs. Dana Migaliova,
Head of Welfare Society for Persons with Mental Disabilities "Viltis"

Date: 19th September 2007

1. What are the main risks of discrimination against persons with severe disabilities in your country?

First of all it is a question of attitude, which further influences development of services network. Looking at the system it seems that everything is foreseen and done but judging by individual situations there are big gaps. Lack of services influences risk to experience discrimination.

Attitude influences behavior of the society, priorities of politicians. Disabled persons quite often are regarded as worthless, there is a wish and pressure to close them, not to try hard for them.

Hospitals of tertiary level[2] are best equipped but they never want to accept persons with severe disability, although they should provide special services in the most severe cases. They see no sense in treatment of the persons with severe disability; they try to abandon a person out from the system. A child and an adult with severe disability needs constant attention, in the case of relapse they need even more care and nursing. Paradoxically a parent has right to receive 80% of his/her salary only during the 10 days of taking care after a child and only 7 days while taking care after an adult. And if a person is sick for weeks or months? Should a parent leave job and labor market?

Next problem is work with consequences. Very few disabled who are 20-40 years now received proper services in their childhood. Consequently today they are not able to attend day care centers, their skills can hardly be developed and improved. They have never been outside their home; they don't know how to behave in the street, they have no skills, no motivation. Parents are used to their child's incapacities, do not trust professionals, they have no motivation to come back to labor market after 10-20 year of staying at home with the disabled child. In Dana's opinion this situation will continue the next 20 years.

2. What are the perspectives of anti-discrimination policies for people with severe disabilities in your country and in the EU?

There is a need for a real political decision on community services. It shouldn't remain on paper. Money, system, mechanism should be foreseen, also services, staff, standards. Decisions without detailed means are equal to zero.

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[2] In Lithuania, the health care system is organized on national (state), regional (counties) and local (municipality) levels and health care services are provided on primary, secondary and tertiary health care levels. Secondary health services (inpatient care and specialist outpatient care) by law are under county administrations; but, in reality, most municipalities continue to run both hospitals and policlinics with a mixture of primary and secondary outpatient care. The chief institution of the county organizes secondary personal and public health care while the dimension and character of activities is regulated according to the Ministry of Health. The Ministry of Health and other respective state institutions under its supervision (e.g. State Mental Health Care Center) execute and organize the personal and public health care activities of the State. Health care institutions of the tertiary level are certified by the Ministry of Health. They can provide primary and secondary health care services only for the purpose of the science and training. Human Rights in Mental Health Care in Baltic Countries. Arunas Germanavicius, Egle Rimsaite, Eve Pilt, Dainius Puras, Dovile Juodkaite, Ieva Leimane – Veldmeijere.

Today in every community there is one social worker who has responsibility to work with families at risk, including families having a disabled member. In every community live several thousands of citizens, high percentage of them are at social risk. What can change one social worker, without additional support, without transportation? Nothing. Today the system works for itself, makes its life easier. State behaves monopolistic, it tries to abandon NGOs and commercial sector from the provision of care services for the disabled. Although there are many laws but they are oriented towards the system, not towards the person. Help and support rarely reaches the person. Only benefits and pensions are paid regularly. Needs assessment is not objective, not individualizeed. There is one survey for the disabled person, concerning its needs, capacities, skills and for the family. Judging from the survey if there is a family person receives less support as his need for help is smaller. Without proper support families try to get ride of the disabled member, sometimes placing him in an institution, sometimes they can breath freely only after he or she dies. There are two ways; none of them is proper and civilized. There is no statistics about the mortality of persons with severe disability. If a person lives in a social care home the case and cause of death is registered. 5 thousand disabled persons live in institutions, the rest (around 20 thousand) live in the families. Cases of their deaths are not separately registered.

Speaking about the European Union there are many differences in every country. F.i., cash payments for care are almost bankrupting in the Netherlands, there are many cases of misusing them. Generous Scandinavian system is also under the question at the moment, there are discussions if it hasn’t reached and trespassed limits of its generosity.

There have been many discussions in Western Europe about quality of life, human dignity, now discussions are more oriented towards financial pressure, satisfaction of basic needs. On the agenda is the question whether it is worth investing in people who will never be able to pay back. There are discussions in Germany and France again about the need for big institutions.

Dana Migaliova likes the systems in England, Scotland and Ireland, although Scotland and Ireland are not very rich countries. .

However it is not fair to state that disabled bring just expenditures. Without disabled persons the need for pharmacy, social technologies, number of many professionals would decrease. Disabled persons also contribute to the development of the society.

3. What are the most important issues to articulate for people with severe disabilities in interest groups rsp. lobby work?

Although basic needs are more or less satisfied, provision of other services doesn’t develop further. In the hierarchy of Maslow Lithuanian system of services for the disabled remains on the first level. Quality of life of the disabled nor of their families is not important.

4. What are the key issues in the field of participation of people with severe disabilities?

Participation of the disabled always surprises politicians, officials and professionals. If a person in the wheelchair asks for the right to speak in some seminar, conference or meeting it is still more or less understandable. Much worse reaction is when a person with speech impairment or mental health problem tries to say something. It is not understandable and unacceptable. It is not acceptable even by professionals, working with disabled people every day. They fell they know better, they don’t want to show personal records, discuss diagnosis, treatment, services. Parents also think they know better what their child wants and needs. Usually parents are the ones who make decisions for their adult sons and daughters about where to live, how to spend free time, about family, friendship and partnership.

5. What are the key issues in the field of discrimination against people with severe disabilities?

Disabled persons have no possibility to articulate their needs, to realize themselves, to live where they want with whom they want, to work, have friends, family and children. Although for the rest of society it goes without saying. Financial exploitation, emotional and physical violence happens quite often disregarding where they live, in an institution or in the family. Only a very few facts come to outside world, which are just a pick of the iceberg.

6. Are there people with severe disability who work within NGO´s or self-advocacy organizations?

Yes, but they are more exceptions. Parents and carers usually disagree. They do not trust their children, are afraid that social benefits will decrease if they will start working. Incapacity limits the right to work very much.

7. How do you co-operate with special interest groups of people with severe disabilities?

There is not clear system of cooperation. Needs of persons with severe disability is usually different from the needs of persons with less severe disability. It is difficult to find a common solution suitable for all. We work together in the Department of Disabled Affairs.

8. What are your experiences to articulate the special needs and interests of people with severe disabilities in public discussions at regional and national level?

Without speaking loud, often and everywhere you won’t reach anything. We organize conferences, meetings, seminars, roundtables, Dana Migaliova goes to the meetings with officials and politicians, talks to journalists. My current strategy is to provide radical information in order to scare and attract attention. F.i. recently I tol to the State Control Department: if disability costs so much let’s introduce euthanasia. It is a cheap and effective way to solve the problems. We shouldn’t play support if we don’t provide it. State avoids responsibility to establish new institutions because it doesn’t want to maintain them further, state is afraid of long term investments in the system. “Viltis” per year receives 4,5 million Litas (1,3 million euro) from the state and takes care of 11.000 disabled members all over Lithuania. Budget of one social care home which takes care of around 300 residents is usually bigger.

Country: Lithuania

Policy-maker: Mrs. Egle Caplikiene
Head of Equal Opportunities Division,
Lithuanian Ministry of Labor and Social Affairs

Date: July 12th 2007

1. What are the main risks of discrimination against persons with severe disabilities in Lithuania?

Poverty is the main risk. Futher it influences other risks: segregation, violence of dignity, self-esteem, self-realization, lack of proper service provision.

2. What are the perspectives of anti-discrimination policies for people with severe disabilities in your country and in the EU?

Assurance of equal rights and opportunities is the main direction we are heading now. Comparing situation we had several years ago and the current situation there are many differences. 10 years ago we could hardly see disabled persons on the street, every day we see more and more of them in our daily life. It is to mention that understanding is more and more coming from the society, not entirely from the government. Mutual understanding and cooperation among both segments is needed. Society becomes more tolerant, it understands need for help, support, also the importance of financial expenditures. There is more intolerance towards ethnical, racial groups than towards the disabled.

3. **Are there policy programs/legislation, which have intended or un-intended effects on persons with severe disabilities?**

There should be a complex of various laws like law regulating equal opportunities, social integration, social insurance, pensions, social benefits and social services. These laws should be followed by laws on specialized areas, strategies, programs elaborating direction of integration of the disabled, adjustment of their living environment, provision of special assistance tools, etc…

4. In which political field is the life situation of people with severe disabilities currently on the political agenda at national level?

There is no special law for persons with complex needs and their family, although there are many laws directly influencing their life: law regulating social services, provision of social benfits, integration of the disabled... Now in the Parliament on the agenda is Law on Equal Opportunities which will influence life of the disabled and persons having complex disability among them. It will be changed by including two directives which were not incorporated before:

- firstly, the person experiencing discrimination in the court can be represented also by an organization working in the area of human rights, not only by himself or his representative;

- secondly, if a person complaints he or she is experiencing discrimination, he won’t have to prove the fact of discrimination. According to the new law, the defendant will have to provide evidence on non-discrimination.

It is to expect this law will influence situation of persons having complex disability.
In the Parliament on the agenda now is the new mechanism of financing social services. According to it municipalities will have responsibility and also financial means to provide services for persons with very severe disability. The main innovation is financial enabling of municipalities to implement this responsibility. Of course these means are not sufficient but it is only beginning.
Government currently received changes of the law regulating transport privileges. It is foreseen to increase benefits for transportation and to allow obtaining special adjusted car for families raising a severe disabled child with constant need for nursing.
These laws are not yet confirmed by the Government but there exist an official project.

5. Who are the most important actors in the national policy field for persons with severe disabilities?

Disabled themselves and NGOs working in the disability field. There is a tradition in Lithuania that they are main initiators of reforms and innovations in the area of disability. Also municipalities, their divisions directlr working with disabled people.
Administrating mechanism consists of ministries, Department of Disabled Affairs.
However initiative rises from people themselves and organizations.

6. What are the key issues in national policy field for person with severe disabilities?

Equal opportunities are the main issue. Provision of support should be balanced so that all the social groups receive equal support according to their needs. Financial balance and efeciteveness of the implementation are also needed. Sometimes there is a situation of big financial expenditures and poor service provision.

7. Are there specific policy programmes for persons with severe disabilities in preparation?

Families would need a separate law. Although families are mentioned in many laws but family issues should be more stressed or separated in a special program. Sometimes arises a question whether persons with severe disability need a separate law or not. Every country finds its own solution, it is difficult to decide which way is better. Probably if it is foreseen in many laws none of the important issues will be forgotten, which may happen if there is one separate law.

Country: Lithuania

Policy-maker: Mr. Dainius Puras,
Member of the Vilnius City Council, Committee of Health
Public Advisor of Minister of Health
Associated Professor
Member of UN Child Rights Committee

Date: August 21th 2007

1. What are the main risks of discrimination against persons with severe disabilities in Lithuania?

It is difficult to divide any because disabled people are limited in all aspects of their life. The services and benefits they receive are not enough to survive in the community. Quality of their life is not assured. F.i. recently Dainius Puras had personal experience with discrimination in the area of health services for the disabled. His brother has a severe disability and Mr. Puras had a feeling that the overtone of the system sounds like this: why do you make these attempts? The shorter will be life of the disabled the easier will be everybody's life, including the disabled himself. It sounds so cynical. In the moments of being honest doctors ask D. Puras why did he take him to the hospital, he was accepted only because he is brother of Associated Professor Dainius Puras. Quite often people like his brother are never treated in the hospital because their condition is too severe. Once D. Puras was asked: he can not walk, he can not sit, how can we make an X-Ray for him? Such questions arise in an University Hospital, not somewhere in a small town. Inflexible systems explain that they never accept people in such a severe condition, although they are created for helping people with disability. System should be not only well organized but also friendly.

2. What are the perspectives of anti-discrimination policies for people with severe disabilities in your country and in the EU?

The proper context of a mature civil society is needed. When Dainius Puras was in Germany he believed Germans are mature enough. He tried to provoke them asking if it is worth to pay higher amount of money for the most disabled children. Germans could not understand his question; meanwhile in Lithuania it is a common understanding that disabled people deserve less than the "normal" part of the society. It is not a problem in the classical medicine: if a child has cancer he gets millions. If the same child has both cancer and mental health problems the answer will probably be: "wait, it is for healthy, normal children". Person with severe disability or complex needs can not apply for expensive service. It creates a vicious circle for some societies: why politicians should invest in the services for persons with severe disability if there is no acceptance in the society? They are not saints; they do what electorate wants them to do. Question of persons with complex needs is in the queue, it is never a priority. Lithuanians do not think that disabled should be first to receive benefits and services. A solution could be to separate the most disabled from the rest and provide them with the services of the highest level. Mr. Puras would love transparency, acknowledgement that nothing is done.

3. **Are there policy programmes/legislation, which have intended or un-intended effects on persons with severe disabilities?**

The Law of the Integration of the Disabled opened the door; at least we can sometimes see disabled persons on the street which was not possible in the Soviet times. But people with the most severe disabilities still hide themselves. Speaking about ideology there is a tendency among liberals: enough services and providers lobbying, lets give them money. Matures citizens, disabled people among them will choose what they need. Maybe it is a modern approach but we know what kind of problems will arise. Dainus Puras doesn’t trust in law in the post-communist world. Law never disturbs you to work with children creatively, including children with severe disability. He saw professionals in Germany working with children which in Lithuania were called “vegetables”, incapable for nothing. Those professionals love their job and achievements: “look, after half a year of work there is an eyes contact, they react to the music…”. People see sense of moving forward, although it is clear that the person will remain disabled.

4. In which political field is the life situation of people with severe disabilities currently on the political agenda at national level?

It would be difficult to name something new, which would be qualitatively new. One of the priorities in mental health strategy is support system for persons with severe disability, complex needs. But the problem is that the strategy can be interpreted as you wish. Therefore it is to expect that in the closest future there will be no alternative to traditional closed residential institutions.

5. Who are the most important actors in the national policy field for persons with severe disabilities?

Traditionally the most important policy makers are Lithuanian Seimas (Parliament), Lithuanian Government, Ministry of Health, Ministry of Social Affairs. In Lithuania we also have many NGOs which gradually become more and more mature; their influence grows and they learn how to make bigger influence, how to change something.

6. What are the key issues in national policy field for person with severe disabilities?

In Lithuania we are stuck in the stadium which could be called obligatory. For us the main importance is to have a good law but we never think of implementing it properly. There is a big gap between papers and the reality. In the United Nations Mr. Puras sees the same situation: governmental delegations arrive and they are asked if everything is foreseen in the law. Reality is not interesting, as the UN doesn’t have fact finding mandate. From this perspective everything is fine – in Ukraine, in Kazakhstan. Similar situation is in the area of integration of the disabled. If a public servant receives a provocative question from the audience, his answer will be a quotation from the law. Law is important, without law would be even worse but serious attitude towards law is also important. Again, it is a question of the mature society. The main question is how to nurture society, to prepare it to accept the disabled, to make them visible.

7. Are there specific policy programmes for persons with severe disabilities in preparation?

It is the biggest dilemma whether there should be a positive discrimination or not. Do we need a special law for persons with severe disability or would it be some kind of discrimination? D. Puras is critical towards early intervention services, which select children with less severe disability, meanwhile those with bigger need are left alone. Of course then treatment is much more effective. Employers also prefer to employ people with less sever disability. In his opinion, financial mechanism should be created allowing to pay more for treatment, education, employment of the most severe persons.

Study on the Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs

www.non-discrimination.eu

Country Report The Netherlands

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Tender on Behalf of the European Commission
D.G. Employment, Social Affairs and Equal Opportunities
Integration of People with Disabilities - Unit G3

Table of Contents

Selected Stakeholder Interviews

1. Summary

This report contains information on the specific risks of discrimination of people with severe disabilities and complex needs in the Netherlands. The report comprises two parts.

In part I the general results are presented. In separate sections attention is given to the data on people with complex needs in the Netherlands, the Dutch policy on people with disabilities, observations about the practice and directions for the future.

Part II, following a life-course systematic, consists of the specific results in 14 domains, each representing a stage of life. Each domain starts with a compact description of the characteristics of the support system in the Netherlands. Finally, specific risks of discrimination for people with severe disabilities or complex needs are formulated as essential for the given domain.

The conclusion of the Dutch study is that people with severe disabilities and/or complex needs are in several domains still at a high risk of discrimination and exclusion.

Due to lack of space references could mostly not be added in this paper but are part of the annotated bibliography.

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Dit rapport bevat informatie over de specifieke risico's van discriminatie en exclusie van mensen met ernstige beperkingen en/of complexe ondersteuningsbehoeften in Nederland. Het rapport bestaat uit twee delen.

In deel I worden de algemene resultaten gepresenteerd. In afzonderlijke paragrafen wordt achtereenvolgens aandacht geschonken aan beschikbare data over mensen met complexe ondersteuningsbehoeften in Nederland, het Nederlandse beleid met betrekking tot mensen met beperkingen en waarnemingen uit de praktijk. Ook worden aanwijzingen gegeven voor de toekomst.

Deel II bevat de specifieke resultaten op 14 afzonderlijke domeinen, die elk een levensfase vertegenwoordigen. Elke domein begint met een beknopte beschrijving van de kenmerken van het Nederlandse systeem van zorg en ondersteuning. Afgesloten wordt met een beschrijving van de specifieke risico's voor discriminatie en exclusie van mensen met ernstige beperkingen en/of complexe ondersteuningsbehoeften op het betreffende domein.

De conclusie van de Nederlandse studie is dat er voor mensen met ernstige beperkingen en/of complexe ondersteuningsbehoeften nog veel kans is op discriminatie en exclusie.

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Ce rapport contient des informations sur les risques spécifiques de discrimination des personnes avec des handicaps sévères et des besoins complexes aux Pays-Bas.

Il comporte deux parties. Dans la partie I, les résultats généraux sont présentés. Des sections séparées traitent d’abord des données sur les personnes avec des besoins complexes aux Pays-Bas, puis de la politique néerlandaise pour les personnes handicapées, et enfin des observations sur la pratique et des pistes possibles pour le futur.

La partie II, suivant les cycles de la vie, comprend les résultats spécifiques obtenus dans 14 domaines, chacun représentant une étape de la vie. Chaque domaine commence par la description du développement de l’individu dans les sociétés modernes à cette étape. Celle-ci est suivie d’une description condensée des caractéristiques du système de soutien aux Pays-Bas. Enfin, les risques spécifiques de discrimination pour les personnes avec des handicaps sévères ou des besoins complexes essentiels à ce stade sont formulés.

La conclusion de l'étude néerlandaise est que les personnes avec des handicaps sévères et/ou des besoins complexes présentent toujours, à plusieurs phases de la vie, un risque élevée de discrimination et d'exclusion.

2. Introduction

Data on people with complex needs

In the Netherlands, there is no clear definition of people who are in situations of major dependence or with complex needs. As a consequence, there are no exact statistics about this group. The Dutch Association of Health Care Providers for People with Disabilities (VGN) distinguishes five specific groups of persons with complex needs:

- Persons with profound intellectual and multiple disabilities. This group has been estimated at ca. 9.000 persons (information from Inspectorate).
- Deaf-blind persons, between 4.200 and 5.100 (estimation of the National Expertise Centre of Deaf Blindness).
- Persons with severe behaviour problems, ca. 4.350 (estimation by De Borg, Cooperation Body of Specialised Providers).
- Persons with autism, totally between 30.000 and 40.000 (estimation of the Dutch Society for Autism).
- Persons with non-congenital brain injuries. There are no statistics about this group as a whole. We know that each year from 600 to 1.200 children and youngsters get severe brain injuries from a traumatic incident, i.e. traffic and sports accidents (information of the Dutch Centre for Brain Injuries).

Being the total population of the Netherlands approximately 16 million people, the four first mentioned categories consists of approximately 0,3% of the population.

The Dutch policy on people with disabilities

In the Netherlands, with respect to persons with disabilities the so-called *compensatory approach* always has been dominant. This approach means that people receive substitutions and additions for what they are going to miss because of their disability. For example, when someone is expected not to be able to earn a salary in a normal paid job, the person is offered a substitute income (social allowance) or substitute work (special jobs created for persons with a disability). Intramural care providers contributed their bit by offering their clients, from the moment they came into the organisation, all kinds of day activities and substitute work. In this system there are no stimuli at all to try to get proper work and get a position in the labour market.

In this approach the Netherlands seem to be quite unique. Other Western countries chose in a much greater extent the *non-discriminating approach*, which means that persons with a disability do as much as possible the same activities as other people do. The approach of non-discrimination is much more connected with participation and integration than the compensating approach, which is protecting in advance. That is why in the Netherlands the wish for integration of people with disabilities has never been so much rooted in society as it is in other countries.

Connected to this approach is the content which is given in the Netherlands to the concept of discrimination. The dominant interpretation of discrimination is linked to the individual level: discrimination is the specific, rejecting way others do react in daily life (on the street, in the supermarket, in public places, etc.) to people with a disability. For many parents of intellectually disabled children this even has been, and still is, one of the reasons to let their child live in a residential institution. With that, they in fact contribute to discrimination at the collective and societal level: they do stimulate social exclusion.

Another consequence of the *compensatory approach* is that there has been no need for legislation with respect to disabled people and certainly not for specific groups like persons with complex needs.

Gradually the political vision on persons with an intellectual disability has changed. Since the end of the 1990’s, general government policy is to encourage people with disabilities to participate in social life as much as possible. This shift is influenced by the change of definition of (ICF model, AAMR) by which disability is being defined as a restriction of the possibility to participate. In the government view, persons with a disability must be able to use the same facilities as anyone else and be as independent as possible. The focus is no longer on the illness or disability but on the persons with the disability, who must be enabled to lead their own life as much as possible. Care previously confined to institutions can now be provided at home, if the person (and/or the legal representative) wishes.

This vision also provides a powerful impetus for shifting the emphasis from residential onto extramural care, and in doing so meeting people's wishes to continue to live independently in their own environment as much and for as long as possible.

There are three main aspects in the Dutch government policy regarding people with disabilities. These aspects are complementary to each other and bring into practice the principle of the inclusive society for the individual person with a disability:

- To organize society in a way that all people can live and function. This means that we have to take into account the needs of persons with a disability in all domains of life.
- To offer special services to them who need these.
- At the level of realisation and execution: offer a reasonable accommodation, with individualized support.

The policy with respect to persons in situations of major dependence or with complex needs does fit with this general policy. Irrespective of the contents of the disability (deaf blind, autistic, severe multiple disabled, etc.), the concept of support is the same: basic support given by regular services => special care given by specialised providers and CCE’s (Dutch Centres for Consultation and Expertise) => support of clients in getting clarified their demands and in going through procedures.

Regarding the legislation, article 1 of the Dutch Constitution states the prohibition of discrimination on any ground, including handicap or chronic illness. The Equal Treatment on the Grounds of Disability or Chronic Illness Act (WGBH/CZ) translates this general principle into application in daily practice. This act is a so-called modular one. It came into force, in 2003, with regard to ‘vocational and professional education’ and ‘work’. The sector ‘public transport’ will come into force in 2010 for road-systems; for railway systems this will be 2030. The expansion of the WGBH/CZ to ‘housing’ is proposed to parliament, expansion in the fields of primary and secondary education and ‘economic transactions’ are under study. It is unknown when these modules will come into force.

Generally, the act makes a distinction between meeting the demands of the organisation (work, school) and the specific facilities which are needed when the person is acting. For instance, when someone in a wheelchair applies to a job which requires to move across the building and the employer does not engage this person because of a disability, the employer behaves against this act, because adaptations can be made.

Observations about practice

Several experts report there is a gap between the general policy of inclusion and the reality of daily life. It is a clear trend that people with mild disabilities make use of regular services and institutions (education, work, housing, etc.). More and more, parents of disabled children choose for living in communities by their child. However, the translation and implementation of the government policy in practice is not successful and is obstructed by a lot of barriers. More specific observations are:

- The connection with the theoretical framework of life course: the further in the life course, the more exclusion, the harder society reacts and the more damage it can give to persons with disabilities. Special points of attention are the moments of transition, particularly the transition from school to work, around the age of 18.
- Research has shown that compared to other citizens in society intellectually disabled persons are in general in a draw back position. Different aspects of this situation are very much connected to each other: no work means less money, which means fewer possibilities to leisure time activities, which means less access to ‘normal’ situations and contacts. Which, by the way, is something else than having no access to professional services.
- There is a general policy about inclusion, but no clear operational policy. In fact, there is no one who steers.

It is fully accepted that for persons with complex needs there are specialised facilities. The population in the Netherlands - generally speaking - prefers institutional care for persons with severe disabilities above living in the local community and use of regular services. Considerations and questions are: that institution more than regular services offer specialized support closely meeting the demands of persons with severe disabilities, that institutional care is on a high qualitative level and that there are lots of bad examples of living in the local community which were extensively discussed in press; good practices are less prominent in press.

At the same time, people experience persons with multiple and complex disabilities not living in a free situation. They are stuck because of the dependence from intensive support and care, which in the Netherlands makes it necessary to live in an institution. To live in society on a relatively independent way is reserved to people with mild intellectual disabilities. However, some parents with multiple and complex disabled children are able to create a position for their child in the society as well. These parents usually are highly educated and have more financial opportunities than others, or know better how to get funds. Besides, they know the way in the bureaucratic system and have knowledge about legislation and regulations.

It is felt that to all kinds of groups with complex needs tolerance is decreasing. There is a lot of embarrassment in practical work. And people are excluded from inclusion. Persons with Down syndrome or a mild intellectual disability are socially accepted, everyone likes to see them living and working. But when you really have to take into account the disabilities and identity of the other person – in case of someone with complex needs – there is much less acceptance. Like the autistic person with whom you precisely have to know how to organise the context.

Several experts do think there is a split arising between two groups of disabled persons in the Dutch society:

Disabled persons in community services	**Disabled persons in institutions**
This group consists of: persons with mild intellectual disabilities and Profound Multiple Disabled (PMD) persons with highly educated parents with financial possibilities. Characteristics: • Care and support takes place from the principle of citizenship and inclusiveness. • Quality of life is a central concept. • Escape from the medical model. • Dispose of Personal Budget • PMD: (a) care and support are individual; there is a personal approach, (b) relatively high qualified staff, (c) lots of small-scaled initiatives, in which parents put money themselves (designing, repair, etc.).	This group consists of: persons with severe intellectual disabilities and Profound Multiple Disabled (PMD) persons with parents without high education. Characteristics: • Medical model is embraced (gives grip). • The disabled person is seen as a patient. • Thinking and working are from the perspective of groups. People live in groups. • Low qualified staff. • There is no choice in housing. The institution says where you have to live.

In a very recent study of the Inspectorate on the quality of care in whole the sector of care to people with disabilities (November 2007) it was found that in three quarters of the field action plans must be drawn up to improve the provision of care and services.

The quality and quantity of personnel is worrying and these matters impact on the continuity of the care and services provided. In 48% of the residential/care locations in the visited organisational units, the Inspectorate considered an action plan to be necessary to address the risk aspect of continuity. The Inspectorate notes that a high continuity risk is almost always accompanied by a high expertise risk. The Inspectorate asked 37% of the residential/care locations in the visited organisational units to draw up an action plan for this risk aspect.

The client's self-determination must be improved by obtaining a greater insight into his/her wishes and by a client-driven organisation. More than one quarter of the residential/care locations in the visited organisational units must take measures to improve the client's self-determination. The Inspectorate's measures and recommendations seek to create conditions for greater familiarity with the use of tried and tested methods for ascertaining the wishes of clients and for supporting them in making choices. It is also important to develop best practices for management methods and styles that will facilitate the client-driven organisation of care and services.

3. Pre-Natal Diagnosis and Counselling

Through the extended possibilities for family planning, parenthood in modern societies has increasingly become a question of individual decision-making. Prenatal diagnostics and reproduction technologies permit the inclusion of characteristics of the fetus in this decision. This extended knowledge brings individuals into difficult situations when they have to make decisions regarding children. These individual decisions are affected by social values, attitudes, anxieties and knowledge of disabilities. They are also influenced by the quality of the counseling process if professional support is available and used. It is important that individual decisions are accepted by the social environment of people concerned. How is this achieved?

3.1. Description of the National Situation

In order to give pregnant women the opportunity to make their own choice in case of bearing a foetus with a disorder, pregnant women are entitled by law to have invasive prenatal diagnostic tests (chorionvillusbiopsy, amniocentesis and cordocentesis) and/or non-invasive prenatal investigation (advanced ultra sound test). Above the age of 35 the tests are given, under the age of 35 on request (indication). The law also dictates that information on genetic risks and prenatal diagnostics has to be given. There are excellent facilities for genetic counselling at the Centres for Clinical Genetics.

Abortion is allowed subject to the provisions of the Termination of Pregnancy Act (WAZ) of 1984. This law dictates that careful consideration must be given to the following items:

- a woman and her physician must agree that her circumstances are compelling;
- the doctor must inform her on other possible solutions;
- to give a woman time for reflection, there must be a lapse of at least five days between her first consultation with her doctor and the actual termination of the pregnancy;
- abortion is prohibited once the foetus is viable oustide its mother’s body. The absolute limit is after 24 weeks. In practice, however, the limit is 22 weeks.
- The aim of the act is to balance two potentially conflicting interests: on the one hand protecting the life of the unborn child, and on the other helping women who are in a difficult position as a result of an unwanted pregnancy. Having a foetus with a serious disorder is an accepted reason for termination of the pregnancy.

3.2. Specific Risks of Discrimination

If the provisions of the law are executed in a careful and integer way, there will be no risks of discrimination of people with severe disabilities or complex support needs. However, if at any point there is no full carefulness there will be significant risks of discrimination. For example, when there is not complete information given to the pregnant woman, or in a situation where pressure on her is exerted to have an abortion (pressure perhaps may be greater when the expected disability is more severe).

4. Early Childhood

For most families, having a baby creates a situation of uncertainty and a need for direction and guidance. Living with a baby or a young child with a severe disability or with severe developmental problems brings parents into a situation with specific and difficult challenges and dependencies. Psychological stress in their daily lives often makes it difficult to cope with their parental responsibilities. When dealing with educational tasks or when specific therapeutical or medical treatment is necessary, parents cannot refer to their own educational experiences, but are dependent on professional support of various kinds. Having access to good medical care, self-help groups and early intervention services from a very early age of the child are decisive factors both for the personal development of the child and for the successful adjustment and coping process of the parents. How is this achieved?

4.1. Description of the National Situation

Distinction can be made between tracing intellectual disabilities and the early care if a disability has been detected. The Netherlands have an excellent network of Municipal Health Centres where preventive activities are carried out: the heel prick (4-8 days after birth, CHT + PKU test) and the Infant Welfare Centres and the Child Health Centres, where by periodic investigations and tests developmental disorders are indicated. In case of positive scores on the tests and/or indication of an developmental disorder by the infant doctor, special teams (VTO-teams) take care of the assessment and diagnostics.

In the care giving so-called early intervention teams play an important role. These multidisciplinary teams must coordinate care and support. The Dutch Association of Health Care Providers for People with Disabilities (VGN), together with other organisations, made a plan in which a model for early diagnostics and assessment and early intervention has been worked out. It’s a plan for individual, timely, structured and long term support at home, called ‘Early, continuous and integral; chains of timely detecting, diagnostic, care, education and support to children with disabilities and their families’. The aim of this plan is to detect children with disabilities as early as possible, to diagnostic adequately and to offer an efficient and effective care and support to themselves and their parents.

From birth, special services are available for intellectually disabled persons and his/her parents: pedagogic homecare, developmental programs, child day care centres for disabled children, special schools, special clubs, et cetera. The care and support are at a high level. Very important is that the specialised support of child and family can start as early as possible.

The support and care for persons with complex needs is in transition. It is going from a well-considered model into a system of individual authority. There still is a lot of improvement on individual authority to make.

4.2. Specific Risks of Discrimination

In the system of early intervention it is crucial that persons with severe and multiple disabilities and complex needs can enter the chain of detection and intervention as early as possible. Not everyone has the same chance; well educated and informed parents have an advantage to other parents.

Another risk of discrimination concerns the connection between the process of intervention and the idea of inclusion. In spite of the increasing possibilities for parents to keep their disabled child at home, from the beginning the focus is on specialised services and there is a strong tendency to hospitalisation. Families go along with that. As young parents with a child with an intellectual disability, you will be shown the route of exclusion. From birth we separate people. It would be better to realise the conditions that a disabled child and its family can stay together and the child can attend regular schools. Regular schools have to take their responsibilities. So the practical model of early detection and intervention should be more supportive to the idea of inclusion.

In any case, we still need more attention for early diagnostics and assessment. For the well-being of the person involved, it's most important to find out the kind of support one needs in the social context in which one lives. With respect to persons with severe behaviour problems we can say that there is a strong connection between early diagnostics and assessment and the intensity of the behaviour. The longer it takes before the right diagnosis is made, the bigger the chance that the behaviour gets more problematic.

5. Childhood: Education and Care

Preschool institutions like inclusive or special kindergartens offer care and education for younger children. They prepare children for school and give them the opportunity to interact with peers. Young girls and boys can broaden their experiences in life and enhance their social skills.

Children with severe disabilities have the same need to interact with peers, to make friends outside the family and to view themselves as a part of a social group. But young children with complex needs are dependent on additional support to participate in preschool education, such as barrier-free access or well-trained educators with specific skills and the intention to cooperate with other professionals. How is this achieved?

5.1. Description of the National Situation

There are children with multiple and complex disabilities who attend regular preschool services like inclusive or special kindergartens, but there are not many. Mostly they stay at home, while still being in the process of diagnostic investigation and search for the right intervention.

In this stage the role of parents is a central one. They have to take up steering and coordination; they have to organise the care, to fix and order, to communicate, to study regulations, etc. That's why it is very important that the specialised support of child and family can start as early as possible. Umbrella organisations made a plan in which a model for early diagnostics and assessment and early intervention has been worked out (see before). For the well-being of the person involved, it's most important to find out the kind of support one needs in the social context in which one lives.

5.2. **Specific Risks of Discrimination**

We may expect that the shift to more integration in the preschool phase the coming years mainly will be related to children with mild disabilities, not to children with severe and multiple disabilities. In terms of inclusion, there are some groups of disabled persons, like children with Down syndrome or autistic children, who more and more participate in regular kindergarten and primary schools. There is a chance that children with severe and multiple disabilities will fall behind further.

6. Childhood and Youth: School

Schools are responsible for a child's education and the teaching of knowledge of varying subjects. Furthermore, school proves to be an important part of young peoples' socialization process by offering the chance to enhance social skills and deepen social contacts with peers.
Children with severe disabilities also need high quality education and access to public schools. Pupils with complex needs are dependent on additional support in order to participate in school education, such as barrier-free access or well-trained teachers with the intention of cooperating with other professionals.
But especially pertaining to them, schools often exercise a kind of segregation. How do children with complex needs find their place in the school system, in which way are their special needs considered and how do professionals cooperate together?

6.1. Description of the National Situation

Next to the regular schools, in the Netherlands there is a extended system of special primary education. It comprises schools providing special education for disabled children and children whose education requires a special approach, catering for either the primary or secondary age group or both. Education of this type is divided into four categories:

- Category 1: schools for the visually impaired, who may also be multiply disabled.
- Category 2: schools for deaf children, partially hearing children and children with severe speech disorders, who may also be multiply disabled.
- Category 3: schools for physically disabled children, children with severe learning difficulties (ZMLK) and chronically sick children (LZK) with a physical disability, who may also be multiply disabled.
- Category 4: schools for severely maladjusted children (ZMOK), chronically sick children who are not physically disabled and children in schools attached to paedological institutes (i.e. institutes associated with a Dutch university which give guidance to special schools).

Children and youth with severe and/or multiple disabilities with intensive need for care until recently were not qualified for the category 3 schools. Consequently, they were left to special day care facilities. This has been changed; now there is education legislation which gives the possibility for attending special or even regular schools. By law children and youth with disabilities and/or severe problem behaviour have the opportunity to choose for mainstream schools with extra assistance or for special schools. Children and youth with severe and/or multiple disabilities have the same choice. They are entitled to get a financial budget (the so-called ‘back pack’).

In terms of inclusion there are some groups of disabled persons (for example people with Down syndrome) who more and more participate in regular primary school. As the schools are hardly prepared to provide differential education, attending regular secondary school is already much more difficult. The older one gets, the more difficult it becomes. So it is important to make use of regular schools as long as possible. When one gets involved in specialized education, it is hard to get back.

6.2. Specific Risks of Discrimination

School is one of the most important domains for inclusion. In the Netherlands the legislation was changed in order to give also people with complex needs the opportunity to attend mainstream schools. That was the intention of the ‘back pack policy’: all children, no matter their level of disability, should be able to go to school. Nevertheless, several years after the introduction of the new law, many children with profound multiple disabilities (PMD) are still looked after by day centres. The educational policy itself may have complicated a successful transfer, the authorities did not force schools to meet any requirements with regard to use of products (curriculum, checklist), to extra training of personnel, or to the acquisition of essential facilities.

The accessibility to regular education for PMD children still is difficult and mostly impossible. Even the access to special education often is problematic because here also limits of level are practised: in the curriculum only little attention is being put into communication, which exceptionally is the most suitable point of impact into the PMD person. Also in the special education the cognitive aspects are considered the most important ones. So in practice, the traditional separation of groups keeps alive.

The further you come in the chain of day centres and schools (day-care centre => special basic school => regular basis school => regular secondary school) the less accessible the organisation is. Even the new legislation did not really change the situation. There are some groups, like people with behaviour problems, which do not have a chance to be included at all. As their behaviour is troubling others they are excluded.

7. Childhood and Youth: Housing and Family Support Services

Due to the variety of modern family life, all children grow up in different environments. These environments can be understood as a social network including all sorts of relationships to individuals or institutions. The family’s living conditions during childhood are very important for social inclusion of the young person in society. The family has a strong impact on his/her primary socialization and influences the access to certain social institutions.

Family support services offer community-based professional support and services for families. Some children and young people live in a foster family, others in foster homes. Are such support systems available? In which way are children with severe disabilities or complex needs and their families involved in these support systems?

7.1. Description of the National Situation

The current policy is that that children with severe and/or multiple disabilities should grow up in their birth families. So they live with their parents, often in combination with stay in a day care centre.

So parents and other relatives have an important role in the support and care for their disabled child or family member. As their strengths and supportive power are limited it is sometimes hard for the parents to keep their disabled child at home. Luckily nowadays there is all kind of provisions that help the parents to keep the child at home as long as possible. There is for example family support that provides services and aid to the parents and the family members who support them and there are guesthouses where children can stay on a temporary base that is specially accommodated for disabled persons. Very important is that the specialised support of child and family can start as early as possible.

While care and support for disabled persons who live relatively independent usually are split up at providers' side, parents have to take up steering and coordination. They have to organise the care, to fix and order, to communicate, to study regulations, etc. However, often they don't have the power and money for that.

Against this background we may say that parents do play an important role in participation and inclusion of persons with multiple and complex supporting needs. They know their child very well and can be helpful with the interpretation of the needs and demands of their child.

At the other hand, parents usually react conservative to ideas of participation and living in the community. Often the reason is that they already went through a lot of things with their child and became cautious to changes. In realising inclusion it is wise to make contacts with young parents and not to put much energy anymore in elder parents.

The family support runs along three lines:

- MEE-organisations, which offer support in giving information (social map), in clarification of the support demand, references, organising contacts with other parents, etc.
- Facilities from the Exceptional Medical Expenses Act (AWBZ).
- Facilities from Social Support Act (Wmo). By this act, municipalities are legally obliged to provide care services for the elderly and the disabled - transport, wheelchairs and special facilities in houses as well as support to families. Patients can apply to a special municipal agency for care services or for an allowance with which to purchase the care themselves. This has led to greater flexibility and a more demand-driven approach among care providers. 'Participation' is the objective of the *WMO*. Social support policy must be based on enabling people, including vulnerable individuals, to participate in mainstream society.

A specific important item in support of families is the transport. If you want to participate in the society you need to be mobile in some way. For persons with PMD mobility requires very specific transport. The regulations are insufficient. For example: if a PMD person who lives in an institution wants to attend a regular school, it formally is conceived as a kind of day activity. So you do not get the transport paid because day activities (transport included) are a part of the total amount the institution for this client get. The part 'transport' in this total amount is so little that travelling to regular social activities for a person is impossible.

If the person lives with the parents, transport is very complicated as well. You can't use the public transport; special taxi transport often is not available. So you have to organise specific solutions (as make an elevator in your own car).

Care providers react different with respect to participation of their youngsters:

- Some providers give individual Active Support, which can stimulate participation and inclusion, others use traditional methods of group support.

- Sometimes the organisation has the opinion that the development of their client is without any perspective. Then the decision has been made to replace the development goals by the goal of quality of life: to give the person a life as good as possible in a residential setting.
- Others combine solid care with an open view to society. The aim of participation is realised from an attitude of carefulness and staying very close to the needs and wishes of the clients. So activities of participation are carefully tuned to the individual needs and abilities.
- Sometimes the ambitions are high, as in the case of the Very Intensive Care (VIC) Workhomes. There the recovery to a normal daily life is seen as a perspective for clients with severe problematic behaviour. To realise that, the method is geared to a recognizable and normal course of daily life based on creating a supportive climate.
- Sometimes, parents take the care in their own hands, helped by de possibility of personal budgets. For instance, they create a company of supportive professionals and volunteers by which their multiple and complex disabled child can have a supported living in the society, far from the residential institutions.

7.2. Specific Risks of Discrimination

Family support services, with exception of transport, are at a high level and by that they can influence the opportunities for participation on a positive way. However, there is a tension between the intention of inclusion and the assessment of the effects on the person. Parents as well as professionals realise that society nowadays is fast and much focussed on production. People with complex needs are vulnerable in such a society. Moreover, society is not eager to meet them, which is something they feel and know well, especially when they got older. We have to develop care and support further in the direction of individualised packages of support for clients.

8. Childhood and Youth: Leisure Time

Young people use their leisure time to do enjoyable and amusing activities and to get free from daily routines. Often free time activities are organized in clubs or in various forms of sportive or cultural associations. But youngsters also spend their free time with peers without adults. Many experiences among young people of the same age are made spending leisure time together, e.g. discovering new social roles, social spaces, friendship or falling in love. Youngsters with severe disabilities or complex needs have the same leisure time needs as their non-disabled peers, but are dependent on additional support to participate in mainstream leisure time activities. How is this achieved?

8.1. Description of the National Situation

Most leisure time activities for children and youth with severe and/or multiple disabilities are organized privately or are connected with the stay on the day care centre, usually with great involvement of volunteers.

Leisure activities for this group, as well as for the group of disabled people as a whole, are not covered by regulations of equal treatment legislation. The Equal Treatment on the Grounds of Disability or Chronic Illness Act has not been expanded to this sector yet.

There also are no regulations for accessibility of public areas where everyone uses to spend their free time (buildings, shops, cafes, cinemas, etc.). Many shops even do not have a slope for wheel chairs. Mostly also outside activities (parks, beaches, etc.) are not accessible to these persons.

8.2. Specific Risks of Discrimination

There are almost no possibilities for children and youth with severe and/or multiple disabilities to participate in the leisure time activities which are available for the other young Dutch citizens. In this domain there is discrimination.

9. Youth and Young Adults: Vocational Training

A successful transition from school to the employment system is usually related to vocational training. After finishing school young people need to find a job according to their interests and abilities with which they can earn a living. Vocational training prepares for the access to the employment system and is an important step into adult life. Youngsters and young adults with severe disabilities are dependent on adapted training courses, assisting technologies, other individual support and barrier free infrastructure to enable their access. How is this achieved?

9.1. Description of the National Situation

Persons with severe and/or multiple disabilities and complex needs do not attend regular schools for vocational training. In the Netherlands there are five special institutes in which these persons are being equipped for normal jobs. As a consequence of the government market policy these organisations have to collect their own money from the market, which made them coming in trouble.

Vocational training is one of the fields the Equal Treatment on the Grounds of Disability or Chronic Illness Act (WGBH/CZ) came into force until now. By this act (2003) discrimination between students and pupils with and without a disability on schools for vocational and professional education is prohibited. Particularly with respect to accessing school; in classes, during traineeships and exams; in providing information on career choices; in making adjustments in order to be able to follow the course.

9.2. Specific Risks of Discrimination

In spite of the non-discrimination legislation in this sector, persons with severe and/or multiple disabilities and complex needs are being discriminated. Regular vocational training is not available for them. Consequently, the discrimination legislation can not be effective for this group because there are no situations the legislation can be applied to.

10. Children and Adults: Social Security and Health Care

Modern societies are shaped by an enlargement of welfare systems and an increasing dependence on social security institutions. It is a challenge for all citizens to clarify their entitlements and to find access to services.

The need for basic social security and to have access to health care services if necessary is important for all people.
In most cases having complex needs leads to an increase of dependence on social benefits and requires special support and services granted by welfare administration boards. Bureaucratic procedures of application approval create special risks of stigmatization. Allowances, benefits and services can improve the possibilities of individual participation, but can also initiate processes of social exclusion. How is this achieved?

10.1.Description of the National Situation

With respect to *health care*, the Health Insurance Act (Zorgverzekeringswet) and the Exceptional Medical Expenses Act (AWBZ) constitute the basis of the health care insurance building in the Netherlands. The Zorgverzekeringswet is a private health insurance with social conditions. The system is operated by private health insurance companies; the insurers are obliged to accept every resident in their area of activity. A system of risk equalisation enables the acceptance obligation and prevents direct or indirect risk selection. The insured pay a nominal premium to the health insurer.

The entitlements that exist under the AWBZ have been defined in terms of functions. Six broadly-defined functions create considerable freedom for arranging indicated care in consultation with a care provider: personal care, nursing, supportive guidance, activating guidance, treatment and accommodation.

By AWBZ, the entire special costs for persons with severe and/or multiple disabilities are paid: care, accommodation, and support. Relevant regulations belonging to this act are:

- During 2007 care providers will be obliged to make a care and support plan for every client. In this plan, the needs for care and the delivered care and services have to be fit to each others concretely.
- This has to do with the introduction of a new financial system. Clients who have an indication for care and accommodation will receive financial facilitation which correspondents with one of 45 sets in which the size of care and services is expressed (ZZP's). At the basis of this set and the demands of the client, provider and client together have to make the translation into concrete agreements about daily services. These agreements have to be admitted in the care and support plan. In this way, the clients are given more direction about their own life.
- From April 2007 it has been possible for persons with an indication for care and accommodation to receive the whole package of care and support from the AWBZ at home (so-called full package system). By this, people with disabilities are being offered an alternative for residential stay and support.

Over the past decade the government has made an important change in the care system with the introduction of the client-linked budget. This personal budget increases people's options so that people can take more responsibility for their own situation and have care that is better suited to their needs. Care can be deployed more flexibly, for instance at home instead of having to relocate to a specific care institution.

With respect to *social security* three acts are of great importance. Together they form a safety net for vulnerable people, like persons with severe and/or multiple disabilities. The creation of this safety net can be considered as belonging to the compensatory approach of this country (see part I).

(a) The Disablement Assistance Act for Handicapped Young Persons (Wajong) makes provision for a minimum benefit for young handicapped persons.
(b) Regulations governing Contributions towards the Upkeep of Disabled Children living at Home (TOG) provides for an additional allowance, apart from child benefit, to parents for the upkeep of a disabled child living at home.
(c) The Work and Benefits Act (WWB) provides a minimum income for all persons residing legally in the Netherlands with insufficient financial resources to meet their essential living costs.

10.2. Specific Risks of Discrimination

Generally, the access for persons with complex needs to medical services is good; the access to public services is not. Because the responsibility of the (medical) care has been placed in the hands of the caregivers, they decide about how you are treated. This is different for other citizens.

Having complex needs leads to an increase of dependence on social benefits and requires special support and services granted by welfare administration boards. The new financial system – by which clients who have an indication for care and accommodation receive financial facilitation which correspondents with one of 45 sets in which the size of care and services is expressed (ZZP's) – is worrying. Because of the financial restrictions of this system organisations are being driven to become intramural institutions again. Smaller groups and households are more expensive, so economically it is more effective to keep the clients residential. This tendency is also shown in the language of workers: you can hear them speak again about 'working on the group' and 'the size of the group'. So the new system seems to initiate processes of social exclusion.

The accessibility of care services and support for persons with multiple and complex needs depends on which provider you have to do with. Actually, there are providers who prefer not to have persons with complex needs as clients, because of financial reasons: they are too expensive for them. The more severe and complex the disabilities are (multiple disabilities, behaviour problems, and severe physical disabilities) the less supply from providers and services is available.

Discrimination is also been observed in other areas of care and welfare. In the psychiatric care there is a lack of knowledge about the specific disabilities and impairments of persons with complex intellectual disabilities. They feel treated without respect.

11. Adults: Work and Employment

Having work or a day occupation is, for financial and other reasons, a very important indicator of social inclusion and quality of life. Going to work not only structures peoples' days and weeks, but also has an important impact on the development of a person's identity. It also provides access to the social security system and is an important basis for participation. For people with severe disabilities, transitional situations from school or vocational training into the employment system must often be systematically planned and organized, because *they are dependent on adapted work places or assistive technologies and other individual support like a barrier-free infrastructure to enable their access. How is this achieved?*

11.1.Description of the National Situation

The government's aim is to get more disabled people out of sheltered work environments into jobs with regular employers (supported employment). That is why the Sheltered Employment Act (Wsw) has been changed. The first phase of modernisation of the Wsw took place in 2004 when the Centres for Work and Income started to assess who is eligible for a job in a sheltered workplace. That used to be the responsibility of local authorities. In the second phase the aim is to increase the number of disabled people who find work outside of sheltered workplaces. This means finding supervised jobs with regular employers or placement in service of a sheltered work company. Municipalities have the task to realise that.

In fact, mainly persons with mild disabilities take advantage of this policy. Only few persons with severe and/or multiple disabilities have a job in a regular setting or have training for such a job. Mostly, they stay or work at special day care centres, which are connected with care providers. These providers have a strong tendency to protect their clients. For example: at the residential institution there is a well functioning bakery but the step of starting a bakery in the village is not done.

With persons with multiple and/or complex disabilities you need employers who enjoy working with this group. There are a lot of jobs which persons with severe disabilities are able to carry out: for instance in garages, playing grounds, etc.

The facilities for day activities are going to be decreased, as a consequence of the new financing system (by which the size of care and services is expressed in one of 45 sets of heaviness). In that system day activities are going to be assessed lower (i.e. cheaper) than housing facilities.

11.2.Specific Risks of Discrimination

Work is one of the domains people do integrate the best. So we especially have to invest in this domain. We see contradictions between the unanimous accepted vision and goals of participation and inclusion in labour situation (legislation included) at the one hand and the practice at the other. This is in particular with regard to people with complex needs. We want participation of these persons in the regular labour process and at the same time no concrete actions have been carried out. In contrary, institutions of support for this complex group (job coaching, training) have to finish their activities because of financial problems which are the result of ministerial withdrawal of financial resources (because of the market principal that they have to fund their own activities). This gap between policy and practice will lead to an increase of discrimination.

In residential services for people with complex needs, staffs prescribe what people must do; they know what the best is for them. Day activities mostly do not aim development of the individual person, they consists of some music, whirlpool bath, hanging around. Workers and managers think in terms of groups; for example the group of autistic persons who need structure. People are sorted out by types of disabilities.

Work is one of the two domains the Equal Treatment on the Grounds of Disability or Chronic Illness Act has been come into force. Because of the very low participation of persons with complex needs in regular work, this law can not be effective for this group because there are no situations this legislation can be applied to.

12. Adults: Housing

Becoming an adult also means making up your mind about how you would like to live: stay in the natural family for a while, live alone, with a partner or family, with a friend, etc. Having privacy, a place to go to, feeling safe and comfortable there, realizing one's own ideas on how to live, are all very important for people in our societies. For people with complex needs it is a big challenge to find their own way to living. They have restricted alternatives for housing because they need barrier-free environments and life-long support. People with severe disabilities do not only need good support services but also counseling to realise their ideas and style of private living. How is this achieved?

12.1. Description of the National Situation

With regard to living, the Dutch government takes as the starting point that everyone with a disability should live in the local community with the necessary support. However, the government does not want to oblige people to do that. Institutional living offers efficient and effective support in many cases. Many persons choose for these arrangements. In the perspective of the parents organisations, freedom of choice is important; but the efficiency and quality of treatment in a specialized setting might overrule this general principle.

A small amount of persons with severe and/or multiple disabilities lives relatively independent in a special assisted living centre or with friends or family, having adaptations in the house and special intensive support (Active Support).

Most people do live in residential settings. This support is financed by Exceptional Medical Expenses Act (AWBZ). These persons can not do anything for themselves what they would like to do. And they live with many regulations. Like the formal distinction between leisure and work. For example, someone rides horseback (which is leisure) and would love it to do after the riding small jobs, like caring for the horses, brushing them, etc. That is not possible because that would be work, which is another category than leisure.

For fear of making mistakes, workers in institutions act strictly in line with the current regulations. They do not want to take much risk. For example, if someone wants to go out for a walk with a client, they only may leave the institutional ground when the accompanying person is authorised to give the medicine in an urgent situation (even when in the last five years the person did not need that medicine). It means that the accompanying person always has to be a nurse. Practically this means that the disabled person does not go outside the institution at all.

Summarised, there are three reasons why participation and inclusion are blocked:

- Good practices do not get imbedded.
- Staff is feared to be tackled to their conduct; so they protect themselves against 'irresponsible actions'.

- Disabled people permanently are overprotected. The reflex of staff to challenges is: ‘let’s not do it, they are not able to do this.

People with complex supportive needs usually live in groups because then their life and support are easier to control and to manage. So human beings are made subordinated to the system. They are put together on the basis of demands. Each person has numerous possibilities to develop, has for instance wishes and opinions about going to work. But the organisation says: ‘No work, first we are going to manage the housing.’
This culture of control is not restricted to residential living, also in case of community living the organisation wants to control. For example, when disabled people live in adjacent houses in the community, the fences between the gardens are removed because of the whole will be being better controllable. Staffs are very good in seeing hurdles on the road.

Residential institutions have problems with using the demand of the client as starting point. Their orientation often is to control everything. Confirmation of this is given by the results of the project ‘phased and stratified supervision’ of the Inspectorate.

Good practices of participation and inclusion show that factors of success are:

- Personal involvement and inspired leadership (in spite of legislation and regulations.
- Everyone, regardless their position in the organisation, respects the client. Dialogue is experienced as a real dialogue.
- Methods (assessments, image making) and attitudes to get to know somebody are applied.
- There is cooperation between the disabled person(s), family and professional workers. There is partnership.
- There are guaranties that the vulnerability can be small, especially financially. (A risk factor is that the personal budget can be reduced easily when the evaluators – in their subjectivity and ignorance – make such a judgment).
- There is no thinking in terms of groups: persons do not need to be equal, everyone is an individual human being with capacities and disabilities.

Especially small and medium-sized providers do succeed in participation projects. These organisations usually provide semi mural, not residential, services and are flexible in anticipating the environment and needs for support (who is the client, what does the client want?), have the vision that behaviour problems are related to not having listened to the person and have an excellent regional network. Another category of successful practices are small-scale services which are created by (groups of) parents.

12.2.Specific Risks of Discrimination

In the Netherlands, the most people with complex needs (persons with severe and multiple intellectual and/or physical disabilities) live in intramural institutions. They are basically excluded from society. In these institutions, even the day activities often are located at the place of living, so people don’t come outside their residential setting at all. And if day activities are elsewhere, people are transported by special vans.

There should be more opportunities for experiments, especially at the basic, micro level of support and services. For example, there should be given more facilities to parents to practice their role as the ‘director’ of their profound multiple disabled child. There are lots of small, professionalized organisations which can support parents in their job. Some parents even make their own organisation around the care and support for their child.

Our house, the place where we eat and sleep, is the basis of our life. If you start with placing someone in an institution in the forest, the city is far away. Some persons with complex needs even form a relatively easy group. For instance profound multiple disabled children: they have not the behaviour problems other groups of persons with intellectual disabilities have, they are not that disordered. They need a lot of care with respect to daily life, which can be organised quite well at individual level quite. However, there is no regulation for individual living. So also in this, there is discrimination.

The level of control is related to the way of living of clients: the more they live in big groups the more control is needed. So we should finish living in institutional groups. Inclusion is the key to less control.

13. Adults: Education and Leisure Time

Leisure time comprises all the time out of work to either relax or find a balance in contrast to every-day-life. Activities can be done on one’s own, organized in clubs or in various forms of cultural or other social facilities. In their leisure time, people in our societies are supposed to act with less formal restrictions and try to achieve a high degree of satisfaction and self-determination in their activities.

Adult education – taking the idea of life-long learning as postulate – can be seen as part of the individual’s leisure time, sometimes connected to work or the expectation that a certain course promotes one’s professional career. Sometimes people participate in adult education courses for the sake of their personal well-being, health or general personal development. For people with severe disabilities the participation in organized leisure time activities or adult education courses very often must be systematically planned and organized, because they are dependent on adapted courses, assistive technologies and other individual support, and barrier free infrastructure to enable their access. How is this achieved?

13.1. Description of the National Situation

Most leisure time activities for people with severe and/or multiple disabilities are organized privately or within the residential organisation they live, often with involvement of volunteers. The activities are not covered by regulations of equal treatment legislation. There also are no regulations for accessibility of buildings people are used to spend their free time (shops, cafes, cinemas, etc.). For instance, lots of shops do not have a slope for wheel chairs. Also outside activities (parks, beaches, etc.) mostly are not accessible.

In situations of independent living it often turns out that it is very difficult to get in contact with other people and to build up your own network. In fact, you are not equal to other people. There are no equality and mutuality between people without and with disabilities. Exceptions are situations in which non disabled persons make an agreement with a disabled person to go out regularly, for instance once a week (buddy projects).

Together with labour and education, leisure time is the domain on which the most profit can be made. Leisure time usually offers a lot of opportunities to develop. For that, you don’t need necessarily to participate in the activity physically; also in the role of observer you can participate, enjoy and learn.

13.2. Specific Risks of Discrimination

There are almost no possibilities for adults with severe and/or multiple disabilities to participate in the leisure time activities which are available for the other Dutch citizens. Persons with intellectual disabilities have less access than other people to free time, networks, friends (who actually do not exist), nature, etc. In this domain there is discrimination and exclusion.

14. Adults: Partnerships and Parenting

According to social trends and changes, the decision of having one's own family is not as easy as it used to be. More and more the decision to get married or to have children is a conscious one based on emotions, being aware of the changes that these decisions will mean.
Not too long ago the idea of people with (intellectual) disabilities getting married or having children was regarded as impossible. People with complex needs who wish to marry or have a child often have to face prejudices. After all, in their parenting they are dependent on special support. Professionals from different services and service sectors have to cooperate to prevent exclusion and discrimination. How is this achieved?

14.1. Description of the National Situation

There is no policy with respect to partnership in general (living with others, to choose other people as a neighbour, buddies, volunteers, etc.). With respect to parenting of people with intellectual disabilities there is discussion and debate about the division of responsibilities between the individual disabled person and society. Government policy is that parenting has to be discouraged in stead of that it must be accepted (which obliged to build up a system of support).

Professionals and interest groups (parents organisations) have suggested to develop legislation by which persons with intellectual disabilities could be obliged to have contraception.

14.2. Specific Risks of Discrimination

By discouraging parenthood instead of focussing on systematic support and coaching during the important stages (decision taking of pregnancy, the pregnancy, after the birth) discrimination and exclusion are stimulated.

15. Adults: Exercising Civil Rights

One developmental task of adulthood is to know and to exercise one's rights. This comprises the rights that a state confers to its people in order to secure protection and political participation, e.g. basic human rights and voting.
For people with severe (intellectual) disabilities, civil rights still cannot be exercised in every case. Additional support is needed to exercise democratic rights like voting. It is also a commonly held belief that people with

severe disabilities or complex needs are in capable of serving in political positions. How can people with severe disabilities exercise their rights as citizens?

15.1.Description of the National Situation

The principal foundation of Dutch government's policy on people with a physical, intellectual or sensory disability is that they have the same rights and duties as any citizen. It is not taken for granted that by being intellectual disabled the autonomy (i.e. the competence to take decisions by your own) can be perceived as felt away. As much as possible the autonomy of the individual has to be the point of departure. The ability to give informed consent legically is an important turningpoint.

For people with severe (intellectual) disabilities the citizenship often is reduced to rights and duties within the context of their concrete living situation. They should have control and authority about the basic matters in their daily life as much as possible. It is self-evident that in order to exercise this they must get all the information they need.

In practice, the civil rights of people with complex needs are not an important topic in the care and support to these people; civil rights of this group mostly are taken for granted.

In an indirect way, the Dutch government since a couple of years tries to guarantee the civil rights of people with disabilities by the Equal Treatment on the Grounds of Disability or Chronic Illness Act (WGBH/CZ). This is a so called modular act, which up till now has come into force in the domains of work and vocational education. In 2010 the sector ‘public transport’ has been planned to come into force, which means that from then discrimination also will be prohibited with respect to: access to public transport, the use of travel information (timetable), all public transport (bus, train, tram, trolley) and buying a ticket. The law does not apply to aircrafts, boats, private bus transport and taxis.

There is not yet a culture of acceptance of this law. If there isn’t such a culture, legislation can not be effective because there will be no situations the legislation can be applied to. Another comment on the WGBH/CZ is that it is not easy to do a plea of it. A lot of administration has to be done. You need to be quite assertive.

There are initiatives in expanding the WGBH/CZ further. Together with the Ministry of Housing, Spatial Planning and the Environment, the Ministry of Health, Welfare and Sport has made a proposal to extend the act to ‘housing’. The Lower House introduced a private member’s bill into Parliament in order to extend the act to all the education and to make the module ‘public transport’ coming into force in 2008 already, which probably not will be effectuated. The Ministry of Health, Welfare and Sport has started a study to explore if whole the economic area can be classed under this act.

15.2.Specific Risks of Discrimination

In two ways people with complex needs are excluded with respect to civil rights. Firstly, there is no broad awareness of the existence of these rights for this group. Rights are taken for granted. Secondly, the Equal Treatment on the Grounds of Disability or Chronic Illness Act, which is meant to protect the rights of (also) people with complex needs, isn’t extended far enough to be a real guarantee for the protection of the civil rights.

What we need is that permanently and consequently all new legislation and regulations beforehand will be examined on the consequences for people with complex disabilities (and disabled persons in general) in terms of accessibility and inclusion. By being proactive we prevent discrimination in advance instead that we have to protest afterwards. The question behind it is: are we, as a society, willing to apply this law also to persons who are so far away from labour, education, free time facilities, etc.?

16. Adults: Ageing and End of Life

Ageing contains a lot of new challenges: Retiring, organizing one’s day in a new way, coping with the loss of abilities and coming to terms with it and with one’s life. Regularly, more support is needed in day-to-day life and thus social dependencies are increasing. Often this means that familiar life settings must be changed because care needs cannot be covered anymore by the given arrangement. Most people don’t want to leave their familiar setting even when their care needs are becoming extensive and complicated. They prefer arrangements which are based on home care services that are reliable and flexible. When people reflect upon the end of their life there is also a wish to die in dignity.
How is this achieved?

16.1. Description of the National Situation

As far as we know (no statistics are available) for persons with complex needs the stage of ageing doesn’t include big changes in living supporting system. The support which is needed in day-to-day life doesn’t increase so much, because it already was at a high level.

To die in dignity is something which is possible for these persons in the same way it is available for anyone else. When for dying in dignity euthanasia is wished, it is possible to realise, under the strict condition of the law. In the Netherlands, euthanasia is understood to mean termination of life by a medical practitioner at the request of a patient. This definition also covers assisted suicide. It may only be carried out at the explicit request of the patient. It allows persons to end their life in dignity after having received every available type of palliative care (which can be defined as: ‘An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by treatment of pain and other problems, physical, psychosocial and spiritual’ – definition of WHO).

16.2. Specific Risks of Discrimination

If the items of the law are executed careful and integer, no specific risks of discrimination of people who have a severe disability or complex support needs can be identified.

Country: The Netherlands

Report on the interview with Drs. W. J. den Ouden, senior policy-advisor Social Support, Ministry of Health, Welfare and Sport (VWS), member of the High level Group of Representatives from the Member States on Disability of the European Commission.

Interviewer: Dr. M.I.M. Schuurman.
Date of the interview: 14 May 2007.

General policy on people with disabilities

Generally, there are three aspects in the Dutch government policy regarding people with disabilities. These three aspects are complementary to each other and bring into practice the principle of inclusive society for the individual person with a disability:

- To organize society in a way that all people can live and function. This means that we have to take into account the needs of persons with a disability in all domains of living.
- To offer special services to them who need these.
- At the level of realisation and execution: offer a reasonable accommodation, which is individualized support.

Special care is financed at a national level by the Exceptional Medical Expenses Act (*Algemene Wet Bijzondere Ziektekosten - AWBZ*). This financing system has been based on functions and domains (care, work, housing, etc.), not on groups of persons or stages of life. Clients who have an evidenced right for care and/or special accommodation in an institutional setting will receive care which correspondents with one of 45 sets in which the amount of care and services needed is expressed.

The local community is responsible for social support at the decentralized level. Housing, mobility, information, advice and support services are some issues (Act on social support, *Wet maatschappelijke ondersteuning - Wmo*).

The Ministry of VWS has the task to maintain the system and to realize the conditions for qualitative good services.

In the fields of education, labour, leisure time, living, transport several provisions are available. Either support to participate in regular services or specialized services.

The policy with respect to persons in situations of major dependence or with complex needs does fit with the general policy. Irrespective of the contents of the disability (deaf blind, autistic, severe multiple disabled, etc.), the concept of support is the same: (1) basic support given by regular services, (b) special care given by specialised providers and CCE’s (Dutch Centres for Consultation and Expertise), (c) support of clients in getting clarified their demands and in going through procedures.

Accessibility of information is an important issue, especially the accessibility for persons with a cognitive disability.

Anti-discrimination policy

Article 1 of the Dutch Constitution states the prohibition of discrimination on any ground, including handicap or chronic illness.

The Equal Treatment on the Grounds of Disability or Chronic Illness Act (*Wet Gelijke Behandeling op grond van handicap of chronische ziekte - WGBH/CZ*) translates this general principle into application in daily practice. This act is a so-called modular one. It came into force (December 2003) with regard to ‘vocational and professional education’ and ‘work’. The sector ‘public transport’ will come into force in 2010 for road-systems; for railway systems this will be 2030. The expansion of the WGBH/CZ to ‘housing’ is proposed to parliament, expansion in the fields of primary and secondary education and ‘economic transactions’ are under study.
Generally, the act makes a distinction between meeting the demands of the organisation (work, school) and the specific facilities which are needed when the person is acting. For instance, when someone in a wheelchair applies to a job which asks him to move across the building and the employer does not engage this person, he behaves against this act, because adaptations can be made.

In most cases expected problems to engage someone with a disability are easy to solve. An example: four secretaries are working at an office and a fifth one is needed. You could divide the simple tasks off the four positions and make a fifth one which might be fulfilled by a person with a learning disability. This can not be forced by law. It deals with awareness of the possibilities of persons with disabilities. This level of consciousness is not achieved generally yet.

The UN convention gives points of departure for the proposition that disability is the result of the interaction between the impairments of a person and the environment (see ICF too). This means in a sense that society is responsible for people with disabilities.

With regard to living, the Dutch government takes as he starting point that everyone with a disability should live in the local community with the support he needs. However, we do not want to oblige people to do that. Institutional living offers efficient and effective support in many cases. Many persons choose for these arrangements. Freedom of choice is important; but the efficiency and quality of treatment in a specialized setting might overrule this general principle.

The population in the Netherlands -generally speaking- prefers institutional care for persons with severe disabilities above living in the local community and use of regular services. Considerations and questions are:

- Institution offer specialized support closely meeting the demands of persons with severe disabilities.
- Do regular services offer the best support?
- Institutional care is on a high qualitative level.
- The level of independency and autonomy.
- Some bad examples of living in the local community are available and are extensively discussed in press; good practices are less prominent in press.

Also in the field of education the policy is that disabled persons do attend regular schools as much as possible. If it is problematically there are two ways of solution: (1) extra financial support from the Student-linked Budget Act (*Wet Leerlinggebonden Financiering - WLGF*), (2) special education. Attending regular education is limited by the opportunities of regular schools to give special support. The solution often is that persons with the same disabilities are clustered on regular schools.

Anyway, there is a clear trend that people with mild disabilities make use of regular services and institutions (education, work, housing, etc.). At the same time, it is fully accepted that for persons with complex needs there are specialised facilities. More and more, parents of disabled children choose for living in communities by their child. Even if their child is severe multiple disabled; however, with respect to this group the shift is very slow.

(This report has been authorized by W.J. den Ouden on 13 July 2007)

Country: The Netherlands

Report on the interview with Melie van Wolfswinkel and Hans Jongmans, staff members of Stichting Perspectief (nation wide organisation which carries out evaluations within services and offers education and trainings, from the perspective of participation and inclusion).

Interviewer: Dr. Martin Schuurman.
Date of the interview: 26 September 2007.

Intramural institutions

In the Netherlands, the most people with complex needs (persons with severe and multiple intellectual and/or physical disabilities) live in intramural institutions. They are excluded from society. In these institutions, even the day activities often are located at the place of living, so people don't come outside their residential setting at all. And if day activities are elsewhere, people are transported by special vans.

These persons can not do anything for themselves what they would like to do. And they live with many regulations. Like the formal distinction between leisure and work. For example, someone rides horseback (which is leisure) and would love it to do after the riding small jobs, like caring for the horses, brushing them, etc. That is not possible because that would be work, which is another category than leisure.

In residential services for people with complex needs, staffs prescribe what people must do; they know what the best is for them. Day activities mostly do not aim development of the individual person, they consists of some music, whirlpool bath, hanging around. Workers and managers think in terms of groups; for example the group of autistic persons who need structure. People are sorted out to types of disabilities.

Fortunately, we also see examples of participation. For example the man who works as a cleaner at a football club and develops himself positively. Only few people get a chance like this.

Positive situations usually are connected with involved and alert persons. For example, a staff worker every day goes for walking with his group of disabled persons. People at the street always watch them at a distance. The man notices that along the route there is rubbish on the streets and he gets an idea: why not asking the local authorities for prickers so that during their walk they can clear the streets and do something useful? They get the prickers and enjoy their cleaning work. They feel valued by doing this. And the people they run into now give them their greetings and have sometimes a chat with them ……..

It's a small and nice example of participation in community. However, there is a big chance that, when this staff member would get another job, this activity would stop.

For fear of making mistakes, workers in institutions act strictly in line with the current regulations. They don't want to take much risk. For example, if someone wants to go out for a walk with a client he only may leave the institutional ground when he is authorised to give the medicine in an urgent situation (even when the last five years the person didn't need that medicine). It means that a nurse has to go with him. Practically it means that the disabled person doesn't come outside the institution at all.

Summarised, there are three reasons why participation and inclusion are blocked:

- Good practices do not get imbedded (see the example of the prickers).
- Staffs are feared to be tackled to their conduct; so they protect themselves against ‘irresponsible actions’.
- Disabled people permanently are overprotected. The reflex of staff to challenges is: ‘let’s not do it, they are not able to do this.’

Often, ‘safety’ has been called as argument for residential living. It’s a false argument because the safety the organisation implements is not the safety which is felt. Often people do feel themselves insecure at the residential environment.

By the way, the possibilities of institutions for participation activities have been decreased by the new financial system, by which clients who have an indication for care and accommodation will receive financial facilitation which correspondents with one of 45 sets in which the size of care and services is expressed. By this system, the spending of money is ruled very strictly so that there is much less freedom to finance new initiatives.

General culture and climate

The care and support to persons with complex needs in the Netherlands are characterised by control and hospitalisation.

Control

People with complex supportive needs usually live in groups because then their life and support are easier to control and to manage. So human beings are made subordinated to the system. They are put together on the basis of demands. Each person has numerous possibilities to develop, has for instance wishes and opinions about going to work. But the organisation says: ‘No work, first we are going to manage the housing.’
This culture of control is not restricted to residential living, also in case of community living the organisation wants to control. For example, when disabled people live in adjacent houses in the community, the fences between the gardens are removed because of the whole will be being better controllable. Staffs are very good in seeing hurdles on the road.

Also in the research you can see the principle of control. For instance, part of the Dutch benchmark in the care for people with intellectual disabilities is the investigation of the satisfaction of the clients. This has been done with the so called CQ-index. This instrument aims to measure the satisfaction of all clients at the same way, irrespective of the kind and intensity of the disability. The questions have been experienced as very difficult and not adapted sufficiently to the way of communication of these people. In an instrument like this questions should do justice to the individual person and be formulated in terms of concrete experiences.

Hospitalisation

The medical model is dominant. Medically, the care for people with complex needs is quite good. Often it doesn’t get beyond that, whereas it should be the start for further development and participation.

There is a lot of hospitalisation in this country and families go along with that. As young parents with a child with an intellectual disability, you will be shown the route of exclusion. From birth we separate people. It is better to realise the conditions that a disabled child and his family can stay together and the child can attend regular schools. Regular schools have to take their responsibilities.

Hospitalisation also is connected with:

- Staff who complains if a client doesn't want to do sensory therapy (Snoezelen). He has to do because the therapist decided it's good for him. In fact, it's the other way around.
- There is a lot of protection by which latent possibilities of development of someone doe not become visible. The picture is that 'for persons who need much support, it is better not to go to shops, supermarket, etc.'
- Disabilities and handicaps are stressed; problematic behaviour is being explained as connected with the personal syndrome and not seen as a way of communication (send out a message).

Inclusion

Generally, inclusion succeeds when parents, having a personal budget, take it in power. Factors of success are:

- The service is small-scaled.
- It is embedded in a small community (village, neighbourhood).
- There are guaranties that the vulnerability can be small, especially financially. (A risk factor is that the personal budget can be reduced easily when the evaluator – in his subjectivity and ignorance – makes such a judgment).
- You are with the right people, with the right contacts and networks. There is cooperation between the disabled person(s), family and professional workers (partnership).
- There is no thinking in terms of groups: persons do not need to be equal, everyone is an individual human being with capacities and disabilities.
- There is no intention for working with blueprints.

For inclusion of people with complex support needs there must be more legislation in our country. For instance with respect to education: special and regular educations have been obliged to go together.
The governmental policy, however, doesn't go into that direction. Government says that inclusion is necessary but doesn't do anything about it. The State Secretary even said last week that 'inclusion is a confession of faith.'
Also the bureaucracy has to e diminished. There are a lot of regulations which are contrary with inclusion.

If we really want to have more inclusion in the Netherlands, care providers should in greater extent take the position of facilitators people (disabled persons, parents) feel themselves supported by. Besides, we need a reversal in thinking and attitudes: we have to focus on possibilities and capacities in stead of disabilities and mistakes; we have to act from spirit and challenges in stead of fear; we have to work from 'how are we going to fix this…' in stead of 'yes, but …….'; we have to think creative in stead of think only in terms of existing formats.

(This report has been authorized by Melie van Wolfswinkel and Hans Jongmans on 13 October 2007)

Country: The Netherlands

Report on the interview with drs. Kees Wijnbeek (manager Sherpa) and Heiltje Stuurwold (parent of a multiple disabled child).

Interviewer: Dr. Martin Schuurman

Date of the interview: 1 Augustus 2007.

The situation in the Netherlands

Healthcare

The accessibility of services and support for persons with multiple and complex needs (MCG) in the Netherlands depends on which provider you have to do with. Actually, there are providers who prefer not to have MCG persons as clients, because of financial reasons: they are too expensive for them. The more severe and complex the disabilities are (multiple disabilities, behaviour problems, and severe physical disabilities) the less supply from providers and services is available.
This fact has nothing to do with (the lack of) expertises which are required for supporting MCG clients, because:

- every provider pretends to take care for these persons;
- nearly all the caregivers have intramural as well as semi mural and ambulant services at their disposal;
- in the past it was no problem for them.

For the MCG group great problems occur on moments of transition. Places at day care centres for children and youth are expensive, but when a youngster reaches the age of 18, the availability of money and opportunities suddenly are much less. What to do after the methyl school, the day centre or the living in the institution? There is no systematic chain of care.

When parents have great difficulties to keep their child at home and there are no possibilities for placing the child in an institutional setting near by, the alternative of intensive professional home support often is not available. The reason is that the insurance offices prefer to drag the child over the whole country to find an institution.
In this country, you are pushed to place your child in an intramural service. Keeping your child at home is systematically made impossible. For instance, the amounts for Personal Budgets are lower than the amounts which are paid for institutional care. And when you have the courage to realise that your child can stay at home and have gain a Personal Budget, there will be a real chance that after three years (when the standard re-judgment takes place) the budget will be reversed because the new evaluator has another opinion about this case than his colleague who assessed the first time. In fact, this is discrimination in a double way.

So the most profitable for the client – with respect to guarantying the continuity in care and support in situations of transition from the one stage to the other – is to live in an intramural setting…….

School and education

The accessibility to regular education for MCG children is difficult and mostly impossible. Even the access to special education often is problematic because here also limits of level are practised: in the curriculum only little attention is being put into communication, which exceptionally is the most suitable point of impact into the MCG person. Also in the special education the cognitive aspects are considered the most important ones. This is another example of discrimination.

The further you come in the chain of day centres and schools (day-care centre => special basic school => regular basis school => regular secondary school) the less accessible the organisation is. Even the Student-linked Budget Act (*Wet Leerlinggebonden Financiering - WLGF*) did not change the situation really. This act (effective on 1 August 2003) gives extra financial support for supervision to individual disabled pupils with a care need assessment, so that they are better equipped to follow adapted primary or secondary education at a regular school.

Each transition in school brings new problems. As a parent you just can hope that your child is allowed to attend the next school; he or she has to do entrance examination.

Mobility

If you want to participate in the society you need to be mobile in some way. For persons with MCG mobility requires very specific transport. The regulations are insufficient. For example: if an MCG person who lives in an institution wants to attend a regular school, it formally is conceived as a kind of day activity. So you do not get the transport paid because day activities (transport included) are a part of the total amount the institution for this client get. The part ‘transport’ in this total amount is so little that travelling to regular social activities for a person is impossible.

If the person lives with his parents, transport is very complicated as well. You can’t use the public transport; special taxi transport often is not available. So you have to organise specific solutions (as make an elevator in your own car).

Labour

With respect to labour we can see the same picture. There is a great tendency to protect the MCG person. For example: at the institution there is a well functioning bakery but the step of starting a bakery in the village is not done.

With EMG persons you need employers who enjoy working with this group. There are a lot of jobs which persons with severe disabilities are able to carry out: for instance in garages, playing grounds, etc.

Leisure time

Together with labour, leisure time is the domain on which the most profit can be made. Leisure time usually offers a lot of opportunities to develop. For that, you don’t need necessarily to participate in the activity physically; also in the role of watcher you can participate, enjoy and learn.

Housing

Your house, the place where you eat and sleep, is the basis of ones life. If you start with placing someone in an institution in the forest, the city is far away. In fact, persons with MCG form a relatively easy group: they have not the behaviour problems other groups of persons

with intellectual disabilities have, they are not that disordered. They need a lot of care with respect to daily life, which you can organise on individual level quite well.
However, there is no regulation for individual living. So also in this, there is discrimination.

In general
Historically, in the Netherlands we have specialised more and more. For instance in the education we made many categories and said to the rest group that 'they are not able to learn'. A comparable process has being go through with housing and care.
By making the building of the specialisation we organised the exclusion. By institutionalising so much (creating super specialisations) we lost the possibilities and opportunities for individual arrangements.
Financially, we have two parallel models: the model of the Exceptional Medical Expenses Act (*Algemene Wet Bijzondere Ziektekosten - AWBZ*) and the model of the Personal Budgets/individual living funds. There is no real transition from the one model to the other.

Lines for the future

In the future we need:

1. De-institutionalising with one to one support. This is something that only can be realised with individual budgets which preferably are higher than the payments of institutions (which can give pulling power).
2. Legislation. In the Netherlands, basic rights can not being enforced individually. It's the same for the right to assistance, budget, education, etc. The Dutch Equal Treatment on the Grounds of Disability or Chronic Illness Act (*Wet Gelijke Behandeling op grond van handicap of chronische ziekte - WGBH/CZ*) has to be translated and applied to the MCG population. Are we, as a society, willing to apply this law also to persons who are so far away from labour, education, etc.?
   The same process of translation and implementation to MCG people has to be going through with respect to other legislation, like the Social Support Act (*Wet Maatschappelijke Ondersteuning - WMO*) and, internationally, the new declaration of the UN.
3. In the policy of the care provider the client has to have the central position. As a provider you have to feel responsibility for the individual client, even if you can't offer all the services the client needs. Providers have to feel more competition in being facilitator. In the world of persons without disabilities there is much more competition.
4. Financing. Much more clarity is needed about flows of money and financial regulations.
5. Personnel and staff. Because of the situation on the labour market, it will be more difficult to get personnel, especially for the MCG group. And the professional demands (knowledge, skills, obligation to be registered) are very high. In fact all clients are being put in the hold of the professionals, also clients with mild intellectual disabilities. But the consequences for MCG clients are worse: they are put together in institutional settings. Only few people want to work in these reserves. In this respect, more inclusion is interesting, because for many workers working in a setting of inclusion is preferable to work in an institution.

(This report has been authorized by Kees Wijnbeek and Heiltje Stuurwold on 1 October 2007)

Study on the Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs

www.non-discrimination.eu

Country Report Poland

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Tender on Behalf of the European Commission
D.G. Employment, Social Affairs and Equal Opportunities
Integration of People with Disabilities - Unit G3

Table of Contents

Selected Stakeholder Interviews

1. Summary

This paper contains information on the specific risks of discrimination of people with severe disabilities and complex needs in Poland.

An introductory part presents general aspects of categorization approaches, availability of data and eligibility procedures. According to the data from the 2002 census, there were 4.5 million of people with disabilities with a legal status of disability in Poland (12% of the general population) and among them were approximately 24% with a legal disability status of significant degree. In Poland, there is no official definition of people with complex needs and the term “people with severe disabilities” is not synonymous with the legal disability status in a significant degree.

Following a life-course systematic the main part of the paper consists of 14 sections with a nearly identical structure. Firstly, it is described what the general developmental tasks for all people in modern societies in a given phase of life are. As people with severe disabilities are depending on specific arrangements or support to cope with life challenges especially in periods of transition the availability of support services or barrier-free conditions are crucial for social participation rsp. discrimination. Secondly, for each phase of life or dimension the characteristics of the support system and other relevant information are presented in a very dense form. On that basis, thirdly, specific risks of discrimination for people with severe disabilities or complex needs are formulated as essential for a given life phase. Due to lack of space, references were mostly not added in this paper but are part of the annotated bibliography.

The Polish Constitution contains a general prohibition against discrimination. Discrimination on the grounds of disability is prohibited also in the Charter of Rights for Persons with Disabilities. Nevertheless, in the disability field in Poland dominates rather the traditional welfare approach than the civil rights perspective. There are several legislative acts which provide frameworks for legislation and policy in the fields of education, rehabilitation, employment and social assistance for people with disabilities. However, insufficient existing solutions, material and immaterial barriers and lack of resources do not allow people with severe disabilities to lead an independent life. Moreover, people with severe disabilities are often treated as children, which is particularly discriminating. Due to this fact, they not only cannot lead an independent life but even cannot develop as mature individuals. Paternalistic views of people with severe disabilities as persons needing above all protection is often behind this.

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Publikacja niniejsza zawiera informacje na temat osób ze znaczną niepełnosprawnością i ze złożonymi potrzebami oraz dyskryminacji, na którą te osoby są narażone w sposób szczególny.

We wstępie przedstawione zostały informacje ogólne dotyczące definicji, klasyfikacji i orzecznictwa oraz dostępnych danych statystycznych. Według danych pochodzących z Narodowego Spisu Powszechnego, w 2002 roku w Polsce żyło 4,5 miliona prawnie niepełnosprawnych, co oznacza, że osoby niepełnosprawne prawnie stanowiły 12% populacji

generalnej. Wśród nich około 24% posiadało orzeczenie o znacznym stopniu niepełnosprawności lub orzeczenie równoważne. W Polsce nie istnieje definicja osoby „o złożonych potrzebach", a używany w raporcie termin „osoba ze znaczną niepełnosprawnością" nie jest równoznaczny z posiadaniem przez tę osobę orzeczenia o znacznej niepełnosprawności. Główna część raportu składa się z 14 rozdziałów, które odpowiadają kolejnym etapom życia osób ze znaczną niepełnosprawnością. zawiera omówienie sytuacji osób ze znaczną niepełnosprawnością na kolejnych etapach życia. Każdy z rozdziałów posiada podobną strukturę. Część pierwszaprzedstawia zwięźle elementy systemu wsparcia i inne informacje istotne dla danej fazy czy wymiaru życia, W części drugiej przedstawiane są natomiast obszary, w których ryzyko dyskryminacji osób ze znaczna niepełnosprawnością czy ze złożonymi potrzebami jest największe na danym etapie życia.

Polska Konstytucja zawiera generalny zakaz dyskryminacji, a Karta Praw Osób Niepełnosprawnych w jednoznaczny sposób zakazuje dyskryminacji, której podłożem jest niepełnosprawność. Pomimo to w polityce niepełnosprawności w Polsce dominuje raczej tradycyjne podejście charakterystyczne dla pomocy społecznej, niż podejście oparte na prawach obywatelskich. W Polsce istnieje szereg ustaw, które tworzą ramy dla rozwiązań w obszarze edukacji, rehabilitacji, zatrudnienia czy wsparcia społecznego dla osób niepełnosprawnych. Jednak istniejące rozwiązania nie są wystarczające, a dodatkowo społeczne, finansowe, administracyjne i fizyczne bariery nie pozwalają osobom ze znaczną niepełnosprawnością na prowadzenie niezależnego życia. Ponadto, osoby ze znaczną niepełnosprawnością są często traktowane jak „wieczne dzieci", Z tego powodu nie tylko nie mogą żyć w sposób autonomiczny, ale uniemożliwia im to często stanie się dojrzałymi jednostkami. Ma to swoje źródło przede wszystkim w paternalistycznym podejściu do osób ze znaczną niepełnosprawnością, które uważa się przede wszystkim za osoby wymagające pomocy.

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Ce document contient des informations sur les risques spécifiques de discrimination des personnes avec des handicaps sévères et des besoins complexes en Pologne.

L'introduction présente des généralités sur les approches de classification, la disponibilité des données et les procédures d'éligibilité. Selon le recensement de 2002, il y avait 4,5 millions de personnes avec statut légal de personnes handicapées (12% de la population générale) et parmi celles-ci, approximativement 24% d'une gravité significative. En Pologne, il n'y a aucune définition officielle des personnes avec des besoins complexes et le terme "personnes avec des handicaps sévères" n'est pas synonyme du statut d'incapacité significative. Le corps du rapport suit les cycles de la vie en 14 sections présentant une structure presque identique. D'abord, une description du processus de développement de l'individu dans les sociétés modernes pour une phase donnée de vie. Les personnes avec handicaps sévères étant dépendantes d'un accompagnement spécifique pour affronter les défis de la vie, notamment pendant les périodes de transition, la disponibilité des services ou l'absence de barrières sont cruciales pour elles. Ensuite, pour chaque phase de vie, les caractéristiques du système de soutien ainsi que toute autre information appropriée sont présentées sous une forme très condensée. Enfin, des risques spécifiques de discrimination pour ces personnes essentiels à cette phase de vie sont formulés.

La Constitution polonaise contient une interdiction générale de toute discrimination et la discrimination en raison du handicap est interdite également dans la Charte des Droits pour les Personnes Handicapées. Néanmoins, c’est l'approche traditionnelle d'assistance qui domine plutôt que la perspective des droits civils. Plusieurs textes législatifs fournissent un cadre pour la législation et la politique dans le domaine de l’éducation, de la réadaptation, de l'emploi et de l'aide sociale aux personnes handicapées. Néanmoins, l’insuffisance de solutions, les barrières matérielles et immatérielles et le manque de ressources ne permettent pas aux personnes avec des handicaps sévères de mener une vie indépendante. De plus, elles sont souvent traitées comme des enfants, ce qui est particulièrement discriminatoire. En raison de cela, non seulement elles ne peuvent pas mener une vie indépendante mais elles ne peuvent même pas atteindre la maturité adulte. La vision paternaliste des personnes avec des handicaps sévères comme personnes exigeant surtout d’être protégées en est souvent la cause.

2. Introduction

National Approaches to identify the group of people with complex needs

In Poland there is no official definition of people with complex needs. There is, however, a legal definition of disability and different assessment procedures. The Charter of Rights for Persons with Disabilities (1997) defines people with disabilities as persons whose physical or mental state constantly or temporary impedes, restricts or prevents them from leading everyday life, taking advantage of education, work and taking up social roles according to the legal and common norms. The Act on vocational and social rehabilitation and employment of disabled persons (hereafter, Act on Rehabilitation) defines disability as temporary or permanent inability to perform social roles, caused by a permanent or long-standing impairment of body functions. Such a state in particular makes the person incapable to work.

In the disability assessment, two main criteria are taken into account: the extent to which disability affects a persons' ability to lead an independent life and to take up employment. There are two main systems for the assessment of disability: assessment for benefit purposes and for non-benefit purposes. Assessment for non-benefit purposes is made by Disability Assessment Boards (this system is regulated by the Act on Rehabilitation). For people under the age of 16, the boards issue a legal disability status, and for people aged over 16, the boards issue a legal disability status with one of three degrees: low, moderate, significant. Assessment for benefit purposes for adults is carried out by the Social Insurance Institution (ZUS). This assessment system is regulated by the Act on Old Age Pensions and Other Benefits from the Social Insurance Fund (hereafter, Pensions Act). There is also an assessment procedure for educational purposes carried out by psychological-educational counselling centres regulated by the Act on Education System. It has to be underlined that within the educational system, children are counted as having disabilities on the basis of their special educational needs evaluation. However, these evaluations can also be made for pupils with milder forms of disabilities who in adult life can be assessed as not having a legal disability status, and who often do not consider themselves disabled.

Available data on people with complex needs

According to the data from the 2002 census, there were 4.5 million of people with disabilities with a legal disability status in Poland (12% of general population). This figure is even higher if people without a legal disability status, but considering themselves disabled, are also included (in this case it is 5.5 million, 14% of the general population). Among them were approximately 24% with a legal disability status of a significant degree.

The most important statistics on people with disabilities and their situation are published by the Central Statistical Office (CSO). There is, however, a need for more consistent, complete and continuous statistics on the situation of people with severe disabilities. It is especially difficult to give consistent information on children with disabilities. The data collected by CSO concerns either young people who have a legal disability status issued by the Disability Assessment Boards, or pupils who have been evaluated as needing special education by psychological-educational counselling centres. However, the second evaluation is issued much more frequently. Data on the situation of the group of people with specific disabilities is very limited and insufficiently disaggregated.

In 2004, the CSO conducted a representative research on the health of the population in Poland, where, among other things, information on the number of people with a legal disability status of significant degree (according to their gender, age, level of education, marital status, economical activity) is provided. There is also some information on the number of people with different kinds of disabilities. The CSO published also annually the series “Statistical Information and Papers” which contains some information on situation of people with disabilities. For instance, information about residential facilities for people with disabilities can be found in “Basic data on health services” and about education in “Education in the school year …”.

Information about the situation of people with disabilities on the labour market can be found in the quarterly survey of economic activity of the Polish population (BAEL), as well as from the data on unemployed persons with disabilities and those seeking a job and currently not employed, contained in the statistical reports of the labour offices (MPiPS-07 report). Some information about the employment of people with disabilities is published also by the State Fund for Rehabilitation of Disabled Persons.

Classification systems, procedures and identification-practises

As mentioned above, there are two main systems for the assessment of disability. The Disability Assessment Boards at the county level are responsible for examining the legal disability status and rights other than rights to social insurance benefits. These boards are responsible for issuing the legal disability status for children up to the age of 16, and the legal disability status in three disability degrees (law, moderate, significant) for people aged over 16 years. A detailed catalogue specifies the extent of conditions and disorders which are taken into account when granting the disability status. Children receive a disability assessment if their “mental or physical efficiency has been impaired” and its duration exceeds twelve months. Additionally, a child’s condition must require complete care, or assistance in meeting the child’s needs must be high in comparison with the level of support required for a non-disabled child of the same age.

In the disability assessment of adults, the Disability Assessment Boards take into account two main criteria: the extent to which disability affects a persons’ ability to take up employment and to perform social roles and lead an independent life. An inability to lead an independent life means an impairment to a degree that prevents the person from satisfying - without the assistance of others - their basic life needs, which include self-service, mobility and communication.

Adults receive a disability assessment in one of three disability degrees:

1. The low degree applies to people with an impairment of body functions, which significantly decreases their ability to work, in comparison with a non-disabled person with similar vocational qualifications, or whose ability to perform social roles is limited, but can be compensated by orthopaedic or technical equipment.
2. The moderate degree applies to people with an impairment of body functions who are unable to work or are able to take up employment only in sheltered workplace conditions, or require partial or periodical assistance of third persons in order to performs social roles.
3. The significant degree of disability applies to people with an impairment of body functions who are unable to work or are able to take up employment only in sheltered

workplace conditions and, due to their inability to lead an independent life, require permanent or long-term care and assistance in order to perform social roles.

People with severe and moderate degrees of disability can also be employed on the open labour market in non-sheltered workplace conditions but the employer has to receive a positive opinion from the State Labour Inspectorate concerning the suitability of the workplace for the person with disabilities.

The disability certificates issued by the Disability Assessment Boards should include also recommendations as to: suitable employment or training; employment in occupational activity centres; participation in occupational therapy workshops; orthopaedic appliances and supplementary aids, if necessary; access to locally available social services and social assistance entitlements (such as social care, rehabilitation and therapy services provided by social welfare units or NGOs); the need for permanent or long-term care or help from another person, in connection with a severely limited ability to lead an independent life.

In determining eligibility for social insurance benefits, the legal confirmation of an inability to work is provided by a certificate issued by the practitioners of the Social Insurance Institution (ZUS). A person identified as being unable to work does not automatically qualify for a pension. The practitioner’s certification of an inability to work includes an evaluation of the degree and duration of inability to work and a prognosis concerning re-establishing the capacity for work. The certificate can stipulate total inability to lead an independent life, or total inability to work, or partial inability to work. People assessed as being totally unable to work may, however, still be considered able to work under conditions specified in the Act on Rehabilitation. Certificates issued by the ZUS practitioner do not include recommendations for any specific type of support, therefore a person with a certificate issued by ZUS practitioners has to apply to the Disability Assessment Boards to specify recommendations for the forms of support that he or she requires. In such cases, the degree of disability is specified in compliance with regulations relating to equivalence certificates: certificate of total inability to lead an independent life issued by the ZUS practitioner is treated on a par with a Disability Assessment Board's certificate of a significant degree of disability; total inability to work is treated on a par with a certificate of moderate degree of disability; partial inability to work and recommended retraining in new skills is treated on a par with a certificate of low degree of disability. However, certificates issued by the Disability Assessment Boards are not considered to be a basis for the payment of pensions as certificates issued by ZUS practitioners are. A person who wants to receive an inability to work pension or social pension must have a certificate issued by a ZUS practitioner.

The disability assessment system in Poland is very often criticised as there are no clear rules, certificates do not specify the kind and degree of support that is essential, there are sometimes issued by specialists with little knowledge and only on the basis of medical specifications without an examination. A person in one system can receive totally different certificates than those in another system, despite the fact that they are theoretically equal. Even a person being in a similar condition but from different regions of Poland can receive different assessment in the same system.

3. Pre-Natal Diagnosis and Counselling

Through the extended possibilities for family planning, parenthood in modern societies has increasingly become a question of individual decision-making. Prenatal diagnostics and reproduction technologies permit the inclusion of characteristics of the fetus in this decision. This extended knowledge brings individuals into difficult situations when they have to make decisions regarding children. These individual decisions are affected by social values, attitudes, anxieties and knowledge of disabilities. They are also influenced by the quality of the counseling process if professional support is available and used. It is important that individual decisions are accepted by the social environment of people concerned. How is this achieved?

3.1. Description of the National Situation

The medical care service for pregnant women is provided by gynaecologists, family doctors and midwives and in case of a high-risk pregnancy in specialised centres and hospitals. The usage of this service is voluntarily and free of charge. However, with the difficult situation in the Polish health care system, many women choose paid private services. According to the annual report of the Council of Ministers on the execution of the Act of Family-Planning there is a need for better early medical care for pregnant women especially in rural areas. Health care services include, among other things, preventive examinations of pregnant women and in that prenatal diagnosis of pregnant women in the risk' groups and above the age of 40. In 2006 the Ministry of Health financed a “Program of complex diagnosis and therapy in prophylaxis of consequences and complications of foetus’ developmental defects and illnesses” aimed at developing an uniform and optimal system of diagnosis for the detection of developmental defects and the implementation of standards in foetus’ therapy. Non-invasive prenatal examinations (ex ultrasonography) are currently part of the standard in the medical care for pregnant women. Invasive prenatal examinations are performed in case of suspicion of genetic or developmental defects of the foetus or of an incurable illness endangering the foetus life. In case of diagnosis of an incurable defect or illness, parents have the right to decide about a termination of pregnancy.

The current legislation allows for abortion in cases in which the mother's life is in danger, or when prenatal examinations or other medical conditions indicate that there is a high likelihood of a severe and irreparable impairment of the foetus or an incurable illness threatening its life, or when pregnancy is a result of an unlawful act (ex from rape). It happens, however, that women, who are entitled to have a legal abortion, according to conditions set up by the law, are sometimes denied the procedure. Illegal abortions are still common, however, it is very problematic to give even an estimated number of them.

Since 1993, when significant changes in this field were introduced, abortions on social grounds are abolished. Pregnancy terminations performed in violation of the law are punishable (the punishment is imposed on the person who terminates the pregnancy and the person who renders assistance to a pregnant women in terminating her pregnancy or persuades her to do so). According to official statistics the number of legal abortions in 2006 was 340. Among these were 246 cases of legal abortions because of an impairment of the foetus. Since 2002 the statistics show that the number of abortions in case of an impairment of the foetus is increasing. Probably, this is due the increasing number of prenatal examinations. In 2006, there were 7739 invasive prenatal examinations (3705 more than in 2005) as a result of which a pathology was diagnosed in 707 unborn children (226 more than in 2005).

In case of impairments of the foetus, an abortion is permissible until the foetus becomes capable of living by itself outside the organism of the pregnant women. Pregnancy termination, in this case, can be performed only by a doctor in a hospital, and a doctor, other than the one who terminates the pregnancy, has to ascertain that the circumstances have really occurred. A written consent of a woman is needed for pregnancy termination.

Abortion is a very controversial political issue in Poland and from time to time is raised by politicians seeking to strengthen anti-abortion legislation. However, there is no special discussion about pregnancy termination in case of an impairment of the foetus.

3.2. Specific Risks of Discrimination

While the number of prenatal examinations is increasing, sometimes there are problems with the accessibility of prenatal diagnosis. It happens that doctors deny access to prenatal diagnosis to avoid the abortion if the examination reveals an impairment of the foetus. On the one hand in case of diagnosis of an incurable impairment or illness, parents have the right to decide about the termination of pregnancy, on the other hand and early diagnosis of a curable illness or impairment allows medical treatment in the prenatal phase as well as early intervention after birth.

Very important issues in the case of an impairment of the foetus are also the way the doctors are informing the parents and the support the family gets. This has not only an impact on the decision about the potential abortion but also on the parental attitudes towards the future child and in general, on how the family will be prepared to welcome the future child as its member.

4. Early Childhood

For most families, having a baby creates a situation of uncertainty and a need for direction and guidance. Living with a baby or a young child with a severe disability or with severe developmental problems brings parents into a situation with specific and difficult challenges and dependencies. Psychological stress in their daily lives often makes it difficult to cope with their parental responsibilities. When dealing with educational tasks or when specific therapeutical or medical treatment is necessary, parents cannot refer to their own educational experiences, but are dependent on professional support of various kinds. Having access to good medical care, self-help groups and early intervention services from a very early age of the child are decisive factors both for the personal development of the child and for the successful adjustment and coping process of the parents. How is this achieved?

4.1. Description of the National Situation

While some services in Poland have solutions available, there is no comprehensive system of early intervention and support. This is, among other things, due to the strong divisions of competencies between the resorts responsible for health care services, social policy and education and the lack of specialists.

There is no special financial support for early intervention. The family can apply for financial assistance according to the general regulations of social welfare and the family benefits system. For some benefits, the child has to obtain a legal disability status issued by Disability Assessment Boards existing in every county (see more under: Childhood and Youth: Housing/Network, Family Support Services).

Health care services financed from public means in the field of early diagnosis and prevention include, among other things, early, multi-specialist and complex care for a child who is susceptible of disability or a child with disabilities. However, because of general funding problems in medical services provided by public health insurance, access to such services in reality is limited and many families choose to pay for private services. In case of some particular disabilities, for example autism, there are even long waiting lists. Access to medical care is also not consistent throughout Poland, as medical and other specialists in the area of early intervention tend to be grouped in large urban centres and clinics and the number of specialists is far from satisfactory. In 2004, the estimated number of centres providing early intervention was no more than 120. These comprised above all medical centres and non-governmental early intervention centres. To use these services, a child has to have a referral from a so called ‘first contact’ doctor. There is no data on the number of children with severe disabilities receiving support.

Within the educational system there are nearly 600 psychological-educational counselling centres (PECC) which provide free of charge and voluntary psychological-educational counselling. According to the law, this service shall be provided for children from birth and for parents to support them with the upbringing and education of their children. However, its importance in early childhood is very limited, because of a lack of specialists and equipment for therapy and diagnosis of young children in most of PECC.

Since 2005 there is also service called 'early development support' which should be available from the moment a disability is detected until the child begins school. To use this service, the child has to obtain an opinion on the need for early development support issued by the PECC. This service can be organised in the PECC as well as in kindergartens, schools and rehabilitation education centres. According to the Methodological Centre for Psychological-Educational Support (MCPES) there are now approximately 70 places in Poland providing this kind of service. Its importance for children with severe disabilities may however be limited as the service is oriented more towards education aiming at the psychophysical and social development of the child and is carried out above all by special teachers and psychologists, and therefore is not comprehensive.

To improve the situation, at the suggestion of NGOs a pilot Government programme has been in progress since 2005 and continues until the end of 2007. This programme, called “Early, multi-specialist, coordinated and permanent help for children who are susceptible of disability or children with disabilities and their families”, is intended to lead to the development of a national programme for early intervention for children with developmental disabilities.

4.2. Specific Risks of Discrimination

Information for families about the available services and support for families is insufficient. Access to psychological counselling for parents is limited. Knowledge about some kinds of disabilities and available support among paediatricians and some other specialists is inadequate. Parents of children with developmental disabilities very often complain that diagnosis of their child is made too late, sometimes when the child is between two and five years old, although signs of problems were identified by parents much earlier. Local paediatricians often do not react appropriately to parents' concerns and do not send the child to a specialist. Parents criticise also the way doctors are informing them about the diagnosis. Due to a lack of specialists, many parents have to use paid private services, although they have the right to free health care. There might even be waiting lists. Families living far away from centres providing early intervention services have additional commuting expenses. Seeking support, parents have to apply to different services and to cope with bureaucratic barriers. The more the disability is rare and complicated, the more the access to specialists is difficult. The lower the resources of the family are, the more difficult the situation of the child is. All this makes seeking support a challenge and parents have to put a lot of effort and expenses into it.

5. Childhood: Education and Care

Preschool institutions like inclusive or special kindergartens offer care and education for younger children. They prepare children for school and give them the opportunity to interact with peers. Young girls and boys can broaden their experiences in life and enhance their social skills.

Children with severe disabilities have the same need to interact with peers, to make friends outside the family and to view themselves as a part of a social group. But young children with complex needs are dependent on additional support to participate in preschool education, such as barrier-free access or well-trained educators with specific skills and the intention to cooperate with other professionals. How is this achieved?

5.1. Description of the National Situation

Younger children until the age of three can attend nurseries which are health care units. In theory, nurseries in Poland have a mainstream nature, however their number is far from satisfactory: they exist only in urban areas and there are waiting lists even for non-disabled children. According to official statistics of the CSO, only 2% of children aged 0-2 used this kind of service in 2005.

Children aged three to six can participate in pre-school classes (in some cases the child can be 2,5 years old). Attendance to public kindergartens is free of charge, but only in the scope of programme principles of pre-school education (at least 5 hours per day). In practice, parents who want they children to attend a kindergarten longer than 5 hours per day have to pay additionally a charge accordingly to rates set by local authorities. There are also charges for additional classes and meals.

Pre-school education for children aged three to five is voluntary. Since September 2004, all children in Poland have to attend the so called 'zero classes'. This compulsory year of pre-school education starts in the calendar year in which the child turns six and can be organised in kindergartens or in pre-school sections of primary schools.

According to official statistics of CSO, in the school year 2006-2007, 55,6% of children aged 3-6 participated in pre-school classes (in towns: 70,4%, in rural areas: 37,2%), but only 41% of children aged 3-5, and nearly 98% of children aged six. Among pre-school pupils there was only 1,3% of children with disabilities (approximately 10.000; most of them in urban areas: 87 %).

Children in Poland can participate in pre-school classes in mainstream, integrated or special kindergartens as well as in pre-school sections within primary school (mostly ‘zero classes’). Since 1989, when the first integrated kindergarten was created, the number of integrated kindergartens and integrated sections within mainstream kindergartens has been increasing rapidly (mostly due to parents’ initiatives). According to statistics of the CSO and the MCPES, there were 9518 pre-school sections within primary schools and 7811 kindergartens in the school year 2006-2007, including 77 special kindergartens and 362 integrated kindergartens and mainstream kindergartens with integrated sections. Integrated kindergartens or kindergartens with integrated sections made up approximately 4,5% of all kindergartens. Approximately one-third of all children with disabilities attending pre-school education were enrolled in pre-school classes in the integrated system and one-fourth in special kindergartens.

Children with disabilities who have been evaluated as needing special education can attend pre-school beyond the age of six, but not longer than until the school year when they reach the age of ten. In this case, children are obliged to attend one year of pre-school before they start compulsory education, i.e. no later than at the age of nine.

There are also special solutions for intellectually disabled children with multiple disabilities and for children with profound intellectual disabilities. Intellectually disabled children with multiple disabilities can attend so called rehabilitation education centres (operated mainly by NGOs) and fulfil there their compulsory pre-school education. These centres combine education with rehabilitation and therapy. As for children with profound intellectual disabilities, there is a special form of education, so called rehabilitation-educational classes. These children have the right to attend such classes from the age of three (see more under: Childhood and youth: School).

Local authorities are obliged to provide free transport to the nearest kindergarten, pre-school section within primary school or rehabilitation education centre for children with disabilities during their compulsory pre-school education (or to reimburse the cost of the child’s and his parent’s travel to school by public transport).

5.2. Specific Risks of Discrimination

Due to lack of data it is difficult to estimate the percentage of children with severe disabilities attending pre-school education. However, the conclusion can be drawn that children with disabilities are included in voluntary pre-school education in very small numbers. Access to voluntary pre-school education for children with severe disabilities is extremely limited in rural areas. It is also impossible to give the number of children with disabilities for whom compulsory education is postponed and how many of them actually attend to pre-school classes or just remain at home until the age of 9. The situation, when a child aged 9 is placed in a group of children aged six is also questionable. There is also a problem with the availability of information. For instance, sometimes parents are unaware that their child has the right to participate in rehabilitation-education classes from the age of three, when the child is not yet in compulsory school.

6. Childhood and Youth: School

Schools are responsible for a child's education and the teaching of knowledge of varying subjects. Furthermore, school proves to be an important part of young peoples' socialization process by offering the chance to enhance social skills and deepen social contacts with peers.
Children with severe disabilities also need high quality education and access to public schools. Pupils with complex needs are dependent on additional support in order to participate in school education, such as barrier-free access or well-trained teachers with the intention of cooperating with other professionals.
But especially pertaining to them, schools often exercise a kind of segregation. How do children with complex needs find their place in the school system, in which way are their special needs considered and how do professionals cooperate together?

6.1. Description of the National Situation

In Poland, education is compulsory for every child from the age of 7 to the age of 18, regardless of whether or not he or she has a disability. Compulsory education begins with primary school (6 years) and lower secondary school (3 years) and lasts until completion of lower secondary school, but not beyond the age of 18. Students with disabilities have the right to attend each stage of education for a longer period than pupils without disabilities: primary school until the age of 18, lower secondary school until the age of 21 and secondary school until the age of 24. Schools are under the responsibility of local authorities. The communities are obliged to provide free transportation to schools for children with disabilities during their compulsory education

Various school options, also non-public, are available for pupils with severe disabilities. These include mainstream, integrated and special schools as well as individual teaching at home. According to law, children with severe disabilities have the right to attend every type of school, as well as the right to individual teaching, curricula and classes, and appropriate adjustments to the content of the curricula in order to correspond to individual abilities. Integrated education refers to teaching a few (3-5) students with disabilities together with non-disabled peers in classes of 15 to 20 children where additional educators provide support to the children with disabilities. In the school year 2006-2007, approximately 19% of children with special needs attended integrated classes at primary level and 10% at lower secondary level. There are also several different types of special segregated schools for pupils with different kinds of disabilities: for pupils with mild intellectual disability, with moderate and severe intellectual disability, with physical disabilities, for the hearing-impaired and hard of hearing, etc. Special schools have to follow the same programme principles of general education as mainstream or integrated schools, but the curriculum has to be adapted to the students' abilities. Children with disabilities (over three years old) can attend also special education care centres (boarding schools) if they cannot attend school in their local area because of their disabilities. Intellectually disabled pupils with multiple disabilities can fulfil their compulsory education in so called rehabilitation education centres (operated mainly by NGOs), which combine education with rehabilitation and therapy. As for pupils with profound intellectual disabilities there is a special form of education, so called rehabilitation-educational classes. These can be organised in schools and some other centres or at the child's family home. The teaching time is four hours per day for teamwork (group of 2-4 children) and two hours per day for individual work.

Although children with severe disabilities have the right to attend mainstream or integrated schools, in practice most children with severe disabilities receive education in a segregated environment. Admittedly, approximately 58% of pupils with disabilities in the school year 2006-2007 attended mainstream or integrated schools at the primary level and 44% at the lower secondary level, but these statistics overestimate the number of pupils with disabilities enrolled in mainstream education as these include also children who were officially registered at a mainstream school, but fulfilled their educational obligation either in special classes existing within the school or outside the school in the form of individual teaching at home, rehabilitation-educational classes etc. In generally, the more severe the disability is, the more likely the child is enrolled in a segregated environment.

6.2. Specific Risks of Discrimination

Mainstream schools are usually not adequately prepared for the education of pupils with severe disabilities (architectural barriers, teacher qualifications, lack of specialists, poor cooperation between mainstream and special schools) and in practice parents are often pressured into agreeing to the education of their children in special schools or through individual teaching. Negative attitudes towards pupils with severe disabilities are still present among both students and teachers. Problems arise also when children with severe disabilities are placed in mainstream schools without adequate support. Legislation quite precisely determined the scope of support for pupils with disabilities in special and integrated schools, but not in mainstream schools. In practice the quality of education of children with severe disabilities in mainstream school varies and these children may not receive appropriate support. Integrated schools which can serve as a successful example in the organisation of teaching pupils with disabilities together with non-disabled peers often have problems in dealing with the education of children with more severe disabilities. In case of pupils with severe disabilities, individual teaching at home is frequently overused. Although this form of education should be recommended only when the child’s health makes school attendance impossible or difficult, in practice it is also recommended because the child is not independent enough, because there are problems with transporting the child to school, or because the nearest school is not barrier-free. Those children are often home schooled for most of their school education. This applies particularly to children living in rural areas. A large number of children with severe disabilities also attend special education care centres (boarding schools). This can cause a breakdown of the bonds between children and their families and adversely affects their development.

7. Childhood and Youth: Housing and Family Support Services

Due to the variety of modern family life, all children grow up in different environments. These environments can be understood as a social network including all sorts of relationships to individuals or institutions. The family’s living conditions during childhood are very important for social inclusion of the young person in society. The family has a strong impact on his/her primary socialization and influences the access to certain social institutions.

Family support services offer community-based professional support and services for families. Some children and young people live in a foster family, others in foster homes. Are such support systems available? In which way are children with severe disabilities or complex needs and their families involved in these support systems?

7.1. Description of the National Situation

Most children with disabilities in Poland grow up with their families. If a family cannot look for a child because of his or her disability, there is a possibility to place the child in one of the social welfare homes. According to statistics of the CSO, in 2005 there were approximately 2000 persons with disabilities under the age of 18 in social welfare homes, most of them in homes for children and young people with intellectual disabilities. Children with disabilities can be placed also in so called round-the-clock care and educational centres for children and young people (some of them are just traditional orphanages) or in foster families, usually on the basis of a court decision. These forms of care are for children who are partially or totally deprived of parental care. A child with disabilities can be placed in such a centre if there are no contra-indications. In 2005, there were approximately 1750 children with disabilities in round-the-clock care and educational centres and 4500 in foster families, most of them in foster families of their own relatives. The number of specialised foster families which can take care of a child with severe disabilities is small. In 2005, there were only 29 such families.

Families in Poland can take advantage of the family benefit system or social welfare system. However, both of these systems are based on the idea of subsidiarity. Parents are in the first instance responsible for their children, and support from family benefits or social welfare systems is available only in situations when the resources of families are inadequate (with some exceptions). Family benefits in Poland are funded by the State budget and the eligibility depends on the concerned family’s actual living and financial situation. The income criteria for a family with a child with a legal disability status are higher than in the case of other families. Maximum net household income per person that provides entitlement to family benefit cannot exceed PLN 504, and for a family with a disabled child PLN 583 (for comparison: the average monthly gross remuneration is approximately PLN 2900). The monthly amount of the family benefit depends on the child’s age and fluctuates between PLN 48 and PLN 68. A family with a disabled child can additionally apply for a supplement to the family benefit (net PLN 60-80) and for nursing services (in case one of the parents resigns from work in order to take care of the disabled child: net PLN 420). There is also a nursing allowance, which is granted to all children with a disability status regardless of the income of the family (net PLN 153). There are also some benefits and services available in the social welfare system, however, there the income criteria are even lower – for a family, the net income per person cannot exceed PLN 351. According to the social welfare regulations, families can also benefit from care services or specialist care services, as well as from counselling and social work. Counselling for parents (to support them in the upbringing and education of their children) should also be provided by psychological-educational counselling centres. However, accessibility of care services, specialist care services and counselling is far from satisfactory. There are no family respite care services. Even though NGOs try to fill the gap, the support for families with severely disabled children in Poland is insufficient

7.2. Specific Risks of Discrimination

A limited access to support services can result in a situation where families with children with severe disabilities and/or complex need are pushed aside to the margin of social life. In many cases, to provide 24-hour-care for the child, one member of the family (usually the mother) must give up their job. Some support services are granted on the grounds of a separate administrative decision and as such may not be granted. The more the child is disabled, the more the support system is insufficient. Financial support for families does not allow for the higher costs associated with a disability. The income criteria as well as the amount of various benefits are too low. In a particularly difficult situation are families with a child who needs expensive rehabilitation, treatment or medicines. Those families are at very high risk of poverty even if at the beginning they are in a good financial condition.

8. Childhood and Youth: Leisure Time

Young people use their leisure time to do enjoyable and amusing activities and to get free from daily routines. Often free time activities are organized in clubs or in various forms of sportive or cultural associations. But youngsters also spend their free time with peers without adults. Many experiences among young people of the same age are made spending leisure time together, e.g. discovering new social roles, social spaces, friendship or falling in love. Youngsters with severe disabilities or complex needs have the same leisure time needs as their non-disabled peers, but are dependent on additional support to participate in mainstream leisure time activities. How is this achieved?

8.1. Description of the National Situation

The Charter of Rights of Persons with Disabilities (1997) acknowledges the right of people with disabilities to full participation in cultural life as well as in sport and recreation as form of participation in civil society life. According to the Act on the Education System, the Polish educational system ensures the right of pupils to develop their interests and talents through participation in outside school activities as well as through developing their social activity and increasing their leisure-time competencies. There are plenty of different outside school establishments in the framework of the educational system which offer various forms of leisure time activities with quite a large number of participating children. The percentage of children with severe disabilities and complex needs who participate in such activities is, however, unknown. It can be only presumed that these are mostly segregated activities as well as organizers of such activities are not favourably disposed towards participation of children with challenging behaviour.

Students enrolled in individual teaching are particularly disadvantaged. While it is the obligation of the school to ensure that children receiving individual teaching participate in school life and that they have a cohesive personal development and integration with their peers, this has to take into consideration the child’s health and be “within reasonable limits”. This can curtail participation in such activities of children who are not welcomed at school because of specific difficulties. Moreover, issues concerning the transportation of children to non-compulsory school activities can make children’s participation difficult or impossible.

There are also other facilities which offer leisure time activities run by local communities and non-governmental organisations. As for children with severe disabilities, besides activities offered by their schools, the most important are leisure time programmes which are organised by different NGOs and often partly funded by using public funds. On the one hand, these activities are usually well adapted to the needs of children with specific disabilities, but on the other hand, these leisure time activities do not always follow an integrated approach.

8.2. Specific Risks of Discrimination

The access to mainstream leisure time activities for children and young people with severe disabilities is limited because of an insufficient number of barrier-free facilities. In a particular situation are youths with certain disabilities, for instance with challenging behavior, as they are not welcomed at many places. Children and young people with severe disabilities in rural areas are also disadvantaged, as the access to leisure time services is more limited than in towns and cities. Serious difficulties in integration with peers face also pupils enrolled in individual teaching.

9. Youth and Young Adults: Vocational Training

A successful transition from school to the employment system is usually related to vocational training. After finishing school young people need to find a job according to their interests and abilities with which they can earn a living. Vocational training prepares for the access to the employment system and is an important step into adult life. Youngsters and young adults with severe disabilities are dependent on adapted training courses, assisting technologies, other individual support and barrier free infrastructure to enable their access. How is this achieved?

9.1. Description of the National Situation

After completing lower secondary school, students with severe disabilities can continue their education in various kinds of mainstream (or integrated) and special schools at secondary level: general secondary schools, vocational basic schools and specialized secondary schools, and later on at post-secondary level. In theory, young people with severe disabilities can attend any school at secondary level, but in practice access to some secondary schools for people with particular disabilities is limited and they attend in the overwhelming majority only special schools or are enrolled in individual teaching at home. Most mainstream schools have architectural barriers making them inaccessible to people with physical disabilities and negative attitudes towards people with severe disabilities are still evident among both students and teachers. The concept of e-Learning is still new and in practice there are no possibilities for people with severe disabilities in the framework of e-Learning. A significant percentage of school-leavers with severe disabilities do not continue their education at secondary level after completing compulsory education. In the school year 2006-2007, most young people with disabilities at secondary level attended special schools, approximately 76%, while mainstream and integrated schools were attended only by 24% (and among these nearly 30% were enrolled in individual teaching). General secondary schools and specialized secondary schools are intended for students who are intellectually able to attend; therefore students with intellectual disabilities can attend only vocational basic schools. These schools are, however, sometimes criticised for outdated teaching aids and teaching skills that are no longer required or marketable. Young people with moderate and severe intellectual disabilities are usually enrolled in special job-training schools. These schools have been developed for a few years to enhance opportunities for education of this very group of people. Access to integrated schools at the secondary level is very limited and in 2006-2007 only 4% of students with disabilities were enrolled in integrated education. Integrated education at this level has much shorter history than at compulsory level, and its shape is still under discussion. In practice, in this form of education mostly students with milder disabilities are enrolled as integrated schools at secondary level have even bigger problems in dealing with the education of students with more severe disabilities and complex needs than those at compulsory levels. The number of students with disabilities at post-secondary level is unknown. However, in the school year 2006-2007 there were 19 special schools at this level with 566 students. Despite the fact, that the number of students with disabilities at universities is on the increase every year, the inclusion in higher education is still far from satisfactory. According to the CSO data, in 2006 the percentage of students with disabilities constituted 1% of all university students in Poland.

For vocational training and vocational rehabilitation, young people with severe disabilities can be referred to occupational therapy workshops. Occupational therapy workshops offer people with disabilities an opportunity to participate in social and vocational rehabilitation so as to gain, or regain, employability through occupational therapy. The creation and operation of occupational therapy workshops is financed above all by the State Fund for Rehabilitation of Disabled Persons. The majority of participants in these workshops are young people with a legal disability status in a moderate or significant degree, mostly with multiple disabilities and usually with intellectual disabilities. Apart from an indication of the degree of disability, to participate in such workshops a person must have a recommendation for participation in occupational therapy. Currently, there are more than 600 occupational therapy workshops in Poland with approximately 20.000 participants with disabilities. More than half of the existing workshops are operated by NGOs.

9.2. Specific Risks of Discrimination

The Polish Constitution provides that ‘everyone shall have the freedom to choose and to pursue his occupation’ (art. 65). The lack of accessible schools adapted to the needs and possibilities of people with severe disabilities as well as very limited personal assistance services not only deprive this very group of people of their right to choose freely their future occupation but in fact does not allow them to gain an occupation at all. In a particularly difficult situation are people with severe disabilities with seriously challenging behaviour as at this level of education a certain level of emotional and social development is required. Disrespectful treatment towards students with severe disabilities is still evident in the Polish schools.

10. Children and Adults: Social Security and Health Care

Modern societies are shaped by an enlargement of welfare systems and an increasing dependence on social security institutions. It is a challenge for all citizens to clarify their entitlements and to find access to services. The need for basic social security and to have access to health care services if necessary is important for all people.

In most cases having complex needs leads to an increase of dependence on social benefits and requires special support and services granted by welfare administration boards. Bureaucratic procedures of application approval create special risks of stigmatization. Allowances, benefits and services can improve the possibilities of individual participation, but can also initiate processes of social exclusion. How is this achieved?

10.1.Description of the National Situation

People with disabilities in Poland have a disproportionate risk of being poor. Amounts of the disability financial services in Poland are set at a very low level and various kinds of social benefits (old age pensions, inability to work pensions, social pensions and other social benefits) are the main sources of income for 84% of people with disabilities. The number of people receiving income from employment is only 8%. Currently, a person who is entitled to a social pension and to nursing allowance receives monthly approximately PLN 600 (net). Admittedly, this is above the minimum subsistence estimated by the Labour and Social Affairs (about PLN 370 for households with one person in 2006), and a little above the poverty line (PLN 477), but below the social minimum (about PLN 800). Moreover, the social pension has to be suspended if a person takes up employment and receives a monthly income that is higher than 30% of the average monthly wage (in case of an inability to work pension this is 130%). According to the CSO’ statistics, in 2005 14% of those families where at least one member was disabled lived below the level of minimum subsistence (and 20,5% below the poverty line), compared with 11,6% of families without disabled people (17,2% below the poverty line). In particular, families with disabled children are at risk of poverty. In 2005, 17,8% of families with at least one child with a legal disability status lived below the minimum subsistence and 35,6% below the poverty line. It has to be underlined, that these statistics may underestimate the true extent of poverty among people with disabilities because they do not take into account the additional costs that disabled people may incur because of their disabilities. On the other hand, there is an opinion that financial social assistance in Poland is too easily accessible and every year the number of pensioners is decreasing.

People with severe disabilities often have problems with access to health care services. According to the Polish Constitution everyone has the right to health protection. People with disabilities have also the right to medical rehabilitation. Health care services are free of charge if provided by the health care providers who concluded contract with the National Health Fund. However, because of serious financial and organisational problems in the health care system, even the common citizens face difficulties when accessing the medical services and waiting time for some services is inconceivably long. Problems with the accessibility of some free of charge services and low income constitute a barrier to paid private services. This means that in some situations people with severe disabilities give up some necessary treatment or rehabilitation. Access to some modern medical treatment and medicines could be particularly difficult especially in case of rare diseases. The Citizens' Rights Commissioner and NGOs working for the benefit of people with different types of disabilities point out every year serious problems with the accessibility and quality of health care services for people with disabilities, also for people who are residents of institutions. In case of people with profound intellectual disabilities, doctors demanded that staff from the institution is present during the stay of the residents in the hospital. Sometimes the help was limited to consultation, although the patient's condition was serious. The Ombudsman pointed out also some irregularities in using coercive measures in mental hospitals in Poland. Another problem is the stereotypical way of thinking about people with severe disabilities and lack of understanding of their actual needs, which can even pose threats to their life. Two cases of people with intellectual disabilities living in institutions were described where doctors confused the physical suffering with aggressive attacks, although the personnel of the institution suggested that the aggressive behaviour was just the way the persons tried to communicate their suffering. After several weeks of psychiatric treatment in the mental hospitals, both persons died and only the autopsy proved that these person were suffering because of a physical illness.

10.2. Specific Risks of Discrimination

On the one hand, people with severe disabilities are indeed at a particular risk of poverty. However, on the other hand, even people being well-off suffer from the stigma of being poor, helpless, dependent on social welfare and having plenty of privileges. Sometimes they even have to face suspicions that they try to wheedle something. Amounts of disability financial support do not take into account the cost of independent living, integrated in the society. The low amount of financial assistance and the lack of other assistance services (see also: Housing) does not allow a person with severe disabilities to become independent to the highest extent of his or her possibilities and thus contributes to his or her dependency situation. People with disabilities complain also about a lack of information and bureaucratic procedures.

Difficulties with accessibility and quality of health care services and a stereotypical way of thinking can pose threats to health and even life of persons with severe disabilities, and paternalistic, disrespectful treatment may violate their dignity.

11. Adults: Work and Employment

Having work or a day occupation is, for financial and other reasons, a very important indicator of social inclusion and quality of life. Going to work not only structures peoples' days and weeks, but also has an important impact on the development of a person's identity. It also provides access to the social security system and is an important basis for participation. For people with severe disabilities, transitional situations from school or vocational training into the employment system must often be systematically planned and organized, because they are dependent on adapted work places or assistive technologies and other individual support like a barrier-free infrastructure to enable their access. How is this achieved?

11.1. Description of the National Situation

Employment of people with disabilities is in Poland encouraged above all through the quota system and other legislative solutions, mostly incentive for employers. For instance, an employer employing persons with disabilities is entitled to a monthly subsidy from the State Fund for Rehabilitation of Disabled Persons to finance their salaries. The level of financing depends on the degree of disability and is more profitable for people with a legal disability status of a significant degree. However, the existing incentives have not been successful in increasing the number of people with severe disabilities who have entered the work force.

The end of the 1990's and the beginning of the current decade witnessed a rapid growth of unemployment in Poland. Although the trend turned positive and the unemployment rate among the general population has been systematically going down, the economic activity of people with disabilities is still decreasing. In general, people with disabilities in Poland have much lower rates of employment than people without disabilities. The labour force participation rate was approximately 18% in 2006 (compared with 60% of all employable persons; BAEL). The employment rate is particularly low among people with a disability status of a significant degree (7% in 2006). Although the unemployment rate among people with disabilities is not much higher than in the general population (17,5% compared to 14,9%), most people with disabilities are just economically passive and do no register in labour offices. Moreover, people who are entitled to pensions or benefits cannot register as unemployed. The regulation in accordance with the social pension has to be suspended when the pensioner receives a monthly income from employment that is higher than 30% of the average monthly wage (as compare to 130% in case of inability to work pension), provides an additional disincentive.

Very few people with severe disabilities are employed at all on the open market. There is no scheme for supported employment in Poland, however there are some regional initiatives undertaken by NGOs. The overwhelming majority of people with disabilities is employed in individual agriculture (40%) and on the sheltered labour market (40%). There are two forms of sheltered employment in Poland: sheltered enterprises and occupational activity enterprises. There are more than 2000 sheltered enterprises, however most employees there have a legal disability status in the low or moderate degree of disability. On the other hand, the number of occupational activity enterprises, which offer employment to people with severe disabilities, is insufficient.

Like other Polish citizens, people with severe disabilities have the right to use the labour market services. However, the offer for people with severe disabilities is very limited. NGOs try to fill the gap by providing labour market services in non-public training institutions and employment agencies.

For people with severe disabilities who cannot take up employment, participation in meaningful day activities is crucial. Occupational therapy workshops and community self-help homes play a very important role in this sphere. However, the second are centres of day support in the system of social welfare only for persons with mental disorders (including persons with intellectual disabilities). There are some other forms of day centres, operated mainly by NGOs (mostly using public funds), but in general there are not enough to meet the demand and there is an important problem with the existing gap between schools and follow-up services. Very often, as people with severe disabilities leave school, many services come to an end and students and their parents often do not know where to turn for assistance. Due to the lack of follow-up services, many people with severe disabilities often end up isolated at home, with no services. Additional problems creates the lack of flexibility of existing solutions. Once the participants of the occupational therapy workshop take up employment, they are no longer entitled to any activities offered by the workshops. Participants (and their parents) have a good reason to fear that, if they are not successful to maintain employment, there is no possibility to return to services offered by the workshop.

11.2. Specific Risks of Discrimination

People with disabilities are usually perceived as a homogeneous social group and not as individuals with a variety of different situations. The lack of solutions tailored to the needs of people with specific disabilities and negative attitudes of employers, co-workers, personnel in institutions constitute barriers to the access to employment. Low level of education of people with severe disabilities as well as over-protective parents or guardians and passivity of people with disabilities themselves and their fear of losing social benefits make this situation even worse. People with severe disabilities are often stereotyped as persons who cannot fulfil the role of employee and are above all considered as clients of social welfare system and objects of charity and not people with equal rights. The existing solutions not only do not provide for the majority of people with severe disabilities opportunities to gain a living by work freely chosen, but also for (an unknown) number of people do not provide meaningful day activities at all.

12. Adults: Housing

Becoming an adult also means making up your mind about how you would like to live: stay in the natural family for a while, live alone, with a partner or family, with a friend, etc. Having privacy, a place to go to, feeling safe and comfortable there, realizing one's own ideas on how to live, are all very important for people in our societies. For people with complex needs it is a big challenge to find their own way to living. They have restricted alternatives for housing because they need barrier-free environments and life-long support. People with severe disabilities do not only need good support services but also counseling to realise their ideas and style of private living. How is this achieved?

12.1. Description of the National Situation

There is no policy towards deinstitutionalisation in Poland. There are some community-based services in the system of social welfare but they are not sufficient to support independent living of people with severe disabilities and/or complex support needs. Personal assistance is still a new and developing concept. Although some NGOs and local authorities provide personal assistance services, access to them as well as the form of these services is very limited. Some services explicitly exclude persons with specific disabilities. There is no sheltered housing system in Poland, although there are some sheltered apartments. However, there are almost no opportunities for people with severe disabilities and/or complex support needs to find a place in sheltered housing. In practice, if a family cannot take care of a person with severe disabilities there is actually only one possibility – the social welfare home which provides 24 hours care. The right to be placed in a social welfare home has a person who needs 24 hours care because of age, illness or disability, who cannot lead an independent life, and for whom the necessary help in form of care services cannot be provided. The person is referred to the nearest home of a relevant type. A person who needs intensive medical care is directed to chronic medical care homes or to nursing care homes. According to law, if a person who absolutely needs help does not agree to be placed in a social welfare home, the welfare authorities are obliged to notify the relevant court or public prosecutor; then the decision is taken by family court.

There are six kinds of social welfare homes in Poland: for children and young persons with intellectual disabilities (up to 30 years old; however, in particular situations people can remain in the home after the age 30, for example if they have difficulty adapting to changes in the environment), for adults with intellectual disabilities, for old persons, for persons with chronic diseases, for persons with chronic mental illness, and for persons with physical disability. According to the CSO data, the total number or residents in residential facilities in 2005 in Poland was nearly 90.000. Although newly established homes cannot have more than 100 residents, this requirement does not apply to facilities established before the year 2000. Therefore there are still social welfare homes with several hundreds of residents and homes where more that four persons live in one room (four persons is the minimal standard). Every social welfare home in Poland must provide services according to standards which are set in the regulations on social welfare homes as well as develop individual plans to support the residents. There are also some regulations which allow residents of social welfare homes to return to the local community and start an independent life, but their importance for people with severe disabilities is very limited as these are rarely used and then mostly for people with less severe disabilities.

12.2. Specific Risks of Discrimination

First of all, it should be stressed that living in an institution - not freely chosen, but because of the absence of alternatives - curtails the civil rights of a person. Social welfare homes in Poland are fossilized structures that often do not care for developing the independence of residents because it just means additional problems at work. Some of the institutions are still of the old type: placed far from local communities, closed, overcrowded, where residents spend their time without meaningful activities, and were the human rights and dignity of residents can easily be violated. The Government has no information concerning abuses in social welfare homes. However, the Commissioner for Civil Rights' Protection every year points out problems of people with disabilities living in institutions. Reports prepared by non-governmental organisations revealed sometimes rather shocking details about some residents' lives and the enormous difference between the legal standards and the reality. There is nothing wrong with the fact that standards are set for the residential institutions in Poland. However, quite large public funds which are allocated to let the institutions reach the standards may be a disincentive towards a real deinstitutionalisation policy.

13. Adults: Education and Leisure Time

Leisure time comprises all the time out of work to either relax or find a balance in contrast to every-day-life. Activities can be done on one's own, organized in clubs or in various forms of cultural or other social facilities. In their leisure time, people in our societies are supposed to act with less formal restrictions and try to achieve a high degree of satisfaction and self-determination in their activities.

Adult education – taking the idea of life-long learning as postulate – can be seen as part of the individual's leisure time, sometimes connected to work or the expectation that a certain course promotes one's professional career. Sometimes people participate in adult education courses for the sake of their personal well-being, health or general personal development. For people with severe disabilities the participation in organized leisure time activities or adult education courses very often must be systematically planned and organized, because they are dependent on adapted courses, assistive technologies and other individual support, and barrier free infrastructure to enable their access. How is this achieved?

13.1. Description of the National Situation

People with severe disabilities and complex needs face barriers in all spheres of leisure time activities. This is due to the lack of accessibility, due to mobility problems and the financial situation as leisure time activities are usually connected with some expenses. The number of mainstream leisure activity centres adapted to the needs of people with disabilities is still far from satisfactory, even though the Construction Law provides that buildings shall be designed and constructed in a way to ensure necessary conditions to use public buildings by people with disabilities. According to the CSO statistics, the following facilities were adapted to the needs of wheelchair users in 2006: 56% of all cinemas, 24% of the museums, 36% of the art galleries, 15% of the public libraries and 21% of all community centres. In many cases, transportation and the lack of personal assistance services constitute the barriers. Leisure time activities are mainly organised privately, although adults with severe disabilities can also participate in leisure time events financed by public means and organised mainly by non-governmental organisations. An important role in financing recreation and sports activities for people with disabilities plays the Ministry of Sport and the State Fund for Rehabilitation of Disabled Persons. Day centres, occupational therapy workshops and sheltered enterprises also provide various forms of leisure activities for their participants and employees. People with severe disabilities can also participate in so called rehabilitation holidays that combine rehabilitation with leisure elements. Participation in rehabilitation holidays can be subsidized by the State Fund for the Rehabilitation of Disabled Persons.

The lack of accessibility means, however, that people with severe disabilities can not participate in their free time in continuing education programmes. Continuing education is an integral part of the Polish educational system. It is provided at all levels of general and vocational education, in schools as well as in the community. According to the Act on Education, continuing education takes place in schools for adults, in centres for practical training, in centres for continuing education and in other in-service training units (public and non-public). These can obtain accreditation from the school supervisor and as training units offer vocational courses for unemployed persons financed by public funds. Although the reform of the continuing education in Poland has been underway since the early 1990s, there still remains a lot to do. In 2003, the Ministry of Education drew up a new strategy for continuing education for the years 2003-2010. People with severe disabilities are usually not included in programmes offered by educational units provide life-long education (not by law, but in practice). A study prepared for the Ministry of Education showed that among persons enrolled in various kinds of continuing education, in 2005 there were only 0,9% of persons with special educational needs, among them mainly people at risk of social exclusion.

13.2. Specific Risks of Discrimination

People with severe disabilities in Poland are totally excluded from the mainstream system of continuing education. The lack of accessibility and the lack of financial resources mean also that many people with severe disabilities have to spend their time at home. The access to mainstream leisure time activities for people with severe disabilities is very limited. Although there are leisure time activities for people with disabilities, these are sometimes not suited to the needs and possibilities of persons with specific disabilities. Leisure time activities for people with severe disabilities are rather considered in the context of special events for this very group, than as freely chosen inclusive activities.

14. Adults: Partnerships and Parenting

According to social trends and changes, the decision of having one’s own family is not as easy as it used to be. More and more the decision to get married or to have children is a conscious one based on emotions, being aware of the changes that these decisions will mean.
Not too long ago the idea of people with (intellectual) disabilities getting married or having children was regarded as impossible. People with complex needs who wish to marry or have a child often have to face prejudices. After all, in their parenting they are dependent on special support. Professionals from different services and service sectors have to cooperate to prevent exclusion and discrimination. How is this achieved?

14.1.Description of the National Situation

According to the CSO statistics, figures on the marital status in 2004 indicate that the percentage of married people with a legal disability status is significant (aged 15 and more) and more or less the same as in the rest of population. People with disabilities are even less frequently single, but are much more frequently widowed, especially women (26% of women with a legal disability status of a significant degree are widowed compared to 6% in the non-disabled population). This reflects the structure of the population of people with disabilities in Poland, where more than 45% constitute people aged 60 and more. Looking at this figure, we have to remember that this includes only people living in households; those living in institutions are not included.

In general, every Polish citizen who is older than 18 can get married. A women under 18 years of age (but not younger than 16) can apply for a permission to the court. There are, however, some restrictions applying to people with mental health problems or intellectual disabilities. According to the Family and Guardianship Code, a person with “mental illness or mental deficiency” cannot get married and such a marriage can be dissolved. However, if the state of physical or mental health of such a person does not endanger the marriage or the health of a future child, the court can give the person permission for marriage. In a particular situation are also the people who are under guardianship. A person under ‘plenary guardianship’ in Poland cannot get married at all and a person under ‘partial’ guardianship has to ask the court for a permission to marry.

In the Polish law there are no regulations directly related to sterilisation and there is no sterilisation foreseen in the catalogue of contraceptive methods. Generally, sterilisation in Poland is illegal. There is also no legal possibility to force someone to use contraceptive methods (including in institutions).

Legislation in Poland does not mention anything about the right of people with severe disabilities to become parents; therefore they have to be treated in the same way as other citizens. In a particular situation are, however, people placed under guardianship. Legally incapacitated persons cannot have the legal parental authority over their children. In such a situation the court appoints a legal guardian for the children. If a single man placed under ‘plenary’ guardianship fathers a baby, neither he nor his guardian can acknowledge the child. A man under ‘partial guardianship needs to have the consent of his legal representative. If there is the need for a legal abortion in case of a woman placed under ‘plenary’ guardianship, a written consent of her legal representative is required as well as her own written consent, unless her mental state renders her incapable to consent.

14.2.Specific Risks of Discrimination

In theory, people with severe disabilities, with the exceptions specified by law, have the same right to partnership and to parenting as other citizens. In fact, however, there are no services supporting married couples with severe disabilities in their parenthood and they can count only on the support of their families and relatives. People with severe disabilities, especially people with intellectual disabilities are often treated as everlasting children, which is particularly discriminating. Due to this fact, they not only cannot realise their dreams about partnership or parenthood, but are also limited in their development as mature individuals.

Sexuality of people with severe disabilities is also a taboo; especially for people with intellectual disabilities, but it concerns people with physical disabilities as well. There are plenty of myths and prejudice towards this sphere of life of people with disabilities. Not long ago, one of the Polish courts tried to judge if a sexually abused intellectually disabled girl could feel pain. Education about this sphere of life is insufficient. Bearing in mind that people with severe disabilities are more endangered by sexual abuse, this is even more alarming.

15. Adults: Exercising Civil Rights

One developmental task of adulthood is to know and to exercise one's rights. This comprises the rights that a state confers to its people in order to secure protection and political participation, e.g. basic human rights and voting.

For people with severe (intellectual) disabilities, civil rights still cannot be exercised in every case. Additional support is needed to exercise democratic rights like voting. It is also a commonly held belief that people with severe disabilities or complex needs are in capable of serving in political positions. How can people with severe disabilities exercise their rights as citizens?

15.1. Description of the National Situation

The Polish Constitution contains a general prohibition of discrimination; however, article 32 does not specifically mention people with disabilities. The most comprehensive anti-discrimination legislation can be found in the labour law, as Poland had to fully transpose the EU Employment Directive. Discrimination on the grounds of disability is prohibited also in the Charter of Rights of Persons with Disabilities. The Charter was, however, approved in the form of a resolution. Therefore it is not legally biding, but rather represents the will of the Parliament. In fact, the traditional welfare approach dominates in the disability field in Poland. Currently, NGOs try to promote the civil rights perspective using the new UN-Convention on the Rights of Persons with Disabilities.

According to law, people with severe disabilities have the same rights as other Polish citizens. Severe disability in Poland is, however, often connected with strong restrictions in citizens' and basic human rights. Some people are even deprived of their civil rights in compliance with the law, because they are fully legally incapacitated. This applies to people with intellectual disabilities, with autism and mental illness. The legal incapacitation is a form of legal protection and should work for the benefit of the person placed under guardianship; however, it focuses entirely on prohibitions and restrictions. In Poland, persons can be placed under 'plenary' guardianship if they cannot "control their behaviour" because of mental health problems, intellectual disability or other "mental disorders", particularly alcoholism or drug addiction. If the circumstances do not warrant 'plenary' guardianship, but a person needs assistance to manage affairs, he or she can be placed under 'partial' guardianship. People under 'plenary' guardianship do not have the right to conclude any legal acts and any legal action they take is invalid. The legal capacity of a person under 'partial' guardianship is partially restricted. A person under 'partial' guardianship can carry out certain transactions relating to everyday life and administer his or her income without the agreement of the supervisor. In practice, 'plenary' or 'partially' incapacitated persons lose all or some of their civil rights. Such persons do not have the right to vote and cannot be members of associations. A person under 'plenary guardianship' cannot even sign an employment contract and therefore cannot take up employment, cannot get married, etc. Sometimes there are also grave breaches of the law that have serious consequences for the legally incapacitated person. In 2002, some research was conducted in collaboration with the Polish Association of Persons with Mental Handicap and the Clinic of Rights at Warsaw University which showed that guardianship in Poland was often overused and misused. In case of people with intellectual disabilities and autism, courts generally prefer ‘plenary’ guardianship although ‘partial’ guardianship is a milder form of legal interference in a person’s autonomy. Very often, decisions taken about people with intellectual disabilities or with autism are permanent and final, despite of the fact that there is a right to seek review. Measures have been taken to change this situation by the Commissioner for Civil Rights. In March 2007, the Constitutional Tribunal adjudicated that rules that do not allow a person under guardianship to repeal the judgment on the guardianship are inconsistent with the Polish Constitution. In the justification of the sentence, the Tribunal underlined the need to change the current legislation.

Another problem is an apparently neutral legislation which actually constitutes indirect discrimination due to a lack of accessibility and of a barrier-free environment. For instance, people with severe disabilities face particular difficulties to exercise their voting rights. Existing solutions created to support people with disabilities in voting are insufficient and a large number of polling station is not barrier free. People with severe disabilities who are not able to leave their home and appear in person at the polling station are in practice totally deprived of their right to vote because in Poland people have to personally participate in elections, and there are no other possibilities to vote. People with disabilities in many places have difficulties with access to public buildings and consequently to courts, offices, etc. Lack of alternatives and dependency also restrict civil rights. This applies for example to situations when a person has to live in an institution or has to do only one kind of work because no other alternatives exist.

15.2. Specific Risks of Discrimination

Apart from the situations describe above, it must be underlined that discrimination of people with severe disabilities is not only created by bad laws, problems with accessibility, lack of alternatives, etc, but also by attitudes of the society. In practice, parents, guardians, specialists, staffs in residential institutions, etc. often do not want grant some rights to the dependent person. Paternalistic views of people with severe disabilities as persons needing, above all, protection is often behind this. Still some people with severe disabilities (especially people wit intellectual disabilities) are regarded as everlasting children.

16. Adults: Ageing and End of Life

Ageing contains a lot of new challenges: Retiring, organizing one’s day in a new way, coping with the loss of abilities and coming to terms with it and with one’s life. Regularly, more support is needed in day-to-day life and thus social dependencies are increasing. Often this means that familiar life settings must be changed because care needs cannot be covered anymore by the given arrangement. Most people don’t want to leave their familiar setting even when their care needs are becoming extensive and complicated. They prefer arrangements which are based on home care services that are reliable and flexible. When people reflect upon the end of their life there is also a wish to die in dignity.
How is this achieved?

16.1.Description of the National Situation

Over the past several years, the number of elderly persons in Poland has been increasing, and simultaneously the number of people with complex needs and/or severe disabilities of advanced age. According to the CSO statistics, people aged 60 and above constitute a huge percentage of the population of people with disabilities in Poland (45%).

The accessibility of healthcare services and social welfare services is similar to the situation of younger people with disabilities. This is due to the fact that in social welfare regulations disability and age usually are quoted both as criteria for qualifying for services from the social welfare system. The income criteria and the satisfactory level apply also. There are, however, some forms of day activities addressed particularly to elderly people, like senior clubs or Third Age Universities.

According to the social welfare regulations, a single person (or a person whose family cannot provide help) who because of age illness or other reasons needs other people's help is entitled to care services or specialist care services. These services can be, however, insufficient in the situation of people with severe disabilities and/or complex needs and such a person has to seek a place in a social welfare home.

The quality of palliative care in the public health care services is often criticised and there is the opinion that in the hospitals people die sometimes in conditions which abuse their dignity. To increase the availability of and access to high quality palliative care for patients and their families, a network of high quality non-public hospices has been developing for several years in Poland. However, it is still inadequate to meet the demands.

Ageing of people with disabilities in Poland is rather considered in the context of general problems of the ageing society and the fact that the ageing of the society leads to increasing numbers of people with disabilities or complex needs is stressed above all. The particular situation of people with life-long disabilities of advanced age is rarely under consideration.

There are a few critical transition moments in the life of a person with severe disabilities connected with ageing. Firstly, when the parents of such a person have to take care also for their own parents. This poses an additional burden on these families. Secondly, when the parents themselves start to grow old and a moment comes when they are unable to provide support and care for their children. The parents' death may have also serious psychological consequences for the person with complex needs. And at last, the ageing of persons with severe disabilities does not only mean that their needs grow. To help people to prepare themselves to pass away is also an important issue.

16.2.Specific Risks of Discrimination

The Polish society still perceives elderly people as a whole in terms of a category of socially weak people requiring social assistance, and, thus placing a burden on the rest of society. Consequently, the situation of people with severe disabilities of advanced age might be regarded above all as a social problem. Bearing in mind all the problems with health care services and social welfare services as well as the situation of residential institutions there is a high risk that the situation of people with complex needs may get worse as they age. When a person with severe disabilities reaches the non-productive age, many services, especially day activity services, come to an end. From time to time media in Poland report about residential institutions abusing the dignity of elderly residents. There is no information if and to which extent the residential institutions provide psychological support for people with severe disabilities in connection with ageing and ultimate questions and how the last days of these people look like.

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Date: 19th September 2007

The interview was made personally during approximately one hour.

In your opinion: What are the main risks of discrimination against persons with severe disabilities in your country?

The main risk related to discrimination of persons with severe disabilities is most of all related to the sphere of everyday functioning in life. They are the persons who often necessitate considerable support. In Poland if a person in situation of major dependence with severe disabilities has no family, the only alternative that he or she faces is a residential institution. Such person has no other choice but to leave their home and their environment.

The second issue is the accessibility of education which despite one's disability should enable a person to develop skills, to feel useful and that relates to another sphere, i.e. employment. Needless to say in the long run the purpose of education is to prepare a person for taking up a job in future. If the access to good quality education is hindered and if the access to education on the levels higher than primary is hindered, we can conclude that generally we do have a problem with the access to education. If a child must go to a special school because ordinary schools are not adjusted to educate disabled children, then in future such a child is often doomed to welfare, to special institutions, to social exclusion. I think that it mostly concerns people with intellectual disabilities.

Another sphere is work. People with disabilities are presently doomed to work most of all in sheltered enterprises. Though it may sound improbable, but the employment level of people with disabilities in the 80's was the same as it is now. And after all since 90's we have had a new system, a new legislation, we have had the State Fund for Rehabilitation of Disabled People (later referred to as: PFRON); huge financial means have been allocated to employment and rehabilitation of people with disabilities. Despite all that in the 80's we had about 600 000 disabled persons on the labour market and at present we also have about 600 000.

Another sphere is access to civil rights. In a month an election is going to be held, however, not every person with severe disabilities will reach a ballot box. In Poland it is not possible to vote by mail or via the Internet which makes voting impossible to many people, e.g. lying persons. Adaptation of polling stations is still another problem. As far as my personal experience is concerned I usually arrive at a polling station and an electoral committee brings a ballot paper outside to me, although they have no right to do so, but I simply cannot get in a polling station. Thus it is often so that the persons with severe disabilities have problems with enforcing the rights they are guaranteed in the Constitution.

In your opinion: What are the perspectives of anti-discrimination policies for people with severe disabilities in your country and in the EU?
In my opinion Poland needs the Poles with Disabilities Act which would be similar to corresponding acts effective in the United Kingdom or the United States. As it is known by our experience in Poland the dispersion of regulations related to people with disabilities in various acts does not work. We do have regulations obliging the adaptation of newly-built and renovated public utility objects and so what? These regulations are often not observed. Presently in Warsaw one of its most presentable streets – Krakowskie Przedmiescie – is being renovated. Despite repairs numerous architectural barriers have not been eliminated, e.g. at the entrance to such institution as the Polish Academy of Sciences one step has been left for no understandable reason at all. Another example is parking lots for people with disabilities. What is the purpose of having parking lots for them guaranteed by traffic regulations if the regulations are not obeyed. The sanctions for violating this regulation are little and what is more, these regulations are often not executed.

What are the most important issues to articulate for people with severe disabilities in interest groups rsp. lobby work?
Most of all there are no systematic actions and clear, far-reaching targets in Poland.

What is of considerable importance is the introduction of the institution of a personal assistant. I have already said that the persons with severe disabilities, complex needs, and dependency are presently doomed to residential institutions in Poland or some other centres run by foundations or parents' associations. We need such alternations of the system that would allow these people to live independent life.

Still another issue relates to local, state and international transport. It is also a matter of introduction and maintenance of some standards.

In Poland the accessibility to work for people with disabilities is another important issue. It is related to disability assessment system and pension system as well. Many disabled persons are afraid that if they go to work and suspend their pension in future they would not be able to get it back. I think it is one of the main barriers in Poland that prevents from employing people with disabilities.

What is more there is a necessary of better support of families whose member is a disabled person. It must be remembered that one parent, usually a mother, in a family with a disabled child often gives up work. Thus it is a must to regulate rules of law that guarantee retirement insurance or financial support.

I am also of the opinion that income criteria entitling to some benefits are determined in an improper way. Let me just give the example of electric wheelchairs. It is possible to finance modern, electric wheelchairs from PFRON. However, this financing is only available for the persons whose income does not exceed PLN 1500 per person and there are many disabled persons who earn more but still cannot afford to pay PLN 20 000 for the wheelchair. It seems as if these persons were punished for their activity. I do not want to say that the system should support only the active persons, what I mean is that they should not be punished for their activity. In Poland there is no system which would serve to solve problems of people with disabilities. Until we have reasonable regulations, until we have a well-planned state policy within this field and reliable planning and activity on the level of local governments we will still face the problem of social exclusion of people with disabilities. Lately I have been to the United States. There a person who takes up a job receives financing to a car and is financed with respect to many facilities connected with adaptation to the surrounding, while in Poland such a person loses entitlements for he/she starts to earn too much. PFRON implements a new financing program which would cover 50% of a car value for people with disabilities, at this point again the problem of income criteria appears. Once more there will be a group of disabled persons who earn too much to apply for such financing and still earn too little to be able to buy an adjusted car. On the other hand the persons who meet income criteria may still find it difficult to find means to pay for the other 50% of car value.

What are the key issues in the field of participation of people with severe disabilities?
Many of the issues have been already discussed by me; however at this point I would like to relate to quite another issue i.e. access to culture and tourism. Obviously there are some local initiatives taken, but they are a consequence of the invention of particular persons or organisations, rather than effective norms. Lack of standards results in bad adjustments. Since there are no norms in Poland specifying what a toilet for people with disabilities should look like it is never the same. In the cinemas adjusted for people with disabilities, a disabled person usually has to sit in the first row. The lack of adjustments means limitation of one’s right to choose. I do think that many students with disabilities choose a particular faculty not necessarily as it is their dream one, but because it is the adjusted one. When I go on holidays I do not go where I want to go, but I go where a hotel is adjusted to the needs of people with disabilities and where I can get to with no problems. What needs to be considered as well is the attitude towards people with disabilities. When we often ask why there are so few rooms adapted for people with disabilities, we are told directly that when a non-disabled tourist arrives at such hotel and it turns out that all rooms are booked and the only room that is vacant is a room for disabled persons they do not want to stay there. I do not understand why since non-disabled persons park their cars willingly in parking places or make use of the toilets for people with disabilities.

What are the key issues in the field of discrimination against people with severe disabilities?
I have already discussed the issue of discrimination. At this point I would like to stress out all the stereotypes which tend to function in Poland. The stereotype of a person with disability as a less useful, less efficient and poor person who is associated solely with troubles is deeply rooted in consciousness. Let me give such example. Once I asked in one of the shops why during its renovation the entrance was not adapted for people with disabilities. In answer I heard that people with disabilities cannot afford to buy things that are sold there so there was to point. People with disabilities are often perceived as the group of poor dependant persons who require constant assistance and who are objects of charity events.

How do you co-operate with special interest groups of people with severe disabilities?
In Poland the cooperation of non-governmental organisations does not look too good, either. We do not constitute an integrated, well-cooperating group who could be a partner for the government or the parliament. Obviously we do cooperate with other non-governmental organisations, to mention just our participation in works of organisations associated in a group acting under the Commissioner for Civil Rights Protection. We also cooperate with municipal authorized representatives for the disabled affairs. Though in my opinion non-governmental organisations often find it difficult to cooperate with one another. We have

learnt that everyone works on their account and that it is the particularistic interests of organisations that matter.

We also belong to Workability Europe and for a short time now we have been a partner of the British organisation Shaw Trust.

What are your experiences to articulate the special needs and interests of people with severe disabilities in public discussions at regional and national level?

At the beginning let me present a few afterthoughts. I have an impression that the community of people with disabilities is tired with all these incessant discussions, participation in conferences or advisory panels whose conclusions or good practices are not taken into consideration by politicians. The issue of disability appears during election time and takes the form of election slogans, but later it is marginalized. The leaders of the community of people with disabilities who have experience as well enormous knowledge do not have partners in local governments and the state government who could put what they have to offer into practical solutions.

By all means we do try to take part in discussions every now and then. In order not to sound groundless let me just refer to our latest initiative, i.e. we are preparing Bill on the Poles with Disabilities following to some extent the example of the American and the British legislations. Soon a debate concerning this bill will be held in the Constitutional Tribunal. We also carry out numerous medial campaigns. Moreover, I think that our informative means play an important role in the discussion. We issue a magazine “Integracja” (The Integration) with a circulation of 15 000 copies where we often write about the problems of persons with severe disabilities. We also have an informative portal whose audience rating amounts to 200 000 a month. A TV program and info line functions as well.

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The interview was made personally during approximately 1,5 hour.

In your opinion: What are the main risks of discrimination against persons with severe disabilities in your country?

It is a very difficult question. Firstly, it should be looked in the context of existing legal solutions, i.e. whether they bring any risk of discrimination and exclusion. Secondly, it should be looked at from the practical point of view, i.e. what barriers hinder or prevent such persons from functioning in the similar way as their peers do. It should be considered if it is not the legal regulations and environment that create such barriers which result in the discrimination of people with disabilities. What is meant here is not just conscious activities which are evidently discriminative, but also legal omissions or pretermissions of some specific conditionings and needs resulting from severe and complex disability. Such omissions turn into lack of possibilities of equal participation and may cause discrimination. The areas of discrimination are to some extent different depending on the age of a disabled person and it relates to specific social roles that are to be fulfilled in consecutive stages of one’s life. In case of children it is mostly education and contacts with peers as well as the widely understood possibility of development. In case of adults it is most of all access to employment and also availability of education which is important at every age as well as the possibility of fulfilling the roles of family nature. This personal sphere is very important but yet it is unappreciated. What is also important is the sphere of activity in one’s free time. If the lack of activity in one’s free time is not caused by the limitations connected with the disability, but with the lack of adequate reaction of the environment we may have to deal with discrimination.

Obviously it will not always be the discrimination targeted or directed at a particular “Smith”. At every stage of planning and activity what needs to be considered is the fact that we are different and that the persons with severe disabilities stand out from so-called statistical average. If we undertake activities for so-called statistical average, i.e. ordinary citizens, and we do not take into consideration specific needs we may cause discrimination of the persons who stand out from such average. In fact it concerns lots of social groups, not just the persons with severe disabilities. It can manifest itself by lack or omission of some activities.

Some things may result from insufficiency of financial means. Although it should be remembered that each case of disability differs from another. Even in the group of the persons with severe disabilities there are the persons whom we are more likely to grant more entitlements to and the ones who would be granted slightly fewer entitlements. There is still a lot to be done in this sphere. If we analyze the legal solutions it can be observed that for some time now there has been the tendency of departure from the system which would place such persons in institutions. The present trend is opposite to the one that manifested itself at the beginning in the 90's, i.e. the system of complete institutionalization. By all means it is a very good trend. I still think though that plenty needs to be done to become noticeable, to begin with financial issues and to end with changes in consciousness. The barriers existing in the consciousness of persons, e.g. specialists, seem to be the most serious obstacle to move forward. If we, ourselves, do not give others the right to be independent regardless of their degree of disability, we will not make any efforts or undertake any activities to change it all. How fast we can move forward depends on the way of thinking of politicians, officials, specialists and families of disabled persons and the persons from their environment. What we also lack in the system is holistic approach support. Each sector is only responsible for only one sphere, i.e. one for welfare, another for pension bodies, another for local governments and still another for health service etc. Their activities are not integrated at all, even financially. We have various ways of financing different activities which do not necessarily meet. Local governments are often not allowed to spend their means on integrated activities but must spend them on the activities specified in particular regulations. What we have to deal with is some sectoring of policies and finances which results in some sectoring of thinking of the problems characteristic for people with disabilities. Consequently it may prevent from e.g. preparing a complex and individual support program for a disabled person. What must be remembered as well is the fact that people with disabilities do not live in void. Support should also be given to the families which if left alone with their problem, may not be able to handle it. Even if a family is able to cope emotionally and organizationally, after some time they may just feel burnt out due to their seclusion. If it is so that an average Smith may receive only split aid and at the same time the family he/she lives in is not supported, the efficiency of the system is questionable. The basic question that must be asked is what must be done to change it. In my personal opinion the only solution is to ensure means and possibilities in the immediate environment of a disabled person which would allow to initiate integrated aid programs based on close cooperation of a disabled person, who must remain the subject of these activities, and his/her family and specialists.

Another issue is a matter of the disability assessment system. In Poland hitherto solutions definitely need to be reconsidered. Presently we have a few assessment systems which are not coherent and that also complicates the system of aid which in specific situation may be unclear.

In your opinion: What are the perspectives of anti-discrimination policies for people with severe disabilities in your country and in the EU?

I think that in some time we will see binding regulations on disability in European Union. The pressure of the disabled environments aimed at the improvement of European legislation within this sphere is continuously increasing. Presently we have the Convention on the Rights of Persons with Disabilities approved by the Untied Nations and also signed by the European Community. Obviously Union authorities shall strive to make member states ratify the aforementioned convention. The activities aimed at the comprehension of particular regulations will be undertaken. I do think that all activities that the member states will have to undertake will finally result in accepting the directive prohibiting the discrimination of people with disabilities. Although it is not so simple as there are considerable differences on the level of life and affluence between particular member states. Working out common standards would not present any implementation difficulties to some countries, while for others, in particular the new Union member states it could be beyond their power, especially if the period of reaching such standards was specified. On the other hand if we do not determine the deadline we may never do it. However, I am thinking whether we in Poland differ so much from other European countries. We may speak about these issues in Poland in a bit different way, in a bit different language register and we may not be so bold in our declarations, but if we consider everyday approach I do not think there is such a gap between us, say nothing of the life standard which makes the life of people with disabilities easier and undoubtedly the first 15 countries of UE are in these issues more advanced than we are. Are those societies really so touchy about the issues of the discrimination of the disabled? It may be so as far as the declaration level is concerned, but whether it is so in reality I do not know. Recently I have encountered the research on discrimination within the territory of the European Union. The citizens of the Union have been asked what quality is the most discriminating one in their opinion. It turned out that the disability is on the first place in this ranking. Our societies may not be so ready to avoid situations which cause discrimination.

Are there policy programmes/legislation, which have intended or un-intended effects on persons with severe disabilities?

Undoubtedly this is the case. For example in the Act on professional and social rehabilitation and the employment of people with disabilities particular entitlements of disabled employees having legal disability status of moderate and significant degree of disability are determined. Although there are not too many of such regulations, but the legislator noticed that these persons found it harder to fulfil obligations of an employee. People with disabilities are for example entitled to shorter working time, a longer holiday leave, a break during work, a rehabilitation vacation. These solutions are addressed at the persons who are already employed. As far as the persons with complex needs who are not employed yet, but who want to enter the open labour market are considered, we do not have relevant system solutions, e.g. we do not have institutions of supported employment, we lack regulations related to vocational assistants or job couches although such programs are created by both public and non-governmental organizations which make use of the means available within EFS or the Union initiative EQUAL. In future the instruments of this kind should become a permanent element of Polish regulations. In case of other regulations for example the provisions of building law we have specific solutions related to the erection of public utility buildings in such a way so as to ensure accessibility to such building for the persons of limited mobility, the persons on wheelchairs and as far as the principle is concerned they are included in the group of severe disability; however, there are few system solutions addressed at other groups of people with disabilities that are specific due to the nature of their dysfunction. Needless to say it is not only the degree of disability, but also its nature that determines one’s capability of independent and efficient functioning. Various groups should be addressed at with correspondingly adequate solutions. There are more and more solutions which are directed at e.g. the blind or the deaf, while there are still relatively few solutions offered to e.g. the persons with intellectual disability who in particular are subject to marginalization not only due to the lack of support instruments, but also due to the lack of access to information. The information commonly available is not edited with a view to such persons. What is more there are no legal solutions within this range which would require important information to be prepared and made available in a comprehensible register, though in practice it happens more often nowadays.

In which political field is the life situation of people with severe disabilities currently on the political agenda at national level?

Generally the sphere of social policy is very wide as it includes the issues of welfare aid, social protection, social and vocational rehabilitation, employment etc. All these spheres should take into account the situation of the persons with severe disabilities and it happens more and more often. The Polish specificity means that we have a very numerous population of people with disabilities and at the same time a few different classifications. And thus for example the time of disability occurrence influences the entitlements to social protection and the type of such rights. We have a few different systems of disability assessment. The support offered to a disabled person may differ depending on the place where the person works, i.e. if it is on the open or sheltered labour market. Not all employers may count on the same assistance in relation with employing a disabled person. We could enumerate more and more such divisions, whereas there is no division which would be most desirable, i.e. the division into the persons requiring intensive support provided on continuous-basis and the persons who would require support in a much smaller range or even do not need it at all. And this is the division which we do not have, though the main stream of support should be directed most of all at this first group singled out on the grounds of the aforementioned criterion. Though it is not so visible yet, we can observe some changes in the way of thinking related to this issue. Working out the guidelines for a new system of support provided to people with disabilities we have stressed out this need, i.e. focusing efforts and means for the benefit of aid offered to those who without such assistance are not able to cope on their own with the difficulties resulting from their disability. Although the social policy is this sphere which creates the basis of support, people with disabilities are ordinary citizens and as such should be able to make use of all solutions that are directed at the whole society under the equality of rights; thus what is meant here is the whole sphere of education, health care, communication and transport policy, building issues and accommodation on the level of local governments. It is the sphere of activities belonging to a commune and a county. Each sphere of activity which concerns ordinary people is the sphere where such issue should be noticed and in particular the situation of the persons with severe disabilities.

Who are the most important actors in the national policy field for persons with severe disabilities?

On the state level the government administration and the Parliament are the leading performers, the former one is to recommend some solutions, the latter to enact regulations. The government administration has also some possibilities of creating law by issuing executive deeds to particular acts.

On the state level I would enumerate at least two more performers. They are most of all mass media which mould our views, opinions, which consolidate some stereotypes or try to fight them. If mass media show a disabled person most often a disabled person with severe disability is presented. Such persons are presented either as super heroes who despite their severe disability realize themselves in life or as victims of some events beyond their power, as poor persons who must be helped. Most of all they are shown in intervention TV programs. As a matter of fact people with disabilities are never shown as ordinary people. Mass media strengthen such image and may exert very strong impact on possible changes. When I speak about the government or the parliament I also speak about the people who create such structures. Their own views correspond to their activities. A way of thinking about these issues is very important as well.

Another group of performers which may not be so spectacularly visible but still has crucial influence on everything that has been already said is the scientific environments. They can for example show that some current opinions are not reflected in reality at all, let me just give the example of the employment of people with disabilities. The findings of recent research show that people with disabilities are not so willing to go to work. Thus it should be considered whether our efforts should be rather aimed at encouraging people with disabilities to take up a job. We need to look closer at the existing support systems, in particular at social protection system, to check if by chance they are of discouraging character.

We have discussed the performers on the state level, whereas the performers who are directly interested are of huge importance, i.e. people with disabilities and their environment e.g. their families.

What are the key issues in national policy field for person with severe disabilities?

Most of all it must be remembered that the Union means that we have at our disposal and which are designated for vocational activation and the employment of people with disabilities are directed exclusively to the persons with significant and moderate degree of disability, including the persons with very serious dysfunctions. There are also a few target programs realized by the State Fund for Rehabilitation of Disabled People which can be made use of by the persons with significant degree of disability, e.g. the program to support education and work of the persons with the sight dysfunction who may receive financial means for the purchase of computer equipment or the program directed to the persons with limited mobility with significant degree of disability who may be granted financial means for the purchase of an adjusted car. Presently a guidance governmental program “Early, multi-specialist, coordinated and continuous help for children who are susceptible to disability or children with disabilities and their families” (2005-2007) is realized. This program is some extent a reply to system insufficiency resulting from the lack of activities integration which has already been discussed. However, generally at this moment no complex governmental program directed at people with disabilities is not realized, although there were attempts in the past to realize a program of this kind.

Are there specific policy programmes for persons with severe disabilities in preparation?

The Ministry of Labour and Social Policy has prepared the guidelines for a new support system of people with disabilities that this winter were to be verified. However, due to the fact that the final form of these guidelines is influenced by e.g. changes planned by the European Commission and since such changes concerning the support of employers have not been specified yet, we need to wait so as not to form a system which would have to be changed in future.

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Service Provider:
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Interviewer: Ms. Ewa Wapiennik, Academy of Special Education, Warsaw

Date: 17th September 2007

The interview was made personally during approximately 1,5 hour.

In your opinion: What are the main risks of discrimination against persons with severe disabilities in your country?
In my opinion it is the category of persons particularly discriminated. Firstly due to the fact that there is total ignorance related to what these persons could make use of and moreover such information is not available easily. Generally it may be said that only these persons or their families who are very inquisitive gain some information and what follows a benefit itself. The risk of discrimination is also connected with the poverty of the large number of people with disabilities and their families. This poverty is the consequence of the state's lack of sufficient support offered to such families which would allow them to improve their material situation unaided. If there is a person in situation of major dependence in a family, usually one member of such family, most often one of the parents, must give up their job. While it is true that we have a nursing benefit for the parents of a disabled child who to look after their child must give up working; it must be said that firstly, the amount of such benefit is small and it does not improve considerably the material situation of such family; secondly; many persons are not entitled to such benefit as their income per person exceeds the income criterion determined in proper regulations (whose threshold is very low); and obviously such family incurs additional costs related to the disability of one of its members. A large number of adults with severe disabilities, provided that it appeared at the developmental age, are entitled to receive a social pension, but again its amount is below a social minimum.

Many years ago in the 80's a fixed benefit from the welfare was established for the persons who became disable before they reached 18 years of age and were unable to work. After the transformation that fixed benefit was changed into a social pension initially paid by the welfare, presently it is paid by ZUS (Social Insurance Institute). When that fixed benefit came into being the policy concerning the disability was based on providing care and minimum means for living. The amount of that benefit was determined on a very low level, i.e. below social minimum. Since the introduction of that benefit a lot has changed in the approach towards people with disabilities. International standards have altered. It is commonly known that active life in integration costs more than passive life in isolation. Passive life in isolation may even be related to a lack of need to have e.g. shoes. What is enough then is slippers and sitting at a window or in front of a TV set. There is no need to buy a ticket for public transport, but then one may not have any aspirations. We face the situation of conflict, i.e. conflict of the benefit which was created for another kind of politics in the epoch of care and the epoch where the activity of a disabled person is the greatest value, where it is important to support such a person to help him be active, productive and exercise his rights. For this reason nowadays the old concept of the social pension does not fit the current concepts, to present values which should dominate in the politics of disability. To sum up the social pension does not take into consideration present priorities. What is more it still is, though after recent changes to smaller extent, the obstacle to make use of some instruments of labour market. The entitlement to a social pension is also limited in the situation when a disabled person receives another income (from the sources specified under the regulations) if such income exceeds the amount of 30% of average monthly remuneration. Another problem constitutes the concourse of entitlements to social pension and family pension. It could be said that the family pension should replace hitherto care aid of parents. After their death one could e.g. pay for the aid provided by a personal assistant from such family pension. However, under the regulations if there is the concourse of a social pension and a family pension, the latter one is reduced considerably. Thus after parents' death the life quality of the persons with severe disability can decrease dramatically. As there is no money for personal assistance after death of parents the only alternative is a residential institution which is paid anyway in the amount of 70% of the benefit.

Discrimination is often conditioned with the lack of information, lack of families' skill to apply for services and also some discretion of officials' decisions. The environment is full of so many barriers that people with disabilities leave their homes. Sometimes they are ashamed to do so. In case of the elderly with severe disabilities they are often taken care of by their parents who are very advanced with their age. Due to their own age they often suffer from numerous diseases, frequently not treated for many years because all their life was devoted to looking after their disabled child and they had neither time nor strength or means to take care of themselves.

The institutions of welfare demonstrate very little mobility. Welfare employees do not have enough recognition concerning the number of persons with complex needs living in their district and the type of situation such people live in. If one does not apply to a welfare center, the welfare has no idea that such person exists. The life quality of many families whose family member is a disable person and of many people with disabilities themselves is lowest in Poland, excluding the homeless. In my opinion it is a very serious problem. In most case the burden of taking care of a dependant person rests on their family which is not supported and in result the caring potential of a family runs out rather quickly. Frequently it leads to giving such a person to a residential institution which is a drama for both the carers and the disabled person who, needles to say, has some place in life, some social circle and must lose it all.

Disability assessment is another source of discrimination. In Poland we do have a very bad assessment system. In the assessment of eligibility for social insurance benefit only one medical practitioner decides whether a person is able to work and quite often he/she is not a specialist in many diseases he/she gives his/her opinion about. Very often the decision is taken on the grounds of sole documentation. In the assessment system for of eligibility for rights other than rights to social to social insurance benefits we do have evaluation teams, but sometimes they do not assess in their full panel and sometimes there is no doctor of proper specialization in an evaluation team, although it is required by law. It happens that two assessment systems issue contradictory assessment. The issue of assessment awakes extreme emotions among people with disabilities also because the persons being in similar condition but from various regions of Poland receive different assessment. Let me give an example of disability assessment on ability to lead independent life as the assessment is vital as far as granting numerous services is concerned. In Poland there are regions where, please excuse me for using colloquial language, a chairman of an evaluation team says to a person with severe intellectual disabilities and his/her family that for them “the inability to lead independent life means that a persons lies in bed and has diapers”. It is very difficult to explain that a person may walk and even somehow manage with self-service but still be unable to live independently due to the lack of recognition at taking decisions due to their helplessness. Thus in some regions of Poland a person of a specified condition receives the assessment of being able to lead an independent life, while in another one the person with the same characteristics is defined as being not able.

In your opinion: What are the perspectives of anti-discrimination policies for people with severe disabilities in your country and in the EU?

In Poland as a matter of fact we do not have a strategy to solve problems of people with disabilities. Such problems are dealt with by various sectors which do not cooperate with one another. There are huge gaps in law which may result in discrimination caused by lack of proper regulations or lack of allowing for particular needs of people with disabilities in local activities. It often happens so that even if we have good solutions they are not coordinated with finances. We do not have any institution which would deal with the problem of discrimination. In Poland nobody looks at the persons with severe disability in the context of discrimination. There is even no consciousness that there should be such policy. Problems are solved rather residually often consequently to the publicity some problem is granted by mass media (e.g. due to some dramatic incident), instead of being solved systematically. The problems of people with disabilities are often looked at from the level of realization and not from the level of higher values, including non-discrimination. If we do not look this way we often feel sorry that a disabled persons cannot go out of their home, but we do not have money to change it. If we look at it from the side of the value, it should be considered what needs to be done for this social group for the rights of the persons with severe disability to be observed.

In my opinion European Union should put more pressure on the realization of already implemented union regulations, including employment directive. I also think that it an absolute must for the Union to accept a directive forbidding discrimination of people with disabilities. If we take into consideration what was said above, i.e there is no thinking about people with disabilities in the context of discrimination, only a directive as harsh law can change it.

What can you say about the difficulties of people with severe disabilities having access to support from professional services?

I have already discussed it to some extend. While it is true that the benefits are included in regulations, their obtainment is entrenched with numerous criteria, e.g. welfare services are granted free of charge at some income threshold per person, but this threshold has been determined on a very low level. Other families, whose financial situation is not so much better may apply for services within welfare for a fee. The whole procedure is over-bureaucraticised and service obtainment depends on an official’ decision. If a person applies for some service he/she must obtain information, apply for it and also prove by presenting proper documentation that he/she is entitled to it, then he/she waits for the decision whether the service will be for free of or for a fee and if it is going to be a service for a fee how much it will cost. The threshold of payment is very high particularly if the poverty of majority of families with a disabled person is considered.

All care services provided at home are of limited time duration and are hard to obtain, moreover they tend to be rather schematic and non-elastic enough. There is no possibility to adjust a service to one's individual needs, in fact a service is selected from the already existing service catalogue like cleaning, shopping, meal preparing, bathing. Whereas, there is no money for more sublime services, particularly the ones connected with participation in social life. What is more they are not of obligatory character. The services are granted on the grounds of a separate administrative decision and as such may not be granted. Needless to say, it is not a system in which one feels safe.

How many and what kind of people are excluded from all or certain services and get only support from their families?

Most of all we do not have the knowledge about the number of persons in situation of major dependency in Poland. We do not know how many of them live with their families. Lack of definition determining who the person in situation of major dependence or with complex needs is does not allow to specify the range of the problem.

On the grounds of the experience of our Association which manages numerous centers of daily support for persons with severe disabilities I may say that their needs are not fulfilled, as in each center there is a waiting list. Some conditions have to be met for such a person to be able to make use of a vacancy, even if we have it. What we often have problems with is transport particularly in rural areas. As a matter of fact only the institutions that have their own means of transport are able to provide services to the persons from rural areas. Provision of daily activities in this type of institutions and transport presently is the only possibility for a dependant person to leave his/her home for a few hours a day and for their family to actively realize themselves in their lives.

It seems that the biggest problems with access occur most of all within the services provided by the institutions offering activities during a day. We have plenty of communes or counties where such institutions simply do not exist though it cannot be said that such persons do not live in these regions. It means that if this category of persons benefits from such services at all, it occurs at their homes. However, plenty of them are left with no support whatsoever. The specialist services are not well-thought out, either. They are of rehabilitation character, but due to the fact that they are provided at home in most cases, they do not contribute to one's integration with the environment; though a large number of such services could be provided in the open environment, only the transport to the place of their realization would require support. What is more, the persons providing specialist services must fulfill high requirements as far as their qualifications are concerned. Whereas the funds destined for these services are not so big and thus lots of highly-qualified specialists do not want to visit homes. The welfare system concerning people with disabilities is archaic. It is the system based on infrastructure which to a large extent is institutional, anti-integrational, isolating and deactivating. The situation is the same as in case of social pension. Law and system solutions do not keep pace with modern postulates of social policy. We do not have a category of supportive services, individual planning or budget at all.

In which areas of the support system do you see problems of availability or bad quality?
Access barriers have either territorial character, as I have already mentioned, or result from the lack of a given form (or places within a given service) within a given area. The most dependant persons, i.e. the ones who require really big help or the ones who have serious behavioral disorders, have the biggest problems with accessibility. Such persons demand substantial expenditure of work and financial means and as such are not willingly accepted to daily institutions, to give an example let me just mention community self-help homes.

The quality of services varies a lot. In case of some institutions, like community self-help homes, we simply lack standards. However, even standards cannot guarantee good quality. For a few years now we have had standards of services to be provided by residential institutions despite that mass media often comment on some institutions where the rights of their inhabitants are drastically violated. It is the aspect of control that should be given more attention to. As a matter of fact, the government has recently lowered the standards as numerous institutions could not meet them. The level is really diverse. In case of welfare centers they are often old buildings and if they are new, they are quite often built according to the “institutional” plan. In case of inhabitants with complex disabilities also the number of staff is not efficient, either. Needless to say number of staff and their qualifications guarantee the quality of life of such institution’s inhabitants. I think that in case of very dependant persons the quality of life the majority of welfare centers guarantees is so low mostly due to economic reasons, infrastructure quality, too little number of not qualified enough staff. Another problem is the model of life in such an institution, few activities, monotony, non-mobility etc. The worst quality is encountered in residential institutions.

If the system was analyzed it could be said that there are too few services and the services provided are not the right ones. The persons living with their families do not receive enough support, while the persons staying in residential institutions there is too little money and too few employees working directly with inhabitants and too little active life. Quite able-bodied persons are in relatively best situation while the most dependant in the worst situation.

Are there differences in quality of services for people with mild, profound and severe disabilities?
Persons with severe disabilities should be able to benefit from a large offer of services and of service of continuous nature; while due to financial reasons the services are usually granted only for a specified period of time and they are rather conventional. The aforementioned persons are also not accepted to daily institutions as these places neither can nor want to take care of them. Such persons are simply “too problematic”, particularly if they have very big behavioral disorders and if there is also a need of providing medical services, e.g. a person must be probe-fed.

Which structural problems do you see in the service system and in service providing?
We have no diagnosis of needs within services and institutions. Nobody is in control of various institution being established and thus we have counties where there are plenty of such centers and they even compete with one another, but there are also counties where there are no centers at all. We would avoid such situation if a good social diagnosis existed. However, it requires planning of social policy on all levels and this is what we lack.

What problems do you see in intersectoral co-operation, in service planning and delivery?
We have statutory regulations related to cooperation between local governments with non-governmental organizations, yet a real partnership exists in very few places in Poland. Very often the authorities do not implement and do not understand the principle of subsidiarity. We also have to do with politicization of local government levels. It is an important blockade for realistic planning and realistic cooperation. Generally we also lack cooperation between particular sectors and the system is not internally compatible. Therefore in my opinion there is no system, what really exists is some section solutions.

What are the main concepts for the support of people with severe disabilities in your country? Are there differences between provider groups? Are there "taken for granted assumptions" in this field that foster discrimination?
If ordering parties are non-governmental organizations, particularly of parents or people with disabilities themselves, the postulate to be able to live actively in integration is very powerful. Though especially parents still think that disabled persons need not necessarily work, that obtainment of a social pension which must be suspended when such persons takes up a job, is a safer solution. Thus in case of many parents we face a deeply rooted conviction that a disabled person is to integrate with the environment, but remain passive at the labour market; while the state policy supports isolative forms. There is no money on housing with support, even long-term plans of gradual turn from institutional model are not prepared.

Since our Association mostly supports persons with intellectual disabilities I would like to say a few words about them. Generally it is thought that a person with intellectual disabilities is not able to speak on their own behalf. For many persons it is still a shock when they see self-advocates speaking. It is still regarded that a person with intellectual disabilities should be most of all taken care of and that within this help one is entitled to have control of such person. It relates to both parents and staff working in institutions. I consider it highly discriminative as it limits the possibility of subject development of such persons. They cannot build up their identity of free persons as they are constantly within the fetters of care. This stereotype is breached with much difficulty. It is harder to alter the attitude of staff than to build infrastructure. Such caring approach deprives the person with intellectual disabilities of the possibility to influence their life. If we had e.g. more supported flats and more workplaces, more persons would have a chance to influence their life.

What are the biggest challenges for the development in service providing for persons with severe disabilities?
We need new regulations which would support new forms of services, means for the new forms, new methods of educating new employees to work in new institutions, clear quality standards and also change in consciousness of parents, personnel and decision-makers.

What experiences have the service providers with personalised service delivery and personal budgets?
The first factor that limits it all is a rigid method of financing. In Poland the same amount is designated per each person though the conditions and states of persons vary considerably. This rigidness and incapability of negotiation constitutes a very important obstacle. In Poland no individual budgets are prepared.

Study on the Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs

www.non-discrimination.eu

Country Report Romania

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Tender on Behalf of the European Commission
D.G. Employment, Social Affairs and Equal Opportunities
Integration of People with Disabilities - Unit G3

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Selected Stakeholder Interviews

1. Summary

The Romanian County Report is an overview of the actual stage of the reform of the system for the welfare and protection of people with severe disabilities, focused on progress, problems and discrimination risk. As of January 2007, the new legislation related to the protection of disabled people (Law 448/2006) has come into force but not all mechanisms for its implementation have yet been made operational. There are significant discrepancies between law and practice. Among structural causes of such discrepancies we can list: *lack of consistency* among legal provisions; *major differences* between progress made in child welfare reform and reform in the protection of adult people with disabilities as well as delayed reform in education and health; *prejudices* on all levels (from central authorities to individual members of the community); difficulties to eliminate *outdated practices* (the legacy of totalitarian regime lacking individual rights approach, accompanied by a paternalist and authoritarian state, unprepared to acknowledge society's real problems); lack of *national monitoring system; insufficient number and inappropriate training* of specialised staff;.

We take into consideration in each chapter two categories of people with severe disabilities or complex needs: people living in family and people living in the children or adults protection system. In the process related to implementation of the new law, which we are happy to have, on the difficult road from theory to practice, each step we make in acknowledging the problems encountered and their analysis may become a step in finding solutions.

Due to lack of space, references could mostly not be added in this paper but are part of the annotated bibliography.

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Raportul de tara privind Romania este o privire de ansamblu a stadiului actual de dezvoltare a sistemului de protectie a persoanelor cu dizabilitati intelectuale severe, care evidentiaza atat progresele, cat si problemele cu care ne confruntam, precum si riscurile de discriminare care afecteaza aceasta categorie a populatiei.

La inceputul anului 2007 a intrat in vigoare **Legea 448/2006 privind protecția şi promovarea drepturilor persoanelor cu handicap,** fara a fi inca operationale toate mecanismele de aplicare in practica. Ne confruntam inca cu mari discrepante intre lege si aplicarea ei – si putem enumera principalele cauze ale acestora: *lipsa coerentei* intre norme legislative; *diferente majore* intre progresele inregistrate in reforma protectiei copilului si reforma protectiei adultilor cu dizabilitati, precum si intarzierile reformei in domeniul educatiei si in cel al sanatatii; *prejudecati* la toate nivelele (de la autoritati centrale pana la fiecare membru al comunitatii); *practici perimate* greu de eliminat (mostenirea unui regim totalitar lipsit de abordarea centrata pe drepturile fiecarei persoane, cu un stat paternalist si autoritar, nepregatit sa recunoasca problemele reale ale societatii); *lipsa monitorizarii* la nivel national a problematicii persoanelor cu handicap de toate varstele; *insuficienta numerica si pregatirea inexistenta sau de multe ori inadecvata* a personalului de specialitate.

In fiecare capitol al raportului am luat in considerare doua categorii de persoane cu dizabilitati severe: persoane care traiesc in familie si persoane care se afla in sistemul de protectie a copilului, respectiv a adultului cu handicap.

Pe masura ce am avansat in scrierea acestui studiu, am realizat si mai mult complexitatea problematicii respectarii drepturilor persoanelor cu dizabilitati intelectuale severe. In procesul de aplicare a noii legi, pe care ne bucuram ca o avem, in drumul greu de la teorie la practica, fiecare pas pe care il facem in recunoasterea problemelor cu care ne confruntam si in analiza lor poate deveni un pas in gasirea unor solutii.

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Le rapport national roumain est un aperçu de l'état réel de la réforme du système d'aide et de protection des personnes avec des handicaps sévères, aperçu centré sur les progrès accomplis, les problèmes et le risque de discrimination. Depuis janvier 2007, la nouvelle loi relative à la protection des personnes handicapées (Loi 448/2006) est entrée en vigueur mais tous les mécanismes de mise en oeuvre ne sont pas encore opérationnels. Il y a cependant loin de la loi à la pratique. Parmi les causes structurelles de telles divergences, nous pouvons citer : *le manque de cohérence* dans les dispositions juridiques; *les différences importantes* entre les progrès réalisés dans la réforme de protection de l'enfance et celle relative aux adultes handicapés ainsi que le retard de celle de l'éducation et de la santé ; des *préjudices* à tous les niveaux (des autorités centrales jusqu'aux citoyens individuellement); des difficultés à éliminer *des pratiques désuètes* (le legs du régime totalitaire manquant d'approche individuelle des droits, accompagné d'un état paternaliste et autoritaire, non préparé à reconnaître les problèmes réels de la société); l'absence *de système de contrôle national ; un personnel en nombre insuffisant et mal formé*.

Nous prenons en considération dans chaque chapitre deux catégories de personnes avec des handicaps sévères ou des besoins complexes : les personnes vivant dans leur famille et les personnes vivant dans le système de protection des enfants ou des adultes.
Dans le processus relatif à la mise en oeuvre de la nouvelle loi, loi que nous sommes heureux d'avoir, sur la route difficile de la théorie à la pratique, chaque avancée dans la reconnaissance des problèmes rencontrés et leur analyse peut devenir une avancée dans la découverte de solutions.

2. Introduction

Romania is now in the process to fully reform the system for the welfare and protection of people with disabilities. Romania has ratified most major international conventions relating the promotion of rights of people with disabilities and the Constitution acknowledges the right to special protection for people with disabilities. As of January 2007, Law 448/2006 has come into force but not all mechanisms for its implementation have yet been made operational. One may safely assert there are significant discrepancies between law and practice, between beautiful and generous principles and the real life of people with disabilities. Among structural causes of such discrepancies we can list: *lack of consistency* among legal provisions; *major differences* between progress made in the child welfare reform and reform in the protection of adult people with disabilities as well as delayed reform in education and health (child welfare reform had an earlier start and represented an important political criterion in preparation of Romania’s accession to the European Union; *prejudices* on all levels (from central authorities to individual members of the community); difficulties to eliminate *outdated practices* (the inheritance left by a totalitarian regime lacking individual rights approach, accompanied by a paternalist and authoritarian state, unprepared to acknowledge society’s real problems); *insufficient number and lacking or often inappropriate training* of specialised staff; *lack of national monitoring* of the issue of people with disabilities irrespective of age.

The field of disability has not been the object of an unitary approach. For instance, the issue of children with disabilities are dealt with by four governmental structures – the National Authority for Protection of Children Rights (NAPCR), the National Authority for Persons with Handicap (NAPH), the Ministry of Education, Research and Youth, the Ministry of Public Health – which have not succeeded in adopting unitary terminology and insure complementarity and consistency of policies and programmes. The word “handicap” is used in official law and policy, even the Romanian Constitution refers to the protection of “handicapped people”- this old terminology is stigmatizing for disabled persons. Child protection legislation use the phrase “disabled children”, whereas education policies – “children wits special needs” or, in some cases, “children with deficiencies”.

The law currently establishes ten types of handicap (physical, visual, auditory, somatic, deaf-blindness, psychic, mental, etc.) and four degrees of handicap: mild, average, accentuated, severe. There are no specific provisions for persons with severe intellectual disabilities. Rights and facilities provided by the law are approached from a handicap degree and not handicap type point of view; statistic data available are general as well. Thus, according to NAPH statistic figures, there were 462.207 registered persons with handicap on 30 June 2007, of which 445.473 in family care and 16.734 looked after in social protection institutions. Of the 462.207 persons with handicap, 94.110 are people with intellectual handicap, which represents 19,60 % of their total numbers.

The concept of “intellectual disability” is not defined in legislation, the most used being “intellectual handicap”. There are no specific provisions for people with severe intellectual disabilities, a category which generally is seen mainly as people with learning difficulties. Order 725/2002 of the NAPCR and the Ministry of Health establishes three structural and functional categories of intellectual disability: mild intellectual disability (without other associations), moderate and profound intellectual disability. Persons with mental health problems are under the jurisdiction of the Ministry of Public Health, not of the National

Authority for Persons with Handicap, and their numbers are therefore not included in the statistical figures above.

Diagnosis and assessment of disability for children and for adults are made by different procedures, but there are also common aspects. The local Service for Child Complex Evaluation (SEC) existing in each General Directorate for Social Assistance and Child Protection has recently been also extended for the Complex Evaluation of Adults. The Complex Evaluation Service (CES) performs the medical, social and psychological evaluation of the child and the adult, respectively, making recommendations for the person's appointment of a degree of handicap. Decisions on children's and adult's respective appointment of a degree of handicap are made by separate commissions, under the County Council:

- The Child Protection Commission
- The Medical Expert Commission for People with Handicap

Intellectual disability levels are classified according to the IQ level specified in ICD-10: mild, moderate, severe and profound.

Intellectual Disability Level	IQ level	
	Children	Adults
Mild	50-65	50-70
Moderate	35-49	35-49
Severe	<35	20-34
Profound		<25

The evaluation methodologies and tools are now undergoing reform and the NAPH representative we have discussed with in preparation of the present study asserts this is one of their priorities.

Following appointment of a degree of handicap, the respective person is to receive state support consisting of financial benefits and social and rehabilitation services, respect of the person's entitlement to health, education, accommodation, labour etc.

In what follows, a presentation will be made of the way in which people with disabilities are or are not provided this support during their life; the following are worth highlighting however in a general overview:

- Services addressing children, adults with severe intellectual disabilities and their families are insufficiently developed and diverse and only to a little extent meet their needs;
- Residential institutions, even restructured, small ones, represent the most frequent type of service but most of them are remote from communities and do not provided their beneficiaries with social integration programmes. The most serious aspect is that there are still institutions and psychiatric hospitals in place that provide completely inadequate living conditions, seriously violating the rights of people with intellectual disabilities;

- Community based services such as day care or respite centres are underdeveloped, best practice models being mainly identified in NGOs and public services involved in efficient cooperation with NGOs;
- The health and education systems, the vocational training one included, have a lot to achieve yet as far as their overall reform is concerned; however, there are opportunities to promote specific structural changes to insure health and education to people with intellectual disabilities in an indiscriminate manner. Lack of education and vocational training make professional integration impossible, which is why the right to labour is conditioned by respect of rights to education.
- There are no consistent policies for the initial and permanent training of the staff working in the system and the improvement of their attitude towards the users. For instance, disabled children in residential care are looked after by a carer with no specialised training whatsoever.
- The community is little prepared to accept and integrate people with intellectual disabilities; the population is used to accept state benefits without getting involved and showing no initiative and creativeness;
- An exception is provided by associations of children’s with intellectual disabilities parents, which have had outstanding development, in order to advocate for their children’s rights; such associations have been able to develop community based services and have become a “voice” for other NGOs as well, which defend the rights of disadvantaged categories.

While making progress with this study, we have been able to even better grasp the complexity of the issue of respect of people with severe disabilities rights. In the process related to implementation of the new law, which we are happy to have, on the difficult road from theory to practice, each step we make in acknowledging the problems encountered end their analysis may become a step in finding solutions.

3. Pre-Natal Diagnosis and Counselling

Through the extended possibilities for family planning, parenthood in modern societies has increasingly become a question of individual decision-making. Prenatal diagnostics and reproduction technologies permit the inclusion of characteristics of the fetus in this decision. This extended knowledge brings individuals into difficult situations when they have to make decisions regarding children. These individual decisions are affected by social values, attitudes, anxieties and knowledge of disabilities. They are also influenced by the quality of the counseling process if professional support is available and used. It is important that individual decisions are accepted by the social environment of people concerned. How is this achieved?

3.1. Description of the National Situation

Family planning (including abortion in the first three months of pregnancy only at the pregnant woman’s request or approved by her when recommended by the specialist physician) is one of the first health measures approved in Romania after the 1989 Revolution. During the 18 years of democracy progress has been made in this line as well as in the prenatal diagnosis techniques of severe disabilities, but there are very few adequately equipped specialised cabinets and these have mainly been developed in large cities. Such cabinets provide pregnant women’s testing and counselling for both the woman and her family in difficult circumstances, when decisions have to be made to terminate the pregnancy because of the foetus disability diagnostic. Unfortunately however, it is only educated mothers with good material situation who request such (quite costly) tests. There are no statistic figures available on the rate of pregnancy terminations on request of pregnant women following foetus disability diagnostic.

In the situation of women with severe intellectual disabilities, who were legally declared unable to discern, their legal guardian is the one who makes the decision to terminate the pregnancy with medical approval, in the first three months of pregnancy. A specific situation is that of women in residential care (hospitals and institutions for persons with severe disabilities); certain such institutions include them in contraception programmes with no previous consultation of either the women in question or their legal guardian.

In its Strategy for Promotion of Mental Health (O 374/2006), the Ministry of Public Health stipulates the creation of prenatal counselling centres. These centres will function mainly in towns and thus access to prenatal counselling in the rural area remains a problem.

3.2. Specific Risks of Discrimination

Access to health services in general and to specialised services for pregnant women in particular is difficult for women with severe disabilities – and this occurs in a general context of discrimination related to respect of the health right of several disadvantaged categories. As medical services performing foetus disability diagnosis are few and difficult to access, it is only a limited number of women who can identify the risk of giving birth to a child with severe disabilities. Counselling these women receive in such circumstances is mainly medical, no social values being approached and the end result is a decision for pregnancy termination. There is great anxiety of giving birth to a child with disabilities and that is why families do not take risks. The situation is even more difficult in residential units, where staff is afraid of birth of a child with disabilities, but no research has been made in that respect. This subject is generally considered a taboo.

4. Early Childhood

For most families, having a baby creates a situation of uncertainty and a need for direction and guidance. Living with a baby or a young child with a severe disability or with severe developmental problems brings parents into a situation with specific and difficult challenges and dependencies. Psychological stress in their daily lives often makes it difficult to cope with their parental responsibilities. When dealing with educational tasks or when specific therapeutical or medical treatment is necessary, parents cannot refer to their own educational experiences, but are dependent on professional support of various kinds. Having access to good medical care, self-help groups and early intervention services from a very early age of the child are decisive factors both for the personal development of the child and for the successful adjustment and coping process of the parents. How is this achieved?

4.1. Description of the National Situation

Following ten years of efforts and radical changes in the child welfare and protection system in Romania, since 2004 we have one of the most up-to-date and complex Laws for the Protection of Children's Rights (272/2004). The Law lays emphasis on the respect of EVERY child's rights, it acknowledges the key role of parents and the state takes it upon itself to provide support to child and family. This a legal frame contributing to the prevention of child abandonment, a problem that has, unfortunately, plagued Romania for years. An important group among children at abandonment risk from birth or at very young ages is that of children with intellectual disabilities. Child abandonment was “encouraged” by the medical staff itself, who “advised” the family to leave the child with disabilities in state care, because they were not likely to be able to deal with their child. Progress has lately been made in that respect, related to set up of a medical staff – social workers partnership, through which the family is encouraged and supported to keep the child. Since early childhood, the disabled child has the right to education, recovery, rehabilitation, compensation, and integration, which are adapted to his or her own abilities, for their individual development. Child evaluation is made by the Service for Complex Evaluation (SEC) existing on County level, in each General Directorate for Social Assistance and Child Protection (DGASPC). The evaluation report and SEC recommendations go to the Child Protection Commissions (CPC), that is responsible for determining the children’s degree of disability and the special protection measures (the personalised plan of services). The Commission is created under each County Council or Local Council of Bucharest sectors. It has an interdisciplinary character and works under the management of the President of the County Council. Evaluation of the child and determination of his/her degree of disability is not a purpose in itself, but they have to lead to raising the life quality of children, by improving the care and personalised recovery intervention. A case manager is appointed by the DGASPC to insure provision of personalised care to the child with disabilities and his/her family. The case management method is modern and useful in the case of children with severe disabilities, but its application is still at its early stagers in Romania. There is a lack of case management trained professionals. Because of the incipient stage in the development of services, support received by the family is often limited to financial benefits. Existing Day Care services with services for early childhood are only situated in large cities. “Mobile team” type projects have lately started working, which travel to the home of children with disabilities families, families in rural areas included. An important role in that respect belongs to specialized NGOs, which develop innovating community-based services, carry out lobby activities and engage parents in associative life. There are increasingly fewer children with severe disabilities in the child protection system, who live in residential units. For an as appropriate as possible early education in a familial environment, Law 272/2004 forbids institutionalisation of children between 0 and 3 years old; for them it stipulates foster care instead. Although there is a strong foster care network in Romania, only few maternal assistants have the necessary preparation to take care of children with severe disabilities.

As of the autumn of 2007, work has been underway for a national early education curriculum, also including a chapter addressing children with severe disabilities. An additional new development is authorities’ concern for specialised training of foster carers looking after children with severe disabilities.

Diagnosis and early recovery services are insufficient; they generally exist only in big cities. They are not accessible to children in the rural area.

4.2. Specific Risks of Discrimination

In spite of all efforts made by authorities and civil society alike, there is still a significant risk of abandonment of children with disabilities directly after birth. Discrimination risks may occur in both circumstances, whether the child is abandoned or not – as early as the evaluation of the degree of handicap, because of lack of trained professionals as well as working tools for complex evaluation. Activity of CPC commissions is difficult, because of the high number of cases debated within a session. There is an insufficient number of case managers to coordinate personalised rehabilitation plans of children with disabilities in family, foster and residential care. Children with severe disabilities and their families do not receive enough early intervention specialised support and rehabilitation services. Those in remote/ rural areas are the most discriminated.

5. Childhood: Education and Care

Preschool institutions like inclusive or special kindergartens offer care and education for younger children. They prepare children for school and give them the opportunity to interact with peers. Young girls and boys can broaden their experiences in life and enhance their social skills.

Children with severe disabilities have the same need to interact with peers, to make friends outside the family and to view themselves as a part of a social group. But young children with complex needs are dependent on additional support to participate in preschool education, such as barrier-free access or well-trained educators with specific skills and the intention to cooperate with other professionals. How is this achieved?

5.1. Description of the National Situation

The child with disabilities reaching preschool age, the CPC decides on his/her direction towards special kindergarten or day care centre in the child protection network of services also providing education activities. Unfortunately however there are few options. There are special kindergartens within the Romanian education system – but there are no such units for children with severe mental disabilities. The Ministry of Education, Research and Youth holds no statistic figures on the number of children with severe disabilities in need of or receiving preschool education but only general statistics. Such data are not monitored by the National Authority for Children Rights Protection (ANPDC) either.

In order to meet needs of children with severe disabilities, specialised day care centres began to be created by General Directorates of Social Assistance and Child Protection with public funding. There are also centres created by NGOs (especially parents' associations), but these services are expensive and they are difficult to develop and sustain. Therefore, their number is insufficient.

There is serious lack of professionals (educators, therapists of various specialisations) to work with children with severe disabilities of preschool age, thus insuring their education, recovery and socialisation. University trained specialists have good theoretical knowledge, but insufficient practical abilities in working with children with severe disabilities and their families. Professional training activities sustained by NGOs with European expertise have been successful, but they need to be developed.

Children with severe disabilities in the system, looked after in placement centres, family type group homes or foster care, who receive education programmes in their care or day care unit do not attend the community kindergarten.

The national curriculum for pre-school special education units / kindergartens for children with severe or mixed disabilities will improve.

5.2. Specific Risks of Discrimination

At preschool age, children with severe disabilities run the risk of becoming a discriminated category among the discriminated. More often than not, they are rejected by special kindergartens operating in the education system. Families lack real and constant support. Even if specialised day care centres have started to work, that also take over the function of “Preschool education”, these are still insufficient and little accessible on community level. Specialists and transportation means are lacking – the most disadvantaged in that respect being rural areas or small towns remote from a university centre. Mobile teams are still at project stage and only existent in certain counties. That is why most children with severe disabilities do not receive preschool education and stay at home with their parents, often with no friends of their own age.

Discrimination risks also occur in evaluation/reevaluation circumstances, when the CPC has to direct the child to special kindergarten. Evaluation is sometimes superficial and the supply of kindergartens and day centres is still scarce.

6. Childhood and Youth: School

Schools are responsible for a child's education and the teaching of knowledge of varying subjects. Furthermore, school proves to be an important part of young peoples' socialization process by offering the chance to enhance social skills and deepen social contacts with peers.
Children with severe disabilities also need high quality education and access to public schools. Pupils with complex needs are dependent on additional support in order to participate in school education, such as barrier-free access or well-trained teachers with the intention of cooperating with other professionals.
But especially pertaining to them, schools often exercise a kind of segregation. How do children with complex needs find their place in the school system, in which way are their special needs considered and how do professionals cooperate together?

6.1. Description of the National Situation

The entire Romanian child welfare, protection and education legislation asserts that the child has the right to receive an education which would allow him or her to develop his or her capacities and personality, in non-discriminatory conditions.

The education of persons with disabilities is made through special education units, individual integration within mainstream education, special groups / classes integrated in school mainstream units, educational services through mobile / itinerant support teachers, home studies until graduation from high school but no later than 26 years old, “hospital bed” education during hospitalisation, educational alternatives.

The law does not refer to disability degrees as far as the education is concerned, but in reality the education system includes special schools for children with sensory disabilities or mild mental disabilities, *but not for children with severe disabilities.* During the mandatory school period, local authorities have the obligation to ensure home schooling of immobile disabled persons. Children with severe mental disabilities should therefore be able to study only at home – but home schooling for children with intellectual disabilities is not available in practice. There are not enough mobile/itinerant teachers, and the education forms mentioned above are still at a pilot stage. The quality of education in special schools is inadequate for children with intellectual disabilities; the curriculum and the priority for teachers is to teach reading and counting skills, without pedagogical aims related to personal development, social integration, life skills development.

Children and young people with severe disabilities in the protection system receive education programmes within their care unit – placement centre or family type group home, but they do not attend mainstream schools. Schools in Romania are in fact little prepared to integrate children with disabilities, buildings and furniture are not made accessible for them, suitably trained staff is lacking. Although documents make wide use of “Inclusive education”, this has only been implemented punctually and when parent’s associations became involved, through advocacy and external funding. It is also parent NGOs which, with external technical and financial support, have succeeded in creating schools that suited needs of children with intellectual disabilities. Models are in place, but combined efforts are needed from authorities to develop them.

6.2. Specific Risks of Discrimination

The educational system is discriminative: children with severe disabilities can at most be integrated into special schools. The ones that do go to normal schools are pushed aside, and teachers don’t pay them too much attention. There are very few transportation means for the child to get to and from school.

Another instance of discrimination consists in the fact that children with disabilities who attend special schools do not receive their monthly benefit from the state, whereas non-disabled children do not lose it if they attend school.

The category of children with severe mental disabilities is the most severely affected by the lack of specialised teachers, lack of adequate didactical materials, lack of adapted curriculum. The legal provisions about the right to education are not properly respected in practice.

Children with severe mental disabilities in rural areas are the most discriminated. Their parents have to make particular efforts for their education and their success in that respect has mainly been secured through set up of associations advocating for the rights of their own children and identification of funding resources for projects.

7. Childhood and Youth: Housing and Family Support Services

Due to the variety of modern family life, all children grow up in different environments. These environments can be understood as a social network including all sorts of relationships to individuals or institutions. The family's living conditions during childhood are very important for social inclusion of the young person in society. The family has a strong impact on his/her primary socialization and influences the access to certain social institutions.

Family support services offer community-based professional support and services for families. Some children and young people live in a foster family, others in foster homes. Are such support systems available? In which way are children with severe disabilities or complex needs and their families involved in these support systems?

7.1. Description of the National Situation

Family support In Romania is mostly financial: parents of a child with severe disability benefit from paid vacation (until the child turns 7). The parents who take care of disabled children who need treatment for inter-current illnesses benefit from working hours reduced to 4 hours, until the child turns 18. They also receive paid vacations for taking care of the child. Until the child turns 7, the mother receives a monthly allowance from the Ministry of Labour, Social Solidarity and Family, for raising children with disabilities. The family also receives an increased by 50% support allowance for children with disabilities living in a family. All these financial allowances and rights to medical vacations are respected.

The rights referring to housing are clearly provided for in Law 448/2006 on the protection and promotion of the rights of persons with disabilities: public authorities have to take measures to introduce a priority criterion for low level renting of dwellings that belong to the public state domain, approving an additional room as compared to the minimal housing standards stipulated by the law referring to renting dwellings from the public or private domain; the level of rent in these dwellings is minimal. Because the number of dwellings is insufficient and their price has risen suddenly, the provisions of the new law on the protection and promotion of the rights of persons with disabilities are difficult to put into practice.

All support services for parents are insufficiently developed in Romania. Even more so services specialised for support of parents of children with mental disabilities.

Although the law offers a generous framework for developing counselling services, schools for parents, day care centres, respite centres, in reality these services are poorly developed or do not exist. Counselling centres for parents exist in each county, but they address all parents and do not have the capacity to provide specialised support. There are parents' NGOs that have developed day care centres and counselling services, generally with international financial support, but these initiatives are still punctual.

Children and young people in residential care are highly dependent on the institution. There are few protected apartments; residential units predominate, even if living conditions have improved. Because of the residential environment they have been raised in, they encounter difficulties in community integration. In fact, neither the community is prepared enough to integrate them. There is still a lot to be done and mentalities are the most difficult to change. Innovative projects of certain NGOs should be better advertised and generalised.

7.2. Specific Risks of Discrimination

The general accommodation shortage in large cities in Romania particularly concern disadvantaged categories, the more so families looking after children with severe disabilities. In rural areas, even if the dwelling area is larger, utilities are lacking: running water, drainage, heating – therefore living conditions for children and young people with severe disabilities are not proper. Poverty often affects a family with a child with disabilities. The mainly financial character of the state benefit creates dependency of the poor family on this support and even parents' apprehension that the next evaluation would determine improvement of the child's condition and decide appointment of a lower degree of handicap (in spite of the law's good intentions, the result has been perverted).

Insufficient development of community based services and actual scarcity of case managers for work with each family result in poor participation of children and young people with severe disabilities in community life.

8. Childhood and Youth: Leisure Time

Young people use their leisure time to do enjoyable and amusing activities and to get free from daily routines. Often free time activities are organized in clubs or in various forms of sportive or cultural associations. But youngsters also spend their free time with peers without adults. Many experiences among young people of the same age are made spending leisure time together, e.g. discovering new social roles, social spaces, friendship or falling in love. Youngsters with severe disabilities or complex needs have the same leisure time needs as their non-disabled peers, but are dependent on additional support to participate in mainstream leisure time activities. How is this achieved?

8.1. Description of the National Situation

Disabled preschool children, pupils and university students, together with their personal assistants and professional personal assistants, have the right to free participation in resting camps, once a year, irrespective of the education form they attend. However, this is ensured especially by NGOs in the field; camps in the public system are not accessible to children with severe disability mainly because they lack conditions adapted to the physical environment and they lack enough and well specialised personnel.

Children and young people in family care do not receive special leisure time programmes except for cases when they have access to a day care centre or if parents are trained in that respect.

Children in residential services in the protection system have the right to leisure. The law stipulates elaboration of an individualised plan for leisure. These are new legal provisions included in the minimum compulsory standards for residential services for children with handicap, but they are still difficult to put into practice. Staff is insufficiently prepared for organising leisure activities. There are few training courses for educators and these do not cover the need for specialisation in organising games, stimulating participation, socialisation of the child and the young person with severe disabilities. Moreover, because of the low level of wages, the number of educators in residential institutions is small. Because of lack of accessibility, children can with great difficulty participate in activities in the community. The positive fact is that most residential services and day care centres for children with disabilities have lately been endowed with transportation means that allow organisation of trips and enable children's leaves from their institutional environment.

Such initiatives as the "Special Olympics" have started to be developed successfully, allowing young people with intellectual disabilities to be involved in sports activities and enjoy peer and community appreciation. These are activities with beneficial effect on the community as well and they favour citizens' involvement in the social integration of children and young people with intellectual disabilities.

8.2. Specific Risks of Discrimination

As previously mentioned, for children with severe disabilities living in family or foster care, insufficient development of day care type community based services is a source of discrimination risks, including with respect to their right to playing and leisure time. Parents are overwhelmed by daily routine and do not particularly concern themselves with organising their child's leisure time in the community, together with other children. If they do not attend special school either, these children have even fewer friends.

Children in residential care run the risk of discrimination as too little time is allocated to leisure in the daily timetable and, in addition to being insufficient as their numbers are concerned, care staff have no knowledge of organising their leisure time.

9. Youth and Young Adults: Vocational Training

A successful transition from school to the employment system is usually related to vocational training. After finishing school young people need to find a job according to their interests and abilities with which they can earn a living. Vocational training prepares for the access to the employment system and is an important step into adult life. Youngsters and young adults with severe disabilities are dependent on adapted training courses, assisting technologies, other individual support and barrier free infrastructure to enable their access. How is this achieved?

9.1. Description of the National Situation

Vocational education is insufficiently developed for all categories of people. Although this is one of the programmes promoted by the Ministry of Education, Research and Youth, results are barely visible.

For persons with disabilities there are very few specialisations in professions which have no connection with labour market demands. The Ministry of Education, Research and Youth and the Ministry of Labour, Social Protection and Equal Opportunities intend to optimise schooling contents by taking such demands into consideration (according to a joint protocol signed by both ministries). Even if vocational schools exist in the community, these are only accessible to children with mild mental disabilities, NOT to children with severe disabilities.

The "Rights of People with Intellectual Disabilities – Access to Education and Employment "OPEN SOCIETY INSTITUTE 2005" monitoring report makes the following mention: "No support is provided, either through the educational system or other State-supported channels, to help people with intellectual disabilities make the transition from school to employment" and nothing has changed over the past 2 years. Current legislation is rigid and inadequate for people with intellectual disabilities: a primary school diploma is required for vocational training.

Only NGOs' initiatives prove that it is possible to develop vocational training for youth with severe disabilities as well, but such experiments have not yet been taken over by the state and this is a complex and lengthy process.

Disabled children in residential and foster care have to be provided with a personalized plan of professional integration, which should include vocational training. Vocational training initiatives in the child welfare and protection system are only limited to small sized workshops for woodwork, tailoring, gardening or animal breeding, whose success is short term, children are not provided with certificates and the respective activities are not considered from a marketing perspective as well.

9.2. Specific Risks of Discrimination

All people with severe disabilities are subject to discrimination because the education system provides them no opportunity to acquire marketable skills. It is only those who have attended primary special school who may go further to vocational training and are allowed to practice it later on – but these are quite few.

After becoming 18, young people who have grown up in the child protection and welfare system have to transfer to adult services. In the absence of vocational training, their chances of integration become minimal. The trauma of having to leave the environment of their upbringing and their transition to adulthood, which they are completely unprepared for, are added to their impossibility to find a job and therefore they run the risk of remaining passive people in state care their entire life.

10. Children and Adults: Social Security and Health Care

Modern societies are shaped by an enlargement of welfare systems and an increasing dependence on social security institutions. It is a challenge for all citizens to clarify their entitlements and to find access to services. The need for basic social security and to have access to health care services if necessary is important for all people.

In most cases having complex needs leads to an increase of dependence on social benefits and requires special support and services granted by welfare administration boards. Bureaucratic procedures of application approval create special risks of stigmatization. Allowances, benefits and services can improve the possibilities of individual participation, but can also initiate processes of social exclusion. How is this achieved?

10.1. Description of the National Situation

The new Law for protection of People with Handicap provides a wide range of social security measures for disabled children and adults – but they all depend on assignment of a degree of handicap. For instance, a person with severe handicap is entitled to 179 lei (50 Euro) monthly allowance, 80 lei (25 Euro) as complementary budget, a personal assistant employed by the city hall (more often than not the person’s own mother or some other family member), free urban transportation, 12 free railway tickets, and so on.

The amounts are insufficient given the current prices of basic products and services. Aiming at recovery / rehabilitation, people with disabilities have the right to support aids, walking aids, adaptation of vehicles etc, (costs supported by the state through health insurances).

The child has the right to receive social security and social insurances, according to the resources and the situation of the child and of the people responsible for child maintenance. With support from European programs, most old institutions where children with disabilities lived in improper conditions have been closed down. Progress has been made in the development of family type services, day care and recovery centres. But these services function mainly in county capital cities and are coordinated by the General Directorate of Social Assistance and Child Protection.

The focus is on the continuity of services, so that, after turning 18, the person transfers from the service for children to a similar service for adults. But the supply of services for adults is insufficient from a quantitative and qualitative point of view, because of the difference between the reform in the child protection system and the reform of the system for the protection of adults with disabilities.

Community services for severe disabled people are insufficiently developed. Disabled children (including those with severe disabilities) are entitled to a personal assistant, based on their social, psychological and medical evaluation. This facilitates the possibility to maintain them in the family. Adults with disabilities have the same right. Progress has been made in defining the personal assistants’ status and in professionalising them. The NAPH has elaborated a model of training and has provided funding for projects to train personal assistants.

The condition of people with mental disabilities in health care institutions (psychiatric hospitals) is critical. Their needs are not at all met by the mental health system, they live in inhuman conditions and many of them are expected to remain in the facility for life. Mentally retarded patients are a distinct group for whom psychiatric hospitals are not the proper place to be.

All persons with disabilities benefit from medical assistance within the health insurance system, but one may notice violation of their right to health in most protection institutions. Moreover, there are regional inequalities evident in population coverage with medical staff. Therefore, in 2005, the number of inhabitants per physician in the rural area was more than 6 times higher than in the urban area. The number of community nurses is entirely insufficient, there being 26265 persons per community nurse in the rural area. The North-East is the least covered with medical staff in the rural area (2778 inhabitants/1 physician). Under such circumstances, the person with severe disabilities has very little access to health care and medical staff perception is that “nothing else can be done anyway”.

10.2. Specific Risks of Discrimination

The right to health and adequate community services for all people with severe intellectual disabilities is not suitably observed and efforts are made more for children and less in what adults are concerned. Rural population of all ages has only limited access to community based and health services. Residents of psychiatric hospitals are a systematically marginalised social group, discriminated and subjected to inhuman treatments that reveal lack of respect for fundamental human rights. In general, these persons do not benefit from the psychiatric treatment required by their health condition, nor do they benefit from other rehabilitation programs imperative to make them function at full physical and mental capacity.

11. Adults: Work and Employment

Having work or a day occupation is, for financial and other reasons, a very important indicator of social inclusion and quality of life. Going to work not only structures peoples' days and weeks, but also has an important impact on the development of a person's identity. It also provides access to the social security system and is an important basis for participation. For people with severe disabilities, transitional situations from school or vocational training into the employment system must often be systematically planned and organized, because they are dependent on adapted work places or assistive technologies and other individual support like a barrier-free infrastructure to enable their access. How is this achieved?

11.1. Description of the National Situation

Legislation encourages employment of people with disabilities: any disabled person who wishes inclusion in the labour market has free access to evaluation and professional orientation, irrespective of age, type and degree of disability. The protected employment forms are the protected job and the authorised protected unit. Thus, the employer of the person with disabilities benefits from fiscal facilities and the persons with disabilities who start their own business are tax-free. Legislation provides for the Government to pay the salary of employees with disabilities, but only for 18 months, after which the employer has no obligation to retain the employee. The National Agency for Employment is developing a programme for people in distress, including persons with disabilities.

The implementation of these policies is still at its early stages, the number of employees with disabilities is very small. There are no statistical data available regarding employment of people with severe disabilities. In addition to that, Romania has a high overall unemployment rate which makes it difficult for people with severe handicap to compete for a job on the market. In very high competition conditions, people with intellectual disabilities have almost no chance of finding employment.

In Romania there are also sheltered workshops, yet access is limited for people with complex needs. In some cases, the families are overprotective and represent an obstacle in their child's professional integration. The lucrative potential of people with intellectual disabilities is almost entirely neglected by family, social workers and authorities alike.

The lack of specialised employment services for people with severe disabilities is a great problem. The best good practice example in this matter is Pentru Voi Fondation - Center for Assisted Employment ; this centre provide assistance for finding jobs on the open market,

orientation for selection of a vocation, job coaching, consultancy for parents and professionals.
The best results so far however have been obtained by NGOs (for instance “Pentru Voi” Timisoara) that have created protected units in partnership with local authorities. The programme of assisted employment of this foundation is a model. They have also organised training on this topic, addressing specialists from public and private services.

11.2. Specific Risks of Discrimination

Discrimination risks increase with age. The person remains stigmatised if has followed the path of special education; he/she has no social abilities developed. He/she has no knowledge of how to seek employment, has no resort to employment support/mediation services for.
Many people with disabilities are forced to choose between disability benefits and employment and they opt to continue receiving disability benefits payment. Passive measures are in fact encouraged. In conclusion, people with severe disabilities have very limited access to employment.

12. Adults: Housing

Becoming an adult also means making up your mind about how you would like to live: stay in the natural family for a while, live alone, with a partner or family, with a friend, etc. Having privacy, a place to go to, feeling safe and comfortable there, realizing one’s own ideas on how to live, are all very important for people in our societies. For people with complex needs it is a big challenge to find their own way to living. They have restricted alternatives for housing because they need barrier-free environments and life-long support. People with severe disabilities do not only need good support services but also counseling to realise their ideas and style of private living. How is this achieved?

12.1. Description of the National Situation

The right referring to housing is the same as for children. There are the same huge problems because of the housing shortage. Because of the same reason it is expensive to buy and organise protected dwellings; few persons with disabilities can enjoy independent living in a protected accommodation. Adults with severe disabilities usually live in the family residence or a residential unit.

Most often, the family of a person with severe disabilities is poor, in bad need of resources, and therefore the living space is either very small (in the urban area) or has no facilities (in the rural area).

As far as adults in residential care are concerned, living conditions have improved in comparison to the disastrous ones prior to reform; there are a lot of things to achieve however to secure personalized space, adjusted to specific needs. The government will continue to provide funding for the rehabilitation of residential units, whereas NGOs are involved in advocacy to provide people with severe disabilities the opportunity to live in the community, not in residential institutions.

The community however does not give too great a chance for the integration of people with severe intellectual disabilities. There are many physical barriers (even if a protected apartment is arranged in a block, there are no access ramps; community based services for all citizens are not accessible to this category) and mental barriers (citizens have difficulty in understanding the people with disabilities situation, are afraid of contacts with them, have the tendency to exclude them and at best feel pity for them). Lack of accessible public means of transportation is a problem. But the new law is compelling local public authorities to buy adapted means of transportation and adapt existing ones. Authorities also have to organise transportation programmes adapted to persons with disabilities. It is not only the problem of adapting the means of transportation, but also the problem of infrastructure, of adapting the underground / railway stations and the tramcar / bus stops; these facilities are insufficiently developed.

There are no counselling services for private living addressing people with complex needs. Families too are a barrier because they cannot conceive that their son or daughter might live as independent adults.

12.2. Specific Risks of Discrimination

Discrimination risks occur in observation of the right to housing – people with severe intellectual disabilities are disadvantaged as related to the other categories of people with disabilities.

Articles 24/25 - Law 448/2006 **on the protection and promotion of the rights of persons with disabilities** are subject for interpretation. The adult with physical disabilities and the family who raises a child with disabilities can benefit from a favourable credit, but not a family who takes care of an adult with intellectual disabilities. Furthermore, bank personnel is not well informed and reticent in the relationship with intellectually disabled people.

Giving primary importance to restructuring of institutions and not to development of community based services, authorities encourage discrimination of people with complex needs with respect to their right to private, proper, independent living inside the community.

13. Adults: Education and Leisure Time

Leisure time comprises all the time out of work to either relax or find a balance in contrast to every-day-life. Activities can be done on one’s own, organized in clubs or in various forms of cultural or other social facilities. In their leisure time, people in our societies are supposed to act with less formal restrictions and try to achieve a high degree of satisfaction and self-determination in their activities.

Adult education – taking the idea of life-long learning as postulate – can be seen as part of the individual’s leisure time, sometimes connected to work or the expectation that a certain course promotes one’s professional career. Sometimes people participate in adult education courses for the sake of their personal well-being, health or general personal development. For people with severe disabilities the participation in organized leisure time activities or adult education courses very often must be systematically planned and organized, because they are dependent on adapted courses, assistive technologies and other individual support, and barrier free infrastructure to enable their access. How is this achieved?

13.1. Description of the National Situation

Adults with severe disabilities and their companions benefit from free entrance at museums, sports and cultural activities. The law stipulates that tourism agents have to organise accommodation for persons with disabilities, for those with severe disabilities included. But these efforts are still in their early stages.

Practically there are few possibilities for leisure of adults with disabilities that live in their families, but the situation of those in institutions is still difficult. “Leisure time” in a residential setting is often not valorised and is more a “waiting time” (waiting for the meal, treatment etc.). One cause for that is the fact that personnel is scarce and lacks preparation for this type of activities.

Because of above mentioned physical and mentality barriers, people with severe disabilities in residential and family care spend very little time in the community. Financial resources are necessary for leisure time and tourism, but adults with disabilities and the caring family often can barely provide daily basic care from benefits. Lack or an insufficient number of day care centres for adults with disabilities is evident in that respect as well, these being services able to insure respect of the right to leisure time.

13.2. Specific Risks of Discrimination

Because of their lacking resources, of their family’s or caring residential staff’s incapacity to also take care of this aspect, but also for reasons of barriers on community level, people with severe disabilities cannot enjoy spending their leisure time in the same way as other people; this aspect has often been neglected. Legal rights are not observed in practice.

This discrimination is one of the effects of lack of day care type community based services and insufficient number of professionals able to carry out such activities essential for the person’s social integration.

14. Adults: Partnerships and Parenting

According to social trends and changes, the decision of having one’s own family is not as easy as it used to be. More and more the decision to get married or to have children is a conscious one based on emotions, being aware of the changes that these decisions will mean.
Not too long ago the idea of people with (intellectual) disabilities getting married or having children was regarded as impossible. People with complex needs who wish to marry or have a child often have to face prejudices. After all, in their parenting they are dependent on special support. Professionals from different services and service sectors have to cooperate to prevent exclusion and discrimination. How is this achieved?

14.1. Description of the National Situation

The right to get married and the life of couples are respected. For people legally declared unable to discern, the legal guardian or curator establishes the marriage. It is not allowed to sterilise a person without his/her consent, except for situations when this is required by the persons’ health condition. When the person with disabilities, irrespective of age, is partially or totally incapable of administrating his/her personal goods, he/she benefits from juridical protection such as guardianship and juridical assistance. The equal treatment of all people is stipulated. Non-discrimination principles are present in the entire legislation on child protection and person with disabilities protection. However there is still a lot to do to put them into practice, because of lack of accessibility and mentality problems. This is a complex and lengthy process.

No research is available to highlight the way in which people with severe disabilities/complex needs have a normal couple life or get married/ have a child. Birth of a child to parents with severe disabilities is looked upon with apprehension and considered an irresponsible act, because the child "is sure to inherit his/her parents and will turn into a burden for everybody". Should a person with severe disabilities have the perspective of becoming a parent, his/her own family will panic because of their opinion that there will be another family member to look after. A similar approach occurs in residential settings: potential births by women with severe disabilities are seen as perpetuation of the problem and increase in the number of "assisted persons".

14.2. Specific Risks of Discrimination

Although no research is available on this topic, it is obvious that people with complex needs/severe disabilities have very little chance of having a couple's life, formalized or not. Everything is a consequence of the impossibility to live an independent life as well the opposition of parents, professionals and community members to the respective person's perspectives of raising a family.

Should an occasional or long term sexual relationship result in pregnancy, there is fear and resistance from the family / institution. Nobody will encourage the birth of a child to a couple with severe disabilities which therefore is discrimination with respect to a fundamental human right, to procreate and enjoy the birth of an offspring.

15. Adults: Exercising Civil Rights

One developmental task of adulthood is to know and to exercise one's rights. This comprises the rights that a state confers to its people in order to secure protection and political participation, e.g. basic human rights and voting.
For people with severe (intellectual) disabilities, civil rights still cannot be exercised in every case. Additional support is needed to exercise democratic rights like voting. It is also a commonly held belief that people with severe disabilities or complex needs are in capable of serving in political positions. How can people with severe disabilities exercise their rights as citizens?

15.1. Description of the National Situation

When the person with disabilities, irrespective of age, is partially or totally incapable of administrating his/her personal goods, he/she benefits from juridical protection such as guardianship and juridical assistance. If the adults are found without judgment abilities due to their intellectual disability, they will be put under interdiction (legal or juridical measure) resulting in the limitation of the exercise of civil rights. Interdiction requires that a person has a guardian, appointed by the State Guardian Authority under the direct supervision of the local authorities. According to the Civil Code, people under interdiction lose their civil rights, which may be exercised by the guardian, except for their individual rights (the right at vote, the right to be elected, the right to work etc). In case of conflict between the person and his/her guardian, it is possible to make a complaint to the State Guardian Authority and, where the complaint is found valid, this authority can decide change of the guardian. The guardian is usually a family member. There is no statistical information available regarding the number of persons with severe intellectual disabilities who are under the guardianship.

With respect to exercise of the right to vote, existing services do not provide specialised assistance to persons with severe disabilities/complex needs. Given the very precarious preparation for independent living, preparation in view of exercise of citizens rights is also lacking. Usually going out very little, such persons also stay at home on election day. They are not comfortable in the community and the community is not prepared to accept and integrate them

15.2. Specific Risks of Discrimination

Even if there are – very few – cases when they do exercise their right to vote, people with severe disabilities do it formally. Discrimination is obvious and it results from lack of preparation for independent living, which should have consistently started from childhood. The community pays no attention to this aspect. It is only strong NGOs, which succeed in stimulating self- representation of people with disabilities which have good results in respect of civil rights. People with severe disabilities are not present in NGO boards, even if these are supposed to represent their own rights.

16. Adults: Ageing and End of Life

Ageing contains a lot of new challenges: Retiring, organizing one's day in a new way, coping with the loss of abilities and coming to terms with it and with one's life. Regularly, more support is needed in day-to-day life and thus social dependencies are increasing. Often this means that familiar life settings must be changed because care needs cannot be covered anymore by the given arrangement. Most people don't want to leave their familiar setting even when their care needs are becoming extensive and complicated. They prefer arrangements which are based on home care services that are reliable and flexible. When people reflect upon the end of their life there is also a wish to die in dignity.
How is this achieved?

16.1. Description of the National Situation

Still living people with severe intellectual disabilities who are over 50 years of age in Romania are entirely people who have lived under the communist regime, when their issues were kept completely hidden from the public eye. At best, such persons are in the care of their own families, by members of the extended family as there probably are no living parents left, but most of them live in hospital type residential care, no one has made efforts for their integration in the community, they have been isolated and kept in hiding their entire life, as not compatible with the status of "new person of the multilaterally developed society". Living conditions in the hospital environment are improper for respect of the person's rights.

Protection policies for elderly people in Romania are generally insufficiently developed. There are very few residential institutions and home care services for elderly persons, comparative to existing demands. Mainly NGO initiated home care services have started to be promoted are by public services as well, but they are also insufficient. Elderly people with severe disabilities are difficult to be entered into a residential center and finding a person for care at home is equally difficult.

The right to palliative care is acknowledged, but unfortunately there are very few organisations that provide such services. Moreover, these do not have the necessary competences to provide palliative care to people with severe intellectual disabilities. Active euthanasia is not allowed in Romania.

16.2.Specific Risks of Discrimination

Elderly people with severe disabilities are discriminated regarding their right of a decent life in residential institution or at home, with specialized support. The discrimination is more obvious, because in Romania there is an important and generalised lack of services for elderly people – both residential and home services. The elderly residential centres and the services at home are working on the basis of “waiting list”; in these conditions the centre’s management prefer to accept the people without handicap.

Country: Romania

Service provider (public sector): Mihaela Ungureanu – Chief of Service for Disabled Adults Evaluation - General Directorates of Social Assistance and Child Protection **Sector 1 Bucharest**

Date: **07.08.2007**

Place: Bucharest

The interview was made at CRIPS premises, approximately two hours.

AT:
How do people with severe disabilities have access to specialized services they need*?*

M.U:
For the moment, there are no community care alternative services, there are only residential units. We don't have services that allow the maintenance of people with severe disabilities in families or communities. People with severe disabilities who live in families can only benefit of a personnel assistant, who is paid by the state, or financial support (monthly allowance equivalent with the monthly salary of the personnel assistant).

A.T: How do you establish the diagnostic / the degree of the person's disabilities?

M.U:
The diagnostic is established by a specialized doctor. With this diagnostic, The Service for Complex Evaluation makes a paper of analysis of current situation which is presented to the Commission for Evaluation of Adults with Disabilities. This Commission releases the certificate of person with disabilities.

A.T: What kind of people with severe disabilities cannot benefit (partial or total) of the services to which they have the right?

M.U: Unfortunately, people with mental disabilities do not have access to services – nor residential or alternative. In Bucharest there are no specialized residential services (public nor private). A few years ago, people from Bucharest could benefit of the services provided by the Neuropsychiatry Center for Recovery and Rehabilitation (CRRN) "Balaceanca". For the moment, this center can only assist people who live in Ilfov district.
We collaborated with other districts that have CRRNs' and we have solicited 2-3 places for our beneficiaries (the costs of accommodation and assistance were provided by the DGASPC Sector). But it is very difficult, because the number of places available is very small, almost inexistent.
We have approximately 5 requests per year. That is why we asked the Local Council of Sector 1 to approve our budget for building and arranging 2 family-type residential services (with 10 places for home). The negotiations are in progress.

A.T: What happens with people with severe disabilities living together with their family?

M.U:
Families are trying to support them. They take the person with severe disabilities to the hospital for a while or they have the support of their relatives.

A.T: In which field of services do you consider that there are problems caused by the inexistence of those services or by their poor quality?

M.U:
There are problems especially with the residential services for people with severe disabilities. The existing funds were not used. There are funds, although they are not local-funds. ANPH (National Authority for Persons with Severe Disabilities) had a few PINs. But we don't have the expertise for developing and implementing such projects. I will give you an example: our colleagues from DGASPC Calarasi have been working on a project for modernizing the CRRN from Plataresti. They were going to renew a building and construct two more. They haven't succeeded and the projects' deadline is near by.
There is another problem: it is considered that persons with severe disabilities (especially those with mental disabilities) "stand no chance". So there are no possibilities for recovery. The employees of these centers are not financially motivated. There are a small number of employees compared to the large number of beneficiaries and to the degree of difficulty of this activity. The initial training continues to be at a poor level.
I don't know if there are models of proper practices in Bucharest.

A.T: The problems caused by the lack of services, are they financial-type problems?

M.U: I wouldn't say there are financial-type problems. There were both external and internal funds. There are also possibilities for local financing (district councils). I think the cause is the lack of a professional expertise. The employees aren't specialized for specific types of disabilities. Meanwhile, I think we have been focusing too much on residential services, without developing alternative services.

A.T: What do you think about the cooperation between the city's sectors in planning and providing services?

M.U:

There are no problems at this level, but it is true that we do not interfere too much. For example, the cooperation between DGASPC Sector 1 and the Ministry of Public Health is based on punctual situations.: for a committed patient, waiting to attend the assistance services of DGASPC, we cooperate in realizing the psycho-social inquiry reports.

A.T: What are the main ideas / concepts the assistance of people with severe disabilities is based on? Are there any differences between the groups of service providers? Are there any stereotypes / prejudice?

M.U:
Yes, I think so. There is a new wave of opinions, opposed to the old one, based on the large residential institutions. Now we are focusing on de-instutionalization and developing alternative services or residential family-type services (of a small capacity). The ANPH stated the idea of small residential services.

A.T: Which are the biggest challenges regarding the development of the system of services for people with severe disabilities?

M.U: The use of standard evaluation instruments. It is a challenge and we know that ANPH is working on it.
The level of implication of parents has changed: they are starting to be more interested, to look, and to adapt.
There is one more thing: although the community is reticent in these matters, there exist some opportunities. For example, we lobby the Local Council of Sector 1 and we have good results, we have support.
Regarding the rate of employment of people with severe disabilities, we are starting to have good results.

A.T: What is your opinion regarding the person-focused services providment and the personal budget?

M.U: Theoretically speaking, it is possible. In case there were a sufficient number of services for those persons to choose their type of service, it would be possible. We had a case like this, when the beneficiary chose not to benefit from a specialized service.

Country: Romania

Service provider (private sector): Laila ONU – Executiv Director, “Pentru Voi” Foundation,

Date: **27.08.2007**

Place: Timisoara

Interviewer; Aurora Toea

The interview was made at “ Pentru Voi” premises, approximately two hours and completed by email by Laila Onu.

1. How do people with severe disabilities have access to specialized services they need*?*

Pentru Voi, as a community based service, provides people with severe disabilities with access to a specialized day center, where they can develop and find meaningful occupation. Besides education (social skills, self determination, autonomy), socialization (walks, visits, events in town), occupation (work for a multinational company), the day centre provides physiotherapy and psychological counseling. Specialized transportation is also provided – from the users’ homes to the day center and back.

Pentru Voi and, in most of the cases, the families as well, provides the support the persons with severe disabilities need in order to access the specialized or mainstream services. The staff from Pentru Voi mediates their relation with the local authorities (including the commission for the assessment of the disabled and the bureaucratic chain of reaching their rights).

2. What kind of people with severe disabilities cannot benefit (partial or total) of the services to which they have the right?

The most severe disabled, who need most of the services and support, are sometimes not included or partly included in the service provision. It is due to the limited budget, which does not allow the employment of, let’s say three support staff to deal only with one user. In the last year, since we have a new day center specialized only for severe disabled persons, we managed to include even profound disabled persons in our daily program (around 15 persons, out of 42). But still there are persons with no access to services.

Accessibility – physical and informational – is a big issue in the benefit of the services and rights they are entitled to. Most of them are not aware on the right and services they should benefit, so they need a representative.

4. In which field of services do you consider that there are problems caused by the inexistence of those services or by their poor quality?

All the services related to community. Except Pentru Voi's initiative, there are, country wide, less than 10 similar services. Still most of the disabled live in institutions or at home, with their parents, who get older and older and in most of the cases are overwhelmed. Persons with disabilities in general do not have access to community living facilities and mainstream services. Let's take hospitals for one example – they are not accessible, the doctors are not aware on the disability issue, they show no attention.

5. What do you think about the cooperation between the city's sectors in planning and providing services?

As far as Timisoara and Pentru Voi are concerned, I am pleased with the cooperation with the city hall. A representative of the town hall is member of our board and the city ensures the financial coverage of all our operational costs. Unfortunately, it still is, after ten years, a unique model of partnership in Romania.

Cooperation between different local authorities' services could be much improved. Data is not transmitted from one institute to another, so the person must queue for every little detail or information. And all the documents and recommendations issued by the state related to one person are vague and not at all specific to the person.

6. What are the main ideas / concepts the assistance of people with severe disabilities is based on? Are there any differences between the groups of service providers? Are there any stereotypes / prejudice?

There are local initiatives having as starting point NGOs and / or parents considering disability as a human rights issue and promoting the concept of community based services. Those services are based on shared values and principles, and respect the rights of the disabled. But still, mostly among the policy makers and authorities, renovated institutions are considered as very good alternatives for the disabled.

There are significant differences in the opinions of different groups of service providers and there are major gaps in the quality of the services provided by some NGOs and the state. There still functions a huge state owned mechanism regulating the disability field and the service provision system. There are also differences among the attitudes of the staff.

What they do not understand, in my opinion, is the simple concept that the service should be flexible and be focused on the person's needs. Authorities make exhaustive lists of services they considered needed and each provider shoud find its place in that list. But when talking about disability, it is impossible to make nomenclatures of services and fit the persons inside. The system should work vice versa.

One of the major prejudices we faced is that persons with severe intellectual disabilities can not live in the community. We have proved that they can and we plan to show it, with a strong voice, at national level and to the policy makers. Other stereotypes are: disability as a psychiatric problem, disabled are aggressive, dangerous, unpredictable. The adults with intellectual disabilities are seen as children, and consequently their rights as adults are not respected. They are not seen as useful to the society. Sometimes, disability is still related to a sin, or guilt or punishment.

We consider that these stereotypes are related to the poor information about disability and we plan to implement media and advocacy campaign showing the reality.

7. Which are the biggest challenges regarding the development of the system of services for people with severe disabilities?

Rigidity of the state system, prejudice, fear of losing existing jobs, fear of change, lack of initiative. Not the money, but the improper use of the money.

Training of the staff working in the system and the attitude towards the users is a major challenge as well. In the mainstream curricula, even in psychology faculty, topics related to disability are not included.

8. What is your opinion regarding the person-focused services provident and the personal budget?

This is how the system should work. It is the only way the person with disability is truly empowered.

But the legal system should be reinforced with a serious follow up on its implementation. Even if in Romania we have already the person centered approach and the personal budget mentioned in the law as general principles, these concepts are not at all put in practice. In the families most of the decisions are not participatory, so do not include the person with disability as well. The professional still consider they know the best for their client. Training and monitoring are crucial for a proper accomplishment of the system.

Country: Romania

Stakeholder: Mrs Monica Stanciu, Chief of Service, National Authority for Persons with Handicap

Date: October 24th 2007

Interviewees: Mrs. Aurora TOEA

Place

The interview was made at the headquarters of ANPH and took approximately 2 hours.

1. Could you comment on the description of the situation of people with severe disabilities in the summary of our national report?

You have a good grasp of the characteristics of the present situation in Romania. Romania has a new and modern law but there are still many things to do, as implementation of its provisions has brought to light the many remaining weaknesses: very hard to eliminate stereotypes and practices, limited local authority expertise in identifying needs, setting up adequate services and taking up responsibilities provided by the law, inconsistent approach of the disability sphere.
As far as concerns the typology of your preoccupations, we can specify that the law establishes 10 types of handicap (physical, visual, auditory, somatic, deaf-blindness, psychic, mental etc.) and 4 degrees of handicap: mild, average, accentuated, severe. There are no specific provisions for persons with severe mental disabilities. Rights and facilities provided by the law are approached from a handicap degree and not handicap type point of view, as for instance, a person with severe handicap is entitled to 179 lei monthly allowance, 80 lei complementary budget, a personal assistant employed by the city hall (more often than not the person’s own mother or some other family member), free urban transportation, 12 free railway tickets and so on.

According to ANPH statistic figures, there were 462.207 registered persons with handicap on 30 June 2007, of which 445.473 are in family care and 16.734 are looked after in social protection institutions. We should also specify that our institution is decentralised and does not possess its own mechanisms for collecting data, therefore using general directorates for social protection and child welfare as information resources, that is the very county institutions also responsible, among other things, for payment of persons’ with handicap entitlements.
Of the 462.207 persons with handicap, 94.110 are people with mental handicap, which represents 19,60 % of their total numbers. Statistic data are available on our institution’s website, www.anph.ro

2. Is there a clear definition of the category people with severe disabilities?

The intellectual disability concept is not included and defined in Romanian legislation. This category generally consists of persons with learning difficulties. There are medical criteria underlying appointment of a handicap degree. Such criteria are currently reconsidered in order to be able to insure a person's medico-psycho-social approach in view of providing the most adequate services the person needs. Persons with mental diseases are in the care of the Ministry of Public Health and not the ANPH.

3. In your opinion: What are the main risks of discrimination against persons with severe disabilities in your country?

ANPH efforts are directed towards reducing discrimination risks for all persons with disabilities, but one cannot ignore their existence and importance.

Discrimination risks occur on the person's evaluation. Evaluation is currently performed according to medical criteria only. As mentioned before, criteria meant to replace present ones show care for a much more detailed approach. This is the first time when the law provides for a person's multidisciplinary evaluation, from the social, educational and vocational viewpoint, but there are few adequate evaluation tools.

Discrimination risks increase with age. The person remains stigmatized if the educational path chosen has been special education – the person has no social abilities or has not been taught to develop any. He or she is unable to look for employment, receives no support/mediation services – all these being at pilot phase in our country.

Great difficulties are encountered in search for housing, the more so in the current housing crisis undergone by our entire society.

An additional very complex problem is providing legal assistance to persons with mental handicap and here too there are significant discrimination risks.

4. Could you explain how evaluation is performed for a child/an adult with disabilities?

On the level of each county or Bucharest city sector, there is one structure in place under the subordination of the county council, called the general directorate for social protection and child welfare (DGASPC), which is responsible for social issues on county level. There is a service in each such directorate in charge of complex evaluation, performing evaluation of children and adults according to criteria approved through order (legal act) and which are different from each other. The service for adult persons' complex evaluation (CES) has been recently created, based on the new law. The CES team makes the medical, psychological and social assessment, based on which it writes a complex evaluation report underlying the child's appointment of a handicap degree by the Commission for Child Protection, under the subordination of the county council.

As far as adults are concerned, the CES performs their social, medical, psychological and vocational evaluation, as well as assessment of their educational and social integration level. Based on this evaluation, an evaluation report is set up, which is submitted to the evaluation commission, which decides on the appointment of a handicap degree and, where necessary, the respective protective measures.

There are elements in common therefore: evaluation is performed by the CES, made up of specialists in various areas of expertise, based on criteria which differ from children to adults and their appointment of a handicap degree is made by a commission (one for children and the other for adults), under the county council.

The difference between the two consists in the ways of litigation: in the case of children, appointment of a degree of handicap may be disputed in court, whereas for adults, the contestant may first approach the higher commission (included in the ANPH structure) and then the court.

I would like to highlight the highest importance of evaluation again, as it places a mark on the entire person's destiny. That is why this should be done with increased professionalism, responsibility and adequate tools.

5. What are the key issues in national policy field for person with severe disabilities?

Present policies are directed towards respect of the rights of all persons with handicap, that is including the rights of persons who make the object of the study.

We are concerned about the situation of persons in residential care – reform of the inherited system (large residential units, remote from cities and employing insufficient and untrained staff) is a priority. Large institutions have to be restructured and community based alternatives have to be created. This process has already started, and many counties have found solutions to close such institutions; each county has a restructuring plan, approved by our institution, which has been interested in suitability to goals of the National Strategy for the protection, integration and social inclusion of persons with handicap.

It is to the same extent that we are interested in the issue of people living in family care and development of a large range of community based services in support of persons with handicap and their families – day-care centres, respite centres, counselling services. The legal framework for Protected Working Units has recently been defined in order to favour professional integration of persons with disabilities.

6. Are there specific policy programmes for persons with severe disabilities in preparation?

As already mentioned before, the ANPH has no specific programmes for this type of persons, but persons with severe disabilities fall under the general category of our programmes beneficiaries.

Once the types of disabilities have been more clearly defined, we need to make a detailed evaluation of priorities for each category as such, in order to set up specific programmes as a next step.

7. To conclude, could you mention three priority elements which, in your opinion, can make an essential contribution to improve people's with severe disabilities quality of life?

The first such element is ***ongoing monitoring*** of such persons' situation. Lack of objective and updated information preclude sound analysis of the issue and elaboration of efficient programmes.

The second element is ***correct monitoring*** of such persons' situation. Evaluation is decisive for an individual's life and we are in charge of the course established by the evaluation commissions.

The third element is ***training of the staff***, including not only all staff categories – from specialists working in the ministries, going through DGASPC directors and heads of services, to the personal assistant and carer, but also local authorities in cities and villages, who are not outside the system; on the contrary, they have and should take up great responsibilities in integration of people with disabilities.

Study on the Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs

www.non-discrimination.eu

Country Report Spain

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Tender on Behalf of the European Commission
D.G. Employment, Social Affairs and Equal Opportunities
Integration of People with Disabilities - Unit G3

Table of Contents

Selected Stakeholder Interviews

1. Summary

This paper contains information on the specific risks of discrimination people with severe disabilities and complex needs have to face in Spain. Due to lack of space, references have not been added to this paper but are part of the annotated bibliography.

An introductory part presents general aspects of categorisation approaches, availability of data and eligibility procedures. According to disability statistics, around 2 % of the population is categorised as ‘severely disabled’, but as there is no homogeneous categorisation system, available data might not represent prevalence adequately. Following a life-course systematic, the main part of the paper consists of 14 sections with a nearly identical structure. Firstly, a description of the general developmental tasks for all people in modern societies in a given phase of life is provided. As people with severe disabilities are depending on specific arrangements or support to cope with life challenges, especially in periods of transition, the availability of support services or barrier-free conditions are crucial for social participation rsp. discrimination. Secondly, for each phase of life or dimension the characteristics of the support system and other relevant information are presented in a very dense form. On that basis, thirdly, specific risks of discrimination for people with severe disabilities or complex needs are formulated as essential for a given life phase.

The Law 51/2003 prohibits discrimination on the grounds of a citizen’s disability, LISMI (1982) and the Law 39/2006 (Work and Social Affairs) provide a common framework for legislation and policy in the field of rehabilitation and social care for disabled people. Despite an increasing sensitivity towards civil rights, people with severe disabilities and/or complex needs are under high risk of discrimination especially as far as their social rights are concerned. New laws still recent and not fully applied, cultural and physical barriers, availability of services non homogeneous in all over the territory, intersectorial co-ordination or State budgetary allocations to face their needs, not only in terms of rehabilitation but also in terms of full social participation, hinder the real chances of these people to exercise their rights and live a full life as the rest of the citizens.

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Este informe contiene información sobre los riesgos específicos de discriminación en personas con discapacidades y necesidades complejas de apoyo en España.

En la introducción se presentan aspectos generales de enfoques de clasificación, disponibilidad de datos y procedimientos de reconocimiento de minusvalía. Con respecto a esto, las estadísticas disponibles indican que alrededor del 2% de la población tiene una discapacidad severa. Dada la falta de unificación de los sistemas de clasificación, estos datos pueden no representar la prevalencia de forma adecuada. Siguiendo una sistemática de “curso de la vida”, la parte principal del informe consiste en 14 secciones con una estructura bastante parecida. Primero, se describen cuáles son las tareas de desarrollo general en cada etapa de la vida para todas las personas en una sociedad moderna. Como las personas con discapacidades severas necesitan de una organización de soporte adicional para afrontar los retos que se le presentan en la vida, especialmente en los momentos de transición, la disponibilidad de servicios de soporte o condiciones de accesibilidad, son cruciales para su participación social respecto a la discriminación. En

segundo lugar, para cada fase o dimensión de la vida se presentan las características del sistema de soporte y otras informaciones relevantes que describen la situación a nivel nacional. En base a la descripción anterior, en tercer lugar, se presentan los riesgos concretos de discriminación para las personas con discapacidades severas o necesidades complejas formulados como esenciales para una fase dada de la vida. La ley 51/2003 prohíbe la discriminación debida a motivos de discapacidad, la LISMI (año 82) y la actual ley de promoción de Autonomía Personal (año 2006) proporcionan un esquema común, regulando derechos, servicios disponibles para las personas con discapacidad. A pesar de ello, las personas con discapacidades severas y necesidades complejas de apoyo se enfrentan a importantes riesgos de discriminación especialmente con respecto a sus derechos sociales. Nuevas leyes todavía recientes y no completamente aplicadas; barreras culturales y físicas; disponibilidad de servicios desigual a lo largo de todo el territorio; problemas de coordinación intersectorial; calidad de servicios disponibles; dotación de recursos económicos del estado para hacer frente a sus necesidades, no solo de rehabilitación sino de participación social plena; dificultan las posibilidades reales de estas personas de una vida en igualdad de derechos que el resto de ciudadanos.

Ce document contient des informations sur les risques spécifiques de discrimination auxquels doivent faire face les personnes avec des handicaps sévères et des besoins complexes en Espagne.

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Ce document est un aperçu des risques spécifiques de discrimination que rencontrent les personnes avec des handicaps sévères et des besoins complexes en Espagne.

Une introduction présente des généralités sur les approches de classification, la disponibilité des données et les procédures d'éligibilité. Selon les statistiques relatives au handicap, environ 2% de la population est classée comme «sévèrement handicapée », mais comme il n'existe pas de définition homogène, les données disponibles pourraient ne pas représenter correctement la prévalence. Le corps du rapport suit les cycles de la vie et se compose de 14 sections avec une structure presque identique. D'abord, une description du développement de l'individu dans les sociétés modernes à une phase donnée de vie. Comme les personnes avec handicaps sévères sont dépendantes, pour affronter les défis de la vie, de dispositions ou de soutien spécifiques particulièrement pendant les périodes de transition, la disponibilité des services ou l'absence de barrières sont cruciales pour elles. Ensuite, pour chaque phase de vie, les caractéristiques du système de soutien ainsi que toute autre information appropriée sont présentées sous une forme très condensée. Enfin, des risques spécifiques de discrimination pour les personnes avec des handicaps sévères ou des besoins complexes essentiels pour cette phase de la vie sont formulés.

La Loi 51/2003 interdit la discrimination en raison du handicap d'un citoyen, LISMI (1982) et la Loi 39/2006 (Travail et Affaires Sociales) donne un cadre à la législation et à la politique dans le domaine de la réadaptation et des services sociaux pour les personnes handicapées. Malgré une sensibilité croissante aux droits civils, les personnes avec des handicaps sévères et/ou des besoins complexes présentent un risque élevé de discrimination, notamment en ce qui concerne leurs droits sociaux. Mais les chances réelles de ces personnes d'exercer leurs droits et de vivre pleinement comme le reste des citoyens sont diminuées par des lois encore récentes et pas entièrement appliquées, des barrières culturelles et physiques, une disponibilité des services non homogène sur l'ensemble du territoire, une coordination intersectorielle ou des dotations budgétaires d'État insuffisantes pour faire face à leurs besoins, non seulement en termes de réadaptation mais également en termes de participation sociale..

2. Introduction

National Approaches to identify the group of people with complex needs.

In Spain, the “official” **status of disabled person** and the scale to assess the disability has existed for over 20 years. This scale (Royal Decree 71/1999) is intended to define the procedure that needs to be followed in order to admit, pronounce and grade a disability. It comprises four independent scales:

- A scale to assess the deficiencies, which also contains a reference to daily living limitations. Eventually, it grades global disability.
- Two scales to assess limitations in activities such as the use of public transportation and the support required in activities that involve mobility, self-care and psychic autonomy.
- A scale to assess environmental and personal factors in context: scale of social complementary factors.

The first scale is used to determine the **activities of daily living** (ADL), which are divided into *self-care* and *other activities* of daily living. Then, the scale tries to establish the severity of the disability using a “qualitative” classification of 5 types, depending on which activities of daily living are being affected, either the *self-care activities* or the *other activities*.

- *No Disability* (Class1:0%): There might be some deficiencies but these do not justify a decrease in the ADLs.
- *Mild Disability* (Class 2: 1-24%). The deficiencies justify some difficulty in the ADLs.
- *Moderate Disability* (Class 3: 25-49%). The deficiencies provoke a significant decrease or impede the realisation of some ADLs but they do not affect self-care activities.
- *Severe Disability* (Class 4: 50-70%). The deficiencies provoke a significant decrease or impede the realisation of some ADLs. Some of the self-care activities can be affected.
- *Very Severe Disability* (Class 5:75%). The deficiencies are severe and impede the realisation of all ADLs.

Next to the scale that determines the degree of disability, there is also the **“Checklist to determine the need of a third person’s support”**. The latter has not been used by every Autonomous Community. To be entitled to receive specific and non-contributive financial aid in a situation of dependency, the person needs to score, at least, 15 points in the checklist. The whole checklist is comprised of 40 items, and it focuses basically on the evaluation of self-care and mobility activities, but at the same time, gathers information on other activities, context factors and the need for special support.

In April 2007, a new checklist scale was approved (at national level) that will serve to identify the degree of “dependency” for the later application of the provisions system planned by the Law for the Promotion of Personal Autonomy (2006).

This new concept of “dependency”, clearly influenced by the ICF, sympathises with the need to be helped in the performance of Activities of Daily Living (ADL) defined as: “Those activities a person performs frequently that allow him or her to lead an independent life, feel integrated in his or her normal environment and fulfill his or her social role”. These activities are classified into 9 groups: application of learning and knowledge; general tasks and demands; communication; mobility; self-care; domestic life; interaction and personal relationships; main areas of life and social, civic and community life. It evaluates the degree and level of dependency from the age of 3 and establishes the specific assessment checklist for children under 3. It determines objective criteria to assess the degree of autonomy for people, their ability to perform basic activities of daily living and their need for support and supervision of people with intellectual disability or mental disorders. The assessment takes into account any reports concerning the person's health and his or her environment. It also allows determining situations of moderate dependency, severe and very severe dependency.

a) Grade I: moderate dependency. The person needs help to perform several basic activities of daily living, at least once a day; the person needs support on a periodical basis or is limited to exercise his or her autonomy. The person should score between 25 and 49 points on the Disability Rating Scale (DRS).
b) Grade II: severe dependency. The person needs help to perform several basic activities of daily living, twice or thrice a day, but the person does not need the permanent support of a caregiver or needs wide support to perform his or her personal autonomy. The person should score between 50 and 74 points on the Disability Rating Scale (DRS).
c) Grade III: very severe dependency. The person needs help to perform a number of basic activities of daily living, several times a day, and because the person lacks the physical, mental, intellectual or sensory autonomy, he or she needs permanent support from other persons or has general support needs for his or her autonomy. The person should score between 75 and 100 points on the Disability Rating Scale (DRS).

So far, Spain has not had a homogeneous method or instrument to assess situations of dependency. On the contrary, the range of scales has been multiple. These scales have been mainly used, adapted or invented with regard to people with very severe disabilities of diverse typology, who live in residential services. A second approach to these assessment scales is the "social and health" approach. This approach is the result of the attempts to co-ordinate the social and health services of the different Autonomous Communities.

The responsibility of the assessment is clearly conditioned by the assistance model and its funding sources. In this way, the governments of the Autonomous Communities finance and are organise the residential model (which at the same time is co-financed in the social and health fields for providing other services) and local entities in charge of the home assistance model.

We find assessments or dependency scales that come from the following systems or services:

1. Health; hospital application (treatments, referrals, home hospitalisation, palliative care, etc).
2. Health; itinerant services application (home assistance, coordination with hospital referrals, referrals to social and health services).
3. Health; middle and long distance application (chronic diseases, rehabilitation…)
4. Social; social, and health services application and application to residential services for the elderly (social and health referrals, people with very severe disability over 65, etc).

5. Social; application to home and community-related services for people with disabilities (social and health referrals, people with very severe disability under 65, etc).
6. Social; application to home and community-related services (domestic help, day care centres, referrals).
7. Social; basic regulation on the assessment of people with disability at national level. (Non contributive financial aid on the grounds of support need by a third person, technical help and modification of architectural barriers, research of residual capacities, referrals to other services, etc).

To all these “official” dependency assessment scales we could add some more, for example, those which come from the social and incapacity for work or the legal or educational fields.

Available data on people with complex needs

The official available national data are the result of the “Survey on Disability and Health State” (EDDES, 1999) carried out by the Spanish Ministry of Work and Social Affairs on people residing with their families. The survey was based on the Recommendation for Physical and Psychological Dependency approved by the Joint Ministerial Committee of the European Council (1998) and is perfectly coherent with the International Classification of Functioning, Disability and Health (ICF) of 2001.

9% of the Spanish population have some kind of disability, this percentage is around 4,5% among people under 65. In the case of moderate, severe or total disability the percentage is about 2%.

According to other statistical sources from the year 2000, 1,550.000 people have achieved official recognition of their disability, which represents about 3.8 % of the Spanish population. This information contrasts sharply with the aforementioned data (4,5% of people with disabilities under 65). No data are available about the number of people with severe or very severe disabilities.

Classification systems, procedures and identification-practises

“Disability Certificate” applications are to be submitted to the Social Services of the Public Local Administration. Together with the application form, any medical, psychological and social report the applicant might possess, needs to be attached. Later on, the applicant will be invited to an interview with members of the Assessment and Advice Team (psychologist, social worker and doctor) in order to determine the degree of disability. If the applicant meets the minimum required, that’s 33%, the resolution will be communicated by post. This minimum must be met to be eligible for benefits and social resources. The whole process can take at least seven months.

The procedure to assess the degree of dependency that has been carried out during the last months can also be submitted to municipalities. At this early stage and given the large amount of applications to be assessed, the Provincial Public Administrations hire external assessment services to apply the Disability Rating Checklist. These services visit the applicants at home or the facility they reside in, and by applying the checklist they score the level of assistance required. The result will be a degree of dependency and subsequently, the kind of benefits they have a right to, according to the law.

Until now, the Administration resolves to which existing services the case should be referred. This is done on the grounds of a global diagnose of the person and the various existing institutions that provide specific services (intellectual disability according to degrees, cerebral palsy, autism, mental disorders, etc.). Regarding the allocation of places in the different types of services, the procedure might vary. In the case of places in public services, the administration makes unilateral decisions. In other cases, the administration comes to an agreement with the agency, once the latter has met the person and determined whether they can help or not. This is mostly the case of non-profit organisations that have agreements with the Administration.

3. Pre-Natal Diagnosis and Counselling

Through the extended possibilities for family planning, parenthood in modern societies has increasingly become a question of individual decision-making. Prenatal diagnostics and reproduction technologies permit the inclusion of characteristics of the fetus in this decision. This extended knowledge brings individuals into difficult situations when they have to make decisions regarding children. These individual decisions are affected by social values, attitudes, anxieties and knowledge of disabilities. They are also influenced by the quality of the counseling process if professional support is available and used. It is important that individual decisions are accepted by the social environment of people concerned. How is this achieved?

3.1. Description of the National Situation

The Health Act foresees prenatal diagnosis in women over 35. Prenatal diagnosis should be done before the 24th week of gestation, are free of charge and conducted with the mother’s consent.

It is the obstetrician who advises the mother to undergo the diagnosis tests, explains the procedure, the possible consequences and the decisions that might need to be taken after them. Our society is constantly sending subliminal messages in which consumerism and beauty prevail. If a prenatal diagnosis results in a confirmed disability it is very likely that the woman will want to terminate her pregnancy. The most frequent forms of prenatal diagnosis are amniocentesis and chorionic biopsy. There are few genetic abnormalities in which the foetus can receive the appropriate treatment; in most of the cases there is no effective intrauterine surgery. Some genetic advisors might advise to carry the pregnancy to term arguing that the newborn will be healthy. However, there are few professionals and parents of people with disabilities who disagree with this opinion.

The Organic Law 9/1985 considers that abortion is not punishable if this is performed within the first 22 weeks of pregnancy when there is a substantial risk that if the child were born it would suffer from physical or mental abnormalities as to be seriously handicapped. Another exception establishes that therapeutic abortion can be performed at any time to preserve the physical or mental health of the pregnant woman. In the first case, at least two qualified specialists must certify that abortion is necessary. Most of the abortions in Spain are performed under the second claim, 98% of them to avert a serious risk to the mental health of the pregnant woman, which may conceal reasons prohibited by law. In practice, these kinds of abortions are performed in private clinics. In the year 2002, 70 000 legal abortions were performed in Spain, 8.4% per 1,000 women. 2.53% of these abortions are performed on the grounds of genetic malformations of the foetus. Although abortion rates are not official, an estimated 300 000 abortions are performed every year. The government has alluded to surveys that indicate that 65% of the Spanish citizens are in favour of the eugenetic abortion.

3.2. Specific Risks of Discrimination

Eugenic abortion is partly justified by the lack of assistance by the Administration to children with disabilities. The current law deals with an unfair situation: on the one hand, there are the families who decide to have a disabled child and do not receive any help; on the other hand, there are the cases of the “wrongful birth”, in which the mother sues for being burdened with a disabled child, something she could have avoided. The mother might receive in this case important compensations.

The pregnant mother runs the risk of receiving wrong and hasty information, in many cases the result of ideological issues or of receiving an excessively unilateral advice in which all possible options are not discussed with the mother.

4. Early Childhood

For most families, having a baby creates a situation of uncertainty and a need for direction and guidance. Living with a baby or a young child with a severe disability or with severe developmental problems brings parents into a situation with specific and difficult challenges and dependencies. Psychological stress in their daily lives often makes it difficult to cope with their parental responsibilities. When dealing with educational tasks or when specific therapeutical or medical treatment is necessary, parents cannot refer to their own educational experiences, but are dependent on professional support of various kinds. Having access to good medical care, self-help groups and early intervention services from a very early age of the child are decisive factors both for the personal development of the child and for the successful adjustment and coping process of the parents. How is this achieved?

4.1. Description of the National Situation

The National Health System legally covers this stage at national level: Healthy Child Programme, Neonatal Examination and Application of Therapeutic and Rehabilitation Procedures, all of them considered a universal right.

In the field of public health, paediatricians and paediatrician’s nurses are the central figures in local health centres and serve as a reference to parents and other programmes and community services. They can request complementary medical tests and consultations with specialists and/or hospital services.

The Quality and Cohesion of the National Health System Act (1672003) assumes responsibility in matters of Early Intervention such as information and follow-up activities regarding Health Promotion, Basic Rehabilitation, Intervention and Specific Services for Childhood.

Until now, despite the existence of a legal national framework, there have been great co-ordination problems and important inequalities among the Autonomous Communities who have powers over the arrangement and provision of education, health and social services.

These problems and inequalities are related to implementation, resources of the early detection plans and treatment of developmental disorders until the age of 6 (50 000 children with some type of disability, 2.24%.

The family, the child's paediatrician or other organisations can demand intervention. Early Childhood Intervention Centres (CDIAT) are the foremost specific structures available: 800 all over Spain. These rehabilitation services are currently linked to the national hospital network (in the case of severe pathologies that need ortopedic, traumatic and neurological rehabilitation); to public rehabilitation services; to specific centres generated by the associative movement and finally to private centres agreed with the Social Services. All of them, to a certain extent, have an interdisciplinary character. Some Autonomous Communities still lack the necessary infrastructure to cover children and families' needs, 20 years after the activation of these centres.

In short, no public and universal guaranteed service exists. The existing services find themselves in an intersectorial vacuum where the health system, nor the education administrations, nor the social services want to bear responsibility.

4.2. Specific Risks of Discrimination

Health personnel is not always trained to inform about a disability, deal with parents and listen to them in order to make a diagnosis and most of all, to deal with a disabled child so that he mustn't wait long at the doctor's practice. When a child is discharged from hospital, there is no co-ordination between the paediatrician and the services he shall be referred to.
At the moment, there are some Early Childhood Intervention Centres that are not specialised in early intervention and work with non-qualified personnel. These centres do not fully cover the child nor the family's needs.

If a child with complex needs is born in Spain within a family of immigrants who have no residence permit, he faces greater chances of discrimination.

Another disadvantage is added if the child lives in certain Autonomous Communities where the resources are not organised by areas, (for example, in rural areas). The location of the Early Childhood Intervention Centres, usually far from other primary attention services and family services, hinders the necessary contact with other professionals, the acquaintance of the patient with the natural environment and the socio-economic reality of each community.

The costs derived from technical aid, tansportation and/or consultations to specialists are usually higher than the financial aid received by the families, which might cause difficulties to gain access to the required services. There is a lack of definition of the powers, follow-up strategies and co-ordination among the involved public and private administrations as well as a deficiency of protocols in the minimum number of activities that need to be developed regarding the individual planning of the intervention. There is a lack of global, individual and natural environment interventions, and there is a lack of involvement of all actors, especially that of the child and his family, who should be active and key participant in the process.

5. Childhood: Education and Care

Preschool institutions like inclusive or special kindergartens offer care and education for younger children. They prepare children for school and give them the opportunity to interact with peers. Young girls and boys can broaden their experiences in life and enhance their social skills.
Children with severe disabilities have the same need to interact with peers, to make friends outside the family and to view themselves as a part of a social group. But young children with complex needs are dependent on additional support to participate in preschool education, such as barrier-free access or well-trained educators with specific skills and the intention to cooperate with other professionals. How is this achieved?

5.1. Description of the National Situation

In Spain, the entry of women into the labour market brought about the arrival of kindergartens. They served as a social assistance service for families and did not have a well-defined educational purpose. Similarly to what happened in the rest of Europe, kindergartens developed, on the one hand, due to social demands and, on the other hand, due to its consolidation as a public service with a decidedly educational approach in a second phase.

In Spain, Preschool Education (between the ages of 0 to 3) is optional. Although art. 15 of the LOE (Organic Law on Education) states that Public Administrations will promote a gradual increase in the number of public preschool places and will guarantee enough public preschool places, either in public or private financed schools. However, the offer is still inferior to that of the following period (between the ages of 3 and 6). This situation hinders the equality of opportunities for children with disabilities in that age group.

The Act 39/2006, on “Promotion of Personal Autonomy and Care of Dependent People” has regulated, 24 years after the LISMI Law, and without detriment to the services established in the fields of Education and Health, specific services for children under the age of 3 according to the degree of disability, as a universal and subjective right. These specific services are the following: Home Assistance (art.23); Financial Aid for specific services and support to non-professional caregivers. The Royal Decree 504/2007 approved the checklist for the assessment of the degree of dependency of children under the age of 3. The Autonomous Communities will be responsible for the application of this regulation for which they will receive direct funding from the State.

The economic contribution that beneficiaries will have to make in order to cover the expenses of the service has not been established yet. However, the criterion that will be adopted according to the type of services and economic resources has already been made public. The Act contemplates the development of a Comprehensive Plan of Assistance for dependent children under 3 carried out by the Public Administrations. This Plan would facilitate early intervention and the rehabilitation of their physical, mental and intellectual capacities. Among other requirements, the children must prove residence in Spain. The Ministry of Work and Social Affairs estimates that about 3 000 children might benefit from this right.

5.2. Specific Risks of Discrimination

The choice of kindergartens is scarce, unsatisfactory, deficient, and poorly organised for this age group. Because kindergartens are not widespread services and the number of them increases gradually, they do not always have the necessary resources (e.g. support personnel) to assist children with complex support needs. For this reason, these children have more chances to be excluded from the existing services.

6. Childhood and Youth: School

Schools are responsible for a child's education and the teaching of knowledge of varying subjects. Furthermore, school proves to be an important part of young peoples' socialization process by offering the chance to enhance social skills and deepen social contacts with peers.
Children with severe disabilities also need high quality education and access to public schools. Pupils with complex needs are dependent on additional support in order to participate in school education, such as barrier-free access or well-trained teachers with the intention of cooperating with other professionals.
But especially pertaining to them, schools often exercise a kind of segregation. How do children with complex needs find their place in the school system, in which way are their special needs considered and how do professionals cooperate together?

6.1. Description of the National Situation

Both the National authorities and the authorities of the Autonomous Communities share the responsibility for education. National authorities define education as a universal and complimentary right for children between the ages of 3 and 18 (compulsory for children aged 6 -16) and the integration principle of joint schooling for normal children and children with special educational needs (SEN). They also design the school curriculum and the organisation of the centres. Regional authorities are responsible for the direct management of public schools or the agreement with private schools within the different geographical zones to ensure that every child receives education according to law.

The National Law configures special education as a last resort and specific offer for children seriously disabled whose complex needs cannot be cared for at ordinary centres. Special education can be provided until the age of 21 for those cases that cannot receive support at ordinary schools.

The fact that every autonomous community has the power to implement educational policies has led to an uneven development of the education among the programmes in ordinary schools or in special education services for children with complex support needs in the Spanish territory.

In practice, special education schools are the common model for this kind of pupils. Yet, special education classrooms are also available within other specific services such as day care centres, occupational centres or adult residential services. In many cases, these units are managed by Associations of Relatives and in agreement with the Public Education Departments. The teaching staff is comprised of teachers with a degree in Special Education, who receive their salary from the Public Administration Departments. In this case transportation is complimentary for the children. In rural areas this is the most common model. The “closed” classroom model within ordinary schools that has been developed in 4 autonomous communities provides one special education teacher and one assistant for a group of 4 to 5 children with SEN in a classroom. These children will share for the most part recreational activities and some teaching hours or subjects with other non-disabled children.

Both models involve professionals such as social workers, psychologists, speech therapists, physiotherapists and counsellors. The curriculum of special education centres must be based on the general skills taught in Primary Education. However, for those pupils with severe disability some restructuring needs to be made concerning Identity and Personal Autonomy, Awareness of the Environment, and Communication. The Ministry of Education estimated that, in 2006, 48.2% of the children with multiple deficiencies and 19% of children with autism were attending school in specific centres. It is interesting to highlight that in certain cases, for example the Basque Country, 95% of the children with Special Educational Needs (SEN) attend ordinary schools.

According to data provided by CERMI, in 2004, 37% of the children with disabilities or their families experienced some kind of discrimination at the moment of integrating into the ordinary education system. Discrimination was more manifest in the cases of intellectual disability, mental illness, multiple deficiencies and sensory disability than in the cases of physical disability. These discriminatory practices seem to happen more often in Primary and Secondary education than in Preschool education.

6.2. Specific Risks of Discrimination

In practice, present regulations on education do not guarantee the right every child with SEN has to a school place that provides him with all the necessary support, in a public or agreed school near to his residence and where his brothers or sisters also attend. This situation aggravates in rural areas: schools are usually located far away and children are forced to travel; establishing social contacts with other children their age within their natural environment becomes an almost impossible task.

In ordinary schools, the teaching staff is not always trained to take care of pupils with SEN, mostly because this kind of support is not part of the educational projects and curricular planning of the centres. This situation repeats itself with regard to academic programmes for educational studies that not always include didactic strategies for children with complex support needs. Depending on the Autonomous Community where the child lives, access to ordinary schools will be more or less limited. Segregated schools are the most frequent choice and available option for this group.

7. Childhood and Youth: Housing and Family Support Services

Due to the variety of modern family life, all children grow up in different environments. These environments can be understood as a social network including all sorts of relationships to individuals or institutions. The family’s living conditions during childhood are very important for social inclusion of the young person in society. The family has a strong impact on his/her primary socialization and influences the access to certain social institutions.

Family support services offer community-based professional support and services for families. Some children and young people live in a foster family, others in foster homes. Are such support systems available? In which way are children with severe disabilities or complex needs and their families involved in these support systems?

7.1. Description of the National Situation

The LISMI (Law on Social Integration of Disabled People, 1982) acknowledges the right of people with serious disabilities to receive home care, personal and domestic assistance. Therefore, it relegates residential services and home groups in the community to cover the basic needs of people with disabilities who do not have a home or a family, or present major problems of integration into their families.

According to EDDES (1999), in Spain about 25 000 people aged 6-14 with severe or total disability and who live with their parents, need support for basic or instrumental activities of daily living.

Until now, professional and family support services related to this age group and this particular environment have been the responsibility of the Social Services, which designed programmes that were, or were not, renewed on a yearly basis, depending on the budgetary resources. The programmes were usually designed according to the different services (family support, family respite, leisure, family counselling) together with Associations of Relatives.

Respite services have been provided at weekends in residencies or home groups. Residencies that allow people with disabilities to stay temporarily are not common use, which makes it especially difficult for the family during the two months of the summer holiday.

The Childhood Services of the Local Administrations determine who the Foster families or Substitute Homes will be if the true family of the child cannot take care of the child or in case of social problems. In these situations, the responsibility and guardianship of the child will have to be assumed by the Administration. It is not habitual to use long-term residence services for this age group, but if necessary it is usually the case for boys or girls with multiple disabilities or behavioural problems.

7.2. Specific Risks of Discrimination

The insufficient network of support services, information and family counselling, respite services and guidance and behavioural support services at this stage of life is especially risky for people with intellectual disability and mental illness or serious behavioural problems because this might lead to an institutionalisation or early departure of the child from the family home. The social service system that has been developed for this stage of life is insufficient, new and varies among the Autonomous Communities, as well as being characterised by the scarce presence of community support.

8. Childhood and Youth: Leisure Time

Young people use their leisure time to do enjoyable and amusing activities and to get free from daily routines. Often free time activities are organized in clubs or in various forms of sportive or cultural associations. But youngsters also spend their free time with peers without adults. Many experiences among young people of the *same age are made spending leisure time together, e.g. discovering new social roles, social spaces, friendship or falling in love. Youngsters with severe disabilities or complex needs have the same leisure time needs as their non-disabled peers, but are dependent on additional support to participate in mainstream leisure time activities. How is this achieved?*

8.1. Description of the National Situation

In Spain there is no specific legislation that takes into account this period of life. Kids or youth clubs are the most widespread leisure system for this age period. These clubs can be private, promoted by the local community, or can belong to religious organisations.

In accordance with non-discrimination legislation, any person is entitled to join these clubs. However, disabled people might come across architectural barriers that hinder physical access to the facilities, since the implementation of the Law on architectural barriers is quite recent. Most of the people with disability do not participate in these ordinary leisure groups and people with severe disabilities are an exception, although no data on the subject has been found.

The most frequent leisure programmes are organised by associations of users or relatives of people with disabilities that, at best, receive partial funding from local social services when their budgets allow them so. They usually offer regular activities of 2 or 3 hours per week, weekend excursions and dance and computer courses; during the summertime it is possible to go for 10 or 15 days to youth hostels located in cities or towns all over Spain. These activities are usually arranged in large groups, more than 10 people, accompanied by volunteers. Some Autonomous Communities also organise sport activities.

In the last two years there have been some attempts to provide customised leisure activities such as trips based on the common interests of several people accompanied by a volunteer. The type of activities they participate in, having a drink, going to the cinema or the disco are carried out within the community but they are not socially integrated. Access to these programmes of activities is more difficult for people with complex support needs, and even more difficult if the person lives in a residential home. In these cases, leisure activities are planned by the centre and carried out by their own staff.

As these programmes depend heavily on the agreements and annual subsidies of the Department of Social Services, they do not cover the current demand. Apart from the partial financial aid, the users contribute by paying a membership fee and part of the costs of the specific activity.

The support and variety of leisure activities for people with complex support needs depend largely on the family and will be more or less diverse according to the leisure activities of the family itself.

8.2. Specific Risks of Discrimination

People with more complex needs cannot enjoy leisure activities within normalised groups. In most cases, and above all if they live in residencies, they do not have access, or this is very limited, to specific leisure activities organised by associations of relatives. The activities might encounter transportation problems because not all local public transport is adapted to the needs of people with severe disabilities. This sort of problem happens mostly in rural areas or in home groups where there is less personnel and it is difficult to find support volunteers. The costs of the activities can also constitute an obstacle because the financial aid many families receive is used to cover the basic expenses. The timetable, typically from 14.00 to 19.00, of the activities, offered by these specific leisure groups does not always allow participation in community activities such as going to the cinema, a concert, etc.

9. Youth and Young Adults: Vocational Training

A successful transition from school to the employment system is usually related to vocational training. After finishing school young people need to find a job according to their interests and abilities with which they can earn a living. Vocational training prepares for the access to the employment system and is an important step into adult life. Youngsters and young adults with severe disabilities are dependent on adapted training courses, assisting technologies, other individual support and barrier free infrastructure to enable their access. How is this achieved?

9.1. Description of the National Situation

According to data from 1999, 35% of the people with disabilities between the ages of 10 and 64 had not completed primary education, whereas the same range of general population of the same age group who had not completed their studies was only 11%. The education level of people with disabilities is related to gender and age but also to the type of disability. The highest levels of education were found among people with sensory disabilities. On the contrary, the lowest levels of education were found among people with intellectual disabilities and behavioural disorders, communication and learning problems and self-care problems. People with physical disabilities were situated in an intermediate group.

The basic national legislation is the “Law on Education 2/2006 LOE”, and it must be applied 5 years within its publication date. Secondary Education, from the age of 16, marks the need to combine the principle of common education with attention to diversity by adopting organisational and curricular measures.

Compulsory Secondary School lasts for four years. According to law, the Public Administrations of every Autonomous Community must organise the corresponding vocational qualification programmes intended for students older than 16. As a rule, the complete programme will comprise 2 learning cycles, a middle grade and a superior grade, and provide different branches of learning in accordance with the national catalogue of qualifications. The curriculum of vocational training must include, as stated by law, practical training in work centres and promote training adapted to specific needs. It is also the responsibility of these administrations to reserve a number of places for students with disabilities.

In order to gain access to vocational education, compulsory secondary education has to be completed. However, the admission requirements to vocational education are more flexible and defined by the public administrations for students over 17. Apart from Vocational Education, there is also Arts Education (music, dance, drama, fine arts and design) that can be combined with compulsory secondary education or with vocational training. In practice, people with severe disabilities, intellectual disabilities included, do not have access to the ordinary programmes of vocational education. They remain in special education schools where they are allowed to stay until the age of 21 and follow an alternative and specific programme called “Transition to Adult Life”. These courses are not the equivalent of ordinary classes and a connection with the ordinary system practically does not exist.

Another national system is the INEM (National Employment Institute), which offers training courses for unemployed people who did not earn a vocational education diploma. People with severe disabilities do not have access to this service.

9.2. Specific Risks of Discrimination

People with severe disability and complex support needs have problems to gain access to ordinary vocational school programmes, even not to specific courses for people with disabilities owing to the lack of support personnel their condition requires. They may have to confront problems such as architectural barriers, poorly trained personnel and administrative obstacles.

10. Children and Adults: Social Security and Health Care

Modern societies are shaped by an enlargement of welfare systems and an increasing dependence on social security institutions. It is a challenge for all citizens to clarify their entitlements and to find access to services. The need for basic social security and to have access to health care services if necessary is important for all people.

In most cases having complex needs leads to an increase of dependence on social benefits and requires special support and services granted by welfare administration boards. Bureaucratic procedures of application approval create special risks of stigmatization. Allowances, benefits and services can improve the possibilities of individual participation, but can also initiate processes of social exclusion. How is this achieved?

10.1. Description of the National Situation

The General Health Law (1984) and its later adjustments organise the health benefits of the general health system in Spain. In the beginning, the health system covered possible health risks by applying work-related dues. Subsequently, the law has experienced a major development and has enlarged the list of pathologies within the benefits’ framework. Thus, including a greater number of people and communities fall within the health system and health network at a national level. The foundation of this law is that every citizen has a right to health services and it grants political power to the autonomous communities for a further development. It covers areas such as health benefits in case of illness or hospitalisation; benefits for temporary disability leave; accidents, retirement and unemployment for every citizen who pays contributions. People who present a high level of disability (65% or more), are entitled to health benefits and financial aid through pensions granted by the health system or the administrations of the autonomous communities, even though they might not have paid contributions to the health system. In the case of financial aid, the amount is usually the equivalent of the minimum wage, and a bit higher if the recipient has been granted the help of third-person help. In the case of adults, some of these benefits are compatible with orphan’s allowances if the parents should pass away. In many cases, all these benefits do not cover the minimum income a person with complex support needs requires in order to gain access to the resources and options people without disabilities from their community might enjoy (housing, leisure, etc.) for which they usually depend on their families all their life.

The existing generic health services are insufficient for people with severe disabilities. Every autonomous community applies its own criteria with regard to health assistance provided to the different groups of people with disabilities. These differences usually relate to amount, quality and availability of the service. Examples are: the complimentary pharmaceutical benefits, the portfolio of services provided by the national health system, the universal accessibility to health centres, as well as the procedures, the family benefits for children under 18, dental and gynaecological services, etc.

A person who has been officially recognised as disabled or handicapped is entitled to receive the certificate of physical, psychic or sensory, which allows him to gain access to individual financial aid and support services. Adult people with complex support needs use more often non-ordinary specific health services and rehabilitation services since these are usually available in residential services or day care centres where they are taken care of. People with disabilities who live in normalised environments make use of the community health resources.

10.2. Specific Risks of Discrimination

On occasion, people with severe disabilities do not have access to all services the public health system provides. Sometimes, the difficulty lies in the insufficient training of the professionals and specialists who take care of them, in the information they receive or even in the physical access to facilities of the health services (e.g. adapted transport, mammography devices for people in a wheel-chair, adapted scales).

It can also occur that the systems, which grant the condition of disabled, do not assess correctly some of the disability conditions derived from mental health problems or brain injury.

Having access, to ordinary dental care, gynaecological check-ups, physiotherapy, etc is very complicated.

People, who have suffered a brain injury due to a car accident, are entitled to use the health system through the insurance companies. In many cases, the insurance companies are not willing to assume the expenses of the necessary treatments.

11. Adults: Work and Employment

Modern societies are shaped by an enlargement of welfare systems and an increasing dependence on social security institutions. It is a challenge for all citizens to clarify their entitlements and to find access to services. The need for basic social security and to have access to health care services if necessary is important for all people.

In most cases having complex needs leads to an increase of dependence on social benefits and requires special support and services granted by welfare administration boards. Bureaucratic procedures of application approval create special risks of stigmatization. Allowances, benefits and services can improve the possibilities of individual participation, but can also initiate processes of social exclusion. How is this achieved?

11.1.Description of the National Situation

The LISMI and the Labour Law 53/2003 contemplate the entry of people with disabilities to the ordinary or protected labour system. Several Royal Decrees regulate some measures that release companies partially or totally from the quota reserved to disabled persons; others that promote jobs for disabled people by merging the fees that companies pay to the national health system and others that regulate special employment centres, whose organisation is similar to that of ordinary companies but which comprise personal adjustment and social services.

Another existing regulation is the regulation of "labour enclaves"[1] used as a means to promote employment for people with disabilities. In short, there will be new regulations on employment with support. The current legislation does not contemplate an employment quota according to the level of disability but only according to the number of employees with disabilities. As a result, it often occurs that only people with mild disabilities are employed. No public funding exists to pay salaries that take into account the level of productivity.

The data provided by EDDES in 1999 estimated that about 32%, of the people with disabilities, in the working age, were employed. This is about half a million people. The rest (2 out of 3) were unemployed or had never worked. In order to evaluate these figures accurately we must bear in mind that the employment rate of the population at the moment the survey was conducted (64.5%) doubled the rate of people with disabilities. These data not only showed a very low employment rate but also a high unemployment rate (26.1% against 16.6% of the rest of the population).

Only, 1 out of 4 people in the working age is employed. The number of men that are employed is considerably higher that the number of women. When looking at younger groups, the differences between people with disabilities and the general population are not so significant. However, in the case of older groups the differences rise considerably. In conclusion, we might say that the employment situation is improving, mostly, for young people.

According to CERMI (2003), in Spain there are 1 000 000 people with disability in working age. A third of these people works in precarious jobs or is unemployed and only 10% has a steady job under good conditions. The employment rate (15%), apart from being very low, points out the existence of jobs inferior in quality to those of the general population. According to the results of the survey on discrimination for disability, 31% of the respondents declare having suffered some sort of discrimination at work.

Only 1% of the Spanish workforce represents people with disabilities. According to the employment rate, Spain is ranked 24 among the 25 countries of the European Union.

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[1] A group of people with disabilities works in a regular company but is supported by a supervisor. They are hired by the labour service for people with disabilities. They do not have any labour relationship with the regular company.

11.2. Specific Risks of Discrimination

People with complex support needs rarely find a job in the regular labour market. They are excluded from this market, partly because obligations to fulfil the norms on positive discrimination are largely ignored and because the law itself does not explicitly include this group.

The high degree of support the guidance and training of this group requires; their intensive support need both to access the labour market and to keep the job; the lack of flexibility of the existing types of contracts which should take into account these people's needs and finally the incompatibility of these contracts with the current system of benefits and assistance poses great obstacles for their integration. People with complex support needs hardly ever join occupational services and day care centres are the only social resource the law suggests. These day centres are usually specific centres according to the disability (cerebral palsy, intellectual disability, old age, autism, etc). The organisation of day care centres, normally segregated, with non-functional activities or activities that are not adapted to the chronological age of the users, turns these centres into places where the risk of inactivity and social exclusion is high.

12. Adults: Housing

Becoming an adult also means making up your mind about how you would like to live: stay in the natural family for a while, live alone, with a partner or family, with a friend, etc. Having privacy, a place to go to, feeling safe and comfortable there, realizing one's own ideas on how to live, are all very important for people in our societies. For people with complex needs it is a big challenge to find their own way to living. They have restricted alternatives for housing because they need barrier-free environments and life-long support. People with severe disabilities do not only need good support services but also counseling to realise their ideas and style of private living. How is this achieved?

12.1. Description of the National Situation

Many people with complex support needs can principally count on their families' support. Home assistance depends on the social services of the municipality. Most of the people with support needs, in their adult age, live in residential services, specific residences according to the type of disability, which accommodate between 60 to 100 people. To a lesser degree, they live in home groups in the community.

Until now, people with complex support needs gained access to the residential services established by the LISMI (82) through the Social Services of the Autonomous Communities. The Autonomous Communities have their own legislation and power to assess and guide every person and they also finance the residential model.

It is estimated that in 1999 around 200 000 people were living in residential environments against 1 500 000 who were living at home with their families. People with serious mental disorders were still living in psychiatric hospitals.

For this reason, the access to residential services has largely depended on the budget every autonomous government dedicated to this purpose. This situation has generated great differences in the typology of the services and the availability of places. As a result, a person might have to wait for months during a critical period of his life such as the loss of a family member or a behavioural crisis.

Most residential services are managed by non-governmental organisations (associations of relatives) that receive financial aid trough agreements with the Administration, albeit never sufficient to provide quality services. There are few public residential centres. People themselves contribute a share of their income, for example 75%, to the funding of the received service.

The new Law on Personal Autonomy (2006) establishes that every person, depending on his dependency level, has the universal right to residential services. The Spanish Government will provide funds to the part of the National Budget dedicated to the creation of enough new residential places to cover the increasing needs of the Spanish population or to pay a salary to the main caregiver in the family. The Law also considers, as a last resort, the possibility of direct payments when the services are not covered. The definition of residential service everyone is entitled to is based on the need of support more than on his or her right to self-determination.

12.2. Specific Risks of Discrimination

The Social Services system does not guarantee enough availability to cover all the needs.
Insufficient availability of residential services, waiting lists. Attention only to cover basic needs (personal care), similar to those of seniors and not to cover other areas of social and community participation.

Widespread segregated residential services, which in many cases are located far away from the natural environment of the person.

Due to the organisational model, individualisation, self-determination, basic rights and social integration are not favoured.

The Administration does not exert any control. Standards to regulate the quality of the service based on results from the quality of life of the persons do not exist. Only in some cases do we find regulations on the physical characteristics of the facilities and personnel ratios. Some institutions develop quality management systems in order to fulfil administrative requirements for the award of services. In practice, they do not improve the received service but on the contrary, they perpetuate segregated, overcrowded services where the person's self-determination is not taken into account.

13. Adults: Education and Leisure Time

Leisure time comprises all the time out of work to either relax or find a balance in contrast to every-day-life. Activities can be done on one's own, organized in clubs or in various forms of cultural or other social facilities. In their leisure time, people in our societies are supposed to act with less formal restrictions and try to achieve a high degree of satisfaction and self-determination in their activities.

Adult education – taking the idea of life-long learning as postulate – can be seen as part of the individual's leisure time, sometimes connected to work or the expectation that a certain course promotes one's professional *career. Sometimes people participate in adult education courses for the sake of their personal well-being, health or general personal development. For people with severe disabilities the participation in organized leisure time activities or adult education courses very often must be systematically planned and organized, because they are dependent on adapted courses, assistive technologies and other individual support, and barrier free infrastructure to enable their access. How is this achieved?*

13.1.Description of the National Situation

No specific legislation on the participation of people in leisure activities or adult education exists. There is one exception, the LIUNDAU (51/2003), which contemplates accessibility and later additionally plans and oversees the adoption of positive action rules meant to avoid and compensate for the disadvantages people with disabilities have to face to fully participate in political, economic, cultural and social life.

Adult education is regulated by the Law on Education (2/2006) as a permanent learning process. Among others, one of its fundamental goals is "the development of programmes to amend any risks of social exclusion of the most underprivileged groups".

In practice, leisure, cultural and sports offers are promoted and organised by Associations of Relatives and Users with the help of volunteers. The offer, which is aimed at peer groups, usually offers activities for the weekends and the summer holidays. To a lesser extent, they also offer sport activities (swimming-pool, gymnastics, etc) and training courses (informatics, reading, writing, etc).

People with disabilities who live within a community (family, home groups) have access to these activities. They enjoy most of their free time at home, sometimes with their families and having little access to ordinary environments.

Access to ordinary Adult Education is limited to people with mild disabilities. There is no specific offer in this field. In the last years, leisure activities with a more individual and regular character have been promoted.

13.2.Specific Risks of Discrimination

Gaining access to leisure time activities and ordinary programmes of adult education is almost impossible for people with complex support needs, unless their relatives support this. Their participation in these activities only occurs among groups of peers and in limited environments of the community. At best, there is some physical integration but rarely a social integration.

The risks of discrimination in matters of accessibility, both physical access and access to support services still prevail.

People who live in institutions or rural environments have less leisure time offers and these are less diverse. They also have fewer opportunities to exercise their right to self-determination and choice.

The income people with complex support need have is very low and, normally, this is used to cover the expenses of their basic needs. In many cases, this money is not enough to enjoy the same sort of leisure activities as those of their fellow citizens.

14. Adults: Partnerships and Parenting

According to social trends and changes, the decision of having one's own family is not as easy as it used to be. More and more the decision to get married or to have children is a conscious one based on emotions, being aware of the changes that these decisions will mean.

Not too long ago the idea of people with (intellectual) disabilities getting married or having children was regarded as impossible. People with complex needs who wish to marry or have a child often have to face prejudices. After all, in their parenting they are dependent on special support. Professionals from different services and service sectors have to cooperate to prevent exclusion and discrimination. How is this achieved?

14.1. Description of the National Situation

The right to motherhood of women with disabilities is stated in different international guidelines. These documents mention the right of people with disabilities to marry and start a family; their right to receive attention of their reproductive health, including birth control and health and information services about motherhood. These regulations include people with severe disabilities who require general assistance in activities of daily living, even though they cannot assume direct care of children. The Spanish legislation does not penalise voluntary sterilisation or the sterilisation of people with serious psychic disorders. It contemplates the right of women with disability to consent, having being previously informed, regarding abortion or sterilisation. However, there are different reasons that cause situations of inequality:

- Social exclusion from those contexts that allow interpersonal relationships where a partner can be found.
- Non-existence of specific complementary services that support the care of children.
- Separation of the mother with disability from her child as she is considered not capable, on the grounds of disability, by the professionals who intervene in assessment procedures (concession of guardianship and custody or parental custody).
- Health personnel who advise against pregnancy and perform caesarean sections extensively for the high risk it involves in women with disabilities.
- In general, society thinks that people with disabilities cannot have a partner or children and bring them up. This reflection does not take into account whether there are public resources that help carry out this right.
- The opposition of the family environment.
- Discrimination in the access to assisted reproduction techniques and adoption.
- Insufficient access to gynaecological services, delivery preparation courses and courses to protect disabled women against sexual harassment.
- The generalised practice of sterilisation of people with intellectual disability, more common among women than men, is closely linked not only to procreation but also to sexuality.

14.2. Specific Risks of Discrimination

In Spain people with complex support needs are socially discriminated with regard to policies and resource provisions that would help them all along the different stages the starting of a family require:

- Social interaction in order to find a partner.
- Marriage
- Pregnancy
- Adoption
- Children’s education

Family and society reject the idea that people with complex support needs can start a family.

15. Adults: Exercising Civil Rights

One developmental task of adulthood is to know and to exercise one’s rights. This comprises the rights that a state confers to its people in order to secure protection and political participation, e.g. basic human rights and voting.

For people with severe (intellectual) disabilities, civil rights still cannot be exercised in every case. Additional support is needed to exercise democratic rights like voting. It is also a commonly held belief that people with severe disabilities or complex needs are in capable of serving in political positions. How can people with severe disabilities exercise their rights as citizens?

15.1. Description of the National Situation

Spanish legislation comprises a set of regulations to safeguard and protect people with disabilities whenever a restriction of their civil rights needs to be applied (on the grounds of disability, having committed a criminal offence, etc).

The law 51/2003 on equality of opportunities, non-discrimination and universal accessibility of people with disabilities is undergoing a later development with regard to accessibility regulations and the law on infraction and penalties used as a last resort to fight discrimination. Given that these law require a gradual application of 8 years, their impact cannot be determined yet although users’ organisations regard them as very positive and important laws.

Legal incapacity is recognised when a sentence has been pronounced according to the Civil Code, art. 199 and 200, proving that the person does not have the capacity to act. The process of incapacitation is applied according to the Civil Procedure Rules (LEC) 1/2000. It is the trial court judge who pronounces the sentence, and the relatives or the barrister who bring the lawsuit. The sentence will categorise the type of incapacity, either as total or partial. Incapacity is reversible if new circumstances have to be observed. A person with the status of incapacity loses the right to vote. Once the incapacity has been recognised, guardianship (total incapacity) or partial guardianship (partial incapacity) need to be considered.

If there is a conflict of interests among the persons and their representatives, there is always the figure of the defender who can intervene in these situations. There are also guardianship foundations (public or private entities with the public duty of defending the person under their tutelage) for those cases in which a guardian has not been appointed. They take care of the person and his or her assets. These foundations have delegates who engage in the follow-up of the personal needs and never provide direct services (residential services, educational services, etc.). They act as informed and demanding users in all matters related to the services the persons under their tutelage receive.

In practice, there are few services dedicated to giving legal counsel concerning the promotion of the rights and duties of people with disabilities and their families; to giving legal information and guidance about the steps that need to be taken in judicial and administrative processes and to supporting the empowerment of the users and their families. These tasks are usually the responsibility of the personnel of the Social Work departments and the associations of users, who are not always sufficiently adapted or specialised.

With regard to the application of the Penal Laws, the Penal Code of 1995 contemplates people with disabilities from two angles:

1. Exemption from criminal responsibility, specifying who will be exempted partially or totally and arguing extenuating circumstances (e.g. no understanding of the offence on the grounds of anomaly or psychic alteration).
2. Deprivation of liberty safeguards (e.g. confinement for medical or educational treatment).

There are people with physical or psychic disabilities spending time in prisons, which put into question the power of justice to identify or bear in mind the legal defences that apply to people with disabilities.

15.2.Specific Risks of Discrimination

The lack of information and support in matters of rights and duties sometimes brings about new rulings concerning incapacitation and guardianship, but they come late and do not guarantee or protect the rights of the persons as they should. In practice, sometimes these rights are overprotected, sometimes they are not respected, principally in the cases of people with mental illness and brain injury.

The insufficient judicial control over the work developed by the appointed tutors provokes wrongful use of the person’s economic resources; an unsteady control of how other needs (emotional, care, etc.) are covered by the service providers.

This is particularly significant in the case of adults who live in residencies or hospitals for a long term because they have no relatives left. The lack of awareness of mental disorders and brain injury as incapacitating factors can give rise to inadequate incapacitation sentences and, subsequently, to situations of insufficient protection or to sentences of unspecified total incapacitation that will prevent the persons from exercising some of their basic rights for which they are capacitated.

16. Adults: Ageing and End of Life

Ageing contains a lot of new challenges: Retiring, organizing one's day in a new way, coping with the loss of abilities and coming to terms with it and with one's life. Regularly, more support is needed in day-to-day life and thus social dependencies are increasing. Often this means that familiar life settings must be changed because care needs cannot be covered anymore by the given arrangement. Most people don't want to leave their familiar setting even when their care needs are becoming extensive and complicated. They prefer arrangements which are based on home care services that are reliable and flexible. When people reflect upon the end of their life there is also a wish to die in dignity.
How is this achieved?

16.1. Description of the National Situation

In the last 20 or 30 years, the ageing of people with disabilities is a growing reality. This is mainly due to all social, technological, therapeutical and rehabilitation advances. In Spain, more than half of the people with disabilities are over 65, which emphasises the reality of the gradual ageing of the population. People with disabilities face greater chances of premature ageing before 65, which, in many cases, demands a previous organisation of the formal support systems and services before that age (e.g. retirement, occupational workshops as alternative, housing adaptation, transportation, support personnel).

When people with disabilities have lived with their families until middle age, it is very likely that the person might be referred to nursing homes by the public administrations, even if the person is still able to carry out daily living activities.

Retirement at the age of 65 and pre-retirement at the age of 60 entail a new planning of day care services, which is not always available. In many cases, people with disabilities are not given the possibility to receive a work disability pension or an early retirement pension.

People with disability who live in residential community services (group homes, etc) are destined to end up in regular residences for senior citizens or large residences for people with disabilities, if their needs of support in daily activities increase and thus depriving them of the relationships and life environment they have enjoyed for years. The lack of knowledge and prejudices professionals of the Public Health System show complicates the diagnosis and treatment of illness which would be related to premature ageing and not to disability.

National legislation does not allow euthanasia. In October of 2007, the Spanish government was discussing its decriminalisation.

16.2. Specific Risks of Discrimination

People with complex support needs run more risks of not having their incapacity to work, for reasons other than their disability, recognised and also for making use of their right to early retirement.

Risk of being referred to residences for senior citizens when they come close to the age of 55, despite performing without problems daily living activities.

Country: Spain

Service providers representative:
FEAPS, Spanish Confederation of Organisations for People with Intellectual Disabilities

Interviewee: Mr. Javier Tamarit Cuadrado, Manager Department of Quality Control

Date: 13th August 2007

The interview was held in person for about one hour and a half.

Could you comment on the description our national report gives about the situation of people with severe disabilities?
People with severe disabilities have their lives planned out from the moment they are born. They receive Early Childhood Education, to later on attend Special Education Centres, Adult Day Care Centres and eventually end in Residential Centres. Generally speaking, there are no other options. We can say that physical integration in our environment is increasingly present, but that's about it.

In your opinion: What are the main risks of discrimination against persons with severe disabilities (in your country)?
Mainstream conceptions about people with more complex needs focus on disability and pathology rather than on the person itself. To this day, society does not deem their participation to be indispensable. Both environment and (the) society's thinking are very important; however, what society often shows are feelings of sorrow and compassion. The abuse of power is another likely risk. People with complex needs are dependent on the kindness of those who assist them. Unfortunately, no control systems that guarantee significant results for the person and the intervention exist. A competent professional practice is based on three pillars: technique, ethics and empathy. It usually happens that we come across either a good professional competence, which lacks the necessary empathy or ethics, or a great ethical and emphatic component that lacks the necessary technique.

(In your opinion:) What are the perspectives on anti-discrimination policies for people with severe disabilities in your country and in the EU?
In principle, the current legislation is sufficient. Some regulations worth mentioning are for example: the LIUNDAU, a very effective anti-discrimination law; the accesibility law; the signature of the UN Convention on the Rights of People with Disabilities and the Law for the Promotion of Personal Autonomy. This legal framework should help guarantee non-discrimination, however, it does not have an effect on people with severe disabilities. It is often the case that the integration of these people is not even attempted owing to erroneous conceptions about their capabilities and rights.

What can you say abouth the difficulties that people with severe disabilities face regarding professional services?
Theoretically, every person with an intellectual disability receives support from some kind of service although it takes time and it is not always the right service.

How many and what kind of people are excluded from certain services and get only support from their families?
Discrimination and segregation are still common in schools because there is not a widespread belief in their integration capabilities. We can still find people with behaviour disorders in psychiatric hospitals or in prisons that we cannot include in our services because it is not widely believed that they must be part of society.

In which areas of the support system do you see problems of availability or bad quality?
The most vulnerable situations are found in adult day care centers or in residential centers for seriously disabled people. Here, we usually come across a great dose of empathy and even ethics but very often we come across a lack of technical competence.

Are there any differences in the quality of services for people with mild, profound and severe disabilities?
Yes, there are. In the case of people with less need for support there have been great advances, mostly based on the person itself, on their quality of life and on their right to a full citizenship (characterised by participation, a sense of belonging and rights).

Which structural problems do you see in the service system and in service providing?
The services for people with disabilities originated in a particular historical and cultural moment, when the central conception was health and assistance needs. Nowadays, this conception must change and it is necessary to undergo a reorganisation, a redesign and a reprogramming of the services and focus all of them on the individual. To achieve a correct organisational change very powerful strategical movements need to take place: transformational leadership, human competency, external control and most of all the goodwill of those responsible to carry out these changes.

FEAPS tries to provide the mechanisms and tools for the change to happen. By promoting cultural change, FEAPS tries to hinder the perpetuation of old practices and thus generate opinions and resources for changes to happen. The main goal is to reach a general consensus, to mobilise systems of beliefs, to change cultures, to implement transforming pilot activities and generate examples of good practice.

Which problems do you see in intersectoral co-operation, (in) service planning and delivery?
The coordination systems among the services are almost non-existent. People with disabilities have specific needs that would require a coordinated response from all the services: an interconnection net. This is even more difficult for people with complex needs.

What are the main concepts concerning the support of people with severe disabilities in your country? Are there any differences among provider groups? Are there any "taken for granted assumptions" in this field that foster discrimination?
For FEAPS the main concepts are INDIVIDUAL, QUALITY OF LIFE, SELF-DETERMINATION (this concept has a dimension particularly important), and ETHICS. Other entities, even the public administrations, are gradually approving of these concepts. However, this seems to happen more in theory than in practice.

What are the biggest challenges for the development in service providing for persons with severe disabilities?

- The most important challenge is to accomplish a cultural change by raising awareness, by relevant practices and by showing in the media that everything is possible. The exclusive concepts of assistance, rehabilitation and recovery need to be changed.
- To achieve an intersectoral coordination (health, education, social welfare, etc.)
- To guarantee, from the beginning, the involvement of people with disabilities in diagnosis, assessment, design and development of intervention plans focused on a quality of life project and on the actions to promote change from the organisations.
- To ensure systems of control for personal achievements from the organisations themselves and also from the public administration.
- A salary rise and an increase of the direct care personnel in order to find a solution for the serious problem caused by the current work rotation situation and the lack of staff.
- A change in children's education. This should be oriented towards a humanistic ethic.

What experience have service providers with personalised service delivery and personal budgets?

None. Perhaps the application of the Law for the Promotion of Personal Autonomy might bring something about but most probably the law will focus only on senior citizens or physical disabilities and only as a second resource in case no other services are available.

Country: Spain

Interviewee: Javier Romañach Cabrero, Member of the
Independent Living Forum

Date: 29th of October 2007. It was a one-hour telephone interview.

Could you comment on the description of the situation of people with severe disabilities in our national report?

The Spanish Legislation observes every person’s rights WHATEVER HIS OR HER CONDITION. However, in practice people with different types of diversity are subject to permanent discrimination as a result of insufficient protection policies that can guarantee equal opportunities and non-discrimination.
In your opinion: What are the main risks of discrimination against persons with severe disabilities in your country?

We are not talking about risks but about facts. We observe discrimination in a wide range of fields such as leisure time, work, access to all kinds of services, communication, access to information, etc. Discrimination can also be detected at a judicial level in matters such as abortion, sterilisation, biomedical research, etc.
Anti-discrimination policies are destined to slow progress as long as the following circumstances are not changed:

- Establishment of the medical-rehabilitation model within our society and within the area of social services.
- Absence of an inclusive curriculum at all educational levels.
- Lack of judicial expertise with regard to discrimination of people with functional diversity.
- Lack of an effective implementation of the United Nations Convention (on Human Rights).
- Absence of anti-discriminatory policies on the public procurement official complaint.
- Absence of official complaints made by the group of people with functional diversity.
- The same conditions of equality are not guaranteed within the Spanish territory, because of the structures and the State model.

In your opinion: What are the perspectives of anti-discrimination policies for people with severe disabilities in your country and in the EU?

From my point of view, anti-discrimination prospects will advance slowly because it exists much confusion about the model of functional diversity. According to this model, the person’s dignity is the most relevant concern, and taking this as a starting point, rights should be enjoyed by anyone. Yet, the problem here is that the current prevailing model is ”disability”, with influence of ICF (International Classification of Functioning, Disability and Health) and WHO, whose approach focuses on medical - rehabilitation and whose premises of “physical” and “moral” autonomy are mixed up, have influenced this model. This situation will continue to generate new inequalities.

What are the most important issues to articulate for people with severe disabilities in interest groups rsp. lobby work?

- Lack of efficient social policies that guarantee equality of opportunities. For instance, in the field of independent life policies, direct payment and personal assistance are necessary.
- Discrimination in matters of transportation, education, communication and information, access to work and to services still exists.
- Lack of compensation for the high costs functional diversity entails.
- “Repayment” social policies (more taxes are paid for being different not for having more money).
- Lack of technical aids, assistance interpreted as a right.
- Lack of training in political activism and Human Rights.
- Lack of activists.
- Lack of awareness of the existing discrimination practices.
- Lack of academic research on the modern paradigms of functional diversity.

What are the key issues in the field of participation of people with severe disabilities?

- The same issues as I previously mentioned.
- The social model is embedded in a culture focused on the “sickness”, even among us as a group; we need to change this model into a culture of “rights”.

What are the key issues in the field of discrimination against people with severe disabilities?

- The same issues as I previously mentioned.
- The assessment scales created to define rightful provisions and services, based on “medical-rehabilitation” premises instead of ‘non-discriminatory and equality of opportunities” premises, perpetuate wrongful and discriminatory policies in the long run.
- Inoperative provisions and services in order to ensure the equality of opportunities, which perpetuate “dependency” and “conspicuous consumption” versus “contribution”.
- Concerning rights, the current services generate continuous flaws. At the moment, 80% of these rights are related to services and 20% to economic provisions. These figures should be reversed.
- Cultural change: words can change thoughts. Diversity is a neutral word whereas disability has a negative connotation.

Are there people with severe disability who work within NGO´s or self-advocacy organizations?

- Yes, there are. However, there is little experience regarding the making of official complaints because of the non-compliance with anti-discrimination laws. NGO’s are not used to making formal complaints, when complaints are made these are always rejected and judges are not aware of this problem.
- The movement needs better articulation.

How do you co-operate with special interest groups of people with severe disabilities?

- I am an active member of the Independent Living Forum.

What are your experiences to articulate the special needs and interests of people with severe disabilities in public discussions at regional and national level?

- Citizen participation with direct access to relevant politicians.
- Internet networking.
- Dissemination of the independent life model and diversity model.
- Training in Bioethics and Human Rights

- Citizen complaints
- Use of the mass media
- Participation in the intellectual debate and in the technological, philosophical and bioethical debate.
- Creation of documents of meticulous analysis.

Country: Spain

Policy-maker: County Council Department of Social Affairs and Housing of the Basque Government.

Interviewees: Fernando Consuegra, Social Affairs Vice-counsellor

Date: 19th of July 2007

The interview was held in person for about one hour.

Could you comment on the description of the situation of people with severe disabilities in our national report?
My first impression is that the network of support services that people with intellectual or sensory disabilities have at their disposal is of a better quality and more specialised than, for example, that of senior citizens. This is because an influential social movement has been one step ahead of the Administration. Regarding coverage, intensity, organisation, etc., the differences are noteworthy. A series of elements have contributed to important advances such as the work developed within schools (adaptation processes, incorporation, etc) or leisure time. The levels of coverage are remarkably high, almost 100%. These people have their own universe and caregivers, diagnoses, itineraries or case managers are basically in the hands of the associative movement in spite of the existence of public responsibility. The high interconnection between the third sector and the Public Administration results in important agreements and in the joint development of projects.

In your opinion: What are the main risks of discrimination against persons with severe disabilities in your country?
Regarding employment, there is no transition towards the ordinary market, although important advances have taken place in the last years and special care centres or occupational centres are the final destination for people with disabilities.
On the subject of housing for people with severe disabilities I am especially concerned about massification, large residential settings and homogeneous groups in the living organization. For economic reasons big units were created in the past. These can be suitable on a temporary basis but cannot serve as a vital model.
On the other hand, the vision on transport for people with reduced mobility that can suffer from permanent or transitory disabilities is rather weak.

In your opinion: What are the perspectives of anti-discrimination policies for people with severe disabilities in your country and in the EU?
With regard to employment, the big challenge is the investment that needs to be made in the ordinary market to lay further emphasis on transition and employment programs backed by the average enterprise.
Regarding housing, the groups who share flats should be smaller, based on a communal perspective and thus reproduce the family way of life of no more than 5 or 6 members. Even large residential nursing homes should be divided into smaller family-like units. Intermediate stages, which allow them to live with their families and attend day care centres despite their severe disability, should also be created. Family support is the big challenge in this case. The

figure of the personal assistant might be crucial for the family to relieve pressure and avoid states of exhaustion and at the same time create more chances for the person to remain in his/her environment.

Transport is another big challenge; it is essential to design a transport network to make mobility and accessibility easier.

Are there policy programs/legislation, which have intended or unintended effects on persons with severe disabilities?

On the subject of employment we are elaborating a Disability and Dependency Plan.

Disability does not necessarily involve dependency if reliable support or technological aid are available. The plan will be approached from a global and interdisciplinary perspective, which means that it will affect not only social services but also transport, education, culture, housing, etc. The plan is to follow the same methodology at the level of Country Councils and City Councils.

On a large scale, we want the general policies of each department to assist citizens whether disabled or not. On a small-scale, this is not longer a family or personal issue but a social and political question. The institutions and the third sector should develop a new way to approach the social needs of these people. The traditional approach cannot fulfil the needs that in the past were satisfied by family or by associations in charge of every aspect.

There is a great risk that the associations for people with disabilities might become the only providers or global operators and that the public system might lose the responsibility for assessment and follow-up.

So far many policies proclaiming rights have been presented but no specific portfolios of services or commitments. A law on agreements, instead of annual agreements, should be designed to provide support and lend stability to the services. An agreement, contrary to a contract with the public administration is not legally binding. This is essential to lend stability and vigour to the system, mostly to the third sector because the field of disability cannot be understood without it.

In which political field is the life situation of people with severe disabilities currently on the political agenda at national level?

In the field of intellectual disability the Basque Country is the leading Autonomous Community in Spain. We must create models based on a communal perspective, remain in a familiar environment and promote interdisciplinary practices. All systems should assume their share of responsibility and not everything should be concentrated on Social Services (Transport, Housing, Employment, etc). The Health System has contributed largely but must continue working to keep them going.

Who are the most important actors in the national policy field for persons with severe disabilities?

It is the third sector. There are no great differences between the third sector and the providers, unlike senior citizens who have pensioners and retired people associations and the providers of residential services, which are business groups or foundations promoted by city councils and social entities.

What are the key issues in the national policy field for persons with severe disabilities?
I don't see many discriminatory practices. Some controversy might arise from the incorporation to work of 3% of the people with disabilities, but nowadays it is necessary to maintain and increase this norm. The greatest risk is that every department might not introduce legislation to tackle specific problems.

Are there any specific policy programmes for persons with severe disabilities that already exist?
The Law for the Promotion of Personal Autonomy is a positive initiative as it acknowledges subjective right. The Basque Government intends to establish a norm that admits this subjective service not only with regard to dependent people but also to everyone with a disability and to those with other social needs, exclusion, vulnerability, etc. However, this law has posed several problems. Firstly, the lack of dialogue and little willingness to reach agreements with the Autonomous Communities and secondly, the fact that this law is a sectorial non-interdisciplinary law which has to take into account, for example, social and health fields, employment and leisure time. This law is exclusively linked to residential nursery homes, day care centres, home aid, etc. It establishes a minimum for the whole country, but it is responsibility of the Autonomous Communities to put it into practice.

Are there any specific policy programmes for persons with severe disabilities being elaborated?
The plan earlier mentioned on dependency and disability.

Study on the Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs

www.non-discrimination.eu

Country Report Sweden

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Tender on Behalf of the European Commission
D.G. Employment, Social Affairs and Equal Opportunities
Integration of People with Disabilities - Unit G3

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Selected Stakeholder Interviews

1. Summary

This paper contains information on the specific risks of discrimination of people with severe disabilities and complex needs in Sweden.

An introductory part presents the two most important legislations for persons with severe disabilities and complex needs - the Act concerning Support and Service for Persons with Certain Functional Impairments (SFS 1993:387 - LSS) and the Assistance Benefit Act (1993:389). Statistics of the services from 1 October 2006 show that the number of persons in need of services has increased by 3 percent between 2005 and 2006. The total number of persons with severe disabilities receiving services according to the LSS-law is about 0,6 percent of Sweden's population.

Following a life-course systematic the main part of the paper consists of 14 sections with a nearly identical structure. Each phase of life or dimension, the characteristics of the support system and other relevant information are presented in a very dense form. The specific risks of discrimination for persons with severe disabilities or complex needs are formulated as essential for a given life phase. Due to lack of space, references could mostly not be added in this paper but are part of the annotated bibliography.

The country report shows that the Swedish legislation is good but the implementation is not so good. The differences between the services given by the 290 municipalities are very different and a risk for discrimination is obvious. The municipalities are completely independent and cannot be forced to provide services according to the legislation. The municipalities are very often looking for special solutions and special services.

Lack of knowledge in the staff and lack of professionals are other risks for discrimination. Regarding the accessibility half of the public schools are not available for children with severe disabilities. There is no longer any specific education for teachers working with children with severe disabilities. Two forms of schools – one for children without disabilities and one for children with severe disabilities are also discriminating. The necessary cooperation between the health care system and the municipalities does not always function in a good way.

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Kort sammanfattning av den svenska landsrapporten

Denna rapport innehåller information om specifika risker för diskriminering av personer med svåra funktionsnedsättningar och komplexa behov i Sverige.

I introduktionen presenteras de två viktigaste lagstiftningarna för personer med svåra funktionsnedsättningar och komplexa behov – Lag om Stöd och Service för vissa funktionshindrade (SFS 1993:387 – LSS) och Lagen om Assistansersättning (1993:389). Statistik från 1 oktober 2006 visar att antalet personer i behov av servicen har ökat med 3 procent mellan 2005 och 2006. Det totala antalet personer med svåra funktionsnedsättningar som får service enligt LSS-lagen är ca 0,6 procent av Sveriges befolkning.

Huvuddelen av landsrapporten består av 14 sektioner med nästan identisk struktur som följer livscykeln. Varje fas eller dimension I livet, det utmärkande stödsystemet och annan relevant information presenteras i en kompakt form. De specifika och viktigaste riskerna för diskriminering av personer med svåra funktionsnedsättningar eller komplexa behov är beskriva efter varje fas i livet.

Landsrapporten visar att den svenska lagstiftningen är bra men realiserandet är inte så bra. Skillnaden mellan den service som ges av de 290 kommunerna är väldigt olika och en risk för diskriminering är uppenbar. Kommunerna är fullständigt oberoende och kan inte tvingas att tillhandahålla service enligt lagstiftningen. Kommunerna försöker ofta hitta speciella lösningar och ge speciell service.

Brist på kunskap hos personal och bristen på professionella är en annan risk för diskriminering. När det gäller tillgängligheten är hälften av de kommunala skolorna inte tillgängliga för barn med svåra funktionsnedsättningar. Det finns inte längre någon specifik utbildning för lärare som arbetar med barn med svåra funktionsnedsättningar. Att det finns två skolformer – en för barn utan funktionsnedsättningar och en för barn med svåra funktionsnedsättningar- är också diskriminerande. Det nödvändiga samarbetet mellan hälso- och sjukvården och kommunerna fungerar inte alltid så bra.

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Ce document contient des informations sur les risques spécifiques de discrimination des personnes avec des handicaps sévères et des besoins complexes en Suède.

Une introduction présente les deux législations les plus importantes pour ces personnes - la Loi sur le Soutien et les Services destinés aux personnes avec certains handicaps fonctionnels (SFS 1993:387 - LSS) et la Loi sur les Allocations d’aide à la personne (1993:389). Les statistiques au 1er octobre 2006 montrent que le nombre de personnes ayant besoin de services a augmenté de 3% entre 2005 et 2006. Le nombre total de personnes avec des handicaps sévères bénéficiant de services selon la Loi LSS représente environ 0.6 % de la population suédoise.

Le corps du rapport suit les cycles de la vie et comporte 14 sections avec une structure quasi identique. Pour chaque phase de vie, les caractéristiques du système de soutien ainsi que toute autre information appropriée sont présentées sous une forme très condensée. Les risques spécifiques de discrimination pour les personnes avec des handicaps sévères ou des besoins complexes considérés comme essentiels pour cette phase de vie sont formulés. Par manque de place, la plupart des références sont reportées dans la bibliographie.

Le rapport national montre que la législation suédoise est bonne mais que sa mise en oeuvre laisse à désirer. Les services fournis par les 290 municipalités sont différents et un risque de discrimination est évident. Les municipalités sont complètement indépendantes et ne peuvent pas être obligées à fournir des services conformes à la loi. Les municipalités cherchent très souvent des solutions et des services spécifiques.

Le manque de professionnels, mais aussi leur manque de connaissances sont un risque supplémentaire de discrimination. La moitié des écoles publiques ne sont pas accessibles aux enfants avec des handicaps sévères. Il n'y a plus de formation spécifique pour les enseignants travaillant avec des enfants ayant des handicaps sévères. Il existe deux sortes d'écoles – l'une pour les enfants sans handicap et l'autre pour les enfants avec des handicaps sévères, ce qui est aussi une discrimination. La coopération nécessaire entre le système de santé et les municipalités ne fonctionne pas toujours correctement.

2. Introduction

National Approaches to identify the group of people with complex needs

In Sweden there is no comprehensive consensus on exactly how to specifically identify those people with complex support needs. In the Act concerning Support and Service for Persons with Certain Functional Impairments (SFS 1993:387 LSS) some grounds to identify the persons in question can be found. Section one mentions: “This Act contains provisions relating to measures for special support and special service for those 1. who are mentally retarded, are autistic or have a condition resembling autism, 2. who have a considerable and permanent intellectual functional impairment after brain damage when an adult, the impairment being caused by external force or a physical illness, or 3. who have some other lasting physical or mental functional impairments which are manifestly not due to normal aging, if these impairments are major ones and cause considerable difficulties in daily life and, consequently, an extensive need for support and service.”

Ten types of services are specified by LSS, Responsibility for most of them resides with Sweden’s municipalities. County councils are responsible for counselling and other personal support (counselling and support).

The ten types of services are

- advice and other personal support that requires special knowledge about problems and conditions governing the life of a person with major and permanent functional impairments,
- help from a personal assistant or financial support for reasonable costs for such help to the extent that the need for financial support is not covered by assistance benefit pursuant to the Assistance Benefit Act (1993:389),
- escort service,
- help from a personal contact,
- relief service in the home,
- short stay away from the home,
- short period of supervision for schoolchildren over the age of 12 outside their own home in conjunction with the school day and during the holidays,
- arrangements for living in a family home or in residential arrangements with special service for children and young people who need to live away from their parental home,
- residential arrangements with special service for adults or some other specially adapted residential arrangements for adults,
- daily activities for people of a working age who have no gainful employment nor are doing a training.

Municipalities reported that, on 1 October 2006, 55,800 persons received one or more LSS services, excluding counselling and support. This is 1 500 more than 2005 and an increase of 3 percent.

County councils and municipalities responsible for counselling and support reported that, on 1 October 2006, 9,500 persons had been granted counselling and support in accordance with

LSS. The total number of individuals who received LSS services on 1 October 2006 is estimated at somewhere between 58,000 and 59,000, corresponding to roughly 0,6 percent of Sweden’s population.

The total number of LSS service inputs was nearly 107,200. Most of those involved – about 25,800 individuals – received daily activities. Just over 20,900 resided in special homes for adults with disabilities, or other specially adapted homes for adults. About 17,400 had support by a contact person, 10,500 received short stay away from home, 9,700 had assigned companions and 9,500 received counselling and support. Other services provided by LSS concerned fewer than 5,000 individuals per service.

There were more men than women who received special services provided by LSS, although the proportion of women who had support by a contact person was greater than the proportion of men.

About 29 percent of all LSS services were provided to children and young people aged 22 or younger, about 65 percent were provided to those aged 23-64. Those aged 65 and older received six percent of the total.

About 150 children and young people resided in family homes and just over 1,200 resided in special housing for children and young people.

Just over 20,900 persons who resided in special homes for adults or other specially adapted homes for adults, just over 600 resided in specially adapted homes.

Personal Assistance

The Swedish Social Insurance Agency decides on assistance allowance if the person with severe disability needs personal assistance for the basic requirements for more than 20 hours a week. If the need for assistance is 20 hours per week or less, the municipality will decide on the allowance. The government sets a standard amount for assistance allowance each year.

To obtain assistance allowance, the individual must need personal assistance for the basic needs for more than 20 hours per week. Personal assistance with basic needs means help with personal hygiene, dressing and undressing, eating, communicating with other persons or other assistance that requires detailed knowledge about the disability. If the person with disability need assistance with basic needs, the individual may also be entitled to personal assistance for other qualified personal needs in the day-to-day life, if they are not satisified in any other way.

The law is written in such a way as to give the person with severe disability considerable influence over how the support is to be provided. The person with disability can decide himself/herself, how to arrange the assistance, by, for instance:

- Being employer himself/herself and employing one or two assistants, or
- Requesting assistance through the municipality, or

- Forming an association or co-operative with other disabled persons, which will employ several assistants, or
- Using another company or organisation, or
- Being partly employer himself/herself and partly having assistance through the municipality or another body.

The person with disability can also receive assistance allowance if he/she intends to use a member of the family. The household member is then to be employed by the municipality or a freestanding body, for instance, a co-operative. Any other organising body than the municipality is to have a valid F (corporate) tax card "F-skattsedel" and be registered as an employer with the Tax Agency "Skatteverket".

When The Assistance Benefit Act was passed through the Swedish Parliament (Riksdag) in May 1993 the estimated number of persons in need of personal assistance was about 7,000. The real number today is about 16,000.

3. Pre-Natal Diagnosis and Counselling

Through the extended possibilities for family planning, parenthood in modern societies has increasingly become a question of individual decision-making. Prenatal diagnostics and reproduction technologies permit the inclusion of characteristics of the fetus in this decision. This extended knowledge brings individuals into difficult situations when they have to make decisions regarding children. These individual decisions are affected by social values, attitudes, anxieties and knowledge of disabilities. They are also influenced by the quality of the counseling process if professional support is available and used. It is important that individual decisions are accepted by the social environment of people concerned. How is this achieved?

3.1. Description of the National Situation

In Sweden we have free abortion up to the 18th week of pregnancy according to the Abortion Act (1974:595) and the woman has the right to make her own decision about her body. Abortion after the 18th week of pregnancy is allowed only if there are special circumstances. A special examination is made and the woman needs an approval from The National Board of Health and Welfare.

Prenatal diagnosis is putting the expectant mother and father in a very serious situation. On one hand a child with for instance Down syndrome has the right to be born and on the other hand the expectant parents with serious hereditary deceases must be given the chance to take the risk to give birth to a child.

The Swedish Parliament decided in 1995 that all pregnant women will be offered information about prenatal diagnosis. The information are given by a doctor who is competent in prenatal diagnosis. When it is needed the expectant parents may receive counseling from a clinical geneticist. The pregnant women should always be informed about their right to refrain from prenatal diagnosis. The women have the right to be informed about the total result even things not sought after by the medical examination.

All pregnant women over 35 years of age are offered prenatal diagnosis. If all would be tested only 20-30 per cent of the unborn children with Down syndrome would be discovered as about 70 per cent of all children with Down syndrome are born from mothers under the age of 35.

If the medical examination of the fetus shows Down Syndrome, almost all women decide about abortion before the 24th week of the pregnancy.

There are several methods used today to diagnose different illnesses with the fetus during the pregnancy. If the fetus has a lesion there are few methods of treatment which in practice means that the women decide about abortion. The quick development of prenatal diagnosis and reproduction technologies has resulted in ethical, legal and medical consideration.

3.2. Specific Risks of Discrimination

The development of the methods for general screening may change the attitudes towards persons with disabilities in a negative way.

The way the doctors are informing the pregnant women is also a very important issue for the decision about abortion. The doctors are influencing not only by the talk but by the body language and the attitudes.

If all pregnant women should be examined for Down Syndrome, children with this diagnosis will decrease. This will of course also reduce the costs in the society. But when listening to adult persons with Down Syndrome you will all realize that persons with Down Syndrome are a great asset to the society. They have also the right to life.

4. Early Childhood

For most families, having a baby creates a situation of uncertainty and a need for direction and guidance. Living with a baby or a young child with a severe disability or with severe developmental problems brings parents into a situation with specific and difficult challenges and dependencies. Psychological stress in their daily lives often makes it difficult to cope with their parental responsibilities. When dealing with educational tasks or when specific therapeutical or medical treatment is necessary, parents cannot refer to their own educational experiences, but are dependent on professional support of various kinds. Having access to good medical care, self-help groups and early intervention services from a very early age of the child are decisive factors both for the personal development of the child and for the successful adjustment and coping process of the parents. How is this achieved?

4.1. Description of the National Situation

A newborn child with severe disabilities is very well taken care of within the health system in Sweden according to the Health and Medical Services Act (HSL 1982:763). All necessary medical treatment is available from the beginning. The child’s doctor sends a letter of referral to the nearest habilitation centre. Sometimes the parents get in touch with the habilitation centre themselves. The habilitation centre always needs a medical and psychological opinion before an early intervention programme is started. In the habilitation centre there are a lot of experts – paediatrician, psychologist, social worker, occupational therapist, special teacher, speech therapist, physiotherapist etc. These specialists are working in a team around the child and the whole family. One of the experts in the team is chosen the main contact person to the family.

During the first meeting with the parents the contact person try to find out what kind of support the parents need. An investigation is made and together with the parents a habilitation plan is set up. In the plan there is a description of the child’s ability and development and the parent’s qualifications to cope with every day life with the child. The habilitation plan is regularly followed up at least once a year.

The support to the child and the parents may be individual or in groups and takes place in the child’s home, in the centre or elsewhere. Some examples of support provided by the habilitation centre are

- Different kinds of training to improve the mobility of the child,
- Alternative forms of communication
- Information about technical aids
- Information to the parents about what kind of support and services that can be applied for in the society and help to the parents to apply for such support
- Therapeutic talks with the parents

A person needing help with such things as dressing, using the toilet, eating or communicating can obtain personal assistance. Children with severe disabilities who need looking after for a large part of the day and night may be entitled to personal assistance. The personal assistant may be one of the child´s parents. Responsibility for personal assistance rests with the municipality and social insurance service according to the Assistance Benefit Act (1993:381).

The parents can get a back-up family who can take care of the child a few days now and then according to the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS 1993:387).

If the biological family cannot take care of their child with severe disabilities the municipality tries to find another family (family home according to the LSS law). There are no institutions for children in Sweden today. Children has the right to a family.

All children and young people receive free dental care up to and including the year in which the person reaches the age of 19.

4.2. Specific Risks of Discrimination

Many newborn children with severe disabilities spend quite a long time in hospitals. When the professionals in hospitals think it is the time for the child to come home the municipalities sometimes do not feel ready to take the responsibility.

Sometimes it takes a long time several weeks or months until the expert team in the habilitation centre get in touch with the family. The first weeks in the child´s and parent’s life are very crucial for the parent’s ability to cope with their new situation.

The habilitation team cannot always meet the needs of the child and the family. The reason may be lack of knowledge in the team, lack of time, lack of financial resourses etc. The attitude of the habilitation team towards the parents is also very important. The parents must have faith in their child and in their own possibilities to cope with the new life situation.

Parents have sometimes been offered euthanasia for their child in the hospitals. Persons with severe disabilities are completely without legal rights in the meeting with the health and medical system. Parents very often have to fight for their child and their right to a meaningful life. The health system has a focus on curing the child and not on a good life despite the disabilities. The professionals do not always see the purpose of the lives of persons with very severe disabilities.

5. Childhood: Education and Care

Preschool institutions like inclusive or special kindergartens offer care and education for younger children. They prepare children for school and give them the opportunity to interact with peers. Young girls and boys can broaden their experiences in life and enhance their social skills.
Children with severe disabilities have the same need to interact with peers, to make friends outside the family and to view themselves as a part of a social group. But young children with complex needs are dependent on additional support to participate in preschool education, such as barrier-free access or well-trained educators with specific skills and the intention to cooperate with other professionals. How is this achieved?

5.1. Description of the National Situation

The Swedish childcare system includes pre-school activities for children between one and six years of age and school-age childcare for school children of six to twelve years of age. The pre-school system consists of pre-schools, family day-care homes and open preschools. School-age childcare consists of family-day-care homes and out-of-school centres according to the Social Services Act (SoL 2001:453).

The pre-school class is a voluntary form of school within the state school system. Municipalities are required to offer children places in pre-school classes from the autumn term of the year in which a child turns six until the child starts his/her compulsory schooling.

Central and local authorities are jointly responsible for Swedish schools. The Government sets up national general objectives in the Education Act (1985:1100), curricula and course programmes and ensures compliance. The municipalities run the schools in accordance with the national objectives and must provide children, adolescents and adults with various disabilities with an education equal to the education received by others in the community. This objective can only be attained if there is sufficient knowledge about the pedagogical consequences of disability, expertise in special needs education and suitable educational materials. The municipalities need to build up and continuously develop this expertise. Therefore the Government through the Swedish Institute for Special Needs Education provides support to the municipalities and assists in producing and adapting educational materials. The Institute is a nation-wide authority for coordinating state support for special needs education and is a resource for people working with children, adolescents and adults with disabilities. The task is to provide support to the community. Their core activity is to provide advice and support to teaching teams, teachers for special needs education and other members of staff who work with children, students and adults with disabilities. This may be advice on matters impacting the pedagogical consequences of disabilities. For example the learning environment can be developed in both short and long-term perspectives, how to produce an action plan, the need to adapt or specially develop educational materials and equipments.

Children with severe disabilities or complex support needs are provided with childcare through the ordinary childcare system, like all other children. There are still a few special pre-schools for children with severe disabilities. The reason is that the ordinary pre-schools do not have educated teachers and/or staff skilled to take care of these children. Parents sometimes do not feel safe to send their child to the regular pre-schools.

Parents of children with severe disabilities need relief so that they can relax and do things which the child does not take part in. The relief service also makes it easier for the parents to go away or to devote themselves to the other children in the family. Relief service is obtainable regularly and also on a contingency basis according to the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS 1993:387). It has to be available both in the daytime in the evenings and at night and during weekends and public holidays.

Children with severe disabilities are entitled to be admitted to short-stay homes also according to the LSS law. This can mean a short-stay home admitting large number of children, or a back-up family receiving one child only. Short-stay homes exist in order for persons with severe disabilities to have the chance of a change of scene and also to give the family a break.

Children with severe disabilities are entitled to assistance allowance. Personal assistance is defined as a programme of personally designed support to be given in specific situations by a limited number of persons according to The Assistance Benefit Act (1993:389).

If you are a parent and are looking after a sick or disabled child at home, you may be able to get childcare allowance. A condition of this is that the child needs special supervision and care for at least six months or that you have special additional costs as a result of the child's disability according to Social Insurance Act (1999:799).

Parents with a disabled child may be entitled to car allowance in some cases if they need the car to travel somewhere with the child. All children and young people receive free dental care up to and including the year in which the person reaches the age of 19.

5.2. Specific Risks of Discrimination

The knowledge among staff in schools or elsewhere is not always sufficient to meet the needs of the child with severe disabilities. The municipalities do not always provide the staff the education needed. The status of the work is not very high. The wages are low and the change of staff is high. There is no longer any specific education for teachers in the special schools in Sweden.

Sometimes the short stay homes do not function for some persons with severe disabilities. The staff is not skilled to take care of people with such severe disabilities. It seems to be difficult for the municipalities to build up the quality needed. The parents dare not send their children to the short stay homes because they have bad experiences.

The number of persons with severe disabilities in every municipality makes it necessary for the municipalities to cooperate. This does not always happen the way it should.

When the child grows older the need of short time care usually increases and the municipalities cannot always meet these demands. The difficulties for the parents to keep up a normal social life sometimes also increases. To keep up all the contacts around the child can also be a problem for the parents. The other children in the family may also be heavily affected in this situation.

6. Childhood and Youth: School

Schools are responsible for a child's education and the teaching of knowledge of varying subjects. Furthermore, school proves to be an important part of young peoples' socialization process by offering the chance to enhance social skills and deepen social contacts with peers.
Children with severe disabilities also need high quality education and access to public schools. Pupils with complex needs are dependent on additional support in order to participate in school education, such as barrier-free access or well-trained teachers with the intention of cooperating with other professionals.
But especially pertaining to them, schools often exercise a kind of segregation. How do children with complex needs find their place in the school system, in which way are their special needs considered and how do professionals cooperate together?

6.1. Description of the National Situation

The Swedish Education Act (1985:1100) stipulates that all children and young people must have access to equal quality education, irrespective of gender, their geographical place of residence and their social and financial situations. Sweden has nine years of compulsory schooling from the age of seven and education throughout the state school system is free of charge. Alongside the state school system are independent schools, open to all. Independent schools must be approved by the National Agency for Education. Education at independent schools must have the same objectives as municipal schools but may, for example, have a religious or educational profile that differs from that of municipal schools.

The compulsory school system comprises primary and lower secondary schools, Sami schools, special schools for students with impaired sight, hearing or speech, and special needs schools for students with learning disabilities. Parents do not usually incur any costs for teaching materials, school meals, health care or school transport.

Most children with hearing impairments and nearly all visually impaired and disabled children are taught in compulsory schools. However, deaf children and children with serious hearing impairments go to special schools. Special schools comprise ten grades and are to provide education that is equivalent, as far as possible, to that given in compulsory schools. There are also special schools for deaf children or children with hearing impairments who are intellectually disabled.

Special needs schools are available for intellectually disabled children. Compulsory special needs schools comprise nine grades, either at primary and lower secondary special needs schools or training schools. Training schools are for students who are so intellectually disabled that they are unable to benefit from education at special needs schools at primary and lower secondary levels. Students at special needs schools are entitled to a tenth school year.

Central and local authorities are jointly responsible for Swedish schools. The Government sets up national general objectives in the Education Act, curricula and course programmes and ensures compliance. The municipalities run the schools in accordance with the national objectives. The municipalities must provide children, adolescents and adults with various disabilities with an education equal to the education received by others in the community. This objective can only be attained if there is sufficient knowledge about the pedagogical consequences of disability, expertise in special needs education and suitable educational materials. The municipalities need to build up and continuously develop this expertise. Therefore the Government through the Swedish Institute for Special Needs Education provides support to the municipalities and assists in producing and adapting educational materials. The Swedish Institute for Special Needs Education is a nationwide authority for coordinating state support for special needs education. The Institute is a resource for people working with children, adolescents and adults with disabilities. The task is to provide support to those responsible for special needs education in government operated schools and independent schools under central supervision. Their core activity is to provide advice and support to teaching teams, teachers for special needs education and other members of staff who work with children, students and adults with disabilities. This may be advice on matters impacting the pedagogical consequences of disabilities. For example the learning environment can be developed in both short and long-term perspectives, how to produce an action plan, the need to adapt or specially develop educational materials and equipments.

Most of the children with severe disabilities are in special schools. One often talks about different kinds of integration. Even this is questionable with respect to the deeper meaning of the concept. Sometimes it is just a matter of location. You have a special group or a class from a special school located – ”integrated” – within or close to the ordinary school. The amount of time devoted for common activities may be very restricted and often concentrated to leisure-time activities of taking part in a common film show, concert or something like this. Some children are entitled to have support from personal assistants in the school.

6.2. Specific Risks of Discrimination

About 50 % of all school buildings are not accessible for children with physical disabilities.
There is no longer any education for special teachers in Sweden. The knowledge among the teacher has decreased.

The numbers of pupils in the special needs schools have increased by 100 % during the last 12 years. The result is that children with intellectual disabilities today receive less support. The numbers of pupils in the classes have increased and the quality of the education has become worse.

For some children personal assistance is necessary for the children to go to school and sometimes these assistants are not welcomed by the teachers and school staff. Sometimes a power struggle between the professionals and the individual takes place.

There is a long, long way to go, before we reach a real integration. The questions of integration cannot be seen as problems to be solved within the frame of special education. They must be seen as a challenge to the school as a whole.

Integration is a challenge for every family with a disabled child and we know that integration into family life is possible. If it can work in the family, why not in schools?

Some people think that school integration is a movement against special education. It is not – on the contrary: school integration will lead to a revival of special education, within the ordinary school system. Special education is a service, not a place.

The expectations of the children with severe disabilities are too low. The pupils are not given the knowledge and tools they need to develop.

7. Childhood and Youth: Housing and Family Support Services

Due to the variety of modern family life, all children grow up in different environments. These environments can be understood as a social network including all sorts of relationships to individuals or institutions. The family's living conditions during childhood are very important for social inclusion of the young person in society. The family has a strong impact on his/her primary socialization and influences the access to certain social institutions.

Family support services offer community-based professional support and services for families. Some children and young people live in a foster family, others in foster homes. Are such support systems available? In which way are children with severe disabilities or complex needs and their families involved in these support systems?

7.1. Description of the National Situation

According to the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS 1993:387) some support measures are available for children with severe disabilities and their families. Advice and support means getting help from a person with an expert knowledge of life with severe functional impairment – child and youth habilitation staff, for example. This measure can be viewed as a supplement to habilitation, rehabilitation and social service. LSS advice and support is usually a county council responsibility, but it can also be a municipal one.

A person needing help with such things as dressing, using the toilet, eating or communicating can obtain personal assistance. Children with severe disabilities who need looking after for a large part of the day and night may be entitled to personal assistance. The personal assistant may be one of the child's parents. Responsibility for personal assistance rests with the municipality and social insurance service.

Parents of children with severe disabilities need relief so that they can relax and do things which the child does not take part in. The relief service also makes it easier for the parents to go away or to devote themselves to the other children in the family. Relief service is obtainable regularly and also on a contingency basis. It has to be available both in the daytime in the evenings and at night and during weekends and public holidays.

Children with severe disabilities are entitled to be admitted to short-stay homes. This can mean a short-stay home admitting large number of children, or a back-up family receiving one child only. Short-stay homes exist in order for persons with severe disabilities to have the chance of a change of scene and also to give the family a break.

Children aged over 12 with severe disabilities can obtain short-term supervision before and after school hours and in the school holidays. This supervision can be arranged in various ways, to suit the child. It can take place in the regular municipal leisure centre, in a special group or in the home.

Children and young persons with severe disabilities can be entitled to a ”family home” often known as a ”back-up family”. There is no hard and fast boundary between family homes and short-stay homes. The child may stay there frequently or infrequently for long or short periods, according to the needs of both child and family.

Children and young persons with severe disabilities can be entitled to accommodation with special services when, owing to their functional impairment, they are unable to live at home with their parents. A small number of children need to live permanently in special service accommodation, while others alternate between living there and at home with their parents.

Very often there is a need of a housing adjustment grant for the adaptation of the apartment to make it possible for the person to live there. The service is stipulated according to Allowance for home equipment for the handicapped Act (1992:1574). The municipalities are responsible for this service. Parents do not have to pay for any service under LSS law.

Technical aids are usually available free of charge. Responsibility for them is shared between several different authorities. The county council technical aids centre is responsible for most technical aids, but those which are needed in schools are a school responsibility. Technical aids the parents can buy in the open market they have to pay themselves. The adaptation of the technical aids is done by the communities.

If you are a parent and are looking after a sick or disabled child at home, you may be able to get childcare allowance. A condition of this is that the child needs special supervision and care for at least six months or that you have special additional costs as a result of the child’s disability according to Social Insurance Act (1999:799).

Parents with a disabled child may be entitled to car allowance in some cases if they need the car to travel somewhere with the child.

All children and young people receive free dental care up to and including the year in which the person reaches the age of 19.

7.2. Specific Risks of Discrimination

The network around a child with severe disabilities is enormous. It is not seldom that a family needs 50 different contacts to cope with everyday life. Very few of those contacts know about each other. The community is too complex. There are not enough professionals to support the families in a good way. The parents need a coordinator to handle the life situation.

If the parents do not know about the rights in the different legislations and meet professionals who do not inform the parents in a good way the children with disabilities may not get the right support.

8. Childhood and Youth: Leisure Time

Young people use their leisure time to do enjoyable and amusing activities and to get free from daily routines. Often free time activities are organized in clubs or in various forms of sportive or cultural associations. But youngsters also spend their free time with peers without adults. Many experiences among young people of the same age are made spending leisure time together, e.g. discovering new social roles, social spaces, friendship or falling in love. Youngsters with severe disabilities or complex needs have the same leisure time needs as their non-disabled peers, but are dependent on additional support to participate in mainstream leisure time activities. How is this achieved?

8.1. Description of the National Situation

Those children and young persons with severe disabilities living in residential arrangements with special service also have the right to leisure and cultural activities according to according to the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS 1993:387).

Regarding leisure time most persons with severe disabilities cannot participate in the ordinary leisure and cultural activities offered by the community. Even if they like and enjoy music, concerts and movies the public is not expecting loud noises, epileptic seizures during the performance.

Many handicap organizations are arranging leisure time activities of different kinds. To be able to arrange activities the organizations sometimes receive financial support from the community.

The non-profit organizations for instance sports associations sometimes organize leisure time activities for people with disabilities.

Municipal transport services according to The Transportation of the Disabled Services Act (1997:736) are a special type of public transport for people who have great difficulty getting about on their own or traveling on public transport. The journeys are made by taxi or specially-adapted vehicles. Those who need help during the journey are entitled to bring an escort. Every municipality decides about the number of journeys the persons with disabilities are allowed to and the costs for every journey.

The Swedish Riksdagen (Parliament) decided in May 2000 about a National Action Plan “From patient to citizen” (1999/2000:79). The national objectives of disability policy are

- A social community based on diversity
- A society designed to allow people with disabilities of all ages full participation in the life of the community
- Equal opportunities in life for girls and boys, women and men with disabilities
- Every municipality, every county council and region is working on the following tasks in particular
- Identifying and removing obstacles to full participation in society for people with disabilities
- Preventing and fighting discrimination against people with disabilities
- Making it possible for children, young people and adults with disabilities to lead independent lives and to make their own decisions in life.

8.2. Specific Risks of Discrimination

Quite often there is not sufficient staff in the group homes to give good leisure time activities according to the legislation. The non-profit organizations often do not accept the participation of persons with severe disabilities.

Persons with severe disabilities are often dependent on technical devices of different kinds but they are not allowed to receive the equipment necessary for leisure time activities. They have to pay from their own money. These arrangements can be very costly sometimes.

Lack of knowledge about the life situation for persons with severe disabilities or complex support needs is a problem and a risk of discrimination.

Persons with severe disabilities are very often locked out of public concerts, movies etc. If the audience would be informed beforehand as well as the actors special performances could be arranged. Many public premises are not accessible for persons with physical disabilities, hearing problems etc.

Some municipalities do not allow enough transport services enabling the persons with severe disabilities to participate in leisure time activities. The costs also differ between the municipalities and this makes it difficult for the person to participate as others.

9. Youth and Young Adults: Vocational Training

A successful transition from school to the employment system is usually related to vocational training. After finishing school young people need to find a job according to their interests and abilities with which they can earn a living. Vocational training prepares for the access to the employment system and is an important step into adult life. Youngsters and young adults with severe disabilities are dependent on adapted training courses, assisting technologies, other individual support and barrier free infrastructure to enable their access. How is this achieved?

9.1. Description of the National Situation

After ten years in the special schools the young adults can on a voluntary basis receive vocational training for four additional years. The municipalities are responsible for vocational training according to the Education Act (1985:1100). For young adults with severe disabilities the vocational training is given in individualized programmes. The number of pupils in every group is small. The pupils can together with their parents form the education according to every person's interests and needs. All pupils have their own schedule. The areas for vocational training can be alternative forms of communication and social interaction. Alternative forms of communication can be adapted sign language, the use of pictures, symbols and body language. Other areas can be different types of physical actions and esthetic activities. The pupils can develop their abilities to work with music, drama etc. Social training is an important area in the vocational training. The pupils can be trained to understand and meet the reality in a better way.

It is important that the vocational training also takes up issues about being an adult person and to participate in the society. The expectations on the individual must not be too low but not too high either. Persons with severe disabilities can also change and develop as others. To have the possibility to experience new things and to meet good attitudes from the environment are essential for the person to develop and to take initiatives. The person must get the opportunity to make his/her own decisions and also to make mistakes. It is from mistakes we all learn.

9.2. Specific Risks of Discrimination

The vocational training can sometimes increase the expectations with the young adult in a way which is unrealistic. The persons have often great difficulties to participate in the activities in the society. The society seems not to be ready to meet the needs of the young persons with severe disabilities.

The knowledge of the teachers and staff around the persons with severe disabilities is essential for the personal development of the people with severe disabilities. Adult persons with severe disabilities are sometimes treated like children and this is a real risk of discrimination.

The people in the environment very seldom allow the person with severe disabilities to make mistakes. Persons with severe disabilities must have the possibility to try new things and get new experiences.

10. Children and Adults: Social Security and Health Care

Modern societies are shaped by an enlargement of welfare systems and an increasing dependence on social security institutions. It is a challenge for all citizens to clarify their entitlements and to find access to services. The need for basic social security and to have access to health care services if necessary is important for all people.

In most cases having complex needs leads to an increase of dependence on social benefits and requires special support and services granted by welfare administration boards. Bureaucratic procedures of application *approval create special risks of stigmatization. Allowances, benefits and services can improve the possibilities of individual participation, but can also initiate processes of social exclusion. How is this achieved?*

10.1.Description of the National Situation

The starting point for disability policy is the principle of universal equality and equal rights. Central, local and regional governments are jointly responsible for ensuring that people with disabilities enjoy good health and financial and social security. Existing differences between people with disabilities and others in society are to be eliminated. Economic swings must not be allowed to present obstacles to the goal of creating equal living conditions. In the end, welfare is about people's access to resources and opportunities that allow them to live their lives as they themselves have envisaged.

The national responsibility of The National Board of Health and Welfare covers county council health and medical services as well as municipal social services. To meet this responsibility, the Board carries out national reviews, follow-ups and evaluations of operations and national reforms. The Board is also responsible for national supervision of the health and medical services.

Care, service and education are governed by a number of laws such as the Social Services Act (SoL 2001:453) the Health and Medical Services Act (HSL 1982:763) and the Education Act (SkolL 1985:1100). Public initiatives are to improve the individual's chances of living an independent life. To this end, the above laws are supplemented by the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS1993:387).

The Act concerning Support and Service for Persons with Certain Functional Impairments (LSS) is a law that sets out rights for persons with considerable and permanent functional impairments. Its ten measures for special support and service are to provide such persons with good living conditions.

The LSS entitles persons to the special support, and special services that they may need over and above what they can obtain under other legislation. The LSS supplements other legislation, and does not involve any curtailment of the rights provided under other legislation.

A person who is not satisfied with a decision on a measure under the LSS can appeal this in an administrative court of appeal, in the first hand the County Administrative Court.
The Swedish National Insurance Office works with financial support including parental insurance, remuneration to the disabled, care allowances, financial aid for specially adapted automobiles, remuneration for personal assistance, and other allowances for the disabled.

10.2.Specific Risks of Discrimination

Economic swings in the municipalities are making difficulties for persons with severe disabilities to get their needs fulfilled. All municipalities are breaking the law every day.

Even if the society talks about equal opportunities in life for girls and boys, men and women with disabilities we know that girls and women are discriminated.

There are obstacles to full participation in society for people with severe disabilities.

Persons with severe disabilities do not always get the best health care because of bad attitudes and lack of financial resources.

If the people with severe disabilities, parents or legal guardians do not know about the rights according to the legislation the person with disabilities will not obtain the support. The official in the municipality is entitled to inform about the rights but this does not always happens.

Each individual is to have the maximum possible influence and co-determination regarding support provided under LSS. This is not always the case. Parents or legal guardians very often decide on the person’s behalf.

The rehabilitation and habilitation for adult persons with severe disabilities is not sufficient. For instance there are difficulties to get physiotherapy.

11. Adults: Work and Employment

Having work or a day occupation is, for financial and other reasons, a very important indicator of social inclusion and quality of life. Going to work not only structures peoples’ days and weeks, but also has an important impact on the development of a person’s identity. It also provides access to the social security system and is an important basis for participation. For people with severe disabilities, transitional situations from school or vocational training into the employment system must often be systematically planned and organized, because they are dependent on adapted work places or assistive technologies and other individual support like a barrier-free infrastructure to enable their access. How is this achieved?

11.1. Description of the National Situation

Work is an important factor in participation in the life in the community. A job does not only provide income, it also provides people with a social context and an opportunity for personal growth.

People with severe disabilities very seldom have a regular job in Sweden. Municipalities are responsible for ensuring that people with disabilities who do not have a job are provided with a meaningful occupation or daily activities. This is regulated both in the Social Services Act (SoL) and the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS). The overall goal of the activities is to improve the individual’s chances of getting a job. For some people with extensive functional impairments, it may not be possible to achieve this goal, so the goal might sometimes instead be participation in a meaningful occupation during the day. Daily activity must suit the differing needs and preferences of the participants. It must be developmental. The activity can take place in special premises or at local businesses. Daytime activity participants receive habilitation allowance as an incentive in some municipalities but not all. Every municipality decides about the habilitation allowance.

The municipalities are also responsible for the transportation from the person’s home to the daily activities. The journeys are made by taxi or specially-adapted vehicles. Those who need help during the journey are entitled to bring an escort. Every municipality decides the costs for every journey.

There is an act regarding discrimination in working life – Act on Prohibition of Discrimination in Working Life of People with Disability (1999:130).

11.2. Specific Risks of Discrimination

In some municipalities the participants in a daily activity receive habilitation allowance as an incentive. As this differs from municipality to municipality it is a risk of discrimination.

The person with severe disabilities is mostly not allowed to choose the place of the daily activities or the contents of the activities. In small municipalities they cannot provide different activities for the persons with disabilities. The municipality next-door may have the activity the person wants but this needs cooperation between the municipalities. Such a procedure often fails because of the costs.

The people with severe disabilities are not always allowed to take their own decisions and to choose things in their everyday life. The parents and staff do not always have faith in the person's ability and possibility to develop. It is important to be allowed to make mistakes sometimes. It is also important to have the possibility to break routines and old pattern in life and do things in another way.

12. Adults: Housing

Becoming an adult also means making up your mind about how you would like to live: stay in the natural family for a while, live alone, with a partner or family, with a friend, etc. Having privacy, a place to go to, feeling safe and comfortable there, realizing one's own ideas on how to live, are all very important for people in our societies. For people with complex needs it is a big challenge to find their own way to living. They have restricted alternatives for housing because they need barrier-free environments and life-long support. People with severe disabilities do not only need good support services but also counseling to realise their ideas and style of private living. How is this achieved?

12.1. Description of the National Situation

Most people with severe disabilities are living in community based residential arrangements although quite many of them are still living in their birth family. For those living in the families there are respite care services offered by the municipality according to ”Act concerning Support and Service for Persons with Certain Functional Impairments” (LSS 1993:387). Personal assistance can also be provided when persons with severe disabilities live in their family according to the Assistance Benefit Act (1993:389). The parents can also be personal assistants. Residential arrangements are also offered according to the LSS law.

The most common form of residential arrangements with special service for adults is called group housing. Usually this means a few homes in a detached house, a terrace house or a block of flats. The group accommodation includes communal areas, and care and service are available there all day and night. In a group accommodation normally 4-8 persons (sometimes up to 12 persons) are each living in a flat of their own. Another type of housing is a number of flats in the same stairway in a block of flats, with one flat reserved for staff and which functions as a meeting point for those living in the building. The municipalities are responsible for the group accommodations according to the LSS law. There are some private service providers offering residential arrangements but they are also financed by the municipalities.

The people with severe disabilities can also receive housing according to the Social Services Act (SoL 2001:453). According to this law the person has to pay a sum of money from his own income for the support. When LSS law is used the person does not have to pay for the support at all. The quality of services according to LSS law is also higher.

A number of people with severe disabilities are living in a flat of their own and get support from personal assistants. The personal assistants can be employed by the municipality or by a private service-provider. It is up to the person with severe disabilities to choose which service-provider he wants. If the person is not able to choose for himself a legal guardian can do so. Normally the people with severe disabilities need service day and night and when the support is needed more than 20 hours a week the Swedish National Insurance Office is covering the costs. The person with severe disability can move from one municipality to another and the money for the personal assistance is also moved.

Very often there is a need of a housing adjustment grant for the adaptation of the apartment to make it possible for the person to live there. The service is stipulated according to Allowance for home equipment for the handicapped Act (1992:1574). The municipalities are responsible for this service.

The people with severe disabilities have a lease for their own flat and pay the rent from their disability pension. They can also receive an accommodation allowance to cover the rental charge.

A person who is not satisfied with a decision on housing under the LSS can appeal this in an administrative court of appeal, in the first hand the County Administrative Court.

12.2.Specific Risks of Discrimination

The opportunity to decide for oneself about the life one leads is important in terms of personal development and the sense of having an identity of one’s own. Everything possible should accordingly be done to identify what each individual resident wants and would like. In this context the individual’s opportunities for communicating with his or her surroundings are of decisive significance. Often he or she will have difficulty in finding words in which to express needs and wishes. He or she will be dependent on staff that know him or her well and can interpret the signals that he or she sends out.

Very few persons with severe disabilities living in a group accommodation have had the possibility to choose their housing, their neighbors or personnel. People with severe disabilities have the right to live the same life as others do. This means that they are entitled to care and security and to having their individual needs and requirements met without having constantly to adapt themselves to a group or collective.

The municipalities do not build enough group accommodations and the persons have to wait years until they can move to a flat of their own. At the same time the numbers of persons in each group accommodation have increased which can lead to a negative effect for the individuals. The LSS law is stipulating 4-6 persons in a group accommodation.

13. Adults: Education and Leisure Time

Leisure time comprises all the time out of work to either relax or find a balance in contrast to every-day-life. Activities can be done on one's own, organized in clubs or in various forms of cultural or other social facilities. In their leisure time, people in our societies are supposed to act with less formal restrictions and try to achieve a high degree of satisfaction and self-determination in their activities.

Adult education – taking the idea of life-long learning as postulate – can be seen as part of the individual's leisure time, sometimes connected to work or the expectation that a certain course promotes one's professional career. Sometimes people participate in adult education courses for the sake of their personal well-being, health or general personal development. For people with severe disabilities the participation in organized leisure time activities or adult education courses very often must be systematically planned and organized, because they are dependent on adapted courses, assistive technologies and other individual support, and barrier free infrastructure to enable their access. How is this achieved?

13.1. Description of the National Situation

Swedish adult education is extensive and has a long tradition. Adult education takes many forms, from state or municipal adult education to employment training, staff training or continued professional development in working life. Liberal adult education has a long history in Swedish adult education. It is characterized by the fact that it is “free and voluntary”, that is free from central government control and voluntary for its participants. Liberal adult education primarily includes activities conducted by folk high schools and study associations.

Adult education for the intellectually disabled is another part of the public adult education system. The scheme, which is divided into basic adult education and upper secondary level education, is intended for adults with intellectual disabilities, acquired brain injuries, autism or autism-related conditions.

The 1 January 2007 marked the introduction of the right to basic adult education for the intellectually disabled for people who do not have the skills that compulsory special schools are designed to provide but who are capable of benefiting from such an education. The system follows the same curriculum as municipal adult education but uses specially adapted syllabuses.

To be able to participate in the education the persons with severe disabilities may need technical aids, modified teaching materials and even personal assistance according to The Assistance Benefit Act (SFS 1993:389).

Regarding leisure time most persons with severe disabilities cannot participate in the ordinary leisure and cultural activities offered by the community. Even if they like and enjoy music, concerts and movies the public is not expecting loud noises, epileptic seizures during the performance.

Those children and young persons with severe disabilities living in residential arrangements with special service also have the right to leisure and cultural activities according to LSS law (SFS 1993:387).

Many handicap organizations are arranging leisure time activities of different kinds. To be able to arrange activities the organizations sometimes receive financial support from the community.

The non-profit organizations for instance sports associations sometimes organize leisure time activities for people with disabilities.

13.2. Specific Risks of Discrimination

Quite often there are not sufficient staffs in the group homes to give good leisure time activities according to the legislation.

Lack of knowledge about the life situation for persons with severe disabilities or complex support needs is a problem and a risk of discrimination.

The non-profit organizations normally do not accept the participation of persons with severe disabilities.

Persons with severe disabilities are often dependent on technical devices of different kinds but they are not allowed to receive the equipment necessary for leisure time activities. They have to pay from their own money. These arrangements can be very costly sometimes.

Persons with severe disabilities are very often locked out of public concerts, movies etc. If the audience would be informed beforehand as well as the actors special performances could be arranged.

Many public premises are not available for persons with physical disabilities, hearing problems etc.

Some municipalities do not allow enough transport services enabling the persons with severe disabilities to participate in leisure time activities. The costs also differ between the municipalities and this makes it difficult for the person to participate as others.

14. Adults: Partnerships and Parenting

According to social trends and changes, the decision of having one's own family is not as easy as it used to be. More and more the decision to get married or to have children is a conscious one based on emotions, being aware of the changes that these decisions will mean.
Not too long ago the idea of people with (intellectual) disabilities getting married or having children was regarded as impossible. People with complex needs who wish to marry or have a child often have to face prejudices. After all, in their parenting they are dependent on special support. Professionals from different services and service sectors have to cooperate to prevent exclusion and discrimination. How is this achieved?

14.1. Description of the National Situation

When we think about persons with severe disabilities we normally do not think about parenting. Of course there may be exceptions, for instance when a person has got a severe disability after becoming mother or father. The municipality is always responsible to take care of children in such a situation. The general policy is that a severe disabled person should have the possibility to meet his/her child on a regular basis if the child cannot live with his disabled mother or father.

In the Marriage Code (1987:230) there are no restrictions for persons with disabilities to get married if they are 18 years old or older. Under 18 years of age the couple needs to apply for permission.

Normally the residents in a group home are not allowed to choose their partners/neighbors. The officials in the municipalities are of course trying to fulfill the wishes from the persons but there are many things to take into account when a new group home is to be established. On the other hand it is possible for two persons with severe disability to try to find a common flat and live together and at the same time contact the official in the municipality who has to provide with the staff support needed. There are not so many parents who know about this possibility and even less who take the opportunity.

Parents may have brought up several non-disabled children and supported them when moving from home. But when it comes to the child with a severe disability they do not always know what to do. They apply for a group home for their child without knowing very much about this service.

14.2. Specific Risks of Discrimination

The information from the municipalities is not always the best. The parents or legal guardians do not know the legal rights and cannot apply for the services for the person with severe disability.

The persons with severe disabilities are seldom allowed to choose their neighbors in for instance a group home. They need to get support to be able to make their own decisions in everyday life. The staff needs education to fulfill the needs of the persons.

15. Adults: Exercising Civil Rights

One developmental task of adulthood is to know and to exercise one’s rights. This comprises the rights that a state confers to its people in order to secure protection and political participation, e.g. basic human rights and voting.
For people with severe (intellectual) disabilities, civil rights still cannot be exercised in every case. Additional support is needed to exercise democratic rights like voting. It is also a commonly held belief that people with severe disabilities or complex needs are in capable of serving in political positions. How can people with severe disabilities exercise their rights as citizens?

15.1. Description of the National Situation

The cornerstone of Swedish disability policy is the principle that everyone is of equal value and has equal rights. The fundamental responsibility of ensuring good health and social and financial security for people with disabilities is shared by national, regional and local government. The aim of the policy is to close the gap between disabled and non-disabled people.

Local authorities (municipalities) are responsible for social services, and regional government (county councils) for health care. Municipal social services and the health and medical services of county councils are governed by framework legislation which specifies the framework and objectives of activities but which also affords municipalities and county councils ample opportunity to interpret the law and shape their activities according to their own guidelines.

In Sweden the National Board of Health and Welfare and a number of other government bodies are responsible for issues relating to the disabled. These bodies are tasked with safeguarding the rights and interests of disabled people by co-coordinating, supporting and promoting such issues in their dealings with other authorities.

All people with severe disabilities in Sweden have all the civil rights which any other persons have. The only restriction possible is if you cannot take care of your own finance or speak for yourself. In those cases a legal guardian is appointed. There are two forms of legal guardians – one is functioning as an advisor and the person can still decide for himself and in the second case the legal guardian is fully taking over the person’s finance and the person has nothing to say about financial matters. Most people with severe disabilities need a legal guardian. This service is stipulated in the Act on The Children and Parents Code (1949:381). The legal guardian can be the support for the person to take control over his/her own life – self determination.

All persons with severe disabilities have the right to vote in general elections as any other person in Sweden. You have to be 18 years of age on the day of election at the latest.

Even if you do not even understand what voting is, you have the right to vote. As legal guardian you can bring the person to the polling station and help the person to vote.

15.2.Specific Risks of Discrimination

The persons with disabilities cannot always choose their legal guardian and they may have big difficulties to get rid of a legal guardian they do not like.

There is a risk of discrimination if the persons with severe disabilities want to buy some things and do not get the money from the legal guardian. The legal guardians can control the people’s life in a way they do not like and they cannot do anything about it.

The inferior control of legal guardians is a risk of discrimination of people with severe disabilities.

Regarding activities quality assurance is very important and something has to be done about this matter.

Legal security is another area that has to be improved.

16. Adults: Ageing and End of Life

Ageing contains a lot of new challenges: Retiring, organizing one's day in a new way, coping with the loss of abilities and coming to terms with it and with one's life. Regularly, more support is needed in day-to-day life and thus social dependencies are increasing. Often this means that familiar life settings must be changed because care needs cannot be covered anymore by the given arrangement. Most people don't want to leave their familiar setting even when their care needs are becoming extensive and complicated. They prefer arrangements which are based on home care services that are reliable and flexible. When people reflect upon the end of their life there is also a wish to die in dignity.
How is this achieved?

16.1. Description of the National Situation

The number of persons with severe disabilities living in community based residential arrangements has increased immensely the last 20 years in Sweden. The large institutions have been closed. This means that the quality of living for people with severe disabilities also has increased. They are growing older and older mostly thanks to better health care and better living conditions. Of course there are some of them who do not live as long as non disabled people because of all medical problems.

Most of the persons with severe disabilities living in group homes are staying there until they die. Some of them are moved to special accommodations for elderly mostly run by the municipalities.

The daily activity ends when the persons with disabilities reach the age of 65 according to the LSS law (Act concerning Support and Service for Persons with Certain Functional Impairments SFS 1993:387). Sometimes it is possible to prolong the time for the persons to go to the daily activity centre. It depends on among other things if there are not too many younger persons on the waiting list.

When persons with severe disabilities no longer have a daily activity to go to they often become very passive and grow old. Very little of activities are offered to them.

The municipalities are responsible for technical aids for the elderly living in group homes and special accommodations for elderly. The people with severe disabilities receive some medical care in their daily life in the group homes. The staff gets support from a special nurse. If the person need more specialized medical care the county councils are responsible according to the Health and Medical Service Act (HSL 1982:763).

Very often there is a need of a housing adjustment grant for the adaptation of the apartment to make it possible for the person to live there. The service is stipulated according to Allowance for home equipment for the handicapped Act (1992:1574). The municipalities are responsible for this service.

People over the age of 65 are entitled to a greater degree of support for dental care.

Municipal transport services are a special type of public transport for people who have great difficulty getting about on their own or traveling on public transport. The journeys are made by taxi or specially-adapted vehicles. Those who need help during the journey are entitled to bring an escort. Every municipality decides about the number of journeys the persons with disabilities are allowed to and the costs for every journey.

16.2.Specific Risks of Discrimination

Sometimes you can see a group accommodation where both young adults and very old persons are living together. This is not always a good combination because of the different needs of the persons.

The knowledge about persons with severe disabilities and ageing is low among the nursing staff and other professionals. There is not very much research either. The staff gets experience over time but this is not enough. How is it to become old and having a severe disability?

When persons with severe disabilities no longer have a daily activity to go to they often become very passive and grow old. Very little of activities are offered to them.

The combination of intellectual disabilities and psychiatric problems and ageing gives a very complex situation for the person. The same goes for deaf-blind and intellectual disabilities in combination with ageing.

There are reasons to expect that the number of persons with severe disabilities will continue to get older and older.

Country: Sweden

Policy-maker: Mrs Barbro Westerholm,
Member of the Swedish Riksdag (Parliament)
Professor emerita

Interviewees: Mrs. Barbro Westerholm
Mrs. Elaine Johansson,
FUB Sweden and Eldorado Centre,
Gothenburg, Sweden

Date: June 18th 2007

The interview was made over the phone approximately one hour.

Could you comment on the description of the situation of people with severe disabilities in our national report?
Because of lack of time I have not had the opportunity to read the country report.

A quick summary of the report says

- Good legislation
- Lack of knowledge among professionals of different kind
- Big differences between the municipalities
- Lack of financial resources in the municipalities
- The attitudes against persons with severe disabilities

I agree that we have a good legislation in Sweden but I think that the evaluation of the LSS law is necessary. This will be ready in March 2008. I am confident that the modification of the law will be carried out in a good way under the supervision of Mr. Kenneth Johansson. I hope that this work will lead to a better life situation for persons with severe disabilities. It is essential that this group of people can feel safe and secure in their everyday life.

We need more research in this field and also research with another focus. The current research is very seldom based on everyday life of persons with disabilities in general and of persons with severe disabilities in specific. When sitting in Riksdagen (Parliament) we need good basic data to make proper decisions. Next year a new bill about research will be presented to Riksdagen (Parliament) about future research. I hope this will develop the research in a proper way.

From my experience I think that the society has become tougher for people with disabilities in general. When I today meet parents having children with severe disabilities I can see that they have almost the same problems and are discussing the same issues as 30 years ago.

In your opinion: What are the main risks of discrimination against persons with severe disabilities in your country?
Riksdagen (Parliament) and the municipalities are producing very good reports with beautiful words but the reality is far away. There is also some bad planning in the municipalities. Even if the person with disability has the right to support according to the legislation you cannot force the municipality to provide the service. As a member of Riksdagen (Parliament) we

cannot impose sanctions on the municipalities. The municipalities are completely independent and can make their own decisions.
The good will of the professionals, politicians and staff is not the problem.

In your opinion: What are the perspectives of anti-discrimination policies for people with severe disabilities in your country and in the EU?
We have very good laws this is not the problem. It is the implementation of the laws that is the problem. Other important questions are the attitudes and the lack of knowledge.

The government will present a bill during the autumn of 2007 regarding anti-discrimination. A new law will come into force on the 1st July or 1st October 2008.

Are there policy programmes/legislation, which have intended or un-intended effects on persons with severe disabilities?
As I said before I hope that the modification of the LSS legislation will lead to improvements for persons with severe disabilities. Apart from the coming anti-discrimination law I do not think we need further legislation.

In which political field is the life situation of people with severe disabilities currently on the political agenda at national level?
The evaluation of LSS is one thing and then once a year the members of the Swedish Riksdag (Parliament) have the opportunity to propose a motion. But I must admit that there have not been so many regarding persons with disabilities the last time.
Persons with disabilities are not on the agenda at the moment. The current issues in the government is work, schools and to some extent old people. But the situation of people with severe disabilities is not discussed at the same time.

Who are the most important actors in the national policy field for persons with severe disabilities?
Without any doubts the handicap organizations are the main actors. But I feel that the national organizations are not so strong today compared with a few years ago. Perhaps there are organizations on the local and regional level that have strong pressure groups.
Other important actors are the ministers in the Ministry of Health and Social Affairs and the elected representatives in the Swedish Association of Local Authorities and Regions (SALAR). These actors are quite new in the field and I think that they do not have any extensive knowledge about the life situation for persons with severe disabilities.

What are the key issues in national policy field for person with severe disabilities?
The key issues in the national policy field for persons with severe disabilities are to work with the implementation of the different legislations. The lovely words in the legislation must get better substance for the individuals. The weakness of the Swedish social system is that Riksdagen (Parliament) is deciding about the laws and the municipalities have the task to implement the laws independently.

Are there specific policy programmes for persons with severe disabilities in preparation?
I have already mentioned the work to amend the LSS law. The mandatorship of the LSS law in the future is currently discussed and the answer we will have in March 2008. Another very

important policy programme is “From patient to citizen. A national action plan for disability policy.” All municipalities and county councils and the two regions are working with this plan at the moment. The work shall be finished 2010. This plan is not specific for persons with severe disabilities but for all persons with disabilities.

Country: Sweden

NGO representative: Mrs. Lena Johansson, working in the Parents Council for The Association of the Swedish Deafblind, Stockholm

Interviewees: Mrs. Lena Johansson
Mrs. Elaine Johansson, FUB Sweden and Eldorado Centre, Gothenburg, Sweden

Date: 26th June 2007
The interview was made personally during approximately one and a half hour.

Could you comment on the description of the situation of people with severe disabilities in our national report?

I agree with the country report. Each municipality looks different from the other. I wish there was a little more equality in the way the local authorities are dealing with the different matters. Many parents and legal guardians do not have the strength to carry on with the issues.

I know that there are a number of persons with deafblindness within the rehabilitation services we do not get in touch with in the Association of the Swedish Deafblind. It seems as if the disability deafblindness disappears among the other more visible disabilities and this situation runs the risk of creating an unnecessary isolation for these persons. These persons can also lose important communication training.

These last years some good research about communication for early deafblindness among children have taken place. This information must be spread over the country.

I think that a better cooperation between the rehabilitation centres and education till all professionals who work with persons with severe and multiple disabilities would solve many problems.

The legislations are excellent but the implementations do not function in a proper way. There are many actors around a person with deafblindness and it is very important that there is cooperation between them to make life easier.

The disability deafblindness was recognized as a specific handicap by UN a few years back.

In your opinion: What are the main risks of discrimination against persons with severe disabilities in your country?

Persons who are deafblind from birth cannot influence their own situation. It is necessary that there are people around who are competent both about how the society functions and knows the individual well. Otherwise there is a great risk for isolation. This group of people has another way of communicating. The communication is the most important thing for this group.

The main risk of discrimination against persons who are deafblind is that they are dependent on staff without knowledge in the persons´ way of communicating.

Most people looks upon this group of people without any expectations and see them as a great load for the society demanding a lot of resources. There is a difference between children, youngsters and adults who have their disability from birth and those who got the disability later on in life.

The parents need to have so many contacts with so many authorities and this is discriminating and a very difficult situation. There is a great need of coordinators to support the persons with severe disabilities and their parents.

In your opinion: What are the perspectives of anti-discrimination policies for people with severe disabilities in your country and in the EU?

I know that there is an overhaul of the LSS law and I hope this will not be negative for persons with severe disabilities. We have some antidiscrimination laws and policies but they seem not to work, as it is so difficult to prove when a person feels discriminated. I do not know anything what is going on in the EU in this field.

What are the most important issues to articulate for people with severe disabilities in interest groups rsp. lobby work?
I come back to the communication. It is so extremely important for persons with deafblindness. There are too many professionals that are not skilled in the way people with deafblindness communicate. I would like to quote the American politician Daniel Webster. He said already in 1950 "If all my faculties were taken from me with one exception, I would choose to keep the ability to communicate for with that I should soon regain all the rest."
The strength of the handicap movement is very important when there are big changes in the society. I have got a feeling that the national handicap organizations are not as strong as they should be. Nowadays parents for instance do not have time to take an active interest in the work in the handicap organizations.

What are the key issues in the field of participation of people with severe disabilities?
To be able to participate in the everyday life and in the society the person with deafblindness must have a functioning communication with competent people around.

What are the key issues in the field of discrimination against people with severe disabilities?
For instance you cannot put a person with deafblindness in an ordinary group of people just like that. All changes must take time otherwise the person will be very confused and unhappy. The number of people with deafblindness is so small. This makes it necessary that the municipalities are cooperating when establishing new activities.

Are there people with severe disability who work within NGO´s or self-advocacy organizations?
No people with deafblindness from birth are able to work neither in the society nor within a NGO organization because of the disabilities.

How do you co-operate with special interest groups of people with severe disabilities?
We are cooperating with a lot of different organizations in the society – other handicap organizations, the deafblind teams, the Swedish Institute for Special Needs Education etc. We are participating in working groups and reference groups of different kinds.

What are your experiences to articulate the special needs and interests of people with severe disabilities in public discussions at regional and national level?
Persons with deafblindness are in need of technical devices and the county councils and the municipalities are handling these matters in very different ways. When technical devices are well-functioning they are a very good asset for the individuals.

I have quite good experiences regarding the contact with people working on regional and national level. I think they are listening to us but it takes such a long time and the education of professionals/staff must be intensified.

Country: Sweden

Service Provider: Mrs. Cecilia Andén Blanck, The JAG User Co-operative, Stockholm, Sweden

Interviewees: Mrs. Cecilia Andén Blanck
Mrs. Elaine Johansson, FUB Sweden and Eldorado Centre, Gothenburg, Sweden

Date: June 26th 2007

The interview was made by phone during approximately one hour and a half.

Could you comment on the description of the situation of people with severe disabilities in our national report?

I agree with everything in the country report. Sweden is still in many ways in a transition period, between the former system of support aiming to "take care" of people with disabilities, and the newer perspective of empowering people to take control over their lives. Since 1994 there is a legal right to personal assistance, which is more or less a revolution in self-determination. But at the same time there is a range of other different services to choose between, and many of them are organised and given in traditional ways, with the old perspectives. I also want to stress the importance of housing adjustment grants for persons with severe disabilities. This support is a basic condition for a good life for persons with severe disabilities

The Act concerning Support and Service for Persons with Certain Functional Impairments (LSS) and The Assistance Benefit Act is great legislations. The work with the National Action Plan "From patient to citizen" is also a very important policy document regarding preventing discrimination against people with disabilities.

In your opinion: What are the main risks of discrimination against persons with severe disabilities in your country?

The legislation is good but the attitude against persons with severe disabilities is not so good. The main risks of discrimination are staff within the health and medical services. Parents have told me that they have been offered euthanasia for their child in the hospitals. Persons with severe disabilities are completely without legal rights in the meeting with the health and medical system. Parents very often have to fight for their child and their right to a meaningful life. The health system has a focus on curing the child and not on a good life despite the disabilities. The professionals in the health system do not always see the purpose of the lives of persons with very severe disabilities.

Sometimes the short stay homes do not function for some persons with severe disabilities. The staff is not skilled to take care of people with such severe disabilities. It seems to be hard for the municipalities to build up the quality needed. The parents dare not send their children to the short stay homes.

For these children personal assistance is necessary for the children to go to school and sometimes these assistants are not welcomed by the teachers and school staff.

Persons with severe disabilities are completely dependent on technical devices of different kinds and they are not allowed to receive the equipment necessary for leisure time activities. They have to pay from their own money.

We are living in a society where the intelligence is focused and essential.

In your opinion: What are the perspectives of anti-discrimination policies for people with severe disabilities in your country and in the EU?
The government will present a bill during the autumn of 2007 regarding anti-discrimination. A new law will come into force the 1st July or 1st October 2008.

The Swedish government has signed the UN Convention about persons with disabilities. Before ratifying the convention there sill be an overhaul of the Swedish legislation. This work has just started. I do not know anything about the timetable.

What can you say about the difficulties of people with severe disabilities having access to support from professional services?
The persons with severe disabilities are not satisfied with the services from the municipalities. They do not get what they want. They have to fight all the time for things we non-disabled take for granted.
The LSS law gives the person with severe disability the right to self-determination and freedom of choice. This seems the officials in the municipalities to have forgotten. The person with severe disability has to suit the activities instead of the contrary.
The decision makers seem not to see the joy of living when for instance a person with severe disability has received an electrical wheel-chair. The person has to prove that he/she can handle the wheel-chair first.

How many and what kind of people are excluded from all or certain services and get only support from their families?
I do not know how many but I know that there are parents taking care of their child without getting any support. These families are normally “discovered” when the child becomes a teenager. Of course the child has gone to school but the parents have not applied for any other services in the municipality. I do not see these problems as structural ones.

In which areas of the support system do you see problems of availability or bad quality?
The main problem is when the municipalities do not see the individual but the activities and the person with severe disability has to adapt to the activities. This leads to bad quality.
Sometimes a power struggle between the professionals and the individual takes place.

Are there differences in quality of services for people with mild, profound and severe disabilities?
Those persons with disabilities standing outside LSS law think that they do not have good quality of the services. The support from the Social Services Act is normally not so good. At the same time it is very important to know that the life conditions for persons with severe disabilities generally are worse than for the other groups.

Which structural problems do you see in the service system and in service providing?
The current situation with the divided mandatorship between the municipality, county council and the state is a big problem. I think that it is important that the government and Riksdagen (Parliament) take responsibility for the finance of for instance personal assistance also in the future without taking the outermost responsibility for from the municipalities.

What problems do you see in intersectoral co-operation, in service planning and delivery?
The society has become more complex. Persons with severe disabilities are dependent on a lot of different stakeholders and the cooperation between them is not functioning properly. I think that every person with severe disability needs a coordinator to receive good support.

What are the main concepts for the support of people with severe disabilities in your country? Are there differences between provider groups? Are there “taken for granted assumptions” in this field that foster discrimination?
As far as I know there are big differences between provider groups and between the different municipalities.

When the society does not show respect for the freedom of choice and the individual’s right to self-determination this situation can foster discrimination. All human beings have ability to self-determination at least by showing approval or disapproval. The right to have a legal guardian can have impact on self-determination for the person with severe disabilities. Who has the power – the individual or the society? This issue must be solved.

What are the biggest challenges for the development in service providing for persons with severe disabilities?
The biggest challenge is to change the attitudes among professionals, politicians, decision makers and the public in general.

What experiences have the service providers with personalised service delivery and personal budgets?
The best thing that ever happened in the field of persons with severe disabilities is the LSS law and the right to personal assistance. This has had an important and decisive impact on the lives of persons with severe disabilities in Sweden these last 13 years.
We do not have the system of personal budgets. But I think it seems to be interesting and I would like to try it in Sweden.

Study on the Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs

www.non-discrimination.eu

Country Report United Kingdom

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Tender on Behalf of the European Commission
D.G. Employment, Social Affairs and Equal Opportunities
Integration of People with Disabilities - Unit G3

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Selected Stakeholder Interviews

1. Summary

This report describes the risks for discrimination for people with complex needs in the UK. It is based on the author’s knowledge and expertise in the field as a researcher in learning disability for 20 years, additional information gathered on legislation and policy for this study, and observations from stakeholders, the families of case study participants and professionals involved in good practice initiatives. The introduction provides further background to the UK report and is followed by brief summaries of information relating to risk of discrimination, structured using the life stage framework employed by all the country experts involved in this study. Due to lack of space, references could mostly not be added in this paper but are part of the annotated bibliography.

There are no definitive statistics on the numbers of people with complex needs in the UK. This is because this information has not been collected as part of large scale surveys of the population, and information that was collected focussed on conditions rather than support needs. The latter is further complicated by the separate handling of data collection by the different countries comprising the ‘UK’. Nevertheless all four countries’ approach to legislation and policymaking in this area is underpinned by the same philosophy on equality and human rights. Despite legislation promoting equal treatment of people with complex needs, however, implementation has proved difficult. Minority status and assumptions regarding individual abilities and aspirations limit the potential of people with complex needs. Consequently, there are identifiable risks for discrimination against people with complex needs across life stages.

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Ce rapport décrit les risques de discrimination pour les personnes avec des besoins complexes au Royaume-Uni. Il est basé sur la connaissance et la compétence de l'auteur comme chercheur dans le domaine du handicap mental durant 20 années, sur des informations supplémentaires au niveau de la législation et des politiques menées, ainsi que sur les observations des acteurs concernés, des familles de personnes participant aux études de cas et de professionnels travaillant dans les bonnes pratiques recensées. L'introduction donne plus d’information générale sur le rapport et est suivie par de brefs résumés concernant le risque de discrimination, structurés en utilisant le cadre des cycles de la vie utilisé par tous les experts nationaux impliqués dans cette étude.

Il n’existe aucune statistique définitive sur le nombre de personnes avec des besoins complexes au Royaume-Uni. Ces informations n'ont pas été collectées dans le cadre des vastes enquêtes de population, et les données rassemblées concernent plus les conditions que le besoin d’aide. Ceci est encore compliqué par le traitement distinct de la collecte de données dans les différentes régions du Royaume-Uni. Toutefois, la même philosophie d’approche de la législation et de l’élaboration des politiques, basée sur l'égalité et les droits de l'homme, prévaut dans les quatre régions. Malgré une des textes qui promeuvent l'égalité de traitement, la mise en oeuvre s'est avérée difficile. Le statut de minorité et les a-priori sur leurs capacités individuelles et leurs aspirations limitent le potentiel des personnes avec des besoins complexes. En conséquence, il existe pour ces personnes des risques identifiables de discrimination, tout au long des cycles de la vie.

2. Introduction

Definition of ‘Complex Needs / Situation of Major Dependence’

The terms ‘Complex needs’ and ‘Situation of Major Dependence’ relate to the lived reality of a wide range of people in the UK. As the latter, arguably, also have ‘complex’ needs (in terms of arranging support, if not the characteristics of their condition) I will use only the term ‘complex needs’ from here on.

Typically, people with complex needs have been treated as separate groups. Groupings have included ‘people with severe learning disabilities’, ‘people with acquired brain injury’, ‘children with life limiting conditions’, or ‘older people with dementia’. For each group a different set of professionals and informal support organisations, often developed from parent or carer organisations, have developed independently from one another. The terms severe and profound are used to describe people with learning disabilities with complex needs. However, even here, the boundaries between one category and the next are unclear. Within the statutory system a functional definition of disability is generated by requiring disabled people to meet ‘eligibility criteria’ for Social Security Benefits, in particular the Disability Living Allowance and Attendance Allowance. Such criteria to some extent override the medical labels attached to disability by focussing on need for support. However, these are blunt tools for our purposes as, even amongst those receiving the highest rates of benefit, there will be many who do not have complex needs.

Within this study, I have adopted the definition used by this study group, which is also based primarily on support needs and not on the nature of the conditions that create the need. The report therefore focuses on people who require constant support on a daily basis. This support may take the form of technological assistance or human support that is necessary to facilitate optimum health or access to personal, private and social environments. Such a definition is more aligned with the ‘social model’ of disability endorsed by many disabled people.

Data on prevalence of ‘complex needs’

Given the above, it is difficult to establish a true prevalence of people with ‘complex needs’. Surveys of the populations of the UK tend to collect data on people with disabilities either under vague categories, for example the Census in 2001 included terms such as ‘permanently sick or disabled’, or through listings of impairments or functional difficulties, such as ‘sight problems’, ‘mobility problems’, ‘pain’. For example, the ‘Disability Survey 1996/7’ of people living in private households, developed a severity of disability ‘score’ in order to estimate prevalence by severity, by asking whether individuals had any of a range of conditions. It is important to emphasise that these statistics exclude those living in congregate facilities. None of these figures are entirely satisfactory for the purposes of this report because they are likely to include many people with less severe disabilities, or miss significant groups entirely. Nevertheless, to give an indication of scale 73,440 people *living in private households* (4% of the population) are estimated to have a ‘severe’ disability in Great Britain (England Scotland and Wales)[1]. Figures from the 2001 Census for Northern Ireland

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[1] Grundy E, Ahlburg D, Ali M, Breeze E and Sloggett A (1999). Results from the 1996/97 Disability Follow-up to the Family Resource Survey, DSS, Research Report No 94

give a figure of 110,754 for adults identified as being ‘permanently sick or disabled’ (9.33% of population)[2]. However this figure includes only a small proportion of people with complex needs. There is anecdotal evidence that the number of people with complex needs is increasing, however, which causes some difficulty for those local organisations with a duty to provide services to this group. Further work is being undertaken within the relevant governmental departments in the countries of the UK to generate better estimates of the numbers of people with a range of disabilities in an attempt to facilitate service planning for these groups.

Disability in context in the UK

The UK is not a single country, although in the recent past much of the legislation for Great Britain has been passed in the national parliament in Westminster. Over the past 10 years the countries of the UK have become increasingly autonomous in legislation and policy following creation, or reinstatement, of national governmental bodies. Nevertheless, the same underpinning philosophy of equality and human rights guides legislation in each country. Consequently, while the direction of policy is in agreement, the mechanisms and timeframes for implementation differ to some extent. Northern Ireland is, in many respects lagging behind Great Britain in terms of disability policy, but is currently undergoing a major structural review of Social Care, Education and Heath Departments. Nevertheless there is evidence that all four countries are following the same general policy thrust. For example, following a report by the Law Commission on capacity to make decisions in 1995[3], Scotland was the first UK country to pass legislation to protect individual rights to self determination in their Adults with Incapacity (Scotland) Act 2000. The Mental Capacity Act 2005 enacted similar legislation for England and Wales, while in Northern Ireland a recent publication, stemming from the Bamford Review of Mental Health and Learning Disability (Northern Ireland), proposes adoption of a comprehensive legislative framework on mental capacity[4] and includes many of the same safeguards and definitions adopted in the Mental Capacity Act 2005. Given this harmony in legislative and policy direction across the 4 countries of the UK in relation to disability issues, and the strict time limits for conducting the present study, the following report quotes legislation and policy documents for England and Wales, where there is separate country legislation. Some legislation however applies to all four countries. However, where substantial differences in approach are noted for Scotland and Northern Ireland in legislation and policy, these will be highlighted.

The UK has a long tradition of legislating to improve the situation of disabled people. Stakeholders agree that the UK appears advanced in this respect compared to many other countries. The policies promoting care in the community date back to the 1960s and legislation directing that disabled children should be educated at their local school have been in place for thirty years. Despite this political will for inclusion in society, implementation has been slow. It is arguable that in practice, although implementation is very variable, the UK is little more advanced than any other Western EU country. Additionally, adoption of target

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[2] (2002) *Northern Ireland Census 2001: Key statistics tables* [Accessed 8/11/2007] Available from: www.nisranew.nisra.gov.uk/Census/pdf/Key%Statistics%20ReportTables.pdf

[3] Law Commission (1995) *Mental Incapacity.* HMSO: London

[4] The Bamford Review of Mental Health and Learning Disability (Northern Ireland) (2007) A Comprehensive Legislative Framework: Executive Summary. August 2007 Available from www.rmhldni.gov.uk/index/published-reports/cl-framework.htm

setting as a lever for change in relation to improving services for the UK population appears to have had negative impact on disabled people in some areas because focus is shifted to targeted issues while those important to minorities, including disabled people, are given low priority. There is therefore an urgent need for policy makers to make disability a mainstream issue and routinely consider the impact of initiatives on disabled people.

Finally, it should be noted that Northern Ireland differs from Great Britain in one major respect and this is defined by the legacy of 'the troubles', the conflict that plagued the country for more than thirty years. During this period many geographical areas and districts became divided along religious lines with great animosity between Catholic and Protestant communities. Today there are still concerns for individual safety in specific parts of the country and this complicates the delivery of services to people with complex needs. Since the peace settlement between the conflicting parties there is much greater freedom of movement and expression. However some of the same concerns remain about a small minority engaged in extremist groups who continue the conflict. The inclusion debate for the UK, therefore, is additionally complicated in this country by layers of pre-existing segregation by religious and other groupings. Nevertheless, there is strong legislation in relation to the right to equality for disabled people as enshrined in the Northern Ireland Act 1998 and the section 75 duty to promote equality for this group.

3. Pre-Natal Diagnosis and Counselling

Through the extended possibilities for family planning, parenthood in modern societies has increasingly become a question of individual decision-making. Prenatal diagnostics and reproduction technologies permit the inclusion of characteristics of the fetus in this decision. This extended knowledge brings individuals into difficult situations when they have to make decisions regarding children. These individual decisions are affected by social values, attitudes, anxieties and knowledge of disabilities. They are also influenced by the quality of the counseling process if professional support is available and used. It is important that individual decisions are accepted by the social environment of people concerned. How is this achieved?

3.1. Description of the National Situation

In the UK, pregnant women receive free antenatal care from their family doctor (GP) and local hospital maternity department. Women are entitled to paid maternity leave from employment for 6 months and a further 6 months unpaid leave. Women who are not in employment are entitled to social benefits. Policy on the support for the unborn child is promoted through delivery of woman centred support services during pregnancy aiming to ensure the best start in life for the newborn child (NSF for Children, Young People and Maternity Services 2004).

Ante-natal screening is common practice in the UK, particularly for older mothers (over the age of 35). Screening is provided to monitor the growth of the unborn child and identify potential problems. The Abortion laws for England Scotland and Wales allow women to opt for an abortion where they can argue that there is risk of mental or physical health difficulties for themselves, or their other children, up to 24 weeks gestation. Women are given counselling to help them come to a decision and then agreement is gained from two doctors for the abortion to be performed. In Northern Ireland no abortions are allowed other than to save the life of the mother, with the result that many Irish women travel to England for an abortion. Where screening tests identify a ‘substantial risk’ of ‘serious handicap’ (The Abortion Act 1967), women are able to have an abortion at any stage of pregnancy.

What constitutes ‘serious handicap’ is not entirely clear. Many people with Down’s syndrome are arguably not ‘seriously’ handicapped, though the majority will continue to need support with daily living throughout their lives. However the identification of a ‘substantial risk’ that an unborn child has Down’s syndrome often leads to abortion. The decision to abort a child is not taken lightly, a is a sensitive issue for parents and health professionals involved in this aspect of health care. Conversely, strenuous efforts are often made to save the life of a premature baby born as early as 24-25 weeks gestation. Many of these children will grow up with arguably ‘serious’ disabilities. A recent symposium on Neonatal and Fetal medicine, which consulted widely with appropriate stakeholders, concluded that extensive efforts should not be made to save the life of a very premature baby at high risk of severe disability in later life – in consultation with parents. As part of the background to the report they point to research identifying poor levels of support to families and the difficulties they are likely to encounter in caring for their child with severe disabilities.

The above example illustrates the lack of balanced information available to parents antenatally on the impact of disability on the person and their family. Widely available information tends to be negative and not a balanced reflection of the facts.

3.2. Specific Risks of Discrimination

Information provided to parents tends to give an unduly negative picture of the impact of a child with disabilities on the family.

Unborn children with suspected ‘serious’ disabilities are at high risk of abortion compared to children who are not so identified before birth.

4. Early Childhood

For most families, having a baby creates a situation of uncertainty and a need for direction and guidance. Living with a baby or a young child with a severe disability or with severe developmental problems brings parents into a situation with specific and difficult challenges and dependencies. Psychological stress in their daily lives often makes it difficult to cope with their parental responsibilities. When dealing with educational tasks or when specific therapeutical or medical treatment is necessary, parents cannot refer to their own educational experiences, but are dependent on professional support of various kinds. Having access to good medical care, self-help groups and early intervention services from a very early age of the child are decisive factors both for the personal development of the child and for the successful adjustment and coping process of the parents. How is this achieved?

4.1. Description of the National Situation

Babies born with severe disabilities may be negatively valued, at worst parents my reject their child, many others may worry about whether their child will receive all possible treatment to ensure survival. In the UK babies and young children are cared for by their mother with support from a father in most cases, for the first few months of their lives. Where babies are rejected by their parents a fostering system operates while an adoptive family is sought for the child.

From approximately six months of age many parents return to their job on a full or part time basis and their child (from the ages of 6 months to 3 years approximately) may spend a considerable period of time in the care of another family member, a child minder (a person who takes care of a small number of children within her own home), or in a day nursery where larger numbers of children are cared for by qualified nursery nurses. The government provides some financial assistance towards the cost of childcare for this group but this is usually subsidized by parents to meet the full cost. However, most providers would be unlikely to offer care for children with complex needs, considering themselves ill equipped and untrained to include these children.

It is the duty of local government authorities to ensure that children ‘in need’ and their families are supported. They are required to provide ‘day care’ for those under the age of 5 who are not attending school. Parents’ income is assessed by the authority and they may be asked to pay for some of these services. ‘Every Child Matters’ policy guidance in England and Wales aims to support children and families with the goal that they should – be healthy; stay safe; enjoy life and achieve goals; make a positive contribution to society, and; achieve economic well-being. The ‘Getting it Right for Every Child’ programme in Scotland has similar goals. A range of service initiatives, such as ‘Sure Start’ have been implemented to support parents/carers by providing early intervention where children have been identified as having ‘complex needs’ and provide effective protection from potentially abusive situations. Integrated services – providing health, social and/or other services - are promoted as the most child/family centred practice. However the availability of support services tends to be patchy. Local government, in different geographical areas, interpret practice guidance in light of local knowledge of the issues, competing priorities and budget restrictions. Quality and quantity of support is therefore variable across the country. Support from voluntary organizations also tends to fluctuate by geographical location. High occurrence of this type of support is more likely in urban areas and less common in rural localities. In addition, in both local government and voluntary organization run schemes, high quality services may flounder due to lack of funds or trained personnel to implement them.

Babies and children with complex need tend to be cared for by hospital based paediatricians who meet all their health needs, rather than a family doctor (GP). Children with rare conditions may be cared for by a specialist based many miles from the family home, affecting ease of access to health services provided by consultants. GPs may feel untrained to deal with common health issues when they occur in a child with a complex disability and so this can make access to primary healthcare difficult.

Equipment necessary for daily living can also be difficult to access, due to funding limitations made more acute by the need for regular replacement of some equipment as children grow. The housing needs of children with disabilities also can be overlooked where families are left unaware of the help that is available.

4.2. Specific Risks of Discrimination

Babies and young children with complex needs are likely to experience limited access to child care services. The quality and quantity of support from local authority and voluntary sources is likely to be variable depending on the part of the country the family live in, creating discrimination in service provision based on geographical location. Babies and children with complex needs may not be able to access their family doctor's services in the same manner as other children in their community. Where access needs are assessed and need for equipment – such as a custom-fit wheelchair, or car seat – agreed, such items may still not be forthcoming due to funding or availability issues, denying the child access to the wider community and its facilities.

5. Childhood: Education and Care

Preschool institutions like inclusive or special kindergartens offer care and education for younger children. They prepare children for school and give them the opportunity to interact with peers. Young girls and boys can broaden their experiences in life and enhance their social skills.

Children with severe disabilities have the same need to interact with peers, to make friends outside the family and to view themselves as a part of a social group. But young children with complex needs are dependent on additional support to participate in preschool education, such as barrier-free access or well-trained educators with specific skills and the intention to cooperate with other professionals. How is this achieved?

5.1. Description of the National Situation

In the early years, parents are encouraged enroll their children at a local nursery school for at least part of the week from the age of 3 years (NSF for Children 2004). Often children with disabilities will be offered nursery provision within school from the age of 2, in line with local authority duties to provide day provision for children with disabilities (Chronically Sick and Disabled Persons Act 1970). Arguably, this allows for the early implementation of strategies to optimise learning opportunities to these children.

In response to legislation, many nursery schools have established inclusive practices enabling children with disabilities to attend. However many of these 'mainstream' nurseries are still likely to consider themselves unable to offer places to children with complex needs, especially those needing support with health needs. Consequently 'special' schools and nurseries that cater only for children with disabilities continue to fill this need in many areas. This enables disabled children to benefit from nursery education and social contact with other disabled children. However, it is unlikely to generate the same play and friendship opportunities as a place in an inclusive nursery setting. Nevertheless there is some evidence that children with complex needs are beginning to be accommodated in mainstream settings. This may mean, for those with the most severe disabilities, co-location rather than 'inclusion' in mainstream.

Benefits provided towards the cost of child care in the early years are focused on enabling parents to take paid employment. The effect of this has been to increase the quantity and range of child care options, including paying a relative to care for a child in their own home. However it is unclear to what extent these options have been made available to children with complex needs. As noted above in relation to nursery school provision, many may not feel that they can cope with a child with severe disabilities.

Where funding is made available to support initiatives to benefit disabled children, it is often not ‘ring-fenced’ that is, conditions attached to the funds so that they can be only spent on the intended service. Consequently these funds may be used to subsidize general service expenditure.

5.2. Specific Risks of Discrimination

Young children may not be enabled to receive nursery education with their non-disabled peers. They are likely to be excluded from activities where the risk is deemed unacceptable in a service provision system sensitive to litigation. Similarly, they and their families may not benefit from the full range of child care options due to the severity of their disability.

6. Childhood and Youth: School

Schools are responsible for a child's education and the teaching of knowledge of varying subjects. Furthermore, school proves to be an important part of young peoples' socialization process by offering the chance to enhance social skills and deepen social contacts with peers.
Children with severe disabilities also need high quality education and access to public schools. Pupils with complex needs are dependent on additional support in order to participate in school education, such as barrier-free access or well-trained teachers with the intention of cooperating with other professionals.
But especially pertaining to them, schools often exercise a kind of segregation. How do children with complex needs find their place in the school system, in which way are their special needs considered and how do professionals cooperate together?

6.1. Description of the National Situation

Education is provided free of charge in the UK to children up to 19 years of age, and attendance at school is compulsory for children aged 5 to 16 years. Policy promotes an inclusive approach to education during the compulsory school years (Education Acts 1976, 1981, 1996, 2001, 2006). Northern Ireland was rather later than the rest of the UK, in respect of enacting legislation on the right of disabled people to education, which was first appeared in 1986. The response to this legislation was to build new ‘special’ schools for this group, which in later years has created problems in regard to a move to ‘inclusive’ education in mainstream schools. Progress in this is also affected by the segregated nature of education in NI which is divided along religious and ability dimensions, making delivery much more fragmented than in the rest of the UK.

In general, children are entitled to attend their local mainstream school, provided the school does not provide a justifiable reason to exclude them, and their parents agree. In addition, a recent directive supports gaining the child’s view whenever possible. However there is a perception that inclusion has been attempted without adequate planning or resources to facilitate success. The education of disabled children still largely considered separately from ‘mainstream’ education issues.

Schools that admit children with complex health needs struggle to cope, and this may lead effectively to exclusion from school settings, where educational authorities are unprepared or unable to meet the ongoing health care needs of a child in school. Parents sometimes provide the ongoing health care needed, to enable their child to attend school. Parents of children with severe disabilities and little or no communication skills also express concern about the vulnerability of their children in school settings. Where communication skills are poor it is crucial to have adequate knowledge of the care needs of a child so that they can be supported appropriately. Some children attend residential schools often many miles away from their families, if their needs cannot be met locally and this is considered the best option for them.

The need for differentiated educational provision is exacerbated as children reach their teenage years and correspondingly fewer attend mainstream secondary school provision, compared with nursery and primary settings. As a result, there remain a number of ‘special’ schools which increasingly cater for pupils with the most complex needs. Indeed, some parents campaign to keep their children out of mainstream schools because they believe, or have evidence, that their child cannot cope in busy mainstream settings. This situation arises where, despite legislation designed to meet the needs of children with disabilities, schools maintain teaching practices/environments unsuitable for this group.

The challenge of educating children with widely differing aptitudes and capabilities within a single classroom setting is well known. Research into the optimising ‘inclusion’ in education is ongoing, however, the slow pace of progress combined with the justifiable parental priority of achieving the best education possible for their child, at the time that child is of school age, has arguably stalled the push for inclusion of children with complex needs in mainstream educational settings. Segregation is, to some, seen as preferable to an ‘experimental’ inclusion opportunity in a mainstream school.

6.2. Specific Risks of Discrimination

Target setting in terms of number of children reaching set goals on Standard Attainment Tests, and league tables based on child achievement, provide a disincentive to school to accept children with learning difficulties. Such children may not be able to achieve the target grade and their presence acts to lower the school’s average and hence their position in the league table. This is a blow to the status of the school and makes it less attractive to parents.

The enactment of legislation on entitlement of children with disabilities to attend mainstream schools without the necessary re-structuring of school environments in the broadest sense, to allow children with complex needs to access them acts as a continuing barrier to experiencing education among their non-disabled peers.

7. Childhood and Youth: Housing and Family Support Services

Due to the variety of modern family life, all children grow up in different environments. These environments can be understood as a social network including all sorts of relationships to individuals or institutions. The family's living conditions during childhood are very important for social inclusion of the young person in society. The family has a strong impact on his/her primary socialization and influences the access to certain social institutions.

Family support services offer community-based professional support and services for families. Some children and young people live in a foster family, others in foster homes. Are such support systems available? In which way are children with severe disabilities or complex needs and their families involved in these support systems?

7.1. Description of the National Situation

The family, as an institution, is promoted as the best environment to support children to meet their optimum potential. However, 'the family' is viewed as comprising a number of different configurations, including two parent and single parent families. Children who are not able to live with their natural parent(s) are placed with foster or adoptive parents, on the whole. In order to access services a diagnosis or 'label' needs to be acquired. For some, their condition does not easily fit the available labels and so they sit uncomfortably within services for the nearest 'fit'. For example children with autism tend to receive the label of 'learning disability' though their needs can be quite different to others with this label. For families with a child with complex needs, multi-agency support, based on a single assessment framework, is promoted within policy. Services are directed to be child and family centred. Families are entitled to apply for a range of financial support benefits, including Direct Payments, to help with costs.

Single assessments, accessed by multi-disciplinary teams are potentially highly beneficial for children with complex needs due to the reduction in duplication of information giving, testing and so on. It also enables professionals to avoid giving conflicting advice and duplication of effort. Local authorities have been required to appoint a Director and Lead member for Children's Services. There have also been calls to combine education, social and health services for children in a single body – the Children's Trust. However, the setting up of such trusts has not been fully realised. Where joint children's services are configured, they often consist of educational and social services alone.

Bringing up a child with complex needs incurs additional expense over and above those normally associated with child rearing. Mothers of children with complex needs are less likely to take up employment due to caring responsibilities and are therefore unable to take this route to ease financial burden. Where additional equipment is assessed as required, it is not always available, often there are long waiting lists to get essential items for mobility such as wheelchairs. Parents may pay to privately acquire essential equipment to avoid an unacceptable wait for publicly funded equipment – a further burden on family finance and well-being. Poverty is a reality for many families with children with complex needs.

Housing policy provides a range of options and benefits for people on low incomes and on social security benefits. A Disabled Facilities Grant is available help to pay for adaptations to the home to meet the child's needs. This benefit is not means tested for disabled children under the age of 19. This means that family income is not considered when deciding on the amount of money that should be provided for adaptations to the house. Physiotherapists usually assess the need for adaptations to a house. Situations like this, however, can be stressful where professionals seek to dispute parents' wishes rather than support them, and do not have a thorough understanding of the child's needs. There can be a tendency to try to fit the child/family needs into 'normal' provision rather than adopting a family-centred focus. Parents who challenge the system can become labelled as 'awkward' and some fear that this may affect their access to services in the future. Where there is a mismatch between the services that families feel they need and those they are offered, it can negatively affect their ability to cope in the long-run, sometimes with tragic consequences.

7.2. Specific Risks of Discrimination

The absence of health services from joint children's services can mean that children with complex health needs receive all their support from a health service not designed to meet the full range of a child's needs when living in the family home. The child's life is entirely characterized by their medical needs and this has implications for access to a range of environments open to non-disabled children, and those with less severe disabilities.

Necessary housing adaptations and appropriate equipment are crucial if a child with complex needs is access their home and the wider physical and social world. Waiting lists for equipment and services, which may be years long, is a barrier to living an 'included life', and particularly untenable for children with life limiting conditions.

8. Childhood and Youth: Leisure Time

Young people use their leisure time to do enjoyable and amusing activities and to get free from daily routines. Often free time activities are organized in clubs or in various forms of sportive or cultural associations. But youngsters also spend their free time with peers without adults. Many experiences among young people of the same age are made spending leisure time together, e.g. discovering new social roles, social spaces, friendship or falling in love. Youngsters with severe disabilities or complex needs have the same leisure time needs as their non-disabled peers, but are dependent on additional support to participate in mainstream leisure time activities. How is this achieved?

8.1. Description of the National Situation

Leisure activity for children often comprises play with friends, often met through school, at the family home or, with facilitation from parents, at a local park, sports venue or cinema complex. Leisure for teenagers tends to become increasingly less parent directed and, while younger teenage children will still access local parks and sports facilities, this tends to become less popular than spending time with friends for older teenagers. Most of this activity happens in their own, or a friend's, home as there is a general lack of suitable meeting places for young people. Attempts by local authorities to provide suitable leisure venues for teenagers have met with varying degrees of success.

Facilities for leisure, including cinema complexes, sports centres and theatres, should be accessible to people with disabilities, by law. The Disability Discrimination Act specifically stresses that physical access and enhancements such as those required by people with hearing or visual impairments should be provided. More recently the Education and Inspections Act 2006 requires local education authorities to ensure that facilities for educational and recreational leisure are made available to children and young people up to the age of 20, and for young adults with learning disabilities up to the age of 25. However, a clause relating to the ‘reasonableness’ of making adjustments in the Disability Discrimination Act, allows organisations to argue against change based on relative cost.

In response to the leisure needs of children and young people with disabilities, leisure opportunities or supporters have been provided by a number of charitable organisations. A number of these are segregated from the mainstream. For children attending ‘mainstream’ schools, non-disabled friends can enhance their social life considerable. However this is likely to be the exception rather than the rule, and many children with complex needs are reliant on their brothers or sisters to include them in their social contacts.

In order to access the local community many children with complex needs require suitable support, for those with mobility problems, an appropriate wheelchair and supportive moldings are required. As children can grow quickly the provision of replacement chairs and moldings can be costly and difficult to obtain.

8.2. Specific Risks of Discrimination

It is unclear as to how leisure setting operators have responded to the Disability Discrimination Act provisions. While, those facilities within the control of local and national governments are likely to have made necessary adjustments, or special arrangements for access, the response of the private sector is less sure. Limited access to leisure venues, partly due to physical accessibility, but also to availability of suitable human support is likely to mean limited opportunities for people with complex needs to make friends, or for teenagers, to develop more intimate relationships.

Difficulty in obtaining suitable equipment may leave the child with physical disability in physical discomfort, or in danger of worsening their health due to a lack of physical support.

9. Youth and Young Adults: Vocational Training

A successful transition from school to the employment system is usually related to vocational training. After finishing school young people need to find a job according to their interests and abilities with which they can earn a living. Vocational training prepares for the access to the employment system and is an important step into adult life. Youngsters and young adults with severe disabilities are dependent on adapted training courses, assisting technologies, other individual support and barrier free infrastructure to enable their access. How is this achieved?

9.1. Description of the National Situation

Policy promotes provision of opportunities for vocational training and experience for all young people, who must be provided with suitable education and training between the ages of 16-19 years. Education courses are offered at many further education establishments and there are a number of training schemes available through agencies such as ‘job centres’. Increasingly there is emphasis on supporting people with disabilities in employment training by offering support to the individual and/or incentives to employers.

Much of the training for this age group is provided through Further Education Colleges. These colleges provide educational opportunities to all post 16 age groups, and in some circumstances to 14/15 year old children in collaboration with their secondary school. A number of educational opportunities have been offered to people with more severe disabilities. Some work experience or work 'taster' sessions may be available through college, but these have been criticized for their limited range. Target setting for the further education sector has, however, recently led to the prioritisation of 'L2' qualifications. Consequently many colleges have reduced the number of courses available to those studying below this level, such as those indicated above, in favour of maximizing student intake at level 2.

Work Based Learning (WBL) for young people is a general name for government funded schemes which give employment centred training to 16-18 year old people. Training programmes might be a mix of work experience (unpaid), on-the-job training or off-the-job training. Apprenticeship programmes help young people achieve higher level vocational qualifications and skills. They are available mainly for 16 and 17 year old school and college leavers, but may be offered to people aged 18 and over who can complete the apprenticeship before the age of 25.

The extent to which these training routes are accessible to young people with complex needs is unclear. However, the Disability Discrimination legislation demands that they should be accessible to this group, provided that there are no 'reasonable' justifications not to do so. An 'Access to Work' scheme designed to facilitate the transition into the work environment, is available to disabled people. While many needs are successfully identified and met, others such as communication needs tend to be poorly supported. In general there are few training positions available to young disabled people.

However there is a general assumption that people with complex needs will not work in paid employment, and this may not be possible for some, but engagement in a valued activity is important for self-esteem and means to overcome stigma.

9.2. Specific Risks of Discrimination

The range and availability of vocational training is not comparable with that offered to non-disabled peers. Prioritisation of higher level qualification courses has reduced the availability of post 16 education for people with learning disabilities still further in some areas. Access to work funds and employment support schemes are likely to favour those with less severe disabilities, who require less support and who may potentially achieve and maintain unsupported employment, because the funding for agencies providing this type of support is outcome based.

10. Children and Adults: Social Security and Health Care

Modern societies are shaped by an enlargement of welfare systems and an increasing dependence on social security institutions. It is a challenge for all citizens to clarify their entitlements and to find access to services. The need for basic social security and to have access to health care services if necessary is important for all people.

In most cases having complex needs leads to an increase of dependence on social benefits and requires special support and services granted by welfare administration boards. Bureaucratic procedures of application approval create special risks of stigmatization. Allowances, benefits and services can improve the possibilities of individual participation, but can also initiate processes of social exclusion. How is this achieved?

10.1. Description of the National Situation

The UK operates a system of social benefits available to the entire population. Benefits include payments to families with children, regardless of income, unemployment benefit (available only to those who have paid National Insurance contributions) and a range of social security payments (based solely on assessed need). In addition, the National Health Service provides free health care to the whole population. However there exists, alongside the NHS, a small private health sector that caters for less severe health problems and dentistry.

Social security payments to people registered as sick or disabled have recently been reformed to emphasise their role in supporting disabled people to work, rather than providing payments because they do not work. The benefit system does not interact well with attempts by people with complex needs to gain work experience. Any expenses paid to accommodate their support needs are treated as income and their benefit payments reduced in line. Where a person is in high cost residential accommodation paid employment can leave them no better off than remaining unemployed, as income is set against accommodation and support costs. People with complex needs, are exempt from the employment related requirements under the Welfare Reform Act, due to their high support needs. Their Employment and Support Allowance contributes towards daily living expenses, mobility within the community, and a range of other expenses. Direct payments from local authorities have been offered to people with complex needs and their families so that they can purchase the support they want. However, there can be an assumption that people with complex needs are unable to take advantage of Direct Payments because of their disability. A few people have benefited from Individualised budgets that pools money from all relevant sources. However administrative difficulties mean that few people have been able to achieve this to date.

Despite health policy directives towards equality of treatment, people with complex needs are often at a disadvantage compared to those without disabilities because their health needs are not targeted by government initiatives and as a minority population, their needs do not impact on the statistical measures on which performance in the health services are measured. Young adults commonly find that the healthcare for their condition they have received through childhood disappears as they reach adulthood and they receive no routine healthcare except when their condition changes. Some of these adults' healthcare continues to be met through children's services, others receive none. In Wales, however, annual health checks are now offered to people with learning disabilities in an attempt to ensure they receive appropriate and timely health care. Diagnostic overshadowing, attributing symptoms to a person's disability, has been common for people with complex needs. Similarly for those whose behaviour is challenging to services there has been a tendency to treat the behaviour, rather than its cause which can be health related for people with severe learning disabilities who have little or no verbal communication.

As with educational contexts, health provision is required to include all citizens. However, those with learning disabilities or severe communication problems are disadvantaged in using a setting where their particular access needs, in relation to information, consultation and support, are not met. Training for professionals in these contexts often omits education on the needs of these groups, hence they are unprepared to deliver care to them. The Disability Equality Duty (stemming from the Disability Discrimination Act) now requires public authorities to promote inclusion and strive for equality of outcome for those with disabilities with the general population.

10.2. Specific Risks of Discrimination

Within the health field, diagnostic overshadowing means that health needs are attributed to the person's primary condition or label, and proper investigation is omitted. The system of targets within the health service focuses resources on prioritized areas. Consequently untargeted areas, such as the health of people with complex needs, tend to be sidelined. Lack of training in the needs of disabled people means that many health staff, among others, are ill equipped to provide equitable health care to this group.

Direct payments are one key means for people with complex needs to gain power and control over their lives, however assumptions about ability to benefit from this scheme, and geographic differences in the extent to which the scheme is promoted can prevent them from being empowered in this way.

11. Adults: Work and Employment

Having work or a day occupation is, for financial and other reasons, a very important indicator of social inclusion and quality of life. Going to work not only structures peoples' days and weeks, but also has an important impact on the development of a person's identity. It also provides access to the social security system and is an important basis for participation. For people with severe disabilities, transitional situations from school or vocational training into the employment system must often be systematically planned and organized, because they are dependent on adapted work places or assistive technologies and other individual support like a barrier-free infrastructure to enable their access. How is this achieved?

11.1. Description of the National Situation

UK citizens may begin their working life from the age of 16, however between the ages of 16 and 18 many jobs have a strong training element. Eighteen is the normal age for entry into the labour market. Work provides, not only income but status in society and social contact with colleagues and sometimes the wider population. The labour market is driven by innovation and competitiveness which are largely economic goals. As such this creates a disincentive to include people with complex needs. Schemes designed to support people with disabilities into employment are funded on an outcomes basis and this in turn affects their eligibility criteria for support which tend to favour disabled people who have fewer support needs and therefore able to enter and sustain a position in employment more quickly.

Disability discrimination legislation aims to protect employees with disabilities in the work environment. However the extent to which people with complex needs benefit from such legislation is unclear. The discrimination legislation allows employers to 'discriminate' if they can provide 'justifiable reasons' for their actions. Welfare Reform Act, devised to support disabled people to work, lacks emphasis on supporting people with complex needs into 'occupation', which is an important status gaining opportunity.

People with complex needs in residential homes are faced with a disincentive to get work due to the high cost of care provided to them and the way earnings are deducted from benefits leaving them no better off financially if they work. Expenses received from undertaking voluntary work is often also counted as 'income' leaving the person worse off financially and therefore penalized for acquiring work experience that may benefit them in the jobs market.

For people with more severe disabilities there tends to be an assumption that they do not want, or are not capable of working. There appear to be increasing numbers of people with complex needs reaching adulthood, and the local authorities, who are largely responsible for providing services to this group, do not seem to have been prepared for this eventually. As noted above, however, different local authorities operate different eligibility criteria for services and so support for employment is likely to vary with the place that the person lives. Day time care services tend to focus on the wider group for whom the authority is required provide care, that is older people, and often younger adults with severe disabilities are inappropriately placed within this provision.

11.2. Specific Risks of Discrimination

The benefit system operates as a disincentive for disabled people to gain vocational experience, or paid employment where they live in residential care homes. The cost of support needed by a person with complex needs is likely to be high and therefore the trade off with income from any employment robs them of the status of being an earner. The benefits from a valued role in society are not just financial. It is only through exposure of the non-disabled population to their disabled peers and vice versa that equality and reduction of stigma is likely to be achieved. Poor levels of general education also put disabled people at a disadvantage in terms of gaining meaningful employment. Within the workplace communication needs are among the hardest to meet and poor provision in this respect put people with these needs at an even greater disadvantage.

12. Adults: Housing

Becoming an adult also means making up your mind about how you would like to live: stay in the natural family for a while, live alone, with a partner or family, with a friend, etc. Having privacy, a place to go to, feeling safe and comfortable there, realizing one's own ideas on how to live, are all very important for people in our societies. For people with complex needs it is a big challenge to find their own way to living. They have restricted alternatives for housing because they need barrier-free environments and life-long support. People with severe disabilities do not only need good support services but also counseling to realise their ideas and style of private living. How is this achieved?

12.1.Description of the National Situation

In the UK, most citizens strive to become a house owner and there has therefore traditionally been only a small rental housing sector, within which local authorities have been a major part with their ‘social housing’. Recent housing price rises have now made the cost of a ‘starter’ home unaffordable for many first time buyers and these houses have largely been bought by individuals wishing to invest capital in a ‘buy to let’ scheme. Hence there has been a rise in the availability of houses to rent. UK citizens often enter the housing arena on completion of their education and gaining their first job, or due to finding a partner with whom they wish to share their life.

Most people with complex disabilities live with family members, however it is becoming more common for those reaching adulthood to move from the family home into supported accommodation. This accommodation can take a variety of forms, however where a person has complex needs it is likely to include ongoing support from a carer it is usually employed or funded by the local authority or voluntary organisation. The local authority has duty to provide suitable accommodation where a disabled person does not have adequate housing facilities, which they may do through their own housing stock, or in association with another provider organisation. Social Services take a lead role in to assessing, and providing services to meet, need. UK policy is in favour of offering the full range of housing options to people with ‘long term conditions’ a term that will include those with complex needs. Particular emphasis is given to the person having the option to remain in own home with appropriate adaptations, equipment and support. However, potential problems arise because assessment of need and provision of adaptations or support is provided by a single agency. Consequently, local budget and staffing restrictions are likely to impact on the achievement of supported living in community housing.

In Northern Ireland a large number of people with complex needs are still resident in hospital accommodation. Resettlement plans are underway, however most of the available housing resources are allocated to this activity which has left other community housing projects short of funds. Housing provision in this country is additionally complicated by the legacy of ‘the troubles’ and the division of communities along religious lines.

Moves from family settings often occur in crisis situations for people with complex needs relating to a family member or the person themself. This tends to result in placement in unsatisfactory accommodation because of a lack of prior planning.

Pilot projects have shown that disabled people who have used Direct Payments to purchase the services they want, have achieved happier, valued lifestyles that are less expensive than traditional service provision. Independent living is the goal for many advocacy groups and increasingly seen in government circles as an appropriate aim. However, within wider society segregationist attitudes tend to remain which focus on the person’s disability and make progress difficult.

12.2.Specific Risks of Discrimination

Lack of income to enter the housing ownership race, and availability of adequate staff support are likely to limit the housing options available to most people with complex needs. People with complex needs may be denied some types of community provision because providers claim that they cannot meet their level of need.

Young people with complex needs may be inappropriately placed in a residence with older people rather than their own age group due to their care needs.

Where people with complex needs live in residential care homes they tend to have low levels of personal control over their lives. They may not complain about treatment because they fear losing their home.

13. Adults: Education and Leisure Time

Leisure time comprises all the time out of work to either relax or find a balance in contrast to every-day-life. Activities can be done on one's own, organized in clubs or in various forms of cultural or other social facilities. In their leisure time, people in our societies are supposed to act with less formal restrictions and try to achieve a high degree of satisfaction and self-determination in their activities.

Adult education – taking the idea of life-long learning as postulate – can be seen as part of the individual's leisure time, sometimes connected to work or the expectation that a certain course promotes one's professional career. Sometimes people participate in adult education courses for the sake of their personal well-being, health or general personal development. For people with severe disabilities the participation in organized leisure time activities or adult education courses very often must be systematically planned and organized, because they are dependent on adapted courses, assistive technologies and other individual support, and barrier free infrastructure to enable their access. How is this achieved?

13.1. Description of the National Situation

Education policy emphasises a life long commitment to education and learning particularly in a changing employment climate that demands new skills to satisfy the national labour market. Hence academic and vocational training courses are available at further education and higher education colleges, and university and are open to people of all ages. Local authorities are required to provide 'reasonable' educational and training opportunities for adults – taking into consideration abilities and aptitudes of potential students. Low expectations regarding the capability and aspirations of people with complex needs tends to mean that their needs in this regard are not considered. Similarly, directives on meeting the educational needs of disabled people are assumed not to include people with complex disabilities.

Leisure time in the UK is characterised by a wide range of activities. The availability of out-of-home leisure activities varies with geographical location, with the largest range available in the cities and least choice in rural areas. The Disability Discrimination Act emphasises the duty of providers to ensure that leisure venues are physically accessible, however the extent to which compliance is monitored is unknown. The discrimination legislation, however, allows organisations to argue that the cost of making changes to facilitate access is 'unreasonable' and receives some dispensation for this. On the other hand, policy on keeping disabled people safe has had an impact on the extent to which they are able to make 'risky' decisions, for example, to go white water rafting. Tensions arise due to service providers' 'duty of care' and their fears over liability to prosecution if they are not considered to have adequately 'cared' for an individual put at risk. The lives of people with complex needs, therefore, often lack spontaneity.

People with mental health problems may loose their social contacts when their illness is in its active phase or as their condition deteriorates, as with dementia. This can lead to them becoming increasingly isolated with few leisure opportunities beyond immediate family contacts.

Local education authorities have new duty to provide educational and recreational activities for people with learning disabilities aged 20-24 years. How this will be realized is, as yet, unclear.

Further Education Colleges in the UK receive additional funding to provide resources or support for disabled students, and in all countries apart from England students can claim small bursaries to support them while they study. Again it is not clear what criteria are given for allocation of grants, however because available courses are likely to be 'employment focused' they are often offered at NVQ Level 2 and above which will be unsuitable for many people with complex needs, particularly those with learning disabilities.

13.2. Specific Risks of Discrimination

People with complex needs may not have the same access to leisure venues because the cost, or extent of changes required to make the venue 'accessible' may be argued to be 'unreasonable'. A particular issue recently highlighted is the lack of adult changing facilities in public places. This curtails the ability of an adult with complex needs who is incontinent, to use certain leisure venues.

It is unusual for people with complex needs over the age of 25 to attend educational facilities. People with complex needs including intellectual impairment, are likely to have limited access to further education, compared to those without intellectual impairment, in their adult years.

Insurance providers may refuse to offer cover to people with complex needs for certain activities, such as horse riding, despite providing similar cover to non-disabled people who arguably undertake far riskier activities.

14. Adults: Partnerships and Parenting

According to social trends and changes, the decision of having one's own family is not as easy as it used to be. More and more the decision to get married or to have children is a conscious one based on emotions, being aware of the changes that these decisions will mean.

Not too long ago the idea of people with (intellectual) disabilities getting married or having children was regarded as impossible. People with complex needs who wish to marry or have a child often have to face prejudices. After all, in their parenting they are dependent on special support. Professionals from different services and service sectors have to cooperate to prevent exclusion and discrimination. How is this achieved?

14.1. Description of the National Situation

The Human Rights Act 1998 states that individuals have the right to marry and start a family. Until recently marriage and parenthood were seen as inappropriate for many people with disabilities, particularly those with learning disabilities. Decisions are still taken by others on the reproductive capability of women with severe learning disabilities, with sterilisation not an uncommon practice. These decisions are often made by close relatives, in the sincere belief that it is in the ‘best interests’ of the women concerned.

Changes introduced in the Mental Capacity legislation aims to ensure that people with ‘mental disabilities’ are empowered to make their own decisions when it can be demonstrated that they have the ‘capacity’. However, where it can be argued that they do not have capacity to make decisions, potentially in the case of sterilisation, their close carer, usually parent, may still condone this option in ‘best interest’. In the past doctors and other health professionals would act on the requests of parents, even if the person with learning disabilities had voiced an opposing view. The new legislation will place the onus on professionals to ensure that the capacity of the person to make their own decision is appropriately assessed. However, this may create tensions with family members where they hold a different view.

Policy direction promotes family centred support services. These services are likely to have important role in supporting parents with complex needs. The concept of offering support to such parents, so that they can be good parents is new, largely because intimate relationships would have been prevented in the past, and so support services are still gaining expertise. Nevertheless, it is not uncommon for parents with disabilities to have their children removed by the Social Services department, because they are considered unable to adequately care for their child.

14.2. Specific Risks of Discrimination

Although people with complex needs have a right to marry and have a family, their opportunities to meet a potential partner tend to be limited. This is due partly to the lack of suitable venues for meeting people and, for some people, the need for a supporter to help them gain access to them. Many adults with severe learning disabilities remain in their parents’ home and may not have appropriate support to access the types of venue where they may meet a potential partner. For people with complex needs, although they have a right to have a family, their relatives and supporters often consider this inappropriate.

15. Adults: Exercising Civil Rights

One developmental task of adulthood is to know and to exercise one’s rights. This comprises the rights that a state confers to its people in order to secure protection and political participation, e.g. basic human rights and voting.
For people with severe (intellectual) disabilities, civil rights still cannot be exercised in every case. Additional support is needed to exercise democratic rights like voting. It is also a commonly held belief that people with severe disabilities or complex needs are in capable of serving in political positions. How can people with severe disabilities exercise their rights as citizens?

15.1. Description of the National Situation

People with disabilities have the same right to vote as any other citizen in the UK. However, under common law people with learning disabilities or mental illness would not be allowed to vote if, on polling day, they are considered incapable of making a reasoned judgment. In terms of their relationship with general society, however, it has been suggested that there is lack of interest in this group, even when tragedies occur. People with complex needs lack a political voice and, as a minority, their treatment, or lack of treatment, makes little impact on organizational targets or in terms of media interest. As such people with complex needs are dependant on effective systems and advocates to ensure that their interests are considered along with the ‘mainstream’.

People with complex needs lack status and autonomy because of the focus on their disability and because they use social resources and have not been enabled to contribute. This has led to paternalistic attitudes within services. Within the general population, however, misapprehensions have sometimes arisen leading to ‘hate crime’ where people with disabilities have been abused by non-disabled people. This has led some disabled people to fear for their safety within the community.

Local social services have duty to provide for consultation with organisations of disabled people in relation to a number of their activities. However, the extent to which this happens in reality is not known. Disability Discrimination Act places particular responsibility on public authorities to actively work to eliminate discrimination and unfair treatment and promote equality of opportunity, positive attitudes towards people with disabilities and promote them in public life.

People, including those with complex needs, are now assumed in law to have capacity to make their own decisions until it is shown otherwise. In response to the Human Rights Act provision that no one should be subject to inhuman or degrading treatment, it has been made an offence for a carer to abuse or ‘willfully neglect’ a person believed to lack capacity to make their own decision.

The Disability Discrimination Act has worked well to ensure the physical accessibility of the built environment in many places. However, it has been found difficult legislation to use as a means to fight discrimination in the courts. Greater success has been achieved using the Human Rights Act. Nevertheless, the recent revision of the DDA which has introduced the Disability Equality Duty may improve this situation.

Ongoing advocacy is very important for people with little or no communication skills. Legislation on mental capacity provides for an independent advocate to support such people who have no other support, on particular issues. Where people develop complex disabilities in later life it is important that provision is legally made for someone to represent their interests. With conditions such as Alzheimer’s disease, the opportunity to make such provisions can be lost if an early diagnosis is not made because in later stages they will be unable to provide the appropriate consent.

15.2. Specific Risks of Discrimination

Minority status coupled with complex needs makes intentional or unintentional oversight of the needs and rights of this group of people more likely.

Minority status and segregated residential placements have made this group ‘invisible’ in society, generating the conditions for social ‘myths’ and assumptions to grow, breeding the conditions for victimization once they take up their place in local communities.

People with complex needs are effectively excluded from activities such as campaigning. This is partly because it is difficult to get funds to meet their ‘access’ needs, but also because such activities tend to occur at central ‘business’ locations, which people who struggle with daily living find difficult to travel to due to lack of physical energy.

16. Adults: Ageing and End of Life

Ageing contains a lot of new challenges: Retiring, organizing one’s day in a new way, coping with the loss of abilities and coming to terms with it and with one’s life. Regularly, more support is needed in day-to-day life and thus social dependencies are increasing. Often this means that familiar life settings must be changed because care needs cannot be covered anymore by the given arrangement. Most people don’t want to leave their familiar setting even when their care needs are becoming extensive and complicated. They prefer arrangements which are based on home care services that are reliable and flexible. When people reflect upon the end of their life there is also a wish to die in dignity.
How is this achieved?

16.1. Description of the National Situation

In older age the distinction between people with lifelong complex needs and older members of the general population becomes blurred as their support needs become more similar. Policy supports notion that older people should be supported to retain their independence in their own home for as long as this is feasible. However, where the adaptations to a home are costly and high levels of human support are required, particularly in response to health needs, it has been common practice for local authorities to promote residential care for older adults. In Scotland, however, personal care is provided free of charge to older people who need this service, while living in their own home. Recent research has suggested that adaptations and care in the home can be no more expensive than the ‘care home’ alternative and yields more benefits in terms of the satisfaction for the person.

With older age complex needs can develop in families that have not experienced this level of need before. In particular where a spouse develops dementia in old age, particular strains are placed upon their partner, and sometimes their adult children, who often assume the role of caring for them. The nature of this mental illness creates particular difficulties to those providing daily support and, where this is a spouse, at a time when that person is also likely to be suffering effects of old age. Complex needs, in this respect, span more than the needs of the individual and incorporate those of the person providing ongoing support.

There are greater numbers of people with complex needs living to older ages, which is creating new challenges for service providers. Amongst these are the numbers of people with Down’s syndrome living to 50 years and beyond, who are at increased risk of developing Alzheimer’s disease in later life.

The label of dementia, even for previously very able people, often excludes them from taking part in decision making, even about day to day matters. These people gradually become excluded from activities normally undertaken by people of this age. In England and Wales the NSF on older people provides valuable guidance on optimal levels of service, however no additional funds are available to support improvements, or penalties given against organisations that fail to comply with policy directives.

Policy directs that health and social care should be provided regardless of age and on basis of clinical need alone. Where there is competition for resource, however, clinicians are often placed in a position of having to prioritise care for particular individuals. These decisions tend to be made on assumptions about quality of life and there have been attempts to quantify this through the ‘QUALY’ (quality adjusted life years). The guise of statistical ‘rigour’ does not, however, change the fact that guesses and judgements are made (sometimes without sufficient evidence) on the quality of a person’s lived experience. Some hospitals may operate a ‘Do not resuscitate’ policy (that is should the person suffer a life threatening health episode no attempt is made to help the person survive) where it is deemed by the physicians involved that the quality of life the person may enjoy in the future, will be poor. This is an issue for any person with profound and multiple disabilities at any stage of life, but a particular issue for older people with complex needs.

In the UK an ‘end of life’ programme has been set up to improve care at this stage of the life cycle. It places particular emphasis on training for those working in public services to look after dying people and their carers. This may lead to better informed decisions being made on the situation of people with complex needs.

16.2. Specific Risks of Discrimination

Many of the people with the most complex needs will not have survived to older adulthood. For the remainder, the risks of discrimination for older people, with and without complex needs, tend to merge in this life stage. This happens where assumptions are made on the quality of life experienced by individuals. Within the health care context, however, this can be a life or death decision. The issue of finite material resources plays a part in such decisions and so the difficulty of making equitable judgments in this area is not underestimated.

Older people who develop dementia while resident in a care home may not have their mental illness diagnosed because of the impact this will have on the level of care expected from the residential provider. This affects the dementia sufferer’s access to the full range of appropriate services. Diagnostic overshadowing also occurs for people with dementia, as symptoms of ill health may be inappropriately attributed to their mental health problem.

Country: United Kingdom

Baroness Campbell of Surbiton, DBE 18th September 2007
Commissioner
Commission for Equality and Human Rights (CEHR)

Jane commented that the main risk for discrimination against people with severe disabilities arises from the prevalent attitude in society that places a negative value on their lives. This is especially clear where a child is born with a severe disability and the prevailing sentiments are of loss and guilt over an imagined lost opportunity to avoid this event, as well as a perspective from society that the child is better off dead. It must be emphasised that this is not the attitude of all professionals or of all new parents, however it is a generally held view. In turn, knowing that this view exists leads to concerns by parents over whether a child with severe disability will be given the medical treatment they need to live.

Nevertheless, the situation for children with severe disabilities has improved considerably in recent years. Much more support during the early years and later childhood has been provided as a result of the government's 'Every Child Matters' policy.

Anti-discrimination legislation in the UK has proved effective in many ways. For example, physical access to the built environment is far better than it was 15 years ago. The directive to make 'reasonable' adaptations has enabled people with severe physical disabilities to move around the community with greater ease. However the attitudinal shift referred to above, has not been as great. In particular, access to employment lags behind other areas of progress.

NGO Specific Questions

Lobby work

Jane believes that the most important issue for people with severe disabilities requiring lobby work is Independent Living. There is work to be done to ensure that people with severe disabilities gain access to the support they need to enable them to lead a fulfilling life. This includes support to get up, go to work and so on, but not to have to personally pay for this support. For people with severe disabilities this means that they should be given choice and control over their lives and to be enabled to have flexibility in how they approach life. This is at the heart of liberation politics.

Key issue in participation

Without doubt another of the key issues that adversely affects participation in society is communication. People with severe disabilities, including communication difficulties, do not tend to have their communication access needs met, and meeting these needs is among the most difficult to get right. The situation is made worse by the discomfort so-called 'normal' communicators often feel in the presence of those who do not use verbal communication.

Key issue in discrimination

Jane suggests that human rights are a key consideration for people with severe disabilities. The Human Rights Act is increasingly being used by policymakers and professionals as a lever to challenge prevailing practices and champion provision of effective support. However, many people with the most complex needs live in residential care homes. This means they are subject to low levels of personal control, poorer levels of care and increased levels of abuse, compared to those enabled to live independently. The equality legislation has in many respects created a ‘level playing ground’ for people with disabilities – that is equal opportunities to non-disabled people – but does not tackle some of the most deep seated problems that affect people with complex needs. Public services provide a safety net that prevents individuals suffering intolerable conditions, but they do not empower them.

People with severe disabilities and NGOs

On the whole people with complex needs do not work within NGOs or self advocacy groups, in Jane’s experience. She has observed that there are a very small number of people who need dedicated human assistance to participate, working in such organisations. She has met no one with severe communication problems in the groups that she has belonged to, and only one person, from a learning disability action group, who used non-verbal communication. The communication barrier is very difficult to break through. Overall therefore Jane has seen little evidence of people with severe disabilities routinely participating in the work of NGOs or self advocacy organisations.

Co-operation with special interest groups of people with severe disabilities

Jane’s work has tried to involve those with severe disabilities as much as possible. However she does not believe in routinely trying to include representatives of the wide range of disabilities in a tokenistic way. Where there is evidence that a person or group has a particular interest in an issue that her organisation is working on, attempts will be made to include them. However this can only be done if their access needs can be met.

It is difficult to get funds to facilitate access. Such money often comes from medical and social care budgets which are hard pressed and will always, reasonably, fund critical care needs ahead of participatory access needs. In order to obtain funding a political directive is required that says such participation will be funded, from its own budget.

Articulating the needs and interests of people with severe disabilities

Jane has personally championed the cause of people with complex needs who live in institutions and are therefore ‘invisible’ to society. These people are obliged to continue living in residential care because the community response is that ‘we cannot cope with this level of disability’. Consequently these individuals are missing from our society. This segregation denies them their humanity. Jane has always campaigned that ‘all life has equal value’. This is a particularly important message for children with severe disabilities, both in terms of the right to be born, and in terms of receipt of treatment for medical conditions throughout life.

Jill Malcomson **28th August 2007**
Alzheimer's Society

In response to the Country Report, Jill suggested adding emphasis to the need for reliable and flexible home care services. People with dementia have distinct needs but their family carer also should be considered when assessing support required. Dementia onset is usually in older age, and it is often a spouse of similar age, who automatically assumes the role of 'carer' regardless of their suitability or willingness to do so. The age of the carer, in addition to the stress of the caring role, demands that the needs of the 'carer' and 'cared for' are balanced. In some cases the assumption that a family member will become the carer of the person with dementia is inappropriate, for example that an adult son will perform personal care tasks for his elderly mother, and other arrangements should be offered.

The major risk for discrimination arises from exclusion from the decision making process. Regardless of their capabilities before the onset of their illness, acquiring the label of 'dementia' often means that people are not consulted on either day to day, or major decisions. Jill hopes that the new Mental Capacity legislation will force a change in routine practice. The legislation promotes the assessment of ability to make a decision, at the time the decision needs to be made.

People with dementia are often excluded from normal social activities. The stigma of dementia often manifests when group members make it clear that the person with dementia is not welcome. This can exclude them from a number of general groups, such as lunch clubs for the elderly or even religious services or activities. The social networks of the person with dementia, and often by association of their carer, gradually reduce to nothing.

Policy has been developed to help combat age discrimination, however it is additionally complicated when the older person has complex needs. The National Service Framework for older people has outlined milestones for the achievement of optimal life experiences for older people, but provides no additional funding to promote implementation, or penalties for ignoring policy directives. Overall therefore the legislation has been good, but in practice little is happening.

Service specific questions

Access to support

People with dementia have little access to speech and language therapy, or occupational therapy, there is a great deal of local variation in the availability of practitioners. In addition, the ability of Community Mental Health Teams (CMHTs) to support dementia sufferers is also variable. Some districts have specialist older persons' teams from which to draw support, in others there is only a 'general' mental health team. In particular, the availability of psychological support is inadequate. In a few districts there is none at all. The diagnosis of dementia is not consistently given early enough to be able to implement an optimal level of service. A diagnosis is needed at an early point in the disease so that psychological support can be put in place to help the person plan their future. Where the diagnosis is given in the later stages of the disease, the opportunity for the individual to have choice and control over their future is lost. Due to the stigma associated with the condition, doctors can be reluctant to give a diagnosis of dementia, or refer the person on to dementia services. They are reluctant to share the diagnosis with the person concerned, or, with consent, with their family members.

Exclusion from services

It is estimated that, for late onset dementia, more than 430,000 people are cared for in the family home, and 250,000 are in residential care. The true figures are hard to assess however, as many people in general residential care homes may develop dementia but never be formally diagnosed. Most residential homes are not registered to provide nursing care, which is a more expensive form of provision. This proves a disincentive to declare residents with dementia because the nature of provision would need to change. Any figure of prevalence, therefore, is likely to be an underestimate. It also means that these individuals will receive fewer appropriate services. This is particularly likely where the resident has no family advocate for their rights.

There are also cultural difficulties in service provision. Older people from black and minority ethic groups may be doubly disadvantaged where they lack proficiency in the English language and knowledge of the service system. In addition, the British perception of the nature of debilitating conditions, such as dementia, is not shared by all cultural groups. This can be an additional barrier to support. For example, some in the Chinese community see dementia as a reflection on the person's own lifestyle and behaviour in the past; a punishment to be endured. This also has implications for statutory care where staff originate from these communities. Where perception of the nature of dementia is not shared, attitude can be a problem and affect care given. For dementia sufferers this is a potentially serious problem as they are physically and psychologically vulnerable people. Recognition of abuse in the family home is also very difficult. Often people with dementia only communicate their experience through metaphor, or only show physical signs of distress. These signs may not be recognised. Inadequate training of staff is also a problem.

Quality of services

In many instances the philosophy of the service is good, but practice is poor. There is a lack of availability of services to this group, particularly 'respite' care to enable a family carer to have a break from caring. Such respite services need to be regularly accessible and, importantly, perceived as trustworthy by carers. Where such breaks are unavailable, care within the family home may be unsustainable in the long term, ending in a crisis where the person with dementia is moved to a residence that the family find unsatisfactory. Funds are available from government for respite care but not in a form that promotes flexible, reliable provision. Organisations providing this service need to keep beds full to maintain their income and provide a quality service. Respite stays are short, consequently some beds may remain empty for periods of time when demand is low. This loss of income creates reluctance to offer respite accommodation.

People in the early stages and late stages of dementia have different needs. In the early stage the main need is for psychological services, whereas in later stages nursing care is required. There is a new recognition of the importance of providing quality services for people at the end of life. Hospices are expert in pain management and support but people with dementia do not tend to access them. Jill speculates that this may be due to lack of availability of places. She comments that the hospice approach is valuable but not practiced in many places providing continuing care. In this final stage of life pain management is important, as is the recognition of the development of other conditions such as cancer. Currently doctors often attribute developing symptoms to a person’s dementia and so they may not be investigated adequately.

The service system

In the English service system the Primary Care Trust (PCT) is the main organisational body responsible for services to people with dementia. When service delivery was re-organised, joint health and social care commissioning was lost and their funding was given to the PCTs. In general, PCT commissioners were unaware of independent providers in this sector and so the range of provision reduced. Progress in service delivery has therefore stalled.

Information sharing is a problem especially in the voluntary sector. Voluntary sector staff are only given information by statutory agencies when it is crucial. However a greater sharing of information would allow such organisations to provide better care. Family members assume agencies share information. This information gap could have a serious effect on the service user.

UK policy promotes independent living for people with complex needs. It is commonly felt that the person with dementia should remain in the place where they were happiest. As noted above, however, assumptions that the interests of the person with dementia and their carer are the same, need to be avoided. Jill feels that the biggest challenge for services is to provide a well trained workforce. The training budget of any organisation needs to be adequate, therefore, so that appropriate training can be undertaken. As a result standard of service delivery are likely to improve.

Rob Greig **27th July 2007**
National Director for 'Valuing People' /
Co-Chair Disability Task Force

In response to the draft 'Country Report' Rob commented that an area not highlighted, is that of 'hate crime' and fear for safety in the community. In the UK there have been several examples in recent months of people with learning disabilities being targeted for abuse or even killed by non-disabled people. The current thrust within the policy-making community is that people with disabilities should be empowered. Choice and control should be transferred from those who have traditionally directed the lives of these people, to disabled people themselves. Their needs should be seen holistically and not segmented chronologically and by agency.

Rob commented that there are a wide array of initiatives aimed at improving outcomes by using a more person-centred, holistic philosophy in relation to service provision and support to individuals and families. However there have been difficulties in implementation. Inclusive education, often implemented without adequate planning or resources, not lived up to its promise. There are some inconsistencies where older legislation undermines the intent of newer initiatives, due to the way funding responsibility is determined. This may lead to a situation where a person is forced to live in residential care, with the associated limitations on rights and freedoms, as a move to live in independent supported tenancy could lead to a change in which local authority is responsible for paying for their services – with the new authority potentially declining to 'pick up the tab' because of differing interpretations of eligibility criteria. There is therefore a disincentive to move to more independent living for some people. In addition, some authorities take the view that people who are unable to consent to a local housing tenancy agreement should remain in residential care homes.

Main risks for discrimination

This is seen as stemming from the attitude of the public towards disability and general disinterest in issues affecting people with disabilities. Neglect of the needs of people with disabilities in legislation and policy in the past has led to a situation where levels of interest and concern about this group, as reflected by press coverage, are negligible. Even the most tragic situations gain scant coverage. People with complex needs lack a political voice, consequently their concerns and issues are not heard. Where they are subject to discrimination, their experiences and views may not be expressed in any conventional or recognised manner. As a minority group, changes to improve their situation are often too small to impact on statutory service provider's performance targets or to be widely reported in the media. This means that they may be given low priority by the organisations concerned.

An associated factor stems from the low expectations held by professionals and policy makers regarding the capabilities and aspirations of people with disabilities. Legislation tends to be aimed at larger groups, ignoring the specific needs of those with more complex needs.

Perspective on anti-discrimination policy in UK

In general, there is a view that the UK has an excellent policy framework in relation to the rights and needs of disabled people, better than at any time in the past. However, due to the lack of sanctions to enforce compliance, its promise has not been delivered into the daily lived experience of people with disabilities. Even where action is taken, service providers and professionals may presume that directives, for example to support disabled people into employment, do not apply to those with more complex needs. Discrimination arising from such interpretational factors may be avoided in the future where legislation and policy provides a clearer steer on the range of people covered under such directives.

Policy specific questions

Unintended consequences

Policy tends to focus on achieving solutions for the majority and as a consequence misses the minority. One example is the introduction of ‘league tables’ for schools, intended as a means to encourage schools to improve their standards by demonstrating higher and higher levels of achievement among pupils. This initiative proved a disincentive for schools to admit children with complex needs, in particular those with cognitive impairments, because of their impact on overall school performance and consequently their place in the league table. Target setting in health policy has also meant that the focus of healthcare providers has concentrated on targeted areas and the important but untargeted needs of those with complex disability tend to be ignored.

On the Agenda

People with complex needs are on the agenda in the Department of Health to a greater extent than for some time – but this is still a low priority compared to other political priorities. A number of disturbing reports about their treatment within the healthcare system requires a response from Government. Disturbingly, they are also on the agenda because the number of people with complex needs in the population as a whole has grown to such an extent that some Local Authorities are in crisis, because they are driven to overspend their budgets.

This group is also on the agenda of the Office for Disability Issues (Department for Work and Pensions) in relation to rights and equalities. They are also to some extent on the agenda of the Department for Education and Skills, in terms of the provision of inclusive education.

Actors in the field

The main actors in the field include.

- The National Forum of People with Learning Disabilities who have had an important impact in a number of ways – for example it is primarily their work that has led to Hate Crime getting onto the political agenda
- Mencap who produced a report on healthcare for people with learning disabilities which has had an impact on government activity.

- The Learning Disability Coalition, recently formed from organisations of and for people with learning disabilities, who are communicating with a Minister and so potentially may have an impact on policy making in the future.
- The wider Independent Living movement who clearly represent people with physical disabilities, though tend not to represent the particular issues of people with learning disabilities, and are influential.
- The Learning Disability Task Force who were influential in the past but less so in recent years. However they are now ‘getting their act together’ once again and becoming more influential.

Key issues

The key issue for policy makers currently is making existing policy happen on the ground.

Policies in preparation

The ‘Valuing People’ learning disability policy is currently being refreshed and an ‘Independent Living’ review is underway.

Study on the Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs

People with severe disabilities and/or with complex needs and their families are at risk of discrimination in almost all areas of life. They are mostly not considered in policy development and implementation at local, regional, national and European level. It is high time for all stakeholders to undertake positive action against the high risk of discrimination of this group of European citizens.

These are some of the conclusions drawn by the participants of the "Study on the Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs" that was financed by the European Commission. The study was managed by the Commission's Unit for the Integration of People with Disabilities (Unit G3) in the Directorate General for Employment, Social Affairs and Equal Opportunities.

Inclusion Europe, the European Association of People with Intellectual Disabilities and their Families, was responsible for the coordination and implementation of the study. The research work has been lead by Dr. Johannes Schädler of the Zentrum für Planung und Evaluation Sozialer Dienste (ZPE) of the University of Siegen. Twelve National Research Experts from Belgium, the Czech Republic, France, Germany, Italy, Lithuania, the Netherlands, Poland, Romania, Spain, Sweden and the United Kingdom were responsible for collecting and analysing national data and representatives of nine European NGOs contributed to the development of the policy recommendations.

The results and recommendations of the study are presented in four Volumes:

- **Volume I: Policy Recommendations**
- **Volume II: Research and Analysis**
- **Volume III: Country Reports and Stakeholder Interviews**
- **Volume IV: Examples of Good Practice**

They are available on the website of the European Commission at **ec.europa.eu/employment_social/disability** or on Inclusion Europe's website at **www.inclusion-europe.org.**

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