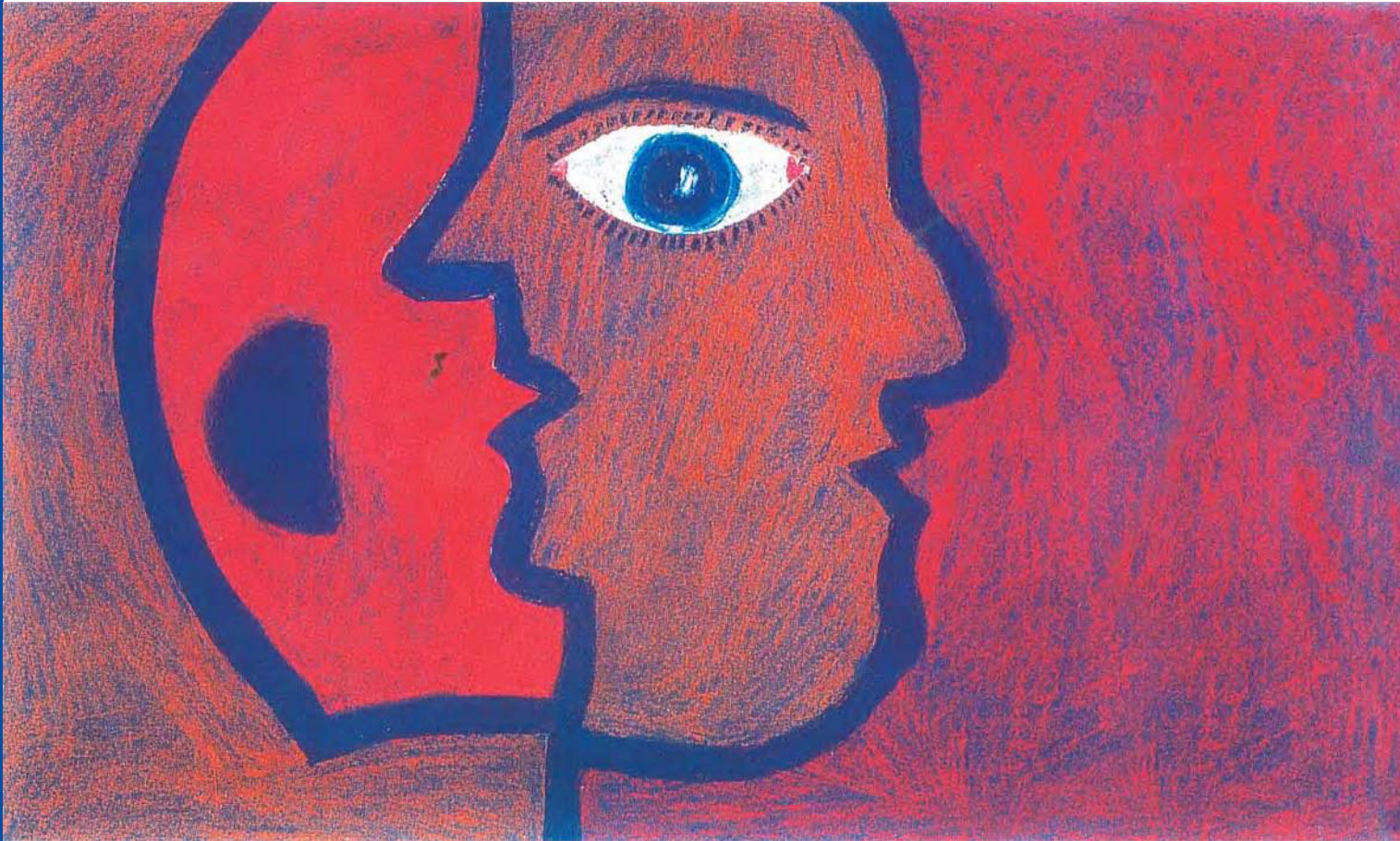


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# **The Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs**



Report of a European Study  
**Volume 2: Research and Analysis**

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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 2: Research and Analysis**

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

**www.non-discrimination.eu**

## **1. Research Section of the Final Report**

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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**

## 1.1 Summary of the Research Section

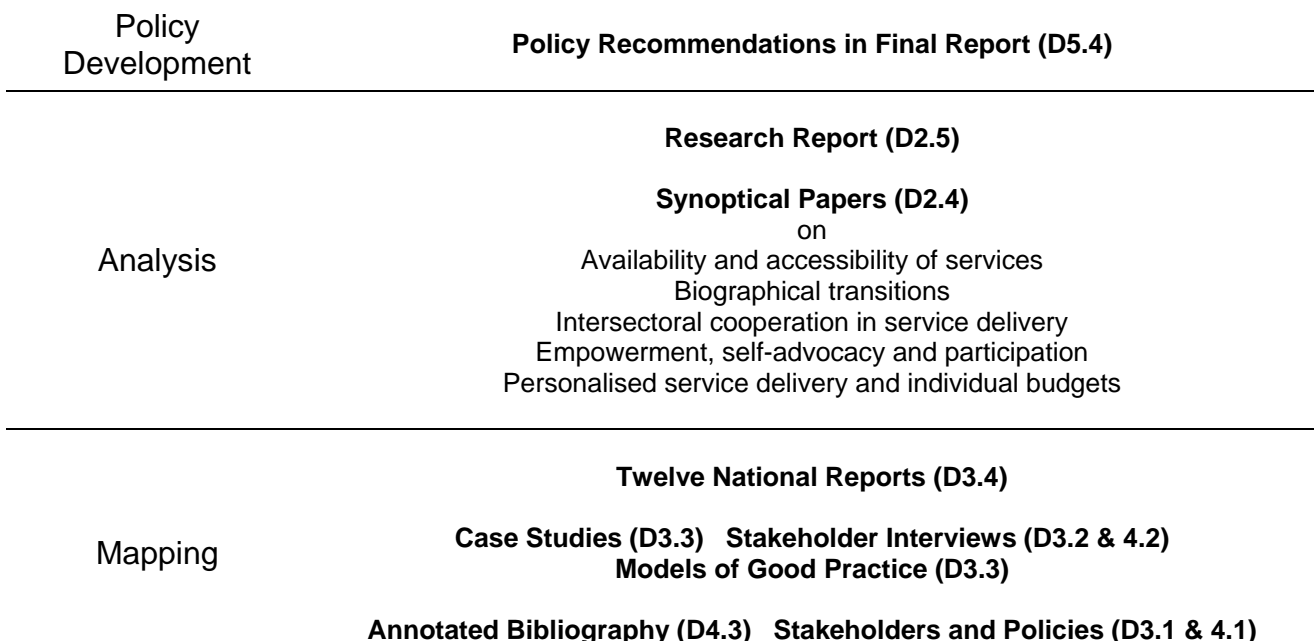
This Deliverable comprises the Research Report of the present Study that will be part of the Final Report of the project. It describes the research work undertaken and presented in the other Deliverables of the project. Thus, it must be understood in conjunction with the other Deliverables, especially the five Synoptical Papers and the twelve Country Reports.

This project report contains a comparative study in a representative sample of twelve Member States of the European Union on specific risks of discrimination against persons with severe disabilities or complex support needs. The project was coordinated by Inclusion Europe with scientific support from the University of Siegen, Germany, and was conducted between December 2006 and April 2008. Participating countries were Germany, France, the United Kingdom, Italy, Spain, Poland, Lithuania, the Czech republic, the Netherlands, Belgium, Sweden and Romania.

The research study conceptually follows the social model of disability and is developed in a universalistic perspective of human rights of all people with disabilities expressed by the UN Convention on Human Rights for Persons with Disabilities. This universal perspective provides the basis for non-discrimination legislation and policies at European and national level.

The methodological basis of the study is a life-course oriented approach. Life-course orientation functions on the one hand as a social scientific model for the empirical analysis of discrimination of people with disabilities with high and complex support needs. On the other hand it is used as a structure for recommendations for European and national non-discrimination strategies.

The following graphic provides a summary overview of the mapping, analytical and policy development work that is undertaken by this study, including the Deliverable numbers:



It is clear that the five synoptical papers presented in Deliverable 2.4 are the central analytical step to identify issues central for non-discrimination strategies. They focus on to 'availability and access', 'personalized services', 'self-advocacy and empowerment',

'intersectoral cooperation' and 'transition'. The general finding is that progress has been made concerning formal non-discrimination and equality of people with and without disability. But very often, in these policies people with complex support needs are not sufficiently considered or completely excluded. Especially when comparing their life situation with the demands of the UN Convention, one can say that in some major areas the target group of this study so far does only little profit from improvements and progress that have been made.

The report finishes with a table of recommendations for European and national strategies and policies against discrimination of people with severe disabilities and complex support needs.

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Ce document comprend le rapport de recherche de cette étude qui fera partie du rapport final du projet. Il décrit le travail de recherche entrepris et présenté dans les autres livraisons du projet. Il doit donc être compris en lien avec les autres documents produits, et notamment avec les cinq synoptiques et les douze rapports nationaux.

Ce rapport contient une étude comparative sur les risques spécifiques de discrimination des personnes avec des handicaps sévères ou des besoins complexes dans douze Etats Membres de l'Union européenne constituant un échantillon représentatif. Le projet, coordonné par Inclusion Europe avec le soutien scientifique de l'Université de Siegen en Allemagne, s'est déroulé de décembre 2006 à avril 2008. Les pays participants sont l'Allemagne, la France, le Royaume-Uni, l'Italie, l'Espagne, la Pologne, la Lituanie, la République tchèque, les Pays-Bas, la Belgique, la Suède et la Roumanie.

Cette étude est basée sur le concept du modèle social du handicap et prend pour perspective les droits de l'homme mentionnés dans la Convention des Nations Unies sur les Droits des Personnes Handicapées. Cette perspective universelle fournit les fondements d'une législation et des politiques de non-discrimination aux niveaux européen et national.

La méthodologie de l'étude est une approche par les cycles de vie. Cette approche par les cycles de la vie fonctionne d'une part comme modèle scientifique pour l'analyse empirique de la discrimination des personnes handicapées avec des besoins sévères et complexes. D'autre part, elle est utilisée comme structure pour les recommandations en faveur de stratégies nationales et européennes pour la non-discrimination.

Le graphique suivant donne un aperçu général du plan ainsi que du travail analytique et politique entrepris au cours de cette étude, y compris les documents à livrer.

Conclusions  
politiques

**Recommandations politiques dans le Rapport Final (D5.4)**

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**Rapport de Recherche (D2.5)**

**Documents Synoptiques (D2.4)**

Analyse

sur  
la disponibilité et l'accessibilité des services  
les transitions biographiques  
la coopération intersectorielle dans la fourniture des services  
l'autonomie, autoreprésentation et participation  
la fourniture de services personnalisés et les budgets individuels.

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**Douze Rapports nationaux (D3.4)**

Information

**Etudes de Cas (D3.3) Entrevues avec des décideurs politiques (D3.2 & 4.2)  
Exemples de Bonnes Pratiques (D3.3)**

**Bibliographie analytique (D4.3) Décideurs politiques et Politiques (D3.1 & 4.1)**

Les cinq synoptiques présentés dans la Livraison 2.4 représentent la phase analytique centrale pour identifier les questions fondamentales pour les stratégies de non-discrimination. Ils se concentrent sur « la disponibilité et l'accès », « les services personnalisés », « l'auto-représentation et l'autonomie », « la coopération intersectorielle » et « la transition ». La conclusion générale est que des progrès ont été réalisés en ce qui concerne la non-discrimination et l'égalité formelles des personnes avec et sans handicap. Mais très fréquemment dans ces politiques, les personnes avec des besoins complexes ne sont pas suffisamment prises en considération ou sont complètement exclues. Tout particulièrement lorsque leur situation de vie est comparée avec les exigences de la Convention des Nations Unies, on peut dire que le groupe cible de cette étude a très peu bénéficié jusqu'à présent, dans des domaines majeurs, des améliorations et des progrès réalisés.

Le rapport conclut par un tableau de recommandations pour des stratégies nationales et européennes contre la discrimination envers ces personnes.



## 1.2 Introduction

This introductory chapter is to provide a basis for the conceptualisation and evaluation of research activities for this project. Firstly, in a historical perspective socio-political developments are outlined that have led towards a universal framework of citizen's rights explicitly including persons with disabilities no matter what kind or degree of their impairment. In this context it refers to the recent UN Convention on the rights of persons with disabilities. This is followed by definitions of equality and discrimination that make it possible to operationalize discrimination in research activities. A further part reflects the EU-laws and regulations on non-discrimination. Finally it is shown how severe disability and complex support needs can be seen in the perspective of a life-course approach.

## 1.3 Policies for people with severe disabilities and/or complex support needs: towards a universal framework of citizen's rights

In European and other Western countries public policy for people with severe disabilities and/or complex support needs has always addressed a very fundamental political question: do people, whose physical, sensorial, cognitive or mental functions are widely impaired, qualify for citizenship? Can they generally - or to which extent - be considered worthy of carrying and exercising citizen's rights? As a consequence, public policies for people with severe disabilities have always been shaped by the political concepts and ideologies that were dominant at the time.

In the historical process of modernization in Western countries the understanding of an individual and a citizen has remarkably changed. Political theory shows that for a long time the status of a citizen was closely related to the right to enter contracts. Thinkers of classical liberalism conceived the individual as a completely developed, adult person, able to make contracts and using this ability for contracting to act self-determined and to care for his subsistence. The individual citizen is free, has property, is the head of a household, is male and has a white skin. Being a citizen and thus having rights and obligations against the state, he pays taxes and is (or should be) allowed to political participation. On this basis he economically and socially operates with other 'citizens', negotiating and entering contracts, and thus configures market networks of 'free' individuals. All other people, who own no property and are not head of households are traditionally in an either absolute precarious situation of paupers completely unprotected against any social risks. Or they are in a subordinate position, dependent on a 'patron' towards whom they change obedience against a certain subsistence and protection. As they are not self-subsistent and are not able to make contracts, there is no right for self-determination and a citizen status is not accessible. Historically, these dependent persons were e.g. women, children, people with other skins than white, and people with disabilities. Theorists like Karl Polany<sup>1</sup> have tried to explain how these two traditional forms of social relations in capitalistic societies – the contract and the hierarchy – have also had an impact on the essential structures of social protection systems. As a result of forced proletarianization of rural population masses of uprooted people competing for poorly paid jobs in early industries, many were not able to care for their own subsistence and became dependent on social support. It is not possible here to describe these developments closer with all the differences between European countries. But within the early social support systems of the industrial age in European countries a developmental path was started that also shaped further developments. The systems of social protection were started and continued aiming at assuring and disciplining potential workforce, therefore highly

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<sup>1</sup> Polany, Karl (2001): The Great Transformation: The political and economic origins of our time. Boston

paternalistic seeing the dependent person primarily as a member of a collective whose life is to be strongly regulated by bureaucratic and social structures that do not foresee individual rights.

It was the English sociologist Thomas H. Marshall<sup>2</sup> who analyzed in the late 1940ies how in the processes of conflicts between social classes and democratization the old liberal concept of citizenship has been challenged and changed. This processes can be understood as a struggle of economically disadvantaged classes of societies for 'full citizenship' comprising 'juridical rights', 'political rights' and 'social rights', that have to be guaranteed by the democratic state to all its citizens - individually and collectively. In his concept of 'social citizenship' having social rights is conceived as a precondition for full citizenship. In this sense there are apparent parallels to the more recent 'capability approaches' developed from an economic perspective on poverty and development by Amartya Sen<sup>3</sup>, which focus on increasing the real 'practical opportunities' that disadvantaged groups and individuals have. They seem to provide an important additional model for disability research and policy, but can only be mentioned here.

After the defeat of Nazi-regime in 1945, sensibility against racist ideologies, colonialism, discrimination and social injustice was high and led to an internationally growing dominance of universalistic ideas of human rights. In 1948, the Universal Declaration of Human Rights were adopted and proclaimed by the United Nations' General Assembly, stating that "Everyone is entitled to all rights and freedom set forth in this Declaration, without distinction of any kind, such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status" (Art. 2). The list of rights refers to all elements of 'full citizenship' such as the right to equality before the law (Art. 7), the right of all to take part in government of their country (Art. 21), the right to freedom of movement (Art 13) the right to marry and found a family (Art. 16), the right to social security (Art. 22), the right to work (Art 23), to rest and leisure (Art. 24), the right to an adequate standard of living, access to health and social services (Art 25), the right to education (Art. 26) and the right to participate in cultural life of the community (Art. 27)<sup>4</sup>.

In 1950 the Council of Europe codified the European Convention of Human Rights also supporting the principles of universal rights and citizenship that include political participation and social rights like equal access to public services<sup>5</sup>.

It was due to the activities of the great social movements of the 20<sup>th</sup> century like the women's liberation movement, the civil rights movement against racism, or the disability movement that the status of a citizen 'de jure' more and more was recognized as a universal right of all persons.

As none of the early declarations mentions people with disabilities, it was a big step forward for the rights movement of people with disabilities that the United Nations expanded the principle of human rights in the 1970s explicitly to people with disabilities. In 1971, the United Nations proclaimed the 'Declaration of the Rights of Mentally Retarded Persons'<sup>6</sup> and in 1975 the 'Declaration on the Rights of Disabled People'<sup>7</sup>. In the following decades these declarations were specified in detail in the 'Standard Rules on the

---

<sup>2</sup> Marshall, Thomas H. (1950): Citizenship and social class and other essays. Cambridge

<sup>3</sup> Sen, Amartya (1999): Development as Freedom, New York

<sup>4</sup> See e.g. <http://www.un.org/Overview/rights.html> (called on May 20th 2008)

<sup>5</sup> See e.g. <http://conventions.coe.int/Treaty/en/Treaties/Html/005.htm> (called on May 20th 2008)

<sup>6</sup> See e.g. [http://www.unhchr.ch/html/menu3/b/m\\_mental.htm](http://www.unhchr.ch/html/menu3/b/m_mental.htm) (called on May 20th 2008)

<sup>7</sup> See e.g. <http://www.unhchr.ch/html/menu3/b/72.htm> (called on May 20th 2008)

Equalisation of Opportunities for People with Disabilities<sup>8</sup> approved by the United Nations in 1991. These disability-related declarations confirmed strongly that universal rights are equally valid for people with disabilities, but also required all governments to provide specific services to ensure that people with disabilities with disabilities would be able to exercise their rights as full citizens. Discrimination against disability became a public issue that in many European countries led to the explicit changes in constitutional texts stating equal rights of people with disabilities<sup>9</sup>.

At international level, in December of 2006 the 'Convention on the Rights of Persons with Disabilities'<sup>10</sup> was approved by the General Assembly of the United Nations, and is now in the ratifying process in State Parties. The convention's preamble draws an explicit line with a number of similar conventions for protecting human rights of groups at risk of discrimination<sup>11</sup>.

In accordance with other accepted international definitions<sup>12</sup>, the Convention is recognizing that disability is "an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others"<sup>13</sup>. As stated in Article 1 it is the purpose of the convention "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity". In the context of this paper it is worth mentioning that the convention explicitly refers to 'all' persons with disabilities no matter what kind or degree of impairment they have.

Central to the present convention, that covers a broad set of relevant issues, are principles like 'respect', 'non-discrimination', 'full participation', 'equality' and 'accessibility' (Art. 3). Part of the convention is a reporting mechanism requiring all state parties to report regularly on their results of implementation (Art. 35, 36, 37) All EU-countries have announced that they are going to ratify the text.

## 1.4 Equality and Non-discrimination in human rights protection

As a result of the outlined developments the principles of equality and non-discrimination are central to any modern system of human rights protection.

Although international human rights instruments have core equality provisions in common, the text and interpretation of these equality provisions reveal different facets of equality protection which vary considerably from one legal system to another one.

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<sup>8</sup> See e.g. <http://www.un.org/esa/socdev/enable/dissre00.htm> (called on May 20th 2008)

<sup>9</sup> See also Deliverable 3.1 of this project, which contains a list of legislation and non-discrimination policies in the participating countries

<sup>10</sup> See e.g. <http://www.un.org/disabilities/> (called on May 20<sup>th</sup> 2008)

<sup>11</sup> Like the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, the International Convention on the Elimination of All Forms of Racial Discrimination, the Convention on the Elimination of All Forms of Discrimination against Women, the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, the Convention on the Rights of the Child, and the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families.

<sup>12</sup> Like the International Classification of Functioning (ICF) of the World Health Organization

<sup>13</sup> See the Preamble of the UN 'Convention on the Rights of Persons with Disabilities'

There are two broad conceptual approaches to equality evident in equality and non-discrimination provisions in both domestic and international law<sup>14</sup>:

Formal or 'juridical' equality refers to a basic idea that individuals in like situations should be treated alike. Formal equality focuses on equal treatment based on the appearance of similarity regardless of the broader context. Structural factors can ensure that regardless of any equal treatment or prohibition of direct discrimination, certain groups fall behind the rest of society. Therefore, applied on its own and if differences are not taken into account as well as similarities, consistency of treatment is inadequate to ensure the broader aims of equality.

'Substantive equality' refers to the notion that individuals in different situations should be treated differently. It encompasses two distinct ideas – equality of results and equality of opportunity.

'Equality of results' requires that the result of the measure under review must be equal. It recognises that apparently identical treatment can in practice reinforce inequality because of past or ongoing discrimination or differences in access to power or resources.

'Equality of opportunity' suggests that the law can ensure that all individuals have equal opportunity, taking into consideration their different starting positions, to gain access to the desired benefit. Equal opportunity aims to provide equal chances but not results. Civil rights legislation provides equal opportunities for underrepresented or vulnerable groups by opening the gates for those who have been unable to participate in the society.

Discrimination on the basis of disability" is defined in the UN Convention of 2006 as "any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation" (Article 2)<sup>15</sup>.

More concretely, in Community (and other) discrimination law four types of conduct can be differentiated that are prohibited:

**Direct discrimination** is based on the idea of formal equality. It may be defined as less favourable or detrimental treatment of an individual or group of individuals on the basis of a prohibited characteristic or ground such as, sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation

**Indirect discrimination** occurs when a practice, rule, requirement or condition is neutral on its face but impacts disproportionately upon particular groups, unless that practice, rule, requirement or condition is justified.

**Harassment** may be defined as occurring where unwanted conduct takes place with the purpose or effect of violating the dignity of a person and of creating an intimidating, hostile, degrading, humiliating or offensive environment.

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<sup>14</sup> For an analysis of equality concepts, see: Fredman, Sandra (2002): *Discrimination Law*, Oxford

<sup>15</sup> See the UN 'Convention on the Rights of Persons with Disabilities'

**Victimisation** may be defined as any adverse measure taken by an organisation or an individual in retaliation for efforts to enforce legal principles, including those of equality and non-discrimination.

The following part describes those parts of EU-law and regulations that refer to the described types of discrimination.

Direct discrimination:

Article 2.2(a) of the **EU Race Directive**<sup>16</sup> provides that

“direct discrimination shall be taken to occur when one person is treated less favourably than another is, has been or would be treated in a comparable situation on grounds of racial or ethnic origin.”

The **EU Employment Framework Directive**<sup>17</sup> uses the same formulation (article 2.2 (a)) but applies it to a broader list of prohibited grounds listed in Article 1 (including disability).

Consideration of less favourable treatment requires the judge to make a comparison between the situation of the claimant and that of any comparator by which the treatment given to the claimant is less favourable than that given to the comparator. It may not always be possible for the claimant to point to a real person who is in the same circumstances as he is. The Directive permits a comparison to be made between the complainant's situation and the situation of another person whose circumstances are not identical. If there is evidence that shows that the person who treated the complainant less favourably would treat others in similar circumstances better, the complainant can demonstrate direct discrimination.

Indirect discrimination:

EU law has played the main role in developing the concept of indirect discrimination (which is not often guaranteed in international Human Rights instruments), in defining the concept and indicating how it may be enforced.

EU law prohibits indirect discrimination on the grounds of disability unless it can be justified. The grounds for justification are broad.

In Article 2.2 (b) of the Employment Directive it says:

Indirect discrimination shall be taken to occur ***where an apparently neutral provision, criterion or practice would put persons having a particular religion or belief, a particular disability, a particular age, or a particular sexual orientation at a particular disadvantage compared with other persons unless:***

- (i) that provision, criterion or practice is objectively justified by a legitimate aim and the means of achieving that aim are appropriate and necessary, or

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<sup>16</sup> See European Commission (2000): Council Directive 2000/43/EC on implementing the principle of equal treatment between persons irrespective of racial or ethnic origin ([http://ec.europa.eu/employment\\_social/fundamental\\_rights/pdf/legisln/2000\\_43\\_en.pdf](http://ec.europa.eu/employment_social/fundamental_rights/pdf/legisln/2000_43_en.pdf); called on May 20<sup>th</sup> 2008)

<sup>17</sup> See European Commission (2000): Council Directive 2000/78/EC on establishing a general framework for equal treatment in employment and occupation ([http://ec.europa.eu/employment\\_social/fundamental\\_rights/pdf/legisln/2000\\_78\\_en.pdf](http://ec.europa.eu/employment_social/fundamental_rights/pdf/legisln/2000_78_en.pdf); called on May 20<sup>th</sup> 2008)

- (ii) as regards persons with a particular disability, the employer or any person or organisation to whom this Directive applies, is obliged, under national legislation, to take appropriate measures in line with the principles contained in Article 5 in order to eliminate disadvantages entailed by such provision, criterion or practice.

### Harassment:

EU law, through its Employment Framework and Race Directives provides a very clear definition of harassment<sup>18</sup>.

Under Articles 2(3) of each instrument, harassment is defined as follows:

“Harassment shall be deemed to be a form of discrimination within the meaning of paragraph 1, when ***unwanted conduct related to any of the grounds referred to in Article 1 takes place with the purpose or effect of violating the dignity of a person and of creating an intimidating, hostile, degrading, humiliating or offensive environment.*** In this context, the concept of harassment may be defined in accordance with the national laws and practice of the Member States.”

This definition above notes that the unwanted conduct “takes place with the purpose or effect” of violating dignity. This suggests that even if the purpose is not to harass, establishing a degrading effect is sufficient for a finding of harassment.

### Victimisation:

‘Victimisation’ in discrimination law describes any adverse measure taken by an organisation (including employers and public authorities) or an individual in retaliation for efforts to enforce legal principles, including those of equality and non-discrimination.

The clearest example is where an employee complains about – or takes legal action – because of harassment or any other denial of equal treatment, and the employer responds by dismissing or failing to promote the employee.

In a similar manner, the EU Race and Framework Directives both define victimisation as one form of unlawful discrimination.

Article 11 of the Employment Framework Directive:

Member States shall introduce into their national legal systems such measures as are necessary to protect employees against dismissal or other adverse treatment by the employer as a reaction to a complaint within the undertaking or to any legal proceedings aimed at enforcing compliance with the principle of equal treatment.

**Positive action or affirmative measures** are proactive measures taken by a government or private institution to remedy the effects of past and present discrimination by providing reverse preferences favouring members of classes previously disadvantaged.

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<sup>18</sup> See: ‘Harassment at the Workplace’, The Report of the Employment and Social Affairs Committee of the European Commission, July 2001, 2001/2339 (INI).

**Reasonable accommodation** describes a modification of current practices or structures in a way that favours the full inclusion of a disabled individual and is reasonable when the necessary investment and the effect are compared. In the context of presently existing European legislation (Directive 2000/78/EC establishing a general framework for equal treatment in employment and occupation<sup>19</sup>), it denotes any modification of, or adjustment to a job, an employment practice, the work environment, or the manner or circumstances under which a position is held or customarily performed that makes it possible for a qualified individual to apply for, perform the essential functions of, and enjoy the equal benefits and privileges of employment.

Positive measures:

The Employment Framework Directive includes a provision on positive measure (Article 7):

1. With a view to ensuring full equality in practice, the principle of equal treatment shall not prevent any Member State from maintaining or adopting specific measures to prevent or compensate for disadvantages linked to any of the grounds referred to in Article 1.
2. With regard to disabled persons, the principle of equal treatment shall be without prejudice to the right of Member States to maintain or adopt provisions on the protection of health and safety at work or to measures aimed at creating or maintaining provisions or facilities for safeguarding or promoting their integration into the working environment.

The EU case-law regarding gender positive discrimination has been strictly interpreted by the ECJ. Therefore it is too early, since we don't have any case-law, to say if the ECJ will interpret this provision in a relatively narrow meaning too or not (in relation to paragraph of Article 7).

Some Human Rights law books tend to include mainstreaming as a measure of positive discrimination.

Reasonable accommodation:

Again, EU law is one of the unique instruments that is describing the reasonable accommodation duty, in its Article 5 of the Employment Framework Directive.

Reasonable accommodation for persons with disabilities:

In order to guarantee compliance with the principle of equal treatment in relation to persons with disabilities, reasonable accommodation shall be provided. This means that employers shall take appropriate measures, where needed in a particular case, to enable a person with a disability to have access to, participate in, or advance in employment, or to undergo training, unless such measures would impose a disproportionate burden on the employer. This burden shall not be disproportionate when it is sufficiently remedied by measures existing within the framework of the disability policy of the Member State concerned.

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<sup>19</sup> OJ L 303/16 2.12.2000

Accommodation measures aim to remove discriminatory effects on a 'protected' individual or group, such as people with disabilities. Legal requirements to take such measures stem from the recognition that identical treatment of individuals and groups does not always eliminate discrimination. Without measures to accommodate their needs, certain groups could be so disadvantaged that they are unable to participate fully in life and work.

In its preamble the UN Convention on the Rights of Persons with Disabilities adds another important approach to the list of positive action against discrimination: 'universal design', defined as the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design without excluding assistive devices for particular groups of persons with disabilities where this is needed<sup>20</sup>.

As shown, the legal rights position of people with disabilities no matter what form or degree of impairment they have has been confirmed by a strong framework of international and European rights and laws. The challenge obviously lies in practical implementation on the level and situations where people with disabilities live.

Referring to legal developments on UN and European level also expresses the importance of maintaining a universalistic framework of human rights particularly for people with severe disabilities. In this perspective it is essential that public services and institutions guarantee an appropriate standard of living and assure that all people with disabilities are included in mainstream health, social and educational services as essential for their inclusion in universal citizenship. Particularly for people with severe disabilities as being mostly persons with high support needs and little financial resources market dynamics and consumerism can become a threatening risk for their citizen status. Easily they can be viewed as 'negative consumers', undeserving of public expenditure and not in the responsibility of the state but of charities and 'faithbased' agencies<sup>21</sup>.

## **1.5 Understanding severe disability and/or complex support needs in a life course perspective**

### **1.5.1 Understanding severe disability and complex needs**

An approach towards understanding what 'severe disability' or 'complex support needs' means must necessarily be made within the discourse on understanding disability in general. In past decades, research and discussions focusing disability have developed towards a social interpretation of disability, highlighting the special meaning of social structures ("social model") rather than individual differences between people. Disability can be viewed as a social problem caused by social processes<sup>22</sup>. Taking this as a general basis, life experiences of people with disabilities can be thought about in new ways. In this sense having a disability can mean exclusion from important areas of social life. It is not so much the person with an impairment that cannot fulfill expected social roles, but it is the disabling society that turns impairment into disability. According the UN-convention it has to be recognised that disability "results from the interaction between persons with

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<sup>20</sup> See the UN 'Convention on the Rights of Persons with Disabilities'

<sup>21</sup> Cumella, Stuart (2007): New Public Management Services for People with an Intellectual Disability: a Review of the Implementation of Valuing People in England, in press

<sup>22</sup> Barnes, Colin / Mercer, George (2003): Disability, Cambridge



impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others<sup>23</sup>.

In addition to this social interpretation of disability it is also raised that disability can be seen in a cultural perspective, that is rejecting the connotation of negativity which often automatically to disability. In this approach it is referred to elements of group history of people with disabilities and specific cultural traditions that create group identities and self understanding of a minority fighting for the political acceptance of their culture<sup>24</sup>.

There are at least four aspects that are helpful to consider when thinking about severe disabilities<sup>25</sup>. Impairment existing in whatever way cannot be denied and helps to understand the facts concerning the **body (or mind)**. Nevertheless, characteristics of the body are always shaped by elements of (social) **structure**, by specific forms of **culture** the persons lives in and in which he or she develops her or his **identity**. It is these dimensions in which severe disability can be seen as a result of complex interactions between the individual and society.

Understanding disability in the context of society was mostly influenced by the movement of people with disabilities and then found its way into political debates and of course scientific research. The most important aspects of this point of view are

- that there are people with impairments, but that disability is something else;
- that disability comprises exclusion from full participation in social life or society;
- that exclusion is not necessary or inevitable (which seems to be the most important point in this context); and
- that it is useful to see people with disabilities as an oppressed individuals in society. but also as a minority group challenging tolerance of societies against the 'culture of disability'

Obviously, processes of social exclusion and the construction of disability are complex, especially when it comes to explain concrete phenomena of life situations of person with severe disabilities.

On this background to categorise disabled citizens with severe disabilities and /or complex needs in terms of "impairments" or "pathologies", as it was done for too long by epidemiologists, seems inappropriate. Instead, understanding and assessment must be realised in the perspective of personal abilities, respecting their individuality as a 'centre of initiative'<sup>26</sup>. Account must be taken of individual needs and aspirations, potentials in relation to the increased vulnerability and higher risk for discrimination that people with disabilities face. Therefore this project defines disabled citizens with severe disabilities and complex needs

- in relation to their **specific needs** which are diverse and complex and can cause social exclusion;

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<sup>23</sup> See the UN 'Convention on the Rights of Persons with Disabilities'

<sup>24</sup> Waldschmidt, Anne (2005): Disability Studies: Individuelles, soziales und/oder kulturelles Modell von Behinderung? *Psychologie & Gesellschaftskritik* 29 (2005), Vol. 1, pp. 9-31

<sup>25</sup> Here the argumentation follows the thoughts of Priestley, Mark (2003): *Disability .A Life Course Approach*, Cambridge

<sup>26</sup>This expression is taken from Yeatman, Anna (2004): Social policy, freedom and individuality, in *Australian Journal of public Administration* (63)4, p.68 "Individuality means, that each individual is valued and regarded as a centre of initiative, and that rights, relationships, procedures, institutional practices and policies are designed accordingly"

- in relation to their reduced **ability to represent themselves**, which without additional support for realising self-determination and participation can cause discrimination.

'Complex needs' can be conceived as a framework for understanding multiple interlocking needs of a disabled person that span a variety of health, social care or education issues. There is no generic complex needs case. The common characteristic is that each individual with complex needs shows a unique interaction of different care needs which vary in depths (intensity of services needed) and/or breadth (range of services). These needs, because of their complexity, are specific to each person in his/her everyday life: mobility, nutrition, and personal hygiene, dressing or communicating. These skills pose different dependency problems for each individual and his/her family. By needs and entitlements, persons with complex needs address various sectors of the social security system. A person-centered approach to provide individualised service arrangements that is essential to promote personal development and prevent social exclusion is dependent on intersectoral cooperation and intersectoral case-management from the earliest possible moment of the individual's life-course. Precondition of course is that services and other necessary support are available and accessible including their affordability.

Although these "categories" have undefined parameters, the following groups could be highlighted to describe the group of people that is referred to in this project.

- Persons with "multiple impairments",
- Persons who have several impairments and/or chronic diseases at the same time,
- People with one very severe and complex disability.

### **1.5.2 Severe disabilities in a life course perspective**

In this project, a life course perspective is seen both as an adequate theoretical framework for understanding contemporary disability debates and as methodological basis for identifying specific risks of discrimination of people with severe disabilities and complex support needs. Life course can be defined as "a central organizing principle in modern societies, rather than a description of individual life careers"<sup>27</sup> Traditionally, life course approaches use the somehow predictable progression through different life stages as a basis. In consequence, especially social institutions, such as family or school, play an important role. This implies, however, an understanding of the 'normal' or 'usual' life course, and idealized version of life pattern based on cultural norms and rules. In the so-called idealized life course, the idea of normality is focused, although real life, of course, offers a great amount of varieties in the life-circle. Nevertheless, institutions and policies play an important role when thinking about 'problems' and deviations in the life circle. Mainly, understanding the idea of a 'normal' life course makes it easier to understand the following arguments concerning the social construction of disability.

Thinking about life in modern societies, it becomes also clear that traditional and predictable ways of the life circle are not as common as they used to be: life is more and more understood as a project that the individual has to manage. This idea also allows to have a closer look at disability occurring later in life, understanding it in a way as a 'biographical interruption': traditional concepts of 'usual life' have to be thought about once more and it offers the chance to see diversity in life circle. It is obvious that individuals do

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<sup>27</sup> Priestley, Mark (2003): Disability. A Life Course Approach., p.4, Cambridge  
The Specific Risks of Discrimination. Volume 2

not construct their biography apart from others, but that social relations and contexts always play an important role in one's biography: life course is constructed and organized within and by society as well as by the individual.

Individuals in modern societies develop their biographies in relation to social institutions, that structure and frame individual life. 'Transitions' are essential for the development of biographies and personal growth of individuals also depends on how transitional tasks are coped with. The term 'institution' is used here in a wide sense for social sets of rules with a very high degree of stability and sanction. Such institutions are e.g. kindergarten or other general preschool facilities, school, vocational training facilities, social security systems, the housing market or the labor market. The institution of the family also in modern societies is of special importance as a frame for individual biographies. In this perspective the life course is shaped by the way the individual copes with the challenges of transition situations from one life step to another, e.g. starting kindergarten, school, leaving family, starting work, starting life as a pensioner. But besides such socially normed transitions there are also situations of transition that are caused by critical life events (e.g. death of family member, severe illnesses, accidents, personal crisis). The important characteristic of all biographic transitions is that they are moments of change, in which successful coping and personal development but also individual failure can happen. The new life situation is characterized by new demands, unknown expectations and challenges, but at the same time it can offer new opportunities for personal growth and opportunities for becoming a full member of society.

Effects of exclusion of people with disabilities take place especially in situations of 'biographic' transitions. In these situations often decisions are taken that have wide ranging effects on the further life course. For people with severe disabilities transitions into new situations are always related with changes in their support needs and service arrangements. The availability of adequate services and the possibility to realise their citizen's rights for protection and participation become crucial for a successful coping with the transition challenges.

In many European countries, reform efforts have started years ago, the recent European disability strategy is supportive also for member states where reform activities have only just begun. Results so far cannot satisfy. The traditional system of special institutions and special facilities still is the dominant model in most European countries. Immanently it tends to create parallel worlds for people with disabilities apart from normal society with many problematic impacts for people with disabilities. Having intensive support needs still very often forces people with disabilities to use services that for various reasons operate on the basis of a segregating model. The more areas of daily life of a person with disability are structured by special institutions, the more the individual development is affected by their restrictions. The higher the disabled person's dependency of support the more likely exclusion from 'usual' social contexts will take place which is related with discrimination and restrictions for individual life opportunities.

Based on mainstreaming concepts disability politics must see their most essential objective in supporting people with disabilities to develop their biography in the context of 'normal' social institutions and places, because this is a decisive condition for participation.

Coming back to understanding severe disability it is therefore helpful to understand risks of discrimination as the link between individual biographies and social barriers. The perspective of a life course approach gives both a methodological and a normative

framework for systematic analysis of discrimination. In this context, questions can be raised like:

*“Why, have states gone to such lengths to limit or prevent especially the birth of severely disabled children? Why have severely disabled children been so often excluded from mainstream education? What is the significance of youth culture and youth transitions for young people with severe disabilities? How does the expectation of an ‘independent’ adulthood – for example in relation to employment or parenting – contribute to the production of severe disability in modern societies? Why are older people with severe and multiple impairments rarely seen as disabled in quite the same way that younger adults with similar problems often are? Why are different moral standards applied to the death and dying of people with severe and without disabilities?<sup>28</sup>.”*

These assumptions provide a conceptual frame to develop instruments for empirical research on the questions of this project. Taking the life situation of persons with severe disabilities and complex needs as a starting point the life-course oriented approach made it possible both to collect data on patterns of social protection, services and public attitudes and to identify risks of discrimination in each life step.

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<sup>28</sup> These questions were adapted from Priestley 2003, p. 2  
The Specific Risks of Discrimination. Volume 2

## 1.6 Methodological Approach

### Aim and objectives

The objective of the project was to undertake a comparative study in a representative sample of twelve member states of the European Union which improves the understanding of issues related to the risks of various forms of discrimination in relation to disabled citizens having complex needs and/or a high dependency.

Using a life-course approach as described above the study wanted to identify the risks of possible discrimination and social exclusion which people with severe disability could face, in particular in their interaction with the following welfare state sectors and fields of social life:

- Social protection, including social security;
- Healthcare, including access to all forms of medical treatment, health services and medical care;
- Social services, including care and support services;
- Social advantages;
- Information and communication;
- Education and training.

In this respect the study was to take into account in a life-course perspective including aging risks

- aspects of accessibility, availability, affordability and quality of services provided to persons with disability in order to identify situations where inequalities and delivery gaps could occur;
- aspects of intersectoral cooperation between relevant social security and social service systems;
- aspects of service provision with regard to personalised services, protection and procedural safeguards, reasonable accommodation.

All national reports were evaluated synoptically according to criteria derived from aspects listed above. On this basis conclusions were drawn on how policy makers could benefit in the future from identifying specific policy fields where the risk of discrimination is higher for people with severe disabilities and where social exclusion of these persons can be combated.

As a result, this study aimed at further advancing the paradigm-shift from system centred to person centred services.

The objectives of the project were structured in four steps:

#### Step 1:

- Review and mapping of the policy approaches and legislation on the national level targeted specifically for people with disabilities having complex needs in the countries involved;
- Review and mapping of the schemes through which independent living of people with disabilities having complex needs is typically organized in the countries involved;

- Mapping and interviewing the existing associations of and for people with disabilities having complex needs and/or a high dependency and their families on national level in the countries involved.
- Identification of the obstacles people with disabilities having complex needs face in a life-course perspective. The analysis will cover the field of social protection, including social security, access to quality medical, educational and social services, housing and employment.
- Identification of possible discrimination of families of people with disabilities with complex needs and/or a high dependency.

#### **Step 2:**

- Deepening insights in discriminating institutional and social contexts by conducting five case studies in a selected region of each country involved.

#### **Step 3:**

- Comparison and analysis of national data and reports
- Identification and presentation of good practices of ensuring independent living and quality of life of persons with complex needs with respect to organization, user involvement, quality assessment, procedural safeguards, personal assistance schemes, financing systems and training aspects.
- Working out a proposal for a catalogue of participation indicators to measure progress of non-discrimination processes on national and local community level.
- Developing recommendations for policy makers concerning discrimination risks of persons with complex needs and protection strategies on various political levels

#### **Step 4:**

- Intermediate report on the issues identified in Phases 1, 2 and 3, in a form suitable for stakeholders and policy-makers, and together with an executive summary targeted at the general public that could be incorporated into the biennial report of the Commission on the situation of people with disabilities.
- Presentation of draft report in a seminar
- Final report including seminar discussions and results

The following methodological steps were taken:

#### **Ad Step 1**

- **Task 1: Review of European and international data sources and development of web-based template for data collation**

Existing sources of data were reviewed to identify material relevant to the study. These included official reports, relevant reports from non-governmental organisations (e.g. Inclusion Europe Country Reports, European Disability Forum publications) as well as specific studies. This work was carried out by Dr. Johannes Schädler from the University of Siegen and lead into the production of a template to guide the collation of data from each country. The template was developed in consultation with the team of the European research consultants that was set up for the project. The research consultants provided additional expertise in the areas of people with severe and multiple intellectual disabilities and in the area of people with severe and multiple physical disabilities. Together with the 'research consultants team' definitions and group categorizations were clarified.

The form of the template was web-based, in order to facilitate the composition of the different data to a single data set directly usable for statistical and qualitative analysis. Programming work was done by the University of Siegen.

- **Task 2: Collation and analysis of data on national policy approaches, legislation, typical service schemes and associations**

In order to collate data and produce reports on national situations in the twelve countries involved, national experts were contracted. In April 2007 there was a training seminar for these national experts with introductions in project methodology and research tools.

For each country, contact was made with the relevant government departments for health, social affairs, employment and education. to identify possible sources of data, using both the advice and assistance of existing professional networks. As responsibilities and political structures differ from country to country it was cleared with each national expert which government level is to be addressed and how the local level can be involved.

The team for collecting national data comprised the following National Research Experts:

<b>Expert</b>	<b>Country</b>
Marie JASPARD	Belgium
Jan ŠIŠKA	Czech Republic
Jesus SANCHEZ	France
Albrecht ROHRMANN	Germany
Christine Mary CAHILL	Italy
Egle RIMSAITE	Lithuania
Ewa WAPIENNIK	Poland
Aurora TOEA	Romania
Maria José GOÑI GARRIDO	Spain
Elaine JOHANSSON	Sweden
Martin SCHUURMAN	The Netherlands
Alison ALBORZ	United Kingdom

Although allocation of responsibility for national data collection needed to be clear for effective project management, one of the strengths of this project was that the consortium members have overlapping contacts and networks through their previous work. Thus they had multiple possible points of contact and sources of information.

In September 2007 there was a second meeting of national researchers, consultants and the policy committee to discuss the state of the ongoing research process.

## **Ad Step 2**

- **Task 1: Research on cases in national regions**

In order to get deeper insights in the situation of persons with complex needs and their families in each country the national researchers documented and analysed three 'case situations' from the same national region. For comparative reasons in all countries involved the 'cases' were selected according to agreed criteria and their combinations (e.g. age, gender, type of needs, socio-economic situation, family-involvement in care arrangement).

### Ad Step 3

- **Task 1: Evaluation and comparison of national data and reports**

The University of Siegen worked out a series of five synoptical papers with results from national reports, that were extracted from the national template data and reports. The papers will inter alia focus on the following central issues: education, biographical transitions, intersectoral cooperation, empowerment and participation, personalised services. They contain preliminary assessments of evaluation and first comparative results. These papers were discussed and further developed via e-mail communication and on experts meetings and were the input for the Policy Committee to develop the recommendations.

- **Task 2: Examples of good practice**

Supported by the national researchers and research consultants' team the University of Siegen collected and documented examples of good practice with regard to the relevant criteria of the project: organization, personalised services, user involvement, quality assessment, procedural safeguards, personal assistance schemes, financing systems, intersectoral case management and training. With regard to their transferability 10 outstanding examples were selected for the project report with the support of the expert teams. According to the type of examples adequate forms of presenting and distributing will be checked (e.g. multi-media cd-rom).

- **Task 3: Recommendations for policy-makers**

Key issues of the synoptical papers were summarized in a preliminary version of recommendations for policy-makers. Recommendations aim at relevant political levels (local, regional, national and European) and concern inter alia legislation aspects, aspect of 'good governance', access of infrastructure and integration of measures in the mainstreaming policies and services. This version was prepared by the University of Siegen and Inclusion Europe. The preliminary recommendations were discussed and further developed by the Policy Committee.

### Ad Step 4

- **Task 1: Reports**

The interim report, final report and executive summary were prepared by Inclusion Europe and the University of Siegen and the research consultants. The reports incorporate material contributed in steps 1, 2 and 3. Interpretation of the results and their implications will be strengthened by using the Policy Committee as a 'sounding-board'.

- **Task 2: Seminar**

A seminar was organised in March 2008 by Inclusion Europe to discuss the results of the draft final report with national researchers, consultants, the Policy Committee and representatives of the Commission; in this context, a draft version of the Policy recommendations was presented to the High Level Group in March as well. Content of the full report will thus be shaped by the response of the Commission to the draft report and the final Seminar.

A Final Conference is organized by Inclusion Europe in June 2008. There, the research team, the national experts and the members of the Policy Committee will present and discuss the results of the study.

The following graphic summarises the methodological approach of the Study and provides the respective numbers of the relevant Deliverables.



Policy  
Development

**Policy Recommendations in Final Report (D5.4)**

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**Research Report (D2.5)**

**Synoptical Papers (D2.4)**

on

Analysis

Availability and accessibility of services

Biographical transitions

Intersectoral cooperation in service delivery

Empowerment, self-advocacy and participation

Personalised service delivery and individual budgets.

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**Twelve National Reports (D3.4)**

Mapping

**Case Studies (D3.3) Stakeholder Interviews (D3.2 & 4.2)**

**Models of Good Practice (D3.3)**

**Annotated Bibliography (D4.3) Stakeholders and Policies (D3.1 & 4.1)**

## 1.7 Introduction to the Synoptical Papers

The series of Synoptical Paper produced by this study evaluate synoptically the results of the Country Reports in the twelve participating European countries under the perspective of discrimination<sup>29</sup>. For this purpose five important areas of discrimination were chosen:

1. Availability and accessibility of services and infrastructure
2. Biographical transitions
3. Intersectoral cooperation in service delivery
4. Empowerment, self-advocacy and participation
5. Personalised service delivery and individual budgets.

Following the life-course approach of the study, the synoptical comparison focuses on the chances and risks of the target group to manage their life course in relation to typical social institutions without disadvantages. According to this approach, the existence of disadvantages and discrimination is not recognizable by an isolated view of the individual situation or an isolated view to institutional practices in organisations. Discrimination can be seen as lack of capabilities to manage everyday life in a self-determined way and, in particular, to manage transitions in the life course in a socially valued manner.

Within the synoptical approach, satisfying solutions had to be found for various methodological problems:

1. Discrimination concerning access to material (e.g. income) and non-material resources (e.g. social services) as well as related possibilities for a self-determined life management and transitions in the life course depend very strongly on the socio-economic situation of a country. The lack of access to particular resources can be an obvious discrimination in one country, while this resource in another country is not available for a majority of people in general. Therefore, it is impossible to build the comparison on key figures (e.g. income, number of certain services per 1,000 inhabitants, etc.). The indicators in these Synoptical Papers rather illustrate how the opportunities for people with complex support needs appear in comparison to other members of society.
2. Nevertheless, a comparison needs common reference points for all participants of a study. For the purpose of the Synoptical Papers, the UN Convention on the Rights of Persons with Disabilities was chosen as reference. For that reason the papers are not only descriptive but have a normative basis as reference point. Wherever it is possible, the papers refer to this document as explicit or implicit reference point<sup>30</sup>.
3. In the definition of discrimination, the papers refer to the EU terminology with the distinction of direct and non-direct discrimination, harassment and victimization.
4. According to the issue, every Synoptical Paper has its own structure. The papers try to follow the life-course oriented structure of the Country Reports whenever possible. In some papers, however, it was necessary to give an overview of the situation in countries and highlight only typical examples of discrimination. In some papers only a few transitions in the life course were chosen to clarify risks of discrimination in the selected field.

On the basis of these Synoptical Papers, conclusions can be drawn on how policy makers could benefit in the future from identifying specific policy fields where the risk of discrimination is higher for people with disabilities with complex needs and how social exclusion of these persons can be combated.

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<sup>29</sup> Within the Synoptical Papers, reference is made to national legislation. Detailed information on the particular laws and acts can be found in the Deliverables 3.4 (Country Reports) and 3.1 (Database with Stakeholders and Policy Approaches) of this study.

<sup>30</sup> See the UN 'Convention on the Rights of Persons with Disabilities'

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

**www.non-discrimination.eu**

## **Synoptical Paper**

### **2. Availability and Accessibility of Services and Infrastructure for People with Severe Disabilities or with Complex Needs**

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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**

## 2.1 Summary of the Synoptical Paper

Following the UN Convention on the Rights of Persons with Disabilities, disability results from the interaction between persons with impairments and attitudinal and environmental barriers<sup>31</sup>. Availability and accessibility of services and infrastructure are considered to be indeed central issues for the quality of life of persons with severe disabilities.

This Synoptical Paper gives an overview on discrimination risks in terms of availability and access described in the twelve Country Reports of the study and lists discrimination risks for people with complex support needs. Results show a similarity across life-stages and sectors: service provision for people with disabilities has improved in Europe in the past years, of course in relation to the different starting points of the participating countries. Nevertheless, there is a tendency that both social services and infrastructures tend to be selective and as a result, exclude those who have a high support need or severe disabilities. The more mainstream-oriented services become, the less people with complex needs tend to be part of the target group. On this background, a policy for non-discrimination must have a clear and specific strategy to involve children and adults, men and women, with severe disabilities into mainstream programmes.

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Selon la Convention des Nations Unies sur les Droits des personnes handicapées, le handicap résulte de l'interaction entre des personnes présentant des incapacités et les barrières comportementales et environnementales. La disponibilité et l'accessibilité des services et des infrastructures sont considérées comme des questions centrales pour la qualité de vie des personnes avec des handicaps sévères.

Ce synoptique offre une vue d'ensemble sur les risques de discrimination en termes de disponibilité et d'accès décrits pour ces personnes dans les douze rapports nationaux et en établit la liste. Les résultats montrent une similitude quelle que soit l'étape de la vie ou le secteur : ces dernières années, la fourniture de services destinés aux personnes handicapées s'est améliorée en Europe, en fonction bien sûr du point de départ des divers pays. Cependant, on peut constater que les services sociaux comme les infrastructures ont tendance à être sélectifs, ce qui provoque l'exclusion de ceux qui ont un besoin élevé de soutien ou des handicaps sévères. Plus le service devient un service ordinaire et courant, moins les personnes avec des besoins complexes vont faire partie du groupe cible. En fonction de cela, toute politique de non-discrimination doit avoir une stratégie claire et spécifique afin d'inclure enfants, adultes, hommes et femmes avec des handicaps sévères dans les programmes ordinaires.

## 2.2 The Normative Basis

When it is recognised that disability results from the interaction between persons with impairments and attitudinal and environmental barriers, availability and accessibility of services and infrastructure are indeed central issues for the quality of life of persons with severe disabilities. The UN Convention on the Rights of Persons with Disabilities refers to accessibility in detail:

1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons

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<sup>31</sup> See the UN 'Convention on the Rights of Persons with Disabilities'  
The Specific Risks of Discrimination. Volume 2

with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:

- (a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;
  - (b) Information, communications and other services, including electronic services and emergency services.
2. States Parties shall also take appropriate measures to:
- (a) Develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;
  - (b) Ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities;
  - (c) Provide training for stakeholders on accessibility issues facing persons with disabilities;
  - (d) Provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;
  - (e) Provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;
  - (f) Promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;
  - (g) Promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;
  - (h) Promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.<sup>32</sup>

The twelve Country Reports contain differentiated information on the availability of and access to mainstream institutions and services for people with severe disabilities and complex support needs. Affordability of services here is regarded as one criterion of accessibility. In this paper, the life-course approach used in the Country Reports will be followed and relevant points of discrimination concerning availability and accessibility of services for people with severe disabilities and complex support needs will be highlighted for each life stage and sector.

### **2.3 Prenatal Diagnosis and Counselling**

In all participating countries, routine check ups and medical care for pregnant women are generally available. In all countries there is additional medical testing available, either if the woman is over 35 (e.g. in CZ, NL, SE, ES, IT) or if there is a specific risk for the mother or the foetus. In most countries this treatment is free of charge.

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<sup>32</sup> See Article 9 of the UN 'Convention on the Rights of Persons with Disabilities'

Abortion is possible in all countries either in the first weeks of pregnancy (IT, FR, DE, CZ, LT, SE) or if mother or child are at risk<sup>33</sup>. This mostly also includes the risk of a foetus' impairment, identified after additional testing. In these cases, a termination of pregnancy is allowed significantly longer, e.g. until the 22<sup>nd</sup>-24<sup>th</sup> week of pregnancy (IT; DE, LT, NL, ES) or until the birth of the baby (UK, FR, BE).

Risks of discrimination can be identified at different levels when talking about birthrights. On the one hand, one can say that the availability of and access to medical care and prenatal diagnosis is given in most countries. In some countries, such as Poland, Romania and the Czech Republic, there are difficulties reported. Especially in rural areas, medical care is less available than in the bigger cities, or there are not enough centres that take over pregnancy examinations. Especially in Romania there is a lack of possibilities to find out about possible risks for the foetus. From the parent's point of view, limited access to medical care and prenatal diagnosis during pregnancy can be identified as direct discrimination.

Furthermore, from the parent's perspective, there are also risks of non-direct discrimination. These occur mostly in the area of counselling. In Lithuania, for example, there is no proper psychological and social counselling; In Romania, some teams working in medical institutions are insufficiently prepared for providing advice and information. In the Czech Republic, some parents have to search long for a facility that will do the abortion even if the indication is legally given. In Poland also, abortions are sometimes denied so that illegal terminations of pregnancy are still common practice. The same problem occurs in Northern Ireland where abortion in case of foetus impairment is forbidden in general: many women have to come to England to have a termination of pregnancy. In Lithuania, there is no peer counselling available when discussing abortion.

Harassment can also occur when thinking about information and counselling. The National Experts state that it is difficult to get proper information concerning the possible impairment of a foetus and its consequences (RO, ES, SE, UK, PO, UK, BE, CZ, LT) . Information is given from a medical point of view and the mothers/parents are left alone with their decisions. Often, disability is described as a burden and the negative descriptions lead to a devaluation of disability. The mothers and parents might feel guilty if they decide to have the baby.

In some countries, an ethical discussion is mentioned when talking about abortion and the applied practice in case of a foetus' impairment (IT, BE, CZ).

To summarize the results from the different national reports, one can say that there are two major problems in the field of prenatal diagnosis and counselling: on the one hand, medical care and prenatal diagnosis are not available on an equal basis all over Europe. Secondly, talking about counselling, parents are mostly given advice from a medical point of view and there is the tendency to push them into a certain direction, in this case abortion of a foetus with possible impairment. Thinking about children with severe disabilities, the pressure on the parents might be assumed to be even higher.

The UN Convention does not mention this life stage explicitly, but article 10 refers to the "right to life", which means that "States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others". "The best interest of

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<sup>33</sup> In Northern Ireland, a termination of pregnancy is only possible if the life of the mother is at risk and forbidden in all other cases.

the child shall be a primary consideration” (article 7) and the best health care available shall be available without discrimination (article 25)<sup>34</sup>.

If one takes the results of the national reports and the demands of the UN Convention, it becomes obvious that two things can be improved in Europe to come closer to the convention: firstly, the availability and access to prenatal diagnosis must increase. Secondly, counseling must consider the whole family situation, including the children's point of view, and must not focus on a medical point of view.

## 2.4 Early Childhood

After the birth of a child with severe disability and in the first years, early intervention services and family support are an important factor in the support system. Thinking about Early Intervention, different situations can be described according to the country reports:

In most countries, Early Intervention and family support are available, but nevertheless, there are usually specific problems:

At first, the Swedish and the Dutch report state that in general, the system of early intervention is of high quality: in Sweden, support is available from the very beginning and by a multidisciplinary team, habilitation plans are developed. In the Netherlands, there is also a good network of support available.

In the majority of reports, regional differences are described; families living in rural areas are disadvantaged as they have to travel long ways to get the support they need (ES, LT, CZ, PL, UK, DE, IT). Access then becomes a question of the post code.

When thinking about the quality of services, e.g. diagnosis in health care centres, the training of the professionals is a question that is highlighted several times (SE, ES, RO, BE, PL, UK, FR). Parents may have to face the fact that they are sent from one expert to the other (BE), that Individual Plans cannot meet the child's need (SE), that there is once again a focus on assessment and a medical point of view (NL) or that experts are powerless when being confronted with complex cases (FR). Discrimination in this case is strongly connected with a devaluation of (severe) disability. Furthermore, mothers and fathers have sometimes problems to get the information they need (CZ, PL, FR, DE, IT), so that access may for example become a question of good education and knowing where to get support (NL, ES). It is described as difficult to become well-informed about all possibilities of support and where to get this or who is responsible for taking over costs, so that there is a risk that financial problems are a barrier to access. In the British and in the German report, the question of assistive tools is also raised: sometimes parents have difficulties to get the material they need to support the child.

The National Experts also describe that in some countries, there are more problems with the availability of Early Intervention and family support: in Spain, for example, there are bigger coordination and implementation problems, due to a lack of infrastructure/unclear definitions of powers and big regional differences. In Lithuania, structural problems are also a barrier to access; furthermore parents have to pay for counselling which makes this kind of support inaccessible for poorer families. As disability and poverty often come together, this is a real discrimination risk. Also in the Czech Republic, the system of Early

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<sup>34</sup> See the UN 'Convention on the Rights of Persons with Disabilities'

Intervention is still weak and parents have to travel far to get adequate support. Poverty and a lack of information are main risks of exclusion from family support here. The situation is comparable in Poland where there is no comprehensive system of Early Intervention available. Structural and regional differences as well as a lack of information do also occur in Poland – besides, there are long waiting lists for (good) services. In Romania, the abandonment of children with (severe) disability has been common practice until recently and even if now families have an entitlement to get care from interdisciplinary teams, this is just in the early stages: mobile teams have just started their work, Early Intervention is not sufficient and day care centres are available only in larger cities.

Summarizing the results of the country reports, one can say that cases of direct discrimination are reported, namely where Early Intervention and family support are not available and therefore not accessible. A lack of family support can create situations where parents and children have severe problems to manage support. Families in smaller towns and villages are directly discriminated when for them support is not available due to a shortage of support services in rural parts of countries. When families have to pay for support services, this is discriminating for those families that do not have much money – as disability and poverty often go together, this can be a real threat for the families. Problems with structures and implementation of services really hinder the child in its development and participation; this can also be identified as direct discrimination due to restricted possibilities.

Non-direct discrimination is also reported in the description of the national situations: parents – standing in for their child's and family's interest – sometimes feel that they are sent from one expert to the other and that they do not get the information they need. When information is easier to access if the parents are well-educated or wealthy, this is discriminating. In some reports, a lack of knowledge of professionals is described. In these cases, young children with severe disabilities are at specific risk of discrimination as they might be disadvantaged, especially if the disease is rare and experts are hardly available. Again, a mostly medical point of view is applied and this might lead to a devaluation of people with severe disabilities.

The UN Convention mentions that the child's best interest should be taken as a basis (Article 7); respect for the home and family are mentioned in Article 23. Equal access to health care is named in Article 26; there emphasis is put on the availability of early intervention, also in rural areas. Care should be free of charge and of high standard. Article 26 mentions rehabilitation: it should “begin at the earliest possible stage, and (be) based on the multidisciplinary assessment of individual needs and strengths; support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation”<sup>35</sup>.

Comparing the claims in the UN Convention with European reality, one can say that especially the demand for early intervention in all regions cannot be fulfilled yet. Families in rural areas are still disadvantaged – there are cases where the quality of support can still be improved and where barriers to access could be eliminated by creating services

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<sup>35</sup> See the UN ‘Convention on the Rights of Persons with Disabilities’



free of charge. The demand for constant training of professionals is of special importance when thinking about severe disability which is often connected with rare diseases or symptoms. Especially children with complex needs can be best cared for if the team around the child is informed best. So, to put in a nutshell, the situation for severely disabled children can be improved around Europe when talking about Early Intervention and family support, mostly concerning availability and access to high quality support and care.

## **2.5 Childhood: Education and Care**

This area puts a focus on preschool education in the twelve participating countries. Different systems exist for children with and without disabilities. In general, one can say that there are mainstream kindergartens, special kindergartens and more or less inclusive models. In most countries, as far as the reports say, preschool education is voluntary (e.g. PL [one year obligation], ES,SE) or children have an entitlement to visit a kindergarten (DE, LT, IT). Sometimes it is free of charge (e.g. DE, PL).

The situation in the twelve countries can be distinguished according to the different models existing for children with (severe) disability.

In only a few countries, children with disabilities are mostly included into mainstream day care centres. In Italy, for example, there is no system of special education and children, also with complex needs, can join the mainstream facilities. In Sweden on the other hand, there are still a few special preschools left, but mostly there is the tendency to inclusive education. In Germany, most federal countries are on their way to integration and remarkable changes could be made within the last years. Nevertheless, there are still some typical problems: in Italy, for example, the problem is that children are mostly included into an existing environment with a lack of awareness for special needs. In Sweden, the staff is sometimes not trained to meet the needs of all children. In Germany, there are still big regional differences (among the federal countries or rural and urban areas) when talking about integration. Due to different models available, there are still conceptual deficits and organizational barriers. Summarizing this with a view to access, one can say that access to mainstream education is possible in general in these countries and is relatively popular and spread.

In many countries, inclusive education is on the agenda and possible by law – nevertheless, there is still a lack of implementation. In Lithuania, for example, the system of preschool education is still developing, but inclusion is available in general. In France, inclusion is also on the political agenda, but in practice, not many children are included into mainstream facilities – although the number is increasing. Still there is an insufficient number of places. In the UK, integration – where realized – can be understood more as co-location than as a real inclusive setting.

There are countries where inclusion is still an exception. In Poland, for example, children mostly visit special rehabilitation centres or stay at home with their mothers. The situation is comparable in the Czech Republic. In Belgium, the number of children visiting inclusive day care centre is still very low and day care services with different quality are offered. In the Netherlands, there are some inclusive settings and some special preschools, but especially children with severe disabilities stay at home very often until they start to attend school. In Spain, the system of preschool education for younger children is still not very well organized and there are hardly any possibilities for children with complex needs under 3 to attend a mainstream day care centre (the situation for children over three years

is referred to when talking about school). In Romania, the system of early childhood education is still developing and especially children with complex needs are described as a discriminated group among the discriminated.

The most striking aspect concerning preschool education is that although inclusion is possible in general almost everywhere, there is a huge gap between the policy of integration and common practice. When a child with severe disability cannot visit a mainstream institution or an inclusive kindergarten because of his or her disability, this can surely be identified as direct discrimination.

Furthermore, aspects of non-discrimination also become obvious in the reports: first, one can summarize that even where inclusive education is available and almost common practice, there is still a lack of training so that access to quality care is doubtful sometimes. Structural and architectural barriers can occur and make it difficult to realize the idea of inclusive settings and cultures.

The UN Convention demands equal access to education for children with disabilities in article 24. Yet, there are still barriers to mainstream education. The system of special day care centres does not enable children to make peer contact in a setting of diversity. Regional differences once again disadvantage families in rural areas. Early exclusion may lead to the start of a life as a “disabled person”. Parents have to face prejudice concerning their child and are confronted with a devaluation of disability again<sup>36</sup>.

## **2.6 Childhood and Youth: Schooling**

In all countries, children have a legal right to education or schooling is compulsory, mostly between around 6 and 16/18 years. Nevertheless, this does not automatically mean access to mainstream education. Especially in the area of schooling, there are striking similarities between most countries.

Italy is the only country in this study without a system of special schools. There, children with disabilities visit mainstream schools. But: especially children with complex needs have to face the problem that they are to be included into existing systems; there is also a lack of continuity in assistant teachers. Access to equal education, compared to the quality other children receive, has to be doubted in some points.

In general, a European policy towards integration or inclusion can be stated. Legislation is rather sufficient and there is the possibility for children with disabilities to visit mainstream schools. In practice, this is not the case for those pupils who have a high support need. With the exception of Italy, children with complex needs are mostly educated in either special schools, boarding schools/ schools within residential care or – rather seldom - at home with no schooling realised in practice (NL, RO).

In the different countries, there are some striking facts that should be mentioned separately: in Sweden, for example, the number of children being educated in special schools has been increasing in the past years. In the UK, in Spain, Romania, France, Germany, the Netherlands and in Lithuania most schools, the experts explain, are not prepared for the specific needs of children with severe disabilities. It can be assumed that this is valid for all countries, even where not explicitly mentioned.

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<sup>36</sup> See also the section on schooling.

Again, direct discrimination occurs for children with severe disabilities: in general, one can summarize that children with complex needs do not really profit from a policy towards inclusion as for them, integration into mainstream schools is hardly possible. Main obstacles to access are architectural barriers or a lack of concepts and adapted curricula (e.g. SE, RO). Once again, families in rural areas are disadvantaged (ES, RO, PL).

The risk of experiencing non-direct discrimination is also given: the lack of training of staff is an obstacle that children have to face: it is a barrier to receiving the best education possible (ES; RO; FR).

Harassment may occur where children with disabilities have to face long transportation every day as special schools are centralized (DE, LT, BE).

It can be assumed that most of these problems do occur more or less in most countries as the systems of education tend to be similar for children with severe disabilities.

The UN Convention refers to education in article 24:

1. States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and life long learning directed to:
  - (a) The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;
  - (b) The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;
  - (c) Enabling persons with disabilities to participate effectively in a free society.
3. In realizing this right, States Parties shall ensure that:
  - (a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;
  - (b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;
  - (c) Reasonable accommodation of the individual's requirements is provided;
  - (d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;
  - (e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.
4. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:
  - (a) Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;
  - (b) Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;

- (c) Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.
5. In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.
6. States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities”.<sup>37</sup>

The national reports show that in most countries, the demands of the UN Convention cannot be fulfilled. Inclusive settings are still an exception, especially when thinking about children with severe disability and about secondary education. Education on equal basis with others cannot be achieved when special schools are the common setting for children with complex needs as then, children with and without disability can neither experience diversity nor community and participation of all children. Being referred to a special school can be the start of a so-called “career as a disabled person” and limits the possibilities to be a full member of the community.

Especially in those cases where children receive home-schooling or do not visit a school at all, they are excluded from the general educational system, which is against the demands of the UN Convention. Necessary support cannot be guaranteed in all cases, neither when thinking about additional material or curricula nor assistant teachers. So, with focus on the UN Convention, a lot can be demanded for children with complex needs in the field of school education.

Equal access to mainstream education, with all necessary assistance and adaptations, seems to be the most important challenge.

## **2.7 Childhood and Youth: Housing and Family Support Services**

In all country reports, the experts state that children mostly live at home with their parents and sisters and brothers. If the child cannot live at home, residential care is available all over. Foster care for children with severe disability up to now does not play an important role in the participating countries (with the exception of Sweden).

In the Czech Republic, in Lithuania, Romania, partly also in Spain, Italy and Poland, there is no real system of family support available. In Lithuania, social policy changes towards family support and benefits are offered, but especially for poorer families, residential care is the only real possibility for children with complex needs. In the Czech Republic, there are practically no mobile services and for now, the number of children in residential care cannot decrease. In Italy, the system of family care is not well developed and not free of charge which hinders access for families that are not wealthy. Domiciliary support is

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<sup>37</sup> See Article 24 of the UN 'Convention on the Rights of Persons with Disabilities'

available, but quantity and quality differs a lot. In Romania, the family services are still insufficient. Additional problems occur: in the urban areas, there are not enough dwellings for families who cannot afford to buy a house themselves. In rural areas, there are still problems with the living conditions, e.g. running water. Poverty becomes a real barrier for people who have a child with complex needs. In residential care, the conditions improved, but children are still in a very dependent state there. In Spain, families have the right to receive home care, but there are not enough services, furthermore there is a lack of counselling and information. The tendency still is towards residential care in case of severe disability. In Poland, family can get benefits, but mobile services are not well developed these days and access to them is limited. As benefits tend to be too low, poverty is also a problem.

In the other countries, family support services are available, but mostly there are also different obstacles: in Belgium, the services are sometimes not sufficient and only specialized services (next to general care services) are available. The number of home services is too low. In France, the situation is similar: parents get benefits, but networks do not work properly. The services also only show up if the diagnosis of the child is clear. In Germany, family support is available and mobile services work rather well. Still, there is no clear legal basis for financing these services. Parents lack information and so sometimes cannot realize their rights. Self-help groups exist, but not everywhere.

In the UK, there are long waiting lists for family support services and also for technical aid. This hinders the child's and families' integration into community.

In the Netherlands, the system of family support care is well developed and accessible. Parents get information, medical care and social support for their child. Still, society is not well prepared to integrate these families into their community and the question of transportation is still unclear. Also in Sweden, there is a well developed network around the child, including personal support at home. Nevertheless, parents tend to get lost within the system as they lack a coordinator in the complexity.

Most National Experts also refer to respite care services in their reports. In Belgium and the Netherlands, children can profit from short stay homes, as well as in Sweden. In the Czech Republic, a system of respite care is just starting. In Italy, respite care is available, but as mentioned earlier, they are not free of charge and not sufficient. In France, the situation is similar as there are not enough services for families. In Germany, there is a lack of legal basis to ensure the financing of respite care.

In Poland and Spain, short stay homes or respite care service are not common.

Direct discrimination, here defined as less favourable treatment, can be identified in those cases where support services do not really exist and where families are left on their own. This might result in an even more challenging situation for the parents. Again, parents and children in rural areas are disadvantaged as support in some cases is rather available in bigger cities and as some services are not free of charge; those families that do not have much money are discriminated. Direct discrimination also occurs where children are put into residential care because of their disability – in some cases this is surely related to a lack of available family support.

Non-direct discrimination can be identified in residential care when children remain in a very dependent state. For the family, non-direct discrimination appears when information

and counselling are not sufficient and when parents do not know whom to turn to. If services are not specialized for children with complex needs, this is also discriminating.

Harassment can occur when families in their community are not well integrated and when attitudes and behaviour show that society still is not really ready to welcome all families and all children. Especially children with severe disabilities and their families may have to face the fact that they are not well integrated and accepted; this clearly goes into the direction of victimization.

In the UN Convention, there are several articles that can be applied to the housing situation of families and to family support: Article 19 of the convention mentions the fact that every person shall have to opportunity to choose his or her place of living in the community. One can say that parental support is necessary to achieve this aim as the situation with a severely disabled child otherwise can be too challenging. The number and availability of family support services must in consequence increase in some countries and/or be better established. Furthermore, personal mobility (Article 20) and respect for home and family (Article 23) are important aspects in this context. Habilitation and rehabilitation shall be guaranteed (Article 26). To summarize this in connection with the national reports, it seems to be important to strengthen parents in their situation and offer support and counselling to let the numbers of places in residential care decrease<sup>38</sup>.

## **2.8 Childhood: Leisure Time**

In all countries, children with severe disabilities hardly have access to mainstream leisure time activities. The national reports reflect that the area of leisure time seems to be filled with various barriers. At first, in all countries there are still many architectural barriers when thinking about access to cultural activities. Many theatres, cinemas or youth clubs are still not barrier free – even if by law they should be (e.g. UK; DE, IT) .

There are integration programs almost everywhere, but these are not widespread and often do not work well, especially for youngsters with a high support need. There are still organizational and conceptual barriers (CZ, DE) and staff is not well prepared for teenagers and kids with a high support need.

So young people with disabilities mainly have access to two different types of leisure time activity: they can either spend the time with their family, but of course, activities depend on the parent's interests and financial means, as emphasized in the Italian report.

Secondly, there are activities organized within the disability field. In all countries, there is some kind of activities available. Sometimes, leisure time is organized within the day care centre (e.g. LT, NL) or the residential home (e.g. RO, SE). The problem is that these activities do not support participation in the community, but young people stay among themselves and are confronted with the same staff all the time – in some cases, there is not enough staff available (SE). Very often, this is connected to a lack of possibilities to choose. Children stay in large groups and perceive leisure time as a collective experience. They then hardly have access to peers without disability and also lack role models to identify with. Rather a disability culture than a youth culture may then be established. Those children that are taught at home are additionally disadvantaged as they cannot even participate in these activities (PL)

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<sup>38</sup> See the UN 'Convention on the Rights of Persons with Disabilities'

The same is true where special services, e.g. from NGO's or charitable organizations, organize the free time (e.g. UK, DE, PL ES). Parents are afraid that their child might not get adequate support in its free time (UK, FR) and very often, the public attitude towards people with severe disabilities show that mainstream programmes are not ready to integrate children with a high support need yet (FR, LT, CZ). Free time tends to be monotonous for youngsters with disabilities as the German report summarizes – or therapies are a major part of leisure time, as mentioned in the Italian report. Access to romantic relationships and love is additionally limited for young people with severe disabilities: they lack possibilities to get to know people their age (especially in an atmosphere without adults) and as sexuality of people with disabilities tends to be a taboo still, they have to face the fact that they hardly have access to sexual experiences.

Furthermore, the access to transportation occurs to be a problem. Sometimes, it is organized and financed more or less (e.g. SE, DE), but in some cases, the families themselves have to pay for transportation which means another severe obstacle to free time activities. In Poland on the other hand transportation tends to be a general problem. In rural areas, even activities organized by special services are not available everywhere (ES) or not free of charge (ES, SE). In the Romanian report it is stated that there is a general lack of activities as daily routines are overwhelming and hardly leave space for anything else.

In Romania, organised holidays are not available for children with disabilities (RO). In Germany and Italy, there are special holiday programmes for youngsters with disabilities – yet the problem of segregation continues in this case.

Especially in the field of leisure time children with severe disabilities are directly discriminated. The reports show that access to mainstream activities is hardly possible. Architectural barriers hinder participation and contact to peers without disability and in consequence, equality cannot be achieved. Non-barrier free environments discriminate on a personal level.

Non-direct discrimination occurs where a lack of adapted programmes, e.g. in youth clubs, limit access to mainstream activities. In this case, there is also a risk of having to experience harassment.

In Article 30 of the UN Convention, participation in cultural life, recreation, leisure time and sport are mentioned. Equal access is mentioned as well as appropriate measures to ensure development according to the possibilities of the individual<sup>39</sup>. As mentioned above, the reality in the participant European countries shows that this has not been achieved yet and that measures are necessary to enable also children with complex needs to participate in leisure time activities on equal basis with others.

## **2.9 Young Adults: Vocational Training**

In all countries, vocational training is available in general for young people leaving school. Nevertheless, access to mainstream facilities or the first labour market is almost impossible for youngsters with severe disabilities. Again, there are some striking

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<sup>39</sup> See the UN 'Convention on the Rights of Persons with Disabilities'

similarities in the different countries. Some relevant facts concerning vocational training can be summarized as follows:

In the Czech Republic, Spain and Poland, there are problems with physical accessibility. Technical aid is also not sufficient and so only a vocational training in a segregated environment is possible.

In Lithuania and the Netherlands, despite a favourable legislation, people with severe disabilities also hardly have a chance to find a job in the regular labour market and legislation to prevent discrimination is not effective in this case. Market forces, the Italian, German and French report comment, make it especially difficult for people with intellectual disabilities to participate in mainstream educational programs and the possibilities for young people with high support need are restricted. Outcome based orientations, the report from the UK says, are a further challenge and impeach access. Young people with disabilities are not really being prepared to participate in the labour market and in France, for example, there are waiting lists for special training centres. Often, the Polish report emphasizes, access to secondary education is limited in general and there is not enough well trained staff. The Swedish report also refers to this problem: even if training in small groups is available, the participants are sometimes treated like children and society does not seem ready to integrate people with severe disabilities into the labour market. This may lead to a disrespectful treatment. And even if people by law have the right to choose employment, people with severe disabilities can sometimes not be employed at all (PL) or are considered to be “unemployable” (BE, DE).

In Romania, legislation is insufficient as well. People with high support need can start to work in sheltered workshops, but their chance to be integrated is next to nothing. In Spain, administrative problems and a lack of support are mentioned as barriers to access.

To summarize the results, one can say that direct discrimination occurs in the field of vocational training as access to mainstream training is hardly possible for youngsters with complex needs. Physical accessibility is a barrier. In some countries, legislation is not sufficient to prevent discrimination. Even where the right to choose employment freely is stated in law, this cannot be realized in practice.

Non-direct discrimination appears when first, special programmes are created that do not prepare for participation in the regular labour market or when, secondly, regular programmes do not consider the special educational needs of persons with severe disability.

Harassment in this context means that youngsters with complex needs do not receive the education they need to develop to their fullest potential. If young adults are treated like “eternal children”, there is no chance for them to experience that their skills and personalities are fully accepted and valued.

Article 24 of the UN Convention refers to education and in this context, to vocational training: It should be available without discrimination and on an equal basis with others. As the descriptions above show, this is hardly reality in the participating countries. Measures are necessary to include also youngsters with severe disabilities into vocational training. Article 27 refers to work and employment and demands for equal chance to earn a living, choose and find a job in the (first) labour market<sup>40</sup>. Young people with complex needs are

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<sup>40</sup> See the UN ‘Convention on the Rights of Persons with Disabilities’  
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discriminated as on the one hand, they are not being prepared to take up regular employment and on the other hand, they lack possibilities to access mainstream training programmes<sup>41</sup>.

## **2.10 Adulthood: Work and Employment**

The situation is similar when having a closer look at the situation of employment of people with severe disabilities in the life course. In all countries, people with high support need hardly have any chance to find employment in the regular labour market. Most national experts point out that legislation in general favours employment of people with disabilities in the first market (BE, PL, RO, UK, FR, IT, NL, LT, CZ), but practice is different: Adults with severe disabilities are at a high risk of being unemployed (BE, PL, IT, LT). Even if social benefits are granted, disability coherences with a higher risk of being or becoming poor.

There is a sort of protected work sector in all countries. Mostly, there is a sort of sheltered workshop or sheltered employment available. Nevertheless, these offers are not always open for people who are in a situation of major dependence. Some striking facts are presented in a summary:

In Sweden, for example, municipalities are responsible to offer meaningful daily activity to all persons, but often day care centres are the only real chance and within them, the possibilities to develop tend to be limited – people with severe disabilities are easily overprotected by their families, as the Romanian report points out. In Germany, the problem is similar: workshops require a minimum of economically viable work and as a result, people with high support need are often left to day care centres. In Poland, there is no supported employment available and registering as unemployed can be the only chance. Day care centres are available, but not sufficient – just like in Lithuania. People with disabilities sometimes do not know where to turn to and are perceived as a homogenous group. Stereotypes are still common and the risk to become and remain in a situation of passivity is high. A similar description can be found in the Spanish report. The German report summarizes: people with severe disabilities are still stigmatized and disadvantaged without being given the chance to earn a living. In Belgium, legal measures to include people with disabilities are considered insufficient and people with disabilities that lose their job are at risk of being without income for several months.

Another problem is the low level of education of people with severe disabilities, as remarked in the report from the UK. Especially where specific needs have to be met, e.g. concerning communication, the risk to be excluded is extremely high.

The system of specialized employment is still in the early stages in Romania and there are not enough places available. The older people are there, the less they had the chance to receive some training and the risk to be in a state of passivity increases.

In the Netherlands, in contrary, there is a rather good system of day care in general, but here means are being reduced and the number of places decreases. The gap between a policy of inclusion and practice cannot be closed so far. In the Czech report, there are similarities: despite anti-discrimination policy, even sheltered workshops do not really offer places for people with complex needs. And: if they are under legal guardianship, they

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<sup>41</sup> See also the section on work and employment

cannot sign an employment contract (without the guardian's consent) which makes it almost impossible for this group to find regular employment.

The field of work and employment has a lot in common with the sector of vocational training. At first, one can say that direct discrimination appears where the chances to find a job in regular employment are so limited. Even if legislation guarantees the right to choose employment, most people with severe disabilities cannot realize this in practice. The chances to earn a living are strongly limited and people with complex needs stay in a state of dependency on welfare and benefits. This in consequence means that they have just limited possibilities to take over valued adult roles and the risk to experience victimization rises.

Non-direct discrimination occurs where measures to ensure employment in the first labour market are not sufficient to enable adults with complex needs to participate. Work assistants are still not common practice and there is a general lack of adapted workplaces that meet the needs of people with severe disabilities.

Sheltered workshops or day care centres seem to be a measure to ensure daily activity and occupation to a certain extent, but on the other hand, they can be identified as segregating environments that hinder participation in society and community.

The UN Convention refers to work and employment in detail:

1. States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:
  - (a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;
  - (b) Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances;
  - (c) Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others;
  - (d) Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;
  - (e) Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment;
  - (f) Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;
  - (g) Employ persons with disabilities in the public sector;

- (h) Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;
  - (i) Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;
  - (j) Promote the acquisition by persons with disabilities of work experience in the open labour market;
  - (k) Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.
2. States Parties shall ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour.<sup>42</sup>

As already shown, the demands of the UN Convention concerning work and employment cannot be realized very comprising in most countries. Access to the first labour market is very limited and employment of persons with severe disability in the first sector is not really favoured. Measures are necessary to on the one hand, enable people with disabilities to receive appropriate education and preparation for employment and on the other hand, jobs in the first labour market must be created. As a result, the number of places in day care or sheltered workshops can decrease and a work environment that meets the needs of adults with severe disability leads to an increase of participation.

## **2.11 Children and Adults: Social Security and Health Care**

In all countries, people with disabilities have the entitlement to receive health care. Nevertheless there are obstacles mentioned everywhere.

At first, there are some problems with the availability of routine check ups or treatment at doctor's. In the UK, for example, people with severe disabilities do not have access to routine treatments except their situation changes. Their special needs concerning access are not met in these cases. In Spain, generic health services are also insufficient. In the Polish report, the expert informs about the fact that despite free services, there are still financial and organizational problems as barriers to access. Furthermore, access to adequate health care is difficult if people have rare diseases. If people with severe disabilities living in traditional residential institutions have to be treated in hospitals, someone from the home has to be present all time which is of course not easy to manage. The Swedish report highlights a gender aspect: in the system of health care, girls and women are often disadvantaged. The Swedish expert mentions that people with severe disabilities do not always get the best health care available. In Lithuania, persons with high support need do not have access to sufficient care as there are long waiting lists for medical treatment sometimes and no personal rehabilitation plan is available there. The main form of treatment in residential care is just through medication and a lack of doctors or psychiatrists is a further barrier. In Italy, some services stay invisible and cannot be entered as people are not being informed about their existence. In Sweden, it tends to be difficult to get physiotherapy. In Germany, especially access to dental care is difficult to access as doctors are not prepared for people with special needs.

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<sup>42</sup> See the UN 'Convention on the Rights of Persons with Disabilities'

Further main barriers to access are architectural ones. In Germany – as just mentioned – and the Czech Republic, some doctors cannot be reached as their rooms are not in a barrier-free environment. In the Czech report, it is stretched that people with complex needs do almost all the time need help and assistance to be able to access medical care. This may not be underestimated as – in connection to what is stated in the Swedish report - this may end up in a lack of influence as other people - guardians or parents - make the decisions for this group of people. Also in the Netherlands, where access to health care is good in general, many buildings are not barrier-free.

Another major problem when reflecting access to health care is the availability of information (IT, PL, BE ES). Persons with complex needs and their assistants are sometimes not well informed about their possibilities and rights concerning health care, as the Polish report emphasizes.

On the other hand, medical staff is also not well informed about persons with high support need. There is a lack of training and information (FR). As mentioned above, there is the tendency to just cure the symptom, e.g. challenging behaviour, rather than the cause (UK). Respecting patient's privacy tends to be difficult in case of a person with high support need (CZ).

The country reports also refer to the system of social security in the specific country. In the Czech Republic and Germany, it is mentioned that the system of social insurance is linked closely to the status as an employee, but that for people with severe disabilities, benefits are also available. In the other countries, people with complex needs and/or their families are entitled to welfare or benefits as well. They may differ in the extent but in general, one can summarize that they aim at covering additional costs caused by the impairment and comprise a sort of disability pension, money for assistive technology or tax reductions.

Some specific problems are mentioned here as well: in Germany, the fragmentation of the system is a real problem when talking about access as sometimes it is not clear who can be responsible for e.g. the covering of costs. This threatens the quality of life of people with complex disabilities and their families. A too complex system is a real problem in Belgium as well.

Additionally, the German, Spanish and Dutch report refer to the fact that people with severe disabilities are not very welcome customers in the system of insurance or in the services.

To summarize the results, direct discrimination occurs when people with severe disabilities have limited access to health care. There are in some countries financial and organizational problems. In general, on the one hand, children and adults with complex needs have to face architectural barriers when needing health care. On the other hand, the reports show that it is difficult to receive the highest quality of support available, especially when the disability or disease is a rare one. Girls and women tend to have less access to health care in Sweden, for example, so that gender aspects need to be considered as well.

Non-direct discrimination occurs where professionals are not well enough trained to meet the specific needs of people with severe disabilities and again, a lack of information is a barrier to access. Possibilities and rights are not always well promoted. People with severe disabilities, especially with intellectual disabilities, have limited possibilities to make decisions concerning their health and sometimes lack information on their personal

situation – this touches the terms of harassment and victimization as well. In this context, one has to mention that respecting people's privacy in case of medical treatment is especially difficult in case of complex needs and intellectual disability.

Social security is available in general, but nevertheless, there are also some striking barriers for access. Summarizing the national descriptions one can say that disadvantages appear when normally, social security is linked to the status as an employee. Non-direct discrimination in this case means that also those who do not work have to right to receive welfare, benefits and social security, but in practice, disadvantages are obvious.

Harassment can be experienced when talking about insurances as people with severe disabilities are not always welcomed customers.

Too complex systems, furthermore, can threaten the quality of life of people with disabilities and the term of victimization comes to mind.

Article 25 of the UN Convention refers to equal access to health care at the highest attainable standard without discrimination due to disability. Health insurances should be available on equal basis and community services should be provided as close as possible to a person's home, also in rural areas.

Social protection is mentioned in Article 28 and it should be available without discrimination or disadvantage due to disability<sup>43</sup>.

As shown above, the demands of the convention cannot be fully realized. Although social security and health care are available to a certain extent, there are still numerous barriers to access highest quality of care. The results show that mainly access to medical treatment is limited due to architectural barriers and a lack of training of professionals. Those living in rural areas have to face even more barriers concerning the availability of health care. Still, care and security are not available on equal basis with others.

## **2.12 Adulthood: Housing**

In all countries, the vast majority of people with complex needs has two main options concerning their living situation: a part stays in the birth family, at least as long as possible, another part moves to a residential institution.

In the states of Eastern Europe (RO, LT, CZ, PL), traditional and big institutions used to be very closed towards the community and people with (severe) disabilities remained mainly invisible. Sometimes the living conditions were very poor and threatened human rights. Nowadays, the situation changed and the situation in residential homes improved.

In all countries, there are forms of residential care available – somehow Sweden is an exception as there are no big institutions, but just group homes, available. All other national reports point out that residential care is still common practice and the dominant form of living for people with complex needs. Some important facts will be summarized again:

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<sup>43</sup> See the UN 'Convention on the Rights of Persons with Disabilities'

In Lithuania and Poland, there are still many big institutions; isolation from the community is accepted by society and policy. Sometimes, the Polish report stated, these residential homes are overcrowded and some are still of the “old type”: they do not offer meaningful activity to the clients and some conditions are a risk for the person’s dignity.

The fact that traditional institutions are not integrated into the community is mentioned in most reports (RO, BE, PL, ES, NL, CZ, DE, LT, IT) and is a major topic in current discussions.

In Spain, there are not enough places available and people have to wait long to get a place in a residential home. Waiting lists are also mentioned in the Belgian report: people hardly have any choice in which institution they would like to live and sometimes clients must take a place that is far away from the birth family. The same problem is described in the German report. Furthermore, there are regional differences concerning the availability of residential care.

In the big and traditional institutions, the German report states, a lack of privacy is still common practice due to multi-bed rooms. It can be assumed that this is true for other countries as well. In Italy, the UK and Spain, there is sometimes no reference to age and young and old people live together without considering their age-related needs. The Dutch report emphasizes that residential care somehow forces people who live in groups and that they as a result lack control about their lives. Sometimes, daily activity is offered within the institution and people hardly have a chance to develop independence: the Czech report points out as well that people with complex need living in traditional institutions can hardly make any choices concerning their live or daily routines. In addition, the Belgian report refers to the fact that as a result, the quality of life in residential care depends on the human resources available.

Supported or Independent living is known in all countries, but – with the exception of Sweden - not the dominant form of living.

In France and the Czech Republic, people with complex needs hardly live at home as necessary adaption and financial resources are not sufficient. Mainly architectural barriers, the Romanian and German report add, are a barrier to supported living. In the UK and Germany, the number of people profiting from supported living is increasing, but especially for people with severe disabilities, there are still financial problems. In Romania, a shortage of accommodations is a real problem for people with disabilities that would like to rent their own flat. Furthermore, there are no counselling services available and families are afraid that the “child” might not manage to live in its own – the situation of overprotection is topic in the Dutch report as well. In Spain, the problem is similar: self-determination and independent living are not really favoured and as a result, not sufficiently supported. In Poland, some services exclude people with certain disabilities so that persons with high support need are at high risk of being excluded from community based living.

In Sweden, there are mainly group homes in the community (4-8 persons in average) or people with complex needs live in their own flats and profit from the system of personal assistance. Nevertheless, there are some problems described: sometimes people have to wait long for a place in a group home and can hardly choose where exactly they would like to live. They remain in a state of high dependency on the staff.

A number of major risks of discrimination in the field of housing are connected to residential care, as the reports show. At first, direct discrimination appears where people are limited in their possibilities to choose their place of living freely because of their disability. Often residential care homes with places available are far away from the birth family and due to waiting lists, there is no chance to choose a place close to home. Especially for those adults who have a high support need, there is a lack of alternatives to residential care which discriminates directly.

Harassment in housing and residential care can occur in institutional care: it can be experienced when waiting lists are a barrier to access residential care. Often, harassment appears within residential care: big institutions lack privacy on the one hand, on the other hand there are sometimes no meaningful activities offered or day care takes place within the institution itself. Usually, residential care homes are not well integrated in the community and often, clients stay among themselves as they lack possibilities to participate in community activities. They miss control about their lives and the possibility to make choices.

Furthermore, direct discrimination appears where independent or supported living is rejected to those adults who have a high support need. They have less access to this form of living than people with mild or mostly physical disability. This is direct discrimination. Architectural barriers are a barrier to access and often, necessary adaptations and financial resources are not sufficient.

If people with complex needs manage to live on their own, there remain some further discrimination risks. First of all, it is striking that independent living of people with severe disabilities is still not favoured all over. Parents, on the one hand, do not trust in their children's ability to live on their own; professionals have doubts and the community is not always open to welcome people with complex needs. This can be summarized under the term of victimization.

The UN Convention refers to independent living and inclusion into the community in article 19:

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- (b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs<sup>44</sup>.

The national reports show that essential parts of this demand cannot be realized in practice. At first, participation and inclusion in the community are not a reality as many

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<sup>44</sup> See the UN 'Convention on the Rights of Persons with Disabilities'

people with complex needs still live in institutional care and these traditional residential homes are not well integrated into community. There are also strong limitations on the choice of place of residences and in the decision with whom to live together. Especially in those cases where multi-bed rooms are still common practice, this right is often violated. Access to supported living in the community, as demanded in the convention, is especially limited in case of complex needs, as already summarized above. In consequence, it is not accessible on equal basis with others.

## **2.13 Adulthood: Leisure Time and Education**

All country reports highlight that people with severe disabilities are not included in to mainstream adult education and that they have limited access to leisure time activities.

The leisure time activities that are available are often among the family or in the context of residential care and the day care centres (IT, BE, PL, RO, LT, NL) . There are also offers by organizations for people with disabilities (SE, DE, ES). Nevertheless, these activities are mainly among peers and not well integrated in the community. In the Romanian report, it is mentioned that leisure time often means waiting time, e.g. for dinner. Some activities are related closely to therapies (BE). In the UK, insurances do not want to take people with severe disabilities as members when it comes to insuring activities like horse riding. To summarize: the number and variety of activities are not sufficient (BE).

People with severe disabilities do hardly have access to mainstream adult education. Although life long learning is a well known concept, there are only some offers for people with high support need. In Sweden, people have the right to get education, but often have to spend their own money on it which makes access harder for people with disabilities. Financial problems are also common in Romania and Poland when thinking about spending free time. Transportation problems occur (SE, PL). In Italy, the Czech Republic and Germany, there are some special educational programmes for people with disabilities. Some of these programmes do not meet the special needs of people with (severe) intellectual disabilities (NL, ES). In Poland, for example, there are hardly any chances to continue education on adult ages. Again, people in rural areas are disadvantaged (CZ).

Some buildings that offer education or leisure time activities are not accessible for people with severe disabilities as they are not barrier-free (NL, IT, BE, DE, FR, ES).

The situation on leisure time of adults is very similar to the one of children and youngsters in general. To summarize the results of the national reports one can say that direct discrimination occurs where access to mainstream activities is strictly limited either due to architectural barriers or because of intellectual disabilities of the participants.

Non-direct discrimination and victimization appear where activities are offered within the disability field: offers are available, but still in segregated environments with hardly any chance to get in contact with peers without disabilities.

Article 30 of the UN Convention guarantees the right to participate in cultural life, recreation, leisure time and sports without discrimination. Equal access is mentioned as an important measure to prevent exclusion. This right, as the reports show, is violated very often as exclusion is still common practice and there is not enough effort to prevent it<sup>45</sup>.

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<sup>45</sup> See the UN 'Convention on the Rights of Persons with Disabilities'  
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When it comes to adult education and life-long learning, one can say that especially people with intellectual disabilities lack possibilities to participate. There is a lack of adapted programmes and a lack of knowledge among professionals how to train this group of people. Very often, there are no offers for this people. This is direct discrimination as this group as a result has no access to adult education. In cases of physical disabilities, architectural barriers are still a barrier to access.

Article 24 of the UN Convention refers to the right to education and it is emphasized that people with disabilities have a right to get education to develop to their fullest potential. Learning life and social skills are mentioned as well as the right to receive life-long education “without discrimination and on equal basis with others”. This principle cannot be realized. Even if in some countries there is the tendency to include also people with (severe) disabilities into education programmes, these efforts are not sufficient up to now. Leisure time and adult educating are hardly on the political agendas, but of major importance when talking about inclusion into the community<sup>46</sup>.

## **2.14 Adulthood: Partnership and Parenting**

The country reports contain different information on this topic. Some national experts refer to the legal situation, some put emphasize on the living situation. Nevertheless, they give an overview on the situation of persons in situation of major dependence concerning parenting and partnership. Main facts can be summarized as follows:

In Poland, the Czech Republic and Lithuania people under legal guardianship cannot get married and cannot possess parental custody. Sexuality of people with (severe) disabilities is still a taboo in many countries (PL, CZ, IT, FR). People with complex needs are considered incapable of having children (CZ, IT) and there are many myths around partnership and parenting of people with disabilities. The Czech report states that having children is a topic not even discussed for people with high support need. In Lithuania and Romania, parenthood of people with severe disability is considered as an additional burden from the family’s point of view. In Lithuania, in residential institutions, intimate life is under control; pregnancies are terminated.

In Sweden, people with severe disabilities can marry, but the municipality will take care of the child that might be born. The policy is that parents can meet their child. In Spain, people with disabilities also have the legal right to start a family. In Romania, a legal guardian has to establish the marriage.

In Belgium, people with complex needs can marry and also possess custody. Partnerships are respected and couples can e.g. share a room. There are support services available, but work in this area needs to be extended. In the Netherlands, there is no real policy towards parenting and people with complex needs are discouraged to become a parent.

In Germany, the situation has changed recently. Sexuality and starting a family have been a taboo until recently, but now is more on the agenda. Still, people with severe disabilities lack possibilities to meet a partner and start a relationship. They do not always have a chance to realize their childwish. Furthermore, there are some problems with the authorities: which one takes the responsibility for the family? Facilitated abortions may occur. Changes are also described in the UK where services to support parents exist, but

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<sup>46</sup> See the UN ‘Convention on the Rights of Persons with Disabilities’

still the opportunities to start a family are limited and where it is not uncommon that the child is taken away from its parents.

The reports from France and Spain state that parents with disabilities do not get enough support.

Sterilization is illegal (without the person's consent) in Poland, Belgium and Romania. The Spanish and the French report state that it might be possible that a person gets sterilized without consent.

To summarize the results of the national descriptions, one fact is striking: access to partnership and parenting is very limited in all countries. Several reasons are identified in the national descriptions.

Direct discrimination is obvious where the civil rights of persons with severe disability are restricted, e.g. in case they cannot enter marriage or possess parental custody in general. Sterilization without consent or enforced terminations of pregnancy are also cases of direct discrimination.

Non-direct discrimination in the field of parenting and partnership occurs where couples are tolerated, but lack support to live on their own so that as a result, they have difficulties to start a family. Where the attitude towards parenting is slowly changing, there are still not enough support services or chances to really integrate into the community so this also discriminates. In general, one can say that the living conditions of youngsters and adults with severe disabilities limit the possibilities to find a possible partner very much: sheltered workplaces or day care within the institutions, activities mostly among the same group of peers and restrictions in residential care with limited possibilities to make choices do not offer equal chances to meet a partner in comparison to peers without disability.

Harassment and victimization can be found in the public attitude towards partnership and parenting of persons with complex needs. To name just two examples, one can say that partnerships are not considered possible as adults with disability are in some cases still perceived as children and parenting is not even thought about.

Article 23 of the UN Convention refers to respect for home and the family:

1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:
  - (a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;
  - (b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;
  - (c) Persons with disabilities, including children, retain their fertility on an equal basis with others.
2. States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases

the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.

3. States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.
4. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.
5. States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting<sup>47</sup>.

With a focus on legislation, the demands of the UN Convention cannot be fulfilled as in some countries, people with severe disabilities do not have equal access to marrying or parental custody. The right to decide about the number of children they would like to have or to decide about their place of living is often limited. European reality shows that measures have to be taken to ensure that people with severe disabilities have equal access to start a partnership, to marry and live a life as couple, but also to start a family and have children that can stay within their birth family.

## **2.15 Adulthood: Exercising Civil Rights**

In all countries, people who have difficulties in making responsible decisions can get a legal guardian. Some major facts – this time in alphabetical order of the participating countries -on guardianship will be summarized to give an overview on national situations. In Belgium, every citizen over the age of 18 has the right to exercise all civil rights. Nevertheless, most people with disabilities do either have the status of “prolonged minority” or “provisory administration”. A person in one of these statuses gets a kind of legal guardian who helps to make decisions, to administrate goods or conserve capacity for acts relative to the status of the person (voting, marrying, adoption).

In the Czech Republic, equal access to fundamental rights and freedom is a topic on the agenda. A framework to prevent discrimination is under preparation these days. When turning 18, one acquires full legal capacity. Adults with disability can either be under partial or plenary guardianship. In case of complex needs legal capacity is mostly deprived and someone else will represent this person under law. Plenary guardianship means a loss of the right to vote, the right to be elected or to sign e.g. employment contracts.

In France a person with disability has the same civil rights as anyone else in general. However, these rights can be restricted and a legal guardian, very often the parents, takes over the protection of the person. Since 2005, the law on equal rights and opportunities states that people under guardianship do not lose their right to vote.

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<sup>47</sup> See the UN ‘Convention on the Rights of Persons with Disabilities’

In Germany, citizen's rights strengthened in the 1990ies. There was a legal reform on guardianship. Civil rights and legal status are not determined by a person's disability. Secondly, there is a movement towards the establishment on equal rights and opportunities, e.g. manifested in the basic law or the "General Equality Act" of 2006.

In Italy, there is also a law on equal treatment and non-discrimination. Just like in the other countries, a person can get under legal protection; mostly a family member takes this task. The right to vote remains with the person with disability.

The Lithuania constitution also claims that all persons shall be treated equally before the law. A person with disability can be declared incapable and in consequence loses his or her civil rights: he or she cannot marry, vote or make any important decisions anymore then. Reconstruction of a person's rights is seldom.

In the Netherlands, the main idea is that people with disabilities have the same rights as everyone else. In practice, these rights can be reduced to the context of the concrete living situation. There is also a law on equal treatment.

In Poland, there is a general prohibition on discrimination in the constitution. People with severe disabilities have the same rights in general. Incapacitation is possible and a person can be put under guardianship. In practice, this means that a person loses his or her civil rights: he or she cannot vote, marry or sign contracts.

In Romania, a person can also be put under guardianship if considered necessary. This means a loss of civil rights except for "individual rights" like voting, being elected, having the right to work.

The Spanish law contains paragraphs on equal opportunities and non-discrimination. Nevertheless, if the person has a legal guardian, he or she loses the right to vote.

In Sweden, the basic idea is that everybody has equal value and rights. A person with severe disability keeps all civil rights, but if necessary, he or she gets a legal guardian to e.g. look after financial affairs.

In the UK, there is also some legislation on non-discrimination. Also there, people with severe disabilities can get a legal guardian if they cannot make decisions themselves. They keep their right to vote.

In the country reports, some specific problems are mentioned when talking about exercising civil rights. In Belgium and the Netherlands, there is a lack of awareness for the fundamental rights of people with disabilities in some cases. In practice, it might be difficult for persons with disabilities to get to the polling station (FR, IT; PL, RO) and access cannot be granted. Especially residential care restricts the possibilities to exercise rights (DE). The Czech report emphasises that fact that guardians are responsible for too many clients and as a result, there is an absence of monitoring. In community homes in Sweden, the same problems can occur as especially people with severe disabilities lack control about their lives and quality controls are not enough. In Spain, insufficient control is also a topic; there is a lack of information and support concerning civil rights. The French report, for instance, mentions the importance of education in this context to raise awareness for rights and duties of a person. A change in the public attitude and also legislation can help to improve the situation for those with high support need when talking

about civil rights, the reports from the Netherlands and Poland state. Still, as mentioned from the United Kingdom, people with complex needs remain somehow invisible and are excluded from mainstream activities and participation in democracy. The risk to lose all civil rights (LT) must be minimized as far as possible.

To summarize the descriptions of the national reports, one fact is very similar everywhere: people with severe disabilities that cannot make all decisions on their own – or who are considered to not be able to do that – can be put under some kind of guardianship. Two main models are common practice in this context: one idea is that the person keeps all his/her civil rights and gets support e.g. just in financial affairs. The other model is that a person under guardianship loses his or her civil rights and the guardian is responsible for the legal decisions. In the second case direct discrimination is obvious as in these models, adults with complex needs are not guaranteed or granted the same rights than the other people of their state. They experience disadvantage and unequal treatment very obvious.

This surely violates the demands of the UN Convention: it is referred to the fact that all people shall be equal before and under the law (Article 5); they should be able to “enjoy legal capacity on an equal basis with others in all aspects of life”. Where civil rights are restricted and a person for example is not allowed to vote, legal capacity cannot be exercised.

But even where civil rights are kept, this does not automatically mean that people with complex needs have the possibility to exercise them. As described above, accessibility of e.g. polling stations is rather bad. The UN Convention states that measures are to be undertaken to provide access to exercise the legal capacity of people with disabilities (Article 12). Up to now, measures have not been effective enough to ensure that civil rights are on the one hand granted, and on the other hand can be exercised<sup>48</sup>.

## **2.16 Adulthood: Ageing and End of Life**

The European population is an ageing one. There are more and more older and old people and this development will continue in the next decade. These facts are also true for people with severe disabilities: they grow older. Furthermore, a relevant part of people with disabilities is in retirement age. For elderly people with disabilities, there are some main facts described in the reports.

The Dutch report states a general lack of awareness of the needs of elderly people with disabilities. Their (civil) rights are not protected well enough and the service systems are not well prepared for the changes that age brings.

In Belgium, there are two networks of caring: the sector for elderly and the one for people with disabilities. The same problem occurs in Germany. If a person becomes disabled over the age of 65 in Belgium, he or she cannot get the status “disabled” anymore and goes directly to the geriatric sector. For people with disabilities growing older, it is a major question how to arrange care and support. If the parents cannot give support anymore a good follow-up has to be found. This comprises different areas of live.

The report from UK also refers to the problem of dementia and Alzheimer: people with these diseases tend to be excluded from decisions concerning their lives.

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<sup>48</sup> See the UN ‘Convention on the Rights of Persons with Disabilities’

One question is the one of housing: in France, for example, some services and support end when a person turns 60. Adaptations of houses do sometimes not work properly or fast enough. There is a lack of retirement houses in France. In Italy, there is a general lack of service provision for the elderly – also concerning housing. The question of residential care or home care is raised and the problem of isolation and exclusion comes to the agenda. The German report states that sometimes a whole new arrangement of care can become necessary and this is difficult to manage. Furthermore, there is a lack of protection against the dynamics of big institutions. Debates on the quality of life are simplified and not taken as important. People with complex needs that are ageing tend to be excluded from society as people see themselves confronted with their own fears concerning ageing (DE). In Lithuania, this group of citizens mostly lives in residential care; there is a lack of alternative services. In the Polish report, the situation of dying in residential care is also mentioned. Some conditions violate the person's right to die in dignity. Hospices are still rare and sometimes fail to meet people's needs.

In Spain, most old people with disabilities live in residential homes or nursing homes. There is the risk that they are referred to residences for senior citizens rather than to those that meet their needs concerning disability.

In Sweden, older people with disabilities either stay in their group homes or they are referred to special homes for old people. The housing adjustments are taken over by the municipality. Sometimes, young and old people live together in group homes which tends to not always be a good combination.

The question of quality of life is raised in the UK report as well.

In Romania, old people with disabilities were rather hidden in the traditional institutions under the communist regime. There are very few services for this group of people and some of them still live in hospitals where the conditions do not meet their needs. Residential care homes are rare for old people and the services prefer people that do not have a high support need. The ideas on palliative medicine are known, but there are not many services that provide this medicine. A lack of daily activity is stated in the Romanian and in the Swedish report.

The French report states that services and leisure time activities are even harder to access for old people with disabilities. In Lithuania, there is a general lack of services for elderly people with disabilities. They are, as the report states, one of the most vulnerable groups as they hardly have a person that defends their rights or stands in for them. They cannot attend day care centres (anymore) and hardly find a service meeting their particular needs. The old people of today that live with a lifelong disability experienced a primarily medical treatment under the old regime and hardly experienced support or education. In Poland, some services come to an end of the person reaches retirement ages. In Spain, there are hardly any day care services available for old people with complex needs.

Another area refers to the support need itself and to care by professionals. In the Czech Republic, there are hardly any services for the elderly. They mostly live in hospitals and nursing homes. Old people with severe disabilities experience a lack of respect from the staff. Sometimes, it tends to be difficult to identify them as a group with specific needs. Sometimes, their needs cannot be met and they are at risk of being neglected and

discriminated. The Spanish report also refers to the fact that among staff there is a lack of knowledge concerning ageing and disability.

A major problem, the Polish report states, seems to be the fact that the growing older of people with severe disabilities is even more seen as a burden or as a social problem than in younger age.

In the Netherlands active euthanasia is possible under strict restrictions if a person wishes to die. In Belgium, there is a new law on euthanasia. In the Czech Republic, in Germany, Spain, Romania and Lithuania active euthanasia is forbidden. The other reports do not comment on this topic.

To summarize these results, one can say that the major problems occur in the network of care. On the one hand, there is not enough support at home available, so that once again, residential care seems to be the only alternative – especially as in age the parents of the person with disability cannot help anymore. Another topic is the one of services coming to an end in age: day care centres are not common practice for old people and as a result, they lack possibilities to participate in activities again.

A lack of awareness for the situation of older people with complex needs is mentioned. In consequence, still there are not enough services, counselling centres or offers in general. This group remains mainly invisible and lacks someone to step in for their rights.

Direct discrimination again appears where old people with complex needs are obviously disadvantaged, here: in the field of housing for example. There is a shortage of barrier-free flats and of support services.

Harassment and victimization occur when a lack of awareness leads to life situations that stay under the possibilities of older people with high support need.

The UN Convention does not refer to ageing of people with disabilities in particular, but a number of articles can be applied to ageing and end of life: personal mobility is mentioned in article 20; the right to integrity is referred to in article 17 and inclusion into the community in article 19. Respect for privacy (article 22) and access to health care (article 25) and habilitation and rehabilitation (article 26) should be guaranteed<sup>49</sup>.

With a look at the country reports, it becomes obvious that measures are necessary to meet the demands of the UN Convention. At first, the situation concerning health care has to be improved, as already mentioned before. It can be assumed that for older people with disability, access to medical treatment does not improve, but exactly this would be necessary. Inclusion and integrity can be achieved through on the one hand the extension of offers, services and supported living environments, on the other hand through awareness-rising in the population.

## **2.17 Conclusion**

This paper lists discrimination risks for people with severe disabilities and complex support needs concerning issues of availability and accessibility of both services and public infrastructure. The general pattern of the findings is similar across life-stages and sectors:

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<sup>49</sup> See the UN 'Convention on the Rights of Persons with Disabilities'

service provision for people with disabilities has improved in all countries in the past years, however of course in relation to the different starting points. But there is a tendency in social services for people with disability to be selective and to exclude people with severe disabilities from services, the more mainstream-oriented services become, the less people with severe disabilities are parts of target groups. On this background, a policy for non-discrimination must have a clear specific strategy to involve people with severe disabilities in mainstreaming programs.

The same is relevant for creating accessible public infrastructure. Here the UN Convention suggests the term of 'universal design' as an planning principle for non-discrimination: "Universal design" means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. "Universal design" shall not exclude assistive devices for particular groups of persons with disabilities where this is needed (Art.2)<sup>50</sup>. Planning strategies in this direction should also explicitly consider accessibility problems of persons with severe disabilities and complex support needs.

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<sup>50</sup> See the UN 'Convention on the Rights of Persons with Disabilities'  
The Specific Risks of Discrimination. Volume 2



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

**www.non-discrimination.eu**

## **Synoptical Paper**

### **3. Biographical Transitions**

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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**

### 3.1 Summary of the Synoptical Paper

When analysing discrimination risks from a life-course perspective, biographical transitions can be seen as crucial periods in individual biographies of people with complex needs. Biographies in modern societies are shaped by the way that individuals cope with the challenges of transition and for children and adults with complex needs, those moments of change inherit a higher risk of exclusion than for others. Reports show that there is only very little sensitivity in support systems concerning the successful coping with transition situations of people with severe disabilities. The conceptual importance of individual planning procedures is mostly not yet realised in practice, structures are missing or not sufficient and resources are not adequately allocated. Very often there is the 'taken-for-granted-assumption' that a certain life stage or activity area is not possible for people with severe disability and therefore respective planning is not necessary because there will be no transition anyway. As a result, most people with disabilities are differentially excluded when assessment and planning procedures exist.

It is recommended that individual planning procedures should be institutionalised with appropriate resources for all 'socially normed transitions' and also be available in other critical life situations as an integral part of a local or regional system of support services. They should be participative, follow an inclusive life-course-orientation and should explicitly include people with severe disabilities and complex support needs. Furthermore, they should be prepared with good cooperation mechanisms to avoid breaks and loss of information between distinct education, health or social services.

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Dans l'analyse des risques de discrimination par rapport aux cycles de la vie, les transitions sont des périodes cruciales dans les biographies des personnes avec des besoins complexes. Les trajectoires de vie dans les sociétés modernes sont façonnées par la manière de faire face aux défis des transitions et, pour les enfants et adultes avec des besoins complexes, ces périodes représentent un plus grand risque d'exclusion que pour les autres. Les rapports montrent que les systèmes d'aide n'ont que peu conscience des enjeux liés à la réussite de ces passages pour les personnes avec des handicaps sévères. La plupart du temps on ne réalise pas que la portée conceptuelle d'une planification individuelle n'est pas réalisée, les structures manquent ou sont insuffisantes et les ressources ne sont pas allouées de manière adéquate. Souvent, on croit trop facilement que telle transition ou tel domaine d'activité n'est pas envisageable pour les personnes avec des handicaps sévères et, dès lors, la planification n'en semble pas nécessaire. Ainsi, le résultat est que les personnes les plus handicapées sont exclues de diverses manières lorsque les procédures d'évaluation et de planification existent.

Il est recommandé de formaliser, avec les moyens appropriés à leur réalisation, les procédures de planification individuelle de toutes les « transitions de vie normalisées » et qu'elles soient également disponibles lors d'autres moments critiques de la vie des personnes. Elles devraient être participatives, avoir une approche inclusive et explicitement inclure les personnes avec des handicaps sévères et des besoins complexes. De plus, elles devraient être préparées avec des mécanismes de coopération de qualité afin d'éviter des ruptures ou des pertes d'information entre les différents services d'éducation, de santé ou sociaux.

## 3.2 Background

Trying to identify specific risks of discrimination in a life-course framework helps to see biographical transitions as crucial periods in individual biographies of people with severe disabilities and complex support needs. Like any other people they live in a social environment with patterns for life courses that provide a framework for individual biographies for men and women. Biographies are shaped by the way the individual copes with the challenges of transition situations from one life step to another, e.g. starting kindergarten, school, leaving family, starting a family, starting work, starting life as a pensioner. But besides such socially normed transitions there are also situations of transition that are caused by critical life events (e.g. death of a family member, severe illnesses, accidents, personal crisis). The new life situation is characterized by new cognitive demands, unknown role expectations and practical challenges. New competences, abilities and skills have to be learned and acquired. Thus, coping challenges in transition situations can offer new opportunities for personal growth and opportunities for taking new and positive valued roles and positions in society. The important characteristic of all biographic transitions is that they are risky moments of change, in which successful coping and personal development, but also individual failure can happen. In developmental psychology, positively coped critical life events are seen as the 'motor of development of the adult person' (Filipp 1995).

For women and men with severe disabilities biographical transitions are as important as they are for other people, but bear higher risks because transitions in new situations are always related with changes in their support needs and service arrangements. On the one hand it can be stated that processes of exclusion of women and men with disabilities from mainstream life-course orientations start especially in situations of 'biographic' transitions. In these situations often decisions are taken that either interrupt 'usual' life course orientations of persons with severe disabilities, e.g. with the effect of prescribing the continuing role of the 'eternal child'. Transitions can also become 'turning points' (Abbot 1997<sup>51</sup>) that get the potential to change individual biographies in an unwanted direction, e.g. unwanted early retirement because of a disability following a heavy accident. Another important example in this sense is when mothers and fathers have to cope with the fact that their child is severely disabled. For such critical life events that happen only to a minority of people, societies have not developed adequate forms or rituals for coping. Mainstream oriented support models should be sensitive to the importance of exclusion from 'usual' life course patterns both in socially normed and in other transition situations. When a certain stage of life is coming to an end, there should be procedures for mainstream oriented follow-up measures and person-oriented planning.

As transition periods are decisive for the further development of the individual's biography one must be aware that these periods are times when decision-making processes can be related with personal experiences of having control over one's life or being 'processed' by others. Many adult people with severe disabilities and complex support needs experience this loss of control in transition phases as biographical injuries. They tell their life story in 'passive voice'. It is a story of suffering, fall and loss of control. Events in their life seem to follow a quasi automatic course and are not conceived as controllable. People's life orientations seem to become more and more discouraging and passive.

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<sup>51</sup> Abbott, Andrew (1997): On the concept of Turning Point. In: Mjösset, Lars; Engelstad, Frederik; Brockmann, Grete (ed.): Comparative Social Research, Vol. 16. Grundwisch, London, S. 85 - 105

Therefore, individualised planning procedures that contain elements of comprehensive assessment and service planning are very important in all biographical transition periods of people with severe disabilities and complex support needs. They should be conceptualized in a way that people with severe disabilities and their families experience them as sources of control, encouragement and activation. It would be a concrete possibility to realize a central principle of the UN Convention on Human Rights of Persons with Disabilities, namely to show “Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons”<sup>52</sup>.

The following synopsis gives an overview on transition problems for people with severe disabilities in participating EU countries.

### **3.3 Childhood: Family Support, Housing**

In all countries it is reported that most children with disabilities live at their parent’s home. But in Eastern European countries the percentage of children who are placed in infant institutions seems to be higher. There are still some large institutions and as long as family support does not improve, the number of places will not reduce.

Obviously in all countries, foster care is becoming increasingly important. From Sweden it is reported that families can have a “back-up family” that supports them and from time to time, looks after their child with disability.

A general pattern is also that many mothers have to quit their jobs in order to take care of their child with severe disability, which has a heavy impact on the family’s income situation and the mother’s biography.

Early Intervention services have a high gate-keeping function. It can depend very much on their conceptual approach and their organisational context whether integrated or separated educational settings are chosen, when children with disabilities come to pre-school age.

Transition planning is mostly not systematically institutionalised but depends on rather informal or voluntary processes. The tendency is that the support system still directs most families, especially those with a child with intellectual disability, to special institutions.

Despite support care, families are at risk of losing the possibility to lead a “normal” family life.

### **3.4 Childhood: Education and Care, Schooling**

Children with severe disabilities are nearly always referred to special schools, day services or special residential services when these exist. Even though integrative schooling is possible by law, there are no equal opportunities for those children who have a high support need. In some cases, access to school education is refused.

In spite of this trend, there are remarkable differences between countries. In the following some characteristics are presented.

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<sup>52</sup> See Article 3 of the UN ‘Convention on the Rights of Persons with Disabilities’

In the Czech Republic, preschool inclusion is not very common up to now. There are cases where the mother stays at home with the child. This multiplies other disadvantages: the mother can lose her job and might feel excluded from social life. She becomes more dependent on social allowances and the child lacks peer contact. Special kindergartens are available, but this in consequence leads to early exclusion. Possibilities to make friends with children of the same age in the community are limited.

In Italy and Sweden, mainstream schools are open for all children, also for those with high support needs. There is no system of special schools. Nevertheless, this does not automatically create inclusive environments.

In Germany changes in preschool education have been remarkable and inclusive settings are increasingly realized. Still there are some special kindergartens and in some regions there are hardly any alternatives. Almost all children with severe disabilities visit school, but except in some very few model programs, children with severe disabilities have not had nor currently have access to inclusive school integration. 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').

In Lithuania, law ensures education of all children. Integrative kindergartens are available, but in many cases, specialized preschools are seen as providing better and more professional services for children with high support needs. This tends to be the beginning of a 'disability career' on the other hand.

At school, inclusion is also possible, but in case of severe disability, special schools are common practice. In some cases, the child is removed from the family during the week in order to get education in a special school. Families expect the institution to meet the child's need in a better way. Especially in socially weaker families, disability of the child and the option of residential care become the main reasons for choosing specialized boarding schools.

The Netherlands have an extended system of special education. Until recently, almost all children with multiple disabilities were left to special day care centres. This has changed and there is an increasing policy towards integration. Still, the older the child gets, the more difficult it is to make use of regular schools. Once getting involved in special education, makes it difficult to return. So in practice, the traditional separation is kept alive.

In Poland, children until the age of 3 can attend nurseries, then they turn to kindergartens. The number of children being included in mainstream institutions is increasing, but still, special solutions are chosen very often, e.g. rehabilitation education centres. Children with (severe) disabilities can stay in preschool until the year in which they turn 9. Being together with 6-year old is questionable, the report remarks. In fact, many children stay at home with their mothers until they are 9 years old.

Integration in school is possible, but realized more often in the primary years. There are also different types of special schools available. Boarding schools are chosen in some cases. In general, one can say that the more severe the disability is, the more likely it is that the child visits a special school. Furthermore there is the possibility that children receive home-schooling; this is frequently overused.

In Romania, there are not many alternatives to special kindergartens or day care centres; still the number of preschool institutions is insufficient. Children with severe disabilities tend to become “discriminated among the discriminated”. Special schools are not always open for pupils with complex needs or do not achieve to meet the special needs in case of high support need. Home schooling is possible and used.

In Spain, preschools for children between 3 and 6 do not offer equal opportunities for those who are severely disabled. Integration at school is possible by law and special education is to be the last resort, but in fact, special schools are still the common model. Often these classes are connected to other services like adult day care, occupational centres or residential facilities.

In Sweden, children have the right to visit a preschool in their community. Yet, there are still some special preschools left. Access to equal education must be assured for children with disabilities, but especially for those with intellectual disabilities special schools are available. There are training schools for those who, due to a severe intellectual disability, cannot profit from education at primary or secondary level. Students at special schools are entitled to 10 years of schooling (9 years are compulsory).

In Spain, one third of all children with disabilities do not complete their primary education; this is related to gender, but also to the type of disability. The lowest levels can be found among those with intellectual disabilities, behavioural disorders, communication and learning problems and self-care problems.

In the UK, preschool is available from the age three on, but those children with disabilities will be offered nursery provision from the age of 2. Often, preschools do not feel ready to welcome children with complex needs, so special kindergartens are chosen. At school, policy goes toward inclusive settings, but exclusion and special schools still remain. Some children attend residential schools often far away from home.

### **3.5 Vocational Training, Work and Employment**

The general pattern of the reports is that, people with complex needs do not really profit from support to integration in the first labour market, neither concerning vocational training nor afterwards. In some cases, they are judged as “not employable” or they quit on their own as they cannot manage a job. Many people with severe disabilities are unemployed. Even in the sheltered workshops, there is a tendency towards efficient production and people with complex needs are disadvantaged.

There are different models to raise the number of people with disabilities in vocational training or regular employment. Still, it is not sure how flexible these models are for people with complex needs. Over-regional “vocational training centres” are often not accessible for people with intellectual and severe disabilities, but only for those with mainly physical disabilities. In practice, most people with high support need do not receive the vocational training they would need to find a job afterwards. Legislation does not adequately address the problem of transition. Effective programmes would require more intersectoral cooperation. The unemployment rate is very high among those needing a lot of support. So the right to work and choose a job freely in fact cannot be realized.

The following description in the Polish reports seems rather typical also for many other countries: most youngsters with severe disabilities do not continue their education after the compulsory years. They can visit job training schools or visit occupational therapy

workshops. They are deprived when they cannot choose their job (and as a result in a way their future) freely. Especially for those with challenging behaviour, the situation is difficult.

Many people with severe disabilities remain unemployed and the activities for this group are decreasing. Furthermore, those who receive benefits cannot register as unemployed. There is no scheme of supported employment in Poland, but day care centres are available; in general there are not enough to meet 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 create lack of flexibility of existing solutions. Once the participants of the occupational therapy workshop take up employment, he or she is 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 back to services offered by the workshop.

In Romania 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.

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. Moving further through adult age, many of those with severe disabilities remain unemployed. Employment programmes are still in the early stages.

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.

Another important general pattern is that 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.

### **3.6 Adults: Housing**

In most countries transition from living with the birth family to other forms of living is practised as a placement procedure with little or no individual choice.

In the Belgian report it is stated that people with severe disabilities usually remain dependent very much on their social network or on assistance. Places in residential care are not always easy to get, so in case the family has an emergency state, there are priority

lists. In most cases, there are long waiting times for residential institutions. Possibilities to live independently are limited.

In the Czech Republic most adults with severe disabilities either remain in their family or move to a residential institution. When staying with the family, they are threatened by exclusion from society and community life – the same is supposed to be true for residential care as possibilities to make decisions are limited there.

In France, the situation is similar concerning the fact that people with severe disabilities either stay at home or live in residential care. Policy guarantees a choice between independent living, residential care or support at home. In practice, the network of assistance might not be sufficient and living in a private setting cannot be realized.

Staying in the birth family or moving to residential care are also the two main options for people with severe disabilities in Germany. Concerning residential homes, there is a certain regional difference; there are also waiting lists and sometimes a person can only get a place far away from parents and family.

In Italy, families care for their members with disabilities. As an alternative, rehabilitation centres are available. However, this lasts not more than 10 years; then the person is supposed to be rehabilitated and/or can move to a social-education centre. In fact, there are not really alternatives to residential care if the family cannot give support. So, even if inclusion works for children, segregation in adult life is still the most common practice in Italy.

In Lithuania, residential institutions, also large ones, are still popular. There, people experience an absence of choice and limited possibilities to realize an independent life, even to a certain extent.

In the Netherlands, the starting point is the idea that everyone should be able to live in the community. In practice, residential institutions are still supposed to offer the most effective support in many cases. Day care is often provided within the institution which might lead to exclusion from the community. Independent living remains an exception. Financing structures nowadays might lead to an extension of residential care.

In Poland, there is no policy towards deinstitutionalization and if the family cannot care, residential institutions – still including big ones - are the only alternative.

In Romania, there are problems because of a housing shortage: families with a member with severe disability- that are additionally often threatened by poverty - have huge problems finding a flat they can either pay or that has a certain standard. Many adults with complex needs still live in residential care. In the last years, the situation there has improved and living conditions are much better nowadays.

In Spain, the alternative to staying in the family is residential care as well. There are institutions that are specific according to the type of disability and usually, they have 60 to 100 places. Often, these accommodations are similar to those for seniors, located far away and overcrowded.

In Sweden, people with complex needs mostly live in community homes: these group homes have 4-8 places. The idea is to ensure a life in the community. Few people have a flat of their own combined with personal assistance. In the last few years, the number of



people in each group housing has been increasing which might lead to a negative effect for the individual.

In the UK, most adults strive to become house owners. That is why not many flats to rent are available. Usually, people with complex needs live with their parents or move to a residential home. In Northern Ireland, a large number of people with complex needs are still residents in hospital accommodation. Case-management procedures on local government level are established and should be responsive to person-centred planning approaches, but are not provided with sufficient resources.

### **3.7 Partnership and Parenting**

Even if national laws in all participating countries states that people with severe disabilities can marry and start a family, this was considered impossible in most countries until recently. Now the situation slowly changes. 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 intellectual 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. But there are differences between countries:

In Belgium, there seems to be a relatively new awareness of the fact that also people with severe or intellectual disability have the right to access love life and partnership. Services and parents have the duty to inform about contraception and sexuality in general so that the person with disability is empowered to make decisions on his/her own. Up to now, there are a few examples where people with intellectual disability manage to raise their child.

In the Czech Republic, people under guardianship can only enter into marriage with the approval of the court and cannot exercise parental custody. Opportunities to find a partner are very limited in practice and having children is often not even discussed. In general, there are severe limitations for people with complex needs in this area of life, especially in residential care.

In France, the majority of adult people with complex needs do not live in partnerships in contrast to the rest of the society. There are still many obstacles in finding a partner and starting a family. For many people with severe disabilities, there are reduced possibilities to express their will, but more and more, adults with complex needs want to participate in "normal" life in the community – partnership and parenting are part of it. Still, especially sexuality is a taboo for many services and there is no sufficient awareness of this topic.

In Germany, people with complex needs also have limited possibilities to find a partner, and start a family. As result, they are more frequently single. The attitude of society and professionals towards sexuality and partnership is changing and even parenting is accepted in some cases. Still, many children of people with disabilities cannot grow up with their parents. In this life area, exclusion is experienced on a very personal level. As they usually remain dependent on support – often from their parents- there is the tendency that they are treated as "eternal children". Professional support cannot replace the backing found in partnerships and primary networks, which is based on emotional affection. This

creates behaviour patterns that often foster dependence and impede personal developments for autonomy, which can become possible in the process of transition into adult life.

In Italy, partnership and parenting of people with severe disabilities is still practically absent from the political agenda. They are considered to be taboos and as a result, the possibilities to start a relationship or parenthood are limited. At home with the parents, adults with complex needs are often perceived as children and in residential care, the organization aims at the “prevention of problems”.

In Lithuania, the situation is different as partnership and even more parenting do not seem to go together with disability. In residential care, there is a lot of control and starting a relationship with sexuality is almost impossible. Pregnancies are always aborted.

In the Netherlands, there is no real policy towards the acceptance of parenthood of people with disabilities but in many cases, it is still discouraged.

In Poland, people with disabilities are more frequently single or widowed than the rest of the population<sup>53</sup>. Those under guardianship cannot enter into marriage nor have parental custody. There are no services supporting married couples. Usually, they cannot realize their dream about partnership or parenting. Sexuality is still a taboo and there are myth and prejudice.

In Romania, life of couples is respected, but in practice, there are not many chances to realize partnership – on a formal or informal level. Pregnancies of women with disabilities are feared by staff and parents and the birth of a child is considered irresponsible.

In Spain, the right to marry or have children is given for people with complex needs. But in practice, there are no services that support parents and usually, the child would be taken away from the mother. Society thinks that people with disabilities cannot have a partner.

In Sweden, concerning marriage, there are no legal restrictions, but normally severe disability and parenthood are not considered to go together..

### **3.8 Ageing and End of Life**

In the vast majority of country reports it is stated that Europe has an ageing population and that more and more, people with severe disabilities come to higher age. They live longer than their parents, who usually take over care, guardianship or other responsibility. In consequence, the support arrangement might need changes. Furthermore, in many countries, the majority of people with disabilities are of retirement age, so that ageing and disability are highly related to each other.

In Belgium, there are two systems for older people with disabilities: the geriatric medical sector and the social sector for care for people with disabilities. Elderly people of more than 65 years who become disabled cannot request the status of disabled person and therefore they directly go to geriatric sector. On the other hand, ageing people with disabilities can remain in the disability services, but can also be re-oriented - if no adapted medical care is available - to care retirement homes in the geriatric sector. The “handicap

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<sup>53</sup> There is a higher risk of being widowed when having a disability due to the fact that a large amount of people with disabilities is in retirement age.

sector” works principally with education staff. The medical care is sometimes not sufficient. One of the main questions nowadays is how a good follow-up can be guaranteed and how adequate care can be ensured.

In the Czech Republic, older people with complex needs might need a wider network of care than before. In practice, many people with severe disabilities end up in nursery homes or hospitals. There are no special facilities for this group. Ageing tends to be reduced on economical questions; neglecting needs is a major risk.

In France, three main types of problems worry traditionally the partners concerned by the ageing of people with disabilities:

- the reduction of the capacities of the person with disability 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 person and the disappearance of their parents who are often their main helpers.

The evolution of the situation of a person with severe disability can require fast adaptations of its environment and diverse systems of helps and accompaniments. The answers are often too partial and too slow. They would always be conceived with the person by a multidisciplinary team of nearness.

The rigidity of the establishments of reception may induce breaks of care for persons whose situation is changing. This is often the case for persons with severe disability. The criteria of admittance of establishments can pull their exclusion.

In Germany, there is a distinction between the disability sector and the geriatric sector. Nowadays, ageing of people with disabilities raises increasing awareness,, but up to now, 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 traditional institutions for people with disabilities in this situation.

In Italy, most elderly people with disabilities live in nursing homes or some other kind of institutional care. Still, this is somehow an open issue as service provision is not well developed yet.

In Lithuania there is no special legislation concerning services for elderly people with disabilities. They are described as a very vulnerable age group. First of all, they usually have no more contacts to their families (parents are dead; contacts to other relatives are lost during long residence in residential care). Hence there is no one to support their rights, interests, to take special attention to their needs and preferences. Secondly, elderly people with disabilities belong to the generation which was treated under the ideology of Soviet defectology science. Usually they were placed in a large institution at a very early age and undergo a long and unsuccessful medical treatment. They were perceived as uneducable; professionals never tried developing their social and daily living skills.

According to the experts, very few elderly people with disability received proper services in their childhood. Consequently today they are not able to attend day care centres, their skills can hardly be developed and improved. They have never or rarely been outside their home or care institution; they don't 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.

In the Netherlands, ageing does not lead to big changes in the support arrangements of a person with severe disabilities.

In Poland, there are the following critical transition moments in the life of a person with severe disabilities connected with ageing: first, it is when the parents of such a person have to take care also about their own parents. This poses additional burden on these families. Secondly, when the parents themselves start to grow old and a moment come when they are unable to provide support and care for their children. Parents' death may have also serious psychological consequences to the person with complex needs. And at last, the ageing of the persons with severe disabilities does not only mean that her or his needs grow. To help people prepare themselves to pass away is also an important issue. Palliative care is sufficient and some people die in conditions that threaten their dignity. Many services come to an end when retirement age arrives.

In Romania, in the communist era people with severe disabilities were mostly hidden in big institutions, often in bad living conditions. Nowadays these people are among the older population. There are few residential institutions, which also have waiting lists. People without disabilities are preferred.

In Spain, older persons with disabilities might be referred to nursing homes. 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 of 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.

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 people with disabilities 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<sup>54</sup>. 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.

In the UK, “end of life” programmes have been set up to improve care at this stage of life. But especially for those developing dementia, care is often not sufficient.

### **3.9 Conclusions**

People with severe disabilities and their families have to cope with specific problems in transition situations. There are very often no cultural patterns to rely on in these situations that they are familiar with. This results in a loss of orientation, and a high dependency on the availability of a reliable, but flexible support system. This reliability and flexibility of support services can be created by individual service planning procedures that are available in periods of biographical transitions.

Reports show that there is only very little sensitivity in support systems concerning the successful coping of transition situations for people with severe disabilities. The conceptual importance of individual planning procedures is mostly not yet realised, structures are missing or not sufficient and resources are not adequately allocated. Very often there is the ‘taken-for-granted-assumption’ that a certain life stage or activity area is not possible for people with severe disability, and therefore respective planning not necessary because there will be no transition anyway. As a result the most people with disabilities are differentially excluded when assessment and planning procedures exist.

Individual planning procedures should be institutionalised with appropriate resources for all ‘socially normed transitions’ and also be available in other critical life situations as an integral part of a local or regional system of support services. They should be participative, follow an inclusive life-course-orientation and should explicitly include people with severe disabilities and complex support needs. Furthermore, they should be prepared with good cooperation mechanisms to avoid breaks and loss of information between distinct education, health or social services.

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<sup>54</sup> Act concerning Support and Service for Persons with Certain Functional Impairments SFS 1993:387

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

**www.non-discrimination.eu**

Synoptical Paper

### **4. Empowerment, Self-advocacy and Participation**

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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**

## 4.1 Summary of the Synoptical Paper

Empowerment, self-advocacy and participation are terms closely related to each other. When participation refers to more than just physical presence, but also to social roles in interactions and to the power to influence social situations, self-advocacy and empowerment refer to the social movement of people with disabilities.

This Synoptical Paper shows that in the participating countries, progress has been made in the last decade according to self-advocacy, empowerment and participation, of course related to the different starting points. Nevertheless, in all countries people with complex needs and severe disabilities face particular barriers when trying to develop abilities and power skills to exercise control over their lives or their service arrangements. There are considerable risks for people with severe disabilities to be excluded from transition into adult life-phases and specific life areas. In many relevant policy areas, among them education, work, housing and civil rights, men and women with high support needs are not considered to be part of the target group for full participation and inclusion.

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Autonomie, autoreprésentation et participation sont des termes qui se répondent. La participation est plus qu'une simple présence physique, c'est aussi interagir dans des rôles sociaux et un pouvoir d'influencer des situations sociales ; l'autoreprésentation et l'autonomie font référence au mouvement social des personnes handicapées.

Ce synoptique montre que dans les pays de l'étude, des progrès ont été réalisés ces dix dernières années dans les domaines de l'autoreprésentation, l'autonomie et la participation, par rapport bien entendu aux différents points de départ. Cependant, dans tous les pays, les personnes avec des besoins complexes rencontrent des barrières spécifiques lorsqu'elles tentent de développer aptitudes et outils leur permettant de contrôler leurs vies ou l'organisation de leurs services. Le risque est grand pour ces personnes d'être exclues de la transition vers la vie adulte et différentes activités. Dans beaucoup de domaines importants, notamment l'éducation, le travail, le logement et les droits civils, hommes et femmes avec de besoins complexes ne sont pas pris en compte pour une pleine participation et inclusion.

## 4.2 Background

Empowerment, self advocacy and participation are terms closely related to each other. The UN-Convention reflects in its preamble, "that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others".<sup>55</sup> According to the International Classification of Functioning, Disability and Health (ICF), 'participation' can be defined as "involvement in a life situation".<sup>56</sup> This comprehensive understanding means more than physical presence of a person, but refers to social roles in interaction and to the power to influence social situations. Thus, participation becomes a general target for disability policies, and habilitation and rehabilitation strategies. Participation is not a quality that a person owns per se, but has to be learned in the process of individual socialization. This process is influenced by families, by the education systems, by individual roles, by representing oneself and many more factors.

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<sup>55</sup> See the UN 'Convention on the Rights of Persons with Disabilities'

<sup>56</sup> See e.g. <http://www.who.int/classifications/icf/en/> (May 20<sup>th</sup> 2008)

The terms 'self-advocacy' and 'empowerment' refer to the social movement of people with disabilities. They fought and fight for both, the respect of their capacity to manage their own life (with adequate support) and for effective possibilities to advocate for their interests themselves. Power and control over one's own affairs are fundamental for modern concepts of full citizenship. Self-advocacy approaches try to find ways how people with disabilities can voice their individual or group interests in their day-to-day life and in society. Empowerment has a psychological and political dimension. It focuses on processes by which individuals who are highly dependent can enable themselves e.g. in political or self-help groups or by professional support to acquire individually or in a group of peers a maximum of power to exercise control over their lives. In the UN Convention this is also conceived as participation in political and public life. According to this article States Parties do not only have to ensure the full political rights but also have to "promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and [to] encourage their participation in public affairs"<sup>57 58</sup>.

In addition to the analysis presented in this Synoptical Paper, the Study has produced a database of relevant stakeholders (Deliverable 3.1). As this database shows, there are well-organized structures in the participating countries concerning the structures of self advocacy and NGO's. But one can also see that the smaller the specific group of people with complex needs is, the more difficult it is to find an organization that represents the very special needs of a certain group.

The following synopsis wants to show in selected fields how and to what extent these principles are of influence in the participating countries of this project.

### **4.3 Early Childhood, Housing and Family Support**

To see participation as target of habilitation or rehabilitation in early childhood means to empower families to cope with their challenges and to come to a 'usual life' in the sense of remaining in usual life course patterns. To have and to live with a child with severe disability should neither be a biographical catastrophe nor an unwanted biographical 'turning point'. But 'usual life' is – as reports show – threatened by negative stereotypes, by missing of adequate services, by services with an unbalanced focus to medical and therapeutic treatment, and by harassing application procedures for services.

The following problems are listed in the country reports:

In Belgium, parents may get the feeling that they are sent from one professional to another. They feel they lack information and do not have a personal contact person. Parents want to be more recognized in their competencies and want to keep a dominating place in the child's life. Some parents are able to articulate their wishes and needs, but parents from a weaker social background have communication difficulties with family services. The services are also not always open for a partnership with the parents. Participation and empowerment in this context mean – as demanded in the report – to perceive the parents as experts for their child and their situation and to encourage them to express their support need.

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<sup>57</sup> See Article 29 of the UN 'Convention on the Rights of Persons with Disabilities'

<sup>58</sup> See the UN 'Convention on the Rights of Persons with Disabilities'



In the Czech Republic, one important aim of Early Intervention is to return or maintain the parent's competence; yet this system is very weak. There is a lack of awareness of the demanding situation of a family with a child with severe disabilities. Having a look at relief services, there are some rehabilitation stays or summer camps offered, also by self-help organizations. They aim at supporting the child's autonomy and independence out of the well-known family system. In general, there are self-help groups and associations of parents that are very important for support and its provision; many initiatives changed and improved local possibilities of support for children with complex needs. Up to now, these groups are not available everywhere, but tend to focus on bigger cities.

In France, the report contains the demand to set up a program of assistance for parents so that caregivers are less excluded from social life. Especially mothers, who most of the time care for their child with disability, hardly have the chance to keep their job or invest in activities with others.

In Germany, children and parents depend very much on the conceptual approach of their Early Intervention services as those sometimes give the tendency towards inclusive or special settings as well. Concerning family support and the family's situation, there are professional counselling services, but as those mostly belong to the mainstream sector, they do not perceive themselves competent to give advice to families with a special support need. Self-help groups are very important, but do not exist in all regions. Often, the members of these groups are also not able to provide sufficient counselling and parents feel left alone with their questions and problems. Thinking about short time care, there are services in Germany that offer some time away from home for youngsters with a high support need. The report states that these times can positively influence autonomy and independence as the children and teenagers can learn how to deal with non-family members or how to articulate support need.

In Italy, many families are not sure of what steps to take after birth of a child with disabilities. Most of the support is provided through the family itself and its network. Concerning guidance through the system of support and information or benefits, disability associations have an important part in this regard.

In Lithuania, some important services like counselling, individual or group therapy are provided only on a private professional basis and as a result are not affordable for all parents.

In the Netherlands, a plan is set up for the individual child, aiming at giving best care and offering efficient support to the parents as well. The system of support is in transition and changes to a model of individual authority these days. Still, those parents that are well-informed and well educated are in advantage. As the situation of the family is mostly challenging, support is very important – the parent's power is usually limited; still they keep the steering part. In this context, one can say that parents play an important part when talking about participation of children with severe disabilities as the parents are the one who know their child best and who can be very helpful with the interpretation of the child's signals. Still, many families react rather conservative to the idea of participation in the Netherlands. But also the care providers take over an important part as they can also push inclusion and participation or empowerment: offering individual and active support can stimulate participation. The goal to keep up quality of life can improve services delivery in terms of realizing the client's need and an open view to society favours inclusive settings. Sometimes, informal solutions are possible and it is the parents who arrange the support for their child and who do all the coordination in the natural

environment and this of course also empowers the family and steers inclusion at the same time.

In Poland, family support services are insufficient. Parents can profit from free of charge counselling in psychological-educational counselling centres, but these offers are also limited. As parents often have to give up their job to take care of their child, the family is threatened by exclusion from social life.

In Romania, families lack constant support. Some centres have been developed, mainly by NGO's and parent's associations, that offer care and information – yet, these services are not all free of charge and not affordable for all families. Family support is not sufficient and although counselling centres exist in each county in theory, they do not have the possibility to offer specialized support to all families.

In Spain, there is a lack of support and not all actors are sufficiently involved in the support arrangement. Especially the parents and the child's family should have an active role and be key participant which is in practice not always the case. Counselling services are not sufficiently available.

In Sweden, a habilitation plan for the individual child is set up together with the parents. Nevertheless, families tend to have difficulties to keep up their social contacts.

In the UK, like in other countries, mothers of children with complex needs are less likely to take up employment due to caring responsibilities. Poverty and sometimes exclusion from ordinary life structures are a reality.

In the perspective of discrimination one can distinguish two different kinds of problems:

- The lack of sufficient support in early childhood in some countries can be seen as indirect discrimination. Children with disabilities and especially children with severe disabilities and/or special support needs are not explicitly disadvantaged but through lack of support their individual development is heavily restricted and they are excluded from participation as children in community life. In those countries where Early Intervention or family support services are not or only very rarely available, the parents' social contacts and existing informal networks can be threatened. As a result, children with disabilities and their families can suffer a bad quality of life.
- Also in countries where family support seems comparatively well established, elements of indirect discrimination are stated. Although support is available, families with children with disabilities are in a difficult position: their parents are the ones to step in for their child's interest. They struggle with communication problems and coordination of support. They might feel left alone and without proper counselling. It's a form of indirect discrimination through harassing procedures and lack of awareness of the life situation of families with children with severe disability.

#### **4.4 Education and School**

Education is to provide the basic competences, abilities and skills to act in society and to articulate own interests. Education is necessary for a person to be perceived as a member of society and to take over positively valued social roles. In this perspective it is a very important precondition of participation and it is the fundament for acquiring competences for self-determination.

Education of children with and without disabilities in mainstream institutions is a chance for all to participate and learn about diversity. Children with severe disabilities that are included into mainstream kindergartens and schools experience social belongingness.

In most countries in education policies integration or inclusion officially are favoured approaches. Nevertheless, possibilities tend to be unavailable for children with severe disabilities and in consequence, they nearly do not profit from educational policy efforts towards mainstream education for all children.

In Belgium, inclusion of children with disabilities is generally possible in kindergarten and school in general, but access is still limited, especially when it comes to school.

In the Czech Republic, integrative kindergartens exist, but in case of high support need, children often stay at home with their mothers. At school, integration is possible by law, but still an exception for children with severe disabilities.

In France, inclusion is also favoured in general, but still far from being the major concept. Especially after primary school, children with severe disabilities are guided towards special schools. About 2000 children in France are not schooled; the majority of them have a high support need. This is a real threat for the child as it hardly gets the chance to be socially recognized or to have a social status in a group of peers.

In Germany, more and more children with severe disabilities are included into integrative kindergartens, but when it comes to school, the situation changes and, although possible by law, young people with complex needs in the vast majority visit special schools.

In Italy, kindergartens and schools are designed as inclusive settings as there is no system of special schools. Still, this does not mean full participation as a consequence and sometimes there is there danger that the child with disabilities is integrated into an existing 'regular' system and there is no inclusive culture established.

In Lithuania, integration is also possible in general, but mostly, children with severe disabilities visit special kindergartens and schools which for them means that start of a disability career.

In the Netherlands, there is a general development towards inclusion, but none who steers. In fact, children with severe disabilities very often do not visit a preschool, but stay at home. In this context, the role of the parents is a central one as they have to take the coordinating part. Law offers the chance to visit a mainstream or special school, but many children with a high support need visit day care centres.

In Poland, the inclusion of children with disabilities into mainstream kindergartens is increasing, mostly due to parent's initiatives. Still, when it comes to school, integration is not realized here and many children with complex needs are still schooled at home.

In Romania, children with severe disabilities mostly visit special kindergartens - when it comes to schooling, many of them should receive education at home, but this is not available in practice. Inclusive education could be established in some cases where parents associations became involved. When thinking about children with intellectual disabilities - who especially lacked adapted programs- there are some successful projects initiated by NGO's that met the needs of slow-learners as well.

In Spain, many children with complex needs stay at home with their mothers when they are in kindergarten age although by law, inclusion is possible. At school age, special schools are still the major form of education for pupils with severe disabilities although law favours integration into mainstream settings here as well.

In Sweden, education in the community is favoured and inclusive kindergartens are known. Yet, pupils with a high support need still visit special schools more often than children with light or moderate disabilities. Another problem is that the expectations of youngsters with severe disabilities are often too low and that pupils are not given the knowledge and tools they need to develop.

In the UK, many mainstream nurseries are still unable to offer places for children with severe disabilities although in general, inclusion is favoured. The situation is similar at school, where pupils with high support need are still segregated into special schools. Sometimes parents express their fear that a child with little communication skills might not get heard in mainstream schools.

The reports show that although almost everywhere inclusion is favoured in general, it is still not common practice and especially when it comes to schooling, segregation is still widespread all over Europe. According to the UN-Convention (article 24) that is a fact of serious discrimination<sup>59</sup>. Special education is connected with special social rules, which hardly open possibilities of self-determination and which are in contrast to the goal of empowerment. Special education often prepares children and youngster with complex needs for a life in segregating social facilities, like sheltered workshops and special housing facilities. The dominantly segregating education system for children with disabilities in most of the European Countries can be seen as one of the main reason for the lack of full participation of people with severe disabilities.

#### **4.5 Children and Adults: Leisure Time**

Besides formal institutions of learning and working the development of a person's individual identity of a woman or a man is seriously influenced by informal processes in leisure time activities. Young men and women find their aims and identities in peer groups and they make very important experience with roles in such groups. Most people in modern society look for access in different groups and social activities. Smaller and more binding groups of confidence and larger groups for instance to articulate interests or to spend leisure time. From the perspective of participation also for men and women with severe disabilities it is of interest to have the possibility to join different kind of groups or to create group and not to be fixed on a small number of special offers.

In Belgium, there is a general movement starting towards the inclusion of people with disabilities into mainstream leisure time activities, but up to now, these cases remain rare. Especially parents request for the integration of their child with disability with satisfactory care in terms of quality and quantity. Still, integration projects remain individual initiatives mostly. When it comes to adult education, there are some initiatives where professionals aim at the development of self-autonomy of people with intellectual disabilities, but those are not enough.

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<sup>59</sup> See the UN 'Convention on the Rights of Persons with Disabilities'  
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The situation is very similar in the Czech Republic where integration also is not common practice and where a general lack of leisure time activities can be stated. The idea of life-long learning is more and more established and by now, people with disabilities are given the opportunity to complete their compulsory education as adults. The Czech NGO's and Inclusion Czech Republic play an important role in providing services and they also support self-advocacy groups.

In France, youth clubs do not easily welcome children with disabilities and also for adults, access to mainstream activities and holidays is limited. Measures of the State Secretary to consumer goods and tourism aim at awareness and mobilisation of the whole tourism professional and at the consideration of the disabled needs and wishes.

In Germany, most offers for children with disabilities are made by self-help organizations or services providers. Usually, there is not much inclusion into mainstream youth clubs. Concerning adult education, there are more and more courses adapted to the special needs of people with (intellectual) disabilities, sometimes in own centres for adult education. Favourite issues are self advocacy, disability studies and other themes to empower.

In Italy, the trend is towards an increasing number of students with disabilities enrolling into state universities, but still, people with complex needs lack opportunities to participate in leisure time activities. Especially in residential care, there are not many chances to prove self-determination.

In Lithuania, access to mainstream activities is still very limited for children as well as for adults. Initiatives of individuals that would like to study are often not supported and no opportunities to realize these ideas are trying to be found.

Access to mainstream activities is also limited in the Netherlands and in the report it is stated that especially those people who prefer independent living have to face the fact that they have to build up their own network of friends and social partners.

In Poland, the situation is similar to the one in other countries. An additional fact that is mentioned in this report is that children that are schooled at home are at special risk of being excluded from leisure time activities with peers.

In Romania, participation in leisure time is also not consistently granted, yet there have been some programs recently: 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.

In Spain most youngsters with severe disabilities do not participate in youth clubs or mainstream activities; the situation is even more difficult for those who live in residential care as time plans are strict and do not go together with individual free-time wishes. There is a lack of possibilities, for children as well as for adults, to express and realize wishes and self-determination.

In Sweden, many youth clubs do not accept the participation of young people with complex needs, whereas it would be necessary to be involved in order to learn how to live an independent life and how to make one's own decisions. People with severe disabilities,

the report demands, must have the same opportunities to make new experiences and to try out things.

The report from the UK states that in some cases, expectations of people with complex needs are too low and as a result, needs cannot be met when it comes to leisure time activities or adult education.

The country reports overall show an increasing awareness but a very different situation of participation in mainstream activities in leisure time and in continuing education. In no country a satisfying degree of inclusion is reached. In the perspective of discrimination one can differentiate between two different levels:

- The level of interaction in groups or social situations: these situations are obviously influenced by direct discrimination and harassment with the result of reserve or fear to participation for men and women with severe disabilities. According to the UN-Convention it can be seen as a task of the governments “To promote positive perceptions and greater social awareness towards persons with disabilities” and other measurements but they can’t take direct influence to interaction in social groups<sup>60</sup>.
- The level of structural aspects of mainstream activities: governments have to consider aspects of non-discrimination in providing and financing public services for leisure time activities. For instance a non barrier-free environment of youth clubs or adult education facilities is a direct discrimination of people with disabilities.

As a result exclusion from mainstream education is a serious problem of discrimination in all countries of our sample.

## **4.6 Vocational Training, Work and Employment**

Participation in the first labour market is not only an important factor for the achievement of valued adult roles, but also for (economic) independence. In this way the labour market status has a strong influence on self-determination and by this is a very central risk for person with disabilities, and even more for people with severe disabilities and complex needs.

In Belgium, there are government strategies to support employment of people with disabilities in the first labour market, but for people with severe disabilities, there is hardly any chance to receive vocational training in the regular market or to find a job there. As a result, unemployment is widespread among people with complex needs.

In the Czech Republic, the chances in the open labour market are also extremely rare for youngsters and adults with severe disabilities. The Charter of fundamental Rights and Freedoms demands to “choose freely [...] a profession” but this does not reflect reality. Persons under plenary guardianship cannot enter an employment contract without the guardian’s signature. This limits self-advocacy and autonomy of people with disabilities in a decisive way.

In France, access to the first labour market is also very difficult and although the sheltered workshops are now part of the regular labour market; this still does not mean integration.

In Germany, inclusion into the first labour market is hardly reality and people with severe disabilities either stick to sheltered workshops that also have an entrance unit promoting a

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<sup>60</sup> See the UN ‘Convention on the Rights of Persons with Disabilities’  
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kind of vocational training or they visit day care centres. The unemployment rate is twice as high among people with disabilities. In consequence, people with disabilities are denied the right of participation and adults with complex needs do not have access to meaningful and respected positions in society to a large extent. In the labour market itself, 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'.

Although inclusion is promoted in Italy as well, market forces, the report states, do not leave much space for individual abilities and young people and adults with severe disabilities are often excluded from mainstream programs and workplaces. This limits the individual's possibilities to develop some kind of independence and personal autonomy, improve self-esteem and quality of life.

Vocational training and employment are also still quite segregated in Lithuania. Although there are some initiatives to promote inclusion, many adults with complex needs remain unemployed.

In the Netherlands, youngsters with complex needs do not attend regular vocational training and afterwards, mostly stay in day care centres. There are contradictions between the vision of participation and reality in labour situations.

In Poland, most adults with severe disabilities do not continue their education; they are threatened by unemployment to a high extent.

Unemployment of people with high support need is also a major problem in Romania. Vocational training and jobs in the first labour market are not available in practice and as a result, poverty becomes an additional barrier for participation. Limited access is the main emphasize in the Spanish report as well.

In Sweden, vocational training is also arranged in separate settings and in small groups for young adults with complex needs, but there, alternative forms of teaching are applied that aim at developing (alternative) forms of communication and abilities. Nevertheless, pupils should be more encouraged to take their own decisions and make their own mistakes. There are also cases where young adults with severe disabilities are still treated like children and this of course limits people's trust in them to develop and make their own decisions. Day care centres are very common for adults with high support need. Yet, people hardly have a chance to choose the centre they would like to visit. In daily life, decisions cannot be made self-determinate as parents and staff do not always trust in the person's ability to decide for him-or herself.

In the UK, people with severe disabilities also do not participate in regular vocational training or employment.

The reports show that people with complex needs are mostly excluded from the regular labour market in general. Occupation possibilities in day care are partly available, but there are cases where people with complex needs tend to be treated there as according to the model of the "eternal child".

According to the UN Convention, States Parties have to recognize the right of persons with disabilities to work on an equal basis with others. "This includes the right to the

opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities”.<sup>61</sup>

It is a high risk of discrimination for people with complex support that most programs for labour market integration are targeted only to people without or only with little support needs. Thus, such labour market policies do not only exclude people with severe disabilities but also contribute to manifest this exclusion.

General assumptions in policy programs and institutions for rehabilitation create a strong link between high support need and incapacity to work and to earn a living. That excludes people with complex support needs from full participation in the society.

## **4.7 Adults: Housing**

Self-determination and empowerment can be realized when thinking about housing: making one's own decision where and how to live are decisive factors for participation. Independent living might encourage participation in community life and contribute to activate people with severe disabilities and develop a positive self-concept.

In Belgium, authorities keep on promoting independent living as a way to encourage autonomy. Direct payments can be understood as one instrument to achieve this aim. Still, in contrast, the quality of life and policy in the traditional institutions is not led by principles like self-advocacy and empowerment.

In the Czech Republic, residential care is still the dominant form of living. There, participation and individual choice are often threatened. Since 2007, people with disabilities can make contracts with services providers to receive support at home. This empowers people and encourages them to take over decisions in life.

The aim of the French disability policy is to offer people a real choice between living at home, living in intermediary environments or vocational and accommodation centres. To what extent this is realized in practice cannot be judged, but the report refers to the fact that most people with complex needs live in residential care or at home so that one can assume that the possibilities to choose are limited in reality.

In Germany the number of people with disabilities living independently is increasing, but still, residential care is more dominant. Residential facilities are not well integrated in the community and participation of users is usually regulated in the “Law on Homes” (Heimgesetz). Since the 1990ies, people with disabilities and their families engage in the development of community services. So far, the right to an individual dwelling can mostly be claimed by people with light and moderate or dominantly physical disabilities. No effective instruments are so far available to facilitate participation of people with severe cognitive impairments and non-lingual communication in evaluation and quality assurance programs. Great expectations regarding the improvement of self-determination accompany the implementation of direct payment schemes, which will be available in 2008 as a regular form of benefit.

In Italy, independent living is also available for people with complex needs in theory. Funding for independent living projects can be applied for through the Disability Unit of the

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<sup>61</sup> See Article 27 of the UN ‘Convention on the Rights of Persons with Disabilities’



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. Inclusion, one can summarize is favoured for children, but segregation is still common practice in adult age.

In Lithuania, residential care is the only possibility for the majority of people with complex needs. Here, self-determination and empowerment are not encouraged very often. There is an absence of choice in residential homes and preferences are hardly considered. Although there are cases where a person does not want to leave his or her environment, means: home, there are no alternatives. Community living is still considered to be a too expensive service.

Dutch policy favours living in the community and self-determination is an important term in this context. Up to now, only a few people can realize living independently. In institutions, people with severe disabilities tend to be overprotected; living in groups does not encourage self-advocacy. Some services have problem with taking the client's needs as starting point. Nevertheless, examples of supported living that personal involvement and partnership are decisive factors for success.

In Poland, independent living is still new and developing. According to law, if a person who absolutely needs help does not agree to be placed in social welfare home, the welfare authorities are obliged to notify the relevant court or prosecutor; then the decision is taken by family court. 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 general residents. There are also some regulations which allow residents of social welfare home return to the local community and start independent life, but their importance for people with severe disabilities is very limited as these are rarely used and mostly for people with milder disabilities. To summarize facts concerning self-advocacy and empowerment one can say that in residential care people are not encouraged to take their own decisions and there is no policy towards self-determination in traditional Polish institutions.

In Romania, possibilities for community integration are very limited due to mental barriers on the one hand and a real lack of services on the other hand.

In Spain, residential services are still very common and due to the organizational model, individualization, self-determination and basic rights or social integration are not favoured. In Sweden, some people with complex needs can realize to live in a flat of their own with personal assistance. 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.

In the UK, independent living is the goal for many self-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. Still, some types of services may be denied to people with complex needs. For those living in residential care, possibilities to express wishes are limited and sometimes users do not dare to complain as they are afraid of losing their home.

Although progress has been made in Europe, people with complex needs do not profit from the movement towards supported living very often. The problem of discrimination in this area is similar to the labour market integration. By failing the target group of people with complex needs from programs for supported living, the exclusion from housing market and individual support services is legitimated. Residential care and institutional mechanisms are a serious barrier to participation as the reports show that possibilities to choose, decide and control daily life are limited in residential care. According to the UN-Convention governments have to ensure that "persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement" (article 19)<sup>62</sup>. This challenge includes all men and women with disabilities and does not exclude anybody due to the intensity of his or her support need.

## 4.8 Exercising Civil Rights

The UN-Convention reaffirms that persons with disabilities "enjoy legal capacity on an equal basis with others in all aspects of life" Governments shall ensure "that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body"<sup>63</sup> . .

At the same time, governments shall "promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs"<sup>64</sup> .

In Belgium, persons with severe disabilities can be put under prolonged minority and in this case, the guardian will conserve civil rights like voting or marrying are conserved. Up to now, the rights and interests of people with complex needs remain partly invisible for the public eye and sometimes are not defended appropriately.

In the Czech Republic, NGO's representing people with (severe) disabilities have advocated for the inclusion of disability as an explicit ground for non-discrimination in the Charter of Fundamental Rights and Freedoms. Still, legislation deprives people with under guardianship in their political rights.

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<sup>62</sup> See the UN 'Convention on the Rights of Persons with Disabilities'

<sup>63</sup> See the UN 'Convention on the Rights of Persons with Disabilities'

<sup>64</sup> See Article 29 of the UN 'Convention on the Rights of Persons with Disabilities'

In France, progress has been made on the rights of people with severe disabilities, but the right to vote is not promoted very well. The demand is that education should encourage participation in democracy.

In Germany, the awareness of people's rights concerning those with severe disabilities has also been raising in the last years. Important drives to improve civil rights are set by the "Commissioners for the interest of the Disabled" and by the "disability advisory committees" on the different political levels.

In Italy, the right to vote is promoted for everyone, still there is the necessity to advocate for persons with severe disabilities who are not capable of self-determination in order to hold up their civil rights.

In Lithuania, people with complex needs are at constant risk of losing their civil rights which goes together with the civil death of a person.

In the Netherlands, there is no broad awareness of the existence of rights of people in situation of major dependence.

Although in Poland people with complex needs in general have the same rights, they cannot always be exercised easily and are often restricted.

In Romania, there is a lack of support to exercise e.g. the right to vote.

In Spain, a person under guardianship loses the right to vote. In practice, there are few services dedicated to giving legal counsel concerning the promotion of rights and duties of people with disabilities and their families.

The Swedish report puts emphasize on the fact that people with complex needs do not always have the opportunity to choose their legal guardian. It is assumed that guardians in some cases do have to much control about the lives of people with disabilities and that they lack possibilities to participate or take decisions.

The report from the UK focuses on the fact that people with disabilities, especially those with complex needs, still lack status and autonomy and that ongoing advocacy as a consequence is very important.

In some European countries, basic civil rights are still not or not fully granted for people with severe disabilities and/or those under guardianship. This limits the possibilities to self-advocate and be a full member of society as well as the chances to participate in democracy. Where civil rights are granted, there are still many barriers, e.g. when thinking about possibilities to get to polling stations.

## **4.9 Ageing and End of Life**

In Belgium, there is a mainly medical lobby for old people with complex needs. Society, the demand is, must ensure security for the weakest stronger. The Czech report also emphasizes that the needs of this group are not recognized and detected properly. That answers to the support need must be diversified is also mentioned in the French report.

Ageing in Germany is of growing importance; still up to now there is a lack of specialized services. Italian associations of people with disabilities 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.

In Italy, the situation of isolation with limited social networks is stated. In Lithuania, old people with severe disabilities are identified as one of the most vulnerable groups and their rights and interests are hardly advocated for.

In the Netherlands, active euthanasia is possible if wished.

In Romania, old people with severe disabilities have been living isolated for a long time. They have not at all been encouraged to advocate for their rights and needs.

A lack of daily activity is emphasized in the Swedish report; it goes together with the risk of turning into a passive life situation.

The reports do not say much about participation and ageing or end of life. Still, it becomes obvious that there is a lack of awareness for the needs and rights of old people with severe disabilities. As they usually do not have parents anymore to step in for their rights, they are in a position where their interests are not represented very well.

#### **4.10 Conclusions**

To summarize the results of the country reports according to criteria of self-advocacy and empowerment of people with severe disabilities one can say that progress has been made in all European countries in the last decade. But in all countries there is a high risk that persons with complex needs do not profit from these efforts. They are not 'de jure' but 'de facto' excluded from exercising civil rights, because their specific situation of dependence is often not adequately considered. In many relevant policy areas, like education, work, or housing, men and women with severe disabilities and complex support needs are not considered as a target group for full integration and inclusion

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

**www.non-discrimination.eu**

Synoptical Paper

## **5. Personalized Service Delivery and Individual Budgets**

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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**

## 5.1 Summary of the Synoptical Paper

Personalized services are important for giving people with severe disabilities the opportunity to manage their life according to their own wishes and needs and to participate in mainstream activities.

In this Synoptical Paper, it is shown that services need to be both flexible and reliable and a lack of personalized offers was identified as a significant risk of discrimination. Still, incentive structures created by public financing systems and predominant institutional routines make it attractive for decision-makers to provide service delivery in traditional institutional forms. Very often there is a gap between official policies of inclusion, based on personalized offers and the reality of exclusion as a result of institutionalization of people with high support needs. New sets of rules are recommended that refer to conceptual frameworks of service delivery, but also rules on financing systems that foster personalized service models, e.g. direct payments.

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Des services personnalisés sont importants pour donner aux personnes handicapées la chance de mener leur vie suivant leurs désirs et leurs besoins propres et de participer aux activités courantes de la vie.

Dans ce synoptique, on montre que les services doivent être à la fois flexibles et fiables et que le manque d'offre personnalisée a été identifié comme un risque significatif de discrimination. Mais les structures des systèmes de financement public et la prévalence d'habitudes institutionnelles font que les décideurs préfèrent les prestations de service sous la forme institutionnelle traditionnelle. Il y a très souvent un fossé entre la politique officielle prônant l'inclusion et une offre personnalisée et la réalité qui est l'exclusion, résultat de l'institutionnalisation des personnes. De nouvelles règles sont proposées, relatives au cadre conceptuel de prestation des services mais aussi aux systèmes de financement, encourageant les modèles de services personnalisés, par exemple le paiement direct.

## 5.2 Background

People with complex support needs are dependent on personalized service delivery to develop their personality as a man or a woman, to manage their daily life according to their needs and wishes and to participate in mainstream activities. Personalised services have to be both flexible and reliable and must respect as much user control as possible. In this respect, the lack of personalized service delivery has to be considered as a very basic cause of discrimination.

In accordance with the UN Convention on the Rights of Persons with Disabilities, States have to „recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation” (article 19)<sup>65</sup>.

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<sup>65</sup> See the UN 'Convention on the Rights of Persons with Disabilities'  
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To provide personalised services is not only a conceptual challenge but also a challenge of service management. Social services as organisations, based on legal entitlements, for many reasons tend towards institutional standardization of their offer:

- It seems more economic and practical, i.e. 'efficient' to allocate material and personal resources in a centralised facility, to institutionalise people with disabilities there and to provide services in categories of 'places' and 'groups' than to deliver individual assistance in 'normal' environments as a part of an individual service arrangement.
- In modern societies service organizations tend to specialize for reasons of legitimation. It is very important for service provider organizations to claim their responsibility for a special, homogenous group. That facilitates the communication of a clear mission to the environment and promises stability for the organization itself. Such specialised organizations claim to deliver a high professional standard and they underline the requirement of safety measures and specialised care in special facilities.
- The existence of special disability service provider organizations facilitates and legitimates the exclusion of persons who are considered as 'difficult' in other organizations, and thus facilitates the recruitment of new clients.

Incentive structures created by public financing systems and predominant institutional routines make it attractive for decision-makers to provide service delivery in traditional institutional forms.

This gives an explanation why in countries, which do not have strong legal sets of rules for personalized service delivery and against standardized institutional care, the dynamic of the 'special institution' is dominating the support system. Often one can find a wide gap between the officially expressed normative principles of special disability institutions and the reality of exclusion as a result of institutionalisation of people with high support needs in special services.

New sets of rules must refer to conceptual frameworks but also to financing systems that foster personalised service models. This is of special importance for persons with complex support needs because they have a higher risk to be excluded from mainstream activities by traditional standardized systems. In past years, new sets of rules for personalized service delivery have been developed that focus on individual needs assessment and personalised service planning. In this context, 'personal budgets' as comparatively new form of public financing of services have become a central issue in the discourse on emancipation of people with high and complex support needs.

This Synoptical Paper firstly provides a short overview of personalized service delivery and individual budget in each of the twelve countries. After that, general problems will be addressed in two different exemplary fields. 'Preschool education' was chosen as an example of a statutory regulated field with well established mainstream services, housing' and 'employment' were chosen as examples on how personal service delivery can be improved through personal budgets.

## **5.3 Summary of Country Reports**

### **5.3.1 Belgium**

Children with severe disabilities can get a sort of personalized services in childhood when having a look at education and care. In some cribs and teaching schools, there are some

projects that favour the integration of one child with disability per class, but often with the condition to get help from an extra person (nursery or parents). Still, these cases are rare.

When it comes to school, integration of children with disabilities into mainstream classes is also possible, but not common practice. Family support services, on the other hand, are often not specialized enough to meet the families individual needs.

Concerning leisure time activities, integration help services subsidized by regional agencies for the integration of the people with disabilities as well as specialized association and mutual insurance are very active in the development and organisations of leisure adapted activities for children and teenagers with disability.

When it comes to vocational training, integration help is available, but in practice not for people with complex needs. People with disabilities can get additional help at their place of work in the regular labour market, but – as mentioned above – this is hardly accessible for those adults who have a high support need.

For people with severe disabilities who would like to live at home the public authority grants a help bonus to adapt the housing. Personal budgets aim to encourage the autonomy of people with disability 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 1.000 persons use personal budgets in Flanders against 19 in Wallonia.

Partnerships are more and more respected, also in traditional institutional contexts: couples can share a room. There are also support services that offer help for parents with intellectual disabilities so that in some cases, the child can grow up with its parents (but still, people with complex needs do not have sufficient access to partnership and parenting).

### **5.3.2 Czech Republic**

In the Czech Republic, there is a new law that also refers to the idea of personal budgets: the new law on social services entered into force on 1 January 2007 with the aim to satisfy basic needs which cannot 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 level of so called “dependency” of a person. Contracting the service between service provider and a person with complex needs is also included in the new legislation.

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

Although family support services are available and although they try to offer support that meets the families´ needs, these services are still insufficient in number and availability differs from region to region.



For children in kindergartens, there is a chance to visit a mainstream institution on the basis of inclusion. Still, this is not common practice and children with complex disabilities often cannot participate in these programs.

A new law on schooling offers all children the possibility to receive education “which correspond[s] to their educational needs and possibilities” – that means they can visit mainstream schools. An assistant teacher can be hired - although the source of funding is not mentioned in the new law. Nevertheless, there is a lack of personal support in classes and children with severe disabilities do not really profit from inclusion.

In some regions (mainly bigger cities) there are self-help groups that are very important for family support. Still, respite care is not well developed and not well known among parents. In the area of leisure time, there are some financial grants to support integration, but the effects are not very broad.

When it comes to vocational training, there is the possibility to do training on the job with the help of an assistant – yet there is the question if these models are flexible enough to meet the needs of severely disabled youngsters.

Concerning work, the government policy aims at integration of people with disabilities, but again, this is hardly available for people with complex needs as those who are under plenary guardianship cannot sign an employment contract.

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.

When staying in the family, the report refers to the fact that 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. 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.

Concerning partnership and parenting, 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 a taboo. The right of persons with complex needs or severe disability having a child is not even discussed.

### **5.3.3 France**

In France, children with disabilities can attend a mainstream preschool, but this is still difficult to access. There is a lack of equipment and financial means.

Also at school, children with disabilities can in principle be included. 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 establishments (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 be also helped by assistants of school life (help for the writing, the installation of material, the accompaniment during the meals, the inter-classes, 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 helped children are generally the ones who have the most severe disabilities or complex needs. But the children and the teenagers with severe disabilities are more often referred to in specialized establishments, especially after the primary education.

When it comes to work, legislation promotes the inclusion of people with disabilities into the first labour market. Yet, this is not common practice for adults with a high support need. People in sheltered workshops now have the status as a full worker with guaranteed wages.

Information on Housing is also given: when diversifying service offers and concentrating them on the disabled needs, the 2002 law should also favour they life at home and more particularly the life of those who have severe disabilities or complex needs. Combined allowances such human aids, social and health support will help to alleviate the consequences of a disability through technical or human assistance. The aims of the French disability policies is to guarantee the disabled a real choice between living at home, living in intermediary environments or in more classical 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 with disability (SAMSAH), a kind of "medical SAVS". These double prices services correspond to a real alternative between medical accommodation centres. They health care prices package are on the charge of the Social security which depends of both general councils and local authorities.

The possibilities to find a partner are still very limited, especially in institutions, and parents do not always find the human support they might need.

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

The individualized compensation is fundamental, especially for those with complex needs. Every person with a 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 or her needs in all the domains (environment, transport, formation, employment,

resources, technical aids, human helps, etc.). It can be revised on the request of the person according to the evolution of his disability in the environment.

### **5.3.4 Germany**

In Germany, a rehabilitation plan is set up for children with severe disabilities; their families can get support from ambulatory services. Nearly all children with complex needs visit a kindergarten; there is the possibility to include children with disabilities into mainstream institutions. Especially in the field of preschool education there have been remarkable changes in the last few years.

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 children with disability 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.

Family support and respite care services are available as well as – at least in some regions – self-help groups.

When it comes to vocational training, there are special services that aims at including also people with disabilities into the first labour market. In practice, these services are not available for youngsters with intellectual disabilities.

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.

The number of services for supported living is increasing, but still, this is not the dominant model in Germany. 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. Claiming the right of individual assistance in a private flat is only possible for a small group of people with predominantly physical disability. No instruments are so far available for the participation of people with severe intellectual disability and non-lingual communication in evaluation and quality assurance programs of services. Even if access to mainstream leisure time activities is still very limited, at least the focus on adult education of people with disabilities has changed within the last few years and there is a number of adapted programs available.

Concerning partnership and parenting, the situation is slowly starting to change. Parents with (intellectual) disabilities start to get support from services putting a focus on individual family situations. Still, this needs to be extended – the public attitude is not yet in favour of people with disabilities having children.

For people with severe disabilities getting older, a new mix of care is needed, but there is a lack of provided support meeting individual needs.

The new rehabilitation legislation makes it possible to grant benefits for daily life activities as a personal budget, if people with disability want so. Starting in 2008 it's an obligation to grant benefits in this way. It's an important political goal to get more flexibility in service providing by personal budget but until now there is a great reservation in using personal budgets.

### **5.3.5 Italy**

A child with a disability has a personalized rehabilitation plan or maintenance program from 0 to 18. In Italy, the informal sector still offers most of the support to the individual family – the system of family support services and respite care is not well established.

Children with complex needs have the right to visit a kindergarten; mainstream kindergartens are available for all children and work inclusive. Children with special educational needs are allocated a support teacher.

As there is no system of special schools in Italy, children with complex needs are entitled to visit mainstream institutions, also with the help of a support teacher. There is a work group for integration that collaborates of the pupil's individual educational program (PEI) on the basis of a functional diagnosis. 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.

Some parish youth clubs promote the inclusion of children with disabilities into their programs, but this depends on local initiatives.

When it comes to vocational training, there are programmes that aim at supporting 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. 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.

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. The principle of inclusion exists through the disability employment register but in practice this is not so efficient.

For people with complex needs living at home, there is the possibility to get domiciliary support. 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.

There is a growing trend in enrolment of students with disabilities in state universities. Universities must have a Disability Help Desk that provides services for students with disabilities. The services offered differ from university to university. Specific services become operational on the specific request of the student and within the limits of available resources.

Partnership and parenting are still not on the political agenda in Italy and there is a lack of specialized support for families.

For the elderly people with disabilities, there is the possibility to get support at home; yet these services are not spread enough.

### **5.3.6 Lithuania**

In Lithuania, the family is entitled to get counselling and support. Yet, the system of family support is not well established.

In general, children with complex needs can also visit an inclusive preschool setting, but this is still in the beginning.

Although in principle, inclusion at school age is possible and many children with special educational needs visit mainstream schools, this is hardly possible for children with a high support need.

Although there are several legal regulations foreseeing vocational training for people with disabilities, this activity is still under experimentation and probation. Various state institutions (Lithuanian Labour Exchange, Lithuanian Labour Market Training Authority, centres for professional qualification, most vocational schools, vocational training centres, established by local municipalities, etc...), also many NGOs implement a number of national and international programs, projects with the goal vocational training of the disabled and their integration in labour market. In practice, vocational training for youngsters with disability is still separated from the mainstream.

Looking at the sector of work and employment in general, people with disabilities are entitled to get additional support in the labour market. There are many provisions foreseen enabling integration of the people with disabilities in the labour market. However there is a lack of a coordinated, all-embracing system of employment of people with disabilities.

Although there are financial means to push integration, these efforts are not enough. Still, there are not personal rehabilitation plans set up in the traditionally run institutions.

Since community living is an expensive service there are very few independent living homes in Lithuania. Care services at home also doesn't properly cover the need for care for persons with complex needs, therefore big residential care institutions still are very popular.

Concerning partnership and parenting, there are some benefits for parents with disabilities and NGO's support them with humanitarian aid. Still, this is not the rule but rather a fragment and for the Lithuanian people, parenting and disability do not go together.

There are no specialized services for old people with complex needs.

### **5.3.7 Netherlands**

In the Netherlands, an individual plan is set up for children with complex needs. These days, the system of support and care is in transition from a well-considered model to a system of individual authority. Still, there are improvements that have to be made.

Children with a high support need in preschool age mostly stay at home. Integration programs will – in the coming years – not really include those with severe disabilities. At school, a new legislation gives the possibility for all children to attend a mainstream school: by law children and youth with disabilities and/or challenging behaviour have the opportunity to choose for mainstream schools with extra assistance or for special schools. Children and young people with severe and/or multiple disabilities have the same choice. They are entitled to get a financial budget (the so-called 'back pack'). The intention of this back-pack policy, to summarize, was to also enable children with more severe disabilities to visit mainstream institutions but in practice, they are still excluded and their education is done mostly in day care centres.

Family support is available in the Netherlands. Sometimes, parents take the care in their own hands, supported by a personal budget. For instance, they create a company of supportive professionals and volunteers by which their child can have a supported living in the society, far from the large residential institutions.

Concerning social security and health care, the Exceptional Medical Expenses Act (AWBZ) is an important basis for the care of people with severe disabilities. 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 corresponds 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 client is given more direction about his 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.

When having a look at work, the government policy aims at including people with disabilities into the mainstream labour market. Still, mostly people with mild disabilities profit from those programs.

In the Netherlands, many people with severe disabilities live in institutions. 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). In general, 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.

There is no policy towards partnership and parenting of people with disabilities in the Netherlands – it is discussed and in some cases accepted, but no differentiated system of support has established yet.

### **5.3.8 Poland**

In Poland, family support is still insufficient. Although integration of children with disabilities into mainstream preschool programmes has been increasing, access is still very limited for those with a high support need.

At school, the situation is similar: integration is possible, in general, but hardly available for children with severe disabilities. The practice of individual schooling at home is overused.

When it comes to vocational training, young adults with disabilities can attend secondary school education in principle, but access is very limited. There is no scheme for supported employment in Poland.

In Poland there is no policy towards deinstitutionalisation. There are some community-based services in the system of social welfare, but they are insufficient to support independent living of people with severe disabilities and/or complex support needs. Personal assistance is still new and developing concept. Although some NGOs and local authorities provide personal assistance services, but access to them as well as the form of these service is very limited. Some services explicitly exclude persons with specific disabilities.

There are no services supporting married couples or parents with disabilities. The situation of old people with severe disabilities is not very different from the one of younger people. There are hardly any specialized services.

### **5.3.9 Romania**

In general, one can say that 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.

For children, there is a General Directorate for Social Assistance and Child Protection (DGASPC). One aim is to improve the care and personalized recovery intervention. Still, families do not receive enough support. At school, integration is possible in general, but not for children with severe disabilities.

Vocational training is also almost inaccessible for youngsters with a high support need. Community services for people with severe disabilities are insufficiently developed. Children with disabilities (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.

Legislation favours the employment of people with disabilities, but these services are at an early stage. 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.

There are no big chances for integration of people with severe disabilities into society and there are no counselling services for private living.

Partnership and parenting are not supported in practice. For older persons with disabilities there are hardly any services.

### **5.3.10 Spain**

In Spain, families with a child with severe disability are entitled to home support. In practice, the network is insufficient.

At school, the general principle favours inclusion and special education is supposed to be the last resort. Assistant teachers are available, but in practice, children with complex needs still visit special schools.

Concerning vocational training, centres are obliged to reserve some places for pupils with special educational needs, but youngsters with high support need cannot really access mainstream vocational training.

Legislation encourages employment of people with disabilities. In short, there will be new regulations on employment of people with support need.

Having a look at the situation of housing, home assistance depends on the social services of the municipality. 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.

There are no support services for parents with disabilities. Older people with complex support need are mostly referred to nursery homes.

### **5.3.11 Sweden**

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 needs 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 satisfied 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;
- Requesting assistance through the municipality;
- Forming an association or co-operative with other people with disabilities, which will employ several assistants;
- Using another company or organization;
- 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 organizing 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.

For children with complex needs, a personal habilitation plan is set up. The support of children takes place individually, e.g. at home. 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.<sup>66</sup>

Children are entitled to receive education within the community. Still, many pupils with high support need visit special schools.

Vocational training is mostly realized within a special setting, but there, individualized plans are set up. People with severe disabilities normally do not have a regular job in Sweden, but visit day care centres.

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<sup>66</sup> see the Assistance Benefit Act (1993:381).

Most people with complex needs live in a group home in the community. 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 or she 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.

In case people with disabilities become a parent, the municipality takes the care for the child. There is the policy to encourage contact and visits.

For older people with severe disabilities, there are two options: they either stay in their group home or they are moved to special accommodations for elderly.

### **5.3.12 United Kingdom**

Families are supported in the UK from early childhood on. Services are to be family and child centred. Inclusion has been established in many preschool institutions. Some of them are still unable to offer places for children with complex needs. Concerning school, policy favours integration as well. But until now, a number of special schools remained.

Increasingly, there is an emphasis on supporting people with disabilities in employment training, but these opportunities are limited for youngsters with a high support need. Discrimination legislation aims at protecting employees with disabilities, yet it is unclear to what extent people with complex needs profit from this policy. The cost of support needed is likely to be high.

Concerning social security, 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. 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.

When it comes to housing, pilot projects have shown that people with disabilities 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.

For parents with (intellectual) disabilities, policy promotes family centred support service. Still it is not uncommon that children are removed from the families.

The report states a lack of support for those elderly people with disabilities who develop dementia.

## **5.4 Conclusions - General aspects of individual service delivery in selected fields**

In order to clarify the obstacles and challenges for individual service delivery, conclusions focus on selected fields of preschool education and adult services.

### **5.4.1 Personalized service delivery in preschool education**

In all countries of the sample it is the rule that children can visit preschool facilities. The possibility to join preschool education is seen as very important for parents in terms of family support on the one hand and for the development of children on the other hand. In some countries a legal right for the visit of preschool facilities exists, in other countries at least strong efforts to make it possible for all children can be found.

In no country children with disabilities in general are excluded from preschool education and from preschool education in mainstream organizations. But in many countries of the sample one finds a shift to exclusion of children with complex needs through the existence of special facilities and insufficient support in mainstream settings. In this way, the discrimination of children with complex support needs is not a result of political prescriptions, but of implicit rules and lack of an inclusive orientation in practice.

In the study, different groups can be found:

- In a small group of countries mainstream organizations in the preschool system are available for all children (Italy, Sweden).
- In another group of countries integration projects are developed in various projects, but integration is not a compulsory orientation for preschool education. It is the risk of parents to find an appropriate place or keep their child at home (Belgium, Czech Republic, Lithuania, Netherlands, Poland, United Kingdom, Romania, Spain)
- In addition to the lack of a general inclusive orientation in some countries the possibilities of integration are different between regions. In many cases it is difficult to find mainstream organizations in rural areas or there are different rules among regions in one country (Czech Republic, Germany, Lithuania, Poland, United Kingdom).
- In some country reports it becomes clear, that the decisions on integration depend to a large extent on the decision of professionals and/or parents, because they assume an insufficient support for children with disabilities in mainstream kindergartens or other preschool facilities. At the same time they are aware of the variety of specialized organizations that in their view or according to their experiences provide better learning environments children with severe disability. (Czech Republic, France, Germany).

Also in countries like Italy and Sweden with no special system of preschool education for children with disability, problems to create an adequate inclusive environment and culture are reported. Some special preschool facilities still exist in Sweden. In this way parents sometimes hesitate to send their child to the regular kindergartens and pre-schools.

As a result it can be found, that in spite of the orientation to inclusive education, children with complex support needs are often excluded from mainstream education. There is a wide range of variety between realisation of integration only in a few projects and as a

dominant approach. Especially if there is no legal obligation to provide access for all children, whether classified as disabled or not, we find strong tendencies to lower the efforts to include children with complex needs. For organizational reasons, professionals tend to look for alternatives in special education settings or leave the parents alone with the challenge to find a suitable facility.

To ensure personalized service delivery in mainstream organizations like preschool education, school or vocational training in all countries need 'institutionalised rules' to implement the idea of equal rights and the possibility for choice from the UN Convention.

As a result of the country reports the direction of those rules can be stated:

- To minimize the risk of exclusion from mainstream facilities all alternatives have to be blocked. If mainstream schools or other educational facilities organisations cannot refer to special organisations or to refuse the right to visit a mainstream organisation, all professionals and all people who are in charge of managing mainstream institutions have to recognize their responsibility.
- Mainstream organisations need assistance for doing their job. Especially in countries with a tradition of special education it is a chance for professionals and former special services to transfer their know-how in mainstream organisations.
- To deliver personalized services especially for people with complex support needs good intersectoral cooperation is needed. It is necessary to avoid an understanding of support needs in education settings as individual problems but as the challenge to arrange the environment of playing and learning as an inclusive one.
- Individualized service delivery must be embedded in a good system of Early Intervention and family support, which allows families to create an individual perspective for their future and for the future of their member with complex support needs.
- The goal of inclusive education is not the individual integration of some children with special needs, but to build up a culture of inclusion that respects and cares for the individual needs of every child.

#### **5.4.2 Personalized service delivery in the field of housing and work**

To find a suitable flat or a good job in modern societies are considered as challenges for adults. There is a strong momentum of individual responsibility in these fields, although everybody knows that chances for individual forthcoming are deeply linked to opportunities in the society. The risk of discrimination lies in the mechanism that people with complex need do not find a possibility to earn a living.

The risk of discrimination in the field of housing is the lack of resources to find a barrier-free flat and to pay for sufficient support. For that reason, it is a challenge for the social support system to enable and empower people to make their own decisions with choices equal to others. The governments have to ensure that there is no structural inequality for people with disabilities in the labour market or in the housing market as precondition of individual success and life quality in these fields. People with complex support needs have no perspective to live in their own flat or to do a satisfying job without assistance.

In the field of employment and occupation we find the following situations in all countries of our sample:

- A higher unemployment rate of people with disabilities in general.
- A protected work sector for people with complex needs.
- Individual support in regular labour market for some groups of people with disability.

- Incomes from social security systems.

It is obvious that there is a tension between the improvement of access to the labour market and the status of inability to work, which gives access to alternative social incomes. As a result, the not coherent mix of welfare policy includes a high risk for a person with complex support needs to be excluded from the labour market. Thus, in the context of this synoptical paper one can see the standardized form of support as an important problem. Individual attributions, certified by medical doctors prescribe a path to face the individual problems to find a job and to earn a living.

In all countries one can find ideas of 'normalization', 'self-determination', and 'participation' to improve the possibilities for an independent living of people with disabilities but the situation in the field of housing is different. Several strategies to ensure the necessity of support in daily life for people with complex support needs can be found, for example:

- A predominant support in residential services versus a support in own flats.
- Lack of barrier-free housing versus strong efforts to barrier-free housing
- Lack of barrier-free transportation versus strong rules for barrier-free transportation

The strategies which are needed to avoid discrimination of people with complex support needs in the employment field in some points are similar to those aiming to avoid discrimination in statutory organized mainstream services but they have to face other problems that are caused by the dynamic of markets.

- The possibilities of blocking alternatives of employment for instance in sheltered work sectors are limited because of the high risk of unemployment and pressure to apply for retirement.
- The possibilities of blocking alternatives of housing in special facilities are difficult as long as there is not enough barrier-free apartments and not enough decentralized services available.

Therefore, three strategies are possible:

- Following the principles of normalization, the social welfare policy can set rules for service providing according to the UN Convention on the Rights of Persons with Disabilities<sup>67</sup>. In most of the country reports one can find national practice and rules, which do not comply with this Convention. All countries need a more intensive evaluation of the quality of rules and routines for service providing in their countries and an improvement based on the principles of the UN Convention.
- To face the steering problems in service providing under conditions of markets some countries have introduced individual budgets, which enable the users to buy their needed services themselves. The idea of individual budgets can be seen as the most extensive attempt to avoid the risk of exclusion through the dynamic of special service organizations.
- Anti-discrimination policy is not limited to activities of public institutions. It's the only way for marketed orientated societies to reduce discrimination in the regular labour market and the housing market. Anti-discrimination policy has a long tradition, for example most European countries know an obligation to employ people with disabilities. But regulations like that often fail to strike the living conditions of people with complex needs.

In actual fact, the welfare policy in these fields has to be a mix of these strategies and the process of European integration can make a contribution to improve the principles of an inclusive society by reducing discrimination and personalized service delivery.

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<sup>67</sup> See the UN 'Convention on the Rights of Persons with Disabilities'

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

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Synoptical Paper

### **6. Intersectoral Cooperation in Service Delivery**

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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**

## 6.1 Summary of the Synoptical Paper

Intersectoral collaboration refers to the promotion and co-ordination of the activities of different sectors for an inclusive development of communities in a way that puts the burden of coordination on the system without reducing users' control on their support arrangements.

The paper shows that for persons with severe disabilities welfare state fragmentation and lack of cooperation between services from different sectors are not abstract problems, but in many respect very concrete challenges with a very high potential for discrimination. Caused by their often complex support needs, persons with severe disabilities are dependent on the social care system with its various levels, on the health care system, the education system, but also on various government authorities at different levels that are responsible for general public affairs such as traffic, employment, pension, housing or public security etc.

When people with severe disabilities – whether they are children or adults - are placed in institutions, mostly system responsibilities are clear and there is not much need for cooperation between service sectors or services from one sector. But in order to live a life 'as close to normality as possible' in mainstream community settings, using those services all people use, people with severe disabilities and their families are heavily depending on the ability and readiness of such cooperation. Lack of intersectoral (and intrasectoral) cooperation between services in planning and allocation of resources can be one of the decisive discrimination factors, why people with severe disabilities are excluded from living a life in normal settings.

On this background, a consistent non-discrimination policy for people with severe disabilities and complex support needs should consider cooperation between different services especially from different sectors of high importance. Recommended is a strategy comprising four elements: oblige intersectoral cooperation by law, institutionalize cooperation by implementing planning structures, practice and learn cooperation, make cooperation a routine and monitor it.

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La collaboration intersectorielle s'entend comme la promotion et la coordination des activités de différents secteurs vers une société inclusive, en faisant peser la charge de la coordination sur le système sans réduire le contrôle des usagers sur l'organisation de leur soutien.

Ce document montre que pour les personnes avec des handicaps sévères, la fragmentation des aides sociales et le manque de coopération entre les services de différents secteurs ne sont pas des problèmes abstraits, mais souvent des défis bien concrets qui constituent un risque très élevé de discrimination. Ces personnes, en raison de leurs besoins souvent complexes, sont dépendantes du système social à tous les niveaux, du système de santé, du système d'éducation, mais aussi de différentes administrations, responsables de domaines généraux tels que la circulation, l'emploi, les retraites, le logement ou la sécurité publique, etc.

Lorsque les personnes avec des handicaps sévères –enfants comme adultes – sont placées en institutions, les responsabilités sont claires et la coopération entre différents secteurs ou différents services n'est pas vraiment nécessaire. Mais pour vivre « le plus

normalement possible » dans le tissu social ordinaire, en utilisant les mêmes services que tout le monde, les personnes avec des handicaps sévères et leurs familles sont lourdement dépendent fortement de la compétence et de la volonté d'une telle coopération. Le manque de coopération inter- et intra-sectorielle pour la planification et l'allocation des ressources peut être un des facteurs déterminants de discrimination, qui explique pourquoi les personnes avec des handicaps sévères sont exclues d'une vie dans un cadre normal.

Sur cette base, toute politique logique de non-discrimination envers ces personnes devrait prendre en compte la coopération entre les différents services, notamment ceux qui sont importants. La stratégie proposée repose sur quatre éléments : imposer une coopération intersectorielle par la loi, institutionnaliser la coopération en mettant en œuvre des structures de planification, s'entraîner et apprendre à coopérer, faire de la coopération une habitude et la contrôler.



## **6.2 Background**

Due to developmental paths and traditions, most countries with developed welfare state structures face the problem of a high fragmentation of the different sectors of their social security systems. Not only that in most countries, like the ones represented in this project, there is no unique definition of 'disability' across the social, employment, health care or education systems, also classifications of needs are different and follow sector-specific rationalities. As a consequence, problems of uncoordinated bureaucracy, incoherent classification procedures, uncoordinated service delivery by badly regulated care markets, or - most importantly - inactivity or delay of urgently needed service delivery due to unclear responsibilities are widely seen as major challenges in the development of welfare state services.

In addition, also perverse incentive structures can be found that direct decision-making processes on services for people with recognized support needs against generally valued principles, in order to shift budget responsibility from one sector to another and vice versa. Thus, fragmentation leads to costly deficits in effectiveness not only for the public, but also for the quality of life of service users. In nearly all countries involved in this project in recent years, there have been some political efforts to reduce these negative impacts by institutionalizing procedures for better intersectoral cooperation both at the level of systems and at the micro-level of case-management. But obviously, sectoral thinking and acting seems to be very difficult to overcome, and as the following synopsis shows, substantial cooperation cannot be expected per se, but has to be institutionalized and learned.

## **6.3 Prenatal Diagnosis and Counseling**

From a system perspective, the most relevant professionals in the area of prenatal diagnosis and counseling are obviously medical doctors. Not only because they are in the position of examining women or men who are planning to become parents or women who are pregnant and with a risk of fetus impairment. All country reports of this project also show that the information resulting from the fetus diagnosis is dominantly seen as being medical, that it has to do with medical facts and is communicated in medical terms. Mostly this is connected with the message to have the pregnancy terminated if fetus impairment is found. More social or cultural information on disabilities or on positive experiences of other parents of children with disabilities are not available or not systematically given. But even though this seems to be the general pattern, there are differences between countries reported when it comes to involvement of professionals from other disciplines or psychosocial counseling centres.

In some countries, like the Netherlands, there are well developed facilities for genetic counselling at Centres for Clinical Genetics with multidisciplinary teams. In other countries, like in Lithuania, the Centres for Genetics have a purely medical profile. In Germany, a woman needs to have a consultation independent of the medical examination if she wants to terminate pregnancy, but not in case of foetus impairment. In France, two doctors must give evidence if a woman wants to terminate pregnancy due to medical reasons. In the Czech Republic, Germany, France, the UK and other countries there are services for pregnancy counselling, self-help-groups and other voluntary organizations offering independent counselling, but there is often no routine cooperation with clinical genetics. As result, most reports state a lack of balanced information.

## 6.4 Early Childhood and Family Support

There are two basic directions of support in which professional services can deal with families with children with severe disability: a) to support the child in his birth family, or b) to take the child out of the family and place it in an infant institution. The first direction, the 'family model' is reported from all Western European countries of the sample. The normative assumption is, that children with severe disabilities should grow up in their families like all other children, there is medical and social support, but also a normative pressure on parents (i.e. mostly on mothers) to take over responsibility for the child. This includes the moral obligation to cooperate with the often very specialized professional system that comprises medical doctors, various therapists, or social workers. The second direction of 'early institutionalisation' is reported as a still relevant orientation in Eastern European countries like the Czech Republic or Romania, even though clear shifts towards the family model are there as well. In the model of early institutionalization, the assumption is that families should be relieved from the burden of care by placing the child with disability in an institution because it is not possible to provide enough support for the child in its family. There are no intersectoral cooperation problems reported in this model, but of course in the 'family model' there are such - but also cooperation problems of services within the same sector.

In some countries it seems typical that in the early childhood age families with children with severe disability are 'surrounded' by medical, therapeutical and educational experts, all offering very specialized services, and parents are in the difficult position to make informed choices. In some countries, like Sweden, Germany or the UK, relief services for families exist. In Sweden, the network around a child with severe disabilities is very extended. It is not seldom that a family has 50 different contacts to cope with in everyday life, so that the parents need a coordinator to handle their life situation. If the parents do not know about their 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.

A very central problem is the lack of coordination between services that often lead to very full time-tables of families but also to confusion on therapeutic objectives. In some countries, like Italy, Family Counseling Clinics offer coordinated assistance and information. The Child and Adolescent Neuropsychiatry and Psychology Unit is responsible for working out an Individual Plan, that provides a joint basis for doctors and therapists with different orientations. Also in other countries it is accepted that there has to be an Individual Support Plan for early intervention services, but as health and social care programs are usually involved, joint planning seems to be very difficult because of budget interests from both sectors.

In the UK, 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. Mismatches between the services that families feel they need and those they are offered can negatively affect their ability to cope in the long-run.

In other countries, like Spain, Lithuania, the Czech Republic or Romania such coordination problems do not exist at the same level or not at all because respective services are not or only difficult to access due to centralization or affordability reasons.

## **6.5 Education and Leisure time**

Children with severe disabilities mostly have special educational needs and nursery care needs, often also they need assistive tools like wheelchairs, communication tools etc. and last, but not least, barrier-free environments when they want to visit educational facilities. Whereas in special kindergartens or special schools facilities are usually prepared, mainstream kindergartens and schools are often not, as reports show for many countries. Adequate conditions for inclusive education for children with severe disabilities still have to be created in terms of competent staff, therapeutical and technical support, transport and accessibility. In all countries, discrimination laws prescribe barrier-freeness as an obligation not only for public buildings but also in a more general understanding in terms of 'universal design' of public infrastructure. In this sense the implementation of the concept of inclusive education would need a consistent interdisciplinary and intersectoral planning approach that focuses on the specific needs of a child with complex needs and is realized in joint assessment and joint allocation of resources in normal kindergartens and schools. This is by far not realized in most of the countries of this project.

In all countries, children with severe disabilities hardly have any access to mainstream leisure time activities. They either spend their free time within the family or within the disability field. In most countries there are some disability organizations that offer programmes or activities are run within special schools or day care centres.

For example in the Czech Republic, 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 disabilities, especially towards persons 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 while fostering a public attitude of pity towards these so-called "poor" people.

In Belgium for example, a general movement of opening to integration seems to start in the youth welfare sector, including attempts for more adaptations of places, staffs, as well as more training for animators but means are not always following.

In many countries, there is a widespread system of youth clubs, but hardly any cooperation with initiatives from the disability field. 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 youngsters with severe disability.

Generally it is striking that systematic efforts for education, rehabilitation and care of children with severe disabilities seem to get less the older the children become and that

families become more and more left alone with their obligation to care for their child with special needs.

## **6.6 Vocational Training**

In all countries, there are vocational training programs available, but most young adults with severe disabilities cannot participate in mainstream programs. Access to these programs preparing for professional careers on the first labour market is still very limited for them. Mostly programs are not adapted and efforts to open access possibilities for youngsters with severe disabilities are lacking strength and coordination. There seems to be a general assumption that people with complex needs will not work in paid employment. The description from the Czech Republic, seems typical for many other countries of our sample: vocational training as part of school education is hardly accessible for youngsters with complex needs. The second possibility is the one of training as 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, the question remains whether these models are flexible enough to meet the complex needs of persons with severe disabilities. Effective transitional programmes would require systematic cross-sectoral collaboration between the Ministry of Education, Youth and Sport and the Ministry of Labour and Social Affairs.

## **6.7 Services for Adults**

Following socially normal patterns of adult life in terms of work, private housing, or partnership and family is very difficult for people with severe disabilities and complex support needs. In spite of the European Directive on Equal Treatment in Employment and Occupation, in all countries in this sample they have almost no access to the first labour market, even when there are supporting services or financial compensations for employers. But all countries report efforts to provide employment for people with disabilities in form of self-help firms, sheltered workshops or in quasi-normal parallel forms of employment. Of course there are big differences between countries regarding the extent, systematic implementation, and the income and social security situation that is related to the respective system in the European countries involved. There are countries like Germany and France with a well established system of sheltered workshops, other countries like the UK, Belgium or the Netherlands, where sheltered workshops are established only in some regions, and other countries where such facilities only start to be established.

In general, for people with more severe disabilities there tends to be an assumption that they do not want to work or are not capable of working. This assumption implies the exclusion of people with severe disabilities from the labour market and from the responsibility of the Offices of Labour. Responsibilities are then handed over to the social service sector, and day activities fall into the often limited day care budgets of social care

services at local level. Not all systems have funding for day activities for people with severe disabilities as it is reported from Sweden, where people get a comparatively generous budget for this.

When people with severe disabilities are placed in centralised institutional facilities it is not intersectoral cooperation that creates difficulties, but still sector or administrative level responsibilities can become problematic. In some countries, like Germany or Italy, the form of support is related to the question whether the local or the regional level of the social care system is responsible to cover costs for residential care. In other countries, like the UK, there are problems of having the Health Services and the Social Care Services as responsible bodies for service provision parallel to each other but with different conditions for users. Under these conditions, the assessment of individual needs often changes its function from a tool for designing personalised services to a tool for deciding about the sector (health or social care) or political level (local or regional) that is to take budget responsibility.

When - according to processes of disability mainstreaming – more people with severe disabilities are reaching adulthood and live in 'normal', private dwellings in the community it is mostly the local authorities, who are largely responsible for providing services to this group. An adult person with severe disabilities and complex support needs who seeks to live an ordinary life in his/her community most probably needs a variety of support and assistance. Of course, it is in the interest of local authorities to join budget responsibility for these services with other sectors, like health, labour, long-term care insurance, accident insurance, pension etc. In order to come to a good coordination of services and costs there have to be adequate forms of planning procedures, where all relevant actors play their part - with respect to the person with disability concerned. This includes clarity about coordination functions. In countries where these processes are rather new many local authorities do not seem to have been prepared for this, adequate planning tools and planning procedures are not used or not used sufficiently. This fosters situations where institutionalisation is the only alternative that people with severe disability seem to have.

## **6.8 Recommendations**

Intersectoral collaboration refers to the promotion and co-ordination of the activities of different sectors for an inclusive development of communities in a way that puts the burden of coordination on the system without reducing users' control on their support arrangement.

For persons with severe disabilities, lack of cooperation between services from different sectors is not an abstract problem, but in many respects a very concrete challenge with a very high potential for discrimination. Caused by their often complex support needs, persons with severe disabilities are dependent on the social care system with its various levels, on the health care system, the education system, but also on various government authorities on different levels that are responsible for general public affairs such as traffic, employment, pension, housing or public security etc.

When people with severe disabilities – whether they are children or adults - are placed in institutions, mostly system responsibilities are clear and there is not much need for cooperation between service sectors or services from one sector. But in order to live a life 'as close to normality as possible' in mainstream community settings, using those services all people use, people with severe disabilities and their families are heavily depending on the ability and readiness of cooperation between the sectors and services involved. Lack

of intersectoral (and intrasectoral) cooperation between services in planning and allocation of resources due to missing experience and routines, inability or unwillingness can be one of the decisive discrimination factors, why people with severe disabilities are excluded from living a life in normal settings.

On this background a consistent non-discrimination policy for people with severe disabilities and complex support needs should consider cooperation between different services especially from different sectors of high importance. A strategy could consist of four elements:

### **1. Oblige intersectoral cooperation by law**

All organisations of the different sectors of the social security system act on the basis of a respective set of laws. In order to avoid that cooperation with services from other sectors is regarded as voluntary and in order to express a clear political will, governments should make sure that legal regulations for cooperation to support people with disabilities are existing. Where those are in place, it should be evaluated whether they are sufficient and effective also to support people with severe disabilities to live a life as 'usual' as possible.

### **2. Institutionalize cooperation by implementing planning structures**

Backed by a legal mandate, intersectoral cooperation a lieu on the local political level must have appropriate procedures and committee structures that are flexible and effective. On the level of the person with disability, cooperation is about joint assessment of needs and entitlements, elements of support arrangements, costs and service provision. It is necessary to develop a form of case-management with clear contact persons that put the burden of coordination on the 'system' without disrespecting user control of the support arrangement.

Beyond the level of the individual person with severe disabilities, cooperation needs a joint local planning framework with a clear mission for an inclusive community oriented towards the UN Convention on the Rights of Persons with Disabilities. Within a local participation planning approach principles of universal design should be lobbied and disability services should get a robust inclusive orientation.

### **3. Practice and learn cooperation**

Professionals from different service sectors or service fields often do not only come from different disciplines but also come from systems with different interests, priorities, procedures and different organizational cultures. In the cooperation, these differences have to be brought together in a consistent result which is to be a joint concept of a case situation of a person with severe disabilities or a planning initiative. As cooperation means giving and receiving, it has a high potential for conflict. In terms of winning and losing influence or under conditions of competing service providers in a care market, cooperation can easily be seen as a disadvantage and not as a 'win-win-situation'.

Also such experiences of managing conflicts should be seen as a learning process aiming at a better mutual understanding of the concept of disability and discriminating factors in the respective local environment.

#### **4. Make cooperation a routine and monitor it**

Cooperation can be regarded as successfully implemented when it has become a part of routines of the relevant actors involved. When planning processes are established and case management procedures are clear both for service professionals and people with disabilities and their families, there is still good reason to reflect systematically the quality of cooperation between services from different sectors. As an important indicator for a regular monitoring of cooperation it can be recommended to assess the quality of cooperation in transition processes of individual persons with severe disability and complex needs.

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

**www.non-discrimination.eu**

### **7. Annotated Bibliography**

**Coordinator:** Inclusion Europe – Galeries de la Toison d’Or – 29 Chaussée d’Ixelles #393/32 – B-1050 Brussels  
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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**



Author	Title	Source	Internet Source	Year	Summary
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ADICAE (Asociación de usuarios de bancos, cajas y seguros)	Informe en relación a la situación y problemas de valoración y jurídicos de las personas afectadas por daño cerebral	FISLEM (Fundación Socio-Sanitaria de Castilla-La Mancha por la Integración Socio-Laboral del Enfermo Mental)		2006	A practical guide, designed to serve as a legal working tool that should be used to give protection and adequate care to people affected by cerebral damage.
Alonso Seco, J, M <sup>a</sup> et al.	Políticas para la Discapacidad.	Real Patronato de Prevención y de Atención a Personas con Minusvalía. Madrid, España		1999	Comparative seminar about disabilities in Spain, Germany, France, United Kingdom and Sweden.
APF/CLAPEAHA	Enquête portant sur les besoins des enfants et des adultes atteints de handicaps complexes de grande dépendance ne pouvant se représenter eux-mêmes	Association des paralysés de France/Comité de liaison et d'actions des parents d'enfants et d'adultes atteints de handicaps associés, 2003, 128 p.		2003	The results of the survey show the consequences of the inadequacy between specific needs and lack of adapted structures. Results also show parents' concerns from childhood to adulthood, ageing and retirement and also as far as financial, social support, quality of life improvement are concerned.
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BARTHOLOME Christophe	Analyse transversale des études associatives portant sur les besoins des personnes handicapées et de leurs proches	Observatoire de l'accueil et de l'accompagnement de la personne handicapée du Conseil Consultatif de la COCOF, Bruxelles		2006	Transversal analysis of six studies of associations (polyhandicap, autism, intellectual disability, brain trauma, families). Guidelines for policy makers.
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BDF Newlife	Not too much to ask: Campaign Report		<a href="http://www.bdfnewlife.co.uk/docs/your_story/BDF_Report_NTMTA_legal.pdf">www.bdfnewlife.co.uk/docs/your_story/BDF_Report_NTMTA_legal.pdf</a>	2007	This campaign report outlines the difficulties many disabled children have in accessing equipment they need to protect them from injury or from their condition worsening, as well as to allow them to reach their full potential.
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Danielsson, Lennart; Liljeroth, Ingrid	Vägval och växande - specialpedagogiskt perspektiv ( Ways of choosing and growing - a special educational perspective)	Almqvist&Wiksell	<a href="http://www.liber.se">www.liber.se</a>	1996	To see the complex reality of the development of human beings and to get knowledge is the best fundament to work with persons with problems. All human beings are ruled by the same mechanism.

Author	Title	Source	Internet Source	Year	Summary
de Girolamo, Giovanni; Picardi, Angelo; Santone, Giovanni; Semisa, Domenico; Morosini Pierluigi for the National Group PROGRES	Le Strutture Residenziali e i loro ospiti: I risultati della fase 2 del progetto nazionale PROGRES	Il Pensiero Scientifico (Ed.), Roma, Italy		2004	"Residential Care Facilities and their Guests: the Results of Phase 2 of the National Project PROGRES" commissioned by the Ministry of Health) provides the most complete and detailed description realised in Italy of psychiatric Residential Care Facilities (Strutture Residenziali (SR) psichiatriche) and their guests. All the Italian regions, with the exception of Umbria, participated in Phase 2 for a total of 265 psychiatric SRs with approximately 3000 patients, a sample equal to 20% of those assessed in Phase 1, (described in de Girolamo et al., 2002; Gruppo Nazionale PROGRES, 2000) which assessed and provided a general description of 1.370 SRs with more than 4 beds in all the Regions of Italy.
Deckmar, Maud	<i>Freds bok</i> (Fred's book)	Ord och Tanke AB, Sweden	<a href="http://www.go.to/deckmar">www.go.to/deckmar</a>	2003	A mothers struggle during the growth of her son Fred, who has autism. The life of a family changed the day Fred was born - the first child in the family.
Defensor del pueblo	Daño cerebral sobrevenido en España. Un acercamiento epidemiológico y socio-sanitario.	Defensor del pueblo	<a href="http://www.defensordelpueblo.es">www.defensordelpueblo.es</a>	2006	A general study on the different aspects that are involved with the attention, recovery and integration of people with Happened Cerebral Damage in Spain
del Luca, Davide; Raffin, Cinzia; Capat, Odette	Dossier autismo: Dal dire al fare	Ed. S.E.Co.S., Pordenone, Italy		2004	"Autism Dossier: Betwixt Cup and Lip ... " is a publication on the quality of services in the treatment of autism and contains numerous data, surveys and a epidemiological study relative to the syndrome.
Deutsche Heilpädagogische Gesellschaft (ed)	Schwere Behinderung in Praxis und Theorie - ein Blick zurück nach vorn. Texte zur Körper- und Mehrfachbehindertenpädagogik	Düren, Germany		2004	This publication presents the contribution to a conference from scientist and service providers. Subjects of the conference were self-determination and participation of people with high support need.
DI DUCA Marco, BURNOTTE-ROBAYE Jocelyne	Récréation ouverte : guide pratique pour l'intégration des enfants en situation de handicap dans les activités de loisirs	APeCH asbl		2006	Affordable and simple guide for non-specialized people about leisure time integration of disabled children.
Dijk, Ineke van, Gendt, Corry van & Vink, Marjon	Looking Forward. Developments in Early Intervention for children with visual impairment Edited by:	Zeist: Bartimus	<a href="http://www.bartimus.nl">www.bartimus.nl</a>	?	Presents a picture of early intervention for children with visual impairment as provided by the three organisations for the visual impaired in the Netherlands: Bartiméus, Sensis and Visio. This book looks at the care recipient's perspective, the themes of assessment, treatment and support, and cooperation with other care services.
Dodan Mariana	Strategii de integrare si socializare a persoanelor cu handicap	I.N.P.C.E.S.P.H		1998	Methods and techniques related to the social inclusion of persons with handicap

Author	Title	Source	Internet Source	Year	Summary
Eglė Rimšaitė.	Residential care institutions: disciplinary society or social work institutes?	Sociology. Sociology. Thought and Action, 2006 2		2006	One of the most established forms of care for people with mental disabilities and mental illnesses in the former Soviet Union and in Central and Eastern Europe was treatment in large institutions – psycho neurological care homes. From one side, these institutions are integral part of social care systems and they pursue goals of social work: support integration, reduce social exclusion, and fulfill the clients' needs. From the other side, various scientists portray institutions of this type as totalitarian institutions where the living can be identified as mortification (Tobis 2000) or disciplinary society institutions (Foucault), criticize for violations of human rights and humiliation of human dignity. From the outlook of two confronting perspectives, the following article discusses the main mission of these institutions: promote integration to society by supplying social services or aggravate social exclusion by limiting their rights, possibilities and right to privacy
Emerson, E.	Poverty and People with Intellectual Disabilities	Mental Retardation and Developmental Disabilities Research Reviews 13, 107-113		2003	This review outlines the consistent reporting in a number of studies of an association between poverty and intellectual disability. It explores the underlying reasons for this association.
Equipo Plan de Calidad FEAPS	Manuales de Buenas Prácticas de FEAPS: Ocio en la Comunidad	FEAPS	<a href="http://gw.feaps.org/feaps/manuales_bb_pp/ocio.pdf">http://gw.feaps.org/feaps/manuales_bb_pp/ocio.pdf</a>	2000	Advice on how to provide support for leisure in the community to people with mental disabilities and to their families according to their demands, needs and expectations and about how to organize the services to carry out that objective.
Equipo Plan de Calidad FEAPS	Manuales de Buenas Prácticas de FEAPS: Atención de día	FEAPS	<a href="http://gw.feaps.org/feaps/manuales_bb_pp/atencion_dia.pdf">http://gw.feaps.org/feaps/manuales_bb_pp/atencion_dia.pdf</a>	2000	
Equipo Plan de Calidad FEAPS	Manuales de Buenas Prácticas de FEAPS: Vivienda y Residencia para personas con retraso mental	FEAPS	<a href="http://gw.feaps.org/feaps/manuales_bb_pp/vivienda.pdf">http://gw.feaps.org/feaps/manuales_bb_pp/vivienda.pdf</a>	2001	Advice on how to provide support at home and in residential care for people with mental disabilities and to their families according to their demands, needs and expectations and about how to organize the services to carry out that objective.
Equipo Técnico Inmerso	El Libro Blanco de la Dependencia.	Secretaría de Estado de Servicios Sociales, Familia y Discapacidad del Ministerio de Trabajo y Asuntos Sociales, España	<a href="http://www.seg-social.es/inmerso/dependencia/may_libro_blanco.html">http://www.seg-social.es/inmerso/dependencia/may_libro_blanco.html</a>	2005	A diagnosis of the situation of dependent people in Spain, those that cannot carry out basic tasks of daily life by themselves, mostly elder people and people with disabilities
Eriksson-Dobrovich, Ia (ed)	Learning Outdoors - Handbook for adults with mental disabilities	Uppsala, Sweden	<a href="http://www.limproject.org">www.limproject.org</a>	2007	To be out of doors, leaving your house, apartment, school or work place for a visit in the open air is natural to anyone. The aim of this handbook is to give ideas, hints and guidelines how to work with outdoor learning for people with intellectual or mental disabilities. The book is one of the results of the Learning in Motion-project run by seven different organizations from five European countries. Our vision is: To improve life quality for the target group through Outdoor Education.
Faivre, H., Meeus, N., Menzel, E., Parent, A.	Los marginados entre los marginados. Personas con discapacidades de gran dependencia	Foro Europeo de Personas con Discapacidades, Bruselas, Bélgica	<a href="http://www.edf-feph.org">http://www.edf-feph.org</a>	2000	The objective of this book is to stimulate action and dialogue at National and European level regarding the rights of people with disabilities and great dependence who cannot defend their own interests: right to citizenship, physical integrity, representation, opportunities and quality of life.

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Firkowska-Mankiewicz, A.; Szeroczyńska, M.	Paktyka ubezwłasnowolnienia osób z niepełnosprawnością intelektualną w polskich sądach. Raport z badań.	Journal - Człowiek-Niepełnosprawność-Spółeczeństwo (Person-Disability-Society), 2, p. 87-118	<a href="http://www.aps.edu.pl/pliki/1174039858.pdf">http://www.aps.edu.pl/pliki/1174039858.pdf</a>	2005	This report presents the findings of the research into legal incapacitation of people with intellectual disabilities in Poland. As part of the research, 393 court records were analysed which had been registered in six district courts. The findings prove far-reaching irregularities in using incapacitation in Poland.
Föreningen JAG	<i>Utan dig kan jag inte smaka på snön</i> (Without you I cannot taste the snow)	Föreningen JAG	<a href="http://www.jag.se">www.jag.se</a>	2005	25 persons each have written about persons in need of personal assistance and the everyday life. The relationship between the persons with severe disability and the assistants is described in a wonderful way with human warmth and humour.
Freyhoff, Geert; Parker, Camilla; Coué, Magli; Greig, Nancy (ed.)	Included in Society. Results and Recommendations of the European Research Initiative on Community-Based Residential Alternatives for Disabled People	Brussels, Belgium	<a href="http://www.community-living.inf">www.community-living.inf</a>	2004	This publication is a result of the project "Included in Society" aiming at analyzing the conditions in and prevalence of large residential institutions for disabled people in Europe. The participating organisations and universities collected information on the living conditions in large residential institutions in 25 European countries. This is the basis for policy recommendations addressing the need for more community based services for disabled people.
Freyhoff, Geert; Parker, Camilla; Coué, Magli; Greig, Nancy (ed.)	Included in Society. Results and Recommendations of the European Research Initiative on Community-Based Residential Alternatives for Disabled People	Brussels, Belgium	<a href="http://www.community-living.inf">www.community-living.inf</a>	2004	This publication is a result of the project "Included in Society" aiming at analyzing the conditions in and prevalence of large residential institutions for disabled people in Europe. The participating organisations and universities collected information on the living conditions in large residential institutions in 25 European countries. This is the basis for policy recommendations addressing the need for more community based services for disabled people.
Freyhoff, Geert; Parker, Camilla; Coué, Magli; Greig, Nancy (ed.)	Included in Society. Results and Recommendations of the European Research Initiative on Community-Based Residential Alternatives for Disabled People	Brussels, Belgium	<a href="http://www.community-living.inf">www.community-living.inf</a>	2004	This publication is a result of the project "Included in Society" aiming at analyzing the conditions in and prevalence of large residential institutions for disabled people in Europe. The participating organisations and universities collected information on the living conditions in large residential institutions in 25 European countries. This is the basis for policy recommendations addressing the need for more community based services for disabled people.
Fridlind, Eva-Stina; Johansson, Elaine; Liljeroth, Ingrid; Åkerlund, Anna-Lena	<i>Eldorado för personer med grav utvecklingsstörning - Aktivitet&amp;Kultur&amp;Kunskap</i> (Eldorado for persons with profound intellectual disability - Activity&Culture&Knowledge)	Göteborgs Stad Centrum, Eldorado/Handikapp institutet	<a href="http://www.eldorado.goteborg.se">www.eldorado.goteborg.se</a>	1998	Eldorado is an activity-, educational and cultural centre for persons with profound intellectual and multiple disabilities. This book is an evaluation of the activities. The purpose has been to increase the understanding of the complex situations Eldorado is working in. We are struggling to see the overall picture of the services and to study the processes.
Fröhlich, Andreas; Heinen, Norbert; Lamers, Wolfgang (Eds.)		Düsseldorf, Germany		2001	This publication presents an overview of educational and therapeutic concepts for people with complex needs which have essentially influenced the German practice in different life-domains.
Furenhed, Ragnar	<i>En gåtfull verklighet</i> (A puzzling reality)	Carlsson Bokförlag	<a href="http://www.carlssonbokforlag.se">www.carlssonbokforlag.se</a>	1997	How do people with severe and profound intellectual disability experience their lives? Do we have any possibility to understand or communicate with persons who miss spoken language? In this book these questions are in focus. From interviews with parents and staff a picture of our knowledge about these persons become visible.



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Gadner, J.F. and Nudler, S.	Quality Performance in Human Services. Leaderships, values and vision.	Paul Brookes Publishing Co. Baltimore, Maryland		1998	This book shows human services directors, managers and staff how to implement a leadership model that is person centered and performance driven. It offers effective strategies for raising the level of quality in the contemporary workplace by linking the critical elements of leadership, values and vision.
Gerland, Gunilla	A Real Person - Life on the outside	Souvenir Press Ltd, London, Great Britain		1997	From the earliest years Gunilla Gerland knew that she was different. In this remarkable book she writes with poignant clarity of a childhood in which, surrounded by her family, she was nevertheless alone.
Germanavičius, Arūnas; Pūras, Dainius; Rimšaitė, Eglė; Juodkaitė, Dovilė; Leimane – Veldmežere, Ieva; Pilt, Eve	Human Rights in Mental Health Care in Baltic Countries		<a href="http://www.gip-vilnius.lt/leidiniai_angl/HRinMentalHealthCare.html">http://www.gip-vilnius.lt/leidiniai_angl/HRinMentalHealthCare.html</a>	2006	The policy paper gives an overview of current developments in mental health care policy in all three Baltic countries and provides recommendations to move services toward the norm of least restrictive care and community-based services and away from institutions. Recommendations are geared to governments, institutions in the countries addressed, national and international human rights advocates, and private and public donors. The text serves as a source of information for program planners, an advocacy guide for human rights organizations, and guidance for funds allocation for governments and donors.
Germanavičius, Arūnas; Pūras, Dainius; Šakalienė, Dovilė; Rimšaitė, Eglė; Mališauskaitė, Lina; Povilaitis, Robertas.	Human rights monitoring in residential institutions for mentally disabled and psychiatric hospitals		<a href="http://www.gip-vilnius.lt/leidiniai/human_rights_monitoring_report.pdf">http://www.gip-vilnius.lt/leidiniai/human_rights_monitoring_report.pdf</a>	2005	Recurrent cases of inappropriate treatment and patient abuse clearly demonstrate the ineffectiveness of psychiatric hospitals and especially residential institutions for the mentally disabled. Both the geographic remoteness of residential institutions for the mentally disabled and the Professional isolation of their staff create closed communities with their own culture of disrespecting human dignity and human rights, a problem which is compounded by the absence of adequate monitoring and supervision.
Geus, R.	Persoonsgerichte planning en active support. Een begeleidingsmethodiek voor mensen met een ernstige verstandelijke beperking	Utrecht: NGBZ/NIZW Zorg	<a href="http://www.vialns.nl">www.vialns.nl</a>	2006	Description of a method of supporting for people with severe intellectual disabilities.
Gillberg C; Cederlund M; Lamberg K; Zeijlon L	The Autism Epidemic	Journal of Autism and Developmental Disorders, 36:429-35		2006	Brief Report: The registered prevalence of autism in a Swedish urban area
Gohet, Patrick	Bilan de la mise en œuvre de la loi du 11 février 2005 et de la mise en place des Maisons départementales des personnes handicapées	Ministère du travail, des relations sociales et de la solidarité, 2007, 96 p.	<a href="http://www.travail-solidarite.gouv.fr/IMG/pdf/RAPPORT_GOHET_-_AOUT_07.pdf">http://www.travail-solidarite.gouv.fr/IMG/pdf/RAPPORT_GOHET_-_AOUT_07.pdf</a>	2007	The necessity to realise a real project of living according to the main principles of disability policies are stressed here around four points: education; employment; accessibility; local houses for people with disabilities. A real "cultural and institutional revolution" is on the move.
Gohet, Patrick; Paraton, G; Boyer Marianne et al.	Les vacances des personnes lourdement handicapées et de leurs familles	Cahier du temps libre et de la créativité, 1996, No. 27, pp. 33-35		1996	This review of different holidays schedules for severely dependent persons is following by three studies discussing and analysing holidays conditions and solutions for severely dependent persons and they families.
GOODE David, MAGEROTTE Ghislain, LEBLANC Raymond	Qualité de vie pour les personnes présentant un handicap : perspectives internationales	Editions De Boeck Université, Bruxelles		1999	Policy perspectives from 10 countries about quality of life for disabled people with intellectual disabilities: household, employment, school, leisure, etc. Theoretical and practical approaches.

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Göransson, Kerstin	<i>De liknade varandra men inte mer än andra - Begåvningshandikapp och interpersonellt samspel</i> (They looked alike, but no more than others do - Intellectual disability and interpersonal interaction)	HLS Förlag	<a href="http://www.hlsforlag.se">www.hlsforlag.se</a>	1995	The purpose is to develop a model for analysing interpersonal interaction. Thereafter, based on the foundation of this model, construct an analysis of research as well as content and methodological analysis. The model of interaction is developed from a structuralistic perspective. Scientific results indicate that the intellectual factor is not influenced on the way people interact. Scientific results also show that persons with intellectual disability probably have a deviant way of communicating with others.
Grupo de Atención Temprana. (GAT)	El libro Blanco de Atención Temprana	Real Patronato de Prevención y de Atención a Personas con Minusvalía. Madrid, Spain	<a href="http://www.minusval2000.com/investigacion/libroBlancoAtencionTemprana/LibroBlancoAtencionTemprana.htm">www.minusval2000.com/investigacion/libroBlancoAtencionTemprana/LibroBlancoAtencionTemprana.htm</a> - 7k -	2000	This document intends be a reference for public administrations, professionals, associations and families that is designe to help the institutional incoordination and solve organizational and resource deficiencies.
Gruppo Solidarietà	Handicap - Servizi - Qualità della Vita	Castelplanio (AN), Italy	<a href="http://www.grusol.it/Pubblica.asp">http://www.grusol.it/Pubblica.asp</a>	2001	"Disability - Services - Quality of Life" is a rielaboration of the papers presented at the Gruppo Solidarietà seminars held in October-November 2000 on the theme 'Quality Processes in Services for Adults with Severe Intellectual Disability and Community Homes for the Disabled: Models and Experiences'. Part 1 proposes reflections and processes in situations of severe intellectual disability. Too often services discard individualised rehabilitation and educational actions to propose container services fwchich lack any reference to quality of life and the social context in which the personl ives. Part 2 tackles the issue of residential care provision. The realisation of small community homes is still far from being normal practice and institutional care is still the dominant form of provision. The papers present examples of processes using community home models in regular social contexts which respond to the primary need of every person to live in an ambient based on the family model.
Gruppo Solidarietà	Handicap Grave: Autonomia e Vita Indipendente	Castelplanio (AN), Italy	<a href="http://www.grusol.it/Pubblica.asp">http://www.grusol.it/Pubblica.asp</a>	2002	"Severe Disability: Autonomy and Independent Living" is a collection of contributions from the Gruppo Solidarietà seminar of November 2001 on 'Severe Disability: Local Programming of Services from Needs to Provision'. In particular, the publication explores the possibility of monetary contributions becoming an integral part of support programmes for persons with a physical disability, and for families, in the case of persons with intellectual disability.
Gruppo Solidarietà	Dalla riforma dei servizi sociali ai livelli essenziali di assistenza: Una lettura nella prospettiva dei più deboli	Castelplanio (AN), Italy	<a href="http://www.grusol.it/Pubblica.asp">http://www.grusol.it/Pubblica.asp</a>	2002	"From the Reform of Social Care Services to Essential Levels of Care: a Reading from the Perspective of the Most Vulnerable" retraces the debate which led to the approval of Law 328/2000 (Reform of Social Care Services) and analyses the situation developing within the so-called health and social care services after the issuing of the Directions on the Integration of Health and Social Care and the Decree on the Essential Levels of Health Care. This reading aims to offer instruments for further investigation and reflection for anyone involved with services (providers, users, voluntary workers).



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Gruppo Solidarietà	Politiche e servizi sociosanitari. Esigenze e diritti	Castelplanio (AN), Italy	<a href="http://www.grusol.it/Pubblica.asp">http://www.grusol.it/Pubblica.asp</a>	2005	"Social Policy and Health and Social Care Services: Requirements and Rights" reflects on institutional competencies, planning, management and service ownership but, above all, attempts to understand how organisational structures and modes of provision respond to the urgent requirements of users. Requirements which, however pressing, risk remaining unsatisfied if they cannot be transformed into rights or, as too often happens, become denied rights when they are declassified to simple needs.
Gruppo Solidarietà	Disabilità. Dalla scuola al lavoro	Castelplanio (AN), Italy	<a href="http://www.grusol.it/Pubblica.asp">http://www.grusol.it/Pubblica.asp</a>	2006	"Disability. From School to Work" is a collection of articles which outline a process which sees the person, with their possibilities and potentiality, at the centre. No-one should ever be defined exclusively for what they do not know, what they cannot do or what they are not ... . It should not be the absence of something which distinguishes a personal profile but rather the capacity to feel, to communicate, to act and to think in a particular personal way. To accept the fact that a person with a disability is above all a person means to concentrate on their need for normality, rather than on the stereotypical needs of a generic category.
Guvernul Romaniei	Strategia nationala pentru protectia, integrarea si incluziunea sociala a persoanelor cu handicap in perioada 2006-2013 - Sanse egale pentru persoanele cu handicap - catre o societate fara discriminari	ANPH	<a href="http://www.anph.ro">www.anph.ro</a>	2005	Government Policies and strategic lines for 2006-2013 in order to insure the protection and the social inclusion of people with handicap
HAELEWYCK Marie-Claire, ALLARD Béatrice	Budget d'assistance personnelle. Recherche action sur la mise en application d'un système de financement direct de l'aide aux personnes en situation de handicap. Rapport final	Université de Mons-Hainaut		2005	First results of the action-study financed by the Health, Social Action and Equal Opportunity Ministry of the Walloon Region about personal budgets. How to assess needs and resources, practical proposals.
Hahn, Martin Th.; Fischer, Ute; Klingmüller, Bernhard; Lindmeier, Christian; Reimann, Bernd; Richardt, Michael; Seifert, Monika (Eds.)	„Warum sollen sie nicht mit uns leben?“ Stadtteilintegriertes Wohnen von Erwachsenen mit schwerer geistiger Behinderung und ihre Situation in Wohnheimen. Zusammenfassende Gesamtdarstellung des Projektes WISTA, Teile I – IV.	Reutlingen, Germany		2004	This publication presents the results of an research project on community-based living of adults with complex needs in Berlin. The focus lies on the development of these people, the situation of the staff, the material and social environment, the role of parents.

Author	Title	Source	Internet Source	Year	Summary
Heywood, F and Turner, L.	Better outcomes, lower costs: Implications for health and social care budgets of investment in housing adaptations, improvements and equipment: a review of the evidence.		<a href="http://www.officefordisability.gov.uk/docs/better_outcomes_report.pdf">www.officefordisability.gov.uk/docs/better_outcomes_report.pdf</a>	2007	This review of evidence considers the costs and benefits of residential provision for people with severe disabilities compared to providing adaptations and support for these people to continue living in their own homes in the community. Findings suggest that adaptations and support at home save costs in relation to residential provision and home care without adaptations. In addition a number of associated benefits are described for the individual and cost savings for funders related to prevention of accidents and other health issues.
Hinz, Andreas (Ed.)	Schwere Mehrfachbehinderung und Integration: Herausforderungen, Erfahrungen, Perspektiven	Marburg, Germany		2007	This publication presents an overview of concepts and experiences with integration of people with complex needs in different life-domains, especially in school.
Hvinden, Bjorn; Halvorsen	Which way for european disability policy?	Scandinavian Journal of Disability Research, Volume 5, No. 3-2003,pp. 296-312		2003	In the article the authors discuss the challenges facing European disability policy and in what direction it is likely to move in the years to come.
IGZ (Health Care Inspectorate)	Verantwoorde zorg voor gehandicapten onder druk. Toets op risico's in de 24-uurszorg voor mensen met een verstandelijke beperking 2006-2007.	Den Haag: IGZ	<a href="http://www.igz.nl">www.igz.nl</a>	2007	Results of a study aiming to obtain an insight into risks and potential improvements in providing care and services in this field, to determine the steps needed for improvements, to identify risky care and to drive the further development of quality levels for care for the handicapped.
IMP 140 (Belgique), AIRe (France)	Jeunes en difficultés psychologiques : penser, parler, agir en Europe	Editions Champ Social		2003	In Belgium, like in several other european countries, working with young people with behaviour problems is included in policies for disabled people. However, their reality concern all fields : justice, psychiatry, social field, education...
Inclusion Europe	Equal Rights for all! Access to rights and justice for people with intellectual disabilities	Inclusion Europe	<a href="http://www.inclusion-europe.org/publications.htm">www.inclusion-europe.org/publications.htm</a>	2005	This report presents difficulties in access to rights and justice for people with intellectual disabilities in all EU Mebers States. It outlines also some principles that cover the most important aspects of legal capacity, legal assistance, legal protection and representasion of adult with intellectual disabilities.
Inclusion Europe	Poverty and Intellectual Disability in Europe	Inclusion Europe	<a href="http://www.inclusion-europe.org/publications.htm">www.inclusion-europe.org/publications.htm</a>	2005	This report provides an overview of the situation of persons with intellectual disabilities and their families in Europe with respects to aspect of poverty and social exclusion. It also includes some necessary measures and policy recommendations.
Inland Revenue Office	Guida alle agevolazioni fiscali per i disabili - aggiornata con la legge finanziaria 2007	Rome, Italy	<a href="http://www.agenziaentrate.gov.it">www.agenziaentrate.gov.it</a>	2007	Guide to VAT reductions and tax concessions for persons with disabilities and the families of dependent persons with disabilities. Published annually by the Italian Inland Revenue office. Tax concessions vary according to the type of disability and can be a percentage or total deduction on tax returns .
ISS - Higher Institute of Istituto Superiore di Sanità - Centro Nazionale di Epidemiologia, Sorveglianza e Promozione della Salute	Progetto Nazionale Salute Mentale	Rome, Italy	<a href="http://www.epicentro.iss.it/problemi/mentali/iss.asp">http://www.epicentro.iss.it/problemi/mentali/iss.asp</a>	2001	"National Mental Health Project" for the promotion of large-scale research in the mental health field and is characterised in particular by its training initiatives and actions of support for the diffusion of evidence-based intervention, the promotion of multicentric research projects, evaluation instruments and manuals, as well as the publication of the scientific results of research.

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ISTAT	L'integrazione sociale delle persone con disabilità	Rome, Italy	<a href="http://www.istat.it/salastampa/comunicati/non_calendario/20050704_00/">http://www.istat.it/salastampa/comunicati/non_calendario/20050704_00/</a>	Year of reference: 2004, published 2005	The Social Inclusion of Persons with Disabilities' is a survey carried out by ISTAT in 2004 in relation to persons with disabilities living with their families and investigates inclusion in their social context and the factors hindering their inclusion. A total of 1632 persons with a disability between the ages of 4 and 67 years (and therefore excluding the aged) were interviewed telephonically, representing a population of 1641000 persons of the same age range.
ISTAT (National Statistics Institute) & Ministry for Social Solidarity (Welfare)	Diabilitaincifre - Il sistema di informazione statistica sulla disabilità		<a href="http://www.disabilitaincifre.it/">http://www.disabilitaincifre.it/</a>		Web site of the Italian Disability Statistics Information System. It contains two main areas - Themes and Analysis - and provides information and data on social security, families of disabled persons, accidents, education and inclusion, work and occupation, health, health and social care, transport and social life. It comprises data sources, a glossary of terms, guidelines, research summaries, explanatory texts in the area of disability and disability policies.
Jiménez Lara, A. y Huete García, A.	La Discriminación por motivos de Discapacidad	CERMI	<a href="http://www.famma.org/interes/informe_discrimina.doc">http://www.famma.org/interes/informe_discrimina.doc</a>	2002	This document is an analysis of the answers to a questionnaire undertaken by The Spanish National Council of Disabled Representatives(CERMI) among the associations of the sector, to gather information about the discrimination that people with disabilities suffer in different fields.
Jonas Ruškus	Handicap as a Social-Cultural Construct: a Problem of Attitudes	Journal "Social Sciences", Kaunas Technical University, 1999 20(3)	not available	1999	The problem of the attitudes toward handicapped people is analysed from theoretical aspect. Many social and changes in values in Lithuanian society during the past decade gave birth to the paradigm's dilemma in social integration and special education of handicapped people. In this context, the attitudes of the society and of the educational community towards handicapped people, the significance of their integration and education are discussed. From this point of view some problem areas came to light: 1) What theoretical model grounds the conception of social integration and special education of handicapped people? 2) What is the impact of the social representations and attitudes on the conceptual ground of social integration and special education? 3)Collision of what paradigms of social integration and special education is going on in Lithuania today? The collision of two approaches, traditional clinical and modern interactional, is observed in special education in Lithuania. The author of this article conveys the approach of symbolic interactional theory on the handicap situation. Some of reciprocal
Jonas Ruškus, Gintautas Mazeikis	Disability and Social Participation.	Šiauliai University Press	not available	2007	The book presents theoretical discourses, practical experiences, facts and arguments that indicate that social participation is a perennial concept, capable of becoming a breakthrough, or methodology for creating new opportunities in disability situations. Persons with disability and their family's social participation is a reflected conflict of interests roused process, inferring participants mutual understanding and equal involvement in the construction of an empowering project, the social identity of persons with disability and the strengthening of roles in developing the individualization of persons with disability, realization of their qualities and in terms of maximizing their potential.

Author	Title	Source	Internet Source	Year	Summary
Juodkaite, Dovile	Lithuanian Mental Health Policy: Shifting from Deinstitutionalization Towards Community Integration			2005	This publication analyzes Lithuanian legislation and government policy on mental health and social care systems, describes current situation of people with mental disabilities and the barriers they face in exercising their fundamental rights to community integration, safe and proper living conditions within the community.
Juodkaite, Dovile; Gečaitė, Klementina	Rights of People with Intellectual Disabilities in Lithuania	EU monitoring and advocacy	<a href="http://www.viltis.lt/leidiniai/book/id_angliskas.pdf">http://www.viltis.lt/leidiniai/book/id_angliskas.pdf</a>	2005	This report is one of a series of 14 country reports prepared by the Open Society Institute's EU Monitoring and Advocacy Program and the Open Society Mental Health Initiative. The report presents an overview of the opportunities and challenges facing people with intellectual disabilities in accessing education and employment. It provides an important contribution to research on this group, one of the most vulnerable groups throughout Europe.
Kaszyński, H.	Osoby chore psychicznie jako grupa beneficjentów organizacji pozarządowych świadczących usługi na rynku pracy	Polish-American Freedom Foundation	<a href="http://www.fise.org.pl">www.fise.org.pl</a>	2006	This study tries to make diagnosis of the particular situation of people with mental health disorders on the labour market in Poland. It presents also some examples of good practices and recommendations.
Kistner, Hein	Arbeit und Bewegung. Entwicklungsfördernde Arbeit für Menschen mit schweren Behinderungen	Düsseldorf, Germany		2005	This publication presents the results of the project "Right to work for people with complex needs" which took place in an anthroposophical institution. In this project specific working places for people with intellectual disabilities an severe challenging behavior were developed.
Klauß, Theo; Lamers, Wolfgang (Eds.)	Alle Kinder alles lehren... Grundlagen der Pädagogik für Menschen mit schwerer und mehrfacher Behinderung	Heidelberg, Germany		2003	This publication presents the contributions to an international conference from scientists and teachers. Subject of the conference was the education of children and young persons with complex needs in school. The focus of this book lies on theoretical conceptual approaches in different countries.
Kościelska, M	Niechciana seksualność. O ludzkich potrzebach osób niepełnosprawnych intelektualnie.	Jacek Santorski PRESS	no available	2003	This book presents stereotypes and attitudes towards the sexuality of persons with intellectual disabilities in Poland. It includes also interviews with persons with intellectual disabilities and shows their various problems and needs in this area.
Laima Mikulenaite	Children Autism at the Early Age	Society "Viltis"	not available	2004	This book contains information about the symptoms of autism, because early diagnostics and intervention is especially important for further development of the child and wellbeing of his family.
Lamers, Wolfgang; Klauß, Theo (Eds.)	...alle Kinder alles lehren! - Aber wie? Theoriegeleitete Praxis bei schwer- und mehrfachbehinderten Menschen	Düsseldorf, Germany		2003	This publication presents the contributions to an international conference from scientists and teachers. Subject of the conference was the education of children and young persons with complex needs. The focus of this book lies on concepts and experiences in school.
Le Clainche, Christine; Demuijnck, Geert	Handicap et accès à l'emploi: efficacité et limite de la discrimination positive	Centre d'études de l'emploi-CEE, Noisy-le-grand, 2006, No. 63. 31 p.		2006	This article shows the existence of discrimination toward people with disabilities in employment and analyses social opinion related to disability and access to employment through two social surveys.
Leigemann, Reinhard	Arbeit ist möglich! Arbeitshilfen und Arbeitsplätze für Menschen mit schweren Behinderungen	Düsseldorf, Germany		1996	This publication presents a documentation of working places and examples for specific kinds of support for people with complex needs in sheltered workshops.

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Malisauskaite, Lina	EU, Human rights in Europe		<a href="http://www.viltis.lt/leidiniai/book/detail.php?ID=4355">http://www.viltis.lt/leidiniai/book/detail.php?ID=4355</a>	2006	This publication provides main information about the structure of the EU, its main institutions. It also describes human rights guaranteed for everybody in the EU despite of their age, race, gender, other political social or economical factors. Information is also provided in easy-to-read language.
Mansell, Jim; Ericsson, Kent (ed.)	Deinstitutionalization and Community Living. Intellectual Disability services in Britain, Scandinavia and the USA	Chapman & Hall, London		1996	The number of people in institutions for the intellectually disabled has fallen markedly over the last 25 years. This book reviews the changes that have taken place, identifies the lessons that have been learned and highlights the issues that remain to be obtained.
MDAC	Guardianship and Human Rights in the Czech Republic	Budapest, Hungary	<a href="http://www.mdac.info/projects/guardian.html">http://www.mdac.info/projects/guardian.html</a>	2006	The document analyses existing guardianship arrangements for adults who have been adjudged to have reduced capacity to make personal and financial decisions. Shortcomings of the current legal guardianship instruments are highlighted and recommendations offered.
MENCAP	Death by indifference		<a href="http://www.mencap.org.uk/html/campaigns/deathbyindifference/reports.asp">www.mencap.org.uk/html/campaigns/deathbyindifference/reports.asp</a>	2007	This publication uses six case studies to highlight discrimination against people with severe learning disabilities in the healthcare system that arguably led directly to their death.
MERCIER Michel	L'identité handicapée	Presses universitaires de Namur		2004	Study about the identity of disabled people. Results from research in several fields: re-education, employment, emotional and sexual life, discrimination, trauma, etc.
Mihaela Sterian, Anca Rozorea, Corina Ogrezeanu, Catalin Bucinschi	Operationalizarea Clasificarii Internationale a Functionalitatii si Dizabilitatii - Un prim pas	I.N.P.C.E.S.P.H		2004	Explanation on ICF - concepts and practical issues. Recommendations for application in Romania.
Milenaar, Ton	Experiences of Caretakers with their Special Children Living Together in the Community in Japan and the Netherlands	Own Edition		2007	Comparative research between Netherlands and Japan regarding the care and support to people with special needs.
Ministry for Employment and Social Affairs	Libro Bianco sul Welfare - Proposte per una società dinamica e solidale	Rome, Italy	<a href="http://www.annoedisabili.it/documenti.html">http://www.annoedisabili.it/documenti.html</a>	2003	The 'White Paper on Welfare' represents a snapshot of the welfare state in Italy and defines Welfare priorities: services and fiscal justice for families, support in extreme poverty, actions in favour of the non self-sufficient, greater protection and evaluation of disability and, in particular, new policies to overcome the demographic problem. A novelty lies in the fact that the traditional family model (married couples) are placed at the centre of the social security system.
Ministry of Finance & Ministry of Education	Quaderno Bianco sulla Scuola - una scuola di qualità per tutti	Rome, Italy	<a href="http://www.invalsi.it/invalsi/com_stampa.htm">http://www.invalsi.it/invalsi/com_stampa.htm</a>	2007	"White Paper on Schools: Schools of Quality for All" investigates the situation in Italian schools and identifies their strong and weak points. It outlines scenarios for development and identifies possible solutions. The establishment of an evaluation system, centred on the INVALSI (National Institute for the Evaluation of the Educational System in Mainstream Education and Vocational Training) is considered an indispensable basis for a stable process to improve the quality of schools.

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Ministry of Health	Piano Sanitario Nazionale 2006 - 2008	Italy	<a href="http://www.ministerosalute.it/publicazioni/ppRisultatiPSN.jsp">http://www.ministerosalute.it/publicazioni/ppRisultatiPSN.jsp</a>	2006	The National Health Plan 2006-2008 first examines the scenarios which will strongly characterise the Italian healthcare system in the next 3-5 years in terms of opportunities and constraints. It considers contextual elements in relation to the economic, demographic and epidemiological situation, and scientific and technological development. Finally, the elements which characterise the current institutional phase (Federalism in Healthcare) and the preceding cycles of the National and Regional Health Plans are taken into account in relation to the new national Plan. Of particular interest for the area of disability, Objectives 5.3 - Non Self-sufficiency: the Aged and the Disabled, and 5.4 - Protection of Mental Health.
Ministry of Health	Relazione sullo stato sanitario del paese 2003 - 2004	Italy	<a href="http://www.ministerosalute.it/publicazioni/ppRisultatiRSSP.jsp">http://www.ministerosalute.it/publicazioni/ppRisultatiRSSP.jsp</a>	2006	Report on the State of Health of the Country (Italy) 2003 - 2004
Ministry of Health, Welfare and Sport	Disabled People	<a href="http://www.minvws.nl/en/themes/disabled_people/">http://www.minvws.nl/en/themes/disabled_people/</a>	see source	2007	Description of the principal foundation of Dutch government's policy on people with a physical, mental or sensory disability. The reader can go his way further through themes.
Mo Gårdgruppen	<i>Inte riktigt som andra Livet sett med dövblinda ögon - som ung, som vuxen och som förälder</i> (Not quite like others. Life through the eyes of death-blind persons - being young, being an adult and being a parent)	Mo Gårds tryckeri, Finspång	<a href="http://www.mogard.se">www.mogard.se</a>	2006	This book is about children and young persons with sight and hearing impairments, death-blindness. This book is for people meeting persons with death-blindness professionally or privately - parents and other relatives, teachers, nursing staff and persons who are death-blind.
Mo Gårdgruppen	<i>Barn med dövblindhet</i> (Children with deathblindness)	Mo Gårds tryckeri, Finspång	<a href="http://www.mogard.se">www.mogard.se</a>	2004	"The biggest sorrow in life is not that my child has a deathblindness but the struggle against the authorities" was said by parents participating in the Nordic conference for parents with children with deathblindness in May 2004. This book can be a guidance for professionals meeting parents having children with severe disabilities.
MOBILE - Selbstbestimmt Leben Behinderter e.V. (ed.)	Handbuch Selbstbestimmt Leben mit Persönlicher Assistenz. Ein Schulungskonzept für AssistenznehmerInnen	München, Germany		2001	This book is a guideline to independent living with self-employed staff especially for people with high support need. It is written by activist of the disability rights movement and give a very good overview about the history and reality of independent living in Germany as well as information related to the legal possibilities for independent living.
Moerberbeek, Jozien	The strength of simplicity. The story of the development of the Very Intensive Care - Workhomes	ASVZ group	<a href="http://www.asvz.nl">www.asvz.nl</a>	2004	Description of the method of the Very Intensive Care (VIC) – Workhomes and the vision behind it.
Nuffield Council on Bioethics	Critical care decisions in fetal and neonatal medicine: ethical issues		<a href="http://www.nuffieldbioethics.org/fileLibrary/pdf/CCD_web_version_22_June_07_(updated).pdf">www.nuffieldbioethics.org/fileLibrary/pdf/CCD_web_version_22_June_07_(updated).pdf</a>	Nov 06	This report outlines the results of a series of discussions undertaken with stakeholders on a number of ethical questions regarding decisions to provide or withhold medical treatment for babies who have life threatening conditions and/or are expected to have severe disabilities.
NVA ( Dutch Society for Autism ) et al	Convenant Autisme. Op weg naar geïntegreerde zorg voor alle mensen met autisme in Nederland	Bilthoven: NVA	<a href="http://www.autisme-nva.nl">www.autisme-nva.nl</a>	2007	The Autism Covenant aims, from a coherent and collective approach by the partner organisations, to improve the care and support to people with autism.



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Open Society Institut	Drepturile persoanelor cu dizabilitati intelectuale. Accesul la educatie si angajare. Raport monitorizare - Romania 2005	Open Society Institut		2005	The report reveals significant discrepancies between law and practice in Romania in two sector: education and labor market. Related to the specific situation of people with intellectual disabilities.
OSI/EUMAP	Rights of People with Intellectual Disabilities. Access to Education and Employment. Poland	Open Society Institute/EU Monitoring and Advocacy Program	<a href="http://www.eumap.org">www.eumap.org</a>	2005	This report is one of a series of country reports prepared by the EU Monitoring and Advocacy Program and the Open Society Mental Health Initiative. The report presents an overview of the opportunities and challenges facing people with intellectual disabilities in accessing education and employment in Poland.
Pérez Bueno, L.C.	1º Plan Integral de Acción para mujeres con discapacidad 2005-2008	CERMI		2005	An instrument of planning for the different responsible organisations which guarantee equal rights to girls, and young and older women with disabilities in Spain. It is an integral plan that gathers proposals from different environments of competency for a great number of areas or type of disabilities.
Perrard,Patrick;Ruessier,Cécile;Gaberan,Philippe	Vie et grande dépendance : de la relégation à la reconnaissance	Reliance, 2006, No. 21, pp. 27-100		2006	Reflections around reception structures device and support programme for people with multiple impairments and great dependence condition and contribution to avoid isolation situation.
Pérez Bueno, L.C.	Por la Igualdad Unidas en la Diversidad	CERMI		2005	This book shows the reality of women with disabilities, their desires, their frustrations, their fights and their recoveries. It also shows their victories, their advancement and their triumphs.
Petry, Katja	Measuring the quality of life of people with profound multiple disabilities. Development of a questionnaire.	Leuven (BE): Katholieke Universiteit Leuven		2007	Results of a research study aiming the development of a valid, reliable and useful instrument to measure the quality of life (QOL) of people with profound multiple disabilities. The theoretical QOL framework of Schalock has been used.
Piccoli, Marco	I progetti di Assistenza p	Verona, Italy		2006	This unpublished dissertation describes the conceptual basis, procedures and programming of "Self-managed Personal Assistance (Independent Living) Projects realised by the Disability Services of the Province of Verona, Veneto Region,Italy" and is the basis of the example of Self-managed Independent Living in the Good Practice section.
Pierluigi Morosini (ISS)	Una Politica per la Promozione della Salute Mentale	Rome, Italy		2001	The document by Pierluigi Morosini (ISS) examines initiatives for the prevention of mental disorders and the promotion of positive mental health.
Pietro Vittorio Barbieri, National President Italian Federation for Overcoming Handicap (FISH)	Linee d'azione per l'integrazione scolastica degli Alunni con handicap in situazioni di particolare gravità (a cura della FISH*)	Rome, Italy	<a href="http://www.superando.it/content/view/1208/116/">http://www.superando.it/content/view/1208/116/</a>	2006	"Guidelines for the Inclusion in School of Pupils with Severe Disabilities" is a comprehensive document drawn up by the Federation (FISH) and presented to the Ministry of Education. It examines the various aspects of inclusive education and possible solutions to still unresolved problems concerning the majority of pupils who, because of serious learning difficulties and often additional functional difficulties, require personalised educational plans which, despite being linked to the class curriculum, are differentiated in relation to those of the other pupils in the class. Each aspect is examined in relation to a model of inclusion based on legislation and good practice, the problems explained and normative solutions proposed.

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Plop Adrian	Politici active de integrare socio-profesionala a persoanelor cu handicap. Perspective Europene si realitati romanesti	I.N.P.C.E.S.P.H		2001	Active Policies for disabled people integration in society and on the labor market. Theoretical and practical approach. Study concerning the present situation and Romania and presentation of perspectives in Europe.
Preda Vasile, Pah Iulian	Calitatea vietii persoanelor cu deficiente	I.N.P.C.E.S.P.H		1999	Quality Life concepts. Indicators related to the disabled people quality life.
Rauche, Christian	Quel accompagnement pour répondre à la fragilité des personnes polyhandicapées accueillies en MAS et FAM ?	Bulletin d'informations, CREAI Bourgogne, No. 270-2007.pp.7-15		2007	This publication is a reflection on the quality of life and health condition of people with multiple impairments living in special institution.
Raynaud, Philippe; Weber, A mandine	Les adultes ayant des incapacités lourdes dans les actes essentiels de la vie quotidienne	Etudes et résultats, DREES, 2005, No. 439. 12 p.	<a href="http://www.sante.gouv.fr/drees/etude-resultat/er439/er439.pdf">http://www.sante.gouv.fr/drees/etude-resultat/er439/er439.pdf</a>	2005	The results of the 1999 HID survey show that persons who can not realise by themselves at least one of the nine essential acts of existence in six domains of daily life: washing, dressing, feeding, going to the toilet, transfer and moving in the house, are physically impaired (three-quarters), 40% have mental impairment and 20% have both mental and physical impairments.
Redmond, B. and Richardson, V.	Just getting on with it: Exploring the service needs of mothers who care for young children with severe/profound and life-threatening intellectual disability.	Journal of Applied Research in Intellectual Disabilities, 16, 205-218		2003	This journal articles describes service needs for families with a child with severe disabilities. It outlines difficulties related to a lack of services, lack of equipment, having to pay privately for equipment and eligibility problems for children under the age of 4 who have not had a formal diagnosis of intellectual disability.
Rodríguez-Blázquez, C.; Salvador-Carulla, L.; Romero, C.; Atienza, C.	Necesidades de Atención a Personas con Retraso Mental y Transtornos Psiquiátricos en España. El informe Biomed/Aldapt	Ponencia en las III Jornadas Científicas de Investigación sobre Personas con Discapacidad dentro del Simposio "Programas de atención para personas con retraso mental y problemas psiquiátricos", Salamanca, Spain	<a href="http://www.usal.es/~inicio/investigacion/jornadas/jornada3/actas/simp2.pdf">www.usal.es/~inicio/investigacion/jornadas/jornada3/actas/simp2.pdf</a>	1999	A report into the situation of the psychiatric care of people with mental disabilities in Spain, including outcomes, conclusions and very important recommendations with the aim of reaching an agreement and to lay out some guidelines of "good practice."
Ruskus, Jonas	Disability Phenomena	Siauliai University Press		2002	Monography analyses social and cultural phenomena of disability.
Rymsza, A.; Gnaj, K.	Autyzm w orzecznictwie o niepełnosprawności - wnioski z badań w województwie mazowieckim. Raport 2006.	SYNOPSIS FOUNDATION, Warsaw, Poland	no available	2006	This report presents the findings of the research and the most important problems of the assessment disability system in case of people with autism. The report includes also propositions of changes.
Rywiková, B.	Paní Šuránková své úsilí nevzdává. (Mrs Šuránková does not give up.)	Journal - Residenční péče (Residential Care), 3, 2007, p. 16		2007	The article comes back to an issue of caged beds which was risen by the Czech and international media in 2005. The author claims that problem of using means such caged beds has not been solved by an amendment of the law which almost forbids using caged beds. The author on example of family with a person with sever dependency needs demonstrates complexity of the problem.



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Salaševičiūtė, Rimantė; Bedorf, Audronė; Blažys, Vytautas; Juodkaitė, Dovilė; Kurienė, Aušra; Kurutyte, Agnė; Migaliova, Dana; Povilaitis, Robertas; Pūras, Dainius; Rimšaitė, Eglė	Children's Rights Situation in the Residential Care and Education Institutions in Lithuania		<a href="http://www.gip-vilnius.lt/leidiniai_angl/ChildrenRightsSituation.html">http://www.gip-vilnius.lt/leidiniai_angl/ChildrenRightsSituation.html</a>	2006	Children living in residential care and education institutions become increasingly dependent on the system, and their independence is not developed. Responsible institutions and instances lack collaboration, initiative and efforts to bring the child back to the family and the society before he reaches legal age; and usually, when the child reaches the legal age, his prolonged stay in the institution has "programmed" his unsuccessful integration into the society.
Salvador Carulla, L., Martínez-Leal, R., Salinas, J. A., Martorell, A., Almenara, J. y Bas, P.	Trastornos de la salud mental en las personas con discapacidad intelectual. Declaración Feaps e informe técnico.	FEAPS	<a href="http://www.feaps.org">www.feaps.org</a>	2007	Information about the key circumstances surrounding people with intellectual disabilities and mental health disorders, about their needs and the best internationally renowned models to cover those needs and to guide them towards a healthy and full life.
Sartori, Francesco; Bonadonna, Gianni; Bartoccioni, Sandro; edited by Barnard, Paolo.	"Dall'Altra Parte",	Ed. Rizzoli		2006	This book narrates the personal story of serious illness and suffering of 3 prestigious doctors, as they experience the Health Service as patients "From the Other Side" and their proposal to contribute to the establishment of a new doctor-patient relationships and more in general to the humanisation of treatment as essential elements of a Health Service nearer to the needs of citizens. On the basis of their proposal, the Ministry for Health has instituted the Council of 'Ill Doctors', the objective of which is a White Paper on the humanisation of medicine.
Savy, Jean; Fauvre, Henri; Hamoney, Claude; Herault, Marcel et al.	Les exclus parmi les exclus	Réadaptation, 2005, No. 518, pp. 7-46		2005	The authors discuss the challenge facing the government in dealing with severely dependent children and adults with disabilities who suffer from exclusion and are deprived of their fundamental rights.
SCHPILKA Philippe	Grandes dépendances : rapport final du groupe de travail grandes dépendances	AWIPH	<a href="http://www.guidesocial.be/redirect.php?url=http://www.fissaaj.be/SPIP/IMG/doc/Grandes_dependances_2007_Rapport_et_conclusions.doc">http://www.guidesocial.be/redirect.php?url=http://www.fissaaj.be/SPIP/IMG/doc/Grandes_dependances_2007_Rapport_et_conclusions.doc</a>	2007	Conclusions of the Working Group on "major dependence" of the Management Committee of the Walloon Region. This group comprised associations, institutions and administrations.
Seifert, Monika	Menschen mit schwerer Behinderung in Heimen. Ergebnisse der Kölner Lebensqualität-Studie	Journal: "Geistige Behinderung" 41, 202-222		2002	This article presents a summary of the results of a Study on Quality-of-Life of people with complex needs in residential homes. The theoretical framework for exploring quality of life was founded on the multidimensional concept presented by Felce & Perry (1997).
Seifert, Monika	Mehr Lebensqualität. Zielperspektiven für Menschen mit schwerer (geistiger) Behinderung in Wohneinrichtungen – mit Checklisten zur Evaluation der professionellen Arbeit	Marburg, Germany		2003	This publication presents a summary of the results of a Study on Quality-of-Life of adults with complex needs in residential homes and checklists for staff to evaluate their work concerning the physical, social, material, productive and emotional well-being of these people. The items of the lists are founded on the results of the study.

Author	Title	Source	Internet Source	Year	Summary
Seifert, Monika	Lebensqualität von erwachsenen Menschen mit schweren Behinderungen – Forschungsmethodischer Zugang und Forschungsergebnisse. In: Zeitschrift für Inklusion-online.net 1 (2) URL: www.inklusion-online.net	Journal: Zeitschrift für Inklusion-online.net 1 (2)	URL: www.inklusion-online.net	2006	This article presents the theoretical framework and the methodological approach of the Study on Quality-of-Life of people with complex needs in residential homes. The core of the qualitative research are participant observations in daily life of these people. The article includes examples of the observations.
Seifert, Monika; Fornefeld, Barbara; Koenig, Pamela	Zielperspektive Lebensqualität. Eine Studie zur Lebenssituation von Menschen mit schwerer Behinderung im Heim	Bielefeld, Germany		2001	This publication presents the results of a qualitative research project on Quality of Life of people with profound multiple disabilities in residential homes which was realized at the University of Cologne. The theoretical framework for exploring quality of life was founded on the multidimensional concept presented by Felce & Perry. In order to evaluate the staff's daily work with people with profound intellectual and multiple disabilities the research group developed Checklists which can help to raise the quality of life of these people.
Servais Paul, Steichen Robert	Handicap. Accueil, solidarité et accompagnement en famille	Bruylant - Academia		2002	Book about ethical questions. - from pregnancy to childhood: announcement and kindergarden - from school to adult age: training, integration, services - from adult to end of life: accompaniment
Šiška, J., Vránová, J.	Comparative Cost Analysis: Community-based services as an alternative to institutions, Country Report - the Czech Republic		not published yet	2007	The overall aim of the research project is to provide scientific evidence to inform and stimulate policy development in the reallocation of financial resources to best meet the needs of people with disabilities, through a transition from large institutions to a system of community-based services and independent living. <i>Not published yet</i>
Stansfield, A.J., Holland, A.J. & Clare, I.C.H.	The sterilisation of people with intellectual disabilities in England and Wales during the period 1988 to 1999	Journal of Intellectual Disability Research 51(8), 569-576		2007	This article reviews case notes from referrals to the Official Solicitor's Office for sterilisation. The researchers note that the referrals are almost always for people with IDs.
SYNOPSIS Foundation, Warsaw, Poland	Sytuacja dorosłych osób z autyzmem w Polsce	SYNOPSIS FOUNDATION, Warsaw, Poland	<a href="http://www.autyzm.akademia-synopsis.pl/">http://www.autyzm.akademia-synopsis.pl/</a>	2004	This report was based on an analysis of 105 cases studies. It shows the general situation of adult with autism in Poland in 2004.
Tadema, Annemarie	From policy to practice. Developments in the education of children with profound intellectual and multiple disabilities	Groningen: Stichting Kinderstudies		2007	Results of the development of (a) an instrument to categorize the characteristics of children with profound intellectual and multiple disabilities, (b) a suitable curriculum for these children. The research was conducted because of the implementation of the Student-linked Budget Act ('the backpack').
Tamasauskiene, Jurate	Mental Disability and meaningful activities	Society "Viltis"	<a href="http://www.viltis.lt/lt/leidiniai/book/detail.php?ID=4355">http://www.viltis.lt/lt/leidiniai/book/detail.php?ID=4355</a>	2006	This issue presents a day care centre "Sviesa" that has been open for over 14 years. Social workers and special educators present centres' workshops in which they have transformed the lives of disabled adults through collectively work, sharing of responsibility, development of purpose, improvement of imagination.

Author	Title	Source	Internet Source	Year	Summary
Tamasauskiene, Jurate	The light of the disabled	Society "Viltis"	<a href="http://www.viltis.lt/leidiniai/book/2006%20sviesa.pdf">http://www.viltis.lt/leidiniai/book/2006%20sviesa.pdf</a>	2006	Mental disability is not a disease, but a special need which requires supporting evidence during whole life. Therefore, it is important to treat people with mental disabilities as individuals that can improve their skills. We must understand that improvement process continues incessantly. Moreover, each person, including people with severe disabilities, can give a lot to his/her peers.
Tamasauskiene, Jurate	Communities' influence on a successful work of the day care centre of the disabled.	Society "Viltis"	<a href="http://www.viltis.lt/leidiniai/book/2006%20Bendruomenes%20itaka.pdf">http://www.viltis.lt/leidiniai/book/2006%20Bendruomenes%20itaka.pdf</a>	2006	This issue tells about creation and consolidation of Vilnius day care center's Šviesa community. At present this community unites clients, employers, parents and caregivers of clients as well as representatives of society, such as pupils, students, and volunteers. Social workers, parents of persons with mental disabilities, and volunteers will find in this issue a wealth of helpful advices. On the other hand, it will be a new impulse for the whole society to believe that both disabled and abled people can enrich each other by sharing their experiences.
The Government of the Czech Republic	Midterm Conception of the State Policy Towards Persons with Disabilities, Government Resolution No. 605	Prague, CZ	<a href="http://www.vlada.cz/scripts/detail.php?id=17889">http://www.vlada.cz/scripts/detail.php?id=17889</a>	2004	In relation to European strategic documents this Government Resolution analyses a development of the state policy towards persons with disabilities since early '90. Together with the outcomes of the analyses the document sets up actions and goals for respective government bodies.
The Government of the Czech Republic	the National plan for the support and integration of persons with disabilities 2006 - 2009.	Prague, CZ	<a href="http://www.vlada.cz/cs/rvk/vvzpo/dokumenty/dokumenty.html">http://www.vlada.cz/cs/rvk/vvzpo/dokumenty/dokumenty.html</a>	Updated 2007	The plan is the principal document of the Government Board for Persons with Disabilities and is based on the Strategy of the governmental policy towards persons with disabilities.
The Ministry of Labour and Social Affairs	The report of Justification - The Act on Social Services No. 108/2006 Coll., and the report of introduction	Prague, CZ	<a href="http://www.mpsv.cz/files/clanky/4088/Annex_3_social_services_act.pdf">http://www.mpsv.cz/files/clanky/4088/Annex_3_social_services_act.pdf</a>	2006	Report of Justification (Důvodová zpráva) provides reasons for the "new" act on social services which regulates conditions governing assistance and support to persons in adverse social situations (hereafter "the persons") provided through social services and an allowance in respect of care (care allowance), conditions governing the issue of the authorization for the social services provision, execution of public administration in the field of social services, inspection of the social services provision and prerequisites for performance of social services activities. This Act was designed with aim to fundamentally shift the role of person with disability (including persons with complex needs) from a passive object of care to an active citizen and a consumer of social social services.
the Public Defender of Rights	PRAVDA Z NÁVŠTĚV ZAŘÍZENÍ - Ústavy pro tělesně postižené Report from Visits to Institutions for Persons with Physical Disabilities), Summary of the report available in ANNUAL REPORT ON THE ACTIVITIES OF THE PUBLIC DEFENDER OF RIGHTS IN 2006	Prague, CZ	<a href="http://www.ochrance.cz/dokumenty/document.php?back=/cinnost/index.php&amp;doc=695">http://www.ochrance.cz/dokumenty/document.php?back=/cinnost/index.php&amp;doc=695</a>	2006	The ombudsman visited several institutions for persons with physical disabilities with aim to monitor practices of this institutions in relation to human rights of the residents. Attention paid to e.g. freedom of movement, legal competence and many others aspects of life in close institutions..

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Thompson, J. R., Bryant, B., Campbell, E. M., Craig, E. M., Hughes, C., Rotholz, D. A., Schalock, R. L., Silverman, W., Tassé, M. J., y Wehmeyer, M.	Supports Intensity Scale (SIS). Users Manual.	American Association of Mental Retardation. AAMR		2004	Instrument of planning designed to help professionals to determine the support needs that people with disabilities require in their daily life.
TILMANS-CABIAUX Chantal, DUCHENE Joseph	Risquer de naître. Médecine prénatale et tests génétiques	Presses universitaires de Namur		2002	Authors reflect on the power of bio-medicine: stories, analysis, discussion. Genetical causes and disability.
UILDM - Italian Union for the Fight against Muscular Dystrophy	Dossier : Satira e Disabilità		<a href="http://www.uildm.org/dossier/vignette/index.htm">http://www.uildm.org/dossier/vignette/index.htm</a>		"Satire and Disability" illustrates how the themes associated with handicap and disability can be tackled from very diverse viewpoints. The UILDM web site provides a collection of recent contributions of some of the best Italian satirical cartoonists on this theme.
Van Bael Michèle, Vankriekinghe Sophie	Mener sa vie professionnelle avec une personne de grande dépendance, est-ce un défi ?	Bruxelles, AFRAHM		2004	Study financed by the Social and Health Ministry of the Walloon Region: employment, non-discrimination, equal opportunities, services, needs, personal budgets for family carers.
Vandiver, V.L., Johnson, J. & Christofero-Snider, C.	Supporting Employment for Adults With Acquired Brain Injury: A Conceptual Model.	Journal of Head Trauma Rehabilitation. 18(5): p. 457-463, September/October 2003.		2003	Description of the Brain Injury Assessment Model (BIAM). This model can be used as a handle for vocational judgment of clients with brain injuries.
Vann, B; Šiška, J.	From 'cage beds' to inclusion: the long road for individuals with intellectual disability in the Czech Republic	<i>Disability &amp; Society</i> Routledge, part of the		2006	The article provides a general overview to the development of residential social services for persons with disabilities in the Czech Republic. It is concluded that the government policy on social inclusion is weak to bring significant changes in the process of deinstitutionalisation in the Czech Republic.
Verdugo, M. A.; Ibáñez, A. y Arias, B.	La Escala de Intensidad de los Apoyos (SIS)	INICO. AAIDD (antes AAMR)	<a href="http://inico.usal.es">http://inico.usal.es</a>	2007	Spanish version of the Supports Intensity Scale of Thompson et al. Published by the AAMR in 2004.
VGN (Dutch Association of Health Care Providers for People with Disabilities)	De professionele gehandicaptenzorg. In dialoog werken aan de kwaliteit van bestaan.	Utrecht: VGN	<a href="http://www.vgn.org">www.vgn.org</a>	2007	Brochure in which the professional care to people with disabilities in the Netherlands has been described
Vitale, Gianfranco	"Il Silenzio Intorno"	Ed. ANANKE, Torino, Italy		2006	"The Silence All Around" narrates the story of Gabriele, told by his father as a communal portrait of a human condition without hope through the experiences of the persons close to Gabriele. This book is about autism but is a book for everyone, in order to reflect on the human condition of the disinherited and the useless trouble to invent fake paradises for them by 'those who think a way of living is life'.

Author	Title	Source	Internet Source	Year	Summary
Vivanti, Giacomo	Disabili, famiglie e operatori: chi è il paziente difficile?	Vannini editrice, Gussago (BS), Italy		2006	"People with Disabilities, Families and Professionals: Who is the difficult Patient?" contains strategies for the construction of collaborative relations between professionals and the parents of children and people with disabilities in the area of autism and developmental disabilities. It tackles and discusses the difficulties involved and their causes. It suggests numerous possible remedies aimed at creating shared communication and collaboration. The book contained an extensive bibliography and list of publications.
Welti, Felix	Behinderung und Rehabilitation im sozialen Rechtsstaat	Tübingen, Germany		2005	This book deals with social rights of people with disabilities in Germany. The author explained the historical development of disability policy and analyzed the principle of welfare state, antidiscrimination as well as the topics of human dignity, equalization, self-determination and participation in German social law.
Winlund, Gunnel	<i>Se mig! Hör mig! Förstå mig! See me! Hear me! Understand me!</i> )	ALA, FUB Sweden	<a href="http://www.fub.se">www.fub.se</a>	2004	Persons with profound, severe and multiple intellectual disabilities are totally dependent on the knowledge and engagement of the persons in their environment. This book is an educational working material for parents and staff of different kinds. There is also a DVD showing six adult persons.
Zucman, Elisabeth; Savy, Jean; Camberlein, Philippe et al.	Polyhandicap et personnes handicapées	Réadaptation, 2007 No. 537, pp. 5-50		2007	Non profit organization for people with disabilities are discussing the management of people with multiple impairments. Fears related to a doctrine of desinstitutionalization from the European Parliament and which will be detrimental to people with multiple impairments are also discuss here.
	Personnes ayant un handicap de grande dépendance	Bruxelles, Forum européen des personnes handicapées		2000	Document about persons in situation of major dependence, their needs and rights. Recommendations for policy makers at national and european levels.
	Vieillesse, dépendance et lieux de vie	L'observatoire		2005	Articles about ageing people in Belgium: how many people, what kind of services, nursing, definition and evaluation of dependency, policy recommandations.
	EUFORPOLY II : Europe, Formation, Polyhandicap	Euforpoly II		2001	Community program Leonardo Da Vinci 2000 - 2001: synoptical results
	Egalité des chances et qualité de vie pour familles avec un jeune enfant handicapé	Dienststelle für Personen mit Behinderung (DPB)		1998	Stress, resources and needs of families with a disabled child: stories, theoretical report, discussion. Meeting of 13 October 1998 in the German-speaking region of Belgium.
	Charte européenne de l'aidant familial	COFACE Handicap		2007	Guide to protect the rights of family carers
	Symposium "déficiences neuro-motrices : regards croisés"	CETD		2005	Meeting organized on 19, 20 and 21 May 2005 in Brussel by a specialized centre for CMI children : kindergarden, cares, needs...
	Rapport d'activités 2005	AWIPH		2006	Statistical data from regional level on disability policy: 2005.
	Rapport annuel 2005	SPF Sécurité Sociale DGPH		2006	Statistical data from federal level on disability policy: 2005.
	Handylex		<a href="http://www.handylex.org/">http://www.handylex.org/</a>		Web site with data base of national legislation, Official Gazzette, news, analysis of legal aspects relating to new laws and bills , circulars, notes and decrees relevant to persons with disabilities.

Author	Title	Source	Internet Source	Year	Summary
	Handicap Grave: Ritardo mentale e pluriminorazioni sensoriali	Edizioni Centro Studi Erickson, Trento, Italy		Specialistic Journal, 3 issues annually	"Severe Disability: Mental Retardation and Multi-sensorial Impairment" is a specialistic journal issued 3 times yearly, published in collaboration with the Lega del Filo d'Oro (National Association for Deaf and Blind Persons), the Italian Association of Psychology and Cognitive-Behavioural Therapy and member of the Association for Advancement of Behavior Therapy (USA) and the Erickson Research Centre, Trento. Its readership comprises professional educators,, psychologists , educationalists, neuropsychiatrists, rehabilitation therapists and speech therapists. The Journal's objective is to present the best of national and international scientific research concerning severe disability in an attempt to diffuse a culture of evidence-based practice and operational models in a context of educational and social inclusion.
	Employment of the intellectually disabled and their carers	Society "Viltis"	<a href="http://www.viltis.it/leit/leidiniai/book/ida_rbinimas_internetu_i.pdf">http://www.viltis.it/leit/leidiniai/book/ida_rbinimas_internetu_i.pdf</a>	2005	This publication will make you aware of the legal aspects of the employment of the disabled and provide with informatikon about the employment process itself. It is dedicated to the disabled persons, their parents and carers, professionals and other stakeholders. It also contains practical information and advice.
	Procese de schimbare in viata persoanelor cu dizabilitati intelectuale din Romania	Inclusion International		2006	Study of process of change in the lives of persons with intellectual disability - in national and local context. Include successful projects , case studies, good practice models, definition of concepts.



## **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](http://ec.europa.eu/employment_social/disability) or on Inclusion Europe’s website at [www.inclusion-europe.org](http://www.inclusion-europe.org).

