Communities of Gatekeepers and Communities of Advocates: Being Disabled in Eastern Europe
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Introduction

During the socialist past and in the post-socialist transition, disablement has been a continuous experience for people with physical, sensory and intellectual impairments across Eastern Europe (1). In this chapter, I analyse and compare figures on disability, and legislation and regulations regarding the formal and actual rights of disabled people in Eastern Europe, giving some ethnographic descriptions of their everyday life in some communist and post-communities countries (2). Their existent formal rights as well as daily practices reveal how different political and social traditions view disability and construct it at the same time.

I cover four issues in detail: hierarchies of disability; defining disability; legislation for and regulation of disabled people; cultural images and representations. In the first of these, I focus on disabled welfare recipients' experiences of an intentional and unintentional hierarchy that was predicated upon the cause of disability. During the socialist era, representations of disability caused by war or other politically-motivated reasons were favoured by the state leadership and prioritised above 'other disabilities', especially intellectual disabilities caused by birth, or impairments that occurred at work or

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during leisure time throughout a person's life cycle. As a result, from World War II until the mid-1980s, disability representations of the 'invalids of war' were the only disability representations that were almost always positive and appeared in the public sphere. These were also highly gendered, as the 'invalids of war' were almost exclusively men.

In the second issue, I show that the post-socialist period has been characterised by a major shift in numbers and definitions of what constitutes disability and who is a 'disabled person'. This shows that medical labels, most often seen as 'objective' diagnoses, reflect social changes and political transformations. In spite of this, the medical model is still predominantly used by different professionals when assessing the person's impairment and deciding upon schooling, vocational trainings, ability to work.

In the third, I compare the legislative framework with the actual citizenship rights of people with disabilities to demonstrate that despite several legislative changes after 1991, many of these do not today translate into the actual rights of disabled people. And, in the fourth issue, I demonstrate that old-fashioned cultural images and representations of disability as well as daily practices act as local gatekeepers of actual equality and that disability as difference still produces inequalities and not a valuing of diversity. Meanwhile, initiatives undertaken by disabled activists, critical professionals and the relatives of disabled people are gradually providing powerful advocates for change.

State Bodies: Hierarchies of Disabilities

On 3 December 2000, the International Day of People with Disabilities, thousands of women and men from Kiev and other towns in the Ukraine took to the streets to demonstrate against the decision of the state to reduce the social benefits of the relatives of people who died or had become disabled after the nuclear disaster in

Chernobyl. Women were carrying black-framed photographs of those close to them and one said, facing the camera:

> 'Why does the state not shorten the social benefit money to the invalids of war who have much more than we have?' (*BBC-Europe*, 04/12/2000).

Their photographs were the frozen reminders of denied communist atrocities including environmental disasters and pollution all across Eastern Europe. At the same time, the woman exposed the hierarchies of disabilities where only 'heroic invalids' (the law still uses the phrase 'invalids of war') were seen as socially acceptable or deserving disabled people entitled to proper social benefit money and covered by public images of disability. Thus, the demonstration showed that in the Ukraine, some people with disabilities have more citizenship rights than others.

The civil society movement that brought so many people to the streets of Kiev was one of the larger civil society actions that targeted unequal redistribution of resources as well as the poor representation of people with disabilities. On this occasion, the Kiev protesters demanded the recognition of different disabilities, and transformation of the hierarchies of 'deserving' welfare recipients favoured by the state. Their protest opposed the subjugation of individuals to state aims and emphasised every individual's right to proper treatment and a dignified life instead of a 'bare life' (Agamben, 1998). The protesters fought against forgetting disabled people and against the continuing social rejection of everyone with a disability except for the one whose disability was seen as the consequence of serving the 'bigger' aims of the state. The Kiev protesters were an example of 'globalisation from below'(Giddens, 2000) and showed an alternative picture of the Eastern Europe to the one still presented by some Western academics: closed and pathology-prone societies with little self-reflexivity and potential for future changes (cf Templeman, 2004).

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Hierarchies of disability remain current in Eastern Europe today, but draw on past representations. For example, in socialist Yugoslavia, the 'heroic invalids' were almost always men who were members of the partisan forces against the Nazis during World War II. Several documents from the post-war period when the Communist Party came to power, show that 'invalids of war' were privileged while looking for jobs and places at high school and universities. Local municipalities recommended them for jobs or scholarships with the justification that 'the comrade is an invalid of war' (Zaviršek, 2005). Disability itself became a symbolic marker and the permanent visible proof that the person is one of 'us'. They were called 'the ours' (*naši*) in opposite of 'not ours' (*ne-naši*), who were people who could not prove that they were involved in the partisan liberation struggle or that they supported the new communist leadership. Similarly, in the Soviet Union, the 'invalids of war' got substantially higher pensions than the rest of the Soviet population. So, 'invalids of war' became privileged welfare subjects who consumed a lot of state money; other disabled people were seen as less deserving welfare recipients and got fewer social benefits (Dunn, 2000). Thus, the hierarchy of disability constructed 'invalid state bodies' that included some 'deserving invalids' alongside needy, but 'less deserving' ones.

Women were included in the latter category. Yugoslav women, for instance, became well-known for their massive participation in the Liberation War within the unique Anti-Fascist Front of Women of Yugoslavia (1942-1953), which was set up by the Communist Party to support the Partisan Resistance and had up to 2 million women members. Out of these, about 100,000 were active in Partisan Struggles, and out of these, 40,000 were badly wounded (Milić, 1993). After the War, their contribution in war was acknowledged only to a limited degree.

The transgression of gender differences that occurred during times of wars and revolutions was replaced with the old gender order immediately after these battles officially ended. While the

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dominant public image of the 'invalids of war' remained that of the 'deserving man', women with disabilities vanished from the public sphere. A woman's disabled body was never incorporated into the heroic representations of the state body. Rather, it was associated more with stigma and shame. Visual materials such as photographs and films from the interwar and post-WW II rarely include photographs of impaired women.

The old-fashioned gender order commemorated disabled men as the heroes of war, while the female disabled body could only disturb that symbol of heroism. A disabled female body could only represent reality and not a cultural and a political myth. Thus, it could only be a reminder of horror and suffering and a symbol of the lack of rather than heroism. Regardless of the fact that women fought on equal ground with men during the war and revolution they remained, as in the West, closely connected with gendered domains in the household and caring for children, men and the nation (Dominelli, 2005). This gender order was the main reason why the narratives of women with disabilities were neither remembered nor narrated in the public sphere. The same was true for other East European countries, where women with disabilities, with rare exceptions, had no public representation, not even the one of 'heroic exception' (cf Gerber, 2000).

The phenomenon of the politically constructed 'heroic invalid' can be found in other countries with Communist governments. For example, in China, the story of Deng Pufang, the son of the important late-20th century Chinese politician Deng Xiaoping, provided a famous exception and is widely known. In that country, all sorts of disabilities are highly stigmatised and people with disabilities are often hidden at home. Deng Pufang's disability was admired rather than despised. He started to carry a 'heroic body' when he attempted suicide by throwing himself out of a window in 1968 when Maoist activists occupied Beijing University. Deng Pufang happened to be a student there, and after he had been interrogated, tortured and signed a full self-criticism of himself as

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the son of the liberal Deng Xiaoping, he injured himself (Kohrman, 2003).

Thus, disability did not ascribe him the status of a victim, but rather, his paralysed body came to manifest his 'heroism'. His body became politicised as the heroic symbol of the liberals against the Cultural Revolution of 1966-1976 and helped him to establish the first China Disabled Person's Welfare Fund in 1983. Nevertheless, that his disability acquired the status of a heroic body remained a 'famous exception'.   It neither broadened the idea of what constituted normality for disabled people, nor extended civil rights for disabled people, except for some contained within the individual-based medical model of rehabilitation.

Very little is known about enormous efforts of people with disabilities who have fought for their rights in Eastern Europe during the 1970s and 1980s. Yet, such resistance existed. In 1978 for instance a group of physically impaired men established the 'Action group' for the protection of the rights of disabled people in Soviet Union which was soon ostracised as a movement of "political opponents" (Dunn and Dunn 1989). They were silenced and forced by state welfare institutions to become dependent recipients of care, in spite of their efforts to become economically independent and creative. While the "invalids of war" became the privileged welfare subjects who consumed a lot of state money, other people with disabilities were seen as less deserved welfare recipients and got less social benefits.

After the end of the Communist regime in the Soviet Union, the hierarchy of the welfare subjects also changed. War veterans no longer obtained the higher benefits and so their experience of poverty is now closer to that of other people with disabilities. In Russia today, disabled veterans of WW II live in extreme poverty regardless of the numerous social benefits and symbolic privileges that they had attained under the Communist regime. For example, when comparing their ration of food with those of prisoners in

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1992, Dunn (2000) found that the latter ate better than disabled veterans, who could not afford to buy meat and milk.

In Slovenia, another hierarchy can be observed between the so-called 'invalid organisations' and the new disability activists' organisations. The former were set up and financed by the socialist state but still today retain their privileged position and claim that people with disabilities should continue to be called 'invalids' (*invalidi*), and be 'cared for' by state institutions. Disability activists who had established organisations in opposition to the 'invalid' ones during the 1990s have been challenging the 'invalid' identity with its passive recipient connotations and demanded a new terminology that would be less stigmatising while advocating for welfare system reforms.

In 2004, Slovene invalid organisations succeeded in amending the Constitution to name 'invalidity' as a human condition that should not be the cause of discrimination. In doing so, they opened a larger debate on citizenship rights for disabled people and the questioning of a welfare regime that prioritises dependent care instead of independent living. Disability activists interpreted the motivation of invalid organisations in debates about constitutional change as being interested in maintaining the status quo and affirming their own influence because they wanted to retain both the terminology describing disabilities and the practices associated with it. Despite disability activists' protests, Article 14 of the Constitution was passed in the terms proposed by invalid organisations. This clause guarantees equal human rights to all citizens, 'regardless of nationality, race, gender, language, religion, political and other beliefs, economic status, birth, education, social status, *invalidity,* or any other personal circumstance' (*Constitution of the Republic of Slovenia*, Article 14).

Although constitutions themselves do not guarantee actual equality in every day life, legislative changes are highly relevant especially in societies with a strong normative knowledge which categorises people according to inabilities and impairment itself.

The constitutional change in Slovenia serves as an example of what so often happens to minority groups in post-socialist countries when they gain some formal rights but have not yet fully acquired grounds for equal treatment and citizenship status. The resistance against changing the name '*invalid*' into a less stigmatising word prolongs the disablement of disabled people from the times of state socialism to the present neo-liberal governance and shows the common (un)conscious intention of the new neo-liberal political elites influenced by the old post-socialist lobbies, that nothing shall be changed for the enlargement of the rights of minority people in everyday life.

Disability Numbers in Flux

As I emphasise above, the political and social processes of transition after 1991 have been dominated by neo-liberal market rules and neo-liberal social values which have in fact only emphasised the already existent attitudes towards people with disabilities. At present, the terms 'persons with disabilities' and 'person with intellectual disabilities' are not used in any of the relevant legislation in Eastern European countries. They still use terms such as 'invalid' and for people with intellectual disabilities there exist many different labels within the same country. These include 'mentally retarded persons' in Bulgaria; 'persons with special needs' in Slovenia; 'people with altered working capacity' in Hungary; 'person with mental disabilities' in Lithuania, Estonia and Bulgaria; 'mentally handicapped' in Romania; 'persons with disturbance in mental development' in Slovenia; and 'persons with physical and mental disorder' in Croatia.

One feature characterising the post-1991 period is the considerable arbitrariness and fluidity of disability diagnoses and labels which depend on welfare regimes, value systems, political constellations and individual struggles. Medical diagnoses that

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pretend to be objective and value-free are fluid and dependant on different social factors. They are not only medical, but also political categories which influence to a large extent, a person's rights and citizenship status. In many East European countries, for example, Russia, the number of people with physical impairments has been increased tenfold in response to individual and state strategies aimed at removing working people over 50 years old from the labour market in response to neo-liberal dictats (cf Smirnova Iarskaia, 2005).

At the same time, new ideologies about 'integration' in Slovenia have considerably reduced the number of children with intellectual disabilities, a move that highlights the arbitrariness of medical and behavioural labels. Thus, during the period 1990 to 2001, the number of children with intellectual disabilities decreased dramatically - almost by half (*Rights of People with Intellectual Disabilities in Slovenia*, 2005) while the number of children with physical disabilities remained more or less unchanged. One of the important factors behind this decline have been conceptual changes including a heightened understanding of the impact that the label 'intellectual disability' has on a person's life and citizenship status.

While the welfare regime of the state socialist period emphasised 'protection' and 'life long care by a state institution', the new neoliberal welfare regime shows a slight shift towards concepts like rights, self-determination, participation and inclusion. This has been reflected in a new professional awareness of the lifelong stigmatisation of children identified as having an intellectual disability. Most of these children are diagnosed with borderline or mild intellectual disabilities, ensuring that these two labels represent a very heterogeneous group of children. Many of them experience multiple forms of social deprivation including economic vulnerability, emotional disadvantage, violence, abuse and ethnic discrimination - especially if they are Roma children.

Social disadvantages were very often medicalised in the past and children who experienced them were diagnosed as having

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intellectual disabilities as occurred for Roma children, children in care or children who had parents deemed a 'social problem' (Zaviršek, 2002). A special school in Slovenia in the areas with a bigger Roma population is informally called the 'Gypsy School' (*ciganska šola*), as most of the children came from the local Roma settlements. Experts rationalise this medicalisation of ethnicity by claiming that categorisation is a result of the Roma children's poor knowledge of the national (Slovenian) language, their external appearance and their family's socio-economic background.

In other east European countries, similar processes are evident. In 1999, at the initiative of the European Parliament Special Rapporteur for Romania, Baroness Emma Nicholson, some 38,000 children who attended special schools were reassessed according to the usual assessment procedures. Approximately half of these children were assessed as being capable of performing to mainstream educational standards, and were reassigned to mainstream schools (*Rights of People with Intellectual Disabilities Romania*, 2005:46), indicating how arbitrary these labels are.

The Formal and Everyday Invalidisation of People with Intellectual Disabilities

Alongside these shifts in the labelling of disabled people is the increasing gap between the formal and actual citizenship rights of disabled people in post-communist countries in east Europe. The everyday and symbolic hierarchies of disability place people with intellectual disabilities at the bottom and define them as incapable of work. In Slovenia, for instance, their position is regulated primarily by the Act Concerning the Social Care of Mentally and Physically Handicapped Persons passed in 1983 and not amended since (*Official Gazette of the Republic of Slovenia*, 41/1983).

The Act defines disability status for those people above the age of 18 who are diagnosed with moderate, severe and profound

intellectual disabilities and confers on them the status of 'invalids' and entitles them to various types of care. Covering 7,242 people in 2002, it provides the grounds for daily, part-time or residential care in an institution or with a foster family and guarantees some financial support such as the disability allowance and assistance allowance. Under this law, they are considered unable to ever live independently and are incapable of work and can only be placed on training programmes and in sheltered workplaces.

Similarly, in 1980, Soviet legislation introduced monthly state payments for children with disabilities under the age of 16 (Azarova, 1995). This benefit was transformed into a social pension in 1990 through the Law of 20 November 1990 (*On State Pensions in the Russian Federation* cited in Azarova, 1995). This development shows a similar attitude of long-term invalidisation of a person once labelled as disabled. In spite of numerous legislative changes within the system of social welfare, the area of children and adults with intellectual disabilities has not changed much. Like in Slovenia, the Russian Federation continues to uphold legislation passed during the 1980s, thus continuing the inappropriate labelling of disabled people, as occurred through the *On Measures for the Further Improvement of Conditions for Disabled and Handicapped Children* of 27 March 1986 (Azarova, 1995).

To enter the European Union, Slovenia passed a new law on the Vocational Rehabilitation and Employment of Invalid Persons in 2004. This formally gave several opportunities of protected and inclusionary employment schemes to disabled people. In practice, the law had not been implemented by the end of 2005 and it continues to exclude all those people who had already been automatically excluded as unable to work and live independently according to the law of 1983 considered above.

Another example of the gap between formal rights and everyday practice are processes of deinstutionalisation which were ensured according to the National Plan of Social Security (2000-2005) and set in force by the Ministry of Labour, Family and Social Affairs in

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the Republic of Slovenia in 2000. Despite this document, the majority of people with disabilities still live in large institutions where the average length of stay is from eight to ten years, which is indicative of the endemic long-term institutionalisation and segregation (Flaker et al., 1999, 2004; Zaviršek, 2000). Although the cost of institutional care is much higher than community-based care, the government actually encourages institutionalisation by ensuring free institutional care for children and young people.

In cases where the child remains at home, however, the carer receives minimal support. The nursing allowance should cover the additional costs of care, but ignores the full-time caring work done mainly by women members of the family. 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 in their permanent place of residence covers the remainder of the costs. In spite of the formal deinstitutionalisation principles, individuals who do not live in residential care cannot use the amount of money set aside for monthly institutional care for personal assistance at home because the Slovene legislation does not allow for individual funding.

Another paradox regarding the formal and the actual rights of people with disabilities is the issue of schooling for children labelled as intellectually disabled. During the preschool period, Slovenian children defined as having disabilities are assessed by a Placement Commission and assigned a category of intellectual disability. The Placement Commission also decides in which school programme the child will be placed. Slovenia does not have a special law on integration, but some new laws that promote more inclusionary principles, for example, the Primary Schools Acts from 1996 and the Placement of Children with Special Needs Acts from 2000 (*Rights of People with Intellectual Disabilities in Slovenia*, 2005:70).

A growing tendency towards integration can be observed amongst certain categories of children with special needs. Children

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with physical and sensory impairments are increasingly integrated into the mainstream school system. However, a paradox is that even under Article 10 of the new law, the Regulation on the Organisation and Work of the Commissions for the Placement of Children with Special Needs and that on the Criteria for Defining the Sort and State of their Disabilities of 2003, only children with borderline intellectual disabilities can be integrated into mainstream schools (*Official Gazette of the Republic of Slovenia*, 54/2003; 93/2004). Children with other intellectual disabilities, e.g., those labelled as moderate, severe or profound, are not included. In addition, only children with mild intellectual disability can be enrolled in special schools while all other children have to go to school in residential homes. So, despite these new laws, children with intellectual disabilities remain almost entirely excluded from processes of social integration in Slovenia.

Something similar can be observed in neighbouring Croatia which promotes inclusion in some government documents while at the same time, the law on mainstreaming covers only children with mild intellectual disabilities. Children given other more severe diagnoses are contained within separate segregated schools (*Rights of People with Intellectual Disabilities in Croatia*, 2005:79).

The opposite of what happens in these two countries occurs in Estonia where there has been a large increase in the number of children with special needs - the label that includes children with different impairments, in mainstream schools. From 1998 to 2002, approximately 25 percent of all children in primary education are children with special needs. Although the number sounds very promising, it is important to notice another division, which is that the majority of children out of that 25 percent were integrated in special classes in the framework of mainstream schools, and only 7 percent were in fact placed in mainstream classes outright (*Rights of People with Intellectual Disabilities in Estonia*, 2005:51).

In Slovenia, a paradox between formal and actual citizenship rights is also evident in the area of guardianship. On the level of

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formal rights, people with disabilities can get back their removed full capacity rights. In practice, persons with intellectual disabilities cannot resume their legal capacity because Article 54 of the Non-litigious Civil Procedure Act of 1986 states that legal capacity can be returned only 'if there are no more reasons why it was taken away in the first place' (*The Official Gazette of the Republic of Slovenia*, 30/1986; 87/2002; 131/2003). As persons once categorised as 'persons with intellectual disability' remain so labelled for their entire life, they cannot get their legal capacity status back, even if they once had it. There are no known examples of the return of full legal capacity rights among people labelled 'intellectually disabled'.

Communities of Gatekeepers

In spite of the normative ideals of community and communitarianism in Eastern Europe during the Communist regime, the term 'community' in post-communist societies is reserved for homogeneous groups of people permanently living in the same territory. The ethic of community life is not based on respecting the heterogeneity of personal experiences and differences, but on the ethic of sameness. The idea of equality is understood as sameness - we are equal as long as we are the same; and not in terms of an equality of differences - we are all different and all equal.

Social anthropologists have pointed out several ambivalences of 'community life'. One emphasises small-scale populations based on inclusivity, equality and justice in everyday life. The other indicates that members who are well-protected and equally included during good times may be brutally excluded during times of food shortages and economic crises. This becomes especially relevant if they belong to minorities and lower classes. A recent example of this form of discrimination elsewhere was exposed by large

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numbers of poor people of colour being left behind unsupported in New Orleans in the destruction caused by Hurricane Katrina.

From an exclusion perspective, communities are Machiavellian-like societies in which human being interact with each other for self-interested profit and experience others as potential opponents and enemies. The community in such situations is a dangerous place, where the dominant group claims 'common' ethical values and 'joint' interests. One of their aims is to protect themselves from potential violence. Another is to circumvent confrontations about valuing diversity. This explains why so many people in east Europe try to avoid people with disabilities: most of them believe that having disabled people close to their homes might increase violence and compromise their 'imagined community'.

After 1991, the new culture of expressing individual voices and values in Central and Eastern Europe led to the NIMBY (not-in-my-backyard) phenomenon becoming part of everyday reality. This NIMBYism is one of the reasons for the slow pace of deinstitutionalisation. In most cases, when a new group home, a kindergarten or a day centre for persons with intellectual disabilities is planned, the local population engages in direct action to prevent its opening by occupying the streets, mobilising neighbourhoods and claiming economic, cultural and symbolic rights over 'their' village, town and the whole territory.

Opposition to the proposed development of new community services is reflected the new deinstitutionalisation efforts and in professional inaction in promoting inclusionary living. Rather than engaging in outreach work aimed at altering local people's perceptions of difference, professionals - whether from institutional, community or neighbourhood bases, remain embedded in old practices and impede deinstitutionalisation initiatives. This has been particularly damaging in the setting up of new day care centres for children despite political support for such action. In Slovenia, for example, the National Programme on Social Security (2000-2005) promoted inclusion and social services within the community,

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which was only partially done in regard to people with long term mental health problems. In 2005 there were 27 group homes in Slovenia for a total of 120 residents with long term mental health problems (Cizelj et al., 2004). In addition to that there exist 10 day centres for mental health users across the country, which are accessed by approx. 450 persons yearly. There are also 9 centres for information and counselling which are yearly used by cca. 550 people who experience mental health problems (ibid.). By comparison, forty times more people still live in larger residential institutions. Despite of the fact that de-institutionalisation has been a normative orientation, the number of people with intellectual disabilities living in community settings remains very low and their numbers are still not known, except for the numbers of day centres described later on in the article.

Similarly in Estonia, the non-governmental organisation called The Estonian Mentally Disabled People Support Organisation-EVPIT reported NIMBYism amongst the parents of non-disabled children after the government started with inclusion of children with intellectual disabilities in mainstream kindergartens. The organisation carried out a project of the employment and training of 12 support teachers for children with intellectual disabilities in mainstream kindergartens between 1999-2001. The teachers were trained to support children with intellectual disabilities getting more social skills and making inclusion successful. During the process of working with children, the teachers faced NIMBY from the side of the parents of non-disabled children which they haven't expected. This was probably one of the reasons why the project did not continue and ended up in 2002 (*Rights of People with Intellectual Disabilities in Estonia*, 2005:59).

These examples show that NIMBYism is not so much an economic response by individuals who fear that new community-based social services might lower the price of their properties, but an expression of a common sense values orientation against any kind of diversity, especially that of people with disabilities. It also

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shows the predominance of the medical model while assessing impairment with no understanding of person's actual everyday rights. The protesters, always local people, have usually used hate speech to violate the rights of people with disabilities but on some occasions also appeared weaponed with garden tools to express their anger and willingness to use violence in order prevent the area from falling to 'the others', in the name of diversity. In some cases, they succeeded in preventing the establishment of group homes and kindergartens because professional workers had invested little work in community negotiations that would pave the way for their acceptance. Like those in the streets of Kiev, the people who opposed such initiatives called themselves a 'civil society' movement. This shows that the word 'civil society' is currently being used for critical as well as conservative or rightwing actions when addressing issues of diversity.

People who speak about 'common values', most often oppose the processes of deinstutionalisation and individual self-determination being exercised by disabled people and promote the logic of spatial segregation and invisibility of disabled people. The 'common values' they espouse are the majority's own values. A young woman whose cousin gave birth to a baby with Down's Syndrome was told that village people believed that the disability had been caused her not arranging a big wedding and marrying a man who was 'not for her' (personal communication, 2004). Here, an individual's action and an autonomous decision are seen as a sin that can be punished. A disabled child is the punishment a woman incurs in becoming a decision-making person in her own right.

Communities of Advocates

In the past few years in Slovenia, parents of children and adult persons with intellectual disabilities have provided very successful examples of individual and collective advocacy. These advocates

were active in the areas of: mainstreaming children with disabilities in primary schools; advocating for direct funding (Flaker et al., 2004; Zaviršek, 2005); and establishing some successful parent advocacy organisations (Zaviršek et al., 2002).

Parents gain greater self-esteem and develop new ways of fighting for rights which were widely absent under the Communist regime. They have become better informed about their rights, and less dependent upon professional workers. Some parents started to write complaints to the Ombudsman of the Republic of Slovenia in order to advocate for the rights of their children, especially in cases where they were supposed to be placed in special schools (Zaviršek, 2005). A successful example of these was a pilot project to support two girls who had Down's Syndrome being included in a mainstream primary school in Ljubljana. The project was designed by the university teachers in the field of special education and the relatives of the girls who have themselves a long term academic career. During a joint struggle of three parties: parent organisation, independent academics active in promoting inclusion and the school authorities of that particular school, the representatives of the Ministry of education decided to make a written order to allow two girls to be placed in the first class of the mainstream school and to obtain few hours of paid support by the state. The important paradox which occurred during that process was that in spite of legislative commitment of Slovene government to promote inclusion and mainstream education, the representatives of the Ministry of Education and the National Institute of Education tried to prevent the inclusion and challenged the intellectual abilities of both girls to become enrolled in ordinary school. The representatives of both governmental bodies have focused on impairment and traditional practice of segregated education, and were mostly reluctant to shift their thinking from focusing at the intellectual dis-ability caused by Down syndrome towards focusing at the individual abilities and supportive network which were of a fundamental importance in the lives of these two girls. The power

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struggle between birocratic-political elites and independent advocates including carers, intellectuals and teachers, ended up to a successful action which has important consequence for other children with intellectual disabilities. It has been for the first time that young people with Down syndrome had the right to attend mainstream school. The project has showed also that in cases when children get more paid support for school activities, they can be successful and can remain in the mainstream education. Therefore, one of the suggestions for welfare politicians and educational authorities was to increase the hours of paid support which is currently provided by the government for children with intellectual disabilities who attend mainstream education in order to be successfully included.

Another important level of collective advocacy is taking place within non-governmental organisations (NGOs) across east Europe. For example, since 2003 in Slovenia, the Association for the Theory and Culture of Handicap (YHD), a disability activist NGO, has been running the programme, *Independent Living of Disabled People* (Pečarič, 2002; Neodvisno življenje, 2004). They provide a network of personal assistance for people with disabilities who want to live outside of institutions (Osebna asistenca za neodvisno življenje, 2004). In Hungary, where more children with intellectual disabilities than in any other east European country can enter mainstream education, NGOs have started to run innovative or 'alternative schools' where even more children with intellectual disabilities can receive mainstream education (*Rights of People with Intellectual Disabilities in Hungary*, 2005:20). Another NGO, Pentru Voi from Romania, provides supported employment services to people with intellectual disabilities, and has already assisted 22 persons in finding jobs on the open market (*Rights of People with Intellectual Disabilities in Romania*, 2005:52). This is an important achievement compared with the state welfare institutions which in most countries across east Europe provide sheltered employment

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instead of paid work. In the sheltered employment institutions people labelled as "mentally disabled" have to work, but their work is seen as a "therapeutic activity" for which they obtain symbolic payment regardless of their actual skills and working capacities. In Slovenia, for instance the yearly governmental budget for sheltered workplaces in 2003 was three billion Slovene Tollar (cca. 12.5 million Euro). The money was used to finance 29 public sheltered workplaces with 2,066 people with intellectual disabilities working in those shelters (*Rights of People with Intellectual Disabilities in Slovenia,* 2005: 100-106). In comparison with expenses provided by the Ministry of Labour, Family and Social Affairs for other spheres of social welfare, this sum of money is rather high which means that people with intellectual disabilities are seen as having a high level of consumption as welfare recipients, but are denied to be seen as those who are also able to produce in the open market.

During 2005 one of the biggest shelter employment institutions in Ljubljana hosted four workshops which aimed to promote the development of community living and work in the ordinary environments of people with intellectual disabilities (3). The workshops attended professional workers from different sheltered workplaces across Slovenia and people with disabilities who work in sheltered employment. The professionals who participated in the workshops (most of them were occupational therapists and social workers) estimated that there are currently between two and five percent individuals with intellectual disabilities who would be able to work in paid employment but instead of that, work in sheltered workplaces. The major reasons for that they saw in legislative obstacles, public prejudices, negative expectations of employers and professional practice which promote sheltered placements instead of independent living. During the workshops some professionals expressed their worries that the future development towards independent living and employment in ordinary work places might cause that "they will loose the best workers" who today work in

sheltered workplaces and do a great amount of work which is traded in the open market by sheltered workplaces themselves (wooden boxes for different purposes, coloured candles, scarves, postcards, greeting cards, souvenirs, etc.). This example shows a great ambivalence of the professionals towards advocacy work for people with least social and political rights in the society. On the one hand they want to advocate for active rights of their clients, but on the other hand they fear changes and rather passively advocate for the welfare recipient status of their clients.

Concluding Remarks

As this chapter has shown, the redistributive rights (welfare redistribution as well as economic redistribution) and the recognitional rights (the rights of public representation, symbolic rights) of people with disabilities in east Europe has to be researched on the level of formal rights and everyday practices. Along with examples of exclusionary practices there are many different ways of individual and collective engagement in community struggles for better services and entitlements. Most disability activists have moved towards an anthropological understanding of disability and a social model while most 'invalid organisations' retain the medical one.

Disability activists emphasise that disability is a socially constructed phenomenon that changes over time and that the form it takes depends upon the political system and other positionalities in which a person is located. They also stress that the experience of disability is an individual one that depends on the social images and actual citizenship rights held by people with disabilities and not a universal experience. It is also obvious that disability activists see

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themselves as different from members of invalid organisations and that not all people with disabilities share their visions of the future.

Different examples of community-based struggles and knowledge of the global disability movement also teaches social workers and other caring professionals in east Europe and across the globe, how to promote new values, ethics and practical skills (Gilbert et al., 2005). The practices of caring professionals need orienting towards: understanding and discussing the personal experiences of disability; focusing on the strengths of and barriers encountered by a particular individual; promoting a perspective that looks at how to ensure support for disabled persons in their everyday lives instead of emphasising a lack of abilities; supporting community actions and collective advocacy; promoting the dissemination of examples of best practice in empowerment and independent living; supporting the skills of individuals and groups that oppose the dominant and hegemonic structures that inhibit disabled people.

While all these skills and values-orientations are evident globally (Albrecht et. al., 2001), Eastern European countries also need their own models of best practice examples that would serve as role models of encouragement for future changes. Instead of focusing on the category of disability itself, both global battles and regional struggles have to focus on the particular needs and desires of specific disabled individuals and how these could be met in a given community context.

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(2) I use the category, east Europe to refer to those countries that are geographically located in the eastern part of Europe and Eastern Europe to refer to those countries covered by Communist and socialist regimes before the fall of the Berlin Wall.

(3) The workshops were part of a larger research on new employment models for people with intellectual disabilities with major emphasis on working and living on the farms across Slovenia. The project was directed by Vadnal (2005), and the workshops were carried out by the author of this article.

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