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**Between Formal and Actual Rights of People with Intellectual Disabilities in Slovenia**

### **Introduction**

Disability people's experiences were never integrated into the culture of Eastern European societies which becomes most obvious, when reports and testimonies concerning the lives of people with disabilities, from different countries living in asylums, became public knowledge (McCagg and Siegelbaum 1989, Buda and Gondos 1998, Zaviršek 2000, 2002). An extended comparative research about the enforcement of rights in psychiatry in Eastern European countries show, that the users have no rights to make an informed consent, experience the absence of personal respect and safety, have no privacy and no advocacy support system (Buda and Gondos 1998). People with disabilities who have lived in public care institutions have been often treated as not sharing the same humanity and personhood with their guards and professional staff. Still today, people with disabilities are either highly dependent on family support or live in large public care institutions. In both cases they are not part of community everyday life.

The everyday and the symbolic hierarchy of disability place people with intellectual disabilities on the bottom. In Eastern Europe they are still today defined as a group that is incapable of work. In Slovenia for instance this is regulated primarily by "The Act Concerning the Social Care of Mentally and Physically Handicapped Persons" passed in 1983 and has never been amended since then,<sup>1</sup> At this time, Slovenia was the first Republic of Yugoslavia to pass an act concerning the social care of people with intellectual and physical disabilities which was considered a breakthrough in securing the rights of this group. The act confers on people with disabilities the status of "invalids" and entitled them to various types of care. It provides the grounds for daily, part-time or residential care in an institution or with a foster family, and guaranteed some financial support, such as the disability allowance and

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<sup>1</sup>Official Gazette of the Republic of Slovenia, 41/1983.

assistance allowance. The Act defines disability status for those people above the age of 18, who are diagnosed with moderate, severe and profound intellectual disabilities. Under this law they are considered unable to ever live independently and are incapable of work and can only be placed into training programs and sheltered workplaces.

At present the terms “person with disabilities” and “person with intellectual disabilities”, are not used in any of Eastern European legislation. They still use terms such as “invalid” (Latin. *invalidus* = weak, powerless), and sometimes also “mentally retarded persons”, while more recent legislations refers to “persons with special needs,” “person with mental disabilities” and “persons with disturbance in mental development.”

### **The raise of social welfare institutions for people with intellectual disabilities**

The history of a continuous care of people with intellectual disabilities can be traced to the year 1908, when the Council of the Slovenian region (*deželni svet*), which was a part of the Austro-Hungarian Empire had sent three teachers from Ljubljana to Vienna to get the “first lectures how to educate pupils in special schools”.<sup>2</sup> Soon after that year, the first special unit within an ordinary school in the Slovenian region was established in Ljubljana in the year 1911.<sup>3</sup> The director of the school was a teacher Janez Levec, who remained on that position until 1924, while Ana Lebar became a teacher responsible for so called “special classrooms”.

The first approaches towards the children with intellectual disabilities were brought from the German speaking tradition and the teachers were the first professionals dealing within this field. They promoted two arguments for special care for the disabled children. One was the love argument, according to which love towards the children include also loving the cripples. The second was the moral argument, which was based on the belief that education prevents those children to become beggars, criminals and outcasted in different asylums or farms. They claimed that the state has to take care for the “underdeveloped children”, which was not a common view. A well-known anthropologist and devoted eugenics from that period, believed, the state should not spend so much money for the “underdeveloped” children, but

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<sup>2</sup> The teachers were a woman Anica Lebar, and two men Ivan Krulc and Ivan Dimnik.

<sup>3</sup> After the establishment of the special unit of the elementary school Prule, another school was build in Maribor (1913) and in Moste (1923), which is today part of the Ljubljana capital.

put them in the asylums and made-houses, while rather use this money for educating the “devoted children” (Škerly 1933). Teachers decided also upon re-schooling the child from the ordinary to the special school. Neither doctors nor social workers played any important role. Later on, after the year 1921 when the Regulation on the Organization of the Schools for Poorly Talented Children (*Pravilnik o ustroju šol za slabonadarjene otroke*) were adopted, the care and the education of the disabled children were divided between teachers and medical professionals. After that period the bio-birocratic expertise and the biopower of the medical professionals gradually started to dominate.

In 1924 the special unit for the disabled children becomes an independent school called “elementary school Graben” with six classes. In 1940 the school moved into the heart of the old part of the city Ljubljana, where remained until today (called “elementary school Janez Levček”). After the 2. World War the school expanded and opened a boarding institution and different units for occupational therapy.

During the twenties the school went through several turbulent years, where they lack the coal for heating (they even had to close the school for a shorter period) and rooms. Beside poverty, several discussions touched upon the actual effects of such type of education, and raised the question whether the children should rather be sending back to ordinary people’s schools (*ljudske šole*). At the end of the twenties already, in 1929, the country got the National Schools Act (*Zakon o narodnih šolah*), which seemed to strengthen the position of special education and proposed that the special school in Ljubljana should become a full term school with an additional boarding unit. During the 1930ies there were some national counting of the schools and the children in the area called Dravska banovina of Kingdom of Yugoslavia. There were again more and more suggestions for an additional institution for the long term stay of the disabled children.

Social workers were mentioned in the school chronicle for the first time in the school year 1958/59, when the first students of the newly established School for Social Workers (1955) visited the special school (Urh 2005). In the year 1962 there was a defectologist (special educator) who was responsible for the “social work matters”, and the first social worker Jaromira Knez Javoršek was employed not earlier than in 1965 (Urh 2005).

The sixties of the 20<sup>th</sup> Century were the golden years of the establishment of new welfare and educational institutions. They built new boarding schools, units for occupational therapy for severely disabled children and young people, few sheltered workplaces and several old people's homes where they even placed young people with severe disabilities. One of the reasons for this development was that in the year 1960, the former Yugoslavia passed the law on obligatory elementary education for all children, including children with special needs, regardless of their disability.<sup>4</sup> The consequence of the legislative change was the increase of the numbers of children in the special school and in other institutions which already existed by that time. The long term separation from the ordinary school environment was seen as the major condition of help for the children with intellectual disabilities. This belief which dominated the whole era of the post-communist Yugoslavia, is partly still existent between today's teachers and social workers.

The establishment of special and boarding schools should prevent the development of the "un-social" behaviour, and to introduce the residents to different sort of occupation. "Occupational therapy" was understood as the major preventative activity from criminal behaviour and other deviances. It was not asked whether the occupation activities increase the person's social skills, everyday knowledge, self-determination and autonomy. It was rather important that the person showed the suppression to the strict length of working hours, repetitional activities and the discipline of work and breaks. These attitudes help to imagine the past images and expectations directed to the people with intellectual disabilities and additionally, tell us about the current views which are transgenerationally transported into today's social welfare regime.

### **The fluid category**

In Slovenia, like in most other post-communist countries, the so called "transition period" from "one-party regime to democracy" became very soon dominated by neo-liberal market rules and neo-liberal social values which only emphasized the already existent attitudes toward people with disabilities. In many Eastern European countries, like in Russia for

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<sup>4</sup> Zakon o posebnem šolstvu. Uradni list Ljudske republike Slovenije, Ljubljana, 3. november 1960, številka 34.

instance, the number of people with physical impairments has been increased up to ten times, which was the consequence of the state strategy to remove the working labour older than 50 years of age out of the new neo-liberal market (Iarskaia Smirnova 1999).

In the same period, in Slovenia (population of 2 million people), due to the new ideologies of “integration”, the number of children with intellectual disabilities has been decreased which shows the arbitrariness of medical and behavioural labels. Over the period 1990 to 2001 the number of children with intellectual disabilities decreased dramatically by almost one half. In 1990 there were 6245 children with intellectual disabilities who were the recipients of social welfare services (centres of social work), but in 2002 there were only 3351 of the children with the same category. By contrast, the number of children with physical disabilities remained more or less unchanged (1478 persons in 1990 and a slight increase up to 1552 persons in 2002).<sup>5</sup> One of the important factors of this decline has been conceptual changes regarding the understanding of intellectual disability, which have been reflected in a new professional awareness about the lifelong stigmatization.

Most of these children are diagnosed with borderline or mild intellectual disabilities (71 per cent of all intellectually disabled in 2001) which obviously shows that these two labels represent a very heterogeneous group of children. Many of them may experience multiple social deprivations, including economic vulnerability, ethnic discrimination, emotional disadvantages, violence and abuse. Social disadvantages were very often medicalized in the past and children who experienced them were diagnosed with intellectual disabilities, in particular Roma children, children in care or children whose parents were seen as a “social problem” (Zaviršek 2004). In the past, teachers also often tried to place under this category children who were, as told by some teacher, “just creating disturbances” in the classrooms.

The noticeable decline in children diagnosed with borderline and mild intellectual disabilities is therefore only partly the result of the general decline of birth rate but has more to do with the conceptual shifts in assessment and policies of 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

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<sup>5</sup> Statistical yearbook of the Republic of Slovenia, no. 181/2002, table 10.14.

loose and undefined classification. For this reason, 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. The medical labels of the later relate to the symbolic status of their relatives who experience civic disability (Zaviršek 2004). This is particularly true amongst children from ethnic minority groups.<sup>6</sup> Roma children are almost ten times more likely than non-Roma children to be categorized as having "mild intellectual disabilities" and referred to primary schools with an adapted programme (special schools). Experts rationalize this fact saying that categorization is a result of the poor knowledge of Slovene language of Roma children, the socio-economic background of their families and their external appearance (clothes, hair). This is another example where people who are economically and socially more vulnerable are seen as being "guilty" for their lack of economic and social performances. Even more so, they are responsible for the categorization.

### **The institutional network for children and adults with intellectual disabilities**

In 2002, there were 7.242 persons registered as invalids according to the Act Concerning Social Care of Mentally and Physically Disabled Persons 1983 and registered at the centres for social work. Adults with mild intellectual disabilities are not systematically registered in any of the statistics. Most people with intellectual disabilities live with their families which is approximately 70 per cent of adults and more than 90 per cent of children.<sup>7</sup> Parents of a child who is cared for at home and requires special care and protection are entitled to a child nursery allowance to cover the increased costs for the family. The number of beneficiaries of this allowance is growing every year, from 2,619 in 1996 to almost twice that number in 2002. The higher numbers of children living at home is a consequence of many changes, including more day-care 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".* (parent from parent organization, personal communication 2004).

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<sup>6</sup> EU Accession Monitoring Program, Minority Protection 2001

<sup>7</sup> Human Rights of Persons with Intellectual Disabilities, 2002.

For children and young people with moderate, severe and profound disabilities there are several residential institutions in Slovenia providing education, training, work and care, according to the educational, health and social security legislations. They are called “Centres for training and care of children and young people with moderate and serious intellectual disabilities” (5 institutions) and “Day centres” (5 institutions). Children living in the former institutions either return to their families during weekends and summer holidays or remain in the institution all the time. The strong emphasis on institutional based practice is shown in the fact the in five Centres for the training of children and young people live 821 children<sup>8</sup>

Adults with intellectual disabilities are placed in six types of residential institution out of which some are more open type and others are a close asylum-type residential institutions for the care for adults with moderate, severe and profound intellectual disabilities. The open type are “social care institutions for training” which ensure institutional care and prolonged education and training and “centres for residential care of adult people”. Although old people’s homes are supposed to provide care for older people, these places are also supposed to care for adults with moderate, severe and profound intellectual disabilities who might be younger than 65 years. In 2002 there were 124 persons in such special departments of old people’s homes who were younger than 40 years of age. An additional institution are sheltered workplaces in different towns which ensure also institutional care in residential homes and in group homes for all together 524 persons across the country.

The average length of stay in these institutions is from eight to ten years, which is indicative of the endemic long-term institutionalization and segregation of people with intellectual disabilities in Slovenia (Flaker 1999, Zaviršek 2000). Although the cost of institutional care is much higher than community-based care, the government actually encourages institutionalization by ensuring free institutional care and primary education for children with physical and intellectual disabilities according the Slovene Constitution from 1991 (Article 52). In cases where a child remains at home, however, the carer receives only very minimal support. The nursing allowance should cover the additional cost of care and not the full time caring work done most often from female part of the family.

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<sup>8</sup> Statistical Yearbook of the Republic of Slovenia, 2000-2002.

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 (from 550 Euro to 1400 Euro). People themselves can not use this amount of money to cover personal assistance at home, rather than living in residential care, because the Slovene legislation does not include individual funding.

### **Between formal and actual rights**

One of the issues which challenge the disabled persons' actual rights is the Slovenian current system of **guardianship**. It means, that a person whose legal capacity is taken away, comes under the protection of another person. If legal capacity is completely removed, the rights of the person are equivalent to the rights of a child aged less than 15 years of age. In the case of partial restriction, the person's rights are equivalent to those of a child aged less than 18 years of age.<sup>9</sup> People diagnosed with moderate, severe and profound intellectual disabilities are declared completely or partially legally incompetent by the courts and do not enjoy the rights of an adult and are dependent on their parents or legal guardian. They become eligible for a disability allowance. People with mild intellectual disabilities however, attain full legal capacity once they become adults.

The obligations of the guardian are the same as in the case of a juvenile under 18 years of age, 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, but only supplements the will of a person whose legal capacity has partially restricted. In the latter case, the person can decide upon their personal affairs on their own initiative, but the guardian has to agree with their decision.

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<sup>9</sup> In 2002, there were 4,837 adults under guardianship in Slovenia (Statistical Information, 2003, No. 170, section 12). There is no state institutions who would have information how many people of all people under guardianship are people with intellectual disabilities. Statistical Information, 2003, No. 170, section 12.



Full legal capacity brings with it important rights, including the right to vote, marry, be a witness in a criminal court procedure, and work. In the past there were more cases of full removal of legal capacity than is the case at present. For the last few years there are more cases of partial restriction of legal capacity and prolongation of parental rights – a rare form of guardianship used in some Eastern European countries. Even if the parents do not (or cannot) financially maintain their adult child, they can still be their guardian since their parental rights can be extended. 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 when parents do not want to prolong their parental rights, the social welfare institution or the centre for social work itself is appointed as legal guardian. In such cases, the institution decides on questions such as legal procedures and financial issues, in the name of the persons. Parental guardianship affords some special rights, including extra days of holiday and tax reductions, but also obligations like reporting to the Centre for Social work about their work and expenditures connected to the property and funds of user.

As legal guardians, parents have the right to be informed about every change planned in connection with their child. This can include changes in medical or psychiatric treatment (including if the child starts taking contraception pills) or arranging a doctor's appointment, or even planned changes in the child's living arrangements (such as a move to another room). Many researches show how often parents can not be only the advocates for their adult children but are part of the oppressive structures (Iarskaia-Smirnova, 2005). A social worker has told:

*"We experience that it is better to consult parents even in cases when their adult daughter wants to dye her hair."* (personal communication, 2004)

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 which happened in 2004:

*"I went to the pharmacy to get some tablets for my son but they told me that I have to pay for them quite a lot of money (about 200 USD). 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 realized that the National Institute for Health Insurance keeps my son under the category of a child, because I have the parental guardianship over him."* (personal communication, 2004)

At present there are no official examples and proceedings about how many, who and why had the legal capacity status returned. The Director of a sheltered workplace in Ljubljana has said:

*"We fought for the return of the legal capacity for some of our inmates from the residential home but in 23 years since I've been working here, no one got back the legal capacity."* (personal communication, 2004)

According to the legislation persons with intellectual disabilities can not get the legal capacity status back, since law states that legal capacity can be returned "if there are no more reasons for why it was taken away in the first place".<sup>10</sup> Since persons that were once categorized as persons with intellectual disability remain categorized for their whole life, they can not get the legal capacity status back, even if they once had it.

On the one side, there are new laws and new perspective that focus on self-determination of individual person, but on the other side the existing guardianship system is still very rigidly based on a label system of disabilities which is seen as being universal and natural. From the critical perspective the system should be replaced by various forms of advocacy (professional, peer, citizen), according to individual needs. Independent advocacy should be enforced also because of the existing guardianship system. Interestingly enough, the demands for the abolishment of the current system of legal capacity removal and the prolongation of parental rights, did not come from caring professions but from layers themselves (Novak 2003).

### **Against parallel education**

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<sup>10</sup> Article 54, The Non-litigious Civil Procedure Act 1986, Official Gazette of the Republic of Slovenia, 30/1986, 87/2002, 131/2003.

Another paradox regarding the formal and the actual rights of people with intellectual disability is the issue of schooling. Slovenia does not have a special law on integration, but some new laws promote more inclusionary principles.<sup>11</sup> A growing tendency towards integration can be observed as certain categories of children with special needs are increasingly integrated into the mainstream school system. At the beginning of school year 1999/2000, there were 816 primary schools in Slovenia with 185,554 children enrolled. Exact data about numbers of children with disabilities included in this figure is unknown, but the numbers of children with special needs (the term used for children with sensory impairments or with some specific learning difficulties or with the category borderline intellectual disability) integrated into ordinary primary schools is growing from year to year. From the side of the teachers and social workers the integration is desired since some schools otherwise wouldn't have enough children enrolled in them and classes and schools would get closed.

During the preschool period children who are defined as having disability are assessed by the placement commissions and given a category of intellectual disability. The placement commissions also decide into which school program the child should be placed. Sometimes, the child who did not really have any kind of intellectual disabilities, but rather was slow in doing exercises or did not obey the teacher's orders (for example, the child was talking to others, moving around or did not want to write) was placed into a special school.

The paradox is that even by the new laws, only children with borderline intellectual disabilities can be integrated into mainstream schools.<sup>12</sup> Even though a special program for children with special needs in mainstream schools exists, it does not mention children with intellectual disabilities.<sup>13</sup> However, in line with the new Placement of Children with Special Needs Act from the year 2000, parents seem to have more power to decide upon the children's future. Some professionals even described 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 in mainstream schools. Some teachers speak about few children with "mild intellectual disabilities" who are placed in mainstream schools

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<sup>11</sup> Primary Schools Act from 1996 and the Placement of Children with Special Needs Act from 2000.

<sup>12</sup> Article 10, Regulation on the Organization and Work of the Commissions for the Placement of Children with Special Needs and on the Criteria for Defining the Sort and Stage of their Disabilities 2003, Official Gazette of the Republic of Slovenia, 54/2003, 93/2004.

<sup>13</sup> See Instructions for educational programs with adapted implementation and additional expert support for 9-year elementary school.

without a written order from the National Institute for Education. The consequence is that children who did not receive written order are not entitled to additional professional help and individualized program. Due to the growing awareness of parents and some professionals, obviously more children are being placed in the “milder” category of intellectual disability instead of a more “severe” one, so that they can attend mainstream schools. However, even though they can attend a mainstream school, a child with the borderline category is already stigmatized. The experts emphasised that the label has also a positive effect, because it ensures that the child gets some additional expert support at the school (up to 5 hours per week). Precisely this is a problematic moment which shows the dominance of the medical model between social workers as well as teachers. Instead of providing proper support for child’s individual needs, the child has first to be labelled in order to get some state support. Also the work of the placement commissions is still based predominantly on a medical model, since in the practice the expert knowledge of health professionals is more important than of the teacher or social worker.

### **Community practices as a collective advocacy**

In the last few years parents of children and adult persons with intellectual disabilities have become the most successful examples of individual as well as collective advocacy. In recent years parents gain greater self esteem and use a new way for fighting for their rights, which was widely absent during the communist regime. Some parents started to write complaints in order to advocate for the rights of their children. The Ombudsman Report for the year 2002 mentioned 9 complaints by parents who criticized long placements procedures and ignoring the wishes of the parents.<sup>14</sup> In the Ombudsman report from 2003 the number of similar complaints have increased up to 24 where the parents complaint against long procedures of the II level commissions (6-10 months) and the complaints against “pitiable and sometimes humiliating responses of the bureaucrats”.<sup>15</sup> They also complaint against the decisions of the commissions to re-place the child from mainstream to the special school and against the delays during the process. Sometimes parents might wait for the written order up to one year, although they are supposed to receive it within six weeks, according to the law. Until the order is issued, however, the child is not entitled to additional professional support or

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<sup>14</sup>Ombudsman of the Republic of Slovenia Report for the year 2002 , pp. 87-109.

<sup>15</sup> Ombudsman of the Republic of Slovenia Report for the year 2003, pp. 115- 116.

supplementary classes. Children with intellectual disabilities do not have the right for personal assistant (the right is entitled only to physically disabled children). Professionals and parents complain also about the decisions of placement commissions which have to specify the amount of hours of additional help for the child. They say that the commissions want to spare money and write a smaller amount of hours for professional support that are the needs of the child.

Regarding the integration in mainstream schools the Ombudsman Report from 2003 emphasized that : a.) “there is no clear and comprehensive concept of inclusion”; b.) “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>16</sup> On the basis of this complaints the Report from 2003 also criticizes the Placement of Children with Special Needs Act from the year 2000, which does not ensure that all children with special needs can go to mainstream school and points out the inconsistencies between the existent Act and everyday practice. The proposal of the Ombudsman is that the Convention of the Rights of the Children should be more respected, which means that children with intellectual disabilities have to have more possibilities for social inclusion. There are also some complaints from parents regarding the categorization process. In 2003, there were 24 such complaints.

Beside the formal complaints, not known in the communist past, some parents created an alliance against professional workers and state decisions and made enormous achievements due to joint parent advocacy struggles. One of the newer examples of integration is an example of two girls with Down syndrome that have been included in a mainstream primary school in Ljubljana. Project was developed as a pilot project by a group of researcher including a respectful academic who is a close relative of one of the girl. Placement commission categorized the girls with the borderline intellectual disability in order to be placed in mainstream school. In 2003, parents and researchers started to negotiate with the school, which was prepared to accept both girls. Even though they had support by school, teachers, parents and pupils, Ministry of Education and Education Institute did not actively support the initiative, but in opposite, expressed “doubts” about integration. Representatives of Education Institute had questioned the decision of the Placement commission and

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<sup>16</sup> Ombudsman of the Republic of Slovenia Report for the year 2003, p.117.

placement into mainstream school. They questioned the ability of the girls to “follow the program”, because they were supposed to get only 5 hours additional support per week, defined by present law. Both girls started with the 1 class in spite of the fact that they got the written order of the Education Institute of the Republic of Slovenia, 3 months after the school started already. The written order made possible that they got 5 hours of additional expert help. Both of the girls got some extra additional help which is not ensured by law for all children, but they got it as being a part of a “research project”. The consequence of these was that they were successful and that all professionals involved (special educators, psychologist, social workers, parents, teachers) gave a very positive response of the integration. Also National Education Institute has, after the first year, gave the permission for the continuation of the mainstream school. Today both of them are in the 2 year of the primary school which is the first time in national history that a person with Down syndrome is allowed to be part of mainstream education.

It is obvious, that without an enormous individual and collective pressure, the girls would not be accepted into the mainstream school. Nevertheless, this is a great example for other parents and people with disabilities, even when they are less social, economic and symbolic power, to advocate for the rights of their children. It also shows that with a larger extend of individual support (more extra hours of individual help) than it is presently ensured by the law, children with intellectual disabilities could be much more successful in mainstream schools as they are today.

### **Direct funding and personal assistance**

Direct funding refers to the state welfare system which transfers a certain amount of money directly to a person’s personal account for providing assistance or any other social service needed. The basic idea is not transferring the money through the institution that provides service, but directly to the recipient of welfare money. So far there is one project based on direct funding, where local authorities at Slovenian coast provided direct funding to some individuals with intellectual disabilities in order to choose social services themselves. The project was initiated in 1992 by Sklad Silva, an organization 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 realized that their children would lack basic human rights and self-determination if they were to be placed there.

The parents at Sklad Silva sought examples of good practices in the UK and in neighbouring countries. Their main criteria were projects which promoted self-advocacy, independent living and the full inclusion of people with disabilities into society. In cooperation with three municipalities, the group initiated a five-year project of direct payments. One of the aims of the project was to assess whether the direct payments could be established throughout the country, as one of the possible choices for people with disabilities. 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. Currently 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 and the recipients of the direct funding have been increasingly learning to live independently.

Since 2003 the Association for the Theory and Culture of Handicap (YHD), a disability activist NGO, has been running the program “Independent Living of Disabled People”. They provide a network of personal assistance for people with disabilities who want to live outside of institutions. Personal assistance can be chosen by the person with disabilities themselves. Personal assistants are employed under Active Labour Market Policy Programmes, that are in biggest part financed by Employment office, the rest is covered by some municipalities, users contributions and the lottery money. At the end of 2004 there were 77 persons with disabilities use the personal assistance scheme, 8 of those have intellectual disabilities.

All of the examples show many different personal and collective battles of people who came together in order to struggle collectively for their rights and the rights of their relatives. They show the success of collective advocacy which does not happen on a large scale but in small communities and groups.

## **Conclusions**

In the neo-liberal systems of Eastern Europe the transition from education to employment is one of the most difficult issues regarding people with intellectual disabilities. There are no support programmes for job seekers with intellectual disabilities. In Slovenia after completing a training or vocational education programme only those who are categorized as having “mild disturbance in mental development” can apply as job seekers at the local office of the National Employment Service, but then face competition on the labour market and very rarely get a job.

With Vocational Rehabilitation and Employment of Disabled People Act from the year 2004, the government has brought the Slovene legislation into line with European one. Even though it includes European recommendations and directives it still uses old term “invalids” and it does not include people who have the “invalid” status according to the Social care of Mentally and Physically Disabled People from 1983. They are still today automatically marked as incapable for work and can only get employment if they renounce this status and loose rights they are entitled to according to the Act (including assistance allowance). More than one year after the enforcement of the new law, politicians and experts do not have a single interpretation on its implementation. Also professionals within welfare field are divided. Some of them claim that the Act will bring positive change for people with intellectual disabilities, while others claim that especially for people with moderate, severe and profound intellectual disabilities, nothing will change.

That is why one of NGO’s fighting for the rights of disabled people proposed the amendments to the law, so that everybody, regardless of the sort of disability would have a right to find a paid employment, but some representatives of “invalid organizations”, including the parents of people with intellectual disabilities, have opposed the proposal and succeeded. While disability activists promote the anthropological understanding of disability and a social model, most of old para-state “invalid organisation” keep the medical model. Disability activists emphasis that disability is a constructed phenomena which change over time and depend on political systems. They also stress that the experience of disability is an individual and not universal experience which depends very much on the social images and actual citizenship rights of people with disabilities.



Different examples of community based struggles and the knowledge of global disability movement also teaches social workers and other caring professionals in Eastern Europe and across the globe, how to promote new values and practice new skills and ethics. The practice of caring professions have to be oriented toward: discussing and understanding personal experience of disability; focusing on the strengths and the barriers of a particular individual person; promoting the perspective which looks at how to ensure support in every day life of a person with disabilities instead of emphasising the lack of abilities; supporting community actions and collective advocacy; promoting information of the examples of best practice of empowerment and independent living; supporting such skills of individuals and groups which can oppose the dominant and hegemonic structures. Instead of focusing on the category of disability itself, the global battle as well as the regional struggles have to focus at the particular needs and desires of a person and how could they be met in a particular community context.

Most Eastern European countries don't have a comprehensive anti-discrimination framework in which discrimination on the grounds of disability is specifically prohibited. Formally anti-discrimination frame is given by constitutions that ensures equality and prohibits discrimination, but constitutions themselves don't guarantee actual equality in every day life. In Slovenia, one of a new documents is Implementation of the Principle of Equal Treatment Act which recognizes also people with disabilities as those who are deprived. The Act describes them as a group with limited employment opportunities. Nevertheless, people with intellectual disabilities face a huge gap between formal and actual citizenship rights. In spite of new progressive documents and laws, as was analysed in the article, and which ensure formal rights, the everyday practice needs much longer period to be transformed.

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