

# Rights of People with Intellectual Disabilities

Access to Education and Employment

Slovenia

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## 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, and Equal Opportunities for Women and Men. Reports on the Regulation and Independence of the Broadcast Media are also forthcoming in 2005. 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)**, part of OSI's Public Health Programs. 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 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 14 countries monitored, plus an overview report resuming the main findings across all the countries, will be published separately. 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 report reproduced in this volume underwent significant revision based on the comments and critique received during this process. EUMAP assumes full responsibility for its final content.

## Foreword

This report is one of a series of 14 country reports prepared by the Open Society Institute's EU Monitoring and Advocacy Program and the Open Society Mental Health Initiative. The report presents an overview of the opportunities and challenges facing people with intellectual disabilities in accessing education and employment. It provides an important contribution to research on this group, one of the most vulnerable groups throughout Europe.

The initiative of producing this report 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 report goes 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, this report makes 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 this report.

*Geert Freyhoff*

Director  
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# I. Executive Summary and Recommendations

## 1. 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-

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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 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 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.

## 2. 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

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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.

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.

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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).

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.
  - 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.

## II. Country Overview and Background

### 1. LEGAL AND ADMINISTRATIVE FRAMEWORK

*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 Equal Treatment Act, 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 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.*

#### 1.1 International standards and obligations

Slovenia has ratified all major human rights instruments, including those with provisions relating specifically to the rights of people with disabilities. Slovenia succeeded to the International Covenant on Civil and Political Rights<sup>4</sup> (CCPR) and the International Convention on the Rights of the Child<sup>5</sup> (CRC) in 1991; and the International Covenant on Economic, Social and Cultural Rights<sup>6</sup> (CESCR) in 1992.

Slovenia ratified the European Convention on Human Rights and Fundamental Freedoms<sup>7</sup> (ECHR) in 1994 and it has signed, but not ratified, Protocol No. 12 to the ECHR.<sup>8</sup> It also ratified the Revised European Social Charter<sup>9</sup> (RESC) in 1999.

<sup>4</sup> International Covenant on Civil and Political Rights (CCPR), 23 March 1976, 999 U.N.T.S. 171.

<sup>5</sup> International Convention on the Rights of the Child (CRC), 2 September 1990, 44 U.N. GAOR Supp. (No. 49) at 167, U.N. Doc. A/44/49 (1989).

<sup>6</sup> International Covenant on Economic, Social and Cultural Rights (CESCR), 3 January 1976, 993 U.N.T.S. 3.

<sup>7</sup> European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR), 3 September 1953, E.T.S. 005, available on the COE website at <http://conventions.coe.int/Treaty/en/Treaties/Html/005.htm> (accessed 22 October 2004).

<sup>8</sup> Protocol No. 12 to the Convention for the Protection of Human Rights and Fundamental Freedoms, E.T.S. 177 (not yet in force), available at <http://conventions.coe.int/Treaty/en/Treaties/Html/177.htm> (accessed 22 October 2004).

<sup>9</sup> Revised European Social Charter (RESC), 1 July 1999, C.E.T.S. 163, available at <http://conventions.coe.int/Treaty/en/Treaties/Html/163.htm> (accessed 22 October 2004).



Slovenia has ratified all eight fundamental Conventions of the International Labour Organization (ILO)<sup>10</sup> and has also ratified ILO Convention C159 on Vocational Rehabilitation and Employment (Disabled Persons) and ILO Convention C142 on Human Resources Development 1975.<sup>11</sup>

## 1.2 Domestic legislation

In Slovenia, the formal anti-discrimination framework is provided by the Constitution, which ensures equality and prohibits discrimination.<sup>12</sup> On 15 June 2004, the Constitution was amended to specifically include disability (the exact term used is “invalidity”) as an explicitly prohibited ground for discrimination.<sup>13</sup>

Slovenia has incorporated international standards on disability in national legislation. In 1996, it translated the UN Standard Rules on the Equalisation of Opportunities of Persons with Disabilities 1994<sup>14</sup> into Slovenian and published them as a booklet. In accordance with the Rules, Slovenia passed the Sign Language Act 2002<sup>15</sup> and the Invalid Organisations Act 2002,<sup>16</sup> which has enabled better dialogue between the Government and NGOs and other organisations representing people with disabilities and their families.

Slovenia became a member of the EU on 1 May 2004 and has implemented EU legislation pertaining to people with disabilities, including binding Community laws (EU Directives and Resolutions) and non-binding statements of principle (EU

<sup>10</sup> The International Labour Organisation (ILO) has identified eight fundamental ILO Conventions. These are Convention No. 29 on The Abolition of Forced Labour Convention, 1930; Convention No. 87 on Freedom of Association and Protection of the Right to Organize, 1948; Convention No. 98 on Right to Organize and Collective Bargaining Convention, 1949; Convention No. 100 on Equal Remuneration, 1951; Convention No. 105 on Abolition of Forced Labour, 1957; Convention No. 111 on Equality Discrimination (Employment and Occupation) 1958; Convention No. 138 on The Elimination of Child labour Minimum Age, 1973; Convention No. 182 on Worst Forms of Child Labour, 1999.

<sup>11</sup> Slovenia has also ratified ILO Recommendation R168 on Vocational Rehabilitation and Employment (Disabled Persons) 1983.

<sup>12</sup> Constitution of the Republic of Slovenia, Official Gazette 33/91, 42/1997, 66/2000, 24/2003, 69/2004, art. 14 (Equality Before the Law), (hereafter, Constitution).

<sup>13</sup> Constitution, art. 14

<sup>14</sup> Although not a legally binding instrument, the UN Standard Rules represent a strong moral and political commitment of governments to take action to attain equalisation of opportunities for people with disabilities. The rules serve as an important instrument for policy making and also form the basis for technical and economic cooperation. UN Standard Rules on the Equalization of Opportunities of People with Disabilities, adopted by the UN General Assembly 48<sup>th</sup> Session, Resolution 48/96 of 20 December 1993.

<sup>15</sup> Slovenia is one of only 25 countries to have passed such an act. The Sign Language Act 2002, Official Gazette 96/2002.

<sup>16</sup> The Invalid Organisations Act 2002, Official Gazette 108/2002.

Resolutions). In particular, Slovenia has transposed into national legislation the provisions of the European Union's Council Directive 2000/43/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation<sup>17</sup> (hereafter, the Race Equality Directive); and the European Union's Council Directive 2000/78/EC<sup>18</sup> (hereafter, the Employment Directive).<sup>19</sup>

The provisions of the Constitution were supplemented in 2004 by the adoption of the Act on the Implementation of the Principle of Equal Treatment 2004 (hereafter, Equal Treatment Act), which entered into force on 7 May 2004.<sup>20</sup> This act explicitly includes disability (again, the exact term used is "invalidity") as a prohibited ground for discrimination.<sup>21</sup> This act aims to ensure equality for all people, in particular in the areas of education, employment and access to goods and services,<sup>22</sup> and to bring Slovenian legislation fully in line with EU requirements.

The status and rights of people with intellectual disabilities in Slovenia are regulated primarily by:

- The Placement of Children with Special Needs Act 2000 (hereafter, Placement Act).<sup>23</sup>
- The Act on the Social Care of Mentally and Physically Disabled Persons 1983 (hereafter, Social Care Act).<sup>24</sup>

<sup>17</sup> EU Council Directive 2000/78/EC of 27 November 2000, establishing a general framework for equal treatment in employment and occupation, (hereafter, Employment Directive).

<sup>18</sup> EU Council Directive 2000/43/EC of 29th June 2000, implementing the principle of equal treatment between persons irrespective of racial or ethnic origin, (hereafter, Race Equality Directive).

<sup>19</sup> European Commission, *Annual Report on Equality and Non-discrimination 2004*, DG Employment and Social Affairs, European Commission, Brussels, 2004 available on the Commission website at [http://europa.eu.int/comm/employment\\_social/news/2004/jul/annualrep2004\\_en.pdf](http://europa.eu.int/comm/employment_social/news/2004/jul/annualrep2004_en.pdf) (accessed 6 December 2004), pp. 15–16, (hereafter, European Commission, *Equality and Non-discrimination 2004*).

<sup>20</sup> The Act on the Implementation of the Principle of Equal Treatment 2004, Official Gazette 50/2004 (adopted on April 22 2004), (hereafter, Equal Treatment Act).

<sup>21</sup> Article 1 of the Equal Treatment Act: "This law provides the common grounds for ensuring equal treatment for all people who want to implement his or her rights and obligations and for enabling basic freedom in all spheres of social life, especially in the field of employment, working relationship, [...] regardless of any personal conditions such as national background, race or ethnic background, sex, health conditions, invalidity, language, religious or any other belief, age, sexual orientation, education, financial status, social status or other personal conditions."

<sup>22</sup> Equal Treatment Act, art 1.

<sup>23</sup> The Placement of Children with Special Needs Act 2000, Official Gazette 54/2000, 36/2004, (hereafter, Placement Act). NB. The amendments to the act in 2004 were just to correct some minor articles, there were no changes in content.

<sup>24</sup> The Social Care of Mentally and Physically Handicapped Persons Act 1983, Official Gazette 41/1983, (hereafter, Social Care Act).

- The Act on the Vocational Rehabilitation and Employment of People with Disabilities 2004 (hereafter, Vocational Rehabilitation Act).<sup>25</sup>

The Placement Act regulates the placement of children with special needs into different training and education programmes. Although the act was introduced in 2000, it only entered into force in 2003, following the adoption of its implementing regulation – the Regulation on the Organisation and Work of the Placement Commissions for Children with Special Needs and the Criteria for Defining the Sort and Stage of Disabilities<sup>26</sup> (hereafter, Regulation on Placement Commissions and placement criteria). This regulation provides a definition of intellectual disability<sup>27</sup> and of the five levels of intellectual disability used for the diagnosis of children for educational purposes (*borderline, mild, moderate, severe* and *profound*).<sup>28</sup> It also regulates the work of the commissions responsible for diagnosis and placement.<sup>29</sup>

The Social Care Act was passed in 1983 and has not been amended since.<sup>30</sup> At that time, Slovenia was the first Republic of Yugoslavia to pass an act concerning the social care of people with mental and physical disabilities and this act was considered a breakthrough in securing the rights of this group. The act confers on adults (aged over 18) an “invalid status” and entitles them to various types of care.<sup>31</sup> It also provides for their daily, part-time or residential care, in an institution or with a foster family,<sup>32</sup> and guarantees them some financial support, such as the disability allowance and assistance allowance.<sup>33</sup>

The Social Care Act is nonetheless discriminatory and outdated, in that people who have the “invalid status” according to the act (including adults with *moderate, severe* and *profound* intellectual disabilities) are automatically determined as incapable of independent life and work. They can only be placed into training programmes and sheltered workplaces.<sup>34</sup> They can only take up employment if they renounce the

<sup>25</sup> The Act on the Vocational Rehabilitation and Employment of People with Disabilities 2004, Official Gazette 18/76, 8/90, 63/04, 63/2004, (hereafter, Vocational Rehabilitation Act).

<sup>26</sup> Regulation on the Organisation and Work of the Placement Commissions for Children with Special Needs, and on the Criteria for Defining the Sort and Stage of Disabilities 2004, Official Gazette 54/2003, 93/2004, (hereafter, Regulation on Placement Commission and placement criteria).

<sup>27</sup> Regulation on Placement Commission and placement criteria, Line 1

<sup>28</sup> Regulation on Placement Commission and placement criteria, para. 1.

<sup>29</sup> Regulation on Placement Commission and placement criteria, art. 24-35.

<sup>30</sup> The Social Care Act was initiated by the proposal of an organisation called the “Union of Associations for help to mentally retarded people” in order to provide social benefits to people unable to carry out profitable work.

<sup>31</sup> Social Care Act, art. 3.

<sup>32</sup> Social Care Act, art. 3, 4 and 5.

<sup>33</sup> Social Care Act, art. 3, 7.

<sup>34</sup> Social Care Act, art. 1.

“invalid status” and thereby lose the rights to which they are entitled to under the act, including social security benefits.<sup>35</sup>

Slovenia does not have comprehensive legislation on the employment, social integration or rehabilitation of people with disabilities. Vocational rehabilitation is covered by the Vocational Rehabilitation Act, which was last amended in 2004. These amendments introduce important changes in the area of employment for people with disabilities and introduce a right to vocational rehabilitation.<sup>36</sup> However, people with “invalid status” under the Social Care Act, are not covered by the provisions of the Vocational Rehabilitation Act.<sup>37</sup>

Rehabilitation is also partially addressed in the Health Care and Health Insurance Act 2004<sup>38</sup> and regulated by the Compulsory Insurance Rules 2003, which covers both physical and psychological rehabilitation.<sup>39</sup> However, one NGO has indicated that the provisions for physical and psychosocial rehabilitation in the Health Care Act and the Compulsory Insurance Rules are unsatisfactory.<sup>40</sup> Neither provides for the right of *all* categories of people with disabilities to physical and psychosocial rehabilitation and instead list only certain medical diagnoses for which this is possible (intellectual disability is not among them).

### *Specialised bodies*

The Human Rights Ombudsman is the most important institution for informal and out of court protection of “human rights and fundamental freedoms in relation to state authorities, local self-government authorities and bearers of public authority, the office of the ombudsman for the rights of citizens”.<sup>41</sup> The Human Rights Ombudsman has four deputies with competencies in specific areas.<sup>42</sup>

<sup>35</sup> Social Care Act, art. 3, 7, 8 and 9.

<sup>36</sup> Vocational Rehabilitation Act, art. 4.

<sup>37</sup> Article 10 states that “invalidity status” under the Vocational Rehabilitation Act can only be granted to those who do not already have this status according to other laws. Vocational Rehabilitation Act, art. 10.

<sup>38</sup> The Health Care and Health Insurance Act 2004, Official Gazette 9/1992, 13/1993, 126/2003, 20/2004, (hereafter, Health Care Act).

<sup>39</sup> The Compulsory Insurance Rules 2004, Official Gazette 30/2003, 78/2003, 84/2004.

<sup>40</sup> Interview with Tomaž Jereb, director, Association Sožitje, Ljubljana, 1 February 2004. Association Sožitje is an NGO, existing since 1963, which is an umbrella organisation of parents with children with intellectual disabilities. It is comprised of 51 local associations throughout the country.

<sup>41</sup> Constitution, art. 159.

<sup>42</sup> The four Deputy Ombudsmen deal with, respectively, complaints in the field of limitations of personal freedom, social security, court and police procedures; labour relations and administrative matters; constitutional rights, housing, public services, environment and planning; and social security and children's rights.

The Equal Treatment Act foresees the establishment of an advocate (or advocates) for equal treatment, within the Office for Equal Opportunities Department, to deal with alleged cases of discrimination.<sup>43</sup> However, in parliamentary debates there have been some doubts expressed about the real competencies of this advocate, given that this position is within a governmental office and so cannot be considered as strictly impartial. The role of the advocate will also be informal; he or she will only be able to point out breaches of equal treatment, recommend changes and direct the case to a relevant inspectorate.

## 2. GENERAL SITUATION OF PEOPLE WITH INTELLECTUAL DISABILITIES

*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 to be 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*

<sup>43</sup> The Equal Treatment Act extends the competencies of the present advocate for equal opportunities for women and men. Equal Treatment Act, art. 11, 14 and 17.

construction, while children with moderate to profound intellectual disabilities are still automatically referred to residential institutions for educational purposes.

## 2.1 Definitions

At present, the terms “person with disabilities” and “person with intellectual disabilities” are not used in Slovene legislation. Older legislation, such as the Social Care Act, still refers to “invalids” and “mentally retarded persons”<sup>44</sup> and even some more recent legislation has retained these terms. For example, the Constitution has an article on “invalid rights”<sup>45</sup> and the Vocational Rehabilitation Act 2004 similarly uses the term “invalid” throughout.

Some recently adopted legislation is more progressive and introduces less stigmatising terms. The Placement Act and its implementing regulation refer to “children with disturbance in mental development” (children with intellectual disabilities), or use the broader term “children with special needs”. The definition given for a “person with disturbance in mental development” is a person having “poor cognitive, verbal, motor and social skills in comparison to the average skills level of a person of the same age, which reflects an unbalanced development between the mental and chronological age of the person”.<sup>46</sup>

Given these recent changes in terminology, Association Sožitje has highlighted the fact that the Non-litigious Civil Procedure Act 2003 still uses the outdated term “mentally retarded person”.<sup>47</sup> Sožitje is advocating for this inappropriate and stigmatising term to also be replaced by the term “person with disturbance in mental development”.<sup>48</sup> Although this term may also be considered by some to be stigmatising, Sožitje recommends it as the best term to use in future legislation.

The fact that some legislation refers to adults with more severe intellectual disabilities as “children” is also contested. The Association Sožitje has also been active in advocating for legislation referring to adults with intellectual disabilities to consistently use the term “persons” rather than “children”. In particular, the organisation recommended changes to the recently introduced Personal Income Tax Act 2004, although the Government did not accept these changes.<sup>49</sup> This act defines the rights of

<sup>44</sup> Social Care Act, art. 3.

<sup>45</sup> The Slovene title of Article 52 “*pravice invalidov*” is translated as “rights of disabled persons” in the official English translation of the Constitution. Article 52 states that “disabled persons shall be guaranteed protection and work-training in accordance with the law. Physically or mentally handicapped children and other severely disabled persons have the right to education and training for an active life in society. The education and training referred to in the preceding paragraph shall be financed from public funds”. Constitution, art. 52.

<sup>46</sup> Regulation on Placement Commission and placement criteria, Line 1.

<sup>47</sup> The Non-litigious Civil Procedure Act 2003, Official Gazette 30/1986, 20/86-1-changed, 30/1986, 87/2002, 131/2003, (hereafter, Non-litigious Civil Procedure Act).

<sup>48</sup> Interview with Tomaž Jereb, 19 February 2004.

<sup>49</sup> Interview with Tomaž Jereb, 19 February 2004.

people who in accordance with the Social Care Act are considered incapable of work and are cared for after turning 18 years of age; it refers to this group of people as “children” regardless their age.<sup>50</sup>

In 2004, however, there has also been particular debate about the validity of still using the outdated term “invalidity” in new legislation. In June 2004, the Constitution was amended and the term “invalidity” was added as an additional explicitly prohibited ground for discrimination under Article 14. Before this amendment, Article 14 guaranteed equal human rights to all citizens “regardless of nationality, race, gender, language, religion, political and other beliefs, economic status, birth, education, social status, or any other personal circumstance”.<sup>51</sup>

The advocates for this amendment were primarily those organisations which have traditionally represented the interests of people with disabilities in Slovenia and who still use the term “invalid” (these organisations are referred to as “invalid organisations”). Some disability activists believe that those organisations which fought to include the term “invalid” in the Constitution were primarily motivated by maintaining a *status quo* in disability terminology and practice, premised on the medical model of disability, and hence ensuring their own influence.<sup>52</sup> By contrast, disability activists have claimed that the real priorities should instead be the drafting and an implementation of a new Act on anti-discrimination, as the Equal Treatment Act is viewed as too broad and not specific.

There are some substantial differences between the invalid organisations and the disability activist organisations established after 1991, regarding their understanding of the rights of people with disabilities. The activities of invalid organisations are based on a needs-driven approach, retaining the existing public care institutions. The approach of disability activist organisations is based on the concept of the rights to self-determination and independent living of people with disabilities. At present, however disability activist organisations remain systemically marginalised in comparison with the invalid organisations. For example, of all proceeds from the national lottery that go towards the financial support of organisations representing people with disabilities and

<sup>50</sup> Under the Personal Income Tax Act, a person who in accordance with the Social Care Act is considered incapable of working is a “supported family member”, regardless of his or her age. The Personal Income Tax Act 2004, Official Gazette 54/04, 56/04, 62/04, 63/04, art. 109.

<sup>51</sup> Constitution, art. 14 (Equality before the law).

<sup>52</sup> One of those voicing this concern is the disability activist organisation Association for the Theory and Culture of Handicap (YHD) whose members advocated against this change at the Parliamentary Commission for Constitutional Changes in 2003. YHD stressed that the rights of “invalids” are mentioned in the Constitution several times and that disability was already included as a prohibited ground for discrimination in Article 14 under the general ground of any other personal circumstances”. Another disability activist, Rafael Zupančič, wrote a letter on this subject to the President of the Parliament of Slovenia and to Dr. Adolf Ratzka, President of the Institute of Independent Living (IIL), Stockholm. This letter started with the words “to append the word ‘invalidity’ in the Slovenian Constitution would be to support the silent internal discrimination which has been significant for this country for many years”. Rafael Zupančič, email sent on 27 May 2004.

their families, 95 per cent is received by the “traditional” invalid organisations and only five per cent by disability activist organisations.<sup>53</sup>

## 2.2 Diagnosis and assessment of disability

There are different assessments of disability for educational purposes (for children); and for employment purposes and access to social benefits (for adults).

For educational purposes, the Placement Act and its implementing regulation legislate the diagnosis of children with intellectual disabilities and their placement in different educational programmes at the pre-school, primary school and lower vocational levels. The Placement Commissions for Children with Special Needs (hereafter, Placement Commissions), which are under the authority of the National Institute for Education (NIE),<sup>54</sup> are responsible for the diagnosis of intellectual disability.

In the former Yugoslavia, and in Slovenia prior to 2000, Categorisation Committees were responsible for diagnosis. The process of diagnosing a child with a certain level (or category) of intellectual disability is therefore still commonly referred to as “categorisation”. However, this can have a serious stigmatising connotation for the child concerned, as there are commonly many negative stereotypes associated with “categorised children”.

For educational purposes, intellectual disability is diagnosed according to five levels, defined as follows:<sup>55</sup>

- *Borderline* intellectual disability: “an unbalanced development of a child who can, if integrated in a programme of adapted implementation with additional professional help (integration in mainstream schools) achieve minimal required standard of knowledge.”
- *Mild* intellectual disability: “a child has lower learning abilities. In an adapted environment he or she can acquire basic school knowledge, but not equal to the minimal required school standards. With proper treatment they can achieve lower vocational education and capacity for independent social life”.

<sup>53</sup> Recently, the Court of Audit found that the Foundation FIHO, the national organisation which decides on the distribution of the lottery money supposed to be used for national disability (and other) organisations, had invested some money into buying FIHO stocks, instead of dividing the money between applicants. This independent evaluation also established that many of the leading persons of FIHO are also managers in some invalid organisations. Jelena Gačič, “Kdaj spet revizija v FIHU?”, (“When will FIHO again be evaluated?”), in *Daily Delo*, p. 2, 26 May 2004.

<sup>54</sup> The National Institute for Education (NIE) is part of the Ministry for Education and Sport. The NIE is the leading institution for development and expert decision making within primary education. In the case of children with intellectual disabilities, they are obliged to lead formal procedures of categorisation and inclusion. Formally they are supposed to work with kindergartens and schools, and to involve parents and teachers.

<sup>55</sup> Regulation on Placement Commission and placement criteria, para. 1.



- *Moderate* intellectual disability: “specific skills are differently developed. They can learn basic reading, writing and calculation, and can develop better musical, artistic and motor skills. They are able to co-operate in simple conversation and can understand instructions. They can also use different forms of communication, and are able to communicate their needs and wishes. They can take care of themselves to a certain amount, but for rest they need assistance through all of the life. They can perform easy manual tasks”.
- *Severe* intellectual disability: “the child can acquire the simplest skills. He or she often needs care, understands simple messages and responds to them, can orient themselves in a familiar environment. Usually intellectual disability is combined with physical disability or illness”.
- *Profound* intellectual disability: “the child can be involved in some activities, needs constant care, protection, help and assistance. He or she has limited mobility. Often intellectual disability is combined with another condition or illness. Understanding of instruction is very limited”.

For adults (age 18 years old and over), assessments of working capacity and employability are presently made by Expert Commissions, under the National Employment Service. However, following amendments to the Vocational Rehabilitation Act that entered into force on 21 May 2004, new Rehabilitation Commissions have now taken over this responsibility.<sup>56</sup> In practice, however, the Commissions only assess adults with *mild* intellectual disabilities.

Adults are not diagnosed with *borderline* intellectual disabilities. This level of intellectual disability is only considered relevant for educational purposes, when placing children in certain educational programmes. When young people with *borderline* intellectual disabilities enter the labour market, they lose this category and are no longer considered as having disabilities; they are considered able to be employed, as other adults.

Adults with more severe intellectual disabilities (*moderate*, *severe* or *profound* intellectual disabilities) are given “invalid status” under the Social Care Act. They have the right to social security benefits, but are automatically determined as incapable of profitable work, a provision not in line with internationally accepted standards. People diagnosed as having *moderate*, *severe* or *profound* intellectual disabilities retain this diagnosis for life with no opportunity for reassessment. Although they can take up employment, if they renounce the “invalid status” they then lose most of the rights to which they are entitled to under the act, including social security benefits.<sup>57</sup>

<sup>56</sup> Vocational Rehabilitation Act, art. 29-32.

<sup>57</sup> However, they are still able to claim some benefits under the Pension and Disability Insurance Act, such as the *assistance allowance*. Pension and Disability Insurance Act 2004, art. 137–142. Pension and Disability Insurance Act 2004, Official Gazette 106/1999, with latest amendments 136/2004, Odl.US: U-I-273/01-21.

## 2.3 Guardianship

As with the general population, people with *mild* intellectual disabilities acquire full active civil capacity (“*poslovna sposobnost*”, which translates directly as “business capacity”) at the age of 18 years old. They are no longer part of any official Government statistics on people with disabilities and can enjoy equal rights with people without intellectual disabilities.

People diagnosed with *moderate*, *severe* or *profound* intellectual disabilities who have “invalid status” under the Social Care Act are, however, in all cases declared completely or partially incapacitated by the courts, placed under guardianship, and accordingly become eligible for a disability allowance. They do not enjoy the rights of an adult and are dependent on their guardian. In the case that an individual’s civil capacity is completely removed, this is equivalent to *plenary* (full) guardianship, while partial restriction of an individual’s civil capacity is equivalent to *partial* guardianship.

In 2002, there were 4,837 adults under guardianship in Slovenia.<sup>58</sup> There is no State institution with information on how many of these are people with intellectual disabilities.

### *Guardianship procedures*

In Slovenia only the courts can make decisions to restrict or remove an individual’s civil capacity, and appoint a guardian.<sup>59</sup> The grounds for an order restricting or removing an individual’s civil capacity are that the individual is deemed “incapable of taking care of himself of his interests” due to “mental illness, intellectual disabilities, addiction to alcohol or illegal drugs or other reason influencing his/her physical or psychological state”.<sup>60</sup>

In the case of adults with *moderate*, *severe* and *profound* intellectual disabilities who have “invalid status” according to the Social Care Act, the courts determine (full or partial) civil incapacity status after the age of 18 years old in accordance with the Non-litigious Civil Procedure Act. The court procedure can be initiated with a petition from a centre for social work;<sup>61</sup> a public attorney; a spouse or other person who lives with the person in question for a long time; or a relative or close family member (partner, mother, father, sibling, grandparent, uncle or aunt).<sup>62</sup> The person concerned can also

<sup>58</sup> Statistical Office, Statistical Information, 7 July 2003, No. 170, section 12, p. 5, table “Adults – according to some forms of social protection” (in Slovene).

<sup>59</sup> The Marriage and Family Relations Act 2004, Official Gazette 15/1976, 30/1986 (20/1988-1-changed), 1/1999, 14/1989, 13/1994, 82/1994, 29/1995, 26/1999, 60/1999, written order of constitutional law: U-n-273/98, 70/2000, 42/2003, written order of constitutional law: U-l-312/00-40, 16/2004, (hereafter, Marriage and Family Relations Act).

<sup>60</sup> Non-litigious Civil Procedure Act, art. 44.

<sup>61</sup> The centres for social work were established in 1961 and remain to this day the most important institution of social welfare in the country. There are 62 centres for social work, across the country.

<sup>62</sup> Non-litigious Civil Procedure Act, art. 45.

initiate the procedure at his or her own request, if deemed by the court to be “able to understand the meaning and consequences of the procedure”.<sup>63</sup> A specialist doctor first examines the person, then the court makes its decision on the basis of findings, evidence, diagnosis and expert opinions.<sup>64</sup>

If the conditions for ordering guardianship are fulfilled, the court will then determine either partial restriction (*partial* guardianship) or full removal (*plenary* guardianship) of civil capacity. In the past, there were more cases of full removal of civil capacity than is the case at present.<sup>65</sup> Over the last few years, there have been more cases of *partial* guardianship and prolongation of parental rights, which is another form of guardianship.<sup>66</sup> The prolongation of parental rights is most often used in cases where a person is diagnosed with intellectual disability before the age of 18 years old, and the parents’ rights are prolonged after the child attains this age.

In most cases a family member is appointed as the guardian. If the person does not have parents, social welfare institutions (usually the centres for social work) take on the role of legal guardian. In those cases where parents do not want to prolong their parental rights, a social welfare institution or centre for social work is appointed as the legal guardian. In such cases, the institution represents the ward under law and decides on financial issues in the name of the ward. However, in cases where a residential institution is appointed as guardian, a potential conflict of interests arises, that could potentially enable abuse of the wards’ interests.

The obligations of the guardian are the same as in the case of a juvenile under the age of 18 years old, but the extent of the obligations depend on whether the guardianship is *partial* or *plenary*. According to the law, the guardian replaces the will of a person whose legal capacity is completely removed (*plenary* guardianship), but only supplements the will of a person whose legal capacity has been partially restricted (*partial* guardianship).<sup>67</sup> In the latter case, wards can decide upon their personal affairs (for example, carry out transactions that do not have civil obligations) on their own initiative, but the guardian has to consent to their decision.<sup>68</sup> In the case of people with intellectual disabilities, the prolongation of parental rights is equivalent to *plenary* guardianship.

The Marriage and Family Relations Act establishes the role and responsibilities of guardians and also sets limitations on their powers.<sup>69</sup> Guardians have the responsibility

<sup>63</sup> Non-litigious Civil Procedure Act, art. 45.

<sup>64</sup> Non-litigious Civil Procedure Act, art. 48.

<sup>65</sup> Interview with Tomaž Jereb, 19 February 2004.

<sup>66</sup> Interviews with: Tatjana Podlipec, director, sheltered workplace Tončka Hočever, Ljubljana, 24 March 2004; and Tomaž Jereb, 24 April 2004.

<sup>67</sup> Non-litigious Civil Procedure Act, art. 203, 208.

<sup>68</sup> Marriage and Family Relations Act, art. 203, 208.

<sup>69</sup> Marriage and Family Relations Act, art. 187 to 193.

to act on behalf of their ward, including representing them under law, but are allowed to manage the possessions of the ward only with the prior consent of the centre for social work.<sup>70</sup> However, the guardian is no longer obliged to live with the ward, to financially support them, or to take care of them in any other way. Even if parents do not (or cannot) financially maintain their adult child, they can still be their child's guardians, if their parental rights are extended. These changes were made on the recommendation of the Association Sožitje, so that parents no longer have to financially maintain their children after they turn 18 years of age, just because of the child's disabilities.<sup>71</sup>

Parental guardianship affords some special rights, including extra days of holiday and tax reductions for the guardian.<sup>72</sup> However, if the parents become legal guardians they also have some obligations, such as reporting to the centres for social work about their activities on behalf of the ward and about any expenditure connected to the property and funds of the ward.<sup>73</sup>

Both in cases where a person is under guardianship, or where parental rights have been extended, there is no mechanism in Slovenia to protect the interests of wards. There are no official regulations or legislation in place to specify how wards should be protected from abuse. There are also no official complaints procedures. People generally refer to the Ministry of Labour Family and Social Affairs (hereafter, Ministry of Labour), which accepts complaints in this area. In 2003, the ministry dealt with 84 complaints about the work of guardians, but there is no information available as to whether these cases all concerned people with intellectual disabilities.<sup>74</sup>

There are almost no cases where the courts have returned legal capacity to a person. The Director of a sheltered workplace in Ljubljana has said that in 20 years she has not come across one such case.<sup>75</sup> In fact, according to present legislation, it seems that people with intellectual disabilities cannot get back their legal capacity status, since the law states that legal capacity can only be returned, "if the reasons for which it was taken away in the first place no longer exist".<sup>76</sup> However, once a person has been diagnosed as having *moderate*, *severe* or *profound* intellectual disabilities, he or she retains this diagnosis for life and is therefore unable to get back legal capacity status.

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<sup>70</sup> Marriage and Family Relations Act, art. 191.

<sup>71</sup> In accordance with an older version of the act, parents were obliged to maintain their child with disabilities. Marriage and Family Relations Act 1989, Official Gazette 15/1976, 14/1989, art. 123.

<sup>72</sup> Interview with Tomaž Jereb, 24 April 2004.

<sup>73</sup> Marriage and Family Relations Act, art. 194.

<sup>74</sup> Social database 2003, provided by Petra Hribar, Family Unit, Ministry of Labour, Family and Social Affairs (hereafter, Ministry of Labour).

<sup>75</sup> Interview with Tatjana Podlipec, 24 March 2004.

<sup>76</sup> Non-litigious Civil Procedure Act, art. 54.

### *Rights of people under guardianship*

Full civil capacity brings with it important rights, including the right to vote, marry, be a witness in a criminal court procedure and work. For adults whose civil capacity has been partially restricted, the court can allow them to perform some transactions independently, without the guardian's consent, such as signing an employment contract and entering employment.

However, adults with full civil incapacity are completely denied access to employment,<sup>77</sup> even if the guardian consents to their employment. They can only be involved in sheltered workplaces and other social programmes under special conditions. Those who are not placed in sheltered workplaces often work on farms or help their parents.<sup>78</sup> Their guardians usually take decisions about all aspects of the person's life. Parents often see financial benefits, since they will receive the disability allowance of 50,000 SIT per month (or approximately €209)<sup>79</sup> if their child is considered legally incapable.<sup>80</sup>

Regardless of their chronological age, adults with intellectual disabilities who have restricted legal capacity are accorded the status of a "child" under some existing legislation and therefore cannot fully take on the role and responsibilities of an adult. One parent who has guardianship for his adult son with intellectual disabilities recounted an incident that happened in 2004:

I went to the pharmacy to get some tablets for my son but they told me that I had to pay for them quite a lot of money (about \$200). They told me that the National Health Insurance pays for these tablets only if they are prescribed for adults but not for children. I couldn't persuade him that my son is 46 years old. I realised that the National Institute for Health Insurance keeps my son under the category of a child, because I have the parental guardianship over him.<sup>81</sup>

Some legal professionals are advocating for legal capacity, as well as the prolongation of parental rights, to be abolished.<sup>82</sup> Some experts suggest that the existing system of guardianship should be replaced by various forms of advocacy, according to individual needs.<sup>83</sup>

<sup>77</sup> Social Care Act, art 1; Marriage and Family Relations Act, art. 179-200.

<sup>78</sup> Interview with Tomaž Jereb, 19 February 2004.

<sup>79</sup> The exchange rate used throughout this report is €1 = 239.854 Slovenian Tolars (SIT).

<sup>80</sup> Interview with Tatjana Podlipec, 24 March 2004.

<sup>81</sup> Interview with Niko Mohorčič, member, Sklad Silva, Fjeroga, 21 April 2004.

<sup>82</sup> Barbara Novak, "Civilnopravni položaj polnoletne osebe z omejeno sposobnostjo za samostojno odločanje" ("The Non-litigious Status of an Adult with Restricted Ability for Autonomous Decision Making"), in *Pravnik*, vol. 58, 2003, No. 9-12, pp. 579-592.

<sup>83</sup> Tomaž Jereb, director, Association Sožitje, comments on 1 July 2004, following the OSI roundtable, Ljubljana, 18 June 2004.

## 2.4 Statistical data

In Slovenia, detailed statistics on the numbers of children with intellectual disabilities are available from information on school placements and social benefit take-up. However, for adults there is no national system for the regular collection of statistics on all adults with intellectual disabilities.

Until 2000, the centres for social work were responsible for issuing written school placement orders, based on an expert report of the Categorisation Commissions.<sup>84</sup> Statistics on the number of children registered with the centres each year as clients were collected by the Central Registry of the Ministry of Labour. The Placement Act 2000 transferred this authority to National Institute for Education (NIE). In both cases, detailed statistics on the total number of children diagnosed with intellectual disabilities are available, also disaggregated by level of intellectual disability (see section III.1.3).

The numbers of children diagnosed with intellectual disabilities has decreased significantly over the last decade.<sup>85</sup> As shown below in Table 1, over the period 1990 to 2001 the number of children with intellectual disabilities decreased dramatically – by almost one half. By contrast, the number of children with physical disabilities remained more or less unchanged. It is likely that this annual decline is due to a number of different factors, including a general decrease in the overall birth rate in Slovenia. However, a more important factor has been conceptual changes regarding the understanding of intellectual disability, which have been reflected in a new professional awareness about the lifelong stigmatisation that diagnosis often entails. As a result, assessments and diagnosis are made more carefully.

**Table 1. Recipients of social welfare services by centres for social work (1990–2002)**

	Number of children – breakdown by year						
	1990	1995	1998	1999	2000	2001	2002
Children with physical disabilities	1,478	1,071	1,234	1,244	1,250	1,240	1,552
Children with intellectual disabilities	6,245	4,594	3,948	3,671	3,779	3,213	3,351

Source: Statistical Office<sup>86</sup>

<sup>84</sup> In the former Yugoslavia, the Placement Commissions were called Categorisation Commissions.

<sup>85</sup> In 1991, 5,732 children were categorised as having “deficiency in mental development”. In 2001, only 3,213 children were assessed in this category; a decrease of 44 per cent in one decade. Statistical Information No. 181/2002, p. 2, section 12.

<sup>86</sup> Statistical Office, Statistical Yearbook 2002, Table 10.14, available (in English) on the Statistical Office website at <http://www.stat.si> (accessed 15 March 2005).

Although some statistical data is available, there is no regular national system for the collection and updating of statistics on all people with intellectual disabilities in Slovenia. The figures of Government institutions, such as the Ministry of Family, Labour and Social Affairs and the Statistical Office, differ greatly and to date no explanation has been given for these discrepancies.

According to data from the Ministry of Labour, in 2002 there were 7,242 persons registered with the centres for social work as “invalids” under the Social Care Act.<sup>87</sup> As of 7 July 2003, the Statistical Office recorded 4,258 adults with intellectual disabilities who were registered with the centres for social work as “invalids” under the Social Care Act.<sup>88</sup> The data on people with disabilities collected by the National Employment Service is not available disaggregated by type of disability and in any case would only include information on (some) people with *mild* intellectual disabilities.<sup>89</sup> Adults with *mild* intellectual disabilities are not systematically registered in any of the official statistics, as they are considered able to work, like other adults, and are not eligible for social benefits (the *borderline* category does not exist for adults).

The Association Sožitje collects its own statistics on people with intellectual disabilities. They have registered a total of 37,400 adults and children with intellectual disabilities, of which 9,970 had *moderate* and *severe* intellectual disabilities and 2,500 had *profound* intellectual disabilities.<sup>90</sup> This seems to indicate that the real number of adults with intellectual disabilities is significantly higher than official records. The lack of consistent official data is an important barrier to assessing the situation of adults with intellectual disabilities in Slovenia.

## 2.5 Deinstitutionalisation

In Slovenia, most people with intellectual disabilities live with their families – approximately 70 per cent of adults and more than 90 per cent of children.<sup>91</sup>

For children and young people with *moderate*, *severe* and *profound* disabilities, there are ten residential institutions in Slovenia providing education, training, work and care, in accordance with legislation on education, health and social security. These include five centres for the training and care of children and young people;<sup>92</sup> in 2000, there were

<sup>87</sup> Ministry of Labour, written comments received on 6 July 2004, following the OSI roundtable, 18 June 2004.

<sup>88</sup> Statistical Office, Statistical Information, No. 170/2003, (in Slovene), Section 12, Social Security, No. 4, p. 3, Table 1.2 “Adult persons who are the users of centres for social work on 31 December 2002.”

<sup>89</sup> See: Section IV.3.1.

<sup>90</sup> Interview with Tomaž Jereb, 17 May 2004.

<sup>91</sup> Association Sožitje, “Human Rights of Persons with Intellectual Disabilities”, Sožitje, Ljubljana, 2002, p. 15.

<sup>92</sup> Dornava, Dobrna, Radovljica, Crna na Koroskem and Ig.

821 children living in these residential institutions.<sup>93</sup> There are also five day centres<sup>94</sup> which, according to Slovene legislation, provide programmes of care, education, health and social security.

Adults with intellectual disabilities are placed in several types of residential institution:

- Social care institutions for training: these ensure institutional care and prolonged education and training. There are five such institutions.<sup>95</sup>
- Centres for residential care of adults: these operate together with sheltered workshops in ten locations.<sup>96</sup>
- Social care institutions: there are five of these asylum-type residential institutions, for the care of adults with *moderate*, *severe* and *profound* intellectual disabilities.<sup>97</sup> They provide some training programmes for these adults.
- Special units in homes for the elderly: there are three homes, which care for adults with *moderate*, *severe* and *profound* intellectual disabilities.<sup>98</sup> Some of the units are in the same building as the home for the elderly, while others are physically segregated from the home.
- Special departments in homes for the elderly: there are seven special departments that care for adults with *moderate*, *severe* and *profound* intellectual disabilities and physical disabilities.<sup>99</sup> In 2003, there were 1,697 people in these special departments including 103 people aged under 39.<sup>100</sup>
- Sheltered workplaces providing institutional care in residential homes and group homes: there are public sheltered workplaces providing institutional care for 524 people, in 11 towns.<sup>101</sup> There are also some private sheltered workplaces that have

<sup>93</sup> Statistical Office, Statistical Yearbook 2001, Table 10.11, available (in English) on the Statistical Office website at <http://www.stat.si> (accessed 15 March 2005).

<sup>94</sup> In Maribor, Celje, Novo mesto, Ljubljana-Siska, and Predlov trg (Ljubljana). The Dolfka Boštjančič centre, Draga, operates in five different locations, including three of these day centres.

<sup>95</sup> Črna na Koroškem, Dobrna, Dornava, Ljubljana and Radovljica. Ministry of Labour, written comments received on 6 July 2004, following the OSI roundtable, Ljubljana, 18 June 2004.

<sup>96</sup> Črna na Koroškem, Dobrna Radovljica, Dornava (Dornava has five apartments: four in Ptuj and one in Dornava) and Škofljica.

<sup>97</sup> Dutovlje, Križevci by Ljutomer, Hrastovec, Ponikve and Žalec.

<sup>98</sup> Idrija (home for elderly people, Jože Primožič – Miklavž), Sevnica (home for elderly people, Impoljca) and Podbrdo (home for elderly people, Podbrdo).

<sup>99</sup> Ilirska Bistrica, Novo mesto, Loka by Zidani Most Impolica, Ljubljana-Bežigrad, Idrija, Podbrdo, Metlika.

<sup>100</sup> There are 61 homes for elderly people in Slovenia. In 2003 they had 13,498 wards. Statistical Office, Statistical Yearbook 2004, p. 4, available (in English) on the Statistical Office website at <http://www.stat.si> (accessed 15 March 2005).

<sup>101</sup> Tolmin, Radovljica, Maribor, Novo mesto, Črnomelj, Domžale, Celje, Dornava, Krško, Gornja Radgona and Črna na Koroškem.



received a license from the State to also provide institutional care;<sup>102</sup> these provide residential care for 69 people in three towns.<sup>103</sup>

The average length of stay in these institutions is between eight and ten years,<sup>104</sup> which is indicative of the endemic long-term institutionalisation and segregation of people with intellectual disabilities in Slovenia.<sup>105</sup> Although the cost of institutional care is much higher than community-based care, the Government actually encourages institutionalisation by ensuring free institutional care and primary education for children with physical and intellectual disabilities.<sup>106</sup> In cases where a child remains at home, however, the carer receives only very minimal support.<sup>107</sup>

Since 2000, the “National Programme on Social Security by the year 2005” has promoted inclusion and community-based services.<sup>108</sup> Despite this, the number of people with intellectual disabilities living in community settings remains very low. In 1999, there were 23 group homes in Slovenia for a total of 96 residents. By comparison, forty times more people were living in the larger institutions.<sup>109</sup>

There is an increasing tendency, however, for the larger institutions to open day centres, especially for children. By providing care for children during the day, these centres enable children to live outside the residential homes. At present, there are 92 children using day centre facilities in Slovenia.<sup>110</sup> One such example is the Dolfka Boštjančič centre in Draga, a Government operated institution. This centre operates in five different locations, of which three are day centres. One of these is Mali dom Ljubljana, a day centre for children and young people with *moderate, severe* and

<sup>102</sup> Ministry of Labour, written comments received on 6 July 2004, following the OSI roundtable, 18 June 2004.

<sup>103</sup> These are in Ljubljana, Maribor and Medvode.

<sup>104</sup> School for Social Work, Ljubljana, “Forms of living of adults who need organised care and support: analysis and proposals”, unpublished research, 1999, p 159.

<sup>105</sup> D. Zavirsek, *Hendikep kot kulturna trauma, (Disability as the Cultural Trauma)*, Ljubljana, 2000, (hereafter, Zavirsek, *Disability as the Cultural Trauma*).

<sup>106</sup> Constitution, art. 52.

<sup>107</sup> The child nursing allowance is intended to cover the additional costs of care. The monthly child nursing allowance is 19,300 SIT (or approximately €81) or 38,590 SIT (€161) depending on the type of disability. Parental Care Act, art. 80.

<sup>108</sup> The “National Programme on Social Security by the Year 2005” outlines conceptual changes to the system of social welfare in Slovenia by the year 2005. These changes include expanding the network of social actors and services, to promote a better quality of life for (in particular) vulnerable groups of people such as children and adults with disabilities; women who were victims of abuse; and the elderly. “National Programme on Social Security by the Year 2005”, Official Journal, 31/2000, (hereafter, National Programme on Social Security 2005).

<sup>109</sup> School for Social Work, Ljubljana, “Forms of living of adults who need organised care and support: analysis and proposals”, unpublished research work, 1999, p 159.

<sup>110</sup> Ministry of Family, Labour and Social Affairs, comment at the OSI roundtable, Ljubljana, 18 June 2004.

*profound* intellectual disabilities, and multiple disabilities. In Mali Dom, 36 children live in the institution permanently, while a further 14 children can now attend the day centre on a daily basis, while living at home with their families.

The increasing availability of day centres has enabled more children with disabilities to be cared for at home, rather than being sent away to institutions. This is reflected in the significant increase in the number of recipients of the *child nursery allowance*, to which the parents of a child who is cared for at home and requires special care and protection (including children with *moderate*, *severe* or *profound* intellectual disabilities) are entitled.<sup>111</sup> As shown below in Table 2, the number of beneficiaries of this allowance is growing every year, from 2,619 in 1996 to almost twice that number in 2002. Although, there is no data available on how many of these are children with intellectual disabilities, the increase is a result of many changes over this period, including more day centres in local communities and the negative reputation of public residential institutions. Parents are also becoming better informed about their rights. As one interviewed parent recounted, “we've lost some years of nursery allowance because the social worker didn't tell us we have the right for it”.<sup>112</sup>

**Table 2. Beneficiaries of nursery allowance (1996–2002)**

Beneficiaries of nursery allowance	Year						
	1996	1997	1998	1999	2000	2001	2002
Number of children	2,619	3,705	4,132	4,424	4,731	4,963	5,219
Amount paid out (SIT millions)	26	495	568	641	723	829	1,175

Source: Statistical Office<sup>113</sup>

Adults in residential care pay part of the costs from their own resources (such as benefits or pensions) or the resources of their parents or other relatives, while the municipality (of their permanent place of residence) covers the remainder of the costs. Residential care in public institutions for people with intellectual disabilities varies extensively and there seem to be no criteria by which the significant differences in costs between the different institutions can be explained.<sup>114</sup> According to disability activists and the reports of carers, however, at present individuals cannot use the funding provided for their residential care to cover the costs of personal assistance at home

<sup>111</sup> The Act on Parental Care and Family Income 2003, Official Gazette 97/2001, 76/2003, 110/2003, art. 80 (hereafter, Parental Care Act).

<sup>112</sup> Interview with a parent from Association Silva, a parents' advocacy organisation, 21 April 2004.

<sup>113</sup> Statistical Office, Statistical Yearbook 2004, Section 10.21, p. 200, available (in English) on the Statistical Office website at <http://www.stat.si> (accessed 15 March 2005).

<sup>114</sup> The monthly fee at an institution can range from 121,000 SIT to 302,000 SIT (or approximately €505 – €1,259)

instead of living in residential care.<sup>115</sup> This is because Slovene legislation does not include provisions for direct funding.<sup>116</sup> For the system to change, however, and for care in the community to be encouraged, it is important that funding should instead be allocated for each individual with disabilities, to enable them to choose and buy the services they prefer.

Slovenia does, however, have some experience of direct funding for people with intellectual disabilities. One example is a five-year project of direct payments initiated in 1992 by the NGO Sklad Silva, in cooperation with three municipalities.<sup>117</sup> One of the aims of the project was to assess whether direct payments could be established throughout Slovenia, as one of the possible choices for people with disabilities.<sup>118</sup> Initially the project included four adults with intellectual disabilities, but today that number has risen to 13. They live in their own homes either with their family, or partner, or alone and work in sheltered workplaces. Direct payments are meant to cover the costs of personal assistance and also to enable people to achieve their life goals and improve their quality of life. This year is the fourth year after the official conclusion of the project, but all three municipalities are still running the scheme. Direct payments are received on the basis of an individual plan and budget that is revised yearly.

Another example of direct funding is a programme established by the Association for the Theory and Culture of Handicap (YHD), a disability activist NGO. Since 2003, YHD has been running the programme “Independent Living of Disabled People”. Through this programme, a network of personal assistance is provided for people with

<sup>115</sup> Various personal communications between 2002–2005, with members of different NGOs.

<sup>116</sup> “Direct funding” refers to a system in which State funding is paid directly to the individual concerned (to the person’s personal account) for provision of assistance or any other social service required, rather than transferring the money through the institution that provides the service. The idea is to empower people with disabilities and give them the possibility of choice.

<sup>117</sup> Faculty of Social Work, University of Ljubljana, Pilot project on “Direct funding”, unpublished report, December 2003.

<sup>118</sup> Sklad Silva is an organisation led by the parents of adults with intellectual disabilities. A main concern for these parents is that their children would have to be placed in institutions when they become too old to take care of them. However, after experiencing some of the residential institutions during the time their children lived there, they realised that their children would lack basic human rights and self-determination if they were to be placed there. Before initiating this project, the parents at Sklad Silva sought examples of good practices in the UK and in neighbouring countries. Their main criteria were that projects should promote self-advocacy, independent living and the full inclusion of people with disabilities into society. The parents of one of the adults with intellectual disabilities have donated a house to the organisation. The users come to this house almost daily and sometimes stay overnight. They are increasingly learning to live independently.

disabilities who want to live outside of institutions.<sup>119</sup> These pilot projects on direct funding present an innovative model that could speed up the process of deinstitutionalisation in Slovenia, and encourage independent living. Such initiatives show that direct payments for personal assistance can promote the necessary conditions for independent living.

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<sup>119</sup> The person with disabilities can choose the type of personal assistance they prefer. In the framework of this programme, personal assistants are employed under active labour market policy (ALMP) programmes which are largely financed by the Employment Office, and in part by some municipalities, users contributions and the Foundation FIHO. Approximately 77 people with disabilities use the YHD personal assistance scheme, of which eight have intellectual disabilities. Interview with YHD.

### III. Access to Education

#### 1. LEGAL AND ADMINISTRATIVE FRAMEWORK

*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, meaning 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 an increasing pressure from the parents of children with mild intellectual disabilities, for their child 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 only to people living in the larger towns and cities.*

##### 1.1 The right to education

The Constitution ensures the possibility of education for all citizens.<sup>120</sup> Article 52 states that children with physical and intellectual disabilities “have a right to education and training for active social life”. Article 56 defines the rights of children.

Slovenia has implemented a number of EU Resolutions on education.<sup>121</sup> The main legislation relating to the education of children with intellectual disabilities is:

<sup>120</sup> “Education is free [...] the State forms conditions for citizens to acquire adequate education”. Constitution, art. 57.

<sup>121</sup> For example, the provisions of the EU Resolution Concerning the integration of children and young people with disabilities into ordinary systems of education were integrated into the Placement Act. Resolution of the Council and the Ministers for Education meeting within the Council of 31 May 1990 concerning integration of children and young people with disabilities into ordinary systems of education, Official Journal C162, 03/07/1990 P.0002–0003.

- The Placement of Children with Special Needs Act 2000 (hereafter, Placement Act).<sup>122</sup>
- The Primary Schools Act 2004.<sup>123</sup>
- The Kindergarten Act 2003.<sup>124</sup>
- The Organisation and Financing of Education Act 2003.<sup>125</sup>

The primary education of children and young people with intellectual disabilities is regulated by the Primary Schools Act, which applies to all children, and the Placement Act.

The Placement Act replaced the Act on the Education and Training of Children with Disturbances in their Physical and Mental Development,<sup>126</sup> and represents a significant addition to the legislation specifically addressing the education of children and young people with special needs, including children with intellectual disabilities. The act entered into force on 6 June 2003, following the adoption of its two implementing regulations.<sup>127</sup> It states that the provision of education for children with special needs is based, among others, on the principles of equal opportunities and inclusion of parents in the educational process.<sup>128</sup> However, in spite of this principle of equal opportunities, only children with *borderline* intellectual disabilities may be integrated into a mainstream school, which is an example of discrimination.<sup>129</sup>

The Placement Act defines the various programmes of education and training for children with special needs at pre-school, primary and secondary levels.<sup>130</sup> The act and its implementing regulations establish and regulate the placement procedures for these programmes, and define which groups of children can be placed into the various educational programmes.<sup>131</sup> They also clarify the placement process and the role and responsibilities of the Placement Commissions. This includes the decision on which

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<sup>122</sup> Placement Act 2000.

<sup>123</sup> The Primary School Act 2004, Official Gazette 12/1996, 33/1997, 59/2001, 71/2004, (hereafter, Primary School Act).

<sup>124</sup> The Kindergarten Act 2003, Official Gazette 12/1996, 44/2000, 78/2003, 113/2003, (hereafter, Kindergarten Act).

<sup>125</sup> Organisation and Financing of Education Act 2003, Official Gazette 12/1996, 101/1999, 22/2000, 64/2001, 101/2001, 108/2002, 34/2003, 79/2003.

<sup>126</sup> The Act on the Education and Training of Children with Disturbances in their Physical and Mental Development, Official Gazette 12/1991, 54/1992, 56/1992 (corr.), 54/2000 (not in use since 1 July 2000).

<sup>127</sup> Regulation on Placement Commission and placement criteria.

<sup>128</sup> Placement Act, art. 4.

<sup>129</sup> Placement Act, art. 10.

<sup>130</sup> Placement Act, art. 3, 5 and 11. One of the implementing regulations of the act, the Regulation on Placement Commissions, also covers vocational training. Regulation on Placement Commission and placement criteria, art. 11.

<sup>131</sup> Regulation on Placement Commission and placement criteria, art. 7-15.

specific programme the child should follow, and the content of the written placement orders the commissions issue.<sup>132</sup> The act also provides for some rights to aid and personal assistance.<sup>133</sup>

The Kindergarten Act gives priority to the mainstreaming of pre-school children with special needs and assures their integration into mainstream kindergartens or inclusion into so-called “developmental units”.<sup>134</sup> Together with the Primary Schools Act, the Kindergarten Act also obliges mainstream schools to ensure equal opportunities for children with special needs.<sup>135</sup> However, there are no supplementary regulations to define what “equal opportunities” actually means in practice.

The Organisation and Financing of Education Act 2002 establishes equality as a goal in education and states that the education system in Slovenia shall aim at “guaranteeing optimum development to individuals regardless of their sex, social and cultural background, religion, national origin and physical and mental handicap”.<sup>136</sup> However, the educational goals listed in the act are not legally binding.<sup>137</sup>

### *Specialised bodies*

Until recently, there was no Government body dealing exclusively with the rights of children. In 2002, the Ministry of Labour established the Council for Children within the Office of the Human Rights Ombudsman. However, the need for an Ombudsman specifically for children’s rights was also recognised and in January 2003, Parliament appointed a fourth Deputy Ombudsman within the Office of the Human Rights Ombudsman, to deal exclusively with social security and the rights of children.

In 2002, the Office of the Human Rights Ombudsman received nine complaints regarding the rights of people with intellectual disabilities. Most were initiated by parents, and the majority concerned long placement procedures that ignored the wishes of the parents and a limited use of the Placement Act 2000.<sup>138</sup> In 2003, the number of similar complaints increased to 20. Again, most were from the parents of children with

<sup>132</sup> Placement Act, art. 24.

<sup>133</sup> Placement Act, art. 10, 19, 27.

<sup>134</sup> Developmental units are special units in regular kindergartens, for children with special needs. Each unit has between three and eight children and there are 60 such units in Slovenia.

<sup>135</sup> Kindergarten Act, art. 3; Primary School Act, art. 11.

<sup>136</sup> Maja Katarina Tratar, *Report on measures to combat discrimination in the 13 candidate countries (VT/2002/47)*. Country Report Slovenia, Migration Policy Group (MPG) and MEDE European Consultancy, May 2003, available on the MPG website at <http://www.migpolgroup.com/uploadstore/SLOVENIAFinalEN.pdf> (accessed 2 December 2004), p. 12, (hereafter, MPG, *Slovenia report*).

<sup>137</sup> MPG, *Slovenia report*, p. 12.

<sup>138</sup> Human Rights Ombudsman, *Annual Report 2002*, pp. 87–109, abridged version available (in English and Slovenian) on the website of the Human Rights Ombudsman at <http://www.varuh-rs.si> (accessed on 9 September 2004), (hereafter, *Ombudsman Report 2002*).

intellectual disabilities, regarding long procedures of the second level Placement Commissions (six to ten months) and about the “pitiable and sometimes humiliating responses of bureaucrats.”<sup>139</sup>

Regarding the integration of children with intellectual disabilities into mainstream schools, the *Annual Report 2003* of the Human Rights Ombudsman emphasised two important points. First, that “there is no clear and comprehensive concept of inclusion”. Second, that “the everyday situation of children and young people with intellectual disabilities has not improved in comparison with last year in spite of new regulations”.<sup>140</sup>

The *Annual Report 2003* of the Human Rights Ombudsman also criticises the Placement Act, in that it does not ensure that all children with special needs can attend a mainstream school. The report also highlights the inconsistencies between the existent act and everyday practice. In particular, parents’ complaints stress that:

the State did not provide a network of mainstream schools which would accept children with mild disturbances in mental development [*mild* intellectual disabilities] and children with moderate and multiple disabilities in order to provide the transition between different programmes.<sup>141</sup>

The proposal of the Ombudsman is that the UN Convention on the Rights of the Children (CRC) should be better respected, which means that children with intellectual disabilities must have more possibilities for social integration.

## 1.2 Structure and administration of the education system

In Slovenia the type of school and educational programme in which a child with intellectual disabilities is placed depends on the level of intellectual disability diagnosed by the Placement Commission.<sup>142</sup> Integration in mainstream primary schools is possible only for children with *borderline* intellectual disabilities, while children with *mild* intellectual disabilities are sent to primary schools with an adapted programme (special schools). Children with *moderate*, *severe* and *profound* intellectual disabilities are usually directed to residential institutions; during their schooling they fall under the jurisdiction of the Ministry for Education and Sport, until the age of 18 and after this age the Ministry of Labour.

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<sup>139</sup> Human Rights Ombudsman, *Annual Report 2003*, pp. 115–116, available (in English and Slovenian) on the website of the Human Rights Ombudsman at <http://www.varuh-rs.si> (accessed on 9 September 2004), (hereafter, *Ombudsman Report 2003*).

<sup>140</sup> *Ombudsman Report 2003*, p. 117.

<sup>141</sup> *Ombudsman Report 2003*, p. 117.

<sup>142</sup> Placement Act, art. 7, 8, 10, 13 and 14.



### 1.2.1 Compulsory education

In Slovenia the term of compulsory education was extended from eight to nine years in all primary schools, from the school year 2003.<sup>143</sup> Primary education for children with intellectual disabilities has been compulsory since 1960; before then, many children with intellectual disabilities stayed at home and helped their parents in the household or on the farm.

For children with intellectual disabilities in schools with an adapted programme (special schools) – mainly children with *mild* intellectual disabilities – education is compulsory from age six to 15, as for other children. For those in mainstream schools (children with *borderline* intellectual disabilities), the Primary Schools Act states that their schooling can be prolonged beyond the formal compulsory schooling age for a further two years, if the educational programme has not been accomplished within these nine years.<sup>144</sup> In Slovenia, a child's knowledge and skills are measured mainly by examination grades; exam results reflecting a lack of knowledge are the basis for the decision to prolong a child's primary schooling. The legal limit for children attending a primary school is 17 years old.

For children and young people with *moderate*, *severe* or *profound* intellectual disabilities, recently implemented Government regulations have extended the maximum age at which they can receive education and training from age 17 to age 21, or at most age 26 years old.<sup>145</sup> Even before these changes, school authorities and staff were generally very flexible in this regard and in most cases adapted the period of education to the needs of the child, in some cases up to the age of 26.<sup>146</sup> However, in some cases young people completed elementary school programmes before turning 18 years of age and so could not be included in sheltered workplaces (minimum age 18). According to the new regulations, these children can now receive a prolongation from the Placement Commission and stay on in the educational system until they enter a sheltered workplace; they no longer have to leave institutional care for a year. Examples of such extensions being ordered already exist in practice. In 2003, the Placement Commission in Draga ordered extensions for 139 young people (between the ages of 21 and 26 years old) with intellectual disabilities. As of July 2004 the commission had given extensions to a further 46 young people.<sup>147</sup>

<sup>143</sup> Primary Schools Act, art. 3.

<sup>144</sup> Primary Schools Act, art. 55.

<sup>145</sup> "Special educational programmes at the primary level", available on NIE website at [http://www.zrss.si/doc/\\_Posebni%20program\\_sposni%20del.doc](http://www.zrss.si/doc/_Posebni%20program_sposni%20del.doc) (accessed 1 May 2005).

<sup>146</sup> Telephone conversation with a social worker from a primary school with an adapted programme, who wishes to remain anonymous, 16 February 2004; Interview with Matej Rovšek, 1 April 2004, Ljubljana, written comments received on 1 July 2004.

<sup>147</sup> Ministry for Labour, Family and Social Affairs, written comments received on 6 July 2004, after the OSI roundtable, Ljubljana, 18 June 2004.

### 1.2.2 Educational programmes

The Placement Act defines the educational programmes available for children and young people with specific types of disabilities; all educational programmes are financed from the State budget.<sup>148</sup> For all children with special needs, the Placement Commission decides on the appropriate programme for the child, with the active participation of the parents and educational institutions.<sup>149</sup> An expert group of special educators and teachers in the school where the child is placed must evaluate and adjust this programme during the school year, according to the child's progress. The parents themselves can decide if they want their child to be educated at home instead.

In accordance with the Placement Act, regardless of the type of school in which a child with special needs is placed, the school must prepare an individual educational programme (IEP).<sup>150</sup> This plan should be evaluated and rewritten yearly and *must* be re-evaluated within a maximum period of three years. The IEP includes a methodology tailored to specific areas of learning; defines the methods and type of additional expert help required; and sets out necessary adjustments in the organisation of classes or in the evaluation of the child's knowledge. At the end of the school year, the same expert group evaluates the adequacy of the programme and prepares a new one for the following year.

The type of school that a child with intellectual disabilities will attend, and the educational programme that he or she follows, depends on the diagnosed level of intellectual disabilities.<sup>151</sup> There are different types of educational programme available for children with intellectual disabilities at pre-school, primary and secondary levels. The main types of programme for children with special needs are:

- Programmes with “equal educational standards”, in which children with special needs are taught using the same curricula as other children, in a mainstream school;
- Programmes with an “adapted implementation”, in which additional support is provided for children with special needs, such as a support teacher or special equipment; and
- “Adapted programmes”, which are taught in special schools or special units of mainstream schools.<sup>152</sup>

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<sup>148</sup> Regulation on Placement Commission and placement criteria.

<sup>149</sup> Placement Act, art. 4, 20, 28.

<sup>150</sup> Placement Act, art. 27.

<sup>151</sup> Placement Act, art. 7, 8, 10, 13 and 14.

<sup>152</sup> Details of all the educational programmes mentioned in this section are available (in Slovenian) on the web page of the Ministry for Education and Sport at [http://www.mszs.si/slo/solstvo/posebne\\_potrebe.asp](http://www.mszs.si/slo/solstvo/posebne_potrebe.asp) (accessed 12 December 2004).

However, an important problem regarding the education of children with intellectual disabilities is that not all of these educational programmes are available in every school. This means that in practice the school system in Slovenia still effectively segregates children. The Association Soncek advocates under the slogan “one school for all” and emphasises the fragmentation of current legislation in this area.<sup>153</sup>

#### *Available educational programmes – pre-school level*

At the pre-school level, there are two educational programmes available for children with intellectual disabilities:

- “Programme for pre-school children with special needs, with adapted implementation and additional expert support” – available in mainstream kindergartens;
- “Adapted programme for pre-school children” – available in developmental units of mainstream kindergartens and in special kindergartens in residential institutions.

#### *Available educational programmes – primary level*

At primary level there are four types of educational programmes for children with special needs (three of them are only for children with intellectual disabilities). The majority of children with intellectual disabilities are placed in special schools or in other institutions with special programmes. Children with intellectual disabilities follow four types of educational programmes:

- “Programme with an adapted implementation and additional expert support” – for children with special needs who are integrated in mainstream primary schools. This is based on the same national curriculum that is obligatory for children without disabilities and has equal educational standards. Although it does not specifically mention children with intellectual disabilities, some children with *borderline* intellectual disabilities, who are integrated in mainstream primary schools, are placed on this programme.
- “Adapted programme with an equal educational standard” – this programme is officially designed for children with physical and sensory disabilities and is taught in special schools. It is interesting that this programme does not officially include children with intellectual disabilities. However, in practice some children with intellectual disabilities in special schools are also placed in this programme, as children with the other types of disabilities are more often integrated in mainstream schools.

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<sup>153</sup> Written comments received from Jelka Bratec, manager of a group home and professional co-worker at the Association Soncek, 2 August 2004.

- “Adapted programme with a lower educational standard” – for children with *mild* intellectual disabilities who are either in special schools or in special units of mainstream schools. It does not have equal educational standards and is currently under revision.<sup>154</sup>
- “Special programme of care and education” – for children with *moderate, severe* and *profound* intellectual disabilities in residential institutions. This programme was revised in spring 2004.<sup>155</sup>

### *Available educational programmes – secondary level*

At secondary school level there are a wide range of educational and vocational programmes.<sup>156</sup> However, children and young people with *borderline* and *mild* intellectual disabilities can enrol in schools with the following programme:<sup>157</sup>

- “Programme of lower vocational education with adapted implementation and additional expert support.” This programme is implemented in some of the secondary schools in Slovenia offering 2.5-year courses. This means that pupils with *mild* intellectual disabilities can only enrol in a small number of programmes and receive additional support. The instructions for the implementation of this programme provides details on working methods, knowledge evaluation, the timetable, special equipment, and additional support.<sup>158</sup> The instructions also state the principles for teachers working with pupils with *mild* intellectual disabilities. These include a positive attitude, provision of support by special experts, analysis and follow-up of the pupils’ individual educational plan, and the creation of a non-discriminatory environment.

Importantly, young people with *moderate, severe* and *profound* intellectual disabilities have no secondary level educational programmes at all.

<sup>154</sup> Ministry for Education and Sport, *Instructions for educational programmes with an adapted implementation and additional expert support in nine-year primary school*, draft document, (in Slovene), available on the NIE website at [www.zrssi.si](http://www.zrssi.si) (accessed 22 July 2004), (hereafter, Ministry for Education and Sport, *Instructions for educational programmes with an adapted implementation*).

<sup>155</sup> Ministry for Education and Sport, *Special care and education programme – elementary school level*, (in Slovene), available on the NIE website at [http://anton.lj.zrssi.si/doc/\\_Posebni%20program\\_splosni%20del.doc](http://anton.lj.zrssi.si/doc/_Posebni%20program_splosni%20del.doc) (accessed 22 July 2004), (hereafter, Ministry for Education and Sport, *Special care and education programme – elementary school level*).

<sup>156</sup> These include secondary vocational education (four years); secondary professional education; vocational technical education; secondary general education (gymnasiums); secondary school exam training; and programmes for the international secondary school exam.

<sup>157</sup> Regulation on Placement Commission and placement criteria, art. 11.

<sup>158</sup> Ministry for Education and Sport, *Instructions for the implementation of vocational education with adapted implementation and additional expert support*, available (in Slovene), at <http://www.mszs.si/slo/ministrstvo/organi/solstvo/pdf/Navodila.pdf> (accessed 15 March 2005).

### *Transfer between educational programmes*

Most children with *borderline* and *mild* intellectual disabilities begin their education in mainstream school and are later placed in special programmes, either at a special school or in a special unit at a mainstream school. Although the Placement Act provides for the right of children with *borderline* and *mild* intellectual disabilities to transfer between different educational programmes,<sup>159</sup> the Ministry for Education limited this right in 2003.<sup>160</sup> Since then, children with *mild* intellectual disabilities can be placed on an “adapted programme with lower educational standards” in a special school or a special unit in a mainstream school, and only have the right to participate in “expanded programmes”, such as morning and afternoon care, interest activities and trips and excursions.<sup>161</sup> Transfer into mainstream classes for some school subjects is not possible.

In addition to legislative barriers, another important obstacle to transfer between educational programmes is the significant distance between most schools. Children with intellectual disabilities are not entitled to have a personal assistant, but would often need a person to accompany them on the bus to be able to travel between schools. Prejudices against children with intellectual disabilities, on the part of teachers, and children without disabilities and their parents, can also prevent transfer between programmes. Children who attend special schools can experience discrimination such as verbal humiliation and even physical violence when they attend classes in a mainstream school. One expert has observed that other pupils “throw things at them and call them names.” The following comments from children with intellectual disabilities are illustrative of the discriminatory attitudes they face from other students:

“They know it is an easy programme and they call you stupid or say that you don’t belong in their company” – seventh grade student age 15.

“They say to me, why do you go to that school [...] it is stupid, idiotic? It’s for stupid people [...] those that don’t learn and know nothing” – student age 11.

“They don’t say anything to me, except that it is a school for invalids and that everybody is crazy there [...] they also say that I’m a gypsy, which is even worse than being crazy” – seventh grade student age 16.<sup>162</sup>

As a consequence of these legislative and other barriers, in practice only a few students with intellectual disabilities are able to transfer between educational programmes.

<sup>159</sup> Placement Act, art. 13.

<sup>160</sup> Ministry for Education and Sport, *Navodila komisijam za usmerjanje otrok s posebnimi potrebami*, (*Instructions for the placement commissions*), a written document sent to members of placement commissions, No. 604-01-2/2003, 22 December 2003. Presented at the First National Conference of Defectologists (special pedagogues), Ljubljana, 24 March 2004.

<sup>161</sup> Regulation on Placement Commission and placement criteria.

<sup>162</sup> Branka D. Jurišič, “The views of pupils enrolled in mainstream primary school and in a special school”, text from a professional symposium in Šelih, A. et al. (eds.), “Integration between Yesterday, Today and Tomorrow”, Association Sožitje, Ljubljana, 2003, pp. 36–50.

There are modest possibilities for cooperation between special schools for children with *moderate*, *severe* and *profound* intellectual disabilities, and special schools for children with *mild* intellectual disabilities. From time to time, children with *moderate*, *severe* and *profound* intellectual disabilities who are in residential institutions are also allowed to be involved in the expanded programmes of special schools and in special pedagogical activities available at special schools, such as computer work or social learning.<sup>163</sup>

### 1.3 Diagnosis and assessment of disability for educational purposes

Since 2003, the Placement Act and its implementing regulation<sup>164</sup> have introduced important changes in the procedures for diagnosis and placement of children with intellectual disabilities (the act uses the term “children with disturbances in mental development”). The new regulation defines “children with special needs”<sup>165</sup> and the five levels of intellectual disability for children and young people.<sup>166</sup> The previous regulation also referred to the same five levels of intellectual disabilities, but the definition used for each level was stricter and measured by IQ level.<sup>167</sup> The new regulation is more focused on a qualitative description of the abilities and skills of the individual child or young person, rather than concentrating only on a measurement of IQ.<sup>168</sup> The Placement Act also promotes a more individualised approach; an individual plan has to be prepared for each child with special needs entering a special or

<sup>163</sup> Regulation on Placement Commission and placement criteria.

<sup>164</sup> Regulation on Placement Commission and placement criteria.

<sup>165</sup> In addition to children with intellectual disabilities, the term “children with special needs” also encompasses children with visual or hearing impairments; children with speech disturbances; children with physical disabilities; children with learning difficulties or behavioural challenges; and chronically ill children. Regulation on Placement Commission and placement criteria, para. 1.

<sup>166</sup> See: Section II.2.2.

<sup>167</sup> Regulation on the Placement and Reports of Children, Youth and Young Adults with Disturbances in Physical and Mental Development 1977, Official Gazette 18/1977, (hereafter, Regulation on Placement and Reports). This regulation was replaced by the Regulation on Placement Commission and placement criteria.

<sup>168</sup> The example of a child with *moderate* intellectual disabilities is indicative of the difference between old and new models: According to the criteria defined in the old regulation, “children with *moderate* intellectual disabilities are less capable of independent work, but are able to maintain contact with surroundings, follow basic hygiene independently, and learn to perform simple tasks. Their IQ is between 36 and 50”. Regulation on Placement Commission and placement criteria, para. 1. According to the criteria defined in the new regulation, “a child has different capabilities, that are differently developed. At school, he/she can learn basic reading, writing and calculating, but is capable of achieving more at other areas (motor activities, art, music). He/she can co-operate in a dialogue and understands instructions. He/she is capable of communicating own wishes. Considering personal care he/she can do easy tasks, but needs assistance and support through all his/her life. He/she can be trained to perform easy, practical tasks, but rarely they can become so independent to lead a completely independent life”. Regulation on Placement Commission and placement criteria, para. 1.

mainstream school, which has to be reviewed at least every three years time. The process itself is also ongoing, not a one-off evaluation as was the case previously.<sup>169</sup>

### *Placement Commissions*

In accordance with the Placement Act, the Placement Commissions are responsible for the assessment of all children with special needs, including children with intellectual disabilities. They are also responsible for making placement decisions on the type of school each child should attend. Although professionals claim that children are placed in an appropriate educational programme, the Placement Commissions are still responsible for naming the particular kindergarten, school or other educational institution into which the child should be placed.<sup>170</sup> The Placement Commissions issue approximately 800 placement reports each year, of which 700 are for children with disabilities and the remainder are for children with behavioural challenges.<sup>171</sup>

The Placement Act defines the responsibilities of the Placement Commissions.<sup>172</sup> There are 45 first-level Placement Commissions across Slovenia, each covering a certain geographical area.<sup>173</sup> They operate in centres for social work, counselling centres, health centres, institutions for the training and education of children with special needs, and local authorities.<sup>174</sup> The commissions are under the responsibility of the Ministry for Education and Sport, which in turn is responsible for appointing the members of each commission, in collaboration with the Ministry of Labour.<sup>175</sup>

The members of the Commissions meet monthly to deal with new cases. Each Placement Commission comprises six members.<sup>176</sup> There are four permanent members: a paediatrician, a social worker, a (mainstream or special education) teacher or tutor, and a psychologist. The two other members are selected according to the type

<sup>169</sup> The Act on the Education and Training of Children with Disturbances in their Physical and Mental Development, last amendment Official Gazette 54/2000 (not in use since 1 July 2000).

<sup>170</sup> Regulation on Placement Commission and placement criteria, art. 32.

<sup>171</sup> Government of Slovenia, *Poročilo o izvajanju invalidskega varstva v Republiki Sloveniji, (A report of implementation of care for invalids in Republic of Slovenia)*, May 2001, Office for the Disabled and Chronically Sick, available at <http://www.sigov.si/uzi/publikacije/porocilo2000.doc> (accessed 1 June 2005).

<sup>172</sup> Placement Act, art. 20-26.

<sup>173</sup> There are 17 Placement Commissions in Ljubljana; seven in Maribor; four in Kranj; two in Celje; two in Novo Mesto; three in Koper; four in Nova Gorica; four in Murska Sobota; and two in Slovenj Gradec. As most Placement Commissions are located in Ljubljana, parents bring their children to Ljubljana from other towns and cities to receive an evaluation, which represents a financial burden. Interview with Branka D. Jurišič, special pedagogue and member of a Placement Commission, 10 March 2004.

<sup>174</sup> Placement Act, art. 16.

<sup>175</sup> Placement Act, art. 20.

<sup>176</sup> Placement Act, art. 16.

of disability of the child in question.<sup>177</sup> Usually a child is sent to the commission that is nearest to his or her home town, but that does not mean that the child's personal paediatrician will be a member of the commission.

### *Assessment procedures*

The assessment and placement procedures are usually initiated at the request of the legal guardian of the child, in most cases the child's parents. In the case of a child with intellectual disabilities, at the age of three years old the child is usually first directed to a specialist doctor by the family doctor. The specialist can then suggest that the parents refer their child to a Placement Commission, if they think that this is in the best interest of the child. If a child's legal guardian does not agree to a suggested referral to a Placement Commission, the child's kindergarten or school, or another medical or social welfare institution also have the right to initiate the assessment procedure without the parent's consent. In such cases, the National Institute for Education (NIE) is responsible for leading the assessment process.<sup>178</sup>

Once the assessment procedure has been initiated, the future of the child depends on the decision of the Placement Commission. Each member first runs some tests, and interviews the child and their parents. However, the Regulation for Placement Commissions does not precisely state what exactly the members should observe,<sup>179</sup> nor does it prescribe any specific methodology, or the main areas to be examined. Psychologists use verified measurement instruments (tests) such as the Čturič Developmental Scale, but the scale and other tests used by the psychologists are over 20 years old and therefore outdated. Doctors often use pre-existing medical documentation, while social workers talk to parents about their living conditions.

Due to this lack of common standards and guidelines, two different commissions can produce very different reports on the same child.<sup>180</sup> There are a variety of different measurement systems in use (such as tests, scales and exercises) which have not been adequately re-evaluated or systematised. The World Health Organization's *International Classification of Functioning and Health*<sup>181</sup> (ICF) is presently being translated and adapted for Slovenia.<sup>182</sup> This will, hopefully, establish a more systematic

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<sup>177</sup> Interview with Branka D. Jurišič, 10 March 2004.

<sup>178</sup> Placement Act 2000, art. 20.

<sup>179</sup> Interview with Branka D. Jurišič, 12 March 2004.

<sup>180</sup> Dr. Stane Košir, special pedagogue and member of a Government co-ordination body for the adoption of ICF, at the First Congress of Defectologists, Ljubljana, 24 March 2004.

<sup>181</sup> World Health Organization, *International Classification of Functioning and Health* (ICF), WHO, Geneva.

<sup>182</sup> The Slovene translation of the ICF is not yet available.



methodology for the different fields of expertise, as it will also provide a range of social and environmental factors influencing the individual.<sup>183</sup>

Each of the members finally presents an expert report before the Placement Commission, which then forms a joint expert opinion.<sup>184</sup> This includes recommendations on the type of additional expertise or assistance required; the school that the child should attend; and necessary accommodations required for the classroom.<sup>185</sup> The expert opinion is then sent to the higher counsellor at the NIE, who in turn forwards it to the child's parents or legal guardian. The child's parents can react to the expert opinion within a given time, after which the higher counsellor issues a written placement order. Parents do have the right to challenge the decision of the Placement Commission. In case of such appeals a new second-level commission performs a second evaluation.

The role of the responsible regional unit of the NIE is to deliver the placement order to the parents and also to the kindergarten or school in which the child has been placed. The relevant authorities of the kindergarten or school must then prepare an individualised education and training programme for the child, within at least 30 days of receipt of the order.<sup>186</sup> They are then responsible for monitoring the adequacy of this programme, within the time frame set out in the placement order.

In accordance with the Placement Act, the Placement Commission has to set a deadline for reassessment, which cannot exceed three years.<sup>187</sup> The commission itself decides when the child is supposed to come back for a "control check up". Often, preschool children and younger pupils are supposed to see the commission more often (once a year).<sup>188</sup> If needed, following reassessment the child can be placed in a more appropriate care and education programme.<sup>189</sup> A main advantage of the new act is that the placement order can be re-evaluated and changed if necessary. However, some experts consider that this makes no sense for people with more severe intellectual disabilities, given that their condition will not change in any way.<sup>190</sup>

<sup>183</sup> The ICF methodology can be used by any profession dealing with people with disabilities. Andrejka Fatur-Videtič First Congress of Defectologists, Ljubljana, 24 March 2004.

<sup>184</sup> Placement Act, art. 21.

<sup>185</sup> Placement Act, art. 24.

<sup>186</sup> Placement Act, art. 27.

<sup>187</sup> Children who have been placed by a Placement Commission must receive a reassessment between one and (maximum) three years after the initial assessment, in order to evaluate the child's progress at the school. Placement Act 2000, art. 8.

<sup>188</sup> Interview with Branka D. Jurišič, 10 March 2004.

<sup>189</sup> Interview with Branka D. Jurišič, 10 March 2004.

<sup>190</sup> Interview with Branka D. Jurišič, 10 March 2004

### Placement decisions

The placement of a child in a particular school or educational programme is made according to the child's diagnosed level of intellectual disabilities. It is important to note that, by law, only children with *borderline* intellectual disabilities may be integrated into a mainstream school.<sup>191</sup> However, even though a child with *borderline* intellectual disabilities can attend a mainstream school, because of this "categorisation" the child is nonetheless often stigmatised by other children. The only positive aspect of the diagnosis is that in such cases the child can receive additional expert support at the school.<sup>192</sup>

As shown below in Table 3, most children diagnosed with intellectual disabilities are diagnosed with either *borderline* or *mild* intellectual disabilities, 71 per cent in 2001. However, this group of children represents a very heterogeneous group. Many of these children may experience multiple social deprivations, including economic vulnerability, ethnic discrimination, emotional disadvantages, violence and abuse. Social disadvantages were very often medicalised in the past and children who experienced them were diagnosed with intellectual disabilities. This was particularly the case for Roma children; children in care; or children whose parents were seen as a "social problem".<sup>193</sup> In the past, teachers also often tried to place children who were just creating disturbances in the class under this category.<sup>194</sup>

**Table 3. Children with intellectual disabilities registered as clients of the centres of social work (1998–2001)**

Level of intellectual disabilities	Number of children – breakdown by year				Breakdown by level of intellectual disabilities – for 2001 (per cent)
	1998	1999	2000	2001	2001
Borderline	1,138	1,126	1,098	1,021	32
Mild	1,380	1,337	1,324	1,242	39
Moderate	752	764	861	613	19
Severe	233	209	248	171	5
Profound	245	235	248	166	5
Total	3,748	3,671	3,779	3,213	100

Source: Statistical Office<sup>195</sup>

<sup>191</sup> Placement Commissions Act, art. 10.

<sup>192</sup> Placement Act, art. 7 and 8.

<sup>193</sup> Darja Zaviršek, "Surviving Ethnicity and Disability: Minority Children and Public Care" in Sven Trygged, (ed.), *Moving Away from Residential Care*, Stockholm University, Department of Social Work, 2004.

<sup>194</sup> Interview with Matej Rovšek, principal, Janez Levec special boarding school, Ljubljana, 9 April 2004.

<sup>195</sup> Statistical Office, Statistical Yearbook, 2002, 181, p. 2, Table 1.

A noticeable decline over recent years in children diagnosed with *borderline* or *mild* intellectual disabilities is also apparent from Table 3.<sup>196</sup> This is only partly the result of the general decline of birth rate, and has more to do with the conceptual shifts in assessment and policies for integration. The criteria for diagnosing a child with *borderline* or *mild* intellectual disabilities are concerned primarily with low learning skills, meaning that the child has difficulty following classes and cannot achieve the required minimum standards of knowledge. Assessments based on these criteria reflect a very loose and undefined classification. For this reason, the diagnosis of *borderline* or *mild* intellectual disabilities tends to overlap with other factors, such as the economic and social status of a child's family.<sup>197</sup> This is particularly true amongst children from ethnic minority groups, including Roma.<sup>198</sup>

In the past, the diagnosis of *borderline* intellectual disabilities was often used to "protect" children and provide them with an easier educational programme.<sup>199</sup> In many cases, however, the child concerned did not really have any kind of intellectual disabilities, but was just slow in doing exercises or did not obey the teacher's orders (for example, the child was talking to other children, moving around or did not want to write). These children were very often subsequently placed in special schools.<sup>200</sup>

At present, however, due to the growing awareness of parents and some professionals, increasing pressure is being put on the Placement Commissions to give children an assessment of *borderline*, rather than *mild*, intellectual disabilities, so that they can be integrated in mainstream schools. In practice, this means that more and more children, who would until a few years ago have been diagnosed with *mild* intellectual disabilities, are today diagnosed with *borderline* intellectual disabilities and integrated in

<sup>196</sup> Until 2000, the centres for social work maintained statistics on the number of children who were clients of the centres (including those diagnosed with intellectual disabilities), with data collected by the Central Registry of the Ministry of Labour. The Placement Act 2000 transferred this authority to the NIE. However, in both cases statistics are available broken down according to each child's level of intellectual disability.

<sup>197</sup> Telephone conversation with a social worker from a primary school with an adapted programme, 16 February 2004; Interview with Tomaž Jereb, 19 February 2004.

<sup>198</sup> EU Accession Monitoring Programme (EUMAP), *Minority Protection in Slovenia*, 2001, OSI Budapest; available on the EUMAP website at [http://www.eumap.org/reports/2001/minority/sections/slovenia/minority\\_slovenia.pdf](http://www.eumap.org/reports/2001/minority/sections/slovenia/minority_slovenia.pdf) (accessed on 8 September 2004).

<sup>199</sup> Comment of an anonymous defectologist at the first congress of defectologists, Ljubljana, 24 March 2004.

<sup>200</sup> It can also still happen that a child with a speech impediment can be categorised with *mild* intellectual disabilities at the age of ten, which means that the child will not receive the proper assistance, resulting in poor school results and placement in a lower educational programme. Comment by Branka D. Jurišić, special pedagogue and member of a Placement Commission, at the OSI roundtable, Ljubljana, 18 June 2004.

mainstream schools. This, despite the fact that the law does not foresee the integration of children with *mild* intellectual disabilities into mainstream schools.<sup>201</sup>

Children assessed in this way with a lower level of intellectual disabilities may be able to attend a mainstream school. However, in the absence of adequate support for these children (as is the case at present), such inaccurate, “lenient” diagnoses and placement decisions in practice often lead to children having an educational experience that does not meet their real needs.

Some professionals have highlighted the fact that children assessed in this way with a lower level of intellectual disabilities are subsequently placed into educational programmes that are too demanding for them and, as a result, they are even less successful. In practice, some teachers in mainstream schools tend to give the children with *borderline* intellectual abilities positive marks, even if they do not achieve the proper standards. Some believe that this is a result of teachers feeling sorry for children, while others emphasise that the real reason is that by having children with disabilities in class, the school receives higher funding.<sup>202</sup> The commission cannot place a child in a special school if they have received positive marks in a mainstream school. However, it can happen that a child in the fourth grade has no basic mathematical skills, and so must be transferred to a special school as mainstream schools are at present not prepared for teaching children with more severe intellectual disabilities.

For example, in one special school (school with adapted programme) for children with intellectual disabilities in Ljubljana, in 2004–2005 there were almost no children in the first class. Those children who would previously have been diagnosed with *mild* intellectual disabilities had instead been diagnosed as having *borderline* intellectual disabilities and were enrolled in mainstream schools.<sup>203</sup> Nonetheless, in many such cases, children are later reassessed as having *mild* intellectual disabilities’ once they reach class five to seven in the mainstream school and the educational programme becomes more demanding. As a result, the special school gets filled up again in the higher classes and there is no overall decrease in the number of children attending the school. Here again, the problem of children having no effective support to help them remain in a mainstream school becomes obvious.

Similar processes are observed in those special schools that accept children diagnosed with *mild* intellectual disabilities, who should actually have been assessed with *moderate* intellectual disabilities. Referring to a child with *mild* intellectual disabilities, a Placement Commission member said:

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<sup>201</sup> Placement Act, art. 10.

<sup>202</sup> Branka D. Jurišič, special pedagogue and member of a Placement Commission, 10 March 2004, written material received on 31 July 2004, following the OSI roundtable, Ljubljana, 18 June 2004; Telephone conversation with a social worker in a special school who wishes to remain anonymous.

<sup>203</sup> Comment from Matej Rovšek, OSI round table, Ljubljana, June 2004.

Parents teach them how to draw a triangle and to write their name, then tests show mild intellectual disability and they are placed in special school, but at the end of the programme they haven't acquired any new knowledge, since they couldn't follow the classes. At reassessment they are placed in special care and education programmes for children with severe disabilities and actually they are not progressing but regressing.<sup>204</sup>

### *Complaints about placement procedures*

Several critiques have also been made concerning the composition and operation of the Placement Commissions:

First (and most importantly), children are assessed by experts who usually do not know them personally. The permanent members of the commission usually have not met the child prior to the assessment and placement procedures and, in addition, the child's parents have little influence in the placement decision.<sup>205</sup> The *Annual Report 2003* of the Human Rights Ombudsman refers to the complaints of several parents who felt that they had not been sufficiently involved in the decisions of the Placement Commission.<sup>206</sup> Members of Association Sonček have stressed that parents and also people with disabilities should be equal members of the commissions.<sup>207</sup> The Regulation on Placement Commission and placement criteria does stipulate that one member of the commission must be a teacher. However, it does not specify that this should be the child's teacher, or at least a teacher known to the child. In practice, therefore, even the teacher on the Placement Commission does not know the child who the commission must assess. One school counsellor observes that:

In the past it often happened that the members of the commission would call the school to ask the child's teacher for his or her opinion of the child. However, now that there is always a member of the commission who is a teacher, they call less often. It also happens that the parents are not invited to the assessment and the members of the commission only consult them by phone.<sup>208</sup>

<sup>204</sup> Interview with Branka D. Jurišič, 10 March 2004.

<sup>205</sup> Darija Erbus, *Izkušne mater bednikepiranih otrok, (The Experiences of Mothers of Children with Intellectual Disabilities)*, (in Slovene), Thesis for Postgraduate Diploma in social work, Ljubljana, 2004; Interview with Marija Kavkler, Doctor of Pedagogical Sciences, 26 March 2004; Group Interview with teachers from the specialisation study "art therapy" who wish to remain anonymous, Faculty of Education, University of Ljubljana, 27 March 2004.

<sup>206</sup> *Ombudsman Report 2003*, p. 117.

<sup>207</sup> Marija Božič, "Družina z invalidnim članom – majhen sistem znotraj velikega druž benega sistema", ("A Family with an invalid – a small system within a large societal system"), in Journal 5, Association Sonček, 2004, (hereafter, Božič, *A Family with an invalid*).

<sup>208</sup> Darija Erbus, "The Experiences of Mothers of Children with Intellectual Disabilities", thesis for Postgraduate Diploma in social work, 2004.

Second, some experts have stated that at present there are too many members in each commission and that there is not enough teamwork.<sup>209</sup> The members are often retired experts with an older type of education, who have not received adequate (re)training. For example, a member of one commission observed that she had been a member of a commission for ten years, yet in all this time had not received even one training session.<sup>210</sup>

Third, many professionals believe that the work of the commissions is still based predominantly on a medical model of disability, since in practice the expert knowledge of health professionals is prioritised over that of teachers or social workers. This is also shown by the fact that every commission must include two medical professionals, although the formal aim stated in the law or regulations of the commissions is to assess the child's abilities rather than his or her medical condition.<sup>211</sup> In addition, often the president of the commission has the final say in the recommendations included in the joint expert opinion prepared by the commission, in which the reports of doctors or psychologists (based on measurement of intelligence) prevail. The final decision can depend on the power relations between the members of commission.<sup>212</sup>

Fourth, professionals and parents complain about the decisions of the commissions concerning the specified number of hours of additional help that children who have been placed should receive. They say that the commissions try to save money by specifying a smaller number of hours of professional support than that actually required by the child. The law itself is discriminatory; children with intellectual disabilities do not have the right to a personal assistant – this right is reserved for children with physical disabilities.<sup>213</sup>

There have recently also been more complaints from parents about the decisions of the Placement Commissions in individual cases, mainly because parents are now better informed than in the past and want to prevent their child from being sent to a special school. Parents and activists often criticise the fact that a child has to be stigmatised by being “categorised”, just to get the right for special assistance.<sup>214</sup> Parents also complain that the commissions emphasise the child's disabilities rather than their needs for support. Although commission members say that parents usually get the result they

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<sup>209</sup> Interview with Marija Kavkler, 26 March 2004.

<sup>210</sup> Interview with a member of a Placement Commission, who wishes to remain anonymous, 10 March 2004.

<sup>211</sup> Mojca Peček “Integration versus Segregation – the case of Slovenia”, in *Mediterranean Journal of Educational Studies*, Volume 6, No. 2, 2001, pp. 45–64; Group Interview with teachers from the specialisation study “art therapy” who wish to remain anonymous, Faculty of Education, University of Ljubljana, 27 March 2004.

<sup>212</sup> Interview with Matej Rovšek, 1 April 2004.

<sup>213</sup> Placement Act, art. 10.

<sup>214</sup> Interview with Branka D. Jurišič, 10 March 2004.

want and that their child is usually sent to the school they request,<sup>215</sup> interviewed parents claim that the opinion of the commission dominates and that the commissions do not provide them with proper information.<sup>216</sup>

In 2003, there were 24 complaints to the NIE from parents regarding assessment and placement procedures. Most concerned the decision of a commission to place a child in a special school, which meant moving the child away from a mainstream school. Others were about the diagnosis of the child as having *mild* intellectual disabilities, from parents who wanted a *borderline* diagnosis for their child.<sup>217</sup> Finally, a number of complaints concerned delays in the Placement Commission's decision to move a child from a mainstream school into a school with a special programme. In some cases, parents had to wait for the written order for up to one year although according to the law they should receive it within six weeks.<sup>218</sup> However, until the order is issued, the child is not entitled to additional professional support or supplementary classes. There are several reasons for these delays. Some of the commissions are overloaded with cases,<sup>219</sup> while in other cases delays are caused by the slow and sometimes unprofessional work of the commissions, mainly because the members of the commissions have other employment. One of the solutions to the problem of delays is therefore the professionalisation of the commissions. At present, commission members do not receive adequate training and the commissions are not well organised at the national level.<sup>220</sup>

#### 1.4 Early intervention services

At present, early intervention services for children with special needs are regulated by the Placement Act.<sup>221</sup> However, NGOs (the Association Sožitje and the Association Soncek) have proposed that separate legislation should be introduced which would specifically address early intervention services – the Early Intervention for Children

<sup>215</sup> Telephone conversation with Darja Sedej Rozman, social worker, NIE, February 2004.

<sup>216</sup> Members of the parents organisation Sklad Silva, April 2004; Darija Erbus, *Izkušne mater hendikepiranih otrok, (The Experiences of Mothers of Children with Intellectual Disabilities)*, postgraduate diploma work, 2004, Faculty of Social Work, University of Ljubljana.

<sup>217</sup> Darja Sedej Rozman, higher counsellor, and Natalija Vovk Ornik, counsellor to the director, NIE, written comments received on 9 July 2004, following the OSI roundtable, Ljubljana, 18 June 2004.

<sup>218</sup> Telephone conversation with a social worker from a primary school with an adapted programme, who wishes to remain anonymous, 16 February 2004.

<sup>219</sup> Interview with Branka D. Jurišić, 10 March 2004.

<sup>220</sup> Interview with Natalija Vovk Ornik, chairperson, Unit for the Processing of Placements, NIE, 14 May 2004.

<sup>221</sup> Placement Act 2000, Art. 4.

With Special Needs Act. Such an act would ensure early intervention as a right and would be based on a multidisciplinary approach.<sup>222</sup>

Children are most often diagnosed with intellectual disabilities at pre-school age, usually when parents start the process of enrolling their child in a kindergarten or school. The oldest age at which a person can be assessed under the Placement Act is 17 years old, but there is no minimum age. In practice, though, children with more severe intellectual disabilities are usually detected at a younger age.

In most cases, it is the paediatrician who first recognises developmental problems in a child. On the advice of the maternity hospital where the child was born, newly born babies from around the country may be directed to a paediatric hospital if developmental problems are suspected. One specialist has said that some parents of children with intellectual disabilities cannot accept the fact that their child is different from others and therefore reject any early intervention help, and then it is often too late for early treatment.<sup>223</sup> By contrast, many parents have reported that they did not receive any sort of help when they needed it. Professionals stress that with early intervention many more disabilities might be discovered and that early treatment might help the child to receive special accommodations, and learn social skills as soon as possible while still at an early age.

From birth, children with intellectual disabilities receive assistance and support mostly from the so-called mental-hygiene departments, and from developmental dispensaries. The developmental dispensaries focus more on the physical and medical aspects of a child's development, while the mental-hygiene departments focus on a child's cognitive and psychological development.

Although early intervention services are also available in the developmental units of kindergartens, parents try to avoid this option, as they fear that their child will, as a result, later be "categorised" by the Placement Commission.<sup>224</sup>

### *Mental-hygiene departments and developmental dispensaries*

The developmental dispensaries each have their own paediatrician, who follows the development of any child who was born with risk factors such as low birth weight, developmental disturbances due to genetic specificities, or injuries received during the birth procedure. The paediatrician also checks for any developmental difficulties in the course of compulsorily medical checks of babies, during the first year of their life. The

<sup>222</sup> Božič, *Family with an invalid*.

<sup>223</sup> Nevenka Zavrl, "Zdravstvena skrb za otroke s posebnimi potrebami", ("Healthcare of Children with Special Needs"); in Černe, T (ed.), "For Forty Years We Live Together", Association Sožitje, Ljubljana, 2003, pp. 76–79, (hereafter, Zavrl, *Healthcare of Children with Special Needs*).

<sup>224</sup> Branka D. Jurišić, written material received on 31 June 2004, following the OSI roundtable, Ljubljana, 18 June 2004; However, in order to attend the developmental unit of a kindergarten, a child does not necessarily need to be first assessed by a Placement Commission; such assessments are usually first made when a child commences primary school.



paediatrician can decide whether a child requires early intervention services such as physiotherapy or working therapy, or should be referred to a psychologist, speech therapist, special pedagogue or other expert.

The mental-hygiene departments operate within the framework of the basic healthcare system, in units in health centres and in some educational institutions (kindergartens, schools, residential institutions). The mental-hygiene departments monitor a child's progress from birth and run different programmes for children (and young people) with different levels of intellectual disability.<sup>225</sup> Children with other types of special needs, including children with sensory impairments or physical disabilities and children with behavioural problems, are treated in other centres specialising in their type of disabilities.<sup>226</sup>

The mental-hygiene departments operate in health centres. Their role is to provide preventative healthcare in the first year of life; to inform parents about the child's disabilities; and to provide regular check-ups up to the age of two years old. Their staff should consist of medical experts such as paediatricians, physiotherapists and special educators. In practice, however, the mental-hygiene departments often do not all have the necessary professional staff. For example, sometimes there is no special teacher or physiotherapist and in many cases the paediatricians are absent from the centres, because of study (for further specialisations).

According to the Association Sožitje, experts of those departments often exist only 'on paper' and therefore the frequency and quality of treatment is insufficient.<sup>227</sup> Association Sožitje carried out research which found that half of all questioned parents reported that the early intervention programmes of the mental-hygiene departments were not available where they lived, but only in the larger towns and cities. Only 27 per cent of these parents could use these programmes in their hometown.<sup>228</sup> Parents

<sup>225</sup> There are different programmes for children with *mild* physical disabilities and *borderline* intellectual abilities; children with *mild* intellectual disabilities and physical disabilities (or combined disabilities), placed in primary schools with an adapted programme (special schools); children with *moderate* and *severe* intellectual disabilities, placed in social institutions; and children with *severe* disabilities who are cared for at home. Zavrl, *Healthcare of Children with Special Needs*, pp. 76–79.

<sup>226</sup> Ministry of European Affairs, *Guide for the Rights of Disabled People*, (in Slovene), Public Relations and Media Office, Office for the Disabled and Chronically Sick, Ministry of European Affairs, available on the Government website at: [http://www.soncek.org/zakonodaja/vodnik\\_po\\_pravicah\\_invalidov.htm](http://www.soncek.org/zakonodaja/vodnik_po_pravicah_invalidov.htm) (accessed 1 May 2005) p. 85, (hereafter, *Guide for the Rights of Disabled People*).

<sup>227</sup> Interview with Tomaž Jereb, 19 February 2004.

<sup>228</sup> Inclusion Europe and Association Sožitje, *Rights of Persons with Intellectual Disability – Country Report Slovenia*, Inclusion Europe, Brussels, January 2002, available on Inclusion Europe website at [www.inclusion-europe.org/documents/331.pdf](http://www.inclusion-europe.org/documents/331.pdf), p. 13, (hereafter, *Inclusion Europe/Sožitje – Slovenia report*).

complained that in some mental-hygiene departments people have to wait for up to six months to get an appointment.

There are 20 mental-hygiene departments and developmental dispensaries in Slovenia, operating in health centres or general clinics. The network is divided such that each developmental dispensary covers 20,000–23,000 children, from birth to the age of 19 years old.<sup>229</sup> Each developmental dispensary is obliged to take in all children with special needs from their geographical area, and also any other child that is brought in by their parents.<sup>230</sup>

The team in each developmental dispensary should consist of one paediatrician (with an additional knowledge of neurology); two neurophysiotherapists; a part time work-therapist, a part time speech therapist, a nurse, a part-time psychologist, a special educator and a social worker.<sup>231</sup> In many cases, however, the developmental dispensaries do not have sufficient funding for the whole team. In Novo Mesto for example there are two developmental dispensaries, one in the hospital and one in a health centre, with only two and four specialists, respectively. In some cities there are more developmental dispensaries, but without a whole team of experts. In such cases full and complete treatment cannot be provided.

There are many weaknesses in the present system for the provision of early intervention for children with intellectual disabilities. Children often do not get equal or quality treatment.<sup>232</sup> In particular, children and parents who live in larger cities tend to make more use of available programmes than those living in rural areas.<sup>233</sup> Due to this situation, a group of parents of children with Down's Syndrome carried out a project on early intervention which was financed by the EU Phare Programme. The project resulted in the translation of eight booklets on the methodology of early intervention.<sup>234</sup> In addition, early intervention experts (including a retired "defectologist",<sup>235</sup> a speech therapist and a physiotherapist) were engaged, so as to provide individual treatment for the children. However, this sort of treatment is only available to those that can afford to pay for these services.<sup>236</sup>

<sup>229</sup> Zavrl, *Healthcare of Children with Special Needs*, pp. 76–79.

<sup>230</sup> Interview with Branka D. Jurišić, 10 March 2004.

<sup>231</sup> Zavrl, *Healthcare of Children with Special Needs*, pp. 76–79.

<sup>232</sup> Interview with Tomaž Jereb, 19 February 2004.

<sup>233</sup> Interview with Tomaž Jereb, 19 February 2004.

<sup>234</sup> Alenka Šelih, law professor, president of Association Sožitje, written material received on 29 July 2004, following the OSI roundtable, Ljubljana, 18 June 2004.

<sup>235</sup> The stigmatising term "defectologist" is still used in Slovenia, rather than "special educator".

<sup>236</sup> Interview with Tomaž Jereb, 19 February 2004.

## 2. GOVERNMENT EDUCATION POLICY

*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, rather 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.*

### 2.1 The EU and Government education policy

Slovenia became a member of the EU in 2004. At the time when Slovenia was still an EU candidate country, the situation of people with intellectual disabilities was not an issue on which the EU focused in its regular monitoring of Slovenia's efforts to meet EU accession criteria. The Regular Reports issued by the European Commission on Slovenia's progress towards meeting the political and economic criteria for membership did not address the education of people with disabilities.

The Slovenian Government defined the policy of social inclusion as one of its priority policies back in 2000, and in December 2003 Slovenia signed a "Joint Memorandum on Social Inclusion" (JIM) with the European Commission.<sup>237</sup> Slovenia adopted its "National Action Plan on Social Inclusion 2004–2006" (hereafter, NAP/Inclusion) in July 2004.<sup>238</sup> This addresses some basic challenges, strategies, aims and measurements in the areas of social inclusion.<sup>239</sup> The NAP/Inclusion recognises people with disabilities as one of the groups most at risk of poverty and social exclusion.<sup>240</sup> It also recognises low educational levels as a main determinant of poverty and social exclusion and includes a number of objectives aimed at improving access to education. These objectives include: ensuring the conditions for the successful inclusion of pupils with

<sup>237</sup> Ministry for Labour, *Joint Memorandum on Social Inclusion in Slovenia*, Ministry for Labour, 18 December 2004, DG Employment and Social Affairs, European Commission, available on the website of the European Commission at [http://europa.eu.int/comm/employment\\_social/soc-prot/soc-incl/si\\_jim\\_en.pdf](http://europa.eu.int/comm/employment_social/soc-prot/soc-incl/si_jim_en.pdf) (accessed 15 March 2004), p. 19, (hereafter, Slovenia JIM).

<sup>238</sup> Government of Slovenia, *National Action Plan on Social Inclusion 2004–2006 (NAP/Inclusion)*, Ljubljana, July 2004, available on the European Commission website at [http://europa.eu.int/comm/employment\\_social/social\\_inclusion/naps\\_en.htm](http://europa.eu.int/comm/employment_social/social_inclusion/naps_en.htm) (accessed 15 March 2004), (hereafter, NAP/Inclusion 2004–2006).

<sup>239</sup> Ministry of Labour, Public Information, 29 July 2004, (in Slovene), available on the Ministry website at <http://www.sigov.si/mddsz/aktualno/290704c.htm> (accessed 29 December 2004).

<sup>240</sup> Especially those with no disability status; with severe disabilities; who are unemployed; and/or with unsuitable housing conditions. NAP/Inclusion 2004–2006, p. 5.

special needs in primary and secondary schools; and facilitating the inclusion of students with special needs in the widest possible range of vocational programmes.<sup>241</sup>

## 2.2 Reform of the education system

In Slovenia, there is ongoing reform of the education system for children with special needs, which is under the jurisdiction of National Commission for the Renovation of the Education System for Children with Special Needs, (hereafter, Renovation Commission). However, to date this reform has had almost no impact on improving equal opportunities and inclusion of children and young people with (specifically) intellectual disabilities.

The aims of the Renovation Commission are to establish the basis for the reform of the educational system for children with special needs; to create alternative educational programmes; and to evaluate and accredit existing educational programmes.<sup>242</sup> The Commission has stated that change is necessary at many different levels and should include the drafting of appropriate standards; changes to the content of the curricula; provision of new textbooks; changes in the organisation of programme implementation; and improved teacher training.

Although nine-year compulsory education was introduced for students starting their education in the school year 2003–2004 (prior to this, the duration of compulsory education was eight years), to date not all programmes for elementary education have been designed and teachers in special schools have had to improvise.<sup>243</sup> In the context of these ongoing reforms of the educational system, and in accordance with the Primary School Act and the Placement Act, in 2003 and 2004 four important documents concerning the education of children with special needs were prepared by the Renovation Commission and adopted. These documents are intended for professionals who educate children with special needs, including intellectual disabilities. They foresee organisational changes to the educational programmes for this group of children, including with respect to the evaluation of what the child has learned; adaptations to the educational environment; and provision of additional

<sup>241</sup> NAP/Inclusion 2004–2006, pp. 14–15.

<sup>242</sup> Ministry for Education and Sport, *General information on the National Commission for the Renovation of the Education System for Children with Special Needs*, (in Slovene), National Commission for the Renovation of the Education System for Children with Special Needs (hereafter, Renovation Commission), Ministry for Education and Sport, available on the Ministry website at [http://www.mszs.si/slo/solstvo/razvoj\\_solstva/posebne\\_potrebe.asp#splosnipodatki](http://www.mszs.si/slo/solstvo/razvoj_solstva/posebne_potrebe.asp#splosnipodatki) (accessed 15 March 2004).

<sup>243</sup> Interviews with: Matej Rovšek, 9 April 2004; and Elvira Agič, social worker, Janez Levec special boarding school, Ljubljana, 9 April 2004; Aleš Čakš, “Otroci s posebnimi potrebami Prikajšani v šoli, ožigosani v družbi” (“Children with special needs – deprived at school, stigmatised in society”), in *Daily Delo*, 7 March 2004.

support. However, the educational programme for children with special needs in special schools (and special units in mainstream schools) is still being revised.

The first document covers pre-school education in kindergartens. The annex to the “Programme for pre-school children with special needs with adapted implementation and additional expert support”<sup>244</sup> regulates the organisation of classes, and pedagogical guidelines on aspects such as individuality, respect for differences and autonomy. It also stresses the importance of additional training for teachers and assistant teachers in kindergartens.

The second document is, “Instructions for educational programmes with an adapted implementation and additional expert support in nine-year primary school” (hereafter, Instructions for educational programmes with an adapted implementation – nine years).<sup>245</sup> It covers primary education for children in mainstream classes in mainstream schools. However, this document does not include children with intellectual disabilities among the groups of children defined as eligible for adapted implementation. The instructions apply only to children with difficulties in certain areas of learning; blind and partially sighted children; children with speech impediments; children with physical disabilities; chronically ill children; and children with behavioural problems. This means that there are no instructions for the implementation of educational programmes with an adapted implementation for children with *borderline* intellectual disabilities in mainstream schools.

The third document covers elementary level education in special institutions and training centres, “Special care and education programmes – elementary school level”.<sup>246</sup> These programmes cover the education and training of children and young people with *moderate, severe* and *profound* intellectual disabilities. Changes to these special programmes have been necessary following the implementation of a new regulation in 2004, which permits an extension of the elementary education of these children up to the age of 26.<sup>247</sup>

The fourth is a document on vocational education (two and a half years), “Instructions for the implementation of secondary vocational educational programmes for students

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<sup>244</sup> “Programme for pre-school children with special needs, with adapted implementation and additional expert support”, available on the website of the National Education Institute at: [http://anton.lj.zrsss.si/doc/VRTCI\\_Navodila\\_za\\_prilagojeno\\_izvajanje.doc](http://anton.lj.zrsss.si/doc/VRTCI_Navodila_za_prilagojeno_izvajanje.doc) (accessed 1 May 2005).

<sup>245</sup> Ministry for Education and Sport, *Instructions for Educational Programmes with an Adapted Implementation*.

<sup>246</sup> Ministry for Education and Sport, *Special Care and Education Programme – Elementary School Level*.

<sup>247</sup> Ministry for Education and Sport, *Special Care and Education Programme – Elementary School Level*.

with special needs in mainstream school.”<sup>248</sup> The instructions include a separate article on students with *mild* intellectual disabilities, based on principles appropriate to the learning needs of this group. These include a positive attitude from teachers and school friends; additional help and support from the school; and monitoring and assessment of the individual educational plans. Teachers are advised to take into account students’ individual capabilities and divide work into smaller parts that they can more readily follow. This draft document also envisages the involvement of parents in the education process and envisages that secondary schools could adapt the implementation of programmes by themselves and provide additional professional support.

### 3. EDUCATION PRACTICE AND POLICY IMPLEMENTATION

*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 unit”) 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, though, 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*

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<sup>248</sup> Ministry for Education and Sport, *Instructions for the Implementation of Educational Programmes of Vocational and Specialised Training with Adapted Implementation and Additional Expert Help*, (in Slovene), available on the Ministry’s website at [http://www.mszs.si/slo/solstvo/pdf/Navodila\\_poklic\\_strok\\_izobr.pdf](http://www.mszs.si/slo/solstvo/pdf/Navodila_poklic_strok_izobr.pdf) (accessed 3 January 2005), (hereafter, Ministry for Education and Sport, *Instructions for Vocational Educational Programmes with an Adapted Implementation*).

*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 which provide alternatives to residential care and permit children with more severe intellectual disabilities to remain with their families.*

### 3.1 Inclusive education

#### 3.1.1 Pre-school education

Pre-school education for children with special needs is regulated by the Placement Act; the Education Organisation and Financing Act; and the Kindergarten Act. The Kindergarten Act gives priority to the mainstreaming of pre-school children with special needs.<sup>249</sup> However, since this group also includes children with physical and sensory disabilities, and children with behavioural challenges, it is not clear to what extent this also applies to children with intellectual disabilities. Nonetheless, children with *mild* and *moderate* intellectual disabilities can enrol in mainstream kindergartens and follow the “Programme for pre-school children with special needs, with adapted implementation and additional expert support”.

Those children who because of their special needs cannot attend mainstream kindergartens are directed to special units in some mainstream kindergartens (developmental units). These units implement the “Adapted Programme for pre-school children with special needs”. Such adapted programmes are also available in special kindergartens for children with *moderate*, *severe* and *profound* intellectual disabilities. These can be in developmental units of mainstream kindergartens or in special kindergartens in some residential institutions.

These two types of educational programme establish the principles to be applied in educating pre-school children with special needs, including early intervention, inclusion, individualisation and a holistic approach, and highlight the role and significance of adults in a child’s formation of a positive self-image. The programmes also establish guidelines for the implementation of the curriculum in all kindergartens that enrol children with intellectual disabilities. In these kindergartens, a holistic approach is sought, involving educators, assistant teachers, counsellors, parents and doctors.

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<sup>249</sup> Kindergarten Act, art. 20.

### 3.1.2 Mainstream primary schools

The integration of children with intellectual disabilities into mainstream schools is still at an early stage. Slovenia does not have a special law on integration, although this is addressed in the Primary Schools Act, and the Placement Act and its implementing regulations. Nonetheless, a growing tendency towards integration can be observed, as certain categories of children with special needs are increasingly included into the mainstream school system.

In accordance with the Placement Act and its implementing regulations, only children with *borderline* intellectual disabilities can be integrated into mainstream primary schools.<sup>250</sup> In such cases parents can insist on the integration of their child, even if the Placement Commission placed their child in a primary school with an adapted programme (special school).

Under the Placement Act, however, parents now have more say in the decisions concerning their children. In consequence, some professionals report that parental pressure has led to some children with *mild* intellectual disabilities being instead diagnosed with *borderline* intellectual disabilities so that they can be integrated into mainstream schools. There are even some children who have been diagnosed with *mild* intellectual disabilities who are placed in mainstream schools without a written order from the National Institute for Education (NIE). However, the consequence is that those children who did not receive a written order from the Placement Commission are not entitled to additional professional help or an individualised programme.

At the beginning of school year 1999–2000, there were 816 primary schools in Slovenia with 185,554 children enrolled. Exact data on the numbers of children with disabilities included in this figure is not available. However, the numbers of children with special needs who are integrated into mainstream primary schools is growing from year to year.<sup>251</sup> A main reason for this is demographic. As the number of school-age children falls, some schools are being forced to reduce the number of classes. Integration has therefore become increasingly attractive for some schools which otherwise would not have enough children enrolled. One child with intellectual disabilities is legally regarded as three non-disabled children, both in terms of funding and class size.<sup>252</sup>

A special programme for children with special needs in mainstream schools now exists – “Programme with an adapted implementation and additional expert support”. However, this programme does not specifically mention children with intellectual disabilities, and there is no specific programme for children with *borderline* intellectual disabilities.

<sup>250</sup> Regulation on Placement Commission and placement criteria, art. 10

<sup>251</sup> Personal telephone conversation with Nives Molan, representative of the Ministry for Education and Sport, in connection with another research project, February 2003.

<sup>252</sup> Regulations about normative and standards implementing the programme of nine year primary schools, Official Gazette 81 of 23 July 2004.



This programme refers to the right of children with special needs to an “adapted implementation” and an “adapted environment in the classroom”.<sup>253</sup> An “adaptation implementation” in this context means, for example, that a child with reading difficulties has the opportunity to tape the lessons or use a computer that reads text. A child with special needs could also have the right to special arrangements concerning, for example, the class timetable or assessments of what the child has learned. The Placement Commission is responsible for preparing an expert opinion on how to adapt the implementation of the programme to the needs of each child. The commission should also specify any other kind of additional help the child may need. However, in 2000–2001, 8.1 per cent of children who were “categorised” did not receive additional support despite the suggestions of the Commission.<sup>254</sup> An “adapted environment in the classroom” means, for example, that a child can sit in the front row, to be as close to the teacher as needed, and also allows for special technical aids such as a special chair or other learning aids.

The Placement Commission is also responsible for recommending the form of “additional expert support” required by the child, and to ensure that the child receives an “individualised educational programme”.<sup>255</sup> For children with *borderline* intellectual disabilities, in accordance with the Placement Act “additional expert support” means that children can receive up to five hours additional assistance per week, provided by professional staff at the school or external professionals, in kindergartens, schools or residential institutions. The child can receive this additional help during class time (either in the classroom or outside) or at their home, through the so-called “mobile service”.<sup>256</sup> The Placement Commission specifies the type of additional professional support to be provided; their placement order states how many hours of additional help each child requires, and for which subjects. The school is responsible for preparing an individualised educational programme for the child; this is evaluated and rewritten yearly, and must be re-evaluated within a maximum period of three years period.

The Placement Act opened the door for integration in the education system and, conceptually, the new system of schooling for children with special needs should offer more opportunities for different approaches in teaching and learning. It should also

<sup>253</sup> Ministry for Education and Sport, *Instructions for Educational Programmes with an Adapted Implementation*, pp. 7–31.

<sup>254</sup> Branka D. Jurišić, “Komi je prilagojeno izvajanje programov s prilagojenim izvajanjem”, (“To whom is the adapted implementation adapted to?”) in Alen Kofol (ed.), bulletin from the Symposium of Janez Levec special boarding school, Ljubljana, 2002, p. 32.

<sup>255</sup> Primary Schools Act, art. 11.

<sup>256</sup> The Ministry for Education and Sport established the mobile services in 1994. These are specifically intended for children with special needs who are integrated into mainstream schools and offer additional support to the child, either in the class or at home. The mobile services are provided either by special educators or by teachers at the school, with the help of other external experts. During individual treatment lessons, the role of this mobile professional support is to help the child acquire the required knowledge to be able to cope with the curriculum.

allow more children to attend mainstream primary schools, in which they could be provided with specific forms of support according to their needs. However, parents and social workers are not satisfied with the first results of integration and believe that teachers are not adequately prepared and trained for working with children with intellectual disabilities.<sup>257</sup> In particular, teachers in primary schools have not received any additional training. Most special educators still promote special schools, and some teachers reject the integration of children with intellectual disabilities.<sup>258</sup> Some teachers believe that the education system is set too competitively for integration to succeed.<sup>259</sup> In addition, the parents of children without disabilities are not well prepared for integration.

Although the Ministry for Education and Sport prepared the Placement Act, it would seem that in practice the ministry and the NIE only partially support the inclusion of children with intellectual disabilities. This is illustrated by the fact that the Instructions for educational programmes with an adapted implementation – nine years do not explicitly mention children with intellectual disabilities, only “children with special needs”. Until now, the Ministry for Education and Sport has not sought feedback from NGOs, parents or independent experts on the integration programme, which is yet to be evaluated.

A recent example of successful integration is the case of two girls with Down’s Syndrome who have been included in a mainstream primary school in Ljubljana, under a pilot research project. The Placement Commission categorised the girls with *borderline* intellectual disabilities and placed them in a mainstream school. In 2003, parents and researchers started a dialogue with the school, which was prepared to accept both girls. However, although they had support from the school (from teachers, parents and students), the Ministry for Education and Sport and the NIE had doubts about their integration.<sup>260</sup> Representatives of the NIE questioned the decision of the commission to place the girls in a mainstream school. In particular, they questioned the ability of the girls to follow the educational programme given that existing legislation limits additional expert support to only five hours per week.<sup>261</sup> Both girls were enrolled in the first class at

<sup>257</sup> Telephone conversation with a social worker from a special school who wishes to remain anonymous, 12 January 2004; Interviews with Elvira Agič, 9 April 2004; Matej Rovšek, 9 April 2004; and with a group of teachers and carers from the post-graduate specialisation programme “Art therapy”, Faculty of Education, University of Ljubljana, who wish to remain anonymous, 26 March 2004.

<sup>258</sup> Interviews with a group of teachers and carers from the post-graduate specialisation programme “Art therapy”, Faculty of Education, University of Ljubljana, who wish to remain anonymous, 26 March 2004.

<sup>259</sup> Telephone conversation with a social worker at a special school, who wishes to remain anonymous, 12 January 2004; Interview with Matej Rovšek, 9 April 2004.

<sup>260</sup> Marija Kavkler, Doctor of Pedagogical Sciences, one of the leaders of the project, 26 March 2004.

<sup>261</sup> Darjas Sedej Rozman, Natalija Vovk Ornik, NIE, written comments received on 9 July 2004, following the OSI roundtable, Ljubljana, 18 June 2004

the mainstream school, despite the fact that the written order of the NIE permitting five hours of additional expert support was only received two or three months after the school year had started. As this was a pilot project, the two girls did also receive some supplementary additional help, which is not ensured by law for all children. The consequence of this was that the two girls were successful and all those involved (special educators, psychologist, social workers, teachers and parents) gave a very positive response to their integration. As a result, after the girls had completed the first year, the NIE gave permission for them to continue their education at the mainstream school.<sup>262</sup>

This example shows that with a larger extent of individual support than is presently provided for by existing legislation, children with intellectual disabilities could be much more successful in mainstream schools than they are at present. A similar network of help and support should therefore be organised for all children with intellectual disabilities in mainstream educational programmes.

### 3.1.3 Special schools

In Slovenia, there are 53 special primary schools (schools with an adapted programme) for children with *mild* intellectual disabilities; most of these are day schools but there are at least 11 boarding schools for children with intellectual disabilities. In 2002–2003, a total of only 1,945 students (36 per cent were girls) attended these schools.<sup>263</sup> Each year the number of children in those schools is dropping, both due to a natural decrease and also as a result of the new legislation enabling the integration of children with special needs into mainstream schools. For example, in the school year 2003–2004, there was no first class in the Janez Levec special boarding school for children with *mild* intellectual disabilities, due to the fact that so many children had been integrated into mainstream schools.<sup>264</sup> Parents are increasingly better informed and want to avoid their child being “stigmatised” by attending a special school.

The main specificity of special schools offering an “adapted programme for children with special needs” is their lower standard of education in comparison to mainstream schools. There are differences both in the level of education – more time for each specific subject, more repetitions, group learning – and the ways used to assess how much the child has learned – more emphasis is placed on individual preferences. The curriculum is adapted from the national curriculum and only covers basic subjects such

<sup>262</sup> Alenka Šelih, Law Professor, President of *Sožitje*, written comments received on 29 July 2004, following the OSI roundtable, Ljubljana, 18 June 2004.

<sup>263</sup> Statistical Office, Statistical Yearbook 2003, p. 115, tables no. 6, 7, available (in English) on the Statistical Office website at <http://www.stat.si> (accessed 15 March 2005).

<sup>264</sup> Comment at the OSI roundtable, Ljubljana, 18 June 2004.

as Slovene language, mathematics, nature and society. Children do not learn physics, chemistry or history.<sup>265</sup> Not long ago there was no foreign language learning at all.

In special schools, children with intellectual disabilities follow the “adapted programme with a lower educational standard”. However, education professionals have highlighted the inadequate working conditions for teachers of students with special needs in primary schools with an adapted programme.<sup>266</sup> This programme is still not adapted to the new nine-year compulsory schooling; teachers do not have appropriate textbooks and use photocopies of the textbooks for mainstream schools, which are inappropriate for primary schools with an adapted programme.<sup>267</sup> A newly adapted curriculum for programmes with an adapted implementation for children with intellectual disabilities is presently in preparation and will amend the existing one.<sup>268</sup>

According to current regulations only children with *mild* intellectual disabilities, and in exceptional cases only, children with *moderate* intellectual disabilities, are directed to these programmes.<sup>269</sup> In most cases, children with *moderate*, *severe* or *profound* intellectual disabilities are placed in special programmes of care and education in residential institutions.<sup>270</sup> In some cases, children with more severe intellectual disabilities who had been placed in these programmes have instead been enrolled in a special school for children with *mild* intellectual disabilities. For the children concerned, it is clearly a good thing if they attend a special school rather than be placed in a residential institution. However, as the special schools are not yet equipped for, or able to cope with, the needs of children with more severe intellectual disabilities, in practice this often meant that these children did not even acquire those skills for which they had been assessed as capable of acquiring. The programme in the special school proved too demanding for them and, as a result, some developed mental health problems.<sup>271</sup>

Many experts claim that the pressure by parents to include their child into programmes perceived as being less “stigmatising” is too strong. However, if experts in this field could ensure a “friendlier” general climate for children with intellectual disabilities and if adequate support was available to enable the integration of children with more severe intellectual disabilities, perhaps the pressures of parents would not need to be so strong.

<sup>265</sup> Only some basics of these subjects are included under other subjects. Interview with Elviro Agič, a social worker, Janez Levec special boarding school, Ljubljana, 9 April 2004.

<sup>266</sup> Interview with Matej Rovšek, 9 April 2004.

<sup>267</sup> Aleš Čakš, “Otroci s posebnimi potrebami, Prikrajšani v šoli, ožigosani v družbi”, (“Children with special needs – deprived at school, marginalized in society”), in *Daily Delo*, 7 March 2004; Interview with Matej Rovšek, 9 April 2004.

<sup>268</sup> Interview with Matej Rovšek, 9 April 2004.

<sup>269</sup> Regulation on Placement Commission and placement criteria, art. 13 and 14.

<sup>270</sup> Regulation on Placement Commission and placement criteria, art. 14.

<sup>271</sup> Interviews with: Branka D. Jurišič, 10 March 2004; and Tatjana Podlipec, 24 March 2004.

The numbers of pupils attending all types of primary schools with an adapted programme has been steadily falling, as shown below in Table 4.<sup>272</sup> From 1990 to 2000 student numbers decreased by 28 per cent, from 4,847 to 3,467 students. The views of experts on this are divided. While some see this as a positive development, others fear for the future of the special schools.

**Table 4. Pupils in primary schools with an adapted programme (special schools) – (1990–2000)**

School Year	Number of schools <sup>273</sup>	Number of students	Number of girls
1990-91	78	4,847	1,903
1995-96	77	3,963	1,481
1996-97	78	3,961	1,512
1997-98	76	3,739	1,411
1998-99	69	3,531	1,326
1999-00	68	3,595	1,410
2000-01	67	3,467	1,325

Source: Statistical Office<sup>274</sup>

Despite the fact that the number of students in special schools has been steadily falling, as yet there has been no public discussion on reforming the special school system. On the contrary, this tendency has instead led to children with learning difficulties and Roma children (without intellectual disabilities) being placed in special schools for children with *mild* intellectual disabilities. A social worker who is a member of a Placement Commission commented that, “in our part of the country, we are lucky that we have Roma children, otherwise we would have to close down the school with an adapted programme.”<sup>275</sup> Due to inadequate assessment procedures (see section III.1.3), Roma children are in any case almost ten times more likely than non-Roma children to be categorised as having *mild* intellectual disabilities and referred to primary schools with an adapted programme. In 2002–2003, the number of non-Roma children in primary schools was 175,035, of which 2,531 attended schools with an adapted programme (1.4

<sup>272</sup> Statistical Office, Statistical Yearbook 2003, Table 6.8, available (in English) on the Statistical Office website at <http://www.stat.si> (accessed 15 March 2005).

<sup>273</sup> Primary schools with an adapted programme for children with intellectual and/or physical disabilities.

<sup>274</sup> Statistical Office, Statistical Yearbook 2003, Table 6.8, available (in English) on the Statistical Office website at <http://www.stat.si> (accessed 15 March 2005).

<sup>275</sup> Darja Završsek, “The Ethnic Rights of the Ethnic Minority Children”, in V.L. Dominelli, W. Lorenz et al. (eds.), *Beyond Racial Divides. Ethnicities in social work practice*, Ashgate Publishing Company, Burlington USA, 2001.

per cent). By contrast, the number of Roma children in mainstream primary schools was 1,223, while 126 (9.3 per cent) were in primary schools with an adapted programme.<sup>276</sup>

Research has shown that the disproportionate categorisation of Roma children can be based on factors such as poor knowledge of Slovene language; the socio-economic background of their families; and even their external appearance.<sup>277</sup> This is another example where people who are more vulnerable are seen as themselves being “guilty” for their categorisation. The responsibility for the failure to include such children in mainstream education is not acknowledged as laying with the schools rather, in the system at large. For example, some experts have said that it is less important if a Roma child is placed in special school since he or she “would not get a job anyway”. One educator at the Counselling Centre for Children and Youth in Ljubljana even told some couples wishing to adopt a Roma child that, “Roma children are biologically incapable of learning mathematics”.<sup>278</sup> These examples highlight the racism and prejudice of some experts, which can also influence their decisions on the placement of Roma children.

## 3.2 Education outside the school system

### 3.2.1 Home schooling

Home schooling is rare in Slovenia. The concept only developed with the transition from eight-year to nine-year compulsory primary schooling. Home schooling is mentioned in the Primary Schools Act 1996<sup>279</sup> and the Placement Act of 2000, but only in the sense of a possible way of schooling.<sup>280</sup> If a child is educated at home they must achieve the same educational standard as in a public school.

Parents must first submit a request for home schooling of their child. The right to home schooling is reserved for children who have been assessed by the Placement Commission. In accordance with the “Regulation on Elementary Education of Children with Special Needs at their Home”, home schooling is possible only for “justified reasons” and when the “proper conditions” defined in the regulation are fulfilled.<sup>281</sup> “Justified reasons” are determined by the Placement Commission in cases when a child, due to “deficiencies, obstacles or disability” cannot attend class or

<sup>276</sup> Ministry for Education and Sport, data provided by NM, January 2003.

<sup>277</sup> Research data of S. K., who in her diploma thesis, researched the documentation of Roma children in one of the schools with an adapted programme. The research showed that Roma children are primarily directed to primary schools with an adapted programme because of the way they look. (data available from the reporter).

<sup>278</sup> Interview with Tanja Skornšek Pleš, parent, 27 April 2004.

<sup>279</sup> The Primary School Act, art. 88.

<sup>280</sup> The Placement Act provides for home schooling, if there are justifiable reasons. However, these “justified reasons” are not actually defined in the act. Placement Act, art. 18.

<sup>281</sup> Regulation on Elementary Education of Children with Special Needs at their Home 2004, Official Gazette 61/2004, (hereafter, Regulation on Home Schooling), art. 2.

could achieve a better educational level through home schooling.<sup>282</sup> “Proper conditions” are fulfilled when a qualified person<sup>283</sup> is found to teach the child and proper equipment and didactical aids are ensured.<sup>284</sup> Children taught at home receive support from teachers at the school where they will be enrolled.<sup>285</sup> However, while elementary school tuition in Slovenia is free, parents must pay for the hours when teachers are working at the child’s home.

In practice, examples of home schooling are very rare in Slovenia. There were only three home-schooled children at primary and secondary level in 2004.<sup>286</sup> There was an example highlighted in the media in 2004 of a child who is taught at home and for whom the Ministry for Education and Sport only pays for five hours tuition a week. In an interview, staff from the school where this child is enrolled stated that this home schooling is more demanding for both the child and the teachers, and that the number of teaching hours and social contacts is much smaller than in a school.<sup>287</sup>

### 3.2.2 Education of children in residential care institutions

The Placement Act, and its implementing regulation, is the main act regulating education in residential care institutions.<sup>288</sup> The content of the educational programme in such institutions is defined by the “Special care and education programme – elementary school level”, which was introduced in 2004. This programme is obligatory for all children with *moderate*, *severe* and *profound* intellectual disabilities and is also used for young people and adults in their inclusion into life and work. The programme is divided into three levels: pre-school – from age one to elementary school; elementary school – primary level (compulsory nine year education) plus a maximum extension of six years; and training for life and work (four to five years).

The educational programme can be implemented at the institution and also allows for transition to a special school. The content of the programme is not significantly different from the old programme, which was introduced in 1994. The emphasis is on such aspects as perception, movement, and development of independence, speech

<sup>282</sup> Regulation on Home Schooling, art. 4 and 5.

<sup>283</sup> The qualified person must fulfil the criteria for the implementation of programmes of care and education of children with special needs defined in the Education Organisation and Financing Act and other legislation.

<sup>284</sup> Regulation on Home Schooling, art. 5.

<sup>285</sup> Parents have to formally enrol the child in a school, even if he or she will be taught at home.

<sup>286</sup> Aleš Čakš, “Šolanje na domu. Izjeme so redke, a dovoljene”, (“Home schooling. Exceptions are rare, but allowed”), interviews with Judita Kežman and Elido Bandelj, State Secretaries, Ministry for Education and Sport, in *Daily Delo*, 5 January 2004, p. 7.

<sup>287</sup> Aleš Čakš, “Šolanje na domu. Izjeme so redke, a dovoljene”, (“Home schooling. Exceptions are rare, but allowed”), interviews with Judita Kežman and Elida Bandelj, State Secretaries, Ministry for Education and Sport, *Daily Delo*, 5 January 2004, p. 7.

<sup>288</sup> Regulation on Placement Commission and placement criteria, art. 13.

development, social conduct and manual skills. Each child should work according to his or her individualised programme.

In 2000, there were 821 children (of which 486 were boys)<sup>289</sup> living in the five residential care institutions for children and adolescents with *moderate, severe* and *profound* intellectual disabilities.<sup>290</sup> Some children stay in the institution during the week and go home at the weekends. There was a total of 838 staff working in these institutions, of which 160 were healthcare personnel (the figures for social welfare personnel are not available). This is indicative of an evident dominance of the “medical model” in the care of these children, despite the fact that these institutions are a part of the social care system. The number of children in institutions is expected to fall, due to the number of day centres now opening across the country.<sup>291</sup> At present, however, there are no figures available on the number of children with intellectual disabilities attending such centres.

The Government has stated in the “National Social Security Plan to 2005” that it supports the establishment of day centres as an alternative to residential care.<sup>292</sup> However, a new institution for people with severe physical and intellectual disabilities is nonetheless being built in a remote area on the Slovenian coast. This will provide placement and care for about 40 children from the region, as previously parents had to place their children in institutions more than 100 kilometres from home. The parents’ organisation Sklad Silva<sup>293</sup> had suggested that the authorities should instead rent several houses in the region and establish smaller living units, which would promote independent living.<sup>294</sup> However, this suggestion was not taken up. Although many parents see such a centre as necessary, given that at present they have to drive their children to centres located far away, it would nonetheless have been preferable for the Government to consider providing more individualised, community based services for these children.

<sup>289</sup> Statistical Office, Statistical Yearbook 2001, Table 10.11, available (in English) on the Statistical Office website at <http://www.stat.si> (accessed 15 March 2005).

<sup>290</sup> The five residential care institutions are at: Dornava, Dobrna, Radovljica, Crna na Koroskem and Ig.

<sup>291</sup> Ministry for Labour, Family and Social Affairs, “V središču”, (“In focus”), November–December 2002, Ljubljana. Also available (in Slovene) at [http://www.gov.si/mddsz/november\\_december.pdf](http://www.gov.si/mddsz/november_december.pdf) (accessed 2 May 2005).

<sup>292</sup> Ministry of Labour, Family and Social Affairs, National Social Security Plan to 2005, Official Gazette 31/2000.

<sup>293</sup> Sklad Silva is a parents-led organisation from the coastal region of Slovenia, with around 200 members.

<sup>294</sup> Interviews with parents from Sklad Silva, Fijeroga, 21 April 2004.



## 4. 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.*

### 4.1 Vocational education and training

The two and a half-year lower vocational programme is the only vocational education programme in which children with *mild* intellectual disabilities can enrol. This programme is offered at secondary vocational schools and is only open to those who have had at least six years of education in a mainstream elementary school or who have completed a special school. As discussed previously, the Ministry for Education has recently published a draft set of instructions for this educational programme.<sup>295</sup> These instructions state the principles of vocational education for children with *mild* intellectual disabilities; the methods of evaluating the child's knowledge; available professional staff support; and additional help and support available for those working with pupils with special needs.

However, since employers now want better-qualified workers, the interest for these programmes is falling and some are being cancelled.<sup>296</sup> Such programmes now exist only in Ljubljana and some other cities, which means that they are inaccessible for many young people with intellectual disabilities. In the school year 2003, there were only 15 such programmes available, most of which offer male-orientated vocations such as assistant baker, butcher or pastry cook.<sup>297</sup> Girls are therefore even more restricted in their choice of programme than boys. There is only one traditionally female profession, assistant housewife, although girls do also enrol also on the programmes for assistant baker, pastry cook or farmer.<sup>298</sup>

<sup>295</sup> Ministry for Education and Sport, *Instructions for Educational Programmes with an Adapted Implementation*.

<sup>296</sup> Interview with Tomaž Jereb, 19 February 2004.

<sup>297</sup> Interview with Tina Priveršek, a social worker, 16 March 2004.

<sup>298</sup> Špela Urh, "Položaj oseb z oznako duševne prizadetosti s posebnim poudarkom na izključenosti intelektualno oviranih žensk", ("The status of a person with intellectual disabilities with a special emphasis on the exclusion of women with intellectual disabilities"), in Darja Zaviršek (ed.), *Tako lepa, pa invalid! Socialno delo proti diskriminaciji hendikepiranih žensk*, (So beautiful, but disabled! 'Social work against the discrimination of disabled women'), in *Socialno delo* (special edition), 44, 1-2, 2005.

In 2003–2004, there were 432 students enrolled on these programmes, of whom 51 per cent were young people with *mild* intellectual disabilities.<sup>299</sup> In the school year 2003–2004, 86 per cent of children from a primary school with an adapted programme for children with *mild* intellectual disabilities went on to do a two and a half year lower vocational programme.<sup>300</sup>

Children and young people who due to their intellectual or physical disabilities cannot be involved in mainstream vocational and secondary schools receive training in residential institutions, where they attend work training units and follow a special programme of education and care. This programme is open to people with *moderate*, *severe* and *profound* intellectual disabilities. These units can be part of a primary school with an adapted programme (special school) or located at a separate institution.

The work training units run special vocational training programmes; orientation programmes; art classes; and working production.<sup>301</sup> An emphasis is placed on the social development of the person. These programmes enable a young person to prolong their primary education (this prolongation is referred to as “training”) and they can now be extended up to the age of 26 years old. At the end of the training, the trainee receives a certificate with a narrative description of their achievements.

People with intellectual disabilities would have a greater access to employment if the residential care institutions that train them cooperated more with potential employers, so that they could try to place these young people in supported employment or enable them to access short-term training placements.

## 4.2 Employment services and vocational rehabilitation

After completing a vocational education or training programme, 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. Those who have completed the two and a half-year lower vocational programme are in fact no longer considered as having intellectual disabilities. If they cannot find work, they can register as unemployed and receive unemployment benefits like all other unemployed people. There is no official data on what happens to these young people after they finish the programme of lower vocational education. However, their employment opportunities are nonetheless very

<sup>299</sup> Ljubica Lukan, consultant to the Ministry for Education, presentation at the first Congress of defectologists, Ljubljana, 24 March 2004.

<sup>300</sup> Interview with Natalija Vovk Ornik, counsellor to the director, NIE, 14 May 2004.

<sup>301</sup> The working production programme includes the following techniques and skills: work with paper and cardboard (squashing, tearing, gluing, painting, printing); work with textiles (squashing, cutting, netting, hand and machine sawing, colouring); work with wood (moving, folding, grinding, sawing, drilling, polishing, binding, painting); work with synthetic materials (cutting, sawing, polishing, designing, painting); work with metal (wire designs, binding, painting).

limited, regardless of gender.<sup>302</sup> The centres for social work only get involved if the person applies for social benefits, by which time the person is usually already in a very precarious position, both financially and socially.<sup>303</sup>

The unemployment rate is very high among people with intellectual disabilities,<sup>304</sup> but still there are no support programmes specifically targeted at job seekers with intellectual disabilities.<sup>305</sup> An employee of the Employment Office stated that she had never met a person with intellectual disabilities at the office, as most are placed in sheltered workplaces or on rehabilitation programmes.<sup>306</sup> However, it is unusual for people placed in rehabilitation programmes to subsequently find employment as most are directed to the centres for social work and depend on social benefits.

There are a few sheltered companies (referred to as “invalid companies”)<sup>307</sup> which provide training and vocational rehabilitation for adults with more severe disabilities. These include Sonček (in Ljubljana) and Sončna pot (in Maribor),<sup>308</sup> both operated by Association Sonček; and Želva,<sup>309</sup> operated by Association Sožitje. However few people with intellectual disabilities are able to access these programmes.

<sup>302</sup> Interview with Sandra Stare, employment office, Kranj, 17 February 2004.

<sup>303</sup> Telephone interview with a social worker from a special school who wishes to remain anonymous, 12 January 2004; Interview with Tomaž Jereb, 19 February 2004; Interview with Matej Rovšek, 9 April 2004.

<sup>304</sup> Interview with Tina Priveršek, social worker, 16 March 2004.

<sup>305</sup> Interview with Matej Rovšek, 9 April 2004.

<sup>306</sup> Interview with Sandra Stare, 19 February 2004.

<sup>307</sup> Sheltered companies (referred to as “invalid companies”) provide employment for people with disabilities (including intellectual disabilities) who have skills above that required for work in sheltered workplaces. They must fulfil a quota of at least 40 per cent of workers with disabilities. See also section IV.2.2.

<sup>308</sup> The Association Sonček is an invalid organisation for children with cerebral palsy and their parents.

<sup>309</sup> Želva operates a centre for vocational rehabilitation which offers vocational and psychosocial rehabilitation using a by “learning by doing” methodology. Those involved in this programme can choose between the following professions: dressmaking, carpeting, gardening, cleaning and building caretaker. The programme usually lasts from 18 to 24 months and is divided into three to four stages. People gradually learn about their chosen profession and about basic working procedures; at the end they perform tasks independently. Želva employed 273 people in 2002 in the areas of production and service. The aim of this programme is to involve people who have limited working abilities, but whose abilities are too high for work in a sheltered workplace. Instructors and mentors trained in social work and work therapy are responsible for the implementation of the programmes. Information from the website of the Želva sheltered company for people with intellectual disabilities, introduction page, available at [www.zelva.si](http://www.zelva.si) (accessed 8 September 2004).

## IV. Access to Employment

### 1. LEGAL FRAMEWORK

*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 which came into force on 21 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.*

#### 1.1 National legislation

The Constitution provides the legislative basis for the right to work and for fair conditions of employment. Article 49 ensures freedom of work, freedom in the choice of employment, and access under equal conditions to any employment position. Article 52 states that people with disabilities “shall be guaranteed protection and work training in accordance with the law”. Under Article 66, the State “shall create opportunities for employment and work, and shall ensure the protection of both by law”.

The most relevant national legislation to the employment of adults with intellectual disabilities is:

- The Vocational Rehabilitation Act 2004
- The Equal Treatment Act 2004
- The Employment Relationship Act 2004<sup>310</sup>
- The Employment and Insurance Against Unemployment Act 2004 (hereafter, Employment Act)<sup>311</sup>

<sup>310</sup> The Employment Relationship Act 2004, Official Gazette 42/2002, 20/2004, (hereafter, Employment Relationship Act).

<sup>311</sup> The Employment and Insurance against Unemployment Act 2004, 5/1991, 12/1992, 12/1993, 71/1993, 38/1994, 80/1997, Supreme Court written order: U-1-343/94, 69/1998, 67/2002, 2/2004, 10/2004, (hereafter, Employment Act).

- The Social Security Act 2004<sup>312</sup>
- The Social Care Act 1983

Slovenia acceded to the EU on 1 May 2004 and has implemented EU legislation in the area of employment, including binding Community laws (EU Directives and Resolutions) and non-binding statements of principle (EU Resolutions).<sup>313</sup> Slovenia has transposed into national legislation the provisions of the EU Employment Directive, through amendments to the Vocational Rehabilitation Act and the introduction of two new acts, the Equal Treatment Act and the Employment Relationship Act.<sup>314</sup>

The Equal Treatment Act entered into force on 7 May 2004. The act recognizes some groups of people as underprivileged, including people with disabilities.

The Employment Relationship Act, adopted in 2002, specifically forbids discrimination on the grounds of medical condition or disability.<sup>315</sup> It also includes an article on anti-discrimination, which forbids discrimination against “invalids” in employment, working conditions and promotion.<sup>316</sup> Importantly, this does not apply to people with intellectual disabilities who have “invalid status” under the Social Care Act.

The Social Care Act defines the rights to “guidance, care and employment under special conditions” of adults with “invalid status” under this act, including people with *moderate, severe* and *profound* intellectual disabilities.<sup>317</sup> This includes forms of work and care that enable people with physical disabilities and/or intellectual disabilities to use their skills and gain new ones, including employment in sheltered workplaces. The discriminative side of the act is that it explicitly defines persons with “invalid status” as not capable of leading an independent life or having paid employment.<sup>318</sup> They are automatically determined as unable to live independently and incapable of working, and can only be placed into training programmes and sheltered workplaces. They can only take up employment if they renounce this status and thereby lose the rights to

<sup>312</sup> The Social Security Act 2004, Official Gazette 54/1992, 42/1994, 1/1999, 41/1999, 36/2000, 54/2000, 26/2001, 110/2002, 2/2004, 36/2004.

<sup>313</sup> The most relevant EU Resolutions in this area are: Council Resolution of 15 July 2003 on promoting the employment and social integration of people with disabilities, 2003/C 175/01; and Council Resolution of 17 June 1999 on equal employment opportunities for people with disabilities, 1999/C 186/02.

<sup>314</sup> See, for example: European Commission, *Equality and Non-discrimination 2004*, p. 16.

<sup>315</sup> The grounds on which discrimination is prohibited under the act include “gender, race, age, medical condition and disability, religious, political and other beliefs, membership in the trade unions, national and social background, family status, economic situation, sexual orientation and other personal conditions.” Employment Relationship Act, art. 6.

<sup>316</sup> Employment Relationship Act, art. 6.

<sup>317</sup> Social Care Act, art. 1.

<sup>318</sup> Social Care Act, art. 1.

which they are entitled to under the act, including social security benefits.<sup>319</sup> The centres for social work are responsible for the implementation of the act.

There is no specific legislation concerning the employment of people with intellectual disabilities. Formally this is covered in the Vocational Rehabilitation Act. Amendments to the act in 2004 introduced for the first time a quota system for the employment of people with disabilities in companies on the open market,<sup>320</sup> and a definition of supported employment.<sup>321</sup> The new act also defines new forms of sheltered employment.<sup>322</sup> Other important provisions concern changes to the procedures for assessing the working capacity and employability of people with disabilities, and the establishment of Rehabilitation Commissions to assess people with disabilities for employment purposes.<sup>323</sup> The act also includes the right to vocational rehabilitation, which is defined as “a possibility to gain proper qualifications for employment”<sup>324</sup> Pilot projects on supported employment are already being implemented in some municipalities like Novo Mesto, Maribor and Ravne na Koroškem.<sup>325</sup>

At the moment, politicians and experts are divided on the implications of the implementation of the amended act. Some claim that it will bring positive changes for people with intellectual disabilities, while others claim that, especially for people with *moderate*, *severe* and *profound* intellectual disabilities, in practice nothing will change. Despite the positive elements of the new act, there are several aspects which disability activist organisations have highlighted as unsatisfactory. First, the Vocational Rehabilitation Act 2004 still uses the old term “invalid”. Second, the act does not apply to people who have “invalid status” according to the Social Care Act. Article 10 of the Vocational Rehabilitation Act 2004 states that “invalidity status” under this act can only be granted to those who do not already have this status according other laws.<sup>326</sup> This thereby excludes people with *moderate*, *severe* and *profound* intellectual disabilities from any chance of accessing the new provisions of the Vocational Rehabilitation Act.

User-led disability organisations have expressed dissatisfaction with the fact that they were not invited to participate in the drafting of the new Vocational Rehabilitation Act. Although some NGOs sent written comments to the Ministry of Labour, these

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<sup>319</sup> Social Care Act, art. 1 and 3.

<sup>320</sup> Vocational Rehabilitation Act, art. 62.

<sup>321</sup> Vocational Rehabilitation Act, art. 48, 51.

<sup>322</sup> Vocational Rehabilitation Act, art. 41.

<sup>323</sup> Vocational Rehabilitation Act, art. 29.

<sup>324</sup> Vocational Rehabilitation Act, art. 4.

<sup>325</sup> Interview with Aleksandra Tabaj, advisor, Minister of Labour, Family and Social Affairs, 4 March 2004.

<sup>326</sup> Vocational Rehabilitation Act, art. 10.

were not taken into consideration.<sup>327</sup> At the time when the amendments to the act were being discussed, one of the NGOs advocating for the rights of people with disabilities – Association for the Theory and Culture of Handicap (YHD) – proposed an amendment to Article 10, such that *all* people with disabilities would have the right to “invalid status” according to this act. This amendment would have ensured that regardless of the type or level of their disability, and their status under the Social Care Act, *all* adults with disabilities would have been covered by the provisions on the quota system; sheltered and supported employment; and the right to vocational rehabilitation.<sup>328</sup> However, some representatives of invalid organisations (including Association Sožitje) succeeded in countering this proposal.

The Employment and Insurance against Unemployment Act defines the status and rights of the unemployed.

### *Specialised bodies*

The National Employment Service, and at the local level the Employment Offices, the courts and the Human Rights Ombudsman each deal partly with cases of discrimination in employment. As outlined previously, the Equal Treatment Act foresees the establishment of an advocate for equal treatment who will also address cases of discrimination in employment. The Labour Inspectorate, under the Ministry of Labour, is responsible for supervising the implementation of employment legislation, including provisions on health and safety.

## **1.2 Capacity assessment for employment purposes**

The procedures for assessing the employability of adults with disabilities are defined by the Vocational Rehabilitation Act. However, as discussed previously this act only applies to people with disabilities who do not already have “invalid status” according to the Social Care Act. For adults (aged 18 years old and over) with intellectual disabilities, therefore, these procedures only apply to those with *mild* intellectual disabilities.

The recent amendments to the Vocational Rehabilitation Act introduce important changes to the procedures for assessing the employability and working capacity of people with intellectual disabilities. According to the new act, special Rehabilitation Commissions will be formed under the National Employment Service to carry out these assessments, which are at present performed by Expert Commissions under the authority of the National Employment Service. The Rehabilitation Commissions will

<sup>327</sup> The Association for the Theory and Culture of Handicap (YHD) sent written comments and suggestions for changes to the Ministry of Labour, with respect to the proposed amendments to the Vocational Rehabilitation Act. They suggested that under rehabilitation, elements such as assertiveness training and empowerment and training on rights should be introduced, and that people with disabilities should be included in the Rehabilitation Commissions. Interview with Elena Pečarič, president of YHD.

<sup>328</sup> Written complaint against Article 10 of the proposed of the Act, YHD.

be responsible for providing an expert opinion on the degree of working capacity, level of knowledge, working experience and vocational interests of an individual with disabilities. They will also help to establish particular vocational goals.<sup>329</sup> Each Rehabilitation Commission will have five members. In both the old and new act, the medical model prevails as two of the members of the commission (including the President) must be doctors.<sup>330</sup>

In future, the final report of the Rehabilitation Commission will determine the best options and suitable goals for an individual with disabilities. The commission will issue a written order (“final report”) only in those cases where a person with disabilities is defined as “unemployable” and only able to work in supported or sheltered employment schemes;<sup>331</sup> in other cases, there is no written order and the person concerned only receives a report from the Employment Office. In addition, a person who, after being assessed by the Rehabilitation Commission, is given the “invalid status” according to the Vocational Rehabilitation Act has the right to receive vocational rehabilitation. After the conclusion of this rehabilitation, the Employment Office will issue a new assessment of the individual’s employment possibilities. This report must show whether the person can be employed in a regular working environment or in supported or sheltered employment, and also the kind of support the person would need.<sup>332</sup>

As of September 2004, however, assessments were still being implemented according to the Vocational Rehabilitation Act of 1990. According to this act, ten regional Expert Commissions (comprising five members<sup>333</sup>) are responsible for the assessment of the employability and working capacity of a person with disabilities.<sup>334</sup> Nonetheless, the medical experts have the most significant influence in decision-making. The opinion of the medical doctor on the Commission is regarded as particularly important, especially when an individual has medical problems which can present important challenges to their employment. However, for people with intellectual disabilities in particular, giving greater weight to medical opinions in assessing the capacity to work can be inappropriate. This practice should therefore be discouraged and replaced with a multidisciplinary approach, focusing on the individual’s abilities.

<sup>329</sup> Vocational Rehabilitation Act, art 15.

<sup>330</sup> Vocational Rehabilitation Act, art. 29.

<sup>331</sup> A person is defined as “unemployable” if he or she is unable to achieve more than one third of the efficiency of workers without disabilities. Vocational Rehabilitation Act, art. 34.

<sup>332</sup> Vocational Rehabilitation Act, art. 33.

<sup>333</sup> Each Expert Commission comprises: a doctor; specialist in the area of work with people with disabilities; a counsellor from an Employment Office; a social worker, psychologist or sociologist; a representative of the centre for social work; and a health expert for the specific type of disability.

<sup>334</sup> Interview with Dominik Presen, coordinator for employment programmes, National Employment Service, March 2004.



The Expert Commission first carries out an assessment of the working capacity of the individual with disabilities. On the basis of this assessment, the person can receive one of the following three decisions:

1. The person receives “invalid status” under the Vocational Rehabilitation Act and is deemed *incapable of work*.
2. The person receives “invalid status” under the Vocational Rehabilitation Act but is deemed *capable of work*. He or she can seek part-time employment on the open market or employment in a sheltered company (“invalid company”) and has no right to receive a disability allowance.
3. The person does not receive “invalid status” under the Vocational Rehabilitation Act. The person’s level of disability is assessed as being minimal and does not influence the person’s employment possibilities.<sup>335</sup> The person has no right to receive a disability allowance.

Those people who are determined as *incapable of work* (1) receive a written order that can state one of the following:

- The person is incapable of profitable work (even with additional training) and is therefore “*unemployable*”.
- The person could become capable of employment after a training programme, which could last from six months to a year. If this training is successful, a new order can be issued.
- Vocational rehabilitation is recommended.<sup>336</sup>

People who are determined as “*unemployable*” according to the Vocational Rehabilitation Act are directed to a centre for social work. (For people with intellectual disabilities this can only apply to those with *mild* intellectual disabilities, who do not have “invalid status” under the Social Care Act.) They are accorded rights under the Social Care Act and the Social Security Act, including the right to social benefits. The percentage of people who receive the order that they are “*unemployable*” is, according to data from the National Employment Service, between two and a half to three per cent of all people who are assessed (approximately ten people every year).<sup>337</sup> These are mostly people with *mild* intellectual disabilities who can, like everybody else, compete on the open market, but were not able to find jobs even with additional training.

In the case that vocational rehabilitation is recommended, a rehabilitation counsellor is responsible for designing a rehabilitation plan, in co-operation with the “invalid” in

<sup>335</sup> Interview with Dominik Presen, February 2004.

<sup>336</sup> In such cases the rehabilitation counsellor can recommend the following services: counselling and motivation; assessment of skills, working habits and interests; assistance in choosing career goals; search for proper job; analysis of the working environment; design of an adaptation plan for the working environment; assistance for training; and follow up.

<sup>337</sup> Interview with Dominik Presen, March 2004.

question. The rehabilitation plan establishes the “sort, quantity, methods and duration of vocational rehabilitation”.<sup>338</sup> However, many experts and people with disabilities have stated that, to save money, rehabilitation counsellors often suggest a shorter duration of rehabilitation, lasting for around six months. In some cases, professionals reported that at the end of the year, when the local Employment Office had exhausted its budget, vocational rehabilitation could no longer be provided:

In some cases the rehabilitation lasts only 30 hours. There is no money at the beginning of the year, and a lot in March or April. After March, we can employ many people for rehabilitation. After July, when there is no money left, no new people are sent for rehabilitation.<sup>339</sup>

### 1.3 The role of the social welfare system

Until the age of 18 years old, if a child lives at home with his or her family, the parents can receive a *child nursery allowance*, which is intended to cover the increased costs for the family of caring for a child with disabilities.<sup>340</sup> This allowance is meant for children who are cared for at home by their parents because of a long term illness or injury (in this case, the allowance is set at 20,170 84 SIT per month, or approximately €84) and in the case of children with *severe* and *profound* intellectual or physical disabilities (here, the monthly allowance is 40,330 SIT, or €169). Eligibility for the *child nursery allowance* is determined on the basis of the opinion of a medical commission, and not necessarily on the basis of the decision of the Placement Commission.<sup>341</sup>

At the age of 18 years old, the status of a person with intellectual disabilities is defined by the Social Care Act. This act provides “invalid status” and other rights both for people who were diagnosed with disabilities during childhood, and also for people who became disabled after having been in employment.<sup>342</sup> Article 3 of the act defines the

<sup>338</sup> Vocational Rehabilitation Act, art. 32.

<sup>339</sup> Interview with a person who works in an invalid company in N. W. Slovenia, August 2004. Her job is to assess the working capacity of persons who come for vocational rehabilitation and to send her report back to the Employment Office.

<sup>340</sup> Parental Care Act, art. 80.

<sup>341</sup> Parents are entitled to receive the allowance for the whole period during which the child is cared for at home, or until the child attains the age of 18 years old. After this age, the entitlement can be prolonged until the end of the child’s education, but only up to the age of 26 years old.

<sup>342</sup> For people who get disability status after already being in employment, the assistance allowance ranges between: 27,956 SIT (€117) – the lower amount; and 79,877 SIT (€333) – the highest amount (depending on the severity of the individual’s disabilities). Pension and Disability Insurance Act 2004, art. 141. The amount of the assistance allowance received is higher than that received by people categorised during childhood and, together with the pension they also receive, permits this group to attain a decent standard of living. The living standards for people who were never employed are much more precarious, as they are entitled only to the minimal level of assistance allowance and it is not possible to survive on this level of support. The Social Security Act grants all people who are permanently incapable of work a financial support as their only source of income; the benefit per month per single person is 45,524 SIT (€189). Social Security Act, art. 22.

rights of a person with disabilities to social security entitlements. This includes benefits to cover the care and support of people with disabilities who require assistance from another person (usually a family member) to ensure that their basic living conditions are met.

In practice, though, the provisions of the Social Care Act discourage people with more severe disabilities from trying to access employment. In the case that a person with more severe intellectual disabilities has the chance to move into paid employment, they lose their entitlement to the benefits accorded on them on the basis of their “invalid status” under the Social Care Act.

An adult with intellectual disabilities with “invalid status” under the Social Care Act (who is not placed in a residential institution) therefore has two main options in terms of benefits:

- to receive a *disability allowance* and an *assistance allowance*;
- to choose a personal assistant who receives a *family allowance*. The person with disabilities still receives the *disability allowance*, but loses their entitlement to an *assistance allowance*.

For adults, the Social Care Act establishes the minimal social security benefits to which they are entitled, namely the *assistance allowance* and the *disability allowance*.<sup>343</sup> As of 1 April 2004, the *disability allowance* is presently set at 55,675 SIT per month (€232).<sup>344</sup> For a person needing assistance for all of their basic life functions, the *assistance allowance* is presently set at 31,814 SIT per month (€133). For people who need assistance for most of their basic life functions, the corresponding amount is 15,907 SIT per month (€66). The total amount of both allowances (minimum 87,489 SIT or €365) covers the basic living costs of a person who lives with their family, but is too low to cover their required social services, personal assistance or technical aids. It would not cover the costs of a person renting their own apartment and living independently. By contrast, the minimum wage in Slovenia is currently set at 117,500 SIT (€490) per month.<sup>345</sup>

As of 2003, new legislation introduced an additional benefit called *family assistance*.<sup>346</sup> This new provision is intended to compensate families who have an adult family member with disabilities who is not in residential care. Adults with severe intellectual or physical disabilities who require assistance for all their basic life functions can use this allowance as an alternative to institutional care. The family assistant receives a

<sup>343</sup> Social Care Act, art. 7.

<sup>344</sup> Pension and Disability Insurance Act 2004, art. 141.

<sup>345</sup> In April 2004, the minimum monthly gross pay was set at 117,500 SIT (€490) from August 2004; and 122,600 SIT (€511) from August 2005. “Minimum wage under debate”, article accessed on the website of EIRO (European Industrial Relations Observatory) available at <http://www.eiro.eurofound.eu.int/2004/05/feature/si0405102f.html> (accessed 9 September 2004).

<sup>346</sup> Social Security Act, art. 18(a)–(r).

minimal salary defined by law; as of April 2004 this is 111,484 SIT (€465). A family assistant can be either a relative, or a third person who is not a family member but lives at the same housing address as the person with disabilities.<sup>347</sup> However, in most cases the family assistant is a close family member, usually a woman, who has had to give up paid employment in order to prevent her child (or another family member) from being institutionalised on a long-term basis.

There are, however, several restrictions on the selection of the family assistant.<sup>348</sup> First, the family assistant cannot be any person chosen by the person with disabilities, but must either be registered at an Employment Office or already in employment, and must be living at the same address as the person with disabilities if he or she is not a family member.<sup>349</sup> Second, a person who previously lived in an institution must receive an expert opinion from the institution, to confirm that living at home would be beneficial for the person with disabilities. Third, a special commission of the centre for social work must approve the choice of family assistant, with the exception of parents who have previously cared for the person in question. Finally, when the family assistant is approved and placed with the person with disabilities, then the *assistance allowance* is no longer paid. This means that the person receives some support, but is no longer eligible for the personal benefits that he or she previously received; this measure has been criticised by disability activist organisations. One person with disabilities has also suggested that the name “family assistant” should be changed to “personal assistant”,<sup>350</sup> as the term “personal assistant” would emphasise the right to choose between different persons, and not only family members, thereby increasing the personal choice of a person with disabilities.

People with *mild* intellectual disabilities are able to work on the open market and can have the status of an employee under the Employment Relationship Act, so they are eligible for *unemployment benefits* if they are unemployed.<sup>351</sup> The concept of “unemployment” is therefore not applied to people with *moderate*, *severe* and *profound* intellectual disabilities at all.

People with “invalid status” under the Social Care Act cannot register as unemployed at the Employment Office. However, for people who are registered at the Employment Office for long periods of time and are unable to find a job, the Employment Office has, for the last six years, been offering a special programme of social integration including mostly people with *mild* intellectual disabilities. The implementers of this programme were selected through a call for applications and in 2004 there are 17

<sup>347</sup> Social Security Act, art. 18.

<sup>348</sup> Regulation on the Conditions and Procedures for the right to Family Assistance, Official Gazette 84/2004, art. 18.

<sup>349</sup> Social Security Act, art. 18.

<sup>350</sup> Written suggestion received on 20 July 2004 by a person who wishes to remain anonymous, following the OSI roundtable, Ljubljana, 18 June 2004.

<sup>351</sup> Employment and Insurance against Unemployment Act, art. 18, 20.

employers involved in the programme. They receive 140,000 SIT (or approximately €584) per month per employee, half of which goes towards the salary of the employee and the remainder to the employer.<sup>352</sup> This work can include work in an adapted workplace in a regular company, in a sheltered company or in a sheltered workplace.<sup>353</sup>

## 2. GOVERNMENT EMPLOYMENT POLICY

*The 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 receive tax relief and Government subsidies. Although a quota system was introduced as of 10 June 2004, it is still too early to assess the implications of this new system for the employment of people with mild intellectual disabilities.*

### 2.1 The EU and Government employment policy

As an EU candidate, and now as a member country, Slovenia has been progressively adjusting its employment policy in line with the European Employment Strategy, which has full employment as its most important goal. In 2000, Slovenia was one of the first of the then EU candidate countries of Central and Eastern Europe to sign a “Joint Action Plan” (JAP) with the European Commission. This makes several references to the employment of persons with disabilities, in the framework of strengthening policies for equal opportunities.<sup>354</sup> In September 2004, Slovenia published its first “National Action Plan for Employment” (NAP), which covers the period 2004–2006 and will replace the

<sup>352</sup> Dominik Presen, coordinator for the employment programmes, National Employment Service, comment at the OSI roundtable, Ljubljana, 18 June 2004.

<sup>353</sup> However, people working in sheltered workplaces who do not have disability status (including, for example, supervisors) are not eligible.

<sup>354</sup> Ministry of Labour, *Joint Assessment of the Employment Policy Priorities of Slovenia*, 18 July 2000, Ministry of Labour, available on the European Commission website at [http://europa.eu.int/comm/employment\\_social/employment\\_analysis/japs/slovenia\\_en.pdf](http://europa.eu.int/comm/employment_social/employment_analysis/japs/slovenia_en.pdf) (accessed 15 September 2004), p. 14, (hereafter, Slovenia JAP).

JAP. The NAP includes people with disabilities as a target group, and outlines measures taken to increase their access to employment.<sup>355</sup>

In the framework of the EU social inclusion process, Slovenia's "Joint Memorandum on Social Inclusion" (JIM), 2003, recognises people with disabilities as a vulnerable group, facing increasing levels of unemployment. However, it concludes that:

the employment of persons with disabilities in sheltered companies is now the most appropriate, indeed their only, possibility for employment. These are the only form of social economy in recent years.<sup>356</sup>

This conclusion overlooks the significant potential of supported employment programmes to enhance opportunities for people with intellectual disabilities to find work on the open market, and increase social inclusion.

## 2.2 National employment policy

### 2.2.1 National employment strategy

Slovenia has prepared yearly action plans and annual reports on labour market development, based on the European Employment Strategy.<sup>357</sup> The Ministry of Labour has also prepared a "Strategy for the Training and Employment of Disabled Persons, 2003–2006" which aims to contribute to achieving the goals of the National Employment Programme.<sup>358</sup>

The long-term national employment strategy is defined by the "National Programme for the Development of the Labour Market and Employment by 2006" (hereafter, National Employment Programme), which was adopted in 2001 and includes provisions on the employment of people with disabilities.<sup>359</sup> The programme does not specifically refer to people with intellectual disabilities – just people with disabilities in general. The Labour Department of the Ministry for Labour is responsible for monitoring the implementation of the programme. The National Employment Programme establishes 12 key points and indicators for the achievement of the

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<sup>355</sup> Ministry of Labour, *National Action Plan for Employment 2004*, September 2004, Ljubljana, available (in English) on the European Commission website at [http://europa.eu.int/comm/employment\\_social/employment\\_strategy/nap\\_2004/nap2004sl\\_en.pdf](http://europa.eu.int/comm/employment_social/employment_strategy/nap_2004/nap2004sl_en.pdf) (accessed 15 March 2005), pp. 30–31.

<sup>356</sup> Slovenia JIM, p.19.

<sup>357</sup> See, for example: "Employment Action Programme for 2004" and the "Active Employment Policy Programme for 2004", available (in English) on the Ministry of Labour website at <http://www.sigov.si/mddsz> (accessed 15 March 2005).

<sup>358</sup> Slovenia JIM, p. 20.

<sup>359</sup> Ministry of Labour, "National Programme for the Development of Labour Market and Employment by 2006", Official Journal 92/2001, (hereafter, National Employment Programme).

established goals<sup>360</sup> and includes the following important measures to encourage the employment of people with disabilities:

- development of modern methods of disability and skills assessment;
- development of standards for a safe and healthy work environment and the prevention of injuries that could cause disability;
- quality training for people with disabilities (regardless of gender, age or degree of disability);
- introduction of a quota system for the involvement of people with disabilities in education and training programmes (through active labour market programmes and some employers on the open market);
- design and implementation of programmes to promote the integration of people with disabilities into education and training;
- development of measures to encourage employers to employ people with disabilities;
- design of new forms of supported and sheltered working places (including “learning companies”, “integration companies” and “social companies”);
- development of new forms of counselling and of expert and financial support for employers who employ a large number of people with disabilities and require additional staff to support them (such as assistants, mentors or rehabilitation counsellors); and
- continuing support to sheltered companies (“invalid companies”).<sup>361</sup>

The National Employment Programme is implemented through legislation and active labour market programmes (ALMPs).<sup>362</sup> The overall aim of ALMPs is to encourage the employment of vulnerable groups, including people with disabilities. The programmes

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<sup>360</sup> The 12 key points include: an active approach to solving the problem of unemployment; development of a culture of life-long learning; improving education levels; measures for reducing the numbers of drop-outs at all levels of education; measures specifically targeting young people; development of entrepreneurship; creating conditions for creating new jobs; fighting against work on the black market; promoting flexibility; and promoting equal access to the labour market.

<sup>361</sup> National Employment Programme, Official Gazette, 92/2001.

<sup>362</sup> The legislative basis is the Employment Act and the Employment Relationship Act.

are implemented by the Ministry of Labour, through the Employment Offices, in collaboration with employers.<sup>363</sup>

### 2.2.2 Government requirements and incentives

Currently in Slovenia there are two main possibilities for the employment of people with intellectual disabilities: employment in companies on the open market, which for now is only possible for adults with *mild* intellectual disabilities; or work in a sheltered company (“invalid company”). However, most people with intellectual disabilities are placed in sheltered workplaces, which cannot be considered as constituting employment, as the workers do not have an employment contract or receive a wage.

There are a number of Government programmes and measures aimed at encouraging the employment of people with disabilities in companies on the open market. These can be targeted at employers or directly at the person with disabilities. At present, most people with *mild* intellectual disabilities who seek employment (and receive training) in companies on the open market, do so through ALMPs. Data for 2002 reveals that 949 people with disabilities participated in ALMP programmes, of which 38 per cent subsequently found employment.<sup>364</sup> However, there is no specific information available on the involvement of people with intellectual disabilities in ALMPs.

In addition to ALMPs, there are some positive measures aimed at promoting the employment of people with disabilities in companies on the open market.<sup>365</sup> However, these are targeted at people who become physically disabled after already being in paid employment, not people with intellectual disabilities.

People with disabilities who cannot find work in companies on the open market may instead be employed in the sheltered companies (“invalid companies”) which must fulfil a quota of at least 40 per cent of people with disabilities. These companies operate as other companies on the open market, but with several special arrangements.

<sup>363</sup> Active labour market programmes (ALMPs) are a long-term approach to solving the problems of the unemployed, which aim to increase the level of employment; promote business and adaptation to market conditions; help individuals adapt to the needs of the labour market; and promote the equalisation of employment opportunities. The following types of ALMP are available: training and education; public works; training and employment of people with disabilities; promotion of self-employment; co-financing of regional development projects and cooperatives. The Employment Offices direct unemployed people to these programmes and helps them to find employment. The Employment Offices also implement programmes on prevention of unemployment: co-financing of invalid companies; co-financing of additional training of staff; cooperation in the Government programme of restructuring the labour force; and co-financing of the opening new positions.

<sup>364</sup> Internal document provided by Aleksandra Tabaj, Ministry of Labour, 4 March 2004.

<sup>365</sup> For example, an employment contract may be concluded with a person with disabilities without prior announcement or a public announcement of the vacant position; an Employment Office can send a suitably qualified person with disabilities directly to the organisation or employer with the vacancy. Employment Relationship Act, art. 24.



They do not have to pay social security and pension costs for the employee with disabilities and can spend this money on the development of the company,<sup>366</sup> or pay income tax.<sup>367</sup>

Employers in sheltered companies are entitled to State support through co-financing or subsidies. Co-financing is available for adaptations to the working premises, purchase of equipment and technical aids, the creation of new work places and education and training, including for managers. The National Employment Service subsidises the salary of employees with disabilities, gives some money for workplace adjustments and technical resources. According to the Employment and Insurance Against Unemployment Act the income subsidies vary from 25 to 75 per cent of the minimum wage, depending on the degree of disability of the worker.<sup>368</sup>

The amended Vocational Rehabilitation Act of 2004 introduces important new measures to promote the employment of people in companies on the open market, in particular a quota system.<sup>369</sup> With the aim to stimulate the employment of people with disabilities, under this new act all employers with more than 20 employees are required to employ a certain percentage of people with disabilities or pay a penalty, which will be used to fund the creation of employment opportunities. However, it is still too early to assess the implications of the new quota system for the employment of people with *mild* intellectual disabilities (the act does not apply to people with “invalid status” under the Social care Act).<sup>370</sup>

### 3. EMPLOYMENT IN PRACTICE

*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. 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”.*

<sup>366</sup> This money should be spent on, for example, training for people with disabilities; purchase of machinery and tools; adaptation of tools and workplaces for people with disabilities; technological improvements; improvements to work organisations; or improvements to safety at work.

<sup>367</sup> *Guide for the Rights of Disabled People*, p. 85.

<sup>368</sup> *Guide for the Rights of Disabled People*, p. 86.

<sup>369</sup> Vocational Rehabilitation Act, art. 62.

<sup>370</sup> The act defines a financial penalty for non-compliance with the quota system. An employer who does not fulfil the quota is obliged to pay a monthly contribution of 70 per cent of the minimum wage for each person with disabilities not employed; the money collected is placed in the Fund for the Promotion of Employment. Vocational Rehabilitation Act, art. 65.

*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.*

### 3.1 Statistics

In Slovenia, the unemployment rate for people with disabilities of all types has been rapidly increasing since 1992, as the labour market has become more competitive. In December 1999 the National Employment Service registered 14,787 unemployed people with various types of disabilities; by May 2000 this number had increased to 16,141. In August 2004, the number of unemployed persons was 90,314, of which 8,473 were people with disabilities (or 9.4 per cent of all the unemployed).<sup>371</sup>

According to Slovenia's "Joint Memorandum on Social Inclusion" (JIM), at the end of 2001 there were 28,967 people with disabilities with regular employment on the open market, of which 6,154 were in sheltered companies ("invalid companies").<sup>372</sup> From 1992, employment in sheltered companies has become one of the most common ways for a person with disabilities to find a job. Some of these companies also provide training and vocational rehabilitation for people with intellectual disabilities.<sup>373</sup> In 2003, a total of 12,673 people were employed in the 152 sheltered companies in Slovenia, of which 5,993 (47 per cent) were people with disabilities (2,234 women and 3,759 men).<sup>374</sup> There is no information available as to how many of these were people with intellectual disabilities.

At present, there are no specific figures available on the levels of employment or unemployment of people with intellectual disabilities. Although the National Employment Service maintains a register on people with disabilities, this only contains information on individuals according to their employment status, not their type of disability.<sup>375</sup> However, even if a breakdown by type of disability were available this would only include information on people with *mild* intellectual disabilities. Those with *moderate*, *severe* and *profound* intellectual disabilities have "invalidity status" under the Social Care Act and so cannot register at an Employment Office as unemployed or as a job seeker. There is also an additional problem in gathering data on the employment situation of people with intellectual disabilities. People with *mild* intellectual disabilities who complete the two and a half-year vocational programme and subsequently register at

<sup>371</sup> Statistical information provided by Dominik Presen, from the National Employment Service, May 2005.

<sup>372</sup> *Slovenia JIM*, p. 19.

<sup>373</sup> See: Section III. 4.2.

<sup>374</sup> Interview with Aleksandra Tabaj, Advisor to the Minister of Labour, 4 March 2004.

<sup>375</sup> Employment status includes, for example, work and war invalids; those with disability status under the Social Care Act; and young people categorised from an early age.

an Employment Office as job seekers are no longer considered as having intellectual disabilities. There are therefore no specific statistics regarding this group.

Data on the employment situation of people with intellectual disabilities should become more readily available under the amended Vocational Rehabilitation Act of 2004. Article 85 envisages the establishment of a register of data on people who have “invalid status” under the Social Care Act. This register would include information on levels of unemployment; on those individuals assessed as “unemployable” or as employable in sheltered or supported workplaces; and on those with the right to vocational rehabilitation. It would also include information on all people employed in sheltered companies.<sup>376</sup> This register should in future provide a much more accurate situation of the employment situation of people with *moderate*, *severe* and *profound* intellectual disabilities

### 3.2 Supported employment on the open market

There are no current examples of supported employment for people with intellectual disabilities. This is likely to change, as the recently amended Vocational Rehabilitation Act introduces for the first time the legislative basis for supported employment. However it will be some time until the effects of this legislative change can be evaluated in practice.

The act establishes the basis for supported employment and makes it possible for employers to engage people with intellectual disabilities who have some working skills, so are therefore overqualified for sheltered workplaces, yet still need additional support.<sup>377</sup> It defines supported employment as “employment in a regular environment with professional and technical assistance to the person with disabilities, the employer or for the work environment.”<sup>378</sup> The act further specifies that “support can include information, counselling, training, personal assistance, development of individualised working methods, adjustments to the work environment and technical aids”.<sup>379</sup>

At present in Slovenia, people with *mild* intellectual disabilities can be employed in companies on the open market or in sheltered companies (“invalid companies”). However, in practice there are few examples of people with disabilities, including intellectual disabilities, being employed in companies on the open market. For example, in 2003 the Ministry of Labour, announced – for the first time – a public competition rewarding good practices in the employment of people with disabilities. The aim of the award was to promote good practices in companies that do not have any special disability status, but nonetheless employ people with disabilities. Only three companies responded to the public competition, but in the end it was decided not to give the award to any of them. All had only fulfilled the legally binding criteria,

<sup>376</sup> Vocational Rehabilitation Act, art. 85.

<sup>377</sup> Interview with Dominik Presen, March 2004.

<sup>378</sup> Vocational Rehabilitation Act, art. 48.

<sup>379</sup> Vocational Rehabilitation Act, art. 48.

without presenting any innovation or added value that the ministry had recommended, such as training and education or social programmes.<sup>380</sup>

### 3.3 Sheltered employment

The Vocational Rehabilitation Act 2004 introduces an innovative new form of sheltered employment, which will only be open to people with *mild* intellectual disabilities. The act defines this as “sheltered employment in a workplace and in a work environment adapted to the individual abilities and needs of those who cannot be employed in a regular work environment”.<sup>381</sup> According to the act, this form of sheltered employment will be provided mainly by new “employment centres” for people with disabilities.<sup>382</sup>

The difference between sheltered workplaces and employment centres will be in the status of employees; employees in employment centres will have a working contract, which is not the case in the sheltered workplaces. However, to date no such centres have yet been created and many details are unclear, such as whether employment will take place in sheltered conditions or in a regular company. At present the sheltered workplace is the only available form of sheltered employment.

#### *Sheltered workplaces*

In Slovenia, sheltered workplaces serve as a social welfare service for adults with disabilities, providing “guidance, care and employment under special conditions”.<sup>383</sup> The term “employment under special conditions” refers to work (including producing goods) and also to the development of skills and work habits. Although this term is often confused with employment in sheltered companies (“invalid companies”), it is only used in connection with people who are assessed as being “unable to carry out profitable work” and are given the status of “wards”. By contrast, sheltered companies employ people with disabilities who cannot be employed under the same conditions as other workers, but have the status of “invalid workers”.<sup>384</sup>

The sheltered workplace is a social security programme in which the worker does not sign an employment contract, does not have the status of an employee, and only receives a symbolic payment. Although the majority of people working in sheltered

<sup>380</sup> Interview with Aleksandra Tabaj, 4 March 2004.

<sup>381</sup> Vocational Rehabilitation Act, art. 41.

<sup>382</sup> It can also be provided by other employers and will also include work at home. Vocational Rehabilitation Act, art. 41.

<sup>383</sup> The Social Care Act defines “guidance, care and employment under special conditions” for adults with “invalid status” according to the act. Social Care Act, art. 51.

<sup>384</sup> Information provided by Vladuška Cimperman, Sector for Social affairs, Ministry of Labour, February 2004.

workplaces are people with intellectual disabilities, they are not intended exclusively for this group and also include people with physical disabilities and multiple disabilities.

Some sheltered workplaces are directly linked to institutional day care, which means that all those using these services are expected to work in the workplace as a daily activity. This can be coercive, in that these workplaces do not offer a salary and those who do not work – particularly those who are residents – can be excluded from the institution. For example, some people with intellectual disabilities who wanted to live in a group home but did not want to work there were, in consequence, not allowed to live at the group home.<sup>385</sup>

According to data from the Ministry of Labour, in 2004 there were 29 public sheltered workplaces in Slovenia, comprising 15 independent workplaces; five in centres for social work; five in special schools; and four in training institutions. In 2004, there were 2,066 people with disabilities working in these sheltered workplaces, of which 524 were also under the residential care of the workplace.<sup>386</sup> There were a further 456 people with disabilities working in ten private sheltered workplaces; of these, 387 people were in day care and 69 in residential care (at four of these workplaces).

There are some differences between the data on sheltered workplaces provided by the Ministry of Labour and provided in the Statistical Office's Statistical Yearbook.<sup>387</sup> Nonetheless, the data from the Statistical Yearbook presented below in Table 5 is of interest, in that it provides a breakdown of users of sheltered workplaces by the type and level of their disabilities. In 2002, 97 per cent of those working in sheltered workplaces were people with intellectual disabilities and most (78 per cent) had *moderate* intellectual disabilities.

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<sup>385</sup> Interview with a person who wishes to remain anonymous.

<sup>386</sup> Data from the Ministry of Labour, written comments, 6 June 2004.

<sup>387</sup> Data from the Statistical Yearbook of 2003 indicates a total of 199 more users of sheltered workplaces than that of the Ministry of Labour (for 2002). Statistical Office, *Statistical Yearbook 2003*, table no. 5, available (in English) on the Statistical Office website at <http://www.stat.si> (accessed 15 March 2005), (hereafter, Statistical Office, *Statistical Yearbook 2003*).

**Table 5. Workers in sheltered workplaces – breakdown by degree of disability (2002)**

		Degree of intellectual disabilities					
		mild		moderate		severe	none
		with additional disturbances		with additional physical impairment (moving)		with additional mild disturbances	physical disabilities, head injury or no status
Men	1,249	78	18	207	755	145	39
Women	1,016	64	6	127	675	117	29
All	2,265	142	24	334	1430	262	68
By disability group	Total	166		1769		262	68
	As per cent	7		78		12	3

Source: Statistical Office<sup>388</sup>

For adults with intellectual disabilities, only those with *mild*, *moderate* or *severe* intellectual disabilities can work in a sheltered workplace.<sup>389</sup> Those with *profound* intellectual disabilities are excluded from sheltered workplaces and can only enrol in social care institutions, where they are involved in the daily activities of the institution. The criteria for enrolling in sheltered workplaces are established in the Regulation on Standards for Social Care Services 2003 (hereafter, Social Care Regulation). According to this regulation, sheltered workplaces are meant to ensure protection and work (not employment) for people with intellectual disabilities.<sup>390</sup> They should also ensure that the person retains their knowledge and working skills, promote the development of new skills and social and work habits and support the development of individuality and social inclusion in the community and environment.

The Social Care Regulation also defines the role of the sheltered workplace; in particular that it should produce objects for sale as well as providing occupational training. In reality, though, most of the sheltered workplaces provide non-creative, repetitive work such as making pens or other small devices, producing greeting cards or making wooden boxes. Some sheltered workplaces also offer some more complicated tasks such as gardening, knitting, working with textiles or woodcrafts, photocopying or pottery. However, even when the work is not so repetitive, the emphasis is still on sitting behind a desk and working, rather than gaining social skills or new working abilities. In addition,

<sup>388</sup> Statistical Office, *Statistical Yearbook 2003*, Section 12.

<sup>389</sup> Those entitled to a place in a sheltered workplace are adults with *mild* intellectual disabilities and other disabilities; *moderate* intellectual disabilities (alone or with physical disabilities); and *severe* intellectual disabilities and *mild* additional disabilities. Ministry of Labour, Regulation on the Standards for Social Care Services 2003, Official Gazette 127/2003, art. 8, (hereafter, Social Care Regulation).

<sup>390</sup> Social Care Regulation, art. 8.

workers in some sheltered workplaces are often treated as children, which can be observed in the communication between the staff and the people with disabilities.<sup>391</sup> Work is either carried out individually or in groups; each group has a mentor who observes the working process and monitors the presence of workplace users.

Most workers in sheltered workplaces are men aged between 26 and 36 years old who live at home with their parents and are enrolled in the sheltered workplace during the day.<sup>392</sup> Women more often stay at home and help with the family household. In the case of more demanding jobs, sheltered workplaces tend to offer traditional “male” jobs, such as carpentry or metallurgy. Women tend to work in less demanding, simple activities, such as painting (on paper or silk), manufacturing of pens, cutting pieces of materials, or manufacturing clothes lines.

People who work in sheltered workplaces do not have an employment contract even though they usually work eight hours a day. Some workers and staff members have reported that sometimes workers are even required to work overtime if there is a large order to complete (for example, before Christmas or the New Year).<sup>393</sup> For their work at the sheltered workplaces they receive a payment, which is referred to as an “award”. On average the award is between 4,000 SIT (or approximately €17) and 20,000 SIT (€83) per month. The amount of the award is not regulated by the State, but is set by each workplace and also varies according to work performance.<sup>394</sup> Each sheltered workplace has its own regulations. These also outline the criteria for awards; if a person does not fulfil these they do not receive it.<sup>395</sup> The sheltered workplace Tončke Hočevar is planning to start giving an award also for people who do not fulfil the set criteria, but at present their funds are insufficient to cover this. Tončke Hočevar gives awards of between zero and 42,000 SIT (€175) per month to users of its sheltered workplaces; the average is about 5,500 SIT (€23) per month.<sup>396</sup>

The awards received by workers vary significantly. Some receive a relatively high award, while in other sheltered workplaces the only benefits received are new jogging shoes or clothes, or the chance for a joint trip to the sea once a year. Some experts have said that workplaces prefer to involve people who have milder disabilities since they can contribute to a greater profit, especially if they are making products to sell (for example, toys, greeting cards or scarves). In such cases it would be expected that any profits generated would be shared among those that did most of the work. However, the director of one of the sheltered workplaces has said that they do not do this as the

<sup>391</sup> Zaviršek, *Disability as a Cultural Trauma*.

<sup>392</sup> Statistical Office, *Statistical Yearbook 2003*, page 7, table No. 4.2.

<sup>393</sup> Several anonymous interviewees in different sheltered workplaces across Slovenia in 2004.

<sup>394</sup> Information provided by Drago Matkovič, Day Care Leader from the sheltered workplace Tončka Hočevar, February, 2004.

<sup>395</sup> Interview with Drago Matkovič, 20 February 2004.

<sup>396</sup> Interview with Tatjana Podlipec, director, and Drago Matkovič, day care leader, sheltered workplace Tončka Hočevar in Ljubljana, 24 March 2004.

relatives of the workers would anyway take the money from them and it is therefore better to buy them items such as new shoes or clothes.<sup>397</sup> Some of the staff also say that the workplace is anyway not “real employment”, but work under special conditions, which is primarily of therapeutic value and prevents people from being bored.<sup>398</sup>

In most cases, adults with intellectual disabilities working in the sheltered workplaces do not have a guaranteed work place and do not receive corresponding lifelong vocational training.<sup>399</sup> Of the parents of adults with intellectual disabilities working in sheltered workplaces who were interviewed, 84 per cent reported that the compensation their children received was between 1,000 and 5,000 SIT (€4 – €21) per month.<sup>400</sup> Only a small percentage of people with intellectual disabilities earn more than 10,000 SIT (€40) per month. Almost all parents considered that this compensation is too small and that their children deserve better.

In most cases, the person with intellectual disabilities manages the money themselves and some have their own bankcards (in other cases the legal guardians take on this role). They usually spend small amounts of money on sweets, coffee or drinks, and more on presents, mobile phones, CDs, clothes or saving for vacations.<sup>401</sup> As one interviewed worker reported: “my salary means a lot to me. On the 10<sup>th</sup> of every month I receive a bank note which says how much I have earned. If it doesn’t come I didn’t get an award and I’m sad”.<sup>402</sup>

Two other interviewed workers provide an example of how the workers use the awards they receive. Andreja works in a workplace where she makes ladders and other wood products.<sup>403</sup> Majda sews aprons and mends clothes for other people in the institution. They work every day from 8 a.m. to 2 p.m., and have a 30-minute lunch break. For this work, they receive an award of 12,000 SIT (€50). They use this money to pay for part of the monthly cost for the apartment they share (the rent and electricity costs are paid by institution). What is left is for their own needs; usually they have to save for months to be able to buy trousers or a sweater they like. Otherwise, the clothes bought by the institution are often too big or too small and not according to their personal taste. One of them said: “If someone causes any damage to the institute’s property, their award will be taken away from them until the damage is paid for.”

<sup>397</sup> Anonymous interviewee, member of the staff in a sheltered workplace in N. Slovenia, February 2004.

<sup>398</sup> Several similar comments from the staff in sheltered workplaces, OSI roundtable comment.

<sup>399</sup> The Association Sožitje made a short research on users of sheltered workplaces and their parents of children with intellectual disability, the results of which are included in: *Inclusion Europe – Sožitje Slovenia report*, p. 24.

<sup>400</sup> *Inclusion Europe – Sožitje Slovenia report*, p. 21.

<sup>401</sup> Interviews with users of the sheltered workplace Tončka Hočevar, February 2004.

<sup>402</sup> Interview with a person who attends a sheltered workplace daily and makes pens, who wishes to remain anonymous.

<sup>403</sup> Interview with Majda and Andreja, users of the day centre in the social care institution in Dornava, 22 January 2004.



The funding for sheltered workplaces comes mainly from the State Budget, for services and activities defined in Social Care Act.<sup>404</sup> According to a Ministry of Labour, in 2003, sheltered workplaces received in total three billion SIT (or €12.5 million) from the State budget, representing 96.3 per cent of all funds received by sheltered workplaces.<sup>405</sup> The income generated from workplace production and services (including revenue from goods sold) brought in the remaining 3.7 per cent of funding.<sup>406</sup>

Sheltered workplaces can use their own discretion in deciding how to spend the profits from selling products and services. However, the Ministry of Labour has final control over the expenditure of the workplace. All expenditures are set by the Board of the workplace, with the agreement of the Council of Parents (parents of the people working at the workplace). Income generated by the workplace is generally used for awards to the workers; improvements in the quality of the living conditions of residents of institutions; material costs; or summer vacations.<sup>407</sup> According to current legislation such income could also be used to provide higher salaries for the staff at the workplace, but to date the Ministry of Labour has never received such a request from any sheltered workplace.<sup>408</sup>

The products and services provided by the workplaces, such as photocopying, bookbinding and production of cards and toys, are usually sold at market prices. Since workers only receive low awards, it is therefore not exactly clear what the generated income is spent on. Staff in some sheltered workplaces said that they use this revenue to pay for the overtime of staff working weekends, which means that, in effect, those working in the workplaces are paying for their own “care” costs. For this reason, some independent researchers have concluded that the profits generated by workers in sheltered workplaces are in many cases used to cover the living costs of those workers in residential care.<sup>409</sup>

There are several examples of profit-making sheltered workplaces in Slovenia. One example is the Mengeš Centre for People with Intellectual Disabilities. This workplace is a regular factory with fully commercial activities; namely the production of needles for the pharmaceutical company Lek.<sup>410</sup> However, although the workplace was making

<sup>404</sup> Social Care Act, art. 4.

<sup>405</sup> Ministry of Labour, written comments received after the OSI roundtable, Ljubljana, 18 June 2004.

<sup>406</sup> Other potential sources of funding are local budgets; the National Health Insurance Institute (for health services); the Employment Offices (for implementing programmes of training for employment) and donations.

<sup>407</sup> “Regulation on awarding persons with intellectual and physical disabilities, involved in day care and work in sheltered workplace”, internal regulation of the sheltered workplace Tončka Hočevar, Ljubljana.

<sup>408</sup> Ministry of Labour, written comments received after the OSI roundtable, Ljubljana, 18 June 2004.

<sup>409</sup> Vesna Leskošek, “Selektivni znanstveni interes – pregled raziskav o revščini hendikepiranih žensk”, (“Selective scientific interest – an overview of research on the poverty of disabled women”), International Conference “So beautiful, but an invalid”, Ljubljana, November 2003 (unpublished paper).

<sup>410</sup> The pharmaceutical company Lek is one of the biggest companies in Slovenia.

a profit and also receiving funds from the State, the workers still received a low award. Some parents who were guardians of their adult children complained at this practice or even stopped their children from working there.<sup>411</sup>

A second example is the bookbinding workplace run by Janez Levec special boarding school. This is one of the rare workplaces where books are sewn by hand, which means they are of better quality. The workplace also produces paper bags and boxes. The workplace has private orders and also orders from print shops, bookshops, libraries and some governmental institutions. A total of 12 people with *moderate* intellectual disabilities (seven women, five men) work here under special conditions and receive an award of between 25,000 and 35,000 SIT (€104 – €146). The workplace also employs some non-disabled people who receive a wage.<sup>412</sup>

There are some examples of good practices in sheltered workplaces, some of which are becoming more open to public and are offering different sorts of work for workplace users. For example, the sheltered workplace Tončke Hočevar has units in different parts of Ljubljana and those working at the workplace can decide where they want to work and the type of work they prefer.<sup>413</sup> They are also thinking of setting up a stand in the centre of the city to sell products made by the workplace. Tončke Hočevar does not just produce different articles for sale, but also has some contracts for providing other services. An example of good practice is that of three people with *moderate* intellectual disabilities who work in at a Baumax home supply store (they carry out activities such as watering flowers and cleaning pots) in a regular work environment rather than in a workplace. However, the three still do not receive a salary; their status is the same as in a sheltered workplace and the contractual partners are the store and sheltered workplace. The three of them share the salary of one worker, receiving 34,000 SIT (€142) each per month. Tončke Hočevar also plans to find opportunities for employment and care of workplace users on farms around Ljubljana.

These examples show that many people with intellectual disabilities, including those with *moderate*, and *severe* intellectual disabilities – who under the Social Care Act are defined as “unemployable” and “unable to live independently” – are in fact able to work productively and earn (and generate) some income. They highlight the need for a complete change in the current attitude towards people with intellectual disabilities and for more emphasis to be placed on assisting people with intellectual disabilities to access employment. The examples also demonstrate a need for legislative change in the area of employment for people with intellectual disabilities, to break down barriers to employment, provide equal opportunities on the open market, and pave the way for self-sufficiency for people with intellectual disabilities.

<sup>410</sup> Interview with a person who wants to remain anonymous, Association Sožitie, February 2004.

<sup>412</sup> Interview with Matej Rovšek, 9 April 2004.

<sup>413</sup> Interview with Tatjana Podlipec, 24 March 2004.

## V. Conclusions

In Slovenia, the number of children with intellectual disabilities able to access education in an integrated environment has improved significantly in recent years. However, 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 that, for adults with more severe intellectual disabilities, links the right to disability benefits with a status that precludes them from accessing employment.

### *General*

In Slovenia, recent legislation, particularly the Equal Treatment Act, has significantly strengthened the legislative framework for anti-discrimination and Slovenia has transposed the EU Directives on Employment and Race Equality into national legislation. However, Slovene legislation continues to use outdated terminology with respect to people with disabilities (including people with intellectual disabilities) and there is no common definition of intellectual disability. To reduce the stigmatisation of people with disabilities, and harmonise Slovene legislation with current international disability policy, the Government should as a first step seek to change the terminology used in all legislation and policy. Terms with a negative connotation should be replaced by less stigmatising and more internationally accepted terms, such as “person with disabilities” and “person with intellectual disabilities”.

The ability of people with intellectual disabilities to exercise their rights to the fullest possible extent is at present severely restricted. First, the status of people with intellectual disabilities is mainly determined by the outdated Act on the Social Care of Mentally and Physically Disabled People 1983 (Act on Social Care). Under this act, adults with *moderate*, *severe* and *profound* intellectual disabilities are given an “invalid status” which entitles them to social security benefits, but at the same time automatically determines them as unable to live independently or be employed. Second, most adults with intellectual disabilities who have “invalid status” under this act are also placed under guardianship by the courts. Those placed under *plenary* (full) guardianship then lose all their legal capacity and hence are not able to exercise any of their civil and economic rights, including the right to work. To improve the situation of people with intellectual disabilities in Slovenia the Governments must therefore do more to help them “reclaim” the rights they have lost. To this end the Government should, as a priority, amend the Act on Social Care Act to enable people with disabilities to access employment without first having to renounce their disability status

under this act, and thereby lose their entitlement to social benefits. In addition, the Government should seek alternatives to guardianship.

There has been an important process of deinstitutionalisation in Slovenia over recent years and the majority of people with intellectual disabilities live at home with their families. However, more still needs to be done to encourage community alternatives to residential care and thereby the fuller social inclusion of people with intellectual disabilities. Projects initiated by NGOs have demonstrated that direct payments are an important means by which people with intellectual disabilities can be enabled to make choices about their care and live independently. The Government should now seek to improve the legislative basis for direct funding such that direct funding is available throughout the country. In future the Government should also prioritise the construction of small group homes for adults with intellectual disabilities, as an alternative to institutional care.

### *Access to education*

Legislation on the education of children with special needs – including children with intellectual disabilities – has been strengthened in recent years, particularly through amendments to the Placement Act. However, in accordance with this act, only children with *borderline* intellectual disabilities can be placed in mainstream schools, which is the most important barrier to the inclusion of children with intellectual disabilities in mainstream schools. The Government should, as a priority amend the Placement Act, to remove this discriminatory provision and enable children with other levels of intellectual disabilities to also be able to attend a mainstream school.

In addition, although the Placement Act did lead to a number of important changes in placement procedures, parents are still dissatisfied. The decisions taken by the Placement Commissions responsible for assessing children with intellectual disabilities are determinate for the type of educational programme and the school (or kindergarten) into which a child is placed. The Ministry for Education and Sport should therefore initiate further changes to the work of Placement Commissions. These should in particular encourage the increased professionalism of the commissions, and ensure that parents and legal guardians have a bigger role in the decision making process. In addition, monitoring should be carried out of children placed in special schools, to ensure that a child's ethnicity or nationality does not influence placement decisions.

Reforms of the education system has already improved the choice of educational and vocational educational programmes available for children and young people with intellectual disabilities. The Ministry for Education and Sport should now seek to further develop its educational policy and to expand the processes of inclusion for children with all levels of intellectual disabilities. In particular, the Ministry should facilitate transfer between educational programmes, such that children with intellectual disabilities could more readily move on to more demanding educational programmes, and those in special schools could attend at least some classes or activities in

mainstream schools. Although legislation now in place does permit such transfers, practical barriers (in particular transportation) and also the discrimination encountered by children with intellectual disabilities, effectively limit them in practice. In addition, the Ministry for Education and Sport should also amend the “Regulations for the educational programmes with adapted implementation and additional expert support for the nine-year elementary school”<sup>414</sup> to specifically include a reference to children with intellectual disabilities.

The successful integration of many children with intellectual disabilities into mainstream schools is evidenced by the significant decrease in the numbers attending special schools. However, parents, teachers and social workers are not yet satisfied with the integration process. To improve the access to education of children with intellectual disabilities in mainstream schools, the Ministry for Education and Sport should, as a priority, ensure that all children with intellectual disabilities, regardless of the educational programme into which they are placed, have the right to personal assistance and adequate support at school. Due to prejudice and inadequate assessment procedures, Roma children remain disproportionately over-represented in special schools. To counter this, in addition to reforming assessment procedures, the Government should also provide additional training for all those working with children and young people with intellectual disabilities, in particular for those working with children who are members of an ethnic minority. Training on anti-discrimination should be introduced into the curricula of social, educational, medical and special educational professions.

### *Access to employment*

Protection against discrimination in employment for people with disabilities has been strengthened through recent legislation. The amended Vocational Rehabilitation Act is particularly important. It introduces for the first time a quota system for the employment of people with disabilities in companies on the open market and a definition of supported employment, and there are also provisions on new forms of sheltered employment. However, as it stands the majority of people with intellectual disabilities will not be able to benefit from the provisions of this act, as it does not apply to people with “invalid status” under the Social Care Act. To enable people with intellectual disabilities to access employment the Government should therefore as a priority amend this act, to make it also applicable to people with “invalid status” under the Social Care Act.

As the new quota system has only just been introduced, it is too soon to assess its impact on the employment of adults with *mild* intellectual disabilities (the only adults with intellectual disabilities eligible to access it). At present, there are two main possibilities for them to find employment: full-time employment on the open labour

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<sup>414</sup> Ministry for Education and Sport, *Instructions for educational programmes with an adapted implementation*.

market, mainly through active labour market programmes, or work in sheltered companies. However, there is no available data on how many actually find employment in this way. To improve the access to employment of adults with *mild* intellectual disabilities, the Ministry of Labour should ensure that the employment services provided by the Employment Offices, particularly employment counselling and active labour market programmes, are adapted to the specific needs of adults with *mild* intellectual disabilities. In addition, the ministry should seek to collect regular data on the employment situation of adults with mild intellectual disabilities and develop policy to promote the inclusion of adults with mild intellectual disabilities in active labour market programmes.

In most cases, though, adults with intellectual disabilities have no employment of any kind and so are fully reliant on State disability benefits. Although these cover the basic living costs of a person with disabilities living at home with their family, they do not allow them to live independently. People with intellectual disabilities are usually placed in sheltered workplaces, where they do not have an employment contract but receive a small wage. However, although there are examples of good practices, usually the work in sheltered workplaces is repetitive and does not give people with intellectual disabilities the training or social skills they would need to access employment in a company on the open market. The social inclusion of people with intellectual disabilities requires their integration into the wider society, as opposed to segregation in special into work environments. To promote this process, the Government should ensure that supported employment schemes are developed as soon as possible to provide people with intellectual disabilities real alternatives to work in a sheltered workplace.

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