

*Access to Education and Employment for
People with Intellectual Disabilities:
An Overview of the Situation in Central and Eastern
Europe*

Open Society Mental Health Initiative
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Access to Education and Employment for People with Intellectual Disabilities: An Overview of the Situation in Central and Eastern Europe

A. Executive Summary and Recommendations

1. Introduction and Context

Purpose and scope of this paper

This paper provides a general overview of the situation of people with intellectual disabilities living in Central and Eastern Europe (CEE), with a particular focus on access to education and employment, and suggests steps to be taken to address barriers to their social inclusion. [See Box 1 for a definition of intellectual disability.] The paper is based on a series of country reports that were prepared by the Open Society Institute's EU Monitoring and Advocacy Program (EUMAP) and the Open Society Mental Health Initiative (MHI) on access to education and employment for people with intellectual disabilities. The CEE Country Reports considered in this paper are: Bulgaria, Croatia, Estonia, Hungary, Latvia, Lithuania, Poland, Romania and Slovenia.

Importance of access to education and employment

Ensuring equal opportunities to receive education and gain employment is crucial to achieving social inclusion for all citizens and enabling individuals to live and work in the community. These opportunities are central to European Union strategic policy objectives such as putting Europe back on the path of long-term prosperity, achieving full employment, ensuring equal rights for all citizens, and fighting against discrimination.

Overview of the Country Reports

The Country Reports paint a bleak picture for people with intellectual disabilities living in CEE. All of them, with one exception, describe very limited access to both education and employment for people with intellectual disabilities. While the Lithuania Country Report highlights some positive progress in providing access to education for children with intellectual disabilities, its findings in connection with access to employment are similar to those of the other Country Reports. It points out that there are almost no people with intellectual disabilities in any form of employment.

Institutionalisation and the lack of community-based services

Despite many positive political and economic developments across CEE in the last fifteen years, many people with intellectual disabilities continue to be placed in long-term residential institutions where they are often subjected to severe human rights violations. These institutions are generally situated in remote, rural areas which are difficult to access by public transport. Many residents receive visitors rarely, if at all. Consequently, residents are physically and emotionally cut off from the outside world.

Although in some parts of CEE high-quality community-based services are being provided, such services are few and far between. The lack of community-based services means that even those who are not segregated in institutions are socially excluded because there is little support to facilitate their participation in community life. This long-term social exclusion is the most significant barrier to access to education and employment for people with intellectual disabilities in CEE.

2. Access to Education

‘Everyone has the right to education and to have access to vocational and continuing training’
(Article 14 of the EU Charter on Fundamental Human Rights)

While progress has been made in many of the countries monitored, access to education for children with intellectual disabilities is generally poor across CEE. Country Reports identify significant problems such as lack of training for teachers in the special needs of children with intellectual disabilities and a lack of funding for the necessary supports to enable children with intellectual disabilities to be integrated into mainstream education. The main issues are:

- Inadequate procedures for assessment and diagnosis
- Lack of early intervention services [See Box 2 for a description of early intervention services.]
- Limited opportunities for attending mainstream schools
- Inadequacy of education at special schools
- Little or no education provided to children in institutions

3. Access to Employment

‘Everyone has the right to engage in work and to pursue a freely chosen or accepted occupation.’
(Article 15 (1) EU Charter of Fundamental Rights)

Throughout CEE, there is a high rate of employment due to the struggling economies in the region. No doubt this situation exacerbates the appallingly low access to employment for people with intellectual disabilities, as all the CEE Country Reports note that few people with intellectual disabilities are engaged in employment of any kind. The economic situation is not the only factor for these findings, however. There are additional significant barriers for people with intellectual disabilities in gaining employment.

Education systems across CEE are poorly adapted to the needs of children and young people with intellectual disabilities. While improvements are being made in some countries, past inadequate provision of education for children with intellectual disabilities has left most of this population, now adult, ill-equipped to seek paid employment. As an example, the 2001 national census in Hungary revealed that over one-third of people with intellectual disabilities aged 15 or over did not complete the first year of primary school. The Hungary report notes that employment prospects for such individuals are dismal.

In some countries, incentives for people to find work are limited by the structure of social welfare benefits. For example, the Romania Country Report notes that people are forced to choose between disability benefits and employment. While benefits are extremely low, they are half the minimum wage and offer greater security than many jobs, and consequently many people with disabilities opt to continue receiving benefit payments. Similar comments were made in the Estonia country report.

The main factors contributing to the low employment rate of people with intellectual disabilities are as follows:

- Lack of transitional services
- Restrictive assessments of capacity to work
- Discriminatory attitudes of potential employers
- Guardianship
- Lack of supported employment schemes [See Box 4 for a definition of supported employment.]

4. Conclusions and Recommendations

Each CEE country has its own particular challenges in promoting the rights and social inclusion of people with intellectual disabilities as well as opportunities for initiating positive change. However, some barriers to access to education and employment are common to all the CEE countries. The most significant is the continued institutionalisation of people with intellectual disabilities and the dearth of alternative community-based services. Although in many CEE countries the need for deinstitutionalization is accepted in principle, it is still not put into practice. This lack of action is partly attributable to the stigma and discrimination faced by people with intellectual disabilities, as well as to the lack of knowledge and expertise in government about how to close institutions. Another significant barrier to access to employment for people with intellectual disabilities is guardianship. Many people under guardianship are denied their right to work while the system of plenary guardianship represents an unjustified restriction of human rights.

Until these barriers are addressed, the social inclusion of people with intellectual disabilities will continue to be illusory.

Many of the steps to be taken to improve access to education and employment for people with intellectual disabilities, and to advance their social inclusion overall, are matters for European Union (EU) Member States. However, the EU has a crucial role in highlighting the urgent need for such action to be taken; developing strategies and action plans that facilitate such activities (by for example demonstrating the link between EU objectives and increasing access to education and employment for disabled people); and encouraging co-operation amongst Member States.

MHI therefore recommends that the following areas be given priority by policy makers at both national and European levels:

- **Promoting Deinstitutionalization:** The unjustified segregation of people with intellectual disabilities in long-stay institutions is not acceptable and constitutes a severe human rights violation. Beginning the process of closing institutions is an essential next step in promoting social inclusion and protecting the human rights of people with intellectual disabilities, and this work must be undertaken in parallel to developing comprehensive community-based services. Governments must, as a priority, plan and implement policies that require the closure of long-stay institutions and the development of community-based alternatives.
- **Developing Specific Services to Improve Access to Education:** Comprehensive community-based services, including early intervention services, must be developed so that these become available nationwide rather than only to the lucky few.
 - A number of Country Reports highlighted concerns about deficiencies in the procedures for assessing and diagnosing children with intellectual disabilities, and in some countries the disproportionately high number of Roma children assessed as needing placement in special schools was identified as a serious concern. In such countries it is vital that assessment procedures are thoroughly re-evaluated.
 - All CEE countries are party to the ECHR which provides a right to education. Despite this, in many countries hundreds of children are receiving little or no education, often because they are living in institutions where education is not provided. This is unacceptable, and policy-makers must act to ensure that education is made available to all children. Urgent action must be taken to provide community-based services as an alternative to placing children in institutions in the first place.

- **Developing Services to Improve Access to Employment:** Access to the open labour market is crucial to the social and economic integration of people with intellectual disabilities. It allows people to earn a living and to participate more fully in community life. Meaningful work also promotes dignity and independence. To address the extremely high level of unemployment among people with intellectual disabilities, it is necessary to develop policies and other measures such as vocational training and supported employment.
- **Reforming Guardianship:** The current guardianship system in many CEE countries, one which provides extensive powers to guardians and offers inadequate safeguards to those individuals deemed to lack capacity, should be replaced by a system that takes into account the fact that people may lack capacity to make some decisions at certain times but retain capacity to make other decisions at other times. The Commissioner of Human Rights, Council of Europe has called for the implementation of Recommendation No R(99)4 of the Committee of Ministers to Member States on Principles Concerning the Legal Protection of Incapable Adults. This sets out principles for establishing a legal framework for substitute decision-making where such action is required while protecting the rights of those individuals who may lack capacity.

B. Access to Education and Employment for People with Intellectual Disabilities: An Overview of the Situation in Central and Eastern Europe

1. Introduction

The Open Society Mental Health Initiative

The Open Society Mental Health Initiative (MHI), a program of the Open Society Institute, aims to ensure that people with mental disabilities (mental health problems and/or intellectual disabilities) are able to live in the community and to participate in society with full respect for their human rights. MHI works in Central and Eastern Europe and the former Soviet Union.

Purpose and scope of this paper

This paper provides a general overview of the situation of people with intellectual disabilities¹ living in Central and Eastern Europe (CEE), with a particular focus on access to education and employment, and suggests steps to be taken to address barriers to their social inclusion. [See Box 1 for a definition of intellectual disability.]

The paper is based on a series of country reports that were prepared by the Open Society Institute's EU Monitoring and Advocacy Program (EUMAP) and MHI on access to education and employment for people with intellectual disabilities.² Such reports were published for Bulgaria, Croatia, Estonia, Greece, Hungary, Latvia, Lithuania, the Netherlands, Poland, Romania, Slovenia, and the United Kingdom. Access to education and employment for people with intellectual disabilities were the focus of the reports because people with intellectual disabilities are one of the most marginalised groups in today's society. Monitoring their access to education and employment provides indicators of the degree to which people with intellectual disabilities are included in society.

This paper focuses on the key issues arising from the nine CEE countries monitored (referred to in this paper as 'the Country Reports'), but, for comparative purposes, some reference is also made to the reports on Greece, the Netherlands, and the United Kingdom.

Box 1: Definition of Intellectual Disabilities

The term 'intellectual disability' (also described as 'learning disability,' 'developmental 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 characterized by much lower-than-average intellectual ability and results in significant limitations in intellectual functioning and adaptive behaviour as expressed in conceptual, social, and practical adaptive skills.

¹ Although this report focuses on issues relevant to people with intellectual disabilities, many of the findings and recommendations will be equally relevant to people with mental health problems.

² Detailed information can be obtained from the individual Country Reports. These are available on MHI's website <http://www.osmhi.org/index.php?page=202&news=89&pages=&archive=&pastevent=> and at: <http://www.eumap.org/topics/inteldis>. Each Country Report sets out recommendations for addressing the concerns that have been identified and to promote the social inclusion of people with intellectual disabilities.

2. The European Union Policy Context

Importance of access to education and employment

Ensuring equal opportunities to receive education and gain employment is crucial to achieving social inclusion for all citizens and enabling individuals to live and work in the community. These opportunities are central to European Union strategic policy objectives such as putting Europe back on the path of long-term prosperity, achieving full employment, ensuring equal rights for all citizens, and fighting against discrimination.³

Article 13 of the Treaty of Amsterdam (1999) authorizes the European Union (EU) to take action to combat discrimination based on a range of grounds, including disability. An example of such action is the introduction of the EU Directive on Equal Treatment in Employment (2000).⁴ This Directive requires Member States to prohibit discrimination on a number of grounds, including disability, in the areas of employment and training.

In July 2003, the Council of the EU issued a resolution on ‘promoting the employment and social integration of people with disabilities.’⁵ The resolution called upon Member States and the Commission to undertake a range of activities including to:

‘continue efforts to remove barriers to the integration and participation of people with disabilities in the labour market, by enforcing equal treatment measures and improving integration and participation at all levels of the education and training system’

Member States were also requested to ‘collect statistical material on the situation of people with disabilities.’

While acknowledging that education is a matter for individual Member States, the European Commission encourages cooperation in this area. In May 2003, the Council of the European Union issued a resolution on ‘equal opportunities for pupils and students with disabilities,’ noting ‘the need for further appropriate measures to improve access of persons with disabilities to education and training’ and inviting Member States and the Commission to undertake various activities including encouraging and supporting the full social integration of children and young people with special needs ‘through their appropriate education and training and their insertion in a school system which is adapted to their needs.’⁶

Human Rights and Disability

The protection and promotion of human rights forms one of the central principles of the European Union,⁷ and since the formulation of the ‘Copenhagen Criteria’ for membership to the EU in 1993, human rights issues have been ‘at the forefront of the accession process.’⁸ The introduction of the European Union Charter of Fundamental Rights (the EU Charter) not only emphasises the importance of human

³ Strategic Objectives 2005 – 2009, Europe 2010: A Partnership for European Renewal, Prosperity, Solidarity and Security, Communications from the President in agreement with Vice President Wallstrom, COM(2005) 12 final

⁴ Council Directive 2000/78/EC. Further information is available at: <http://europa.eu.int/scadplus/leg/en/cha/c11414.htm>

⁵ (2003/C 175/01)

⁶ Council Resolution of 5 May 2003 on equal opportunities for pupils and students with disabilities in education and training (2003/C 134/04)

⁷ Council of the European Union (2002) *European Union Annual Report on Human Rights 2002*. Luxembourg: Office for Official Publications of the European Communities.

⁸ Williams, A., (2004) *EU Human Rights Policies – A Study in Irony*. Oxford: Oxford University Press.

rights but also reflects a shift in approach from viewing people with disabilities as passive recipients of care to recognising that people with disabilities are equal citizens.⁹

This viewpoint is illustrated by Article 26 of the EU Charter:

'The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.'

The European Parliament's explanatory note to Article 26 points out that it is linked to Article 15 of the European Social Charter which sets out the rights of persons with disabilities to independence, social integration, and participation in community life and that these are objectives which require positive action by the public authorities. It adds:

*'Article 26 of the Charter establishes the "right to benefit from measures" ensuring persons with disabilities independence and integration in the community. Such measures concern a range of areas including education and vocational training.'*¹⁰

The United Nations (UN) Standard Rules on the Equalization of Opportunities for Persons with Disabilities ('the UN Standard Rules')¹¹ are the basis for the European Commission's disability policy. The UN Standard Rules seek to ensure that all people with disabilities, 'as members of their societies, may exercise the same rights and obligations as others.' Although not legally binding, the UN Standard Rules are regarded as a useful guide to the implementation and interpretation of legally binding international human rights treaties. The UN Standard Rules cover education and employment as follows:

- **Rule 6 (Education):** *'States should recognise the principle of equal primary, secondary and tertiary educational opportunities for children, youth and adults with disabilities, in integrated settings. They should ensure that the education of persons with disabilities is an integral part of the education system.'*
- **Rule 7 (Employment):** *'States should recognise the principle that persons with disabilities must be empowered to exercise their human rights, particularly in the field of employment. In both rural and urban areas they must have equal opportunities for productive and gainful employment in the labour market.'*

The European Action Plan for disabled people 2006 – 2007

The introduction to the European Commission's European Action Plan for disabled people 2006 – 2007¹² (the Disability Strategy) states:

'Equality of opportunity is the objective of the European Union's long-term strategy on disability, which aims to enable disabled people to enjoy their right to dignity, equal treatment, independent living and participation in society.'

Ensuring equal access to education and employment is essential if equality of opportunity is to be achieved. Without access to education, an individual's opportunities to work are extremely limited. Without employment, individuals are reliant on state benefits and/or the support of friends and family. Being out of work and on a low income limits opportunities to engage in social activities.

⁹ See notes on Article 26, section 4 *Summary of European Union Policy*. Available online:

www.europarl.eu.int/comparl/libe/elsj/charter/art26/default_en.htm

¹⁰ http://www.europarl.europa.eu/comparl/libe/elsj/charter/art26/default_en.htm

¹¹ Available at: www.un.org.esa/socdev/enable/dissre00.htm

¹² Situation of disabled people in the enlarged European Union: the European Action Plan 2006-2007, COM(2005)604

The Disability Strategy highlights the connection between education and employment:

*'The inactivity rate of disabled people is twice that of non-disabled people, indicating both low levels of reintegration following LSPHD [long-standing health problem or disability], and comparatively low educational and vocational training levels.'*¹³

Statistics in all Member States show a correlation between the prevalence of LSPHD and the level of education, although the Disability Strategy notes that this could be caused either by disability at birth or during childhood which limits the possibility of education, or because people with a low education have non-qualified jobs in dangerous environments.

3. The Situation of People with Intellectual Disabilities in Central and Eastern Europe

Overview of the Country Reports

The Country Reports paint a bleak picture for people with intellectual disabilities living in CEE. The reports on Bulgaria, Estonia, Hungary, Latvia, Poland and Romania describe access to education and employment as 'highly limited,' 'severely limited,' or 'very limited.' Whereas the Lithuanian report is positive about progress in the integration of children with intellectual disabilities into mainstream schools (estimating that nearly 8,000 such children are in mainstream schools), this is in stark contrast to the level of access to employment in Lithuania which is 'extremely limited; almost none have any form of employment or work.'

In Slovenia, progress on integrated education is reported to be at an early stage with very little improvement for access to education for children with intellectual disabilities. The situation in employment is similar to that of the other countries, being 'extremely minimal.'

The Croatia Country Report summarises the level of access to education and employment for people with intellectual disabilities in Croatia as follows:

*'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 ... offered only through NGOs that can reach only a tiny fraction of those who would benefit.'*

The EU Disability Strategy states that 40% of disabled people are employed as compared to 64.5% of people without disabilities and remarks that this statistic merits serious concern. It should therefore be of even greater concern that the Country Reports suggest that the figure for people with intellectual disabilities in employment in CEE is significantly below 40%, in some countries virtually zero.

¹³ Page 5 of the Disability Strategy

Institutionalisation and the lack of community-based services

Despite many positive political and economic developments across CEE in the last fifteen years, many people with intellectual disabilities continue to be placed in long-term residential institutions where they are often subjected to severe human rights violations.¹⁴ These institutions are generally situated in remote, rural areas which are difficult to access by public transport, thereby limiting opportunities for families and friends to visit. Consequently, residents are physically and emotionally cut off from the outside world.

An in-depth study of residential institutions in France, Hungary, Poland, and Romania (funded by the European Commission) found that:

Residents often live lives characterized by hours of inactivity, boredom, and isolation. Staff numbers are frequently too low to provide habilitation and therapy. The physical environment is relatively impersonal and does not provide the kind of privacy and homeliness that the general population expect[s]. Contact with family, friends and community is limited. In this situation practices develop that should be unacceptable, such as keeping people in bed all day or the use of cage beds to confine people.’¹⁵

Unsurprisingly, the study concluded that institutional care has a significant negative impact on the quality of life of the residents.

Although in some parts of CEE high-quality, community-based services are provided, such services are few and far between. This lack of services means that those who are not segregated in institutions remain socially excluded because there is little support to facilitate their participation in community life. Thus, the most significant barrier to access to education and employment for people with intellectual disabilities in CEE is that they are segregated from the rest of society.

A number of the Country Reports highlight the slow process of deinstitutionalisation as a major concern. For example, the Hungary Report states:

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 report adds that the main reason for this situation is a lack of community-based services. It states that although they do not wish to do so, parents are often:

‘compelled to institutionalise their children due to lack of adequate community-based support services.’

The Latvia Country Report also comments on the slow deinstitutionalisation process and affirms that a significant number of children are still living in institutions. The report urges:

‘As a priority, the Government should ensure that alternative community care services, such as day centres and residential community facilities (for example group homes) are made available for people with intellectual disabilities throughout the country.’

¹⁴ See for example Amnesty International Bulgaria, *Far from the eyes of society: Systematic discrimination against people with mental disabilities*, Amnesty International, 2003

¹⁵ *Included in Society: Results and Recommendations of the European Research Initiative on Community-based Residential Alternatives for Disabled People*. Editors: Geert Freyhoff, Camilla Parker, Magali Couc, Nancy Greig, October 2004. www.community-living.info.

Deinstitutionalisation and the development of community-based services

The importance of developing comprehensive, community-based services alongside the closure of institutions is highlighted in the Greece Country Report. While acknowledging the progress that has been achieved over the last 25 years, the report identifies a continuing problem with access to education and employment:

'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 service of any kind. Some regions of the country ... do not have the necessary structures and resources to meet the needs of people with all levels of intellectual disabilities.'

The need to turn policies into action

Another theme running throughout most of the reports is a frustration that, while Governments have produced policies or legislation that have the potential to improve the lives of people with intellectual disabilities, the implementation of such policies and legislation is slow or inadequate. For example, Hungary has a comprehensive disability policy, the National Programme on Disability Affairs, which addresses education and employment. However, the Hungary Country Report notes that implementation has been slow and that 'most foreseen projects have not yet been realised.'

Furthermore, concern about governmental failure in implementing policy is not confined to CEE countries:

'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 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 the policy for people with disabilities in general, and the programmes intended for their benefit fail to produce results.'

Poor collection of data

In all nine CEE Country Reports, concerns were raised about the absence of comprehensive, reliable data on people with intellectual disabilities. This situation is partly a result of insufficient data-gathering processes, as research findings generally do not disaggregate by type of disability, making it difficult to determine what applies to people with intellectual disabilities and what does not. The lack of sufficient data is also due to problems with terminology. Many reports note a reliance on out-dated and stigmatising terms in relevant legislation and diagnostic procedures; a lack of, or inconsistencies in, the definition of 'intellectual disability;' and inconsistencies in the application of terms in the diagnostic process. As an example, the Bulgaria report notes that the

'four different bodies assessing disabilities 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) ... However this data does not include all people with intellectual disabilities and the lack of standardised diagnosis procedures casts some doubt on its reliability'.

4. Access to Education

'Everyone has the right to education and to have access to vocational and continuing training'

(Article 14 of the EU Charter on Fundamental Human Rights)

While progress has been made in many of the countries monitored, access to education for children with intellectual disabilities is generally poor across CEE. Country Reports identify significant problems such as lack of training for teachers in the special needs of children with intellectual disabilities and a lack of funding for the necessary supports to enable children with intellectual disabilities to be integrated into mainstream education. The main issues are:

- Inadequate procedures for assessment and diagnosis
- Lack of early intervention services [See Box 2 for a description of early intervention services.]
- Limited opportunities for attending mainstream schools
- Inadequacy of education at special schools
- Little or no education provided to children in institutions

Inadequate procedures for assessment and diagnosis

In most of the countries monitored, children with intellectual disabilities are categorised into one of four broad categories of disability: 'mild,' 'moderate,' 'severe,' and 'profound.' The procedures used in determining such categories as well as the quality of such procedures vary from country to country. For example, in Lithuania there have been positive changes to the education system, and the Lithuania Country Report notes that the assessment procedures used to assign special education are effective:

'Parents are generally satisfied and feel that they and their children are adequately consulted, and that parental choice is reflected.'

However, such positive reports are not the case in many other countries. The Bulgaria Country Report raised serious concerns about assessment procedures, stating that the process 'is often superficial, inconsistent, and fails to take into account the individual capacity and potential of the child under examination.' In Slovenia, there have been reforms to the assessment procedures but '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.' In Poland the assessments are carried out by multi-disciplinary specialist teams in psychological-educational counselling centres but 'the quality ... varies. The centres are often understaffed and overworked and the equipment for therapy and diagnosis is often inadequate.'

The reports for Bulgaria, Hungary, Slovenia, and Romania highlight the disproportionately high number of Roma children diagnosed with intellectual disabilities. In Romania, research from 2001 indicated that up to 70% of the students in special schools are Roma.¹⁶ In Hungary, the report notes that, according to the 2001 Census, Roma accounted for 1.9% of the total population and a comparable percentage (2.1%) of all people with disabilities:

¹⁶ European Roma Rights Center, *State of Impunity: Human Rights Abuse of Roma in Romania, 2001*, p. 64 available at www.errc.org/publications/reports/romaniaE_2001.doc

‘However, Roma comprised a staggering 29.4 percent (16,700 people) of the total number of people with intellectual disabilities. This statistic reveals the alarming frequency with which Roma children are routinely misdiagnosed with intellectual disabilities, and it highlights the fallibility of the diagnosis process itself. Roma children are also significantly over-represented in special schools.’

The Poland Country Report notes concerns about the number of Roma children without intellectual disabilities being placed in special schools. Following complaints from Roma associations there is currently ‘much stricter control and such misdirection now rarely occurs.’¹⁷

Lack of early intervention services

Early intervention involves services and other support that is provided to infants and young children and their families and that aims to maximise the children’s development and inclusion. Neurologists and special educators have noted that early intervention services are extremely important for children with intellectual disabilities, because these services assist children in the development and maintenance of skills during a critical developmental period, and they enable children with intellectual disabilities to narrow developmental gaps. Early intervention services can also help to ease a child’s integration into a mainstream educational setting. Children with intellectual disabilities who do not have access to early intervention services consistently demonstrate less aptitude in communication, movement, intellectual and socialisation skills, and their opportunities for future meaningful education are severely limited.

The Country Reports demonstrate that there is a significant range in both the quality and existence of early intervention services across CEE. The Estonia Country Report states that early intervention services for children with intellectual disabilities in Estonia simply do not exist in either practice or legislation. The situation in both Romania and Bulgaria is similar, as in each country early intervention services are provided by only one non-governmental organization. The Poland Country Report states that, ‘while there are positive examples of early intervention services operated by NGOs, at present there is no formalised (governmental) system of early intervention.’

In Croatia, though some early intervention services exist, they are limited. According to parents,

‘many social workers fail to alert parents to the various benefits that may be available to them, either due to a lack of information or even in order to reduce the number of claims for financial support.’

In Hungary, early intervention for all children with special needs is mandated by the Public Education Act. However, the Hungary Country Report explains that in spite of this legislation, access to early intervention services remains limited due to a lack of communication:

‘Parents are often unaware of the existence of ... the available early intervention services until after their children have finished kindergarten, when the services are less effective. The early intervention network in Hungary is inadequate and cannot guarantee equal access to early intervention services throughout the country. While Professional Committees [the primary providers of early intervention services] have a legal mandate to provide early intervention

¹⁷ Concerns about the disproportionate numbers of Roma children being placed in special schools in the Czech Republic was the subject of a legal challenge to the European Court of Human Rights. In February 2006 the chamber of the European Court of Human Rights held, by a majority of 6 – 1, that this practice did not amount to a violation of Article 14 (freedom from discrimination) in conjunction with Article 2 of Protocol 1 (right to education) of the European Convention on Human Rights. (DH and others v the Czech Republic, (Application no. 57325/00), 7th February 2006: <http://www.echr.coe.int/echr/>.) The Court’s decision has been the subject of widespread criticism and leave has been given for the decision to be reviewed by the Grand Chamber. The hearing is likely to be held in early 2007.

services, in practice they rarely do so. As a result, NGOs attempt to fill this gap, and NGO initiatives have inspired the Government to improve the system of early intervention.'

The situation in Lithuania is an exception among the CEE countries monitored. The Lithuania Report states that:

'...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.'

Box 2: What is early intervention?

'Early intervention' describes a wide range of multi-disciplinary services offered to children with developmental disabilities between birth and school age in order to:

- Prevent the development of disabilities;
- Diminish the long-term effects of disability and assist children with disabilities in key areas such as physical, cognitive, linguistic, social and emotional development;
- Support families in maximizing their children's development and fostering the development of children's independent living skills to promote social inclusion; and
- Facilitate inclusion in mainstream education for children with intellectual disabilities.

Limited opportunities for attending mainstream schools

In a number of countries, children with intellectual disabilities, *in theory*, have the right to attend a mainstream school. However, putting this right into practice is dependent on a number of factors, in particular funding. For example, in Latvia very few children with intellectual disabilities attend mainstream school, and it is suggested that this is due to the fact that mainstream schools do not receive 'earmarked subsidies' to enable them to meet the special needs of children with disabilities. The Latvia Country Report also notes a further disincentive, namely the loss of benefits that are available to children attending special schools. If parents move their children from special to mainstream schools, they will lose benefits to free medication, food, and transportation.

The Bulgaria Country Report states that there 'remains a chronic lack of resources needed to promote effective education of children with intellectual disabilities.' The Estonia Country Report states that, in practice, mainstream schools will not enrol children with intellectual disabilities because they cannot provide the necessary support services.

In Poland, it is reported that children with intellectual disabilities are able to attend mainstream schools, but as the necessary supports are not provided, generally 'students with intellectual disabilities start out in integrated schools but transfer to special education as they get older.' Although the Lithuania Country Report has many positive findings in relation to access to education, it notes that in smaller towns options may be limited, and the only choice may be to attend special boarding school. Furthermore, there remain

significant barriers to integration such as a lack of suitably qualified teachers, transportation problems, and a lack of support services for parents of children with intellectual disabilities.

The Hungary Country Report states that parents may only request that their child is enrolled at a specific school if that school has the necessary capacity, including staff and funding, for the type of education required. Consequently, many school directors 'cite lack of capacity when refusing admission to students with intellectual disabilities,' and most parents are thus prevented from enrolling their child in a mainstream school.

The Latvia Country Report notes that one school, the Sabile Secondary School, has been successful in establishing a special class for children with intellectual disabilities, with the children attending several mainstream and physical education classes. The report urges the replication of this model and suggests that in the next stage children with intellectual disabilities should be included in mainstream classes.

The need for mainstream schools to increase their ability to cater to young people with intellectual disabilities is also highlighted in the United Kingdom Country Report. The report identifies a tension between the goal of inclusion and the suggestion that there is a role for special schools in serving young people with severe disabilities:

'The reality is that as others feel the benefit of accessibility measures in mainstream schools, children and young people with severe or profound intellectual disabilities, or people with intellectual disabilities and behavioural problems, will be channelled down the special school route. This thinking is undoubtedly based on notions that special resources, special environments and special methods are the best way to provide education and security for these young people. It is also based on the idea that people with significant intellectual disabilities who share classes with age peers will be disruptive and damaging to the education of others.'

The report points out that this approach has far-reaching adverse consequences:

'This still leaves the prospect of non-disabled generations being deprived of knowing their peers with intellectual disabilities, and vice-versa, and of carrying this lack of knowledge, fear and suspicion into adult life. In employment, employers are needed who are aware of, and responsive to, the needs of people with intellectual disabilities; employers who have been at school with their peers with intellectual disabilities, and so recognise their potential and are keen to make "reasonable adjustments" to help them enter work.'

Inadequacy of education in special schools

Many of the Country Reports raise concerns about the adequacy of education provided in special schools. Descriptions of the standards of education in special schools range from poor (Bulgaria, Croatia, and Greece), inadequate (Romania), variable (Poland), and unclear (Latvia), to 'acceptable and sometimes even excellent' (Hungary). The Latvia Country Report states that there is very little information on the quality of special schools, although individuals interviewed raised concerns regarding the overall quality of education and the lack of motivation of teachers to increase students' level of knowledge. Parents and NGO representatives in Romania reported that the special schools were merely satisfactory, with parents commenting on teachers' 'lack of adequate training, motivation and concern for working with children with intellectual disabilities.' Although the Hungary Country Report is reasonably positive about the quality of education in special schools, it notes that special schools are segregated and foster the social exclusion of the students (most are located outside of town or city centres). Furthermore, materials and staffing vary according to location, funding, and school leadership.

All the CEE countries are party to the European Convention on Human Rights which provides the right to education,¹⁸ and all the CEE countries have the right to education enshrined in national law. However, in some countries this right is not realised for children with intellectual disabilities in institutions:

- In Croatia, children in institutions may lack access to education, as not all residential institutions provide educational programmes. Among those institutions that do provide education to resident children, there is no regular inspection of educational quality.
- In Latvia, there is no legislative framework or Government policy for the education of the 900 children in residential institutions. The Country Report refers to initiatives in two institutions that provided access to education, but ‘in the other residential institutions, children have very limited access to any education.’
- In Lithuania, although on the whole there has been very positive progress in integrated education, the report found that approximately 650 children and young people under the age of 21 were living in boarding homes. These young people 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.’
- In Romania, even special schools exclude children with anything more than mild intellectual disabilities. Statistics available in 2004 indicated that there were 51,779 school-age children with disabilities in Romania, but only 28% of these children were receiving any education. It is not known how many of these children have intellectual disabilities. For many children with moderate to profound intellectual disabilities there are no educational options at all.

5. Employment

‘Everyone has the right to engage in work and to pursue a freely chosen or accepted occupation.’

(Article 15 (1) of the EU Charter of Fundamental Rights)

Throughout CEE, there is a high rate of unemployment due to the struggling economies in the region. No doubt this situation exacerbates the appallingly low access to employment for people with intellectual disabilities, as all the CEE Country Reports note that few people with intellectual disabilities are engaged in employment of any kind. The economic situation is not the only factor for these findings, however. There are additional significant barriers for people with intellectual disabilities in gaining employment.

As noted above, education systems across CEE are poorly adapted to the needs of children and young people with intellectual disabilities. While improvements are being made in some countries, past inadequate provision of education for children with intellectual disabilities has left most of this population, now adult, ill-equipped to seek paid employment. As an example, the 2001 national census in Hungary revealed that over one-third of people with intellectual disabilities aged 15 or over did not complete the first year of primary school. The Hungary report notes that employment prospects for such individuals are dismal.

¹⁸ Article 2 of Protocol 1 of the European Convention on Human Rights provides ‘No person shall be denied the right to education’.

In some countries, incentives for people to find work are limited by the structure of social welfare benefits. For example, the Romania Country Report notes that people are forced to choose between disability benefits and employment. While benefits are extremely low, they are half the minimum wage and offer greater security than many jobs, and consequently many people with disabilities opt to continue receiving benefit payments. Similar comments were made in the Estonia country report.

Also contributing to the low employment rate of people with intellectual disabilities are:

- Lack of transitional services
- Restrictive assessments of capacity to work
- Discriminatory attitudes of potential employers
- Guardianship
- Lack of supported employment schemes [See Box 4 for a definition of supported employment.]

Lack of transitional services

In all countries monitored, the services offered to assist young people make the transition from education to employment were inadequate. In most of the countries there were little or no support services or vocational training. In the countries where such services are provided (Latvia, Hungary, and Poland) the services do not correspond to labour market needs.

Restrictive assessments of capacity to work

In most countries monitored there exist procedures for assessing a person's capacity to work, and in many countries people with intellectual disabilities are assumed to lack any such capacity. The Lithuania report notes that:

'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.'

The report, however, notes that, at the time of monitoring, the Government was consulting on reforming disability assessment procedures.

The Bulgaria Country Report notes that the body responsible for assessing work capacity 'overwhelmingly finds that people with even *mild* intellectual disabilities have a 70 per cent reduced capacity to work, or no capacity to work at all.' The report also notes that an assessment of 71% or greater reduced working capacity makes it extremely difficult to find work, as most employers are unwilling to hire people with that degree of disability. The Croatia Country Report states that people assessed with a moderate or greater level of intellectual disability are considered unable to work independently 'although this classification is primarily based on IQ and may have little bearing on the person's ability to perform a specific job.'

Discriminatory attitudes of potential employers

In most countries monitored, the EU Employment Directive had either been incorporated into national legislation or was in the process of being transposed.¹⁹ However, some Country Reports raised a concern

¹⁹ Some Country Reports raised concerns whether relevant legislation complied fully with the Directive. The Estonia Country Report noted that, at the time of monitoring, Estonia had not adopted specific legislation to comply with the Directive.

about implementation, in particular that its relevance to people with intellectual disabilities will be overlooked. The scope of the duty to provide ‘reasonable accommodation’ will be a key to the success of such legislation in achieving equal treatment for people with disabilities. Some Country Reports note the concern that employers are likely to be reluctant to make the necessary accommodations. For example, the Romania Country Report notes that the relevant legislation ‘does not measure up to standards set by the EU’s Employment Directive regarding “reasonable accommodation for disabled people”.’ The report adds:

‘Although Romanian legislation stipulates that all employers should ensure all adaptation and facilities that are needed for eliminating all impediments to the employment activities of people with disabilities, in reality, equal treatment in the workplace is not enforced, and employers are unwilling to invest in adaptations and facilities for people with disabilities.’

The Latvia Country Report states that the Latvian legislation introduced to comply with the EU Employment directive does not provide specific provision for people with intellectual disabilities. It therefore suggests that it will be important to take a broad interpretation of ‘reasonable accommodation’ so that this term includes accommodations, such as flexible working times, which will be relevant to people with intellectual disabilities.

Both the Romania and Lithuania Country Reports refer to the negative attitude towards people with intellectual disabilities as a significant barrier to employment. The Bulgarian Country Report recommends that the government prepare a public awareness campaign to highlight the measures needed to support the employment of disabled people and ‘to increase awareness that people with intellectual disabilities can be productive employees.’

Guardianship

In many countries, a major barrier to people with intellectual disabilities gaining employment is the system of guardianship. Although the arrangements for guardianship and the extent to which it is used vary, all Country Reports referred to the existence some form of guardianship system.²⁰ [Box 3 provides a general description of guardianship.]

In some countries, being under guardianship means that the person has no right to work; in other cases, a guardian would need to sign an employment contract; and in some countries it is simply unclear whether or not the right to work exists. In Slovenia, all those under guardianship lose the right to work. The Lithuania Country Report states that, at the age of 18, most people with intellectual disabilities are declared legally incapable and lose the right to work. In Croatia, people under guardianship are presumed to be precluded from working. The Poland Report suggests that a guardian would have to sign an employment contract but acknowledges that the law is unclear. Similarly, the Hungary Report states that it is unclear whether or not those under ‘plenary’ guardianship can work, and there have been cases in which potential employers have refused to employ people because of this lack of clarity.

Both the United Nations and the Council of Europe have raised concerns about the human rights violations that can arise through the use of guardianship. A report to the General Assembly of the United Nations in July 2003 pointed out that guardianship is frequently used to deprive individuals with mental disabilities of their legal capacity, so that they are unable to make some of the most important and basic life decisions, without proper procedural safeguards such as fair hearings or periodic reviews by a competent

²⁰ In Latvia the term ‘guardianship’ refers to a system for minors aged under 18. Adults who are declared by the courts to be “lacking capacity to act” are placed under trusteeship (but this is similar to the system of ‘guardianship’ in other countries. Most adults with intellectual disabilities are not placed under trusteeship (in 2002 1,187 people were under trusteeship.

judicial authority.²¹ The report also noted that guardianship may be used to circumvent laws relating to admission to mental health institutions. The Council of Europe's Commissioner for Human Rights has highlighted similar concerns and has called for the implementation of Recommendation No R(99)4, Concerning the Legal Protection of Incapable Adults.

Box 3: Guardianship

The term 'guardianship' describes the legal arrangements for decision-making on behalf of adults (usually aged 18 years or over) who are deemed by a court to lack the capacity to make decisions for themselves.

There are two types of guardianship: 'plenary' or 'full' guardianship and 'partial' guardianship.

- **Plenary guardianship:** The person loses his or her legal capacity to act and is no longer recognized as an individual before the law. Guardians are given extensive powers, and those subject to guardianship have little or no freedom to make decisions even if they are capable of doing so. In some jurisdictions, individuals placed under plenary guardianship are prevented from making such decisions as whether to get married and from exercising their right to vote in parliamentary elections.
- **Partial guardianship:** This is a less intrusive system whereby a 'guardian' is appointed to make decisions in connection with specific issues about which the individual is considered to lack decision-making capacity. In partial guardianship, guardians have less extensive powers than in plenary guardianship, and individuals are free to make decisions in connection with matters which are not covered by partial guardianship guidelines.

Lack of supported employment schemes

Supported employment services are poorly developed in CEE, with all of the Country Reports identifying the limited availability, or non-existence, of such services. [Box 4 sets out a description of supported employment.] The Latvia Country Report describes what is meant by supported employment and why it is important for people with intellectual disabilities:

'[Supported employment] provides assistance such as job coaches, transportation, assistive technology, specialised job training and individually tailored supervision. It is an important way for people who are traditionally denied employment (due to the perceived severity of their disability) to get jobs and to be provided with long term on-going support.'

Where services for people with intellectual disabilities are available, they tend to be in the form of 'sheltered workplaces.' The Bulgaria country report describes what is meant by 'sheltered workplaces' and explains why they are an inadequate means of enabling people to gain meaningful employment:

'Sheltered workplaces are segregated employment environments which only employ people with disabilities. Such segregated workplaces do not offer real opportunities for people with intellectual disabilities to make the transition to employment on the open market, nor do they promote the social inclusion of people with disabilities.'

²¹ <http://daccessdds.un.org/doc/UNDOC/GEN/N03/443/22/PDF/N0344322.pdf?OpenElement>

Box 4: What is Supported Employment?

Supported employment is a service that facilitates competitive employment in integrated settings on the open market for individuals with intellectual disabilities who have traditionally been denied employment and who need ongoing support to perform their work.

Supported employment services provide assistance such as job seeking and coaching, transportation, assistive technology, specialized job training, and individually tailored support and supervision. NGOs and/or government agencies that provide these services offer intensive and individualized support to people with intellectual disabilities for accessing and maintaining jobs as well as providing ongoing support and consultation to employers and co-workers.

Supported employment services never take place in sheltered workshops or other segregated settings that serve solely people with disabilities.

Although some of the Country Reports have identified good examples of supported employment programmes, these examples are rare. For example, the Country Reports for Croatia, Latvia, and Romania identify only one supported employment programme in each of these countries. Although supported employment seems to be the most developed in Hungary, services are still quite limited, being provided by only five non-governmental organisations. The report notes that supported employment was introduced by the Salva Vita Foundation (a non-governmental organisation) in 1998, and thus far Salva Vita has supported more than 150 people with intellectual disabilities:

'Everyone involved in the programme, including the employers, are satisfied with the foundation's employment services.'

6. Conclusion

Equal access to education and employment are two crucial means of ensuring that people with intellectual disabilities living in CEE are included in society as equal citizens. The individual reports have identified each country's particular challenges in promoting the rights of people with intellectual disabilities and in ensuring that their social inclusion. The recommendations proposed to address these challenges need to be taken forward as a matter of priority. It is essential that national governments work alongside professionals, NGOs, people with intellectual disabilities and their families, and other stakeholders (including international donors) to implement these recommendations. In many countries there are examples of good practice, and it will be important to build on these successes and involve those who have expertise in developing such models of good practice.

Unfortunately, as this paper demonstrates, barriers to access to education and employment can be found throughout the CEE countries. The most significant barriers are the continued institutionalisation of people with intellectual disabilities and the dearth of alternative community-based services. Although in many CEE countries the need for deinstitutionalization is accepted in principle, it is still not put into practice. This lack of action is partly attributable to the stigma and discrimination faced by people with intellectual disabilities as well as to the lack of knowledge and expertise in government about how to close institutions and develop alternative community-based services.

Another significant barrier to access to employment for people with intellectual disabilities is guardianship. Many people under guardianship are denied their right to work, and the system of plenary guardianship represents an unjustified restriction on individuals' human rights.

Many of the steps to be taken to improve access to education and employment for people with intellectual disabilities, and their social inclusion in general, are matters for Member States. However, the European Union has a crucial role in highlighting the urgent need for such action to be taken; developing strategies and action plans that facilitate such activities (by for example demonstrating the link between EU objectives and increasing access to education and employment for disabled people); and encouraging co-operation amongst Member States.

Until the barriers to education and employment are addressed at all levels, the social inclusion of people with intellectual disabilities will be illusory.



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