



# access

to education  
and employment  
for people with  
intellectual disabilities

## Summary Reports



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EU MONITORING AND ADVOCACY PROGRAM



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## Summary Reports

From autumn 2005, the Open Society Institute published a series of individual country reports on access to education and employment for people with intellectual disabilities<sup>1</sup>. The summary reports bring together the main findings of each of the country reports – the Executive Summary and the Recommendations – in a condensed format.

## Preface

The **EU Monitoring and Advocacy Program (EUMAP)** of the Open Society Institute monitors human rights and rule of law issues throughout Europe, jointly with local NGOs and civil society organisations. EUMAP reports emphasise the importance of civil society monitoring and encourage a direct dialogue between governmental and non-governmental actors on issues related to human rights and the rule of law. In addition to its reports on the Rights of People with Intellectual Disabilities, EUMAP has released monitoring reports focusing on Minority Protection, Judicial Independence and Capacity, Corruption and Anti-corruption Policy, Equal Opportunities for Women and Men and on the Regulation and Independence of the Broadcast Media. EUMAP is currently preparing reports on Equal Access to Quality Education for Roma; publication is expected in 2006.

EUMAP reports are elaborated by independent experts from the countries being monitored. They are intended to highlight the significance of human rights issues and the key role of civil society in promoting governmental compliance with human rights standards throughout an expanding Europe. All EUMAP reports include detailed recommendations targeted at the national and international levels. Directed at Governments, international organizations and other stakeholders, the recommendations aim to ensure that the report findings directly impact on policy in the areas being monitored.

The present reports have been prepared in collaboration with the **Open Society Mental Health Initiative (MHI)**. MHI seeks to ensure that people with mental disabilities (mental health problems and/or intellectual disabilities) are able to live as equal citizens in the community and to participate in society with full respect for their

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<sup>1</sup> The term “intellectual disability” (also described as “learning disability” or “mental retardation”) here refers to a lifelong condition, usually present from birth or which develops before the age of 18. It is a permanent condition that is characterised by significantly lower than average intellectual ability and results in significant functional limitations in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills.

human rights. MHI promotes the social inclusion of people with mental disabilities by supporting the development of community-based alternatives to institutionalisation and by actively engaging in policy-based advocacy.

Throughout Europe people with intellectual disabilities still face serious stigma, prejudice and significant barriers to realising their fundamental human rights. Discrimination against people with intellectual disabilities is deeply rooted and widespread, standing in the way of positive change. Providing real access to education and employment for people with intellectual disabilities is key to ensuring their social inclusion, and enabling them to live and work in the community as equal citizens. The EUMAP reports focus specifically on these two areas because of their importance to people with intellectual disabilities and because of the existence of international standards, and national law and policy, relating to these areas.

Monitoring of the rights of people with intellectual disabilities was based on a detailed methodology (available at [www.eumap.org](http://www.eumap.org)), intended to ensure a comparative approach across the countries monitored. The reports cover the eight Central and Eastern European (CEE) countries that joined the EU in May 2004 (the Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Slovakia, and Slovenia), Bulgaria and Romania, expected to join in 2007, one candidate country (Croatia), and three older EU member States (Greece, the Netherlands, and the United Kingdom).

The preparation of reports on both member and non-member States highlights the fact that international human rights standards apply equally, and provides an opportunity to comment on general trends in the development and the policy application of these standards. The States selected represent a geographical spread and illustrate a spectrum of policy, practice and implementation.

Reports on each of the countries monitored have been published separately in bilingual volumes. First drafts of each of the country reports were reviewed at national roundtable meetings. These were organised in order to invite comments on the draft from Government officials, civil society organisations, self-advocates, parents, and international organisations. The final reports underwent significant revision based on the comments and critique received during this process. EUMAP assumes full responsibility for its final content.

## Foreword

Each of the country reports prepared in this series, by the Open Society Institute's EU Monitoring and Advocacy Program and the Open Society Mental Health Initiative, presents an overview of the opportunities and challenges facing people with intellectual disabilities in accessing education and employment. The reports provide an important contribution to research on this group, one of the most vulnerable groups throughout Europe.

The initiative of producing the reports fulfils important objectives. There is a clear need for comprehensive studies based on reliable research about the situation of people with intellectual disabilities in Europe. Without reliable information, the strategies and policies targeting this particular group of people are often inadequate in terms of meeting their real needs. The monitoring underlying the reports also aims to provide a comparative overview on the countries analysed. The present reports go far beyond previous reports that have brought this issue to the attention of European and national decision-makers.

Presenting a wider picture, this series of reports provides a thorough analysis of the situation of people with intellectual disabilities in their access to education and employment in eight new EU Member States (Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Slovakia and Slovenia), two accession countries (Bulgaria and Romania) and one candidate country (Croatia). To give a broader view of practice across Europe, Greece, the Netherlands and the United Kingdom have also been studied. The conclusions of the series of reports indicate that people with intellectual disabilities in Europe continue to face significant barriers as far as real access to education and employment is concerned. Discrimination also remains a major issue, despite measures taken at the national level and within a larger European context.

The reports also stand for the importance of civil society monitoring and the overall involvement of different stakeholders in dialogue regarding the human rights of people with intellectual disabilities. A local expert in each country prepared the monitoring report, while local NGOs were involved throughout the monitoring process, providing the basis for broad consultation wherever possible. A central goal of this monitoring is to promote greater awareness and discussion of the issues at stake for people with intellectual disabilities at the local, national, and international levels.

Across the countries monitored, common problems continue to block access to education and employment for people with intellectual disabilities. In many countries, data on the situation of this group is extremely limited or insufficiently disaggregated, making it difficult for Governments to develop policy tailored to their needs. What data there is, shows that while integration of children with intellectual disabilities in mainstream schools is generally increasing, a more fundamental process towards

inclusion, as presented in the 1994 Salamanca Declaration on Special Needs Education, has made little headway. Many children throughout the region are still segregated in special schools or denied an education altogether, leaving little hope that they will be able to find jobs as adults. In most countries monitored, there is only the most basic support for the transition from education to employment.

Existing incentive schemes in many countries, particularly hiring quotas, have not been successful in increasing the number of people with intellectual disabilities who have entered the work force. More specifically targeted programmes must be developed to meet the needs of this group. Throughout Europe, NGOs have piloted effective projects offering supported employment to people with intellectual disabilities, providing assistance such as job coaches, specialised job training and individually tailored supervision. However, this approach has not yet been adopted as Government policy and therefore the opportunities it offers cannot be extended to a much larger group of people.

The reports highlight numerous obstacles that people with intellectual disabilities face in accessing education and employment in various countries across Europe. Improved legislation still needs to be adopted and implemented nationally as well as at the EU level. Existing models of good practice in inclusive education and supported employment should be replicated on a more extensive scale. These reports should help domestic and European decision-makers to develop effective policies ensuring the inclusion of people with intellectual disabilities into society.

From the perspective of Inclusion Europe, the European Association of People with Intellectual Disabilities and their Families, the reports make a very important contribution to the present discussion on access to education and employment for people with intellectual disabilities. We only can encourage local, national and European decision-makers, service providers and disability and social NGOs to consider and follow the recommendations developed in the reports.

*Geert Freyhoff*

Director

Inclusion Europe

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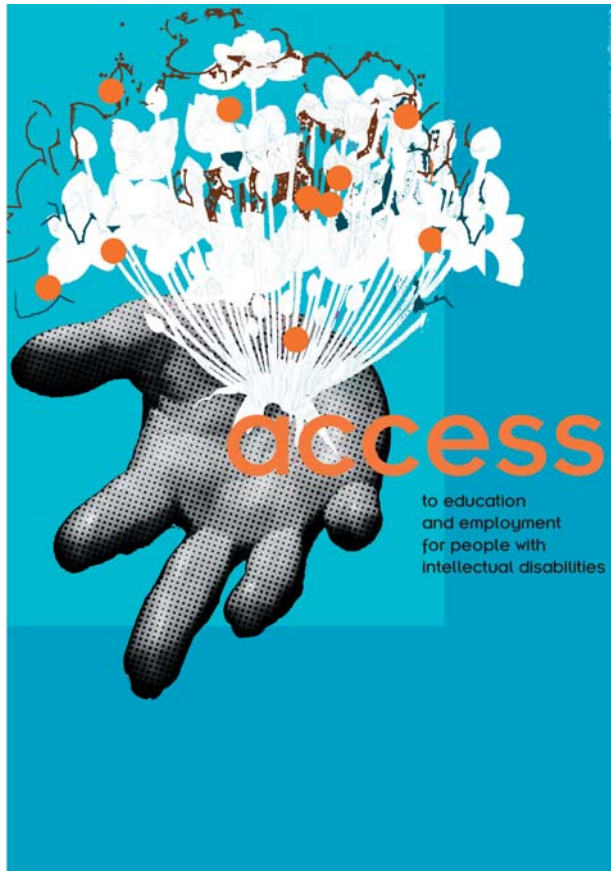
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EU MONITORING AND ADVOCACY PROGRAM



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MENTAL HEALTH INITIATIVE

# Rights of People with Intellectual Disabilities: Access to Education and Employment

Summary Reports

*Bulgaria*

The complete set of country reports, in English and translated to national languages,  
can be accessed online at: [www.eumap.org/topics/inteldis/reports](http://www.eumap.org/topics/inteldis/reports)  
Hard copies can be ordered at: [www.eumap.org](http://www.eumap.org)



## EXECUTIVE SUMMARY

Throughout Europe people with intellectual disabilities<sup>1</sup> face major stigma and prejudice and are confronted with significant barriers to realising their fundamental human rights. Discrimination against people with intellectual disabilities is deeply rooted and widespread, standing in the way of positive change. Providing real access to education and employment for people with intellectual disabilities is critical to ensuring that they can live and work in the community as equal citizens. There is a strong link between education and employment: without access to adequate education, people with intellectual disabilities cannot secure meaningful employment. This denial of access leads to life long dependency, poverty and social exclusion adding to the stigma of intellectual disability. This monitoring report focuses specifically on the areas of education and employment because of their importance to people with intellectual disabilities, and because of the existence of both international standards and national legislation that specifically address them.

Access to education and employment for people with intellectual disabilities in Bulgaria remains highly limited. Although new programmes adopting a modern, inclusive approach have been adopted, older policies segregating people with intellectual disabilities remain in force. Incremental changes are being made, many prompted by the EU accession process, but much work remains to be done to shift attitudes towards acceptance of people with intellectual disabilities as active, participating members of society.

The Bulgarian Government has taken important initial steps towards better inclusion of people with intellectual disabilities, particularly in education. While Bulgaria has demonstrated good intentions through the adoption of policies addressing the education of children with disabilities, much remains to be done to ensure that people with intellectual disabilities leave school equipped with the skills to be active, contributing members of society. The limited options available in education are matched by the even more restricted possibilities for people with intellectual disabilities to secure meaningful employment. Ensuring that the policies adopted in recent years reach their potential will go far towards helping people with intellectual disabilities to reach their potential as well.

### *Background*

Bulgaria has ratified most international instruments that pertain to people with disabilities but has not signed Protocol 12 to the European Convention for the

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<sup>1</sup> The term “intellectual disability” (also described as “learning disability” or “mental retardation”) here refers to a lifelong condition, usually present from birth or which develops before the age of 18. It is a permanent condition that is characterised by significantly lower than average intellectual ability and results in significant functional limitations in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills.

Protection of Human Rights and Fundamental Freedoms (ECHR). While the Constitution does not afford protection against discrimination on the grounds of disability, supplemental anti-discrimination legislation enacted to comply with the EU anti discrimination *acquis*, in particular the Protection against Discrimination Act, does include disability as a protected ground. An independent body charged with addressing cases of discrimination, the Commission for Protection Against Discrimination, is provided for in new legislation; however, this body has not yet been established. A new Law for the Integration of People with Disabilities was adopted in September 2004 and entered into force on 1 January 2005. It provides for the creation of additional bodies to specifically address issues relating to people with disabilities, as well as a more inclusive approach to education, and improved data collection. Regulations for implementation of this law were also adopted in December 2004.

As Bulgaria lacks a unified definition of intellectual disability that is used consistently in law and policy, basic information regarding people with intellectual disabilities is somewhat unreliable. Some legislation uses terminology that is outdated and stigmatising, and not in line with international standards for the classification of intellectual disability. Definitions from the outdated International Classification of Diseases, ninth revision (ICD-9) are used in much of the medical legislation in force, but legislation in other areas uses various terminology. In the diagnosis procedure as well, the four different bodies assessing disability for various purposes employ different terminology, which is not used consistently or in line with recognised standards. Detailed statistical data is available on the number of people with intellectual disabilities in each district (and their level of intellectual disabilities); there are an estimated 49,000 people with intellectual disabilities in Bulgaria. However, this data does not include all people with intellectual disabilities and the lack of standardised diagnosis procedures casts some doubt on its reliability. This data is not disaggregated by age, sex, or ethnic origin; nevertheless, the disproportionately high number of Roma diagnosed with intellectual disabilities is a clear trend indicating that diagnosis procedures should be reformed. Both *plenary* and *partial* guardianship exist in Bulgarian law. People under guardianship retain the right to work, but for those under *plenary* guardianship, the guardian must sign the employment contract on behalf of the ward, which can in practice be a serious impediment to employment. Guardianship presents problems primarily for people in institutions, who are likely to be under the *plenary* guardianship of the institutional director. A conflict of interest emerges in such cases, as the ward cannot leave the institution or find employment without the guardian's permission. There is no effective oversight as to whether the wards' interests are respected. Around 8,000 people remain in institutions, including residential schools.

### *Access to education*

The Constitution recognises the universal right to education. However, for students with intellectual disabilities, access to secondary and higher education is sharply restricted, as most such students will not meet the requirements for a diploma. For the vast majority of people in institutions, there is no access to education at all. After

changes to the regulatory framework in 2002, all children with intellectual disabilities may attend mainstream schools, regardless of their diagnosis. Serious concerns have been raised regarding the assessment procedure, however; the process is often superficial, inconsistent, and fails to take into account the individual capacity and potential of the child under examination. There is no national system of early intervention centres, although NGO services are available in limited areas; comprehensive early intervention services provided by multidisciplinary teams must be made widely available for children with intellectual disabilities, to address their needs at the earliest and best time possible.

Before June 2003 there were no long-term governmental programmes or strategies for special education. In general, even children with *mild* intellectual disabilities were excluded from mainstream schools and placed in special schools, while children with more severe intellectual disabilities were regarded as “uneducable” and placed in institutions or cared for by their parents at home with no educational options. However, in the past several years, Bulgaria has implemented a number of initiatives aimed at improving education for children with intellectual disabilities. As part of the “National Strategy for Equal Opportunities for People with Disabilities 2003–2005” (hereafter, National Disability Strategy), the Government has set out a series of specific measures related to education. A National Action Plan for Implementation of the Strategy was also adopted by the Council of Ministers in December 2003. National NGOs were consulted in the preparation of the Strategy, but to date the State has taken few concrete steps towards implementation of its provisions. The EU has not addressed the education of people with disabilities in its regular reporting on Bulgaria as part of the accession process; however, a recent initiative to identify schools for a mainstreaming pilot project has been funded by the EU’s Phare programme.

There remains a chronic lack of resources needed to promote effective education of children with intellectual disabilities, in both mainstream and special schools. Adapted textbooks and curricula are extremely limited, and many of the texts that are available are out of date. General teacher training does not include a component on working with children with intellectual disabilities; current pilot projects aim to train “resource teachers” to support integration in the classroom, a promising initiative that should be rapidly implemented and expanded to meet needs across the country. Resource centres, which would provide support to integrated mainstream schools, are also called for in new legislation, but further regulations must be elaborated to ensure that these structures are established in line with the goals of the Salamanca Declaration.

Since August 2002, parents of children with intellectual disabilities can choose whether to send their children to mainstream or special schools regardless of their diagnosis. To date, however, resources to make this policy effective, including adequate preparation of teachers, students, and communities as well as financial support, have not been made available. Mainstreaming is taking place only on an extremely small scale, with only a very few students with intellectual disabilities integrated into inclusive classes in mainstream schools. Most children with mild to moderate intellectual disabilities

remain in segregated special schools, where generally the facilities are poor, materials scarce, textbooks out-of-date or unavailable, and teachers poorly trained and motivated. The declining birth rate in Bulgaria has increased competition for students among schools reluctant to cut staff, a phenomenon that has exacerbated the over-representation of Roma in special schools, arising from the poorly controlled assessment procedures that too often are discriminatory.

Very few children with intellectual disabilities receive home schooling; although this option is available by law, the resources to implement it are not available, and parents are not aware home schooling is possible for children with intellectual disabilities. Children in residential institutions generally have no access to education whatsoever, although legally they are no longer considered “uneducable”. As most children in institutions have been abandoned by their parents, there are few advocates for their integration into education, and gradual improvements in institutional care have not yet extended to the provision of appropriate educational programmes either in the institutions or in local schools.

### *Transition from education to employment*

The education system does not adequately prepare people with intellectual disabilities to find employment on the open market. Education simply ends at the eighth grade for students with intellectual disabilities who do not live near an appropriate secondary school. Other students are able to continue their studies through vocational education, although the courses available are limited and for the most part do not offer training in marketable skills. Few students who complete these courses are able to find work outside sheltered environments.

### *Access to employment*

The Labour Code has been amended to specifically prohibit discrimination in employment on the grounds of disability, and the Protection Against Discrimination Act (2003) requires employers to adapt the workplace to accommodate workers with disabilities, in line with the EU Employment Directive. The assessment process to determine both eligibility for benefits and capacity for employment tends to categorise people with even *mild* intellectual disabilities as having a very low work capacity, which severely reduces their possibility of ever finding employment. Although disability benefits are cut or withdrawn if an individual’s income exceeds a certain level, the level of benefits is so low that the incentive to work remains strong.

Bulgaria has introduced a number of ambitious programmes aimed at improving employment levels among various groups, including people with intellectual disabilities. As implementation of these programmes is still in its early stages at present, it is too soon to assess the extent to which they are meeting with success. The underlying principles of these programmes tend to emphasise a move away from dependence on benefits and towards self-reliance. While such an approach could be an important means of aiding people with intellectual disabilities in moving towards

productive employment, without adequate support in a transition period the process could have a negative impact in the short term. Adults with intellectual disabilities, whose previous opportunities for education and training were extremely limited, will require greater help to succeed in supporting themselves, even in part, and benefits should be structured to reflect this situation. Government quota policies also appear to have been of only limited use in increasing the number of people with intellectual disabilities working in the open market, although new employer incentive programmes may have a greater effect in the future, especially as training is included in the budget.

No official statistics on the number of people with intellectual disabilities who are employed are available, but all indicators point to an extremely high level of unemployment in this group. Work in sheltered employment has been available to people with intellectual disabilities, but even this type of segregated employment, which does not enhance social inclusion, has been on the decline in recent years. The types of work that are offered in these workshops tend to be of limited marketability, and therefore do not serve to prepare people for employment on the open market. The proportion of people with intellectual disabilities working in these specialised enterprises for people with disabilities tends to be quite small, but smaller still is the number of people with intellectual disabilities working on the open market. Supported employment services<sup>2</sup> are available on a very small scale through NGOs, but there is no legal or policy framework to develop such initiatives at the national level.

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<sup>2</sup> Supported employment is an employment option that facilitates competitive work in integrated work settings for people with disabilities. It provides assistance such as job coaches, transportation, assistive technology, specialised job training and individually tailored supervision.

## RECOMMENDATIONS

### General Recommendations

#### *International standards*

1. Bulgaria should sign and ratify Protocol No. 12 to the European Convention for the Protection of Human Rights and Fundamental Freedoms establishing a general prohibition against discrimination. Bulgaria should also ratify International Labour Organization Convention C159 on Vocational Rehabilitation and Employment (Disabled Persons).
2. Bulgaria should bind itself to Article 15 of the Revised European Social Charter (ESC) on the right of physically and mentally disabled persons to vocational training, rehabilitation and social resettlement.

#### *Legislation*

3. The Government should eliminate the use of stigmatising and degrading terms to refer to people with intellectual disabilities such as “imbecility”, “retardation”, “oligophrenia”, “handicap” and “mental deficiency” in all domestic law and policy documents and replace them with the term “intellectual disability”.

#### *Coordination*

4. The Government should specifically task the new National Council for Integration of People with Disabilities to oversee policymaking in the field of disability, to promote the social inclusion of people with intellectual disabilities more effectively, and to ensure laws and policies take a holistic and coherent approach in law and policy.
5. The Council should also be given the responsibility for promoting and publicising the results of existing policies to raise awareness of the rights and responsibilities created under these laws and programmes.

#### *Diagnosis procedures*

6. The Ministry of Health Care, the Ministry of Education and Science, and the Ministry of Labour and Social Policy should undertake an urgent review of the procedure for diagnosing children and adults by the relevant bodies, and issue unified, specific, and detailed instructions for diagnosis incorporating medical, social, and educational approaches.
7. The Government should unify the terminology used to diagnose grades of disability and to classify people with disabilities across all legal and policy instruments to ensure consistency of diagnosis and assessment.



8. The Government should provide adequate training for members of diagnostic and assessment bodies and should ensure that there is ongoing independent monitoring of diagnostic and assessment bodies' operating procedures.
9. The Government should ensure that consistent internationally accepted standards (ICD-10 and ICF) are used in determining disability status and that the appeals process is meaningful. The Government should also evaluate how language and/or cultural barriers and racial and class biases may impede accurate diagnosis and assessment.

### *Guardianship*

10. The Government should review the guardianship system in order to ensure that all people placed under guardianship have their rights and interests adequately protected.

### *Data collection*

11. The National Statistical Institute, the National Centre for Health Information, the Employment Agency and the Ministry of Labour and Social Policy should agree upon one consistent definition of “intellectual disability” in line with international standards for use in collecting data on the type of disability, sex, age, employment and legal status of people with disabilities at a national level.
12. The Government should collect and maintain accessible, disaggregated statistical information on people with disabilities, including information on guardianship and legal capacity, with appropriate protection for personal privacy.

## **Recommendations on education**

### *Early intervention*

13. The Ministry of Health Care should ensure that a sufficient number of doctors responsible for diagnosing intellectual disability are available in all district hospitals.
14. The Government should make early intervention services widely available throughout Bulgaria, in order to maximise the potential of children with intellectual disabilities and facilitate their social inclusion to the fullest extent.

### *Inclusive policy*

15. The Ministry of Education and Science should develop standards, methodologies, and financing mechanisms for the mainstreaming of children with intellectual disabilities, ensuring that mainstream schools offer all of the

support and resources necessary for the full inclusion and unhampered development of students with intellectual disabilities.

### *Staffing*

16. The Ministry of Education and Science should make funding available to ensure that each Regional Educational Inspectorate has a separate full-time position for a special education inspector with appropriate qualifications (a university degree in “Special Pedagogy”) and training to competently monitor and support the integration process for children with special needs in mainstream schools.

### *Training*

17. The Ministry of Labour and Social Policy should ensure that each residential institution for children with intellectual disabilities takes all children in the institution to the Regional Expert Medical Commissions for regular review of their diagnoses. The Ministry of Labour and Social Policy should oversee this procedure and collect data provided by the institutions on the type of disability and needs of the children.
18. Universities that offer a course in “Special Pedagogy” should reform their curricula to promote mainstream schooling, with an emphasis on the mainstreaming process and mechanisms.
19. The Ministry of Education and Science should require all staff currently teaching in special schools to regularly take mandatory qualification courses.

### *Local governments*

20. The Ministry of Education and Science should offer the appropriate resources and support to municipalities that would make mainstreaming an authentic option for children with intellectual disabilities.
21. Municipalities must take steps to prepare teachers, parents, and communities for mainstreaming, and provide adequate resources, training, and support for the mainstreaming process.

### *Resources and support*

22. The Ministry of Education and Science should issue a thorough and uniform methodology for designing individual education plans for children with intellectual disabilities, and ensure that teachers receive training on the adaptation of lessons for all children.
23. The Ministry of Education and Science should reform curricula in mainstream and special schools and other educational facilities in order to ensure that the actual needs of people with intellectual disabilities are addressed, including the

development of social and independent living skills and the acquisition of marketable vocational skills.

24. The Ministry of Education and Science should enact the legal provisions relating to home schooling by developing standards and allocating all necessary methodological, human, and material resources to making home schooling for children and adults with intellectual disabilities.

### *Resource centres*

25. The Ministry of Education and Science should ensure that the terms, “resource centre” and “resource teacher” are clearly defined in legislation, in line with recognised standards such as those elaborated in the Salamanca Declaration on Special Needs Education.

### *Advancement to secondary education*

26. The Ministry of Education and Science should reform policy to enable students who have completed primary education to have a viable opportunity to continue their studies in a secondary school of their choosing.

### *Education in institutions*

27. The Government should ensure that all children with intellectual disabilities in residential institutions have access to high quality education. In addition, the Ministry of Education and Science should develop and provide adequate methodological, human, and material resources to ensure an education for children and adults in residential institutions, who have currently very limited educational opportunities of questionable quality.

## **Recommendations on transition from education to employment**

28. The Ministry of Education and Science and the Ministry of Labour and Social Policy should cooperate to reform vocational training for people with intellectual disabilities, and ensure that a range of professional courses offering marketable skills for future employment are available to people with intellectual disabilities.
29. The Ministry of Education and Science and the Ministry of Labour and Social Policy should also join efforts to introduce and support life-long education for people with intellectual disabilities.

## Recommendations on employment

### *Legislation and enforcement*

30. The Government should provide detailed methodologies for assessing working capacity that are in line with internationally accepted standards and should mandate training of the Labour Experts Medical Commissions responsible for assessing the capacity to work.
31. The Government should continuously monitor and evaluate the practices of the assessment bodies to ensure that people with intellectual disabilities receive an accurate evaluation that promotes their access to employment.
32. The Chief Labour Inspectorate should regularly monitor and issue sanctions where necessary to ensure that employers respect quota policies for hiring people with disabilities.

### *Policy coordination*

33. The Government should evaluate the effectiveness of programmes developed to enhance employment opportunities for people with disabilities and implement the necessary structural reforms to ensure the most efficient use of resources, including funds, so that the actual needs of people with disabilities are met.

### *Public awareness*

34. The Ministry of Labour and Social Policy should prepare a public awareness campaign to bring attention to measures supporting the employment of people with disabilities, and to increase employers' awareness that people with intellectual disabilities can be productive employees.

### *Local governments*

35. Municipal authorities should provide support and resources to local NGOs offering employment opportunities for people with intellectual disabilities.

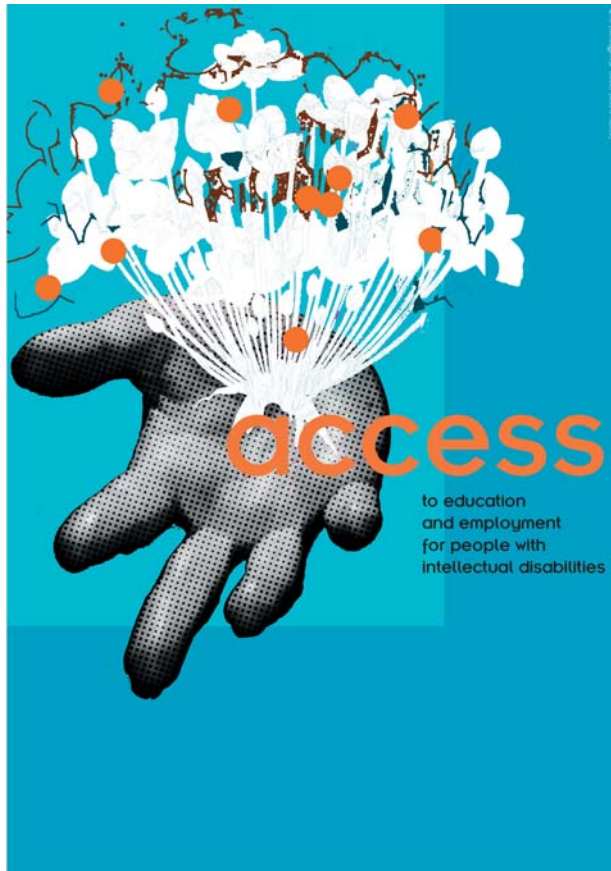
### *Employment services*

36. The Ministry of Labour and Social Policy should establish employment services specifically for people with intellectual disabilities, which include the provision of counselling, job searching and coaching, as well as supported employment services. The Government should ensure these services are staffed by people who have received training in working with people who have intellectual disabilities.



Throughout Europe, people with intellectual disabilities face overwhelming stigma and prejudice and encounter significant barriers to realising their fundamental rights. EUMAP, the EU Monitoring and Advocacy Program of the Open Society Institute, in cooperation with the Open Society Mental Health Initiative, has monitored this situation in 14 countries throughout Europe, both EU members and candidate countries: *Bulgaria; Croatia; the Czech Republic; Estonia; Greece; Hungary; Latvia; Lithuania; the Netherlands; Poland; Romania; Slovakia; Slovenia* and *the UK*. Carried out by local experts and civil society groups, the monitoring focuses on the extent to which people with intellectual disabilities have access to education and employment. This series of reports presents the findings of the monitoring and also makes recommendations for improving the social inclusion of people with intellectual disabilities.

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# Rights of People with Intellectual Disabilities: Access to Education and Employment

Summary Reports

*Croatia*

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## EXECUTIVE SUMMARY

Throughout Europe people with intellectual disabilities<sup>1</sup> face major stigma and prejudice and are confronted with significant barriers to realising their fundamental human rights. Discrimination against people with intellectual disabilities is deeply rooted and widespread, standing in the way of positive change. Providing real access to education and employment for people with intellectual disabilities is critical to ensuring that they can live and work in the community as equal citizens. There is a strong link between education and employment: without access to adequate education, people with intellectual disabilities cannot secure meaningful employment. This denial of access leads to life long dependency, poverty and social exclusion adding to the stigma of intellectual disability. This monitoring report focuses specifically on the areas of education and employment because of their importance to people with intellectual disabilities, and because of the existence of both international standards and national legislation that specifically address them.

Croatia is undergoing a period of intensive reform, as it enters the accession process to the European Union. However, the pace of change for people with intellectual disabilities remains slow, and more focused efforts to support the inclusion of this group is needed. While a national strategy for people with disabilities has been adopted, legislation remains inconsistent, implementation continues to be irregular, and a lack of coordination among the various responsible bodies leaves many people with intellectual disabilities without the support they need to fully engage in society. Education is for the most part segregated, as only children with *mild* intellectual disabilities are placed in mainstream schools; those in special schools often receive a substandard education that leaves them unprepared for employment or any form of independent living. Access to the employment market is equally limited for people with intellectual disabilities; services are not tailored to the needs of this population, and supported employment opportunities are offered only through NGOs that can reach only a tiny fraction of those who would benefit. Croatia should take advantage of this period where international attention and support is at its strongest to demonstrate a clear will to improve the situation of people with intellectual disabilities in all aspects of society.

### *Background*

Generally, Croatia is a party to the major human rights instruments with provisions relating to people with intellectual disabilities, but has yet to ratify the Revised European Social Charter. As a candidate for membership in the European Union (EU),

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<sup>1</sup> The term “intellectual disability” (also described as “learning disability” or “mental retardation”) here refers to a lifelong condition, usually present from birth or which develops before the age of 18. It is a permanent condition that is characterised by significantly lower than average intellectual ability and results in significant functional limitations in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills.



Croatia will be obliged to bring its national laws into line with the EU's anti-discrimination acquis, but at present, there is no comprehensive anti-discrimination legislation. A Government policy addressing the situation of people with disabilities was adopted in 2002, and other policy reforms also include provisions relating to people with disabilities. Although many laws contain references to people with disabilities, poor supporting and implementing regulations affect the impact that legislation has for this group.

Different terms and definitions are used in different sectors of law and policy in Croatia. These variations in terminology can lead to inconsistent application of the law, and even denial of certain benefits. A clear, precise and consistent definition of intellectual disability should be adopted in all law and policy across all relevant fields. The process of diagnosing disability is regulated by a Government Ordinance, which defines four levels of intellectual disability, in line with the ICD-10 classifications. For both adults and children, an Expert Body – an interdisciplinary team, including medical professionals, social workers and psychologists –, establishes the type and level of disability to determine eligibility for social benefits. There is a separate assessment procedure for educational purposes; enrolment commissions conduct an evaluation of each child seeking to enrol.

In Croatia, there are two forms of guardianship, *partial* and *plenary*. If people with intellectual disabilities are placed under guardianship, they are usually placed under *plenary* guardianship. In 2004, there were nearly 15,000 people under guardianship in Croatia. However, detailed statistical data on people under guardianship is lacking. Guardians are usually family members, but in some cases a social worker may be appointed as a guardian. Concerns have been raised regarding the extent to which the current system of monitoring guardianship arrangements is adequate to prevent abuse. Statistical data is limited, again due to inconsistent definitions of intellectual disability, and improving the collection and coordination of data should be a Government priority. There is still a high level of institutionalisation in Croatia; currently, NGO projects on deinstitutionalisation are focused on developing community alternatives to large residential facilities.

### *Access to education*

Children with disabilities have a Constitutional right to education. The broader term “children with developmental difficulties” is used in education legislation, and generally includes children with intellectual disabilities. Current legislation does not provide for comprehensive inclusive education of children with disabilities; only children with *mild* intellectual disabilities are expressly given the right to education in mainstream schools, while those with more serious intellectual disabilities may be placed in separate, special schools or institutions. Educational funding presents certain obstacles to effective support for children with disabilities: because the school's budget must be approved at the national level, the process of adding staff as support for children with intellectual disabilities is difficult.

An enrolment committee comprised of health and education professionals makes an initial assessment as to whether a child is eligible to enrol in school. On the basis of the assessment, the committee may decide on the most appropriate form of education for the child, which may be one of the following: integration with an applied curriculum, partial integration, a special programme in a mainstream school or special school, or a programme for pupils with severe developmental disorders, within a social care institution. Those children believed to have disabilities of a longer-term duration, which render them incapable of enrolling are placed under observation in the nearest school for up to three months. However, legislation does not appear to specify the criteria that determine whether a child is considered “capable” of entering a mainstream school. The final decision on the educational option for a child is issued by the county administrative body for education, based on the evaluation of the enrolment committee. Limited early intervention services are available, but these are far too few to meet demand, and waiting lists are years long. Moreover, parents have expressed concern that early intervention services available to families do not adequately support caring for children at home, rather than in an institution. Healthcare reforms have also resulted in cutbacks to the services available for young children with intellectual disabilities, such as speech therapy.

As part of the process of application for EU candidacy, Croatia has developed a number of reforms targeting the education system and specifically the education of people with disabilities. While the “National Strategy of Unique Policy for the Disabled for the period from 2003 to 2006” does cover education, it does not call for comprehensive inclusion, and implementation of the measures it does set out has been limited.

The Ministry of Education has developed curricula for children with intellectual disabilities based on the individual child’s level of disability, the type of school the child attends (mainstream or special, and the level of inclusion in a mainstream class (partial or full integration). While teachers are encouraged to adapt classroom lessons to meet the individual needs of pupils, including those with intellectual disabilities, training and support for this process are minimal. The Faculty of Special Education in Zagreb trains and prepares teachers for working with children with intellectual disabilities, and has developed a number of model curricula and other teaching aids that could greatly improve the quality of teaching for children with intellectual disabilities, if the Ministry supported their dissemination and use.

In practice, the inclusion of children with intellectual disabilities in mainstream schools is very limited. Only children with *mild* intellectual disabilities are referred to mainstream classes, but even for this small number of children, the level of support in most schools is inadequate. Almost all children with *moderate* to *severe* intellectual disabilities are placed in special schools, and even some children with *mild* intellectual disabilities are referred to these segregated facilities. According to parents, the quality of education in many special schools is poor, and children fail to acquire even the most basic life skills. Children who remain at home due to their disabilities are entitled to

home schooling, but generally children with intellectual disabilities who are cared for at home do not receive any formal education. Children in institutions may likewise lack access to education, as not all residential institutions provide educational programmes. Those that do are not subject to regular inspections that would help to ensure the quality of education provided.

### *Transition from education to employment*

Very limited support for the transition from education to employment is available to people with intellectual disabilities in Croatia. Several forms of vocational education are open to people with intellectual disabilities, some offering a diploma and others only a certificate, which is of very limited use on the employment market. People with intellectual disabilities are entitled to register at their local employment office upon completing their education, but studies suggest few actually do so, and therefore only a small number of people with intellectual disabilities take advantage of the services these employment offices provide. More intensive efforts on the part of the Ministry of the Economy, Labour, and Entrepreneurship to promote these services among people with intellectual disabilities could result in better access to the employment market.

### *Access to employment*

Croatia's Constitution guarantees the right to work, and provides for special protection at work for people with disabilities. Legislation also provides for the right to professional rehabilitation, training for employment, for people with disabilities. Croatia does not yet comply with the requirements of the EU's Employment Directive (2000/78/EC), which will be a condition of entry to the EU. The Labour Law does explicitly prohibit discrimination in hiring and employment on the basis of physical or mental disability.

Eligibility for social benefits is assessed by an expert body at the local centre for social welfare; concerns have been raised that these assessments vary greatly in quality and focus on incapacity, rather than taking into account an individual's potential. The Service for Professional Orientation conducts assessments to determine eligibility for vocational training programmes; this process has come under criticism as it places an undue emphasis on IQ, rather than on specific capacity to perform a given job. People under *plenary* guardianship often do not receive a separate assessment of their capacity to work, as the loss of full civil capacity is presumed to preclude any employment. Several different forms of social benefit are available to people with intellectual disabilities, but the administration of these benefits is problematic; in certain cases, parents have sought to have their children declared unqualified for work so the child retains eligibility for one type of benefit, for example, the family pension.

The EU has placed little emphasis on employment for people with disabilities in its reports on Croatia; however, some EU funds are directed towards vocational training for vulnerable groups such as people with disabilities. Croatia has adopted several employment incentive programmes, with specific provisions relating to people with

disabilities. These measures have had some success in finding jobs for people with disabilities, and people with intellectual disabilities have found work through this programme, although there are no initiatives targeting the population with intellectual disabilities. The long-term success of these efforts remains unclear, as there are indications that retention of employees hired under these measures is poor beyond the period of State salary co-financing. Quota requirements are in place for governmental bodies, and a penalty is applied to workplaces that do not meet hiring quotas for people with disabilities. These penalties are too low to be an effective means of enforcement, however.

Very few people with intellectual disabilities have any form of employment. Exact figures on the number of people with intellectual disabilities who are unemployed are unreliable, as many people do not register as unemployed. Supported employment is available only on an extremely limited basis in Croatia.<sup>2</sup> One NGO, with international support, has developed a supported employment programme, and other organisations may follow, but there is no Government support for such initiatives. Around 400 people with disabilities work in sheltered workplaces, which are segregated and do not enhance inclusion. Although some of these workshops are intended to give participants the skills and training necessary to make the transition to work on the open market, few people are able to actually make the transition from sheltered employment to any other form of work.

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<sup>2</sup> Supported employment is an employment option that facilitates competitive work in integrated work settings for people with disabilities. It provides assistance such as job coaches, transportation, assistive technology, specialised job training and individually tailored supervision.

## RECOMMENDATIONS

### General Recommendations

#### *International standards*

1. Croatia should ratify the Revised European Social Charter and bind itself to Article 15 on the right of persons with disabilities to independence, social integration and participation in the life of the community.
2. Croatia should ratify ILO Convention 142, concerning Vocational Guidance and Vocational Training in the Development of Human Resources.
3. The Government should take steps to develop comprehensive anti-discrimination legislation in line with the EU anti-discrimination directives 2000/43/EC (the Race Equality Directive) and 2000/78/EC (the Employment Directive).

#### *Coordination of policy*

4. The Government should create effective coordination mechanisms among the bodies participating in the “National Strategy for a Unique Policy for the Disabled 2003 to 2006”, to ensure that policy related to people with disabilities is consistent and effectively implemented.
5. The Government should improve the efficiency of its coordination with civil society by organising meetings with groups and individuals to solicit input on policy, and take concrete steps to inform the general public on disability policy and implementation.

#### *Terminology*

6. The Government should ensure that all legislation and regulations related to people with intellectual disabilities contains consistent definitions of intellectual disability, which conform to international standards (ICD-10, ICF).

#### *Data collection*

7. The Government should improve its system for the comprehensive and consistent collection of statistical data on the situation of people with intellectual disabilities by increasing transparency, improving public awareness, and enhancing communication among professionals who access the data. Information on the number of people educated at home, or not receiving education at all, should be gathered and maintained in particular.

#### *Guardianship*

8. The Government should provide all necessary human and financial resources to ensure that guardianship arrangements are monitored comprehensively and in line with current requirements.

9. The Government should elaborate regulations implementing legislation that would allow active civil capacity to be assessed in a separate procedure in all cases, thereby offering people under guardianship greater opportunities for employment.
10. The Government should ensure that the capacity to work of adults with intellectual disabilities who are under guardianship is assessed separately and consistently, to give them an increased opportunity to find employment.

### *Early intervention and other services*

11. The Ministry of Health and Social Welfare, should take steps to ensure that there is adequate funding and staff to fulfil the needs for early intervention services throughout the country and should establish cooperation with the Ministry of Education, Science and Sport in order to ensure continuity with educational rehabilitation services.
12. The Ministry of Health and Social Welfare and the Ministry of the Economy, Labour and Entrepreneurship should establish regular training for all staff of local social welfare and employment centres, to ensure that they are informed of all the services available to people with intellectual disabilities and their families, and sensitive to the needs of these clients.

## **Recommendations on education**

### *Inclusion*

13. The Ministry of Science, Education and Sports should draft amended legislation that adopts an inclusive approach to education, and prioritises mainstreaming for children of all levels of disabilities, not only for children with *mild* intellectual disabilities.

### *Resources and support*

14. The Ministry of Science, Education and Sports should ensure that sufficient financial, technical, and human resources and appropriate support are available for children with all levels of intellectual disabilities in mainstream kindergartens, elementary and secondary schools throughout the country.
15. The Ministry of Science, Education and Sports should ensure that all pre-school teachers, elementary and secondary school teachers have appropriate training in individualised instruction, including adapting curricula, managing classroom diversity, and addressing the specific needs of children with intellectual disabilities.
16. The Ministry of Science, Education and Sports should take steps to disseminate existing materials to assist teachers in adapting curricula, such as

resources developed by the Faculty of Special Education in Zagreb, making such materials available to teachers throughout the country.

17. The Ministry of Science, Education and Sports should formally recognise training and certification programmes NGOs offer to teachers on working with children with disabilities as a means of increasing the number of teachers trained and prepared to work with this group.

### *Education outside the school system*

18. The Ministry of Science, Education and Sports and the Ministry of Health and Social Welfare should cooperate to introduce a quality monitoring system to oversee educational activities in social welfare or healthcare institutions. In institutions where no education is currently available, the ministries should establish programmes to offer an educational option to residents.
19. The Ministry of Science, Education and Sports should develop appropriate standards and allocate all necessary material and human resources towards making home schooling a genuine educational option for children and adults with intellectual disabilities.

### **Recommendations on transition from education to employment**

20. The Ministry of Science, Education and Sports, and the Ministry of the Economy, Labour and Entrepreneurship should closely cooperate to ensure that vocational and other training available to people with intellectual disabilities is adjusted to meet the needs of the market, taking full advantage of available EU funds.
21. The Ministry of Science, Education and Sports should reform the system of vocational training to give people with *moderate to severe* intellectual disabilities the opportunity to participate in professional education, rather than only “training for independent living”, thereby enhancing their potential for employment.
22. The Ministry of the Economy, Labour and Entrepreneurship should develop a programme to encourage people with disabilities to register with the employment office after completing their education, in order to access the services available with these local offices.

### **Recommendations on employment**

#### *Legislation and enforcement*

23. The Government should undertake an analysis to ensure that legislation in each of the health, pension, education, and employment spheres use consistent definitions of people who are capable of working.
24. The Ministry of Science, Education and Sports should enforce the requirement that vocational schools provide three years of follow-up guidance

to their graduates, through the assurance of adequate staff levels, as a means of supporting employment for people with intellectual disabilities.

25. The Ministry of Health and Social Welfare should take steps to amend legislation withdrawing family pensions from people who merely have acquired the qualifications in a particular profession, and replace this provision with a fixed income threshold above which benefits would be reduced or withdrawn.

### *Government incentives*

26. The Ministry of the Economy, Labour and Entrepreneurship should extend existing incentive programmes to encourage the employment of people with disabilities to include part-time work, which is better suited to many people with intellectual disabilities.

### *Supported employment*

27. The Ministry of the Economy, Labour and Entrepreneurship should establish a legal basis for supported employment, and dedicate appropriate resources towards developing supported employment services.
28. The Ministry of the Economy, Labour and Entrepreneurship should collaborate with existing models of good practice in the NGO sector to develop appropriate training for job coaches and support mechanisms to help people with intellectual disabilities find and retain jobs.

### *Monitoring*

29. The Ministry of Science, Education and Sports should monitor the occupationally training and training for independent living programmes for people with moderate to severe intellectual disabilities, to ensure that participants gain skills that will enable them to live as independently as possible.

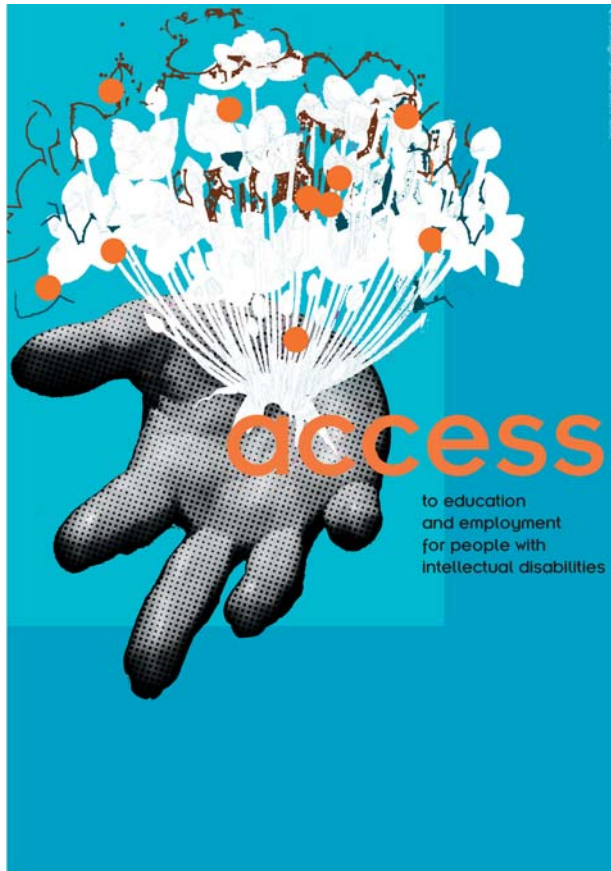
### *Public awareness*

30. The Government should develop a public-awareness programme to reduce employers' negative stereotypes regarding people with intellectual disabilities and raise awareness of the employment potential of these people.



Throughout Europe, people with intellectual disabilities face overwhelming stigma and prejudice and encounter significant barriers to realising their fundamental rights. EUMAP, the EU Monitoring and Advocacy Program of the Open Society Institute, in cooperation with the Open Society Mental Health Initiative, has monitored this situation in 14 countries throughout Europe, both EU members and candidate countries: *Bulgaria; Croatia; the Czech Republic; Estonia; Greece; Hungary; Latvia; Lithuania; the Netherlands; Poland; Romania; Slovakia; Slovenia* and *the UK*. Carried out by local experts and civil society groups, the monitoring focuses on the extent to which people with intellectual disabilities have access to education and employment. This series of reports presents the findings of the monitoring and also makes recommendations for improving the social inclusion of people with intellectual disabilities.

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## EXECUTIVE SUMMARY

Throughout Europe, people with intellectual disabilities<sup>1</sup> face major stigma and prejudice and are confronted with significant barriers to realising their fundamental human rights. Discrimination against people with intellectual disabilities is deeply rooted and widespread, standing in the way of positive change. Providing real access to education and employment for people with intellectual disabilities is critical to ensuring that they can live and work in the community as equal citizens. There is a strong link between education and employment: without access to adequate education, people with intellectual disabilities cannot secure meaningful employment. This denial of access leads to life-long dependency, poverty and social exclusion adding to the stigma of intellectual disability. This monitoring report focuses specifically on the areas of education and employment, because of their importance to people with intellectual disabilities and because of the existence of both international standards and national legislation that specifically address them.

For people with intellectual disabilities in Estonia, access to inclusive education and to any kind of employment remains highly limited. Attitudes towards people with intellectual disabilities have improved over the last decade and the EU accession process has encouraged positive changes in terms of legislation and policy. However, Estonia does not have comprehensive anti-discrimination legislation. While the number of children with intellectual disabilities in the education system is increasing, most of these children are not able to receive education in an integrated environment. Most young people with intellectual disabilities do not receive the education or vocational training they need to later access employment, and the vast majority of people with intellectual disabilities has no employment or work of any kind, so these people are reliant on social benefits. To date, the Government has not adequately addressed the specific needs of people with intellectual disabilities in the labour market.

### *Background*

Estonia is party to most international human rights instruments related to education and employment, including those with provisions on people with disabilities. The Constitution does not explicitly prohibit discrimination on the grounds of disability. Estonia has not yet transposed the provisions of the EU Race Equality Directive or the EU Employment Directive into national legislation. National disability policy is based on the United Nations Standard Rules on Equalization of Opportunities for Persons with Disabilities. Any complaints of discrimination can be directed to the Chancellor of Justice, an independent body that has the special powers of an ombudsman and is

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<sup>1</sup> The term “intellectual disability” (also described as “learning disability” or “mental retardation”) here refers to a life-long condition, which is usually present from birth or which develops before the age of 18. It is a permanent condition that is characterised by significantly lower than average intellectual ability and results in significant functional limitations in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills.

authorised to issue binding decisions in cases of discrimination, in both the public and private sectors.

In Estonia, law and policy use terminology and definitions from the World Health Organization's ICD-10 to diagnose and classify intellectual disability. The term "person with special needs", which includes people with intellectual disabilities, has been recently introduced into Estonian legislation on education. There are different procedures for the diagnosis and assessment of intellectual disability for education (for children); for employment (for adults); and for access to social benefits (for adults and children). Counselling Committees are responsible for diagnosing intellectual disability for educational purposes, according to one of four levels: *mild*, *moderate*, *severe* and *profound* intellectual disabilities. The Medical Examination Commission of the Social Security Board and its regional units (hereafter, Medical Commissions) determine working capacity and also establish an individual's degree of disability (*moderate*, *severe* or *profound*), which in turn determines access to social welfare and other benefits for adults and children. People with *mild* intellectual disabilities are not eligible for these benefits.

There are detailed official statistics on people with disabilities in general. However, these statistics are not disaggregated on the basis of type or level of disability, which means that it is not possible to obtain information across all relevant sectors or, more specifically, on the total number of people with intellectual disabilities in Estonia. Most adults with at least a *moderate* level of intellectual disabilities are placed under guardianship by the courts. Without the consent of the guardian, a person whose legal capacity has been removed cannot sign a contract, including an employment contract. Adults with intellectual disabilities whose active legal capacity has been restricted in certain areas retain the right to work and to sign an employment contract, but their guardians must give their consent for the ward to be employed. If the active legal capacity of adults with intellectual disabilities is restricted in all areas – a condition equivalent to *plenary* guardianship – they lose the right to vote but can still work with the consent of a guardian.

### *Access to education*

The Constitution guarantees the right to education for everyone, and this right is supported by the Education Act. General legislation on basic and secondary education also regulates special education. Children with special needs, including children with intellectual disabilities, have the right to study at a mainstream school in the area where they live, provided the local authorities have ensured a suitable learning environment. Otherwise, the children have the right to attend the nearest school meeting their educational requirements. In practice, for children with intellectual disabilities, this right is often not realised; many mainstream schools will not enrol children with intellectual disabilities on the grounds that they cannot provide the needed support services. Existing regulations do not define exactly what mainstream schools must do to adapt their conditions to meet the needs of children with special needs.

In Estonia, access to early intervention services is very limited, and intellectual disability is usually not diagnosed before the age of seven. This means that children with intellectual disabilities (and their families) do not receive the support they need for successful integration into a mainstream school. The assessments carried out by the Counselling Committees are multidisciplinary and involve parents or guardians. Based on their assessment of a child's level of intellectual disabilities, the Committees *recommend* a type of school for the child. They also recommend the type of class the child should be enrolled in – there are special classes for children with differing levels of intellectual disabilities – and the most appropriate curriculum he or she should follow. However, the parents or guardian of a child with intellectual disabilities must give their agreement for their child to be placed in a special school or a special class. Today, most parents want their child with intellectual disabilities to attend a mainstream school.

Education policy in Estonia has undergone systematic reform since the country regained its independence in the early 1990s. Estonia is one of the few countries to have specifically addressed the educational needs of people with disabilities during its EU accession process. The “Joint Inclusion Memorandum”, developed by Estonia and the European Commission, makes a number of recommendations for improving the inclusion of children with intellectual disabilities at all levels of education. Following Estonia's accession to the EU in 2004, EU Structural Funds are now being directed towards education and vocational training. However, the Government has not yet allocated these funds towards projects specifically aimed at people with intellectual disabilities. National educational policy recognises the importance of improving mainstreaming and life-long education for people with intellectual disabilities. However, the recommendations of key education policy papers – in particular, the “Learning Estonia” education strategy paper of 2001 – are yet to be implemented. The conclusions and recommendations on inclusive education from the “A School for All” project, organised and funded by the Nordic Council of Ministers, could be an important resource for further policy development.

Special, separate curricula are available for children with *mild* intellectual disabilities or *moderate* or *severe* intellectual disabilities. Children with *severe* and *profound* intellectual disabilities are educated in special “nursing” classes. Children with intellectual disabilities in mainstream classes can also follow an individual education plan. However, although this option is increasingly popular, many students with intellectual disabilities are not yet provided with the support they need to follow an individual education plan, mainly because mainstream schools lack the necessary specialists and support system. Teachers do receive training on working with children with special needs as part of their education, but research suggests that more instruction and support for teachers is needed.

Although Estonia recognises certain principles of inclusive education in law and policy, in practice, most children with intellectual disabilities still do not have the opportunity to receive an education in a mainstream setting. The number of children with special

needs (in general) in mainstream schools increased significantly, by 25 per cent, from 1998 to 2002. In 2002–2003, 74 per cent of these children were integrated into special classes in mainstream schools and seven per cent into mainstream classes. There is no available data on the exact number of children with intellectual disabilities in mainstream education, though it is known that, from kindergarten to secondary level, their number continues to increase, in large part due to pressure from parents. In addition, some caution is required in interpreting the actual situation of children with intellectual disabilities, because many of those who are enrolled in mainstream schools in reality study at home. Although this arrangement permits some children to remain at home rather than having to live in a residential special school, it certainly does not fulfil the aims of inclusive education. There is no official data on the total number of children with intellectual disabilities receiving home schooling.

A number of important barriers still limit the extent to which the integrated education of children with intellectual disabilities can develop in practice. These barriers include lack of transportation, large class sizes, and opposition to integration from some teachers and parents of children without disabilities. The most important barrier, however, is the insufficient number of support specialists. In kindergartens, for example, in most cases the local authorities are not able to provide financial support for support teachers, and parents or guardians must themselves cover the cost of a support teacher. About half of all mainstream kindergartens have no access to support from a special educator, so there is a heavy burden on class teachers. Mainstream schools do not receive the funding required to meet the needs of children with intellectual disabilities. Legislative barriers are also significant; although the right to inclusive education exists on paper, existing rules and regulations do not provide the necessary mechanisms for its implementation in practice.

In 2002–2003, there were 5,166 students with special needs – mainly with intellectual disabilities – in special schools, which may be day schools or residential. Due to a lack of other alternatives, many children and young people with *severe* or *profound* intellectual disabilities have no other option but to study in residential special schools, far from their homes. The quality of education in such schools is rather low, due to limited resources: there is a lack of financing, qualified teachers and equipment. For the same reasons, the living standards in residential special schools are also low. It is also common for children with intellectual disabilities to be schooled at home, primarily due to the limited capacity of mainstream schools, which have yet to make the provision of the necessary support services for children with special needs a priority. A large majority of children with intellectual disabilities who appear on enrolment lists at mainstream schools are in practice schooled at home.

### *Transition from Education to Employment*

In Estonia, the vocational education system has recently been reformed, and an increasing number of young people are receiving vocational training. Recent legislative changes have facilitated the access of young people with special needs to vocational

training institutions. In 2002–2003, there were nearly 300 students with special needs, many of whom had intellectual disabilities, studying in vocational educational institutions. The main constraints preventing mainstream vocational schools from accepting students with intellectual disabilities are the lack of qualified personnel and the prevalence of large class sizes. Young people with intellectual disabilities can also be prepared for entering the labour market at the Astangu Coping Centre, which offers “labour therapy” or vocational rehabilitation. The Employment Offices provide no employment services, such as vocational training, for people with intellectual disabilities who are unemployed. These Offices also fail to organise in-service training or re-training specifically for people with intellectual disabilities. In general, people with intellectual disabilities have few options for vocational training, re-training or advanced training in Estonia.

### *Access to employment*

The Constitution guarantees freedom of choice in employment and “special care of the State and local governments” for people with disabilities. There is no specific legislation on the employment of people with disabilities. The Employment Contracts Act does not protect the rights of people with disabilities. As yet, Estonia has not adopted specific legislation to comply with the EU Employment Directive.

People with disabilities who are age 16 or older, and who have been determined by the Medical Commission as having a reduced working capacity of between 40 and 100 per cent, are eligible for either an incapacity pension, if they worked previously, or a national pension. However, people with disabilities with a reduced working capacity of less than 40 per cent are ineligible for social benefits on the basis of their disabilities. The assessment procedures are based on a purely medical approach, and neither the person being assessed, nor his or her parents or guardian, are present at the assessment. Following the amendment of the Social Benefits for Disabled Persons Act, the criteria for establishing the degree of disability and working capacity have been set out more clearly. However, the Chancellor of Justice has received a number of complaints from people whose pensions have been reduced following reassessment of their degree of disability, in accordance with these new criteria. Most people with intellectual disabilities are fully reliant on State benefits, which are currently set at a very low level. Nonetheless, even if they could find employment, there is still often little incentive for them to start working, due to the relatively small difference between the minimum wage and pensions.

During the accession process, several Phare-funded projects sought to improve access to employment for people with disabilities in Estonia. The main aims of these projects were to improve rehabilitation and employment services, and to improve the adaptation of workplaces for people with disabilities. Estonia does not have a quota system for the employment of people with disabilities. The primary way in which the Government encourages the employment of people who are “less competitive on the labour market”, including people with disabilities, is through tax concessions and active employment measures. However, these measures were not specifically designed for



people with disabilities, and they do not meet the specialised needs of people with intellectual disabilities. In particular, the amount of the subsidies are too low to cover the costs of a job coach, and aids, such as instructions in simplified language, are not included under provisions for workplace modification. Generally, awareness of these measures is very low, and in some cases funding for subsidies is not actually available.

Very few people with intellectual disabilities have any kind of work or employment; in fact, only about 12 per cent of people with disabilities are in employment. Official data on the employment situation of people with disabilities is not disaggregated by type of disability. The data also systematically underestimates the total number of people with disabilities who are in the workforce or unemployed, because the figures do not include people with *mild* disabilities. Furthermore, many people with intellectual disabilities do not register as unemployed, and so they cannot benefit from employment services.

Supported employment services are the most important way in which people with intellectual disabilities can access employment on the open market.<sup>2</sup> However, in Estonia, there is no legal framework for supported employment as it is commonly understood, though a definition does appear in a Ministry of Social Affairs regulation. One small project to encourage the employment of people with intellectual disabilities, through use of employment subsidies, was carried out by the Tallinn City Board of Disabled People. The Estonian Mentally Disabled People Support Organization (EVPIT) also provides vocational counselling for adults with intellectual disabilities living in Tallinn. However, there is an urgent need for the Government to encourage the establishment of supported employment services for people with intellectual disabilities. In addition to inadequate State funding and inadequate support services, an important barrier for people with intellectual disabilities who wish to enter the workforce is their lack of preparedness for seeking employment – in particular their lack of vocational training.

There is no official data on the number of people with intellectual disabilities in sheltered employment. Sheltered employment is funded by the State through subsidies paid to both employer and employee. In 2004, there were 46 organisations offering State-funded sheltered employment to 511 people with disabilities throughout Estonia. Most of the organisations were social welfare institutions, such as social care homes and day centres. The “Juks” centre in Tallinn is the only sheltered employment centre specifically for people with intellectual disabilities, and it presently offers work and training for 30 people with intellectual disabilities.

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<sup>2</sup> Supported employment is an employment option that facilitates competitive work in integrated work settings for people with disabilities. It provides assistance such as job coaches, transportation, assistive technology, specialised job training and individually tailored supervision.

## RECOMMENDATIONS

### General recommendations

#### *International standards*

1. Estonia should ratify Protocol No. 12 to the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR); and International Labour Organization Convention C159 on Vocational Rehabilitation and Employment (Disabled Persons).

#### *Legislation*

2. Estonia should transpose into national legislation all the provisions of the European Union's Council Directive 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin (Race Equality Directive); and Directive 2000/78/EC of 27 November 2000, establishing a general framework for equal treatment in employment and occupation (Employment Directive).

#### *Public awareness*

3. Public institutions, in collaboration with NGOs representing people with intellectual disabilities and their families, should work to counter the stigma of intellectual disability by organising information days, seminars and other, similar events, to raise awareness of, and increase knowledge about, people with intellectual disabilities.
4. The Government should, in particular, take steps to raise the awareness of employers with regard to the skills and abilities of people with disabilities and their value as employees on the open labour market. In addition, the Government should better inform employers about governmental programmes and employment services for people with disabilities.

#### *Data collection*

5. With appropriate attention to the protection of personal privacy, the Government should ensure that comprehensive data on people with disabilities, disaggregated by type of disability, is regularly collected and published, across all relevant sectors. In particular:
  - The Ministry of Education and Research should establish and maintain a system for the consistent collection and public dissemination of data on the number of children and young people with intellectual disabilities in the education system, the types of schools and classes they attend at each level, and the number who are schooled at home.

- The Ministry of Social Affairs should collect comprehensive data on the employment of people with intellectual disabilities, including data on supported and sheltered employment.
6. The Government should carry out a “mapping” of past and present projects that target, or have targeted, people with intellectual disabilities – or, more generally, people with special needs. A database should be created with all relevant information about the projects, as well as their results, with the aim of spreading knowledge of best practices.

## **Recommendations on education**

### *Legislation*

7. The Ministry of Education and Research should elaborate regulations, or propose amendments to the Education Act, that clearly specify the conditions required for children with intellectual disabilities to attend mainstream schools, with the intention of promoting the maximum degree of integration, and equality of access, for children with intellectual disabilities.
8. In line with Article 3 of the Salamanca Statement, which calls for all governments to embrace inclusive education, the Ministry of Education and Research, in cooperation with the Ministry of Social Affairs, should introduce specific legislation that unequivocally enshrines the right for children with intellectual disabilities to receive individually tailored support services at mainstream schools, including support teachers, personal assistants, and transport to and from school. The legislation should also ensure the right of a child with intellectual disabilities to attend a mainstream school near to their place of residence.

### *Early intervention services*

9. The Government should ensure that children with intellectual disabilities (and their families) are able to access quality early intervention services throughout the country. In particular, intellectual disability should be diagnosed as early as possible, so that pre-school children with intellectual disabilities can be provided with the support they need for their later integration into mainstream education.

### *Inclusive education*

10. The Ministry of Education and Research should closely monitor the progress of inclusive education for children with intellectual disabilities in Estonia. In particular, it should ensure that children with intellectual disabilities enrolled in mainstream schools are not, in practice, educated at home.

11. The Ministry of Education and Research and the Ministry of Social Affairs should ensure that there is adequate funding to pay for the special needs of children and young people with intellectual disabilities who are included into mainstream education. In particular, the costs of employing support teachers or personal assistants in mainstream schools should be covered.
12. The Ministry of Education and Research and local authorities should ensure that the principle of fully informed parental choice is respected within school placement procedures. In particular, these officials should work to develop the capacity of mainstream schools, to attend to the special needs of children with intellectual disabilities, so that insufficient capacity is no longer a barrier to their integration at mainstream schools.
13. The Ministry of Education and Research should carry out a survey determining the number of children schooled at home and the quality of home schooling. The ministry should ensure that children with intellectual disabilities have the opportunity to attend a school close to home, if their parents so choose.

### *Financing of Education*

14. The Ministry of Education and Research should ensure that local governments fulfil their obligation to enable people with intellectual disabilities to obtain an education. This should include covering the additional costs related to their disabilities, such as transport to and from school and a personal assistant at school. If local governments are not implementing existing laws, a system of supervision must be introduced.
15. The Government should clarify the areas concerning people with special needs that are financed by the Ministry of Education and Research or the Ministry of Social Affairs, to ensure better coordination of services.
16. The Ministry of Education and Research should promote the equalisation of funding amongst schools, ensuring that rural schools in different regions of Estonia are able to provide the same quality education for children with intellectual disabilities as urban schools.
17. The Ministry of Education and Research should increase the annual funding provided to mainstream schools for each child with intellectual disabilities by a higher expenditure “index” (adjusted to the severity of disability), to bring funding for children with intellectual disabilities at mainstream schools in line with the funding provided at special schools.

*Teacher training*

18. The Ministry of Education and Research should develop training programmes, together with a system of certification, for specialised support teachers for children with intellectual disabilities.

**Recommendations on transition from education to employment**

19. The Ministry of Education and Research should continue its involvement in “Transition”, a sub-project of the larger “A School for All”, with the Nordic Council of Ministers. As there are no transition support systems for going from basic school to vocational school, or from vocational school to work, the Ministry should develop a system to offer support in such transitions, to ensure coping in vocational school or at the workplace.
20. The Government should develop supported and sheltered living arrangements, to assist young people with intellectual disabilities who have recently completed school and have yet to enter the labour market in developing independent living skills.

*Vocational training*

21. The Government should ensure that vocational training for people with intellectual disabilities is carried out in an inclusive environment and not in special institutions.
22. The Government should encourage vocational schools and employment agencies to work together to prepare people with intellectual disabilities for the real needs of the labour market.
23. The Government should encourage employment agencies to provide life-long vocational training and retraining for people with intellectual disabilities.

**Recommendations on employment***Legislation*

24. As a priority, legislation should be introduced on supported employment, and the Government should then provide adequate funding to supported employment projects.
25. The Government should initiate legislation to define and support the functioning of social enterprises.

### *Policy*

26. The Government should fully implement the recommendations of the 2004 Phare project “Enhancing employment opportunities for people with disabilities in Estonia”.
27. The Government should develop action plans to tackle the barriers to employment outlined in the “National Action Plan on Poverty and Social Inclusion”, with special emphasis on people with intellectual disabilities.

### *Assessment of capacity for employment purposes*

28. The Ministry of Social Affairs should reform the assessment procedures for degree of disability and working incapacity as follows:
  - The participation in the assessment procedure of the person with intellectual disabilities under assessment – and, where appropriate, of his or her parents or guardian – should be made obligatory. All information and documentation collected under the assessment procedure should be made available, and, if necessary, explained in lay terms, to the person under assessment and his or her parents or guardian.
  - The central focus of the assessment should be the potential, capabilities and needs of a person with intellectual disabilities, replacing the present focus on deficiencies and on what a person with intellectual disabilities *cannot* do.
  - The participation of social workers in the Medical Examination Commission of the Social Security Board and its regional units should be obligatory.
29. The Government should discontinue using the term “incapacity for work” in all policy and legislation, and replace it with terminology that is more positive in connotation, such as “needs for work” or “rehabilitation plan”.

### *Employment services*

30. The Employment Office should establish a database of people with disabilities, registered at the employment office, to be made available to employers interested in employing people with disabilities.
31. The Government should ensure that employers of people with intellectual disabilities have access to support services, such as consultancy services, which assist them in understanding and anticipating the different needs of people with disabilities in the workplace.

32. The Government should ensure that additional State subsidies are made available to fund the adaptation of the workplace for people with disabilities, such that employers are more motivated to hire people with disabilities.
33. Government bodies, local authorities, NGOs and private industry should work together to increase the numbers of people with intellectual disabilities integrated into the workforce. A network of cooperation between employment offices, pension boards, rehabilitation and vocational education institutions should be established.

#### *Active employment measures*

34. The Government should introduce active employment measures that support the return of the unemployed to the labour market and that *specifically* target people with disabilities.

#### *Supported employment*

35. The Government should provide funding for supported employment services, accessible to people with intellectual disabilities throughout the country. This should include continuous counselling, both for employers and people with intellectual disabilities working on the open labour market.
36. The Government should provide employment subsidies for employers to hire job coaches for people with intellectual disabilities. It should also increase the employment subsidy for employers who hire adults with severe intellectual disabilities or multiple disabilities.

#### *Sheltered workplaces*

37. The Government should, while making the establishment of supported employment services its main priority, ensure adequate financing for the purchase of equipment and the adaptation of the workplace for people with intellectual disabilities in sheltered workplaces.

#### *Rehabilitation*

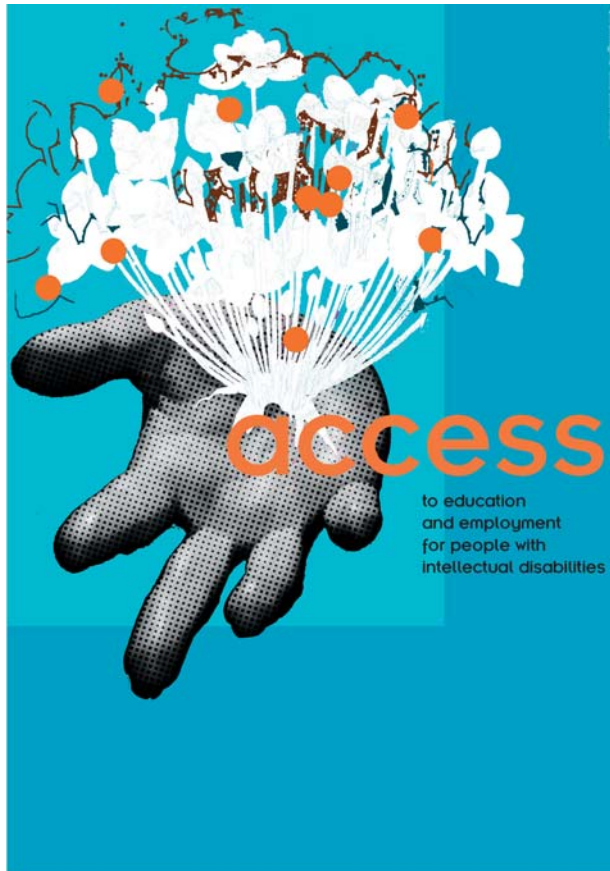
38. The Government should ensure that rehabilitation plans for people with intellectual disabilities focus on the individual's ability to work and their vocational training. Rehabilitation should be more focused on the future employability of people with intellectual disabilities and should prepare them psychologically for the world of work, while also providing them with a vocation.





Throughout Europe, people with intellectual disabilities face overwhelming stigma and prejudice and encounter significant barriers to realising their fundamental rights. EUMAP, the EU Monitoring and Advocacy Program of the Open Society Institute, in cooperation with the Open Society Mental Health Initiative, has monitored this situation in 14 countries throughout Europe, both EU members and candidate countries: *Bulgaria; Croatia; the Czech Republic; Estonia; Greece; Hungary; Latvia; Lithuania; the Netherlands; Poland; Romania; Slovakia; Slovenia* and *the UK*. Carried out by local experts and civil society groups, the monitoring focuses on the extent to which people with intellectual disabilities have access to education and employment. This series of reports presents the findings of the monitoring and also makes recommendations for improving the social inclusion of people with intellectual disabilities.

The summary reports resume the main findings – Executive Summary and Recommendations – of each of the country reports. The complete set of country reports, in English and translated to national languages, can be accessed online at: [www.eumap.org/topics/inteldis/reports](http://www.eumap.org/topics/inteldis/reports). Hard copies can be ordered at: [www.eumap.org](http://www.eumap.org).



OPEN SOCIETY INSTITUTE  
EU MONITORING AND ADVOCACY PROGRAM



OPEN SOCIETY INSTITUTE  
MENTAL HEALTH INITIATIVE

# Rights of People with Intellectual Disabilities: Access to Education and Employment

Summary Reports

*Greece*

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can be accessed online at: [www.eumap.org/topics/inteldis/reports](http://www.eumap.org/topics/inteldis/reports)  
Hard copies can be ordered at: [www.eumap.org](http://www.eumap.org)



## EXECUTIVE SUMMARY

Throughout Europe, people with intellectual disabilities<sup>1</sup> face major stigma and prejudice and are confronted with significant barriers to realising their fundamental human rights. Discrimination against people with intellectual disabilities is deeply rooted and widespread, standing in the way of positive change. Providing real access to education and employment for people with intellectual disabilities is critical to ensuring that they can live and work in the community as equal citizens. There is a strong link between education and employment: without access to adequate education, people with intellectual disabilities cannot secure meaningful employment. This denial of access leads to life long dependency, poverty and social exclusion, adding to the stigma of intellectual disability. This monitoring report focuses specifically on the areas of education and employment, because of their importance to people with intellectual disabilities and because of the existence of both international standards and national legislation that specifically address them.

The situation of people with intellectual disabilities in Greece has improved significantly in the past 25 years, particularly as many of the large residential institutions have been closed or scaled down, and more community-based services have developed. However, access to education and employment for people with intellectual disabilities remains limited. Greece has adopted legislation and policies that emphasise the importance of providing access to education and employment for people with disabilities. The country has taken important steps forward in lowering the levels of institutionalisation and increasing community care options. Nevertheless, most people with intellectual disabilities remain excluded from mainstream school and employment options. The lack of programmes specifically for people with *severe* and *profound* intellectual disabilities leaves this group with very little access to services of any kind. Some regions of the country, particularly rural areas and the islands, do not have the necessary structures and resources to meet the needs of people with all levels of intellectual disabilities. Without greater focus on law and policy in these key areas, people with intellectual disabilities will remain greatly restricted in their participation and inclusion in society. In the first half of 2003, the European Year of Disability, Greece held the European Union (EU) presidency and took the lead in promoting equal treatment for people with disabilities. The Government must now take concrete steps in Greece itself to realise this goal for those with intellectual disabilities, people for whom social inclusion is too often only a promise and not a reality.

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<sup>1</sup> The term “intellectual disability” (also described as “learning disability” or “mental retardation”) here refers to a lifelong condition, usually present from birth or which develops before the age of 18. It is a permanent condition that is characterised by significantly lower than average intellectual ability and results in significant functional limitations in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills.

### *Background*

Greece has ratified most of the major international conventions with provisions relating to access to education and employment for people with intellectual disabilities, but it has yet to ratify the Revised European Social Charter or Protocol No. 12 to the European Convention for the Protection of Human Rights and Fundamental Freedoms. The Greek Constitution establishes the term “people with disabilities” and guarantees the right to measures for their inclusion in society, in line with Greece’s obligations as a signatory to the major international instruments offering protection to people with disabilities. Although measures to promote equal treatment have been proposed in order to comply with EU directives, this legislation has not yet been adopted, and the European Commission has indicated it will bring legal action against Greece for failure to transpose the two anti-discrimination directives.

There is no unified definition of intellectual disability in Greek legislation. Various terms and definitions, some of them stigmatising, are used to refer to people with intellectual disabilities in Greek law and policy. Internationally recognised standards – including the World Health Organization’s International Classification of Diseases, Tenth Revision and the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition – have been incorporated into relevant law, and these standards are generally used in the diagnosis of intellectual disability by medical professionals. The procedures for diagnosis and assessment of disability, both for educational and employment purposes, are extensive and time-consuming; parents have called for these processes to be streamlined. Several forms of guardianship exist under Greek law. Plenary guardianship appears to be the most prevalent option, but it is difficult to be certain, because there is no statistical data regarding the numbers of people with intellectual disabilities who are placed under guardianship. Overall, there is very little statistical information regarding either people with intellectual disabilities or the services available to this population. Census data significantly underestimates the total number of people with intellectual disabilities at around 150,000. Lack of data severely curtails the possibilities of developing informed, appropriate policy for people with intellectual disabilities, and the Government should make the regular collection of data a priority. There has been an important process of deinstitutionalisation over the last decade, but up to 10,000 people with intellectual disabilities are thought to remain in institutional care.

### *Access to education*

The Greek Constitution ensures the right to free education for all citizens, and it also obliges the State to provide support to students with special needs. The Greek educational system includes both mainstream and special schools. It prioritises mainstreaming, at least in theory. Up to the age of 22, people with special educational needs can receive an education in a variety of schools using adapted programmes. In practice, education for children with intellectual disabilities is offered in both mainstream and special schools. In mainstream schools, “inclusion classes” are often organised for children with intellectual disabilities, who spend only part of the time integrated with other students. The assessment procedure for placing children in school

has been criticised as having inconsistent results and being poorly coordinated among the relevant services.

In 2001, a new institution, the Diagnostic Evaluation and Support Centre, or KDAY, was established, to provide and coordinate services for children with special educational needs at the local level. The KDAY is the main body responsible for assessing intellectual disability and determining placement in the appropriate school. However, only half of the KDAYs are operational, and those that do function have not met parents' expectations, particularly with regard to early intervention. Because KDAY centres are not established throughout the country, many families must travel long distances or endure lengthy waiting periods to have their children assessed. The inadequate number of centres, and their current focus on the school-age population, has led to a near-total lack of multidisciplinary early intervention services in most areas, forcing parents to find private alternatives, often at great expense. A KDAY is also expected to draft educational and integration recommendations for each child, but parents have expressed concern that these reports are difficult to understand and often give insufficient information about the service options available. A child's age and level of disability determine which school the child will attend.

While Greece takes part in the European Agency for Development in Special Education, as well as using EU funding for projects related to the education of people with intellectual disabilities, the country's policy in this area does not yet meet the needs of the population. A particular problem is the lack of any programmes for the education of children with *severe* and *profound* intellectual disabilities. Parents and advocates have called for the establishment of a stronger coordination body, which could help ensure that the available educational services are more accessible. The addition of far-reaching awareness programmes for teachers, students and families would also be a significant means of reducing misconceptions and prejudice against people with intellectual disabilities, both in the educational context and in wider society.

The Greek educational system takes an inclusive approach in principle, offering a range of options to children with intellectual disabilities. In practice, however, there are very few children with intellectual disabilities in the education system – only 2,859 in 2002–2003. Many students with *mild to moderate* intellectual disabilities are placed in special schools, while most children with more severe intellectual disabilities have little access to education at all. Although materials and adapted curricula have been developed, the individual needs of students with intellectual disabilities are not met in the classroom.

While mainstreaming is, by law, the preferred approach in Greece, the necessary support to facilitate inclusion is often lacking. Although officially, only 1,000 children with intellectual disabilities are mainstreamed, it is likely that, in areas where there are no services or facilities for children with special needs, many more children with intellectual disabilities study in mainstream schools without any support. Where resources are available, mainstreaming has been highly effective. Parents have expressed concern that special schools place children with highly diverse needs and abilities in a

single class, and that staff in special schools are not prepared to teach each child according to individual ability. Moreover, special schools run on a shortened daily schedule, so children do not receive a full day of instruction and training.

Home schooling is available for children whose health does not permit them to attend school. However, in practice very few children in Greece actually receive lessons at home. Because the law does not specifically include intellectual disability as a grounds for home schooling, there may be an understanding that this form of education is not available for children with intellectual disabilities, except as an expensive private option. Residential care institutions generally are not differentiated between children and adults, and there is very little information as to what, if any, educational opportunities there are in such institutions. NGOs offer a number of much-needed educational services, including training for children with *severe* and *profound* intellectual disabilities and assistance for people with intellectual disabilities who are making the transition from education to employment. The Government should examine ways in which these successful programmes can be supported and expanded to reach the people who currently do not have access to such services.

### *Transition from education to employment*

Vocational training is available through a number of different facilities, including private vocational laboratories. These private facilities often provide a range of services in addition to pre-professional training, and they aim at building skills for independent living. However, the rate of employment for graduates of these programmes remains low. The Government must do more to facilitate the transition from education to employment. Although people with intellectual disabilities greatly benefit from adult and continuing education, there is no State-organised system of “refresher” courses or other training aimed at skill retention and development.

### *Access to employment*

The Constitution specifically guarantees the right to work for people with disabilities, and draft legislation has been elaborated to bring anti-discrimination law into line with relevant EU directives, though this legislation has not yet been adopted. Assessment procedures are bureaucratic and tedious, and they must be repeated, even where a permanent disability is diagnosed. The teams conducting assessments of working capacity are primarily medical specialists, who, in some cases, are not trained to meaningfully assess an individual’s ability to work. Disability benefits are correlated to the level of disability, as well as other factors. Even though these benefits provide an inadequate level of support on their own, they are reduced if other sources of income exceed a given threshold. The lengthy procedures to re-qualify for benefits also discourage people with disabilities from seeking employment.

Greece has received support from the EU to develop programmes encouraging the employment of people with disabilities in general. However, local structures established to support the integration of vulnerable groups have not proven effective in enhancing

employment opportunities for people with intellectual disabilities. Other Government measures, including a quota system that requires State and local authorities to hire people with disabilities, have also had only limited impact on the employment of people with intellectual disabilities, because the quotas are filled by people with other forms of disability. A number of new incentive programmes have been adopted recently, and these may prove more effective.

Available statistical information suggests that very few people with intellectual disabilities are employed, either through incentive programmes or on the open market. No legislation or policy to promote supported employment has been elaborated.<sup>2</sup> The existing projects offering support to people with intellectual disabilities in the workplace are operated by NGOs and can serve only a fraction of the population that could benefit. The ERGAXIA centre, which is enabling 100 people with intellectual disabilities to gain employment on the open market, offers one example of good practice in supported employment. However, Government backing is required to reproduce such models on a wider scale. Sheltered workshops, also established by NGOs, do offer training and occupation to people with intellectual disabilities, but these are segregated workplaces that do not promote social inclusion. Without greater institutional support, there are few opportunities for people with intellectual disabilities to make the transition from sheltered work to the open market.<sup>3</sup>

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<sup>2</sup> Supported employment is an employment option that facilitates competitive work in integrated work settings for people with disabilities. It provides assistance such as job coaches, transportation, assistive technology, specialised job training and individually tailored supervision.

<sup>3</sup> N.B. the data in the Greek report is valid as of June 2005.



## RECOMMENDATIONS

### General recommendations

#### *International standards*

1. Greece should ratify the Revised European Social Charter and bind itself to Article 15, on the right of persons with disabilities to independence, social integration and participation in the life of the community. It should also ratify Protocol 12 to the European Convention for the Protection of Human Rights and Fundamental Freedoms, which entered into force on 1 April 2005.

#### *Legislation*

2. The Government should immediately take the necessary steps to establish a specialised body to promote equal treatment, as required by the EU Race Equality Directive (2000/43/EC), and it should extend the mandate of this body to cover all grounds of discrimination, including disability.

#### *Data collection*

3. The National Statistical Institute, the Ministry of Employment and Social Protection, the Ministry of Health and Social Welfare, and the Human Resources Employment Organisation should develop and maintain a national-level database on the number of people with intellectual disabilities and the number and type of services provided for this population. The data on people with intellectual disabilities should be sorted according to age, gender, degree of disability and employment status.

#### *Institutional care*

4. The Ministry of Health and Social Welfare should immediately take steps to close down the remaining asylum-type institutions for people with intellectual disabilities and people with a dual diagnosis within a reasonable time period.

#### *Community-based services*

5. The Ministry of Health and Social Welfare, the Ministry of National Education and Religious Affairs, and the Ministry of Employment and Social Protection should establish and develop decentralised community-based services, as a key component of the deinstitutionalisation process.
6. The Ministry of National Education and Religious Affairs should take steps to ensure that the KDAY system of diagnostic centres has the resources and personnel needed to provide early intervention services across the country.

### *Diagnosis and assessment*

7. The Ministry of Health and Social Welfare, the Ministry of National Education and Religious Affairs, and the Ministry of Employment and Social Protection should establish assessment units and pre-vocational training centres in all regions, and increase the number of KDAY centres according to the population's needs.
8. The Ministry of Health and Social Welfare, the Ministry of National Education and Religious Affairs, and the Ministry of Employment and Social Protection should ensure that mobile support teams staffed by an appropriate number of specialised experts, such as psychiatrists, psychologists, social workers, doctors and special educators, meet existing needs, particularly in the islands and rural areas.
9. The Ministry of Health and Social Welfare, the Ministry of National Education and Religious Affairs, and the Ministry of Employment and Social Protection should enhance cooperation with schools, teachers and parents, to support the social and educational integration of children with intellectual disabilities through support to the assessment units and prevocational training facilities.
10. To minimise problems and avert inappropriate practices, the Government should continue to develop inspection, supervision and evaluation policies that help ensure the quality of care provided by psychological health and KDAY centres. These policies should consider not only the evaluation feedback of expert evaluators, but also the views of service users.

### *Public awareness*

11. The Government should develop public awareness programmes to reduce stigma, prejudice and discrimination against people with intellectual disabilities, because negative attitudes in the community can hinder access to education and employment for people with learning disabilities.
12. The Government should develop specialised awareness programmes particularly aimed at employees in health and social care services, teachers and State administrators, to raise awareness about the specific needs of people with intellectual disabilities.
13. The Government should develop awareness programmes for parents and families of people with *severe* or *profound* intellectual disabilities, to prevent the isolation of these people at home or in institutions, to contribute to the recognition of their rights and to enhance their ability to participate in education and community life.
14. The Government should establish specialised information offices within existing citizens' service centres, to inform parents who have children with intellectual disabilities or people with intellectual disabilities themselves about

the current legislation and their legal rights, and to direct these people to the current services provided by relevant centres and organisations.

### *Coordination*

15. The Government should establish a high-level body with the authority to coordinate policy development and implementation among the relevant ministries and organisations, in order to provide people with intellectual disabilities with better representation and protection of their rights.

## **Recommendations on education**

### *Data collection*

16. The Ministry of National Education and Religious Affairs should establish and regularly update a database on special schools, educators and other specialists. The database should also contain data on students with disabilities, including those with intellectual disabilities, sorted according to their age, gender, ethnicity, type of disability and type of school in which they study. Furthermore, this database should also include information on the children who do not attend school at all.

### *Implementation of legislation*

17. The Ministry of National Education and Religious Affairs should take steps to ensure that school attendance, which is obligatory for all children, is also enforced for children with intellectual disabilities, who are often kept segregated or confined at home.

### *Inclusive educational policy*

18. The Ministry of National Education and Religious Affairs should make the promotion and development of full inclusion in mainstream schools a priority in education policy, to provide the opportunity for all children, regardless of their disabilities or differences, to learn together, and to build solidarity between children with intellectual disabilities and their peers.
19. The Ministry of National Education and Religious Affairs should issue specific regulations on home schooling for people with intellectual disabilities. The ministry should also develop appropriate standards, and allocate all necessary material and human resources, to make home schooling a genuine educational option for children and adults with intellectual disabilities.

### *Resources and support*

20. The Government should allocate sufficient funding to supply mainstream schools with all necessary human and technical resources, such as audio-visual

and other teaching materials, and counselling support structures for children with intellectual disabilities.

21. The programmes that are implemented with the support of European subsidies and actions should be designed and selected with the direction of the European Agency for Development in Special Needs Education. It is also important to ensure that these programmes continue, and that they maintain their quality after European funding has concluded.
22. The Ministry of National Education and Religious Affairs should seek support to increase the number of secondary schools that are open to students with intellectual disabilities.

### *Teacher training*

23. The Ministry of National Education and Religious Affairs should ensure that there is sufficient funding for teacher training. It is necessary to increase the number of teachers who are trained to provide individualised educational support to students with intellectual disabilities, to promote social integration and acceptance of these students.
24. The Ministry of National Education and Religious Affairs should ensure that there is continuous supervision, education and specialised training for educational staff at all levels of education, and especially for those who work in secondary schools.

### *Curriculum*

25. The Ministry of National Education and Religious Affairs should ensure that the National Education Policy includes a solid, specialised educational programme for students with intellectual disabilities. This programme should be differentiated according to students' needs and degree of disability.
26. The Ministry of National Education and Religious Affairs should develop flexible curricula that are better adapted to provide all children with more developmental and prevocational activities and opportunities. The curricula should be developed according to children's abilities and needs, rather than focusing on academic achievement.

### *Education for people with severe and profound intellectual disabilities*

27. The Ministry of National Education and Religious Affairs and the Ministry of Health and Social Welfare should cooperate to develop day centres offering continuous education, vocational rehabilitation and psychosocial support, to promote the educational and social integration of people with severe or profound intellectual disabilities, a population that has been largely under-served.

## Recommendations on employment

### *Legislation*

28. The Government should propose legislation to promote the development of supported and sheltered employment through incentives, tax exemptions and support for the sale of products produced by people with intellectual disabilities. Priority should be given to programmes developing a supported employment system that meets the needs of people with intellectual disabilities.
29. The Government should develop and implement a legislative framework for the protection and promotion of employment rights of people with intellectual disabilities according to the level of their capacity and abilities.

### *Capacity assessment*

30. The First Level Health Committees and the Ministry of Health and Social Welfare should reform the assessment process for determining working capacity, to ensure that individual capacity and potential are taken into consideration, instead of using a process that relies on IQ levels or other categorisations.

### *Quota system*

31. The Ministry of Employment and Social Protection, and the Human Resources Support Administration should establish a specific requirement for employers to hire people with intellectual disabilities, as part of the existing quota system for people with disabilities.

### *Social welfare benefits*

32. The Government should raise the income threshold at which social welfare benefits are reduced or withdrawn to a level equal to the minimum wage determined by the General National Collective Employment Contract.
33. The Ministry of Employment and Social Protection should take steps to streamline the process that former recipients must go through to re-qualify for benefits when they fall below the income threshold.

### *Supported Employment*

34. The Government should develop a legal and policy framework for supported employment that includes the allocation of appropriate resources to enable people with intellectual disabilities to find work on the open market.

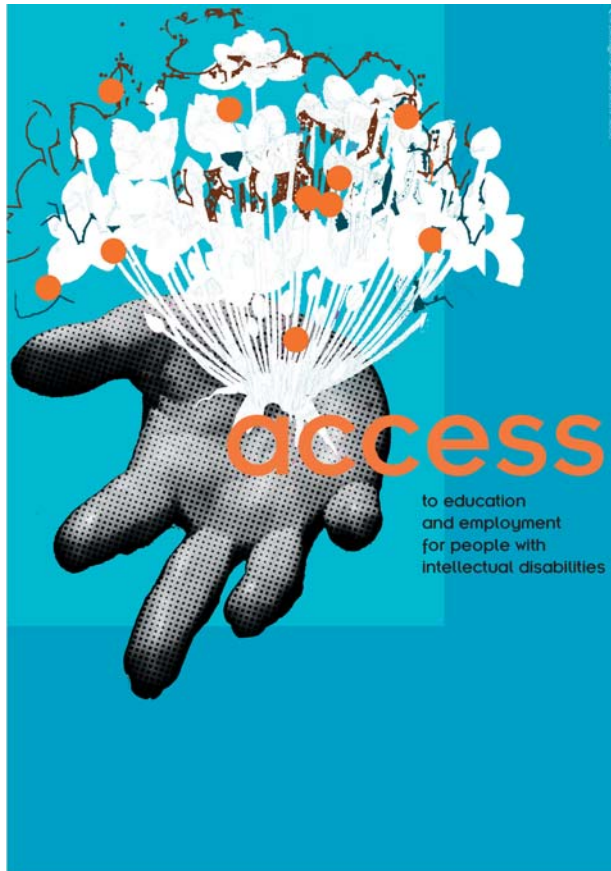
### *Public awareness*

35. The Government should develop specialised awareness-raising programmes that inform employees in public positions, and trade unions, about the vocational capabilities of people with intellectual disabilities.



Throughout Europe, people with intellectual disabilities face overwhelming stigma and prejudice and encounter significant barriers to realising their fundamental rights. EUMAP, the EU Monitoring and Advocacy Program of the Open Society Institute, in cooperation with the Open Society Mental Health Initiative, has monitored this situation in 14 countries throughout Europe, both EU members and candidate countries: *Bulgaria; Croatia; the Czech Republic; Estonia; Greece; Hungary; Latvia; Lithuania; the Netherlands; Poland; Romania; Slovakia; Slovenia* and *the UK*. Carried out by local experts and civil society groups, the monitoring focuses on the extent to which people with intellectual disabilities have access to education and employment. This series of reports presents the findings of the monitoring and also makes recommendations for improving the social inclusion of people with intellectual disabilities.

The summary reports resume the main findings – Executive Summary and Recommendations – of each of the country reports. The complete set of country reports, in English and translated to national languages, can be accessed online at: [www.eumap.org/topics/inteldis/reports](http://www.eumap.org/topics/inteldis/reports). Hard copies can be ordered at: [www.eumap.org](http://www.eumap.org).



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MENTAL HEALTH INITIATIVE

# Rights of People with Intellectual Disabilities: Access to Education and Employment

Summary Reports

*Hungary*

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## EXECUTIVE SUMMARY

Throughout Europe, people with intellectual disabilities face major stigma and prejudice, and are confronted with significant barriers to realising their fundamental human rights. Discrimination against people with intellectual disabilities is deeply rooted and widespread, standing in the way of positive change. Providing real access to education and employment is critical to ensuring that they can live and work in the community as equal citizens. There is a strong link between education and employment: without access to adequate education, people with intellectual disabilities cannot secure meaningful employment. This denial of access leads to lifelong dependency, poverty and social exclusion, adding to the stigma of intellectual disability. This monitoring report focuses specifically on the areas of education and employment, because of their importance to people with intellectual disabilities and because of the existence of both international standards and national legislation that specifically address them.

In Hungary, access to inclusive education and any kind of employment for people with intellectual disabilities remains very limited. The education of children with intellectual disabilities remains highly segregated. Most of these children are educated in special schools, which, though they often provide a good quality education, do not prepare students for social inclusion or equip them with the skills they need to later access employment. Children with more severe intellectual disabilities often do not have the opportunity to attend school and instead receive only several hours of “training” per week. Very few people with intellectual disabilities have employment, and those that are working are mainly in sheltered workplaces.

### *Background*

Hungary has ratified most international instruments, including those with provisions on people with disabilities, but it has yet to ratify the Revised European Social Charter (RESC) or Protocol No. 12 to the European Convention on the Protection of Human Rights and Fundamental Freedoms (ECHR). The Hungarian Constitution does not include disability as a specifically prohibited ground for discrimination. However, the Act on Equal Treatment and Promotion of Equal Opportunities (Equal Treatment Act) introduces a comprehensive anti-discrimination framework, which also covers people with disabilities. The act transposes the provisions of the European Union’s Employment and Race Equality Directives into national legislation. It also establishes a new equality body, whose remit will cover all areas of discrimination, including discrimination on the grounds of disability. This body is to start working in January 2005. The main legislation on people with disabilities is the Act on the Rights and Ensuring the Equal Opportunities of People with Disabilities (Disabled Persons Act).

Hungary has a comprehensive disability policy, the National Programme on Disability Affairs (National Disability Programme), which also addresses access to education and employment. The programme incorporates current international standards targeting

the social inclusion of people with disabilities, and its aims are comprehensive and highly relevant to people with intellectual disabilities. However, there has been no independent evaluation of the programme's impact to date, and the implementation of the programme's goals has been slow. Most foreseen projects have not yet been realised.

Although, at present, there is no single, widely accepted definition of intellectual disability in Hungary, the main reference is the World Health Organization's ICD-10. There are different procedures for the diagnosis and assessment of intellectual disability for educational purposes (for children); for employment purposes and for access to some social benefits (for adults); and for guardianship hearings (for adults). For educational purposes, children are assessed by the Professional Committees for Assessing Learning Abilities (hereafter, Professional Committees). They are diagnosed with one of four levels of intellectual disabilities (*mild, moderate, severe* or *profound*), in accordance with the ICD-10 definitions. For employment purposes and access to social benefits, adults are assessed by the National Medical Expert Institute (OOSZI), which establishes working capacity, and by labour offices and local health services, which jointly conduct assessments of employment capacity.

The 2001 National Population Census indicates that there are approximately 57,000 people with intellectual disabilities in Hungary, a significant decrease from the number reported in the 1990 Census. The decrease can be partly explained by the overall decline in population and by the use of more discriminating procedures for the diagnosis of intellectual disabilities. There is also the possibility that the total of 57,000 is an underestimation, as the 2001 Census relied on the self-reporting of intellectual disabilities. The extent of the misdiagnosis of Hungary's Roma as having intellectual disabilities is revealed by the fact that Roma made up 29.4 per cent (16,700 people) of the total number of people with intellectual disabilities, while representing just 1.9 per cent of the population. The 2001 Census also highlights the alarming fact that over one third of adults with intellectual disabilities (16,010 people) had not even completed the first year of primary school.

The deinstitutionalisation process in Hungary is proceeding only slowly, and a staggering 38 per cent of people with intellectual disabilities live in some form of residential institution. People with intellectual disabilities represent 48 per cent of all residents in these institutions. The main reasons for this high level of institutionalisation are the absence of day centres and the shortage of sheltered workplaces for the employment of people with more severe intellectual disabilities. There is also an urgent need for children with *severe* and/or multiple disabilities to be given equal access to education in a non-residential setting. In many cases, parents do not wish to place their child in an institution. This can be seen by the fact that some children with intellectual disabilities in residential care only attend the institution during the day. However, at present, parents are often compelled to institutionalise their children, due to a lack of adequate community-based support services.

In Hungary, many people with intellectual disabilities are placed under guardianship by the courts at age 18. There are two forms of guardianship: *partial*, under which the

individual's civil capacity is partially restricted, for specific areas or activities; and *plenary*, under which the individual's civil capacity is fully removed. At present, the procedures used in guardianship hearings do not sufficiently take into account individual abilities; monitoring of guardianship decisions is inadequate; and judges mainly impose *plenary*, rather than *partial* guardianship. People under *partial* guardianship retain the right to work and to sign an employment contract. However, there is some confusion as to whether people under *plenary* guardianship can be employed, even if their guardian signs the employment contract. This is mainly due to a lack of harmonisation between the Civil Code and the Labour Code, and the situation has resulted in employers refusing to employ people under *plenary* guardianship in sheltered workplaces or through supported employment programmes.

### *Access to education*

Hungary's Public Education Act is the main legislation governing public education, including special education. The 2003 amendments to the act introduce an explicit prohibition on discrimination on the ground of disability, defined as "lack or impediment of abilities". The Public Education Act includes special provisions on "children with special educational needs", including children with intellectual disabilities, but it does not take an unequivocal stand in favour of inclusive education. It states that parents or guardians can only request enrolment of their child at a specific school if the school has the necessary capacity, including staff and funding, for the type of education required. In practice, many school directors cite lack of capacity when refusing admission to students with intellectual disabilities. This means that most parents are prevented from enrolling their child with intellectual disabilities at a mainstream school. The Education Ombudsman receives a significant number of complaints, from parents of children with intellectual disabilities, concerning inadequate resources and services for the education of their children.

In Hungary, the early intervention network is inadequate, and, throughout the country, many children with intellectual disabilities of pre-school age cannot access early intervention services. Professional Committees are the primary providers of early intervention services, but because the committees are overburdened and do not always have sufficient capacity, a few NGOs try to fill in this gap in services. These NGOs receive State funding for provision of such services. Children receive early intervention services upon the recommendation of the Professional Committees. However, due to a lack of information, most parents are unaware of available early intervention services until after their children have finished kindergarten, when such services are much less effective.

The Professional Committees diagnose intellectual disability for educational purposes. They also make recommendations on school placements and the form of education and required support for children with intellectual disabilities. The Professional Committees, which are multidisciplinary and generally highly skilled, are significantly overburdened as, among other services, they are tasked with providing early intervention and rehabilitation services. There is a concern that assessments are sometimes too short to establish an accurate

diagnosis. Children with intellectual disabilities or autism should be regularly re-assessed. Parents or guardians have the legal right to be present at the assessment and to be informed of the Committee's decision. Parents have the legal right to appeal the Committee's decision, but in practice they rarely do so. In some cases, parents do challenge the decision on school placement, particularly when the school is not in their hometown. In other cases, they simply ignore the decision and enrol the child in the mainstream school of their choice. However, in such cases, the school is often unprepared to meet the child's special educational needs, and the child is later transferred to a special school. The overrepresentation of Roma in special schools is largely due to assessment procedures that give the Committees the discretion to place Roma children in special schools, even where there is little indication that a child would not succeed in a mainstream school. Meanwhile, there is little effort to inform Roma parents of the consequences of placing their children in special schools.

The Hungarian education system segregates children with intellectual disabilities. The diagnosed level of intellectual disabilities determines the quality of education a child is to receive, and, in effect, there is a two-tier system of special education. The Public Education Act recognises two types of State obligations towards children: *tankövelettség*, an obligation to educate a child; and *képzési kötelezettség*, an obligation to train a child. The "obligation to train" is applied in practice to children with *severe* and/or multiple intellectual disabilities. Children with *mild* and *moderate* intellectual disabilities who are deemed "educable" follow the national curriculum, or an adapted version of this curriculum. These children generally attend special schools with other children, though some attend mainstream schools. Meanwhile, children with *severe* and/or multiple intellectual disabilities receive training or stimulation at home, or in groups of four or five at special training institutions. The content of training is essentially unregulated. Children who are deemed "educable" receive 20 hours of lessons per week, compared to a maximum of five hours per week for children who are deemed "trainable". This distinction in entitlement is clearly discriminatory and excludes many children with intellectual disabilities from education – up to 2,500 children with intellectual disabilities deemed "trainable" presently do not have adequate access to education. Children with autism are also often excluded from access to education. There are two separate systems of special schools, one for children with *mild* intellectual disabilities and another for children with *moderate* intellectual disabilities. Both mainstream and special schools are funded on the "funds follow the student" principle, and they receive higher per capita funding for children with intellectual disabilities.

The main reference for Government policy on the education of children with intellectual disabilities is the National Disability Programme, which establishes a number of progressive goals for inclusive education. However, the mechanisms for evaluating the programme and ensuring its implementation are at present inadequate, and many goals in the area of education have not yet been implemented. One important result of the programme thus far has been the establishment of the National Public Foundation for Disabled Children, which supports activities for children with all types of disabilities through a number of programmes promoting social integration. The Foundation has backed a number of projects targeting children with intellectual

disabilities, their families, and the schools that serve them – including mainstream and special schools. Of particular relevance are the Foundation's programmes for improving mainstream schools' preparedness for enrolling children with intellectual disabilities. The work of the Foundation has been widely praised by special educators.

During Hungary's accession to the EU, the European Commission's Regular Reports on Hungary made no mention of the education of children with intellectual disabilities. However, a number of Phare funded programmes supported the education of children with intellectual disabilities, in particular through early intervention and education in special vocational schools. Since its accession to the EU on 1 May 2004, Hungary is eligible for EU Structural Funds. The funds will be used to support projects in a number of areas of direct relevance for people with intellectual disabilities, such as: projects aimed at the mainstreaming of children with special educational needs; projects for lifelong learning; and projects for the development of school infrastructure, including special education.

The decentralised Hungarian education system allows mainstream and special schools to design their own curricula and programmes, in accordance with the National Core Curriculum and the "Curriculum Guidelines for School Education of Children with Disabilities". At present, less than half of the teachers in special kindergartens and primary schools for children with intellectual disabilities hold special education degrees. There are very few special educators employed in mainstream schools. The special education degree programmes offered by the Faculty of Special Education at Eötvös Lóránd University are widely respected, but they tend to produce specialists in one type of disability, rather than special educators who can assess and support children with a wide range of disabilities. All special educators are obliged to receive professional training every seventh year. In general, they say they are satisfied with the quality of the training they receive.

In Hungary, inclusive education is at a very early stage. In 2003, the percentage of children with disabilities attending mainstream kindergartens was a relatively high 68 per cent, but, at the primary level, this figure is much lower, at 17.5 per cent. There is only limited data on the numbers of children with intellectual disabilities attending mainstream schools. In 2002–2003, 2,598 students with intellectual disabilities were mainstreamed at the primary level. The total number of children with intellectual disabilities at all school levels has been estimated at 3,200. Programmes targeting inclusive education have begun to receive more attention. In Hungary, however, debate on whether it is desirable to mainstream children with more severe intellectual disabilities is still ongoing, as evidenced by the lack of consensus amongst educational specialists on this issue. There is also a corresponding need for the formulation of educational policy that explicitly addresses the criteria and process of mainstreaming. Due to the declining birth rate, and the resulting fall in student numbers, in the early 1990s, schools began accepting some students with intellectual disabilities. This process was termed "austere integration", as it had limited success due to the fact that schools were unprepared for the special educational needs of these students. Even today, most mainstream schools lack the

necessary space and sufficient support staff, in particular, special educators. Meanwhile, most school staff, including regular teachers, special educators, and therapists, do not have enough training in special education. Once operational, the proposed special methodological centres should provide very valuable additional support for mainstream schools, and they should encourage further integration.

At present, though, the main way in which children with intellectual disabilities can receive an inclusive education is in innovative schools, or “alternative schools”, which are mostly NGO-operated and, like any other school, eligible for regular State funding. Innovative schools import educational methodologies from other countries. However, although such schools serve as very valuable good-practice models, which could in the future be replicated across the country, they face a number of constraints, notably: a lack of external support and supervision; low salaries; and limited opportunities for continuing education and professional development. In other cases, children with intellectual disabilities and autism are enrolled in mainstream schools through the advocacy of parents. In general, though, most parents and guardians remain unaware of their rights.

Every county must maintain at least one special primary school for children with *mild* intellectual disabilities and another for children with *moderate* intellectual disabilities. In the 2002–2003 school year, at the primary level, 32,231 students with intellectual disabilities were enrolled in special schools, while a total of 6,175 students with intellectual disabilities attended special vocational schools. At present, very few children with *severe* intellectual disabilities and/or multiple disabilities are enrolled in special schools, though their numbers are on the increase. Special schools take two forms: day schools or boarding schools. According to the census, in 2001, there were 2,421 children with intellectual disabilities in special boarding schools. Most special boarding schools are located outside town centres, so transportation can prove a major challenge. The standard and quality of education in special schools in Hungary is acceptable, and sometimes even excellent. However, such segregated settings inherently foster the social exclusion of students. Roma students are very disproportionately represented at such schools, mainly due to inadequate assessment procedures. This tendency has been noted with concern, both by domestic and international observers, and a number of programmes and initiatives have been implemented with the aim of addressing this situation.

In Hungary, few children with intellectual disabilities are schooled at home. Home schooling takes two forms: either special educators visit children in their homes, or students make regular visits to the supervisory special school, usually that nearest to the student’s home. The Public Education Act provides for a system of travelling special educators, but it does not identify a source of funding for the system. Therefore, home schooling and special educational services are generally not available to children with special educational needs living in more rural areas of the country. An estimated 2,000 to 2,500 children with *severe* and/or multiple intellectual disabilities are excluded from any form of education or training. Children with disabilities living in residential institutions can be enrolled in the same three forms of education available to other children: mainstream schools, special schools or home schooling. Generally, children

living in residential institutions study in schools outside the institution, together with other children who have not been institutionalised. There are 2,549 children with intellectual disabilities in orphanages in Hungary.

### *Transition from education to employment*

In Hungary, approximately 60 per cent of students with intellectual disabilities continue their studies at the secondary level, although the number of students with intellectual disabilities at the secondary level is reported to be slowly increasing. Segregation of students with intellectual disabilities in special vocational schools remains pronounced, and primarily students with mild intellectual disabilities have the opportunity to attend mainstream vocational schools. In the 2002–2003 school year, only 555 students with intellectual disabilities attended mainstream vocational secondary schools.

Students with *mild* intellectual disabilities can attend special vocational schools and receive a nationally recognised certificate. Students with *moderate* intellectual disabilities can attend capacity-developing special vocational schools and receive training in independent living skills and simple routine vocational activities, but the certificate they receive is not yet nationally recognised. In Hungary, approximately 8,000 students, mainly students with intellectual disabilities, attend special vocational schools. The main criticism of these schools is that they do not adequately prepare students for work on the open labour market. In particular, most students are not able to access work experience externally from the schools. The “Workplace Practice” Programme, developed by the non-governmental Salva Vita Foundation and supported by the National Public Foundation for Disabled Children, offers one model of good practice in this area. Under this programme, students at capacity-developing special vocational schools are placed in mainstream workplaces in different locations, over a two-year period. Participants who complete the programme have much improved chances of securing employment on the open labour market.

More than 60 per cent of the people with intellectual disabilities who were sampled in the 2001 Census had not finished primary school. The transition from school to employment can be particularly difficult for these children, and there are also difficulties for those who leave residential institutions. Support services are presently inadequate to cope with their needs, and overburdened special educators are unable to assure the required follow-up services. The special needs of children and young people with autism, and their families, are particularly neglected. To address this situation, some schools have established clubs for young people with intellectual disabilities, to assist them with the transition period. However, for this group, there is a need for coordinated Government policy on the provision of follow-up services. At present, the opportunities for adults with intellectual disabilities to access adult and lifelong education are also very limited.



### *Access to employment*

The Hungarian Constitution guarantees the right to work, the right to freely choose a job or profession and the right to equal compensation for equal work without discrimination, but it does not specifically address the employment of people with disabilities. However, the Equal Treatment Act guarantees equal treatment in employment for people with disabilities, and the Disabled Persons Act establishes that, if people with disabilities cannot secure employment on the open market, sheltered workplaces must employ them. The Joint Decree on People with Altered Working Capacity regulates the rehabilitation process, occupational rehabilitation services, and State financial compensation for lost income due to altered working capacity. It also regulates eligibility for State subsidies for employers who employ people with disabilities.

In Hungary, in the area of employment, two types of capacity are assessed for people with disabilities: working capacity and employment capacity. The National Medical Expert Institute (OOSZI) conducts assessments to evaluate the working capacity of adults with intellectual disabilities. The OOSZI's assessment results are expressed as a percentage of altered working capacity. An altered working capacity of at least 40 per cent generally entitles a person to social benefits; it also entitles a person to employment in sheltered workplaces and to employment through a fixed-period subsidy, which employers can obtain from local labour offices. Labour offices and local health services jointly conduct assessments of employment capacity. These assessments are intended to determine the extent of a person's remaining abilities and match their abilities to types of work. Both assessments, of working capacity and employment capacity, are conducted solely by medical doctors, and they focus on health and medical conditions. To better reflect the real potential of people with intellectual disabilities, both assessments need to be comprehensively reformed, so that they ensure a more multidisciplinary and comprehensive approach. NGO service providers in Hungary have already developed some employment assessment procedures that could be used as models for this reform.

People with intellectual disabilities are heavily dependent on social welfare benefits. Most adults with intellectual disabilities do not have the required work experience to access unemployment benefits or the invalidity pension. People with *mild* or *moderate* intellectual disabilities mainly receive various social benefits that depend on a number of factors, such as age and number of years employed. Some people in this group with the required work experience receive invalidity pensions. Adults with *severe* and *profound* intellectual disabilities are eligible for disability support, which they retain even if they secure employment. People who are under the age of 25, have 100 per cent altered working capacity, and do not already receive a pension, are eligible for the invalidity benefit. Given the limited and unstable employment possibilities presently available to people with intellectual disabilities, and the limited access to employment services, social welfare benefits are a steady and stable source of support. These benefits tend to act as a disincentive to employment. Presently, most unemployed people with intellectual disabilities do not register at the local offices of the National Employment Service and, therefore, they cannot

access available employment services or rehabilitation services. This is mainly due to a lack of awareness of their rights and of available services. Furthermore, the staff at the labour offices is not trained to deal with the special needs of people with intellectual disabilities, and, in any case, they cannot meet the current demand for individualised services. As a result, labour offices mainly rely on cooperation with non-governmental rehabilitation and employment service providers.

During Hungary's accession to the EU, the European Commission's Regular Report on Hungary made a number of references to the need to improve the employment situation of people with disabilities in general, but it did not specifically refer to people with intellectual disabilities. However, funds from the EU's Phare programme were used to support a number of projects promoting the employment of this group. Hungary is now selecting projects to be funded through EU Structural Funds. These projects should, in future, make a significant contribution towards improving and tailoring the employment services available to people with intellectual disabilities, and towards increasing their employment rates.

The main Government policy on the employment of people with disabilities is described in the National Disability Programme. The programme contains a number of goals that are highly relevant to promoting the employment of people with intellectual disabilities. Most importantly, it aims to restructure the sheltered employment system, including its legislative framework and system of financing. Another objective is to improve employment services for people with disabilities. This has led to the establishment of Rehabilitational Information Centres (RICs), which are located at county labour offices and are tasked with providing comprehensive support services for people with disabilities seeking employment. However, as with other areas, the implementation of the National Disability Programme's objectives on employment has not been adequately monitored, and many foreseen projects are still at an early stage of implementation.

The Government promotes the employment of people with disabilities – on the open labour market and in sheltered workplaces – through the quota system, State subsidies and tax incentives. At present, however, the tax incentives available are not very attractive, so they do not have a significant impact. Under the quota system, five percent of the staff in all companies employing more than 20 people must be employees with an altered working capacity. The quota system has not been effective, as the penalties for non-compliance, though substantially increased in recent years, still remain too low to act as a real disincentive. Moreover, there is only limited monitoring of companies' compliance with the system. The penalties for non-compliance go towards the Rehabilitation Fund, from which funding is then made available to NGOs providing employment services and sheltered workplaces. Companies fulfilling the quota requirement are also eligible to receive a State subsidy called State Support for Increased Rehabilitational Employment, which covers salary and other costs associated with employing people with disabilities over an 18-month period, with the amount of support subsequently reduced. Sheltered workplaces are also eligible for state subsidies, but NGOs are as yet not eligible.

Despite these incentives, in Hungary, the vast majority of people with disabilities do not have access to any kind of employment. Most people with intellectual disabilities are financially dependent on social benefits or support from their family. Only ten per cent of the population of people with intellectual disabilities, or less than 4,000 people, are in employment, down from 30 per cent in 1990. Very few can access employment on the open market. The few who are working mainly have supported employment. As of 2004, there were only five NGOs providing supported employment services in five cities within Hungary, and legislation on supported employment was not yet in place. The Salva Vita Foundation introduced the supported employment methodology in Hungary in 1998. To date, it has supported more than 150 people with intellectual disabilities on the open labour market. Everyone involved in the programme, including employers, are satisfied with the foundation's employment services. However, there is now a need to replicate this model more widely, and the Government must fund supported employment services across the country.

Although supported employment offers the best opportunities for the social inclusion of people with intellectual disabilities, at present, most people with intellectual disabilities who are able to access employment do so in sheltered workplaces. These workplaces generally do not adequately prepare people with intellectual disabilities for employment on the open labour market. Sheltered workplaces can be social employment centres or target organisations, both of which offer very low salaries for employees with disabilities. Social employment centres are mainly municipally maintained small-scale workshops that provide work opportunities of a limited variety, such as producing textiles and industrial paper. Target organisations are large, for-profit organisations or firms; by law, people with altered working capacity must make up at least 60 per cent of the staff, but in practice the share is closer to 80 per cent. In 2003, the total State subsidies received by target organisations was significant, at approximately €151.2 million. Over recent years, many social employment centres have been transformed into target organisations, as the level of available State subsidies is significantly higher. However, because target organisations only employ more skilled workers, the transformation of the employment centres has resulted in far fewer sheltered employment opportunities for people with *moderate* and *severe* intellectual disabilities. People with intellectual disabilities employed in target organisations are generally satisfied with their work and feel lucky to have been able to find employment.

Target organisations have been criticised by stakeholders for not providing adequate rehabilitation services for employees with altered working capacity. However, at present they are not obliged by law to do so. Draft legislation on the system of State subsidies for enterprises is under preparation. The primary aim of this legislation is to increase the proportion of people with altered working capacity employed on the open labour market. The new legislation is also expected to clarify the roles and expectations of organisations receiving subsidies – including responsibilities related to rehabilitation – and to introduce a mechanism for monitoring the use of subsidies.

## RECOMMENDATIONS

### General recommendations

#### *International standards*

1. Hungary should ratify the Revised European Social Charter of 1996 and should bind itself to Article 15 of the charter, which covers the right of persons with disabilities to independence, social integration and participation in the life of the community.
2. Hungary should ratify Protocol No. 12 to the European Convention on Human Rights and Fundamental Freedoms (ECHR).

#### *Legislation*

3. The Government should take immediate steps to harmonise the provisions of the Labour Code 2003<sup>1</sup> and the Civil Code,<sup>2</sup> to ensure that people under *plenary* guardianship are, by law, permitted to enter into employment.

#### *Specialised bodies*

4. The Government should establish an independent equality body, with appropriate authority and resources to provide genuine remedies for abuse.

#### *Policy*

5. The Government should take all necessary steps to monitor the implementation of the National Programme on Disability Affairs and ensure that all involved ministries are held fully accountable for fulfilment of the established objectives and goals of the programme.
6. As a priority, Parliament should ensure that the Ministry of Education and the Ministry of Employment meet the annual evaluation and reporting requirements established in the Parliamentary Order on the National Programme on Disability Affairs<sup>3</sup> in the areas of education, vocational training and employment.

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<sup>1</sup> Act XX of 1992 on the Labour Code, Gazette 1992/45, 5 April 1992. Last amended by Act CXXV of 2003 on Equal Treatment and Promotion of Equal Opportunities, Gazette 2003/157, 28 December 2003.

<sup>2</sup> Civil Code, last amended by Act XV of 2001 on the Amendment of Certain Acts Regarding Legal Capacity and Guardianship (including the Civil Code), Gazette 2001/51, 4 May 2001.

<sup>3</sup> Parliamentary Order 100/1999 (XII. 10.) on the National Programme on Disability Affairs.

*Guardianship*

7. The Government should, as a priority, issue clear guidelines on guardianship procedures, to improve assessments and ensure that individual abilities are adequately taken into account. Wherever possible, people with intellectual disabilities should be placed under *partial* guardianship, rather than *plenary* guardianship, so that they can exercise their civil rights to the fullest possible extent.

*Deinstitutionalisation*

8. The Government should, as a priority, make financial assistance available to municipalities, to ensure that, as mandated by law,<sup>4</sup> all municipalities with more than 20,000 inhabitants establish day centres.
9. The Government should develop a clear policy on deinstitutionalisation, with the aim of significantly reducing the number of people with intellectual disabilities in residential institutions. In particular, the Government should establish opportunities for independent living alternatives to residential care and increase State support for community-based services.

**Recommendations on education***Legislation*

10. The Government should, as a priority, amend the Public Education Act and relevant secondary legislation, in order to abolish the two-tier classification of students with special needs as either “educable” or “trainable”. The Government should then ensure that those children who are at present classified as “trainable” – in most cases children with *severe* intellectual disabilities and/or multiple disabilities – are no longer deprived of equal educational opportunities, including the opportunity to attend a mainstream school.
11. The Government should ensure the appropriate financial, technical, methodological and human resources to make home schooling a genuine option for those children with intellectual disabilities who would benefit from this educational option.

*Policy*

12. The Government should make the mainstreaming of children with intellectual disabilities a central and overarching goal of Government education policy and take steps to ensure that these children receive adequate support tailored to their individual needs.

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<sup>4</sup> Act III of 1993 on Social Administration and Social Services, art. 77 and 87(c).

13. The Government should ensure that parents or guardians of children with intellectual disabilities have the explicit right to choose to enrol their child in a mainstream kindergarten or primary school near to their place of residence. The Government should also ensure that this right is respected in practice.
14. The Government should gather together information and experience gained from existing alternative models of good practice and quality services in early intervention and inclusive education. Then it should ensure that successful models are widely replicated throughout the country.
15. The Ministry of Education should evaluate the reasons for the high percentage of children with intellectual disabilities who do not complete primary education, with the aim of developing policy to address this situation.

#### *Assessment procedures*

16. The Ministry of Education should develop clear diagnostic standards and methodologies, as well as avenues for effective appeal, to ensure that all children have access to high quality diagnostic services, and that a child's ethnicity does not influence the assessment results. The Ministry should also develop training for professionals working in the diagnostic bodies and establish a nation-wide monitoring system for the diagnosis and evaluation process.
17. The Ministry of Education should, as a priority, take steps to remedy the significant overrepresentation of Roma children in special schools and ensure their integration into mainstream schools.
18. The Ministry of Education should take steps to reduce the workload of the Professional Committees, and ensure that they have the necessary expertise, resources and time, to carry out quality assessments of children with intellectual disabilities. These assessments should prioritise the children's abilities, rather than their disabilities.
19. The Ministry of Education should develop a clear methodology for the assessment of children with autism.

#### *Early intervention services*

20. The Government should take steps to establish a nation-wide early intervention network and ensure that parents are better informed about the availability and importance of early intervention services.

#### *Inclusive education*

21. The Ministry of Education should encourage the development of expertise in mainstream schools, to enhance the education and support of children with intellectual disabilities. In particular, the Ministry should:

- Comply with the Public Education Act<sup>5</sup> by ensuring that county-level special education resource (methodological) centres are established as rapidly as possible – and are provided with adequate resources and staff to provide expertise and additional support for the education of children with intellectual disabilities in mainstream schools.
  - Take steps to ensure that all teachers follow a substantial course on special education as part of their teacher training programme. The Ministry should also ensure that teachers receive regular refresher courses, free of charge.
22. The Ministry of Education should promote the development of special pedagogy and support services for children with multiple disabilities whose predominant disability is intellectual disabilities combined with behavioural challenges, as well as for children with autism. The Ministry should ensure that this group of children receive appropriate educational opportunities and support tailored to their specific needs.

### *Home schooling*

23. In line with the Public Education Act,<sup>6</sup> the Ministry of Education should develop a system of travelling special educators, to ensure that children with severe intellectual disabilities living in rural areas have access to special educational services at home.

## **Recommendations on transition from education to employment**

### *Vocational training*

24. The Government should take steps to ensure that the vocational training offered by special vocational schools and capacity-developing special schools is more geared towards the development of skills valued on the open labour market. In particular, students should be given work practice in inclusive settings, using the Salva Vita Foundation's "Workplace Practice Programme" as one model of good practice.
25. The Government should take steps to ensure that those students who complete studies at capacity-developing special schools receive certificates that are recognised by employers on the open labour market.

### *Follow-up services*

26. The Government should develop policy for the provision of follow-up services specifically designed to meet the needs of children with intellectual disabilities

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<sup>5</sup> Public Education Act 2003, art. 24(1).

<sup>6</sup> Public Education Act 2003, art. 24(1).

and autism, and their families, during the transition period from education to employment. The services should have a focus on support for employment on the open market.

### *Adult education*

27. The Government should ensure that adults with intellectual disabilities are able to access adult education and continuing vocational training that adequately takes into account their special needs.

### *Transitional programmes*

28. The Government should establish more transitional programmes, to assist people with intellectual disabilities in the transition from school to employment on the open labour market. Innovative NGO programmes, such as “transitional workplaces”, should be used as a source of reference for development of these programmes.

## **Recommendations on employment**

### *Legislation*

29. The Government should establish the legislative and regulatory framework necessary to support the State funding of supported employment and the provision of supported employment through a nation-wide network of service providers.

### *Data collection*

30. The Ministry of Employment and Labour should establish a system for the regular collection and publishing of statistics on the employment situation of adults with intellectual disabilities, in order to better target employment and rehabilitation services for this group.

### *Policy*

31. The Government should evaluate ways to ensure that supported employment services and the system of sheltered employment achieve better complementarity, as part of a comprehensive overall system to meet the various needs and abilities of people with intellectual disabilities.
32. The Government should evaluate ways to encourage the employment of people with intellectual disabilities in the public sector, at the local, county and State levels. This would both serve as a positive example and help to raise public awareness.



*Capacity assessment*

33. The Ministry of Youth, Family, Social Affairs, and Equal Opportunities (formerly the Ministry of Health, Social and Family Affairs) and the Ministry of Employment and Labour should ensure that assessments of altered working capacity are conducted by a multidisciplinary team of experts – not only by medical doctors. The assessments should be redesigned to focus on the measurement of each person’s capabilities, in part through observation in different work settings, using established NGO practices as a model. A meaningful appeals process should be put in place.
34. The Government should ensure that the periodic reassessment of altered working capacity is enshrined in legislation and carried out in practice.

*Employment services*

35. The Ministry of Employment and Labour should encourage the registration of unemployed adults with intellectual disabilities at the local offices of the National Employment Service, so that they can access unemployment benefits and the employment and rehabilitation services offered by these offices.
36. The Ministry of Employment and Labour should ensure that staff in the local offices of the National Employment Service undergoes training on how to work with people with intellectual disabilities, so that these people will receive better employment services.
37. The Government should establish Rehabilitational Information Centres (RICs) in every county, to maintain and provide information on employment and names of the local experts for all stakeholders, including employers. The RICs should make available information relevant to the employment of people with disabilities, including people with intellectual disabilities.

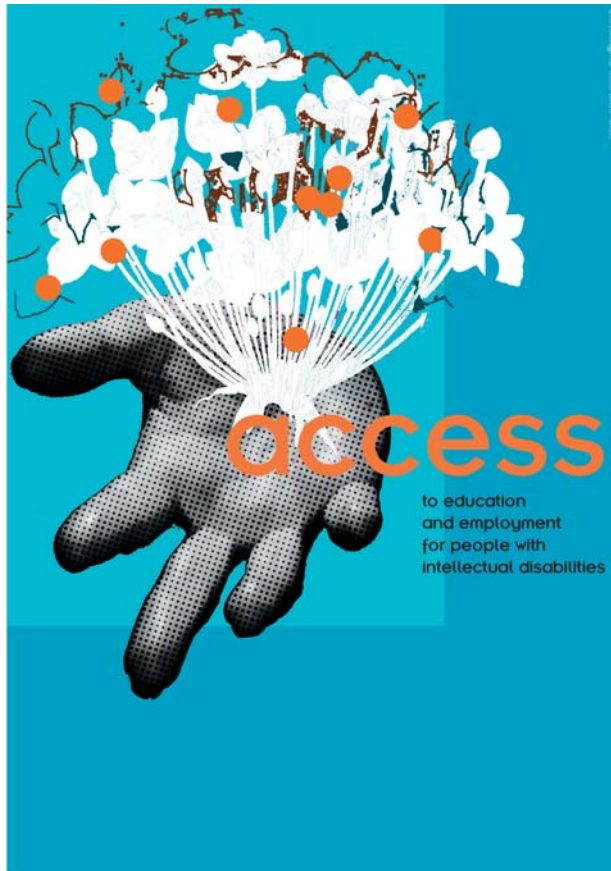
*Access to social benefits*

38. The Government should make all laws and publications that summarise social and unemployment benefits available in easy-to-read formats, to ensure that people with intellectual disabilities and their families are able to access the benefits to which they are entitled.



Throughout Europe, people with intellectual disabilities face overwhelming stigma and prejudice and encounter significant barriers to realising their fundamental rights. EUMAP, the EU Monitoring and Advocacy Program of the Open Society Institute, in cooperation with the Open Society Mental Health Initiative, has monitored this situation in 14 countries throughout Europe, both EU members and candidate countries: *Bulgaria; Croatia; the Czech Republic; Estonia; Greece; Hungary; Latvia; Lithuania; the Netherlands; Poland; Romania; Slovakia; Slovenia* and *the UK*. Carried out by local experts and civil society groups, the monitoring focuses on the extent to which people with intellectual disabilities have access to education and employment. This series of reports presents the findings of the monitoring and also makes recommendations for improving the social inclusion of people with intellectual disabilities.

The summary reports resume the main findings – Executive Summary and Recommendations – of each of the country reports. The complete set of country reports, in English and translated to national languages, can be accessed online at: [www.eumap.org/topics/inteldis/reports](http://www.eumap.org/topics/inteldis/reports). Hard copies can be ordered at: [www.eumap.org](http://www.eumap.org).



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EU MONITORING AND ADVOCACY PROGRAM



OPEN SOCIETY INSTITUTE  
MENTAL HEALTH INITIATIVE

# Rights of People with Intellectual Disabilities: Access to Education and Employment

Summary Reports

*Latvia*

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## EXECUTIVE SUMMARY

Throughout Europe people with intellectual disabilities<sup>1</sup> face major stigma and prejudice and are confronted with significant barriers to realising their fundamental human rights. Discrimination against people with intellectual disabilities is deeply rooted and widespread, standing in the way of positive change. Providing real access to education and employment for people with intellectual disabilities is critical to ensuring that they can live and work in the community as equal citizens. There is a strong link between education and employment: without access to adequate education, people with intellectual disabilities cannot secure meaningful employment. This denial of access leads to life-long dependency, poverty and social exclusion, adding to the stigma of intellectual disability. This monitoring report focuses specifically on the areas of education and employment, because of their importance to people with intellectual disabilities, and because of the existence of both international standards and national legislation that specifically address them.

For people with intellectual disabilities in Latvia, access to inclusive education or any kind of employment remains highly limited. There is an increasing awareness of the need to improve the social inclusion of people with disabilities in Latvia, and the European Union (EU) accession process has encouraged many positive changes in terms of legislation and policy. However, while the number of children with all levels of intellectual disabilities in the education system is increasing, too few are able to receive education in an integrated environment. Most young people with intellectual disabilities do not receive the education or vocational training that they need to later gain access to employment, and the vast majority of people with intellectual disabilities are reliant on social benefits. To date, the Government has not adequately addressed the specific needs of people with intellectual disabilities in the labour market. There is no definition of supported employment<sup>2</sup> in existing legislation, and almost no provision of supported employment services for people with intellectual disabilities.

### *Background*

Latvia is party to most international human rights instruments, including those with provisions on people with disabilities, but has yet to sign and ratify the Revised European Social Charter. Latvia has also not ratified Protocol No. 12 to the European

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<sup>1</sup> The term “intellectual disability” (also described as “learning disability” or “mental retardation”) here refers to a life-long condition, usually one present from birth or one that develops before the age of 18. It is a permanent condition that is characterised by significantly lower than average intellectual ability and results in significant functional limitations in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills.

<sup>2</sup> Supported employment is an employment option that facilitates competitive work in integrated work settings for people with disabilities. It provides assistance such as job coaches, transportation, assistive technology, specialised job training and individually tailored supervision.

Convention on Human Rights and Fundamental Freedoms (ECHR) or the ILO Convention concerning Vocational Rehabilitation and Employment 1983 (No. 159).

Although the Latvian Constitution forbids discrimination, it does not specify the grounds on which discrimination is prohibited. In order to comply with EU directives, a comprehensive anti-discrimination law – the draft Law on the Prevention of Discrimination – was prepared by the Government. However, although this draft law passed its first reading in Parliament, it was subsequently abandoned, in June 2005, on the grounds of its poor legal quality. Instead, a number of existing laws will be amended in order to transpose EU anti-discrimination provisions, in particular the EU Race Equality Directive and EU Employment Directive, into national legislation. The Law on the Protection of the Rights of the Child (hereafter Child Rights Law) includes a chapter on the rights of children with special needs. The most important general law addressing the rights of people with disabilities is the Law on the Medical and Social Protection of Disabled Persons (hereafter, Law on People with Disabilities). The National Human Rights Office (NHRO), an ombudsman-like institution, currently receives and analyses complaints concerning discrimination, including any with respect to people with disabilities, but its recommendations are not enforceable. However, there has been an ongoing discussion as to whether or not Latvia needs an Ombudsman and in June 2005, the Law on the Office of the Ombudsmen passed its first reading in Parliament. According to the law, the NHRO will in future be reorganised and developed into a new Ombudsman's office, taking on additional functions.

The term “intellectual disability” is not used in Latvian legislation. The terms “mental retardation” and “persons with disorders of a mental nature” are the most widely used terms (although the latter is not defined in legislation, and there is no clear policy on whether it may also include people with mental health problems). More recent legislation increasingly uses the broader term “person with special needs”. There are different procedures for the assessment of intellectual disabilities for educational purposes (for children), for employment purposes (for adults), and for access to social benefits (for adults and children). For educational purposes, the assessment of the level of abilities of a child with intellectual disabilities is made by the State and Municipal Medical Pedagogical Commissions. It is based on diagnoses established by certified psychiatrists, who use the World Health Organization's ICD-10 as a reference. The State Medical Commission for Determining Health Condition and Working Ability (hereafter, State Medical Commission) carries out assessments of intellectual disability for employment purposes and for access to social benefits.

At the age of 18, adults with intellectual disabilities may be declared “lacking the capacity to act” and placed under trusteeship by the courts. However, this happens relatively infrequently, mostly for people with *severe* intellectual disabilities. In law, the civil rights of a person under trusteeship are equivalent to those of a minor under guardianship. The Civil Law does not provide for the right to work of people with intellectual disabilities. However, a person with intellectual disabilities who is under

trusteeship should retain the right to work, provided that his or her trustee signs the employment contract. As there have been no cases reported of people with intellectual disabilities who are under trusteeship working, it is difficult to establish if this is the case in practice. There is currently a shortage of suitable trustees for people with intellectual disabilities in residential institutions, which means that some have been unable to gain access to their social benefits. To address this situation, Riga City Council now provides a small monthly allowance to cover some of the costs associated with the trustee's responsibilities. The procedure for determining trusteeship is regulated by the Civil Law of 1937, in which the terminology used to describe people with mental disabilities is archaic and offensive.

In Latvia, there is no unified system of data collection on people with intellectual disabilities, and various official sources offer differing data. The most reliable source of data is the Mental Health State Agency (prior to 2004, called the Mental Health Care Centre), according to which, in 2003, there were 14,281 people with intellectual disabilities in Latvia, including 5,547 children and young people under the age of 18. The Ministry of Education maintains data on the number of children with intellectual disabilities in the education system. The process of deinstitutionalisation has been slow in Latvia. In 2004, there were 842 children with intellectual disabilities in State institutional care, and in private and NGO-run children's homes. For adults with mental disabilities, there is a lack of community-based alternatives to institutional care. In 2004, there were nearly 2,000 adults with intellectual disabilities in specialised State social care homes for adults with mental disabilities, and for the elderly. There were also a number of people with intellectual disabilities in eight psychiatric hospitals that also provide long-term care for patients.

### *Access to education*

The Latvian Constitution guarantees the right to education. It is supplemented by the Child Rights Law, the Education Law and the Law on General Education. Latvian legislation provides for the right to education of children with intellectual disabilities, and addresses the provision of special education in both mainstream and special schools. Children with intellectual disabilities may attend a mainstream school if the school has the necessary provisions suitable for children with special needs, and if it offers a licensed special educational programme. However, the law does not provide for their right to attend a mainstream school that does not have a licensed special educational programme.

In Latvia, there is no national policy on the provision of early intervention services for children with intellectual disabilities under the age of six; the Government does not provide any early intervention services and has not allocated any funds towards making such services available. One model that could be used for developing a clear Government policy in this area is the early intervention programme carried out by the Latvian Portage Association, an NGO. This programme offers a model of good



practice that could be replicated at the national level given adequate State funding and support.

For educational purposes, the State and Municipal Medical Pedagogical Commissions assess children with intellectual disabilities with one of three levels of intellectual disabilities: A (*mild* intellectual disabilities), B (*moderate* intellectual disabilities) or C (*severe* intellectual disabilities). On the basis of this assessment, the Commissions then suggest the special educational programme that the child with intellectual disabilities should follow. Parental choice should be respected as regards the selection of the school that a child should attend. Based on the suggestion of the Commission, and in collaboration with the parents, the District Education Board recommends a local school providing the type of educational programme suggested by the Commission. If the parents do not agree to their child's attending a special school, they should be able to enrol their child in a mainstream school. Nonetheless, if that school does not have the recommended licensed special educational programme, their child may not receive the support needed to achieve his or her full potential.

At present, the integration into mainstream schools of children with special educational needs (in general) is not widespread in Latvia, although the Government is developing policy aimed at encouraging further integration. The 1998 "Equal Opportunities for All Concept" foresees the development of State and regional programmes to promote the early integration of children with intellectual disabilities into mainstream schools. However, as yet many of the education goals outlined in the Concept are yet to be implemented. The "Education Development Concept for 2002–2005" aims to reform the education system, in order to promote the integration of people with special needs into general, professional, higher and special education programmes. Supported by the Nordic Council, Latvia has increased the teaching level of its special educators and established greater cooperation between universities, special and mainstream schools and special and vocational training schools.

In Latvia, schools are responsible for developing the special educational curricula for students with special needs, which must be licensed by the Ministry of Education and harmonised with other programmes of the District Education Board. In addition, special individualised educational programmes are available for children with *severe* intellectual disabilities. The Ministry of Education has defined the level of education required of special educators, who have the opportunity to attend various training courses in addition to basic university education. However, the Ministry does not provide courses free of charge in continuing education for teachers already working in special schools; at present teachers have to pay half of the course costs themselves.

Education for children with intellectual disabilities is provided in mainstream schools (in special classes) and in special schools (day schools and boarding schools). Although there are no legal restrictions preventing children with intellectual disabilities from being educated in integrated classes in mainstream schools, there are no known instances of this occurring in practice to date. At present, the majority of children with *mild* or *moderate* intellectual disabilities attend special schools; only a few attend

mainstream schools. In the past, children with *severe* intellectual disabilities were considered “uneducable” or only received home schooling; however, an increasing number are now able to attend special schools.

The Ministry of Education and Science maintains detailed statistics on the number of children with special needs in the education system, including children with intellectual disabilities. According to the Ministry, in 2002–2003 there were 281 children with intellectual disabilities attending mainstream school, out of a total of 5,823 children with intellectual disabilities attending any kind of school. In 2003–2004, this figure rose to 322 children (out of a total of 5,662) and in 2004–2005, to 360 (from a total of 5,426). According to the Ministry of Education, 42 mainstream primary schools and 16 mainstream secondary schools have integrated children with intellectual disabilities. The number of integrated children in each school ranges from a minimum of four students, up to 40 students (at Nigrande Primary School) or even 50 students (at Auce Secondary School). A particularly good example is that of Sabile Secondary School, which has integrated a significant number of children with all levels of intellectual disabilities. Such examples need to be replicated more widely, on the national level, if children with intellectual disabilities in Latvia are to gain real access to inclusive education. The lack of assistants for children with special needs is one of the main reasons cited why mainstream schools might not be ready to create special education programmes.

In 2003–2004, there were a total of 5,574 children with intellectual disabilities studying in special schools, mainly in the 43 special schools for children and young people with intellectual disabilities. There are now five special schools in Latvia that have been assigned the status of development centre by the Ministry of Education and Science, and serve as resource centres for mainstream schools. However, very little information is available on the quality of education provided to children with intellectual disabilities in special schools, and there is a need for the Ministry of Education to carry out an evaluation on this subject. A main identified obstacle to the further integration of children with intellectual disabilities is inadequate funding for special classes in mainstream schools. Mainstream schools do not receive an earmarked subsidy from the Government for ensuring the special educational needs of students with disabilities, while children in special schools lose benefits such as free medication, food and transportation if they move to a mainstream school. This acts as a disincentive, and means that there are only a very small number of transfers between special and mainstream schools.

In Latvia, a relatively high number of children with intellectual disabilities still remain outside the educational system. In 2002–2003 over 1,400 children received home schooling, but there is no official data on the number of children with intellectual disabilities included in this total, and nor is there any available information on the quality of education received by home-schooled children. There is no legislative framework or Government policy for the education of children in residential institutions. In Latvia the process of deinstitutionalisation is very slow, mainly due to a

lack of State funding for alternative community care services for people with intellectual disabilities. In 2004, there were around 900 children with intellectual disabilities living in residential institutions (social care homes and orphanages). The Vegi Social Care Home in Talsu District (in collaboration with Sabile Secondary School) has developed good practice in enabling children from the home with all levels of intellectual disabilities to receive integrated education in a mainstream school. In addition, the Ainazi Psychiatric hospital for children (for long-term stay) started to provide education for 35 children from September 2005. However, in the other residential institutions, children have very limited access to any education.

### *Transition from education to employment*

Young people with intellectual disabilities have great difficulty in finding work or employment of any kind after completing compulsory education. The main ways in which students with intellectual disabilities are prepared for the difficult transition from education to employment is through participation in “Life Skills” programmes or vocational training. However, although in principle every special school and mainstream school with a special programme should offer a life skills programme, often schools are unable to fully implement them. Similarly, due to a lack of resources and educators, the majority of special schools are also unable to offer vocational training classes. Those courses that are offered often do not correspond to the needs of the labour market. This means that most young people with intellectual disabilities leave school inadequately prepared for the challenges of leading an independent life. At present there are very limited opportunities or support for people with intellectual disabilities to receive professional rehabilitation, adult education, or life-long education.

### *Access to employment*

The Latvian Constitution provides for equal opportunities in employment for all residents. The Labour Law has been amended to transpose the provisions of the EU Employment Directive into Latvian legislation, apart from specifically including sexual orientation as a prohibited ground for discrimination. However, with respect to the employment of people with intellectual disabilities, there are two important “gaps” in Latvian legislation – there is no definition of supported employment in existing legislation, and only inadequate provisions concerning sheltered employment.

The assessment of disability for employment purposes, carried out by the State Medical Commission for Determining Health Condition and Working Ability and its regional structural units, establishes disability status according to one of three disability groups: I (the most severe), II or III. In 2003, the automatic designation of people in disability groups I and II as “unfit to work” (i.e. with 100 per cent working incapacity) was eliminated, and the Commissions now evaluate the working capacity of people with disabilities on an individual basis. Nonetheless, it seems that most people with intellectual disabilities are still being assessed as having no working capacity. This is important, in that only people with *some* working capacity can register as unemployed

and gain access to the employment services of the State Employment Agency (SEA). In particular, they cannot apply for a subsidised workplace through the SEA, as this service is available only for registered unemployed persons.

The State disability pension is calculated as a function of the designated disability group of the person with disabilities. However, most people with intellectual disabilities have not worked, so are not eligible for this benefit, as a three-year working history is required. They instead rely on the State social security benefit, for which people in all three disability groups are eligible.

In Latvia, there is no quota system for people with disabilities and, as yet, no Government incentives to specifically encourage the employment of people with intellectual disabilities. The main implementing institution for labour market policy is the SEA. The most important way in which unemployed people with disabilities can gain access to employment is through active employment measures provided by the SEA, in particular subsidised employment programmes. However, few people with intellectual disabilities have the necessary training or professional education required for eligibility for such programmes. A Government pilot project on the provision of subsidised workplaces for unemployed people with disabilities, initiated in 2001, has been successful in enabling people with disabilities to subsequently find employment on the open market. However, due to a lack of relevant data, it is impossible to establish if – and, if so, how many – people with intellectual disabilities have been able to benefit from this programme. In future, it would be important that such initiatives collect and maintain data on the types of disabilities of the people with access to the programme or project.

The development of specialised programmes for people with disabilities was recognised as a priority in the “Joint Memorandum on Social Inclusion in Latvia” established between Latvia and the European Commission. Following its accession to the EU, Latvia is now eligible for EU Structural Funds. The Government intends to use these funds for the period 2004–2006 to provide employment opportunities and support for people with disabilities seeking employment. In particular, the EU’s European Regional Development Funds (ERDF) programme will be directed towards vocational training for people with disabilities and, of particular relevance to people with intellectual disabilities, will be used to create “specialised workshops”. To date, three projects have received funding for developing specialised workshops – at Strenči Psychiatric Hospital, in Limbazi District (targeting people with special needs) and in Rzekne (for people with both intellectual disabilities and physical disabilities).

In 2002, there were approximately 700,000 people with disabilities in Latvia, of whom only approximately 10 per cent were working. There are no figures on the specific employment situation of people with intellectual disabilities, but most do not have any kind of work or employment and are reliant on State benefits. Almost none are able to gain access to employment on the open market. Since 2000, the NGO Rupju Berns has provided the only supported employment programme in Latvia for people with intellectual disabilities, now operating in Riga and Tukums. By 2003, a total of 28

people with intellectual disabilities were employed in supported workplaces through this programme. One of the main employers involved in this project, McDonalds in Latvia, has reported a positive experience in employing people with intellectual disabilities.

In Latvia, sheltered workplaces in the generally understood sense still do not exist. There are instances of good practices from the “specialised workshops” established for people with intellectual disabilities in day centres. However, here the main aim is to provide an “occupation” rather than employment, and so people do not receive any payment for their work. The “social firm” is another example of sheltered employment in Latvia. Social firms receive funding from the SEA to create jobs for small numbers of people with disabilities. However, to date few social firms have been established, and the interest on the part of employers is very low.

## RECOMMENDATIONS

### General recommendations:

#### *International Standards*

1. Latvia should sign and ratify the Revised European Social Charter of 1996 and should bind itself to Article 15 of the charter, on the right of persons with disabilities to independence, social integration and participation in the life of the community.
2. Latvia should ratify Protocol No. 12 to the European Convention on Human Rights and Fundamental Freedoms (ECHR).
3. Latvia should ratify the ILO Convention concerning Vocational Rehabilitation and Employment 1983 (No. 159).

#### *Data collection*

4. The Government should completely review the system for the collection, regular updating and public dissemination of relevant data on people with disabilities in Latvia in general, and on the specific situation of people with intellectual disabilities.
5. The Government should ensure that, at a minimum, reliable data is collected on the total number of people with intellectual disabilities, their disability group status and their age groups. Discussion should be initiated with the State Medical Commission for Determining Health Condition and Working Ability on the possibility that the Commission in future be able to provide data for the relevant institutions.
6. The Government should ensure that data collected on people with intellectual disabilities is used as the basis for policy-making and for identifying areas where discrimination against this group occurs.

#### *Guardianship*

7. The Government should review the legal basis of trusteeship for adults with intellectual disabilities, and evaluate ways in which those determined by the courts to have limited “capacity to act” would be able to exercise as many of their civil rights as possible, including the right to work. The option of a form of partial guardianship for people with intellectual disabilities, as well as people with mental illness, should be discussed.

#### *Cooperation*

8. The Government should strengthen the collaboration among all the relevant ministries addressing the needs of people with disabilities, in particular the

Ministry of Welfare, the Ministry of Health and the Ministry of Education and Science.

### *Deinstitutionalisation*

9. The Government should allocate funds and other resources to ensure that community care alternatives to residential care are available throughout the country.
10. The Government should ensure the right of children with intellectual disabilities to grow up in their family by providing more support to families with children who have intellectual disabilities. This support should include advice and counselling, financial support, and access to community-based services.

## **Recommendations on education**

### *Policy*

11. The Government should develop a clear policy on improving the access of children with intellectual disabilities to inclusive education, in which they receive education in a mainstream class, along with children without intellectual disabilities.
12. The Ministry of Education and Science should promote the establishment of inclusive kindergartens throughout Latvia that would be accessible to children with all levels of intellectual disabilities, and provide adequate support and funding.

### *Funding*

13. The Government should include a special budget line at the State level for the inclusion of children with intellectual disabilities in mainstream schools, to cover the various expenses associated with their inclusion, such as teaching materials, classroom adaptations and additional staff.
14. The Government should provide additional funding and support (including training) for teachers in mainstream schools who are working with children with intellectual disabilities.

### *Early intervention services:*

15. The Government should develop a strategy and implementation plan to support the development of early intervention services accessible to children with intellectual disabilities, and their families, throughout the country. The early intervention programme of the Latvian Portage Association, an NGO,

should be used as one model for developing early intervention services in every local municipality in Latvia.

### *Home schooling*

16. The Ministry of Education and Science should collect, and regularly update, data on the numbers of children with intellectual disabilities who are presently receiving home schooling, or are not receiving education.
17. The Ministry of Education and Science should develop a clear policy for integrating as many home-schooled children with intellectual disabilities as possible into mainstream schools, while ensuring that those who continue to need to be schooled at home receive high-quality education that addresses their real needs.

## **Recommendations on transition from education to employment**

### *Vocational training*

18. The Government should make vocational training, in a wide range of professions, widely available for people with intellectual disabilities.
19. The Government should initiate an analysis of the labour market, in order to better target the programmes of vocational training offered to young people with intellectual disabilities (in special schools, mainstream schools and vocational schools) towards the needs of the labour market.
20. The Ministry of Education and Science should cooperate with the Ministry of Welfare to develop a strategy for the training and continuing professional support of social workers in local municipalities, to enable them to provide high-quality support services to young people with intellectual disabilities. This training should focus on how to better assist young people with intellectual disabilities in finding a place to live and work and in accessing social benefits.
21. The State Employment Agency should implement vocational training programmes specifically for people with intellectual disabilities, so that they can obtain adequate vocational training to gain access to employment opportunities on the open market.

## **Recommendations on employment**

### *Legislation*

22. The Ministry of Welfare should, as a priority, define supported employment in law, and establish the necessary secondary legislation and regulations to



ensure implementation of supported employment projects for people with disabilities.

23. The Ministry of Welfare should define sheltered workshops in law, and develop secondary regulations specifying their role and operation. This is particularly important as the Government plans to use EU Structural Funds for creating such workshops. The aim of such workplaces should be to provide training and support for people with intellectual disabilities, to enable them to later gain access to employment on the open market through supported employment. However, it should be specified in law that people working in sheltered workshops should receive a wage or payment for their work.

#### *Active employment measures*

24. The Ministry of Welfare should establish tax allowances, subsidies and other incentives specifically for employers who employ people with intellectual disabilities on the open market.

#### *EU Structural Funds*

25. The Ministry of Welfare and the Ministry of Health should evaluate the accessibility of projects funded by EU Structural Funds to all groups of people with disabilities. In particular, the ministry should review the accessibility of the rehabilitation services receiving support from EU Structural Funds, to the significant number of people with mental health problems who have not been assigned a designated disability group. At present, by law, only people who have been assigned a designated disability group are eligible to receive rehabilitation services.
26. The Government should ensure that people with intellectual disabilities are able to benefit from projects funded by EU Structural Funds. In particular, these funds should be used to support projects providing supported employment.

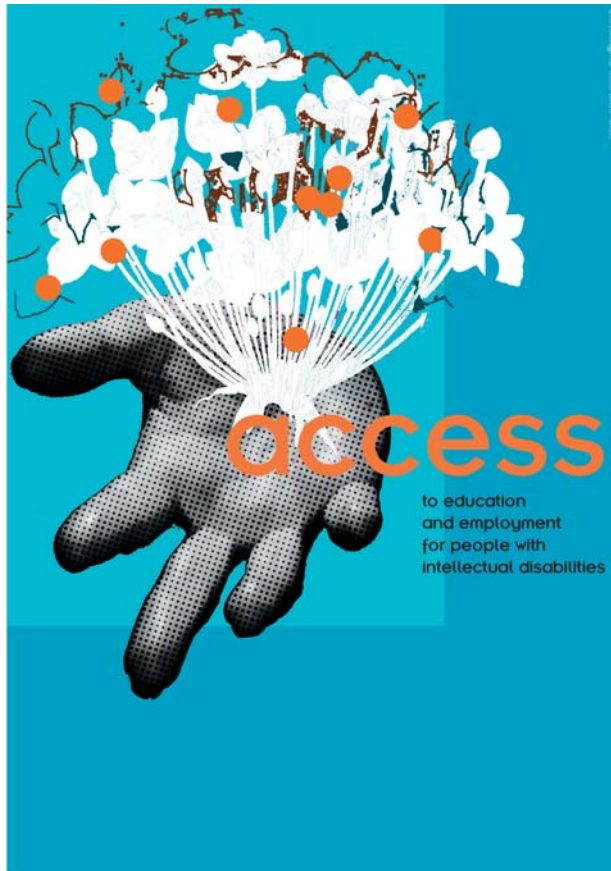
#### *Supported employment*

27. The Ministry of Welfare should provide financial support for supported employment agencies throughout Latvia, similar to those already existing in Riga.



Throughout Europe, people with intellectual disabilities face overwhelming stigma and prejudice and encounter significant barriers to realising their fundamental rights. EUMAP, the EU Monitoring and Advocacy Program of the Open Society Institute, in cooperation with the Open Society Mental Health Initiative, has monitored this situation in 14 countries throughout Europe, both EU members and candidate countries: *Bulgaria; Croatia; the Czech Republic; Estonia; Greece; Hungary; Latvia; Lithuania; the Netherlands; Poland; Romania; Slovakia; Slovenia* and *the UK*. Carried out by local experts and civil society groups, the monitoring focuses on the extent to which people with intellectual disabilities have access to education and employment. This series of reports presents the findings of the monitoring and also makes recommendations for improving the social inclusion of people with intellectual disabilities.

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# Rights of People with Intellectual Disabilities: Access to Education and Employment

Summary Reports

*Lithuania*

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## EXECUTIVE SUMMARY

Throughout Europe, people with intellectual disabilities<sup>1</sup> face major stigma and prejudice and are confronted with significant barriers to realising their fundamental human rights. Discrimination against people with intellectual disabilities is deeply rooted and widespread, standing in the way of positive change. Providing real access to education and employment for people with intellectual disabilities is critical to ensuring that they can live and work in the community as equal citizens. There is a strong link between education and employment: without access to adequate education, people with intellectual disabilities cannot secure meaningful employment. This denial of access leads to life-long dependency, poverty and social exclusion, adding to the stigma of intellectual disability. This monitoring report<sup>2</sup> focuses specifically on the areas of education and employment, because of their importance to people with intellectual disabilities and because of the existence of both international standards and national legislation that specifically address them.

In Lithuania, the access of children and young people to education in a mainstream environment has improved significantly over recent years, and nearly 8,000 children with intellectual disabilities are now integrated into mainstream schools. The opportunities for young people with intellectual disabilities to receive vocational training have also improved, though those with more severe intellectual disabilities are still unable to access the training they require. However, in contrast to the many promising developments concerning the education of people with intellectual disabilities, their access to employment is extremely limited; almost none have any form of employment or work. Government policies have been ineffective in promoting any employment opportunities for this group of people, and in particular there is no framework for supported employment<sup>3</sup> in Lithuania.

### *Background*

Lithuania has ratified most major international human rights instruments, including those with provisions relating specifically to the rights of people with disabilities,

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<sup>1</sup> The term “intellectual disability” (also described as “learning disability” or “mental retardation”) here refers to a lifelong condition, usually present from birth or which develops before the age of 18. It is a permanent condition that is characterised by significantly lower than average intellectual ability and results in significant functional limitations in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills.

<sup>2</sup> Monitoring for this report was carried out during the period November 2003 – February 2005. Any changes to legislation and policy after this period have not been addressed. At the time of publishing, 1 July 2005, new legislation regulating the social integration of people with disabilities in all areas of life will enter into force, but these are not addressed in this report.

<sup>3</sup> Supported employment is an employment option that facilitates competitive work in integrated work settings for people with disabilities. It provides assistance such as job coaches, transportation, assistive technology, specialised job training and individually tailored supervision.

though it has yet to sign or ratify Protocol No. 12 to the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR). The Lithuanian Constitution provides equality before the law for all, but there is no specific prohibition against discrimination on the grounds of disability. In line with the EU Race Equality Directive and the Employment Directive, the legislative framework for anti-discrimination has recently been significantly strengthened with the adoption of the new Law on Equal Opportunities 2003. This law entered into force on 1 January 2005 and includes a specific prohibition against discrimination on the grounds of disability. The mandate of the Equal Opportunities Ombudsman has been broadened in line with this new law, and in the future, the office will be able to address complaints of direct or indirect discrimination on the grounds of disability. The Law on Social Integration of People with Disabilities 1998 is currently the main legislative basis for Lithuanian disability policy. However, a new version of this law – to enter into force on 1 July 2005 – aims to improve the opportunities for, and attitudes towards, people with disabilities in Lithuania, and to promote their social integration. It establishes the principles of equal rights and equal opportunities for people with disabilities and improves their protection from discrimination, including discrimination in access to education and employment. Lithuania has an officially recognised disability policy. Adopted in 2002, the “National Programme for the Social Integration of People with Disabilities 2003–2012”, seeks to promote equal opportunities for people with disabilities, including in education and employment.

There are different procedures for the assessment and diagnosis of people with intellectual disabilities, one for education, which is aimed at children and young people, and one for employment purposes and access to social welfare benefits, which is aimed at people age 18 and over. Intellectual disability is diagnosed and defined in line with the World Health Organization’s International Classification of Diseases, Tenth Revision, according to four levels of intellectual disability: *mild*, *moderate*, *severe* and *profound*. For adults, the individual’s assessed level of intellectual disabilities is used as a basis for assigning one of three disability groups: I, II or III, where group III is the least severe degree of disability. For educational purposes, the child or young person’s level of intellectual disabilities is used as a basis for determining his or her special educational needs.

At present, there is a lack of comprehensive and consistent data that covers people with disabilities and is disaggregated by type of disability. In 2001, the Population and Housing Census included questions on people with disabilities for the first time, but data on people with intellectual disabilities was subsumed within the broader category of people with mental disabilities. Because this category also includes people with mental health problems, the results are difficult to interpret. According to the census, approximately 6,000 people with mental disabilities, or just over one quarter of all people in Lithuania with mental disabilities, live in residential institutions. The census revealed that the majority of adults with mental disabilities are assessed in disability groups I or II. These assessments have significant consequences because, when people with intellectual disabilities in disability groups I and II – which include people with

*moderate, severe* or *profound* intellectual disabilities – attain the age of 18, they are usually declared legally incapable by the courts and placed under a level of guardianship that is equivalent to *plenary* guardianship. They thereby lose all their civil and economic rights. As these rights include the right to sign an employment contract and the right to work, an assessment of disability group I or II represents a significant barrier to employment. Although the law also foresees the possibility of limiting, rather than fully removing, an individual's civil capacity and placing him or her under curatorship, which is equivalent to *partial* guardianship, this is not applicable to people with intellectual disabilities.

### *Access to education*

Lithuanian legislation establishes the right to education for all children, and the Law on Equal Opportunities 2003 strengthens protection against discrimination in education on the grounds of disability. The Law on Education 2003 and the Law on Special Education 1998 are the main laws regulating the education system in Lithuania. Importantly, the Law on Education 2003 specifically provides for the right of children with special needs to be educated in a mainstream school close to their place of residence. The Law on Special Education 1998 regulates the education of children and young people with special educational needs, and it also regulates the structure and administration of special education. Although this law established the basis for inclusive education and is considered by experts to be both progressive and innovative, there have nonetheless been calls for it to be replaced by a unified act on education. Many people concerned with the education of people with intellectual disabilities believe that maintaining a separate law on special education only serves to reinforce segregation within the educational system and increase the stigmatisation of children with intellectual disabilities. Another concern is that in many cases, the secondary legislation necessary to implement the existing laws on education is not yet in place, which means that the rights established under the Law on Education 1998 are not always implemented in practice.

In Lithuania, there is a well-organised and comprehensive system of early intervention, or “early rehabilitation”, services for children with intellectual disabilities. These services are available at three levels, depending on the degree of the child's disabilities, but there is an increasing emphasis on provision of services at the community level. There are already signs that early intervention services have produced good results and helped to improve the level of education that children with intellectual disabilities can later acquire. The assessment procedures used to assign special education for children of school age are also effective. Parents are generally satisfied and feel that they and their children are adequately consulted, and that parental choice is reflected. The parents of a child with intellectual disabilities have the right to choose the type of school that they wish their child to attend.

The educational options for children with intellectual disabilities are: mainstreaming, either with complete integration in a mainstream class or partial integration, in which



some classes are in a special class; education in a special school, an option that can involve partial integration if the child has some classes in a mainstream school; or home schooling. Assessment of intellectual disability for educational purposes is carried out by Special Education Commissions and the Pedagogical Psychological Services. These assessment bodies recommend the most appropriate form of education for a child with intellectual disabilities, and the educational programme the child should follow. The curriculum the child follows can be adapted accordingly, or an individualised curriculum can be prepared. These bodies also recommend the type of support and assistance the child will require. However, although children with special needs have the right to pedagogical support and compensatory equipment, this right is in fact not always realised. In practice, the form of education a child with intellectual disabilities receives still depends to a large extent on the decisions of the child's parents or guardians and the decision of the local municipality. In smaller towns, the available options for children with intellectual disabilities can be very limited, and the only choice may be attendance at a special boarding school.

The EU accession process has played a key role in the development of Lithuanian education policy over recent years and, as a Member State, Lithuania is now eligible for funding from the EU Structural Funds. A portion of these funds will be used for promoting equal opportunities and the full integration of people with disabilities, a task that includes the improvement of education and vocational training services and lifelong learning. The most important reference for national education policy is the "National Educational Strategy for 2003–2012". This introduces significant reforms in the education system, including the decentralisation of the education system and the introduction of a new system of education financing, based on the principle that the "funds follow the student", which should increase funding for special education. The Government has put in place a number of programmes to support the implementation of these reforms, several of which are particularly relevant to the education of children with intellectual disabilities. However, one of the most important elements of the strategy, the reform of the system of education financing, has not yet been successfully implemented. A main problem that has been identified is that a significant proportion of the necessary secondary legislation has either not yet been created or has not been implemented.

There has been a highly significant increase in the number of children and young people with intellectual disabilities who are fully integrated into mainstream schools in Lithuania, up from 1,085 students in 1995–1996, to 7,095 in 2002–2003. In addition, in 2002–2003, nearly 800 children with intellectual disabilities attended mainstream schools through partial integration. Although the Law on Special Education 1998 established the foundation for inclusive education, this increase must also be attributed to a number of more recent positive developments. These include the adjustment of educational programmes to the individual needs and competencies of the child; a flexible system of transfer to a more demanding educational programme; the possibility of transferring a child from a special school to a mainstream school; and improved access to pre-school education. In practice, though, parents of children with intellectual disabilities still tend to accept integration as a "favour" rather than a right,

and their choice of school is often limited by the availability of social and education services. In addition, some teachers, and also the parents of children without disabilities, still resist the inclusion of children with disabilities in mainstream classes. The most significant remaining barriers to integration, though, are a lack of suitably qualified teachers, transportation problems particularly in rural areas, and a lack of support services for parents of children with intellectual disabilities.

The increasing integration of children with intellectual disabilities into mainstream schools has led to a corresponding decline in the numbers attending special schools, down from 5,845 in 1994 to less than 3,488 in 2004. Most children with intellectual disabilities who attend a special school have *moderate* intellectual disabilities. Children with more severe intellectual disabilities are usually placed in boarding homes or do not attend school. Special schools can be day schools or boarding schools. Education in special boarding schools remains a necessary option for a few children with intellectual disabilities, particularly those from the remoter areas of the country. However, the Children's Rights Ombudsman has expressed concern that there are many children with *mild* intellectual disabilities or behavioural challenges who have been placed in such schools, even though they should be integrated into mainstream schools. Specialists advise that, in the future, only children with *severe* or *profound* intellectual disabilities should attend the special boarding schools.

Home schooling is intended for children with an acute medical condition, rather than those with permanent disabilities, such as intellectual disabilities. Home schooling should not exceed 12 months. However, in Lithuania, a relatively high number of children do not attend school and, due to inconsistent methods of data collection, it is not possible to assess the number of children with intellectual disabilities who either do not attend school or who receive home schooling. Better assessments should be possible in the future, as the Ministry of Education and Science has decided to collect such information starting from 2004. In Lithuania, few children with intellectual disabilities live in residential institutions other than special boarding schools. In 2002, there were approximately 650 children with intellectual disabilities living in the three boarding homes intended for young people who have intellectual disabilities and are under age 21. These children, many of whom need intensive care, receive no education of any kind. This is mainly due to the fact that these homes are part of the social care system, rather than the education system, and they lack adequate resources.

### *Transition from education to employment*

Although Lithuanian legislation provides for the right of people with intellectual disabilities to access vocational training, at present most are not able to realise this right in practice. Specialists and parents cite intolerance against people with intellectual disabilities, particularly in rural areas, as a main contributing factor. In addition, although vocational education and training courses have become more accessible to young people with intellectual disabilities over recent years, at present only those with *mild* intellectual disabilities are able to acquire professional vocational qualifications.

Young people with *mild* intellectual disabilities can receive vocational training in state vocational schools, vocational training departments of special boarding schools and three specialised vocational training schools. The Labour Exchange also provides vocational training services, and other employment services, intended for young people with disabilities, but these are not well adapted to the specific needs of people with intellectual disabilities. In any case, most people with intellectual disabilities cannot access these services, as they are assessed as having no working capacity. NGOs play a vital role in providing training and day occupancy for young people with more severe intellectual disabilities after they leave school. A draft strategy for reforming the vocational rehabilitation system in Lithuania has been prepared. This strategy aims to facilitate the vocational integration of people with disabilities and specifically includes recommendations on improving vocational training and rehabilitation services for people with intellectual disabilities.

### *Access to employment*

Lithuanian law guarantees the right to work and to choose a profession. Lithuania has transposed the provisions of the European Union's Council Directive 2000/78/EC (the Employment Directive) into national legislation and strengthened protection against discrimination in employment for people with disabilities. The Law on Equal Opportunities 2003 prohibits discrimination on the grounds of disability in the area of employment. The Law on Social Integration of People with Disabilities 1998 defines employment guarantees for people with disabilities. It also regulates the quota system and additional State subsidies available for the employment of people with disabilities. The new version of this law – to enter into force in June 2005 – will lead to a number of important changes, including improved disability assessment procedures. The Law on Social Enterprises 2004 introduces new forms of support and employment for people with disabilities, including State subsidies for social enterprises for people with disabilities. Although this should lead to the creation of new employment opportunities for people with disabilities, there are two important barriers to the employment of people with intellectual disabilities in social enterprises: first, employees must have some assessed working capacity, and, second, they must also have legal capacity.

For people aged 18 years old and above, assessments of disability for employment purposes and access to social benefits are carried out by the State Medical and Social Examination Commissions, which establish each individual's disability group and degree of working capacity, expressed as a percentage. The commissions can also recommend rehabilitation or training. However, at present, assessments are over-medicalised, inconsistent and time-consuming. Most people with intellectual disabilities have to repeat the assessment every two years, even though their condition will not change and they will not receive any additional support. Furthermore, most people with intellectual disabilities are assessed as having no working capacity, which is a very important barrier to employment. Such an assessment also excludes them from registering at a Labour Exchange and accessing the employment services offered to people with disabilities. In line with the Law on Social Integration of People with

Disabilities 2004, the Government has committed itself to reforming disability assessment procedures. New regulations are presently being prepared, and NGOs representing people with disabilities have been consulted in the preparation of these draft regulations. The overwhelming majority of people with intellectual disabilities are fully reliant on state benefits. In most cases, this means the social pension, because most people with intellectual disabilities have no working capacity and little or no work experience, and thus they are not eligible for a disability pension or an unemployment benefit. The level of the benefits they receive depends mainly on their disability group. However, despite an important increase in the level of the social pension in 2004, it still does not cover the basic living costs of people with disabilities. In most cases, therefore, families must support a family member with intellectual disabilities.

Lithuania's accession to the European Union has resulted in a number of positive changes in employment policy, including policy for people with disabilities. A number of documents prepared during Lithuania's accession process highlighted the challenges faced by people with disabilities in accessing employment. The documents made recommendations aimed at increasing these people's integration into the labour market. Over the next few years, EU Structural Funds will be used for projects directly promoting equal opportunities and full integration of people with disabilities. As yet, though, the extent to which these projects will benefit people with intellectual disabilities is difficult to assess. At present, the main means by which the State encourages the employment of people with disabilities on the open market is through a quota system, which applies to employers with more than 50 employees, and through state occupancy support subsidies for any employers who engage workers with disabilities outside the quota system. Additional employment guarantees are also available to people with disabilities, including priority for active employment measures, such as public works. However, none of these measures have been effective in enabling people with intellectual disabilities to access employment. A particular barrier is that only people with some working capacity are eligible for these benefits, so the majority of people with intellectual disabilities are excluded. In addition, these measures are not well adapted to the specific employment needs of people with intellectual disabilities.

Although Lithuanian law guarantees the right to employment for all, in practice it is not effective enough in encouraging the employment of people with disabilities – whose employment opportunities are in fact decreasing. Moreover, the employment situation of people with intellectual disabilities is particularly grave; almost none are thought to have any kind of employment. Official statistics underestimate the unemployment rates of people with disabilities, as those with no working capacity, including most people with intellectual disabilities, cannot register as unemployed. They also cannot access employment through the quota system, which is one of the reasons why there are no known cases of a person with intellectual disabilities finding employment in this way. People with intellectual disabilities face many barriers, including the negative attitude of employers to their type of disability. In any case, those with more severe intellectual disabilities are usually placed under guardianship,

and thereby lose the right to work. There is no framework for supported employment in Lithuania and almost no instances of people with intellectual disabilities finding employment in sheltered work places. The Law on Social Enterprises 2004 introduces a number of important changes to available State support for the employment of people with disabilities. In particular, it establishes for the first time legislation on the post of job coach, which should permit some people with intellectual disabilities to access employment on the open market through supported employment. In the future, employment in social enterprises may prove a better alternative to the quota system for people with intellectual disabilities. As yet, however, it is still too early to assess the impact of the newly introduced social enterprises on the employment opportunities for people with intellectual disabilities.

## RECOMMENDATIONS

### General recommendations

#### *International Standards*

1. Lithuania should sign and ratify Protocol No. 12 to the European Convention for the Protection of Human Rights and Fundamental Freedoms.

#### *Data collection*

2. The Government should ensure the regular collection and public dissemination of comprehensive statistical data on people with disabilities, disaggregated by type of disability. In order to develop effective policy, data on people with intellectual disabilities, including through National Population and Housing censuses, should be collected discretely, rather than included in the broader category of people with mental disabilities. In particular:
  - The Ministry of Education and Science should collect and maintain data on the number of children with intellectual disabilities who do not receive schooling of any kind or who receive home schooling.
  - The Ministry of Social Security and Labour should ensure that data on the employment situation of people with intellectual disabilities is collected.

#### *Guardianship*

3. The Government should ensure that people with disabilities who are placed under guardianship are able, to the fullest extent possible, to exercise their civil rights, particularly their right to employment.
4. The Government should, as a priority, amend existing legislation, to establish the right of courts to be able to *limit* the active capacity of a person with intellectual disabilities, so that the individual can be placed under curatorship. This could offer an alternative to the current existing option of declaring people *incapable* and placing them under guardianship.

### Recommendations on education

#### *Legislation*

5. The Government should prepare a united legal act on education in Lithuania. The fact that there is a separate law on special education (the Law on Special Education 1998) tends to reinforce the segregation of students with special needs and increase their stigmatisation.
6. The Government should, as a priority, prepare additional secondary legislation on the financing of the integral educational system, for all types of schools. In

particular, funding for after-school and other extra-curricular activities for children with special needs, including intellectual disabilities, should be increased.

### *Policy*

7. The Government should monitor and regularly review progress on its policy to integrate children and young people with disabilities into mainstream schools, vocational training schools and higher education institutions. It should be evaluated as a failure if a child with intellectual disabilities decides to transfer back from a mainstream school to a special school, or if a child's parents decide such a transfer is necessary.

### *Pre-school education*

8. The Government should undertake a review of the pre-school education system and consider making pre-school education obligatory for children with special needs, including children with intellectual disabilities.

### *Home Schooling*

9. The Ministry of Education and Science should monitor the number of children and young people with intellectual disabilities who receive home schooling, which should be considered the schooling option of last resort for these children. The ministry should also carry out an evaluation of the quality of education these home-schooled children receive in practice, with the aim of assessing whether their educational needs are being met.

### *Support services*

10. The Government should ensure that municipalities have a special budget line for the provision of support and assistance that meets the needs of children with intellectual disabilities integrated in mainstream schools. In particular, their transportation to school should be covered, especially in rural areas and in winter. This budget line should be protected from reallocation to other needs and programmes.
11. The Ministry of Education and Science should extend its network of specialists for special pedagogical and psychological assistance, to ensure that these services are accessible throughout the country.
12. The Ministry of Education and Science should ensure that the right of children and young people to compensation technology and special support – such as an assistant teacher, reader, attendant or sign-language interpreter – is ensured in practice.

### *Teacher training*

13. The Government should improve the qualifications and training of all teachers working with children with special needs, including children with intellectual disabilities.

## **Recommendations on transition from education to employment**

### *Legislation*

14. The Government should, as a priority, prepare and draft secondary legislation on the integration of children with special needs in vocational schools. In particular, legislation is needed to regulate the adaptation of the educational programmes of mainstream vocational schools, to ensure that they are accessible to people with intellectual disabilities who wish to gain professional skills or seek a professional qualification.

### *Policy*

15. The Government should review the “National Programme for the Social Integration of People with Disabilities 2003–2012” with the aim of developing a concrete strategy for improving vocational rehabilitation services for people with intellectual disabilities.

### *Employment Services*

16. The Government should ensure that the employment services offered by the Labour Exchange, including vocational training services, are made available to young people with intellectual disabilities and are adapted to their special needs.

## **Recommendations on employment**

### *Legislation*

17. The Government should ensure the full implementation of the Law on Social Enterprises 2004 and the Law on Social Integration of People with Disabilities 2004, through the timely adoption of comprehensive secondary legislation.
18. The Government should introduce legislation and policy to promote the introduction of the supported employment methodology to Lithuania. It should then take steps to make supported employment available to people with intellectual disabilities throughout the country.

### *Disability assessment procedures*

19. The Government, in coordination with the Ministry of Social Security and Labour and the Ministry of Health Care, should, as a priority, ensure that the ongoing review of disability assessment procedures leads to concrete improvements in the quality of assessments for people with intellectual disabilities. In particular:



- Disability assessment procedures for children and adults with intellectual disabilities should not only be based on medical evaluations, but should also take into account social and environmental factors and each individual's special needs, including measures for rehabilitation and educational support and assistance. Disability assessments should therefore be multidisciplinary, and should not be carried out only by medical specialists.
- Special methodologies should be developed for the evaluation of working capacity, in order to better establish each individual's abilities and capacity for work. The evaluation of working capacity for people with intellectual disabilities should aim to facilitate their access to employment, vocational training and occupational programmes provided by the Labour Exchange, as well as to State employment guarantees and pensions and benefits available to people with disabilities. The evaluations should, as far as possible, permit people with intellectual disabilities to gain or retain *some* working capacity.
- The number of reassessments of people with intellectual disabilities should be reduced as far as possible, unless the reassessments lead to improved support for the individual being assessed. Exceptions should, however, be made in any case where a person with intellectual disabilities specifically requests a reassessment.

### *Access to employment*

20. The Government should review the accessibility of employment guarantees and employment through the quota system for people with more severe disabilities, to ensure that more opportunities are created for them to exercise their fundamental right to work. In particular, the Government should ensure that, not only people with *mild* intellectual disabilities, but also people with more severe intellectual disabilities, are able to access employment in social enterprises.
21. The Government should investigate measures to counter the reluctance of employers to employ people with more severe disabilities and people with mental disabilities, including intellectual disabilities. These measures should include State funding for the provision of more appropriate support, including job coaches.

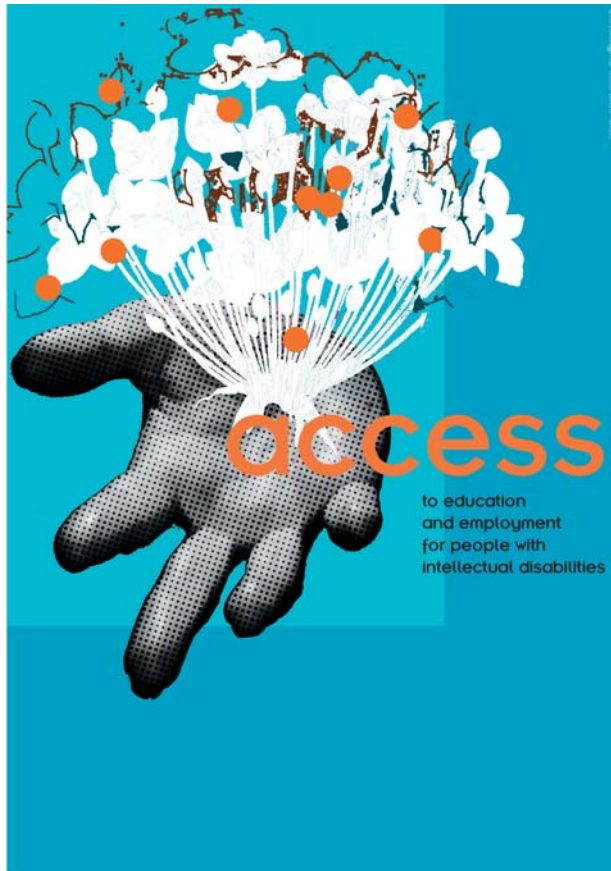
### *Social welfare*

22. The Government should review the social support available to people with intellectual disabilities, including the level of their social benefits and allowances, in order to better address the specific needs of people with intellectual disabilities and their families, and to ensure that their basic living costs are met.



Throughout Europe, people with intellectual disabilities face overwhelming stigma and prejudice and encounter significant barriers to realising their fundamental rights. EUMAP, the EU Monitoring and Advocacy Program of the Open Society Institute, in cooperation with the Open Society Mental Health Initiative, has monitored this situation in 14 countries throughout Europe, both EU members and candidate countries: *Bulgaria; Croatia; the Czech Republic; Estonia; Greece; Hungary; Latvia; Lithuania; the Netherlands; Poland; Romania; Slovakia; Slovenia* and *the UK*. Carried out by local experts and civil society groups, the monitoring focuses on the extent to which people with intellectual disabilities have access to education and employment. This series of reports presents the findings of the monitoring and also makes recommendations for improving the social inclusion of people with intellectual disabilities.

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# Rights of People with Intellectual Disabilities: Access to Education and Employment

Summary Reports

*Netherland*

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## EXECUTIVE SUMMARY

Throughout Europe, people with intellectual disabilities<sup>1</sup> face major stigma and prejudice, and are confronted with significant barriers to realising their fundamental human rights. Discrimination against people with intellectual disabilities is deeply rooted and widespread, standing in the way of positive change. Providing real access to education and employment is critical to ensuring that they can live and work in the community as equal citizens. There is a strong link between education and employment: without access to adequate education, people with intellectual disabilities cannot secure meaningful employment. This denial of access leads to life long dependency, poverty and social exclusion, adding to the stigma of intellectual disability. This monitoring report focuses specifically on the areas of education and employment because of their importance to people with intellectual disabilities, and because of the existence of both international standards and national legislation that specifically address them.

The Netherlands' extensive legal and policy framework related to people with disabilities clearly establishes an approach intended to foster active, independent living for this population, and to ensure its inclusion in the social fabric of the country. However, the experience of this group of people often does not live up to the promise of these policies. The specific situation of people with intellectual disabilities needs to be a focus for continued Government concern; this group's needs are often not adequately addressed in policy for people with disabilities in general, and the programmes intended for their benefit fail to produce significant results. People with intellectual disabilities continue to be placed in institutional care facilities, and the number of such placements is actually increasing, albeit more slowly than previously. Two-track systems in education and employment remain established, educating people with intellectual disabilities in special schools and employing them in sheltered workshops. Initiatives to encourage a more integrated approach to education have not been in place long enough to assess their overall effectiveness, but these measures already appear inadequate to meet the specific needs of people with intellectual disabilities. Likewise in employment, Government programmes appear insufficient to increase the number of people with intellectual disabilities working on the open market. The Netherlands must ensure that its high standards of protection and pledges of equal treatment are realised for people with intellectual disabilities, as they are for all of Dutch society.

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<sup>1</sup> The term "intellectual disability" (also described as "learning disability" or "mental retardation") here refers to a lifelong condition, usually present from birth or which develops before the age of 18. It is a permanent condition that is characterised by significantly lower than average intellectual ability and results in significant functional limitations in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills.

### *Background*

The Netherlands is a party to most major human rights conventions, which become binding upon ratification. However, it has yet to ratify the Revised European Social Charter and the Additional Protocol to the European Social Charter establishing a system of collective complaints. The Constitution guarantees equal protection, while supporting legislation comprises one of Europe's most advanced and established anti-discrimination frameworks. Recently enacted legislation on equal treatment for Chronic Illness and Disability brings the Netherlands into line with the EU Employment Directive; the act currently extends only to the employment and vocational sphere, but its scope could be enlarged to cover other areas such as primary and secondary education. An Equal Treatment Commission is responsible for deciding claims based on the Equal Treatment Acts, and although it cannot issue binding decisions its judgments are usually followed by the courts. The Commission acts as the independent body for the promotion of equal treatment required under General Equal Treatment Act as well as the Equal Treatment on the ground of Disability and Chronic Illness Act.

Although various laws and policies use different terminology to refer to people with intellectual disabilities, assessment procedures employ internationally accepted definitions (DSM-IV) for *mild*, *moderate*, and *severe* intellectual disabilities, based on IQ levels. There are a number of different procedures for assessing eligibility for various forms of education, social welfare benefits, and supported or sheltered employment. There appear to be no serious issues related to guardianship status among people with intellectual disabilities; a number of custodial arrangements exist, ranging from full (*plenary*) guardianship to more limited forms of supervision or control.

### *Access to education*

Children with intellectual disabilities are required to attend school unless they have been granted an exception, which is often the case for people with a very low developmental age. A two-track educational system exists for children with intellectual disabilities, who may either be placed in a mixed school system, which is organised in local networks that include both mainstream and special schools, or in the special school system, in which students are grouped into one of four "clusters" according to their diagnosis. There are waiting lists for children seeking to be placed in the special education system, largely due to the extensive testing that is required for admission. Generally, concerns regarding the assessment process centre on the waiting periods and the bureaucratic requirements which must be met by schools and parents.

Since August 2003, children who received a special education assessment are eligible for pupil-specific funding known as the "backpack". Parents may use this funding to cover the cost of educational support if they let their children attend a school in the regular education system. It is lower for children with intellectual disabilities than for children with other types of disabilities, and parents' discretion over its use is limited. Other State funding distributed to school networks to support children with special

needs is insufficient to provide adequate services. The inadequate level of support in mainstream schools may be one reason that parents are choosing to enrol their children with intellectual disabilities in the special school system. These special schools also benefit financially from increased enrolment. Early intervention (for children aged 0-4) is not a guaranteed right in the Netherlands, but a variety of services, both in day centres and at home, is available throughout the country. It is unclear whether these services are effective in preparing children for education in an inclusive environment, however.

The Netherlands has received EU funding, mainly from the EQUAL programme and the European Social Fund (ESF), to develop vocational training and secondary school programmes for children with intellectual disabilities. However, a substantial proportion of these funds have not been utilised, due to a lack of government co-funding and limited capacity of local schools to access the funds. The Dutch policy “Back to School Together” promotes a more inclusive approach to education; under this programme, certain schools for special education have been brought into the mixed school system, and the “backpack” funding package has been established. Fundamentally, however, the segregated two-track system remains the basis of educational options, and the Government should shift its approach towards an authentic inclusion policy. Moreover, parents and advocates have not been satisfied by the extent to which their input and needs have been incorporated into educational policy. Children with autism, for example, make up the largest group of children who do not attend school, but no specific policy has been directed towards the needs of this group.

Individual schools determine the curricula to be used in the classroom, in line with general goals elaborated by the Government. The Education Inspectorate has found that in many cases, materials and lessons are not adequately adapted for use with children with intellectual disabilities. Teachers receive only limited training for teaching such children, and in-service training is optional.

Although recent policy developments are phrased in the language of inclusion, the Dutch education system remains largely non-inclusive. Thus, the education system does not yet meet the aims of the UN Standard Rules and the Salamanca Statement. In fact, inclusion of children with intellectual disabilities in inclusive settings remains low, and even the goal for inclusion of children with disabilities through the “backpack” funding system over time is only 25 per cent of the population of all children with disabilities. The maintenance of two separate systems, even with the introduction of pupil-specific financing, is not compatible with inclusion.

In 2003, there were some 16,000 children with intellectual disabilities enrolled in special schools, but fewer than 900 students with intellectual disabilities who were considered eligible for the special school network had been enrolled in mainstream schools. Parents and official inspectors have raised concerns regarding the support children with intellectual disabilities receive in mainstream schools, but families of children placed in mainstream settings generally report a positive result. Enrolment in



the special school network has been on the increase, however, for reasons not entirely clear. Inspectors have also indicated that several aspects of special education, such as curricula and goal setting, were inadequate.

Education outside the school system is extremely limited in the Netherlands. Home schooling is not generally permitted, although as many as 2,000 children with disabilities may remain at home without educational options. Children in institutions, who are generally considered to have very low developmental ages, may be exempted from educational requirements; otherwise, children in institutions have the same rights and access to education as those living outside institutions.

### *Transition from education to employment*

Support for students with intellectual disabilities in secondary and vocational schools has been reduced, and there are plans to modify other benefits that would limit the already inadequate funding available for such students. With such insufficient support, as many as 18,000 students with disabilities may leave school annually without a diploma. While special secondary schools have a poor record of preparing students for work on the open market, pre-vocational practical programmes are successfully placing graduates in open-market employment.

### *Access to employment*

The Equal Treatment on the Grounds of Disability and Chronic Illness Act, adopted in 2003, brought the Netherlands fully into compliance with the EU's Employment Directive. The Act covers all aspects of the employment process, including hiring and placement. An extensive legislative framework establishes a range of benefits and services available to most people with intellectual disabilities. Many benefits include support for finding employment. Each employment-related benefit requires an assessment process, which also includes an assessment of capacity to work in a sheltered or supported setting. Although the regulations governing the assessment process require the team conducting the procedure to focus on individual capacity, it appears that often assessments focus on disability and take a medical approach. There have also been concerns about a lack of coordination among relevant agencies. Studies suggest that social welfare benefits may be too low for people with intellectual disabilities to support themselves without other sources of income, mainly from family.

As in the education field, EU funding to support employment of people with intellectual disabilities has been under-utilised. Both the EU's own application procedures, including age restrictions which many see as too high, as well as a lack of support for local governments wishing to apply for funding, contribute to the EU funds going unspent. Government policy has been shifting towards encouraging people with disabilities to support themselves, and to offer incentives for employment. There is no quota system in the Netherlands; the Government has urged employers to adopt voluntary two-percent hiring targets for people with disabilities, but it is unclear if this system is monitored in any way. A number of subsidies are available to employers who

hire people with disabilities, including training and job coaching support. However, the number of people with intellectual disabilities who are in fact employed on the open market remains very small.

In the Netherlands, the number of people with intellectual disabilities able to access either supported employment<sup>2</sup> or sheltered employment is relatively high; around 45 per cent of the estimated 73,000 adults with intellectual disabilities. The majority of people with intellectual disabilities who are employed work in sheltered employment, while many others have employment-like occupation in day centres. Only four per cent of people with intellectual disabilities participate in supported employment, although a much larger proportion has applied for such support under the relevant programmes. The Government has allocated substantial funds towards helping young people with disabilities to find work on the open market, but in some cases local government has been reluctant to implement supported employment policies. In contrast, sheltered employment is well established in the Netherlands; where workers are under contract, they receive pay on a scale negotiated through collective bargaining, and have the opportunity to build skills. However, few people do make the transition from sheltered work to employment on the open market, and despite reductions in waiting lists, the demand for sheltered work still exceeds the available places.

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<sup>2</sup> Supported employment is an employment option that facilitates competitive work in integrated work settings for people with disabilities. It provides assistance such as job coaches, transportation, assistive technology, specialised job training and individually tailored supervision.

## RECOMMENDATIONS

### General Recommendations

#### *International standards*

1. The Netherlands should ratify the Revised European Social Charter of 1996 (ESC) and should bind itself to Article 15 of the charter, on the right of persons with disabilities to independence, social integration and participation in the life of the community. It should also ratify the Additional Protocol to the European Social Charter establishing a system of collective complaints.

#### *Legislation*

2. The Government should ensure that the proposed Social Support Act, which is intended to streamline and further decentralise support services for people with disabilities, specifies the services that municipal governments may not fail or refuse to provide and guarantees that people with intellectual disabilities have the right to participate in social life to the greatest extent possible.

### Recommendations on education

#### *Legislation*

3. The Government should propose expanding the scope of the Equal Treatment on the Grounds of Disability and Chronic Illness Act to include primary and secondary education.

#### *Early Intervention*

4. The Government should establish the right to early intervention, and ensure that such services are carefully monitored to ensure educational quality.

#### *Reform of the special education system*

5. The Government should take steps to abolish the special education system, and the funding which now goes to special education should be given directly to mainstream schools to support children with disabilities.
6. The Ministry of Education should ensure that the Regional Expertise Centres are focused and equipped to support the education of children with special educational needs in mainstream schools.
7. The Government should take steps to give all children the right to attend a mainstream school (public or parochial).

### *Funding*

8. The Government should make student-specific funding available for post-secondary education, including vocational education.
9. The Government should ensure that children with disabilities have the right to receive both person-specific financing from the health care sector (*Persoonsgebonden budgetten*) and pupil-specific financing from the education sector (*Leerlinggebonden financiering*). If pupil-specific funding fails to provide individual therapy and support, person-specific funding should be available to facilitate the educational success of the pupil.
10. The Government should encourage and support secondary schools to access ESF and EQUAL monies for use in preparing high school students with intellectual disabilities for employment.

### *Teacher training and resources*

11. The Ministry of Education should make effective educational materials widely available for use in mainstream schools in order to support teachers and thereby allow more children with intellectual disabilities to effectively participate in regular school settings.
12. The Ministry of Education should provide initial and in-service training and support to teachers in using adaptive teaching methods.

### *Standards and monitoring*

13. The Ministry of Education should develop national standards for adaptive education training and establish appropriate monitoring of such standards.

## **Recommendations on transition from education to employment**

14. The Ministry of Education should establish a programme to facilitate the transition to employment, in which the last two years of special education should be spent in a minimum of four to six work placements with diverse employers, with support provided by school personnel trained to provide employment support.

## **Recommendations on employment**

### *Employment targets*

15. The Government should serve as a role model for other employers by hiring people with intellectual disabilities for Government posts.
16. The “social partners” involved in negotiating collective bargaining agreements should make binding agreements to hire persons with intellectual disabilities in the respective employment sector.

*Access to EU funds*

17. The national Government should encourage and support employer organisations and municipalities to apply for ESF and EQUAL financing for employment projects for people with intellectual disabilities.

*Access to social welfare and other benefits*

18. The Government should propose amendments to make Supported Employment benefits under the Reintegration Act and under the Sheltered Employment Act more flexible and interchangeable so that people with intellectual disabilities can qualify for the one or the other more quickly.
19. The National Social Welfare Benefits Administration Office should assign its employment integration specialists with particular experience working with clients with intellectual disabilities to work actively with municipal governments, to maximise the employment opportunities for people with intellectual disabilities via both the Reintegration Act and the Sheltered Employment Act.
20. The Ministry of Social Affairs and Employment should make available a life-long, person-specific integration/participation budget, which can be applied in both employment settings and day activity settings at the discretion of the recipient.
21. The Government should propose amendments to ensure that people with intellectual disabilities who qualify for Youth Disability Act benefits never lose the right to reinstatement of those benefits if it later emerges that they cannot hold down a job.
22. The Ministry of Social Affairs and Employment should reassess benefits policy to ensure that people with disabilities never earn less by working than by not working, as is now sometimes the case where income from employment can lead to disqualification from certain benefits and an increased personal contribution to care costs.

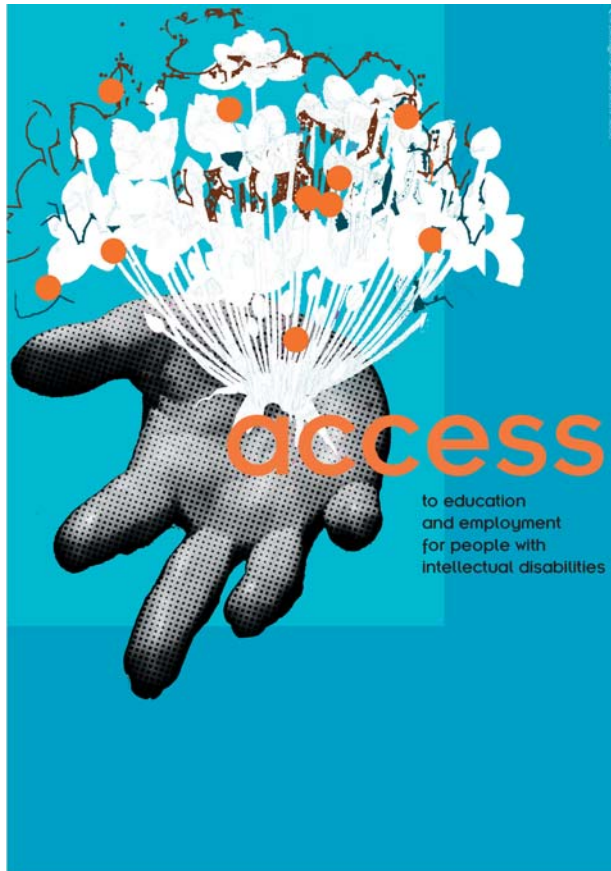
*Day centre activities*

23. The Government should establish an oversight mechanism to monitor and encourage qualitatively good employment-like activities in day activity centres.
24. The Ministry of Public Health should ensure that personnel in adult day centres receive training and support in combining care tasks with employment-like activities.
25. Adult activity centres should be stimulated to focus more on paid employment, and adult day programmes with effective employment projects should be financially rewarded for their success.



Throughout Europe, people with intellectual disabilities face overwhelming stigma and prejudice and encounter significant barriers to realising their fundamental rights. EUMAP, the EU Monitoring and Advocacy Program of the Open Society Institute, in cooperation with the Open Society Mental Health Initiative, has monitored this situation in 14 countries throughout Europe, both EU members and candidate countries: *Bulgaria; Croatia; the Czech Republic; Estonia; Greece; Hungary; Latvia; Lithuania; the Netherlands; Poland; Romania; Slovakia; Slovenia* and *the UK*. Carried out by local experts and civil society groups, the monitoring focuses on the extent to which people with intellectual disabilities have access to education and employment. This series of reports presents the findings of the monitoring and also makes recommendations for improving the social inclusion of people with intellectual disabilities.

The summary reports resume the main findings – Executive Summary and Recommendations – of each of the country reports. The complete set of country reports, in English and translated to national languages, can be accessed online at: [www.eumap.org/topics/inteldis/reports](http://www.eumap.org/topics/inteldis/reports). Hard copies can be ordered at: [www.eumap.org](http://www.eumap.org).



OPEN SOCIETY INSTITUTE  
EU MONITORING AND ADVOCACY PROGRAM



OPEN SOCIETY INSTITUTE  
MENTAL HEALTH INITIATIVE

# Rights of People with Intellectual Disabilities: Access to Education and Employment

Summary Reports

*Poland*

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## EXECUTIVE SUMMARY

Throughout Europe people with intellectual disabilities<sup>1</sup> face major stigma and prejudice and are confronted with significant barriers to realising their fundamental human rights. Discrimination against people with intellectual disabilities is deeply rooted and widespread, standing in the way of positive change. Providing real access to education and employment for people with intellectual disabilities is critical to ensuring that they can live and work in the community as equal citizens. There is a strong link between education and employment: without access to adequate education, people with intellectual disabilities cannot secure meaningful employment. This denial of access leads to life long dependency, poverty and social exclusion adding to the stigma of intellectual disability. This monitoring report focuses specifically on the areas of education and employment because of their importance to people with intellectual disabilities, and because of the existence of both international standards and national legislation that specifically address them.

For people with intellectual disabilities in Poland, access to inclusive education and to any kind of employment remains highly limited. Most children with intellectual disabilities receive education in a segregated environment and are not able to attend a mainstream school. A very positive development is the increasing number of children with intellectual disabilities attending an integrated school, where children with intellectual disabilities are educated alongside children without disabilities. However, at present there are not enough schools to meet the demand from parents. Children with intellectual disabilities do not leave school with the skills they need to access employment. Very few are employed on the open market and there is no framework for supported employment in Poland. As yet, the Government has not done enough to create programmes and initiatives specifically promoting the employment of adults with intellectual disabilities.

### *Background*

Poland has ratified most international human rights instruments, including those with provisions relating to the rights of people with disabilities. However, Poland has yet to sign and ratify the revised European Social Charter; or to sign and ratify Protocol No. 12 to the Protection of Human Rights and Fundamental Freedoms (ECHR). The Polish Constitution, as well as other legislation, provides a general protection from discrimination and guarantees care and integration into social life for people with disabilities. The Act on Vocational and Social Rehabilitation and Employment of Persons with Disabilities (hereafter, Act on Rehabilitation) regulates the vocational and

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<sup>1</sup> The term “intellectual disability” (also described as “learning disability” or “mental retardation”) here refers to a lifelong condition, usually present from birth or which develops before the age of 18. It is a permanent condition that is characterised by significantly lower than average intellectual ability and results in significant functional limitations in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills.

social rehabilitation of people with disabilities, but people with intellectual disabilities are specified in very few regulations.

There is lack of specific data on people with intellectual disabilities in Poland. It can be estimated that there were approximately 130,000 adults with intellectual disabilities in Poland in 2002. This figure includes only those with legal disability status, aged 16 or over, living in households; those living in institutions are not included. Precise data on children is not available. Poland has adopted the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders definition of intellectual disability and the term "mental retardation" is used most frequently in legislation. There are different procedures for the diagnosis and assessment of intellectual disability for educational purposes (for children); employment (for adults); and access to social benefits (for adults and children). For educational purposes, children are diagnosed with one of four levels of intellectual disability (*mild, moderate, severe and profound*). For employment purposes, disability is assessed by the Social Insurance Institute, which determines the right to social benefits, and by Disability Assessment Boards, which establishes legal disability status. For children and adults with intellectual disabilities, legal disability status can only be awarded for those with disabilities of at least a *moderate* level.

In Poland, a significant number of people with intellectual disabilities are placed under guardianship. However, the assessment procedures for placing people with disabilities under guardianship are often not sufficiently comprehensive and the courts usually impose *plenary*, rather than *partial*, guardianship for people with intellectual disabilities. Guardianship does not represent a barrier to employment, as people under plenary guardianship retain the right to work. However, the protection of people under guardianship remains inadequate, as wards do not have access to the legal or other support needed if their guardian violates their rights.

### *Access to education*

The Constitution and other legislation recognise the universal right to education but there is no anti-discrimination legislation which applies specifically to education. The education system is regulated by the Act on the Education System. This includes provisions on children and young people with disabilities, including the right to education at any type of school and to individual teaching, curricula and classes. Cases of discrimination in education can be brought to the Ombudsman or the Children's Rights Ombudsman. Integration is both legislated and encouraged, and various schooling options are available for people with intellectual disabilities. These include mainstream, integrated and special schools, individual teaching (home schooling), remedial classes and education in institutions. Schools are under the responsibility of local authorities and counties. Most funding is from the State budget in the form of educational subsidies, calculated according to a per-capita allowance on the principle of "funds follow the student". However, there has been criticism that the weighting system for children with intellectual disabilities does not allocate enough funding to

meet the real needs of some students. Moreover, the local authorities do not always make budget allocations according to these per-capita regulations, further disadvantaging students needing extra support.

While there are positive examples of early intervention services operated by NGOs, at present there is no formalised (governmental) system of early intervention. Early intervention services are available in medical centres, non-governmental early intervention centres and psychological-educational counselling centres. However, parents are not always aware of these services, which are also under funded and not readily available to children in rural areas. Bureaucracy can present an additional barrier for many parents.

Assessments of disability for educational purposes are carried out in psychological-educational counselling centres by a multidisciplinary team of specialists. These make evaluations of a child's need for remedial classes, individual teaching, or special education (including the form of special education to be provided). Although parents or guardians have the right to challenge an assessment or request a reassessment, in practice few actually exercise this right. Consequently, although the law provides for the transfer of students from special to mainstream education, in practice this rarely happens. The quality of assessment varies, as many centres are understaffed and overworked, and equipment for therapy and diagnosis is often inadequate. There is evidence that in some cases the local authorities have compelled the counselling centres to prescribe forms of education that were available within the county, rather than making a recommendation corresponding to the actual needs of the child.

Poland acceded to the European Union (EU) on 1 May 2004 and will now receive EU Structural Funds. A proportion of these funds will be directed towards programmes for people with disabilities, including on education. However, at present it is too early to assess the impact of these new funds. The reforms of the education system initiated in 1999 have also included special education, although with a significant delay in comparison with other areas of the education system.

As of 2004, one year of pre-school education is obligatory for all children. At this stage, however, it is unclear how this will be organised for children with intellectual disabilities, especially in rural areas. At the primary and lower secondary levels, although children with intellectual disabilities are increasingly being integrated into the mainstream education system, the majority still attend special schools. In 2002–2003, there were a total of 61,677 students with intellectual disabilities in special schools (not including secondary schools) for students with intellectual disabilities. However, special schools suffer from significant under-funding, which has resulted in cutbacks in staffing levels and spending on educational resources, and is leading to their progressive closure. Special schools for children with *mild* intellectual disabilities follow the same programme principles of general education as mainstream schools, but the curriculum is adapted to the students' abilities. Special schools for students with *moderate/severe* intellectual disabilities have separate programme principles of general education. The

quality of special education depends very much on the school and there are sometimes waiting lists for schools with a good reputation.

One of the most promising developments for the inclusive education of children with intellectual disabilities is the growth of integrated schools, in which children with disabilities are taught in the same class as children without disabilities, with the support of additional educators. In 2002–2003, over 4,000 students with (mostly *mild*) intellectual disabilities were enrolled in such schools, which provide quality education for both children with and without disabilities. The number of integrated schools is far too inadequate to meet needs, particularly at secondary level, and parents must compete to secure places for their children. In 2002–2003 there were 34,751 students with intellectual disabilities in mainstream schools (including those in integrated schools). However, the conditions in mainstream schools often do not meet the particular special needs of children with intellectual disabilities, as they are not provided with the support they require. In particular there are not enough specialists to provide support, and teachers do not receive adequate training in disability issues. There is also a lack of flexibility and the curricula are not adequately adapted to the individual needs of the child. Integrated education is more difficult at the secondary school level, particularly for children with *moderate* intellectual disabilities. At present, the educational needs of children with autism are not adequately met in either mainstream or special schools (some of which exclude children with autism). Generally, students with intellectual disabilities start out in integrated schools, but transfer to special education as they get older.

Education outside the education system is provided through individual teaching, and in remedial classes and residential institutions. In 2002–2003, almost 15,000 children with disabilities received individual teaching (home schooling), but the number of children with intellectual disabilities is not known. Individual teaching is intended as a temporary solution for children with severe health problems, but in some cases it can be assigned to meet the needs of the system rather than the needs of the child. Many children remain in individual teaching throughout their school education. Recently introduced Government regulations on individual teaching have been widely criticised for reducing the possibility for home schooled children to attend at least some classes at a school. Remedial classes provide education for children and young people with *profound* intellectual disabilities. These can be organised with the education system (in kindergartens and schools), in special educational care centres, non-governmental remedial centres, social care homes, community self-help homes or medical care centres; or at the child's family home. In some cases, there is a lack of organisation and supervision of remedial classes and an insufficient number of specialists to organise classes. However, many non-governmental remedial centres, such as those provided by the Polish Association for Persons with Mental Handicap (PAPMH), provide a positive learning environment for this group of children.

Education for children with intellectual disabilities is also provided in social welfare homes, special educational care centres and education care centres. In 2002 there were

over 20,000 children with intellectual disabilities in special education centres and education care centres; the precise numbers in social welfare homes are not available. By law, social welfare homes must provide access to education. Children with *profound* intellectual disabilities in social welfare homes attend remedial classes at the home, while children with *mild, moderate* and *severe* intellectual disabilities attend a special school at the home, or a neighbouring special school. Special education care centres are boarding schools where both boarders and non-boarders receive education at various levels. Education care centres do not include a school, but they must nonetheless provide education. Education care centres and special education care centres have for some time been inadequately regulated. New regulations on special education care centres have now been proposed, but have been criticised as insufficient. The Ombudsman has particularly highlighted the fact that many children from disadvantaged families are unnecessarily placed in special education care centres, and that insufficient effort is made to seek more appropriate alternatives for these children. There is also a lack of adequate coordination between the Ministry of National Education and Sport and the Ministry of Social Policy, which both have responsibilities with respect to children in these centres.

### *Transition from education to employment*

In 2004, almost 18,000 students with intellectual disabilities were receiving vocational training and education. Most were students with *mild* intellectual disabilities, who continue their education in special vocational schools. However, courses taught at these schools rarely correspond to the needs of the labour market and even those students who complete such vocational education are often not integrated into the workforce. School-leavers with *mild* intellectual disabilities, who as adults do not meet with the criteria for legal disability status, face particular problems in competing for employment on the open market. The employment services (including employment counselling) provided through the labour offices are not well adapted to the special needs of people with disabilities, so few access these services. The “Junior Programme” is an interesting new initiative intended to enable school-leavers with disabilities to take up apprenticeships. However, the number of apprentices taken on so far is quite low and it is likely that very few of these are people with intellectual disabilities. The fact that those receiving social benefits would have to suspend their entitlements to be eligible for this programme is likely to be the main reason for this. People with intellectual disabilities are effectively excluded from continuing education and their opportunities for rehabilitation are also limited. As a result, after completing school, a large number of young people with intellectual disabilities are not able to participate in any kind of activity or work and so just remain at home.

### *Access to employment*

Polish law guarantees the right to work and to choose a profession. Recent legislation has strengthened protection against discrimination in employment, or in access to vocational training and counselling, for people with disabilities. Poland has fully

transposed the provisions of the EU Employment Directive into national legislation. The Act on Rehabilitation regulates the rehabilitation and employment of people with disabilities. It provides a definition of disability and provisions concerning the assessment of disability. The Government Plenipotentiary for Disabled Persons' Affairs is responsible for supervision of the tasks arising from the act.

The assessments of disability carried out by the Social Insurance Institute and Disability Assessment Boards are both based on medical examination and carried out by a team of specialists. There are no clear rules for carrying out the assessments, which are often open to individual interpretation and do not answer the specific needs of people with intellectual disabilities.

The Disability Assessment Boards determine legal disability status and (for adults) the degree of disability (*low, moderate or significant*). However, the definitions of the degrees of disability set out in the Act on Rehabilitation are discriminatory and not in line with international standards, in that they presume incapacity to work is automatically linked to the ability to lead an independent life. As a result, people who may not be able to lead an independent life automatically receive a recommendation for therapy only, and not for employment. The certificates issued by the boards can be stigmatizing and superficial, and do not specify the kind and degree of support that is essential. Adults assessed by the boards as having a moderate or significant degree of disability and are considered only able to work in a sheltered workplace, although they may also work in non-sheltered employment conditions if the work place has been approved as adapted to their needs. People with *mild* intellectual disabilities cannot receive legal disability status, which thereby excludes them from a number of legal protections.

The assessment of disability carried out by the Social Insurance Institute assesses the ability of the person with disability to work (partial or total inability to work) and to live independently. This assessment determines eligibility to social benefits and also the level of the benefits received. Most people with intellectual disabilities are fully reliant on social welfare benefits (either inability to work pensions or social pensions), but cannot register as unemployed or claim unemployment benefits. However, people with all degrees of disability nonetheless have the right to register at a labour office as seeking employment and use the employment services provided by the labour offices.

As an EU Member State, Poland receives EU Structural Funds, which will be used to improve the vocational and social rehabilitation of people with disabilities and improve their level of vocational preparedness and employability. The main way in which the employment of people with disabilities is encouraged is through the quota system. However, at present most employers prefer to pay into the State Fund for the Rehabilitation of People with Disabilities rather than engage a person with disabilities. Very few people with intellectual disabilities find work through this quota system. Local governments must also implement programmes to develop and maintain the employment of people with disabilities. Targeted programmes are also created and funded from the State Fund, although none of these are specifically addressed at people with intellectual disabilities. NGOs are closely involved in providing employment

opportunities for people with disabilities. In the past, they were rarely consulted on draft legislation, or on the development of targeted programmes, but recent legislation should improve coordination and partnership.

The current high level of unemployment in Poland has particularly affected people with disabilities, who are disadvantaged in entering the work force by the negative attitude of employers, co-workers and over-protective parents. Available statistics on people with intellectual disabilities reveal that most are unemployed on a long-term basis and that their levels of employment and economic activity fall well below that of even people with other types of disabilities. Very few are employed on the open market and there is no framework for supported employment in Poland.<sup>2</sup> There are only a very limited number of Government programmes which train and maintain people with disabilities in employment, such as the “Junior Programme”, but these are not adapted to the needs of people with intellectual disabilities. The best example of supported employment is one operated by an NGO, the Job Coach Project, initiated by the Agency of Supported Employment, in Wrocław.

Employers are supported in a variety of ways when they commit themselves to running one of two forms of sheltered employment: a sheltered workplace or an occupational workshop. The sheltered workplaces receive significant Government funding but employ relatively small numbers of people with intellectual disabilities, and then mostly those with a *mild* degree. These workplaces are segregated and do little to develop the skills needed for employment on the open market. The workplaces have also been criticised for inadequacies such as poor working conditions and mismanagement of funds, and it is also unclear whether they will meet recent EU requirements for sheltered employment. Occupational workshops are a new form of sheltered employment in Poland and provide employment to people with more significant disabilities. However, to date, Government funding for these workshops has been quite limited. A final option for people with intellectual disabilities is the occupational therapy workshops, which are day centres providing individual therapy, often run by NGOs or local authorities. They are not considered as employment, but provide participation in social and vocational rehabilitation. However, although these workshops have trained participants capable of employment, in most cases there is no work available for them.

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<sup>2</sup> Supported employment is an employment option that facilitates competitive work in integrated work settings for people with disabilities. It provides assistance such as job coaches, transportation, assistive technology, specialised job training and individually tailored supervision.



## RECOMMENDATIONS

### General recommendations

#### *Legislation*

1. Poland should sign and ratify the Revised European Social Charter (RESC) and should bind itself to Article 15 of the RESC (on the right of persons with disabilities to independence, social integration and participation in the life of the community).
2. Poland should sign and ratify Protocol No. 12 of the European Convention on the Protection of Human Rights and Fundamental Freedoms (ECHR).

#### *Data collection*

3. While respecting all relevant legislation on the protection of personal data, the Central Statistical Office should gather consistent, complete and continuous statistics on the situation of people with intellectual disabilities, including on their human rights. This should include people with *mild* intellectual disabilities who are currently excluded from statistical records on disability.

#### *Guardianship*

4. The Government should introduce regulations to specify that *plenary* guardianship should be imposed only under limited circumstances, so that wards can exercise their rights to the fullest possible extent.

#### *Deinstitutionalisation*

5. The Government should take steps to eliminate large social care institutions, which are a barrier to social inclusion and limit the residents' access to education and employment. Alternative forms of housing in the community should be made more widely available.

#### *Public awareness*

6. All public authorities, at both the national and regional levels, should in collaboration with NGOs and other organisations working with people with intellectual disabilities, initiate intensive action to change the social perception of the rights of people with intellectual disabilities and to increase public awareness of their situation.

#### *Coordination and support*

7. The Government should create a common strategy and rules of cooperation to improve coordination between the various ministries (the Ministry of National

Education and Sport; the Ministry of Social Policy; the Ministry of Economy and Labour; and the Ministry of Health) responsible for policy on people with disabilities, including those with intellectual disabilities.

8. The Government should prepare and implement a consistent and comprehensive programme of support for people with intellectual disabilities and their families. This should cover all periods of life (from early intervention to care of the elderly) and should include material, psychological and social support. The programme should aim to ensure that families receive comprehensive and reliable information on the forms of support available to them. The Government should coordinate with NGOs which are already providing elements of such a system.
9. The Ministry of Health, the Ministry of Social Policy and the Ministry of National Education and Sport should, in coordination with NGOs and other organisations working with people with intellectual disabilities, ensure that psychological support and counselling is made available to parents at all stages of the life of their child with intellectual disabilities.

## **Recommendations on transition from education to employment**

### *Vocational training*

10. The Ministry of National Education and Sport should ensure better organisation of vocational training in vocational schools.

### *Continuing education*

11. The Ministry of National Education and Sport, together with the Ministry of Social Policy, should ensure that formalised programmes of life-long education are created for adults with intellectual disabilities, including refresher courses and development of skills.

## **Recommendations on education**

### *Education policy*

12. The Ministry of National Education and Sport should develop clear guidelines and financing mechanisms to support mainstream educational opportunities for people with intellectual disabilities.
13. The Ministry of National Education and Sport should undertake a review of the form and concept of special education in Poland to promote inclusive education. New standards of education for children with disabilities should be introduced, with particular attention paid to adapting the education that is offered to the needs and potential of children with *mild* intellectual disabilities.

14. The Ministry of National Education and Sport should analyse the functioning of integrated schools and take steps to increase the number of such schools, in order to create more opportunities for the inclusive education and development of children and young people with intellectual disabilities.
15. The Ministry of National Education and Sport should review the practice of individual teaching (home schooling), such that these alternatives to inclusive education are only provided for those pupils whose health makes school attendance impossible or very difficult. The rules<sup>3</sup> limiting the possibility of conducting individual teaching at school should be changed.
16. The Ministry of National Education and Sport and the Ministry of Social Policy, should, as part of a general deinstitutionalisation programme, take strategic decisions about the concept and function of special education care centres and education care centres. Local schools should be enabled to provide education for children presently resident in centres, for example by developing integrated classes in mainstream schools.
17. As part of an overall deinstitutionalisation policy, the Government should ensure that students attending boarding schools are guaranteed by law certain standards of care and residence. Credible periodic evaluation of the need for the child to attend such a centre should be made and concrete action taken towards returning the child to the family.

### *Early Intervention*

18. The Government should make early intervention services widely available to children from birth to the age of three, with services provided by multidisciplinary teams.

### *Assessment for educational purposes*

19. The Ministry of National Education and Sport should comprehensively review and evaluate the guidelines for assessment bodies to ensure that the educational placement is based on the child's own abilities and needs.
20. The Ministry of National Education and Sport should ensure that assessments for educational purposes are changed from a one-time evaluation to a longer diagnostic process that combines observation with examination.
21. The education of pupils with intellectual disabilities should be based on individual programmes (education and rehabilitation) and be the subject of intense observation and evaluation by multidisciplinary teams.

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<sup>3</sup> Regulation of the Minister of National Education and Sport on the manner and course of organisation of individual teaching for children and young people, 29 January 2003, *Dziennik Ustaw* (an official journal – hereafter, Dz. U.) of 2003, No.23, item. 193.

### *Financing*

22. The Government should implement more effective controls to ensure that local governments comply with the “funds follow the student” approach when making education budget allocations.

### *Educational support*

23. The Ministry of National Education and Sport should ensure that specialists (in particular teachers in mainstream schools and specialists in psychological-educational counselling centres) are better prepared to work with people with intellectual disabilities, by improving the quality of education at university level.
24. The Ministry of National Education and Sport should encourage greater cooperation between teachers from mainstream, integrated, special schools, specialists in psychological-educational counselling centres, methodological consultants and other specialists.
25. The Government should ensure that children and young people with intellectual disabilities, and their parents and teachers, are provided with better access, at the level guaranteed by law, to psychological-educational support.
26. The Ministry of National Education and Sport should ensure that mainstream schools are adapted to be more flexible to carrying out individual programmes. Methods of work used in schools should include real preparation for students' contribution to social life.

## **Recommendations on employment**

### *Legislation*

27. The Government should undertake a review of how the EU Employment Directive has been adopted and interpreted in Poland, to ensure that its provisions are fully implemented with respect to the specific needs of people with intellectual disabilities.
28. The Government should introduce legislation on supported employment and establish a national system of supported employment.

### *Assessment of disability for employment purposes*

29. The Ministry of Social Policy should reform the assessment system of the Disability Assessment Boards used to grant disability status, to reflect internationally accepted standards and eliminate discriminatory provisions linking inability to work with disability status. In particular, the assessments should focus on the opportunities for people with intellectual disabilities to develop and live an active life, and the support required for them to achieve this.

*Employment policy*

30. The Government should review the current employment situation and level of vocational training of people with *mild* intellectual disabilities, to develop policy on integrating them into the labour market, as well as people with other levels of intellectual disabilities.

*Employment support*

31. The Government should improve the system of support for the employment of all people with intellectual disabilities, particularly those with a *moderate* and *significant* degree of disability.

*Social benefits*

32. The Ministry of Economy and Labour and the Ministry of Social Policy should assess the current system of eligibility for *inability to work* pensions and social pensions, and in particular current regulations which constitute barriers to access for some services aimed at vocational activity.
33. The Ministry of Social Policy should set the level of social benefits for people with intellectual disabilities having taken into account the costs of independent living, integrated into society. The level should allow for the higher costs of living an active life in society.
34. The Ministry of Social Policy should review the current situation of the right to inability to work pensions, for people who are *totally* incapable of working because of a disability developing before the age of 18 and who have the right to a social pension, with a view towards granting these people access to insurance pensions during employment.<sup>4</sup>
35. The Ministry of Social Policy should readjust the right to social protection of persons *partly* incapable of working because of a disability which developed before the age of 18, to increase eligibility for social insurance assigned on the basis of inability to work.<sup>5</sup>

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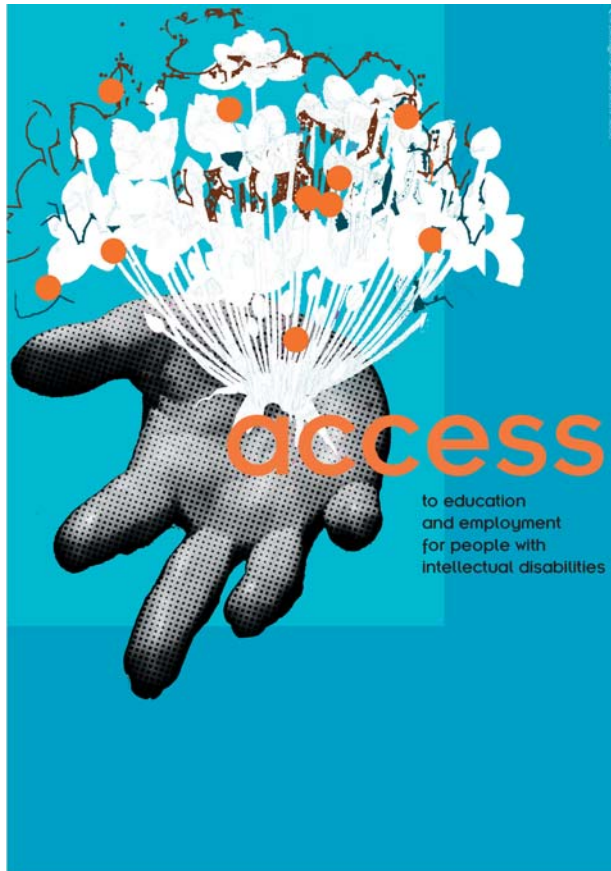
<sup>4</sup> At present, as these persons do not fulfil the third condition required in the Pensions Act – the specified period during which the disability appeared – when they are employed (and are paying compulsory social insurance), they do not have the right to a pension from insurance assigned on the basis of inability to work

<sup>5</sup> At present, these individuals do not have the right to social pensions, nor do they have the possibility of forming a pension from the social insurance assigned on the basis of inability to work. When they are employed and paying compulsory insurance, they still do not have the right to receive a pension from social insurance assigned on the basis of inability to work. This can happen only in the case of deterioration of health within the period of insurance (or no later than 18 months after that period), which is serious enough for the person to be assessed as totally incapable of working. Otherwise, in spite of insurance, the person would not have the right to social insurance assigned on the basis of inability to work.



Throughout Europe, people with intellectual disabilities face overwhelming stigma and prejudice and encounter significant barriers to realising their fundamental rights. EUMAP, the EU Monitoring and Advocacy Program of the Open Society Institute, in cooperation with the Open Society Mental Health Initiative, has monitored this situation in 14 countries throughout Europe, both EU members and candidate countries: *Bulgaria; Croatia; the Czech Republic; Estonia; Greece; Hungary; Latvia; Lithuania; the Netherlands; Poland; Romania; Slovakia; Slovenia* and *the UK*. Carried out by local experts and civil society groups, the monitoring focuses on the extent to which people with intellectual disabilities have access to education and employment. This series of reports presents the findings of the monitoring and also makes recommendations for improving the social inclusion of people with intellectual disabilities.

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# Rights of People with Intellectual Disabilities: Access to Education and Employment

Summary Reports

*Romania*

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## EXECUTIVE SUMMARY

Throughout Europe, people with intellectual disabilities<sup>1</sup> face major stigma and prejudice and are confronted with significant barriers to realising their fundamental human rights. Discrimination against people with intellectual disabilities is deeply rooted and widespread, standing in the way of positive change. Providing real access to education and employment for people with intellectual disabilities is critical to ensuring that they can live and work in the community as equal citizens. There is a strong link between education and employment: without access to adequate education, people with intellectual disabilities cannot secure meaningful employment. This denial of access leads to lifelong dependency, poverty and social exclusion, adding to the stigma of intellectual disability. This monitoring report focuses specifically on the areas of education and employment, because of their importance to people with intellectual disabilities and because of the existence of both international standards and national legislation that specifically address them.

Access to education and employment for people with intellectual disabilities in Romania remains severely limited. Despite the establishment of specialised bodies and the existence of legislation addressing the situation of people with disabilities, the specific needs of people with intellectual disabilities are often not recognised. With support from the European Union (EU), a promising action plan for reforming education towards a more inclusive approach has been elaborated; its implementation could achieve real improvement for people with intellectual disabilities. However, no such plan has been developed for employment. This is a serious shortcoming, as those people who would benefit from increased educational options might nevertheless find themselves without work or the means to support themselves. Increased coordination among the institutions addressing the situation of people with intellectual disabilities will be needed, to ensure that ambitious plans meet expectations and that real gains are made, to the benefit of all society.

### *Background*

Romania has ratified most major international conventions with provisions relating to the rights of people with disabilities, and the Romanian Constitution gives international law precedence over national legislation. In addition to Constitutional recognition of the right to special protection for people with disabilities, in the past several years, Romania has adopted comprehensive anti-discrimination legislation, which has recently been amended to cover discrimination on the grounds of disability. Nevertheless, the legislation falls short of the requirements of the EU anti-

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<sup>1</sup> The term “intellectual disability” (also described as “learning disability” or “mental retardation”) here refers to a lifelong condition, usually present from birth or which develops before the age of 18. It is a permanent condition that is characterised by significantly lower than average intellectual ability and results in significant functional limitations in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills.

discrimination *acquis*. A specialised body, the National Council for Fighting Discrimination, was established in 2002 to hear discrimination cases, but to date no cases related to people with intellectual disabilities have been brought before the council. The National Authority for Persons with Handicap (NAPH), a governmental body, is the highest administrative authority dealing specifically with issues related to people with disabilities; it has eight regional offices responsible for overseeing the implementation of disability policy.

The Romanian Constitution refers to the protection of “handicapped people”, and the word “handicap” is used in official law and policy, though experts agree that such terminology is outdated and stigmatising. There is no specific definition of intellectual disabilities used in legislation, nor are there discrete statistical data on the number and situation of people with intellectual disabilities. Consequently, various institutions collect statistical information on the basis of different criteria, and policy has been formulated without reliable, comprehensive data on the situation of people with intellectual disabilities. Of the more than 14,000 people living in institutions, the proportion with intellectual disabilities is not known. Importantly, however, available data does reveal that only a minority (28 per cent) of the approximately 52,000 children with disabilities “attend a type of education”. There is no official data on the number of children with intellectual disabilities who receive no education at all.

Diagnosis procedures for both children and adults use four-level classification systems in line with the international standards set in the World Health Organization’s International Classification of Diseases, Tenth Revision (ICD-10), but the use of several different reference works in the assessment process may lead to confusion and a lack of standardisation. Recent instructions from the Ministry of Health have helped to improve the consistency of diagnosis and classification. Despite these legal protections, many people with intellectual disabilities cannot exercise their basic rights. The only type of guardianship available in Romania is *plenary* guardianship, an overly restrictive system that does not allow for flexibility in addressing individual capacities and denies the enjoyment of civil rights to the fullest extent possible. Guardianship is not in itself a barrier to employment, as people under guardianship do not lose the right to work.

### *Access to education*

The Constitution guarantees the right to education to all Romanian citizens, and specific education legislation establishes that all children, regardless of the type or level of disability, have the right to education either in school or at home. While the legal framework sets out theoretical conditions for equal education for all, there is very little connection between the legally guaranteed right to education for people with intellectual disabilities and their actual access to education in practice. Thousands of children with intellectual disabilities are simply unaccounted for in terms of education.

Concerns have been raised that the assessment procedure, although conducted by an interdisciplinary team, may be superficial and result in children’s inappropriate placement in special schools, or even in alternative, informal educational services,

rather than in mainstream schools. In particular, the disproportionately high number of Roma children in special schools indicates that assessment process should be carefully monitored to ensure that individual capacity and potential are evaluated fully and without discrimination. Early intervention services are available only to the few families in Romania who are fortunate enough to live near the single NGO providing such support. Recent changes to relevant legislation may further hamper the development of similar community-based services, which are already too few to meet needs across the country.

The Romanian Government has adopted a National Strategy for people with disabilities that calls for inclusive educational policy and aims for allocation of resources based on the principle that “the funds follow the child”. The Ministry of Education has further elaborated an Action Plan of measures that, if implemented, hold the promise of real improvement for the education of children with intellectual disabilities. In particular, the recognition that children with *severe* and *profound* disabilities are also entitled to education and services is an important step forward in educational policy. The EU, through its Phare funds, and particularly the “Twinning Light” programmes, has supported the development of these national policies. However, while the European Commission has urged Romania to maintain its focus on the deinstitutionalisation process, the EU should also take into account the need to provide education for people in institutions who were previously denied education.

Although, in theory, Romanian law and policy support mainstream education for children with disabilities, and all children have the legal right to some form of schooling, in practice, mainstreaming of children with even *mild* intellectual disabilities is very limited, though there are no official figures. The majority of children with intellectual disabilities who attend school attend special schools, but even special schools exclude children with anything more than *mild* intellectual disabilities. Teachers receive little support, training and resources to promote an inclusive environment. The highly inflexible, curriculum-focused approach to education in Romania has been cited as a problem for children with intellectual disabilities. These children also require training in basic independent living skills, in addition to academic skills, to pave the way for social integration and self-sufficiency. An attempt to mainstream thousands of children from special schools in 1999 was not a success, as there was little preparation or support for inclusion in the long-term; many of the children have since returned to special schools. Special schools in Romania offer substandard education in the form of basic reading and counting skills, and thus fail to equip their students with genuine, marketable skills that would allow them to access employment after graduation.

Children found to lack the capacity to attend even a special school are legally entitled to home schooling, but in practice this rarely occurs as no Government funding is allocated to provide it. NGOs offer educational services to such children in some parts of the country, but these organisations can only operate on a very small scale. For many

children with *moderate* to *profound* intellectual disabilities, and for all adults in institutions, there are no educational options at all.

### *Transition from education to employment*

The outlook for people with intellectual disabilities after finishing school is generally bleak: there is little support for making the transition from education to employment. Vocational training is provided for in the law, but in fact, few people with intellectual disabilities acquire marketable skills that would lead to employment on the open market. Civil society initiatives offer training in some fields, but educational requirements for many professions are too high for most people with intellectual disabilities to meet. Opportunities for lifelong education are limited, even though basic “refresher” courses would be an important factor in helping people with intellectual disabilities to retain their skills and increase their chances of finding and maintaining employment.

### *Access to employment*

Romanian law guarantees the right to work and to choose a profession. While anti-discrimination legislation requires employers to adapt facilities to the needs of people with disabilities, in practice such accommodation is not enforced. The same multi-disciplinary committee determines both the capacity to work and eligibility for benefits; although there are frequent appeals regarding the level of disability, and the corresponding level of benefits, only a small fraction of these appeals are successful. The capacity to work is re-evaluated each year. Both the minimum wage and disability benefits are very low, giving little incentive for people with disabilities to seek employment, and, although some people with disabilities are eligible for unemployment benefits, it is not possible to receive both unemployment and disability benefits. Recently amended legislation may offer people with more severe disabilities the opportunity to retain some portion of their benefits while receiving a salary, but it is as yet unclear how effective this measure will be in encouraging employment.

The main mechanism the Government has put in place for improving the employment situation of people with disabilities is a quota system that requires companies and state agencies of a certain size to hire people with disabilities. Larger companies are required to make sure that four per cent of their employees are people with disabilities, but, in practice, employers evade compliance with quota requirements and avoid penalties by advertising positions with qualifications that no person with disabilities could meet. Companies that have a 30 per cent or higher level of employees with disabilities are eligible for various benefits, including tax exemptions. Legislation provides for the Government to pay the salary of employees with disabilities, but only for 18 months, after which the employer is under no obligation to retain the employee.

Romania has a high overall unemployment rate, making it even more difficult for people with intellectual disabilities to compete for jobs on the open market. Supported employment, in which people with intellectual disabilities work closely with a coach or

colleague on the job, has been an effective model for improving employment opportunities for people with intellectual disabilities.<sup>2</sup> A local NGO in Romania has helped a limited number of people to find work by offering this type of support, and the Government should look to the experience and practical knowledge developed by civil society in the development of national employment policy. There are no Government-operated sheltered workshops specifically for people with intellectual disabilities. A very limited number of NGO-operated workplaces do cater specifically to people with intellectual disabilities, but these function primarily as training and occupational facilities, and offer only a segregated working environment for people with disabilities.

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<sup>2</sup> Supported employment is an employment option that facilitates competitive work in integrated work settings for people with disabilities. It provides assistance such as job coaches, transportation, assistive technology, specialised job training and individually tailored supervision.

## RECOMMENDATIONS

### General recommendations

#### *International standards*

1. Romania should ratify Protocol 12 to the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR); International Labour Organization (ILO) Convention No. 159 on Vocational Rehabilitation and Employment (Disabled Persons); and the ILO Convention Concerning Vocational Guidance and Vocational Training in the Development of Human Resources 1975 (No. 142).

#### *Legislation*

2. The Government should ensure that anti-discrimination and other legislation in the disability area conforms to the European Union's Council Directive 2000/78/EC, the "Employment Directive".

#### *Data collection*

3. The Government, in cooperation with relevant institutions, should establish and maintain comprehensive centralised statistical data on people with intellectual disabilities. This data should be collated across all relevant sectors and should be used as a more accurate basis for policymaking in the areas of education and social and professional integration. In particular, data on the type and level of education of people with intellectual disabilities, and their employment situation, should be collected and analysed.

#### *Guardianship*

4. The Government should consider introducing a wider range of alternatives to *plenary* (full) guardianship, such as partial guardianship. People with intellectual disabilities should be able to exercise their civil rights to the maximum extent possible.

#### *Funding*

5. The Government should provide financial resources and support to encourage public-private partnerships at both the national and local levels, as an important means of incorporating the training and experience developed by NGOs into official policy and practice.
6. The Government should provide adequate resources for the timely implementation of the "National Strategy for the Special Protection and Social

Integration of Persons with Handicap in Romania”<sup>3</sup> and follow up with regular monitoring and evaluation of the implementation process.

### *Advocacy and cooperation*

7. Civil society should seek support to establish self-advocacy groups and work through the newly created National Disability Forum to improve advocacy at the national and international levels.
8. The Government should elaborate mechanisms for better cooperation among the actors involved in rehabilitation and social integration programs for people with intellectual disabilities, to ensure a holistic approach that includes appropriate measures to enhance and ensure coherent action and implementation of law and policy. These actors include: the NAPH; the Ministry of Health; the Ministry of Labour and Social Protection; the Ministry of Education, Research and Youth; the Ministry of Public Finance; and the relevant mental disability and human rights NGOs.

## **Recommendations on education**

### *Diagnosis and assessment*

9. The Government should assess the criteria and procedures for diagnosing intellectual disability for educational purposes, to evaluate whether language or cultural barriers may impede accurate assessment. The Government should also ensure that there is adequate monitoring of the diagnostic bodies' operation.
10. The Ministry of Health should take steps to establish a national programme for the early diagnosis of intellectual disabilities, using definitions and methodologies corresponding to international standards.
11. The Government should take steps to put in place a national network of early intervention services to provide multi-disciplinary support to families, infants and young children with intellectual disabilities, to lessen the effects of the child's condition and to maximise the child's development and inclusion.

### *Teacher training*

12. The Ministry of Education, Research and Youth must improve the quality of teacher training for teachers working in special schools and institutions and increase availability of teacher training for those educating persons with intellectual disabilities in the mainstream schools; all teachers should be included in these training programmes.

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<sup>3</sup> Government Decision HG 1215/2002 on the Approval of a “National Strategy for the Protection and Reintegration of Persons with Handicap in Romania”.



*Inclusive education*

13. The Ministry of Education, Research and Youth should develop detailed and consistent procedures for mainstreaming children with intellectual disabilities in regular schools, applying the principle that children with intellectual disabilities in mainstream schools must have access to all the support and resources that would be available to them in special schools. More individually appropriate and flexible curricula for students with intellectual disabilities should be introduced.
14. The Ministry of Education, Research, and Youth should ensure that all the children with intellectual disabilities are educated in an institution that is under the ministry's coordination. The Ministry has the obligation to organise education for people with intellectual disabilities in schools that are adapted in all possible ways to the educational needs of these people.
15. The Ministry of Education, Research and Youth should conduct monitoring to assess how many children with intellectual disabilities remain without access to education of any kind. Based on the findings of this monitoring, the ministry should immediately take steps to ensure that no child is denied an education.
16. The Government should organise public awareness campaigns, in collaboration with NGOs active in the field, to build public support for a more inclusive educational system and to highlight the importance of providing access to quality education for all children, regardless of any disability.

*Education in institutions*

17. The Government should ensure that while de-institutionalisation remains the main focus of the “National Strategy for the Special Protection and Social Integration of Persons with Handicap in Romania”, institutions must offer educational options for those people who must remain in residential care.

*Specialised support services*

18. The Ministry of Education, Research and Youth should ensure that specialized support services for children with severe intellectual and multiple disabilities are available in kindergartens and schools throughout the country, as these children currently have no access to education.

*Financing*

19. The Ministry of Education, Research and Youth should adopt a portable financing system for children with intellectual disabilities, allocating a personal budget to each child with special needs, to pay for the purchase of the appropriate services.

**Recommendations on the transition from education to employment***Vocational education*

20. The Ministry of Education, Research and Youth should provide curricular opportunities for people with intellectual disabilities to learn marketable skills,

and also to be trained in social skills, so that they can make the transition from education to employment in the open market.

### *Lifelong learning*

21. The Ministry of Education, Research and Youth should introduce legislation that supports lifelong education for people with intellectual disabilities, and in particular, offers educational services to people who were or are institutionalised.

## **Recommendations on employment**

### *Legislation*

22. The Government should support the introduction of improved legislation that would create greater employment opportunities for people with intellectual disabilities, and it should take steps to ensure existing hiring quotas for hiring people with disabilities actually result in the employment of people with intellectual disabilities.
23. The Ministry of Education, Research and Youth should introduce legislation for a more flexible system of job training for people with intellectual disabilities, in order to open certain jobs to people who are without a primary school diploma but who have completed appropriate vocational training.

### *Employment services*

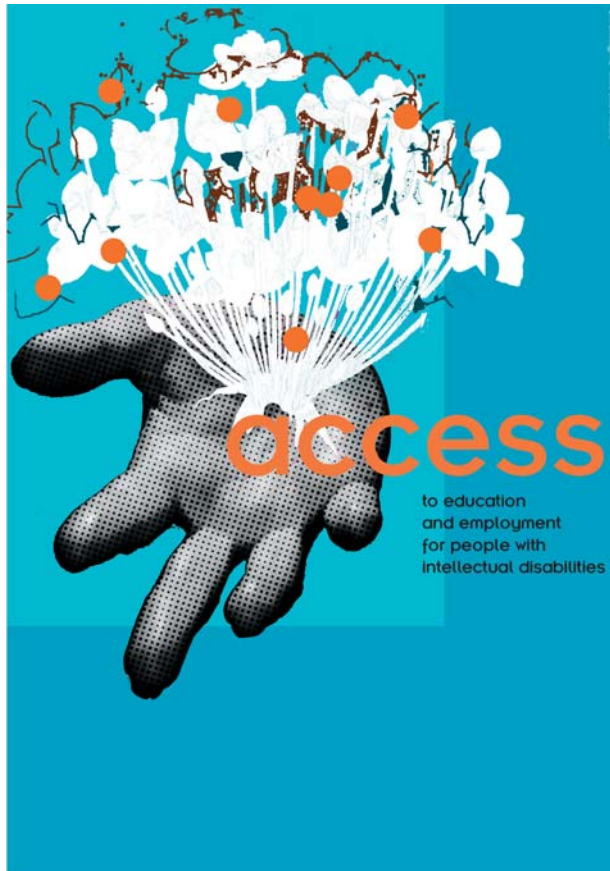
24. The Social Assistance Departments under the local authorities should establish services for adults with intellectual disabilities, to enhance their opportunities for employment on the open market. These services should include counselling services for families, workshops and employment centres, job searching and job coaching, supported employment services and community based residential services.
25. The Ministry of Public Finances should provide a solution for the payment of people with intellectual disabilities that work in day centres so that they do not have to pay taxes on their wages. The amount they receive are very low and taxation reduces the payment still further, to the point that they are insignificant.

### *Supported employment*

26. The Ministry of Labour, Social Solidarity and Family, through its specialised agency dealing with people with disabilities, the NAPH, should look to existing models of best practice in supported employment in Romania and seek to replicate those models in other parts of the country

Throughout Europe, people with intellectual disabilities face overwhelming stigma and prejudice and encounter significant barriers to realising their fundamental rights. EUMAP, the EU Monitoring and Advocacy Program of the Open Society Institute, in cooperation with the Open Society Mental Health Initiative, has monitored this situation in 14 countries throughout Europe, both EU members and candidate countries: *Bulgaria; Croatia; the Czech Republic; Estonia; Greece; Hungary; Latvia; Lithuania; the Netherlands; Poland; Romania; Slovakia; Slovenia* and *the UK*. Carried out by local experts and civil society groups, the monitoring focuses on the extent to which people with intellectual disabilities have access to education and employment. This series of reports presents the findings of the monitoring and also makes recommendations for improving the social inclusion of people with intellectual disabilities.

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## EXECUTIVE SUMMARY

Throughout Europe people with intellectual disabilities<sup>1</sup> face major stigma and prejudice and are confronted with significant barriers to realising their fundamental human rights. Discrimination against people with intellectual disabilities is deeply rooted and widespread, standing in the way of positive change. Providing real access to education and employment for people with intellectual disabilities is critical to ensuring that they can live and work in the community as equal citizens. There is a strong link between education and employment: without access to adequate education, people with intellectual disabilities cannot secure meaningful employment. This denial of access leads to life long dependency, poverty and social exclusion adding to the stigma of intellectual disability. This monitoring report focuses specifically on the areas of education and employment because of their importance to people with intellectual disabilities, and because of the existence of both international standards and national legislation that specifically address them.

In Slovenia, the number of children with intellectual disabilities able to access education in an integrated environment has not improved significantly in recent years. The integration process is still at an early stage and needs to be expanded to also include children with more severe intellectual disabilities. In particular, the ongoing process of deinstitutionalisation should be speeded up, in order to provide, throughout the country, community care alternatives to placing children with intellectual disabilities in residential institutions. The access to employment of people with intellectual disabilities in Slovenia remains extremely minimal; almost none have any kind of employment or work. Among the main barriers to their employment is legislation, which, for adults with more severe intellectual disabilities, links the right to disability benefits with a status that precludes them from accessing employment.

### *Background*

Slovenia has ratified all the main international instruments, including those pertaining to people with disabilities, and has also implemented EU directives in this area, but has yet to ratify Protocol No. 12 to the European Convention on Human Rights and Fundamental Freedoms (ECHR). The Constitution has been supplemented by the Act on the Implementation of the Principle of Equal Treatment 2004, which entered into force on 7 May 2004 and has significantly enhanced the legislative framework for anti-discrimination in Slovenia. Both acts include disability as a specific prohibited ground of discrimination, although the exact term used in the Constitution is “invalidity”. Slovenia has transposed into national legislation the provisions of the EU Race

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<sup>1</sup> The term “intellectual disability” (also described as “learning disability” or “mental retardation”) here refers to a lifelong condition, usually present from birth or which develops before the age of 18. It is a permanent condition that is characterised by significantly lower than average intellectual ability and results in significant functional limitations in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills.

Equality Directive and the EU Employment Directive. However, Slovene legislation continues to use outdated and stigmatising terms both with respect to people with disabilities in general and to people with intellectual disabilities. NGOs have also advocated for amending legislation that refers to adults with more severe intellectual disabilities as “children”. There is no common definition of intellectual disability.

The status of people with disabilities is mainly determined by the Placement of Children with Special Needs Act 2000 (Placement Act); the Act on the Social Care of Mentally and Physically Disabled People 1983 (Social Care Act); and the Act on the Vocational Rehabilitation and Employment of People with Disabilities 2004 (Vocational Rehabilitation Act). The Social Care Act is discriminatory, in that adults given “invalid status” under this act have the right to receive social benefits, but are automatically presumed as unable to live independently or to be employed regardless of their actual abilities. If they wish to work, they must renounce the “invalid status” and so lose their eligibility for social benefits.

There are different procedures for the diagnosis and assessment of intellectual disability for educational purposes (for children), for employment purposes (for adults) and for access to social benefits (for adults). For educational purposes, Placement Commissions are responsible for diagnosing children with one of five levels of intellectual disability (*borderline, mild, moderate, severe* and *profound*). The *borderline* level is only used for children. Since May 2004, new Rehabilitation Commissions are formally responsible for assessing the working capacity and employability of adults with *mild* intellectual disabilities. Adults with *moderate, severe* or *profound* intellectual disabilities receive “invalid status” under the Social Care Act and most are also placed under guardianship by the courts. This can prove to be a significant barrier to employment as those under *plenary* guardianship lose all their civil and economic rights, and so are completely denied access to employment. Recently, however, the courts have begun to more frequently award extended parental guardianship or *partial* guardianship, under which the courts can permit the person to work.

There is no national system for the regular and comprehensive collection of statistics on people with intellectual disabilities and data on adults with intellectual disabilities (in particular those with a *mild* level) is inconsistent and incomplete. However, detailed statistics on children with intellectual disabilities are available from information on school placements and receipt of social benefits. These reveal that the number of children diagnosed with intellectual disabilities has fallen significantly over the last decade, from 6,245 children in 1990 to 3,351 children in 2002. Available data also reveals an important trend towards deinstitutionalisation in Slovenia, with the larger institutions opening day centres as an alternative to residential care. Some projects on direct funding have been initiated, with the aim to promote independent living for people with disabilities and so speed up the process of deinstitutionalisation. Nonetheless, at the same time, at least one new residential institution is under construction, while children with *moderate* to *profound* intellectual disabilities are still automatically referred to residential institutions for educational purposes.

### *Access to education*

The Constitution recognises the universal right to education. The education of children with intellectual disabilities is regulated by general legislation applicable to all children and by the Placement Act, which specifically addresses the education of children with special needs. The Placement Act entered into force in 2003 and opened the door for the integration of children with intellectual disabilities into mainstream schools. However, current legislation still excludes the majority of children with intellectual disabilities from mainstream education; by law, only children with *borderline* intellectual disabilities can be placed in mainstream schools, while children with *moderate* to *profound* intellectual disabilities are ineligible even for special schools.

The diagnosed level of intellectual disability determines the type of educational programme and school (or kindergarten) into which a child with intellectual disabilities is placed. In 2001 there were 3,213 children with intellectual disabilities registered in Slovenia, of which over 70 per cent had *borderline* or *mild* intellectual disabilities. The Placement Act regulates the diagnosis of intellectual disability in children by the Placement Commissions. Since the Act entered into force there have been a number of changes in placement procedures. Nonetheless, there are still complaints that they are over-medicalised; that parents and experts who know the child personally are not sufficiently involved; and that there are often significant delays. Roma children are still misdiagnosed with intellectual disabilities to a significant extent. Lack of common standards and guidelines mean that different commissions can produce very different reports on the same child. There is also increasing pressure from parents for children with *mild* intellectual disabilities to be given the *borderline* diagnosis, so that they can be integrated into a mainstream school. Early intervention services for children below pre-school age are mainly provided through a network of “mental-hygiene” departments and developmental dispensaries operating in health centres. However, lack of resources and qualified staff means that these services are mainly available to people living in the larger towns and cities.

In Slovenia, the integration of children with intellectual disabilities is at an early stage. The ongoing reform of the education system for children with special needs has led to recent changes in the educational and vocational educational programmes available for children and young people with intellectual disabilities. However, the reform focuses more on the integration of children with physical and sensory disabilities, than on children with intellectual disabilities. This means that while increasing numbers of children with physical and sensory disabilities are enrolled in mainstream schools, children with intellectual disabilities are still to a large extent segregated in special schools. Nonetheless, the numbers of children with intellectual disabilities integrated into mainstream primary schools and kindergartens has steadily increased over recent years, due in large part to the preference of parents (and guardians) for a mainstream education for their child.

Pre-school age children with *mild* and *moderate* intellectual disabilities can be enrolled in mainstream kindergartens and follow a special educational programme, while those



with *moderate* and *severe* intellectual disabilities can attend special units (“developmental units”) in mainstream kindergartens. There is now a special educational programme for children with special needs in mainstream primary schools, although this does not specifically refer to children with intellectual disabilities and does not specifically address their needs. In addition, children with intellectual disabilities integrated in mainstream schools receive additional expert support and an individualised educational programme. However, some parents have sought a diagnosis of *borderline* intellectual disability in order to place their children with *mild* intellectual disabilities in a mainstream school, and these children may, as a result, not receive the support they need. Despite some positive examples, many parents and social workers are not satisfied with the first results of integration. In particular, teachers in mainstream schools have not been adequately prepared for working with children with intellectual disabilities and have not received any additional training. Many teachers remain resistant to the integration of children with intellectual disabilities, and most special educators still promote special schools as the best solution for children with intellectual disabilities.

Only children with *mild* – and in exceptional cases only *moderate* – intellectual disabilities can be placed in primary special schools (“schools with an adapted programme”) for children with intellectual disabilities, which can be boarding schools or day schools. Education professionals have highlighted the inadequate working conditions for teachers in these schools; the educational programme for these schools has still not been adapted to the new nine-year compulsory schooling and teachers have not been provided with appropriate textbooks. The number of children in the primary special schools for children with intellectual disabilities has fallen dramatically over the last decade and in 2000–2001 there were only 2,303 students in these schools. However, as yet this tendency has not generated any public debate on reforming the special education system. Instead, special schools for children with intellectual disabilities have sought to enrol children with learning difficulties. Due to the prejudice they continue to face and to inadequate assessment procedures, Roma children remain disproportionately represented.

It is very uncommon for children with intellectual disabilities to receive home schooling. No budget resources are allocated for this purpose, so the costs of home schooling fall to the parents. Children and young people with *moderate*, *severe* or *profound* intellectual disabilities are usually placed in special programmes of care and education in residential institutions and receive education according to a special programme of education and care. In 2000, there were 821 children living in the five residential care institutions for this group. However, the number of children with intellectual disabilities in residential institutions is expected to continue to fall as day centres are opened across the country providing alternatives to residential care and permitting children with more severe intellectual disabilities to remain with their families.

### *Transition from education to employment*

After completing primary education, children and young people with intellectual disabilities can receive vocational education or training, either through a two and a half-year lower vocational education programme for people with *mild* intellectual disabilities, or through a special programme of education and care which is provided in segregated, residential work training units. After completing these programmes, only people with *mild* intellectual disabilities can register as a job seeker at an Employment Office, but they then face competition on the open labour market for which they have been poorly prepared. There are no support programmes specifically targeted at job seekers with intellectual disabilities.

### *Access to employment*

Slovenian law guarantees the right to work and to choose a profession. Recent legislation has strengthened protection against discrimination in employment for people with disabilities. Importantly, amendments to the Vocational Rehabilitation Act that entered into force in May 2004 introduce, for the first time, a quota system for the employment of people with disabilities and a definition of supported employment. There are also provisions on new forms of sheltered employment. The amendments will also lead to changes in the procedures for assessing the working capacity and employability of people with *mild* intellectual disabilities, many of whom are at present assessed as being “unemployable”. However, adults with “invalid status” under the Social Care Act (including people with *mild*, *moderate* and *severe* intellectual disabilities) are entirely excluded from the provisions of the Vocational Rehabilitation Act. They are automatically determined as being incapable of paid employment, and cannot even register at an Employment Office as a job-seeker. They only have the right to “guidance, care and employment under special conditions”, and receive social security benefits. Disability benefits cover the basic living costs of a person with intellectual disabilities living at home with their family, but would not allow them to live independently. In the case that an individual with intellectual disabilities who has “invalid status” according to the Social Care Act moves into paid employment, he or she loses the entitlement to the disability allowance and other benefits connected to this status.

A long-term national employment strategy is defined in the “National Programme for the Development of the Labour Market and Employment by 2006”. This includes a number of progressive measures to encourage the employment of people with disabilities in general, but does not specifically refer to people with intellectual disabilities. The programme is mainly implemented through active labour market programmes, which include people with disabilities as a target group. At present, such programmes are the main way through which adults with *mild* intellectual disabilities may seek employment (and receive training) in companies on the open market, although no official data on this is available. Those who cannot find work in this way can instead be employed in sheltered companies, which must fulfil a quota of at least 40 per cent of people with disabilities and in return receives tax relief and Government subsidies. Although a quota system was introduced as of May 2004, it is still too early

to assess the implications of this new system for the employment of people with *mild* intellectual disabilities.

The unemployment rate for people with disabilities of all types has been rapidly increasing since 1992. Data on the level of employment and unemployment of people with intellectual disabilities is not currently available, although a new register is presently being introduced which should improve data collection. At present, there are two main possibilities for people with mild intellectual disabilities to find employment: full-time employment on the open labour market or work in sheltered companies. There are no current examples of supported employment.<sup>2</sup> However, most people with intellectual disabilities are placed in sheltered workplaces. These cannot be considered as constituting employment as the workers do not have an employment contract and do not receive a wage, only a token “award”. In 2001, over 2,000 people with intellectual disabilities (mostly of a moderate degree) were working in sheltered workplaces. There are some examples of good practices, including a sheltered workplace which has placed people with intellectual disabilities in a company on the open market. However, in most cases the work in sheltered workplaces is repetitive and, as a segregated environment, does not seek to provide people with intellectual disabilities with the employment and social skills they need to access employment on the open market.

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<sup>2</sup> Supported employment is an employment option that facilitates competitive work in integrated work settings for people with disabilities. It provides assistance such as job coaches, transportation, assistive technology, specialised job training and individually tailored supervision.

## RECOMMENDATIONS

### General recommendations

#### *International standards*

1. The Government should ratify Protocol No. 12 to the European Convention on Human Rights and Fundamental Freedoms (ECHR).

#### *Legislation*

2. The Government should, as a priority, amend the outdated Act on the Social Care of Mentally and Physically Disabled People 1983, in order to harmonise it with current international disability policy. These amendments should aim to ensure that all people with intellectual disabilities can access their basic rights and are offered the chance to receive quality training and education in integrated environments; gain marketable skills that would give them access to employment on the open market; and gain unobstructed access to employment services and other social assistance schemes. As a priority, Article 1 of the act should be amended such that people with all levels of intellectual disabilities have the right to access paid employment, without losing their disability status.
3. The Government should introduce provisions on direct payments schemes into the Social Security Act and other legislation, to permit people with intellectual disabilities to make choices about their care and to encourage independent living. Direct payments should be available for people with intellectual disabilities living throughout the country.

#### *Terminology*

4. The Government should change the terminology used in all legislation and policy from terms with a negative connotation (including “mentally disabled person”, “mentally retarded person” and “invalid”) to less stigmatising and more internationally accepted terms (such as “person with disabilities” and “person with intellectual disabilities”). The use of the word “children” in reference to adults with intellectual disabilities should also be eliminated.

#### *Data collection*

5. The Government should improve all data collection on the situation of people with disabilities, and ensure that this data is available disaggregated by type of disability, including intellectual disability. In particular, data should be regularly collected on the number of people with intellectual disabilities who are employed through the new quota system or in social companies, or who access active labour market programmes.

*Guardianship:*

6. The Government should, as a priority, initiate discussion on necessary changes regarding the removal of legal capacity and the prolongation of parental rights, in order to ensure that people with intellectual disabilities are able to exercise their rights to the fullest possible extent. This should include a process of restitution of legal capacity for adults with intellectual disabilities whose legal capacity has been fully removed.
7. The Government should enable all people with intellectual disabilities who have had their legal capacity removed to have the right to an independent advocate, who can protect their interests, rights and wishes in relation to parents, guardians, family assistants and experts.

*Early intervention and Support*

8. The Government should reform the early intervention system, to improve services for children of preschool age with intellectual disabilities and their families. This should include allocating appropriate resources and adequately trained staff to the mental-hygienic departments in health centres throughout the country.
9. The Government should develop and implement good quality programmes for the support of parents of children with intellectual disabilities, including the provision of comprehensive information and emotional support. These programmes should be made available in the communities where people live.

*Deinstitutionalisation*

10. The Government should do more to speed up the process of deinstitutionalisation and should provide people with disabilities with the right to live in the community, rather than in institutions. In particular, the Government should:
  - Prioritise the construction of small group homes for people with disabilities, as an alternative to institutional care, and develop community-based care systems throughout the country.
  - Move away from the placement of children in segregated residential educational institutions, and towards the provision of integrated education for all children with intellectual disabilities.
  - Expand and support the existing pilot project on personal assistance for people with intellectual disabilities, developed by the Association for the Theory and Culture of Handicap (YHD) and develop a family assistance scheme.

## Recommendations on education

### *Legislation*

11. The Government and the Ministry for Education and Sport should, as a priority, amend existing legislation that presently only allows children with *borderline* intellectual disabilities to attend mainstream school.
12. The Ministry for Education and Sport should amend the “Instructions for the educational programmes with adapted implementation and additional expert support for the nine-year elementary school”<sup>3</sup> to specifically include a reference to children with intellectual disabilities.
13. The Government should introduce separate legislation to specifically address early intervention services (an “Early Intervention for Children with Special Needs Act”).

### *Policy*

14. Government education policy should move beyond the “integration” of children with intellectual disabilities and should in future focus on their “inclusion” into the educational system. “Inclusion” is a qualitative process of individual support for a child with special needs and at the same time a process for developing the social competencies of all people connected with the child, in order that the she or he gains the skills required for independent living. A definition of “inclusion” should in future be included in education legislation.
15. The Government should accelerate reform of the educational system and comprehensively review and revise the diagnostic, assessment, and placement procedures for educational purposes to allow for mainstreaming of all people with intellectual disabilities who opt for this possibility.

### *Diagnosis and assessment for educational purposes:*

16. The Government should initiate further qualitative changes to the work of Placement Commissions. These should, in particular, ensure that:
  - The Placement Commission must include professionals who have known the child for a long period of time. In addition, the commissions should ensure a wider cooperation with a network of experts who know the child well.

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<sup>3</sup> Ministry for Education and Sport, *Instructions for the educational programmes with adapted implementation and additional expert support for the nine-year elementary school*, available on the website of the National Education Institute (NIE) at [www.zrss.si](http://www.zrss.si) (accessed 15 March 2005).

- Parents and legal guardians must be present at the assessment process and should have a bigger role in the decision making process.
  - The members of the Placement Commissions should all be experienced experts in their respective fields.
17. The Government should encourage the Placement Commissions to start issuing individual notifications annulling the assessment of intellectual disability, for adults who had *mild* or *borderline* intellectual disabilities as a child. This would help the person concerned access employment.
  18. The Government should ensure that the ethnicity or nationality of children assessed by the Placement Commissions does not influence the decisions taken by the commissions concerning their diagnosis of the level of intellectual disabilities of the child, or the placement decision. The Government should, in particular, monitor the number of Roma children who are placed in special schools (schools with an adapted programme).

### *Curricula*

19. The National Commission for the Renovation of the Education System for Children should develop special education curricula specifically designed for children with intellectual disabilities.

### *Support*

20. The Government and the Ministry for Education and Sport should ensure that all children with intellectual disabilities, regardless of the educational programme on which they have been placed, have the right to a personal assistant, as is already the case for children with physical disabilities.
21. The Government should ensure that all children with intellectual disabilities receive adequate support at school. Expert support should be organised within a maximum period of three weeks from the receipt of placement order, including for children who are placed in programmes with lower educational standards.

### *Training*

22. The Government should provide additional training for staff working with children and young people with intellectual disabilities, which should be based on the newest methods of learning.
23. The Government should provide additional training for experts working with children and young people with intellectual disabilities who are members of an ethnic minority, and introduce training on anti-discrimination into the curricula of social, educational, medical and special educational professions.

## Recommendations on transition from education to employment

### *Vocational training and life-long learning*

24. The Government should encourage the development of cooperation programmes between schools and other educational institutions offering vocational education or training and potential employers, to help young people with intellectual disabilities make the transition from education to employment on the open labour market.
25. The Government should make integrated vocational educational programmes, offering a broad range of qualifications, widely available in Slovenia.
26. The Government should support the development of life-long learning programmes that would enable adults with intellectual disabilities to develop and maintain their skills.

## Recommendations on employment

### *Legislation*

27. The Government should, as a priority, amend Article 10 of the Act on the Vocational Rehabilitation and Employment of People with Disabilities 2004, to ensure that the provisions of this act, particularly on supported employment and the right to vocational rehabilitation, apply to *all* people with intellectual disabilities, including those with an “invalid status” under the Act on the Social Care of Mentally and Physically Disabled People 1983.

### *Supported employment*

28. The Government should promote the employment of people with intellectual disabilities in companies on the open market, regardless of the degree of their disabilities. Supported employment schemes should be developed as soon as possible, to ensure that this becomes a real option for people with intellectual disabilities, and an alternative to working in a sheltered workplace.

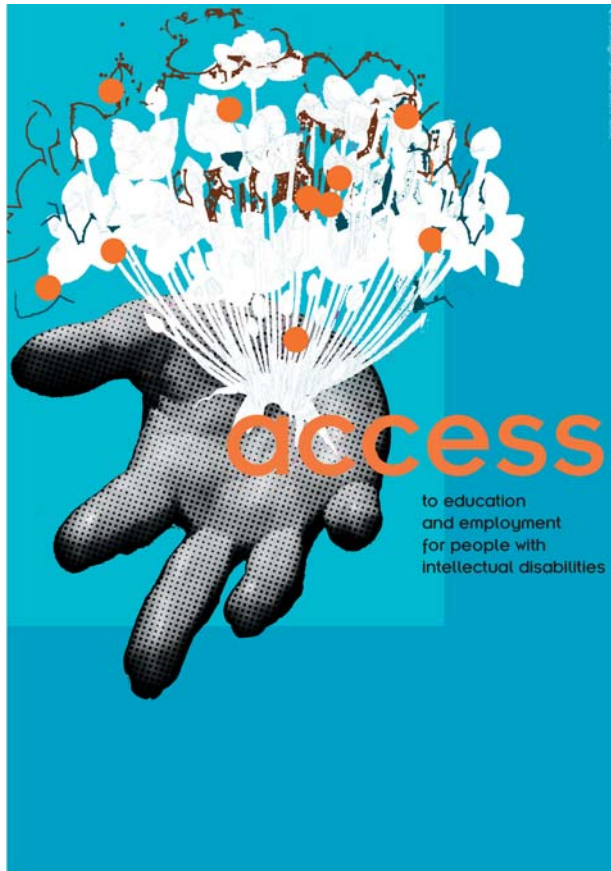
### *Employment services*

29. The Ministry of Labour, Family and Social Affairs should ensure that the employment services provided by the Employment Offices (in particular employment counselling and active labour market programmes) are adapted to the specific needs of adults with *mild* intellectual disabilities. It should also develop policy to promote the inclusion of adults with *mild* intellectual disabilities in active labour market programmes.



Throughout Europe, people with intellectual disabilities face overwhelming stigma and prejudice and encounter significant barriers to realising their fundamental rights. EUMAP, the EU Monitoring and Advocacy Program of the Open Society Institute, in cooperation with the Open Society Mental Health Initiative, has monitored this situation in 14 countries throughout Europe, both EU members and candidate countries: *Bulgaria; Croatia; the Czech Republic; Estonia; Greece; Hungary; Latvia; Lithuania; the Netherlands; Poland; Romania; Slovakia; Slovenia* and *the UK*. Carried out by local experts and civil society groups, the monitoring focuses on the extent to which people with intellectual disabilities have access to education and employment. This series of reports presents the findings of the monitoring and also makes recommendations for improving the social inclusion of people with intellectual disabilities.

The summary reports resume the main findings – Executive Summary and Recommendations – of each of the country reports. The complete set of country reports, in English and translated to national languages, can be accessed online at: [www.eumap.org/topics/inteldis/reports](http://www.eumap.org/topics/inteldis/reports). Hard copies can be ordered at: [www.eumap.org](http://www.eumap.org).



 OPEN SOCIETY INSTITUTE  
EU MONITORING AND ADVOCACY PROGRAM

 OPEN SOCIETY INSTITUTE  
MENTAL HEALTH INITIATIVE

# Rights of People with Intellectual Disabilities: Access to Education and Employment

Summary Reports

*United Kingdom*

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Hard copies can be ordered at: [www.eumap.org](http://www.eumap.org)



## EXECUTIVE SUMMARY

Throughout Europe people with intellectual disabilities<sup>1</sup> face major stigma and prejudice and are confronted with significant barriers to realising their fundamental human rights. Discrimination against people with intellectual disabilities is deeply rooted and widespread, standing in the way of positive change. Providing real access to education and employment for people with intellectual disabilities is critical to ensuring that they can live and work in the community as equal citizens. There is a strong link between education and employment: without access to adequate education, people with intellectual disabilities cannot secure meaningful employment. This denial of access leads to life long dependency, poverty and social exclusion adding to the stigma of intellectual disability. This monitoring report focuses specifically on the areas of education and employment because of their importance to people with intellectual disabilities, and because of the existence of both international standards and national legislation that specifically address them.

### *Background*

The UK has ratified most international human rights instruments, including those with provisions relating to the rights of people with disabilities. However, the UK has yet to ratify the revised European Social Charter, or to sign and ratify Protocol No. 12 to the European Convention on the Protection of Human Rights and Fundamental Freedoms (ECHR). It has also not ratified ILO Convention C159 on Vocational Rehabilitation and Employment (Disabled Persons), 1983.

From May 1997, the UK Government introduced devolution of powers to Scotland, Wales and Northern Ireland, with the Westminster Parliament retaining sovereignty for areas such as foreign affairs, defence and macro-economic policy. The Scottish Parliament and the National Assembly for Wales (NAFW) assumed their responsibilities in 1999, but the Northern Ireland Assembly is presently suspended. Unlike most European countries, the UK does not have a written Constitution, but the UK has a comprehensive legislative framework to counter discrimination and ensure equal rights.

The Human Rights Act 1998 includes a prohibition of discrimination, although not explicitly on the grounds of disability. The most important legislation on the rights of people with disabilities is the Disability Discrimination Act 1995 (DDA). This provides a definition of disability, and measures to prevent discrimination on the ground of disability in the areas of employment; access to goods, facilities and services;

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<sup>1</sup> The term “intellectual disability” (also described as “learning disability” or, in the USA for example, “mental retardation”) here refers to a lifelong condition, usually present from birth or which develops before the age of 18. It is a permanent condition that is characterised by significantly lower than average intellectual ability and results in significant functional limitations in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills.

and buying or renting land or property. The DDA was extended to cover education (in schools and further and higher education) through the Special Educational Needs and Disability Act 2001 (SENDA 2001). In the area of employment, it was further amended through the Disability Discrimination Act 1995 (Amendment) Regulations 2003 (DDA Regulations 2003), which entered into force on 1 October 2004. The Disability Discrimination Act 2005 (DDA 2005) will in December 2006 create a “Disability Equality Duty” on Public Sector organisations to counter discrimination in employment and to actively promote disability equality in all aspects of their work. The DDA and subsequent amendments apply to England, Wales, Northern Ireland and (with minor exceptions) to Scotland. There are regional amendments to DDA which apply to different UK jurisdictions. The DDA 2005 does not fully extend to Scotland and Northern Ireland, but the Scottish Parliament is to legislate to ensure all its additional features are provided there.

In the UK, intellectual disability is defined and diagnosed in accordance with the World Health Organization’s ICD-10. However, the term “learning disability” is mainly used, rather than intellectual disability (as defined in this report). In education, the broader terms “children with learning difficulties” – which includes children with a range of disabilities and conditions, not only children with intellectual disabilities – and “children with special educational needs” are used. The diagnosis of intellectual disability is usually carried out by paediatricians in the health service or associated professionals charged with monitoring the normal development of all children born in the UK, such as general practitioners (GPs) and health visitors. Local Education Authorities are responsible for assessing the Special Educational Needs that result from any disability, intellectual or otherwise.

In the UK, guardianship is infrequently used and, where it is, it is rarely used for people with intellectual disabilities. In England there were only 473 new cases of guardianship in 2004, of which the majority concerned people with mental health problems. In all cases, the guardian was the Local Authority. It is important to note that in the UK, guardianship is a very different power than in many other European countries, and it is not linked to an individual’s capacity. In England and Wales, the Mental Health Act 1983 defines guardianship. A guardian only has three powers; to require the person under guardianship to reside at a specified place; or attend specified places for medical treatment, occupation, education or training; and to require access be given to the individual by a doctor, approved social worker or other specified person. The Mental Capacity Act 2005, which will not enter into force until 2007, will in future provide a comprehensive legislative framework for decision-making on behalf of people who lack the capacity to make decisions for themselves. In Scotland, legislation improving the protection of the rights of adults who lack the mental capacity has already been enacted.

Due to differing definitions of intellectual disability, and the fact that much official data is not available disaggregated by type of disability, official data on people with intellectual disabilities in the UK can be difficult to interpret. Statistical evidence from

epidemiological studies based on IQ assessments (using a two level classification system), indicate around 580,000 people in the UK with *mild* intellectual disabilities and 217,000 people with severe intellectual disabilities. However, depending on the definition used (such as number of people accessing services for people with intellectual disabilities), there may be over two million people with some level of intellectual disability. Internationally, higher poverty levels have been correlated with an increased prevalence rate of *mild* or *moderate* intellectual disabilities (using the ICD four-level classification). There are indications that the higher levels of poverty in Northern Ireland, as compared to the rest of the UK, are therefore reflected in a higher prevalence of *mild* intellectual disability. More than half of people with intellectual disabilities in the UK live with their families. Across the UK, a process of deinstitutionalisation has been ongoing since the late 1980s. Only around two thousand people with intellectual disabilities are now in long stay hospitals. In England, community-based residential services are increasingly available. A proportionally low number (44,000) of adults with intellectual disabilities are in residential homes, of which an increasing number are in homes for three people or less. This tendency is reflected across the rest of the UK.

### *Access to education*

The most important legislation for the education of children with intellectual disabilities is the Special Education Needs and Disability Act 2001 (SENDA 2001), which brought education legislation in line with key international and EU standards. This act only covers Great Britain, but equivalent legislation (the Special Education Needs and Disability (SEND) Order) will also be introduced in Northern Ireland. The SENDA 2001 consolidates and amends previous education legislation – including the Education Act 1996, which provides a definition of children with learning difficulties and special educational needs (SEN). It significantly extends the right of children with SEN, including children with intellectual disabilities, to be educated in mainstream schools. It states that education must be provided in a mainstream school, unless this is incompatible with either the wishes of the child’s parent or the provision of efficient education for other children. The SENDA 2001 also extends the DDA to provide protection against discrimination in education (in schools and further education) on the basis of disability, including in admission and provision of services. Schools are obliged to draw up “accessibility strategies” to facilitate the inclusion of pupils with disabilities and to make reasonable adjustments, so that they are not disadvantaged. The act extends the remit of the DRC for discrimination in education. In England and Wales, claims of unlawful discrimination in education are heard by special tribunals.

Depending on the level of a child’s intellectual disabilities, in the UK intellectual disability may be diagnosed at birth; in the preschool age; or at a later stage in the child’s education. Early intervention services are widely available for preschool children with intellectual disabilities and their families; even children as young as two years old can be offered special education. Recent Government policy has focused on improving the coordination of early intervention services and improving support to families. The

“Sure Start Programme” includes a range of initiatives which will improve services for disadvantaged children, including children with intellectual disabilities, and their families, including extension of home teaching services, such as Portage.

In the UK, the period of compulsory education is nine years, to age 16. Children attend either maintained (State funded) or non-maintained (independent) schools. Children and young people with intellectual disabilities mainly receive education in mainstream schools (either in an inclusive class; or in a special class or unit); special schools (which they can attend from preschool age up to age 19); or pupil support units. Very few receive education in a long-stay hospital or through home schooling on a long-term basis. Children with intellectual disabilities assessed as having *severe*, *moderate* or *profound* learning difficulties (and some children with *mild* intellectual disabilities) will most often be educated in special schools or special needs units.

In the UK, Local Authorities are responsible for the assessment of children’s special educational needs. There are similar assessment procedures in England, Wales and Northern Ireland. In England, assessments are carried out in accordance with a SEN Code of Practice, which has been revised in line with the SENDA 2001, and a similar code for Wales has also been drafted. There are now four levels of assessment, all of which are carried out by multidisciplinary teams which include health and education professionals, and fully involve the child’s parents. In levels one and two, the special educational needs of the child are assessed; additional support provided; and an Individual Education Plan (IEP) prepared for the child. In the case of children with severe and complex special needs, a further level of assessment is carried out. If required (level four), a statement of SEN is then prepared. A statement is only prepared in cases where a child’s needs cannot reasonably be provided within the resources normally available to a school. It details the special educational (and non-educational) provision the child requires and names an appropriate school (or other arrangement) for the child. LEAs (or, in Northern Ireland, the Education and Library Boards) are obliged to provide the form of support detailed in the statement. Parents have the right to appeal the results of the assessment procedures, which have been extended by the SENDA 2001, but do not have the right to choose a school if the LEA considers that a “placement in mainstream would be incompatible with the efficient education of other children.” However, the LEA is obliged to show that there are no reasonable steps that could be taken to prevent incompatibility.

In Scotland, in future there will be significant changes to assessment procedures, in line with recently introduced legislation. The term “additional support needs” will replace “special educational needs”. At present, in Scotland children with SEN receive a Record of Needs (equivalent to the statement of SEN), but parents do not have the right to appeal against the listed measures and there is no appeals tribunal. The proportion of children with a Record of Need varies between education authorities (a similar tendency has also been noted in England) and this is thought to reflect Education Authority concerns over the costs of providing the support listed in the record. In Scotland, at age 14, a Future Needs must be carried out, to establish a transitional planning for the child.

When the child moves from school to further education, responsibility for further assessments is transferred to the Careers Scotland. Similarly, in England and Wales at age 13 a Transition Plan must be drawn up for all children with a statement of SEN. The Connexions service (England); Careers Wales (Wales); and the Careers Service (Northern Ireland) play a similar role to Careers Scotland. In a recent Green Paper, the Government has proposed to reform the Connexions service. The plan is to devolve responsibility for the commissioning of information and advice services to young people and the funding of that goes with it from the Connexions service to Local Authorities, through children's trusts, schools and colleges. This will help integrate Connexions with a wider range of services at local level.

In the UK, a number of EU programmes (including Horizon, Leonardo and Employ) have provided innovative projects for people with intellectual disabilities in transition from school and colleges. Programmes of action aiming to improve the educational achievements of children with SEN have been implemented in England (from 1998) and Wales (from 1999). The goals of these programmes, including increasing the numbers of children with SEN integrated into mainstream schools, are highly relevant to children with intellectual disabilities.

In England, Wales and Northern Ireland, the relevant National Curriculum is mandatory for all pupils in state-maintained schools, up to the age of 14. However, pupils with a statement of SEN can be exempted from the National Curriculum; or the National Curriculum (and its assessment arrangements) can be adjusted accordingly. Given the National Curriculum's academic focus, there are different views among self-advocates and education experts, as to its effectiveness for teaching children with intellectual disabilities. However, there is consensus that this group of children must be given the support they need to achieve the greatest level of achievement both academically and in terms of acquiring vocational skills. In Scotland, schools are responsible for developing their own curriculum, but these must be adapted to the needs of individual pupils, including those with intellectual disabilities. Across the UK, Individualised Educational Programmes (IEPs) must be prepared for pupils with a statement of SEN (or Record of Needs); these are used as a basis for planning, setting targets and ensuring that pupils make progress.

In most mainstream schools, a SEN Coordinator (SENCO) is responsible for developing the school's SEN policy and for helping staff teach and support children with SEN. Teacher training for mainstream teachers includes elements on the teaching of children with SEN, but the extent to which children with intellectual disabilities are taught in mainstream classes, and the severity of intellectual disabilities the children included experience, varies between primary and secondary schools, and between LEAs. Learning support assistants (LSAs) or special needs assistants/teaching assistants provide extra support. Children with severe and complex forms of SEN (including many children with intellectual disabilities) are taught by SEN teachers, primarily in special units or in special schools.



Recent legislation and Government policy has clearly prioritised the education of children with SEN in a mainstream environment. However, at present, the majority of young people with intellectual disabilities are assessed as having learning disabilities of sufficient severity to be educated either in special schools or in segregated special units within mainstream schools. The inclusive education of children with intellectual disabilities has often only been applied to some children with *mild* intellectual disabilities. As an increasing number are integrated into mainstream education at the primary level, parents are now seeking their inclusion in secondary and further education. At present, though, most mainstream schools do not have sufficient skills, experience and resources to provide the support required for the inclusive education of children with intellectual disabilities; special schools are considered to have an important role in preparing mainstream schools for their inclusion. Nonetheless, although policy now recognises that children with *mild* and *moderate* intellectual disabilities should be educated in mainstream schools, there is wide variation in the extent to which young people with more severe intellectual disabilities are educated in mainstream or special schools.

### *Transition from education to employment*

At present, most young people with intellectual disabilities do not leave school with marketable skills and, in particular, do not gain work experience, although some special schools are now offering “job tasters” and a few have arranged for students to find part-time jobs outside of school. The preferred post-school option is a place at a college, either on a special course or in a special unit within the college. However, there is still only limited awareness of the needs of people with intellectual disabilities in further education. Among the barriers they encounter are lack of curriculum flexibility and adequate support staff; courses geared towards success in achieving a qualification, rather than in developing students’ abilities; and a lack of orientation towards employment as an end goal. Many young people with intellectual disabilities are therefore not able to use the skills they learn.

This limited transition from further education to real employment is surprising, given that transition planning is well developed in the UK. Based on the Transition plan, in England Connexions are currently responsible for identifying the needs of young people with SEN, and the Learning and Skills Councils (LSCs) have a statutory duty to ensure that appropriate funding and support for the recommended options are made available. (Careers Wales, Careers Scotland the Northern Ireland Careers Service play a similar role to Connexions). Nonetheless, there are concerns that people with intellectual disabilities are too often passed on to various different courses and “non-work” options, rather than being successfully orientated towards a path leading to employment. All too often, they and their parents are not sufficiently informed of available options and are left confused by the transition from known services to the new adult services. Unlike school, college placements are often not full-time, placing an additional strain on parents. In addition, those who move straight into employment may find a lack of sufficient support. Several reasons have been identified for this,

including a lack of clear overall responsibility for transition planning among the many agencies involved. As mentioned above, there are plans to disband, the Connexions service in England, and move their responsibilities back to Local Authorities.

As an alternative to college courses, there are also some work-based vocational training programmes available for people with special educational needs, in which young people spend most of their time on placement in a company. The “Entry to Employment (E2E)” programme, in particular, is useful for those with *mild* intellectual disabilities. There is also a well-developed system of adult education in the UK, and people with intellectual disabilities are able to benefit from the wide range of part-time courses available at adult education centres.

### *Access to employment*

The UK has a comprehensive framework of employment legislation and has transposed most of the provisions of the EU Employment Directive into national legislation, mainly through amendments to the DDA. When it enters into force, the DDA 2005 should bring UK legislation fully in line with the directive. People with disabilities who wish to pursue complaints about discrimination in employment can be assisted by the Disability Rights Commission (DRC) framework in England, Wales and Scotland, and the Equality Commission in Northern Ireland.

Most people with intellectual disabilities in the UK are reliant on State welfare benefits. The main welfare benefit which people with intellectual disabilities receive is Income Support (IS), including a premium for people with disabilities. This is basically a benefit for people who are not in “remunerative work.” Many also receive the Disability Living Allowance (DLA), as well as other non-disability specific benefits. People with intellectual disabilities usually have the status of “economically inactive” and can continue to receive their benefits without regular review. The social welfare system is designed to facilitate the transition from benefits to employment. On moving into full-time employment, loss of benefits such as the IS can be offset by “top-up” benefits, including the Working Tax Credit. Nonetheless, for people with intellectual disabilities in staffed accommodation, the potential loss of Housing Benefit can still act as a disincentive to moving into full-time employment. Usually, for people with intellectual disabilities, the move to part-time employment while retaining benefits is the preferred option. Under the “Supported Permitted Work” rules, people with disabilities can work up to 16 hours a week in supported work indefinitely, if they receive recognised forms of support. This is a particularly important way for people with intellectual disabilities to join the mainstream workforce, although existing regulations mean that, in practice, they may be even more restricted in the hours they can work, and only receive limited additional income from their work as a result.

The two main areas of assessment for adults with intellectual disabilities are for eligibility for welfare benefits and for Government employment schemes. An individual with disabilities can be referred to specialised Government employment schemes, such as “Access to Work,” WORKSTEP and Employment Support in Northern Ireland,

following an assessment carried out by a Disability Employment Advisor (DEA) of the DWP's Disability Services Teams, or their national equivalents. The DEA develops an action plan that orientates the individual towards suitable opportunities.

In the UK, EU funds – in particular from the European Social Fund (ESF) – have been directed towards programmes encouraging the employment of people with disabilities, including intellectual disabilities. In particular, in the past they have provided a significant source of development funding for supported employment agencies, although due to a shift in priorities the level of funding has now fallen and moved to other scheme types.

The Government has a clear policy on providing new employment opportunities specifically for people with intellectual disabilities, as set out in the 2001 White Paper *Valuing People*. In the UK, there are a number of routes for people with disabilities seeking to enter the job market, including via Jobcentre Plus, where all go to seek work and access welfare benefits as job seekers. The UK no longer has a quota system to encourage the employment of people with disabilities, so their two main options, depending on their level of disability, are mainstream Active Labour Market Programmes (ALMPs) or specialist employment schemes for people with disabilities – provided through central Government and through local authority-run programmes. At present, few people with intellectual disabilities access the mainstream programmes, such as “New Deal” and “Work-based Training”.

In the UK, the majority of people with intellectual disabilities are unable to access employment. Estimates vary, but the most recent statement from the *Valuing People* strategy estimates the number of people with intellectual disabilities in paid employment at only 11 per cent, compared to 49 per cent for people with disabilities in general. Over seventy-five thousand people are estimated to be attending day centres run by local authorities across the UK, which vary considerably in their emphasis on employment preparation. Although exact figures are not available, it can be estimated that around 16,000 people with intellectual disabilities access specialist Government employment programmes for people with disabilities.

Supported employment is one of the most effective ways for people with intellectual disabilities to access employment on the open market. In the UK, NGOs, including Mencap, are heavily involved in the provision of supported employment. It is very difficult to obtain estimates of the number of services offering supported employment, and how many people have jobs through this model. There are over 400 agencies operating in the UK. A significant number are NGOs, but there is no data on exactly how many. People with intellectual disabilities benefit when they have access to a full model of supported employment. The Government offers a number of specialist employment programmes (at one time regarded as sheltered provision) that are relevant to people with intellectual disabilities. The WORKSTEP programme offers jobs through a network of supported factories and of community placements – historically these have provided help through offering employers a wage subsidy, but more recently through more flexible on-the-job staff support and financial assistance packages.

WORKSTEP factory and community placements are supplemented by opportunities offered by Remploy Ltd, the biggest Government-funded national provider. The Government also provides help to people seeking open employment through the “Access to Work programme”, which offers financial help with on-the-job support, transport, work aids and workplace adaptations.

The specialist WORKSTEP and “Access to Work” programmes do now allow for payments for a job coach – a very important element important for people with intellectual disabilities – although in the case of the “Access to Work” programme, this is time-limited. Nonetheless, these programmes do not pay for the full model, from Vocational Profiling through to workplace support and follow-up services. Supported employment agencies are largely funded by local authority social services, but there are increasing calls for central Government mainstream funding to be made available. At present, access to supported employment services is uneven across the UK.

## RECOMMENDATIONS<sup>2</sup>

### General recommendations

#### *International standards*

1. The UK should ratify ILO Convention C159 on Vocational Rehabilitation and Employment (Disabled Persons) 1983.
2. The UK should ratify the Revised European Social Charter of 1996 and bind itself to Article 15 on the right of persons with disabilities to independence, social integration and participation in the life of the community. It should also sign and ratify Protocol 12 to the on the Protection of Human Rights and Fundamental Freedoms (ECHR).

### Recommendations on education

3. The general thrust of Government SEN policy towards the inclusion of people with disabilities in mainstream schools wherever possible is welcomed.<sup>3 4</sup> However, the Government should see through its commitment to bring specialist support, and additional teacher experience into mainstream schools, and adequate resources, if children and young people with intellectual disabilities are to flourish in mainstream schools.
4. The Government should ensure that children can be catered for in their own communities and should reduce reliance on special residential schools, to avoid the removal of young people with significant intellectual disabilities from their locality, peers and families.

### Recommendations on transition from education to employment

#### *Curriculum development*

5. Governments in the UK should place more emphasis on a flexible and individual approach to teaching young people with intellectual disabilities, including the option of using a functional curriculum, rather than on a

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<sup>2</sup> Note: The recommendations in this section are based on conclusions from the OSI roundtable meeting, held in London on 17 May 2004, held to discuss the draft version of this report. Some of the proposals build on the analysis contained in O'Bryan et al., *Framework for Supported Employment*.

<sup>3</sup> Department for Education and Skills *Removing the Barriers to Achievement: The Government's Strategy for SEN*. 2004, available at [http://www.teachernet.gov.uk/\\_doc/5970/removing%20barriers.pdf](http://www.teachernet.gov.uk/_doc/5970/removing%20barriers.pdf) (accessed 30 August 2005).

<sup>4</sup> Scottish Executive, *Moving Forward! Additional Support for Learning*, Scottish Executive, HMSO, Edinburgh, 2003.

modified National Curriculum, for those who would benefit. Any functional curriculum should ensure that young people with intellectual disabilities are taught the skills they need in real home, work, leisure and community life situations, and are able to acquire the basic skills that will enable them to take a place in the work force, with all the associated benefits of status and integration.

### *Transition planning*

6. Governments in the UK should recognise the need for young people with intellectual disabilities, particularly those with more severe intellectual disabilities, to progressively spend more time and instruction in the environments where they will later spend their adult lives-in real home, leisure, community life and, particularly, work situations. To implement this approach, increased support resources should be made available for young people with intellectual disabilities in special schools (and in mainstream schools if they are more fully integrated) and a wider role foreseen for Learning Support Workers in supporting community based learning.
7. Agencies<sup>5</sup> involved in transition should ensure that transition plans are person-centred and participatory.
8. Schools, and careers, social and health services should ensure that the families and carers of young people with intellectual disabilities in transition are equal and collaborative partners, and that they receive the information, support and advice they need, to make informed decisions and think aspirationally about the young person's future.
9. All the agencies with statutory responsibilities in the transition planning process should ensure that the outcomes of transition planning are as specific as possible. The aim of transition planning should be to identify clear outcomes for the future and specific supports to achieve them.
10. Agencies involved in transition should share information more effectively and not use confidentiality as a reason not to share relevant client information needed for planning. They should ensure that there is a more effective handover between children's and adult services at these crucial times. This must be a priority within the emerging system of Children's Trusts in England. A tracking system should be introduced for students as they move through transition and beyond, to ensure that the outcomes of transition plans are delivered.

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<sup>5</sup> Schools, Connexions/Careers Wales/Careers Scotland/Careers Service (Northern Ireland), social services, the NHS (where involved).and NGOs involved in providing any activities, experiences and support.

11. We recognise that Governments in the UK are concerned to make transition effective, and that changes have been proposed<sup>6</sup>. In implementing these, Governments should make sure that agencies involved in transition ensure that in transition years, adult services become progressively involved before young people with intellectual disabilities leave school, rather than delaying this until they do leave. Much can also be gained by all concerned in breaking down artificial barriers and setting up placements for adult life before people leave school.
12. Governments in the UK should clarify which agencies should take a lead in improving transition planning. In particular, the responsibilities of Connexions (or its successor)/Careers Wales/Careers Scotland/Careers Service (Northern Ireland for people with intellectual disabilities should be clarified, along with the resources, staffing and training they need to deliver better outcomes
13. Governments in the UK should promote the concept of a Personal Advisor to help people with intellectual disabilities during the transition process.

### *Supported employment*

14. The departments responsible for developing employment opportunities,<sup>7</sup> along with those responsible for transition planning, should ensure that supported employment placements are made available for young people with intellectual disabilities in school. At present, the majority of supported employment services are for adults, and these services need to be made available across the adult/school divide, in conjunction with education, for example, rather than in isolation. Supported employment agencies should also be available to “pick people up” at age 19-21 after college.

### *Adult education and Lifelong Learning*

15. The agencies involved in Further Education<sup>8</sup> should ensure that young people with intellectual disabilities are not restricted to segregated “access courses” and that curriculum modification, and possibly more powerful systematic instruction techniques are available through Learning Support systems. Learning Support systems should help young people with intellectual

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<sup>6</sup> Prime Minister’s Strategy Unit *Improving the life chances of disabled people: Final Report*, 2005, available at [http://www.strategy.gov.uk/downloads/work\\_areas/disability/disability\\_report/pdf/disability.pdf](http://www.strategy.gov.uk/downloads/work_areas/disability/disability_report/pdf/disability.pdf) (accessed 31 August 2005).

<sup>7</sup> Department of Work and Pensions, Scottish Executive’s Enterprise and Lifelong Learning Department, Department for Employment & Learning (NI), and, under *Valuing People*, Local Partnership Boards.

<sup>8</sup> The LSCs/EIWA/LECs/Department of Education (NI) and Colleges of Further Education.

disabilities take part in a full range of vocational courses, depending on their ability and interests and should be capable of providing personal support to people towards their wider integration into college courses. Courses should be well connected to the local employment market and be responsive, providing training in the skills needed by local industry.

16. Colleges should provide adequately supported work tasters during further education to young people with intellectual disabilities, in the same way as it is currently offered to many non-disabled college students on vocational courses. Such work experience should include support, structure and clear, evaluated objectives for young people with intellectual disabilities.
17. Colleges should develop strong partnerships with local supported employment agencies to provide job finding and work-based support to help young people with intellectual disabilities bridge the gap they still face in graduating into jobs.

### *Funding*

18. Governments in the UK should take steps to ensure that there is greater flexibility in funding of services that can provide individual support young people's transition from school to college and employment, and from training into employment.

## **Recommendations on employment**

### *Modification of the welfare benefits system*

19. The Government should abandon the requirement that applicants for the Permitted Work concession must demonstrate that the work they undertake would "improve or maintain their condition."
20. The Government<sup>9</sup> should explore a more flexible approach to bridging the gap between Incapacity Benefits and the Tax Credits. This should address in particular the 100 per cent taper in Income Support on entering employment, and the inflexibility of the 16 hours per week boundary between Incapacity Benefit and the Working Tax Credit. One possibility would be to extend the lower hours limit of the Working Tax Credit downwards, and allow individuals to opt into it at a different stage, which would, in effect, create a hybrid benefit for people working less than 16 hours, and an in-work credit for people working more than 16 hours.
21. The Government should consider ideas for a more radical reform in the future. This could include:

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<sup>9</sup> Primarily the Department of Work and Pensions and the Inland Revenue.



- Abandoning “incapacity” as an organising principle and replacing it with compensation for “disadvantage in the labour market”. This would remove inherent contradiction between any form of move to work and receiving protection offered by special benefit status. A case in point concerns young people who wish to claim the new non-contributory form of Incapacity Benefit, who will have to declare themselves “incapable of work” before they have had a chance to explore what work means.
- Integrating the Tax Credits and Incapacity Benefits into a single structure that values all forms of work, while providing a guaranteed minimum income should people not be in work, along with continuous and progressive incentives for individuals to work longer hours. By combing both these changes, it would be possible to do away with the need for the Permitted Work Concession, to provide greater financial security through permanent links back to previous levels of financial assistance for people who continue to be at a disadvantage in the labour market.

### *Employment services*

22. Governments in the UK should improve individual planning for people who have greater support needs, including people with more severe intellectual disabilities. Person-centred planning for people who have greater support needs can be time consuming, and it is unlikely that Personal Advisors with large caseloads will be able to undertake this kind of activity on any scale. In such cases, Personal Advisors should be able to contract out the task of vocational profiling to specialist agencies which have the appropriate skills; PA’s should have resources to pay for this service; and should be able to commission services flexibly, in ways that realise the outcomes of this planning process.

### *Enhancing the WORKSTEP programme*

23. The Government should gather information on good practice and innovation in the WORKSTEP programme that cater effectively for people with intellectual disabilities- for example, some WORKSTEP providers have offered individualised support to job applicants and providers- and share such experience across providers.
24. The Government should move WORKSTEP to a support model, rather than a programme model. An important cultural change involves moving away from an assessment process which focuses on eligibility for fixed programmes, and replacing it with individualised action planning, designed to establish what support each individual needs. Thus people should be regarded as “employable” when they want to work and require support.

25. The Government should improve the capacity of the WORKSTEP programme. In particular, the work of WORKSTEP providers could be built on, to encourage individualised support to people with intellectual disabilities and employers, by:
- Combining with other funding sources (such as health and social services) to provide long-term support to those people who need it;
  - Redefining “progression”, within the WORKSTEP context, to include increases in responsibility, job status, hours and wages, as well as independence. This would encourage providers to support individuals’ career development.
  - Increasing available funding and working with providers to increase availability of the full supported employment model.

### *Government leadership*

26. The Government should ensure that the recommendations of the *The Same as You?* report in Scotland are also taken into consideration for improving services in other parts of the UK.
27. The new Equality Duty<sup>10</sup> on public sector organizations is welcomed, and urge Governments in the UK should encourage local authorities, health trusts and other public bodies across the UK to give much greater priority to developing a range of employment opportunities for people with intellectual disabilities. Local authorities and health trusts should, in particular, lead by example by employing more people with intellectual disabilities within their own workforces.
28. The Government should take steps to ensure that people with intellectual disabilities do not fall between the many services and welfare benefit systems that the Government has in place. One idea would to consider commissioning a “social exclusion report”<sup>11</sup> to draw together the issues, and plan to close the gaps that exist.
29. DWP/Jobcentre Plus should take steps to ensure that their services are tailored to the needs of people with intellectual disabilities. In particular:

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<sup>10</sup> The DDA 2005 will require larger public sector organizations to draw up a Disability Equality Scheme to set out how they are actively promoting equality for disabled people. This might include prioritising those disabled groups that have the least presence in the workforce, and changing policies and procedures when they are forming a barrier to equality.

<sup>11</sup> The Government’s Social Exclusion Unit have completed cross-departmental analyses of issues causing social exclusion to particular groups (e.g. *Mental Health and Social Exclusion*, <http://www.socialexclusionunit.gov.uk/page.asp?id=5> (accessed 31 August 2005).

- Personal Advisors, those implementing Jobcentre Plus and DEA teams, should be positive in identifying what work tasks people with intellectual disabilities could do, what work environments would best suit them, and what it would take to support them in jobs.
- There should be increased flexibility in the forms of support that can be funded.
- There should be a shift from a culture of assessing a person's "job readiness", to profiling what people could do with effective support and training, which is crucially important for people with intellectual disabilities.

### *Interagency coordination*

30. There should be improved collaboration between Jobcentre Plus, the specialist supported employment sector, and other key Government departments with an interest in developing employment for people with disabilities (Department of Health), as well as other critical players (for example the Social Firms movement).<sup>12</sup>
31. Such collaboration should, in particular, focus on the large-scale development of training materials designed to improve training for Personal Advisors, WORKSTEP and other staff geared to equipping people with appropriate skills.

### *Supported employment*

32. The Government should make changes to the way supported employment is funded, to enable it to meet the needs of more people with intellectual disabilities. In particular, core funding should be made available for the full model of supported employment from central Government sources.
33. The Government should take a lead in assuring quality in the provision of supported employment services, by introducing quality standards for supported employment providers. These could be based on those that already exist within WORKSTEP, but would reflect good practice specifically in the full supported employment model.

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<sup>12</sup> Social firms are a form of social enterprise set up with the aim of employing people with disabilities and disadvantages in the open labour market. See <http://www.socialfirms.co.uk> (accessed 31 August 2005) for more information.

Throughout Europe, people with intellectual disabilities face overwhelming stigma and prejudice and encounter significant barriers to realising their fundamental rights. EUMAP, the EU Monitoring and Advocacy Program of the Open Society Institute, in cooperation with the Open Society Mental Health Initiative, has monitored this situation in 14 countries throughout Europe, both EU members and candidate countries: *Bulgaria; Croatia; the Czech Republic; Estonia; Greece; Hungary; Latvia; Lithuania; the Netherlands; Poland; Romania; Slovakia; Slovenia* and *the UK*. Carried out by local experts and civil society groups, the monitoring focuses on the extent to which people with intellectual disabilities have access to education and employment. This series of reports presents the findings of the monitoring and also makes recommendations for improving the social inclusion of people with intellectual disabilities.

The summary reports resume the main findings – Executive Summary and Recommendations – of each of the country reports. The complete set of country reports, in English and translated to national languages, can be accessed online at: [www.eumap.org/topics/inteldis/reports](http://www.eumap.org/topics/inteldis/reports). Hard copies can be ordered at: [www.eumap.org](http://www.eumap.org).



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