

Inclusion Europe

The European Association of Societies of Persons with Intellectual Disability and their Families

Inclusion Europe is a non-profit organisation. We campaign for the rights and interests of people with intellectual disability and their families. Our members are national organizations from 34 countries in Europe.

People with intellectual disability are citizens of their country. They have an equal right to be included in society, whatever the level of their disability. They want rights, not favours.

People with intellectual disability have many gifts and abilities. They also have special needs. They need a choice of services to support their needs.

Inclusion Europe focuses on three main policy areas:

- Human Rights for people with intellectual disability
- Inclusion in society
- Non-discrimination

Inclusion Europe coordinates activities in many European countries, including projects, conferences, working groups and exchange meetings. It responds to European political proposals and provides information about the needs of people with intellectual disability. Inclusion Europe advised the European Commission and members of the European Parliament on disability issues.

Inclusion International

Inclusion International (II) is a global federation of family-based organizations advocating for the human rights of people with intellectual disabilities worldwide. II represents over 200 member federations in 115 countries throughout five regions Middle East and North Africa, Europe, Africa and the Indian Ocean, the Americas, and Asia Pacific.

II is one of the largest international disability non-governmental organizations and 1 of 5 disability-related organizations to be officially recognized by the United Nations. Through its national members, regional level organizations and global organization, II works with international agencies including the World Health Organization (WHO), United Nations Educational, Scientific and Cultural Organization (UNESCO), World Bank, United Nations Economic and Social Council (ECOSOC), International Labour Organization (ILO), United Nations International Children's Fund (UNICEF), and regional bodies to promote inclusive approaches to policy, practice and investment strategies.

Poverty and Intellectual Disability in Europe



Report



Supported by the Norwegian Association for Persons with Developmental Disabilities (NFU)



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Foreword

Inclusion Europe and Inclusion International work in Europe and around the world to promote the inclusion of people with intellectual disabilities in all aspects of community life. We are proud to present this report as our collaborative effort and we wish to extend our thanks to the Norwegian Association for Persons with Developmental Disabilities for their support of this global project on poverty and disability.

In every region of the world people with intellectual disabilities and their families are among the poorest of the poor. In each region there are countries and sub-regions that are significantly disadvantaged. Europe is no exception. While Europe as a whole is an economically strong region, the link between poverty and disability is as clear and alarming as it is in other regions of the world. What data exists shows massive unemployment, poor access to education and social and cultural exclusion from the community. The impact of this poverty and social exclusion on family members includes reduced labour market participation, increased costs related to the person's disability and social and cultural exclusion from the community. Families are the vital link between a person with an intellectual disability and their community and yet they themselves face barriers to participation in the community.

This study is the third in a series of five regional studies (the Americas, Europe, the Middle East and Asia) that will contribute to a global report on poverty and disability. Relative to other regions of the world, Europe is rarely thought of as a region where poverty is a significant issue, yet poverty is linked to disability in Europe both at a country level in transition economies and within wealthier countries of the European Union. In EU countries, a response to this issue requires that countries build strategies for inclusion of people with intellectual disabilities and their families in their National Action Plans for Social Inclusion. In transition economies the World Bank reports that "the changes brought by the transition to a market economy required a complete redesign of social protection systems. This includes changes in labour market and other instruments designed to increase the level of community involvement and decrease the level of exclusion."¹ As these reforms progress, a key question raised by this initiative is whether the models of social welfare for people with intellectual disabilities and their families are the only option available to countries in transition or if there are other options for consideration.

More research and data in the area of poverty and intellectual disability in Europe is needed to better understand the issue of multiple disadvantage and to develop policy responses. However, without efforts to link the voices of real people to the process of policy development little will be achieved. Even among other excluded groups in society and people with other forms of disability, the perspectives and experiences of people with intellectual disabilities themselves and their families are poorly understood and rarely heard.

We hope that the findings of this study will help to draw attention to the experiences of people with intellectual disabilities and their families and to provide a way to make their voices heard by governments at different levels.

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¹ <http://web.worldbank.org/WBSITE/EXTERNAL/COUNTRIES/ECAEXT/EXTECAREGTOPSOCPRO/>

Executive Summary

Many persons with intellectual disabilities and their families across Europe experience poverty and social exclusion. In the context of the present study, Inclusion Europe and Inclusion International have attempted to identify the causes of this situation. This report provides an overview of the situation of persons with intellectual disabilities and their families drawing from their own stories and from what research and data exists. It also puts forward measures and policy recommendations that decision-makers at local, national, European level need to take into account to improve the current unacceptable situation.

Disabled persons tend to be poorer than the general population. Also, people living in poverty are more likely than others to be disabled. Poverty and disability reinforce each other, contributing to increased vulnerability and exclusion. Not only does disability exacerbate poverty by increasing isolation and economic strain for the individual, but it also affects the *family and relations* of the person with the disability. The study attempted to capture the situation of persons with intellectual disabilities and their families with respect to aspects of monetary poverty (low income, resulting from various income-related programmes or unemployment) and non-monetary poverty (limited access to mainstream education, health care, housing, community life and participation in policy processes).

In many European countries, income-related schemes for persons with intellectual disabilities are inadequate to meet their actual needs. It is now well known that the presence of a disability causes extra costs for the disabled individual or her/his family. According to the results of our survey, the most common unreimbursed expense incurred by families and individuals with intellectual disabilities is **formal or informal care giving**. Next comes health care, followed by the acqui-

sition of various aids and devices and costs of services (rehabilitation, therapies or day care). Costs related to care giving remain a major concern for families of persons with intellectual disabilities. The survey points out that the majority of persons with intellectual disabilities in Europe continue to live with their families as adults. Care giving is mostly done by mothers, and other women in the family and impacts on the family's status in the labour market and, consequently, on its income. Parents also experience many difficulties in reconciling their professional and private lives when taking care of their dependent child. The parents of children and adults with intellectual disabilities are therefore often victims of "discrimination by association".

Our research shows that the extra costs related to disability supports and lost income are inadequately compensated for by pensions, allowances, benefits, travel concessions, tax relieves, care allowances, training allowances, etc. People with intellectual disabilities and their families bear the burden of these costs privately and as result they are unable to participate and contribute economically and to their communities. Compensation of individuals and families for these extra costs is an important element in a strategy to develop inclusive societies; societies that maximize the human potential of all citizens.

Various attitudinal, legal, physical and social barriers faced by people with intellectual disabilities continue to prevent access to the labour market. Despite the measures taken (i.e. setting up incentives schemes for employers, developing the skills of persons with disabilities to enable them to access employment, providing specific employment supports for persons with disabilities and employers, etc) the employment rate of persons with intellec-

tual disabilities continues to remain extremely low as compared to the employment rate of the general population.

The majority of persons with intellectual disabilities in Europe experience difficulties in accessing mainstream education due to negative attitudes of either schools or communities. Most measures taken by national governments focus on increasing support (i.e. school resources, adequate training of the teaching staff, adaptation of the curriculum) in order to facilitate and increase the access of children with intellectual disabilities to education.

Persons with intellectual disabilities also face discrimination when making use of the mainstream health care systems. The inadequacy of most health care systems in Central and Eastern Europe puts persons with intellectual disabilities and their families in these countries at a further disadvantage as they are often the lowest priority within the system. As a result they deal with high costs of medical care. Inadequacy of mainstream health care systems also concerns some of the "old" member states of the European Union. As a consequence of both the general lack of availability of health care services and poor access, persons with intellectual disabilities have poorer health status than the general population.

Persons with intellectual disabilities in many European countries continue to live in segregated institutions, which is one of the most striking examples of social exclusion. This is often the result of inadequate community supports and services for individuals and for families. The extreme poverty faced by families in Eastern and Central Europe means that families are given few alternatives but institutionalisation of their family member. Conditions within some countries in Central and Eastern Europe are below any acceptable standard. The research conducted among the member societies of Inclusion Europe in the framework of this project clearly demonstrates that poverty and social exclu-

sion of persons with intellectual disabilities and their families is much more prominent in the countries of Central and Eastern Europe. It is essential that specific measures be taken to ensure the human rights and social inclusion of this group of citizens in their societies.

The report concludes that no coherent framework for actions designed to support and implement the inclusion of persons with intellectual disabilities has been developed. This failure is partly due to the lack of understanding and information about the scope and dimension of the policy issues. European and national census data make it difficult to get a clear picture of the number of persons with intellectual disabilities and also to identify households where there is a person with an intellectual disability. Additional information concerning the situation of persons with intellectual disabilities as well as their level of participation in community life is essential. References to disability should be included in the list of indicators used to evaluate social inclusion policies.

Given the complexity of social exclusion, one major challenge for local, national, European and world decision-makers is the mainstreaming of intellectual disability in various policies. Disability issues need, therefore, to be included in the planning, implementation, monitoring, evaluation and revision of policies and actions at all levels – locally, regionally, nationally and internationally.

The European Union has to take over the specific responsibility to address the link between intellectual disability, poverty and social exclusion in its policies on social inclusion and employment. It should monitor specifically the actions and policies of Member States to ensure that this vulnerable group of European citizens can take part in all aspects of European societies.

1 Introduction

The report on “Poverty and Intellectual Disability in Europe” is the outcome of a project developed by Inclusion Europe in cooperation with Inclusion International and with the financial support of the Norwegian Association for Persons with Developmental Disabilities (NFU). The project is part of a three-year global initiative seeking to learn about the experiences and challenges associated with poverty of persons with intellectual disabilities and their families and to develop strategies for addressing their economic and social exclusion.

The draft report was debated during a conference on poverty and intellectual disability organised in Bucharest, Romania, on 21-22 October 2005. The final report, containing also the results of the conference debates will be included in Inclusion International’s upcoming Global Report on the Status of People with Disabilities in the Millennium Development Goals, to be launched at the 14th World Congress of Inclusion International in Acapulco, Mexico in 2006.

The study on Poverty and Intellectual Disability in Europe is based on:

1. Answers to a **questionnaire on poverty and intellectual disability** provided by member associations of Inclusion Europe;
2. A review of existing literature on poverty and intellectual disability;
3. Focus groups organised with several Romanian associations for persons with intellectual disabilities and their families, all of them members of Inclusion Romania. The basis of the focus group discussions was a questionnaire adapted by Inclusion Europe.

The questionnaire used in the drafting of the report intended to provide an overview

of the living and working conditions of persons with intellectual disabilities in Europe as well as of legislation, policies and initiatives aimed at addressing poverty in general, as well as poverty of persons with intellectual disability and of their families in particular. 24 answers were received, coming mainly from member associations of Inclusion Europe in 21 European countries².

As a part of a global initiative to “*link local voices to global change*” this study along with regional studies from other parts of the world is based on the premise that the experience and knowledge of people who themselves experience poverty and disability are the best experts in developing strategies to combat exclusion. The multidimensional nature of poverty and social exclusion requires knowledge not only about the status of people with intellectual disabilities and their families (for example data) but also about the combined impact of public policies and measures on real people’s lives. By listening to the voices of people who live the reality of exclusion we can better understand and therefore address the complexity of barriers that exist in communities and in our unique context.

1.1 Understanding poverty and social exclusion for persons with disabilities

Before embarking upon a study of the situation of persons with intellectual disabilities and their families who are often living in poverty and excluded from the life of their communities, one needs to understand the conceptual framework around notions such as “poverty” and “social exclusion”.

² The member associations of Inclusion Europe gave 22 answers. The National Authority for People with Disabilities of Romania and the Romanian Association “Esperando” also provided answers.

There are various definitions and interpretations of the concept of *poverty* underlining, for instance, strategies and policy actions of different organizations. The general trend is to identify poverty as a multi-dimensional phenomenon³. Thus, the Copenhagen World Summit for Social Development of 1995 as well as the Millennium Development Goals assume that poverty is multidimensional. The World Bank also defines poverty as unacceptable deprivation in terms of economic opportunities, education, health and nutrition, as well as lack of empowerment and security. The United Nations Development Programme (UNDP) introduces the concepts of *human development* (i.e. a process that enlarges people's choices including freedom, dignity, self-respect and social status) and *human poverty* (i.e. deprivation of essential capabilities such as a long and healthy life, knowledge, economic resources and community participation).

The Organization for Economic Cooperation and Development (OECD) identifies

five dimensions in which people "are deprived and perceived as incapacitated in different societies and local contexts"⁴. These dimensions point to various ranges of capabilities, as follows:

- *Economic capabilities* (i.e. the ability to earn an income, to consume and to have assets);
- *Human capabilities* (i.e. health, education, nutrition, clean water and shelter, which are core elements of well-being as well as crucial means to improving livelihoods);
- *Political capabilities* (i.e. human rights, a voice and some influence over public policies and political priorities);
- *Socio-cultural capabilities* (valued participation to the community life) and
- *Protective capabilities* (important for preventing poverty as they enable people to withstand economic and external shocks).

All of these dimensions are interrelated as each of them affects and is affected by the others, pointing out the multidimensional nature of poverty.

Case Study

Poverty and intellectual disability in the Ukraine

"In the Rehabilitation Institute for people with intellectual disabilities there is a boy named Andrey. He is 9 years old and has a Down syndrome. His mother is alone and he lived all his life in a room without windows. Everything is in this single room: bedroom, kitchen, toilet, etc. His mother is a street cleaner and has only a very minimum income.

When the boy came to the center (at that time, he was 5 years old), he could not walk. His mother needed to work to earn their living and she left him at home without care. For his safety she seated him in a corner, put around him chairs and left him a piece of bread. It is not necessary to tell that he could not walk because he had no possibility to move, and he could not speak because he had no possibility to communicate with anybody during his entire life.

Now they still live in the same room but the boy's condition has improved. He can now walk and even run very well. He has a good vocabulary, likes to speak and all people of the center like him very much.

The Centre undertook many meetings with city authorities and had many promises to improve their living conditions, but so far nothing happened. Perhaps the new government will finally solve this problem."

Source: Yanush Koprchac Rehabilitation Institute for People with Intellectual Disability, Ukraine, 2005

³ See the *Human Development Report 2003 – "Millennium Development Goals: A compact among nations to end human poverty"*, UNDP, New York-Oxford, 2003 and *The DAC Guidelines. Poverty Reduction*, OECD 2001.

⁴ *The DAC Guidelines*, OECD, pp. 38-39

At the European level, an “official” definition of poverty⁵ has emerged in the wake of the programmes against poverty and has been retained as a reference by the European Union ever since:

“By poor we mean people, families or groups of people of whom the resources (material, cultural and social) are so limited that they are excluded from the minimal standards of living recognized as acceptable in the member states where they live.”
(Council Decision of 19 December 1984)⁶.

This is known as the *relative poverty* definition and was made operational by the Statistics Office of the European Communities, Eurostat, by means of relating it to the notion of income as a reference threshold:

“A household is considered to be poor when its income places it underneath a certain level, known as the poverty line, and which stands at 60% of the net median income standardized by unit of consumption.”

Concretely, this definition links poverty to low income and inequalities in income distribution. Although the definition emphasizes the multidimensional character of poverty, the notions of either minimal or acceptable standards of living remain

rather vague. So do the contents of the mentioned resources (material, cultural and social)⁷.

Besides its multidimensional nature, the definition also points out the *dynamic* aspect of poverty, as a *process* leading to social exclusion.

Historically speaking, René Lenoir seems to be the first to make use of the term “social exclusion”⁸ in 1974, the excluded comprising disparate groups, from socially unadjusted to disabled or elderly people⁹. Further studies attempt to clarify the relative poverty definition used by the European Union, in the idea of providing the adequate indicators for measuring the two concepts. Thus, the concepts of poverty and social exclusion are seen as *complementary*¹⁰ (rather than *alternative*). The idea of **deprivation** and **lack of resources** appear as the basic components of poverty, which can be therefore defined as **deprivation due to lack of resources**, for example in the form of:

- a. cash income – needed to access the market of goods and services;
- b. income in kind – to meet certain needs directly; and
- c. public services – in areas such as health and education, that are partially or totally protected from the market.

⁵ Ramón Peña-Casas, Christophe Degryse, Philippe Pochet, *European Strategy in the Field of Poverty and Social Exclusion*, European Social Observatory, 2002, p. 11

⁶ *On Specific Community Action to Combat Poverty* (Council Decision of 19 December 1984), EEC (1985), 85/8/EEC, Official Journal of the EEC, 2/24.

⁷ Ramón Peña-Casas and Philippe Pochet, *Les indicateurs monétaires et non-monétaires de pauvreté et d'exclusion sociale dans une perspective européenne*, Observatoire social européen, 2001, p. 21-22

⁸ Generally, the concept of social exclusion is defined by linking it to three relational spheres of integration:
- the economic sphere (comprising issues that pertain to employment and unemployment as well as lack of resources, which is said to be the “field” of poverty);
- the non-use or the non respect of fundamental rights at the social, political and civil level;
- the social relations, that might be deteriorated by an economic crisis or by the non respect of the rights, thus triggering a process of social relegation (ibid., p. 24).

⁹ R. Lenoir, *Les exclus : un français sur dix*, Le Seuil, Paris, 1974 in Ramón Peña-Casas and Philippe Pochet, *Les indicateurs monétaires et non-monétaires de pauvreté et d'exclusion sociale dans une perspective européenne*, p. 23

¹⁰ *Non-Monetary indicators of Poverty and Social Exclusion*. Final Report of the project “Non-monetary indicators of well-being”, CESIS, pp.17-19. For more information, see <http://europa.eu.int/comm/eurostat/research/index.htm?http://europa.eu.int/en/comm/eurostat/research/supcom.95/&1>

Social exclusion is seen as **including** the notion of poverty, which implies two conditions to be satisfied by the two concepts; firstly, the notion of poverty has to answer the question “exclusion from what?”, since the concept of exclusion implies the idea of being in/out of some context. Poverty may be understood as exclusion from basic social systems (i.e. markets of goods and services, labour market, health system, social security system, educational system, etc.). Secondly, social exclusion implies weak or broken social links, but “cannot be seen exclusively in this perspective. Indeed there are forms of poverty that do not necessarily lead to relational exclusion and therefore could not be considered as social exclusion”¹¹.

What is seen as the “**added value**” of the concept of social exclusion in relation to poverty is that the former allows the consideration of types of exclusion that do not result from lack of resources (and cannot, therefore, be considered as poverty).

The idea of evolution is also common to the notion of social exclusion, in the sense of a process leading progressively to more exclusion. When analysing the situations of poverty and of social exclusion, it is interesting to examine the *mechanisms* that lead to them, especially those less characteristic to individuals and more to the society (dynamics within the societies).

Disabled people as a group are poorer than the general population, and people living in poverty are more likely than others to be disabled¹². Poverty and disability reinforce each other, “contributing to increased vulnerability and exclusion”¹³. Not only does disability exacerbate poverty, by increasing isolation and economic strain for the individual, but it also affects the *family* of the respective disabled individual. The result of the “vicious” cycle of poverty and disability is that persons with disabilities are usually among the poorest as compared to the rest of the population.



Source: *Disability, poverty and development*, DFID, February 2000

¹¹Ibid., p.18

¹²Ann Elwan, *Poverty and Disability. A Survey of the Literature*, The World Bank, 1999

¹³*Disability, poverty and development*, Department for International Development (DFID), 2000, p. 2

¹⁴Ibid., p. 4

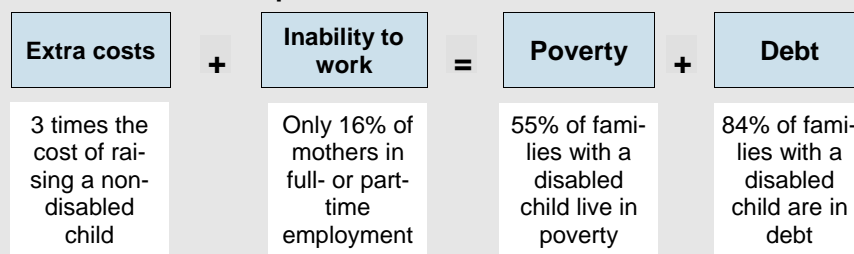
Since poverty is both a cause and a consequence of lack of access to a number of opportunities (educational, health care, employment, etc), it seems clear that, “in a powerful sense, **poverty is in itself dis-**

abling. [...] When physical or mental impairment is added to this ‘poverty syndrome’, the result is almost always devastating for the individual concerned, their families and for society”¹⁵.

Case Study Families with disabled children in the UK

At least 55% of families with a disabled child live in poverty. 84% of families with disabled children are in debt as compared to 47% of all households.
More than 80% mothers of disabled children are unemployed.
31% of families supporting a disabled child are one-parent families.
It costs three times more to raise a disabled child than to raise a non-disabled child.

The financial equation of families with a disabled child



Source: Cathy Langerman et Eve Worrall, *Ordinary lives. Disabled children and their families. A guide for donors and funders*, New Philantropy Capital, juin 2005.

1.2 The European Union strategy against poverty and social exclusion and its relevance for persons with intellectual disabilities

One important process aimed at combating poverty and social exclusion at the level of the European Union was initiated in 2000 during the European Council in Lisbon. The so-called “Lisbon process”

was preceded by some targeted actions (aimed at groups with specific needs, among which, the disabled) as well as by a poorly financed poverty programme set up at the end of the 70s. Next came the recognition under Articles 136 and 137 EC of the Amsterdam Treaty of combating social exclusion as one of the fields where the Community had an active role in supporting and complementing the activities of Member States.

¹⁵Bill Albert, Rob McBride & David Seddon, *Perspectives on Disability. Poverty and Technology*, A Report to Healthlink Worldwide and GIC Ltd, University of East Anglia, Norwich, 2002, p. 18

¹⁶The European Union is an international association of 25 Member States that have ceded some of their sovereign rights to the European Community and have conferred on it powers to act independently. The institutional mechanism of the European Union is made up of the European Commission, the European Parliament, the Council of the European Union, the Court of Justice of the European Communities and the European Court of Audit. The Council and the Parliament share the legislative power, while the executive power is exercised by the Commission (which can initiate legislative proposals and is also the “guardian” of the constituting treaties of the European Union), the Council and the Member States. The European Parliament is also responsible for the drawing up of the EU budget. The Council of the European Union (i.e. a distinct institution of the EU) must not be mistaken for the European Council. The latter refers to the regular summits of the chiefs of EU Member States and governments that give the general policy orientations of the Union, i.e. the overall political vision of the EU.

At the European Council in Lisbon the need was expressed for a new initiative aimed at directing member states in combating poverty and social exclusion. This initiative set as a strategic goal the EU becoming *"the most competitive and dynamic knowledge-based economy...with more and better jobs and greater social cohesion"*¹⁷. This should eventually lead to the eradication of poverty by 2010. The Council also agreed that Member States should co-ordinate their policies for combating poverty and social exclusion on the basis of an open method combining common objectives, National Action Plans and a Community action programme.

In December 2000 the Nice European Council launched the Open Method of Co-ordination in the field of combating poverty and social exclusion and defined a common set of four objectives as follows:

1. *To facilitate participation in employment and access to resources, rights, goods, and services for all;*
2. *To prevent the risks of exclusion;*
3. *To help the most vulnerable;*
4. *To mobilise all relevant bodies.*

European Union definitions of poverty, social exclusion and social inclusion

Poverty: People are living in poverty if their income and resources are so inadequate that they exclude them from having a standard of living considered acceptable in the society in which they live. Because of their poverty they may experience multiple disadvantages through unemployment, low income, poor housing, inadequate health care and barriers to lifelong learning, culture, sport and recreation. They are often excluded and marginalized from participating in activities (economic, social and cultural) that are the norm for other people and their access to fundamental rights may be restricted.

Social exclusion: Social exclusion is a process whereby certain individuals are pushed to the edge of society and prevented from participating fully by virtue of their poverty, or lack of basic competencies and lifelong learning opportunities, or as a result of discrimination. This distances them from job, income and education opportunities as well as social and community networks and activities. They have little access to power and decision-making bodies and thus often feeling powerless and unable to take control over the decisions that affect their day to day lives.

Social inclusion: Social inclusion is a process which ensures that those at risk of poverty and social exclusion gain the opportunities and resources necessary to participate fully in economic, social and cultural life and to enjoy a standard of living and well-being that is considered normal in the society in which they live. It ensures that they have greater participation in decision making which affects their lives and access to their fundamental rights.

Source: *Joint Report on Social Inclusion*, Directorate General for Employment and Social Affairs, European Commission, 2004

¹⁷Lisbon European Council, 23-24 March 2000, Presidency Conclusions; for the entire text, see http://www.europarl.eu.int/summits/lis1_en.htm#a

National Action Plans for social inclusion (NAPs inclusion), seen as an important contribution to the modernisation of the European social model, are supposed to play a key role in this process, as they should translate the common objectives into national policies, while taking into account their individual national circumstances and the particular nature of national social protection systems and social policies.

Inclusion Europe's analysis of the NAPs' process has nevertheless shown that, at the national level, this is not very visible and/or transparent, which gives, for instance, civil society, few chances to influence policy making in the area of social exclusion.

The European Commission has sought to put disability onto the social policy agenda and, more specifically, in the context of social inclusion, it has identified disabled people as a vulnerable group¹⁸ at particular risk of exclusion. Despite various measures taken by the majority of the EU member countries for the promotion of the

social cohesion and the integration of persons with disabilities, various studies conducted in Europe show that:

- Persons with disabilities are particularly exposed to social exclusion;
- The average family income is considerably inferior for a household counting one person with disabilities;
- There is a clear link between the severity of the disability and the degree of poverty and exclusion
- Women with disabilities are often victims of poverty and social exclusion;
- Persons with disabilities living in institutions are not generally confronted with significant poverty but are victims of major social exclusion¹⁹.

The Commission has also developed indicators that identify persons with disabilities as a group at risk of poverty and social exclusion. However, these indicators are not very operational, hence the significant lack of official statistical information with respect to persons with disabilities, which comes out as one of the main findings of our research.

National Action Plans on Social Inclusion

“Disability represents a risk to an individual to become disadvantaged in relation to other members of the society. This disadvantage can even lead to social exclusion. Persons with severe disabilities are most at risk. Notwithstanding the many measures, which were recently adopted in order to prevent social exclusion of this group of people, certain both direct and indirect forms of discrimination appear to prevail in many areas. Comprehensive valid statistical data on numbers and structure of people with disability are still not available and estimates rely on sample inquiries and studies. A study conducted in 1993 on the occasion of preparations for a national plan on countering adverse effects of disability estimated that the number of people with disabilities was 10%

¹⁸“The vulnerable groups [...] Disabled people: All Member States are developing a wide range of actions and instruments to improve the employment situation of disabled people. Merely looking after the financial needs of disabled people through cash benefits is insufficient; as it would still leave many excluded from the labour market and often from society more generally. In addition to vocational rehabilitation and training measures, various types of employment assistance schemes are offered to the persons with disabilities: employment subsidies, sheltered jobs and continued assistance with disability aids and related costs once a person makes the transition from benefits to paid employment”- Joint Report on Social Inclusion, Directorate General Employment and Social Affairs, European Commission, 2004, pp. 50-51

¹⁹*Handicap et exclusion sociale dans l'Union européenne. Le temps du changement, les outils du changement. Rapport d'étude final* – project supported by the European Commission, 2002; the participating organisations were the following: the National confederation of people with disabilities of Greece, the National Councils of Spain, France, Finland and Sweden, Mental Health Europe, Inclusion Europe, the European Blind Union and the European Disability Forum.

of the total population, or 1,200,000 people. Thus, this group of people with specific needs is significant in number, but it is also a very heterogeneous group, depending on type and degree of handicap.

Persons with disabilities living in social institutions are among those who are most at risk of social exclusion. Approximately 19,000 of them live in these institutions permanently (of which 15,000 suffer from mental or multiple disabilities)."

Source: *The National Action Plan on Social Inclusion, 2004-2006, Czech Republic*

"Since 1998 policy towards the disabled in Germany has [...] undergone a paradigm change and realised the biggest legislative reforms since the 1970s, which have noticeably improved the lives of disabled people. It has greatly improved the access of disabled people to the labour market by means of decisive action and concrete targets. Unemployment among severely disabled people, which at an annual average of 18% was well above the general unemployment rate of 11.1%, has fallen sharply to 15.4% (2002).

However, since then the general development of the labour market has also been felt by the severely disabled. The Federal Government will continue along this path and further strengthen the equality and self-determined participation of people with disabilities."

Source: *Strategies to Enhance Social Integration, National Action Plan against Poverty and Social Exclusion, 2003-2005, Germany.*

Difficulties that have been identified²⁰ with respect to the idea of a EU disability policy seem to arise from the fact that each member state's disability policy is a mixture of a number of different policies for different groups. Thus, what counts as disability policy in one state might come under another sphere of policy in another state. For example, some states have separate disability social assistance categories whereas others have a general scheme of social assistance which encompasses provision for the disabled.

While in various communications, the Commission suggests that the "social model" of disability is the one that should be taken into account, it does not advance a common definition of disability. It thus sees disability and disabled persons as a natural target for policies to promote social inclusion. However, this conception has not really been operationalised which means that employment rates among dis-

abled persons and other measures of the well-being of the disabled are proposed as indicators of an aspect of social exclusion and potential benchmarks for disability policy.

The Council of Europe²¹ Action Plan to promote the rights and full participation of persons with disabilities in society also does not contain a definition of disability, as it agrees that this is a matter for individual member states and their national policy. The plan mentions all areas of life of persons with disabilities, but makes only indirect references to poverty.

The Plan aims to provide a comprehensive framework that is flexible as well as adaptable in order to meet country-specific conditions. It is intended to serve as a roadmap for policy makers, to enable them to design, adjust, refocus and implement appropriate plans, programmes and innovative strategies²².

²⁰Deborah Mabbet, *Disability and Social Exclusion in Europe*, Brunel University, 2003, p. 2. The author of the paper also refers to an extensive study performed by the Brunel University with the support of the European Commission in 2002: *Definitions of Disability in Europe. A Comparative Analysis*

²¹The Council of Europe is an intergovernmental organisation, distinct from the European Union, that was established in 1949. It currently groups 46 countries, among which 21 are from Central and Eastern Europe.

²²Draft Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006 – 2015.

A recent study of Inclusion Europe²³ demonstrates that persons with intellectual disabilities have difficulties in access to rights and justice in all EU Member States and accession countries, as well as in other Council of Europe member states. Equal access to rights and justice is fundamental in order to reduce poverty and social exclusion and to strengthen democratic governance.

Due to this limited access to their rights, persons with intellectual disabilities often lack the possibilities to fight actively against their social exclusion. Justice and administrative reforms with the objective to accommodate those who are disadvantaged would therefore lead to the empowerment of people to stand up for their own rights. After centuries of social exclusion, persons with intellectual disabilities are increasingly committed to claim their rights and to use the justice system, if necessary. Governments and the European Union have the obligation to support this process by making sure that all their citizens, without exception, have access to rights and justice.

1.3 Basic data on disability in Europe

There is a clear lack of understanding and information about the scope and dimension of disability in Europe. Eurostat and national census data from Member States make it difficult to get a clear picture of the number of persons with intellectual disabilities, but also to identify household data where there is a person with an intellectual disability.

In a study on the situation of employment of the disabled people in 2002, Eurostat considers the population with “long-standing health problem or disability (LSHPD)”²⁴, understanding by “disabled persons”, “those who have stated they had a longstanding health problem or a disability (LSHPD) for 6 months or more or expected to last 6 months or more”.

According to Eurostat²⁵, the prevalence of this group in the “old” member states of the European Union is the following:

Prevalence of long-standing health problems or disability (LSHPD), EU Member States

	B	DK	D	EL	E	F	IRL	I	L	NL	A	P	FIN	S	UK
Total	18.4	19.9	11.2	10.3	8.7	24.6	11.0	6.6	11.7	25.4	12.8	20.1	32.2	19.9	27.2
Females	17.9	21.1	10.3	10.6	8.0	24.6	10.5	6.3	9.6	26.4	11.6	21.6	33.6	21.7	27.8
Males	18.9	18.8	12.2	9.9	9.4	24.3	11.6	7.0	13.7	24.5	14.0	30.7	30.7	18.2	26.7

Eurostat provides separately the situation for the acceding, candidate (some of

which have become EU member states) and EFTA countries:

Prevalence of long-standing health problems or disability (LSHPD), acceding, candidate and EFTA countries and geographical aggregates

CZ	EE	CY	LT	HU	MT	SI	SK	NO	RO	EUR12	EU15	ACC	ALL	
20.2	23.7	12.2	8.4	11.3	8.5	19.5	8.2	16.4	5.8	14.1	16.4	14.3	15.7	Total
21.1	24.2	11.1	8.5	11.3	7.3	19.1	8.2	17.4	6.5	13.9	16.3	14.5	15.6	Females
19.2	23.1	13.4	8.3	11.3	9.7	19.9	8.1	15.5	5.0	14.4	16.5	14.0	15.7	Males

²³ *Equal Rights for all! Access to Rights and Justice for People with Intellectual Disabilities*, Inclusion Europe Brussels, 2005

²⁴ Didier Dupré – Antti Karjalainen, *Employment of disabled people in Europe in 2002*, Theme 3 – 26/2003, Eurostat, 2003

²⁵ *Ibid.*, pp. 2-3.

Further on, it is quite difficult to tell exactly who are the persons with intellectual disabilities from the following table provided by Eurostat within the same study.

their level of participation in the life of the community is necessary. References to disability should be included in the list of indicators used to evaluate social inclusion policies²⁶.

Additional information concerning the situation of persons with disabilities as well as

Distribution (%) of population with long-standing health problems of disability (LSHPD)

	EU-15	ACC	All		
			F	M	All
Total of all LSHPD	100.0	100.0	100.0	100.0	100.0
Type of LSHPD					
Arms or hands	6.6	3.8	7.1	5.8	6.4
Legs or feet	11.4	14.0	11.3	12.0	11.7
Back or neck	19.0	17.1	18.8	18.1	18.5
Difficulties in seeing	2.6	4.3	2.6	3.0	2.8
Difficulties in hearing	2.1	1.2	1.6	2.4	2.0
Speech impediment	0.3	0.4	0.3	0.4	0.4
Skin conditions	2.6	3.6	2.7	2.5	2.6
Chest or breathing	10.6	6.1	9.9	10.1	10.0
Heart, blood pressure or circulation	12.5	20.6	12.2	15.4	13.8
Stomach, liver, kidney or digestive	5.1	7.1	5.3	5.6	5.4
Diabetes	4.0	4.6	3.6	4.5	4.1
Epilepsy	1.4	1.2	1.3	1.4	1.3
Mental, nervous or emotional	9.6	7.7	9.5	9.4	9.5
Other progressive illnesses	3.4	2.0	3.8	2.5	3.2
Other LSHPD	8.9	6.2	9.9	6.9	8.4
Cause of LSHPD					
Born with it or birth injury	17.9	10.8	16.5	17.3	16.9
Work-related diseases	13.3	12.8	10.8	15.6	13.2
Work-related accident or injury incl. traffic accidents at work	5.6	3.5	2.8	7.7	5.2
Traffic accident or injury (outside of work)	3.3	2.4	2.7	3.7	3.2
Household, leisure and sports, accident or injury	3.5	3.6	3.1	3.9	3.5
Non-work-related diseases	50.2	56.6	55.8	44.8	50.3
Do not know	6.1	10.4	8.4	7.1	7.7
Duration since onset					
Less than 1 year	8.1	5.0	7.7	7.7	7.7
1 =< years < 2	7.8	5.8	7.7	7.4	7.5
2 =< years < 3	8.7	7.4	8.7	8.5	8.6
3 =< years < 5	13.7	13.6	13.9	13.7	13.8
5 =< years < 10	22.2	25.9	22.6	22.4	22.5
> = 10 years	39.4	42.2	39.4	40.3	39.8

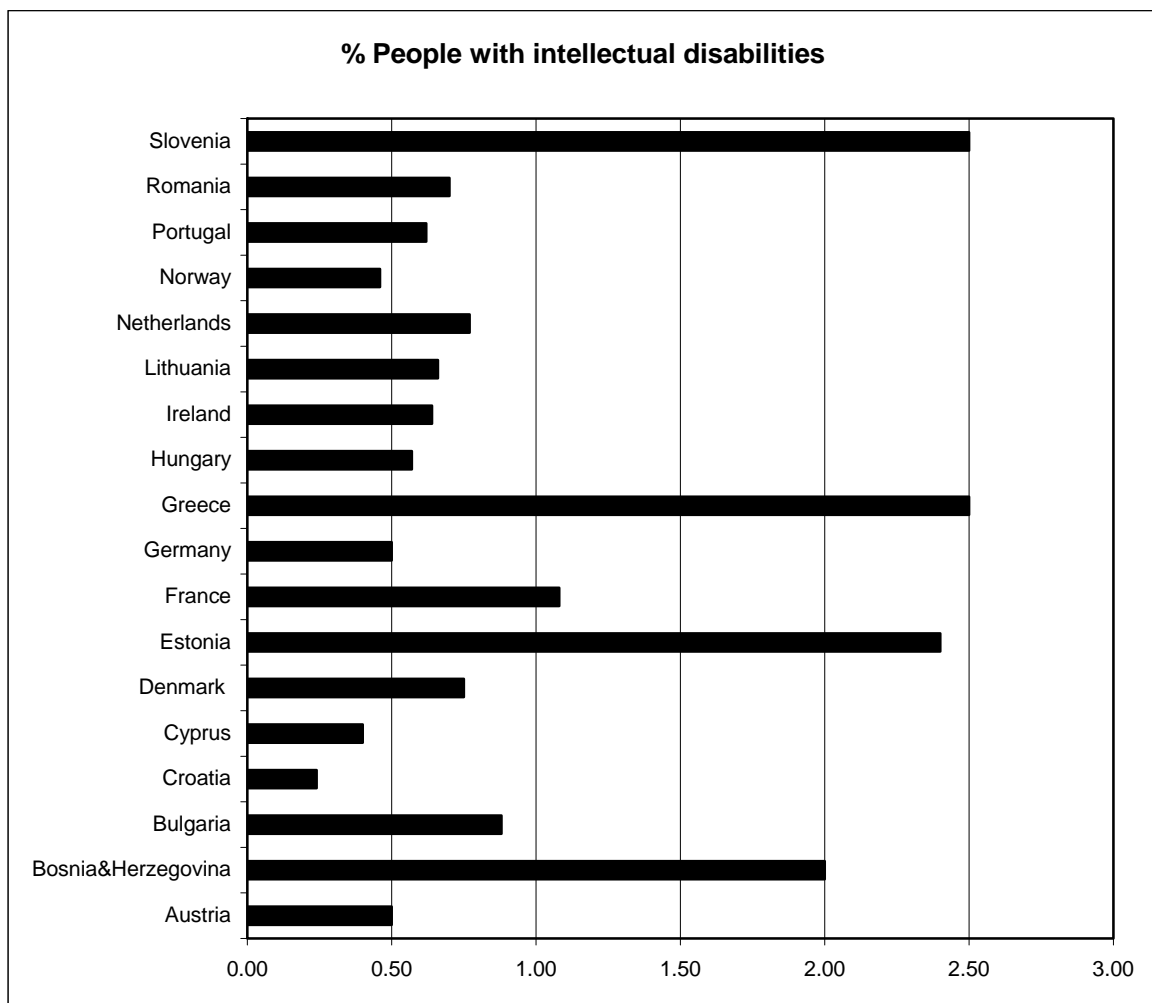
²⁶ *Handicap et exclusion sociale dans l'Union européenne*, p. 89

2. Conditions of Poverty and Social Exclusion for Persons with Intellectual Disabilities and their Families

The purpose of this study is to identify and better understand the dimensions of exclusion and poverty of persons with intellectual disabilities and their families in Europe. Official statistics at the national and European level do not provide data on the particular situation of persons with intellectual disabilities nor do they help to identify their families. Inclusion Europe's 36 national member organizations are an important source of information and knowledge about the lives and living conditions of persons with intellectual disabilities. These organizations support and advocate for persons with intellectual disabilities and their families across Europe.

It is generally recognized that poverty trends are directly related to the level and quality of employment and to the systems of income support²⁷. The information provided in this section of the report is drawn from 24 responses to a questionnaire (Annex II) in 21 European countries.

According to the information from our members, the estimated percentage of persons with intellectual disabilities of the country population of a country varies significantly. This is the reflection of different definitions of intellectual disability.



²⁷ National Plan Against Poverty and Social Exclusion 2003-2005, Ireland, p.3

Case Study

Eugenia, 20 years of age, is a girl with a moderate intellectual disability, who attends "Pentru Voi", Timișoara day centre. She has an organized family, lives with her both parents and has one brother and three sisters. They are living in a house with three rooms, one kitchen, toilet and no bathroom. They have no hot water and no central heating and during winter they are heating only one room.

Eugenia's mother has health problems and needs surgery. Her father is a daily labourer. Two of her sisters are not working. The third sister is still in school. Her brother has severe disabilities and needs permanent medical assistance. He receives from the State Inspectorate for People with Handicap a monthly allowance of 63 RON per month (= 20 EUR). Their mother is his personal assistant.

The family income is 540 RON (approximately 150 EUR) per month. The monthly necessary family expenses are as follows:

- rent for the house	14 EUR
- electricity	9 EUR
- water	11 EUR
- food	100 EUR
- wood for heating	152 EUR
- medication for the mother	<u>20 EUR</u>
Total	306 EUR

Many families therefore are in debt with their rent, electricity and water bills and are not able to heat their houses properly in the winter.

Source: Inclusion Romania, 2005

Within the category of intellectual disability, there are different estimations of the level of disability, for instance, from 4.1% persons with profound disabilities in Ireland to 4.19% in Macedonia, 5% in Slovenia and Greece, 11.11% in Croatia, 13.21% in Romania, 15% in Bulgaria and 19% in Cyprus.

It is difficult to clearly distinguish disability levels within the group of persons with intellectual disabilities, as classifications and definitions of disability vary from country to country. Germany, for example, groups persons with mild and moderate intellectual disabilities together - comprising about 80% of the total population of persons with intellectual disabilities - and persons with severe and profound intellec-

tual disabilities – who are 20% of all persons with intellectual disabilities. In Lithuania, persons with severe and profound disabilities are also counted together in "Disability Group I", representing 13% of the total population of persons with intellectual disabilities, followed by "Disability Group II", i.e. persons with moderate intellectual disabilities comprising 60% of the population, and "Disability Group III", persons with mild intellectual disabilities who make up 27% of all persons with intellectual disabilities.

In some countries, the authorities collect statistical information for policy and planning purposes, in other countries only estimated figures are available.

²⁶ *Handicap et exclusion sociale dans l'Union européenne*, p. 89

Case Study

Poverty and Intellectual Disability in Slovenia

The most typical example of poverty in Slovenia is a person with an intellectual disability living at home alone with his/her old mother. If the mother is a peasant (such cases are numerous), her pension is very low, sometimes lower than social allowances. The only income that this person with a disability has is his/her disability allowance, which makes the family income very low.

Assuming that the person with a disability receives 230 Euro per month and his/her mother another 100 Euro. Their joint income is 330 per month. This is an amount which does not provide for a normal life in Slovenia. Their situation is worse if they own a house, as they must consequently pay taxes.

Members of our member societies are mostly parents from lower social classes with usually low incomes. As our members, they are at least given the possibility to obtain various compensations (bonuses, trips, etc). Parents from higher social classes usually solve their problems with their own money. For instance, they can afford different expert services needed by their children at an early age and are not yet provided free of cost in Slovenia. Poorer parents cannot afford such services. The gap between the poor and the rich becomes bigger and bigger.

Source: SOZITJE Association, Slovenia, 2005

2.1 Low income levels of persons with intellectual disabilities

In the design of the questionnaire for this study, we have assumed that the income of persons with intellectual disabilities and their households mainly comes from two sources: various social transfers (either cash or in-kind contributions) and employment. We therefore required information on the following potential sources of disability-related income support that families and individuals with intellectual disabilities are able to access:

- Pensions / allowances / benefits
- Travel concessions
- Tax relieves
- Care allowances
- Subsidies and training allowances
- Others

We have equally attempted to capture information on the specific expenditure for support to persons with intellectual disabilities at the national level. Most of the

time, this information proved to be unavailable, in some instances there was information available only on national expenditure for all categories of disabilities. Only in a few countries, figures were available on the expenditure for support of persons with intellectual disabilities. Bulgaria spends about 13.650.000 EUR in Bulgaria, including expenses for personnel in residential institutions and day care centres. Cyprus spends approximately 8.000.000 EUR and Germany up to 10,9 Billion EUR (2003 figure) for persons with intellectual disabilities.

The most common form of cash support for persons with intellectual disabilities appears to be the disability allowance. The amounts vary across Europe from 40 – 45 EUR per month in Romania and Bulgaria, 55 - 65 EUR in Hungary and Estonia, 230 EUR in Slovenia, 250 EUR in Greece, 500 EUR in Cyprus, 600 - 700 EUR in France, Germany or Ireland and 1.800 EUR in Denmark.

Case Study

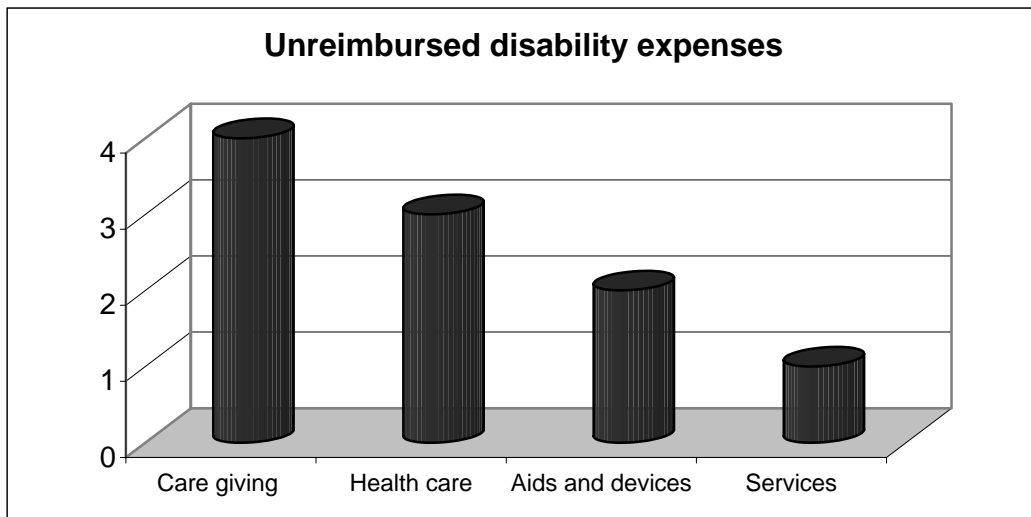
Florin is a 25 year old autistic man. He attends the day centre for adults with intellectual disabilities of Inclusion Romania in Bucharest. He receives a monthly subsidy of 140 RON (approximately 40 Euro). His mother, a widow, is employed as personal carer for her disabled adult son and has a monthly salary of 320 RON (approximately 90 Euro). The salary is provided by the Department of Social Assistance, Bucharest. 460 RON (130 Euro) is their total monthly income.

In Romania, according to the Gallup survey (October 2004), the subsistence income for one person in urban area is 650 RON and in the rural area is 390 RON. Thus, the family in this case study lives far below the poverty line.

Source: *Inclusion Romania, 2005*

It is commonly recognised²⁸ that the presence of a disability causes extra costs for the disabled individual or her/his family. According to the results of the survey, the most common un-reimbursed disability and care giving expense incurred by families and individuals with intellectual dis-

abilities is considered to be care giving (formal or informal). Next comes health care, followed by the acquisition of various aids and devices and costs implied by services (rehabilitation, therapies or day care).



Case Study

Poverty and Intellectual Disability in Estonia

The family lives in the capital of Estonia, Tallinn. The mother has a Masters degree in psychology and she teaches at the university; the father is a linesman. They have two children, the older son is 12 and is severely disabled and the younger is 7 years old. The family owns a private plot from Soviet Union times in the nice area of the city. Both parents work, but the salary rates Estonia for ordinary people provide the family with less income than the Estonian average.

²⁸See, for instance, Noel Smith, Sue Middleton, Kate Ashton Brooks, Lynne Cox and Barbara Dobson with Lorna Reith, *Disabled people's costs of living. More than you would think*, University of Loughborough 2004

Because of lack of money and additional costs required for the disabled child as well as due to the fact that the family needs to spend more time to take care of their child, their living conditions are below the average standards of living. The family lives in a 30 m² cold, damp wooden house that was constructed 50 years ago. They only have cold water and the toilet is outside the house.

Lack of money and services makes it impossible for the family to take vacations or to spend money for cultural activities. All their income goes to food and first-level basic needs. The low income of the family is not due to the lack of education or to the unemployment of one family member. The reasons of their poverty are low salaries, additional costs caused by the disability, insufficient support from the government, and the lack of services.

Source: Estonian Mentally Disabled People's Support Organisation, Estonia, 2005

2.2 Employment of persons with intellectual disabilities

It is commonly recognised that labour force participation is much lower for disabled people²⁹. According to Eurostat, 78% of people with severe disabilities aged 16-64 are outside the labour force as compared to 27% of people without long-standing health problems or disability

(LSHPD). Even among those considered to be in the labour force, the unemployment rate is nearly twice as high among persons with disabilities as compared to the non-disabled. Also, the more severe the degree of disability, the lower the participation in the labour force: only 20% of persons with severe disabilities as compared to 68% for those without LSHPD.

Distribution of the population with LSHPD severity and percentage of the population with specific characteristics in each LSHPD severity group (%)

	EU 15	EU 12	ACC	All		
				F	M	All
Total (%)	100.0	100.0	100.0	100.0	100.0	100.0
Very severe	5.2	5.4	6.3	5.8	5.5	5.7
Severe	4.3	4.4	3.7	4.2	4.0	4.1
Moderate	3.1	2.8	1.3	2.7	2.7	2.7
Mild	6.7	5.6	3.0	5.9	6.0	5.9
Without LSHPD	80.7	81.8	85.7	81.7	81.7	81.6
Employed (%)						
Very severe	18.8	22.5	14.3	18.7	20.3	19.5
Severe	45.7	42.4	35.9	39.7	48.6	44.1
Moderate	67.8	64.4	57.7	59.1	73.7	66.7
Mild	76.6	67.8	69.1	68.3	82.3	75.6
Not disabled	68.8	64.7	66.4	58.1	77.2	67.6

²⁹Didier Dupré and Antii Karjalainen, *Employment of disabled people in Europe in 2002*

Unemployed (%)						
Very severe	2.8	3.0	3.9	2.6	3.4	3.0
Severe	5.6	5.5	9.3	5.5	6.6	6.0
Moderate	6.2	5.8	6.9	5.4	7.0	6.2
Mild	3.5	3.8	3.9	3.3	3.7	3.5
Without LSHPD	5.3	5.7	6.4	5.5	5.4	5.4
Inactive person (%)						
Very severe	78.4	74.6	81.8	78.7	76.3	77.5
Severe	48.7	52.2	54.8	54.8	44.7	49.8
Moderate	26.0	29.8	35.5	35.5	19.3	27.1
Mild	20.0	28.4	27.0	28.4	14.0	21.0
Without LSHPD	26.7	29.6	27.2	36.4	17.4	26.9
Unemployment rate (%)						
Very severe	12.8	11.7	21.6	12.2	14.2	13.3
Severe	10.9	11.4	20.6	12.1	12.0	12.1
Moderate	8.4	8.3	10.6	8.4	8.6	8.5
Mild	4.3	5.4	5.4	4.6	4.2	4.4
Without LSHPD	7.2	8.1	8.8	8.6	6.5	7.4

“The unemployment rate of disabled people and people with long-term health problems in 2002 was three times higher than that of people without disabilities – 26%.”
Source: Estonia’s National Action Plan for Social Inclusion, July 2004

From these official statistics, it is difficult to distinguish exactly the situation of persons with intellectual disabilities. Also, research performed in some European countries shows that employment rates may vary greatly between types of disability. Thus, “people with mental illnesses, learning disabilities or psychic impairments are less likely to be found in employment than people with physical impairments”³⁰.

The issue of the poverty or “at risk of poverty” of persons with disabilities in connection to their participation in the labour market is also acknowledged by the National Action Plans on inclusion:

“Among other reasons, people with disabilities are at a higher risk of poverty because their participation in the labour market and their income from employment are clearly below average.”³¹

Our survey provides a picture of the very poor access that most persons with intellectual disabilities have to employment: 3% for Bulgaria, 12% for Cyprus, 0.5% for Denmark, 2% for Greece, 7% for Hungary, 8.62% for Portugal and 1.24% for Romania. Ukraine and Germany also estimate an employment rate of no more than 1%. Ireland includes in its figures sheltered employment and therefore reaches a comparatively high level of 36%.

³⁰ *The Employment Situation of People with Disabilities in the European Union*, a study prepared by EIM Business and Policy Research, with the support of the European Commission, Directorate General for Employment and Social Affairs, 2001, p. 43.

³¹ Republic of Austria – Second Action Plan for Social Inclusion 2003-2005”, Vienna, July 2003, p. 11. The document identifies a poverty risk rate of people with disabilities of 20% (p. 41).

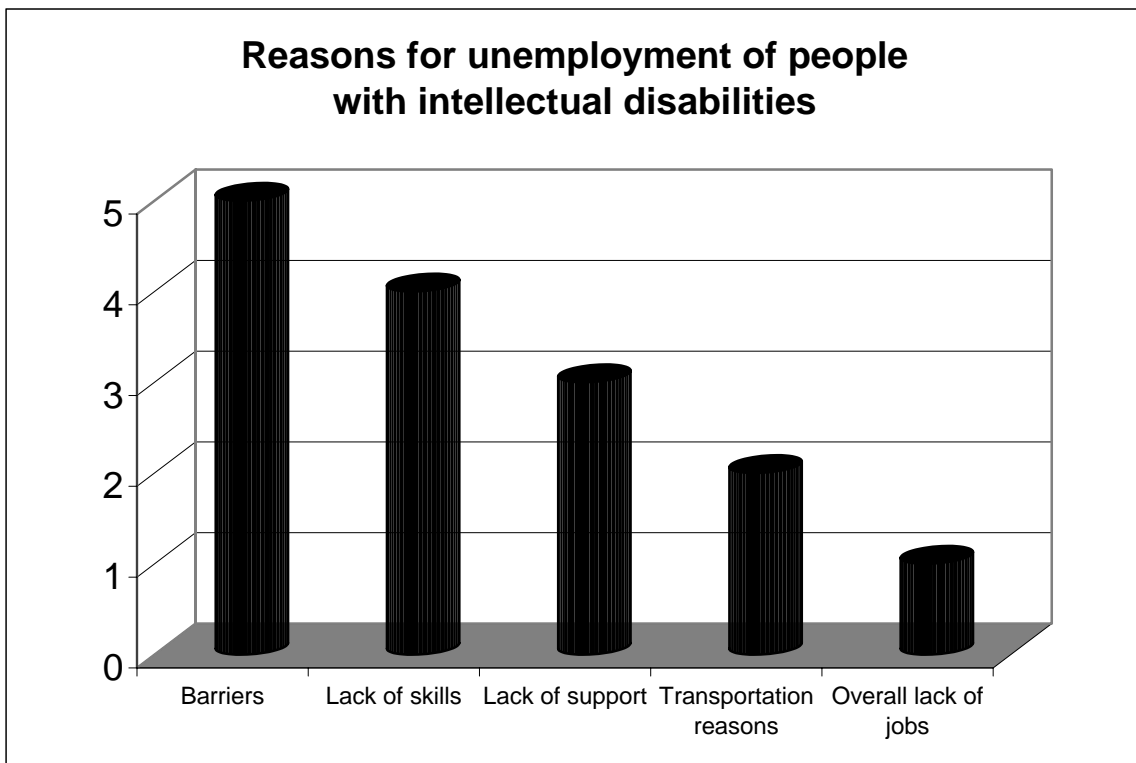
The study reveals significant disparities among the European countries; it also provides some shocking information; in Lithuania, for instance, only 17 persons with intellectual disabilities are employed on the open market (out of 22.121 persons with psychiatric disorders and intellectual disabilities, according to the 2001 census).

The survey points out that among persons with intellectual disabilities who are unemployed, most are unemployed for more than one year. This long-term unemployment is one of the major causes of monetary poverty.

Asked about the possible reasons for the unemployment of persons with intellectual

disabilities, most of the survey respondents named various barriers (attitudinal, legal, physical or social) as a first cause. This is followed by the lack of skills and education that persons with intellectual disabilities experience. The third reason given is the lack of support, followed by transportation reasons and the overall lack of jobs (high overall unemployment rates).

If the survey provides information on employment and unemployment rates of persons with intellectual disabilities, we found it very difficult to establish the inactivity rate.



Case Study

Don Joe's family, Bosnia Herzegovina

"The family lives in a village located 15 km from Tuzla. The family members are parents and children, only the father is employed as a construction worker. The mother has completed primary education and is not employed. She spends her time mostly doing house work and she is the main support to her son with intellectual disabilities. The older son is not disabled and has received training to become a car mechanic, but he is not employed. The youngest member of the family, who has an intellectual disability, was born in 1986. He has epilepsy, sight difficulties, two years ago he got diabetes and is currently undergoing insulin therapy. He has completed a special primary school, attended by children with psychical difficulties. He then went to a secondary school for cooks, also within a programme for persons with psychical difficulties.

He is registered at the employment office, but no job has ever been offered to him. Besides, he does not benefit from social support, except for free health care, because he is enlisted at the employment office.

He has completed his education with much support from his family. During his schooling period, the only support from the government was free public transport for himself and his escort to and back from school. He also benefited from a monthly child allowance of 30 KM (about 15 EUR) granted by the Social Welfare Centre of Tuzla.

The financial situation of the family is extremely modest. The father, as the only one employed for the past eight years, has a monthly salary of 200 to 250 KM (102 to 127 EUR).

The family survives with some additional resources (they work about 1.000 square meters of land, they raise cows and chicken). They spend most of their money on medicines, as they need to buy insulin as well as other medicines. They live in their own house, with good living conditions.

Relations within the family are mostly good. There is understanding for the son with intellectual disabilities but insufficient support from the community has left marks on the family. The mother had to completely devote herself to her son. As a consequence, she neglected her own needs as well as the needs of other family members.

This is a typical situation of a family with a member with intellectual disabilities, indicating the following:

1. Very modest financial situation of the family
2. Insufficient governmental support
3. An insufficiently developed system of social and legal protection
4. Lack of family counselling
5. Training and education are not in accordance with the needs of society
6. There is no support for the employment of persons with intellectual disabilities."

Source: Association "Korak po korak", Tuzla, Bosnia and Herzegovina

2.3 Access to education for persons with intellectual disabilities

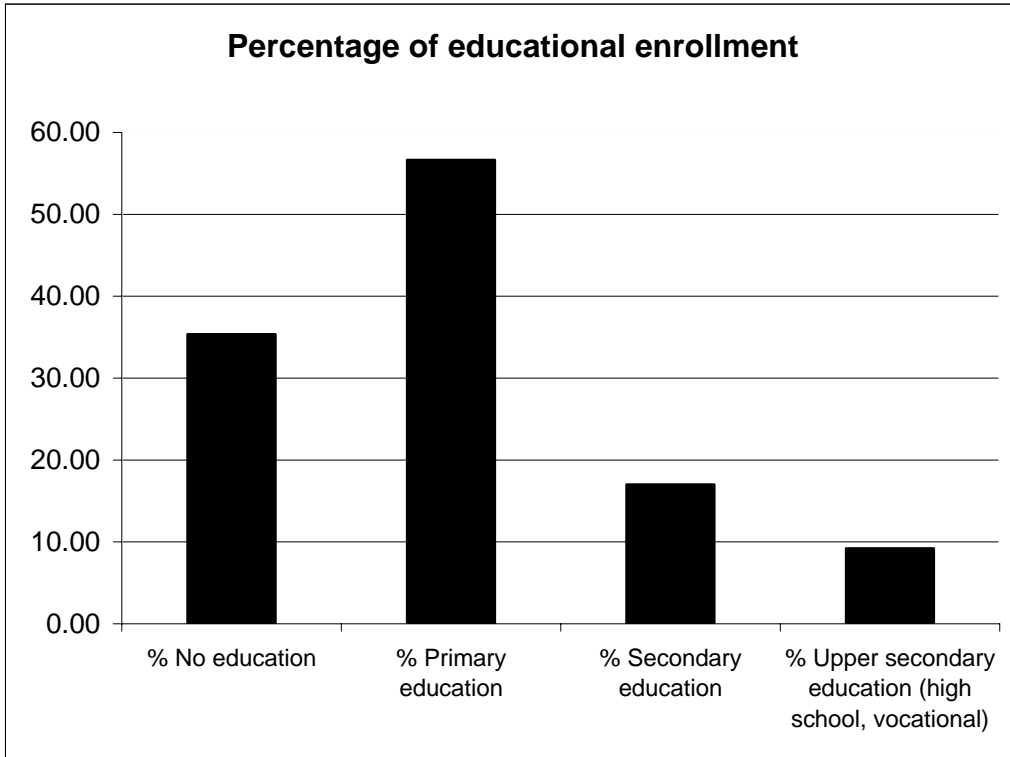
Many studies point out the fact that education has a considerable impact on the social and professional life of an individual. For families who have a child who is denied access to education, the impact is also felt in terms of lost family income and isolation from the community.

Our survey attempted to collect information about the educational attainment of persons with intellectual disabilities in various European countries. Here are the results, based on the estimation of the survey respondents.

Some of the survey respondents also indicated that official information about the overall number of children with intellectual disabilities enrolled in the education system does not exist (Ireland and Macedonia).

The results show that the majority of people with intellectual disabilities attain only primary education. It is expected that the low percentage of persons with intellectual disabilities having pursued secondary or upper secondary education drastically reduce their chances to access the labour

Country	% No education	% Primary education	% Secondary education	% Upper secondary education (high school, vocational)
Austria	-	-	-	-
Bosnia-Herzegovina	-	60	30	-
Bulgaria	25	35	25	15
Croatia	-	-	-	-
Cyprus	15	75	10	0
Denmark	-	70	0	0
Estonia	-	80	2	18
France	-	-	-	-
Germany	-	92	-	-
Greece	88	10	2	0
Hungary	34	46	12	8
Ireland	-	-	-	-
Latvia	-	95	-	-
Lithuania	0	20	70	10
Macedonia	-	-	-	-
Netherlands	-	-	-	-
Norway	-	-	-	-
Portugal	5	45	20	30
Romania	70	20	9	1
Slovenia	0	95	4	1
Ukraine	10.5	50	20	9

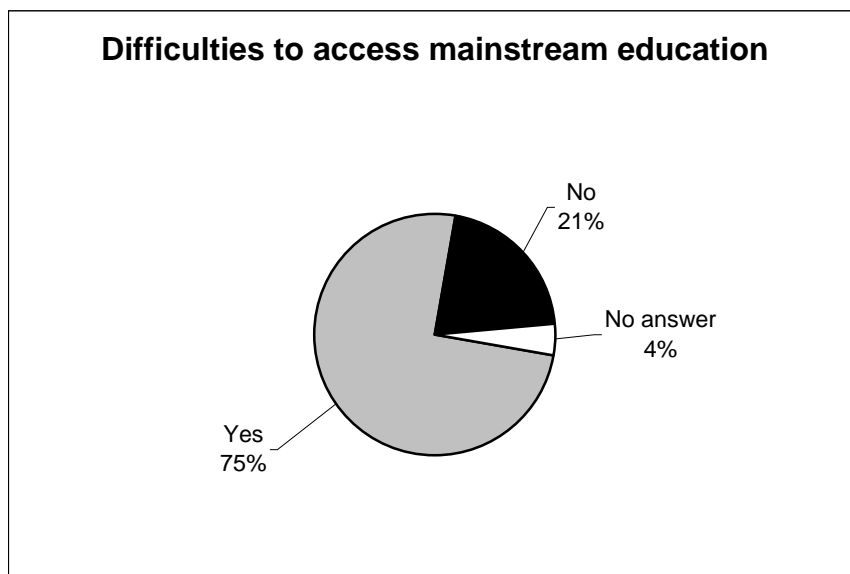


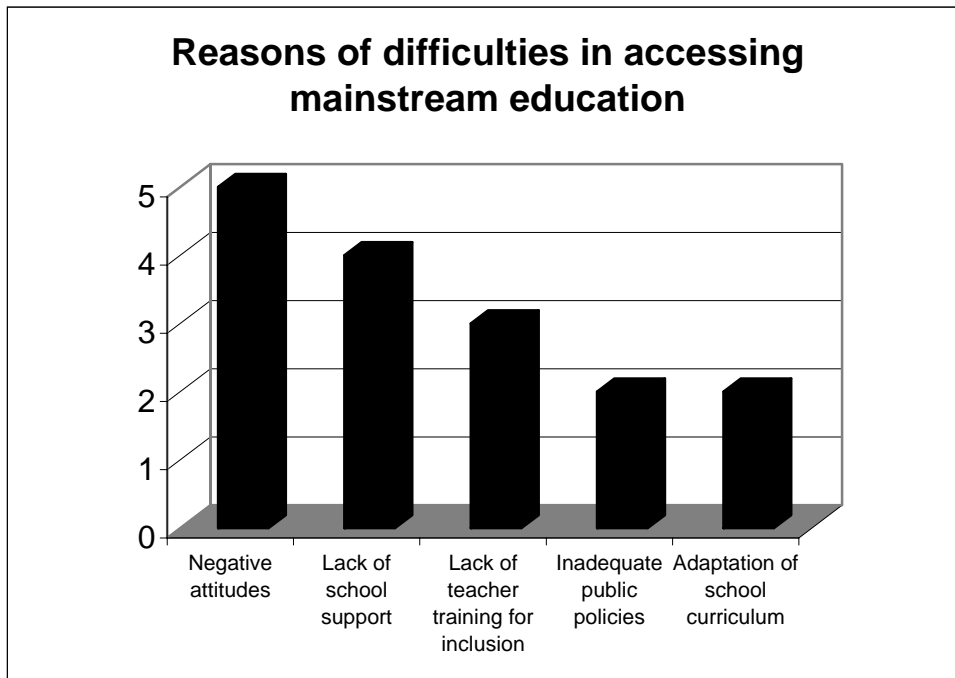
The results of the survey indicate that in most countries studied, persons with intellectual disabilities have difficulties accessing the mainstream education systems.

The reasons given for these difficulties are (in order of importance):

1. Negative attitudes of the school system or the community related to persons

- with intellectual disabilities attempting to access mainstream education
2. Lack of school support, mainly in point of resources
3. Lack of teacher training for inclusion
4. Inadequate public policies
5. Lack of adaptation of the school curriculum.





Case Study

Persons with intellectual disabilities living in poverty in Romania

P.V. is a child with a moderate intellectual disability. He attends a special school. In the first grade, the child attends a mainstream school but he fails for two consecutive years. When he is 14, his mother goes abroad to work. He is left with his father to take care of him. The father is unemployed. Until the departure of his mom, the child showed interest towards a number of activities, such as painting and sports and had many friends.

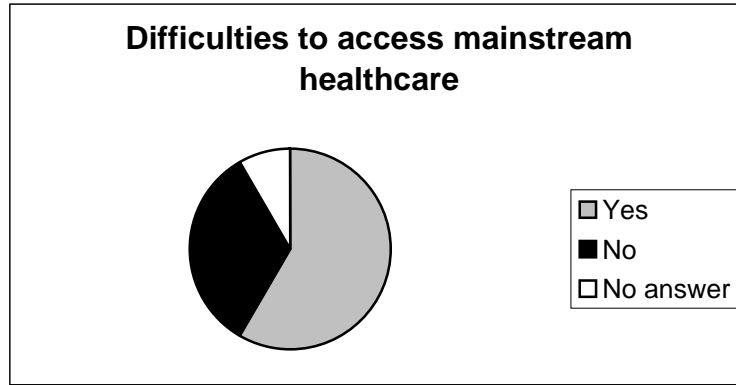
P.V. has a brother who is two years older. The children are in the same grade at school. The father lives in the same room with them and does not get involved in their education. P.V. is doing worse at school and he also has less and less friends.

Source: Inclusion Romania, 2005

2.4 Barriers in access to mainstream health care for persons with intellectual disabilities

Previous research has shown that persons with intellectual disabilities have poorer health status than the general

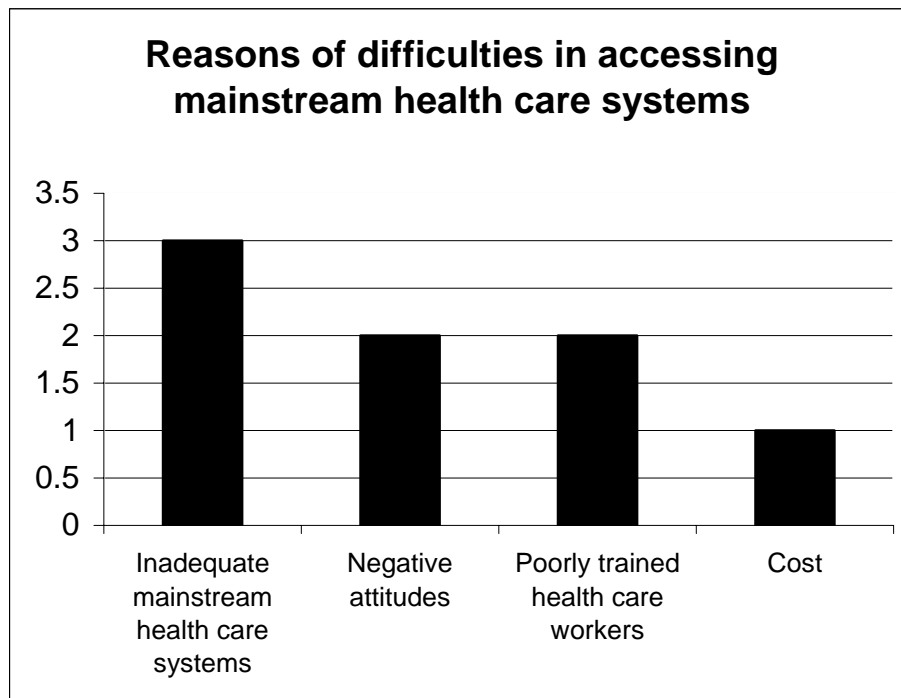
population due to poor access to generic health care and poor living conditions. According to the survey, persons with intellectual disabilities often experience difficulties in accessing the mainstream health care system:



The difficulties are mainly due to the inadequacy of mainstream health care systems, the negative attitudes of the medical staff, the reluctance to provide services to persons with intellectual disabilities and poorly trained health care workers. Cost seems to be a less important factor in accessing mainstream health care systems.

Most countries from the EU15 (including Cyprus) and EEA area that responded to the survey did not identify difficulties in ac-

cessing mainstream health care systems. The situation looks different for the countries in Central and Eastern Europe, which all identified (with the exception of Slovenia) difficulties for persons with intellectual disabilities in accessing mainstream healthcare. There are no major differences identified in the reasons for these difficulties, with the exception of cost, which is more often mentioned by the latter group of countries.



Case Study

P.R. is a girl with intellectual disability. She is 10 years old. Since she was diagnosed, she underwent several treatments in different towns. These are very expensive for her family. When she was 4 years old, her father abandoned her. Now she lives with her mother, but the latter does not always have enough money to buy all the medicines her daughter needs.

The little girl has no friends. She usually accompanies her mother to various places (parks, artistic performances, etc).

Source: Inclusion Romania, 2005

2.5 The situation of families of persons with intellectual disabilities

Studies on the costs of disability³² have established a clear link between disability and poor financial circumstances; disability is likely to result in poverty for disabled individuals and their families.

“Households where the reference person is ill/disabled, unemployed or in home duties are at the highest risk of poverty, with two-thirds of the first group falling below the threshold [...]”.

“The risk of falling below the 60% median income line for households headed by a person who is ill or disabled is 66.5%, compared to the risk of 21.9% for all households.”

Source: National Action Plan against Poverty and Social Exclusion, 2003-2005, Ireland

Families continue to play a major role in care giving for persons with intellectual disabilities. According to our survey, the majority of persons with intellectual disabilities (58.52% according to our data) continue to live with their families, with especially high rates in Greece, Bosnia-Herzegovina, Cyprus and Portugal:

Case Study

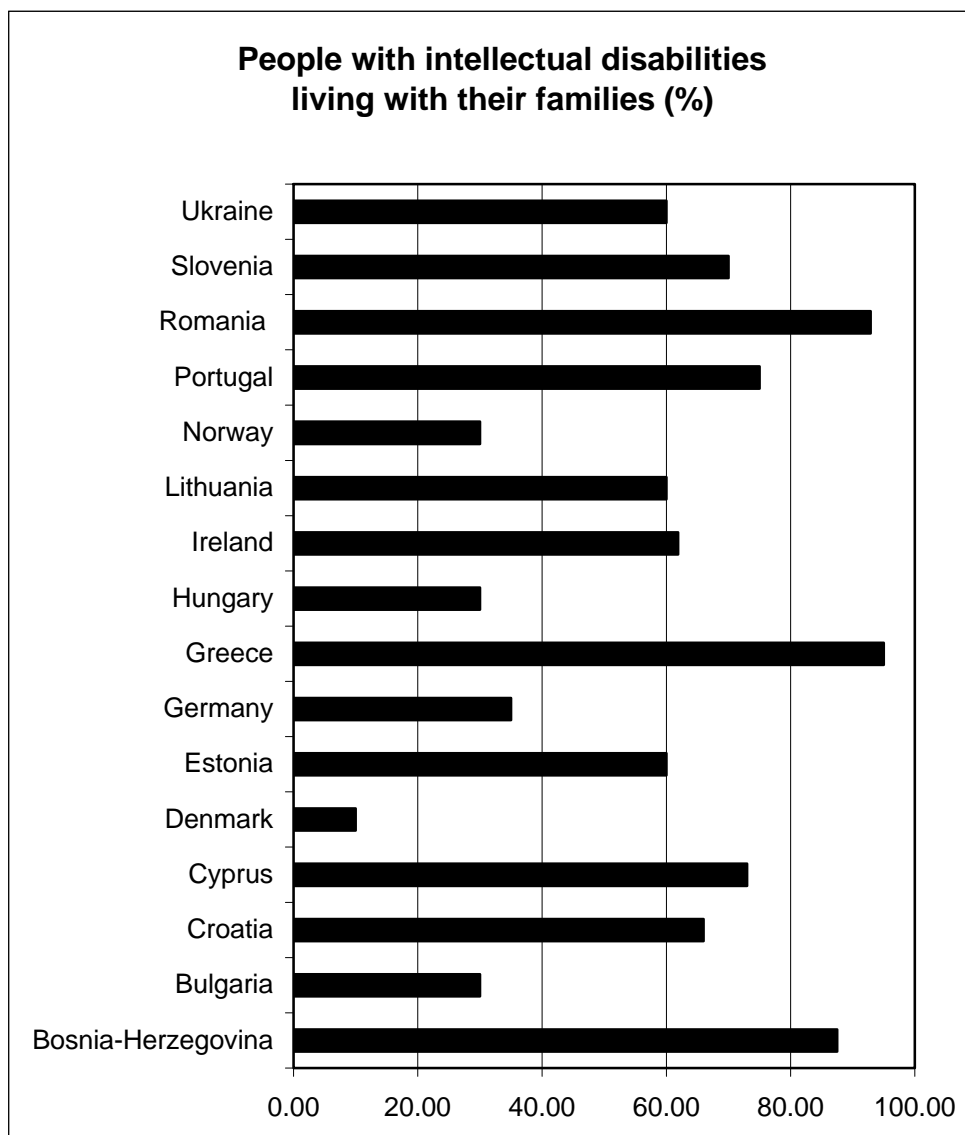
Hungary – poverty and intellectual disability

A mother with five children was left by her husband with one child with a severe disability. The two of them live in a very small village. The mother is taking care of the child and therefore cannot work. They live from the benefits. The child gets no education as no education professional goes to his house.

The child's clothes and diapers have to be changed many times a day, but the mother does not have enough money to buy all of them. She has to wash them all the time.

Source: EFOESZ Association, Hungary, 2005

³²Noel Smith, Sue Middleton, Kate Ashton Brooks, Lynne Cox and Barbara Dobson with Lorna Reith, *Disabled people's costs of living. More than you would think.*



Almost all responses to the survey point out that the **mother** is the family member who is most likely to care for the person with intellectual disabilities. In one instance the father is also mentioned (Germany) together with the mother and in another one, the grandmother (Ukraine), along with the mother.

A study on the situation of families of persons with complex dependency needs in Belgium³³ shows the difficulties that parents experience in the attempt to reconcile

their work and family life because of the demands of taking care of their dependent child. The quality of life of these parents is far from acceptable. For those who are working, having a paid job means an additional stress in the sense that they need to face both care taking and professional responsibilities. For those that stay at home in order to take care of their disabled child, the financial situation is quite difficult and creates tensions within the family. They eventually experience precariousness and social exclusion.

⁹ *Handicap de Grande Dépendance: concilier vie professionnelle et vie personnelle pour les parents*, ANAHM, 2003, p. 56

There are several phases before social exclusion: precariousness, then poverty, followed by social exclusion, i.e. "having lost the sense of social utility"³⁴.

The parents of children with intellectual disabilities are often victims of "discrimination by association". There are many examples, ranging from direct to indirect discrimination. A restaurant that denies access to persons with disabilities, consequently denies their families access.

A family needs to buy or rent an apartment adapted to the needs of their disabled child, which may be significantly more expensive than a regular apartment or home. Renovations and adaptations that might be necessary to make the apartment more accessible to the needs of the child are also costly. Another example of discrimination by association is

when parents are forced to decrease their working time in order to take care of their disabled child instead of the State.

Survey respondents generally evaluate the living conditions of families of persons with intellectual disabilities as poor to adequate.

Countries in the Balkans (Bosnia and Herzegovina, Macedonia, Croatia) as well as countries in the former Soviet Union area (Ukraine, Latvia) report very poor to poor living conditions for families with a member with intellectual disabilities.

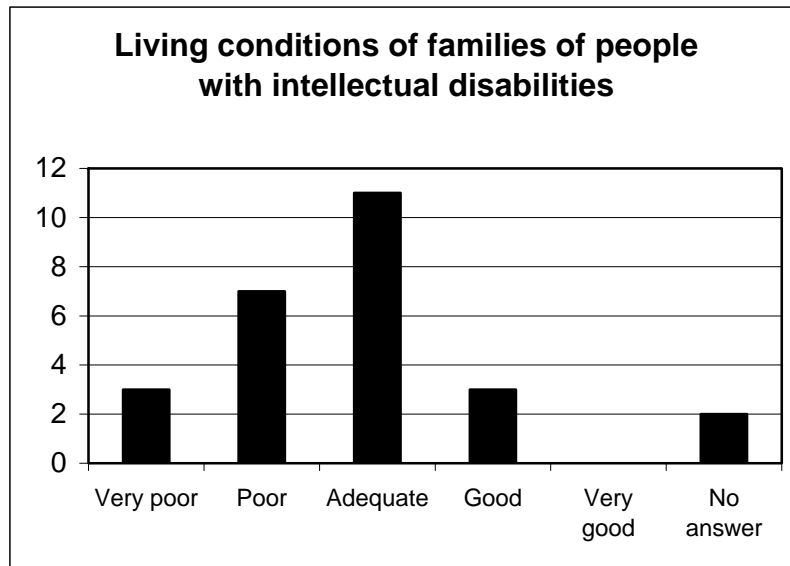
Other countries in Central and Eastern Europe (Bulgaria, Hungary, Romania) report poor to adequate living conditions whereas Nordic countries (Denmark, Norway) estimate the living conditions as good.

Case Study Interview with Myriam

Myriam is 44; she works as an office assistant; she lives alone after her divorce. She educates 4 children: two boys and two girls. Myriam lives with her family in a small house near Charleroi. The eldest child assumes the father role. The second child, Eric, is 18. He has a severe intellectual disability, called West Syndrome. His disability is characterized by a physical hyperactivity; he is constantly moving and therefore needs continuous support during the day and confinement at night. The two younger sisters often take care of their big bother on the weekends. They are very close to him and wouldn't allow their mother to permanently leave Eric in the institution. Eric goes to his father every second Saturday from 10h to 18h. His mother prefers that he come back home, instead of going to the IMP (the Medical-Pedagogical Institute) in order to provide him a maximum of family life. It is very painful for her to have placed him in an institution in order to be able to work and secure the family needs. Even the word "placement" hurts her deeply. The institution has proved to be the only solution to allow for both work and private life. Eric stays there from Sunday evening to Friday evening. If he stayed with his family, he would need a support person from 7h to 17h; this system does not exist in the region and it would probably cost a fortune. In the institution, Eric is put to bed at 19h and is locked into his room until the next morning.

Source: *Handicap de Grande Dépendance: concilier vie professionnelle et vie personnelle pour les parents*

³⁴R. Castel, *L'insécurité sociale, qu'est ce que être protégé?*, Paris, Seuil, 2003



Case Study

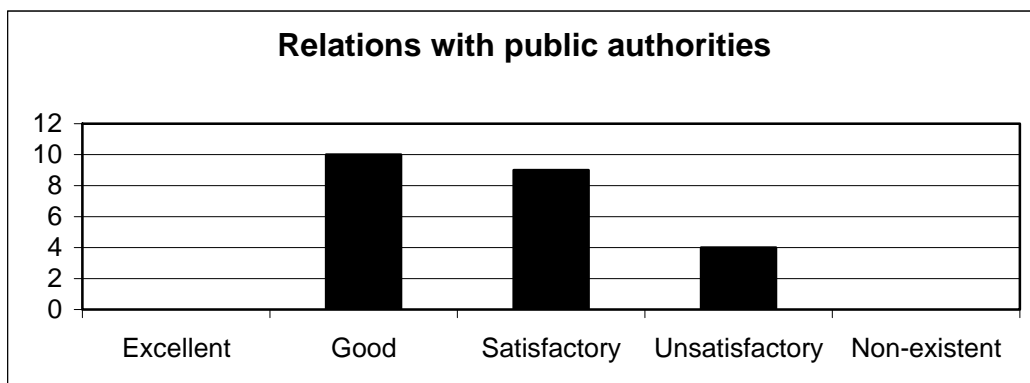
Persons with intellectual disabilities living in poverty in Croatia

This is a story about two sisters with intellectual disabilities who lived in a small village. After the death of their parents, their neighbour was assigned as their foster parent. The sisters did not live with their foster parent but they resumed living in their parents' house. The foster parent did not care for the sisters and the house they were living in was in very poor condition, without sanitary installation and indoor plumbing. There were even rumours about the foster parents abusing the sisters. The two sisters had no access to any community activities and lived in almost complete social isolation.

Members of the Association for Promoting Inclusion alerted public institutions repeatedly. Eventually the responsible centre for social work decided that the sisters had to move from their rundown house and placed them in an apartment where they receive support from members of our NGO. The local branch of our NGO is also trying to raise funds for the renovation of their parents' house.

This is only one story of poverty, in reality we can say that the majority of persons with intellectual disabilities in Croatia live in poverty because almost all of them live in complete social exclusion.

Source: Association for the Promoting Inclusion, Croatia, 2005

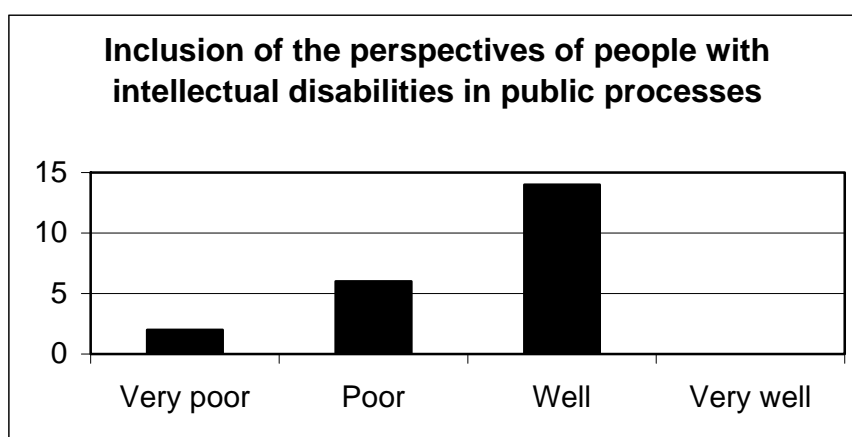


2.6 Involvement of persons with intellectual disabilities and their families in public processes

According to the survey, the member organisations of Inclusion Europe tend to have satisfactory to good relations with public authorities.

Consequently, our members draw a positive picture regarding the inclusion of perspectives of persons with intellectual disabilities in the public processes.

In the context of the drafting process of the National Action Plans on Inclusion, meant to involve a large range of stakeholders, we thought it interesting to explore the extent to which members of Inclusion Europe in the countries of the European Union took part in the elaboration process. However, only 6 out of 14 organizations from EU member states were consulted in the drafting of the NAPs/inclusion³⁵.



2.7 Social inclusion in Eastern European and Eurasian countries: unique challenges

The World Bank recently released a report on the Millennium Development Goals entitled *Progress and Prospects in Europe and Central Asia* which points to the unique challenges faced by countries in this region. "Prior to the transition ECA region countries exemplified cradle-to-grave security with secure jobs for most, albeit low-paying, and with often mandatory labour force participation by both men and women, and pensions for all. [...] The changes brought by the transition to a market economy required a complete re-design of social protection systems. This

included changes in labour market programs, pension systems, and social assistance programs, complemented by social funds and other instruments designed to increase the level of community involvement and decrease the level of exclusion."

For people with intellectual disabilities and their families we know that the transition to market economy has left many even more vulnerable and excluded. The World Bank points specifically to the Roma and to people with disabilities as examples of groups whose social exclusion is particularly acute in this region. Using the Millennium Development Goals as a framework for measuring development progress we can make some general observations for this region:

³⁵The six member organisations of Inclusion Europe are national organisations for people with intellectual disabilities and their families in the following countries: Austria, Greece, Hungary, Latvia, the Netherlands and Slovenia.

³⁶<http://web.worldbank.org/WBSITE/EXTERNAL/COUNTRIES/ECAEXT/EXTECAREGTOPSOCPRO/>

MILLENNIUM DEVELOPMENT GOAL	DATA SHOWS	WHAT WE KNOW FROM PEOPLE
<p>#1 ERADICATE EXTREME POVERTY FOR PEOPLE WITH DISABILITIES AND THEIR FAMILIES</p>	<p>In Moldova one third of households that have a child with disabilities fall into the lowest-income quintile. In Romania households that have children with disabilities have 65 per cent of the per capita income as those without. In Hungary the income of households that have a child with disabilities is 79 per cent. In Estonia, households with disabled members aged 0 to 24 years of age have incomes that are 84 per cent of those households with no disabled members. (UNICEF 2005)</p>	<p>Due to lack of inclusive education, basic services and health care, and employment people with disabilities are prevented from integrating into society. The study survey provides a picture of the very poor access that most people with intellectual disabilities have to employment: 3% for Bulgaria, 7% for Hungary and 1.24% for Romania. Ukraine also estimates an employment rate of no more than 1%. Studies conducted to show the costs implied by disability further established a clear link between disability and poor financial circumstances; disability is likely to result in poverty for disabled individuals and their families</p>
<p>#2 ACHIEVE INCLUSIVE EDUCATION</p>	<p>In Azerbaijan, only 5,000 children with disabilities attend specialized education. In Kyrgyzstan, the known number of disabled school-age children who do not attend any school grew from 1,500 in 1997 to 2,300 in 2002. In Tajikistan, only 25 per cent of children with disabilities aged 7 to 15 attend school. In 1989, 873,000 children across the region were receiving basic education in special schools for the mentally and physically disabled. In 2001, about 1 million children were enrolled in basic special education.</p>	<p>“Conditions vary considerably from one residential school to another and, despite certain improvements, the worst ones are for the disabled children. The living conditions are not up to the special requirements of such cases, nor are the food, sanitary standards, or opportunities for person-to-person contacts.” Kyrgyzstan Country Report, 2002 The focus group studies reported that students with intellectual disabilities have a difficult time accessing mainstream education due to negative attitudes, lack of school support (mainly resources), lack of teacher training for inclusion, inadequate public policies and insufficient adaptation of the school curriculum.</p>
<p>#3 PROMOTE GENDER EQUALITY</p>	<p>UNICEF estimates that only around 1% of girls with disabilities are literate.</p>	<p>Almost all responses to the survey point out that the mother is the only that is most likely to care for the person with intellectual disabilities.</p>
<p>#4 REDUCE THE MORTALITY OF CHILDREN WITH DISABILITY</p>	<p>In Moldova from 1991 to 1996 approx. 4 in 10 children with disabilities were born prematurely (compared to 1 in 10 non-disabled children). More than one third of the mothers said they had chronic diseases, and every fourth mother with a child with disabilities had been advised to terminate her pregnancy.</p>	<p>The focus groups indicated that people with intellectual disabilities experience difficulty accessing health care due to the inadequacy of the mainstream care systems, poorly trained health care workers, negative attitudes of the medical staff and the reluctance to provide services to people with intellectual disabilities; and the cost of health care for families living in poverty.</p>

<p>#5 ACHIEVE THE RIGHTS OF CHILDREN AND FAMILIES</p>	<p>It is estimated that only 2% of people with disabilities in developing countries have access to rehabilitation and appropriate basic services</p>	<p>The focus group results showed countries in the Balkans (Bosnia and Herzegovina, Macedonia, Croatia) as well as countries in the former Soviet Union area (i.e. Ukraine, Latvia) that report very poor to poor living conditions for families with a member with intellectual disabilities.</p>
<p>#6 COMBAT HIV/AIDS</p>	<p>The World Bank performed an international survey which concluded that HIV/AIDS is a significant and almost wholly unrecognised problem among disabled populations worldwide. While all individuals with disability are at risk for HIV infection, subgroups within the disabled population—most notably women with disability. disabled members of ethnic and minority communities are at especially increased risk.</p>	<p>Extreme poverty and social sanctions against marrying a disabled person mean that they are likely to become involved in a series of unstable relationships. Disabled woman are often a target for rape, which puts them at risk. There are almost no sexual education programs targeted towards people with disabilities. The global literacy rate for people with disabilities is estimated to be only 3%, thus making sexual education and HIV/AIDS information difficult to disseminate, especially for those who are deaf and/or blind.</p>
<p>#7 ENSURE ENVIRONMENTAL SUSTAINABILITY</p>	<p>UN statistics state that about 20% of all disabilities are caused by malnutrition and over 10% are caused by infectious diseases</p>	<p>Poor nutrition, dangerous working and living conditions, limited access to vaccination programmes and to health and maternity care, poor hygiene, bad sanitation, inadequate information about the causes of impairments, war and conflict, and natural disasters, all cause disability.</p>
<p>#8 DEVELOP A GLOBAL PARTNERSHIP FOR DEVELOPMENT</p>	<p>Recent estimates indicate that there are approximately 450 million people with disabilities living in the developing world. Approximately 30-40% of households care for a member with a disability. According to UNICEF, disability rates among children in the region have soared – doubling in Albania and Tajikistan, rising 2.5 times in Kyrgyzstan, increasing threefold in Uzbekistan, fourfold in Latvia and fivefold in Russia.</p>	<p>All CEE and CIS countries – like other high- and middle-development countries – still approach disability as firstly a medical issue and secondly a social welfare demand. However, most countries have taken the step of enacting rights-based legislation related to persons with disabilities. The exclusion and systemic undervaluing of people with disabilities perpetuates a cycle of poverty and isolation. Unless disabled people are brought into the development mainstream by creating global partnerships for advocacy and development, it will be impossible to achieve full human and economic rights.</p>

Development efforts in the Eastern European and Eurasian region have focused on five key challenges (all of which have implications for people with intellectual disabilities):

- **Dysfunctional Labour Markets**
As labour market restructuring creates more job insecurity and short term increases in unemployment, families who have a member with an intellectual disability and are likely to have one earner at home providing care are extremely vulnerable to extreme poverty and hunger (MDG #1)
- **Need for Pension Reform**
Government expenditures on pensions have created high tax rates and have significantly limited governments' capacities to provide other needed services and expenditures (infrastructure, education, health care). The disability pensions that people might have access to are restricted and inadequate and the scarce availability of other supports means that people with intellectual disabilities will be among the last groups to be provided access (health care etc.). *"Before 2000, almost no Romanian children with intellectual disabilities were integrated in mainstream schools, as the Commission for Child Protection generally recommended*

placing them in special schools –if education was recommended at all.³⁷"

- **Need for Social Assistance Programmes**
In the first few years of the transition income fell up to 60% increasing poverty levels especially among already excluded groups and decreasing capacity of governments to provide social programmes.
- **Postconflict Environment**
Violent conflicts with ethnic dimensions have amplified divisions in communities and created social unrest which impacts on both formal and informal social safety nets. Families living in isolation in their communities are less able to support and include their family members with a disability.
- **Social Exclusion**
People with disabilities are excluded physically from their communities (lack of accessible infrastructure). There are significant social and attitudinal barriers to their participation and some remain in institutions. Decentralization has brought with it efforts to deinstitutionalize people with disabilities in the region, but macroeconomic factors along with social attitudes continue to present barriers to participation for this group.

3 Conclusions and Recommendations for the Work against Poverty and Social Exclusion in Europe

The findings of the research on poverty and social exclusion in Europe were discussed with more than 100 persons with intellectual disabilities, family members, professionals and policy decision-makers from 36 European countries at a conference in Bucharest, Romania, on 21 and 22 October 2005. The discussions provided valuable input into the policy discussions of Inclusion Europe and Inclusion International as to how poverty and social exclusion of persons with intellectual dis-

abilities could be overcome. The participants identified ten important areas for action:

1. Improve access to education and life-long learning for persons with intellectual disabilities
2. Fight against discrimination of persons with intellectual disabilities in employment
3. Create equal access to mainstream health care
4. Caring at home: Focus on families of persons with intellectual disabilities

³⁷ *Rights of People with Intellectual Disabilities: Access to Education and Employment Romania*, Open Society Institute, 2005

5. Ensure legal capacity and access to rights and justice for everyone
6. Address the link between poverty, exclusion and institutionalisation
7. Compensate for extra costs of disability
8. Develop specific measures for persons with intellectual disabilities in Central and Eastern Europe
9. Create a better base of data for the monitoring of social inclusion policies
10. Mainstreaming of intellectual disability in national, European and world policies

Concrete recommendations for these ten action areas are detailed below.

3.1 Improve access to education and life-long learning

Pre-school, primary and secondary education are important basic elements for the inclusion of persons with intellectual disabilities in society. Education does not only increase their skills and competencies, but is, in inclusive settings, an opportunity to meet and interact with non-disabled children. Also studies of other excluded groups in society show that education is a key element in the fight against poverty and social exclusion.

Due to the nature of their disability, persons with intellectual disabilities need ready access to opportunities for learning throughout their lives. In countries, where basic education is denied to children with intellectual disabilities, life-long learning and adult education take over a new and special role: they must be designed to compensate for this loss of opportunities in basic education.

It was also a striking fact that the majority of persons with intellectual disabilities in Europe experience difficulties in access to mainstream education due to negative attitudes of either schools or communities. It seems that most measures at the level of various national governments - as expressed in the National Action Plans on

social inclusion - focus on increasing support (i.e. school resources, adequate training of the teaching staff, adaptation of the curriculum) in order to facilitate and increase the access of children with intellectual disabilities to education. However, negative attitudes from either schools or communities appear to be the major factor hindering the integration of children with intellectual disabilities in mainstream education systems.

The following actions can be taken at different levels in order to improve education and life-long learning for persons with intellectual disabilities:

Local authorities

- should ensure accessibility of pre-school and school education for everyone.
- must organize disability-awareness trainings for all teachers in mainstream education.

National governments

- must ensure that all children attend primary school education.
- should support the development of adult education and life-long learning for persons with intellectual disabilities.
- should encourage national awareness campaigns on the needs and abilities of persons with intellectual disabilities.
- must create systems for inclusive education for persons with intellectual disabilities.
- should ensure the adequate training of teachers for inclusive education at all levels.

The European Union

- should address the problem of lack of education and life-long learning in its policies against poverty and social exclusion.
- could organize exchanges of good practice in inclusion in all areas of learning for persons with disabilities.
- must monitor policies and actions in the area of inclusive education in the framework of the NAPs/inclusion.

- should encourage Member States to use financing from the Structural Funds to improve inclusive education for persons with disabilities.
- should co-finance actions focused on inclusive education and life-long learning for persons with disabilities from its instruments directed at non-member states, e.g. the Pre-Accession Funds.

The United Nations and International Agencies

- should ensure that the right to inclusive education and life-long learning is addressed in the UN Convention on the Rights of People with Disabilities.
- must ensure that children with disabilities are taken into account in investments and programmes to achieve the Millennium Development Goal on Education and UNESCO's goal of Education for All.

3.2 Fight against discrimination of persons with intellectual disabilities in employment

Various attitudinal, legal, physical and social barriers continue to prevent the access of persons with intellectual disabilities to the labour market. Various measures have been taken to remedy this situation, including setting up incentives schemes for employers, developing the skills of persons with disabilities to enable them to access employment, providing specific employment supports for persons with disabilities and employers, etc. However, these measures do not seem to impact significantly on the employment rate of persons with intellectual disabilities, which continues to remain extremely low as compared to overall employment rate

of the general population.

The reasons can mainly be seen in the direct and indirect discrimination that this group of European citizens face, as well as the lack of reasonable accommodation for their specific needs. This discrimination is caused mainly by negative attitudes of employers and colleagues towards persons with intellectual disabilities.

Policies meant to combat the unemployment of persons with intellectual disabilities should be based on demands put forward by persons with intellectual disabilities themselves:

- *We want to choose where and what we work.*
- *We want more regular work in the open labour market.*
- *We want to have vocational training.*
- *The companies should pay more penalty payment when they have a too small amount of employees with disabilities.*
- *We want the right to support at the workplace and in the vocational training.*
- *We want all necessary support to be paid for us.*
- *We want to be treated as real colleagues.*
- *We want the same rights as employees when we get ill or are on vacations.*
- *We want fair wages.*

Source: Catalogue of Demands by People First Germany 2002

A gradual shift from the traditional approach to the employment of persons with intellectual disabilities should take place towards a new approach, based on cross-sector and more active measures:

Traditional approach	New approach
<ul style="list-style-type: none"> • Passive measures: e.g. employment disability pensions • Quota schemes • Dismissal protection 	<ul style="list-style-type: none"> • Active measures: e.g. support to job searching / application, work experience, temporary work • Anti-discrimination legislation • Campaigns: clarification of facts

<ul style="list-style-type: none"> • Subsidies, wages, tax relieves • Modulation of jobs • Rehabilitation, vocational retraining • Sheltered workshops • Special system approach 	<ul style="list-style-type: none"> • Tailored offers: e.g., supported employment, person-centred planning • Vocational training, learning (with companies from the open labour market) • Integration firms • Cross-sector approach
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Recent publications issued by Inclusion Europe in the framework of the project “Fighting for our Rights – using non-discrimination law to protect people with intellectual disabilities” show the important contribution that legal provisions on non-discrimination in employment and occupation can make to improve access to employment for persons with intellectual disabilities. A meaningful transposition and interpretation of the Council Directive 2000/78/EC, establishing a general framework for equal treatment in employment and occupation, in the EU Member States and accession countries can greatly enhance the accessibility of employment for persons with intellectual disabilities. In other European countries, similar legislation is required.

The following action can be taken by different levels in order to improve employment opportunities for persons with intellectual disabilities:

Local authorities

- should employ persons with intellectual disabilities wherever possible.

National governments

- must ensure that adequate and effective non-discrimination laws protect persons with intellectual disabilities in employment and occupation.
- must take active measures to ensure and finance reasonable accommodation for employees with intellectual disabilities.
- should promote awareness-raising campaigns to improve the negative image of persons with intellectual disabilities.

- should start active labour market measures to promote the inclusion of persons with intellectual disabilities in employment, e.g. by improved access to vocational training.

The European Union

- must ensure that the transposition of the Council Directive 2000/78/EC is effective and meaningful for persons with intellectual disabilities.
- should support exchange of good practice in supported employment.
- should encourage governments to develop pro-active labour market policies for persons with intellectual disabilities.
- should study the loss of economic capacity caused by the economic inactivity of most persons with disabilities.

The United Nations and International Agencies

- should ensure that the right to non-discrimination in employment and occupation is addressed in the UN Convention on the Rights of People with Disabilities.
- should adopt inclusive strategies in their poverty reduction efforts to improve employment rates and labour market participation of people with disabilities and their families
- must include people with intellectual disabilities and their families in strategies to meet the Millennium Development Goals.

3.3 Create equal access to mainstream health care

Persons with intellectual disabilities also face negative attitudes when making use

³⁸ *Legal Interpretation Guidance Note for the Council Directive 2000/78/EC*, Inclusion Europe, Brussels, 2005.

of the mainstream health care systems. Most health care systems in Central and Eastern Europe remain inadequate. Persons with intellectual disabilities and their families in these countries often have to deal with high costs of medical care. Nevertheless, inadequacy of mainstream health care systems also concerns some of the “old” member states of the European Union. As a consequence, persons with intellectual disabilities have a poorer health status than the general population.

The following action can be taken by different levels in order to improve access to mainstream health care for persons with intellectual disabilities:

Local authorities

- raise awareness of local health professionals on intellectual disability.

National governments

- should ensure necessary training and qualification of health care staff to care adequately for persons with intellectual disabilities.
- should provide additional support to persons with intellectual disabilities, if necessary.

The European Union

- should conduct a study on access to mainstream health care for different excluded groups of citizens in all Member States.
- should ensure that all EU citizens have access to healthcare without discrimination.

The United Nations and International Agencies

- ensure that The UN Convention on the Rights of People with Disabilities recognises that persons with disabilities have the right to the enjoyment of the highest attainable standard of physical and mental health without discrimination on the basis of disability.

- promote the inclusion of people with disabilities in development efforts to address population health issues such as HIV/AIDs and other contagious diseases.

3.4 Caring at home: Focus on families of persons with intellectual disabilities

In many European countries, income-related schemes for persons with intellectual disabilities are inadequate to meet their actual needs. Care-giving related costs remain a major concern for families of persons with intellectual disabilities. The survey points out the fact that the majority of persons with intellectual disabilities continue to live with their families. The necessary care work, which is mostly done by the mother, impacts on the family status on the labour market and, consequently, on its income. Parents also experience many difficulties in the attempt to reconcile their professional and private lives when taking care of their dependent child. The parents of children with intellectual disabilities are therefore often victims of “discrimination by association”.

A potentially reduced income for families of persons with intellectual disabilities may have consequences on their living conditions, which were evaluated as generally poor to adequate by the survey respondents. Families of persons with intellectual disabilities are therefore particularly at risk of poverty, mainly due to the unreimbursed costs informal care-giving that they have to cover. The situation in countries from Central and Eastern Europe seems to be even more difficult.

In Moldova, one third of households that have a child with disabilities fall into the lowest-income quintile, while only 8 per cent were in the highest quintile (each quintile represents 20 per cent of all households)³⁹.

³⁹ *Moldova Country Report, 2002 in Innocenti Insight. Children and Disability in Transition in CEE/CIS and Baltic States, UNICEF, 2005, p.25*

*In Hungary, the income of households that have a child with disabilities is 79 per cent [...] of the average of all households with children*⁴⁰.

*Data from Romania show that households with disabled children have poverty rates (25 per cent) more than double the average (12 per cent)*⁴¹.

In Estonia households with disabled members aged 0 to 24 years of age have incomes that are 84 per cent of those households with no disabled members.

Source: (UNICEF, 2005)

The costs caused by disability establish a clear link between disability and poor financial circumstances; disability is likely to result in poverty for disabled individuals and their families.

The following action can be taken by different levels in order to compensate families for taking care of a dependent family member:

Local authorities

- could encourage neighbours and other members of the community to provide voluntary help and support.
- could provide special benefits to families, e.g. theatre tickets, invitations to events, etc.
- should support respite care services in the community.

National governments

- should raise awareness at the level of the whole society about persons with intellectual disabilities and their families living in poverty.
- should make sure that families receive adequate financial support for their care of a dependent family member.
- should make available leisure facilities and activities to persons with intellec-

tual disabilities.

The European Union

- should promote the value of voluntary work in family caring.
- should support campaigns to recognise the value of non-remunerated work for the European societies.

The United Nations

- ensure that the UN Convention on the Rights of Persons with Disabilities acknowledges the role that families play in supporting the inclusion and participation of people with disabilities in society.

3.5 Ensure legal capacity and access to rights and justice for everyone

As outlined before, poverty is not only measured in monetary terms, but has also the important dimension of equal access to rights and justice. Research carried out in the framework of the project “Justice, Rights and Inclusion for People with Intellectual Disabilities”⁴² has demonstrated that persons with intellectual disabilities have difficulties in access to rights and justice in all European countries.

In some cases, adults with intellectual disabilities cannot fully understand the nature of legally binding transactions or decisions, or comprehend their consequences and effects. Legal instruments for formal legal incapacitation, full or partial legal representation (guardianship) or assistance to exercise the right to self-determination are very different. This results in totally different standards of support and protection for persons with intellectual disabilities in the context of decision-making and exercising full citizenship.

⁴⁰ *Hungary country report*, *ibid.*

⁴¹ *Romania country report*, *ibid.*

⁴² *Equal Rights for all! Access to rights and justice for people with intellectual disabilities*, Inclusion Europe Brussels, 2005

The most important aspect of legal capacity, legal assistance, legal protection and representation of adults with intellectual disabilities is that the law recognizes an adult's right to autonomy and self-determination. Legal representation should not be imposed simply because a person takes a decision that other persons do not understand or agree with. In addition, a measure of legal representation should not be established for an adult with intellectual disabilities, as long as the adult can exercise his/her rights with adequate advocacy and assistance for decision-making. Where such a measure is necessary, it should be proportional to the individual circumstances and the needs of the person concerned.

The absence of advocacy structures to facilitate personal decision-making of adults with intellectual disabilities may result in extensive use of measures of partial or full legal incapacitation prior to the appointment of substitute decision-makers, who could take over the task to organize the social support needed by the person concerned. The development of effective support and community care services is substantial to avoid unnecessary infringements to the legal status of persons with intellectual disabilities. It is important that the services offered to persons with intellectual disabilities reflect the broad range of their needs and are offered in the community.

In addition, the legislative framework should recognise that the assessment of the legal competence of a person must not depend only on a medical diagnosis of an intellectual disability, but take into account that a person's ability to act on his own behalf may vary from time to time, depending on the difficulty of the affairs in question, the availability of advocacy services for personal and supported decision-making or other factors. A demand for legal representation should only be considered when there is clear evidence for the necessity to adopt this measure in order to protect the person concerned, as a re-

sult of a fair court procedure. The person concerned must be informed promptly in a language, or by other means, which he or she understands, and must be heard in person by the judge responsible for the procedure. Adequate support during the proceedings must be available free or at affordable costs. However, such a measure should not automatically deprive adults with intellectual disabilities of the right to marry, to make a will, to vote, to consent to or to refuse any intervention in the health field, or to take other decisions of personal character.

Equal access to rights and justice is also fundamental in order to reduce poverty and social exclusion and to strengthen democratic governance. Meaningful access to rights and justice requires that justice and administrative systems accommodate those who are disadvantaged. It is also closely linked to poverty reduction since poor and marginalized people are often also deprived of choices, opportunities, access to basic resources, and of a voice in decision-making. Lack of access to justice limits participation, transparency and accountability.

Like all citizens, persons with intellectual disabilities are entitled to enjoy all services provided by the states. To ensure an effective access, governments must refer to the general principles of mainstreaming, non-discrimination and universal accessibility and should implement minimum standards in the fields of public administration and access to justice. An effective policy for the access to justice and rights by persons with intellectual disabilities must be adopted in co-operation with different stakeholders.

Public administrations should develop and implement quality plans to assure equality of opportunities to citizens with a disability. They should include in those plans quality indicators and good practice guidance. Some form of certificate of good governance in the field of disability should be adopted.

Inclusion Europe strongly supports administrative reforms that aim at simplifying administrative procedures and processes. In addition, personal support for all citizens with difficulties in reading, writing and understanding must be available at every level of public administration. Persons with intellectual disabilities should receive this support whenever necessary, free of charge and without having to make any special request or file an application. A single point of contact could contribute to the simplification of procedures and avoid the duplication of formalities as well as possible contradictions.

Legal awareness is fundamental for the access to justice of persons with intellectual disabilities and governmental as well as non-governmental actors should undertake strategies to promote it. In addition, legal aid schemes should be available and made known to persons with intellectual disabilities, which should include both financial and social support.

The following actions can be taken at different levels of government in order to improve access to rights and justice for persons with intellectual disabilities:

Local authorities

- should ensure the mainstreaming of disability issues in all their areas of responsibility.
- should take specific positive action to make their services accessible for persons with intellectual disabilities.
- should provide accessible information about the rights for persons with intellectual disabilities.
- should develop and implement quality standards for good public administrations.

National governments

- should develop and promote quality standards for public administrations.

- must ensure adequate legislation in the areas of legal capacity and guardianship that complies with the relevant international recommendations and guidelines.
- should provide accessible information about the rights for persons with intellectual disabilities.

The European Union

- should address the issues of legal capacity and access to rights and justice for persons with intellectual disabilities in its work against poverty and social exclusion.
- should include relevant indicators in the review of the implementation of the National Action Plans in the framework of the Open Method of Coordination.

The United Nations and International Agencies

- ensure that the UN Convention on the Rights of People with Disabilities recognizes that all people with disabilities have the right to make decisions on their own behalf and that where support is required to exercise that capacity, the State provide appropriate supports.

3.6 Address the link between poverty, exclusion and institutionalisation

To be confined to live in a segregated institution is one of the most striking examples of social exclusion. As demonstrated by a recent study⁴³, persons with intellectual disabilities in many European countries are living in this situation. Often, this is the result of inadequate community-based care systems or of the poverty of families who have little choice of alternatives to institutionalisation.

There are also some indications that local communities where the majority of the citi-

⁴³ *Included in Society. Results and Recommendations of the European Research Initiative on Community-Based Residential Alternatives for Disabled People*, a study by Inclusion Europe with the support of the European Commission.

zens has inadequate resources, have a lower capacity for the inclusion of persons with disabilities. This is especially prevalent in some Central and Eastern European countries and is also a factor that can lead to the institutionalisation of this group of people.

Another aspect are the conditions within institutions, below any acceptable standard in some countries of Central and Eastern Europe. Persons with intellectual disabilities in those institutions often lack basic things like food, heating, personal property, etc. It must be a priority for all persons and organisations involved to remedy this unacceptable situation.

The following action can be taken by different levels of government in order to improve access to community-based services as alternatives to institutions for persons with intellectual disabilities:

Local authorities

- should commit themselves to quality community-based services for persons with disabilities.
- should ensure a local disability policy planning based on the human rights and full participation of their disabled citizens.

National governments

- must change policies at national level to ensure full participation of persons with intellectual disabilities in the life of society.
- must commit themselves to put de-institutionalisation policies into practice.
- should establish compulsory quality monitoring and evaluation systems for all disability services.
- must support families and local communities to take care of their disabled members.
- should make available suitable and affordable accommodation to persons with intellectual disabilities.

The European Union

- should address the problem of institutionalisation in its policies against poverty and social exclusion.
- should make sure that existing international human rights legislation is implemented for all citizens in all Member States of the European Union.
- should promote the development of compulsory systems of quality development of services.

The United Nations

- ensure that the UN Convention on the Rights of Persons with Disabilities guarantees the right to live in the community with supports

3.7 Compensate for extra costs of disability

It is commonly recognised that the presence of a disability causes extra costs for the disabled individual or her/his family. According to the results of the survey, the most common un-reimbursed disability and care giving expense incurred by families and individuals with intellectual disabilities is considered to be care giving (formal or informal). Next comes health care, followed by the acquisition of various aids and devices and costs implied by services (rehabilitation, therapies or day care).

These extra costs should be compensated for by pensions, allowances, benefits, travel concessions, tax relieves, care allowances, training allowances, etc. However, our research shows that currently these allowances are not enough in the majority of the European countries. This leads to a burden on the disabled individual and the family. It must be the objective of an inclusive society to provide equal opportunities to all its citizens, for which the compensation of the extra costs of disability is essential.

The following action can be taken by different levels in order to compensate for the extra costs of disability:

Local authorities

- could encourage neighbours and other members of the community to provide voluntary help and support.
- should encourage local leisure activity-centres e.g. museums, exhibitions, sports clubs etc. to require lower admission charges for persons with intellectual disabilities.

National governments

- must ensure that all citizens have equal opportunities.
- should design benefit schemes that compensate adequately for the extra costs of disability.
- should provide Personal Budgets or Direct Payment Schemes to allow disabled persons to purchase the support they need.
- could encourage and support volunteer actions to support disabled persons.

The European Union

- must ensure equal living conditions for persons with disabilities in all Member States of the European Union.
- should study and compare the level of compensations for the extra costs of disability in the Member States.
- should develop actions to harmonise the compensation systems in the Member States.

The United Nations

- ensure that the UN Convention on the Rights of Persons with Disabilities recognise the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing, housing, and to the continuous improvement of living conditions including access to clean water, and shall take appropriate steps to safeguard and promote the realisation of this right without discrimination on the basis of disability.
- must develop strategies to address the extreme poverty experienced by people with intellectual disabilities as a part of efforts to meet the Millennium Development Goals by 2015.

3.8 Develop specific measures for persons with intellectual disabilities in Central and Eastern Europe

The research conducted among the member societies of Inclusion Europe in the framework of this project demonstrates very clearly that poverty and social exclusion of persons with intellectual disabilities and their families is much more pronounced in the countries of Central and Eastern Europe. It is absolutely vital that specific measures are taken to ensure human rights and social inclusion of this group of citizens in their societies.

The following action can be taken by different levels of government in order to fight against poverty and social exclusion of persons with intellectual disabilities in Central and Eastern European countries:

National governments

- must ensure that financing available in the framework of the EU Structural Funds or other EU financing instruments is allocated to measures for persons with intellectual disabilities and their families.
- must develop specific measures and policies to combat poverty and social exclusion of this special group of their citizens.
- could apply for financing of the World Bank or other international donors to improve the situation.

The European Union

- must insist and monitor that EU financing instruments are used for improving the social inclusion of disabled persons.
- should require special attention to persons with intellectual disabilities in the National Action Plans against social exclusion.
- should make sure that pre-accession funds as well as funds available to non-member states in Europe can be used to promote the inclusion of persons

with intellectual disabilities and their families.

The United Nations and International Agencies

- Ensure that the UN Convention on the Rights of Persons with Disabilities includes and article on International Co-operation that promotes the inclusion of people with disabilities in development objectives.
- Ensure that development agencies and international financial institutions such as the World Bank adopt inclusive development strategies including research on marginalized groups and the inclusion of people with disabilities in mainstream investments for education, health and pension reform.

3.9 Establish better data for the monitoring of social inclusion policies

The study findings provide evidence that the barriers to economic, social and political participation faced by persons with intellectual disabilities have not been effectively addressed in the European strategies for social inclusion. While some policies exist to support labour market participation, income support or disability-related services, there has been no coherent framework for actions developed to support and implement the inclusion of persons with intellectual disabilities.

To a certain extent this failure is due to the lack of understanding and information about the scope and dimension of the policy issues. Eurostat and national census data from Member States make it difficult to get a clear picture of the number of persons with intellectual disabilities, but also to identify household data where there is a person with an intellectual disability. Additional information concerning the situation of persons with disabilities as well as their level of participation in community life is necessary. References to disability should

be included in the list of indicators used to evaluate social inclusion policies⁴⁴.

The following action can be taken by different levels in order to establish a better data-base for the monitoring of social inclusion policies:

National governments

- should include in their national census data information that allow to distinguish disability from long-standing health problems.
- should also introduce in all census data a distinction between the major disability groups: physical disability, intellectual disability, mental health problems, visual disability and hearing disability.

The European Union

- should include references to disability in the list of indicators used to evaluate social inclusion policies.
- collect statistical information at EU level about the inclusion of persons with intellectual disabilities and other disability groups.

The United Nations and International Agencies

- Ensure that the UN Convention on the Rights of People with Disabilities require governments to collect appropriate information, including statistical data, to enable them to formulate and implement policies to give effect to the Convention.
- Ensure that UNICEF, UNDP, UNESCO and other agencies include data on children and adults who have an intellectual disability in their annual reports (State of the World's Children; UNDP Development report; EFA Monitoring Report etc.)
- Should conduct additional regional level research on the policy issues related to poverty and disability.

⁴⁴ *Handicap et exclusion sociale dans l'Union européenne*, p. 89

3.10 Mainstream intellectual disability in national, European and world policies

A main challenge for policy is the complexity of social exclusion. Policy actions targeted at one sector might focus on strategies that do not address the real barriers faced by people. For example, employment policies may focus on job training while the real barriers to employment are related to attitudes of employers and colleagues. Without a coordinated and multi sector approach to inclusion, sectoral policies are often ineffective.

While some National Action Plans on Social Inclusion identify persons with disabilities as a vulnerable population, the challenge is to develop effective multi-level responses to the complex set of factors impacting on persons with intellectual disabilities and their families.

The concept of mainstreaming refers to the inclusion of disability issues in the planning, implementation, monitoring, evaluation and revision of policies and actions at all levels of society – locally, regionally, nationally and internationally.

Effective mainstreaming must address some key issues at different levels of national and international governance:

- Societies must accept and believe in the principle of equality.
- Societies must implement the existing human rights (i.e. United Nations Standard Rules, UN Convention on Civil and Political rights, etc).
- Information about persons with disabilities who are living in certain areas must be available. It is therefore important to ensure that all groups and individuals are covered and to ensure that persons with invisible impairments also are included.
- Knowledge about the needs of support and services must also be available.
- Authorities must establish a good, continuous cooperation with the organisations of persons with disabilities. These are a genuine source of information about the needs of persons with disabilities; they should also be involved in the planning and implementing measures, monitoring the implementation and planning of new measures.
- Authorities at all levels (local, regional, national) must have good knowledge of what mainstreaming is, why it is important and what it means in practice and in everyday work.
- Mentalities and attitudes must change from protection to inclusion.
- Inclusive legislation and human rights based legislation must have appropriate implementation structures.
- All actors in poverty reduction must be mobilised (governments, NGOs, etc.).
- The family and informal support structures must be strengthened.
- More involvement in European programmes to encourage cooperation and best practice should be encouraged.

Annexes

Annex I: Focus on Romania

Inclusion Romania (The Federation of Organizations of Persons with Intellectual Disabilities from Romania) gathered and compiled in this report the results of the 5 focus groups organized in Romania in the period June-August 2005.

The focus groups were organised on the basis of a questionnaire meant to tackle the following:

- What are the big challenges faced by the persons with mental disabilities and their families?
- How do persons with mental disabilities and their families cope with these challenges? What kind of solutions did they find?
- What are their recommendations for change at local and national level?

The focus groups were organized in the following locations: "Esperando" Association, Baia Mare, "Pentru Voi" Foundation, Timișoara, "Langdon Down 2000" Association, Deva, "Caritatea" Foundation, Constanța and "Inclusion" Day centre, Bucharest

22 persons participated in the focus groups – 8 persons with intellectual disabilities and 14 family members, representing 14 persons with intellectual disabilities (including those who have participated at the focus groups). All these 14 persons with intellectual disabilities attended some form of education (special education in schools, other educational programs). All these persons live in urban areas, in poverty, due mainly to little income, medical problems and expensive treatments, marginalization, family dissolution, unemployment of disabled persons, unemployment or underemployment of family members and other factors.

For persons with intellectual disabilities the most problematic issues related to disability are, starting with the most frequently mentioned: the lack of money / low level of allowance or salary, disempowerment, marginalization; little access to free or low cost medicine, dependency / lack of autonomy, unemployment, problems in communication, lack of access to public transportation, public education, leisure; last comes housing facilities, disturbing environment, dissolution of family, lack of support from the extended family.

For family members of persons with intellectual disabilities the most problematic issues

related to disability are, starting with the most frequently mentioned: the lack of money and the anxiety about the future; the special education which does not offer enough support / mainstream education is not inclusive; the changing and consequently confusing legislation in the disability sector; the social status / stigma and isolation; inappropriate social services and the dissolution of family (lack of support from the extended family, problems in communication, mental fatigue, etc).

The coping mechanisms most frequently mentioned by the persons with mental disabilities were: special education / rehabilitation programs / vocational training; thinking positive; being close with one's family; communication with the others; socializing with other persons with intellectual disabilities.

The coping mechanisms most frequently mentioned by the family members were: resignation, and patience; the access to specialized services for persons with intellectual disabilities; learning about disability; support from persons outside the family and support from NGOs in the disability sector.

The following recommendations were made by the survey respondents:

1. Creation of community based services, make public social services accessible,
2. Employment for persons with intellectual disabilities,
3. Inclusive education, accessible medicine,
4. Awareness campaigns for changing mentality,
5. Encourage the cooperation between local authorities and local NGOs,
6. Improve the legislation regarding disability,
7. Comply with current legislation,
8. Accessible public / private transport,
9. Pension for persons with disabilities, Increase the allowance for disability,
10. More support for the persons with intellectual disabilities,
11. Individual approach for the persons with intellectual disabilities,
12. Pay in time the social benefits, decent housing for families of persons with disabilities, employment opportunities for family members of persons with disabilities,
13. Improve the activity of Disability Evaluation Commissions at the local level
14. Encourage volunteer activities to support persons with intellectual disabilities
15. Financial support like credit, leasing, for family members of persons with disabilities.

Annex 2 Questionnaire

What is the total population of people with intellectual disability in your country?

If available:

___% mild intellectual disability
___% moderate intellectual disability
___% severe intellectual disability
___% profound intellectual disability

1. What are the sources of disability-related income support that families and individuals with intellectual disabilities are able to access?
 - Pensions/allowances/benefits
 - If so, estimated value in Euro per month per family/individual.
 - Travel concessions. If so, estimated value in Euro per month per family/individual.
 - Tax relieves. Please specify.
 - Care allowances. Please describe.
 - Subsidies and training allowances. Please describe.
 - Other. Please specify.
2. Is there information available on the national expenditure for supports to people with intellectual disabilities? If yes, please indicate the approximate amount per year.
3. What is the employment rate for people with intellectual disability in your country?%
4. What is the employment rate for the general population in your country?__%
5. How many people with intellectual disability are unemployed for more than 1 year?__%
6. What is the employment status of families who have a family member with an intellectual disability?
 - 2 or more family members employed__%
 - 1 family member employed__%
 - Jobless household__%
7. Who is most likely to be home caring for a person with an intellectual disability?
 - Mother
 - Siblings
 - Others
 - Father
 - Support worker
 - Others
8. Can you estimate the income status of families who have a member with an intellectual disability:
 - Below average income__%
 - Average income__%
 - Above average income__%
9. What is the average income of a household in your country in Euro?
10. Can you estimate the average income of families who have a member with an intellectual disability?
11. If a person with a disability is not working, what is the main reason? Please rank in order of importance from 1 = most important reason to 5 = not important:
 - ___ Lack of support
 - ___ Skills/education
 - ___ Barriers (attitudinal, legal, physical, social)
 - ___ Transportation reasons
 - ___ Lack of jobs (high unemployment rates overall)
12. What are the unreimbursed disability and caregiving expenses incurred by families and individuals who have an intellectual disability (please rank in order of importance):
 - ___ Care giving (formal or informal)
 - ___ Health care
 - ___ Services (rehabilitation, therapies, day-care)
 - ___ Aids and devices
 - ___ Others, please specify.
13. Do people with intellectual disabilities have difficulty accessing mainstream **Health Care**?
Yes / No
If yes, this is due to:
 - Poorly trained health care workers
 - Cost
 - Negative attitudes/reluctance to provide services
 - Inadequate mainstream health care systems
14. Do people with intellectual disabilities have difficulty accessing mainstream **Education**?
Yes / No
If yes, this is due to:
 - Lack of teacher training for inclusion
 - Negative attitudes (school/community)
 - Lack of school supports (resources)

- Curriculum adaptation
 - Public policy
15. How would you estimate the level of education attained by people with intellectual disabilities in your country?
- No education__%
 - Primary education__%
 - Secondary education__%
 - Upper secondary education (high school/vocational)__%
16. Where do adults with intellectual disability live?
- With their families__%
 - In group homes__%
 - Independently (with friends/on their own/ married)__%
 - In institutions__%
17. Compared to the rest of the population, are the housing conditions in which people with intellectual disabilities live on average:
- Very poor
 - Poor
 - Adequate
 - Good
 - Very good
18. How would you evaluate the housing conditions of families that have a member with an intellectual disability as compared to those of the other families (on average):
- Very poor
 - Poor
 - Adequate
 - Good
 - Very good
19. Do people with intellectual disability have access to community activities (sports and leisure, cultural activities):
- Recreation centers (community centers, health clubs, etc.)
 - Clubs
 - Travel
 - Holidays
 - Competitive sports
 - Movies/museums
 - Others, please specify.
20. What are the key priority issues of your association in advocating for the inclusion of people with intellectual disability and their families? Please rank in order of importance from 1 = most important to 5 = less important:
- __ Education
 - __ Employment
 - __ Discrimination
 - __ Poverty
 - __ Community-based services
 - __ Other, please specify.
21. What are the mechanisms that your association uses to work with governments and public authorities?:
- National Disability Council
 - Regular meetings/consultations
 - Consultations on the National Action Plans Against Poverty and Social Exclusion
 - Child protection committees/authorities
 - Political parties
 - Judicial institutions (courts, etc.)
 - Other, please specify.
22. How would you describe the relationships that your association has with governments and public authorities?
- Excellent
 - Good
 - Satisfactory
 - Unsatisfactory
 - Non-existent
23. Describe the way in which the perspectives of people with intellectual disability and of their families are included in these processes:
- Very poor
 - Poor
 - Well
 - Very well
24. Do you have access to national research or data on poverty and disability in your country? Could you please provide the necessary references (title, author, year of publication, internet link, etc). If the study is in a language other than English or French, could you provide us with a short summary/description?
25. Please describe briefly a story or example of a person with an intellectual disability or a family living in poverty? (Definition: *“By poor we mean people, families or groups of whom the resources (material, cultural and social) are so limited that they are excluded from the minimal standards of living recognized as acceptable in the member state where they live”.*)