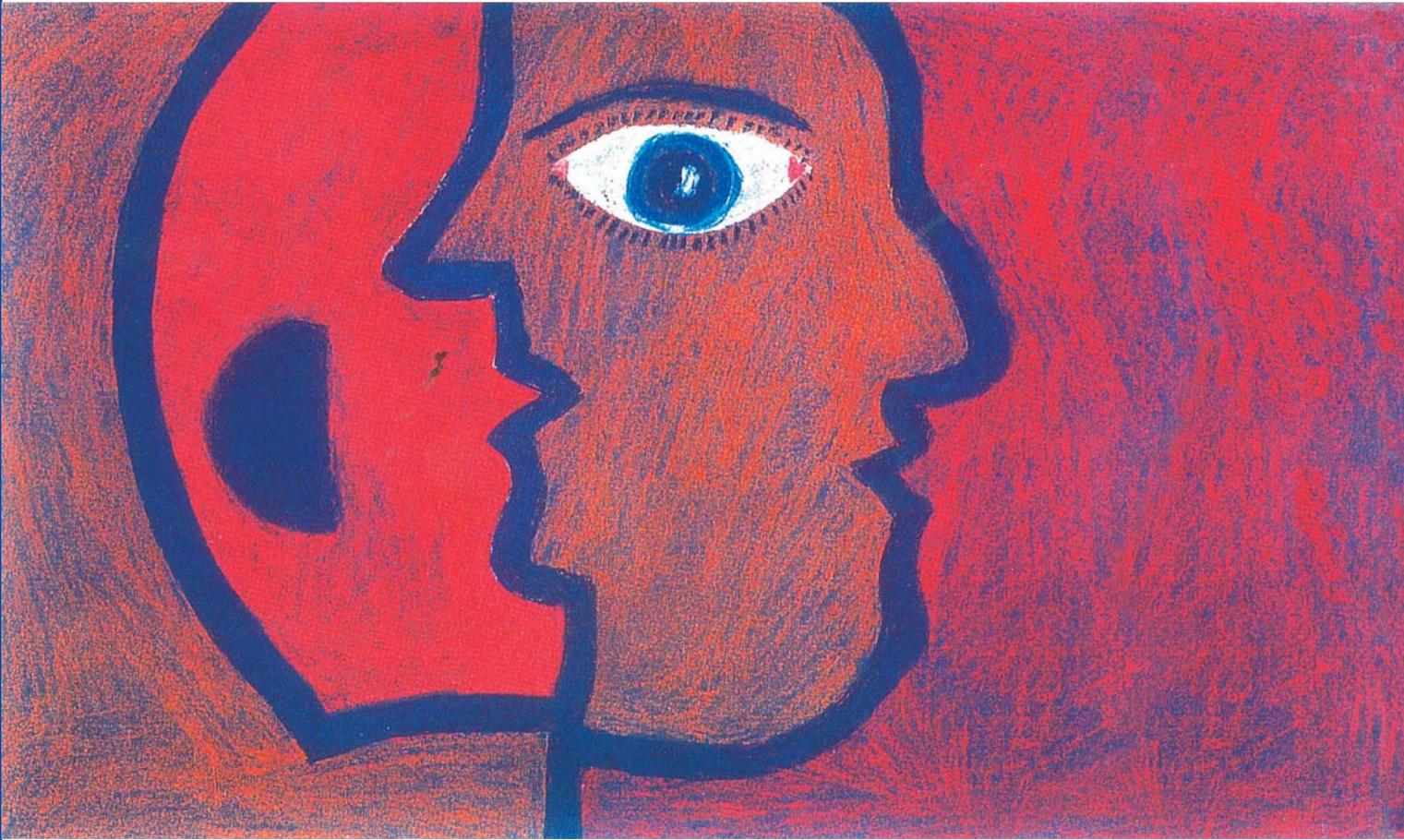

The Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs



Report of a European Study
Volume 1: Policy Recommendations



Supported by the

European Commission

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

Report of a European Study

Volume 1: Policy Recommendations

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Executive Summary

The European Union has commissioned a Study to identify the specific risks of discrimination faced by people with severe disabilities and/or with complex needs. The policy recommendations presented in Volume 1 of the Final Report are the result of extensive research and analysis carried out in Germany, France, the United Kingdom, Italy, Spain, Poland, Lithuania, the Czech Republic, the Netherlands, Belgium, Sweden and Romania throughout the year 2007. The comparative analysis of the twelve National Reports demonstrates that people with severe disabilities and/or complex needs and their families are at a high risk of being discriminated against in all Member States and in all aspects of their lives. On the basis of the UN Convention on the Rights of Persons with Disabilities, this publication recommends actions for the European Union as well as for Member States, disability NGOs and service providers to improve this unacceptable situation.

The basis for action against discrimination of people with severe disabilities must be their inclusion as citizens with full human rights and equal opportunities in all European and national policies.

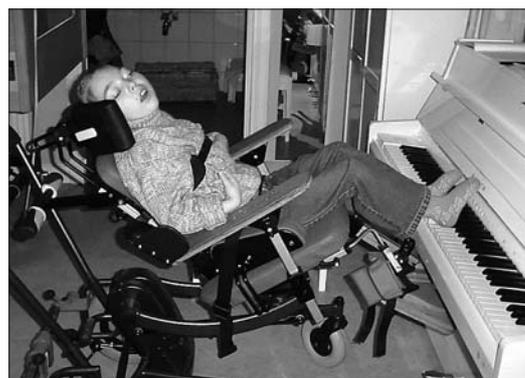
People with severe disabilities and/or complex needs are one of the most excluded groups of citizens in the European Union. Due to the lack of adequate inclusive service systems, they often spend their lives in institutions. As underlying reasons for the widespread discrimination of this group of European citizens, the comparative research identified the values as well as the general market dynamics of modern European societies. Furthermore, the research showed that another risk stems from the perception of a person with severe disabilities or complex needs as not being capable to take over socially accepted mainstream roles in life. This perception goes hand in hand with prejudices and

negative attitudes against this group of people and their families, who consequently often experience discrimination by association. The Study analysed in detail five specific aspects of discrimination:

- Discrimination in the availability and accessibility of services
- Discrimination in biographical transitions
- Discrimination in empowerment, self-advocacy and participation
- Discrimination in access to personalised service delivery and individual budgets
- Discrimination through lack of intersectoral cooperation in service delivery

On the basis of this comparative analysis, the Policy Committee of the Study developed recommendations for action at European and national levels. The Study clarifies that the basis for action against discrimination of people with severe disabilities must be their full inclusion as citizens with full human rights and equal opportunities in all European and national policies.

The European institutions should clarify that these people are not second class citizens. As a general principle, the European Union should in all its actions favour a policy of normalization and mainstreaming of the living conditions and services for people with complex needs with the necessary support that allows normalization and mainstreaming with a proper quality of life. Since personal budgets or direct payments are an innovative and effective way to ensure a high level of personalised support, the European Commission should promote research and evaluation of the existing systems and support exchange of good practices. To aid policy planning processes at local, national and European level, Eurostat should collect reliable statistics. The general recommendations of the Study are then complemented by specific recommendations for different life phases of people with disabilities, identifying existing policy instruments of the European Commission that can be used to improve the protection of people with severe disabilities from discrimination.



The recommendations for action at national level are guided by the objective that all national policies and practices in favour of people with severe disabilities should be aimed at inclusion as full citizens with all juridical, political and social rights. Member States should establish high quality support in the framework of mainstream services. Service providers should become more creative in including people with complex support needs in mainstream services. The process of implementing non-discrimination policies at local community level should be accompanied and guided by participative forms of local planning. Specific recommendations for different life phases complement this section.

The Policy Recommendations of the Study conclude with a proposal for a European Action Plan. It proposes the most important actions that the European Commission, the European Parliament and European disability NGOs can undertake to fight against the discrimination of people with complex needs and/or severe disabilities.

Résumé

L'Union européenne a financé une étude afin d'identifier les risques spécifiques de discrimination auxquels sont confrontées les personnes avec des handicaps graves et/ou des besoins complexes. Les recommandations politiques présentées ici sont le résultat d'une recherche menée en Allemagne, France, Royaume Uni, Italie, Espagne, Pologne, Lituanie, République tchèque, Pays-Bas, Belgique, Suède et Roumanie. L'analyse comparative des rapports nationaux montre que les personnes avec des besoins complexes ainsi que leurs familles ont un risque élevé de discrimination dans tous les Etats membres et dans tous les aspects de leurs vies. Sur la base de la Convention des Nations Unies sur les droits des personnes handicapées, cette publication recommande des actions afin d'améliorer cette situation inacceptable.

Les personnes avec des besoins complexes sont un des groupes qui souffre le plus d'exclusion dans l'Union européenne. En raison du manque de services adaptés ouverts à tous, elles restent souvent toute leur vie à la maison avec leurs familles, souvent avec un soutien insuffisant, ou sont parfois placées dans de grandes institutions résidentielles. Comme raisons sous-jacentes à la discrimination très répandue de ce groupe de citoyens, la recherche comparative a identifié les valeurs ainsi que la dynamique générale du marché dans les sociétés modernes. En outre, la recherche a montré qu'un autre risque provient de la perception qu'une personne avec des handicaps graves n'est pas capable de tenir un rôle social valorisé dans la vie. Cette perception va de pair avec des attitudes négatives vis-à-vis de ce groupe de personnes et de leur famille, qui subit ainsi souvent une « discrimination par association ». L'étude a analysé en détail cinq aspects de discrimination :

- Discrimination dans la disponibilité et l'accessibilité aux services
- Discrimination au moment des transitions de la vie
- Discrimination dans le contrôle de sa vie, l'auto-représentation et la participation
- Discrimination dans l'accès aux services personnalisés et l'attribution de budgets personnels
- Discrimination par manque de coopération entre les divers types de services

Sur la base de cette analyse comparative, le comité d'orientation de l'étude recommande des actions aux niveaux national et européen. L'étude montre que pour agir de façon fondamentale contre la discrimination envers ces personnes, il faut les inclure complètement, en tant que citoyens avec tous leurs droits et une égalité des chances, dans toutes les politiques européennes et nationales.

Les institutions européennes doivent expliquer que ces personnes ne sont pas des citoyens de deuxième classe. En tant que principe général, l'Union européenne doit dans toutes ses actions favoriser une politique de « normalisation » des conditions de vie des personnes avec des besoins complexes, avec le soutien nécessaire à cette intégration et à une bonne qualité de vie. Les budgets personnels étant une manière innovante et efficace d'assurer un niveau élevé de soutien personnalisé, la Commission européenne doit promouvoir la recherche et l'évaluation des systèmes existants ainsi que l'échange des bonnes pratiques. Pour faciliter la planification politique aux niveaux local, national et européen, Eurostat doit recueillir des statistiques fiables. Les recommandations générales de l'étude sont ensuite complétées par des recommandations spécifiques relatives à différentes phases de la vie, identifiant les instruments politiques existants de la Commission utiles pour améliorer la protection des personnes avec des handicaps graves contre la discrimination.

“ Pour agir de façon fondamentale contre la discrimination envers les personnes avec des handicaps graves, il faut les inclure complètement, en tant que citoyens avec tous leurs droits et une égalité des chances, dans toutes les politiques européennes et nationales. ”

Les recommandations faites au niveau national ont pour objectif que toutes les politiques et pratiques en faveur des personnes avec des handicaps graves visent leur inclusion comme citoyens à part entière avec tous leurs droits. Les Etats membres doivent établir un soutien de grande qualité dans le cadre des services communs. Les prestataires de services

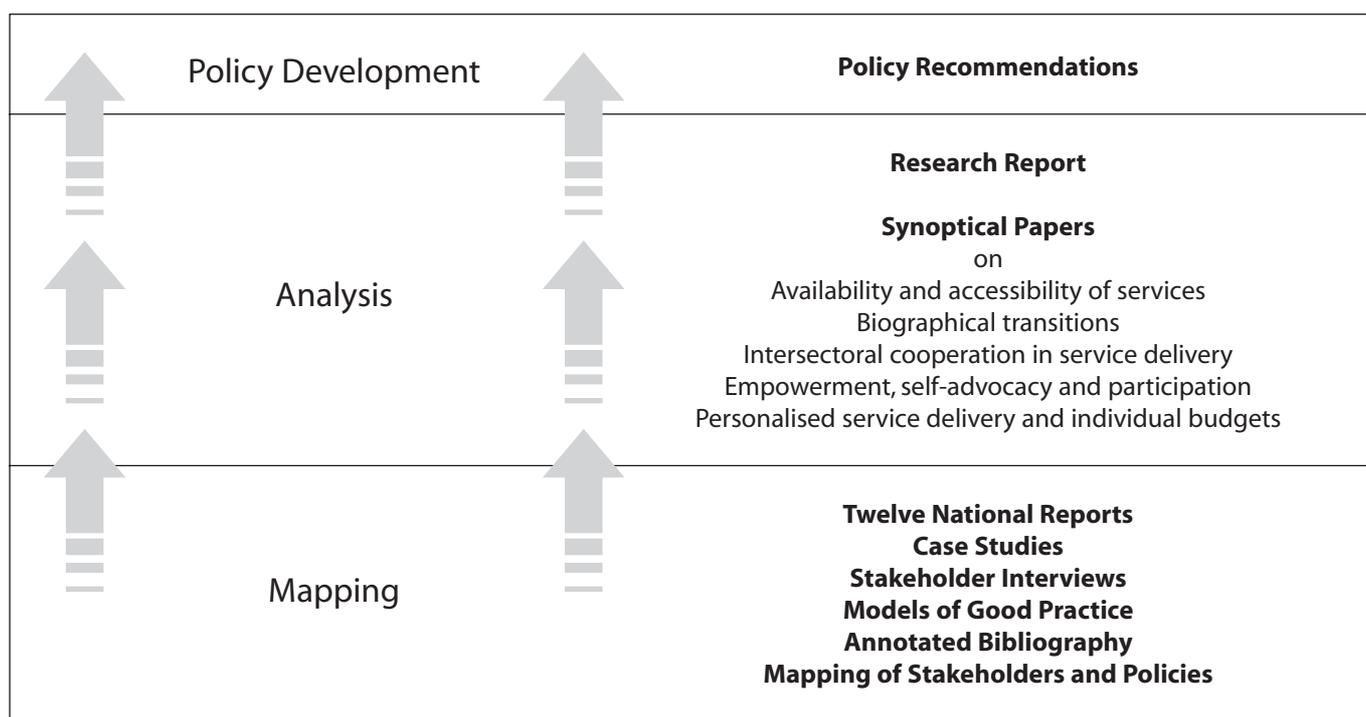
doivent devenir plus créatifs pour apporter le soutien nécessaire aux personnes avec des besoins de soutien complexe dans les services pour tous. La mise en œuvre des politiques de non discrimination au niveau local doit être accompagnée et guidée par une planification locale participative. Des recommandations spécifiques aux différentes phases de la vie complètent cette section.



Les recommandations politiques de l'étude se terminent par la proposition d'un Plan d'action européen. Il propose des actions importantes que la Commission européenne, le Parlement européen et les ONG européennes du handicap peuvent entreprendre pour lutter contre la discrimination des personnes avec des besoins complexes et/ou des handicaps graves.

1 Introduction

The present Study has been commissioned by the European Union to identify the specific risks of discrimination faced by people with severe disabilities and/or with complex needs. The policy recommendations presented in this paper are the result of extensive research and analysis carried out in twelve countries of the European Union throughout the year 2007. The following graphic shows the structure of mapping, research and policy development that was undertaken:



In addition to this paper, the Study has thus produced important background material that provides valuable additional information and insight into the situation of people with severe disabilities and/or complex needs:

- Five Synoptical Papers analyzing in detail the risks of discrimination regarding five main dimensions are presented in Volume 2 of the Final Report.
- Twelve Country Reports on the situation in Germany, France, the United Kingdom, Italy, Spain, Poland, Lithuania, the Czech Republic, the Netherlands, Belgium, Sweden and Romania are presented in Volume 3 of the Final Report.
- A collection of excellent Case Studies and Examples of Good Practice from all twelve countries is presented in Volume 4 of the Final Report.

All reports demonstrate that people with severe disabilities and/or complex needs and their families are at a high risk of being discriminated against in all Member States and in all aspects of their lives. It is the purpose of this paper to propose on the basis of the UN Convention on the Rights of Persons with Disabilities actions for the European Union as well as for Member States, disability NGOs and service providers to improve this unacceptable situation.

1.1 Meeting the people with severe disabilities and/or complex needs

People with severe disabilities and/or complex needs are one of the most excluded groups of citizens of the European Union. Due to the lack of adequate inclusive service systems, they often spend their lives with insufficient support at home with their families or in large residential institutions. Thus, they remain invisible for the most part of the population and also for decisionmakers at European and National level.

People with severe disabilities and/or complex needs

- have one or several severe impairments of functioning, for example a profound intellectual disability, severe cognitive disability, severe behavioural challenges, or a severe physical disability.
- have complex support needs that challenge support and service systems, for example the need for constant 24 hour one-to-one support, or the need to support impairments in two different areas (e.g. deaf-blindness,

intellectual disability combined with mental health problems, physical disability combined with autism, physical disability with mental health problems, etc.).

- have often great difficulty in communicating with other people and may have no verbal communication at all.
- may have severe memory, planning, orientation and structural problems.
- need high levels of reliable support with most aspects of daily life.

Due to the lack of adequate inclusive service systems, they often spend their lives with insufficient support at home with their families or in large residential institutions.

In the further course of this paper, the terms “severe disability” or “complex needs” are used synonymously since the policy recommendations for both groups of people with disabilities are very similar.

The human rights enshrined in the UN Convention on the Rights of Persons with Disabilities must apply equally to all people with disabilities. In the development of policies for people with severe disabilities and/or complex needs, some fundamental values and rights¹ have to be specially reaffirmed. They are also the basis for the recommendations proposed in this paper:

■ **The right to be included**

People with severe disabilities and/or complex needs are citizens with the same rights as everyone else. They must be valued for who they are and be included in all aspects of society with the appropriate level of support that they may need.

■ **The right to be seen**

People with severe disabilities have often been hidden from the eyes of the public. This situation breeds prejudices and fear and is one reason for the strong discrimination they face in all areas of life.

■ **The right to be heard and understood**

Due to their communication problems, people with severe disabilities often have problems articulating their wishes. Training of contact people in communication methods and specific advocacy provisions can make their voices heard.

■ **The right to be considered**

Although their numbers seem to be growing, people with complex needs are a small group of citizens for whom adequate support services can be very expensive. Governments must consider and provide for their needs in all planning processes.

■ **The right to be valued**

People with severe disabilities are often not seen as full citizens. Many people do not consider their life as worth living. Valuing their lives and their contribution to society is essential.

■ **The right to care and to be supported**

People with complex needs often have specific health care needs or need other kinds of support to live included in society. Withholding treatment or necessary support are serious instances of discrimination. Real inclusion in society requires accessible and reliable support.



2 The General Backdrop of Discrimination

The twelve Country Reports presented in Volume 3 of the Report of the present European study found that people with severe disabilities and/or complex needs face risks of discrimination in almost all European countries and in almost all areas of life. On the basis of the comparative research and analysis presented in Volume 2 of the Final Report, this chapter summarizes some of the common and underlying reasons for this situation. It points to the need for the universal framework of human rights to be applied in a meaningful way for persons with severe disabilities.

As the main cross-cutting reason for the widespread discrimination of this group of European citizens, the comparative research identified the values of modern societies, especially regarding what constitutes a life that is worth living. Since many people with complex needs are very limited in their ability to communicate, to interact or to participate in mainstream life, other citizens often view their lives as a burden. This general attitude leads to negative and limiting prejudices that lead to discrimination in all sectors of life. An example is the almost automatic exclusion from the socially accepted roles as partners and parents that is amplified by limited possibilities to meet a partner and to start a relationship.

1/ Mencap, UK: The Profound and Multiple Learning Disabilities Network

Another reason was identified in the general market dynamics of modern European societies. Although there are strong indications that their number is growing, there are generally too few people with severe disabilities to be an interesting market for goods and services or to have a powerful voice in policies. The economy of scale thus works against this group of people, especially in service systems that are anyway under financial pressure. The rigorous application of the market model leads to the establishment of services in small niche markets where competition and consumer protection are almost absent.

Furthermore, people with severe disabilities often have higher needs for support services, but less possibility to pay for them. They thus become “negative consumers” for whom new services, therapies or support methods are not available. They risk to be discriminated by being left behind in old and often medically-oriented service structures whereas their more able peers get access to more inclusive service arrangements.

The comparative research showed that a risk of discrimination stems from the perception of a person with severe disabilities as not being capable to take over socially accepted mainstream roles in life.

In fact, the study showed a general finding that the more mainstream-oriented a service system for people with disabilities becomes, the higher is the risk of persons with severe disabilities to be placed in traditional institutional settings or to be excluded from support. An important aspect is also that the lack of necessary support for people with complex needs who are placed in mainstream settings constitutes a high risk of discrimination.



While the Study identified progress concerning non-discrimination and equality legislation for people with disability in general, it pointed out that people with severe disabilities or complex needs are not sufficiently considered or are fully excluded from the implementation of this legislation. Thus, they often experience discrimination under those laws and from implementation bodies that are supposed to protect them from discrimination.

An important general risk of discrimination against people with complex needs of all ages has to be seen in assessment procedures that are strongly influenced by professional or service provider interests. Reports from several countries show that under such conditions assessment procedures tend to identify only those needs of people with disabilities that a specific service can potentially meet. This is a specific problem for people with complex needs that surpass the expertise of one specific service provider.

The comparative research showed that another risk of discrimination stems from the perception of a person with severe disabilities or complex needs as not being capable to take over socially accepted mainstream roles in life. Thus, people with a severe disability from birth tend to be confined to the role of an “eternal child”. People who acquire

severe impairments as adults are often forced into early retirement and are confined to the role of an ‘old and sick person’, even though they might actually be relatively young. Both roles severely limit life perspectives of persons with severe disabilities as ‘a priori assumptions’ on negative life-course possibilities. This perception goes hand in hand with prejudices and negative attitudes against this group of people and their families who thus often experience discrimination by association.

The Country Reports of the Study showed also an almost complete lack of statistical data on people with severe disabilities and complex needs. While some rare disabilities occur only in very small numbers in each Member State, other disabilities constitute a sizeable population. Accurate data for service planning should be available for all populations, whatever their size.

2.1 Discrimination in the Availability and Accessibility of Services

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. Availability and accessibility of services and infrastructure are considered to be indeed central issues for the quality of life of persons with severe disabilities. The respective Synoptical Paper developed by the Study provides an overview on discrimination risks in terms of availability and access described in the twelve Country Reports.

For people with complex needs and/or severe disabilities, access to services is important during their whole life. While mainstream general services should cater for their support needs, in reality their support is often organised through specialised services. Since those inherently carry the risk of exclusion from the life of society, specific measures must be taken by these services to promote inclusion of their users in society. Furthermore, the risk of discrimination in access to mainstream and special services remains high in all areas of life.

Both social services and infrastructures tend to provide a limited number of services, which may or may not be adequate for persons with high support needs or severe disabilities, thus creating exclusion through lack of appropriate support. 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.

Early intervention services in early childhood have an important effect on the disability and the further quality of life of disabled persons. Discrimination occurs through lower availability of early intervention services in rural areas, the fact that some of these services are not free of charge, as well as structure and implementation problems. This situation continues at school age where the Study found hardly any mainstream schools that are accessible to children with severe disabilities or complex needs. Thus, these children are discriminated and must attend special schools.

A lack of family support services was found in some countries of the study, especially in rural areas. This leads to the discrimination of the families and their disabled members in terms of equal opportunities compared to other families.

Access to health care services becomes discriminatory due to architectural barriers and the lack of specialised high quality services in rural areas. In the system of social security, benefits are often related to the status of an employee and thus exclude people with severe disabilities. Furthermore benefits are often not sufficient to meet the specific needs of this group of people.

Ageing poses specific risks of discrimination of people with complex needs. Support services are often not prepared for their specific needs and a lack of offers for daily activities aggravates their situation. The access to rehabilitation measures or palliative care may be reduced and cases of withholding medical care are reported.

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 in mainstream programmes.

2.2 Discrimination in Biographical Transitions

When analysing discrimination risks from a life-course perspective, life-course 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 management of 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.

Biographies in modern societies are shaped by the way that individuals cope with the challenges of transition. For children and adults with complex needs, those moments of change inherit a higher risk of exclusion than for others.

As a result, most people with severe disabilities or complex needs are differentially excluded from childhood age where assessment and planning procedures exist. Transition between life stages is reduced to a move from one service to another and is often simply done without consultation with or even information given to users or parents. Thus, people with severe disabilities experience their life as a series of uncontrollable events, leading to a fatalistic life orientation.

Due to lack of necessary housing and family support, children with severe disabilities and complex needs often face an early reference to residential care. This leads to greatly reduced possibilities for socially normal life-course transitions.

In vocational training and employment, people with severe disabilities face the stereotype and taken-for-granted assumption that they will not be able to work anyway. This means that no adequate concepts to ensure transition into adulthood and employment are developed. The lack of offers leads to a direct reference to special services often with nursery care character and no preparation for the first labour market whatsoever. They have almost no possibilities to participate in the first labour market, to earn a living or to take over socially valued adult roles. The Study did not find adequate concepts to meet the problem of their transition into employment and thus they have a high risk of being unemployed.

For adults with severe disabilities, the risk of discrimination in the area of housing is the lack of choices: they are either confined to staying in their birth family or referred to residential care institutions. Missing services, old-style service models and legal cost-caveats reduce strongly possibilities for age-appropriate transitions to living included in the community.

2.3 Discrimination in Empowerment, Self-advocacy and Participation

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.

Progress has been made in the last decade in these areas. Nevertheless, in all countries people with complex needs or 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 lifephasages 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.

In all countries people with complex needs or severe disabilities face particular barriers when trying to develop abilities and power skills to exercise control over their lives or their service arrangements.

Access to information and communication is the basis for self-advocacy and participation in society. While specific alternative and augmentative communication methods exist, many service staff members or family members have not been trained in their use and thus cannot practice them in communication with persons with complex needs. Existing technical aids and appliances could support people with complex needs in communicating and accessing information, but a lack of knowledge about them as well as the cost of such systems often do not permit their use.

Families of people with complex needs are also at risk of being discriminated by association and need empowerment and training. If they are not sufficiently supported they may be unable to participate in social life like other families. Families with severely disabled members often have to choose between two discriminating alternatives: the family model where their child stays at home and which is often linked to very moral messages that parents are obliged to care for their child, regardless of its age; or the institutional model which may lead to less participation and social exclusion.

In the area of prenatal diagnosis and counselling, the main risk of discrimination stems from the assumption that a foetus with a presumed severe impairment has less opportunities in life. There is also the risk for the family to be discriminated against if the parents decided to have the child despite a severe impairment. Empowerment here takes the form of balanced and realistic information for parents without which foetuses with a presumed severe impairment are in many countries almost automatically aborted.

Housing and family support services are often not adequate to meet the needs of people with complex needs. Specific housing needs, as for example noise insulation, larger size, room for a support worker, or specific equipment, are often not affordable for families with a child with a severe disability. This may force families to change their housing, thus leading less social participation.

People with severe disabilities experience also a significant discrimination regarding possibilities for and choice of their leisure time activities. This leads for children to a lack of participation in the mainstream youth culture and to further exclusion of the child. Adults with complex needs face discrimination because for them leisure time offers are available almost exclusively within disability services.

Exercising their civil rights is in all countries limited by guardianship laws that do not guarantee equal recognition before the law. Thus, a lack of awareness for their civil rights is often complemented by limited possibilities to participate in democratic processes and in self-advocacy.

2.4 Discrimination in Access to Personalised Service Delivery and Personal Budgets

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.

Services need to be both flexible and reliable, a lack of personalized offers constitutes a significant risk of discrimination. However, incentives 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 choices and the reality of exclusion of people with high support needs. Personalised service arrangements for people with severe disabilities need high quality assessment and planning efforts, experienced staff, appropriate financial resources and flexible service organisations. These high demands contain permanent risks of discrimination.

Services need to be both flexible and reliable, a lack of personalized offers constitutes a significant risk of discrimination.

People with severe disabilities or complex needs also face discrimination in accessing personal budgets or direct payment schemes. Those should allow people with complex needs and their families to purchase the support they want. However, there seems to 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 personal budgets that pool money from all relevant sources. Pilot projects have also shown that disabled people who have used personal budgets to purchase the services they want, have achieved happier, valued lifestyles that are less expensive than traditional service provision. While in some cases personal budgets may not be sufficient for the specific support needs of a person, in many countries they are de facto reserved for people with lesser disabilities.

In the area of childhood education and care, children with complex needs experience discrimination due to a lack of appropriate environments and concepts for pre-school education as well as due to a lack of training and support by professionals that is tailored to their individual needs.

At school, individualised curricula and support for children with complex needs are generally not available. Children are discriminated by this lack of personal assistance, conceptual deficits and lack of qualified teachers.



2.5 Discrimination through Lack of Intersectoral Cooperation in Service Delivery

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.

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 transport, employment, pension, housing or public security etc.

In order to live a life 'as close to an usual life as possible' in mainstream community settings, using the services all people use, people with severe disabilities and their families are heavily dependent 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.

In pre-natal diagnosis and counselling, much of the discrimination against people with complex needs is based on the lack of cooperation between medical services and disability NGOs and other self-help groups. Thus parents of a child with a presumed severe disability often get only negative information about the life prospects of their unborn child. Also in early childhood, the Study identified in many countries a lack of training of relevant professionals, especially in case of rare

diseases or disabilities. A lack of coordination of services and a service orientation to a segregating special education system contribute together with a lack of cooperation with youth welfare services to an increased risk of discrimination

For persons with severe disabilities, welfare state fragmentation and lack of cooperation between services from different sectors are not problems, but in many respects very concrete challenges with a very high potential for discrimination.

At school age, cooperation between teachers, external supporters and families of children with severe disabilities is particularly important. Discrimination can occur when specific needs of the child are not recognised or met because of lacking cooperation.

The coordination of different support services for families with a severely disabled family member is lacking in most countries. This puts an additional strain on the families concerned.

Intersectoral cooperation is especially important in the care for ageing people with complex needs. Care services from the areas of health, old age care and disability often do not cooperate to ensure service access without discrimination.

3 Recommendations for Action at European Level

The basis for all action against discrimination of people with severe disabilities or complex needs must be their fundamental inclusion as full citizens with full human rights and equal opportunities in all European policies and legislation. **The European institutions should clarify that they are not second class citizens and that they have full and equal rights to services and to protection from discrimination in all areas of life.** This could convey to Member States and other citizens that action against negative attitudes and prejudices is overdue.

Article 6 of the Treaty on the European Union binds its actions to the principles of fundamental rights for all its citizens, as guaranteed by the European Convention for the Protection of Human Rights and Fundamental Freedoms. Article 13 of the EC Treaty empowers the European Union to “take appropriate action to combat discrimination based on (...) disability (...)”. For people with severe disabilities or complex needs, these two references are equally binding and the European Union should ensure that they benefit from these rights as any other citizen. It should also ensure that non-discrimination legislation prohibits discrimination of parents, e.g. by insurance companies or employers, because they choose to have a child with severe disabilities.

As a general guiding principle, **the European Union should in all its actions favour a policy of mainstreaming of the life conditions and services for people with complex needs or severe disabilities** with the necessary accommodations that allow normalization and mainstreaming with a proper quality of life. Thus, the European Commission should require proof, in all policies that affect people with severe disabilities, that their specific situation has been considered and that they actually benefit on an equal basis from the implementation of these policies. This criterion should be incorporated as a central element of the monitoring mechanism set up by the UN Convention for the Rights of People with Disabilities.

The European Union should in all its actions favour a policy of mainstreaming of the life conditions and services for people with complex needs with the necessary accommodations that allow mainstreaming with a proper quality of life.

The European Commission should strongly support **awareness-raising** for the situation of people with complex needs and their families. It should ensure that especially the European Year against Poverty and Social Exclusion 2010 has a specific focus on the situation of this group of European citizens. The Commission should in all its actions highlight the importance of diversity in society and favour a policy of participation in democracy.

It is also essential for the fight against the discrimination of people with severe disabilities and complex needs that the institutions of the European Union **strengthen the social dimension of the European Union** with a particular view on groups who, due to their small size and special characteristics, can easily become victim of the general market dynamics in Europe. The European Commission should require Member States to specifically report in the framework of the implementation of Community non-discrimination law and of the National Action Plans on Social Inclusion if and how the interests of this specific group of European citizens have been considered.

Personal budgets or direct payments are an innovative and effective way to ensure a high level of personalised support for persons with severe disabilities or complex needs.

The Commission should also contract **further studies** on people with complex needs under its Research Programmes, especially concerning their equal inclusion in national policies, benchmarking, quality principles and new methods for life planning and service planning. In the area of rare disabilities and medical research, the Commission should support research into those disabilities that occur very rarely so that small numbers of affected people at Member State level do not prevent medical research and development. Through this, the European Union could support a non-discriminatory policy of individualised community care, community planning and personal future planning in

all Member States. It should encourage the cooperation of different mainstream and specialized service sectors, support the collection of data and favour and support learning partnerships between different European countries.

Personal budgets or direct payments are an innovative and effective way to ensure a high level of personalised support for persons with severe disabilities or complex needs. The European Commission should promote research and evaluation of the existing systems and support exchange of good practices. It should encourage Member States to introduce personal budgets or direct payments in their National Action Plans for Inclusion and ensure that access to these systems does not discriminate against people with severe disabilities or complex needs.

The European Commission should facilitate the development of legal frameworks with regard to **social services of general interest** allowing NGO service providers to keep and valorise their specificity. Implementation of market mechanisms without taking in to consideration the specific role of NGO service providers might have a negative effect for people with severe disabilities.

To aid policy planning processes at local, national and European level, Eurostat should **collect reliable statistics** about the life situation of people with severe disabilities and their families in Europe. To this end, national and local governments should be encouraged to collect comprehensive statistics about people with severe disabilities.

3.1 Specific Recommendations

In the area of **prenatal diagnosis and counselling**, the European Union should ensure that in all Member States the right to life of unborn and newborn children with severe disabilities is protected without discrimination. It should ensure that non-discrimination legislation covers this aspect and also prohibits discrimination of parents, e.g. by insurance companies or employers, because they choose to have a child with severe disabilities. In their priority on Life Sciences, Genomics and Biotechnology, the Research Framework Programmes should also support research into "Ethical, legal and social aspects of genetic testing" as identified in the so entitled 2004 publication of DG Research. The European Commission should promote access to balanced and realistic counseling opportunities also in rural areas. It should encourage Member States to cooperate with disability NGOs in setting up these opportunities.

The European Commission should promote inclusive education and inclusive environments for people with severe disabilities or complex needs already from early **childhood**. It should address policy makers at European and Member State level with models of good practice.



The Education & Training 2010 Work Program stipulates that investment in **pre-school** education is of paramount importance for preventing school failure and social exclusion, and for laying the foundations for further learning. Greater efforts have to be made in the Member States and by the European Commission to ensure that children with complex needs are included in all actions to reduce early **school** leaving and the acquisition of key skills. Among other areas, children with complex needs should be considered in all actions to improve IT skills as stipulated by the Council Resolution of 13 July 2001 on e-Learning² or by the Commission Communication of 28 March 2001: The e-Learning Action Plan³.

The European Commission should promote inclusive education and inclusive environments for people with severe disabilities or complex needs already from early childhood.

2/ 2 OJ C 204 of 20.07.2001
3/ COM(2001) 172 final

In pursuing the objectives identified at the Barcelona Council of 2002, “to provide **childcare** by 2010 to at least 90% of children between 3 years old and the mandatory school age and at least 33% of children under 3 years of age”; the Commission should ensure that this childcare is offered without discrimination of children with severe disabilities in all countries of the European Union. The development of childcare facilities and the exchange of good practice in mainstream childcare for children with complex needs should be supported by the Structural Funds as outlined in the Commission Communication “A Roadmap for equality between women and men 2006–2010”⁴.

The European Employment Guidelines encourage Member States to improve the quality of their **school** systems, reduce early school-leaving and do everything in their power to seize the opportunities offered by new technologies to combating social exclusion in general. The European Commission should ensure that these objectives are pursued without discrimination of people with severe disabilities and complex needs. It should also promote the importance of diversity in schools and intensify research and exchange at European level in inclusive education.

The Commission should also ensure that **young people** with complex needs can participate without discrimination in all activities under the “Youth in Action” program⁵. To promote young people's active citizenship is particularly important for this group of European citizens as is the objective to provide non-formal and informal learning opportunities and opening up innovative opportunities in connection with active citizenship. The Commission should stimulate research into possibilities for mainstreaming children and young people in general services catering for the appropriate age group.

In the process of establishing a general framework for equal treatment in employment and occupation, the European Commission should ensure that adequate attention is given to vocational training opportunities for people with severe disabilities and complex needs.

In pursuing the European Disability Action Plan, the Commission should ensure inclusion of people with complex needs in various lines of action in the fields of **education and youth**, for example by promoting exchanges of good practice. It should support the non-discriminatory implementation of Art. 24 of the UN Convention on the primacy of inclusive education in all Member States and ensure that children with severe disabilities and complex needs have equal access to this option.

In the process of the implementation of Directive 2000/78/EC establishing a general framework for equal treatment in employment and occupation⁶, the European Commission should ensure that adequate attention is given to **vocational training** opportunities for people with severe disabilities and complex needs. The European Commission should monitor its implementation in this regard and support the exchange of good practice in reasonable accommodation measures for this group of citizens.

Pursuing the areas identified in one of its Communications⁷, the Commission should ensure that the needs of people with severe disabilities for **learning** and **vocational training** are more properly taken into account by including them as a target group in the PLOTEUS information system (Portal on Learning Opportunities throughout the European Space) and by paying particular attention to projects involving people with severe disabilities in all education, training and youth programmes of the European Union.

Pursuing the European Disability Action Plan and the Council Resolution of 15 July 2003 on promoting the **employment** and social integration of people with disabilities⁸, the European Commission should also ensure that the needs of people with complex needs are incorporated effectively and without discrimination into the European employment strategy and measures financed by the European Social Fund. Participation in the labour market should be enhanced by making public and private employers more aware of disability-related issues, particularly in the context of corporate social responsibility. The Commission should encourage public and private employers to have disability equality training sessions in order to raise their understanding of disability issues.

The modernization of social protection for the development of high-quality, accessible and sustainable health care and long-term care should focus particularly on people with complex needs.

4/ COM/2006/0092 final

5/ pursuing Decision 1719/2006/EC, OJ L 327/30 24.11.2006

6/ OJ L 303/16 2.12.2000

7/ COM(2005) 604 final

8/ OJ C 175/1 24.7.2003

Also the implementation of the Commission Communication⁹ on the modernization of **social protection** for the development of high-quality, accessible and sustainable health care and longterm care should focus particularly on people with complex needs. Exchanges of experience and best practices should be promoted and Member States should be supported in the reform of health care and long-term care for the benefit of social inclusion of people with severe disabilities. The European Commission should develop a strong and comprehensive anti-discrimination policy against disadvantages in **social security** systems.

In the area of accessibility of **housing** and public infrastructures, the Commission should review the issues identified in its Communication "Towards a Barrier Free Europe for People with Disabilities"¹⁰ from the perspective of people with severe disabilities and complex needs and promote exchange of experience and good practice among the Member States. The Commission should especially strongly support a policy to stop residential care in large institutions in favour of creating sufficient support for people with complex needs in community-based settings as stated in Article 19 of the UN Convention on the Rights of Persons with Disabilities.

The European Commission should ensure that the needs of people with complex needs are incorporated effectively and without discrimination in the European employment strategy and measures financed by the European Social Fund.

The European Commission should raise awareness of policy-makers at European, national and regional level to the importance of inclusion in mainstream leisure time and education activities.

The Commission should thus pursue the increased inclusion of people with complex needs in **adult learning** programmes following its Communication on Adult Learning¹¹. It should aim at the removal of discriminatory barriers to access goods, services and information, including culture, leisure and sport to achieve an inclusive barrier-free society. In the area of adult education and training, technological developments, particularly in the ICT field, offer considerable

opportunities to help people with severe disabilities overcome their functional limitations and thus avoid exclusion in a digital developing society. Pursuing the European Disability Action Plan, the Commission therefore should take action in setting-up an international dialogue on accessibility-related concerns and guidelines that takes the needs and abilities of people with complex needs fully into account. The Commission should particularly ensure that "design for all" is really for all, including people with severe disabilities. It should ensure that the budget allocated to research in respect of barrier-free and "empowering" technologies focuses also on the specific situation of people with complex needs.

The Commission should favour creating sufficient support for people with complex needs in community-based settings as stated in Article 19 of the UN Convention on the Rights of Persons with Disabilities.

Pursuing the Commission Communications on "Increasing the employment of older workers and delaying the exit from the labour market"¹² and on "The future of health care and care for the elderly: guaranteeing accessibility, quality and financial viability"¹³ the Commission should pay special attention to the situation of **ageing** people with severe disabilities and complex needs. Especially it should ensure that reforms of pension systems and access to care do not discriminate against this group of people. The Commission should encourage further research in this area and promote the importance of differentiated services for younger and older people with complex needs.

4 Recommendations for Action at National Level

The objective of all national policies and practices in favour of people with severe disabilities or complex needs should be inclusion as full citizens with all juridical, political and social rights. In order to achieve these objectives, Member States should establish high quality support in the framework of mainstream services, thus avoiding social exclusion by special services.

Member States should ensure equal opportunities and non-discrimination in all their legislation and effectively protect people with severe disabilities and their carers from discrimination in all areas of life. This should pay special attention to the exclusion of this group from disability services due to the severity of their disability.

9/ COM(2004) 304 final

10/ COM(2000) 284 final

11/ COM (2006) 614 final

12/ COM(2004) 146 final

13/ COM(2001) 723 final

Member States, service providers and disability NGOs should focus on awareness-raising and **promote respect, solidarity and inclusion** for people with severe disabilities in their country. They should ensure that this group of citizens are visible and included in all public activities and policies. Specific possibilities for independent entitlement counselling of people with complex needs and their families should be established. This counselling should focus on support and activities available in mainstream settings. They should also support people with severe disabilities in the planning of their personal future and of transitions into different life phases.

Member States, service providers and disability NGOs should focus on awareness-raising and promote respect, solidarity and inclusion for people with severe disabilities in their country.

Service providers should become more creative in **including people with severe disabilities or complex support needs in mainstream services**. Specialist providers of disability services should focus on supporting people with disabilities in mainstream settings. The process of implementing non-discrimination policies at local community level should be accompanied and guided by participative forms of local planning. To implement this, training and retraining of professionals is crucial. While to date most are still trained under the old 'medical' model, more community-based services professionals should be trained.

Member States should ensure in all areas of life that life planning procedures are compulsory for all people with complex needs or severe disabilities.

Member States should ensure in all areas of life that **life planning procedures are compulsory** for all people with complex needs or severe disabilities. Adequate resources and staff training must be ensured for this purpose. Disability NGOs should support individuals and their families in these processes. Stakeholder cooperation should be implemented as a working method in this context.

4.1 Specific Recommendations

In the area of **prenatal diagnosis and counselling**, Member States should ensure compulsory counselling services that inform parents of a child with complex needs realistically about problems and chances of their child. An expected severe disability should in no way negate this obligation nor lead to an automatic abortion. If families choose to have a child with severe disabilities, Member States should provide legal guarantees against future discrimination of family members because of this choice, e.g. by insurance companies, medical professionals or in the work place.

Self-help groups of parents and family members play an important role in prenatal counselling. Disability NGOs should take up the important task to support parents of an unborn child with a severe disability in this difficult phase. They should also engage with support of the Member States in awareness-raising for the value of a life with disability and complex needs. Service providers should ensure in cooperation with local authorities that pre-natal counselling is available and accessible in all areas of a country. They should ensure a good intersectoral cooperation with medical services and self-help groups for a professional non-directive counselling.

NGOs should create self-help groups of parents and other family members of children with severe disabilities to empower them in the implementation of the rights of their disabled family member.

Member States should aim to develop a comprehensive education system that is able to provide inclusive education for all children within their local community.

In **early childhood**, special support for children at risk must be obligatory for all health and social services. Member States should ensure that early intervention services are integrated into the mainstream health system, available in all their territory and free of charge. Legislation must aim at the implementation of services and networks. This should include awareness-raising for the specific needs of children with severe impairments and the challenges for their families. Training in child handling and communication should be provided to family members of children with complex needs. Service providers should ensure that planning of socially normal life-course

transitions starts in early **childhood**, involving family members as well as different professionals. This planning should be based on the model of normal life stages of a child and sufficient resources should be allocated for the planning process.

NGOs should create self-help groups of parents and other family members of **children** with severe disabilities to empower them in the implementation of the rights of their disabled family member. Service providers should develop programs for awareness raising and training of staff of all normal settings for children and young people with a view to improving possibilities for their participation in normal activities of their age group. Member States should guarantee the right of each child to live and grow up in their original family with all necessary and sufficient support. Legislation should ban the placement of children with disabilities in residential institutions with long-term hospital character. Foster care and family oriented services with small group structures should be implemented as alternatives for families who cannot care on a permanent basis for their severely disabled child.

Transition to **pre-school and school** should always allow parents and children the choice of inclusive schooling as guaranteed by the UN Convention. Member States should ensure that this option is available without any discrimination based on the severity or complexity of support needs.

Member States should aim to develop a comprehensive education system that is able to provide inclusive education for all children within their community. All **children** with severe disabilities and complex needs should have the right and possibility to attend inclusive mainstream education and schools. It is absolutely necessary that Member States provide adequate support for these children, including a training of the staff of mainstream schools, individualised curricula, barrier-free environments and professional support. Schools need enough resources to educate all children with different needs in heterogeneous classes. Special education should be the exception in duly justified cases and home schooling must be reduced. In **vocational training**, governments should ensure that employment is seriously considered as an option for all people with disabilities. Vocational training then should be provided in mainstream settings with necessary adaptation of the curriculum. This should also be an explicit focus of research initiated by effective incentives.

National governments should ensure that people with severe disabilities can exercise their civil rights in practice.

Governments should develop policies against the automatic exclusion of people with severe disabilities from **work and employment**. The status of “not employable” should never be assigned permanently to anyone, but be subject to periodic reviews for everyone. Furthermore, States should promote valued life roles for adults outside of employment. Service providers and NGO’s from the disability sector should cooperate with those from the **employment** sector in order to promote better work opportunities for people with severe disabilities

National governments should ensure that **health care and qualified rehabilitation programs** are accessible to people with complex needs in all areas of their countries. Initial training of medical professionals should include a mandatory component on severe disabilities and multiple impairments. National legislation should also ensure equality in all **social security** systems whose benefits should be sufficient to address the needs of severely disabled children and adults.

Governments should provide sufficient financial resources for youth work and other fields of nonobligatory activities that promote inclusive mainstream **leisure activities** for children and adults with severe disabilities. To facilitate participation in mainstream leisure activities, government policy should ensure free transportation and free entry tickets for personal assistants as well as the right to participate in adult education.

Legislation should aim at creating barrier-free environments and service providers should create flexible support arrangements for the specific needs of people with severe disabilities. Service providers should train assistants to provide support outside of special settings in the framework of mainstream leisure time events.

Governments should develop and implement a housing policy that remedies the present lack of choices for people with severe disabilities.

Governments should develop and implement a **housing** policy that remedies the present lack of choices for people with severe disabilities. In all legislation and policies concerning housing, Member States should ensure that affordable options are available for families with

a member with severe disabilities. This may include apartments with an extra bedroom for a support worker, noise insulation, extra equipment, wider doors, etc. Service providers should develop concepts of how community living of people with severe disabilities can be supported adequately.

Member States should ensure by law that there is no discrimination in the access to supported housing options. Housing policy should support barrier-free housing opportunities that should be available in all parts of countries. The availability of individualized support services should be ensured, backed by person-centred financing mechanisms like personal budgets or direct payment schemes accessible to all people with disabilities without discrimination. Member States should implement a strong anti-discrimination policy in the housing market.

Member States should cooperate with service providers and disability NGOs to ensure the right of people with severe disabilities to **partnerships** and to start a **family**. Awareness should be raised for the life situation of disabled men and women, their wish to experience sexuality, partnership and family life. Sterilization against the will of a person should be outlawed.

National governments should ensure that people with severe disabilities can exercise their **civil rights** in practice. Education must ensure that self-advocacy skills are promoted to participate in democracy. Legislation related to legal capacity should be revised on the basis of Article 12 of the UN Convention.

Access to day care and meaningful activity must be guaranteed for **ageing** people with complex needs through the implementation of services. Furthermore, any discrimination in the access to health or palliative care services must be outlawed. Services Providers from the health, disability and older people sector should be obliged to cooperate and create new support services for ageing people with complex needs.

5 Proposal for a European Action Plan

The work for equal rights and equal opportunities of people with complex needs and/or severe disabilities has to be undertaken at different levels. Most important is action at local level where people live and need support. However, stakeholders at European level can support these necessary developments. The following list proposes the most important actions that the European Commission, the European Parliament and European disability NGOs can undertake to fight against the discrimination of people with complex needs and/or severe disabilities:

- Develop a **Commission Communication** on better inclusion of people with complex needs and severe disabilities in all European policies reviewing the different policy areas mentioned in these recommendations and emphasizing concrete actions on how to include the interests of this group in European policies.
- Organise meetings of the **European Parliament Disability Intergroup** and of the **Disability High Level Group** focusing on severe disabilities and complex needs.
- Encourage all **European disability NGOs** receiving a running cost grant from the European Commission to develop special actions for the benefit of people with severe disabilities or complex needs.
- Support the creation of a **European Special Interest Group on Severe Disabilities and Complex Needs** that encourages the cooperation of different specialized European NGOs representing people with severe disabilities and complex needs with a view to provide grants for regular meetings of such a group.
- Focus the theme of the **European Day of Disabled Persons 2009** on people with severe disabilities and complex needs.
- Encourage Member States to develop during the **European Year against Poverty and Social Exclusion 2010** specific actions to raise awareness of the social exclusion of people with severe disabilities or complex needs and their families.
- Discuss with Eurostat procedures to **collect reliable statistical information** on people with severe disabilities and/or complex needs and their families.
- Include as a central element of the monitoring mechanism set up by the UN Convention on the Rights of People with Disabilities the requirement to prove, in all policies that affect people with severe disabilities, that their specific situation has been considered and that they actually benefit on an equal basis from the implementation of these policies.

Photo Acknowledgements

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

People with severe disabilities and/or with complex needs and their families are at risk of discrimination in almost all areas of life. They are mostly not considered in policy development and implementation at local, regional, national and European level. It is high time for all stakeholders to undertake positive action against the high risk of discrimination of this group of European citizens.

These are some of the conclusions drawn by the participants of the “Study on the Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs” that was financed by the European Commission. The study was managed by the Commission’s Unit for the Integration of People with Disabilities (Unit G3) in the Directorate General for Employment, Social Affairs and Equal Opportunities.

Inclusion Europe, the European Association of People with Intellectual Disabilities and their Families, was responsible for the coordination and implementation of the study. The research work has been lead by Dr. Johannes Schädler of the Zentrum für Planung und Evaluation Sozialer Dienste (ZPE) of the University of Siegen. Twelve National Research Experts from Belgium, the Czech Republic, France, Germany, Italy, Lithuania, the Netherlands, Poland, Romania, Spain, Sweden and the United Kingdom were responsible for collecting and analysing national data and representatives of nine European NGOs contributed to the development of the policy recommendations.

The results and recommendations of the study are presented in four Volumes:

- **Volume I: Policy Recommendations**
- **Volume II: Research and Analysis**
- **Volume III: Country Reports and Stakeholder Interviews**
- **Volume IV: Examples of Good Practice**

They are available on the website of the European Commission at ec.europa.eu/employment_social/disability or on Inclusion Europe’s website at www.inclusion-europe.org.

