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People with disabilities today

People with disabilities are, in most parts of the world, still seen as an exception to the rule, and as a deviance from the 'normal'. Nevertheless, certain recent global developments demonstrate positive changes in the ways people with disabilities are treated by professional helpers, including social workers, and the lay public. But the differences in the quality of life of persons with disabilities across the world remain huge.

Key words: disabled people, difference, Eastern Europe, post-socialism, Marrakesh Treaty.

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ČAS ZA PRIZNANJE: LJUDJE Z OVIRAMI DANES

Ljudi z ovirami se po večini delov sveta še vedno obravnava kot izjemo od pravila in kot odklon od »normalnega«. Kljub vsemu pa nekaj globalnih dogodkov in sprememb nakazuje pozitivne spremembe v zvezi s tem, kako z ljudmi z ovirami ravnajo strokovnjaki, tudi socialne delavke in delavci in javnost. Ne glede na to pa razlike na področju kakovosti življenja hendikepiranih ljudi ostajajo ogromne.

Ključne besede: hendikepirani, razlika, Vzhodna Evropa, postsocializem, Marakeška pogodba.

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Introduction

People with disabilities are, in most parts of the world, still seen as an exception to the rule, and as a deviant when compared to the 'normal'. Recently, a journalist in one of the Eastern European countries told a woman on a wheelchair who founded the safe house for battered women with disabilities:

> I am really interested to write about women with disabilities experiencing violence, not in this column on women and violence, but in a separate one, dedicated to disabled women!

Why do we still create and re-create separate worlds and realities, and uphold different criteria for the rights and wrongs when treating children and adults with and without disabilities?

It is not just the media. School teachers often claim that separate environments for disabled children are better than integrated ones; most social workers across the globe believe that specialised and often large institutions provide the best treatment and care. In one of the primary schools in a rural area of Slovenia a teacher took the children out to discover the plants and minerals in their nearby natural environment, but left a physically disabled child behind in the classroom to do the same exercise with the aid of a special computer programme. The child's classmates may well have learned the required curriculum, but they also internalised the hidden curriculum: a person with impairments is a burden, and is set apart and left behind. She needs 'special treatment', often at the expense of equal treatment. A story like this one can happen almost anywhere in the world.

The division between 'us' who are believed to be the 'same', and 'them' who are seen as 'different' remains well defined. Social workers also reproduce the normative order of normality with the motto: *We respect and care for those who are different and vulnerable!* The notion of 'difference' is seemingly a non-discriminatory way of addressing people with disabilities, but prevents us from asking: different from what? Is being different not per se implying something of a lesser value? And if people with disabilities do act and respond differently, is it not because of their different life conditions, including the unbearable weight of normality that is reproduced by different social welfare professionals and the general public alike? Vulnerability, too, has become a widely used term that makes people believe that a person is vulnerable by his or her nature or impairments. In reality, it is the social structure and built environment that disable individuals and make them dependent and in need of social interventions and entitlements.

It was more than twenty years ago when Sally carried the banner in one of the western countries with the slogan: *I learned to say 'good morning'; have you learned to say 'person with Down Syndrome' instead of a mongoloid?* The medical term for one particular genetic impairment used an allusion to the Mongols in Asia to describe the 'feeble minded.' It is often forgotten that numerous transnational personal and collective efforts of disability activism originated precisely with the 'vulnerable population.' Their strengths, vision and commitment transformed the care-based approach into the rights-based approach, but they are nevertheless still labelled 'vulnerable.' They advocated for equality and better life conditions for disabled persons and made revolutionary changes in the areas of paid employment, the closing down of long-stay institutions, schooling, and the rights to self-determination across the world and achieved great visibility, but they are still called 'invalids' (*invalidus* in Latin stands for dependent and weak). These designations freeze a person in time, and construct an oppressive and singular identity.

The need for social recognition

The assertion that in the above cases, the professionals acted in a discriminatory fashion towards the disabled would hardly meet with general consent. How can something be discriminatory when it is a widely accepted practice: the creation of separate stories and labels, the keeping alive of segregated education and prolonged institutional confinement? The underlying issue in these stories is the lack of social recognition of persons with bodily, sensory, cognitive and emotional impairment and diagnoses. The disabled are not treated equally to those without visible impairments: they are routinely denied the respect that the majority of people take for granted.

In her 1997 analysis, Nancy Fraser showed that claims for redistributive justice and equal redistribution of goods are as important as social recognition. Social recognition means acknowledgement, and respect towards the individual regardless of his or her personal specificities and lifestyle when the person lives a valuable and decent life. Fraser's demands for the 'recognition of difference' and 'recognising the other' became central in the discussion of human rights that seeks to promote both universal respect for our shared humanity as well as differences among people, societies and cultures. Known as identity politics, these notions were closely connected to the democratisation of societies on the basis of celebrating diversity. Disability and mental health movements were part and parcel of these struggles. The activists demanded that the disabled be treated with dignity and respect in every situation where people without disabilities and diagnoses receive such treatment as a matter of course. It is well documented that non-recognition stirs guilt, self-hatred, self-torture, stigma and unequal opportunities as well as anger and hatred towards the other.

Zygmund Bauman (2008) also shows that denying people social recognition results in the individual feeling of humiliation. He uses a powerful definition by Dennis Smith (*ibid.*: 90) according to which an

> act is humiliating if it forcefully overrides or contradicts the claim that particular individuals are making about who they are and where and how they fit in. People feel humiliated when they are brutally shown, by words, actions or events, that they cannot be what they think they are… Humiliation is the experience of being unfairly, unreasonably and unwillingly pushed down, held down, held back or pushed out.

These social attitudes are widely documented as experienced by disabled people on an everyday basis.

Even though people with disabilities are nowadays rarely explicitly exploited or discriminated against, they nevertheless face economic dependency, the denial of social recognition, withdrawal of respect, and are often refused the entitlements that other people enjoy as part of the support that is taken for granted. Elena Pečarič, a powerful Slovenian activist in one of the disabled people's organisation and a wheelchair user, recalled her experience of not being recognized:

> In my primary school, nobody discriminated against me openly, and I was seen as equal to my classmates. But in all those eight years at the school, I was never invited to my classmates' homes for a birthday party, as it was common for all other children.

The denial of dignity and equality was expressed in a way that was not very obvious; this hidden form of discrimination allowed everybody, the school authorities, the teachers, the parents and the classmates to maintain the image of an inclusionary society with the outside world, as well as a positive self-image. For Elena, the exclusion was a solitary and unrecognised experience.

The importance of developing disability studies in social work education

In many countries across the world disability studies are known and practiced by a tiny minority of people. In social work curricula and university teaching, they are rarely if ever included. In the late 1980s and 1990s they spread to an extent, mainly in the countries of the global north. In Asia, Africa and in Eastern Europe they remain an exception and are rarely included in the ways of thinking of disability.

Disability studies are defined as an interdisciplinary and transdisciplinary field of research that includes historical, cultural, social, economic and political knowledge and their critique, in order to outline the disability phenomena, and the comparative perspective. Disability studies deal with the historical and social construction of the body, the norm and illness, analyse the structural inequalities and processes of othering, issues of visible and invisible forms of violence against people with disabilities, and the impact of culture on the visibility of the disabled. The field's central preoccupation is the question of who constructs the notions of human normality, embeds it in the symbolic order in a given time, space and place, and how. Disability studies lay claim to the importance of the personal stories of the disabled and advocate their place in the professional and public knowledge. It is stressed that the disabled themselves have the right to define their individual needs (where, how, and with whom they would like to live, work, socialize), desires and aspirations. The philosophy of disability studies is therefore the universal liberation of persons with disabilities, based in social activism and advocacy and the struggle for the termination of all structures of social inequality. Disability studies offer an empowering potential to persons with disabilities, their relatives and professionals working in the area alike.

Disability studies thus considerably radicalized, transformed and widened the social work tradition of help and care wherever they were incorporated into the social work curricula. Traditionally, social work was based upon a medical pathological framework within which disabled people were individualized and constructed as volatile bodies prone to corrections. The notion of 'disabled people' is used to emphasise that people with bodily or mental specificities get disabled by societal normativity, everyday barriers, and taken-for-granted discrimination and oppression (Oliver 1983, Oliver, Sapey 2006). On top of this, the term 'people with disabilities' is now widely used to emphasise the 'People First!' tradition whereby people with impairments insist on being seen first as people in their own right, and then as persons with impairments (Finkelstein 1980, Morris 1992, Davis 2006).

Disability studies within social work also question the 'rehabilitation model' that is primarily based on the normative idea that the 'incorrect' needs to be rehabilitated and returned to the state of the 'normal' (rehabilitare is Latin and means returning something into the previous, original state). Instead of rehabilitating the people, social work supports recovery that focuses on incorporating the uniqueness of the person, which is seen as the lack, the change, the trauma and the loss, into the life of the person. Social work facilitates a person's ways to continue living, and supports a person's capabilities to (re)gain control over his or her daily decision-making, and to live an ordinary and good life regardless of impairments and diagnoses.

Global developments

Certain global developments encourage the view that the attitudes towards people with disabilities have changed in the last decades, and that many changes are at least formally agreed upon even as they remain far from being implemented. The UN Convention on the Rights of Persons with Disabilities adopted in 2006 was a breakthrough in the understanding that each person with impairments, regardless of the diagnoses, has the right to education, to work and to live in an ordinary environment rather than being segregated, and that especially girls and women should be protected from violence. No less than158 countries signed the Convention, but fewer hitherto proceeded to ratify it. A mere handful of countries, among them Belarus as the only European country, and certain African countries, failed to sign the document. The critical voices of persons with disabilities claim that in the majority of the signatories, the Convention's principles are yet to be implemented. The reluctance of many signatories to actually implement the UN Convention is obvious even at the level of local languages' translations of the document. In post-socialist European countries, the notion of 'person with disabilities' all too readily translates into the term 'invalid', an old-fashion expression that defines a person with impairments as weak, dependent and unable to work. In India, certain media are keen to omit the word 'rights' in the UN CRPD title, shortening it to the 'United Nation Convention for the Disabled'.[1]

Another recent document that is expected to change the life of more than 300 million people with disabilities across the globe is the Marrakesh Treaty to Facilitate Access to Published Works for Persons Who Are Blind, Visually Impaired, or Otherwise Print Disabled, adopted in June 2013. It is estimated that 1 million books are published each year but only between 1 and 7 per cent are available in a form adapted for people with visual impairments. This goes to show that most visually impaired people are severely discriminated against in the area of access to information and books. An elderly woman from Slovenia with visually impairments who does not use a computer said:

> I feel disadvantaged as the daily news comes to me with a month's delay, when the Organization of the blind and partially blinded distributes its Bulletin in Braille script with a selection of the important news of the month!

Another man said:

> My life-long wish has been to get access to a book as soon as it comes out in print and to the bookstores, and not wait for years to access it when the Organization of the Blind makes an audio copy, if that happens at all! (Personal interviews, 2013.)

An important provision in the Marrakesh Treaty assures that not only the blind and visually impaired will have access to printed materials, but other people as well, as it expands the definitions of those who are in need of access, including people with reading impairments (e.g. people with dyslexia), and those who need support holding a book, turning pages or focusing on a page. In numerous countries this will challenge the narrow 'categorization mentality' that defines who is entitled to a benefit and who is not. In Slovenia for instance, only medically certified people with visual impairments can enter the library for the blind, but not so the elderly with age-related visual impairments who were not, or refuse to be, diagnosed as disabled, nor is access to such special libraries open to young people with dyslexia or other reading impairments who would benefit from using audio books.

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[1] The Hindu,Breakthrough for the blind, July 17, 2014. Available at: http://www.thehindu.com/opinion/editorial/breakthrough-for-the-blind/article6218103.ece?ref=relatedNews.

The Marrakesh Treaty also stipulates that signatory countries are mandated to change the domestic copyright laws to ensure that people with visual impairments and other print disabilities acquire access to all print material in a friendly format: the Braille script, electronic large print, or digitalized audio version. The Treaty also ensures the trade of accessible format copies from institutions and individuals in the countries with easier access to countries with more limited access to print materials. So far, 79 countries, members of the World Intellectual Property Organization, signed the Treaty, headed by India as the first signatory that ratified the Treaty on 20 June, 2014.

Country-specific and regional-specific contexts: the example of Eastern Europe

There exists a widely shared understanding that disability studies, as well as social work, are culture- and country-specific, contextual, and therefore conflicting in their core premises. The ex-socialist European countries, referred to by the geographical euphemism of Eastern Europe, often serve as examples of that in the field of disability studies education, where these professional foci exist, or in the diverse life experiences of the disabled persons, when compared to other European societies.

Across European ex-socialist countries, there is currently a growing interest in disability studies whereby a portion of scholarly work focuses on locally specific histories and understandings of the issues. Until the late 1990s only one English volume existed on the history and culture of disability in the East, by McCagg and Siegelbaum (1989). Russell and Iarskaia-Smirnova (2014) singled out three areas where disability studies from 'the East' diverge from those in 'the West'. Eastern European scholars who publish in disability studies regard state socialism as equally oppressive towards the disabled as capitalism is. Capitalism, in turn, is viewed by the Western neo-Marxists as the cause of disablement. Poverty and structural absence of state welfare support in the transitioning East is seen as re-directing the focus of disability studies from a rights-based approach to a needs-based approach, and the minimal welfare provisions. The absence of disability civic movements in the East is seen as having delayed the development of disability studies, having caused the lack of awareness of structural oppression.

There is little doubt that disability studies in European ex-socialist countries are greatly influenced by the socialist past. In the region where universal economic redistribution was a priority and a normative social goal, recognition of differences was suppressed and any kind of acknowledged difference carefully monitored by the state apparatuses (Zaviršek 2005, 2008). The body/mind disablement was not therefore seen as the right to difference and diversity, but rather as an unfortunate condition that had to be medicalized, institutionalized and supervised. Persons with disabilities were de-normalized from their early childhood. The norm of normality was internalized. The attitude of the parents educating children with 'don't look at the invalids, they are pitiful creatures!' was deeply internalized. As a consequence, there existed a particular mentality well expressed anecdotally: a person from Eastern Europe travelling to Sweden during the early 1990s observed to his wife, 'I wonder why Sweden has so many invalids? I saw them everywhere on the streets and in coffee shops!' The glaring public invisibility of people with impairments during the socialist period was notorious, mostly due to the stigma, and compounded by the lack of a barrier-free environment. As late as in 2012, a doctoral student from Tbilisi State University in Georgia recalled her vivid teenage memory of a sojourn in Germany with her parents where she encountered many people in wheelchairs on the streets 'that she had never seen before in her life' (personal communication, Tbilisi 2012).

Citizens of socialist states were denied the right to express political agency and subjectivity, therefore disability movements appeared late in the day and remained subdued. The ideology of 'the socialist man' gave precedence to the collective rather than the individual. In such a political and ideological context any critical social movement either by disabled people themselves, or parents, relatives and advocates was impossible (Zaviršek 2007). The ideal of the 'new socialist man' was visualised and materialised in a non-disabled worker who was capable of physical and intellectual work. As a consequence, people with minor impairments were often confined to large institutions for life.

The belated modernization of Eastern European societies after WWII resulted in a profusion of closed and semi-closed institutions for the disabled and people with mental health problems. The 'golden era of Eastern European welfare institutions', to paraphrase Foucault's notion of the grand confinement (1988), took place during the time when invigorated criticism against spatial segregation, demands for normalisation (Wolfensberger 1972), anti-psychiatry (Cooper 2001) movements like Psichiatria democratica (Basaglia 1997) and the philosophy of deinstitutionalization pervaded the Western countries. Consequently, until recently, hardly any deinstitutionalization took place in the Eastern European countries. Resistance to any novel approach, however, was sometimes swift and radical. In 2006, the Open Society Fund[2] allotted more than a million dollar grant to a non-governmental organisation in Croatia to encourage deinstitutionalisation and to help relocate the residents from a large long-stay institution for the intellectually and physically disabled into smaller flats and units in the community. Due to the governmental refusal of this process, the NGO in question was forced to return the donation (personal ethnographic notes, 2008).

Until recently, managers of these institutions were hesitant when different community based living arrangements were discussed. Likewise, the professional staff who work in large long stay institutions often refused to give up the safety, and limited engagement, of the work place in the large wards. A social worker in Slovenia, when asked to clean the floor in the small group home of a group of people with long term mental health problems, refused to comply, claiming that such tasks were not part of her job description (ethnographic notes, 2014). In the community-based smaller group homes, professional workers are asked to work in partnership with people with disabilities, supporting them to become as independent and self-sufficient as possible. This is part of the philosophy of deinstitutionalisation that is based in a new self-definition of the professional staff, who are neither those who control not those who care, but who support disabled people where needed to lead a dignified and ordinary life. This is in radical opposition to both the Makarenko-type pedagogy 'to build and socialize a new human being', and to the old-fashioned, charity-control orientation that sought to 'care for and protect' the disabled from the world and from themselves.

Present situation in the region

Today, people with different disabilities in the East European region still suffer great inequalities, and their personal experiences remain silenced and invisible. Poverty, social isolation, poor health conditions, poor education, unemployment, experiences of violence and the denial of their competencies often intertwine and cause disabling conditions and more inequalities. Some countries in the region that have been EU Member States since 2004 (the Baltic states, Poland, the Czech Republic, Hungary etc) maintain a mixture of socialist era legislation from the 1980s, and newly adopted, EU harmonized legislation (Zaviršek 2014). A comparable confusion of concepts, practices and solutions also pervades the social and political arenas concerned with disability.

A case in point, public debates addressing the problem of a non-stigmatizing 'name' for the disabled have been going on in some Eastern European countries for over two decades. Contrary to expectations, the people with disabilities and their organisations often demand to

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[2] The Open Society Fund is funded by the Hungarian-American billionaire and humanist George Soros whose engagement, while controversial, is nevertheless pivotal in ex-socialist European countries. He was and remains one of the most influential international donors that funded democratically oriented, 'open society' NGOs across European ex-socialist countries and beyond, and is, among others, also the founder of the prominent Central European University in Budapest.

be continuously called *invalids*. It would be too easy to say that these people internalized the normative discourse and are simply responding in conformity. The stakes in the battle for the name and social identity are both historically and socially embedded. In a rural, underdeveloped pre-communist gone socialist-industrialist, and finally devastated post-communist economy, a continuity of harsh life marked by lack of resources, and many ideological barriers, asks for more than the right for recognition. During the communist period, social benefits in the form of subsidies and services (especially long term institutions) as well as work-related benefits were given to 'invalids' who were thus stripped of independence, but protected by the state. Sticking to the term 'invalids' nowadays not only signals the hope that welfare benefits are not withdrawn, but also that the old socialist identity of the 'invalid' is preserved, an attribute that may well have invalidated the individual socially, but did protect him or her at the same time. The fear that the state may refuse to care for the disabled who refuse to be invalidated seems well grounded: in Kyrgyzstan for instance, the government does not offer any subsidy to the community based organisations for people with disabilities; they, and their family and advocacy groups are entirely dependent on international humanitarian aid.

No wonder then that one of the post-socialism legacies today is the huge mistrust of the inefficient and corrupt state. This is one of the reasons why parents of children with intellectual disabilities have a vital interest to keep the decision-making power over the child's future in their own hands. In practice this means that the parents vote and advocate that the old-fashion socialist legislation of prolonged parental rights over their child stays in place, as is still the case in all the successor countries of the former Yugoslavia, for instance. In this way, the parents hold, as long as they are alive, complete legal authority over their adult child. Such legal arrangements prevent the much feared state interference. One of the workers in a sheltered workplace said:

> The mother even has the right to decide whether we are allowed to dye the hair of the middle aged daughter, when she expresses the wish to have it dyed. (Ethnographic notes 2011).

There remains a huge discrepancy between the universal right and obligation of children to receive compulsory primary education when it comes to children with disabilities, who either enter special schools or do not attend any school at all. Children with intellectual disabilities are nearly universally prevented by law from entering mainstream education, despite the formal principle of inclusion. One of the most notorious issues is related to the ways the Roma ethnic minority children in European post-socialist countries are steered to segregated education, often mislabelled intellectually disabled in the process. Ethnic minorities children are pathologized rather than offered economic and social support to minimize their difficulties in the school system (Zaviršek 2004, 2009).

The more developed social welfare post-socialist states (with GDP over 20.000 $/year) encounter ethical dilemmas of a different nature still. In social work, the question whether a person's autonomy is equally as important as the care issues looms large; the care-perspective, usually in the form of long term institutionalisation, too often prevails. The needs *vs.* care dichotomy remains a great challenge for social work practitioners on many levels, be it working with individuals, relatives or in social services for persons with impairments.

All these pitfalls notwithstanding, the approaches that stress the rights of persons with disabilities are taking hold. In October 2014, one of the long-stay institutions for young people with intellectual and mixed disabilities in Slovenia celebrated its 40th anniversary. The celebration was held during a conference where only people with intellectual disabilities from all over Slovenia presented their papers. They talked about their work experiences, talents, cultural and sport achievements, about their social and intimate relationships, and their paths towards increased independence. Some shared painful memories of childhood traumas and other unfortunate life events. It was not a real service-users-led event, but at least the first in the country, where on an important conference people with impairments had the chance to share some of their life events with peers and the public, instead of the professionals to hare about their 'treatments'.

Conclusions

It is a matter of fact that disabled people all over the world face very diverse life conditions with respect to the quality of life, access to effective services, and day-to-day living. These differences have different underlying causes, but depend to a large extent on the local cultural values and traditions, the attitudes towards diversity, and economic issues as reflected in the ways the medical and the welfare systems are sustained and populated. There are countries where lack of finances is less of a problem than the cultural view on disability that holds the disabled as incapable of making decisions for themselves. In some countries, even mild impairments can have major social consequences upon the person's autonomy while elsewhere, persons with severe disabilities are fully supported to lead an independent life.

Elsewhere, the family of the disabled person is seen as first and foremost in charge of the life of their disabled member, even if the society at large values individualism over everything else. In other countries still, institutionalized care is the only available option for the majority of disabled people. Only in very few countries there exists a wide range of social services and opportunities for disabled individuals to choose from. There are also wide disparities between the urban and rural areas within countries. People in rural areas often lack access to social services and face many architectural barriers that prevent them from living independently.

Lately, the model of personal budgeting for the disabled was tried in certain well developed countries, notably in Finland. The model aims at converting the costs of services traditionally used by disabled persons (boarding schools, shelter workshops etc.) into a personal budget that allows the person the planning of his or her daily activities and life in the most meaningful way, and to choose services she or he needs and wants. Personal budgeting also demands that disabled people make their own decisions rather than follow those made by their parents or caregivers. A central issue of the model is the proper education of the social workers who work with the disabled on a daily basis. In a recent study from Finland titled 'I know what I want!', a pilot project in personal budgeting included 12 people with intellectual disabilities (Eriksson 2014). All of them wanted to work in an ordinary environment – to do 'real work' – instead of work in the local centres for the intellectually disabled. With the personal budget, they could hire personal assistants to help them with job seeking and managing the barriers in the ordinary work environment. Some enrolled into study programmes and moved from sheltered accommodation into independent housing. All the people included in the study emphasised that personal budgeting improved the quality of their life significantly.

The social work discipline is comprised of social workers who seek to support people, families and communities in their contexts and are today one of the most important agents of change in the area of the rights of people with disabilities across the world.

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