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DISABILITY STUDIES IN POST-SOCIALIST
COUNTRIES AND SOUTH-EAST ASIA

Guest editors: Darja Zaviršek, Jelka Zorn

SELECTED CONTENTS

For contents written in English, see full TOC on the back cover. Articles written in Slovenian:

UREDNIKOVA OPOMBA

S to številko vpeljujemo prakso, ki bo napravila revijo dostopnejšo za tuje bralce in bralke: nekateri članki so objavljeni v angleščini, ki je, hočeš nočeš, postala lingua franca znanosti. Uredniški odbor revije meni, da se lahko tako bolje vključimo na mednarodno prizorišče in pridružimo mednarodnim razpravam. Sam še zmeraj mislim, da je razvoj strokovnega jezika najpomembnejša naloga naše (pravzaprav vsake znanstvene) revije. Ni pa edina. Naša naloga je tudi predstaviti dosežke domače misli v mednarodnem prostoru, še zlasti ker nekateri dosežki, ki bi se sicer zvečine utopili v mednarodni znanstveni publicistiki, niso zanemarljivi. Hkrati pa tako dobimo priložnost, da pritegnemo k sodelovanju več tujih avtorjev in z njimi vzpostavimo konstruktivno razpravo. Upam, da bodo domači bralci in bralke pozdravili to odločitev, saj tudi sami poznajo omejitve, ki jih postavlja zaprtost v nacionalni prostor.

Bogdan Lešnik

UVODNIK

Pred vami je trojna številka revije *Socialno delo* z naslovom »Študij hendikepa v državah postsocializma in jugovzhodni Aziji« gostujočih urednic dr. Darje Zaviršek in dr. Jelke Zorn. Številka prinaša znanstvene članke v slovenskem in angleškem jeziku, ki uporabljajo kritično perspektivo in prinašajo refleksijo o družbeni konstrukciji normalnosti ter opozarjajo na relikte zgodovinskega zapiranja ljudi z različnimi telesnimi, senzornimi in intelektualnimi posebnostmi, ki se danes kažejo kot različne oblike diskriminacij. Te diskriminacije ljudi hendikepirajo.

Socialna okolja, iz katerih izhajajo avtorice in avtorji, imajo tri pomembne skupne značilnosti. Prva je, da gre za države, v katerih študij hendikepa sploh ne obstaja ali pa je šele v zametkih. Druga značilnost, povezana z razmerami postsocializma in slabega ekonomskega položaja večine ljudi v jugovzhodni Aziji, je slab ekonomski, socialni in politični položaj ljudi z ovirami. To povečuje njihov hendikep. Tretja značilnost je od kulture odvisen odnos do različnosti, s katerim imajo težave tako postsocialistične države kot bolj tradicionalne države globalnega juga. V teh družbah različne prirojene in pridobljene ovire niso del človeške barvitosti, temveč breme, problem in vzrok sramu, ki naj ga medicinski, rehabilitacijski, socialnodelovni in pedagoški postopki čim bolj skrijejo, popravijo in odstranijo. Ljudi z ovirami se praviloma obravnava posebej, kot »specifično skupino ljudi«, kot da bi ovira spremenila njihovo človeškost:

> Novinarka nam je obljubila, da bo naredila oddajo o nasilju, a bo o tematiki žensk z ovirami poročala posebej! (Pričevanje hendikepirane uporabnice socialnovarstvenih storitev, 2013.)

Tematska številka se, nasprotno, zavzema za etiko hendikepa, ki telesne, intelektualne in čustvene ovire razume kot del človeške različnosti in izkušnji hendikepa priznava mesto, iz katerega izhaja posebno razumevanje sveta.

Šest prispevkov petih avtorjev in avtoric (Ule, Humljan Urh, Sobočan, Krstulović, Zaviršek) je rezultat raziskovalnega dela, ki je bilo opravljeno v okviru temeljne raziskave, ki jo je financirala ARRS med leti 2011 in 2014 in je imela naslov »Etika hendikepa« (šifra: J5-4073-0591-14). Drugi prispevki so bili predstavljeni na mednarodnem simpoziju »Proti socialnemu trpljenju: socialno delo, ki je na strani ljudi z ovirami v času krize«, ki so ga organizirali sodelavci Katedre za preučevanje socialne pravičnosti in vključevanja Fakultete za socialno delo (Zaviršek, Sobočan, Krstulović, Zorn). Na simpoziju so raziskovalke in raziskovalci iz 15 držav (Madžarska, Hrvaška, Bosna in Heercegovina, Avstrija, Šrilanka, Južnoafriška republika, Kitajska, Gruzija, Rusija, Grčija, Združeno kraljestvo, Indija, Nemčija, Kosovo, Slovenija) predstavili analize položaja oviranih iz perspektive človekovih pravic v primerjalni perspektivi. Mednarodni simpozij (potekal je junija 2013) sta finančno podprli Mednarodna zveza šol za socialno delo (IASSW) in Evropska zveza šol za socialno delo (EASSW). Zbornik povzetkov mednarodnega simpozija in zvočni zapisi vseh prispevkov so izšli v spletnem zvočnem zborniku *Against social suffering: social* *work in alliance with people with disabilities in the times of crisis: compendium of the International Regional Symposium of the IASSW, EASSW and EEsrASSW, Ljubljana, 17th-18th June 2013* (https://www.dropbox.com/s/57z2nrhn3km5mk0/Against_Social_Suffering-EBOOK.pdf).

Vsem trem financerjem se najlepše zahvaljujemo za finančno podporo.

Darja Zaviršek, Jelka Zorn

EDITORIAL

Before you is a triple issue of the journal *Socialno delo* entitled 'Disability studies in post-socialist countries and South-East Asia'; the issue's guest editors are Darja Zaviršek and Jelka Zorn. The articles are in two languages, Slovene and English, and adopt a critical perspective in reflecting on social constructions of normality. They point to the confinement of people with physical, sensory or intellectual disabilities in social care institutions as a source of discrimination. These and other discriminatory practices disable people. The social environments of all the authors featured in this issue share three common characteristics. Firstly, the authors all come from states where disability studies are non-existent or are just beginning to take shape. Secondly, they share an awareness of the poverty and social and political powerlessness currently being experienced by the majority of the population, and especially by many people with disabilities, in post-socialist countries and South-East Asia, and of how this results in the exacerbation of disability. The third commonality is a culturally conditioned attitude towards diversity: in these societies, various impairments (acquired during life or inborn) are not viewed as part of the vast, colorful spectrum of human conditions, but are seen as a burden, an irresolvable problem and cause for shame. Impairments are therefore to be concealed, repaired or diminished through medical, rehabilitational, pedagogical and social work procedures and approaches. People with disabilities are usually treated separately, as a specific group, as if the impairment changes their humanity:

> 'The journalist promised to produce a TV show on violence, but she said she will make a special piece on women with disabilities' (testimony from a woman with disabilities, 2013).

In opposition to these processes, this issue of *Socialno delo* strives for an ethics of disability, in the sense of a consideration of physical, sensory and intellectual impairments as part of human diversity and an acknowledgement of the experience of disability as a point of departure for obtaining special insight into the world.

Six papers from five authors (Ule, Humljan Urh, Sobočan, Krstulović, Zaviršek) are the result of research done in the framework of 'basic research' entitled *The Ethics of Disability*. This research was funded by the Public Research Agency of the Republic of Slovenia and was conducted between 2011 and 2014 (grant number J5-4073-0591-14). The other papers in this issue were presented at the international conference *Against social suffering: Social work in alliance with people with disabilities in times of crisis*, which was organized by colleagues from the Department for Social Justice and Social Inclusion Studies of the Faculty of Social Work (Zaviršek, Sobočan, Krstulović, Zorn). Researchers from 15 countries (Slovenia, Hungary, Croatia, Bosnia and Herzegovina, Austria, Sri Lanka, South Africa, China (Hong Kong), Georgia, Russia, Greece, United Kingdom, India, Kosovo, Germany) presented findings from cutting edge research in disability studies and national and comparative analyses of the situation of people with disabilities. The conference was funded by the European Association of Schools of Social Work (EASSW) and the International Association of Schools of Social Work (IASSW).

The conference resulted in the publication of an audio book that brings together all lectures, abstracts and photographic material from the conference: *Against social suffering: Social work in alliance with people with disabilities in times of crisis: A compendium of the International Regional Symposium of the IASSW, EASSW and EEsrASSW, 17th - 18th June 2013*. Ljubljana: Faculty of Social Work, edited by Zaviršek, Sobočan and Krstulović, available at https://www.dropbox.com/s/57z2nrhn3km5mk0/Against_Social_Suffering-EBOOK.pdf.

We would like to thank all three subsidisers.

Darja Zaviršek, Jelka Zorn

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Darja Zaviršek

TIME FOR RECOGNITION
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 Europa, postsocializem, Marakeška pogodba.

Prof. dr. Darja Zaviršek je redna profesorica, doktorica sociologije, predstojnica katedre za preučevanje socialne pravičnosti in vključevanja ter predsednica Vzhodoevropske regionalne mreže šol za socialno delo v okviru IASSW. Je častna profesorica na Univerzi za uporabne znanosti Alice Salomon v Berlinu. Kontakt: darja.zavirsek@fsd.uni-lj.si.

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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Izvirni znanstveni članek

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OPREDELITEV HENDIKEPA IN RAZVOJ ŠTUDIJA HENDIKEPA V SOCIALNEM DELU

Mednarodna perspektiva

Študij hendikepa se z nekajdesetletnim časovnim zamikom uveljavlja tudi v postsocialističnih državah in problematizirajo teoretske koncepte, kot so hendikep, utelešena razlika, etika hendikepa, ter poudarja, da je sodelovanje ljudi z ovirami pri raziskovanju in poučevanju ključno. Študij hendikepa preučuje, kako je konstruirana normalnost in kakšni so kulturno specifični odzivi na telesne posebnosti, ki določajo, kako dobro bodo ljudje z ovirami živeli v določeni družbi. Članek prinaša analizo teh konceptov in prakse v slovenski situaciji.

Ključne besede: disriminacija, uporabniško gibanje, izobraževanje, etika hendikepa, drugačnost.

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DEFINITION OF HANDICAP AND DEVELOPMENT OF DISABILITY STUDIES IN SOCIAL WORK: INTERNATIONAL PERSPECTIVE

The disability studies which analyse theoretical concepts such as disability, embodied difference and the disability ethics have been developed in postsocialist countires with a great delay. The author shows how beside these concepts disabled people's involvement in research and teaching is of a crucial importance. The article shows how normality has been created and contructed in a society like Slovenia and shows the socially constructed responses towards bodily specificities which determine the quality of life of persons with impariments in different societies. The article reflects upon the above mentioned concepts from the perspective of the current situation in Slovenia.

Key words: discrimination, users' movement, education, disability ethics, difference.

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Uvod

Vse daljša življenjska doba prebivalstva razvitih držav na eni strani ter revščina, slabe delovne razmere, novo suženjstvo in vojne, ki jih doživljajo ljudje v revnejših in večinoma podeželskih območjih ekonomsko razvijajočih se držav, na drugi strani bodo povzročili, da se bo večina svetovne populacije v življenju kdaj srečala s kako vrsto hendikepa (Zaviršek 2009). Šaljivi izrek pravi, da smo ljudje, gledano v vseživljenjski perspektivi, le začasno nehendikepirani. To je mogoče res, ne pomeni pa, da bomo vsi doživeli enake vrste diskriminacij ali da ima hendikep v času starosti enake posledice kot hendikep v otroštvu, mladosti, zreli dobi in v času pomembnih življenjskih prehodov.

Strokovno delo socialnih delavk in delavcev, ki so sodelovali pri obnovi skupnosti in psihosocialnem okrevanju ljudi po cunamijih, potresih in orkanih na različnih koncih sveta (cunami leta 2004 na Šrilanki, potres leta 2008 v Sečuanu na Kitajskem, orkan Katrina leta 2005 v ZDA ipd.), je vprašanje hendikepa pri preživelih postavilo v samo središče socialnega dela. Družboslovne znanosti, med njimi tudi socialno delo, danes revidirajo stara prepričanja in priznavajo, da je večina telesnih in mentalnih ovir pridobljena v času posameznikovega življenja in da različnih vrst hendikepa, tudi intelektualnega, ne moremo raziskovati, ne da bi razumeli učinke revščine, rasizma in drugih oblik nasilja (tudi psihične in spolne zlorabe) in več generacij trajajoče prikrajšanosti ljudi za zdravje v nepravičnih družbah. Mit o dednosti se je zrušil tudi na tem področju.

Pot do velike spremembe gledanja, ki so jo utemeljili hendikepirani aktivisti, svojci in akademiki, ki so ovirane ljudi podpirali, je znana kot premik od medicinskega modela hendikepa k socialnemu. Ponekod se je začel v prvi polovici 20. stoletja, predvsem po drugi vojni, drugod pa šele konec 20. stoletja – v Vzhodni Evropi na primer. Premik je pomenil zavračanje medicinskega pogleda in pogleda popularnih medijev (gl. Zaviršek 2000 in Andraž Kapus v tej številki) na vsakdanje življenje oviranih ljudi. Medicinski model je skupaj z nekritičnimi mediji spregledal, da so prakse zapiranja ljudi, prisila v repetitivne dejavnosti, prikrivanje zlorab, ki so jih posamezniki doživljali v javnih in cerkvenih institucijah, in celoten sistem varstva hendikepiranih ustrojeni tako, da bolj ustrezajo modelu zaposlovanja socialnih delavk, pedagogov, specialnih pedagogov, psihiatrov, animatorjev, medicinskih sester in vzgojiteljic kot pa ljudem z ovirami samim. Nobenega dvoma ni, da imamo povsod, kjer še dominira medicinski model, opraviti z relikti prakse zapiranja, ki je bila v Evropi znana od 17. stoletja (Foucault 1998 [1962], Zaviršek 2000).

Članek prinaša kratek pregled teoretskih konceptov, kot so hendikep, drugačnost, utelešena razlika, etika hendikepa, in oriše ključne poudarke študija hendikepa (*disability studies*) ter pokaže, kako pomembno je, da pri poučevanju hendikepa sodelujejo tudi ljudje z ovirami.

Definiranje hendikepa in razvoj študija hendikepa

V večini razvitih in razvijajočih se držav so različni avtorji v osemdesetih letih 20. stoletja začeli opozarjati na medsebojen odnos med telesnimi posebnostmi (v medicinskem besednjaku imenovanimi hibe, defekti, nenormalnosti, bolezni), vsakdanjimi izkušnjami, ki jih ima oseba zaradi teh telesnih (ali intelektualnih, psihičnih) posebnosti, socialnim kontekstom, ki je za hendikepiranega poln ovir, in močjo posameznice in posameznika. Tako se je razvil koncept hendikepa *(*angl. *disability*, nem. *Behinderung)*. Ta poudarja, da telesne, senzorne in intelektualne ovire ljudi sicer omejujejo pri vsakdanjih opravilih, resnične ovire, ki so posledica zgodovinskih procesov in katerih posledice so družbene neenakosti, pa nastanejo šele v stiku posameznice in posameznika z izključujočim okoljem. Takšno okolje temelji v normativni predstavi o normalnem telesu in »normalnem funkcioniranju,« pri tem pa vse, česar ne zaznava kot »normalno,« doživlja bodisi kot »nenormalnost« bodisi kot »drugačnost«. Trdovratna družbena prepričanja o normalnem in nenormalnem, torej konstruirana normativnost, ustvarjajo družbena izključevanja. Koncept hendikepa je zato nujno družbeno kritičen, njegovi zagovorniki pa se sprašujejo o izvorih neenakih razmerjih moči v različnih kontekstih in zahtevajo več enakosti.

Ne smemo pozabiti, da so prav ljudje, ki so bili še pred kratkim obravnavani kot povsem odvisni, šibki in brez moči, v socialno delo vnesli največje spremembe, saj so skupaj z redkimi akademiki sredi devetdestih let 20. stoletja razvili koncept hendikepa. V Sloveniji so uvedli zagovorništvo, osebno asistenco, politično participacijo, zahteve po novih medijskih podobah in spremembe zakonodaje, razkrivanje zlorab ipd. Vendar v Sloveniji zakonodaja o njih še vedno piše kot o »invalidih«, torej o šibkih, slabotnih in dela nezmožnih ljudeh.[1] Z drugimi besedami, le peščici strokovnjakov in množici hendikepiranih aktivistov gre zasluga, da sta se tudi v socialnem delu v Sloveniji v drugi polovici devetdesetih let razvila študij hendikepa in praksa vključevanja s poudarkom na neodvisnem življenju, plačani zaposlitvi in drugačnih javnih podobah, ki zmanjšujejo stigmo in spodbujajo politično participacijo oviranih ljudi. Med začetnike, ki so o utelešeni razliki razmišljali v pisanju in poučevanju, sodijo Tanja Lamovec, Dušan Rutar, Elena Pečarič, Klaudija Poropat, Emil Bohinc, Luj Šprohar, Marino Kačič in Darja Zaviršek (Zaviršek 2000, Rasell, Iarskaia Smirnova 2014).

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[1] Spomnimo še enkrat na uporabo pojmov invalid in invalidnost, kot ju definira Slovar slovenskega knjižnjega jezika (1994, str. 309): »invalid - -a, kdor je zaradi prirojene telesne napake, posledic bolezni, poškodbe nesposoben ali delno sposoben za delo; invaliden -dna, -o, prid., ki je zaradi prirojene telesne napake, posledic bolezni, poškodbe nesposoben ali le delno sposoben za delo. Invaliden delavec, rehabilitacija invalidnih otrok, telesno in duševno invalidne osebe. V prenesenem smislu pa: skoraj vsi kipi v hiši so bili invalidni«. Ministrstvo za delo, družino, socialne zadeve in enakost spolov Republike Slovenije je novo Konvencijo Združenih narodov o pravicah oviranih ljudi, ki ima angleški naslov *Convention on the Rights of People with Disabilities,* značilno prevedlo kot: Konvencija o pravicah invalidov. Ker takšno poimenovanje ljudi hendikepira in je v nasprotju z načeli konvencije, bomo v članku uporabljali prevod Konvencija ZN o pravicah ljudi z ovirami.

Hendikep je torej socialna kategorija, ki konceptualizira prepletanje materialnega, čustvenega in socialnega in odslikava družbeno zaznamovane odzive na telesne posebnosti, kot so gibalna oviranost (mišična distrofija, paraplegija, tetraplegija ipd.), senzorna oviranost (težave s sluhom in vidom), intelektualna ovira (posebnosti pri dojemanju sveta, težave pri učenju določenih vsebin ali večine vsebin, posebnosti odzivanja na določene dražljaje ipd.) in težave z duševnim zdravjem (psihiatrične diagnoze, psihiatrične hospitalizacije). Med omenjenimi ovirami so nekatere vidne, druge pa nevidne (multipla skleroza, rak, disleksija, duševne stiske ipd.). Utelešene človeške posebnosti povzročijo družbeno prikrajšanost in diskriminacijo na izobraževalni, ekonomski, socialni in simbolni ravni.

Teoretizacije človeških utelešenih posebnosti obsega študij hendikepa (*disability studies*).[2] Študij hendikepa ne preučuje defekta in hibe, temveč, kako je konstruirana normalnost, da se nekaj pokaže kot »hiba« in »defekt,« in kakšni so kulturno specifični odzivi na telesne posebnosti, ki določajo, kako dobro bodo ljudje z ovirami živeli v določeni družbi. Študij hendikepa torej ovire ne vidi več kot zgolj »osebne izkušnje in nesreče,« temveč je ovira družbeni konstrukt, njegovi pomeni, pojavne oblike in položaj hendikepiranih ljudi v različnih delih sveta pa so odvisni od zgodovine, kulture in družbe in se med seboj zelo razlikujejo. V zadnjih desetletjih je študij hendikepa vplival na poimenovanja, javne politike, izobraževanje strokovnega osebja in kakovost življenja ljudi z ovirami in njihovih bližnjih. [3] Študij hendikepa analizira različne diskriminacije in jih umešča v zgodovinski in socialni kontekst. Med najpogostejšimi so:

1. Diskriminacija na področju izobraževanja:
    - vključenost v paralelno izobraževanje;
    - nizka pričakovanja strokovnega osebja do hendikepirane osebe v izobraževalnem procesu;
    - nizka pričakovanja staršev hendikepirane osebe in odsotnost izobraževanja za starše;
    - neustrezne intelektualne in motivacijske spodbude;
    - neustrezne izobraževalne metode dela in možnosti po končani osnovni šoli;
    - pomanjkanje vrstniškega ozaveščanja, asertivnosti in učenja za samozagovorništvo.

2. Ekonomska diskriminacija:
    - izključenost iz plačanega dela;
    - ustvarjanje paralelnega trga dela za ljudi z ovirami v zaposlitvenih centrih in drugih prekarnih oblikah dela;
    - slaba delovna mesta zaradi nizke izobrazbe ali zaradi predsodkov delodajalcev;
    - nizki dohodki;
    - visoki izdatki za prostorske prilagoditve (stanovanje, delovno mesto), prilagoditve vozil in protetične predmete;
    - izdatki za prevoze in pomoč pri negi in asistenci.

3. Bivanjska diskriminacija:
    - pomanjkanje izbir za ljudi, ki so ovirani od rojstva ali mladosti: živijo praviloma bodisi doma pri starših in sorodnikih bodisi v zavodih, enotah zavodov in stanovanjskih skupinah zavodov;
    - slaba izobrazba, nizki dohodki ali nezaposlenost zaradi predsodkov delodajalcev preprečujejo, da bi ljudje imeli kakovostne bivanjske izbire.

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[2] Te so zlasti na angleškem govornem območju postale del družboslovja kot samostojna disciplina ali pa so vključene v kulturološke študije, študije postkolonializma, redkeje socialnega dela in sociologije.

[3] Delni premik v Sloveniji zaznamo z Akcijskim programom za invalide 2007–2013, ki invalidnost definira kot večdimenzionalen pojav (v skladu z WHO ICF), ki izhaja iz interakcije med fizičnim in socialnim okoljem. Govori o univerzalnih pravicah oseb z ovirami, spoštovanju različnosti, nediskriminaciji, dostopnosti in individualnem pristopu k storitvam na različnih področjih.

4. Socialna diskriminacija:
    - arhitekturne in druge ovire ter slaba dostopnost do storitev, ki so dostopne večini;
    - slabše delovno mesto od posameznikove usposobljenosti;
    - osamljenost;
    - težave pri pridobivanju družbeno cenjene identitete (partnerstvo, starševstvo, status zaupne osebe, vplivne javne osebe);
    - težave zaradi strokovnjakov, ki ne upoštevajo posameznikovega mnenja in ga obravnavajo pokroviteljsko;
    - življenje v zavodih;
    - pomanjkanje spodbud ali odvračanje hendikepiranih posameznikov, posameznic od odločanja za starševstvo;
    - pričakovanja ljudi, da morajo biti »invalidi« zadovoljni z malim.

5. Simbolna diskriminacija:
    - žalostne in neprivlačne podobe oviranih ljudi v javnosti (v medijih, na plakatih) ali stereotipne podobe (srečni in hvaležni obrazi ljudi v zavodih);
    - stereotipne reprezentacije oviranih ljudi v umetnosti (filmih);
    - svojci in strokovno osebje, ki ne želi, da bi gluhi uporabljali znakovni jezik v javnosti (nekateri primeri po Sloveniji);
    - neupoštevanje drugega zaradi predpostavke, da je manj pomemben, ker je hendikepiran;
    - ustvarjanje nevidnosti, npr. spregledovanje osebe z ovirami in njenega mnenja, kot da je ne bi bilo;
    - feminizacija hendikepa, kot da je hendikep šibkost, ki se prilega vsemu, kar je kulturno konstruirano kot žensko; moški z ovirami je potemtakem »nepravi« moški, bližje vsem tistim lastnostim, ki se pripisujejo ženskam.

6. Formalnopravna diskriminacija:
    - nekateri ljudje z ovirami imajo status otroka vse življenje, njihovi svojci pa podaljšano roditeljsko pravico;
    - nekaterim oviranim je odvzeta poslovna sposobnost in jo težko pridobijo nazaj;
    - v življenju mnogih oviranih oseb odločitve sprejemajo le njihovi skrbniki in zakoniti zastopniki, tudi kadar jim poslovna sposobnost ni formalno odvzeta;
    - nefleksibilna zakonodaja, ki ne omogoča, da bi ljudje z ovirami lahko konkurirali na trgu delovne sile in imeli obenem zagotovljeno socialno varnost;
    - nekompatibilnost nekaterih socialnih transferjev s trgom delovne sile: osebe z (minimalnim) dohodkom v obliki invalidske pokojnine nimajo pravice opravljati plačano delo;
    - ljudje z nekaterimi oviranim nikoli niso priče ali porotniki na sodiščih.

Mnoge diskriminacije bi lahko uvrstili kar med oblike nasilja nad ljudmi z ovirami – to je eden od številnih spregledanih problemov (Zaviršek 2014).

Naštete oblike diskriminacij dokazujejo, da je izkušnja hendikepa tako osebna kot družbena in da se potemtakem od ene družbe do druge razlikuje (podaljšana roditeljska pravica je slovenska posebnost; zahodne države imajo institucionalizirano osebno asistenco, večino institucij v katerih so nekoč del svojega življenja živeli ljudje z ovirami pa so zaprli ipd.). Zato študij hendikepa poudarja, da je oviro treba dezindividualzirati in jo razumeti kot oboje, kot utelešeno osebno in kot družbeno ustvarjeno izkušnjo, saj različni družbeni odzivi oviranost povečujejo ali zmanjšujejo. Hendikep ni nikoli naraven ali prirojen, temveč vedno družbeno proizveden; je socialna in ekonomska kategorija, njeni učinki pa so povezani s strukturnimi neenakostmi, ki se v očeh ljudi in strokovnjakov pogosto individualizirajo kot osebne stiske in težave.

Varuhinja človekovih pravic RS je leta 2008 ugotovila, da je slaba dostopnost storitev Slovenskih železnic za gibalno ovirane osebe vprašanje človekovih pravic in temeljnih svoboščin (Letno poročilo Varuha človekovih pravic za leto 2009, 2009: 63). Dejstvo, da so stikala za upravljanje dvigal nameščena previsoko, da bi jih gibalno ovirane osebe lahko dosegle, ni pripisala človekovi bolezni in invalidnosti, temveč temu, da načrtovalci železniških postaj niso upoštevali načela enake dostopnosti. Socialna diskriminacija, ki je v zakonodaji odpravljena, v vsakdanjem življenju ostaja samoumevna, kot dokazuje tudi odgovor Slovenskih železnic v navedenem primeru, da »bodo poskrbeli, da bodo do leta 2013 tipke za upravljanje dvigal na ustrezni višini« (*ibid.*). Slovenske Železnice potrebujejo pet let, da prestavijo tipke v enem samem dvigalu v središču Ljubljane. Takšno ravnanje mora biti deležno odločne kritike, ker se vzrok socialne diskriminacije ne odpravi takoj, temveč se krši v Sloveniji sprejeto Konvencijo Združenih narodov o pravicah ljudi z ovirami (*UN Convention of the rights of persons with disabilities 2006*). Ta ima med splošnimi načeli zapisano pravico do dostopnosti, v 9. členu pa še natančneje določa pravice oviranih oseb do samostojnega gibanja, mobilnosti in javnega prevoza. Še več, vsakdo, ki v državi podpisnici konvencije opravlja storitve, namenjene vsem ljudem, kot so to tudi Slovenske železnice v Sloveniji, je dolžan zagotoviti dostop vsem ljudem, tudi osebam z oviro.

Študij hendikepa ni samo kritika medicinskega modela, temveč tudi socialnega, ki zgodovinske kategorije, kakršne so potrebe, skrb, izbira, pravice pogosto razume nezgodovinsko. Nezgodovinsko razumevanje pomeni, da se omenjene kategorije razume kot »naravne« in kot nekaj danega, ne pa kot zgodovinsko spreminjajoče se in odvisne od vsakokratnih vrednot, ekonomskega razvoja, politike in kulture v različnih lokalnih kontekstih. Spomnimo se samo, kako so se spreminjale teorije potreb, od »temeljnih«, ki jih je določil Maslow, pa do teorij potreb Marte Nussbaum in drugih, ki danes med potrebe uvrščajo tudi samoodločbo, svobodo, potrebno po participaciji, odločanju ipd.

Avtorji v študijah hendikepa poleg tega poudarjajo, da prizadevanje za »polepšanje sivega dne« ni več ustrezna oblika strokovne intervencije, ker temelji na zgodovinsko konstruirani delitvi ljudi na bolne in zdrave, normalne in nenormalne, in ohranja nizka pričakovanja in dvojna merila, ko gre za hendikepirane v odnosu do nehendikepiranih. Namesto delitve se avtorji zavzemajo za:

- ustvarjanje odprtih, vključujočih prostorov brez delitev;
- ozaveščanje in podporo staršem (drugih bližnjih oseb), da se spopadejo s stigmo, in spodbujajo neodvisno življenje svojih otrok (bližnjih oseb);
- zavračanje oblik navideznega vključevanja: takšen primer je opisala socialna delavka, ki je bila v neki slovenski osnovni šoli priča dogodku, ko je na naravoslovni dan razred odšel do bližnjega gozda raziskovat kakovost prsti, deklica na vozičku pa je s spremljevalko morala ostati v razredu, češ da »to isto lahko počne na računalniku«. Namesto da bi učitelj zagotovil pogoje za resnično vključevanje vseh otrok v dejavnosti šolskega programa, je povzročil navidezno vključevanje, saj je deklico po nepotrebnem izločil in diskriminiral ter jo prikrajšal za skupinsko izkušnjo raziskovanja v resničnem, nevirtualnem okolju (Klobasa 2009).

Pionirsko besedilo znotraj opusa študij hendikepa je napisal Victor Finkelstein; konec sedemdesetih let je kritično analiziral medicinske vidike oviranosti in ideje osebne tragedije in razvil koncept socialnega razumevanja družbenih situacij invalidizacije. Njegovo besedilo *Ravnanja in ovirani ljudje* (Finkelstein 1980) je za mnoge pravi politični manifest. V njem trdi, da hendikepa ne smemo razumeti zgolj kot družbeno konstruirane posledice premajhne vključenosti hendikepiranih v družbo, temveč kot problem dojemanja samega hendikepa kot odklona. Kritiziral je prepričanje, da je treba spremeniti predvsem »negativna ravnanja« in stereotipe, češ da naj bi že to izboljšalo položaj hendikepiranih. Po tem prepričanju naj bi bil torej »svet prizadetih tak, kakršen je, spremeniti pa bi bilo potrebno ravnanja neoviranih ljudi, kar naj bi prineslo spremembe v življenju oviranih posameznikov«. Nasprotno pa je njegova zahteva po spremembah je radikalna, saj je že tedaj v celoti zavrnil delitev sveta na hendikepirane in nehendikepirane ljudi. Do spremembe lahko pride le tedaj, ko razlik med hendikepiranimi in nehendikepiranimi ne bo več potrebno poudarjati.

Ohranjanje te delitve poznamo danes v Sloveniji kot na videz nevtralno sintagmo: »ljudje z ovirami so drugačni.« Tisti, ki poudarjajo, da so hendikepirani »drugačni,« se imajo za posebej demokratične in verjamejo, da sta njihova terminologija in vrednostni sistem vključujoča. V resnici pa gre za nadaljevanje starega načina razmišljanja, po katerem so eni »isti,« drugi pa »drugačni« (drugi je vedno za prvim), torej ne-isti. Pod krinko sprejemanja drugačnosti se skrivata stara delitev in reduciranje vseh »drugačnih« na »enake drugačne«: vsi so zgolj »drugačni«. Koncept »drugačnosti« hendikep normalizira kot sprejemljiv odklon od norme in ga hkrati individualizira, ker predpostavlja, da je izvor drugačnosti ovira sama in ne specifična norma normalnosti in izkušnje zatiranja, ki jih kot posledico oviranosti doživljajo hendikepirani posamezniki.

Zagotovo pa je veliko razlik med osebo, ki ni ovirana, in osebo, ki je ovirana in doživlja vsakdanje diskriminacije. Oseba ni »drugačna,« ker je ovirana, temveč je drugačna zato, ker doživlja prej opisane diskriminacije v vsakdanjem življenju. »Drugačnost« torej ni intrinzična, notranja lastnost ovirane osebe, temveč posledica interakcij z zatirajočim okoljem. Še drugače: oseba ni »drugačna,« ker je ovirana, temveč ker je v okolju, ki njen hendikep doživlja kot »drugačnost«, do nje drugačno okolje samo. Zato je beseda »drugačen« diskirminatorska, saj še vedno ohranja polarizacijo »mi«/»oni« ali »normalni«/»drugačni«.

Namesto da hendikep vidimo kot »problem drugačnosti«, je iz perspektive študija hendikepa in načela raznovrstnosti (*diversity*) pomembno razviti koncept »utelešene razlike,« ki sveta ne deli na normo in razliko. Tako postane hendikep »načina bivanja,« »specifična izkušnja« in tudi »prostor upora« (Snyder, Mitchell 2006, Scully 2008).

Študij hendikepa in perspektiva uporabnikov

Študij hendikepa izhaja iz načela, da je treba spodbujati in podpirati uporabniška gibanja in ljudi z ovirami vključevati v raziskovalni in pedagoški proces, saj je njihova »utelešena izkušnja« ključna za emancipacijske premike znotraj področja (Videmšek 2011, 2012). V državah, kjer imajo malo uporabniških organizacij in kjer ni mogoče govoriti o uporabniškem gibanju, tudi uporabniškega raziskovanja in poučevanja ne poznajo. To velja predvsem za nekdanje socialistične države, v katerih se zaradi državnega socializma glas hendikepiranih aktivistov bodisi ni slišal bodisi je ostal zatrt in v katerih sta bila prevladujoča modela pokroviteljstvo in institucionalizacija hendikepiranih; žal sta v teh državah še danes prevladujoča.[4]

Procesi globalizacije informacijske tehnologije so v zadnjih dvajsetih letih zelo olajšali širjenje in internacionalizacijo uporabniškega gibanja, saj je kot eno od gibanj odpora postalo transnacionalno. Dve najpomembnejši mreži sta *Disabled People International* (DPI), ki ima centre po številnih državah po vsem svetu, in *European Network of Independent Living* (ENIL), ki je eno od najmočnejših gibanj v boju proti zapiranju ljudi v zavode in za samostojno življenje. »Globalizacija od spodaj« vključuje milijone ljudi, ki so organizirani v nevladne organizacije in skupine hendikepiranih aktivistov. Taka gibanja so ponekod veliko dosegla pri preoblikovanju državnih politik in pri vzajemni podpori, ki so si jo začeli zagotavljati ovirani ljudje sami (ameriško gibanje hendikepiranih je dolgo podpiralo izraelsko uporabniško gibanje, japonsko uporabniško gibanje je podpiralo uporabniške organizacije v revnejših azijskih državah ipd). Internacionalizacija gibanja hendikepiranih aktivistov je dokazala, da so strukture družbenega izključevanja v različnih delih sveta podobne, zato gibanja povsod po svetu zahtevajo več enakosti. Mednarodno gibanje hendikepiranih je medicinski diskurz o telesnem primanjkljaju preneslo iz medicinskih okvirov na področje družbenega razumevanja hendikepa in na področje človekovih pravic.

V postsocialističnih državah s kulturno tradicijo direktivnega upravljanja z ljudmi »od zgoraj navzdol« obstaja še posebej neenako razmerje moči med strokovnjaki in uporabniki. Ljudje verjamemo, da lahko pritožba proti avtoriteti strokovnjakov in strokovnih ustanov poslabša položaj posameznika. Posledica tega je, da se uporabniki upirajo na pasiven ali agresiven način.

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[4] To je dobro pokazal prvi mednarodni seminar na območju vzhodne Evrope, ki ga je organizirala Kristina Urbanc na Univerzi v Zagrebu, šoli za socialno delo septembra 2008 z naslovom: Service users as experience experts in social work education and research (2007–2009).

Tradicionalna socialna distanca med strokovnjaki in uporabniki krepi prepričanje, da imajo strokovnjaki »ekspertno znanje,« uporabniki pa »zgolj osebno izkušnjo« (Zaviršek 2000, 2009). Izkušnje v tej pojmovni konstelaciji veljajo za preveč subjektivne in čustvene in zato nezmožne »objektivne« resnice, ekspertno znanje pa se zdi zagotovljeno »objektivno« in ga je mogoče posplošiti na »večino« (»vsi invalidi …«). Takšen dualizem ustvarja različni skupini ljudi, strokovnjake in uporabnike/hendikepirane aktiviste. Med njimi naj bi bila tolikšna razlika, da se zdi, da gre skoraj za dva svetova (ko, na primer, strokovna delavka o uporabniku reče: »… pred nesrečo, ko je bil še normalen …«).[5]

V postsocialističnih družbah brez dvoma obstajajo številne kulturne ovire, ki preprečujejo razvoj in širjenje uporabniškega gibanja. Omenimo nekatere: pogled na uporabnike kot na ljudi »s problemi,« ki nenehno nekaj zahtevajo in so s svojimi zahtevami praviloma moteči prejemniki pomoči; pogled na aktiviste kot nerazsodne in preveč subjektivne; prepričanje, da je za ljudi z ovirami dovolj dobro tisto, kar je za nehendikepirane podstandard in nezaželeno (»če bom kdaj invalid, bom šla v dom …«); velik občutek odvisnosti zaradi pomanjkanja ekonomske samostojnosti (»če ne pristanem na življenje v zavodu, nimam kam«); slaba izobraženost svojcev in njihov strah pred ekonomsko ogroženostjo (»boljše kategorizirati otroka, da se pridobijo določene ekonomske bonitete«); zahteve uporabnikov se *a priori* patologizirajo (starši intelektualno oviranih otrok veljajo za »sitne« in »nerazumne;« hendikepirani aktivisti za »nasilne, konfliktne in iracionalne«; zahteve posameznika se interpretira, kot da se je osebi »poslabšalo stanje,« ipd.).

V zahodnih državah imata soodločanje in sodelovanje uporabnikov in strokovnjakov daljšo tradicijo kot v postsocialističnih državah. V Združenem kraljestvu, na primer, kjer je bilo gibanje hendikepiranih najbolj vplivno, od leta 1975 obstaja zakonska obveza za strokovnjake, določena v Zakonu o otrocih (*Children's Act*), da za mnenje in nasvete vprašajo otroke in mlade, kadar odločajo o njih. Od leta 1990 pa obstaja zakonska obveznost socialnih in drugih služb, da uporabnike vključujejo v odločanje. Na Danskem šolski pravilniki določajo, da morajo šole pri otrocih razviti tudi spretnosti otrok za sodelovanje pri sprejemanju odločitev (McLaughlin 2006).

V Sloveniji se je odločilen premik v uporabniškem gibanju zgodil v devetdesetih letih 20. stoletja, ko so številni uporabniki začeli javno pisati in govoriti o osebnih izkušnjah z zdravstvenim in socialnim sistemom, psihiatričnimi hospitalizacijami in o vsakodnevni izkušnji s stigmo. Ena od pionirk na tem področju je bila prof. dr. Tanja Lamovec. Večkrat je preživela psihiatrično hospitalizacijo, leta 2006 pa končala življenje s samomorom; prav samomor je eden od pokazateljev neučinkovite podpore ljudem v stiski in težav ljudi, ki želijo sistemske premike na tem področju. V svoji prvi knjigi (Lamovec 1995 a) se je samoopredelila kot »uporabnica« in strokovnakinja, pozneje pa je bila ustanoviteljica zagovorniških organizacij, skupin svojcev in prve uporabniške organizacije, ki so jo vodili ljudje s težavami z duševnim zdravjem (Lamovec 1995 a, b, c, d, 1996 a, b, 1997 a, b, c). Kot radikalna nasprotnica medicinskorehabilitacijskega sistema zdravljenja psihiatričnih uporabnikov je bila vključena tudi v pedagoški proces na šoli za socialno delo v Ljubljani.

Ko je dopolnila 60 let, je v poslovilnem pismu bridko ugotovila, da je bil boj predolg in da so njene moči za nadaljevanje boja oslabele. Nekateri ljudje so njen samomor razumeli kot kolektivno obsodbo strokovnega ravnanja, ki ni omogočilo učinkovitih podpor, mrež in služb. Drugi pa so ga videli kot zgolj simptom duševne bolezni. Kljub nerazložljivosti dejanja samomora je očitno, da pri ljudeh s težavami z duševnim zdravjem opozarja na spopadanje z vseživljenjskim zatiranjem, ki ga občutijo in doživljajo posameznice in posamezniki.

Leta 1998 je v politični prostor stopila druga dolgoročno pomembna skupina, aktivisti organizacije YHD, Društva za teorijo in kuturo hendikepa (Pečarič 2002). Uvedli so program samostojnega življenja in v njem organizirali usposabljanje za ljudi, ki postanejo osebni asistenti oviranim ljudem na njihovih domovih. Predsednica YHD Elena Pečarič je leta 2005 prejela nagrado za izjemne dosežke na področju dobre prakse Fakultete za socialno delo, leta 2007 pa

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[5] Podatek s terenskega dela avtorice, Ljubljana, 2009.

je dobila dovolj podpisov podpore, da je postala ena od sedmih kandidatk in kandidatov za predsednico Republike Slovenije. Kljub temu so tradicionalne invalidske organizacije njeno delovanje nenehno omalovaževale in ovirale. Od leta 1999 so bili člani in članice YHD pogosti gostujoči predavatelji na Fakulteti za socialno delo, Elena Pečarič pa je dobila naziv asistentke za obodobje med letoma 2006 in 2011.

Obe ikoni slovenskega gibanja hendikepiranih uporabnikov in aktivistov sta pokazali, da jedro neenakega razmerja moči med strokovnjaki in uporabniki v resnici ni v tem, da uporabniki ne bi bili močni in ozaveščeni, temveč da potrebujejo prostor, v katerem bodo slišani in upoštevani. V slovenskem kontektu bi si danes težko zamislili sodoben študij duševnega zdravja in hendikepa, ki ne bi upošteval besedil obeh vodilnih oseb teh dveh gibanj in tudi drugih avtorjev, ki sta jih Tanja Lamovec in Elena Pečarič pritegnili v gibanje in povezali med seboj. Nekdaj so pokroviteljski glasovi, ki so nasprotovali vključevanju uporabnikov v procese odločanja in poučevanja, poudarjali, da lahko osebe, ki se znajdejo v neznani situaciji poučevanja, še bolj podvržemo stresu in jih retravmatiziramo, in so bili velika ovira za uveljavljanje hendikepiranih aktivistov v pedagoški proces, danes pa so takšna prepričanja že del zgodovine pokroviteljstva v socialnem delu. To pa žal še ne velja druge stroke, kot so specialna pedagogika, psihologija in medicina. Ena od izjem je Katedra za družinsko medicino na Medicinski fakulteti v Ljubljani, ki v zadnjih letih vabi ljudi z izkušnjo cerebralne paralize in strokovno osebje Sončka[6], da študentom podiplomskega študija v nekaj urah predstavijo svoje izkušnje in potrebe.[7]

Izkušnja steklene stene hendikepiranih predavateljev

Hendikepirani aktivisti (najprej ljudje s težavami z duševnim zdravjem, pozneje tudi drugi ljudje z ovirami) so od leta 1996 pogosteje sodelovali pri poučevanju na Fakulteti za socialno delo. To je sovpadlo s povečevanjem števila uporabniških organizacij, ki so takrat začele glasneje zahtevati državljanske pravice. Med njimi je bil tudi Luj Šprohar, pisatelj, politik in delavec javne uprave, mož in oče, ki s senzorno oviro živi od zgodnjega otroštva. V predavalnici so bili študentje pri predmetu o teorijah hendikepa očarani nad njegovim slogom poučevanja, govornimi spretnostmi in odkritostjo. Pred njimi je hodil sem in tja po predavalnici, kot da bi bil videč. Ko je enkrat v svoji običajni naglici hotel zapustiti predavalnico, je trčil v podboj vrat in se poškodoval. Študenti so bili pretreseni in hkrati osramočeni, ker mu niso pravočasno pomagali do izhoda in preprečili poškodbe. Kje je torej meja med pokroviteljsko skrbjo in tenkočutno podporo? Da bi preprečili lastno nelagodje (srečanje s človekom, ki ne vidi), so se študenti zanašali na nekakšen šesti čut nevidečega in spregledali, kdaj potrebuje pomoč. Po drugi strani je tudi Luj Šprohar hotel dokazati, da je samostojen in da ne potrebuje podpore. Da bi premagal svoj hendikep v izključujočem okolju, se je moral vesti »herojsko«, da bi se izognil pomilovanju, pokroviteljstvu in neupoštevanju. Ta dogodek je študentke in študente pa tudi predavateljico naučil, da sta podpora in pomoč tabuizirani in da morajo hendikepirani uporabljati najrazličnejše strategije, da bi postali del »normalnega sveta«. Dokazati, da ne potrebuješ podpore, velja za merilo normalnosti. Nehendikepirani svet ni pripravljen sprejeti potrebe po podpori, ki bi temeljila na enakopravnih odnosih in spoštovanju različnosti.

Leta 2005 je Fakulteta za socialno delo organizirala konferenco o diskriminaciji hendikepiranih žensk (Zaviršek 2005) in na okroglo mizo povabila tudi ljudi na vozičku. Vzdolž mize so bili razporejeni stoli in čakali na govorce, ni pa bilo prostora brez stolov za osebe na vozičkih. V pripravah na okroglo mizo, ki so bile organizirane brez velikega premisleka, se je »pozabilo«, da svet ne sestavljajo le ljudje na nogah, temveč tudi na vozičkih. Dejanja nehendikepiranih ljudi vedno znova dokazujejo moč nezavedne predpostavke, da v prostoru javnega sodelujejo le neovirani ljudje.

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[6] Sonček je Zveza društev za cerebralno paralizo Slovenije.

[7] Jelka Bratec, terensko raziskovanje, Ljubljana, 13. 6. 2014. Od leta 1990 so bili hendikepirani uporabniki vključeni tudi v raziskovalno delo na Fakulteti za socialno delo Univerze v Ljubljani.

Še ena oseba s senzorno oviro iz mladosti, Marino Kačič, socialni delavec in psihoterapevt, je od poznih devetdesetih let 20. stoletja sodeloval v izobraževalnem procesu na Fakulteti za socialno delo. Leta 1994 je na javnem predavanju obujal spomine in pripovedoval, kako je po diplomi iz socialnega dela nekaj časa opravljal delo prostovoljca na telefonu za klice v duševni stiski:

> Nekateri so klicali in se hoteli pogovarjati z mano in marsikoga sem tako po telefonu poznal že dolgo. Včasih sem komu povedal, da ne vidim, zaradi nesreče, ki se mi je pri triindvajsetih letih zgodila na delovnem mestu, ko je prišlo do eksplozije pri miniranju kamenja. Največkrat je potem na drugi strani nastala dolga tišina. Ljudje niso vedeli, kaj naj rečejo. Za nekatere je bilo to razodetje, nekateri pa niso nikoli več poklicali. (Osebni zapiski, Darja Zaviršek.)

Pozneje je Marino opravljal psihosocialno svetovanje sorodnikom hendikepiranih ljudi in je ustanovil spletni časopis za ljudi z ovirami na področju vida (RIKOSS[8]). Leta 2006 pa je postal asistent na Fakulteti za socialno delo, in sicer na Katedri za preučevanje socialne pravičnosti in vključevanja na področju hendikepa, spola in etničnosti in na Katedri za socialno delo z družino. Pri poučevanju je ugotovil, da se ovire, ki jih doživljajo hendikepirani ljudje v vsakdanjem življenju, širijo tudi na področje poučevanja:

> Začetki so bili zelo težki. Včasih sem to občutil, kot da sem prišel do »steklenega zidu,« zaradi katerega je moralo miniti precej časa, da se je sodelovanje s študenti premaknilo. Zdaj s študenti delam že šest do sedem let, pa se mi šele zdaj zdi, da mi je uspelo skrajšati čas, ki ga študenti potrebujejo, da postanejo bolj odzivni. Včasih je trajalo ure in ure. Bili so tiho, ko sem jih kaj vprašal, niso odgovorili, če pa so že odgovorili, so bili togi in robati, formalni in previdni, kar je običajno tudi pri drugih ljudeh. (Osebna komunikacija, 2009.)

To je bilo še posebej opazno, kadar se je v predavalnici predstavil kot »človek, ki je slep«.

> Ko sem začel predavati, sem imel predstavo, da je dobro, da se predstavim študentom kot oseba z oviro, »slepa oseba«. Vendar sem bil takoj označen. Aktivirale so se njihove podobe o slepih in v času učnega procesa jih nisem mogel več doseči. Postali so togi in nesproščeni. Ugotovil sem, da je problem beseda »slep«. Če se predstaviš kot slep, si zaznamovan in izgubiš čas, ki ga imaš na voljo, da jih kaj naučiš. Sedaj rečem, da imam »hude okvare vida«, to me ne postavi v vlogo invalida. (Osebna komunikacija, 2009.)

Z besedo »slep« je hotel pokazati svojo odprtost in hkrati poskrbeti za iztočnico za učni proces. Kmalu je ugotovil, da študente, ki so doživeli predvsem segregirano izobraževanje in sami skoraj niso poznali hendikepirane osebe (ali se je niso spomnili, ker so spomin nanjo bodisi potisnili bodisi se jim je zdel tako nepomemben, da se pač »niso spomnili«), tak pristop šokira. Odkril je, da je za neovirane beseda »slep« večji problem kot dejstvo, da predavatelj ne vidi. Študenti, ki niso imeli veliko izkušenj z različnostjo, niso mogli preseči oznake »slepota«. Za nekatere ni mogel biti hkrati hendikepiran in predavatelj. Študentski molk je pričal o tem, da imajo malo življenjskih izkušenj in da se v okolju, v katerem je malo različnosti, niso naučili, kako z njo ravnati, »kaj naj rečejo,« »kako naj se vedejo«.

Drugačen pa je bil odziv študentov, če je na začetku predavanj povedal, da ima »hudo prizadet vid«. Študentje se za to niso kaj dosti zmenili in tako je obveljal za človeka brez ovir. Večina študentov je svoje nelagodje zmanjšala zaradi sugestije, da »nekaj pa le vidi« (»Tega ne morem verjeti, prepričana sem, da nekaj pa le mora videti!«). Marino Kačič je povedal:

> Ko sem se predstavil kot slep človek, sem dobil oznako. Njihove predstave o slepcu so se aktivirale in izgubljal sem čas. Če pa sem rekel, da imam hudo poškodovan vid, zanje to ne pomeni, da sem »invalid«. Velik problem je beseda »slep«!

Marino je opazil, da potrebuje veliko časa, preden se zgodi preobrat in postanejo študentje pripravljeni stopiti z njim v dialoški odnos:

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[8] Več na spletni strani: http://www.zveza-slepih.si/rikoss/index.htm.

> Spraševal sem se, kako bi ta čas skrajšal. Pri tem sem se naučil nekaterih zvijač; vprašam jih na primer, kje sta kreda ali tabla. Prosim jih, naj mi pri čem pomagajo, in jih tako vključim v proces. Zdaj opažam, da se ta čas skrajšuje. Včasih sem potreboval več ur predavanj in seminarjev, preden sem porušil zid molka in nelagodja. (Osebna komunikacija, 2009.)

Predavatelj je kritično razmišljal tudi o že opisani meji med zanikanjem ovire in priznanjem, da človek potrebuje podporo:

> Poskušam vzpostaviti srednjo pot, študente hočem naučiti, da nisem monstrum brez potreb, in obenem, da nisem nemočen, ker sem slep. Hotel sem jih pritegniti v situacijo vzajemnosti, interakcije. Morajo dobiti predstavo o tem, kdo sem, kakšne so moje potrebe. (*Ibid.*)

Marinove izkušnje pričajo o družbeni razsežnosti hendikepa. Simbolni in socialni status, ki ga imajo nehendikepirani predavatelji za samoumevnega, morajo hendikepirani šele pridobiti in razviti različne strategije, da so sprejeti in uspešni. Družbene ovire, s katerimi se srečujejo, so velikanske: poskrbeti morajo, da je »stopnja hendikepa« za študente še vedno »sprejemljiva«; s svojim delovanjem morajo zavračati najrazličnejše stereotipe in se spopadati z odporom študentov, da bi jih sprejeli kot spoštovanja in zaupanja vredno avtoriteto. Opraviti morajo torej veliko več miselnega in čustvenega dela kot nehendikepirani ljudje, da ostane normativni red vsaj na površju nespremenjen, da ne ogroža nehendikepiranih in da se vsaj na površju ne porušijo razmerja moči. Položaj nehendikepiranih je potemtakem lagodnejši, zato upravičeno govorimo o hierarhičnem obratu: ljudje z več družbene moči svoj položaj zanikajo in maskirajo tako, da trdijo, da imajo manj moči kot tisti, ki so v resnici v marginaliziranem položaju (vodja zavoda, centra za socialno delo, fakultete pravi: »Sem nemočen«; Zaviršek 2000). Še več, ljudem z manj družbene moči pripisujejo večjo moč zato, da bi prikrili razmerje neenakosti (»Invalid mi vzbuja občutek nelagodja.«).

Hendikepirani predavatelji torej omogočajo oboje, posredovanje učnih vsebin in živo izkušnjo srečanja in pogovora z osebo, ki ima izkušnje tistega, kar večina pozna le iz knjig. To spodbudi procese depatologizacije hendikepiranih. Tudi študentje v takšnem okolju lažje razkrijejo lastno ranljivost, osebne zgodbe in nevidni hendikep. Študentka socialnega dela, ki je dve leti intenzivno študirala predmete na področju hendikepa, je na primer razkrila, da sta njena starša gluha, šele potem ko je seminar vodila senzorno ovirana oseba. Če je učitelj hendikepiran, številni študentje lažje spregovorijo o svojih travmatičnih izkušnjah. Ena od študentk je razkrila, da ne more imeti otrok, in je o tem prvič spregovorila prav pri predemetu »teorije hendikepa.« V takšnih primerih hendikepiran učitelj razširja meje normalnosti. Ko svojo ranljivost uporablja kot učno orodje, študentom čustveno omogoči, da spregovorijo o svojih ranah in travmah in bolje spoznavajo sami sebe, to pa je pogoj za kakovostno delo v psihosocialnih službah. Daje jim simbolno dovoljenje, da lahko govorijo o svojih izkušnjah.

Situacijo so kot pozitivno prepoznali tudi sami študentje, saj so komentirali, da je poučevanje, ki ga izvaja oseba z ovirami, pristnejše in bližje »resnici« kot tisto, ki ga doživljajo pri nehendikepiranih predavateljih:

> Kadar to reče on, vemo, da je to res! Drugi profesorji velikokrat samo nakladajo. On pa gre v jedro stvari. (Evalvacija s študenti, 2009.)

Včasih je že ovira sama dovolj, da nekaterih ugotovitev ni treba dopolnjevati s številnimi razlagami, saj povedano potrjuje osebna izkušnja. Vendar za kakovostno poučevanje zgolj »izkušnje« niso dovolj. Večina hendikepiranih poudarja, da je treba imeti »reflektirano izkušnjo«, da bi lahko izkušnja postala del produkcije znanja:

> Svoje osebne izkušnje vedno vključim v to, kar poučujem, vendar pa ne počnem samo tega. Osebne izkušnje morajo biti samo del kompleksnega poučevanja. (Marino Kačič, osebna komunikacija, 2009.)

Evalvacija s študenti leta 2009 je pokazala tudi, da se najbolje odzivajo tisti študentje, ki imajo sami izkušnjo hendikepa, saj zato lažje sprejmejo, kar slišijo ali doživijo. So korak pred študenti, ki takih izkušenj nimajo. Nekateri študenti so dejali, da so zato, ker jih je poučevala oseba z ovirami, lažje in z manj osebnih strahov odšli na opravljanje študijske prakse in bolje opravili intervjuje z drugimi hendikepiranimi osebami. Da pa gre pri vsem tem za dolgotrajen proces, sta poudarjala oba, Marino Kačič in Elena Pečarič, ki sta pri opisovanju predavateljskih izkušenj na šoli za socialno delo omenjala srečanje s »steklenim stropom«. Sintagma »steklenega stropa« (*glass ceilling*) se je uveljavila na področju analize neenakosti spolov, ki jo na delovnem mestu doživljajo ženske. Te se v poklicni karieri srečajo z nevidnimi ovirami, ki so težko dokazljive in še težje premostljive. Stekleni strop je metafora za nevidne diskriminacije, ki jih pogosto dolgo ne »vidi« niti oseba, ki je diskriminirana. Ko pa se človek sreča s fenomenom steklenega stropa, svoje izkušnje težko ubesedi in dokaže. Oseba, ki doživi fenomen steklenega stropa, vidi, kam bi lahko prišla, če steklenega stropa ne bi bilo, vidi življenje onstran njega, vendar zaradi strukturnih neenakosti skozenj ne more prodreti.[9]

Študenti so se na hendikepirana predavatelja večkrat odzivali z nesodelovanjem, neodzivnostjo, tihim uporništvom, zavračanjem dela, odsotnostjo na predavanjih, klepetanjem med predavanjem. Marino Kačič se spominja:

> Opažal sem, da vstajajo, brez besed zapuščajo predavalnico in hodijo ven in noter. Nekaj časa sem pustil, da so to počeli. Potem pa sem nekoga vprašal: »Ali odhajate za vedno ali pa se nameravate vrniti?« To jih je šokiralo. Mislili so, da ničesar ne opazim. Potem so nehali. Preizkušali so moje meje. (Osebna komunikacija, 2009.)

Nekateri študentje so pričakovali, da bodo zaradi hendikepa učitelja laže naredili izpit:

> Ena od študentk je napisala esej in med 15 stranmi, kolikor so jih morali oddati, so bile tri prazne. Mislila je, da tega ne bom opazil. (Marino Kačič, osebna komunikacija, 2009.)

Zaznavanje »steklenega stropa« je bilo povezano tudi z že omenjeno dolgotrajnostjo procesa sprejemanja ovirane osebe kot avtoritete, ki poučuje.

Na enem od predavanj Elene Pečarič so se pri razpravi študenti obrnili na navzočo nehendikepirano predavateljico in jo začeli spraševati za pojasnila, ki so se nanašala na predavanje samo, čeprav bi jih pričakovano morali nasloviti na Eleno Pečarič: »Kaj je mislila s tem, ko je rekla, da […]?« (opazovanje z udeležbo, 2009). Študentje so tako ponovili vzorec zatiranja, znan s krilatico: »Ali pije grenko ali s sladkorjem?«, ko se oseba z vprašanjem, ki zadeva hendikepirano osebo, obrača na spremljevalca, namesto da bi neposredno vprašala ovirano osebo. Takšna komunikacijska diskriminacija, znana tudi kot spregledovanje, je lahko bodisi namerna ali nenamerna, posledice pa so objektivacija drugega, dominacija in ustvarjanje nevidnosti.

V postoscialističnih družbah vključevanje uporabnikov v raziskovanje in poučevanje še vedno zahteva veliko kulturnih in strokovnih sprememb. Udeleženost hendikepiranih predavateljev pri poučevanju v socialnem delu omogoča zmanjševanje razdalje med neposredno izkušnjo in njeno interpretacijo. Krajša ko je razdalja med izkušnjo in intepretacijo, ustreznejše in temeljitejše je pridobljeno znanje. Zato drži ugotovitev Marina Kačiča: »Jaz sam sem izkušnja!« (Kačič 2007, 2008 a, b).

Sklep

Številni pomembni premiki na področju nacionalnih zakonodaj in na ravni javnih politik, ki naj bi spodbujale nediskriminacijo hendikepiranih ljudi, so se zgodili kot posledica sprejetja novih zakonodaj in mednarodnih konvencij. V Evropski uniji, Južnoafriški republiki, na Japonskem in še v nekaterih državah so bile sprejete napredne zakonodaje, med drugim takšne, ki se zavzemajo

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[9] Pojem naj bi prvič uporabili dve zaposleni pri Hewlett-Packardu leta 1979, Katherine Lawrence and Marianne Schreiber. S pojmom sta opisali, da se kljub na videz jasni poti kariernega napredovanja pri ženskah ta proces ustavi na točki, od katere ne morejo več napredovati. Pojem se je razširil na druge diskriminirane družbene skupine, ki doživljajo nevidne strukturne neenakosti.

za vključevanje hendikepiranih ljudi v vse ključne tokove družbe (*mainstreaming disability*) in antidiskriminacijske zakonodaje. Zadnja Konvencija Združenih narodov o pravicah ljudi z ovirami (*UN Convention on the rights of persons with disabilities*), sprejeta leta 2006 in v veljavi od leta 2008 (Slovenija jo je ratificirala leta 2008), označuje velik korak h globalnemu doseganju tega cilja. Kljub temu med formalnimi in vsakodnevnimi pravicami hendikepiranih ljudi v Evropi, še posebej v postsocialističnih državah, še vedno obstaja velik prepad med normativo in prakso, zato se velja spomniti slavnega poziva revolucionarja Martina L. Kinga: »Zahtevamo samo to, da izpolnite, kar je zapisano!« Ne samo etika v odnosu do hendikepranih ljudi (*ethics of disability*), ki so jo zagovarjali in razvijali pionirji študija hendikepa v prejšnjih desetletjih, temveč tudi sama etika hendikepa (*disability ethics*), ki pomeni »posebno moralno razumevanje, ki izhaja iz same izkušnje hendikepa« (Scully 2008: 9) in hkrati ne deli sveta na ovirane in neovirane osebe, postaja pomembno področje raziskovanja, strokovnega razumevanja in prakse.

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DISABILITY STUDIES IN HUNGARY

The paper, following the train of thought of the UN Convention on the Rights of Persons with Disabilities, is focusing on the development of disability studies in Hungary. Although Hungary was one of the first countries to ratify the UN Convention on the Rights of Persons with Disabilities (2007), the human rights' based approach is still very weak, due to the weakness of the civil organisations, deficiencies of political democracy, and the party politics dominated permanent transition of the Hungarian welfare state. Disability studies, characterised internationally by the initiative of the disabled persons themselves, were in Hungary, however, a top-down process initiated by researchers and experts. This is reflected in the controversies and slowness of the deinstitutionalisation process, in the dominance of large institutions and in the exclusion of disabled adults from the labour market, instead of the implementation of community based solutions. Governmental approaches and policies are first and foremost targeting economic objectives, e.g. to decrease the budgetary deficit even at the expense of the living conditions of disabled people. The official rhetoric and the organisational solutions have not broken away from the medical model of disability yet.

Key words: United Nations, rights, civil society, employment, independent living, deinstitutionalisation.

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ŠTUDIJ HENDIKEPA NA MADŽARSKEM

Članek prikaže razvoj študija hendikepa na Madžarskem. To je tudi priporočilo Konvencije Združenih narodov o pravicah invalidov. Čeprav je bila Madžarska ena prvih držav, ki je omenjeno konvencijo leta 2007 ratificirala, jepristop, ki temelji na človekovih pravicah, tam še vedno le šibek. Vzroki za to so šibkost civilnodružbenih organizacij, pomanjkljiva politična demokracija in strankarska politika večne tranzicije madžarske države blaginje. Študij hendikepa, za katerega je v mednarodnem prostoru značilno, da so ga razvijale osebe z ovirami, je na Madžarskem doživel obrnjen proces, ki so ga uvedli raziskovalci in strokovnjaki z vrha navzdol. To se kaže v nasprotujočih si težnjah in počasnosti procesa dezinstitucionalizacije, v katerem prevladujejo velike institucije in izključitev oseb z ovirami iz trga dela, namesto da bi bile implementirane v skupnosti utemeljene rešitve. Vladni pristopi in ukrepi zadevajo predvsem ekonomske cilje, na primer zmanjšanje finančnega primanjkljaja, celo na račun življenjskih razmer oseb z ovirami. Uradna retorika in rešitve se še niso oddaljile od medicinskega modela oviranosti.

Ključne besede: Združeni narodi, pravice, civilna družba, zaposlovanje, neodvisno življenje, dezinstitucionalizacija.

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Introduction

Disability studies were defined by the Hungarian Association of Disability Science (Eötvös Loránd Tudományegyetem Bárczi Gusztáv Gyógypedagógiai Kar 2009) as follows:

> Disability science is focusing on the policies and activities of societies to understand the far more social than physical experiences related to disability. Disability science was developed to unravel the phenomenon of impairment from the net of myths, ideologies and stigmas covering social interactions and social policy. This discipline disputes the idea that the social

> and economic status of, as well as the roles assigned to disabled people are the inevitable consequence of their state of health.

This article intends to reveal the situation of disabled people by the analysis of the development of disability studies in Hungary. In our understanding disability studies is not a separate discipline locked in the cage of disability, but an umbrella conception approaching disability and the situation of disabled people based on the principles of the Convention on the Rights of Persons with Disabilities (007). In this paper, the principles of the respect for individual needs (independent living) and the problem of self-organisation (defence of interests, interest representation) are chosen as the guideline, and in three case studies (employment, deinstitutionalisation, and community based services) the realisation of these principles will be demonstrated.

Historical perspective

Approaches

The taproot of disability studies is nourished by the history of special education in Hungary, although its development, especially at the very beginning, was lagging behind the European processes in the field. The main stages of this history are the opening of the Royal Deaf and Dumb Institution in Vác in 1802 and the beginning of the so called institutionalised healing and educating of blind people in 1825. Before enacting the law on education initiated by József Eötvös in 1868 children with learning disabilities were generally excluded from the educational system and then, although just temporarily, educational obligation was extended to children with learning disabilities. In 1875 the first private educational institution for children with learning disabilities was opened and in 1896 the state took over the First Educational and Nursing Institution for the Mentally Retarded.

In the 19th century – as elsewhere in Europe – the new discipline was located at the crossroad of medical science and pedagogy. As a result of the significant German influence, special education gradually incorporated ideas from social sciences and psychology. (Mesterházi 2004)

First, experts in special education were trained abroad and in the 1890s employees of the institutions of special education were trained at special courses in Hungary. The world famous Hungarian special education was launched in the predecessor of the Bárczy Gusztáv Faculty of Special Education, the Teacher-Training College of Special Education at Vác for the further education of primary-school teachers in 1900. (Gordosné 2010.)

After the turn of the century the system approach broadened the scope of special education. As Zoltán Tóth (1933) stated: in the education of disabled children not only the educational protection but social protection gets more and more importance and the whole scope of activities and organisations of disability related issues are an integral part of special education.

After the Second World War it was hard work to maintain the values and achievements of special education as the communist ideology considered it to be bourgeois ideology and incompatible with the socialist ideal of human beings.

The theoretical and practical activities of Gusztáv Bárczi, being himself a practitioner in special education, saved Hungarian special education. His outstanding research results made him known to the politicians, and as a skilful organiser and diplomat he reorganised the discipline under the cover of the conditioning education of Pavlov and thus special education could preserve its complex and multidisciplinary approach to human beings. (Bánfalvy *et al.* 2004)

The price of survival was the isolation of special education and the domination of the medical approach in the functioning of its institutions. Although the leading experts in the field applied a complex and multidisciplinary approach to disability, the profession was still confined to the basic institutions of public education and social protection for decades. Early child development, community based services, career counselling, rehabilitation of adults and several other issues were not institutionalised.

Another part of the root is embedded in the development of institutions of political democracy and human rights. Before the systemic change, in the period of soft dictatorship, rarely, and mainly in the papers of researchers, appeared ideas like independent living, normalisation and complex rehabilitation. The majority of disabled children were trained in segregated institutions of special education; adults, due to the lack of accessibility and alternative forms of living, frequently lived in huge institutions of residential care; employment of disabled persons, if it was possible for them at all, was realised at special work places.

Innovative approaches exceeding the medical model of disability gradually became more and more popular among the professionals. However, systemic, paradigmatic changes were not introduced. Rather, the innovative initiatives were incorporated into the existing structures. Decision makers argued with the utmost importance of economic problems when referring to the reasons for delays to changes in the field. (Tausz, Varjú 1991.)

According to Verdes (2009), a different explanation has to be given. According to him, the large institutions had two functions during the transition. On one hand they made these socially excluded groups, among them the disabled people, invisible, and on the other, large institutions of residential care mitigated the burden of unemployment as these provided work for masses of people.

Consequently, until the appearance of the human rights based approach and the idea of deinstitutionalisation, individual needs were overridden by other types of interests.

Mainstreaming

Although Hungary was one of the first countries to ratify the UN Convention on the Rights of Persons with Disabilities in 2007, the human rights' based approach is still very weak. Complex reasons explain the survival of the medical approach, and the weakness of the social model: among others the fragility of the culture of democracy and the 'permanent transition' of the Hungarian welfare state.

Because of their importance, two pieces of legislation will be emphasized: Act XXVI of 1998 on ensuring equal opportunities for persons with disabilities and Act CXXV of 2003 on Equal Treatment and Promotion of Equal Opportunities, which approach the problems related to disability and the situation of disabled persons in accordance with the European standards.

Although the Disability Act and the first National Disability Program were great leaps forward, these are based on a mix of values and approaches. According to its intention the Act follows a system based approach, but uses the medical model to determine the target group (the type and severity of disability). It shows traces of the human rights based model, referring to the rights of disabled persons when outlining the target areas. And indirectly, when initiating institutionalised state intervention in several areas, especially in the National Disability Program, it intends to enlarge the chances of social participation.

On the basis of Act XXVI of 1998 on ensuring equal opportunities for persons with disabilities, Hungary formulated the first disability programme in 1999, which was in force till 2005, and then a second programme was adopted in 2006 and in force till 2013.

The national programmes of disability affairs specified the responsibilities of the state in different fields (Universal Design, rehabilitation, positive change in the attitude of society towards people with disabilities, deinstitutionalisation, employment etc.), however, both versions are preliminary concepts rather than concrete, enforceable measures and their objective is to improve the quality of life of disabled persons instead of the realisation of the human rights of disabled people and guaranteeing law enforcement.

The development is rectilinear just on the surface, considering practical measures taken in the different fields. A detailed critical description of the problems would exceed the limits of this paper, but the controversies will be delineated in the three case studies.

Even though it disappeared from the legal rhetoric, governmental policies of the past years, first of all the so called reform of the disability benefit system, seem to warm up the approaches of the moral model when arguing for the necessity of changes with referring to the misuse of the disability qualification system and to the scroungers.

While before the change of the political system, with some exceptions, issues discussed in the discipline of special education dominated researches and activities related to disability and the situation of disabled people; after the transition it moved in the direction of social sciences studying human as well as social relations of disabled children (Illyés 2000).

More and more research was carried out on the possibilities of social integration, the toolkit of affirmative action and on the social situation of disabled people. Previously the college of special education was the most important centre for this research. Recently however, sociologists, social workers, social policy experts, economists and legal experts also deal with the subject all over the country. Despite the more and more lively scientific activities in the field, disability studies appeared as an autonomous discipline just after the ratification of Convention on the Rights of People with Disability. In 2008 the Bárczi Gusztáv Faculty of Special Education organised the Research Group on Occupational Rehabilitation where lectures were delivered on the subject for a larger audience for two years and three volumes of the new Disability Studies journal was published. After the change of the government in 2010 financial resources were withdrawn, terminating this programme. However, interdisciplinary research on the situation of disabled persons continued and disability studies became integrated into the mainstream sciences.

A similar process is characterising developments of higher education: courses on the situation of disabled people are integrated into the education of social workers, social policy and minority studies experts.

Concepts

A dual picture is the starting point of any models of disability: the good and the stigmatised, the healthy and the sick, the socially integrated and the excluded, a person with legal capacity and the one deprived of it. This duality presupposes two general actors subordinated to each other. Recognising the oppression of disabled people and the basic findings of the social model of disability more and more attention is paid to the disabled individual, to the individual needs, to the personal experiences and intentions of disabled persons in the latest research and policy development initiatives in Hungary.

> Anomalies of the social model, its rigidity, its transitional character and tightness, the numerous frequently contradictory fragmented approaches of it prove this model is also inadequate to reveal the complexity of disability as it looks for the possibilities of understanding mainly in the intellectual and physical environment. Thus this model is unable to clarify the complex interrelationships between power relations, cultural contexts, discourses and the personal experiences related to disability. (…) It is mistaken when approaching disability just as a macro level social problem, as, among others, the personal experience, the personal struggle and the pain are also constitutive factors of disabled existence. (Könczei, Hernádi 2011.)

Role of the civil society

> Spreading and functioning of the majority of the non-profit organisations - with the exception of the politically neutral ones, like the sport clubs, or the Patriotic People's Front and the trade unions created and influenced by the political power – was impeded by the one party political system as well as by the economic structure (e.g. the lack of free self-organisation and a market economy, the monopoly of the state in providing public services) before 1989. Therefore development of the non-profit organisations after the end of the 1980s significantly diverged from that of the countries with a democratic political system. (Bocz 2010.)

Organisations representing disabled people and organised according to the type of disability (National Federation of Disabled Persons' Associations – 1981, Hungarian Federation of the Blind and Partially Sighted – 1918, Hungarian Association of the Deaf and Hard of Hearing – 1907, Hungarian Association for Persons with Intellectual Disability 1981) were embedded into this structure.

Formation of the political democracy and the market economy resulted in a dynamic development in the non-profit sector as well: in 2012 more than 65 thousand civic and other types of non-profit organisations worked in Hungary.

Some of the civic organisations already existed before the political changes and have continued their activities in more or less the same fields and forms (recreational, cultural and sport activities), while others set new objectives and followed new forms of operation (*ibid.*).

Organisations representing disabled people gradually developed to be real pressure groups. Some groups of disabled people, like people with psycho-social disability or people with autism, who had no targeted interest representation in the past, created their own pressure groups and organisations. As a response to the lack of resources and using the benefits of the taxation system some non-profit organisations also provide services. For instance, under the umbrella of the large residential institutions, foundations are functioning to narrow the gap between financial resources given by the state and the costs of functioning, e.g. by subsidizing programmes, supplying new instruments or contributing to the costs of a new group home. Non-profit organisations providing services frequently supplement the lacking services provided by the state and apply innovative solutions. The government also launched quasi non-profit organisations, like the Public-benefit Nonprofit Company for the Equal Opportunities of Persons with Disabilities. Although a complex system of legal regulations regarding disability and disabled persons exists in Hungary, its gaps, and difficulties in the assertion of their rights, led to the activities of, among others, the Hungarian Civil Liberties Union, a human rights watchdog.

Most of the non-profit organisations for disabled persons came into existence as a result of a top-down process; however some of the non-profit organisations are based on real civic initiatives, like the Association of Independent Living, the Association of Voice of Soul or some consumer run projects.

> Hungarian and international authors agree that governmental policy may to a large extent encourage or hinder the spreading of non-profit organisations and their functioning as service providers by the conscious shaping of the institutional and legal framework. Indirectly (e.g. by tax allowances) and directly (e.g. by providing financial resources and properties) the government may facilitate or restrain their functioning and future development. The quality of cooperation between the government and the non-profit sector is characterised by the nature of involvement of non-profit organisations in the procedure of reconciliation of interests: either they are handled as real partners or just as symbolic supporting actors during the decision making processes. (Bocz: 2010.)

In this respect stormy movements characterise the non-profit sector. At its formation, a serious role was assigned to the National Disability Committee by the representatives of the government and disabled people. However, after enacting the law on the equal opportunities of disabled people the Committee lost its significance in recent years. The National Disability Committee has had no regular meetings since the change of government, although by law, as the advisory body of the government it ought to be convened quarterly. The so called public debate system withered in the past years; although the bills and other types of legal regulations are published, consultation with the interested parties is formal, mainly restricted to the possibility to send opinions to a website. Several organisations representing disabled persons protested against the communication breakdown and not involving disabled people into the process of legislation affecting the living conditions of disabled people.

> The system of reconciliation of interests between the government and the civic and non--profit organisations is characterised by instability; governments and ruling parties strived to create institutional structures providing a more favourable operational environment for organisations 'closer' to them. (Ibid.)

Right to rehabilitation and employment

The Act on the rights of persons with disabilities declares the right to rehabilitation, the implementation of which – also according to the Act – would be provided by rehabilitation benefits and services.

One of the problems was that the issue of rehabilitation was delegated to a public foundation in 1998, which could never have been able to run a nationwide operating rehabilitation system.

In the past sixteen years a complete rehabilitation system on all stages of life and in all sectors, adequate for neither the Convention on the Rights of Persons with Disabilities rehabilitation approach nor for the definition of rehabilitation of the World Health Organization or International Labour Organization was built up.

The need for complex rehabilitation is reflected both in the concepts and in setting up some services (rehabilitation residential facilities and group homes), but in these places effective rehabilitation leading disabled persons back to the community and preparing them for independent living is very rare. A similar situation exists in the public education field, where different schools of special education were established (early childhood intervention, primary schools and vocational education), but these institutions insufficiently prepare young people for work and independent living.

The most serious problems occur in the employment of disabled adults. The employment rate of working age people with disability is 13.4 percent, while their inactivity rate[1] is 74.2 percent (Hungarian Central Statistical Office 2001). The Hungarian labour market is characterised by shrinking work-intensive and widening knowledge-intensive sectors, which excludes people with a low level of education and generates oversupply on the market. In this demand-oriented and knowledge-intensive competition people who have a low level of education and are stigmatised as persons with altered working capacity hardly have any chance to get a job.

Another serious symptom is that more than 50 percent of people with altered working capacity[2] have no other choice than to claim some form of disability benefit, because they either have no job, or their earning is so low that it does not ensure a decent living.

Hungarian legislators have not even been touched by the human rights based approach of disability studies when formulating the system of disability benefits. Evaluating the impact of disability benefits on social security one has to reach the conclusion that budgetary difficulties due to the economic crisis were alleviated by cutting benefits, targeting persons in the most disadvantageous situation and by demolishing the social safety net.

The official rhetoric for communicating the changes uses panels of the radical right differentiating the deserving and the undeserving poor. Soon after getting into power the first news was released on the misuse of disability pensions and on the 'disproportionate number' of claimants.

Referring to the misuse of benefits, a comprehensive review was ordered and restructuring of the complete disability benefit system had begun to make the qualification process tighter. However, the main objective of the so called reform was to reduce expenditures on disability benefits (Janecskó 2011.)

The more rigid procedure was introduced from 2010 to 2011. The same doctors, civil servants and social workers run the so called complex committees assessing the working capacity of the claimants and assigning the subsidies to people with altered working capacity. Statistics of the National Office for Rehabilitation and Social Affairs reveal significant changes in the level of social insurance based benefits rather than in the number of beneficiaries.

The number of disability pensioners under the retirement age decreased to 305,323 persons by 2011 from the 422,695 persons in 2009. These changes were mostly due to the transformation

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[1] Persons neither included in the employed nor in the unemployed category are classified as not in the labour force (also known as inactive).

[2] The term 'persons with altered working capacity' covers not only disabled adults, but persons with long term sickness as well.

of the qualification system and the new legal regulations targeting the disability benefit system, as a result of which fewer new entrants are admitted into the disability benefit system and several persons lost their right during the re-examination process.

The ‘new’ disability benefit system was introduced by the Act CXCI of 2011 on the benefits of the persons with altered working capacity. According to the Act committees responsible for the qualification process have to review the previously issued certifications (approximately 250 thousand persons), however neither the infrastructure nor the number and the expertise of the staff have been developed, just the qualification guidelines tightened again.

The Act does not take into consideration the Convention on the Rights of People with Disability at all. As opposed to the previous form it gave up the human rights based approach, which is a withdrawal to the medical model. The previous system assessed the working capacity as well, while the recent one solely focuses on the health condition of the disabled person and the professionals’ labelling lay the basis of entitlement for the benefits.

The above mentioned Act terminated the formerly existing forms of disability benefits and recently it has not only been the Pension Fund which finances the disability benefits, but the Health Fund. Consequently, not disability pensions, but health subsidies are provided. Persons formerly provided with disability benefits and the new claimants are divided into two groups: in one of them are those who have the chance for rehabilitation and in the other those who allegedly cannot be rehabilitated. Thus not only the nature of the transfer income has been changed, but the amount became significantly lower as well. This concept of rehabilitation is opposed to the wording and spirit of the CPRD and deprives people with altered working capacity from the right to rehabilitation.

Refuting government communication, the number of beneficiaries increased to 450 thousand persons again in 2012, just the composition of this group became more homogeneous and the level of the benefits decreased, endangering the beneficiaries with the risk of getting into poverty.

The real intentions of the government are reflected in the changing level of expenditures on disability benefits. The difficulties of the Hungarian labour market are frequently attributed to the extremely high level of inactivity, the crisis of the pension system to the burdens of financing early retirement schemes. Actually, the real-value of the expenditure on disability benefits is decreasing. The number of people eligible for disability benefits did not significantly change, just state expenditure in the field decreased, consequently the same beneficiaries are provided with lower benefits.

Although all the professional preconditions have been given to implement the right to rehabilitation since 2002, and on the surface the government supports the implementation of the Supported Employment and Back to Work occupational rehabilitation programs based on American and British schemes, the lack of unambiguous political commitment hinders improvements in the field. Although up-to date knowledge and more than ten year’s experience on the procedures of complex rehabilitation is available in Hungary, this know-how is not adopted by the state run services of rehabilitation.

However, several non-profit organisations realise the intention of the CPRD as they provide complex rehabilitation services for the service users. The average success rate, e.g. the integration of disabled people into the labour market is far higher than that of the governmental organisations. This high success rate proves services taking into consideration personal needs are far more effective than uniformity.

Right to independent living

Transition from institutional care to independent living is a good example of people with disability gaining back their right to make decisions about their own life on an equal basis with other citizens. Supported living complemented with community based services can be the basis of independent living.

In Hungary social services for people with disability are still institutionally based. In 2010 16,668 people with disability lived in residential care; 11,939 of them lived in institutions with more than 50 beds and 72 percent of housing services were institutional based (Hungarian Central Statistical Office 2010.)

Throughout history different factors influenced the philosophy and practice of residential services in Hungary. In the 1950s the pedagogical principles of Makarenko, the logic of the state-socialist regime and the availability of real estate contributed to the formation of residential services. Later the technocratic approach focused on the optimal size and on rational maintaining. By the sixties the smaller residential homes were amalgamated so the large institutions became the mainstream. Although in the eighties the new ideas reached the professionals and experts, the structure of the services was not transformed; rather the new approaches were inserted into the existing structure.

The paradigmatic change came in 1998, when the idea of deinstitutionalization (DI) first appeared in the Hungarian legislation. Hungary ratified the Convention on the Rights of People with Disability in 2007, but the first call for an EU funded project proposal in connection with DI was advertised only in 2009 – but with controversial content. It would have allowed the building of institutions of up to 150 beds. Fortunately this plan has never been realised because of the joint efforts of the civil organizations. The final call for proposals appeared in 2012 and the deinstitutionalization process started in 2013. The idea of deinstitutionalization is based on the Convention on the Rights of People with Disability, specifically on Article 19, which maintains the right to live independently and be included in the community.

> States party to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:
> a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
> b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
> c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

If we talk about deinstitutionalization we have to define the word institution as well.

The Guideline of the European Expert Group on the Transition from Institutional to Community Based Care defines institutions with three characteristics (Ministry of National Resources 2012):

- It isolates users from the community/society and forces them to live in cohabitation.
- Users do not have sufficient control over their own life and over the decisions that affect them.
- Institutional requirements take precedence over users' individual needs.

It considers institutionalization as a violation of human rights. The Guideline refers to the Report of the Ad Hoc Expert Group on the transition from institutional to community-based care. This report describes the size of a residential service as an important aspect of the complex definition of institution. According to it a high number of residents living together can increase the development of institutional culture. It considers residential services with more than 30 beds institutions (European Commission Directorate-General for Employment, Social Affairs and Equal Opportunities 2009.)

In contrast, the current Hungarian legislation considers an institution a residential service with more than 50 beds and allows building 'living centres' up to 50 beds involved in the DI process. So there is a risk that in the first period of deinstitutionalization in Hungary small institutions will be built against the interest of the residents (Bugarszki *et al.* 2013).

The whole DI idea is based on the human rights based approach but this idea meets a structure based on institutional care and the medical approach in Hungary. So this structure is resistant to the human rights based approach in many ways. It is not a surprise that the directors and the staff of the large institutions and the local governments where the large institutions operate are the most resistant to the DI process. These stake holders play a key role in the DI process because they transform the large institutions, where they currently work, into supported living, consequently these actors have power to shape the whole DI process. The transformation of their medical approach into a human rights based approach is crucial. (*Ibid.*)

The DI process and specifically the composition of the DI Committee can provide a 'good' example of the decision making process in social policy in recent Hungary. The DI Coordination Committee could work as a space for discussion but the composition of the Committee strongly depends on the government as it delegates the members. Some crucial actors are missing from the DI Committee, for instance the real decision makers, human-rights NGOs and a wider representation of people with disability. DI is co-financed by the EU and the Hungarian government. The DI proposal writing process is a good example for the power of the institution's staff. The basis of the DI process was a complex needs' assessment of the residents managed by independent experts, which could have ensured that the DI is based on the needs of the residents. However, the four interviews made within the Deinstitutionalization Budget Monitoring Project by the Bugarszki-Eszik-Kondor research team with the directors of the institutions proved the final proposals were rather based on the experiences of the staff. (*Ibid.*)

As DI is partly financed from the EU Structural Fund, Brussels passed several recommendations to the government. One of these is the involvement of the stakeholders in the decision making process, with special attention to disabled people and their advocates. (European Expert Group on transition from institutional to community based care 2012.)

Table 1: Stakeholders of the deinstitutionalization, 2013.

	Strongly supportive	**Slightly supportive**	**Strongly against**	**Slightly against**
High capacity to pressure	State run service providers; Human-rights oriented NGOs	Ministry and minister of Finances, Advocacy organizations of disabled people	Directors and staff of the large institutions, Decisions makers of the local governments where the institutions are operating	Ministry of Human Resources, Government, Local governments affected by the DI, median voters, Church run service providers
Low capacity to pressure	Residents and their family members, institutions of higher education, EU			

The role of the Coordination Committee is the professional control of the DI. Their greatest success is that although the current legislation would allow building living centres with a maximum of 50 beds during the first period of DI, in conformity with the approach of the EU, housing services with a maximum of 30 beds will be built. (*Ibid.*)

Advocacy organizations of people with disability delegate four people to the Coordination Committee, which has fourteen members. They have high capacity to pressure the process but they are not uniformly dedicated to the approach of the Convention on the Rights of People with Disability and the Guideline so they are considered to be weakly committed to the DI process. Some of these organizations are not only advocates but service providers as well, so they depend on the government, which is partially financing them. Since these organizations represent people with disability their unambiguous commitment to the DI would be essential. (*Ibid.*)

The non-profit human-rights NGOs like the Hungarian Civil Liberties Union and the Mental Disability Advocacy Centre have an important watchdog role in the process. The events of 2009 showed the key role of the HCLU when they united the civil organizations to prevent the building of institutions with a maximum of 150 beds in the framework of DI. (*Ibid.*)

The increasing importance of the social model is reflected in the composition of the Co-ordination Committee, as not only the Faculty of Special Education, but the Faculty of Social Sciences represents higher education institutions as well. The DI process reflects a paradigm shift from the medical and institution based approach to the human rights based model emphasizing the importance of the principle of independent living. However, the strength of the opponents of the DI increases the risk of the survival of the institutional culture and the chance that the rights of people with disability will be neglected.

Respect for inherent dignity, individual autonomy and freedom to make one's own choices

A comparative research programme (Estonia, the Netherlands, Hungary) to develop new knowledge for professionals about effective components of community support programmes was carried out between 2012 and 2013 with the active participation of two of the authors of this paper. The objective of the research project was to facilitate the empowerment and self-support of persons with psycho-social and other disabilities.

The Hungarian team started its activities by challenging the meaning of community in this context. In the social protection system the meaning of community is to provide services in group homes and day centres in the local community instead of the large residential institutions. According to our understanding the 'smaller' institution and the services organised in the local community represent the first step, but just the first step ahead as these are still institutionalised forms of support.

A participatory action research design was used as the empirical component of the research. Personal and focus group interviews were held with the service users, with relevant members of their network and with professionals.

To reveal the components of the possible second step and to counterbalance our affinity to criticism, good practices and successful cases were chosen to answer the research questions. The partners were non-profit organisations and persons with psycho-social disability who were successfully integrated into some natural human network that is some form of human community.

We found that community-based services are key actors in the process of recovery and in facilitating the evolution of vivid human relationships.

> While we tend to believe that the most relevant help arrives from professionals in the process of recovery we usually underestimate the impact of the informal community. We found that users often prefer public places instead of professional services because they are more integrated, less clinical and they provide a wider range of opportunities to create a new identity beyond mental health care. Local pubs and restaurants, a circle of friends, religious or hobby related groups, neighbourhood friends, colleagues and schoolmates are the natural resources for all of us and these resources usually provide a variety of possible new identities and life. (Community Support Project 2013.)

The recovery of people with psycho-social disability is a long and complex process. Personal needs based measures have to be applied for it to be a success. However, the lack of social housing and flexible work opportunities are serious obstacles to recovery. Managerism, strong dependence on the financial resources provided by the state budget, as well as the officially encouraged anti-poor attitudes and the increasing denial of those who are different push social workers into an unacceptable situation. Social work education ought to react to these phenomena and renew the curriculum to make professionals able to cope with the situation.

The language and meaning is still frequently derived from the medical profession.

> Service providers most of the time are forced to use a rather clinical language as the official language of the service. This is reflected many times in the name of the services, in their entire administration and even in the spoken language they use. Clinical language creates a distance between service users and professionals where the power of narration is obviously in the hand of professionals. On the other hand, one of the key elements of recovery is the opportunity to create a new, personal narrative. To promote the success of this process we need to create space for new languages and narratives within our settings, allowing users to develop their own narratives. (*Ibid.*)

This is the only possible way to demolish the duality of the healthy and the sick, the 'normal' and the deviant. To take possession of the language is one of the significant components of being the master of our own life.

And last but not least, even though prejudice against disabled people decreased in the past years, significant differences can be observed in this respect between the different groups of disabled people. According to the interviews people with mental health problems from time to time face neglect and rejection in society.

> But we found some good examples when this could have been changed. Changes came when real encounters could happen and the qualities of the person overrode the stigma of mental health problems. (*Ibid.*)

Conclusions

International disability policy changed enormously in the past ten years, however, the underlying principles of the Hungarian legislation and professional practice did not develop at an adequate speed. Although significant positive changes were initiated (legislation, beginning of deinstitutionalisation, innovative approaches of the non-profit organisations etc.) negative turns also occurred (changes in the disability benefit system, stigmatisation of people with altered working capacity, etc.). Disability Studies generally developed by the initiative of the disabled persons themselves, however, in Hungary this was a top-down process initiated by researchers and professionals. The human rights based disability policy could still not break through the barriers of the medical profession, changes in the social sector are too slow and the direction of the changes is controversial.

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CIVIL SOCIETY ORGANISATIONS AS A VITAL SUPPORT FOR PERSONS WITH DISABILITY IN CROATIA

The paper provides some information about the development of civil society associations for persons with disabilities in the post-war community in the process of social reconstruction. The Republic of Croatia, as a signatory to the UN Convention on the Rights of Persons with Disabilities took over the role of improving the situation of persons with disabilities in society. However, the current crisis of Croatian society has particularly harmed people with disabilities and their families, as well as their position in society and their participation in everyday life. Beside the state's resources, which are more and more diminished, constant support for people with disabilities from NGOs is becoming a vital resource for their participation in everyday life. This paper presents the work of a few local NGOs engaged in disability activism in the context of a specific evolution of the civil society in Croatia.

Key words: post-war community, agency activism, human rights, Croatian experiences.

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CIVILNODRUŽBENE ORGANIZACIJE KOT KLJUČNA PODPORA OSEBAM Z OVIRAMI NA HRVAŠKEM

Članek opisuje razvoj civilnodružbenih organizacij za osebe z ovirami v povojni skupnosti v procesu družbene rekonstrukcije. Republika Hrvaška je kot podpisnica konvencije Združenih narodov o pravicah oseb z ovirami prevzela nalogo izboljšanja okoliščin oseb z ovirami. Vendar pa je zdajšnja kriza, v kateri se je znašla tudi hrvaška družba, še zlasti prizadela ljudi z ovirami in njihove družine, njihov položaj v družbi in njihovo participacijo v vsakdanjem življenju. Poleg državnih virov, ki so vedno bolj skopi, nevladne organizacije postajajo stalna ključna podpora ljudem z ovirami pri njihovi participaciji v vsakdanjem življenju. Članek prikaže delo nevladnih organizacij na področju aktivizma ljudi z ovirami v kontekstu specifičnega razvoja civilne družbe na Hrvaškem.

Ključne besede: povojna skupnost, aktivizem služb, osebe z ovirami, človekove pravice, hrvaške izkušnje.

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Introduction

Croatia is located in Eastern Europe and until 1989 was a part of the communist bloc, although it was seen as a part of a 'softer' form of communism, compared to the Soviet regime. Centralized and bureaucratic systems existed in all aspects of everyday life and the state took over responsibility for social care, education, health etc (Puljiz 2005). During the 1990s, the context of promoting social change and development in a way of civil activism did not exist in Croatia and society held the state responsible for solving the problems within the community. In accordance with the latter, the civil society initiative and the process of its growth did not exist. What existed was the inherited socialist system in which all of the decisions and the accountability came from the 'top' (i.e. the 'top down' approach) (Bežovan *et al.* 2005, Kekez Koštro *et al.* 2012). The state was not in favour of empowering 'other subjects'. It took a long time for some basic prerequisites to be developed in order to initiate some cultural and professional changes in the direction of new concepts of providing services and engaging in human rights activissm.

During the Croatian War of Independence (1991–1995) and in the middle of the refugee and emigration crisis, civil society organisations (mostly international) took an important role in helping the war victims and thus gained importance within society. At this time civil solidarity grew stronger. However, by the mid-1990s the civil solidarity started to fade and people began withdrawing from society, which in turn deepened the economic crisis, giving way to undemocratic rule, unsupported civil activity and the crises of the middle class where one is preoccupied with their own immediate problems and solidarity is reserved only for the family and those considered close. One can conclude that the growth of the civil society in Croatia was, for the most part, started by and determined by the war. The civil society managed to grow and sustain itself during the political and economic transition in spite of unfertile conditions and little understanding from the political elite in regards to these questions (Bežovan 1995, 2004).

Croatia, like many other countries with a large number of disabled persons of which most are at the low educational level, struggling to find employment and thus are exposed to poverty and social exclusion, needs development of the disability social policy. Like many other countries, Croatia has shown an operational gap between adopting the documents and laws with which the social policy towards the persons with disability would be regulated. Although the UN Convention on the rights of Persons with Disability was signed and ratified by Croatia it did not have a powerful influence as an instrument relevant to the successful implementation of those rights into the everyday life of a disabled person. The fulfilment of these rights depended often on interpretation and the good will of local authorities, resources and professionals. The role of NGOs was often to challenge the 'top down' approach in policy implementation and professional expertise and to raise the voice against violation of the rights of Persons with Disability. On the other hand, with the 'bottom up' approach the focus shifts from the political hierarchy to the formal and informal interaction, compromises and agreements between all the parties involved and thus results in the change of social policy towards the persons with disability. In this regard the role of the local NGOs[1], the most numerous form of Croatian civil society organisations, becomes very important as they act as 'the catalysts for development of the civil society' and as the 'administrators of the healthy society' (Bežovan 1995, 2004). This paper will further present the work of a few local NGOs engaged in disability activism in the context of the specific evolution of the civil society in Croatia.

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[1] An Association is defined in Article 2.1. of the Croatian Law on Assciations: 'An association for the purpose of this Law shall be any form of voluntary association of natural or legal persons which, in order to protect and promote issues of public or mutual interest, environmental, economic, humanitarian, informative, cultural, ethnic and national, educational, social, professional, sports, technical, health care, scientific and other interests and goals as well as their beliefs, and without the intention of gaining profit, submit themselves to the rules that regulate organizations and activities of that form of association.' Apart from the associations, the Croatian legal system differentiates between various trade unions, trusts, employers associations and religious communities.

The examples of successful disability activism in Croatia

The Association for Self -Advocacy

In 2013, the Association for Self-Advocacy[2] (hereinafter ASA) celebrated ten years of successful national and international self-advocated activism. ASA was founded in 2003 in Zagreb, Croatia. This was the first self-advocacy agency in Croatia and the region which was run by people with intellectual disabilities (ID) with help from their assistants. By the establishement of ASA, for the first time in Croatia, the door opened to the process of gaining subjectivity and legitimisation of this population in relation to other persons and groups in society. To gain subjectivity means in fact that these people are no longer objects of representation by other groups (parents, guardians, specialist), but rather express and represent their views by themselves. The legitimacy has to do with the question by whom the advocacy should be represented. From the very beginning, ASA has strived to represent the interests of the broadest population of persons with ID, not just those of its members.

The mission and the aim of this association is to promote equal rights and possibilities for people with ID and, thus help to improve their quality of life. ASA's activities are directed towards helping persons with ID develop competences and to feel empowered in self-advocating, to fight for their human rights, to ignite the public awareness, to influence public policy to improve the social position of persons with ID, but, also, to help promote and develop the self-advocacy movement in Croatia and the region. In its advocacy to promote and protects the rights of people with ID, ASA uses all relevant legal and democratic methods and instruments to achieve its aims. ASA initiated the establishment of the Croatian Self-Advocating Network which, presently, gathers 13 Self-advocating groups from across Croatia. It has become the only association in Croatia to regularly publish easy-to-read brochures and distribute them to self-advocates all over the country (The Constitution of the Republic of Croatia, UN Convention on the rights of people with Disabilities).

The unfavourable socio-political context and the discrimination towards persons with ID in Croatia has been a focal point of ASA's various organised Public Awareness Campaigns. Through campaigning, ASA wishes to draw attention to the legal framework in Croatia, which balances on a thin line between a nominal compliance with the antidiscrimintaion minimum and an everyday virtual impossibility of realisation of basic human rights for the majority of persons with ID.

ASA has been an active member of many international organisations, including Inclusion Europe and the European Coalition for Community Living, with which they have had a successful collaboration over the years. On several occasions, ASA representatives held presentations at the United Nations in Geneva and New York, on behalf of the members of Inclusion Europe, Inclusion International and International Disability Alliances. The latter represents persons with ID. They are also prominent members of the European Platform of Self-Advocates[3] – EPSA (part of Inclusion Europe), which is made up of organisations of self-advocates from different countries in Europe. ASA's President is a Board Member of Inclusion Europe as well as the EPSA Executive. Out of ASA's numerous projects and public campaigns, one can distinguish the following examples of activities that had a significant impact and contribution (as outlined in Association for Self-Advocacy 2013):

- In 2004, ASA published the Brochure entitled *Life stories* (a compilation of self-advocates life stories).
- In the film project *Living proof: The Right to Live in the Community* (2005) members of ASA and one assistant completed a training video on activisim (it uses video and other technology to fight for human rights.) The film has been shown repeatedly on national TV networks, at a number of international seminars and in the United Nations, on the occasion of the

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[2] Their web page: www.samozastupanje.hr.

[3] Their website: http://www.inclusion-europe.org/EPSA.

ratification of the Convention on the Rights of Persons with Disabilities. Members of ASA held more than 50 presentations of the film in schools, welfare centers, documentary and alternative film festivals, conferences, round tables and even in the Croatian Parliament.

- In the framework of a project in 2007, implemented jointly with Inclusion Europe, they gathered self-advocates' groups from five cities and organised two training sessions for them in Zagreb. During the sessions, an easy-to-understand questionnaire was drafted and self-advocates were taught interviewing skills. Self-advocates then proceeded to interview other colleagues in their cities on how they view their own rights and the support in the community. The obtained results clearly show that the greatest number of complaints relates to the impossibility of employment, education, adequate community-based support and money management, as well as legal incapacitation. The report was presented before members of the European Parliament and delegates of the Commission in Brussels and in Zagreb. The report was also presented in 2008 in Vienna, at the meeting of the EU and Croatian parliamentary committees working on the chapter of social policy during the accession process.
- One of the ASA's 2008 activities that deserves to be highlighted most is the organisation of courses for self-advocates on the recently adopted Convention on the Rights of Persons with Disabilities.
- ASA, in cooperation with the Association for Promoting Inclusion, Center for Human Rights and the UNDP publicly promoted the declaration for the Convention implementation through the 'Self-Advocates Promoting the Convention' project framework. Furthermore, in cooperation with the American Association 'Narativ', ASA recorded videos in which activists would tell their stories in a method known as storytelling. In terms of international cooperation and influence, ASA has established connections with about a dozen human rights associations and has competed for the United Nations first NGO report on the human rights situation in Croatia: the Universal Periodic Review. The report outlines the problems of institutionalisation, legal incapacitation, impossibility of education and employment, the inaccurate translation of and a general lack of compliance with the Convention on the Rights of Persons with Disabilities. In 2010, the project of extending the self-advocates' network to ten or more cities in Croatia was successfully realised. Self-advocates' second activist engagement this year focused on the preparation and public promotion of the report on the status and situation of persons with ID in Croatia, produced by the Human Rights Watch. It should also be mentioned that ASA contributed to the creation of the European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families. The Declaration was signed at the 2010 World Health Organisation's Conference. Furthermore, an ASA member attended the WHO Convention on behalf of EPSA.
- Throughout 2011, ASA concentrated their efforts on raising awareness of the necessity of providing easy-to-access information to persons with ID and launched an easy-to-read magazine called *Glas zastupnika* (*Voice of Self-Advocates*). ASA also joined as a partner to the *Pathways 2 project*, implemented by Inclusion Europe. *Pathways 2* was created in order to help include persons with ID in adult education. *Pathways 1*, which preceded this new edition of the project, focused on the development of European standards for easy-to-read information for persons with intellectual disabilities, as well as guidelines for teachers in life-long learning programs on how to make their curriculum accessible to persons with ID. Upon joining the Pathways 2 project, ASA undertook the translation of these resources into the Croatian language, prepared for the production of easy-to-read material and for the implementation of courses in accordance with the Inclusion Europe standards. ASA organised the first conference of the Croatian self-advocates entitled '*You and I, we are same.*'. The key speakers at the conference were self-advocates from the Croatian self-advocacy network. They publicly outlined the problems they encounter on a daily basis and emphasised the need to change the (pre)dominant attitudes towards persons with intellectual disabilities. During the conference, self-advocates had the opportunity to speak directly to decision-makers regarding

the futility of their struggle to enjoy certain basic human rights. Finally, self-advocates wrote a press release for the general public urging for the implementation of and compliance with the UN Convention on the Rights of Persons with Disabilities. ASA also took part in the establishment of Platform 112. The platform was conceived as an alliance of civil society organisations, formed in order to monitor the protection of human rights and the rule of law in Croatia, especially in view of the completed negotiations for Croatian accession to the European Union. In order to lobby for the right to a life in the community, as described in Article 19 of the Convention on the Rights of Persons with Disabilities, at the beginning of 2011 ASA's urged for the creation of the Coalition for Community Living, made up of seven associations of persons with disabilities and the Center for Human Rights. The Association for Self-Advocacy is responsible for the Coalition's first project: Community for All. The project targets decision-makers on a national and regional level and emphasises the need to develop community-based support services that will help include persons with disabilities in all realms of life on the same bases as the rest of the citizens.

- In August 2012, at the Europe in Action conference held in Brussels, European self-advocates elected the (actual) president of the Association for Self-Advocacy as the new president of the European Platform of Self-Advocates and vice-president of Inclusion Europe. Towards the end of 2012, one of the greatest achievements of the Association was made. In partnership with a few other civil society organisations and the ombudsman for persons with disabilities, the Association was directly involved in the ratification of the new Law on the Electoral Register, giving the right to vote to persons with complete legal incapacitation. Thus, Croatia has become one of ten european countries where the right to vote is not conditioned by a person's legal capacity, and has therefore fulfilled part of the requirements stated in Article 29 of the Convention on the Rights of Persons with Disabilities.
- 2013 was characterised by ASA's participation in the debate against the investment of EU funding into the renovation and building of residential institutions for persons with disabilities. During the same year, education for the self-activists and a public campaign that concerned voting rights for people with intellectual disabilities that were formerly precluded from doing so, was conducted. Hence, the TV advert under the banner 'Our Voice, Our Strength' was frequently broadcast during the pre-election period. Furthermore, ASA organised and hosted the second European self-advocates' conference *'Hear Our Voices: Citizens Above All!'* The conference was their contribution to the celebration of the year 2013 as the European year of citizens. The first part of the conference focused on the problem of including persons with ID into democratic processes in the community. The second part of the conference was made up of workshops led by self-advocates and dealing with topics such as legal capacity, the right to live in the community, violence against persons with disabilities and the right to a family.

In 2014, ASA has cooperated with the Ombudswoman for Persons with Disabilities of the Republic of Croatia in creating a proposal for the introduction of the institute of 'Supported Decision Making', as an alternative to the traditional institute of 'Guardianship' to Croatia's new Family Act. At the international level, ASA's representative participated in research on the condition of fundamental rights of persons with IDs and the issue of mental health problems in the 27 EU member states. The research was led by the Fundamental Rights Agency's Research Committee.

Furthermore, it is important to mention that, with the aim of getting subjective insight into the perspective of self-advocates, qualitative participatory research was conducted. ASA's 23 active members took part in the research (Bratković, Zelić 2010). The research provided insight into the experiences and the views of self-advocates with regard to their personal perception about activism, how they represent themselves in everyday community life, how they experience the life in the community and what kind of problems they face and in which way they help and support others who would like to self-advocate. The research confirmed that self-advocates are confident in their role of promoting self-advocacy, that they are ready for positive experiences and effective results of their activities. However, the research also pointed to the barriers that the self-activists face and their evident intention for further promoting and strengthening the self-advocacy movement.

The possibility to 'speak in their own words' is the key force of self-advocacy for people with intellectual disabilities. However, with an aim for a more active struggle for their dignity, respect and a valuable social role, personal and mutual empowerment became another driving force of (their) self-actualization. The support given in the process of self determination serves as the foundation and the stimulus in reaching a higher level of self-advocating. Furthermore, an important facet of their activism is in advocating and supporting the rights of other persons with intellectual disabilities, and especially those who are less fortunate. In advocating their rights, special emphasis is placed on being able to have different opportunities to choose from and to be more involved in the decision making processes which affect their everyday lives and their future. Subsequently, they are now able to intertwine their self-advocating skills with the opportunities given within the community, albeit through living with their families or through the process of deinstitutionalisation (e.g. through social inclusion, housing, employment, marriage). This further emphasises the fact that negative discriminatory experiences from their former special institutional 'treatments' were not the way forward. Thus, further growth and strengthening of the self-advocating movement on a domestic as well as an international level is their future plan. In spite of many prejudices, they are a living proof that with adequate community support, many persons with intellectual disabilities are able to reach their potential and achieve even greater success in the fight for their rights and against discrimination.

The Association for the promotion of quality education of youth with disabilities „Imagine'

'Imagine' was founded in 2005 in Zagreb, and operates across the whole of Croatia.[4] Their mision is to support young people with disabilities to get integrated into the education system with the necessary technical and material support. The University of Zagreb (2014), with more than 65 000 students has about 330 students registered as students with disabilities, which makes it about 5 per every thousand. Beside the institutional help provided by the university, constant support of NGOs is a vital resource for students with disabilities and for those who need to be encouraged to go on with their education. This makes the importance of NGOs in disability activism vital in enhancing equal opportunities in education.

'Imagine' is a member of the Association of Community ICM in Croatia, also a member of the European Youth and Counseling Agency – ERYICA and the Croatian Association of Youth and Students with Disabilities – SUMSI through which it is involved in the work of the European Disability Forum. The association was founded on the following aims:

- encouraging young people with disabilities to participate in the education system,
- providing youths information and counseling,
- informing and advising people with disabilities,
- involving young people in activities related to active participation in society, mobility, employment, education, social protection, health care, culture and sport and leisure,
- including persons with disabilities in activities related to life in the community; family, education, health care, social welfare and pension systems, housing, mobility and
- accessibility, vocational rehabilitation, employment and work, and also raising awareness through participation in cultural, political and public life, recreation, leisure and sport,
- providing assistance to young people with disabilities in everyday life,
- collaborating with teachers and educational institutions,
- developing international cooperation,
- improving quality of life and education for young people with disabilities in Croatia.

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[4] Their website: http://www.zamisli.hr/index.php/kontakt.

Imagine is carrying out a program; *Center for support for students with disabilities*, offering students with disabilities adapted transport services on a regular basis in order to attend their classes, alteration of literature, personal assistance for students with disabilities and typewriting for students with hearing impairment. Also through the program, information on counselling for youths with disabilities, advice and help was offered not just to a population of students with disabilities, but in general to youth with disabilities. In 2005 Imagine began the adaptation of literature for blind and visually impaired students. The International Day of Persons with Disabilities was marked on 3rd December 2005 and an accessible movie screening was provided for blind people. This was an important step in adjusting the program of drama and the arts for the blind called 'I listen, therefore I see'.

Since 2011 Imagine has performed motivational workshops for senior high school pupils with disabilities, encouraging them to enroll into universities. In the same year Imagine started with workshops for youths with disabilities in order to help them prepare for the university entrance exams. In 2012 a new activity was launched, called Orientation Week for Freshmen with Disabilities in Zagreb. The aim of the orientation workshop was to prepare newcomers – students with disabilities – for a new academic year, introducing them to everyday student life, helping them in orientation within the campus, clasrooms, schedules and expectations.

The qualitative research on support for students with disabilities (Jermen, Urbanc 2012) shows that basic support is needed in mobility, class attendance, introducing faculty staff to students and their needs during study, providing help during the learning process, support during exams, information and tehnical support for realisation of students rights. The importance of personal assistance[5] provided by Imagine is recognised as being very useful, according to the research participants. Students with visual impairment were commenting on the need for further cooperation between NGOs and institutions, referring to the tensions among different service providers:

- There's more than enough work for all of them (NGOs' services and institutional services), I don't know why they can't stand each other...
- They should agree upon some things...otherwise, it happens that one notebook was scanned twice, its costs are doubled...
- The aim is to improve life and education quality for students with disability, not personal promotion...

Their recommendations for improving the quality of education for students with disabilities refer to stability and predictibility of financial support for NGOs:

- It means, not depending on projects and whether it is going to be approved or not...
- Our transport service (Imagine) works till 4 p.m. And we have lectures till 6 or even 8; because of the lack of money it is not covered for the whole day.
- To have more stable and predictable financial support for NGOs..instead of making a big deal out of it during election campaigns (statements of students – participants in the research, Jermen, Urbanc 2012).

The Republic of Croatia, as a signatory to the UN Convention on the Rights of Persons with Disabilities (Hrvatski Sabor 2007) took over the role of improving the situation of persons with disabilities in society and so, among other things, made a commitment to admit the right of persons with disabilities to education and to ensure an inclusive education system and lifelong learning. In accordance with the above, Croatia committed to inclusion for people with disabilities into the regular education system, to provide access in general tertiary education, vocational training and lifelong learning without discrimination and on an equal basis with others, and to provide reasonable accommodation for persons with disabilities. However, in practice, Croatian universities and their staff lack the knowledge of how to approach the students with disabilities.

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[5] A personal asssistant is a trained person, who is helping students with disabilities in attending classes and performing tasks which could not be performed independently.

It is commonly believed that the disabled students should be freed from an obligation which in turn shows that there is not much foresight and initiative to find an alternative approach to the issue (Ombudsman for Persons with Disabilities 2011).

In order to enable all potential students with a disability to become a part of the higher education system and to provide them with appropriate support, in 2007 the University of Zagreb established an Office for students with disability, as a referal center where students can get all needed information and direct help. Some of the defined tasks of the Office are: informing students and teachers; international cooperation, creating a database about students with disabilities; activities for increasing accessibility, meeting the specific needs of students with disabilities for attending lectures and learning (transport, adjustment of literature, translation to sign language, personal assistance...). From 2010–2013 Tempus project Education for Equal Opportunities at Croatian Universities has been underway. The aim of the project, led by the Office, *was the* equalising of opportunities in higher education for students with disabilities in the Republic of Croatia and the enhancement of support for students with disabilities in Croatian Universities. It also aimed to initiate the creation of national standards and guidelines for the development of accessibility of higher education for students with disabilities and ensure the accessibility, sustainability and quality of a system of support equalisation. (*Cf.* Eduquality 2014.)

The Association of Physically Disabled in Zagreb

The Association of Physically Disabled in Zagreb[6] (hereinafter the Association) was founded in 1977, as a non-governmental organisation involved in social and humanitarian work. It has 525 members who, for the last 30 years, have been continuously working on the improvement of the quality of living for persons with paraplegia in the greater Zagreb region. Financing of the Association's activities is not systematically solved. A smaller part of overhead costs for the Association's regular activities is covered from municipal funds and membership fees, while most of its activities are financed through other sources, such as grants, donations, gifts and the like. Their mission is raising the social awareness of rights, needs of persons with disabilities and advocating a model for their participation on equal terms in the development of their community. The following programs are conducted on a regular basis:

- Special support program for persons with disability intended to resolve problems in welfare, rehabilitation, acquisition of orthopedic equipment etc.
- Professional rehabilitation program for young members (training in computer and accountancy skills, etc.).
- Projects for removing (architectural) barriers in public and housing facilities.
- Workshops on the improvement of quality of living for persons with a disability (meetings, lectures, actions in the local community etc.).
- Cultural programs (exhibitions, poetry recitals, concerts etc.).
- Assistance at Home project (providing help to persons with a graver disability and elders).

In cooperation with the Ministry of Science, 19 rooms in the Student dormitory 'Cvjetno naselje' in Zagreb were adapted to the needs of students with a disability. The Project lasted for two years and was concluded with an opening ceremony on the 21st of September 1998, a total of EUR 236,000 was invested.

In cooperation with the Ministry of Education and Sport, an elevator was installed and the associated adjustments were made in the 'Eugen Kvaternik' elementary school in Velika Gorica, a little town near Zagreb, to allow children with disabilities to attend regular education programs in an integrated environment. The Project lasted for a year and was completed with an opening ceremony on November the 6th 1999, a total of EUR 75000 was invested. Similar projects were implemented in 2001 in two elementary schools.

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[6] Their website: www.dti.hr.

Apart from its long term activism in raising social awareness for the rights of the disabled, the Association became known as the creator and organizer of the Festival of Equal Opportunities (F=M), taking place in Zagreb since 2002. Today, the Festival represents one of the main urban events advocating for the right of persons with disability. Every May, for the last 12 years, in Zagreb the Festival of Equal Opportunities has taken place – it is a two day public event featuring urban culture performed by persons with disabilities. The Program includes some 80 acts performed by over 900 people from Croatia and abroad. The organising team consists of approximately 20 experts and 130 targeted volunteers – students from a dozen Faculties of Zagreb University. In preparation for their work, student volunteers attend training on disability. Volunteering at the Festival they acquire precious experiences by working in teams and communicating with persons having various physical or sensual impairments, as well as those with decreased mental capacities. A Visual Art program encompasses an urban group exhibition featuring 60 authors of various artistic expressions and painting techniques bound together by physical disability as a common denominator.

Conclusion

A specific historical and social activity of the NGOs in offering support to the persons with disability is a social resource which needs to be treasured for several reasons:

- Encouraging self-activism of persons with disability and also activism within the community in general.
- Promoting advocacy for a better quality of life for persons with disability through supporting their convergence to everyday life experiences and by initiating the social actions and changes in which the opinions and needs of the disabled and their families are acknowledged.
- Future NGOs activism should be specifically directed towards the development of disabled persons' potential for the purpose of their empowerment as actors in the public decision making process. One can argue that, during the process of creating a public policy for the disabled, the associations that represent their rights and disabled persons themselves are to be involved in all the stages of the process i.e. from the definition of the issues through to formulating the best approach, to further choosing the policy option that is to be followed and to the implementation and monitoring of the same (Petak 2012).

The process of 'NGO-isation' (Zaviršek 2007) points to the sudden existence of a vast number of non-governmental organisations through which the necessary social changes are carried out, but, at some point, they become the only 'responsible' carriers and actors of social change. In this context, one could challenge the role of a democratically elected government and its responsibility to initiate and support the social changes within society. Referring on the tensions among different service providers (between different NGOs or NGOs and institutions) there is a need for better coordination among all relevant social actors in order to address all important disability issues on the national political agenda, by including the perspective of persons with disability (Lisak 2013). It requires all stakeholders to be willing to have a debate and dialogue, to be ready to respect the experience of others and to be open for user participation and evaluaton.

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DISABILITY, POLITICS AND CULTURE IN KOSOVO

The article focuses on social policy, politics and cultural representations of disability in post-war and post-independence (2008) Kosovo. It recounts the living conditions of people with disabilities that continue to be harsh as they face multiple levels of exclusion and oppression, stigmatisation, and violence. Seeking to understand agency, the article analyses the relationship between the state and disability movement. It also explores the ways in which disability, as an embodied condition and a form of social identity, functions in the cultural imagination and systems of representation. Three specific points will be made. First, the article seeks to show that the legislative instruments concerning disability ensure de jure but not de facto equality. The existing legal model of disability has not eased the social divisions and inequalities in the broader social structure in Kosovo. Second, it explains how participation of the disability movement in the political processes in general, and social policy formation in particular, has challenged the hierarchical 'social geography' and opposed the ideologies of ableism. Third, disability as an embodied condition and a form of social identity in the cultural imagination is predominantly that of an abject body. The categories of the body dominant in discursive representations are those of physically disabled and war-induced disabilities, rendering other types of disabilities invisible. The article will show how the body politic as well as social, economic, and cultural discourses and formations in Kosovo are premised on a binary matrix of the abled and disabled body and identities.

Key words: body, identity, agency, representation, handicap.

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OVIRANOST, POLITIKA IN KULTURA NA KOSOVU

Članek se osredotoča na socialne ukrepe, politiko in kulturne reprezentacije oviranosti v povojnem in neodvisnem (2008) Kosovu. Poroča o življenjskih razmerah ljudi z ovirami, ki so še naprej izključeni na več ravneh, zatirani, stigmatizirani in izpostavljeni nasilju. Pri razumevanju zastopništva raziskuje odnos med državo in gibanjem oviranih. Raziskuje tudi, kako oviranost funkcionira v kulturnih predstavah in sistemih reprezentacij. Predstavi tri okoliščine. Prvič, poskuša pokazati, da pravni instrumenti na področju oviranosti zagotavljajo de jure, ne pa tudi de facto enakopravnost. Obstoječi zakonski model oviranosti ni odpravil družbenih delitev in neenakopravnosti v širši družbeni strukturi Kosova. Drugič, pojasni, kako je participacija gibanja oviranih v političnih procesih na sploh in še zlasti v oblikovanju socialne politike načela hierarhijo »družbene geografije« in kako nasprotuje ideologijam »neprizadetega telesa« (abelism). Tretjič, oviranost – kot utelešeno stanje in oblika družbene identitete v kulturni imaginaciji – se predvsem nanaša na zavrženo telo. Kategorije, ki prevladujejo v diskurzivnih reprezentacijah, se nanašajo na fizično oviranost in tiste hendikepe, ki jih je povzročila vojna – druge oblike oviranosti pa so nevidne. Članek pokaže, kako telesne tehnike kot tudi socialni, ekonomski in kulturni diskurzi in formacije na Kosovu temeljijo na binarni matrici oviranega in neoviranega telesa in identitet.

Ključne besede: telo, identiteta, zastopništvo, reprezentacija, hendikep.

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Introduction

In Kosovo disability has been recast as a human rights issue and also made part of social policy. Yet disability policy and practice in Kosovo has predominantly been premised on physical and mental impairments through a medical approach to rehabilitation, paying little attention to other types of impairments (Turmusani 2002: 1). Scholarship on disability in Kosovo is yet to emerge. Whilst the body of scholarly work has dealt with Kosovo's history, war experience, post-war reconstruction, as well as nation- and state-building, disability has gained little attention. Hence the lived experience: social, economic, political and cultural, of the people with disabilities[1] in Kosovo remain unaccounted for in academic scholarship. This text seeks to fill this gap.

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[1] In this text the term 'people with disabilities' is used to underline the definition made by the people with disabilities themselves. This is to acknowledge their agency and striving for a dignified representation (see www.disabilityisnatural.com).

However, some action research has focused on disability in Kosovo (Turmusani 2002, Mental Disability Rights International 2002, KOAPS 2006, Coalition 'Equal Opportunity' 2007, Broad Survey of Persons with Disabilities in Kosovo 2011), and on others disability was situated in the analysis of the social policy or within the framework on children's rights (UNICEF 2009, UNDP 2010, Friedrich Ebert Stiftung and Center for Human Rights 2010). The relevance of this study lies in its engagement with a set of concepts on disability, disability policy and its effects on the lives of the people with disabilities; agency; and last, but not least, contextual materiality of the body and culture in Kosovo.

This article analyses the evolving pattern of the social policy on disability. It looks at the institutional: state and civil society responses on disability, on one hand, and the enmeshment of corporeality in the symbolic systems on the other. It provides an overview of the legal articulations on disability in Kosovo as it has developed over the last fourteen years, as well as the social services available to people with disabilities. The analysis provided here takes into consideration the legacy that the socialist state left behind as well as the 1998–1999 Kosovo war and venues that such legacies have opened up for social policy and disability in post-war reconstruction. The article recounts the living conditions of people with disabilities, which continue to be harsh as they face multiple levels of exclusion and oppression, stigmatisation, and violence. Seeking to understand agency, the article analyses the relationship between the state and the disability movement. Last but not least, it explores the ways in which disability, as an embodied condition and a form of social identity, functions in the cultural imagination and systems of representation.

As a matter of method, this inquiry into disability is grounded in the materialist theory studying disability as a socio-political and cultural construction. In this process attention is paid to social conditions that have mediated responses to disability involving unequal relations of power and the effects on people's lives: economic, social, and psychological (Wendell 1996: 23, Garland-Thomson 2001: 5, Russell 2011). The analysis provided here draws on readings of different texts: laws and regulations on disability, social statistics and representations of disability, as well as interviews with the disability activists in Kosovo.

The article makes three specific points. Firstly, the legal model of disability is embedded in the principle of universalism and uniform redistribution – the flat amount of €60 per month disability pension is a case in point. It has not eased the existing social divisions and inequalities in the broader social structure in Kosovo. The legislative instruments concerning disability ensure *de jure* but not *de facto equality.* As a consequence people with disabilities lack integration in Kosovan society. Secondly, I contend that participation of the disability movement in the political processes in general and social policy formation in particular, has challenged the hierarchical 'social geography' and opposed the ideologies of ableism. *Thirdly,* in the cultural imagination, *d*isability as an embodied condition and a form of social identity is predominantly that of an abject body. This signification is reinstituted in the symbolic ordering through a range of emotions encompassing bewilderment, fear, guilt – maintaining unequal power relations grounded in the body. Yet the categories of the body dominant in discursive representations are those of physically disabled and war induced disabilities, rendering other types of disabilities invisible.

Situating disability: who is disabled in Kosovo?

Following Susan Wendell's (1996) approach, I resume the inquiry into disability by posing the question: who are the disabled in Kosovo? According to the official statistics there are 93,288 persons with disabilities in Kosovo. Physical disability ranges from the most severe, followed by disabilities due to a long-term illness, to other types of disability present among the Kosovo population such as hearing disability, blindness or impaired sight, mental and learning or intellectual disability (see Table 1). The state is the key actor in regulating social, economic and political life. It is the chief promoter of the 'accepted political reality', setting the institutional and ideological parameters, and regulates law-making (Moore 1988). Hence

Table 1: Demographic data on persons with disabilities in Kosovo, by age, type of disability and gender.

Age	**Deaf or hard of hearing**	**Blindness or low vision**	**Physical disability**	**Learning/ intellectual disability**	**Mental disability**	**Other disabilities and long term illness**
0–14	355	431	1,050	684	616	865
15–19	123	155	513	348	351	418
20–24	200	127	562	315	385	398
25–29	191	135	608	318	456	522
30–34	212	146	926	334	536	708
35–39	245	220	1,312	366	738	1,178
40–44	321	299	1,644	351	780	1,497
45–49	401	488	2,181	294	725	2,068
50–54	564	732	2,587	312	693	2,915
55–59	687	946	3,211	284	667	3,430
60–64	928	1,073	3,515	340	595	3,817
65–69	1,197	1,170	3,745	368	464	3,764
70–74	1,434	1,189	3,757	451	456	3,172
75–79	1,365	1,091	3,054	403	313	2,177
80+	1,712	1,233	2,902	439	358	1,682
Total	**9,935**	**9,435**	**31,567**	**5,607**	**8,133**	**28,611**
Female	4,683	4,788	16,990	2,966	3,916	16,567
Male	5,252	4,647	14,577	2,641	4,217	12,044

Source: Kosovo Agency of Statistics (2013: 109).

I look at how the state defines disability. Let me begin with a presentation on the definitions of disability in the legislation concerning the rights of persons with disabilities in Kosovo.

The sources of policy on disability in Kosovo are to be seen in the light of Kosovo's international state-building and interventions of the different international organisations[2] engaged in the Kosovo protectorate. The state-building project is premised in civic terms and hence on citizenship rights. Thus, as part of the internationally led state-building agenda, the Kosovo state has endorsed all internationally recognised documents on human rights and fundamental freedoms.[3] Grounded in the international human rights standards, the Constitution of the Republic of Kosovo has paid attention to persons with disabilities as one of the social groups whose rights it guarantees. It states that

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[2] After the 1998–1999 Kosovo war, the number of international non-governmental organisations engaged in post-war reconstruction was hovering around 300. Disability issues have received particular attention from international organisations. Around 30 international organisations worked with people with disabilities. However, the international responses to civil society development have been criticised for their inability to create an empowering platform and for having enforced dependency on international help instead (Turmusani 2002, KIPRED 2005, Fagan 2006, 2010, Krasniqi 2010).

[3] The following international agreements and instruments are directly applicable in the Constitution of Kosovo (2008: Art. 22): the Universal Declaration of Human Rights; the European Convention for the Protection of Human Rights and Fundamental Freedoms and its Protocols; the International Covenant on Civil and Political Rights and its Protocols; the Council of Europe Framework Convention for the Protection of National Minorities; the Convention for the Elimination of All Forms of Racial Discrimination; the Convention for the Elimination of All Forms of Discrimination against Women; the Convention on the Rights of the Child; the European Charter for Regional or Minority Languages, and the Convention against Torture and Other Cruel, Inhumane or Degrading Treatment or Punishment.

> No one shall be discriminated against on grounds of race, color, gender, language, religion, political or other opinion, national or social origin, relation to any community, property, economic and social condition, sexual orientation, birth, disability or other personal states. (Constitution of the Republic of Kosovo 2008, Art. 24.)

Moreover, several legal provisions: laws and regulations, address specifically the rights of people with disabilities.[4] In addition, there is a national council and a national strategy on disability was put in place in 2009, as part of the state's response on disability.

As a category within the legal framework in Kosovo, disability encompasses persons with physical, sensory or mental impairments that limit full participation of persons with disabilities in everyday life. There are several definitions of disability at work, albeit relating to different social groups. They pertain to education, social welfare (including pensions), labour rights, and health. In the pre-university education system the term 'children with special needs' is used, referring to children 'whose progress in school is impeded for various reasons' and need additional support in studying (UNICEF 2009: 7). In addition, another definition is that of children with disabilities known as 'permanently disabled children of physical, mental and sensory forms', encompassing children up to 18 years old needing other people's help to carry out daily activities (Law On Material Support for Families of Children with Permanent Disability 2008, Art. 2).

The second set of definitions of disability relates to pensions as a part of the welfare system in Kosovo. In this instance disability is defined in connection with the capability to work. An individual with disability is defined as 'a person totally and permanently disabled and incapable of any form of occupational activity' (Law on Disability Pensions 2003, Section 1, 1.3). Disability defined in health terms encompasses the nexus 'persons with mental disability' and 'physical or mental disabilities'. Moreover, a specific definition of disability relates to the 1998–1999 Kosovo war including two categories: (1) 'the civil invalid of war' and (2) 'invalid of war'. While the former category encompasses disability as a consequence of impairment caused during the 1998-1999 Kosovo war and after the war from the explosive devices left behind when the war ended, the latter includes the ex-combatants of the Kosovo Liberation Army (see Law on the Status and the Rights of the Martyrs, Invalids, Veterans, Members of Kosovo Liberation Army, Civilian Victims of War and their Families 2011, Art. 3, 1.7 and 1.8).

The legislation on disability might be grounded in the international standards on human rights, yet disability as a category in social policy and law-making in Kosovo is defined in a deterministic way. Moreover, the use of the term 'invalid' as a principle of categorisation in social policy is problematic. As Darja Zaviršek has argued, in the post socialist countries of Eastern Europe, and this applies also to Kosovo, people with disabilities are labeled as '*invalid*' – a term signifying inactivity, powerlessness and lack of agency (Zaviršek 2006:2). In Kosovo , the terms *work invalid* and *war invalid* – in the Albanian language *invalid i punës* and *invalid i luftës* – signify dependency, inability to live independently, and posits persons with disabilities as passive recipients of social services and needing care.

Disability is neither a homogeneous notion nor a homogeneous social group. People with disabilities are a diverse group living different forms of embodiment and coping strategies. The fact that disability is experienced differently across class, gender, age and locality, goes unnoticed in the legal model of disability in Kosovo. Moreover, embedded in the principle of universalism, this legal model entails a 'paradox of redistribution' (Korpi, Palme 1998) characterised by the

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[4] Legislation on disability in Kosovo includes the following laws and regulations: (1) on disability pensions; (2) families of children with disabilities, and (3) vocational ability and employment of (4) social assistance and (5) benefits for war invalids and next of kin of those who died in war. Disability has been made an integral part also in the Anti-Discrimination Law (2004); the Labour Law (2010), and the Law on Construction (2004), and in two administrative instructions related to construction and work: (1) Construction Buildings Technical Terms of Accessibility for People with Disabilities (2007); and (2) Administrative instruction for Procedures of Application for Rights in Recognition of Skills, Rehabilitation, and Employment of People with Disabilities (2010). In addition, a three year action plan on disability has been devised under the auspices of the Kosovo Government.

uniform system of redistribution, assumed to be a salient approach to reduce social divisions. Indeed, 'discussions of universalism within a service as desirable in itself and because it advances equality in society' (Hill 2006: 192) remain open in the scholarship, but with reverberations at the practical level. The disability policy in Kosovo is an exemplar of this uniform approach to entitlements for the disability groups. Regardless of the type of disability, they are entitled to a flat amount of €60 per month disability pension. And the families of a child with a disability – around 2000 children with disabilities are recipients of this scheme – are entitled to €100 per month. In both instances the differing needs of people with disabilities, as well as different experiences of disability based on gender, age, and class, is given no weight. It can be argued that such a legal model of disability is flattening out the differences among people with disabilities, rendering invisible their differential social positioning, and ignoring their varying needs, as articulated by the persons with disabilities themselves. Such a response is failing to dismantle the structural inequalities which people with disabilities in Kosovo are facing. This is in no way a pursuit of an 'individualistic logic' akin to liberal individualism, but a contestation of the hierarchical organisation of the social space (Russell 2011: 200).

Disability definitions in Kosovo are largely centered on medical notions. Moreover, disability is assumed as a fixed category and a static condition. The fact that globally the number of people with disabilities is growing is not reflected in this context. For example, the higher risk of disability due to ageing and also of chronic health conditions associated with disability, such as diabetes, cardiovascular diseases and mental illness, or disability influenced by trends in health conditions and those related to environment and other factors – such as road traffic crashes, natural disasters, conflict and substance abuse (WHO and WB 2012: 8), as well as difficult access to health services, are given little consideration in the law-making on disability in Kosovo.

Disability: from legislation to practice

In Kosovo, while there is a legal system to address the rights of people with disabilities, overall awareness among the Kosovo population of its existence is rather low. As shown in Table 2 below, the prevailing public opinion regarding the existing legislation on disability in Kosovo is that while the legislation ensures *de jure* legal protection, it lacks implementation; it is not *de facto* (see Table 2).

Taking a closer look at the data in Table 2, it is noticeable that older people, women and members of the Roma communities are far less aware of the existence of the laws and rights of people with disabilities. For certain, the pessimistic outlook in the broader public opinion in Kosovo is a reflection of the overall low level of trust in the state institutions (see UNDP 2013), and dissatisfaction with economic conditions and quality of life, which the state has failed to address. Kosovo ranks as the poorest country in Europe. One out of every two Kosovars is without a job. Half of the population lives in poverty, on less than €1.40 a day (Kosovo Agency of Statistics 2013).

The aim here has been to explain the gaps and slippages from policy to everyday practice and their limitations, to account for the effects it has in the lives of people with disabilities. The gap between the legal language and practice is evident in countless instances. For example, people with disabilities cannot physically access the health and education facilities they desperately need. They grapple to cover costly medicines, unable to resource appropriate treatment to improve their life opportunities; are largely shut out of the labour market, and thus without any social alliance to improve their wellbeing (UNDP 2010: 13). Today 18,427 people with disabilities, who live on the disability pension (Kosovo Agency of Statistics 2013) of €60 per month, cannot meet the most basic needs: nutrition and medicines. They live below the poverty line of €1.4 a day. Indeed, depending on type of disability, children with special needs attend special schools, they also attend regular schools where they are either clustered in separate classrooms – an attached class, or are included in regular classrooms. In Kosovo there are seven special schools

Table 2: Information on laws on the rights of persons with disability in Kosovo by age, gender, ethnicity and type of settlement (in %).

		Awareness of laws on the rights of persons with disabilities	**Lack of knowledge of laws on the rights of persons with disabilities**	**Don't know/ No answer**
Total	All respondents	42	32	26
	19-30 years old	44	36	20
	31-45 years old	46	29	25
	46-64 years old	39	30	31
	65 and over	24	40	36
Gender	Men	48	31	21
	Women	34	34	32
Ethnicity	Albanian	42	32	26
	Serb	43	37	20
	Roma, Ashkali and Egyptian	18	45	37
	Other ethnicities	48	22	30
Type of settlement	Urban	41	32	27
	Rural	43	33	24

Source: Broad Survey of Persons with Disability in Kosovo (2011: 15).

for children with special needs in education and two classrooms are part of the regular school in each municipality[5] (MEST 2013: 33). Yet children with disabilities have a high percentage of exclusion from education. Barriers faced by children with disabilities are poverty, lack of resources and aid, lack of transportation to and from educational facilities, stigma, inattentive teachers, and the absence of appropriate infrastructure (UNDP 2010: 60).

The quotes below are just a glimpse of the sentiments that people with disabilities in Kosovo live with. The feelings of exclusion, discrimination, and cultural devaluation, permeate the narrators' text as they reflect on their lived experiences.

> Yes, in a way we feel culturally excluded. The only activities that are organised for people with disabilities in Kosovo are those that are planned by the non-governmental organisations that we are part of. Also, we would love to have a TV programme once every two weeks dedicated to people with disabilities in Kosovo. (Male person with disability quoted in *ibid.*: 80.)

> As a female with disabilities you are doubly discriminated against, especially when considering rural/urban biases. For example, in villages, women with disabilities are totally excluded from society. (Female person with disability quoted in *ibid.*: 83.)

Indeed, women with disabilities, especially those living in the rural areas, experience higher levels of exclusion. This stems from both structural and cultural factors. Indeed, in rural areas the infrastructure is not barrier free for people with disabilities, nor is it in the cities/towns. In both locations traditional cultural norms about gender roles are prevailing. But the social pressure to conform to traditional gender roles and sexuality is less tight in the urban settings. The social pressure for conformity is looser in urban areas. This is due to the dispersal of

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[5] Special schools for children with disabilities are located in Mitrovica, Priština, Peć, and Prizren. In total there are 453 children in the special schools in Kosovo. Out of which 234 are children with intellectual impairments, 61 with hearing impairments, 39 with sight impairment, 8 with physical disability, and 111 with multiple impairments (MEST 2013: 35). In the attached classes in schools there are 533 children, out of which 319 are children with intellectual impairments, 37 with impaired hearing, and 8 with sight impairment; 25 with physical disability, and 144 with multiple impairments (UNICEF 2009: 37). Yet 80 per cent of children with disabilities are not included in the education system (see Ministry of education, science and technology 2013).

kinship in the urban localities, contrary to proximity and concentrated dwellings based on kinship in rural areas, thus enabling 'policing' of gender and sexuality.

The government itself, despite being the main actor for guaranteeing the rights of people with disabilities, does not do so. The government buildings offer no access for persons with disabilities. Moreover, they do not comply with the law provisions which oblige all organisations to employ one person with disability per every 50 employees (Law on Vocational Ability, Rehabilitation and Employment of People with Disabilities 2008). Yet one positive example is the Disability Mentoring Day campaign that is based on the international practice. It did succeed in employing a number of people with disability for a short period of time (ranging from a few days to a couple of weeks) in participating companies and government offices. Alas, the campaign has had no long-term effect, as none or very few people have obtained a permanent job following their short-term and probation 'employment' during the campaign (NESst 2011: 14). However, such campaigns raise awareness on disability rights.

Another segment that points to the limitations of the disability policy in Kosovo relates to the politics of care. It is evident that the overall system of social care in Kosovo is weak, including the care for persons with disabilities. In fact, Kosovo's care system is highly dependent on informal care. The empirical data indicate that the majority of care providers for people with disability in Kosovo are women (59 per cent), in fact, mothers (Broad Survey of Persons with Disability in Kosovo 2011: 39). Care is embedded in social values, expectations and institutions. No doubt, parenting and care giving to persons with disabilities, as the data indicate, is gendered. It rests on traditional gender roles reenacting the gendered division of the public and private spheres (Tronto 1992: 183). Moreover, this constitutes a form of '*compulsory altruism*' (Hill 2006: 222) because women are assigned the roles of care for children, the elderly, and persons with disabilities. As the broad survey on disability has indicated in Kosovo, it is the mothers (31 per cent) more than fathers (20 per cent) that are the care providers for persons with disabilities, followed by siblings (11 per cent), and a grandparent (3 per cent). Nurses comprise only one per

Table 3: Assistance provided to persons with disabilities, by gender and ethnicity (in %).

	Total	**Gender**		**Ethnicity**			
	All	Men	Women	Albanian	Serb	Roma, Ashkali, Egyptian	Other
Family members/relatives	73	70	76	73	75	83	66
People from neighbourhood	1	1	1	1	2	3	3
Municipality	3	3	2	3	2	0	7
State	0	0	0	0	1	0	0
Public institutions	0	0	0	0	3	0	0
NGO/Women's NGOs	3	3	3	3	5	1	4
Religious organisations	0	0	0	0	2	0	2
Private sector organisations	0	0	0	0	0	0	0
International organisations	1	1	1	1	1	1	0
Other	0	1	0	0	0	0	0
Nobody	17	19	15	18	3	10	14
Don't know/ Don't want to answer	2	2	1	1	6	2	4

Source: Broad Survey of Persons with Disability in Kosovo (2011: 37).

cent of the care providers to people with disabilities in Kosovo (Broad Survey of Persons with Disability in Kosovo 2011: 39). As the data reveal, a considerable number of people with disabilities live without any assistance from relatives, the state or other social institutions (see Table 3). Nonetheless, the role of relatives in providing care to persons with disabilities is paramount. Yet this is also an indicator of the state's gendered performance shifting social responsibility to the families, more precisely women, to provide care for people with disabilities.

However, I am mindful not to romanticise the private/familial care based system as a site of equal power relations, freed from coercive power. I have domestic violence in general in mind, and violence against persons with disabilities, in particular. The prevalence of domestic violence against people with disabilities in Kosovo is yet to be documented. However, the disability organisations providing support to persons with disabilities have noted that people with disability are subjected to violence at home, especially women with disability. Forms of violence which persons with disabilities have endured include

> being criticized by other family members, called names, sworn at, isolated, made to feel guilty all the time, have decisions made for them without their consent, their pension appropriated by other family members, or threatened with removal from home (KWN 2008: 46).

Physical violence is especially present against persons with mental disabilities. Most of the persons with disabilities are confined to the private domain and live in isolation – which constitutes a form of violence (*ibid.*: 45), and with no place to turn to for help. It is true that the stigma associated with disability in Kosovo is strong, and that persons with disability, especially children, are hidden from the public eye. But the disability organisations have made the point that

> it is rather the lack of social services as well as lack of support to families of people with disability that confines them to isolation. It is not the families to be blamed but the state, which does not provide opportunities for integration for people with disabilities. (Disability activist, interviewed by the author, July 2013.)

Disability as political arena

To show how disability as a discourse has been constructed and also shaped social formations in Kosovo it is necessary to take into account activism and practices of the disability movement. The aim here is also to understand the ways in which the disability groupsare carving space for themselves in civil society and politics in Kosovo.[6] The state and civil society do meet and they can be understood relationally. The emergence of the civil society in Kosovo during the 1990s – a decade that was termed as 'the civil resistance in Kosovo' (see Clark 2000) – was a response and a form of collective organising to counter the exclusionary and brutal regime of the Serbian leader Slobodan Milošević that deprived Kosovo Albanians of political autonomy, the right to education, health, social provisions, and subjected them to imprisonment, forced migration, and war.

Having had to respond to such political and economic cleavages in the 1990s, the civil society organizations were the substitute for the lack of social services, a role which they continued to play in the post-war period. For instance in 1999–2000, 76 per cent of the non-governmental organisations were recorded as service providers (KIPRED 2005: 15). To be sure, I resist framing the civil society development in general and the disability movement in particular, in post-war Kosovo through dichotomous and oppositional categories, such as service providers

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[6] I deploy the term of 'civil society' similarly to Susan Gal and Gail Kligman, meaning 'not primarily as a set of determinate institutions and organisations, which it also is, but as an ideological formation that produces the quite real social effect of newly perceptible boundaries between the state organisations or what can now, as a result of such boundaries, be called voluntary, independent, or "non-governmental« organisations' (Gal, Kligman 2000: 94).

or advocacy groups. I find this misleading because such 'metrics' fail to take into account the historical trajectory of the collapse of the socialist state, war, and post-war protectorate and international state-building processes through which the civil society emerged, was shaped, and has entered the politics and culture in Kosovo. Instead, I pay attention to practices of the disability organisations and responses by the state.

The disability movement in Kosovo includes different non-governmental organisations.[7] However, they are not yet joined in a network; most of them being supported financially by international organisations. Indeed, it is the Association of Paraplegic Children HANDIKOS– a Kosovo based NGO – that has been at the forefront of disability activism in Kosovo. It has also been the main carrier of the community based rehabilitation platform for people with disability.[8] The relationship between the state and the disability movement in Kosovo is complex. I would like to draw attention to two examples to illustrate this relationship and also to show how disability is reconstructed as an arena of political action. The first example is the following:

In August 2010, the Association of Paraplegic Children HANDIKOS donated wheelchairs to the University Clinical Centre of Kosovo – an action that was proudly announced on the webpage of the Ministry of Health (HANDIKOS 2010). Such a practice recurred also in June 2013, when HANDIKOS donated five wheelchairs for another public institution: the Institute of Mental Health (HANDIKOS 2013). True, the disability organisations have been supported by international organisations, bringing important resources as well as ideas and practices on disability issues. But, as a disability activist, has remarked

> It is a paradox, a non-governmental organisation to donate wheelchairs to the public hospital and hence to take on the role of the state. (Disability activist, interviewed by the author, July 2013.)

Moreover, the example given here as a part of a 'political economy of gift exchange' should be read in relation to state-building agenda and the accommodation of the social issues in the state politics. This surely attests to the marginalisation of social issues by the Kosovo state, including disability. Looking at the state budget, one can notice that only 8.8 percent of the Kosovo budget is dedicated to the Ministry of Health and 18.4 per cent to the Ministry of Labour and Social Welfare (see KWN 2013). This mirrors the neo-liberal economic policies and institutional restructuring, to use the concept coined by David Harvey of 'accumulation by dispossession', (Harvey 2003: 137–183) as a strategy of the state handing over responsibilities, through privatization–including social services–to the market and non-state actors. A shortage of budget allocation to social issues is a staple of neo-liberal policies pursued by the Kosovo state.

Indeed, the interaction of the disability movement and the state has not always translated into cooperation, especially not in the processes of policy formation. It has required intense pressure by the disability organisations to be taken into account as actors in the policy formulation on disability. According to the disability rights activist

> Disability organisations were sidelined in the process of the development of the national strategy on disability. We did exert pressure for our inclusion by lobbying the key decision-makers. It required much pressure for our request to be taken into account. (Disability activist, interviewed by the author, July 2013.)

Indeed, these two examples show that the disability movement in Kosovo has made visible the state's evasive tactics from social responsibility: neglect of real social issues, unequal redistribution,

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[7] Disability organisations in Kosovo include the following: The Association of Blind Persons and Persons with Visual Impairment of Kosovo; the Parents Organisation of Children with Disabilities of Kosovo 'OPFAKKOS', the Association of Deaf People of Kosovo, the Federation of Sports of People with Disability of Kosovo; the Association of People with Muscular Dystrophy of Kosovo; Club 'Dëshira' [Desire]; the Association 'HANDICAP Kosovo', and the Association of Paraplegic Children of Kosovo HANDIKOS.

[8] The Association of Paraplegic Children of Kosovo HANDIKOS has 14 community rehabilitation centres and 12 community groups throughout Kosovo. The community groups collect data, identify, and map persons with disabilities as well as provide information on disability issues.

and political marginalization of the agencies representing people with disabilities. This process, however, is hierarchical. War related categories defined 'war veterans', 'the civil invalids of war' and 'war invalids' and their next of kin have been a key feature in the nation-building narratives. They have been symbolically validated in relation to the idea of the 'sublime sacrifice', and on such grounds incorporated in social policy and welfare protection, albeit enabling redefinition of citizenship and welfare rights, and enjoying greater privileges in employment; health services both in Kosovo and abroad; priority to housing; release from property taxes; exemption from tuition fees and priority in admission to education, among others (see the Law on the Status and the Rights of the Martyrs, Invalids, Veterans and Members of the Kosova Liberation Army, Civilian Victims of War and their Families 2011, Art. 8).

Culture and representation

As feminist scholars have long argued, disability is a cultural rather than individual or medical issue, and they have insisted on examining power relations (Garland-Thomson 2001, Wendell 1989: 1996) and the effects of power on the body, politics and culture. Disability is a discursive representation and an expression of the relationship between the body and language. As Stuart Hall has pointed out

> Sounds, words, notes, gestures, expressions, clothes – are part of our natural and material world; but their importance for language is not what they *are* but what they *do*, their function. They construct meaning and transmit it. They signify. (Hall 1997: 5.)

Hence, to read how disability is framed in language and maintained in the symbolic systems, it is important to explore the language and stereotypes – as they are an expression of unequal power relations, influence the disability discourse and practice. Stereotypes are derivative of the culturally accepted norms and values about the body. Foremost, stereotypes relate to ableism as a form of social prejudice and discrimination. The stereotypical views posit people with disability as unfit for independent living, but they are also perceived as mentally ill, sick, and asexual. Stereotypes that affect and cause discrimination, oppression and violence against people with disabilities are those that position them as physically and intellectually less able, emotionally fragile and untrustworthy, with mental health problems.

Attempts to reconstruct the categorisation of people with disabilities as an abject body and subordinated are reflected in the everyday language. Negative and derogatory language is deployed to refer to persons with disabilities. Handicapped person, invalid, deaf, and mute are some of the most common expressions. The term widely accepted by people with disability and disability organizations as best representing their voices is the term 'person with disability' (Coalition 'Equal Opportunity' 2007: 7).

To be sure, the cultural imagining of the body as well as its social meaning is not fixed. The circulation of representations of the body, however, is not monolith, neither in genre nor scenario. In Kosovo, in the flow of imagery depicting the body, it is the sexualised female body that has been made central. Everyday Kosovars are served with various advertisements featuring a sexualised female body in the public sphere. It is not only private capital which is a vector within this system of representation, but also the media, as well as political propaganda. Such representations are not isolated images, rather they form a cultural phenomenon deployed selectively to maximise economic profit and justify international interventions, branding the Kosovar nation, and fashioning a Western/European way of life in Kosovo (Krasniqi 2007).

However, in this proliferation of body imagery in the public space in Kosovo, disability has assumed a role, too. Representations of disability have largely been deployed in connection with awareness raising campaigns on human rights, disability issues, or on specific international human rights days, by different actors: the disability movement, international organisations, as well as the state. Yet as such, these representations have been

> constant visible reminders to the abled-bodied that the society they live in is shot through with inequity and suffering, that they live in a counterfeit paradise, and that they too are vulnerable (Murphy 1987: 55–56).

In Kosovo, in the dominant visual coding, a particular type of disability has been given prominence – the physically disabled body. A case in point is Image 1, representing disability by the organisation of the Association of Paraplegic Children HANDIKOS which, as mentioned earlier, has been the main actor on disability rights in Kosovo. Image 2 is a representation of disability in the Kosovo media. More precisely, Image 2 appeared in the electronic media in Kosovo on 3 December 2013, to mark the International Day of persons with disabilities. Such images were deployed largely by the print media, not only on this day, but whenever discussing the issue of disability.

Several elements should be highlighted in these two images. Foregrounding the male body confined to the wheelchair, these representations show how gender and culture relate to identity, corporality and subjectivity. It reifies the subjectivities of people with disabilities by flattening identities of people with disabilities, reducing it to that of the male body physically disabled. These images maintain a symbolic landscape of the body mediated by an 'affective economy'– to borrow the term from Sara Ahmed (Ahmed 2004: 8), to instill bewilderment, fear, guilt, and pity. Yet this 'flow of emotions' running through these representations naturalises the broader social/political/economic/cultural discourses and formations premised on a binary matrix of the able and disabled body and identities.

Image 1: Representing disability.

Source: HANDIKOS (2013).

Image 2: Representation of disability in the media.

Source: Telegrafi (2013).

Conclusions

Disability is contingent on the social and cultural context that effect practices of people with disability (Linton 1998: 527). How disability is understood not only has an enormous impact on the ways people with disabilities make sense of themselves and their lives but also on how institutions shape and perpetuate their practices. By focusing on Kosovo, I have argued here that the disability policy signifies a heightened sensitivity of the state toward the needs of people with disabilities. The legal model of disability as well as social practices at large have regarded persons with disabilities as unable to work, unfit for society, sick, and incapable of independent living. Yet it is war related disability that has assumed a greater symbolic importance in the nation-building ideologies, but also helped reconfigure citizenship and welfare rights.

The disability model gives primacy to medical approaches at the expense of social and cultural constructions that view disability as a product of an adverse environment that discriminates against people with disabilities and assigns them an inferior status in society. Moreover, as has been shown here, people with disability enjoy poor social protection and services as the state's neo-liberal agenda has maintained social issues on the margins. To be sure, effects of the neo-liberal ideology and economic policies in the Kosovo state-building politics, on the lives of people with disability in Kosovo, have yet to be documented and theorised. Disability has emerged as a new social identity and it has been accommodated as a category in social policy and welfare provisions. A critical analysis of the limits and the potential of the disability policy and institutional practices should involve radical politics that question and rework the binary reconstruction of identities, politics, language and culture.

In the cultural imagination disability is perceived as an abject body and sustained through stereotypes against people with disabilities. It is a fact that stereotypes underpin the public imagination and interact in such a way as to establish hierarchical restructuring of fixed identities around able-bodiedness, gender, disability, and class. Indeed, this is by no means uncontested. The disability movement, apart from having introduced disability as a political arena, has also been an important source of support and care for people with disabilities in Kosovo as the state has failed to provide quality social services for the people with disabilities.

In the proliferation of body imagery in the public space in Kosovo disability has also assumed a role. Yet in the symbolic landscape the image of the male body with physical disabilities has maintained a central position naturalising the broader social/political/economic/cultural discourses and formations on the gender and body binaries and hierarchies.

This study of disability in Kosovo has proved the usefulness of the materialist theory to challenge norms and practices based on power relations and for transformative politics by intervening in the process of policy making. This involves resisting practices which operate through top down approaches and limiting agency.

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Špela Humljan Urh

KULTURNI VIDIKI HENDIKEPA ROMOV

Romi so v Sloveniji ena od večjih kulturnih manjšin. Pogosteje se spopadajo s slabim zdravstvenim stanjem, a to ni zgolj posledica staranja, pač pa tudi socialnega položaja in situacij kompleksnih neenakosti. Srečujejo se s: krajšo življenjsko dobo, boleznimi in okužbami, ki so posledica slabih stanovanjskih in ekonomskih razmer, pogostimi nosečnostmi in splavi, kroničnimi boleznimi dihal majhnih otrok. V uvodnem delu prispevka so na kratko predstavljena temeljna izhodišča kulturno kompetentnega socialnega dela. Sledi obsežnejši raziskovalni del, ki prav tako temelji na načelih občutljivega raziskovanja. V njem avtorica spoznava perspektivo Romov in njihovo interpretacijo oviranega telesa. V prispevku so obravnavane teme: poimenovanje oviranosti, hierarhija med ovirami, razumevanje izvora oviranosti, odnos do oviranega telesa iz perspektive oviranega posameznika (lastna percepcija), romske družine in širše romske skupnosti.

Ključne besede: oviranost, kultura, zdravje, etničnost, raziskovanje, družbeni status.

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CULTURAL ASPECTS OF DISABILITY AMONG THE ROMA

The Roma are one of the largest ethnic minority groups in Slovenia. A lot of researchers point to a link between ill health, ethnic minority origin and poverty. Roma, throughout Europe, are often faced with poor health, which is not merely a consequence of aging, but also of social situation and situations of complex inequalities. They face lower life expectancy, diseases and infections resulting from poor housing and economic conditions, frequent pregnancies and miscarriages, chronic respiratory diseases of Roma children. In the first part the need for cultural sensitivity in social work is discussed. The second part presents ethnographical data gathered by anthropological approach exploring the Roma perspective of their interpretation of the 'disabled' and 'ill-health' body. The following topics are pointed out: terminology, the hierarchy between the various disabilities, cultural explanations why disability occurs (the cause of disability) and also the anticipated roles of an indivudal, family and Roma community in relation to the disability.

Key words: handicap, culture, health, ethnicity, reasearch, social status.

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Uvod – poznavanje etnične realnosti manjšin kot prvi pogoj kulturno kompetentnih služb

Študije o razumevanju vpliva etničnosti na hendikep so v Sloveniji skoraj neznane, v tujini pa redke, a jih je vedno več. Posebej v državah z večetničnim prebivalstvom je mogoče zaslediti objave, ki se osredotočajo na skupine domorodcev in priseljence (Stone 2005, Laird 2008). Avtorji teh raziskav ugotavljajo, da se etnične raznovrstnosti in neenakosti kažejo v odnosu do razumevanja hendikepa, bolezni in zdravja. Osebe, ki so hendikepirane ali bolne, namreč ne živijo v praznem prostoru, v okolju, za katerega bi veljala popolna odsotnost zunanjih kulturnih in strukturnih vplivov, temveč v družinah in skupnostih, za katere veljajo določene kulturne navade, ki so rezultat prevladujočih kulturnih norm, prepričanj, tradicionalnih praks.

> Z vidika socialnega dela je treba upoštevati kulturno specifične prakse pripadnikov kulturnih manjšin, ki se bolj ali manj razlikujejo od kulturno specifičnih praks dominantne družbe, z namenom zagotavljanja učinkovitih storitev. Etnična občutljivost se osredotoča na poznavanje kulturnih posebnosti posamezne etnične skupine, kamor spada poznavanje kulturnih vrednot, norm, navad in šeg, na poznavanje zgodovinskih izkušenj pripadnikov etničnih/kulturnih manjšin, zavest o njihovem aktualnem položaju v družbi in razumevanje dinamike etničnosti ter na posledice etničnega razmejevanja. (Humljan Urh 2013.)

V številnih družbah so strokovnjaki praviloma pripadniki srednjega ali višjega sloja, pripadniki etnične večine, katerih kultura je včasih bolj ali manj drugačna od kulture številnih manjšin v posamezni državi. Zato pa so različna tudi njihova pričakovanja do določenih praks in načinov razmišljanja (Husband 1995). Evropocentrične vrednote namreč oblikujejo evropski pogled na hendikep, to pa ni nujno tudi izraz razumevanja koncepta med pripadniki etničnih ali kulturnih manjšin (npr. o vzrokih ovire, načinih skrbi za otroka z ovirami). Pomembno je tudi razumevanje in upoštevanje družbene različnosti. Določene vrednote, prepričanja in vedênja niso univerzalni. Zato je pomembno vprašanje, kako dominantna večina definira hendikep in oblike oz. načine pomoči pripadnikom kulturnih manjšin, ki jih potrebujejo zaradi svojega hendikepa. Pri tem se je pomembno izogniti praksam kulturnega imperializma, tj.

> načinom vedenja in ravnanja, ki jih zatirani skupini vsiljuje dominantni simbolni in vrednostni sistem, vsiljevanju izkušenj dominantne skupine in njenega pogleda na vsakdanje življenje ter njeni interpretaciji sveta (Zaviršek 2000: 28).

Sotnik in Jezewski (2005: 15) naštejeta koncepte, ki jih je po njunem prepričanju treba upoštevati pri zagotavljanju storitev za uporabnike, ki prihajajo iz kulturno drugačnega okolja: koncepti tujstva, begunstva, imigrantstva, kulture, kulturne različnosti, stereotipiziranje, akulturacija, kulturna kompetentnost. Socialne delavke in delavce, ki se ne skrivajo znotraj profesionalne etične anestezije, temveč prepoznavajo družbene in kulturne različnosti in se odzivajo nanje, Charles Husband (1995) označi kot moralno aktivne socialne delavce in delavke. Kultura pripadnikov etničnih manjšin je namreč drugačna od kulture strokovnjakov, saj večji del strokovnjakov pripada večinski populaciji.

Groce (2005) prav tako trdi, da je treba v situacijah zagotavljanja strokovne pomoči posameznikom z imigrantskim ozadjem ali pri delu z družino, ki prakticira tradicionalne kulturne običaje, ki se razlikujejo od kulturnih običajev večinskega prebivalstva, razviti večjo etnično občutljivost. Potrebnega je več znanja in občutljivosti za to, da znajo strokovni delavci razlikovati med kulturnimi praksami, načinom preživetja kot obrambnim mehanizmom za življenje v revščini in drugimi dejanji, ki so kršitev človekovih pravic. Etnična občutljivost pomeni torej biti ozaveščen o različnih kulturnih običajih, vrednotah, prepričanjih, navadah kulturne manjšine, prav tako pa zahteva razumevanje, da vse kulturno določene vrednote, običaji, navade pomembno vplivajo na interakcije med ljudmi. Neupoštevanje tega (etnična neobčutljivost) lahko povzroči rasizem in izključevanje.

Položaj Romov na področju zdravja

Več tujih raziskav opozarja na povezavo med slabim zdravjem, pripadnostjo etnični manjšini in revščino (Ivančič *et al.* 2008, Harriss, Salway 2009, Evropski center za pravice Romov 2014). Slabo zdravstveno stanje ni zgolj posledica staranja, pač pa predvsem socialnega položaja in situacij kompleksnih neenakosti, ki zaradi vsakodnevnih eksistenčnih skrbi povzročajo npr. duševne stiske, visok krvni tlak, težave s srcem. Zato skrb za zdravje ni odvisna zgolj od hotenja posameznika in njegovih kulturnih navad, temveč tudi od širših družbenoekonomskih okoliščin, ki posameznikom omogočajo uresničevanje zdravega življenjskega sloga. Zdravje je potemtakem sposobnost, da človek obvladuje ne le svoje fizično telo, temveč tudi družbeno okolje.

Številna poročila Evropskega centra za pravice Romov (2014) navajajo veliko zdravstvenih težav Romov, kot so: krajša življenjska doba, bolezni in okužbe, ki so posledica slabih stanovanjskih in ekonomskih razmer, pogoste nosečnosti in splavi, kronične bolezni dihal majhnih otrok. Poleg tega Barany (2002: 176–177) v svojem obsežnem delu o položaju Romov v Vzhodni Evropi poroča o opazno višji stopnji fizičnih in intelektualnih hendikepov med Romi v primerjavi z večinsko populacijo ter o njihovi nižji pričakovani življenjski dobi – ta je na primer na Madžarskem 10 let nižja od večinske populacije, za bolgarske Rome pa obstaja nekaj več kot 4-krat manjša verjetnost kot za večinsko populacijo, da dosežejo 60 let starosti.

Leta 2004 je bila v Združenem kraljestvu objavljena študija o zdravstvenem položaju Romov in t. i. popotnikov (*travellers ali travelerji*) (Report on health status of Gypsy/Travellers published in UK 2005). Raziskava je pokazala, da ti trpijo za izrazito slabšim zdravjem v primerjavi z neromsko populacijo enake starosti in spola. Raziskava je pokazala celo 2- do 5-krat pogostejše zdravstvene težave med Romi in popotniki v primerjavi s preostalo britansko populacijo. Najpogostejše so bolezni dihal (astma, kronični kašelj, bronhitis), depresija in tesnobnost.Zbornik *Romi in zdravje* (2010), ki je do danes edina publikacija, ki je celovito opozorila na zdravstveni položaj Romov v Sloveniji, opisuje več primerov, na katerih vidimo, da so Romi socialno ogrožena populacija s povečanim tveganjem za nastanek zdravstvenih težav. Toda čeprav so prepoznani kot socialno in ekonomsko ranljivejša populacija, pa Slovenija nima za to posebej sprejetega programa ukrepov ali strategije na nacionalni ravni. Prav tako je malo znanih podatkov o zdravju Romov, ki bi bili sistematično zbrani. Dostopni so podatki raziskave o vedenjskem slogu romskega prebivalstva, ki je bila izvedena na vzorcu 258 prekmurskih odraslih Romov, starih med 25 in 64 let (Belović 2010: 57). Pokazali so na njihovo slabo telesno aktivnost, visok odstotek kadilcev, na čezmerno telesno težo in bolezni dihal. Med Romi je zaznati, da je skrb za zdravje pogosto drugotnega pomena, saj ima prednost skrb za eksistenco (urejanje bivalnih razmer, iskanje zaposlitve ipd.), še posebej pri tistih, ki živijo v najbolj deprivilegiranih okoljih. Zaradi vsega naštetega so Romi na področju zdravja ranljivejši, po besedah Vere Klopčič (2010: 82) celo »med zdravstveno najbolj ogroženimi skupinami«.

Metodološki opis

Uvod

Naša kvalitativna raziskava je potekala od septembra 2011 do decembra 2012. Fokus raziskovanja so bili Romi v Sloveniji z izkušnjo hendikepiranosti (telesne, senzorne, intelektualne), tako odrasli kot otroci. Osredotočila sem se na dojemanje najrazličnejših oviranosti in odnos do njih pri samih Romih in Rominjah. Oviranost in bolezen med Romi sem želela opredeliti kot kulturno posredovan koncept. Zanimale so me kulturne posebnosti v dojemanju oviranega in bolnega telesa med to etnično skupino.

Prvi korak v raziskovanju je bil posnetek stanja hendikepiranih odraslih in otrok v romskih naseljih po Sloveniji[1]. Naslednji korak je bil oblikovanje anketnega vprašalnika. Obsegal je tri tematske sklope: vloga hendikepiranega posameznika v romski skupnosti, vloga romske družine v odnosu do hendikepiranega posameznika in odnos širše romske skupnosti do hendikepa. Oblikovanje vprašalnika je nastalo ob branju knjige *Culture and disability: providing culturally competent services* (Stone 2005). Tretji raziskovalni korak je bila izvedba intervjujev na terenu.

Obiskala sem predvsem Rome in Rominje, ki živijo v slabših, materialno prikrajšanih in velikokrat izoliranih okoljih (tu se kaže tudi večja socialna izključenost v odnosu do neromskega okolja). Izvedla sem 17 intervjujev z Romi in Rominjami iz Bele krajine, Posavja, Novega mesta, okolice Grosuplja, Ljubljane, pogovarjala pa sem se tudi z devetimi ključnimi osebami (romskimi aktivisti, socialnimi delavkami, patronažno sestro, predsedniki romskih društev, prostovoljci) iz Prekmurja, z Dolenjske, iz Trebnjega, Ribnice, Kočevja. V raziskavo sem poskušala zajeti vse slovenske regije, v katerih so naseljeni Romi, vendar je bila ponekod odzivnost tako slaba, da se ljudje niso želeli pogovarjati o oviranosti ali bolezni, saj so menili, da je to »zelo občutljiva tema«. Pri nekaterih sta bila očitna sram in skrivanje (npr. gluhi deklici so nenehno iztikali slušni aparat, ko je bila v javnem prostoru). Nekateri pa so verjeli, da bi pogovor o tem v hišo prinesel zlo ali še več bolezni in trpljenja. Ljudje, s katerimi sem se pogovarjala, živijo v romskih naseljih, bodisi v zidanih hišah z urejenimi sanitarijami, elektriko in vodo bodisi v barakah brez električnih in vodovodnih napeljav. Obiskala pa sem tudi nekaj družin, ki živijo v zasilnih namestitvah, kot

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[1] Seznam zaradi nepopolnih podatkov ni objavljen, temveč je v osebnem arhivu avtorice.

sta kontejner in šotor. Pogosto v eni hiši živijo tudi do štiri generacije skupaj, ki so med seboj solidarne pri vsakdanjih opravilih (skrb za bolne, ovirane, otroke, gospodinjstvo, hišna opravila) in finančnih odgovornostih.

Pogovarjala sem se z gospo brez noge na invalidskem vozičku, z dvema mamama z otrokom z Downovim sindromom, s sinom hendikepirane mame, ki je omejene rasti in ima sklepno revmo v rokah, z dvema družinama z gluho deklico, z odraslim Romom s kombinirano oviro (gibalna in intelektualna oviranost) in njegovim očetom ter razširjeno družino, z Rominjo srednjih let, ki zaradi poškodbe hrbtenice hodi skljućeno, z odraslim Romom s cerebralno paralizo, z mamo odraslega sina, ki šepa, s številnimi mamami otrok, ki hodijo v osnovno šolo s prilagojenim programom (v nadaljevanju OŠPP), z odraslim fantom, ki je obiskoval OŠPP, in z odraslim moškim, ki je naglušen. Opravila sem tudi več naključnih, neformalnih pogovorov z drugimi člani romske skupnosti, ki nimajo oviranih otrok ali pa so zgolj sosedje ali znanci družine, ki ima oviranega člana.

Izkušnje občutljivega raziskovanja

Članek prikaže antropološki pogled na hendikep med Romi. Hendikep razumem kot družbene ovire, ki jih doživljajo ljudje zaradi telesnih, senzornih ali intelektualnih posebnosti, ovir, družbenost in telesna materialnost pa sta med seboj prepleteni. Pri raziskovanju sem upoštevala antropološki pristop oz. Geertzovo (1996) načelo raziskovanja »iz domorodskega zornega kota«, ki velja za najvplivnejši način upodobitve etničnih skupin v socialni antropologiji (Eriksen 2004).

Tiste, ki sem jih raziskovala, sem med raziskovanjem vključila kot aktivne sogovornike in s tem upoštevala načelo »emancipatorskega raziskovanja« (Dominelli 2009, Humphries 2000). S tem sem ustvarila situacije, v katerih so postali vidni in slišani. To se mi je zdelo še posebej pomembno ne samo zato, ker je bila odsotnost informatorjev zgodovinsko gledano splošna značilnost moderne znanosti (Okely, Callaway 1995), temveč tudi zato, ker je sam izbor informatorjev v meni sprožil premislek o tem, koliko v polju strokovnega veljajo za kompetentne informatorje glede na družbeno stigmo, ki so je deležni.

Tudi v socialnem delu so bili namreč uporabniki pogosto zlorabljeni tako, da so bile njihove zgodbe predstavljene posredno, kot interpretacije strokovnjakov oz. raziskovalcev, ki so transformirali individualne biografije v profesionalne reprezentacije (Urek 2005). V dialogu z »drugimi« so raziskovalci sicer slišali njihove glasove, vendar ti niso sporočali »kulturnih resnic«. Prav obrobne družbene skupine so imele vedno najmanj priložnosti, da povedo svojo zgodbo. Zato je večinska skupina njihove zgodbe razumela le v okviru lastnih, večinskih kulturnih predstav.

Interpretacije o Romih pogosto temeljijo na stereotipih, ki ustvarjajo podobo, da so manjvredni, nekompetentni. Zato številne pretekle raziskave izražajo hegemonističen raziskovalni pristop, ki utrjuje predstavo o homogenosti Romov, saj vse meče v isti koš in ne upošteva njihove heterogenosti (glede na jezik, religijsko pripadnost, socialno-ekonomski položaj). A prav zavest o raznovrstnosti lahko raziskovalcu vlije večje zaupanje v skupnosti. Prav tako pa je pomembno, da, kot pravi Clifford Geertz (1996), raziskovalec uporabi znanje, ki obsega tisto, kar ljudje, ki so predmet raziskave, vidijo, čutijo, mislijo, si predstavljajo. S takim premikom objekt raziskovanja postane subjekt raziskovanja, saj so vključeni kot posamezniki, kot pripadniki skupin, skupnosti, kulture s svojim doživljanjem, zavestjo in ravnanjem.

Kot raziskovalka sem v raziskovalni prostor vstopala z zavestjo, da se je pomembno s pripadniki kulturne manjšine posvetovati o njihovi izkušnji dojemanja in doživljanja ovir in bolezni. S tem sem zavestno naredila odmik od raziskovalnega pristopa, ki je slep za razlike (*colour blind approach*, Dominelli 1988). To pomeni, da sem izhajala iz predpostavke, da so izkušnje in potrebe Romov z izkušnjo oviranosti tako specifične, da potrebujejo posebno pozornost, v praksi zdravstva in socialnega varstva pa tudi posebne občutljive pristope.

Izogibala sem se pokroviteljstvu v raziskovanju, v katerem ljudje, ki so predmet raziskovanja, nimajo osnovnih informacij o namenu raziskovanja. S tem bi tvegala, da bi se pri njih lahko razvila občutka nezaupanja in manjvrednosti, posledica pa bi lahko bili slabši raziskovalni rezultati. V desetih letih raziskovanja sem si med Romi ustvarila nekaj poznanstev in v tista okolja sem vstopala sama. V okolja, kamor sem vstopala prvič, pa sem vstopala s »ključno osebo«, ki je imela v romskem naselju, romski skupnosti ali romski družini vpliv, ugled, poznanstva ali celo sorodstvene vezi (Rominja, romski svetnik, socialna delavka, dolgoletna prostovoljka v romskem naselju ipd.).

Vendar pa se je prav v teh okoljih pogosto zgodil efekt t. i. helikopterskega raziskovanja (Davis, Keemer 2002: 11), za katerega je značilno, da raziskovalec prileti, zbere podatke in odleti, pri tem pa nima stikov s skupnostjo, ki je predmet raziskovanja, ali jih ima zelo malo. V takih primerih so bili pogovori kratkotrajni, odgovori pa skopi. Posebej mi je ostal v spominu obisk desetčlanske družine z osmimi otroki, ki se je pred enim letom preselila iz marginaliziranega romskega naselja, od koder so zaradi konfliktov v romski skupnosti bežali, večkrat bivali tudi v gozdovih, šotorih, v podeželski vasici, v kateri pa jih okolica ni sprejela in do katere so bili tudi oni sami zelo nezaupljivi. K družini sem pristopila z Rominjo iz drugega kraja, pozno zimsko popoldne, zunaj je bilo že temno, snežilo je. Rominja je potrkala na vrata in ko jih je odprl oče, je trajalo nekaj minut, preden so nas spustili v hišo. Kljub mojemu slabemu poznavanju romščine sem vendarle razbrala, da jih je prepričevala, da gre za raziskavo o otrocih, ki hodijo v posebno šolo, da ne gre za nič škodljivega, nič hudega in nevarnega. Potem pa je še nekaj časa predstavljala sebe in šele takrat so jo bili končno pripravljeni sprejeti. Čeprav je govorila romsko in čeprav je predstavila sebe (prvi stavek, ki ga je v romščini izrekla, je bil: »Tadi Romni!« oz. »Tukaj Romi!«), mene in namen raziskave kot popolnoma neškodljiv, je trajalo razmeroma dolgo, da je družina, ki je živela v izolaciji in je bila zelo nezaupljiva, odprla svoja vrata. Pozneje se je pogovor sproščeno razvil, na koncu nama je družina še pokazala svoj skrivni kotiček, kjer so s stropa visele suhe klobase iz kolin, ki so jih imeli prejšnji teden, in zadovoljno pripomnili, da imajo za zimo na zalogi dovolj mesa.

Že ob prvih stikih z Romi se je pokazalo, da moje raziskovanje ne bo zgolj odtujeno objektivno raziskovanje, temveč sem pogosto imela tudi druge vloge. Šlo je predvsem za vzajemno sodelovanje, saj sem od Romov pričakovala podatke, ki so bili predmet moje raziskave, v zameno za podatke pa sem jim ponudila nekaj »svojega«, nekaj, o čemer sem imela znanje, spretnosti, izkušnje, lastna poznanstva (posredništvo, zagovorništvo, preskrba, informiranje, spremljanje ipd.). Večkrat se mi je celo zgodilo, da so me Romi sami najprej »zaposlili«, šele potem sem se jim lahko približala kot raziskovalka. Spomnim se ženske, ki sem jo večkrat intervjuvala ob različnih raziskovalnih temah. Ko sem jo nazadnje poklicala in ji po telefonu postavila nekaj vprašanj, me je na hitro odpravila in preusmerila temo pogovora na sina, ki kljub srednješolski izobrazbi neuspešno išče zaposlitev. Imela sem občutek, da sem se morala najprej izkazati v nečem aktualnem, praktičnem, s čimer so se v življenju tedaj spopadali, šele potem je bil čas za mojo raziskavo.

Na vzajemne odnose sem zdaj vedno pripravljena in jih sprejemam kot nekaj pričakovanega. Kot raziskovalka od ljudi, ki jih raziskujem, dobim podatke, vendar pa s tem lahko pridobijo tudi osebe, ki so raziskovane ali celo celotna skupnost, ki je predmet mojega raziskovanja. To so situacije, ki zmanjšujejo neenakosti med raziskovalcem in raziskovano skupino, prav tako pa povzročijo tudi pozitivno spremembo v njihovem življenju (Liamputtong 2007). Pri svojem raziskovanju sem pogosto delovala kot informatorka, ko so me Romi spraševali o določenih pravicah, formalnih postopkih. To pomeni, da sem se pogosto znašla v situacijah, v katerih sta se vlogi raziskovalke in socialne delavke prepletali in dopolnjevali.

Kulturni vidiki doživljanja hendikepa in bolezni med Romi

O besedah, hierarhiji in izvoru hendikepa med Romi

Koncept hendikepa ni univerzalen, temveč nanj vpliva določeno kulturno okolje. Groce (2005: 5) navaja, da veliko jezikov ne pozna oz. nima posebnega skupnega poimenovanja za hendikep. V različnih okoljih so se uveljavila različna kategorična poimenovanja, ki obsegajo določene ovire: npr. slepi, gluhi, gibalno ovirani. Težko pa je z eno besedo pojasniti oviro ali določene vrste oviranosti, še posebej fizično nevidne (kot je motnja v duševnem razvoju).

Kultura kot način življenja ljudi, zbirka idej in navad, se prenaša iz generacije v generacijo. Gre za naučeno značilnost določene družbene skupine, ki naj bi bila skupna vsem njenim članom ali vsaj večini. Določa, kako njeni pripadniki čutijo, mislijo, usmerja njihovo delovanje, določa njihov pogled na življenje. Člani določene kulturne skupine navadno dojemajo svojo kulturo kot samoumevno, »naravno«, tiste, ki v njihovi skupini mislijo, čutijo in delujejo drugače, pa kot »notranje tujce«. Vendar pa različne kulture opredeljujejo različne sprejete načine vedenja, ki se od družbe do družbe razlikujejo. To lahko povzroči kulturne nesporazume. Enega od takih nesporazumov sem doživela tudi sama na začetku svojega raziskovanja. Na teren sem najprej vprašala, ali je v posameznih romskih naseljih »kakšen invalid«. Po nekem pogovoru s socialno delavko iz kraja, v katerem sem prav tako obiskala eno največjih romskih naselji, pa sem spoznala, da sem v odnosu do uporabe besed izhajala iz popolnoma etnocentrične pozicije, saj se njeni podatki o številu hendikepiranih Romov v naselju niso ujemali s podatki, ki sem jih pridobila od Romov. Socialna delavka je naštela veliko oseb, ki imajo oznako duševne motnje v razvoju, Romi, s katerimi imam poglobljene stike, pa teh ljudi niso omenjali. Pozneje se je pokazalo, da Romi z besedo *invalido* označujejo zgolj fizične in senzorne tipe oviranosti (pri tem ne razlikujejo različnih vrst ovir – gluhi, slepi ipd.). Za otroke , ki imajo motnjo v duševnem razvoju, uporabljajo besedo *ubogi otrok*, za odraslega pa *revež* oz. ga opišejo kot nekoga, ki »nima vse čisto v glavi«. Ti ne sodijo v skupno poimenovanje *invalido*. Nesporazum, ki izhaja iz lastne raziskovalčeve pozicije, je očitno kulturno zaznamovan. Po tem dogodku in ko sem obiskala še nekaj Romov in raziskovala njihove zgodbe, sem bila na to pozornejša. Poznavanje oz. razumevanje kulturno zaznamovanih besed in kulturnih načinov uporabe besed se je pokazalo kot pomembno načelo občutljivega raziskovanja.

Groce (2005) trdi, da je v razlagah o izvoru ovire v ozadju težnja po odgovoru, ali so starši oviranih otrok kakorkoli soodgovorni za njihovo oviro. Ta interes izhaja iz težnje po »psihološki distanci« do oviranosti, saj

> posamezniki poskušajo najti logičen razlog, zakaj se je pojavila oviranost pri nekom drugem, in s tem sebi poskušajo zagotoviti, da se jim ne bo zgodilo kaj podobnega (*ibid.*: 7–8).

Med Romi se pojavljajo različne razlage o oviranosti oz. bolezni. Razvrstimo jih lahko v tri skupine: 1) religijske in magične razlage o njihovem izvoru; 2) medicinske razlage in 3) socialno-ekonomski dejavniki.

Religijske in magične razlage

Evans-Pritchard (1937) pojasnjuje, da je v družbah, v katerih prevladujejo religijske in magične interpretacije dogajanj, večja verjetnost, da ljudje tudi oviranost razumejo kot božjo kazen, ali pa so ljudje z ovirami prepoznani kot žrtve čarovništva. Groce (2005: 7) ugotavlja, da še danes v številnih kulturah povezujejo oviranost z »božjo kaznijo, znakom incesta ali ‚slabe krvi' v družini, zakonske nezvestobe moškega, nesreče ali usode«. Srečala sem veliko Romov, ki verjamejo, da je rojstvo otroka s prirojeno oviro znamenje božje kazni staršev.

> Od bratranca hčerka je naredila samomor, oni so čudni, tam je veliko nasilja, alkohola … Saj je bila reva … Tam je nekaj čudnega v družini, kot da nekaj visi nad njimi … Ne vem, kaj bi to bilo. (Mlajši moški.)
>
> Čim je kero dete bolno, so takoj med Romi kletvice, pa da jih je bog štrafal. Zato nočejo o tem govorit. (Starejša Rominja.)
>
> Tako je, bog je tako hotel in tako je. (Oče otroka z oviro.)
>
> Jaz mislim, da je to božja kazen. Neka sila je. Ja, povem to, kaj mislim. Mogoče sem kdaj kaj zgrešila in to ni dalo na mene, ampak na mojo hčerko. Sigurno. (Mama odrasle hčerke, ki je gluha.)

Ovira kot posledica božje kazni se pogosto prepleta tudi z argumentacijami o nalezljivosti ovire (Goffman 1991) oz. poluciji (Douglas 2005). Stigma ima izrazito lastnost nalezljivosti, saj velja prepričanje, da vse, kar je bilo v stiku z »umazanijo«, lahko postane »umazano« (neposreden stik, govor o telesu z oviro). Groce (2005: 7) ugotavlja, da je tudi v nekaterih imigrantskih skupnostih v ZDA ideja o nalezljivosti zelo razširjena. Prav tako so ideje o nalezljivosti razširjene med nekaterimi ameriškimi domorodci, ki svojim otrokom prepovedujejo dotikanje medicinskih pripomočkov, ki jih uporabljajo osebe z oviro (npr. invalidski voziček, bergle, slušni aparat), saj se bojijo, da se bodo prek stika nalezli oviranosti (Thomason 1994).

> Bog lahko tudi tebi takega otroka pokloni, če se ne obnašaš lepo. Se zgodi, če eden nekaj ukrade, pa na primer lahko ženska rodi ubogega otroka. To je nalezljivo. Poznam žensko, ki je bila noseča in je grdo govorila o otroku iz vasi, ki je škilil. Potem pa je tudi sama rodila škilavega otroka. Pa je bog to pogledal! To se dogaja nosečim. Zato nikoli ne smeš grdo govoriti, nikoli ne veš, kdaj se to lahko tebi zgodi, sploh nosečnicam. (Rominja srednjih let, mati treh otrok.)
>
> Nobenkrat med nosečnostjo nisem hodila na preglede, nič me ni bolelo. Zakaj bi hodila za brez veze? Poglej nas, ciganke, ki ne hodmo, zdej pa poglej une, ki grejo tja za vsako figo – majo raka pa take stvari. Kaj guraš tam, kjer je vse zdravo? Potem pa še prej pride … (Starejša Rominja, mati šestih otrok.)

Oviro, ki jo oseba pridobi pozneje v življenju, pa Romi povezujejo z medicinskimi dejstvi (amputacija noge kot posledica sladkorne bolezni, zdravniška napaka ob preveliki dozi zdravila za ledvice, ki je poškodovalo slušni center, ipd.) ali z drugimi okoliščinami (npr. izguba noge zaradi strelne rane, prometna nesreča, počena medenica in vretence zaradi fizičnega nasilja). Pogosto tudi takrat, ko verjamejo, da je hendikep posledica tujih napak ali nesreč, ljudje z ovirami ne veljajo za nedolžne žrtve in jih še vedno povezujejo z božjo kaznijo. To je še posebej opazno med materami oviranih otrok, ki krivdo prevzemajo nase.

> Moji hčerki so zdravniki poškodovali slušni živec zaradi prevelike doze zdravil, ko je bila bolna na ledvicah. Verjamem, da mi je bog nekaj hotel s tem povedati. Ne vem, mogoče sem kaj takega naredila v življenju, pa me je hotel kaznovati. Še danes si to očitam. (Mama odrasle gluhe deklice.)

Medicinski dejavniki (genetski razlogi, zdravniška napaka, dostopnost do zdravstvenih storitev, nezdrav življenjski slog – čezmerno uživanje alkohola)

Sodobna znanost je spremenila odnos do iskanja vzroka oviranosti. Ovire ljudje ne vidijo več kot božjo kazen, temveč vzroke zanjo moderna znanost išče v genetiki, posledicah virusnih okužb in nesrečah. To so danes najpogostejše in najbolj družbeno sprejemljive razlage o vzrokih oviranosti (Groce 2005: 7). To ni izjema niti med Romi, še posebej v okoljih, v katerih je zaznati večjo materialno preskrbljenost, višjo izobrazbeno raven in manjšo socialno izoliranost posameznih družin v romskem naselju.

> Tudi od moža brat ima Downow sindrom in smo vedeli, da bo nekaj takega. Ko sem bila noseča, ni bilo nič posebnega, vse normalno. (Mama17-letnega otroka z Downovim sindromom.)
>
> Moja sestra ima tudi punčko z Downovim sindromom. Slišala sem že, da se lahko to prenaša v družini. (Mama 14-letne deklice z Downovim sindromom.)
>
> Hčerka je hudo zbolela, ko je bila stara leto in en mesec. Peljali smo jo direktno k zdravniku, tam pa so nas na hitro odpravili. Rekli so: »Nismo mi samo za cigane tukaj, punčka je samo prehlajena!« A ona je bila hudo bolna, bila je čisto mlahava, na rokah mi je kar ves čas ležala. Ko je prišla druga zdravnica z dopusta, so naročili cel kup preiskav in takrat so ugotovili, da ima meningitis. Z veliko iglo so ji dali injekcijo v vrat in takrat so ji stisnili slušni živec. Zaradi tega je oglušela. (Starša gluhe deklice.)

Zadnji primer ponazarja tudi primer diskriminatorske zdravstvene obravnave. Prav tako spodbuja premislek o tem, ali bi bili romski otroci prav tako hendikepirani, če ne bi bili Romi, oz. ali so Romi pri zagotavljanju zdravstvenih storitev prav tako marginalizirani in potemtakem deležni slabše kakovosti storitev.

Socialno-ekonomski dejavniki

Nekateri Romi, ki živijo v neurejenih bivalnih razmerah, verjamejo, da je rojstvo otroka z oviro posledica materialnega pomanjkanja, npr. dejstva, da živijo brez vode. Veliko staršev otrok, ki se šolajo v posebnih šolah, prepoznava majhne izobrazbene in zaposlitvene priložnosti kot posledico usmerjanja romskih otrok v posebne šole.

Nekatere kulture razlikujejo različne vrste hendikepov in jih hierarhizirajo. Oliver (1993) navaja nekaj primerov: v nekaterih kulturah so vidni hendikepi ovira pri popolni participaciji ljudi v skupnosti, druge vrste hendikepov pa kultura razume kot božji dar. Ponekod ljudi z epilepsijo obravnavajo kot nadarjene, saj predpostavljajo, da lahko komunicirajo s pokojnimi v času epileptičnega napada. Nekje verjamejo, da je hendikep rezultat družinskih slabih navad ali slabega oz. prepovedanega dejanja, ki ga je posamezni družinski član ali družina storila, in velja za sramoto. Pri Romih se je pokazalo, da že samo poimenovanje izraža hierarhizacijo oviranosti. Tako skupna beseda *invalido* vključuje vse vrste ovir, ne pa tudi *ubogih otrok* oz. *revežev,* ki tako v besedi kot tudi v odnosih oz. interakcijah znotraj romske skupnosti veljajo za tiste, »ki ne pripadajo«, tj. se razlikujejo od »zdrave«, neovirane skupnosti. Odnosna razmerja družine in predvsem širše romske skupnosti do oviranosti so pokazala izrazito hiearhizacijo, pri tem pa velja med Romi intelektualna oviranost za najhujšo vrsto oviranosti.

> Ni problem, če je človek bolan, če je na vozičku. Problem je, če si invalid v glavi. Takrat pa ne moreš sam nič. (Starejši gospod s cerebralno paralizo.)
>
> Najhuje je, če je človek prizadet v glavi. (Mama otroka z Downovim sindromom.)
>
> Taki, kot je on, so največji reveži. Sam si ne more pomagat. (Romska skupnost o moškem srednjih let z intelektualno oviro.)

Dojemanje hendikepa med Romi – perspektiva posameznika, romske družine in romske skupnosti

Osebno doživljanje hendikepa in bolezni med Romi

Dandanes vsaka skupnost teži k temu, da bi se posameznik z oviro čim bolj vključil (Groce 2005). Vendar je njegova vključitev odvisna predvsem od njegove pričakovane vloge kot odraslega. V številnih imigrantskih družbah v ZDA je sposobnost zadovoljevati materialne potrebe družine odločilna pri določanju položaja ovirane osebe v skupnosti (*ibid.*: 9). Pomembno je torej vprašanje, kakšen je njegov ekonomski prispevek v družini, kakšne so priložnosti za poroko, kakšen vpliv ima pri odločitvi, kje bo živel, kdo bo zanj skrbel ipd. Vse to so bila vprašanja, ki sem jih postavila odraslim oviranim Romom in staršem oviranih otrok, s katerimi sem se srečala pri svojem raziskovanju.

Tabuizacija oviranosti in bolezni je med Romi zelo opazna. Pogosto sem zaznala nelagodje sogovornikov, saj so skoraj praviloma težko spregovorili o osebnem doživljanju lastne oviranosti ali se poglobljeno pogovarjali o oviranosti lastnega otroka. Pogosto so me ključne osebe romskega porekla, sami nehendikepirani, opozarjali, da je to težka in občutljiva tema, da bom težko dobila podatke, ker številni svoje hendikepirane otroke skrivajo, ne želijo, da drugi izvejo zanje ipd. Stigma, ki pade na družino, v kateri se rodi otrok z oviro, je lahko v širši romski skupnosti razumljena tudi kot božja kazen za greh, ki ga je storila družina, to pa bi za družino lahko pomenilo tveganje pred izključitvijo znotraj romske skupnosti.

> Poznam družino, ki skriva svojega otroka, ki se je rodila gluha, ne čuje, starša o tem nočeta sploh govoriti. To sem slišala od drugih. Deklico skrivajo, ko ima slušni aparat, nosi trak čez ušesa, ko grejo ven v mesto, dajo njen aparat dol, da se ne vidi, da je gluha. Tako ostali Romi niti ne vejo, kaj ji je. (Starejša Rominja.)

Lahko pa je tabuizacijo razumeti tudi v pomenu druge teorije izvora oviranosti med Romi, teorije o nalezljivosti. Marsikdo namreč verjame, da že sam govor o bolezni ali oviri prikliče v hišo bolezen. Nekateri Romi so ob tem vraževerni in pod vzglavnik dajejo npr. oster nož, za katerega verjamejo, da bo branil družino pred zlimi duhovi (osebni pogovor s patronažno sestro, ki je več let obiskovala romska naselja).

Med Romi je zaznati izjemno veliko tistih, ki imajo nizka pričakovanja do svojega zdravja.

> Srečala sem veliko družin, kjer so kadili ob dojenčku. Ali pa primer bolnice, ki se je zdravila s kisikom na domu. Živela je doma, družina je zelo sodelovala, skrbeli so za aparat, dajanje zdravil. So pa še vedno kadili, kar ne bi smeli. Pogosto je tako, da bi imeli zdravila, ki bi vse pozdravila, ne bi pa radi spreminjali življenjskega sloga. (Patronažna sestra, ki je več let obiskovala romska naselja.)

Ob pogovorih so prevladovali zelo izraženi občutki strahu pred zdravnikom, pred spoprijemanjem z lastnim zdravjem oz. boleznijo. Pogosto so mi pripovedovali o strahu pred zdravniki, a brez utemeljenega razloga.

> Čim manj zdravnika vidim, bolj sem zadovoljen. Tudi zobozdravnika me je strah. Raje bi šel kače futrat, kot pa bi šel k zobarju. (Rom srednjih let.)
>
> K zdravniku grem šele, ko skor na tla padem. (Rominja srednjih let.)
>
> Do bolezni vlada nek velik strah. Ves čas slišim zgodbice, kako ima ta ali on otrok težave s srcem, takoj ko nekaj ni tako, ko se njim zdi, kar začnejo govoriti, da je otrok bolan. Se zelo bojijo bolezni. Prevladujejo panični odzivi in pretiravanje. Tudi recimo pred rojstvom ne želijo kupovati oblekic, ker se bojijo, da z otrokom ne bo vse v redu. Kupijo šele, ko se otrok rodi. Pogosto bolnemu otroku zelo popuščajo, on mora dobit vse, kar hoče, ker je bolan. Velik je strah, da se otroku kaj zgodi. Če samo pade, je velika panika, krivda drugih, takoj govorijo, da se je zelo poškodoval, četudi ima samo eno praskico. Tudi ko je kak manjši pretep, ljudje pripovedujejo, kot da so skoraj umrli in so vsi polomljeni. Na koncu pa vidim, da imajo eno manjšo rano. (Prostovoljka, ki je več let delala v romskih naseljih.)

Darja Zaviršek (1994: 231) ugotavlja, da se status oviranih romskih žensk v družini v primerjavi z drugimi ženskami praviloma poslabša. Doživljajo več zanemarjanj, poniževanj, zlorab, osamljenosti. Drugače pa je s prizadetimi moškimi – njihov status je boljši, še zlasti če je njihova prizadetost posledica vojaških aktivnosti. Pogovarjala sem se s tremi odraslimi Rominjami s telesnimi ovirami (amputacija noge po sladkorni bolezni, poškodba noge zaradi nepojasnjenih razlogov, skljućena hoja zaradi poškodbe hrbtenice), ki so opisovale pritiske, ki jih čutijo iz okolja v odnosu do pričakovanih ženskih skrbstvenih vlog. V dveh primerih, v katerih ženski nista upoštevali medicinskih navodil glede nujnega operativnega posega, je bilo opaziti zelo izražen strah pred izgubo samostojnosti in bojazen, da bi se zmanjšala vloga ženske glede na tradicionalna pričakovanja. V primeru amputacije noge pa se je prav izguba samostojnosti pri mobilnosti pokazala kot najhujše osebno trpljenje te ženske, razlog za izolacijo, skoraj neobstoječe stike s sorodniki in stigmatizacijo širše romske skupnosti. Ko je žensko telo postalo neuporabno, nekoristno in zgolj predmet oskrbe drugih, sta ga družina in skupnost zavrgli. Tudi obe ovirani ženski, ki poznata gospo brez noge, sta jo dojeli kot *veliko revo* in se bojita, da bi se njima zgodilo kaj podobnega. Strah pred izgubo samostojnosti in možnosti opravljanja skrbstvenega dela za druge je za ovirane Rominje, tudi na račun lastnega zdravja, prevladujoč.

> Zdravniki so mi rekli, da bi morala dati nogo odrezat, vendar jaz nočem, se bojim, kako bom brez ene noge? Zdravniki bi jo odrezali, a jaz ne dam. Kaj bom brez noge, kako bom? (Starejša telesno ovirana Rominja, mama oviranega otroka.)
>
> Bojim se. Sej me ni strah sama operacija, sem imela dvakrat carski rez, pri punčki in pri fantu. Strah me ni, samo jaz se bojim, da bi invalid ratala. Lahko da bo potem še slabše, lahko me čisto dol potegne. Kako bom potem skrbela za moje otroke? (Rominja s poškodovano hrbtenico, ki hodi zelo skljućeno.)
>
> Od kolena dol nimam noge. To je bilo zaradi sladkorne. To nisem jaz vedela, potem me je še kap, možganska. Nisem vedela, da imam sladkorno, zelo me je bolelo, jaz pa jočem, jočem, kričim, kričim, mislim, da bo boljše, čakam, čakam, dolgo sem čakala, sem upala, da bo samo od sebe bolje, potem pa vidim, vendar nisem želela stran dati noge. Pa je bilo že zelo hudo in sem morala pod nujno. Sedaj pa nič ne morem, drugi mi nočejo pomagati. (Starejša Rominja z amputirano nogo.)

Po drugi strani pa je pri romskih starših zaznati izrazito, skoraj panično skrb za otroke. Patološki strah in zelo izražen zaščitniški odnos je zaznati v odnosu do otrokovega zdravja, prav tako pa tudi nezaupanje staršev do institucij, zlasti do zdravstvene obravnave njihovih otrok. Verjetno je to posledica slabih izkušenj z ustanovami iz preteklosti in slabe zdravstvene neinformiranosti.

> Otroci ne smejo zajamrat, takoj jih peljemo na pregled. (Oče treh otrok.)
>
> Spominjam se mame, ki se je dolgo upirala, da bi šla hči k specialistu. Bilo jo je strah, imela je veliko nezaupanje do zdravnikov, da bi se hčerki kaj zgodilo. Potem sem spremljala to dekle in njeno mamo na gastroskopijo, saj sem jo edino tako pripravila do pregleda. Ko je dala zdravnica gastro cevko not, je mama rekla: »Ne boš ti mučila mojega otroka! Daj zdravila!« in prekinila postopek. (Patronažna sestra.)

Odnos romske družine do hendikepiranega člana

V večini zahodnih družb je norma nuklearna družina, v več kot v 94 odstotkih družb, gledano iz perspektive večkulturnosti, pa je norma razširjena družina (Groce 2005: 9). Avtorica trdi, da v večini drugih držav in v večini imigrantskih skupnostih v ZDA razširjene družine določajo, kje in s kom kdo živi, s kom se poroči in kdo izvaja zdravstveno pomoč.

Številne družine so poudarjale velik pomen skrbi za osebo z oviro ali dolgotrajno bolnega člana. Tudi vse družine, ki sem jih obiskala, skrbijo doma za družinskega člana z oviro. To sicer ne izključuje možnosti institucionalne oskrbe Romov (npr. v socialnih zavodih, bolnišnicah, domovih za stare), vendar so taki primeri v manjšini (predvsem v primerih najhujših oblik oviranosti, v katerih je potrebna tudi medicinska oskrba). Zelo opazen vzorec družinske oskrbe lahko z veliko verjetnostjo pripišemo njihovemu statusu brezposelnosti, ki jim omogoča čas za skrbstveno delo. Še posebej ženske v družini prevzemajo vlogo skrbnice in podpornice. Srečala sem družino, v kateri je mati v odnosu do 30-letnega sina v vlogi gospodinje, njene hčere in vnukinje zagotavljajo socialne stike in pogovore, najmlajša, dveletna pravnukinja pa »skrbi« za animacijo in igro.

Skrb družine za osebo z oviro obsega tudi popoln nadzor nad razpolaganjem z denarjem, odločanjem o dejavnostih, stikih, o prihodnosti osebe z oviro. Veliko staršev je trdilo, da je njihov »ubogi otrok« večni otrok, ki je nesamostojen, odvisen, brez prihodnosti. Ko sem starše oviranih otrok vprašala, kako vidijo svojega otroka čez 20 let, so jih navadno videli kot enako odvisne od primarne družine in nesamostojne, kot so bili v času našega pogovora.

> Meni je on zmeraj isti. Mislim, da se ne bo oženil. Nima občutka … On je večen otrok. (Mati 17-letnega otroka z Downovim sindromom.)
>
> Je nesamostojna, ne more iti sama v mesto, ne zna se zmenit, ne zna iti sama na avtobus, gre samo sama po naselju, tu se počuti varno, za vse ostalo potrebuje spremstvo. Če bi bila normalna, bi bila že poročena. Ona ima zdaj facebook in ji moški pišejo, ampak ona ne razume nič. Vidiš, ko je hodila v posebno šolo in ne zna jim nazaj odpisati in zato skoz mene kliče, mama, mama, pridi. Pa pišem v njenem imenu in ji prevajam. (Mama 26-letnega gluhega dekleta.)

Pri vseh družinah, ki sem jih obiskala, se je pokazalo, da se po rojstvu oviranega otroka s prirojeno oviro družina ni odločila za več otrok. Oviran otrok je bil zadnji otrok v družini (z izjemo otrok, ki so usmerjeni v posebno šolo zaradi drugih razlogov).

> To je njun prvi otrok, starša bosta šla dati kri, da vidijo, če je z njima kaj narobe, strah ju je, da bi bil drugi otrok tudi gluh. (Rominja o družini, v kateri se je rodila gluha deklica.)
>
> Pogosto, ko se rodi hendikepiran otrok, se na tem ustavi, starši se zelo bojijo imeti še kakšnega otroka. (Rominja na splošno o dojemanju oviranosti med Romi.)
>
> Ona je moj zadnji moj otrok od štirih. Potem se nisem več upala zanositi, da se ne bi kaj takega zgodilo še drugim otrokom. Kaj se zna! (Mama 26-letnega gluhega dekleta.)

V večini primerov je opaziti normalizacijo otrokove ovire znotraj ožje in tudi razširjene romske družine, še posebej kjer več generacij živi pod eno streho. Družine so se naučile živeti z oviranimi člani, razviti svoj način komuniciranja, npr. z gluhimi otroci ali naglušnimi odraslimi, in to jim ne povzroča nikakršnih ovir v vsakdanjem življenju. Več ovir je zaznati v komunikaciji širše skupnosti in oviranega člana.

> Bog ne daj, da jo skrivam. Sej jo vsi poznajo in imajo radi. Ko pridem v trgovino z njo, jo ogovorijo in radi jo imajo. Ne skrivam je, to pa ne. Rada jo kažem okrog. Sej ko je bila majhna, sem jo, kamorkoli sem šla, s sabo vzela, sina pa puščala doma. Bolj sem vozila njo okrog kot sina, ki ni invalid. Rada jo imam tako, kot je. Sej je ona normalen otrok in pameten, ni ona prizadeta. Samo ne sliši in ne govori. (Mama gluhe odrasle deklice.)
>
> Ko smo prišli iz porodnišnice, so jo v družini normalno sprejeli, nič posebnega, kot vsakega drugega otroka. Nič me niso veliko spraševali, kaj ji je, čeprav se ji je na obrazu takoj videlo, da je drugačna. Otrok je isti kot vsi drugi. (Mama 14-letne deklice z Downovim sindromom.)

Bolj poglobljeno raziskovanje odkrije položaj oviranih Romov v družini, ki bi ga lahko opisali z antropološkim konceptom liminalnosti (Turner 1969). Hendikepirani pripadniki večinske, dominantne družbe so pogosteje vključeni v razne oblike rehabilitacijskih in terapevtskih storitev, hendikepirani Romi pa zavzemajo nekakšen vmesni položaj, tj. položaj liminalnosti, v katerem niso popolnoma aktivno udeleženi v vsakodnevnih pomembnih družinskih opravilih in odgovornostih, hkrati pa jih družina sprejema kot polnopravne člane. Po eni strani so torej fizično navzoči, po drugi pa socialno izolirani. Pri bolnih ljudeh je ta liminalnost, lahko bi rekli socialna suspendiranost, začasna, omejena na čas trajanja bolezni, pri oviranih osebah pa je lahko dosmrtna.

> Nič ne počnem. Vsak dan je isti. Posedam, gledam televizijo. Grem ven na sprehod po naselju i tako ... (Mlajši moški z intelektualno in telesno oviro.)
>
> Pustimo ga, da dela, kar hoče. Saj nič kaj dosti ne more. Je ubogi. Ima še vedno plenice … (Mama 17-letnega sina z Downovim sindromom.)

Vendar se tako pri Romih kot tudi v drugih družbah pojavljata tako sprejemanje kot izključevanje hendikepiranih oseb. Še posebej v okoljih, ki se srečujejo z bolj izrazitim materialnim pomanjkanjem in socialno deprivacijo, je ovirana oseba, ki ne more materialno prispevati k blaginji družine, izločena. Prepoznati je mogoče več vrst izključevanja oviranih Romov v družini:

- izobrazbena izključenost (otroci se ne šolajo, niso vpisani v noben program),
- fizična zanemarjenost (slabša oblačila, slabša prehrana, brezbrižnost do zdravja otrok),
- skrivanje oviranih otrok (oddaja v zavod, oddaja otrok k sorodnikom, zanikanje ovire).

Odnos romske skupnosti do hendikepiranega člana

Gorce (2005) trdi, da zelo povezane skupnosti svojim članom zagotavljajo podporo, hkrati pa nadzirajo ***življenje oseb z ovirami*** in tudi to, kako z njimi ravna družina. Tako ima lahko pogled sorodnikov, prijateljev in sosedov velik vpliv na odločitve družine in posameznika z oviro tudi širša skupnost. V nekaterih kulturah ljudje neodvisnost razumejo tudi v situacijah, v katerih oseba z oviro prejema podporo, vendar pa je odvisno, ali podporo izvaja neformalna mreža ali institucija. V prvem primeru ovirana oseba v skupnosti ohrani svojo neodvisnost, v drugem primeru, v katerem postane predmet institucionalne oskrbe, pa jo izgubi.

Med Romi je zelo opazno prepričanje, da mora za bolnega, ostarelega ali hendikepiranega posameznika poskrbeti družina. V vseh primerih, s katerimi sem se srečala v času raziskovanja, razen v primeru najhuje hendikepiranih otrok, ki so institucionalizirani v bolnišnici zaradi potrebe po stalni medicinski oskrbi, so hendikepirani otroci in hendikepirani odrasli živeli doma. Tam je član družine, najpogosteje pa razširjena družina prevzela skrb za osebo. Najbolj aktivno so to vlogo opravljale ženske, Rominje, najpogosteje tiste, ki so že skrbele za svojega majhnega ali odraščajočega otroka. Vendar razumevanje odvisnosti in neodvisnosti med Romi ni odvisno od dejstva, da je oseba v skrbstvenem razmerju, temveč od izvajalca te skrbi. Tako skrb družine za hendikepiranega posameznika ne pomeni njegove odvisnosti. Živeti doma, v širši romski skupnosti in biti odvisen od neformalne podporne mreže, ne pomeni odvisnosti. Če je za nekoga poskrbljeno v družini, se človeka še vedno vidi kot neodvisnega in ima možnost za neformalne oblike podpore, šele institucionalna skrb pa pomeni dejansko izgubo neodvisnosti.

Položaji oviranih oseb v romski skupnosti so različni. Opaziti je velik razpon odnosov, ki bi jih lahko opredelili od popolnega izključevanja, zanemarjanja, ignoriranja, norčevanja in zasmehovanja do usmiljenja, pomilovanja in nazadnje do popolnega sprejemanja. Prav tako je bilo zaznati, da ovira sama po sebi ali vrsta ovire ni prevladujoče merilo izključenosti, temveč je merilo razumevanje nastanka ovire (torej njen izvor). Zgolj v nekaterih situacijah je romska skupnost opredelila intelektualno oviranost kot »najhujše možno, kar se človeku lahko zgodi«. Temu so številni pripisovali magičen izvor. Negativen in magičen odnos do intelektualne oviranosti se med Romi kaže tudi v besedah. Intelektualna ovira ne sodi v splošno kategorijo *invalido,* temveč jo tudi besedno izločijo in ji dajo drugo poimenovanjem, in sicer *ubogi otrok* (za otroka) in *revež* (za odraslega). V tem je zaznati tudi precej pomilovanja in usmiljenja do vseh oseb z oviro. To je lahko eden od argumentov za to, da skupnost ovirane Rome ohranja v situacijah liminalnosti.

> To so zelo ubogi ljudje. Meni se taka oseba smili. (Rom srednjih let.)
>
> Težko je biti invalid. Pa tudi smilijo se nam. Navajeni smo na njega, da je tak. Je pa ubogi, nimaš kaj. (Več sosedov, ki živijo v neposredni bližini intelektualno in telesno ovirane osebe.)

V nekaterih romskih skupnostih, ki jih sestavlja razširjena družina, obstaja vzorec, ki kaže ekonomski interes družine. Številne družine, v katerih je prepoznati vzorce kulture revščine, živijo v večgeneracijski izključenosti, srečujejo se z generacijsko izključenostjo iz trga dela in so znotraj romske skupnosti razvili lastne vire ekonomije. Ti so bodisi ekonomska menjava znotraj romske skupnosti bodisi iskanje priložnosti zaslužka v obstoječem večinskem socialnem sistemu.

Poglejmo nekaj primerov logike ekonomske menjave znotraj romskih skupnosti. Mlad moški je v otroštvu doživel prometno nesrečo. Tako hudo si je poškodoval nogo, da še danes zelo šepa. Kot otroka ga je družina poslala v zavod, saj je bila doma velika revščina. Rominja iz sosednjega naselja mi je pripovedovala o odnosu njegove družine:

> Danes fehta denar in se klati po celi državi in denar nosi domov. Njegova družina izkorišča njegovo šepanje za to, da se ljudem smili in da tako več zasluži. Je dvakrat revež, prvič zaradi noge, drugič pa mu še denar doma pobirajo.

Podoben vzorec je zaslediti pri družinah, ki so v svojo oskrbo vzeli starejšo osebo, ki sama ne more skrbeti zase. V zameno za skrb se dogovorijo za njeno pokojnino, invalidsko nadomestilo ali denarno socialno pomoč. Pogosto so mi socialne delavke pripovedovale tudi o visokih obrestih, ki jih med seboj zaračunavajo ob posojanju denarja in o visokih medsebojnih računih za prevoze k zdravniku ali v bolnišnico na preiskave.

Naslednji primer ponazarja logiko ekonomske koristi v odnosu do obstoječega socialnega sistema.

> Spomnim se, ko je pedagog prišel v posebno šolo in so starši svojim otrokom rekli: »Pleši pleši! Delaj se neumnega, da bodo denar dali!« To so taki, ki so delali svojo deco neumno, a tak so pametni, da so ogoljufali strokovnjake samo zato, da bi dobili denar. (Starejša Rominja iz večjega romskega naselja.)

Take situacije so še posebej pogoste v okoljih, v katerih je pretok informacij med skupnostjo večji, v katerih skupnost izraža višjo stopnjo informiranosti o sistemu obstoječih socialnih pravic v primerjavi z Romi, ki živijo v materialno manj urejenih okolij in je pri njih opaziti tudi višjo stopnjo neizobraženosti. Tako je bilo moč opaziti dva pojava. Nekateri starši so kritizirali sistem posebnega šolstva, saj so menili, da ta poneumlja njihove otroke, jih ne pripravi za življenje (pogosto so to ponazarjali z izjavami: »Končal je posebno šolo, pa se zna samo podpisati!«).

Čeprav obstoječi sistem deluje po načelu izključujočega vključevanja (pridobiti moraš diagnozo, da pridobiš pravico do materialne podpore), pa so nekateri starši romskih otrok v tem videli tudi priložnost za ekonomsko korist. Že res, da prav družba ustvarja hendikepirane Rome, ker jih usmerja v posebne šole, jih prikrajša za poklicno izobraževanje, jih dela manj zanimive za trg dela in jih s tem potiska v kulturo odvisnosti, pa vendar je dodelitev statusa invalida (ki ga otroci, ki končajo OŠPP, pridobijo po Zakonu o družbenem varstvu duševno in telesno prizadetih oseb [1983] in s tem pravico do invalidskega nadomestila) lahko tudi način materialne preskrbljenosti družine. Tako v nekaterih primerih usmeritev otroka v posebno šolo za družino pomeni stigmo in izključevanje, lahko pa pomeni tudi priložnost za finančno korist. Romi v Sloveniji, pa tudi drugod po Evropi, so ena od ranljivih skupin, katere socialni položaj je, v primerjavi s položajem večinskega prebivalstva, slabši. To je še posebej očitno v strukturni brezposelnosti Romov. Ta v vseh evropskih državah presega 50-odstotno brezposelnost Romov (Barany 2002, Humljan Urh 2013).

Analogijo preživitvene strategije revnih Romov, ki z izključevanjem (z etiketo duševne motnje otroka) postanejo vključeni (pridobijo določene socialne pravice) lahko vidimo v Agambenovem (2004) konceptu »golega življenja«. »Golo življenje« se nanaša na minimum človeške eksistence, torej na čisto biološko bivanje. Gre torej za očitno dvojno pozicijo, ki temelji na vključitvi z izključitvijo, na pripadnosti in nepripadnosti. Dvojna pozicija se pokaže takoj, ko se golo preživetje vključi v pravnopolitični red. Tako ima »golo življenje v politiki na Zahodu ta svojevrsten privilegij, da se na njegovi izključitvi utemeljuje mesto ljudi« (*ibid*.: 15–16). Tako lahko vidimo, kako deluje sistem pravic, ki ga je vzpostavila država, do katerih je posameznik upravičen zgolj, če se odpove določenim drugim privilegijem. Hendikep v tem primeru ne deluje kot ovira, temveč kot priložnost. Rome, ki ustvarjajo »norce« iz svojih otrok samo zato, da bi prišli do nadomestila za invalidnost, lahko prepoznamo hkrati kot žrtve in kot prevarante istega sistema. To je v skladu z Agambenovim razumevanjem »novo biopolitično telo človeštva« (*ibid*.: 18).

Sklep

V raziskovanje sem se podala z dokaj romantično predstavo in velikim pričakovanjem, da bom v odnosu do razumevanja hendikepa med Romi odkrila kulturno različne prakse, običaje in interpretacije. Vendar se je pokazalo, da imajo poleg kulturnega vpliva na dojemanje in odnos do oviranih oseb vpliv tudi družbenoekonomski dejavniki. Prav tako se je pokazalo, da je odnos Romov do hendikepiranih posameznikov pogosto zelo podoben odnosu, ki ga ima neromska večinska kultura (npr. v odnosu do posameznikov, v odnosu do institucionalne oskrbe, v odnosu do medicinskega modela). Največ razlik se je pokazalo pri razlagah izvora, saj so v številnih okoljih poleg medicinskega modela prevladovale ideje o magičnem izvoru in božji kazni. Prav tako Rome zelo zaznamujeta sistematična brezposelnost in revščina, zato je ovirana oseba, ki je od države upravičena do določenih prejemkov zaradi oviranosti, pogosto pomemben finančni vir za celotno romsko družino.

Raziskava je znova opozorila na problem množičnega pošiljanja romskih otrok v posebne šole. Vanje so napoteni zaradi socialno-ekonomskih razmer, ne pa zaradi dokazanih intelektualnih ovir. Torej ne smemo sklepati, da je med Romi več prirojenih intelektualnih ovir, temveč da so zaradi deprivilegiranega okolja bolj podvrženi tveganju za razvoj primanjkljajev pri učenju. Čeprav logika posebnega šolstva deluje kot navidezno preprečevanje škode, pa tudi sama pripomore k še večji škodi. Namesto da bi se država ukvarjala z ustvarjanjem strategij za preseganje izključenosti Romov (npr. z odpravljanjem prikrajšanosti), prav prikrajšanost postane argument za še večje izključevanje.

Z razvojem kapitalistične družbe se je utrdilo izključevanje oviranih ljudi iz sfere dela (Oliver 1993). Z razvojem globalne ekonomije v postmoderni družbi pa so se možnosti za zaposlovanje oseb z ovirami še zmanjšale, saj ta zahteva vse večjo delovno storilnost, hkrati pa onemogoča pravico do dela nekaterim skupinam ljudi (Zaviršek 2000). Neoliberalna ideologija namreč zmanjšuje pomen izobraževanja in izboljšanja zdravja vseh ljudi ter uspeh ali neuspeh posameznika definira kot stvar individualnih sposobnosti in naključja. Povečuje se osebna odgovornost posameznika za revščino in slabo zdravje, to pa je vedno stranski produkt ekonomske prikrajšanosti (*ibid*.: 23–24).

Romi so ena od družbenih skupin, ki se srečujejo z visoko stopnjo brezposelnostjo; ta v nekaterih okolij dosega celo absolutno brezposelnost. Romi so kulturno osovražena družbena skupina, zelo podvržena sterotipizaciji o njihovi delovni nesposobnosti in diskriminatorskim odnosom, globalizacija pa le še utrjuje njihovo kulturo revščine (Humljan Urh 2013). Hendikepirani Romi so zato izpostavljeni dvojni izključenosti – sprva kot pripadniki romske skupnosti, ki že *a priori* določa pripadnost kot izvorno kategorizacijo, ki določa vse drugo, kar človek ima, je in zna. Hkrati pa jih izključuje tudi njihova dejanska telesna, senzorna ali intelektualna ovira, ki pa se bolj kot do širše družbe izraža znotraj romske skupnosti. Tako je znotraj romske skupnosti prepoznati tri družbenoekonomske dejavnike, ki opredeljujejo odnos romske skupnosti do hendikepiranih članov:

- *Ekonomski dejavniki.* Ti so v ospredju odnosa v deprivilegiranih okoljih, v katerih vsak član družine pomembno pripomore k družinski ekonomiji – npr. z nabiranjem gob, borovnic, kostanja, starega železa (to je v posameznih družinah pomemben vir prihodka).
- *Bivanjski dejavniki.* Prepletajo se z ekonomskimi – bolj ko je okolje, v katerem Romi živijo, deprivilegirano, materialno prikrajšano, socialno izolirano, večja je izključenost oviranih oseb, saj ne morejo prispevati k materialni blaginji družine.
- *Razmerje med institucijami, družino in posameznikom.* Primaren cilj oz. težnja v večinski družbi je pravica, da oseba z oviro pridobi ali obdrži zaposlitev, hkrati pa se sproži nekakšen rehabilitacijski postopek, da se oseba, ki je pridobila oviro, spet vključi v delovni proces. Vendar taka pričakovanja v *številnih* imigrantskih skupnostih v ZDA veljajo za zanemarjanje in nasilje nad ovirano osebo v družini (Groce 2005). Vloga družine naj bi bila predvsem skrb za ovirano osebo. Tudi med Romi je zaznati, da bolj kot diskurz dela (*workfare*) prevladuje diskurz blaginje (*welfare*). Zaznati je velik pomen oskrbe hendikepiranega posameznika na domu. To je tudi posledica visoke stopnje brezposelnosti vseh članov.

Posledica družbenoekonomskih dejavnikov je večplastna izključenost Romov. Hendikepirani Romi so dvojno nesposobni za delo – kot Romi (romska pripadnost v slovenski kulturi že sama po sebi velja za družbeni hendikep, ki izključuje) in kot ovirani posamezniki (ki se zaradi telesne, senzorne ali intelektualne ovire ne zmorejo vključiti v obstoječi sistem ekonomske logike – bodisi v večinskem okolju bodisi znotraj romske skupnosti). Zato so hendikepirani Romi in Rominje še posebej ranljiva skupina znotraj ranljive romske etnične manjšine.

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Izvirni znanstveni članek

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MEDIJSKE PODOBE LJUDI Z OVIRAMI

Predstavljena raziskava obravnava reprezentacije ljudi z ovirami leta 2012 v treh slovenskih plačljivih dnevnikih z največjo naklado v Sloveniji. Vsebinska in diskurzivna analiza se osredotoča na jezik člankov, naslove, vizualno gradivo in vsebino. Rezultati kažejo, da so reprezentacije ljudi z ovirami stereotipne in stigmatizirajoče. Ovire ljudi so pogosto uporabljene za prikazovanje nesreče in slabih socialnih razmer. Dnevniki ovire ljudi uporabljajo za senzacionaliziranje vsebine člankov. Ljudje z ovirami so najpogosteje videni kot objekti in ne subjekti pomoči. Kritični članki obravnavajo različne teme hendikepa, a pri poročanju ostajajo znotraj obstoječega sistema pomoči in ne problematizirajo pomanjkanja individualizacije in možnosti.

Ključne besede: javni diskurz, jezik, stereotipi, diskriminacija, pomoč, stigma.

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PORTRAYAL OF PEOPLE WITH DISABILITIES IN THE MEDIA

The research presented in this paper explored the representation of people with disabilities in three most circulated Slovenian daily payable newspapers in 2012. The content and discourse analysis focused on language, headlines, visual data and content. The results indicate that the representations of people with disabilities are stereotyped and stigmatizing. People«s impairments are often in the function of symbolical representation of misfortune and bad social conditions. Impairments are also used to sensationalize the content of the articles. Results show that people with disabilities are most often seen as the object and not as the subject of help. Critical articles debate diverse topics concerning disability but rarely question the existing system of help which lacks individualization and opportunities.

Key words: public discourse, language, stereotypes, discrimination, help, stigma.

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Uvod

Položaj ljudi z ovirami je bil vso zgodovino tesno povezan s stigmo, revščino, slabimi možnostmi, zatiranjem in odrinjenostjo na rob družbe. Ljudje z ovirami se tudi v sodobnem svetu srečujejo z diskriminacijo, s kršenjem človekovih pravic, slabimi perspektivami in pomočjo, ki ni individualizirana. To za marsikoga pomeni življenje v institucijah ali odvisnost od pomoči družine.

Kljub dolgoletnemu trudu uporabniških in strokovnih gibanj so spremembe na področjih socialne politike in strokovne pomoči počasne ali pa jih sploh ni. Težava je ne le v okolju, ki ga zaznamujejo ovire, kot sta pomanjkanje denarja in neprilagojena pomoč, ampak v diskurzu, ki ljudi z ovirami potiska v vlogo družbenega »tujka«. Nelagodje, ki ga zbuja navzočnost družbeno »neprilagojenih«, je zasidrano globoko v naši kulturi in se prenaša in vzdržuje z govorico, pisanjem in vizualnimi podobami (Zaviršek 2000).

Pomembno vlogo pri konstrukciji družbene realnosti imajo množični mediji, ki z izbiro tem in načinom poročanja sooblikujejo javni prostor. Družbeni diskurzi in norme se v medijih preverjajo in potrjujejo. Diskurz o marginaliziranih skupinah, ki ga vzpostavljajo mediji, pogosto stigmatizira in diskriminira ter deluje predvsem kot načelo ločevanja med »njimi« in »nami« (Pajnik 2003).

To se kaže pri pogostosti in načinu poročanja o marginalnih skupinah (in s tem tudi o ljudeh z ovirami), ki je minimalno in najpogosteje stereotipizirano. Študije iz Združenih držav Amerike in Zahodne Evrope kažejo, da so bili ljudje z ovirami v preteklosti v medijih največkrat prikazani v luči njihove telesne ovire, osebna kompleksnost in družbeni kontekst pa sta bila zanemarjena (Krogh 2010). Stereotipi o ljudeh z ovirami, ki so se pojavljali v zgodovini in ki so še vedno neločljivo povezani z našo kulturo, temeljijo na praznoverju, mitih in prepričanjih, vzdržujejo pa se lahko zgolj s ponavljajočo se prakso in reprodukcijo (Zaviršek 2000, Barnes 1992).

Metodologija

Leta 2012 smo raziskovali medijske reprezentacije hendikepa v treh slovenskih dnevnih časopisih z največjo naklado – *Delo*, *Dnevnik* in *Slovenske novice*. Pregledali in zbrali smo gradivo, ki se navezuje na širše področje hendikepa. Da bi dobili čim bolj celostno sliko, smo bili pozorni tudi na objave, ki obravnavajo sorodne teme in v katerih je hendikep vsaj omenjen (npr. stari ljudje, področje medicine).

V raziskovalno gradivo je bilo uvrščenih 282 enot (*Delo* 98, *Dnevnik* 97 in *Slovenske novice* 87); obravnavali smo vse zvrsti člankov in pisma bralcev. Tema hendikepa se je redno pojavljala v dnevnih časopisih, vendar ocenjujemo, da glede na širino in pomen področja ni obravnavana zadostno. Statistično gledano se članek o hendikepu v vseh treh časopisih pojavi približno na vsake tri dni, v resnici pa redkeje, saj je aktualnim temam namenjenega več prostora v bolj zgoščenih intervalih ali pa se več nepovezanih člankov pojavi v eni izdaji.

Zbrani članki o hendikepu obravnavajo zelo različno in razpršeno tematiko: šport in zabavo, portrete in zgodbe ljudi, črno kroniko, socialno politiko, socialno varstvo, zdravstvo, arhitektonske prilagoditve in drugo. Zelo malo je bilo člankov, ki bi obravnavali pomembno in aktualno politično temo zaposlovanja. V *Delu* in *Dnevniku*, časopisih, ki se bolj sistematično in kritično lotevata socialnih in družbenih vprašanj, si tematika hendikepa prostor deli z drugimi temami, kot so socialna politika, medicina, duševno zdravje in starost. Članke, v katerih so teme obravnavane podrobneje in z večjo občutljivostjo, so najpogosteje prispevale interesne skupine ob kakem dogodku, akciji ali novi pridobitvi na področju hendikepa. Ker so leta 2012 potekale poletne olimpijske igre, je izstopala športna tematika, vendar člankov glede na pomembnost prireditve ni bilo veliko. Za udeleženke in udeležence paraolimpijskih iger so bile, poleg portretov nekaterih uspešnih slovenskih olimpijcev, rezervirane le kratke informacije o rezultatih tekmovanj.

Večina zbranih člankov ostaja znotraj lokalnega prostora in le nekaj člankov poroča o tematiki hendikepa ali ljudeh z ovirami iz drugih držav. Prevladujejo zabavne teme (olimpijske igre, turizem ipd.).

Zbrano gradivo smo analizirali s kvalitativnimi metodami, pri analizi vsebine in diskurzivni analizi pa smo posebno pozornost namenili naslovom člankov ter spremljajočemu slikovnemu gradivu, uporabljenemu jeziku in vsebini ter načinu prikazovanja ljudi z ovirami.

Uporaba besedišča in jezika

Jezik pripomore k številnim negativnim podobam ljudi z ovirami in vzdržuje diskriminatorski odnos in prakse v družbi (Jaeger, Bowman 2005). Za poimenovanje ljudi z ovirami v člankih slovenskih dnevnikov najpogosteje uporabljajo besedo »invalid«. Pogosto so v uporabi posamostaljene pridevniške besede (npr. slepi, gluhi) ali enobesedni strokovni izrazi iz medicinske stroke (npr. avtisti, distrofiki). Sodobnejše in manj stigmatizirajoče izrazoslovje, pri katerem se poimenovanje začne z besedo »ljudje«, najdemo v člankih, v katerih so avtorji tudi sicer bolje poučeni o tematiki hendikepa. Izrazoslovje, ki poudarja osebo, ne pa njene oviranosti, najdemo tudi v primerih, v katerih želijo avtorji osebo, o kateri pišejo, zaradi različnih razlogov in motivov humanizirati (npr. »Zlorabil dekleti z Downovim sindromom«, *Delo*, 10. 2.).

V vseh treh časopisih najdemo nekaj člankov, v katerih je jezik stigmatizirajoč in zelo žaljiv (npr. »Downovček Sebastian snema modne oglase«, *Slovenske novice*, 27. 9.). Poleg poimenovanja ljudi z ovirami je lahko stigmatirajoča tudi neprimerna konotacija (»Paralizirana 'pretekla' maraton«, Delo, 10. 5.) – v tem primeru je v ospredju negativen pomen ali opozarjanje na

»invalidnost«, včasih pa za opozarjanje na »invalidnost« ni upravičenega razloga (»Invalid zaradi prostitutke ponovno v zapor«, *Dnevnik*, 1. 6.).

Pomen naslovov v medijskem poročanju

Naslovi imajo osrednjo vlogo pri posredovanju vsebine časopisa bralcu, hkrati pa na bralca tudi aktivno vplivajo. Naslovi dosežejo občinstvo, ki je občutno večje od tistega, ki članke zares prebere, saj sporočila dosežejo tudi ljudi, ki časopis samo preletijo, ljudi, ki vidijo oglaševane časopise, časopise v kiosku ipd. (Develotte, Rechniewski 2001). Naslovi so ključni sestavni del vseh časopisnih člankov in drugih medijev.

Funkcijsko jih delimo v tri skupine (Korošec 1998). Uporabljeni so lahko za označbo in predstavitev vsebine članka in imajo torej poimenovalno-informativno funkcijo. Poleg informiranja o vsebini lahko naslovi vsebino hkrati tudi ovrednotijo in predstavijo mnenje avtorja članka. To je informativno-stališčna funkcija. Naslovi torej posredujejo bralcu tudi perspektivo, kako naj članek bere. Hierarhija pomembnosti tem pa je ustvarjana s položajem, velikostjo in obliko črk ipd.

Bralci praviloma naslove v časopisu najprej le preletijo, preden se odločijo, ali bodo članek zares prebrali. Kadar so naslovi usmerjeni v pritegnitev pozornosti bralca in ga prepričujejo, da je vsebina dovolj pomembna za branje (Dor 2003), imajo po Korošcu (ibid.) pozitivno-pridobivalno funkcijo.

V poplavi informacij poskušajo naslovi usmeriti pozornost na posamezno pomembnost natančno določenega sporočila, ki ga naslovi povzemajo, s tem pa postanejo poenostavitveni mehanizmi (Blake 2007). Ker želijo naslovi čim bolj privlačno predstaviti glavne ideje člankov, zelo vpivajo na stališče, ki ga bralec zavzame pred branjem članka. Pri tem ni nenavadno, da v želji po senzacionalizmu vsebina članka ne odgovori na vprašanja v naslovu ali pa so med naslovom in besedilom velike razlike v sporočilu. Naslovi člankov vsebujejo pomemben kulturni element, saj zaradi zgoščenosti sporočila od bralca zahtevajo, da prepozna in umesti tematiko naslova, z uspešnim dekodiranjem sporočila pa sam sebi potrdi, da je del skupnosti, saj razume njen kod (Develotte, Rechniewski 2001).

Naslovi imajo zaradi takojšnjega vtisa, ki ga naredijo na bralca, in zaradi poenostavljenega sporočila, ki kompleksno situacijo ljudi z ovirami povzame in poenostavi, pomembno vlogo pri reprezentaciji hendikepa in lahko ljudi z ovirami v hipu izključijo ali vključijo. Naslov »Napovedal, da bo vse pobil, če mu bodo odrezali noge« (*Delo*, 21. 9.) jasno pokaže pogubno lastnost telesne poškodbe in vzpostavi povezavo med telesno poškodbo in kriminaliteto, s tem pa stigmatizira in izključuje. Izključitev se skriva tudi v poteku dogodkov, saj naslov namiguje, da je bil posameznik pred grožnjo telesne poškodbe v družbo vključen. Da telesne poškodbe ne smejo vplivati na vključenost v družbo, opozarja naslov »Javni promet še ni prilagojen invalidom« (*Delo*, 10. 10.). Naslov predpostavlja aktivne državljane, ki so prav zaradi diskriminatorskih praks izključeni.

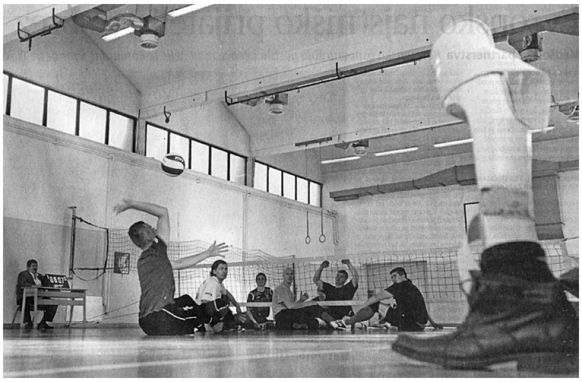
Medijsko poročanje in vizualni viri

V časopisih ima poleg naslovov in besedila člankov osrednjo vlogo slikovno gradivo. Prinaša novo, lastno sporočilo in hkrati z besedilom ustvarja medsebojno komunikacijo. Slike povečujejo učinek zapisanega in dodajajo nove pomene. Vsebinska analiza slik nam razkriva, kdo ali kaj je prikazano na sliki, kako je urejena informacija, skrita v sliki, in kako je materija predstavljena. Poleg vsebine slike nam informacije sporoča tudi kompozicija. Vsebina in kompozicija skupaj čustveno vplivata na gledalca.

Kontekstualno nam slika razkriva veliko več kakor le posamezne elemente, saj so v njej ujeti socialna razmerja in pomeni, to pa zahteva gledalčevo interpretacijo (Phillips, Bellinger 2010), ki je ujeta v kulturne diskurze hendikepa in zelo odvisna od tega, kako gledalec in fotograf te diskurze reproducirata. Pri slikah, ki upodabljajo marginalne skupine, lahko med drugim iz kom-pozicije in vsebine razberemo marsikatera družbena razmerja moči (Huss 2012).

Po zaslugi fotografij, ki prikazujejo ljudi z ovirami, lahko gledalec opazi telesne značilnosti in jim doda pomen ter mesto v diskurzu. Namen fotografije je ustvarjanje materije, ki pozicionira ljudi z ovirami v fokus voajerističnega pogleda in jih s tem utemelji kot »drugega« (Taylor 2008). Pri večini zbranih člankov lahko bralec na podlagi naslova oziroma slik že takoj, ne glede na temo, razbere, da obravnavajo ljudi z ovirami. Pri 162 zbranih besedilih od 282 je hendikep tako ali drugače omenjen v naslovu, drugih 30 naslovov pa hendikep sugerira. 216 besedil je opremljenih s slikovnim gradivom. Pri 153 članki je oviranost na spremljajočem slikovnem gradivu vidna, pri 64 takih slikah hendikep v naslovu ni omenjen. Od vseh člankov in pisem bralcev torej le pri 36-ih na podlagi naslova ali slike ni mogoče razbrati, da članek obravnava ljudi z ovirami.

Slika 1 (»Invalidski prvaki navdušujejo Bosno«, *Delo*, 12. 4.): V članku, ki govori o šampionih, namesto zmagovitih podob na sliki vidimo osebe, ki so v ozadju, v senci svojih ovir.



V vseh treh raziskanih dnevnikih je slikovno gradivo, ki prikazuje oviranost in telesne značilnosti ljudi in opozarja nanje, uporabljeno pogosto in sistematično. To ima poseben vpliv. Pogled ima ključno vlogo pri vzpostavljanju moči in dominacije ter nadzorovanju (Foucault 2004). V pogledu, v katerem so v središču telesne značilnosti ljudi, je skrita delitev med gledalci in »drugačnimi«, deviantnimi opazovanci. Pogled, ki ga konsistentno vzpostavlja vizualno gradivo v medijih, utrjuje in ohranja podrejen položaj ljudi z ovirami v družbi, saj so videni kot »drugi«.

Slikovno gradivo ima izjemno velik simbolni pomen. Z uporabo simbolov iščemo globlji pomen telesnih poškodb in značilnosti. Med zbranimi članki najdemo tudi devet člankov, ki ne pripovedujejo o ljudeh z ovirami, a uporabljajo njihove podobe za simbolni prikaz določene pomanjkljivosti, nesreče ali družbene krivice, to pa utrjuje in reproducira stereotipne diskurze. Če je hendikep simbol za napake in trpljenje, je s tem ustvarjena identiteta ljudi z ovirami – nesrečni so in nezaželeni.

Slika 2 (*Dnevnik*, 27. 2., *Dnevnik*, 30. 6.): Slika zapuščene ženske na hodniku se je pojavila ob dveh člankih, oba pripovedujeta o težavah domov za starejše občane.

Privlačnost hendikepa

Mediji med seboj tekmujejo za pozornost občinstva, saj jim to prinaša dobiček od prodaje in oglasov. Za te namene poskušajo predstaviti svoje informacije kot relevantne, urgentne ali nenavadne. Novice se oblikujejo v procesu selekcije ali poudarjanja, posploševanja ali poenostavljanja, čustvenosti ali senzacionalizma (Molek-Kozakowska 2013). Senzacionalizem ima lahko določeno vlogo pri izbiri predstavljenih vsebin ali kot način podajanja informacij, da so te videti pomembnejše in zanimivejše.

Senzacionalizem je oblika poročanja, ki ga uporabljajo v vseh treh raziskanih časopisih; uporabljajo senzacionalistično podajanje informacij in izbiro senzacionalističnih tem. Po številu senzacionalističnih tem in njihovi intenzivnosti so vodilne *Slovenske novice*.

Raziskava je pokazala, da je vloga ljudi z ovirami v senzacionalističnem prikazovanju dvojna. Lahko so v središču senzacionalizma ali pa je osebna ovira le dodaten »efekt«, ki senzacionalizira prikazane vsebine. V *Slovenskih novicah* senzacionalizem uporabljajo predvsem v primerih, v katerih so podrobno prikazane nesreče in težave ljudi. Kadar se v takih zgodbah pojavijo ljudje z ovirami, so v ospredju zgodbe telesna ovira, nesreča, ki je povzročila oviro, ali neverjetna rešitev. Če nesreča ni povezana s človekovo oviro, je ta sredstvo za senzacionaliziranje vsebine. V obeh primerih je dramatičnost zgodbe podkrepljena z uporabo »šokantnih detajlov« nesreče ali poškodbe oziroma zdravstvenih težav.

V *Slovenskih novicah* je senzacionalizacija vsebine zelo neposredna, pri drugih dveh časopisih pa zmernejša in bolj prikrita. Pogosto je prestavljena v drug lokalni prostor (npr. tuji slavni »invalidi«) in intelektualizirana (npr. velike medicinske novosti). V vseh treh dnevnikih najdemo senzacionalne kriminalne zgodbe, v katerih so ljudje z ovirami žrtve ali storilci, ter zgodbe, v katerih so pretirano poudarjeni uspehi in vzdržljivost oseb, ki so v težavnih razmerah in z oviranostjo presegle same sebe.

Poročanje, ki je enodimenzionalno in čustveno, je zelo povezano s stereotipnim prikazovanjem ljudi z ovirami. Kulturni stereotipi, ki se kažejo tudi v senzacionalističnih vsebinah, prikazujejo ljudi z ovirami kot uboge, žrtve, hudobne, »super kriplje«, objekte posmeha, seksualno abnormalne, družbeno breme, krivce za lastne težave, nezmožne živeti v družbi, kot povsem »normalne« in kot ljudi, katerih oviranost vzpostavlja negativno ozračje (Barnes 1992).

Negativni pomeni, spornost in »nenavadnost« teles in vedênja tistih, ki jih družba vzpostavlja kot »druge«, so uporabljeni za večjo prodajo časopisov, s tem pa ovirana telesa dobijo ekonomsko razsežnost (komodifikacija). Prikazovanje telesne »nenavadnosti« je pogoj, da postane marginalizirana skupina dovolj zanimiva za omembo v javni sferi. Vsakdanja komodifikacija teles s tem nadaljuje prakse zgodovinskega razkazovanja ljudi z ovirami v cirkusih in drugih javnih prostorih (Zaviršek 2000).

Agresivni senzacionalizem za dosego čustvenega učinka pogosto nadomešča žanr personalizacije, kamor lahko umestimo predstavljanje osebnih zgodb ljudi z ovirami in njihovih družin (Phillips 2011). S personalizacijo dobi hendikep človeški obraz. Telesne ovire niso več zgolj življenjska okoliščina, ampak dobijo trpeče obraze ljudi in njihovih svojcev, to pa ustvarja pogoje za sproščanje različnih čustev pri bralcu, od sočutja, usmiljenja in strahu do upanja, dobrodelnosti in sreče. Personalizirana ni nujno samo nesreča, ampak tudi herojstvo posameznikov, ki so premagali vse ovire ali pa nesrečni stoično trpijo. Personalizacijo zelo uspešno uporabljajo članki, ki pripovedujejo o dobrodelnosti. Pri senzacionaliziranih temah personalizacija ustvarja učinek globine in katarze.

Ljudje z ovirami v sistemu pomoči

Podobe hendikepa, ki ohranjajo diskurz izključevanja, so ustvarjene zunaj razprave o družbenopolitičnem kontekstu. Članki, ki raziskujejo politični in socialnoekonomski kontekst hendikepa, so redki (Briant *et al.* 2011). Hendikep ni kontekstualiziran, saj v predstavljenih podobah posameznikov ni prostora za družbene neenakosti.

Pri tem ima pomembno vlogo diskurz normalnosti. Normalnost je koncept z nestabilno vsebino, ki zahteva stalno redifinicijo, to pa ustvarja in določa tudi deviantne odmike od norm, ki so nezaželeni ali pa se jih pod določenimi pogoji tolerira. Diskurz normalnosti je diskurz tistih, ki imajo moč, da normalnost definirajo. Vključevanje v družbo je odvisno od doseganja družbenih norm in interesa posameznika za doseganje teh norm.

Reprezentacije hendikepa normo utrjujejo (Zaviršek 2000). V raziskanih slovenskih dnevnikih so ljudje z ovirami najpogosteje prikazani kot ubogi in nezmožni ali pa kot junaki, ki premagujejo svoje ovire. Pokroviteljski pogled in podcenjevanje nista opazna na prvi pogled, a se kakor rdeča nit pojavljata v večjem delu člankov. Ljudje z ovirami so v dnevnikih najpogosteje videni kot objekt pomoči, ne pa kot aktivni subjekti, ki bi vodili oblikovanje sprememb in novih praks. Napori ljudi so individualizirani (volja in značaj osebe), problemi pa ostajajo slabo povezani ali pa sploh nepovezani z ovirami v sistemu pomoči ali v skupnosti.

Zaviršek (*ibid.*) piše o reprezentacijah, ki utrjujejo normo normalnosti: medicinizacija in tehnizacija reprezentacij, glorifikacija institucij in infantiliziranje stanovalcev, poudarjanje dobrodelnosti neprizadetih, reprezentacije podob »super kripljev«, romantizacija skrbnikov neplačanega dela, prikazovanje ljudi z ovirami kot nevarnih in poudarjanje »nenavadnih« dejanj, ki so iz perspektive neprizadetih vsakdanja.

Omenjene reprezentacije se v očitni ali prikriti obliki pojavljajo tudi v raziskanih časopisnih člankih. Posledica takih reprezentacij je, da informativni, emancipatorski in kritični članki, ki poskušajo spremeniti razumevanje hendikepa in razmerja moči v družbi, znotraj stalne reprodukcije norm in stereotipov izgubljajo izrazno moč. Med članki o hedikepu imajo v slovenskih dnevnikih kritični članki in članki, ki poskušajo na informativen način prikazati težave in rešitve na področju hendikepa, po obsegu sicer nezanemarljivo mesto. Kritični članki so leta 2012 v dnevnikih obravnavali različna področja, kot so javni transport, slaba socialna politika, pomanjkljive storitve, slaba dostopnost ipd. Emancipatorski in informativni članki bi kljub temu morali biti veliko pogostejši, da bi lahko prodrli skozi popularno senzacionalistično, s čustvi nabito pisanje.

V raziskanih člankih, ki smo jih razvrstili v kategorijo kritičnih, je opazno omejevanje kritike znotraj sprejemljivih okvirjev. Članki večinoma razlikujejo dobre in slabe prakse, a se ob sam sistem pomoči in socialne politike le redko obregnejo. V medijskem poročanju v večini primerov ni zaznati, da so določene prakse problematične zaradi sistema pomoči, ki je razpršen, nedorečen in brez jasnih smernic za prihodnost (npr. sistematično uničevanje socialne države in stroke socialnega dela, težave institucionalizacije, neindividualizirane skrbstvene službe). Kritika je poleg tega omejena na lokalni prostor in ne vzpostavi povezave s širšim evropskim prostorom. Članki ne poročajo o težavah ljudi z ovirami in dobrih praksah iz tujine. Omejevanje zaostrovanja kritike lahko razumemo v luči prevladujočih družbenih dizkurzov o ljudeh z ovirami, ki izključujejo in ustvarjajo normo, s tem pa reproducirajo obstoječi sistem. Če bi imeli ljudje z ovirami moč, da bi ustvarjali drugačne podobe, bi celotni sistem spodkopali (Darke 2004). Drugačna redistribucija moči »vključenih« ni zaželena.

Družbeni diskurzi o ljudeh z ovirami in iz njih izhajajoče razumevanje, kakšna bi morala biti pomoč marginalnim skupinam, se nazorno pokažejo v člankih o dobrodelnosti in dobrodelnih akcijah. Iz dobrodelnosti izhaja, da ljudje z ovirami potrebujejo pomoč, a je to vzpostavljeno na negativnih reprezentacijah hendikepa, ki v ospredje postavljajo osebne ovire in nemoč ljudi, hkrati pa poveličujejo dobroto ljudi z večjo družbeno močjo. Tako se ustvarja vertikalna redistribucija moči in možnosti, povečuje pa se razlika med družbenimi skupinami (Shakespeare 2006). Sistem pomoči ostaja nespremenjen in diskriminatorski.

Sklep

Ob članku »Pod košem so zmagovalci vsi« (*Delo*, 10. 12.) opazimo sliko moških, ki igrajo košarko na vozičkih. Šele ko članek preberemo, izvemo, da vsebina prispevka pravzaprav pripoveduje o dnevu košarke, povsem na koncu pa je z enim samim stavkom omenjeno, da so na dnevu košarke sodelovali tudi ljudje z ovirami. Kombinacija naslova, slike in besedila ustvarja pokroviteljski in izjemno podcenjevalen odnos do ljudi z ovirami, ki so kljub poškodovanemu telesu tako kot »normalni« ljudje zmagovalci in so zato na svojo udeležbo lahko ponosni.

Tako neposredna in razkrita stigmatizacija ljudi z ovirami v raziskovanih dnevnikih v letu 2012 ni pogosta. Večina člankov ne poskuša prikazati ljudi z ovirami na negativen način in je napisana na videz nepristransko, saj ne zavzame stališča do hendikepa. Drugačno sliko opazimo šele, ko sestavimo celotno in poglobljeno sliko poročanja in jo umestimo v slovenski in evropski kulturni in družbeni prostor. Ugotovimo lahko, da so ljudje z ovirami predstavljeni na podcenjevalen način, pri tem pa so njihove ovire velikokrat v funciji simbolnega prikazovanja nesreče in slabih družbenih razmer ter so namenjene senzacionaliziranju vsebine. Pri člankih o prilagoditvah in oblikovanju pomoči so ljudje z ovirami videni predvsem kot pasivni prejemniki pomoči.

Izključevanje ljudi z ovirami se je v zgodovini konstruiranja drugega in ustvarjanja norme globoko vsidralo v našo kulturo (Zaviršek 2000). To se kaže v podobah in reprezentacijah ljudi z ovirami v vseh družbenih sferah in s tem tudi pri poročanju množičnih medijev ter v odnosu družbe in politike do problematike hendikepa.

Mediji vplivajo na javno mnenje, percepcijo in vedênje ljudi. Kako so ljudje z ovirami predstavljeni in kako pogosto se v medijih pojavljajo, pomembno vpliva na njihovo podobo v skupnosti. Mediji imajo potencialno moč in s tem dolžnost namesto negativnih in stereotipnih ustvarjati pozitivne in emancipatorske podobe o ljudeh z ovirami, ozaveščati o težavah in dobrih praksah ter poskrbeti, da tema hendikepa iz zasebne sfere v večji meri preide v javno (Sanchez 2010). Tematika hendikepa je kompleksna in zahteva temu primerno ozaveščenost.

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MENTAL HEALTH PROBLEMS IN TAIWAN FROM A GENDER AND ANTI-OPPRESSIVE PERSPECTIVE

A human rights issue

In the Taiwanese context, which is characterized by patriarchal values, mental health problems are considered to be different from physical illnesses. Therefore the ways of dealing with mental health problems are different across genders. This article illustrates how Taiwanese women who experience mental health problems are trapped in an oppressive system constituted by gender inequalities, economic difficulties and mentalism. It also shows how migration and transnational marriage had a profound impact on care work for people with mental health problems and disabilities in Taiwan. By analyzing the situations from the perspective of anti-oppression practice and human rights, it is anticipated to draw implications for future actions with the aim of enhancing the well-being of Taiwanese women.

Key words: Taiwanese women, gender, inequalities, Confucianism.

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DUŠEVNO ZDRAVJE NA TAJVANU IZ PERSPEKTIVE SPOLA IN ANTIZATIRALSKE PERSPEKTIVE: VPRAŠANJE ČLOVEKOVIH PRAVIC

Na Tajvanu, za katerega so značilne patriarhalne vrednote, na težave z duševnim zdravjem gledajo drugače kot na fizično bolezen. Pomembna kategorija je spol, saj determinira obravnavo. Članek prikaže ujetost tajvanskih žensk, ki doživljajo težave z duševnim zdravjem, v zatiralski sistem spolnih neenakosti in ekonomske neodvisnosti. Pokaže tudi vpliv preselitev in transnacionalnih porok na skrbstveno delo za ljudi z duševnimi težavami in ovirami. Avtorica analizira situacije iz antizatiralske perspektive in perspektive človekovih pravic: opiše pričakovane rezultate prihodnjih dejavnosti, s katerimi bi bilo mogoče povečati blaginjo tajvanskih žensk.

Ključne besede: tajvanske ženske, spol, neenakosti, konfucianizem.

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Introduction

Taiwan is an island located in eastern Asia. The population is around 23 million people. Taiwan used to be an agricultural country that was economically poor. In order to transform the agricultural society into an industrial one, the Taiwanese government launched an economic policy in the 1970's that aimed to transform farms and fields into small factories and manufacturing facilities. This economic policy, known through the metaphor 'living room is factory', helped the economy to flourish (Lin, Lin 2009). Years later, this economic policy helped Taiwan to be known as one of the 'four little dragons' in Asia, meaning that Taiwan was economically powerful like a dragon. In the 1990's, the economic policy was transformed into moving small Taiwanese factories to Southern Asian countries. This economic policy was known as the 'moving south' policy. This 'moving south' economic policy had profound impacts on Taiwan's social context. Many Taiwanese businessmen traveled to Southern Asian countries not only to build factories but also brought many workers from there to work in Taiwan. This brought about an era in Taiwan's history of significant migration from Southern Asian countries. In addition, Taiwanese businessmen also brought into the country young and poor women from Southern Asian countries to marry Taiwanese men who are socially and economically disadvantaged, including men with mental health problems or disabilities (Hsia 2000). This marked the era of transnational marriage in Taiwanese history. The era of migration and transnational marriage had a profound impact on care work and particularly caring for people with mental health problems and disabilities in Taiwan.

According to the report of the Ministry of Health and Welfare Taiwan, 24,342 males and 27,521 females suffer from various mental health problems in 2014 (Ministry of Health and Welfare Taiwan 2014). Given the fact that these released official figures are based on medical settings' documents, it is believed that in fact more people suffer from mental health problems, but remain invisible within the medical settings.

Although the western model of psychiatry entered into Taiwan's medical fields a long time ago (the first psychiatric hospital was opened in 1929 in Taipei), mental health problems are, by many Taiwanese people, considered to be of another quality than physical illnesses. Taiwanese culture is embedded with Confucian ideology where the values of family and the superiority of males are highly emphasized. Most Taiwanese are Buddhists and Daoists and their attitudes towards mental health problems are strongly influenced by their cultural and religious beliefs. Mental health problems were considered to be a moral problem in the family in Taiwanese culture and religion (Wen 2012). It was believed that the ancestors or current family members had done immoral things and the punishment returns back to their offspring. Therefore, a Daoist priest would be hired to host a worship ceremony to symbolically pay it back or remedy what they had done before. If it didn't work, then hiding the persons with mental health problems in the house or sending them to an institution out of their family town and never seeing them again are ways of dealing with it in Taiwan still today. This is supposed to cover the 'immoral image' of the family. Therefore, Taiwanese cultural and religious beliefs regarding mental health problems dominated the family members' choices of care for people with mental health problems.

Taking into consideration the cultural, religious and patriarchal beliefs in Taiwanese society, women with mental health problems and female carers for relatives with mental health problems experience oppression in Taiwan. This article aims to illustrate the oppression women with mental health problems experience in Taiwan. It starts by illustrating 2 stories obtained from 2 research projects that had been conducted by the author in 2004 and 2014 respectively. Jun was a participant in research on females with mental illness and was interviewed regarding her life story in the summer of 2014 in Taiwan. Kung's wife, Sabrina, was a participant in research on transnational marriage in Taiwan and was interviewed regarding her marriage in 2004 in Taiwan. By analyzing the situations from the perspective of anti-oppression practice and human rights, it is anticipated to draw implications for future actions.

The story of a woman with mental health problems

Jun is an only daughter who was born in a rich family in Taiwan. Having a boy baby was always the preference of a couple in the Taiwanese culture, however, Jun's parents had expected to have children long before Jun's birth, but didn't due to Jun's mother's health, so they were very excited about Jun's birth. It is the custom that the couple would expect or be required by their parents to have a second child if the couple's first child is a girl, but given the situation of Jun's parents, they are happy with only having one female child. Because of being born in a rich family, Jun's parents bought everything they could for Jun. Everyone thought Jun was a girl with lots of blessings. When Jun reached the school age, her parents sent her to an elementary school that only accepts the so-called 'elite', meaning that it is a school for the elites' children only. Jun's parents spent lots of their time devoting themselves to school activities in order that Jun would receive her school teachers' attentions. After graduating from the elementary school, Jun and her parents disappeared from the neighborhood and no one in the neighborhood knew what happened to this family. Years go by, the mansion of Jun's parents becomes a 'ghost house' in the neighborhood due to lack of maintenance.

One day, a woman in the neighborhood ran into a relative of Jun and finally found out what happened.

In the summer of graduation from the elementary school, every graduate was preparing for going to junior high school and was excited about being a teenager. However, Jun had a breakdown one day and was diagnosed with 'schizophrenia'. This was shocking news for Jun's family; it was believed that it must be a curse for the family. The family treated Jun as a shame to the family and was scared about being discriminated by the neighborhood, so they chose to move out of the neighborhood one night without telling anyone. Jun has become a revolving--door psychiatric service user, being in and out of psychiatric wards. Today, when Jun's mental health is stable she stays at home in a small village with her parents. Luckily Jun's parents are rich enough to support themselves financially and do not need to go out to work, however they do not want to have contact with other neighbors. They are scared of being scorned and isolate themselves.

Jun is female, was a wanted child by her parents, was born in a rich family, therefore she is able to stay at home with her parents and receive basic medical care such as medication or hospitalization when needed. However, Jun's parents still chose to 'hide' her from her upper class circle of friends, which indicates that Jun's mental health problem is considered as a shame. Jun is single and does not have her own social activity group. What remains unsolved for Jun's parents is what to do when they and Jun all become aged.

The story of a woman who is a carer for a man with mental health problem

What happens to a boy or man with mental health problems and a similar family background to Jun? It is still considered as a shame in the family; however the ways of dealing with it might be different. Here is the story of a man. Kung was born as the eldest child in a traditional and conservative Taiwanese family in a village in Taiwan. Since Kung was the eldest boy in the family, he was expected to honor the family and continue the family line according to the culturally prescribed rules for males. Unfortunately, Kung was found to have intellectual disabilities, usually seen as 'developmental retardation', from birth on, which was certainly a big shock for the whole family. Although Kung's parents continued to give birth to several babies and wished that they were able to have a 'normal' boy to take up the responsibilities that Kung was supposed to do, all of their other children were girl babies. In a patriarchal Taiwanese culture only the son, in particular the eldest son, is the legitimate one to continue the family line. Therefore Kung's parents decided that Kung should marry and have children, so that Kung's children will continue the family line. Kung's parents had difficulties finding a Taiwanese woman that was willing to marry Kung. Eventually, they decided to involve a broker (who should help the family to find a woman) and chose him a woman named Sabrina from one of the South Asian countries. Sabrina never saw or knew anything about Kung before their wedding party. Although Sabrina realized that Kung is not 'normal' after their wedding party, her family back in her hometown received a lot of money from Kung's parents; she has no choice but to stay in Taiwan with her new disabled man. Sabrina takes care of Kung and the family hopes that she will have male children with Kung in order to continue the family line. Kung's mother was worried about Sabrina running away from this marriage, so she limited Sabrina's contact with outside world, including Sabrina's parents. Sabrina was not able to establish a social support system in a foreign country. The isolation further made Sabrina vulnerable to crisis events, violence, abuse or other traumatic experiences.

Jun and Kung were both born in rich families, however, the ways of dealing with their mental health and disability problems are different due to their gender. Culturally and in everyday practice, females are still inferior to males and are not legitimate to carry the family name in Taiwan. The choices of Jun's and Kung's parents are reflections of these cultural prescriptions of gender roles. They are both lucky from the perspective of their family financial situation;

therefore they both receive medical care. The story of Kung also reveals the fact that in the cases of men with mental health problems, the care work falls on the shoulders of women: either mothers or women from rural countries that are economically dependent and have little choices in their lives. However, in the case of women with mental health problems, like Jun, the care work falls to no one.

The current paradigm on disability and care in Taiwan

Taiwanese culture is embedded with Confucian ideology that family is highly valued and emphasized. It indicates that family in the culture embedded with Confucian ideology used to be and continues to serve the role of 'private social security system', therefore, the caring issues are considered to be resolved by the family (Hu 1995).

The caring policies for the disabled persons in Taiwan include National Health Insurance, Long-term care, Mental Health Law (December 1990, changed in 2008) and People with Disabilities Rights Protection Act (launched in 2014, first launched as People with Disabilities Protection Act in 1970). In response to the needs of people who suffer from mental health problems and their families, the Mental Health Act first came into force in 1990 in Taiwan (Law and Regulations Database of the Republic of China 2014 a). It has been revised 4 times since then in order to meet the changing needs and paradigm shift in the mental health area. According to the newest version of the Mental Health Law from 2008, it mandates that social workers should work with psychiatrists, nurses, occupational therapists and psychologists together as a team to help people with mental health problems. Therefore, social workers legitimately work in psychiatric medical settings, including acute psychiatric wards or community mental health rehabilitation centers. In addition, it is mandatory that this professional team should work with people with mental health problems and their families to deal with issues such as medication, caring, social skills problems, family relationship problems and similar. Although it mandates that professionals work as a team, the psychiatrists take the lead within the team and are most often those who are powerful in the decision making process. This reflects that the medical model is still a dominant discourse in Taiwan's mental health area.

In Taiwan the National Health Insurance is well established. Everyone is entitled to be taken care of by Taiwan's health care system with a low premium. However, the long-term care system was first introduced in 2006 and is still developing (Tseng 2006). So many issues of chronic illnesses remain unresolved, including the mental health issues. The ideology of family taking up the caring responsibility is included in the long-term care system in Taiwan. Tseng (*ibid.*) indicated that the notion of people with disability staying with and being cared for in their families is central to Taiwan's long-term care system. Placing the disabled persons in institutions is an alternative only when they are not able to stay in their own families. In order to implement it, various programs and services are developed to assist the families in caring for the disabled people. For example, in-home services for the disabled as well as assistive technology services are developed to assist the disabled persons staying at home (*ibid.*). By examining the details of in-home services and assistive technology, it reveals that people with physical disability are defined as the main service users in the long term care policy in Taiwan and people with mental health problems are ignored. In addition, the caring responsibilities are still currently considered as women's work in Taiwan. Women are also responsible for the long-term care for the persons with disabilities and chronic illness. Therefore, it is women, including mothers, wives and female care workers that keep the long-term care system operating in Taiwan. Putting all these together, it explains why parents of men with disability or chronic illness, in particular parents of men with mental health problems, are eager to arrange marriages for their disabled adult sons. Nevertheless, ironically, single women with mental health problems are ignored in this caring system constituted by patriarchal cultural beliefs (Yen 2010).

The Convention on the Rights of Persons with Disabilities (CRPD) was adopted by the UN General Assembly in 2006 (Walker 2013). This convention has several characteristics. Firstly, the human rights of the disabled and anti-discrimination for the disability are emphasized. Secondly, the paradigm of disability shifts from a disease model to a social model, meaning that the disability issues being considered as social issues rather than personal diseases is emphasized. By adopting the social model, it is anticipated that the disable persons' rights to equality, safety, freedom, social inclusions, privacy and free will are ensured and protected (Tang, Chen 2008). Before the Convention, the People with Disabilities Protection Act with the emphasis on protection first came into force in 1970 in Taiwan (Laws and Regulations Database of the Republic of China 2014 b). Its title was changed into People with Disabilities Rights Protection Act and the ideology of the CRPD was adopted in 2014. Examining the details of Taiwan's People with Disabilities Rights Protection Act, protecting human rights, facilitating independent living and social inclusion for the disabled are clearly declared. However, by searching the electronic database of the library in Taiwan, 68[1] articles on disabilities and related social policies were published (most in Chinese) since 2000. Strikingly, the articles mainly focused on 2 topics: employment of persons with disabilities and health care. Any human rights issues of the disabled and social inclusion for the disabled are missing. It is the same in social service agencies which work in the field of disability (Pan, Yen 2011). This reflects that rehabilitation and income, which are basic needs, are still the focus of disability in Taiwan and supported the comments by Zaviršek (2009: 3) that 'countries with moderate disability activists and a weak tradition of political social work have found their niche mostly with rehabilitation science.' This also explained why withdrawing from society and involving a woman from economically inferior areas to care for the man with disabilities are strategies Jun's parents and Kung's parents adopted to deal with the disability issue in the family.

How can the human rights issues and anti-discrimination lens be adopted in Taiwan? The following paragraphs are to introduce anti-discrimination concepts and analyze Jun's and Kung's stories accordingly. By doing so, further actions to enhance the human rights and social inclusions for the disabled in Taiwan will be addressed.

Anti-oppression and mental health problems issues

Anti-oppression refers to a model that aims to understand how structural inequality and social divisions result in oppressing certain groups of people, as well as to understand how to eliminate the causes of oppression (Dominelli 1996). Dominelli (2002) pointed out that the sources of oppression stem from 3 levels, including individual, institutional and cultural levels. Personal attitudes and beliefs are examples of sources of oppression on an individual level, whereas policies and working procedures are those at an institutional level. In addition, cultural values and ideology are examples of sources of oppression at the cultural level. Thompson (2006) indicated that unequal distribution of power firstly results in social exclusion and consequently results in structural inequality. People in the same social context are divided into one group of privileged and another group of disadvantaged respectively due to unequal distribution of power. In addition, certain discourses which tend to explain particular problems are developed usually by the privileged. These discourses became the sources of oppression for certain groups of people through education, religion and media. As a result, the oppressed are given less resources and have inferior status (Dominelli 1996, McDonald, Coleman 1999). Therefore, the oppressed suffer in an interlocking system of oppression (Dominelli 2002, Thompson 2006, Mullay 1993).

Dominelli (2009) adopted the term 'mentalism' to make sense of the oppression and inequality experienced by people with mental health problems. As opposed to people without

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[1] 206 women and social policy articles, 168 children and social policy articles, 81 adolescents and social policy articles are published in the same period of time. The number of disability-related articles is less.

mental health problems, people with mental health problems are categorized as 'others' in most societies around the world from the mentalist perspective, in particular. People that are categorized as 'others' have less power or are deprived of power and are inferior to people without mental health problems. People that are categorized as 'others' are deprived of equal chances, autonomy and are not treated as human being in their own rights. As a result, people that are categorized as 'others' are stigmatized, which may result in working in work conditions that do not secure a minimum wage, or unemployment. Institutionalization becomes the main intervention developed for people that are categorized as 'others.'

Due to the discourse of mentalism, many people with mental health problems experience social exclusion. Barnes (1999) and Zaviršek (2006) both pointed out that people with mental health problems experienced exclusion by various social systems, including the employment system, the housing system and by general public attitudes. As a result, people with mental health problems may live in poverty; they become homelessness and experience harassment or discrimination by the wider society. Within the perspective of social exclusion, they are deprived of resources to enhance their skills to improve their quality of life; they are silenced due to lack of public space for them to reveal their experiences of social exclusion (Zaviršek 2006). Social exclusion turns out to be a traumatic experience for many people with mental health problems. Paradoxically, without the awareness of human rights, certain institutionalization seems like providing people with mental health problems with inclusion that is in fact a form of exclusion (*ibid.*). In order that people with mental health problems be socially and fully included, Barnes (1999) argued that discourses of mental health problems should be critically examined.

Two discourse models of mental health problems are commonly adopted, including the disease model and the discrimination model (Corrigan, Penn 1997). In the discourse of the disease model, mental health problems are considered as dysfunctional symptoms that have a profound impact on people's skills and function. Therefore people with mental health problems need medical doctors and different experts to cure them. In the discourse of the discrimination model, people with mental health problems are considered to only have functional issues, however, the problems they encounter are mainly caused by discrimination. Consequently, they are disadvantaged socially and economically. Therefore, mental health problems should be analyzed and understood in the context of social injustice. The discourse of the disease model became the dominant discourse for many years. However it is currently challenged by the discrimination model.

Several techniques are developed to work with the oppressed in the anti-oppression practice. Unequal distribution of power, sources of oppression and marginalization are utilized as frameworks of assessment; the voices of the oppressed are important and should be listened to carefully by the practitioners; empowerment is an important skill; critical consciousness of discourses of practitioners are important; careful examination of discourses of policies and the ways policies define the service users as well as the distribution of resources are important (Cambridge, Ernst 2006, Sakamoto *et al.* 2009). Ultimately, it aims to make social change, in particular to equally distribute power and resources as well as fairly include everyone in the social system (Sakamoto, Pitner 2005).

Anti-oppression, mental health problems and women

How can one read and make sense of the stories of Jun and Kung from the perspective of anti-oppression? When Jun and Kung were diagnosed as mentally ill, they were both considered as 'others' and were deprived of education and participation in social activities. This reflects that both parents held the beliefs and had a similar value system that mental health is a shameful disease and isolation is the way to deal with it. Sources of oppression include cultural, systematic and individual levels (Dominelli 2002). Jun's and Kung's stories reveal that cultural beliefs are the first source of oppression which are practiced on the individual level.

But not only women and men with mental health problems, also women and people from economically disadvantaged parts of the world are oppressed, as well. The anti-oppressive perspective shows that people who are privileged refuse to share power and resources with the disadvantaged (women and people from economically inferior areas). The privileged purposefully isolate the disadvantaged, for example they discriminate and stigmatize them (Dominelli 1996, McDonald, Coleman 1999). Their discriminatory discourses eventually result in the deprivation of rights. This concept helps to understand why Jun and Sabrina have been deprived. Jun is a female with mental health problem, so she is isolated and only holds a restricted lifestyle. Jun has no say in the decision-making regarding her lifestyle. It is her parents and Taiwanese culture that make the decision for Jun. Jun is deprived of her power of decision-making due to mentalism as well as due to the patriarchal discourse. Kung is a male with mental health problems, which does not restrict the man to enter into marriage. In contrast, Kung is expected to marry and continue the family line, although it is his parents' decision whom he will marry. His parents instrumentalized another person who is also disadvantaged, a migrant woman from a poorer south Asian country, to marry him and to secure the family name and offspring. Compared to Jun, Kung is not isolated as 'others'. The different life choices that Jun and Kung hold reflect that they both are deprived of the power of decision but females are deprived of much more.

Sabrina is a female from an economically disadvantaged area and she becomes inferior due to her gender and economic status. Sabrina is deprived of her own rights in several ways by the privileged, as she became a commodity, without a free choice whom to marry. She was also not given the choice whether she wanted to become a life time carer for a man with mental health problems or not. In addition, Sabrina is under severe control by her husband's relatives and is therefore deprived of chances to establish a support network. This makes her even more disadvantaged in a foreign country. Sabrina is trapped in an interlocking system of oppression.

People with mental health problems often experience social exclusion that eventually results in poverty, unemployment and isolation (Barnes 1999, Zaviršek 2006). Although Jun's and Kung's parents are financially better off, the whole family experiences social marginalization. For example, Jun's parents have to hide from their elite circle of friends and Kung's parents had to hide the son's diagnosis when they tried to get a wife for Kung. Therefore, it is not only the person with mental health problems but the whole family who experience social exclusion in Taiwan. This reflects that the discrimination and isolation on the ground of mental health are still prevalent in Taiwan. From a social work perspective the question is how to change it?

Looking into the future

Several groups, such as the Taiwan Association of Family Caregivers[2] and the Taipei Mental Rehabilitation Association[3], have acknowledged these issues and are trying to lobby policy makers to include women's and gender issues such as female sufferers and female caregivers into the mental health care system in Taiwan. However, there is still a long way to go. This reflects again the cultural beliefs that women are considered to be of a 'second class' and women's issues receive little attention.

What can be done to enhance the well-being of women in the situation of mental health problems in Taiwan? Anti-oppressive practice techniques are useful in developing possible strategies. Consciousness-raising is always the first step and follows the understanding of the unique needs and situations of women. The consciousness-raising helps the public to understand the disadvantaged situations of women with mental health problems as well as the situation of men who are feminized and seen as 'not proper men', when they develop mental health problems. The awareness and understanding then brings the public together to work on the issues and

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[2] Cf.: http://familycare.org.tw/en/index.html (30. 9. 2014).

[3] Cf.: http://www.taipeitimes.com/News/feat/archives/2007/05/27/2003362739 (30. 9. 2014).

hopefully come up with constructive actions. Therefore, conferences on mental health issues are held in Taiwan.

Secondly, the political aspect needs to be changed in order that more resources and policies will be put into these issues. Although this has been a difficult part so far, we believe it will be successfully reached when more people devote themselves to these issues.

Critical examination of the discourse of policies should be done. This includes a careful discourse analysis of mental health relevant policies regarding the definition of service users, the distribution of budget and the inclusion of gender lens.

Critical consciousness of social work practitioners should be developed. Discourses of social work practitioners have profound impacts on practices, including service delivery process and resources referral (Danso 2009, Rossiter 2005). Without critical consciousness of social work practice, social work practice may turn from helping into oppression. This could be done by constant self-examination or supervision.

Lastly, a human rights principle should be included in social work education in Taiwan. By doing so, we will be able to have practitioners that are able to challenge the structural inequality.

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NEGOTIATION OF SELF-IDENTITY AND THE CONTINGENCY OF SELF-ACTUALIZATION AMONG THE STUDENTS WITH DISABILITIES STRIVING FOR HIGHER EDUCATION IN SRI LANKA

The article argues that in the context of the highly competitive state higher educational sector in Sri Lanka the contingency of identity construction and actualization among students with disabilities differs considerably from that of students who are considered as 'not disabled'. This is seen as due to highly contradictory social cues the former receive in the effort to reach higher educational goals in a locality where they experience significant socio-spatial discrimination and deprivation. The process of building self-identity is understood as occurring in three localities, namely, (1) the period prior to entering the higher educational institutions (home and schooling), (2) the period spent in the higher educational institution, and (3) the future world they attempt to actualize, all of which become transitional and reflexive during the process of identity construction. Self-actualization of the students with disabilities in this context is seen as a reflexive, locality specific, contingency which varies with the level of paradoxes they encounter in this process.

Key words: locality, reflexivity, capabilities, segregation.

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RAVNANJE Z LASTNO IDENTITETO IN KONTINGENTNOST SAMOAKTUALIZACIJE MED ŠTUDENTKAMI IN ŠTUDENTI Z OVIRAMI V VISOKEM ŠOLSTVU NA ŠRILANKI

Visokošolsko izobraževanje na Šrilanki večinoma obsega državni sektor visokošolskih institucij; v njih je bilo brezplačno izobraževanje uvedeno leta 1945. Kljub izobraževalnim možnostim, ki so jih študenti z ovirami dobili že leta 1912, na visokošolskih ustanovah študira le zelo malo študentov z ovirami, in sicer zaradi izjemno tekmovalnih izpitnih in selekcijskih procedur ob vstopu na univerzo. Na Šrilanki, v državi, kjer izobrazba velja za pogoj za družbeno napredovanje, je visokošolsko izobraževanje ključno pri oblikovanju ambicij in iz njih izhajajočih identitet med študenti/študentkami. Članek prikaže kontingenco konstrukcij identitete in njihovo realizacijo med študenti in študentkami z ovirami, ki se razlikuje od identitetnih konstrukcij nehendikepiranih vrstnikov, in sicer zaradi protislovnih družbenih sporočil, ki so jim izpostavljeni v izobraževalnem procesu v okoljih, ki jih zaznamujejo družbeno-prostorske diskriminacije in deprivacije. Konstruiranje lastne identitete prepoznavamo v treh fazah: 1) obdobje pred visokošolskim izobraževanjem (dom in prejšnje šolanje); 2) obdobje v visokošolskih institucijah; in 3) prihodnost, ki so si jo začrtali in ki postaja v obdobju konstruiranje identitete prehodna in refleksivna. Samouresničevanje študentov z ovirami je v tem kontekstu videno kot refleksivno, lokalno specifično, odvisno od stopnje paradoksov, s katerimi se v tem procesu srečujejo.

Ključne besede: oviranost, hendikep, lokalnost, refleksivnost, sposobnosti, segregacija.

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Background

In spite of the armed conflict that ravaged the country for almost thirty years and having faced the devastating effects of the deadly Indian Ocean Tsunami in 2004, Sri Lanka has been able to maintain substantial levels in a number of socio-economic indicators, when compared with the regional and world standards. With its population of twenty million (Census 2011), the country maintains a Human Development Index (HDI) of 0.715, placing the country in the high human development category, above the average for countries in the human development group and the average for South Asia (UNDP 2013, UNESCO 2013). The loss in the Human Development Index due to inequality for Sri Lanka is smaller than the average for high HDI countries and for countries in South Asia (UNDP 2013).

The country maintains an average life expectancy of 75 years and a literacy rate of 92.2 percent for the total population (SLLFS 2011). Primary school enrolment has reached 97.5 per cent and the literacy level of 15–24 year-olds has grown beyond 95 percent from 2003 to 2006/07 in all districts across all sectors and for both males and females (UNESCO 2013). Although the country had introduced a free education system in 1945, a system which is almost entirely free until the completion of the first degree at state universities, the introduction of the Compulsory Education ordinance in 1997 had a significant effect on children of school going age.

Gender Inequality Index (GII) is another significant area, which is 0.402 for Sri Lanka, compared to 0.601 for South Asia and 0.409 for countries with high human development[1]. The low disparities between males and females with regard to many aspects are seen as mainly due to the equalities which prevail in education (UNDP 2013).

The objective of this paper is to see if this high level of socio-economic development and prevailing equalities have been able to equally include students with disabilities within the locality of higher educational institutions, creating equal socio-spatial contexts for them for the negotiation of self-identities and self-actualization.

Educating students with disabilities

The history of education for students with disabilities commences in colonial Sri Lanka with the opening of the 'School for Deaf and Blind' in 1912 by the Church of England, followed by other institutions that catered for students with visual and hearing impairments established by Christian, Catholic and Buddhist religious organizations. Later initiatives taken by the Sri Lankan government resulted in the establishment of 26 residential schools with approximately 1,900 students with disabilities by 1977 (UNICEF 2003). The number of students with disabilities enrolled in educational institutions had reached 58,223 by 2003 (Gunasinghe 2004). By 2006 the country had approximately 950 special classes in regular government schools. 'In addition, private schools also implemented educational programmes for children with special education needs' (Lakshman 2009).

Acceptance of inclusive education policies by the government of Sri Lanka over the years has resulted in maintaining the number of special schools at 25, with 114,659 students with disabilities in 2010. Inclusive education is increasingly growing in popularity and at present

totally private and English-medium international schools also have established special education units providing students with disabilities an opportunity to study in regular class rooms (Jayawardana 2010).

Despite many remarkable developments in mitigating the vulnerabilities of students with disabilities in the field of education, studies emphasize that persistent socio-economic disparities within communities and between individuals and groups continue to discriminate against and exclude children with disabilities with regard to educational achievements. Social class, gender and regional disparities in access to newly developed educational opportunities have been identified as the most pressing factors in disadvantaging these young children in education[2], and only 'less than half of all school-aged children with disabilities' (UNICEF 2003: 25) seem to benefit from these significant achievements in the educational sector regarding children with disabilities. According to the Government Census in 2001, only 31.7 percent of children with disabilities in the relevant age category had enrolled in the school system[3] (Census 2001).

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[1] For details please see UNDP 2013: Table 4: Gender Inequality Index; pp 156–159.

[2] 'The greatest barriers to inclusion are caused by society not by medical impairments' (UNESCO 2013).

[3] The data on the same for the 2011 Government Census which was completed in March 2012 is still not available at the time of writing this paper. The educational situation could have changed due to the recent improvements taken place regarding the education of children with disabilities and the infrastructural development in the country.

A number of authors have pointed out the prevailing disadvantageous position of children with disabilities in access to education and the greater impediments encountered by female children with disabilities. The reasons include prevailing cultural ideologies on security, safety and protection of female children, especially those with disabilities, against their potential vulnerabilities, as well as the social factors such as distance to educational institutions and lack of transport, lack of family support etc. (Ahuja, Mendis 2002, Mendis 2004 a, Jayaweera, Gunawardena 2007). Nevertheless, 2011 Census data on the percentage distribution of population (10 years and over) according to literacy by age illustrates that for the age groups 10-14 and 15-19, literacy level has been increased from 92.2 and 52.6 respectively in 2001 (Census 2001) to 99.4 and 99.3 respectively in 2012 (Census 2012) which indicates that school attendance has increased significantly during the decade. This obviously would have included children with disabilities.

Place of the students with disabilities in the Higher Education Sector

University entrance in Sri Lanka has become highly competitive over the years despite the enhanced opportunities. Due to the increased numbers taking the state level examinations for university entrance, large numbers of students who seek admission to universities are denied access in the universities which provide free higher education, and other fee levying institutions approved by the UGC[4] also cater to the higher education sector in the country (UGC 2011), despite the policy decision to provide opportunities for higher education for 'all' those seeking such education (NEC 2009: Policy 5). Only about 10% from the total number of students sitting the General Certificate of Education – Advanced Level (GCE – AL) examination, which is the national level competitive examination which qualifies students to enter the universities of Sri Lanka, secure admission to state universities. This percentage from the students who receive the minimum necessary qualifications to enter a university is approximately 16% (UGC 2012: 12).

Students with disabilities were never barred from entering the higher education sector in Sri Lanka. Nevertheless, the lack of opportunities and the social barriers that prevent those students from equally participating in primary and secondary education, has kept these numbers at a minimal level. With an estimated 8 percent of the population aged over 5 years having some form of a disability in 2012, and 3.6 percent of them falling within the cohort of 20–30 years (Census 2012 – 5 percent sample data) which is the age cohort of the students in the tertiary education sector, higher education for students with disabilities becomes an issue that draws serious concern.

The admission policy of the University Grants Commission includes disability as a special category for admission, 'Blind and Differently abled candidates' that stands outside the general admission and other quotas, although there is no specific percentage allocated for this category (UGC 2012). Admission to a state university almost totally depends on the places available and the number qualifying each year, however, the number of admissions under this special category totally depends on the decision of each university on the numbers of students with disabilities each institution could accommodate each year. Students who sit the G.C.E (A/L) examination using the Braille system come under the category of 'blind' and the students with other forms of disabilities are considered as 'differently abled' who are expected to provide medical proof of their disability to apply for university admission under the special category. The 'blind' become eligible only for courses in the Arts (social sciences and humanities), while 'differently abled' have more options available in the Arts, Commerce, Biological Science and Physical Science streams. To gain entry to a state university under this special category, a student should have reached the

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[4] University Grants Commission (UGC) is the main body endowed with the responsibility of the management of the Higher education sector under the Ministry of Higher Education.

basic minimum qualifications and other special requirements laid out by the UGC for different study streams each year. As such, students with disabilities would not become eligible to enter a university merely because of their disability. However, out of the large numbers of students who receive the basic minimum qualifications mentioned above, the students with disabilities may stand a better chance to enter the university due to the availability of a special category.

According to the UGC policy statement, 'For the purpose of this section, physical disability shall mean a permanent physical impairment, which has affected *normal life*[5]' (UGC 2012/13: 54). The definitions and the nomenclature adopted by the UGC raises a serious issue on how the students with disabilities are officially perceived in the higher education system in the country. Classifying students with disabilities as blind and differently abled[6] segregates the student community with disabilities into further categories, one as belonging to a specific form of disability and the other group as having abilities which are different. The latter category includes people with all disabilities other than the blind. This highly confusing nomenclature which serves the official purpose of assigning the students with visual impairments and students with other forms of disabilities to the recommended study courses[7] provides an inaccurate image of the students with disabilities.[8] Similarly, the much criticized concept of 'normalcy' as an inherent quality of human nature has been uncritically adopted in classifying the students with disabilities as standing out of this normalcy. Such an approach does not provide an opportunity to discard ideological biases existing in the society against total inclusion of people with disabilities, but reinforces differences and therefore inequalities rather than respecting diversity (Zaviršek 2007: 2). According to the UGC Year book for 2011, the total number of admissions under the category of 'Blind and Differently Abled' for the year 2011 was 20 and 44 respectively in the whole state university sector (UGC 2011). It is not apprehensible if the above numbers include all the students with disabilities who seek admission to universities and/or have reached the basic minimum qualifications necessary for admission.

It is against this backdrop that locality and contingency (Battaglia 2009) of students with disability in the higher educational sector in Sri Lanka have been addressed here. It starts with the premise that the subjectivities and identities of being disabled, and the transformations that occur in those subjectivities within the higher educational setting as expressed by the students, are not 'given' to them by their biological constructions, yet, to a considerable extent, would be locality specific contingencies. 'Locality' in this context is the physical, social and cultural location in which the individual person with disabilities is situated. I would argue here that the prime measure of the capabilities (Sen 2000) of the students with disabilities entering higher educational institutions in Sri Lanka would be the title of the degree they obtain (apart from language, communication or artistic skills they would have acquired before) which would become more or less the main marketable resource for them. Faring well at the degree opens for them the opportunity to get included in the 3 percent quota allocated by the Public Administration Circular (1988, No. 27/88) for people with disabilities in the state sector employment which non-graduates with disabilities or graduates without disabilities would not have. However, due to the nature of the locality and unequal opportunities they encounter within the higher educational institution, for the students with disabilities, their level of achievement would

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[5] Italics are my emphasis.

[6] 'Differently abled' is a commonly used term in the country that tends to view people with disabilities as having abilities that are different from others or 'unique' to them. This usage not only is endowed with a sympathetic notion but also places the people with disabilities in comparison to those who are considered as 'abled' emphasizing that people with disabilities do not retain the same abilities which 'abled' people may have. (People with disabilities in local language Sinhalese, are called 'Abadhitha' meaning a person with some effect on ability; while in Tamil, the other local language, the term 'angaweenar', is used bearing the meaning disabled).

[7] For this purpose, a more appropriate nomenclature would be 'students with certain disabilities – visually impaired and other'.

[8] Historically, blindness has been seen as different from other disabilities in many cultures.

necessarily be a locality specific contingency that would produce 'shifting identities of self', 'multiple selves' or 'shifting selves' (Ewing 1990: 253, Bataglia 2009) among them, promoting or jeopardizing their goals in life[9].

In such a context, a degree from a recognized institution becomes an invaluable resource for people with disabilities which would certainly enhance their capability profile at the level of employment. Setting up a higher educational goal by no means becomes an easy target for any student facing highly competitive exams and selection procedures prevailing in the country, nevertheless, for the students with disabilities it becomes an additional exertion given the socio-spatial context within which they live (as exemplified by the low rate of students entering education). The differential experiences of the students with disabilities differently influence the reflexive process upon which they create their self-identities positioning them at different levels within the same locality.

The following analysis is based on my in depth interviews or rather personal dialogues (in which the researcher had very little to contribute) carried out during a three year period (2011–2014) in one university faculty in Sri Lanka where there is a population of students with mixed disabilities. The faculty intake of students with disabilities for each year ranged between 10 and 15 students[10]. Statistics available from 2006 to 2012 showed that a total of 73 students have been admitted to the faculty out of which 39 are female students.

The interviews were carried out informally allowing the respondents to speak at their leisure during free hours when both parties could 'enjoy a break' from their work schedules. The dialogues were carried out with students with different disabilities, their parents, academics and student activists who are emerging out of the still faint discourse of disability they attempt to establish in the university system.

Disability, higher education and negotiation of self-identity

As explained earlier, entering state higher educational institutions is considered luck or destiny rather than an achievement by Sri Lankan students and their families due to prevailing limitations concerning university admission. It becomes so even for the students with disabilities, which cannot merely be attributable to admission related limitations but also to severe social and cultural constraints they encounter throughout their lives.

For the purpose of analysis, I would see the total process of higher education of students with disabilities through three contingent stages, (1) the period prior to entering the higher educational institutions (home and schooling), (2) the period spent in the higher educational institution, and (3) on the future world they attempt to actualize which is reflexive upon both the previous stages. The construction of self-identity of the individual student and the collective identity of the students with disabilities is seen as a process that is reflexive upon these changing localities 'forming a trajectory of development from the past to the anticipated future' (Giddens 1991: 75) creating shifting contexts of socially constructed selfhood (Ewing 1997).

For the students interviewed, home and school provided entirely contrasting experiences. Almost all of them had a very special place at home, and had become the center of attention. It is a common factor that one parent or an extended family member had been totally dedicating

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[9] Bataglia (2009) and Ewing (1990, 2005) use the terms 'Multiple selves', 'shifting selves' or 'shifting identities' to explain the changing self-identity of people with the change of interaction/experience in the same or different localities which make them 'non-locatable' in anthropological studies. My argument here is that, in the context of 'otherness' constructed with regard to the students with disabilities this produces highly inconsistent interactions and contradictory experiences making them become excessively reflexive on different localities in relation to which they construct their self-identities. This in turn could create complex ambiguities of self-identity among them.

[10] Average intake of the faculty approximately is 500 students per year. Nevertheless, this number cannot be compared with the intake of the number of students with disabilities since the latter intake is based on a special admission criterion.

his or her time to caring for the child with the disability[11]. The students with disabilities generally saw this as positive family support. Thushari, a visually impaired female student expressed her displeasure concerning the negative impact she experienced due to such attitudes held by her family members.

> I had my parents, my maternal grandmother, my aunt and my sister at home, all of whom cared for me very much. It is true that I have a visual impairment, but they treated me like my whole body was numb. When I entered the university, it took about two years for me to get to know the surroundings and become independent. (Interview, December 2013.)

As explained in this quote by Thushari, such caring cultural practices could have a differential impact on the development of children, and could result in infantilizing them (Scheidegger *et al.* 2010: 292) and preventing the opportunity for them to become 'political subjects' (Zaviršek 2006: 5). Over protection of female Sri Lankan children with disabilities in order to avoid possible abuses is seen as hindering their opportunities for schooling and social life (Mendis 2004 b).

Schooling did not seem to be a pleasant experience for many students, at least at the initial stages, which was a drastic home to school transition. These experiences changed with the type of school and the level of support received from the school and home to continue their studies. Nimali, a student with a physical disability, reminisced on her school days.

> From those of us who studied together I was the only one who entered university. Others dropped out at different levels, either because of their own disinterest or financial difficulties or due to discouragement from their families. Some parents are highly reluctant to send their children to universities. They worry over their children's safety and ability to live without them. (Interview, October 2013.)

Despite the propagation of inclusive education in the country over the years, the challenges and confusions faced by children who were attending special schools reportedly were comparatively lesser than those encountered by children who received inclusive education. The most highlighted issue was the feeling of 'difference' and 'segregation' within the inclusive school environment. At the special schools, even with the physical segregation, students experienced a sense of belonging. Lack of teachers trained for special education, poor knowledge among the majority of teachers of special needs, low coping ability with the work load and the pace of study seem to be the crucial factors that caused the feeling of difference within the inclusive educational setting. The recollections however, were not always negative. Sisira who had a visual impairment stated,

> I always had problems with the exam paper on science, with graphics etc. But I had one teacher who drew the sketches on my palm to make me understand the shapes.

Entering a tertiary educational institute surpassing physical, social and psychological barriers, contradictions and paradoxes they encounter due to their disability was a reality beyond conception for many students with disabilities. All of them however, had built high aspirations about their future when they entered the university. The high reputation of the university and its highly urban location which they thought would provide them with higher access to resources, further contributed to the enhancement of these aspirations. Kumara said:

> I could not believe my ears when I heard that I got selected to the university. I was overjoyed and I could not control my tears. Still……. I was scared too. Arriving at an unknown city and living there all by myself made me worried. (Interview, September 2011.)

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[11] Stories of negligence, cruelty, discrimination and harassment of children with disability do get reported in Sri Lanka, however, the students who enter university indicated that they often came from supporting and caring backgrounds which made it possible for them to overcome many social and cultural impediments. Scheidegger *et al.* (2010) state that the same situation prevailed in Tibet where a child with disabilities was much loved and received the best treatment in the family, with the best food etc. yet, often families did not have high expectations of the child.

> They had come to the university with mixed feelings. This uncertainty could be part of the trajectory of development of self which would be reflexive upon the experiences they receive at the new locality (Giddens 1991: 75). From that point on, his narration was entirely reflexive, moving back and forth, to and from different localities, home, school and the university. He continued:
>
> I thought I never again will have to face as many problems as I experienced during my primary and secondary education…..Professors are often kind, not like some of the teachers who bluntly told me 'with your disability, you should not be here in this school'. I was angry with my parents when they persuaded me to continue schooling. Nevertheless, at school teachers paid attention to our needs, even with reluctance and complaints. Here there are no complaints but no consideration either. (Interview, September 2011.)

Their self-identity was clearly shifting from one location to the other, moving between paradoxes, from an image of being wanted and loved, to an image of not belonging and being problematic, from the feeling of being accepted to the feeling of being denied and excluded from the same system and from a sense of capability to incapability, all of which were parts of the continuous process of reflexivity contributing to making them what they are (Giddens 1991: 75–76).

Neela who is a partially blind student stated:

> This partial blindness was such a nuisance for me. At school I was accused of lying. Here, at the university, they don't accuse me, nor do they ask me why I keep on staring at them. I am just non-existent.

Although with frustration, she laughed saying:

> sometimes it is better to be blind than partially blind. When you 'peck' on the braille writing pad with a big sound, it draws their attention. (Interview, January 2014.)

Students with disabilities were of the view that the facilities they receive at the faculty have improved over the years and more opportunities are provided to discuss their issues with authorities. Increased accessibility to the facilities including the library, buildings and lecture rooms, special events organized for them, flexibility in exam schedules with extended hours provided, options provided to them in mid-semester exams by some professors, facilities to use Braille systems and hearing aids were appreciated by the students although these were inadequate in meeting even the bare minimum requirements of equal access. The problems, however, they claimed to lie with individual views and perceptions on disability prevailing among the university community as well as in the system. Students were of the view that they receive much support from many fellow students, and academic and support staff, but also apparent were the lack of will, understanding or empathy in changing the conditions.

Students had faced manifest forms of exclusion in certain instances as in the selection of students into different study streams. Many of them experienced a status of 'liminality', or facing rituals of status change (Reid-Cunningham 2009), a change which arise from shifting localities of disabled bodies. Aziz uttered in an offensive and sarcastic tone:

> Some departments brusquely tell that it is a problem for them if we were taken for those study programs … I can understand the fact that some courses which involve specific physical abilities such as hearing or seeing or movement cannot accommodate some disabilities, but this is a baseless rejection.

Many class room activities often seem to overlook the students with disabilities. He added:

> Only a few academics in the university at least try to understand us and see us as human beings. What we receive here most is the sympathy which we do not want. (Interview, October 2013.)

Lack of understanding or concern on the disability issue creates numerous problems for these students both within and outside the university. The following narratives demonstrate the gravity of the issues.

> Professors distribute hand outs and use power point presentations in class as if we are not there.
>
> During the exams they make us move several times according to their convenience.
>
> Some supervisors and invigilators do not like the additional time given to the students with disabilities. But some are highly supportive and tell us to take our own time.
>
> We spend a lot of money on telephone bills just to coordinate with the students who offer to help us to go to exam halls etc.
>
> Crossing the road several times a day to go to administrative buildings and lecture halls, going to various offices, banks etc. and getting the needful done are not easy tasks. Often the drivers are not concerned. People see us with disabilities as an unnecessary nuisance. (Focus group interview, January 2014.)

It was apparent that the intellectual environment within the university has not been able to surpass these cultural conservatisms prevailing in the society. The university and the city life was seen by the students with disabilities as a locality that constructs an image of 'inability' in them. Nimali stated:

> I asked a group of students if they could help my friend with a visual disability to cross the road and go to the next lecture held upstairs. One of them immediately offered help but said to the others, 'Can you wait for me until I drop him off and come back? Poor him.'12 (Interview, October 2013.)

A student activist mentioned:

> Once a group of students had a large bag of veralu (a local fruit) with them and shared them with everyone who was passing by. One who noticed some students with disabilities seated nearby said, 'it is very bad we eat these alone. Let's give them some too.' Although it apparently was a gesture of kindness, I could not resist asking them why there was this difference, to consider all those who pass by as 'we' and the students with disabilities as 'them'. They looked at each other with a scornful look on their faces as if I was out of my mind. (Informal discussion, January 2014.)

When Nilani told the lecturer that she did not follow the long explanation given on the power point presentation due to her hearing impairment the answer she got was:

> I am sorry. You need to understand that I cannot write down everything I said just for you. I have to teach a whole class and I don't have time for this. You may get help from a teaching assistant. (Interview, February 2011.)

Nilani added that the lecturer went on blaming the administration for making it difficult for both the lecturer and the students with disabilities by giving admission to universities without adequate facilities. Nilani further stated:

> I went to the hostel and cried. What am I doing here? I asked myself. I started feeling that I don't belong here.

Such situations, which I call 'benevolent derelictions', could emerge out of contexts where power dynamics (bio-power in the case of disability; see Foucault 1981) becomes a decisive factor in negotiating identity which is expressed through overt and/or covert communication. Ewing (2005) describing identity negotiations that occur based on power dynamics in the anthropological interview process says that people experience many ambiguities in their daily lives due to these power dynamics and identity negotiations which go beyond the 'overt context of communication'. She refers to the colonial subjects or subordination of women in the communicative process as examples of such situations. The university community,

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[12] It is not possible to give the exact translation of the term she used, 'pawne' which I translated as 'poor him'. 'Paw' in the local language these students used, Sinhala, has the literal meaning of 'sins'. Direct translation of the term means, 'Sin, isn't it?' In colloquial speech it is used to connote, 'I feel sorry for the person'.

despite its claim for knowledge and equality, has not been able to overcome the traditional image of 'otherness' towards the members with disabilities in their own community, and both explicitly and implicitly separate them from people 'who are not considered to have disabilities' (Reid-Cunningham 2009: 100). Such communicative actions create an ambiguous locality in which the identity negotiation takes place on the basis of power that is grounded on 'ability or lack of it'. Such contexts of social interactions which are entirely based on 'bio--power' place students with disabilities at the mercy of those who are not considered to have disabilities. Students with disabilities are often not seen as 'capable and complete human beings' who could live independently with 'little assistance', yet, often regarded as 'outsiders' (Becker 1983) who deviate and exhibit 'undesired differentness' from social expectations, and therefore, become stigmatized (Goffman 1963). This delimits the social relations of these students within and outside the university simply to those relations with fellow students with disabilities, thus highly restricting their world of social interactions. This situation converts the bio-medical disabilities into social and cultural experiences producing 'social disabilities' which have nothing or little to do with their bio-medical situation producing a 'culture of disability' (Reid-Cunningham 2009: 107) among these students.

The interviews made it highly evident that the existing human and physical resources in the faculty are grossly inadequate to offer equal or even 'nearly equal' opportunities to the students with disability facilitating their studies. Aziz became vociferous in this regard.

> Our … is really concerned and takes all our demands and complaints into consideration and also takes a lot of trouble to improve the situation, but he receives no support at all from higher ups in this endeavor. Ultimately lack of funds is the main hindrance. What I feel when I see the things that are happening here is that it is the lack of interest rather than the lack of funds. (Interview, October 2013.)

Almost all the interviewees were very critical about the physical space and the lack of proper infrastructure facilities which severely hinder their achievements. Absence of many basic facilities including wheelchair accessible buildings, elevators for upper floors where many classes are conducted, accessible sanitation facilities, braille reading facilities, uneven roads inside the faculty making it inaccessible for wheelchairs, trained support staff or social workers, facilities during examinations such as braille question papers, vehicle facilities providing easier access to distant examination centers or braille translators to ensure that answer scripts are duly translated for examiners, were the most pressing concerns raised by the students. The university was evidently catering for 'societal standards for normative bodies, behaviors, and role fulfillment' (Ingstad, White 1995: 107) and the students with disabilities were expected to negotiate their identities through a process of acculturation of disabilities within this unequal social and physical milieu.

Kasnitz and Shuttleworth (2001: 2) explain that 'disability exists when people experience discrimination on the basis of perceived functional limitations'. When functional limitations are caused by the physical and technological construction of living spaces preventing the optimal utilization of abilities, the situation is seen as a consequence of disability rather than an architectural failure. The 'architectural apartheid' view towards disability adopted in city development, which is replicated in most of the state and commercial buildings and education institutions across the country, together with the demeaning social attitudes, construct 'socio-spatial patterns' that produce stigma and shame culminating in 'devaluation of the disable body'(Imrie 2001: 232). The feeling of inability caused within devalued bodies constructs powerful negative self-images of devalued selves in transforming and shifting self-identities in the locality of the city. Friedner and Osborne (2012) argue that studies emphasizing the 'plight of the disabled' represent them as marginalized and peripheral subjects, neglecting their everyday experiences. Suneetha, who has a physical disability, had to be physically carried by her mother to participate in lectures held in the upper floors of the building. The mother had to leave another young girl in the distant village and reside in the city to care for her daughter with a disability. She was obviously embarrassed when other students offered to carry her up. Her whole intention was to finish the degree as soon as possible and go home. Even within the university, among hundreds of young people of her age, her mother remained her main companion. Social withdrawal was her primary reaction to the process that infantilized her by the physical space in the university.

Discussions with authorities on the physical structure of the university always ended up at the same juncture, as Aziz mentioned, lack of funds. This is the same reason given for the constant postponement of the repairs of the horribly demeaning space allotted for the students with disabilities. A smelly, damp room with mildew growing on the walls was justified on the issue of priority. Disability did not seem to come within the purview of the cost benefit analysis in construction and renovation activities.

Despite many scientific discoveries leading to the production of equipment and devices supporting people with disabilities to counteract certain physical barriers, scientific and technological advancements have not been productive in adequately including diverse populations among their beneficiaries. The quest for the truth in science, which is based on the presumption that 'knowledge precedes social construction' (Seelman 2001: 688), has led scientists to act on the basis of standards of normalcy adversely affecting disabled people, thus placing the social construction of disability out of the scientific discourse. Exclusion of socio-spatial location from the analysis of disability undoubtedly hinders the chances of liberating those individuals with disabilities from their peripheral identity and calling for changed spaces where they could be transformed into political subjects.

The process of building aspirations and their actualization among the students with disabilities occur in this distinct social-spatial context which constructs highly inconsistent and shifting self-identities for them. Neither the examination procedures in the university nor the exceptionally competitive employment market which searches for the most skillful young men and women, makes a distinction between these young people with and without disabilities despite the vastly diverse social and physical spaces that are constructed for them. They are posed with numerous polarized contradictions created by the life worlds they encounter in different localities, from home, school, and higher educational institution to the employment market. The contradictions of acceptance and rejection, care and negligence and dignity and humiliation construct ambiguous, shifting and transformative self-identities influencing the development of aspirations and their actualization. The university community had juxtaposing views on this. A senior academic stated:

> There is no guarantee for any student who enters the university that they will definitely secure a job. Disabled students will also have to face this reality. If they do well, they will have more chances, just like the rest of the students. There is nothing we can do about it.

A student disability activist expressed:

> The students who are considered 'able' come from many social backgrounds and some come from considerably disadvantaged situations. Yet, within the university, they are equal and enjoy equal opportunities. Their dis/advantageous social position could have some bearing on their achievement (eg. food, living environment, ability in English, and computer facilities etc.), yet, they would have ample opportunities to overcome them. However, the students with disabilities face serious inequalities within the university. These are in addition to other common problems we face as students. Ultimately, all of us face the same exams and the same competitive job market. (Informal discussions, October 2013.)

The student population with disabilities however, is not a homogenous group except for the fact that they all have some form of disability. Other than the differences based on the nature of the disability and therefore the abilities, the social class factor could be seen as having a significant power on deciding the effects of locality, self-identity and self-actualization. Gender could not be seen as playing a noteworthy role in the identity construction, perhaps due to the larger female population in the faculty and among the students with disabilities. Despite the claim that female participation in education is low in all disability groups across all ages (UNICEF 2003, Mendis 2004 b), there was no noticeable gender difference in the enrollment of students with disabilities, although a slight increase of female student enrollment can be observed in recent years. Being a female in the Sri Lankan context has a significant impact on the identity formation; however, the university as a specific locality did not seem to have substantial disadvantages for female students with disabilities. Sunila posited:

> I think female students have more support as the majority are female students here. I do not feel that I am deprived within the faculty because I am a female, but I felt and still feel this when I am outside the university. Some of us have experienced unwanted touching etc. in buses and this creates much inconvenience for us. We know that many female students with no disabilities also experience such dirty encounters in public transport. (Interviewed in January 2014.)

An overall impact of the social-spatial conditions prevailing within the city and the higher educational institution on all of the students with disabilities could be identified; however, the process of self-identity formation and self-actualization was highly contingent on the social class factor, thus influencing the level of capability deprivation. Sen (2000: 4–5) writes:

> […] Adam Smith's13 focus on the deprivation involved in not 'being able to appear in public without shame' is a good example of a capability deprivation that takes the form of social exclusion. This relates to the importance of taking part in the life of the community, and ultimately to the Aristotelian understanding that the individual lives an inescapably 'social' life. Smith's general point that the inability to interact freely with others is an important deprivation in itself (like being undernourished or homeless).

This idea can obviously be extended to people with disabilities in general and the students with disabilities in Sri Lankan higher educational institutions in particular. Aziz, who comes from a considerably affluent social background, was obviously different from many others, exhibiting a highly outgoing personality. He proclaimed:

> From childhood I never felt different, although I went to a special school for the blind. My parents liked the idea of arranging special attention for my special needs. However, when I came to the university I did not have the feeling that it would be an unknown space for me. I had the opportunity at home to attend many different events, meet people, and express my views without facing any social barriers. I always had someone to support me when I needed it but I was rather independent. I acquired many skills which many students with disabilities have no opportunity to acquire. Despite all this I felt severely restricted in the university. As my father always says, the university premises have been constructed with no sense of the independent living of the students with disability. I often had to enter into confrontations with people to ensure my own simple day to day rights.14 (Interview, October 2013.)

His capacity to 'appear in public without shame' is apparently what he has gained from his social class background that undermined his physical disability in his social life.

Locality and contingency of self-actualization in the case of disability

The students with disabilities who enter the higher educational institutions enjoy a rare chance of acquiring knowledge and skills which would enhance their capabilities that may position them at a relatively higher level in the social hierarchy. The process of improving capabilities however, would not become a linear scheme for all the students with disabilities alike. Ca-

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[13] Sen (2000) hereby refers to: Adam Smith (1776), *An inquiry into the nature and causes of the wealth of nations* (republished, edited by R. H. Campbell and A. S. Skinner. Oxford: Clarendon Press, 1976).

[14] This particular student was described by some academics as aggressive, and being a 'nuisance' at times.

pability development to a considerable extent is contingent on the location. In other words, capabilities are contingencies that vary according to how each student with disabilities fits into the location, interprets the location and utilizes the location to reach a preconceived goal.

The utilization and interpretation of the locality varied among students with different disabilities coming from different backgrounds; however, the overarching argument was the insensitivity and unfriendliness of the locality in serving their needs. Nevertheless, it was clearly obvious that construction of aspirations for the future was a unique reflexive process for each of them which depended on their negotiated self-identities that shifted between periods, moments and between his/her own self and that of others, according to their differential experience they receive in these localities, as exemplified by the following quotes:

> The problems I have are related to the institutional setting and not to my personal life. Neither do I face any financial or technological constraints, nor any lack of physical support since I am generally accompanied by someone, making these not so difficult to overcome. My friends who do not have the financial or family support face numerous difficulties. (Interview with Aziz, October 2013.)
>
> I am good with the braille system. None of the readings prescribed in the classes are available in braille. We depend on what we hear, but when the lectures are combined with visual aids such as movies, slides, diagrams etc. we hear only part of the story. I don't know what I will have to write for the exam. (Interview with Sisira, February 2011.)
>
> I cannot participate in classes that are held upstairs. Sometimes my friends help me. Some lecturers make an extra effort to help us by providing notes and opting to have separate discussions etc., but not all. Now I have realized that I cannot do much. I will be happy if I can just merely pass the final exam and obtain the degree. (Interview with Nimali, October 2013.)
>
> It was my mother who persuaded me to enter higher education despite my hearing impairment. I read lips and try to follow the lectures. Sometimes, I get fed up because it is very rarely a lecturer would pay attention to the difficulties I am facing. Blind students get more support as everybody can see them. But as my mother always tells me it is a big achievement that I got selected to the university and I have to use this opportunity to the best of my ability. (Interview with Sepali, February 2012.)

Giddens (1991: 54) writes, 'a person's identity is not to be found in behaviour, nor – important though this is – in the reactions of others, but in the capacity to keep a particular narrative going'. The individual's biography must continually integrate events which occur in the external world, and sort them into the ongoing 'story' about the self. The above narratives are stories of self that demonstrate how the process of self-actualization becomes a contingency in a deprived locality creating 'shifting contexts of selfhood'[15] (Ewing 1997) or 'transformative self-identities' (De Lauretis 1986)[16] among students with disabilities. The locality was not always conducive for improving or even utilizing the skills they had achieved prior to entering the university, which prevent these skills from transforming into capabilities required by the employment market. The individual student negotiates his/her self–identity through a highly reflexive process of different stages of their lives which accorded them with or deprived them of those capabilities. As the contradictions of each stage or each moment increase, the process of reflexivity becomes more complex, creating highly ambiguous self-identities among them. William James (1981: 279) says 'self' is the

> sum of all that [a man] can call his, not only his body and his psychic powers, but his clothes, and his house, his wife and children, his ancestors and friends, his reputation and work, his lands and houses, and yacht and bank account. All these things give him the same emotions.

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[15] 'Reflexive, critical consciousness that has usually been associated with the modern subjects' (Ewing 1997).

[16] De Lauretis (1986) says that people are 'transformative' subjects. As evident in the narratives, this 'transformative' nature of self-identity links to the capabilities of the individual which is contingent on the social spatial location. See Giddens (1991) for his views on the 'structuration of identity' and the 'contingent subject'.

In the present context of Sri Lankan society, where conflicting values emerging from a complex of traditional, modern and postmodern social trends influence the interpretation and assessment of 'self', students with disabilities are faced with the dilemma of choosing among the aspects of life within limited opportunities opened for them which they give priority in the construction of self-identity and its actualization. What the students with disabilities can call 'theirs' in this context would be highly limited and contingent upon the socio-spatial conditions imposed upon them.

It was at least half a century ago that Margaret Mead (1965) emphasized the need to include people with disabilities within the realm of 'normal' Americans, stressing the inclusion of human diversity as a prerequisite for understanding human nature. Five decades later, Sri Lankan higher educational institutions still have not been able to produce the social-spatial localities that are conducive for the total inclusion of the students with disabilities. Instead, the existing localities within the higher education institutions reinforce an image of 'other' influencing the identity construction and self-actualization among the students with disabilities.

This does not mean that the process of negotiation of identities or contingency of self-actualization is unique to the students with disabilities. Nevertheless, due to the highly paradoxical experiences that the students with disabilities obtain from one locality to the other and within the locality in differing moments ['shifting from a given value to a contingent value of locatability / (non locatability)', Bataglia 2009: 117], the process of reflexivity and negotiation of self-identities among students with disabilities become a process which they have very little or no control over. It is a highly complex process that produces multiple, conflicting and ambiguous self-identities depending on their varying interpretations of the locality[17], transmitting that same ambiguity to the process of self-actualization. It creates a locality where students with disabilities are deprived of capabilities while their achieved capabilities could remain unutilized or underutilized making their self-actualization process a contingency, rather than a possibility or a reality[18].

Conclusion

Individuals with disabilities have been deprived of equal educational opportunities either due to lack of educational facilities, a situation caused by the identification of the 'disabled body' as divested of capabilities or owing to the exclusion embedded in the inclusive environments laden with cultural norms of stigma, segregation and devaluation. Socio-cultural constructions of disability seem to have an obvious impact on policies and practices adopted by the higher educational sector of Sri Lanka, as exemplified by the disability nomenclature used for the provision of opportunities. For the students with disabilities, achievement in the higher educational sector or self-actualization becomes a locality specific contingency, which depends upon the specific life experiences that influence the reflexive self-identity within a traditional/ modern/ post-modern social complexity. Given the nature of the locality, which is comprised of spatial, material and attitudinal constraints that creates multiple, shifting and ambiguous identities for them, the aspirations they make and their actualization is contingent on their self-identity, which compels them either to become contented with minimum achievement or to strive even harder for higher goals and face yet another competition in the

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[17] Ewing (1990) states that, multiple selves and shifting identities cater to reconcile conflicting and ambiguous self-identities. She further adds, 'Each self-concept is experienced as whole and continuous, with its own history and memories that emerge in a specific context, to be replaced by another self-representation when the context changes' (Ewing 1990: 253). Yet, when the process of identity formation is too complex, conflict and ambiguity seem to be shifting across these multiple selves.

[18] When his philosophical theology is set aside, the Leibnizian concept of 'non-actualized possibilities' becomes highly relevant here. For Leibniz, non-actualized possibilities are the possibilities that become true in some possible world. However, as such, it becomes a contingency and not a possibility, which, given the proper locality, would become actualized, yet, will not become true in another locality (Leibniz's Modal Metaphysics, Stanford Encyclopedia of Philosophy, available at: http://plato.stanford.edu/entries/leibniz-modal).

unfavourable employment market. Unless and until the higher educational sector makes a significant departure from the paradox of inclusion/exclusion that creates contradictions in the existence of the students with disabilities within the sector, self-actualization for them will be a contingency, the conversion of which into a reality is conditional upon external factors such as economic and social power, family support or encountering a new locality where actualization of their aspirations would become possible.

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Izvirni znanstveni članek

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ODRAŠČANJE Z OVIRO

Naracije študentov in študentk z ovirami o življenjskem poteku, prehodih in pomembnih drugih

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Članek govori o značilnostih odraščanja z oviro, o krizah in premagovanju kriz, o vlogi pomembnih drugih, o izobraževalnih prehodih, izkušnjah z institucijami in eksperti. Temelji na analizi rezultatov kvalitativne raziskave študentov in študentk z ovirami. Uporabili smo biografski pristop. To so pripovedi o tem, kako temeljna življenjska izkušnja lahko učvrsti posameznika in posameznico, če ima podporno življenjsko okolje in empatične odzive institucionalnega okolja, ki je podprto z ustreznimi sistemskimi rešitvami. Razlog za uspešne biografije študentov in študentk je, sodeč po izjavah, v tem, da so bili v družini sprejeti in deležni prave mere spodbud in zahtev. To jih je učvrstilo, da so prenesli tudi identitetne krize, krize prehodov v odraščanju in občasne negativne odzive institucij.

Ključne besede: destandardizacija, izbirne biografije, normalizacija hendikepa, vratarji prehodov, varuhi prehodov.

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GROWING UP WITH DISABILITY: NARRATIONS OF STUDENTS WITH DISABILITIES ABOUT THEIR LIFE COURSE, TRANSITIONS AND SIGNIFICANT OTHERS

The article discusses the features of growing up with disability, the crises and overcoming of these crises, the role of significant others, the educational transitions, and the experience with institutions and experts. It is based on the analysis of the results of qualitative research of students with disabilities. A biographical approach has been used. These are the narratives about how a vital life experience can strengthen the individual, provided that they have a supportive living environment and empathic responses of the institutional environment that is supported by appropriate systemic solutions. Judging from the statements of students, the reason for their successful biographies is that they have been accepted by their families and have received the proper level of incentives and requirements. That has strengthened them in the way that they were also able to cope with identity crises, the crises of the transitions to adulthood, and with occasional negative reactions of the institutions.

Key words: de-standardization, choice biographies, normalization of a handicap, gate-keepers, way-keepers.

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Uvod

V zadnjem desetletju se izjemno povečuje število teoretskih razprav in raziskav o spreminjanju odraščanja, izobraževalnih in življenjskih potekov in prehodov. Velika tema teh študij je prehod iz izobraževanja v delo, ki ga prikazujejo kot prehod iz odvisnosti v neodvisnost. Vedno več je tudi razprav o pravicah otrok in mladostnikov v okviru sociologije otroštva. Povečuje se tudi število študij razvoja otrok in mladostnikov z ovirami. Vendar med temi tremi področji – študijami življenjskih potekov in prehodov, sociologijo otroštva in mladosti ter študijami oviranosti – pogosto ni povezanosti, čeprav bi prav s povezavo teh treh področij lahko dobili novo tematizacijo tako študij življenjskega poteka in odraščanja kot tudi študij hendikepa (Tisdall 2001). Izkušnje mladih z ovirami bi lahko dale nove odgovore na vprašanja o premagovanju negotovosti in tveganj sodobnega življenjskega poteka in prehodov. Hkrati bi nove ugotovitve o življenjskih potekih in odraščanju, predvsem ugotovitve o individualizaciji, izbiri, destandardizaciji in deregulaciji življenjskih potekov in prehodov, lahko nakazale strategije novih možnosti življenjskih načrtov mladih z ovirami.

Rezultate raziskave, ki jo tu prikazujemo, poskušamo umestiti prav v te medprostore raziskovanja. Članek temelji na analizi rezultatov kvalitativne raziskave študentov in študentk z ovirami o značilnostih odraščanja z oviro, o krizah in premagovanju kriz, o vlogi pomembnih drugih, izkušnjah z institucijami in eksperti, o načrtih za prihodnost. To so pripovedi o tem, kako temeljna življenjska izkušnja lahko okrepi posameznika in posameznico, a le če ima podporno življenjsko okolje in empatične odzive institucionalnega okolja, ki je podprto z ustreznimi sistemskimi rešitvami.

V članku bomo skušali odgovoriti na ta vprašanja: kaj so temeljni viri in opore, zaradi katerih so študentje z ovirami uspešni v svojem dosedanjem življenjskem poteku in prehodih? Kaj pa so največje ovire na dosedanji življenjski poti? Kakšno vlogo imajo v življenju mladostnikov z oviro ožje socialno okolje, pomembni drugi, kakšno pa institucije, skozi katere so prehajali? Kaj nam njihova izkušnja lahko pove o strategijah odraščanja v času negotovosti na sploh?

Predpostavljamo, da so prav študentje in študentke tisti del populacije mladih z ovirami, ki je uspešno opravil dosedanje življenjske in izobraževalne prehode in imajo premišljen odnos do svoje osebne izkušnje, ki bo prek njihovih pripovedi postala družbena izkušnja. Študije hendikepa so v zahodnem svetu v zadnjih desetletjih problematizirale pokroviteljski pristop družbenih znanosti, ki jih je zanimalo zgolj to, kako naj neovirani ljudje nehajo diskriminirati telesno, senzorno, intelektualno ovirane ljudi. Njej nasproti se je uveljavila etika hendikepa, ki pomeni specifičen pogled na vse sfere družbenega življenja, kakor jih vidijo in doživijo ovirani ljudje sami (Zaviršek 2009). Za tak pristop smo se odločili tudi v naši raziskavi.

Spremembe življenjskih potekov in prehodov v sodobnih družbah: teoretska izhodišča

Interes za raziskovanje prehodov in sprememb v življenjskih potekih se je v družboslovju povečal predvsem v zadnjih dveh desetletjih. To lahko pripišemo velikim spremembam v biografskih izkušnjah in življenjskih načrtih v preteklih desetletjih (Heinz *et al.* 2009). Te spremembe so zopet posledica sprememb v temeljnih institucijah življenjskega poteka; v izobraževalnih poteh, v načinu dela in zaposlitvi, v spremenjenih vzorcih družinskega in partnerskega življenja, v spremenjenih odnosih med spoloma. Pojem življenjskega poteka se nanaša na spremembe v posameznikovi biografski izkušnji in identiteti ter na družbene, institucionalne strukturne spremembe, ki vplivajo na življenjski potek posameznika in posameznice (Sackmann 2007).

Življenjski potek je najpomembnejša institucija socializacije, ker določa normativni okvir, ki daje smernice tako za posamični biografski potek kot za socialno uvrščanje posameznic in posameznikov. Posamični življenjski potek je pot skozi socialne strukture, pri tem pa se biografija posameznice ali posameznika hkrati tipizira in diferencira. Zato je treba spremljati, kako na življenjski potek posameznika ali posameznice delujejo kulturni modeli, družbeni red, institucije na eni strani ter osebna pričakovanja, načrti, značilnosti in načrtovanje biografij na drugi (Heinz 1997). Življenjski poteki pomenijo organizacijo celotnega prostora, v katerem poteka naše življenje.

Kateri so najpomembnejši dejavniki, ki usmerjajo, urejajo življenjski potek posameznice ali posameznika skozi različne socialne prostore? Seznam dejavnikov in mehanizmov je dolg. Eden je prav gotovo družbena in normativna delitev vlog, položajev in resursov. Življenjski potek namreč lahko razumemo kot premike posameznice ali posameznika glede na pomenljive in družbeno zaželene položaje, odnose, pričakovanja, vrednote. Pri teh premikih gre za gibanje, napredovanje, spreminjanje socialnega položaja, tudi za različne odmike, spremembe, stranpoti.

Gre tudi za razvoj socialnih omrežij s širjenjem, oženjem ali spreminjanjem interakcijskega polja, ki je posameznici ali posamezniku v določenem življenjskem trenutku na voljo (Buchmann 1989). In ne nazadnje gre za občutljive in morda bolj subjektivne dejavnike, kot so čustvena ustalitev v procesih odraščanja, uravnoteženje identitet, udejanjanje motivov, želja, hotenj. Hkrati z dejavniki, ki motivirajo posameznike k razvijanju in spreminjanju, deluje še več institucionalnih dejavnikov, generacijski pritisk, medgeneracijska razmerja. Potem so tu še družbeni makroprocesi, ki ohranjajo ali spreminjajo družbeno strukturne ali kulturne razmere za življenjske poteke.

Za posameznika ali posameznico so kot usmerjevalci življenjskega poteka ključni pomembni življenjski dogodki, biografske spremembe, ki (pre)usmerjajo življenjski potek. Razlikujemo med normativnimi in nenormativnimi življenjskimi dogodki. Normativni so pričakovan del življenjskega poteka, so prehodi v naslednjo razvojno fazo, zato se lahko pripravimo nanje, načrtujemo strategije za zmanjševanje obremenilnosti takih dogodkov. To velja zlasti za dogodke, ki značilno zaznamujejo statusne prehode v biografskem razvoju posameznika, na primer odhod v šolo, prehod na naslednjo stopnjo šolanja, prehod v delo, rojstvo otroka. Nenormativni življenjski dogodki pa so tisti, ki nas doletijo nepričakovano, na voljo pa ni kakih izdelanih strategij ali pričakovanj okolja o tem, kako se je treba odzvati nanje (nesreče, nenadne bolezni, izguba zaposlitve, finančne krize).

V klasični moderni so bili življenjski poteki dokaj stabilni in jasno prepoznavni. Posameznikov življenjski potek je bil sestavni del kolektivne zgodovine tiste družbene skupine, ki ji je posameznik pripadal. Govorilo se je o značilnih, normalnih ali normativnih življenjskih potekih in prehodih, ki so seveda temeljili na kulturnih in družbenih modelih (Hagestad 1997). Prav v preteklih dveh desetletjih pa so se pojavile ključne spremembe v življenjskih potekih in prehodih. Družbene spremembe, ki jih določa sodobna neoliberalna ideologija individualizacije in svobodne izbire, so povzročile destandardizacijo in deregulacijo življenjskih potekov.

Posledica teh sprememb je, da biografije postajajo vse manj normativne in vse manj kolektivne, primerljive in vse bolj odvisne od posamičnih odločitev in izbir (Beck, Beck-Gernsheim 2002). Vse manj je zavezujočih predpisov in zahtev in vse več je možnosti, da sami oblikujemo svoj scenarij življenjske poti. Pa vendar se tudi to kaže kot svojska iluzija. Za to ideologijo se ohranjajo ali celo povečujejo socialno-razredne razlike, na katere vpliva, koliko in kakšne izbire ima kdo na voljo oziroma kakšne so možnosti za njihovo uresničitev. Torej individualizacija življenjskih potekov ni samo svoboda možnosti, ampak tudi svojska prisila, drugačna od klasične prisile, ki je bila določena z normami zapovedi, prepovedi in predpisovanja. Sodobna prisila k individualizaciji je določena z zahtevo po biografski samorefleksiji, s sposobnostjo posameznika in posameznice, da prožno premika žarišče svoje identitete in preureja njene elemente tako, da ustrezajo različnim družbenim zahtevam in kontekstom.

Sodobna mešanica prisil in prostosti se danes kaže na dveh strukturalnih ravneh. Prva je v spremembi vrednotenja institucij, ki so osrednjega pomena za posameznika, namreč v pomenskem pomiku od »skupnostnih« institucij srednje ravni (vpliv razredne pripadnosti, družine, lokalne skupnosti) k večjemu pomenu družbenih institucij, kot so trg dela, izobraževalni sistem, socialne, zdravstvene politike, potrošnja. Druga strukturalna raven pa se kaže v spremembi zahtev teh institucij do posameznikov; od natančnega normiranja, nadzorovanja in predpisovanja posameznikovega početja k vse bolj ohlapnemu podajanju omejitvenih pogojev in zahtev, naj vsak sam vzame svoje življenje v svoje roke (Heinz 2003). To predvsem spreminja odločitve in izbire v mladosti in prehodih v odraščanje. Mladi ljudje doživljajo te spremembe ali kot povečanje avtonomije, kot možnosti za posamično načrtovanje in upravljanje s svojim življenjskim potekom ali kot zmanjšanje možnosti za obvladovanje življenja, povečevanje negotovosti in tveganj. Katera doživetja bodo prevladala, je odvisno od kulturnega konteksta, od inkluzivnosti institucij, podpornih omrežij, stabilnosti sebstva in še česa.

Medsebojno ujemanje povečanih tveganj in negotovosti otežuje proces odraščanja. Strategije mladih lahko delimo na tiste, ki sledijo normalnim ali normativnim biografijam in dosegajo konvencionalni status odraslosti, na tiste, ki oblikujejo posamične ali izbirne biografije in živijo samostojne življenjske projekte ter sledijo posamično izbrani življenjski poti, in na tiste, ki živijo marginalne ali robne biografije, ki zaradi socialno-ekonomskih in psiholoških razlogov nimajo možnosti doseči niti konvencionalnega statusa odraslih niti samostojnih življenjskih projektov. Posebej ogrožene so ranljive skupine mladih, med katere sodijo tudi mladi z ovirami. Te so tiste, ki težko sledijo normativnim biografijam in so razpete med možnostjo izbirnih biografij in nevarnostjo robnih.

Teoretski okvir življenjskega poteka ponuja dve pomembni perspektivi za študij oviranosti znotraj socialnokonstrukcionističnega modela: biografski in strukturno-generacijski. Prvi pristop omogoča pojmovanje življenjskega poteka v okvirih individualne biografije in enkratnih življenjskih izkušenj posameznika. Omogoča namreč spoznanje, kako na oblikovanje individualnih biografij vplivajo različni socialni konteksti. Strukturno-generacijski pristop pa ponuja bolj splošen pogled na življenjski potek na družbeni makroravni, ki prek kulturnih ter strukturnih pravil in omejitev definira, kaj naj bi bila »normalna biografija« (Pristley 2003). Z biografskega vidika imamo priložnost spoznati, kako osebe z ovirami doživljajo in premagujejo razne prepreke na svoji življenjski poti. Z generacijskega vidika pa lahko razumemo, kako družbe organizirajo življenjske prehode oviranih na institucionaliziran in strukturiran način. Spoznamo socialne pomene telesnih ali zdravstvenih ovir, njihove vplive na življenjske poteke v različnih življenjskih obdobjih (otroštvu, mladosti, odraslosti, starosti).

Biografske izkušnje odraščanja z oviro študentov in študentk UL – empirična analiza

Teoretske predpostavke o značilnostih življenjskega poteka in prehodov smo empirično preverili s kvalitativno raziskavo študentov in študentk z ovirami, ki študirajo na različnih fakultetah Univerze v Ljubljani. V študiji smo uporabili biografski pristop. Uporaba pripovedi v biografijah in življenjskih zgodbah je zanimiva oblika kvalitativne metodologije, ki nam omogoči vpogled v življenja posameznikov z ovirami v družbenem in kulturnem kontekstu. Kot kažejo podatki Univerzitetne službe za kakovost, analize in poročila je bilo v letu 2012/13 na Univerzi v Ljubljani od 52.634 vpisanih študentov in študentk 310 takih, ki so imeli status študentov s posebnimi potrebami. Sicer nam pregled po fakultetah kaže, da so študentje in študentke z ovirami vključene v skoraj vse študije razen teologije, strojništvo, igralske akademije in akademije za glasbo. Glede na celotno število študentov in študentk je bil njihov delež največji na Fakulteti za socialno delo (1, 44 %), Fakulteti za upravo (1,37 %) in Fakulteti za računalništvo in informatiko (1,26 %).

Raziskava je bila opravljena v okviru projekta »Etika hendikepa: socialne identitete ljudi z ovirami v teoriji in praksi socialnega dela«, katerega nosilka je dr. Darja Zaviršek[1]. V kvalitativni raziskavi je sodelovalo 13 študentk in 9 študentov. Porazdelitev sodelujočih študentov in študentk v raziskavi po fakultetah je taka: 4 študentje s Fakultete za socialno delo (FSD), 4 študentje s Fakultete za družbene vede (FDV), 4 študentje s Fakultete za upravo (FU), 3 študentje s Pravne fakultete (PF), po en študent/študentka s Filozofske fakultete (FF), Pedagoške fakultete (PeF), Ekonomske fakultete (EF), Fakultete za matematiko in fiziko (FMF), Medicinske fakultete, Fakultete za naravoslovje in tehnologijo (NF), Fakultete za šport (FŠ) in Fakultete za računalništvo in informatiko (FI). Intervjuji so potekali v med aprilom in junijem 2013 ustno ali pisno. Za način pripovedovanja svoje zgodbe so se študentje in študentke odločili sami.

Študentje in študentke so se v svojih biografskih pripovedih osrediščili na te teme: spoprijemanje z oviro, značilnost odraščanja z ovirami, upravljanje s ključnimi življenjskimi dogodki in prehodi v odraščanju, pomembni drugi v življenjskem poteku, vloga (izobraževalnih) institucij.

Kaj torej sporočajo študentje in študentke z ovirami, kako doživljajo oviro?

Predvsem sporočajo, da so hendikep sprejeli in da je postal del njihove samopodobe, da jih je spoprijemanje s hendikepom celo okrepilo oziroma da so si zaradi nujnosti po samorefleksiji življenja z oviro pridobili življenjske izkušnje, ki njihovim vrstnikom pogosto manjkajo.

> Se zavedam, da sem hendikepirana, in tega pač, to mi je jasno, tega ne skrivam, samo se pa ne dojemam tako in probam pač, tako kot sem že prej rekla, vse stvari počet, kakor se le da normalno, in tudi drugim povem. (Ana[2])
>
> Vem, da je marsikdo v moji okolici, ki ima mnogo večje težave, kot jih imam sama … da ne sprejema samega sebe, nima integritete, nima samospoštovanja … Zato pravim, da je ta moja xxx meni doprinesla določeno mero samozavesti, ker sem morala delati sama na sebi. (Taja)

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[1] Gre za temeljni projekt, ki poteka v letih 2011–2014 in ga financira ARRS.

[2] Zaradi načela zaupnosti smo imena študentov in študentk spremenili, tudi ne navajamo fakultet, na katerih študirajo.

> Jaz mislim, da me je xxx na to enostavno primorala, da sem postala takšna, kot sem, da moram delat, da se z delom izkažeš, da si lahko zgolj sama sebi poskušam uresničit svojo prihodnost. (Nina)
>
> Jaz načeloma nimam nekako problemov, ker mi tudi ostali rečejo, da sem zelo odprta, pa tudi brez problema govorim o tem … Nikoli se nisem počutila, da bi bila manjvredna ali pa zatirana s strani sošolcev, enako me obravnavajo, ker se tudi sama ne dojemam tako … (Katja)
>
> Saj verjetno je bilo kaj takega, kar nisem mogel, na primer kakšnih hitrih športov z žogo, pa sem probal nekaj drugega … In moram reči, da sem se včasih ustavljal, ali tega zdaj pa jaz ne morem, potem sem se navadil, da je toliko enih stvari, še posebno danes, ki jih lahko delaš, da če ne gre ena, da najdeš drugo. (Nik)

Del uspešne biografije študentov in študentk je sodeč po izjavah v tem, da so imeli neproblematično otroštvo, da jih je ožje okolje, družina, vrtec, vrstniki, sprejelo in se do njih ustrezno odzvalo, kot kažejo njihove izjave:

> Zgodnje otroštvo je bilo čisto srečno, imela sem ljudi, ki so me imeli radi, in to se mi je zdelo vedno pač najpomembnejše. (Taja)
>
> Otroštva nisem preživljal nič drugače kot kdo drugi, veliko sem ga prebil v naravi in v dedovi delavnici. Najbolj se spominjam starih staršev, ki so me pazili, in specialne pedagoginje, ki mi je pomagala reševati probleme z xxx. (Anže)
>
> Ja, meni je bilo v vrtcu fajn. Res so me lepo sprejeli. Nisem čutila, da bi bila drugačna ali pa da bi me zaradi tega izključevali. (Alja)
>
> Jaz sem s tem navajena živet že od rojstva, jaz ne poznam drugačnega življenja, kot je ta. Je pa res, da ko sem bila mlajša, je bilo malo lažje, potem v najstniških letih, se je bilo pa malo težje s tem soočit. (Eva)

Neproblematično zgodnje otroštvo študentov in študentk z ovirami je bilo predvsem posledica ugodnega socialnega konteksta in ustreznega odziva družine in drugih institucij na oviro, pravega števila spodbud, normalizacije hendikepa in življenja. Kot kaže, je bilo ugodno zgodnje otroštvo dobra popotnica za nadaljnje odraščanje, saj je pomenilo prve okrepitve sebstva.

Upravljanje s ključnimi dogodki in prehodi v odraščanju in vloga pomembnih drugih

Življenjske perspektive in variacije v življenjskem poteku se razvijejo predvsem v prehodih, ki povezujejo različna območja in faze življenjskega poteka. Življenjski potek v vsaki organizirani družbeni skupnosti ima svojsko zaporedje prehodov iz določenega življenjskega obdobja v drugo. Ključni prehodi v odraščanju so na primer prehod od predšolskega obdobja otroka v šolsko obdobje pa prehodi med različnimi ravnmi izobraževanja, prehod iz obdobja izobraževanja v zaposlitev ipd. Ti prehodi so po navadi povezani s temeljnimi življenjskimi odločitvami in izbirami ter negotovostmi, ki jih moramo obvladati ob prehodu v novo življenjsko obdobje, zato so svojevrsten življenjski izziv. V vsakem od teh prehodov pridobi človek nov družbeni položaj, pogosto povezan z vstopom v novo socialno institucijo, kot kaže ta izjava:

> Najtežji je bil vstop v šolo … Če moram negativno izkušnjo izpostavit, potem je bila ta najbolj … Ker tudi, če ne bi imela tako vztrajnih staršev, če bi se predala onadva, bi se tudi jaz in bi verjetno bila v zavodu. Samo, ko zdaj gledam nazaj, bi ful velik zgubila, pa sploh ne vem, verjetno bi bila čisto druga osebnost. (Ana)

Fokusna teorija odraščanja, ki obravnava upravljanje z razvojnimi krizami v odraščanju, opozarja na časovno zaporednost posameznih problemskih sklopov, s katerimi se srečujejo mladostniki (Coleman 1989). Po tej teoriji mladostniki lažje in uspešneje rešujejo razvojne naloge, če jih ne razrešujejo sočasno, temveč se v določenem obdobju osrediščijo na posamezne probleme oziroma problemske sklope. Raziskave kažejo, da se pri mladostnikih od 11. do 13. leta zgostijo problemi v zvezi s spolnostjo, ali kot pravi eden od naših intervjuvancev:

> Jaz se sploh nisem zavedal svoje drugačnosti, dokler ni bilo potrebno loviti punc ponoči, do enega štirinajstega leta. (Nik)

Potem se zgostijo problemi z vrstniki, identifikacija z njimi, strahovi pred zavračanjem v vrstniških skupinah.

> Najtežji prehod je bil v moji srednji šoli, zato ker sem imela ogromne, ogromne težave z mojimi sovrstnicami. Me niso sprejemale, pa so stalno hodile kaj tožarit … enkrat so šle k socialni delavki na srednji šoli, pa so ji rekle, da se jim ne zdi fer, da imam jaz prilagoditve, oni pa ne, oziroma, ker se z mano toliko ukvarjajo, z njimi pa ne. So bile kar malo zlobne, to v najstniških letih kar prizadene … tudi to je botrovalo k temu, da sem se odločila postat bolj močna in da ne pustim dejansko, da kdorkoli vpliva na moje odločitve, kar se tiče prihodnosti. Seveda pa sem imela tudi, hvala bogu, ljudi, ki so me podpirali in so me držali kvišku, tako da me to ni tako potrlo. (Taja)

Vrstniške skupine v odraščanju povezujejo prav skupne želje, izkušnje, primerljivi problemi in potrebe, izkušnja solidarnosti in lojalnosti. V vrstniških odnosih se mladostniki učijo strategij solidarnosti, lojalnosti pa tudi tekmovanja, spoprijemanja s čustvenimi konfliktnimi situacijami. V prijateljskih odnosih, še bolj kot v vrstniških skupinah, dobivajo samopotrditev, se učijo samorazkrivanja, zaupanja, vzajemnosti, empatije, kot kažeta izjavi:

> Jaz sem pač tudi sošolcem nakazala, da mi gre zelo na živce, če mi kdo reče, da se mu smilim … (Ana)

> Takrat še ni bilo teh normativov, dvigalo na šoli za posebne potrebe, in sem morala po stopnicah normalno it ... in so mi sošolci pač vedno pomagali. Eden je nesel torbo, drugi me je prijel za roko pa smo šli do naslednje učilnice. Tako da so tudi oni že takrat te medsebojne pomoči izkazali … Po moje so s to izkušnjo druženja z menoj odrasli v bolj odgovorne osebnosti. Tudi sami so to izpostavili, da so imeli to izkušnjo. (Lara)

Odločilna za uspešno odraščanje z oviro je po pripovedovanju študentov in študentk vloga staršev, njihova pripravljenost in zmožnost, da zagotovijo refleksijo o problemu in da vzpostavijo stvarne pogoje in zahteve.

> Ja, nekako sem imela takšno srečo, da sta me in oče in mama vedno obravnavala kot drugim enako, pa sta vedno zahtevala od mene iste stvari kot od drugih. Mogoče malenkost na prilagojen način, ampak mami še zdaj, če se meni zdi, da nekaj ne morem, najprej vpraša, če sem to že probala ... Ful stremita k temu, da pač poskušam čim več stvari delat kot drugi, in sem se tudi sama tega navadila. (Neva)

> Staršem je bilo na začetku težko, saj tega seveda nihče ne pričakuje. Pred kratkim pa mi je mami rekla, da so se stvari tako lepo izšle in da sem postal tako samostojen in neodvisen, kot si ne bi nikoli mislila. Včasih mi brat reče, da mi kakšno stvar tudi zavida. (Matej)

Za vse odraščajoče, predvsem pa za odraščajoče z ovirami so zelo pomembne navzočnost pomembnih drugih oseb ter njihova stabilnost in empatičnost. Pomembni drugi so mediatorji med strukturami in institucijami ter odraščajočim z oviro. Kdo so torej pomembni drugi za študente in študentke z ovirami?

> Predvsem mami, ker je pač bila ves čas z mano in mi je pač stala ob strani, pa tudi nikoli mi ni dajala občutka, da sem drugačna, pod narekovaji povedano. (Mija)

> Me je pa naučila (mati, op. M. U.), da se moram, tako kot vsak otrok, postavit zase, ne glede na stvari, ki se bodo dogajale, in ne glede na položaj, v kakršnem sem. (Jan)

Po pripovedih študentov in študentk sodeč so pomembne osebe predvsem matere, ki so v družinskem okolju prevzele vlogo posebnih skrbnic za otroke z ovirami. Njihova vloga je bila v vseh pripovedih označena kot ključna. Pomembno je bilo, da so bile zagovornice otrok z ovirami, da so jih opogumljale in imele do njih visoke zahteve, da so bile čustvena opora, vendar ne pomilovalne.

> Seveda pa sem imela tudi, hvala bogu, ljudi, ki so me podpirali in so me držali kvišku, tako da me to ni tako potrlo … mami, sestra, pa moram omenit še eno osebo, sicer surdopedagoginja, ki je hodila k meni enkrat na teden po dve uri. Veliko mi je pomagala, da se je z mano pogovarjala … o vrednotah, o ciljih, o samospoštovanju in to mi je dejansko zelo pomagalo. Verjetno se ona tega ne zaveda, ampak mi je veliko bolj pomagala psihološko kot pa surdopedagoško. (Taja)

Vloge ekspertov, s katerimi se odraščajoči z oviro vseskozi srečujejo, niso tako enopomenske. V nekaterih primerih in pripovedih so bili prepoznani kot pomembni drugi ter zaščitniki in motivatorji otrok, v drugih primerih pa kot »vratarji«, ki so usmerjali, dopuščali ali pa onemogočali prehode, na primer v običajno osnovno šolo, v izbrano srednjo šolo, ali kot pravi ena od intervjuvank:

> Ja, to je seveda čisto odvisno spet od učitelja kot posameznika. Nekateri so zelo empatični, zelo se želijo potrudit in prilagajat svoj učni in delovni proces. Nekateri pa sploh ne. (Tanja)

Vloga izobraževalnih institucij, učiteljev, ekspertov v odraščanju in prehodih

Čeprav danes govorimo o individualizaciji življenjskih potekov in prehodov, so ti še vedno odvisni od strukturne lokacije, na primer izobraževalnega sistema v državi, gibanj na trgu delovne sile. Raziskovalci zato govorijo o strukturni individualizaciji, torej individualizaciji, ki je zelo odvisna in je posledica spremembe temeljnih struktur in ne povsem osebne volje in želje (Pollock 1997). To je posebej pomembno za ljudi z ovirami. Ti so še posebej odvisni od strukturnih dejavnikov, kot so izobraževalne, socialne, zaposlovalne politike.

> Jaz sem šel v normalne šole bolj zato, ker so starši želeli … v xxx so pač bili za to, da se me da v Kamnik, da se me da v take zavode, kjer bi pač bil s sebi enakimi … če bi šel tja, verjamem, da mi ne bi uspelo to, kar mi je zdaj. (Jan)

Družbene institucije izhajajo iz predpostavke o pristojnih subjektih, ki se zmorejo odločati tako, da obvladajo kompleksne družbene razmere in se izognejo negativnim posledicam svojih odločitev. Kadarkoli določena institucija ali družbena struktura zahteva od posameznika ali posameznice pristojnost, ki presega njegove ali njene zmožnosti, se pojavi zlom samostojnosti, namreč temeljni razkol med zahtevano in realno možno samostojnostjo oziroma osebno pristojnostjo. Raziskave o izobraževalnih prehodih ugotavljajo, kako močno so izkušnje znotraj šolskega okolja vplivale na življenjske izkušnje, načrte in izbire mladih z ovirami. Šolsko okolje jim daje prve izkušnje o tem, kako bodo obravnavani v širši družbi. Yasmin Hussain (2003) na primer s pomočjo intervjujev z mladimi v Angliji primerja izkušnje in življenjske načrte mladih z ovirami z izkušnjami in načrti njihovih bratov in sester brez ovir. Ugotavlja, da so ambicije tako fantov kot deklet z ovirami v primerjavi z njihovimi sorojenci manjše. Tako otroci kot starši uporabljajo svoje ovire za legitimno opravičilo za odsotnost življenjskih načrtov. Samo mladi, ki so dosegli zaželeno raven šolanja in pridobili poklicne kvalifikacije, imajo izdelane poklicne in življenjske želje in načrte.

> […] kdo me je še izoblikoval … institucija zihr ne, je bilo pa odločilno, da sem skoz hodil v normalno šolo, osnovno pa srednjo potem, pač so določeni učitelji recimo, ki lahko iz tebe izvlečejo tisto, kar pač vejo, da lahko […] ko sem prišel v prvi razred osnovne šole, sem imel razredničarko, ki je pač vedla, da lahko dosežem več, in takrat je bila še mami v šoli z menoj kot spremljevalka, v bistvu takrat je bil nekak tisti odločilen preklik, ker je pač ona hotela, ta profesorca, da jaz pač vse delam sam, pišem sam, delam pač vse sam in po moje je bilo tisto odločilno, ker potem me je mami mene pri pouku čist pustila samega, kot da bi bil normalen. (Žan)

Vhode in izhode v posamezna življenjska obdobja nadzorujejo »vratarji prehodov«, to so izobraževalne institucije, trg delovne sile, politične institucije pa tudi eksperti, svetovalci, socialne delavke, ravnatelji itd. Po drugi strani imamo podporne osebe, ki varujejo ali pomagajo posameznikom premagovati ovire na prehodih, »varuhi prehodov«. O tem priča ta pripoved:

> V bistvu je bilo tako, da šola pač ni bila dost naklonjena temu, da sem na tisti njihovi šoli, ker pač so bile stopnice in se je naredil načrt, mislim, vse je mami pripravila že, načrt za dvigalo, določena sredstva so že prišla, ampak vodstvo šole ni bilo naklonjeno temu, tako da sem pač jaz zamenjal šolo v sedmem razredu … Tam so me takoj sprejel, bilo je tako dost v redu, tam je bil normalen odnos s sošolci, pomagali so mi, so mi dal za kopirat, ni bilo nobenega zajebavanja, nobenih žalitev … (Žan)

V največ primerih naše analize imajo vlogo varuhov prehodov starši, saj se pogajajo z institucijami in lajšajo težave v prehodih. Na to dobro opozarja tudi ta del intervjuja:

> Vid: Zdaj najbolj zamerim osnovni šoli, ker so me hoteli dati v posebno osnovno šolo, in ko bom naredil diplomo, bom šel in jim jo bom vrgel na mizo. Takrat po moje naj bi bilo prvič, da me je to soočilo, da me je nekaj udarilo. Po moje naj bi bil to tisti prvi negativni dogodek, kar se ga spomnim …
>
> I: zakaj, kaj se je zgodilo …
>
> Vid: Mi smo šli na razgovor v osnovno šolo s starši in oni so staršem predlagali posebno šolo, potem so meni rekli, da če ne bom priden, da bom moral iti v posebno šolo.
>
> I: A to že preden ste začeli dejansko hoditi v osnovno šolo?
>
> Vid: Ja, še preden sem dejansko začel hodit v šolo … In mene je to spremljalo skozi celo osnovno šolo …
>
> I: Kako ste to doživljali, kot strah ali kot grožnjo?
>
> Vid: Kadar so to rekli, je pa bilo kot neko ponižanje, nekaj takega je bilo ...

V zadnjih dveh desetletjih so se sicer zgodile pomembne pozitivne spremembe v odnosu do vključevanja otrok z ovirami v splošne oblike izobraževalnega sistema v Sloveniji. Večje spremembe je prinesla Bela knjiga o vzgoji in izobraževanju v Republiki Sloveniji iz leta 1995, ki je botrovala novemu Zakonu o osnovni šoli (1996), Zakonu o organizaciji in financiranju vzgoje in izobraževanja (1996) in Zakonu o usmerjanju otrok s posebnimi potrebami (2000) ter spremembam druge področne zakonodaje. Reforme šolskega sistema za vzgojo in izobraževanje otrok s posebnimi potrebami so se pred tem ukvarjale s kvalitativnim in kvantitativnim razvojem specialne in rehabilitacijske pedagogike in specializiranih oblik vzgoje in izobraževanja, reforma v devetdesetih letih pa je prinesla novo, širšo opredelitev skupin otrok, ki potrebujejo dodatno pozornost in podporo. Namesto razvrščanja v skupine otrok s posebnimi potrebami pa je uvedla usmerjanje otrok v vzgojno-izobraževalne programe. Ključna namena nove zakonodaje sta bila zmanjšanje ločenih oblik šolanja ter vpeljava inkluzivnih in prožnejših oblik šolanja (Krek, Merljak 2011). V zadnjem desetletju je vlada RS sprejela tudi dva akcijska načrta za invalide (*Akcijski načrt za invalide 2013–2017* in *Akcijski načrt za invalide 2014–2021*), katerih

> namen naj bi bil spodbujati, varovati in zagotavljati polnopravno in enakovredno uživanje človekovih pravic tudi za invalide in spodbujati spoštovanje njihovega dostojanstva (*Akcijski načrt za invalide* 2014–2021: 1).

Čeprav imamo torej ustrezne zakonske podlage, pa ob tem država ni pripravila ustreznega načrta in ukrepov, da bi v praksi lahko uveljavili vsa zakonska določila (Zaviršek, Gorenc 2007). Tako ni bilo vseh pogojev za uveljavljanje nekaterih zakonskih določil (denimo pogojev za izvajanje prilagojenih programov v redni osnovni šoli ali pogojev za prehajanje med programi) in načel (na primer za zagotavljanje načela organizacije vzgoje in izobraževanja čim bližje kraju bivanja ali vključevanja staršev v proces vzgoje in izobraževanja) ter za zagotovitev kakovosti izobraževanja vsakega otroka s posebnimi potrebami v skladu z odločbo o usmeritvi (Krek, Merljak 2011: 5–6). Predvsem pa, kot pripovedujejo naši intervjuvanci, strokovno osebje v šolah nima ustrezne izobrazbe oz. dodatne izobrazbe za delo in prilagoditev pouka učencem s posebnimi potrebami:

> Moje mnenje je, da so učitelji, profesorji, svetovalni delavci tako zelo premalo obveščeni in informirani o tem, kaj pomeni imeti neko določeno oviro in kakšne sploh so prilagoditve. Ravno zaradi tega primanjkljaja informacij sem se jaz tudi dostikrat srečevala s tako imenovano nestrpnostjo, tudi s strani profesorjev ali pa učiteljev, ki so zamahnili z roko pa rekli, ah kaj se bom s tabo ukvarjal. (Nina)
>
> [...] mislim, da vsi morajo vedeti. Ker meni se je zgodilo v osnovni šoli ... so mislili, da sem zadet. Zdaj so se vsi prilagodili … Bi pa moglo po moje bit, tudi ... Ne samo to, kako prilagodit, ampak bi moral bit en razgovor o tem, kako sem jaz drugačen ... nekako jim razložit moje vedenje. (Luka)
>
> Ja, imajo pa načeloma vsi premalo znanja … tako da nujno potrebno bi bilo res kakšno izobraževanje naredit, ker sem prepričana, da se bo vsak učitelj, profesor najmanj enkrat v svoji učiteljski, pedagoški karieri srečal z vsaj enim študentom, otrokom, dijakom, ki bo imel neko oviro in se bo mogel on prilagodit. (Manica)

Sklepi

Za osebe z ovirami je odločilno vprašanje, kako se lahko umestijo v družbo, in to tako, da se bo zaradi njihove motnje dogajalo v njihovem socialnem življenju čim manj težav, da jih bo njihovo okolje sprejelo takšne, kot so, in bodo čim bolj neovirano uresničevali svoje življenjske cilje. Neovirana umestitev posameznika v družbo pomeni, da se posameznik dojema in prepoznava kot priznani član nekega reda, ki ni zgolj red stvari in dejstev, temveč je tudi red pomenov in smislov človeških doživljanj, dejanj, namer, govornih dejanj pa tudi družbenih situacij, odnosov med ljudmi in institucij.

Vsi študentje in študentke, ki so sodelovali v pripovedovanju svoje izkušnje v naši raziskavi, so govorili o zgodbah o uspešnem premagovanju ovir odraščanja, o krizah prehodov, pa vendar o izkušnjah, ki so jim izostrili samopodobo in samozavest, ki so jih socialno okrepili in jim omogočili izkušnje premagovanja temeljnih kriznih situacij v življenjskem poteku in prehodih. Oblikovanje ugodne samopodobe in samospoštovanja ni niti preprost niti samoumeven proces v odraščanju. Nasprotno, napetosti in negotovosti so spremljevalni pojavi v odraščanju. Za mlade z ovirami je ta proces dodatno otežen zaradi pogoste stigme oviranosti, ki jim jo pripisujeta večinska skupnost in dominantna kultura. Zato je lahko zelo obremenilno za osebe z ovirami, če se ne čutijo dovolj sprejete v svojem okolju in ob tem doživljajo razne oblike odkritih in prikritih zavračanj in podcenjevanj. Kot kažejo izjave intervjuvancev, so te težave lahko tudi produktivne, saj ženejo hedikepirane k vedno novim osmišljanjem njihovega početja in njihovih vlog v družbeni stvarnosti. Zanimivo, da so problemi, kot so težave pri prehodu iz izobraževanja v delo, visoka stopnja nezaposlenosti, podaljšana odvisnost od izvorne družine, ki jih splošna populacija mladih doživlja množično šele v zadnjem desetletju, za mlade z ovirami prej pravilo kot izjema.

Čeprav se veliko študij ukvarja s težavami otrok in mladostnikov z ovirami pri izobraževalnih prehodih in prehodih v odraslost, pa se v zadnjem času povečuje število študij o uspešnih prehodih, predvsem o pogojih in izkušnjah uspešnih prehodov (Tisdall 2001). Zaradi prevladovanja pokroviteljskega modela v dojemanju hendikepa in marginalizacije ljudi z ovirami so potrebe ljudi z ovirami najpogosteje preučevali iz perspektive dajalcev pomoči in institucij. V zadnjem desetletju so si ljudje z ovirami po zaslugi gibanj za emancipacijo priborili pravico do mnenja, pogosto so motivirani, da govorijo o svojih izkušnjah, potrebah in željah. In ljudje z ovirami so povedali, kako in v kakšnih razmerah lahko polno živijo. Zaradi njihovih izkušenj spoznamo sistemske pomanjkljivosti in napake in premišljene predloge za spremembe (Watson 2002, Gwernan-Jones 2008).

V članku smo predstavili intervjuje z mladimi na terciarni stopnji izobraževanja. Na podlagi njihovih pripovedi lahko sklenemo, kaj so prvi pogoji za uspešno premagovanje ovir v odraščanju. Pokazalo se je, da so kontekstualni dejavniki izjemno pomembni. Najprej je pomembno ustrezno podporno in spodbudno družinsko mikrookolje, saj omogoča otrokom z ovirami prvi pomemben refleksiven odnos do svoje ovire in rudimentarne oblike pozitivne identitete. Hkrati opogumlja mlade za čim aktivnejše spoprijemanje z lastnimi potrebami, željami in zmožnostmi. Otroci z ovirami, ki jih je spodbujalo njihovo okolje, lažje vstopajo v druga institucionalna okolja. Prav resni premisleki in odločitve, ki so jih morali opraviti v razvoju svoje identitete, jim omogočajo, da se bolj zavestno in odgovorno vključujejo v institucije, v katere vstopajo. So bolj kritični kot »normalni« mladi in nam nastavljajo ogledalno podobo institucionalnih in družbenih pomanjkljivosti.

Uporaba pristopa življenjskega poteka v študiju hendikepa nam omogoča ne le globlje razumevanje pritiskov in zatiranja na individualni ali strukturalni ravni, ampak tudi razkrivanje in razumevanje strategij in sil, ki pripomorejo k pozitivnim spremembam na obeh straneh: tako v razumevanju življenjskega poteka ljudi z ovirami kot tudi strategij načrtovanja življenjskih potekov in prehodov na sploh. Individualno-biografski pristop gradi na življenjskih izkušnjah ljudi, ki razvijajo kulturo hendikepa, strukturalno-normativni pristop pa prinaša materialne in socialno konstrukcionistične izkušnje k razumevanju zatiranja v družbi (Pristley 2003).

Nove ugotovitve o življenjskih potekih, predvsem ugotovitve o individualizaciji, izbiri, destandardizaciji in deregulaciji življenjskih potekov in prehodov nakazujejo strategije novih možnosti biografskega načrtovanja mladih z ovirami. Ker pa raziskave življenjskega poteka navadno raziskujejo učinke normativnih izkušenj in ignorirajo učinke bolezni in oviranosti, niso pozorne na pomembne izkušnje strategij spoprijemanja s težavami v odraščanju. Izkušnje mladih z ovirami pa so pomemben vir odgovorov na vprašanja o premagovanju sodobnih negotovosti in tveganj v odraščanju in prehodih v odraslost (Slota 2003).

Kot generacijska lokacija v življenjskem poteku je tudi oviranost družbeni in kulturni proizvod. V kontekstu modernih generacijskih sistemov oviranost dojemamo in razlagamo zelo podobno kot otroštvo in starost, namreč kot obliko »neodraslosti«. Osebe z ovirami se izključuje iz trga dela odraslih, podvrženi so vsiljeni odvisnosti od trga dela neoviranih. Vendar brez »odraslih« odgovornosti obstaja le malo »odraslih« pravic (Tisdall 2001). To dejstvo nam pomaga razložiti, zakaj so v modernih družbah otroci, starejši in ovirani pogosto podvrženi podobnim oblikam institucionalne discipline in nadzora. Raziskovanje življenjskega poteka zato ponuja temeljit razmislek o vplivih generacijskih delitev in politik na oviranost. Tako lahko bolje razumemo, kako razne oblike socialne politike in razne socialne institucije proizvajajo, socialno konstruirajo in nadzirajo oviranost. Ta pristop nam omogoča tudi razkrivanje strategij in silnic za pozitivne spremembe v položaju oseb z ovirami. Tako lahko razkrijemo velik potencial takih študij za pozitivne spremembe njihovih življenjskih potekov. Tako za študij življenjskega poteka kot za študij oviranosti je torej produktivno, če se obe raziskovalni smeri povezujeta.

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NEKATERI VIDIKI OSKRBE KOT VEČPLASTNEGA PROCESA IN ODZIVI SOCIALNEGA VARSTVA NA POTREBE PO OSKRBI V SLOVENIJI

V članku razpravljam o vprašanju, kako najnovejša dognanja o oskrbi vplivajo na organizacijo in odzive socialnega varstva na potrebe po skrbstvenem delu. Skrb za sočloveka je obremenjujoča ne zgolj fizično, temveč tudi duševno in čustveno. Oskrbo moramo nujno razumeti kot večplasten proces, ki poleg praktičnega dela vsebuje tudi kognitivno in čustveno raven dela. V članku razmišljam o spremembah, ki so se na področju oskrbe zgodile v procesu liberalizacije trga, in predstavim nekaj primerov odziva socialnega varstva na potrebe po oskrbi v Sloveniji. Predstavim koncepte pomoči na domu, osebne asistence, institucionalnega varstva in centrov, ki ponujajo kratko namestitev, ter vse analiziram v luči sodobnih teoretskih dognanj in raziskav o oskrbi. V sklepnem delu članka se ukvarjam z večplastnostjo oskrbe otroke z ovirami in predstavim primer centrov za kratko namestitev kot primer storitve, ki je namenjena tako telesni kot čustveni razbremenitvi staršev in oba koncepta vključuje kot ključna dela svojega poslanstva. Odsotnost javnega diskurza o oskrbi kot večplastnem procesu je skrb zbujajoče, saj vpliva na kakovost tako opravljene oskrbe kot tudi delovnega življenja oskrbovalca.

Ključne besede: skrbstveno delo, oviranost, asistenca, institucionalno varstvo, kratka namestitev.

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CARE AS A MULTIDIMENSIONAL PROCCESS AND RESPONSES TO NEED FOR CARE WORK IN SLOVENIA

The paper considers the question how recent developments in theory of care affect the responses of social care providers in Slovenia. Care work is a multi-layered process and includes physical, cognitive and emotional work. The effects of market liberalization on care work and responses of social care providers are analysed. Concepts of domestic assistance, personal assistance, institutional care and respite care are discussed and compared with new theoretical developments and research on care. The conclusion of the article deliberates on the multi-layered care for children with disabilities. The concept of respite care as an example of care provision that intertwines both physical and emotional support in introduced. The absence of public discourse about care in Slovenia is worrisome since it affects quality of received care and quality of work life for people providing care.

Key words: care work, disability, assistance, institutional care, respite care centres.

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Uvod

v strokovni literaturi se koncept oskrbe pojavlja od osemdesetih let 20. stoletja. V preteklih treh desetletjih so bile številne raziskave namenjene formalnim in neformalnim sistemom oskrbe in njihova sklepna ugotovitev je, da je dobra oskrba sestavljena tako iz čustvenega kot iz kognitivnega in praktičnega dela. Tudi v Sloveniji se je sistem socialnega varstva odzval na potrebe po formalnem sistemu zagotavljanja oskrbe za skupine ljudi, ki potrebujejo organizirano oskrbo. Sistem družbene oskrbe za osebe z ovirami, starejše in otroke je v Sloveniji razvejen in se različno odziva na potrebe, ki so nastale v družbi. Čeprav je dostopnih veliko poročil, ki podrobno analizirajo učinke posameznih socialnovarstvenih storitev, je raziskav, ki bi se celostno ukvarjale z odzivom na potrebe po oskrbi in z vprašanjem, kako odzivi upoštevajo najnovejše ugotovitve raziskav, v primerjavi z anglosaškim območjem malo.

Raziskave iz Združenega kraljestva in Združenih držav Amerike se osredotočajo na neformalne sisteme pomoči in ugotavljajo, da sta oskrba in oseben odnos med tistim, ki oskrbo izvaja oskrbo, in tistim, ki jo prejema, neločljivo povezana. Skrbeti za sočloveka ni obremenjujoče zgolj fizično, temveč tudi duševno in čustveno (Finch, Groves 1983). Zgodnejše raziskave, ki so se ukvarjale z oskrbo, so se osredotočale na izkušnjo oskrbe iz perspektive oskrbovalca, ter na breme in ceno oskrbe. Šele v zadnjem desetletju so se pojavile raziskave, ki se osredotočajo na perspektivo tistega, ki je oskrbe deležen. Druga vrsta raziskav je razkrila, da je oskrba pravzaprav vzajemen proces. To zdaj velja za eno temeljnih načel v strokovni literaturi o oskrbi (Parton 2003).

V članku preučim, kako se v praksi uresničujejo najnovejša dognanja raziskovalk in raziskovalcev o oskrbi v nekaterih oblikah organizirane socialnovarstvene oskrbe v Sloveniji in ali oskrba velja za vzajemen proces, ki poleg praktične komponente vsebuje tudi kognitivno in čustveno. Zanima me tudi vprašanje, kako in v kakšni obliki skrbstveno delo v Sloveniji vstopa na trg dela in kakšno je razmerje med skrbstvenim delom v formalnem in neformalnem sistemu. Tako pojasnim področja, ki bi jim koristilo bolj celostno razumevanje koncepta skrbstvenega dela, in tudi tista, ki bi lahko bila primer dobre prakse.

Oskrba in skrbstveno delo

O oskrbi najpogosteje govorimo v kontekstu neplačanega dela, ki ga opravljajo večinoma ženske in vključuje skrb za potrebe družinskih članov. Tradicionalna delitev opredeljuje delo, ki ga ljudje opravljajo v javnem prostoru, kot moško delo, delo, ki se opravlja v zasebnem prostoru, pa kot žensko (Folbre, Nelson 2000). Značilno »žensko« delo je tako skrb za otroke, starejše in bolne, pri delu pa je pričakovan osebni stik, čustvena podpora in, poleg nabora instrumentalnih nalog, tudi intimna povezanost z osebo, ki jo oskrbujejo (*ibid.*).

Čeprav je takšna miselnost prevladovala v 20. stoletju, ločnica danes ni več tako ostra. V primerjavi s položajem z začetka 20. stoletja je danes nekaj povsem običajnega, da ženske stopajo na trg dela, in v tem pogledu so skoraj izenačene z moškimi (*ibid.*). Številne dejavnosti, ki so bile v preteklosti zaupane ženskam in ki so jih v preteklosti opravljale v okviru domačih opravil, so postale razdrobljene na merljive in denarno ovrednotene enote. Ena izmed dejavnosti, ki je iz zasebne sfere prešla v javno, je tudi skrbstveno delo. Med skrbstvene dejavnosti uvrščamo oskrbo otrok, bolnih družinskih članov in starejših, pa tudi vsakdanja opravila, kot so kuhanje, pospravljanje in nakupovanje (Genet *et al.* 2012).

Dejavnosti, ki jih uvrščamo v oskrbo, so s prehodom iz zasebne sfere v javno dobile vsaka svojo dvojnico na trgu dela (Folbre 2006). V zahodnih državah so v skrbstvenih poklicih ali poklicih pomoči (tj. poklicih s področja vzgoje, zdravstva, skrbi za starejše in tudi socialnega dela) zaposlene večinoma ženske. Med zaposlenimi na področju zdravstva v Evropi je kar 76 % žensk, kljub temu pa je odstotek žensk, ki so v zdravstvu zaposlene kot zdravnice, le 36 % (Rechel *et al.* 2006). Skrbstveni poklici so po navadi slabše plačani glede na vložen čas in intenzivnost dela v primerjavi z drugimi, primerljivimi poklici (Folbre 2006).

Nekateri avtorji poudarjajo, da so kot oskrba opredeljene tudi dejavnosti, ki se razlikujejo ne po vsebini, temveč glede na končne prejemnike dela. Storitve, katerih prejemniki so otroci, starejši ali ljudje z ovirami, torej ljudje, ki v družbi navadno nimajo političnega glasu, so najpogosteje opredeljene kot oskrba, čeprav so številne storitve, ki jih prejmejo in veljajo za oskrbo, enake vzporednim storitvam, katerih uporabniki so vsi ljudje in ki jih vsi posamezniki redno kupujejo na trgu (*ibid.*).

Nekatere dejavnosti se pojavljajo tako v zasebni kot v javni sferi. Gre za dejavnosti, ki jih vsak posameznik v zasebni sferi opravi kot del skrbi zase (prehrana, osebna higiena), v javni sferi pa dejavnosti veljajo za razkošje, ki si ga lahko privoščijo le nekateri (*ibid.*). Storitve oz. dejavnosti, ki se pojavljajo tako v zasebni kot v javni sferi, na primer priprava hrane, vplivajo na družbeno razumevanje upravičenosti do oskrbe, saj je na eni strani skupina ljudi, ki si storitev lahko zagotovi na trgu, na drugi pa skupina, ki storitev nujno potrebuje za preživetje, saj si jo sama ne more zagotoviti. Obstaja pa še tretja skupina: skupina, ki nima druge izbire, kot da si storitev zagotovi sama, saj si je ne more privoščiti na trgu, hkrati pa do nje ni opravičena zaradi tega ali onega razloga. Vstop oskrbe na trg otežuje dejstvo, da vseh komponent »dobre« oskrbe ni mogoče denarno ovrednotiti, saj so sestavni deli skrbstvenega dela, na primer iskrenost, potrpežljivost in sposobnost za pogovarjanje, težko merljivi (*ibid.*).

Demografske spremembe v zadnjem stoletju in množičen vstop žensk na trg dela so občutno spremenile tudi razmerje med družino in trgom (Folbre, Nelson 2000). V predindustrijskih družbah, v katerih delo še ni bilo razdrobljeno na merljive in denarno ovrednotene enote, je bila oskrba sestavni del pridobitnega dela, sàmo delo pa je dovoljevalo hkratno izvajanje tako oskrbe kot pridobitnega dela, saj deli nista bili niti prostorsko niti ideološko ločeni (*ibid.*). Posledici neskladnosti in ostre ločitve med pridobitnim delom in oskrbo sta bili v 20. stoletju specializacija storitev in opredelitev oskrbe kot samostojne dobrine (*ibid.*).

Cena oskrbe

V strokovni literaturi pogosto zasledimo razprave o primernosti obravnave oskrbe kot plačljive dobrine (Claassen 2011). Najpogostejši očitek oskrbi kot tržni dejavnosti je, da je »prava skrb za sočloveka« neločljivo povezana s čustveno komponento in iskreno skrbjo za sočloveka, to pa težko denarno ovrednotimo. Pomembno je, da je denarno ovrednotenje oskrbe dodaten dejavnik pri motivaciji za oskrbo. Družba s tem namenom nekaterih storitev ali dejavnosti, na primer prijateljstva, ne opredeli z denarno vrednostjo.

Zadrega, ki jo doživljamo, če izhajamo iz predpostavke, da oskrba potrebuje plačilo, je razmerje med kakovostjo oskrbe in višino plačila, ki ga posameznik prejme za opravljeno delo. Čeprav je višina plačila najpogosteje odvisna od formalne usposobljenosti kadra, sta čustvena komponenta in iskrena skrb kategoriji, ki ju kljub delnemu plačilu ni mogoče zgolj delno opraviti. Podobno osebi, ki oskrbuje, ne moremo zgolj zvišati plačila in pričakovati, da se bo sorazmerno zvišala tudi iskrenost skrbi (*ibid.*). Čeprav plačevanje za oskrbovanje ni problematično samo po sebi, morajo tisti, ki oskrbujejo, nujno prikriti, da je denarno vrednotenje njihovega dela pomembno pri tem, kako iskrena je njihova skrb in kako kakovostna je njihova oskrba (Stone 2005). Težava, s katero se morajo spopadati tisti, ki oskrbujejo za denarno plačilo, je, da so plačniki njihovih storitev najpogosteje tretje osebe, ki niso neposredno vključene v skrbstveni odnos, ali pa je njihovo delo le manjši del širšega sistema ali organizacije. V obeh primerih jih težnje po zmanjševanju stroškov oz. večanju dobička silijo k učinkovitejšemu oskrbovanju, pri njem pa je manj prostora za čustveno komponento ali iskreno skrb (*ibid.*).

Drugi pomislek v zvezi s skrbstvenim delom kot dejavnostjo, ki se samostojno pojavlja na trgu, je pogodbena narava pridobitnih dejavnosti. Ko osebi skleneta pogodbo, jasno določita, v kakšni meri in obliki bo storitev opravljena, s tem pa tudi, katera storitev bo izpuščena. Jasno določene meje, opredeljene v pogodbi, ne morejo upoštevati vseh situacij, v katerih se znajdeta posameznika v skrbstvenem odnosu. Čeprav lahko institucionalne oblike oskrbe zagotovijo 24-urno oskrbovanje, je pomemben del kakovostne oskrbe upoštevanje spreminjajoče se narave potreb (*ibid.*). Skrbstveni odnosi, ki so urejeni s krovno pogodbo, ki ne dopušča fleksibilnosti potreb, ne morejo zadovoljiti specifičnih in spreminjajočih se potreb vsakega posameznika (*ibid.*). Vplivu denarja in sklepanju pogodb za oskrbovanje, se lahko delno izognemo tako, da uporabniki storitev sami razpolagajo z denarjem, ki je namenjen njihovi oskrbi (*ibid.*).

Nancy Folbre je s skupino raziskovalcev opravila več raziskav o porazdelitvi časa, ki je v družini namenjen za skrbstveno delo (Folbre *et al.* 2004). Izviren prispevek raziskovalcev k razpravi je opredelitev konceptov aktivne in pasivne oskrbe. Avtorji podarjajo, da se večji del raziskav, ki obravnavajo časovno komponento oskrbe, osredotoča zgolj na aktivno oskrbo, torej na dejavnosti, ki jih posameznik počne v času, namenjenem oskrbi, in ki zahtevajo določen praktičen napor. Druga oblika, ki je pogosto prezrta, je pasivna oskrba. Pasivna oskrba ne zahteva praktične dejavnosti, temveč zgolj navzočnost posameznika v vlogi oskrbovalca. Avtorji poudarjajo, da pasivna oblika oskrbe v raziskavah pogosto ostane prikrita, saj jo posamezniki lahko opravljajo, medtem ko hkrati opravljajo kako drugo dejavnost (*ibid.*).

V nekaterih primerih je pasivna oskrba celo nenadomestljiv del oskrbe, čeprav tisti, ki izvaja pasivno obliko oskrbe, svoje dejavnosti ne opredeli kot skrbstvenega dela. Dober primer pasivne oblike oskrbe je nadzor otroške igre na igrišču. Čeprav posameznik ne opravlja aktivne skrbstvene vloge in ni v neposrednem stiku z otrokom, je za pasivno oskrbo ključna njegova navzočnost, v primeru odsotnosti osebe, ki bi igro nadzorovala, pa dejanje velja celo za zanemarjanje (*ibid.*). Raziskave, ki upoštevajo pasivno obliko oskrbe, ugotavljajo, da je čas, ki ga posameznik nameni skrbi za sočloveka, občutno daljši, kot so to ugotavljale študije, ki so preučevale zgolj aktivno obliko oskrbe (*ibid.*). Avtorji opozarjajo, da pri pasivni obliki oskrbe pogosto več oseb hkrati zagotavlja pasivno oskrbo eni osebi (*ibid.*). Tako se odgovornost za oskrbo porazdeli, to pa pomeni, da je oskrbovanje za posameznika udobnejše, kdo oskrbuje, pa postane nedoločljivo(*ibid.*). Novejše raziskave ne opredeljujejo več oskrbe in enopomenske opredelitve nadomeščajo s samoopredelitvijo pomena oskrbe z večjim poudarkom na razumevanju lastne odgovornosti do sočloveka (*ibid.*). Avtorji se pri samoopredelitvi odgovornosti osredotočajo na doživljanje in vpliv, ki ga ima oskrbovanje na vsakodnevno življenje posameznika.

Vključitev skrbstvenega dela med tržne dejavnosti prinaša veliko težav in dilem. Koncept oskrbe je kompleksen pojem, neločljivo povezan s kognitivnimi in čustvenimi procesi, pogoja za kakovostno oskrbo pa sta iskrenost skrbi in medsebojna povezanost. Z vstopom oskrbe na trg se pojavljajo številne negotovosti glede tega, kako premostiti razliko med oskrbo, ki jo lahko zagotavljajo družinski člani, in oskrbo, ki jo lahko zagotavlja trg. S tem namenom se v nadaljevanju posvetim etiki skrbi, ki bi jo moral trg upoštevati kot vodilo pri organizaciji plačane oskrbe.

Etika oskrbe

Etika oskrbe je del teorij, ki opredeljujejo želeno in neželeno družbeno ravnanje. Ključne teze etike oskrbe kot koncepta so: a) vsi ljudje so pri doseganju želenih ciljev medsebojno odvisni; b) tisti, ki jih lahko odločitve drugih in posledice teh odločitev še posebej oškodujejo, morajo biti deležni posebnega varstva; c) pomembno je poznavanje osebnih okoliščin, saj le tako lahko zagotovimo, da bodo upoštevani in uresničeni resnični interesi vključenih (Parton 2003).

Kot feministični koncept se etika oskrbe osredotoča na prevladujočo opredelitev oskrbe, v kateri je oskrba kot dejavnost in kot koncept razvrednotena. Eden izmed razlogov za razvrednotenje oskrbe je opredelitev skupine ljudi, ki so deležni oskrbe, kot »pomoči potrebnih«. Zahodna družba najbolj ceni vrednote, kot so individualni dosežki, razumnost in neodvisnost, potreba po oskrbi pa je nasprotje teh vrednot (Tronto 1993). Tronto (2005) piše o štirih temeljih oskrbe:

- pozornost; je temelj etike oskrbe, saj je prvi pogoj, da posameznik prepozna potrebo in se nanjo odzove;
- odgovornost; Tronto opozori na razliko med dolžnostjo, ki deluje kot družbena pogodba, in odgovornostjo, ki dovoljuje spremenljivost družbenih struktur in spolnih vlog in ki posameznika zavezuje k prevzemanju odgovornosti;
- kompetence; so temelj delovanja v praksi;
- odzivnost; Tronto piše, da odzivnost pomeni način razumevanja ranljivosti in neenakopravnosti iz perspektive osebe, ki potrebuje oskrbo, in ne na podlagi lastne predstave o občutkih, ki bi jih sami doživljali v podobni situaciji (*ibid.*).

V nadaljevanju prikažem nekaj primerov vstopov oskrbe na trg v Sloveniji. Prikažem jih v kontekstu ugotovitev raziskav o oskrbi.

Pomoč na domu in varovanje na daljavo

Pomoč (družini) na domu je v Zakonu o socialnem varstvu (2007) opredeljena kot socialnovarstvena storitev. Storitev obsega socialno oskrbo na domu, če podporo lahko nadomesti institucionalno varstvo (15. člen). Pomoč na domu obsega sklope opravil, ki so podrobneje opredeljeni v Pravilniku o standardih in normativih socialnovarstvenih storitev (2010). Sklopi obsegajo:

- pomoč pri temeljnih dnevnih opravilih: pomoč pri oblačenju ali slačenju, pomoč pri umivanju, hranjenju, opravljanju osnovnih življenjskih potreb; vzdrževanje in nego osebnih ortopedskih pripomočkov;

- gospodinjsko pomoč: prinašanje pripravljenih obrokov ali nabavo živil, pomivanje uporabljene posode, čiščenje prostorov in odnašanje smeti;
- pomoč pri ohranjanju socialnih stikov: vzpostavljanje socialne mreže z okoljem, prostovoljci in sorodstvom, spremljanje pri opravljanju nujnih obveznosti, informiranje ustanov o stanju in potrebah ter priprava na institucionalno varstvo (6. člen).

Pravilnik kot upravičence navaja osebe, starejše od 65 let, pa tudi ljudi z ovirami in otroke s hujšimi in hudimi kroničnimi boleznimi. V Sloveniji je bilo leta 2013 v storitev pomoči na domu vključenih 6540 oseb, od tega 87,2 % starejših od 65 let, 3,2 % ljudi s statusom invalida, 3,7 % ljudi s pravico do tuje nege in pomoči, 5,7 % ljudi s kronično boleznijo in le 0,2 % (11) otrok s hujšimi ali hudimi ovirami (Nagode *et al.* 2014). Uporabniki so storitev pomoči na domu praviloma uporabljali v obsegu manj kot 3,5 ure na teden (*ibid.*). Deleži po sklopih opravil kažejo, da večina uporabnikov uporablja storitev pomoči na domu za pomoč pri gospodinjskih opravilih (39,9 %), nekaj manj za družabništvo (33,6 %), najmanj pa pri temeljnih dnevnih opravilih (26,5 %) (*ibid.*). Visoka stopnja potreb po družabništvu opozori, da oskrba ni zgolj praktična dejavnost, temveč del skrbstvenega dela sestavljata tudi oseben odnos in čustvena komponenta oskrbe.

Leta 2013 je posamezna socialna oskrbovalka v povprečju obiskala uporabnika 18,7-krat na mesec (*ibid.*). Enega uporabnika je lahko obiskovalo tudi več socialnih oskrbovalk, podatka o tem, ali organizacije želijo, da uporabnika obiskuje vedno ista socialna oskrbovalka, v poročilu ni zaslediti. V Sloveniji je bilo leta 2013 82 izvajalcev storitve pomoči na domu, med njimi prevladujejo centri za socialno delo (37) in domovi za starejše (24), preostali del izvajalcev pa so zasebniki s koncesijo in specializirani zavodi za pomoč na domu (*ibid.*). V poročilu avtorice zapišejo še, da je ponekod informiranost o storitvi majhna, razlog za to, da se ljudje ne odločajo za uporabo storitve, pa je tudi ta, da pomoč raje poiščejo v svojih neformalnih omrežjih; ta so nadomesten ali dopolnilen vir oskrbe. Gre za organizirano pomoč znotraj družine, prijateljev in za sosedsko podporo. Avtorice so opazile, da imajo nekateri ljudje odklonilen odnos do sprejemanja tuje pomoči (*ibid.*).

Zakon o socialnem varstvu (2007) predvideva storitev, ki se podobna pomoči na domu, socialni servis, a ga ne uvršča v nabor javnih služb. Socialni servis obsega naloge, kot so: prinašanje in pripravljanje obrokov hrane, manjša hišna popravila, pranje in likanje perila, vzdrževanje okolice in stanovanja, družabništvo, storitve za nego telesa in vzdrževanje videza, varovanje prek noči ali celodnevna povezava prek osebnega telefonskega alarma (7. člen). Socialni servis mora zagotavljati vsaj tri storitve s seznama, ena izmed njih mora obvezno biti prinašanje pripravljenih obrokov hrane, razen v primeru zagotavljanja celodnevne povezave prek osebnega telefonskega alarma (ti. varovanje na daljavo). Varovanje na daljavo se izvaja kot samostojna storitev, ki jo zagotavlja socialni servis. Za storitve socialnega servisa je v Sloveniji pri Ministrstvu za delo, družino, socialne zadeve in enake možnosti registriranih 24 izvajalcev (MDDZS 2014 c). Storitev varovanja na daljavo ponujajo tudi nekateri drugi zasebniki, ki niso registrirani pri MDDSZ kot izvajalci storitve socialnega servisa. Ponudniki storitve varovanja na daljavo svoje storitve po navadi oglašujejo s slogani, ki sporočajo, da bo uporabnikovo življenje z uporabo njihove storitve bolj brezskrbno, saj bo, če bodo potrebovali pomoč, zmeraj nekdo v pripravljenosti. Nekatera podjetja za ta namen ponujajo tehnologijo, ki preprosto prikliče nekaj prej določenih telefonskih številk in druge obvesti o tem, da nekdo potrebuje pomoč. Pri storitvi pomoči na domu in varovanju na daljavo gre za delitev koncepta oskrbe na storitev, ki zagotovi aktivno obliko oskrbe, in storitev, ki zagotovi pasivno obliko oskrbe. Varovanje na daljavo je v tem primeru pasivna oblika oskrbe.

Osebna asistenca

Osebna asistenca je organizirana oblika podpore posamezniku, katere vodilo je, da mora biti storitev prilagojena individualnim potrebam, sposobnostim, življenjskim razmeram in pričakovanjem posameznika (Kobal *et al.* 2004). Vodilo osebne asistence je tudi, da mora imeti posameznik čim večji nadzor nad podporo, ki jo prejema. Posameznik sam izbere svojega pomočnika ali pomočnico, se z njim dogovori o njegovih ali njenih nalogah, ga nadzoruje, usposobi in z njim prekine sodelovanje, če to sodelovanje ni več mogoče (*ibid.*).

Pomoč na domu in socialni servis sta časovno omejena na nekaj ur na dan, po navadi se storitev ne izvaja vsak dan in naloge so vnaprej dogovorjene in najpogosteje obsegajo le najosnovnejše potrebe. Zadovoljevanje potreb posameznika je omejeno na delovni čas pomočnika, čas, ki ga lahko vsak dan pomočnik nameniti podpori eni osebi, pa je zaradi večjega števila oseb omejen (*ibid.*). Socialnovarstveni storitvi pomoči na domu in socialni servis se od osebne asistence razlikujeta po tem, da ima uporabnik manj nadzora nad izvajanjem pomoči, izvajalec pomoči pa ohranja klasično vlogo strokovnjaka, čustveni komponenti oskrbe ali vzajemnemu odnosu med uporabnikom in izvajalcem storitve pa je namenjenega le malo prostora (*ibid.*).

Koncept osebne asistence presega tradicionalni koncept skrbi za druge. Ključni prispevek koncepta osebne asistence je, da se izbiranje, odločanje in nadzor prenesejo iz socialne službe na uporabnika ali uporabnico storitve. Osebno asistenco v Sloveniji že od leta 1998 kot program neodvisnega življenja hendikepiranih v praksi izvaja društvo YHD. V analizi programov osebne asistence, ki so jo pripravili na Inštitutu RS za socialno varstvo, Smolej in Nagode (2008) poudarita, da je bilo leta 2007 v Sloveniji 24 organizacij, ki so ponujale storitve osebne asistence. Omenita tudi, da naj bi glede na razpisno dokumentacijo MDDSZ, FIHO in ZRSZ osebno asistenco izvajalo 32 organizacij, vendar pa so nekatere organizacije, kljub temu da so uradno izvajale program osebne asistence, konceptualno izvajale storitev pomoči na domu (Smolej, Nagode 2012). Avtorici poudarita, da je razumevanje razlike med konceptoma pomoči na domu in osebne asistence še vedno omejeno. Brez razumevanja konceptualne razlike med oblikama oskrbe pa spregledamo tudi celostno razumevanje koncepta oskrbe, ki poleg praktične vključuje tudi čustveno in kognitivno komponento in pri kateri je osebni stik med oskrbovalcem in uporabnikom ključen.

Institut družinskega pomočnika, ki je soroden institutu osebne asistence, se v Sloveniji izvaja od leta 2004. Zakon o socialnem varstvu (2007) določa, da lahko posameznik namesto institucionalnega varstva izbere družinskega pomočnika za zagotavljanje podpore v domačem okolju. Družinski pomočnik lahko postane oseba, ki ima isto stalno prebivališče kot oseba, ki ima pravico do izbire družinskega pomočnika, oziroma eden od družinskih članov. Oseba, ki postane družinski pomočnik, se mora odjaviti iz evidence nezaposlenih ali zapustiti trg dela, saj gre za vzpostavitev novega delovnega razmerja. Določila, ki opredeljujejo način dela družinskega pomočnika, predvidevajo tudi, da mora imeti družinski pomočnik »primeren odnos do invalidne osebe in biti usposobljen za komuniciranje in delo z invalidno osebo« (MDDSZ 2014 a). Naloge družinskega pomočnika obsegajo osebno oskrbo, zdravstveno oskrbo, socialno oskrbo, organiziranje prostočasnih dejavnosti in gospodinjsko pomoč. Zakon o socialnem varstvu (2007) določa, da pristojni center za socialno delo ves čas spremlja delo družinskega pomočnika, enkrat na leto pa pripravi poročilo o delu družinskega pomočnika, ki vsebuje mnenje osebe, ki je oskrbe deležen (18k. člen).

Koncepta osebne asistence in družinskega pomočnika sta si sorodna, saj v obeh primerih oseba, ki potrebuje podporo, zaposluje svojega pomočnika. Nekateri avtorji in raziskave opozarjajo, da v številnih primerih osebe, ki potrebujejo podporo, kot osebnega asistenta raje izberejo osebo, ki z njimi ni v sorodstveni zvezi, saj tako pridobijo občutek večje neodvisnosti. Vključitev tretje osebe v oskrbo je odziv na čustveno komponento skrbi, saj je ta lahko med osebami v sorodstveni zvezi bolj zapletena in lahko vpliva na kakovost oskrbe, še posebej pa na razmerja moči v skrbstvenem odnosu (Rechel *et al.* 2006).

Institucionalno varstvo

Institucionalno varstvo je oblika obravnave v zavodu, drugi družini ali drugi organizirani obliki, ki upravičencem nadomešča, dopolnjuje ali zagotavlja funkcijo doma ali lastne družine (MDDSZ 2014 b). Obsega osnovno oskrbo in socialno oskrbo v skladu s predpisi s področja socialnega varstva ter zdravstveno varstvo po predpisih s področja zdravstvenega varstva (*ibid.*). Osnovna oskrba obsega bivanje, organiziranje prehrane, tehnično oskrbo in prevoz. Socialna oskrba je strokovno vodena dejavnost, namenjena izvajanju vsebin socialne preventive, terapije in vodenja. Varstvo pomeni zagotavljanje pomoči pri vzdrževanju osebne higiene in izvajanju dnevnih aktivnosti, oblačenju, premikanju, hoji, orientaciji. Posebne oblike varstva so namenjene ohranjanju in razvoju samostojnosti, razvoju socialnih odnosov, delovni okupaciji, korekciji in terapiji motenj, aktivnemu preživljanju prostega časa ter reševanju osebnih stisk in težav (*ibid.*).

Institucionalno varstvo je v Sloveniji razvejen sistem, ki vključuje raznovrstno populacijo in pomeni najkompleksnejši odziv na potrebe po skrbstvenem delu zunaj matične družine. Institucionalno varstvo se od bolj individualiziranih odzivov na potrebe po oskrbi razlikuje po tem, da je odziv standardiziran, uporabniki prejemajo enak nabor storitev, ki so razdrobljene na delovne naloge, te pa opravljajo zaposleni glede na delovni razpored. Čeprav je mogoče, da se tudi pri takšnem načinu zagotavljanja oskrbe razvije oseben odnos, je zaradi razmerja moči med strokovnjaki in uporabniki ter zaradi pogostih menjav osebja to neutemeljeno pričakovati. Organizirana oskrba v velikih institucijah izgubi pomembno komponento kakovostne oskrbe, saj z delitvijo dela in kadrovsko zasedbo ne upošteva, da je oskrba tako praktično kot kognitivno in čustveno delo, koncept oskrbe pa razume le kot praktično opravljanje osnovnih skrbstvenih nalog.

Centri za kratko namestitev

Koncept centrov za kratko namestitev v Sloveniji še ni razvit, čeprav se je v tujini začel pojavljati že pred dvema desetletjema. Raziskave kažejo, da kar 80 % potreb po skrbstvenem delu zadovoljijo svojci oseb, ki potrebujejo podporo (Parton 2003). Raziskave kažejo tudi, da je opravljanje skrbstvenega dela naporno tako telesno kot kognitivno in čustveno. Centri za kratko namestitev so namenjeni krajši razbremenitvi tistih, ki opravljajo vsakodnevno skrb, največkrat so to družinski člani tistega, ki potrebuje podporo. Čeprav številne družine v celoti same skrbijo za družinskega člana, brez zahtev po povračilu stroškov, ima lahko oskrbovanje tako ekonomske kot čustvene posledice za celotno družino. Centri za kratko namestitev zagotavljajo premor od skrbstvenih dolžnosti družinskim članom, hkrati pa omogočajo pozitivno izkušnjo tudi prejemnikom skrbi. Ti centri pozitivno vplivajo na zdravje oseb, ki opravljajo skrbstveno delo, zmanjšujejo število dolgotrajnih namestitev in razvez (ki so posledica preveč obremenjujočega skrbstvenega dela) ter zmanjšujejo verjetnost zlorab in zanemarjanj (Laverty, Reet 2001).

V literaturi se pojavlja nekaj praktičnih modelov koncepta kratke namestitve.

- Domača oskrba, pri kateri se oseba, ki začasno opravlja vlogo oskrbovalca, pridruži družini v njihovem domu. Priuči se družinskega vsakdana, oskrba pa ni otežena zaradi vstopa v drugo okolje ali prekinitve rutine. Začasno lahko oskrbo opravljajo drugi družinski člani ali plačani strokovnjaki.
- Specializirane ustanove, v katerih je lahko posameznik nameščen nekaj dni ali nekaj tednov. Prednost takšnih specializiranih ustanov je dostopnost nujne medicinske pomoči in strokovnjakov, če je takšna pomoč potrebna. Gre za pomemben odmik od institucionalnega varstva, saj je namestitev časovno omejena in namenjena razbremenitvi.
- Kratka namestitev v izjemnih primerih je dobrodošla, ko se pojavijo nepričakovane potrebe po oskrbi. Različne ustanove lahko zagotavljajo krajšo namestitev, če oseba, ki po navadi izvaja oskrbo, zaradi izjemnega dogodka takšnega dela ne more opravljati.

Koncept centrov za kratko namestitev ni osredotočen zgolj na prejemnika oskrbe, temveč tudi na bližnje osebe, ki izvajajo oskrbo. Oskrbovanje je v konceptu takih centrov opredeljeno kot celovit proces, ki obsega tako čustveno in kognitivno kot praktično delo. Sàmo delo teh centrov ni namenjeno vzgoji ali terapiji, temveč zagotavljanju nove izkušnje posamezniku in izboljšanju kakovosti življenja oskrbovalcem. Koncept kratke namestitve se razlikuje od pristopov, ki obravnavajo posameznikovo potrebo po oskrbi kot sklenjeno celoto. Oskrbo obravnava kot del širše družinske realnosti, v katero so vključeni številni akterji, vsak s svojim prispevkom. Pomeni kompleksnejši odziv na potrebe, ki nastanejo v družini zaradi izvajanja oskrbe, oskrbo pa ne opredeljuje kot zgolj nabor praktičnih del. Opredelitev oskrbe kot celostnega procesa je pomemben korak k izboljšanju kakvosti življenja vseh, ki kakorkoli izvajajo oskrbo ali so je deležni.

Večplastnost oskrbe otrok z ovirami

Centri za kratko namestitev so namenjeni podpori in razbremenitvi tistih, ki vsak dan opravljajo skrbstveno delo. Raziskava o načinih, na katere starši otrok z ovirami uporabljajo tako obliko dopolnilne oskrbe, je pokazala, da starši storitev takih centrov uporabljajo različno (Collins *et al.* 2014). Centri za kratko namestitev so poleg nadomestnih oblik oskrbe namenjeni tudi čustveni razbremenitvi oskrbovalcev (*ibid.*). Avtorji raziskave so ugotovili, da je velik del oskrbe otrok z ovirami prav čustveno delo (*ibid.*). Centri za kratko namestitev v številnih primerih staršem pomenijo tudi simbolno priznanje, da je skrbstveno delo naporno in da si zaslužijo premor (*ibid.*).

V raziskavi o starševski perspektivi koncepta kratke namestitve otrok z ovirami avtorji ugotavljajo, da starši skrbstveno vlogo centrov za kratko namestitev razumejo različno (*ibid.*). Čeprav so ti centri namenjeni zlasti zmanjševanju bremena oskrbovanja, nekateri starši poročajo, da jim ti centri omogočajo opravljati več skrbstvenega dela, saj se lahko posvetijo družinskim članom, za katere jim po navadi zmanjka časa. Nekateri starši vlogo centrov za kratko namestitev vidijo kot način zmanjševanja družbene izolacije. Prepoznavajo pozitiven učinek, ki ga imajo organizirani dogodki ali kratki skupni oddihi na občutek vključenosti v družbo, saj olajšajo dostop do dogodkov, ki se jih brez podpore ne bi mogli udeležiti (*ibid.*).

Skrbstveno delo je kompleksen proces, ki je glede na končne prejemnike oskrbe v svojih oblikah raznovrstno. Ker je v razpravi nemogoče zajeti prav vse oblike oskrbe, v tem članku oskrbo otroke z ovirami obravnavam kot vzorčen primer, pri katerem se prepletajo čustvena, kognitivna in praktična oskrba, hkrati pa morajo strokovni odzivi na potrebe po oskrbi upoštevati tudi razmerje med običajno oskrbo in nego, ki jo potrebuje vsak otrok, in specifično oskrbo, ki jo potrebuje otrok zaradi ovire. Starši, ki skrbijo za otroke z ovirami, svojo skrbstveno vlogo najpogosteje opisujejo kot skrb za otrokov telesni razvoj (Woodcock, Tregaskis 2008). Predšolsko obdobje starši otrok z ovirami opredeljujejo kot najpomembnejše obdobje, za katero pravijo, da v njem ni dovolj dostopnih storitev, s katerimi bi otroku z oviro omogočili zadovoljiv napredek (*ibid.*).

Osredotočenost staršev na doseganje razvojnih stopenj avtorji razlagajo z vplivom nedoločljive meje med oskrbo in nego, ki ju potrebuje vsak otrok, in dodatno oskrbo, ki jo potrebuje otrok z oviro (*ibid.*). Woodcock in Tregaskis (2008) poročata, da so starši otrok z ovirami z delom strokovnjakov najpogosteje nezadovoljni, če strokovnjaki otroke obravnavajo zgolj skozi prizmo medicinske diagnoze in torej ne upoštevajo celovite osebnosti. Strokovnjaki, ki jih starši ocenjujejo kot boljše, si vzamejo čas, da z otrokom spregovorijo nekaj besed, in so po mnenju staršev sočutni (*ibid.*).

Otrokova diagnoza staršem odvzame pravico, da se sami odločijo o oskrbovanju in vzgoji, saj tesno sodelovanje s strokovnjaki pomeni, da obstaja oskrba, ki strokovno velja za pravilno, to pa vpliva na doživljanje oskrbovanja kot nečesa, kar je čustveno naporno (Collins *et al.* 2014). Starši najpogosteje pozitivno opisujejo strokovnjake na podlagi njihove empatične osebnosti. Avtorji poudarjajo, da starši od strokovnjakov ne pričakujejo, da bodo prepoznali vse medicinske težave, s katerimi se srečuje otrok, pač pa, da bodo sodelovali s starši, odkrito komunicirali in prepoznali ekspertno znanje staršev ter ga oplemenitili z lastnim strokovnim znanjem (*ibid.*). Strokovno znanje je v celotni izkušnji nadomestne oskrbe ali podpore enakovredno medosebnemu odnosu, ki se razvije med soudeleženimi v procesu oskrbovanja.

Sklep

Članek se ukvarja s konceptom oskrbe kot večplastnim procesom. Čeprav je ideja o skrbstvenem delu kot o nečem kompleksnem, kar vsebuje čustveno, kognitivno in praktično dejavnost, stara že nekaj desetletij, organizirane oblike oskrbe le redko upoštevajo to kompleksnost. Oskrba je kompleksna dejavnost, saj posega na različne ravni človeškega življenja in se kaže v številnih oblikah, ki dokazujejo človeško soodvisnost. V strokovni literaturi so od začetka devetdesetih let 20. stoletja nehali pisati o bremenu skrbi in so pojem nadomestili z idejo o soodvisnosti in vzajemnosti oskrbe (Folbre, Nelson 2000). Odsotnost javnega diskurza o oskrbi kot večplastnem procesu zbuja skrb, saj vpliva tako na kakovost oskrbe kot na kakovost življenja oskrbovalca. Oskrba je ena izmed dejavnosti, ki zahtevajo, da socialnovarstveni sistem upošteva obe osebi, tako tistega, ki je oskrbe deležen, kot oskrbovalca. Raziskave kažejo celo, da je nujno, da oskrba ni le skupek praktičnih nalog, ki jih opravi strokovnjak, temveč da je oskrbovalcu dopuščena možnost samostojne presoje v različnih situacijah in da ima možnost, da se osebi, za katero skrbi, približa na osebni ravni (Parton 2003).

To sicer ne pomeni, da so praktične spretnosti na področju skrbstvenega dela zanemarljive, prav nasprotno, vendar pa moramo poleg praktičnih spretnosti upoštevati tudi kognitivno in čustveni raven oskrbovanja, saj z njima zadovoljimo potrebo po specifičnosti podpore, ki jo potrebuje vsak posameznik. Namesto da strokovnjak oceni situacijo in potrebe ter predpiše »strokovno« rešitev, uporabnik svojo izkušnjo zaupa strokovnjaku, s tem pa ustvari nov pogled na lastno izkušnjo. Takšen pristop je tudi temelj socialnega dela in upošteva pluralnost človeških izkušenj. Odmik od oskrbe, ki je osredotočena le na strokovnjaka ali oskrbovanca, pomeni, da pri organiziranju podpore upoštevamo soodvisnost in potrebo človeka po osebnem odnosu s sočlovekom. V različnih organiziranih oblikah oskrbi lahko vidimo različne elemente pristopa, ki upošteva skrb kot večplasten proces. Premik oskrbe na trg je spodbudil, da je postala oskrba razdrobljena na majhne merljive enote, ki jih je mogoče denarno ovrednotiti. Komponente skrbi, ki jih ni mogoče opredeliti na ta način, kot sta oseben odnos in čustvena povezanost, so težko merljive in ne morejo biti denarno ovrednotene. Iluzorno bi bilo sicer pričakovati, da bi lahko čustveno delo enako kot praktične naloge oskrbe postalo standardizirana merljiva dobrina. Toliko pomembneje pa je, da oskrbo razumemo kot večplasten vzajemen proces, ki vključuje tako oskrbovanca kot oskrbovalca.

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Natalija Lisak

THE INTEGRATIVE ANALYSIS OF SOCIAL FACTORS IN THE LIFE COURSE OF FAMILIES WITH DISABILITIES

The Croatian society context and disability

This integrative analysis contributes to the conceptualization of the social context that shapes the life course of families with children with disabilities and addresses the role of the Croatian society within that process. Development of community based support and human rights protection in Croatia are important societal changes that ensure access to desired family quality of life in the field of disability. For that reason, the analysis is based on respecting opinions and experiences of parents of disabled children in order to provide insight into the family life trajectories to discover the relevant factors of the social context. The narrative approach was used to collect life stories of families with children who had intellectual disabilities. The social context that shapes the family life course and their further opportunities includes: the underdevelopment of community based services; the legacy of institutional care; the great influence of religious beliefs and Catholic Church institutions; the parents' initiative for rights implementation and system changes; the active role of mothers in everyday family life and supportive family relationships. The results emphasize important community development changes in Croatian society by focusing on the context that shapes the life course perspective of families with disabilities.

Key words: biography approach, life stories, quality of life, identity, human rights.

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INTEGRATIVNA ANALIZA DRUŽBENIH DEJAVNIKOV V ŽIVLJENJSKEM POTEKU DRUŽIN Z OVIRAMI: KONTEKST HRVAŠKE DRUŽBE IN OVIRANOST

Članek pripomore h konceptualizaciji družbenega konteksta, ki oblikuje življenjski potek družin z otroki z ovirami, pri tem pa upošteva vlogo hrvaške družbe v tem procesu. Razvoj služb podpore v skupnosti in zaščita človekovih pravic sta na Hrvaškem pomembni družbeni spremembi, ki zagotavljata dostop do kakovostnega družinskega življenja na področju ljudi z ovirami. V tem pogledu analiza temelji na mnenjih in izkušnjah staršev otrok z ovirami. Pri zbiranju življenjskih zgodb družin z intelektualno oviranimi otroki je bil uporabljen narativni pristop. Družbeni kontekst, ki oblikuje življenjski potek družin in njihove priložnosti, obsega: nerazvitost služb v skupnosti; zapuščino institucionalne oskrbe; velik vpliv religioznih verovanj in institucij katoliške cerkve, aktivizem staršev za uresničevanje pravic in sistemske spremembe; aktivno vlogo mater v vsakdanjem družinskem življenju in podporne družinske odnose. V rezultatih poudarimo spremembe v razvoju skupnosti v hrvaški družbi, zlasti pa kontekst, ki vpliva na življenjski potek družin, ki imajo otroke z ovirami.

Ključne besede: biografski pristop, življenjske zgodbe, kakovost življenja, identiteta, človekove pravice.

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Introduction

People with disabilities face different life chances and have different life experiences related to specific disabling barriers in their society. Those differences can lead to specific occurrences in the political agenda,

> so, for example, while disabled people's organizations in the United Kingdom were campaigning against the principle of charitable support from the National Lottery, people with disabilities in Thailand were protesting to maintain the employment of disabled Lottery tickets sellers. (Priestley 2001: 4.)

The Republic of Croatia signed and ratified the UN *Convention on the Rights of Persons with Disabilities* in 2007 (Croatian Parliament 2007). The ratification of the Convention affected any subsequent legislation framework in the field of anti-discrimination so the *Anti-discrimination Act* was adopted the following year (Croatian Parliament 2008). The *National Strategy on Equalization* *of Opportunities for Persons with Disabilities from 2007 to 2015* (Government of the Republic of Croatia 2007) emphasized the need for the implementation of rights of disabled people by putting them on the political agenda.

In the Republic of Croatia people with disabilities still face various types of barriers in the field of: early intervention support, access to regular preschool and education systems, access to the labour market and income maintenance, the right to independent living and family life instead of institutional care (Lisak 2013). According to the *Human Rights Watch World Report 2013,*

> Officials of the Ministry of Social Policy closed down a state-funded social care home for people with mental disabilities following findings of severe abuse, including lack of food, use of solitary confinement and inadequate sleeping facilities. (Human Rights Watch 2013.)

This highlights the state's intentions to create better living conditions in Croatia for people with disabilities. Still, there are a great number of children and people with intellectual disabilities who live in institutions (UNICEF Regional Office for Central and Eastern Europe 2012). These facts show that even though the master plan for deinstitutionalization was adopted by the government in 2011, still there are issues such as 'small increase in the number of places in community-based housing and support services for people with disabilities' (Human Rights Watch 2013). The formal state care mostly relates to institutional care or family-based care, instead of community based support.

Health care and social services are poor and unequally distributed in the community, which affects to the biggest extent mostly the rural population, vulnerable and discriminated groups such as children, women and persons with disabilities (UNICEF Regional Office for Central and Eastern Europe 2012). According to the statistical report (National Institute of Public Health 2013), 78% of children and adults with disabilities live all their lives within their families and are in need of community based support because social services are underdeveloped or non-existent on local levels, which denies disabled persons access to desirable personal and family life quality.

It is emphasized that development or continuation of community-based services in Croatia should be designed and established to address children and family vulnerabilities through individual plans and strengthen family capacities for providing quality care for their children (UNICEF Regional Office for Central and Eastern Europe 2012).

The historical and political context that shaped the current support system, as well as the theory and practice of the social work profession, was developed by the communist state policy, where public interests were given priority over private ones (Zaviršek 2008). The primary responsibility of the state was to raise the children, considering the parents first of all as part of the labour force (UNICEF Regional Office for Central and Eastern Europe 2012). People with disabilities were considered as not in the labour force and put under the state institutional care into segregated living conditions. From the time of the declaration of national independence in the 1990s up until today, the focus has been on developing community based public services for vulnerable populations such as children and people with disabilities and their families (Lisak 2013), but still the process is slow and influenced by the current economic crisis. Attitudes of relevant policy makers, professionals and even parents still support institutional care, in the sense that a community based service is underdeveloped or non-existent on local or regional levels.

Previous research in Croatia that focused on achieving social standards for people with disabilities has shown that the examples of good social practice are investigated through new models of community based support from the non-governmental organizations in the field of education (Igrić *et al.* 2008), independent living in society and self-advocacy (Bratković, Zelić 2011) of people with disabilities. Still, development of public services under state responsibility and by state funding should be considered more seriously on the policy level.

Previous research focused on the quality of life of people with intellectual disabilities placed in institutions, and people with disabilities who live within their families provided recommendations focused on the need for community based support, family centred approach and supported living in the community (Bratković 2002). That study also emphasized the need for an investigation of subjective perceptions of quality of life by using a qualitative inclusive approach with disabled persons and their families. In accordance with that finding, people with disabilities should be considered as active participants in the process of giving meaning to their lives and shaping their quality of life (*ibid.*).

Another integrative study was focused on the assessment of the situation and needs of persons with disabilities and their families in Croatian society (Leutar *et al.* 2011). To ensure desirable quality of life for people with disabilities and their families, the main functions of the services should aim to: ensure the availability of information, ensure familiarization with granted rights, meet the conditions for raising the educational level of people with disabilities, determine the needs of the labour market, educate in family and partner relationships, support the non-governmental organizations on a local level, organize self-help groups, insure direct payments, support lifelong learning for people with disabilities as additional skills for their employment and empower people with disabilities to advocate for their rights (*ibid.*).

To provide integrative analyse of social factors in the life course of families with disabilities, which was the purpose of the qualitative study presented through this paper, it is important to briefly describe guaranteed family rights and services in accordance with Croatian legislation.

Guaranteed family rights and services

In accordance with the *Family Law* (Croatian Parliament 2003), which recognizes only different sex families, the regulation of family rights and relations are based on the principles of: equality between women and men; mutual respect and support of all family members; protecting the welfare and rights of children and the responsibility of both parents to raise and educate a child; adequate guardianship of children without parental care and adults with mental disabilities. The social rights and services for people with disabilities and their families are regulated by the *Social Welfare Act* (Croatian Parliament, 2012). Guaranteed rights, in accordance with the *Social Welfare Act* (*ibid*), are as follows: financial support for education, disability living allowance or personal independence payment, *assistance* and care allowance, parent caregiver status and inclusive allowance (financial support for persons with disabilities to provide the equalization of opportunities for their involvement in daily life). Guaranteed social services, by the same law are as follows: situation assessment and advisory service, early intervention, professional services at home, integration in educational programs, access to day-care, institutional care and professional support for organized housing in the community.

Even though the process of deinstitutionalization has started, which has also been obvious from the rights articulated by the law, through emphasizing the rights on organized housing in the community and family capacity building, still one of the most widespread social services in practice is institutional care. This seems contradictory and sends a completely different message to people with disabilities and their parents. That is the reason why it is important to hear the voices of persons with disabilities and their family members.

Aim and methods

This paper seeks to answer the question – what is the real priority of the actual political agenda and how does the Croatian social context shape the life chances of people with disabilities and their families from their own perspective? Afterwards, what should be done in order to improve the quality of life of persons with disabilities and their families from their own perspective?

This research was done within the doctoral dissertation and included families with disabled members as active participants in the qualitative narrative study in order to provide insight into the family life trajectories by focusing on opinions and experiences of parents of intellectually disabled children to discover the relevant factors of the social context. Through this kind of qualitative study, life experiences, social factors and family subjective factors were investigated by using the life story and narrative approach with 9 parents of children with intellectual disabilities from three different regions in Croatia: Slavonia, Dalmatia and Central Croatia (capital city Zagreb). Each region was represented by three parents of children with intellectual disabilities under the following criteria: parents of a child integrated in regular educational system, parents of a child integrated in a special educational system and parents of a child who is not included into any kind of support system. The family life period that was investigated in the study was from the child's birth up until 21 years of age and the disability types involved were as follows: Down syndrome, autism spectrum disorders and intellectual disabilities, multiple disabilities. All 9 participants were mothers, from different sex families, with secondary and higher education backgrounds.

The narrative approach was chosen in this study of family life quality because it provides an insight into the entire life course of a person, where the focus is on all past and present experiences that a person had/has (Miller 2000). The reason for using the narrative approach when the focus is on families with disabled children lies in the fact that for these families, from the moment they find out that their child has a disability, a process begins that is lifelong and shapes their quality of life (Brown 1997).

Life course research is defined by Mayer and Tuma (1989) as

> the study of social processes extending over the individual life span, or significant portions of it, especially the family cycle and individuals' personal impairment and disability history (Kasnitz 2001: 68).

The life course event history model (*ibid.*) was used to identify and chronologically map essential events in individuals' lives creating an 'event history'.

The integrative qualitative analysis was done with the focus on finding the patterns in the sequencing of life history events, at transitions in identity and experience related to impairment and disability, as well as their placement in the context of other dynamic life course processes (*op. cit.*).

Findings of the integrative analysis

The social objective indicators that have contributed to the families' life history events and shaped their life course, based on life stories in all three regions, were as follows: lack of early intervention support; non-supportive and discriminative treatment from health, social care and educational systems; discriminative relationships in the Catholic Church organization, support from non-governmental associations and supportive relationships in the family (Lisak 2013).

In the life stories from the region of Central Croatia (capital city Zagreb) the specific objective indicators are positive examples of community based support (day centre, faculty centre for rehabilitation and education, private professional practice) and non-supportive and discriminative treatment from staff of the Catholic Church (*ibid.*).

These findings were based on the citations from the narratives:

> I know my rights and I was ready to fight for them ... together with other mothers ... we arranged that our kids had the teaching assitant support in schools. I can say that the woman from city department for education was friendly and supportive, she got together with us in a school ... we arranged everything. (Narrative 1.)
>
> I am very grateful for the support that we got from the faculty centre ... those workshops and parents meetings were so important for me ... we shared information ... you could easily find out what to do and where to go. (Narrative 2.)
>
> That day centre for children with several disabilities ... it is something that every parent needs ... they organize early intervention, provide daily support for children ... parents were also integrated into the support group...we got counselling ... I remember that was the first thing I did for myself. (Narrative 3.)
>
> We had to go to a private doctor ... that was very important for us ... after visiting him we were calmed down ... the child functioned better ... much better. (Narrative 1.)

> They said he just could not go to kindergarten (catholic kindergarten) ... I don't blame them, they didn't know how to give support ... but I was somehow in shock ... because my sister is a nun and she arranged everything. (Narrative 1.)

In the region of Slavonia the specific objective indicators that shape the life course in the life stories are as follows: increased financial expenses for trips to Zagreb to get assessment and support, non-supportive and discriminative treatment from members of the Catholic Church and financing services by the parents (Lisak 2013).

These findings were based on the citations from the narratives:

> The first year we travelled a lot ... we needed to go for assessment ... and support ... in Zagreb ... every week we travelled to Zagreb ... we spent so much money on travelling ... Zagreb is too far. (Narrative 1).
>
> I talked to a priest ... tried to explain to him that my child can't speak ... he asked me if he can learn how to pray ... again I said you didn't understand me, he just can't ... on the first communion ceremony he was just running across the church ... we could not stop him ... they gave him first communion after the ceremony ... The priest said that he was not satisfied with that ... I was so mad and sad ... again I tried to talk to him ... my child didn't get the ceremony confirmation. (Narrative 2).
>
> We paid for an educational rehabilitator ... to come to our home ... when she started to work with him I was so happy ... he was more successful ... she knew some new approaches ... floor time and so. (Narrative 2)
>
> I paid for a teaching assistant ... my child can go to regular kindergarten with other children ... I asked how teaching assistant support was organized in Zagreb ... to find out what to do. (Narrative 1).

In the region of Dalmatia the specific objective indicators that shape the life course in the life stories are as follows: supporting the institutionalization of children with multiple disabilities; understanding disability as a tragedy in the case of families with children with multiple disabilities; lack of awareness of the local community and increased financial expenses for trips to Zagreb to get assessment and support (Lisak 2013).

These findings were based on the citations from the narratives:

> They told me to give her away ... to go to an institution ... I didn't want to do that ... she is my angel ... she lives with us ... it's like they want to say 'What can you do?', this is too hard to stand ... to take care of her. (Narrative 3.)
>
> One friend told me I am so sorry ... it is like we are constantly labelled ... people look at that as though your life is a tragedy ... they don't know what to say ... but I could feel what they mean. (Narrative 3.)
>
> We tried to develop some support for our children ... parents came together and invited professionals to come to our organization ... we tried to explain but they just were not aware of that. (Narrative 2.)
>
> When he was young we travelled a lot ... I tried to educate myself to give him support, to work with him ... we travelled a lot to Zagreb ... we used to stay for a few days ... we tried to help him, to get support and to learn how to work with him ... I wanted to know what to do when I back home. (Narrative 2.)

These findings from all the narratives highlighted the specific social context that shaped the life course of families with children with intellectual disabilities and their quality of life.

Social context and the life course of families

Social context represents the contribution of social, political and cultural environment on a life course of an individual at a particular time and in a particular place (Priestley 2001). In this study of life quality of families with children with intellectual disabilities in the regions of Central Croatia, Slavonia and Dalmatia, the social context that shapes the life course represents: the contribution of the capitalist social order, the rights guaranteed by the democratic political system, the legacy of the socialist tradition within the political system, the values of family life and family support, as well as the importance of Christian values and the Catholic church (Lisak 2013).

The social context that shapes the families' life course and their further opportunities includes: exclusive and discriminative attitudes of employees in the health, education and welfare systems; the great influence of religious beliefs and the institutions of the Catholic Church; the underdevelopment of community based services; the legacy of institutional care; the parents' initiative for rights implementation and system changes; the active role of mothers in everyday family life and supportive family relationships.

Discriminative and exclusive attitudes and treatment by professionals

Discriminative and exclusive attitudes and treatment by professionals in the health, education and welfare systems also contribute to the quality of life of families with intellectually disabled children addressed in this study. Health system professionals do not provide parents with relevant and appropriate information, which leads to lack of assessment and suitable support for their children, and furthermore, tends to develop distrust and fear of the future (Lisak 2013). Serious undermining of the guaranteed rights and personal dignity by health care professionals were present in the case of families with children with multiple disabilities (*ibid.*). Attitudes of the health care professionals towards children with intellectual disabilities and their parents are still shaped by the dominant medical model of disability, which leads to the challenge 'to be sick' as explained by Hunt (1966). The perception of suffering, inability, limitations and pain leads to a tragic life for these children, their worthlessness and helplessness.

Discriminative attitudes of the professionals from the education system represent prejudice as well as lack of knowledge and previous experience, which deprives children of their right to be included in the regular educational system (Lisak 2013). The attitudes of the professionals in the educational system attest to the long-standing history of special educational systems for children with disabilities.

The attitude and behaviour of professionals in the social welfare system is impersonal, exclusive for guaranteed rights and supportive for institutional care (*ibid.*). Multiple and restrictive assessment without appropriate individual plans for support and lack of personal and professional familiarization with a child resulted in excluding a child from the local community (*ibid.*). The above mentioned experience confirms the thesis that the social welfare system in Croatia is formed as a so-called paternalistic model or a model in which 'professionals provide services as a gift to a customer' and such a paradigmatic assumption means that the user is a passive recipient of welfare services and that the services are a 'gift' from the professional group that is 'given' on the basis of needs assessments (Mihanović 2012). In this context, it is impossible not to mention the role of long-term institutionalization of persons with disabilities under the influence of the system of government and politics of socialism (Zaviršek 2008), as a form of absolute social welfare for people with disabilities in segregated conditions, without planning their involvement in the community. This specific context shapes the life course of families and the attitudes of social welfare professionals.

Influence of religion

Even today, in secular societies, religion has significant influence, which is based on diakonia and charitable activities aiming to provide spiritual care and support for their members in the community (Rommelspacher 2010). According to the life stories, the Christian religion contributes to the quality of life of families with intellectually disabled children, in that it empowers parents to deal and cope with disability in everyday life. The Catholic Church as an organization provides families with experiences of discrimination by excluding their children from religious ceremonies and Catholic Church kindergarten. This leads to recommendations for increasing awareness of accepting differences in the Catholic Church organization. The Catholic Church represents an institution of cultural universalism, which is based on the doctrines of the Christian faith (Staub-Bernasconi 2010). However, if such cultural universalism in social functioning is associated with political structures or economic power structures, it becomes selective in terms of exclusion from the Christian community based on diversity. Based on the fundamental principles of the Catholic religion, every human being should be fully respected in its diversity, which is why the discriminative and exclusive attitudes described in these life stories are contradictory and unacceptable.

The underdevelopment of the community based services and the legacy of institutional care

Experiences of discrimination indicate the lack of community based services and the presence of institutional care for children with intellectual disabilities. The reform of the social welfare system started the process of deinstitutionalization and the transformation of state residential care homes (Ministry of Health and Welfare 2011). This transformation process should redefine the role of service providers through the development of a new system of social services which should provide the community with the ultimate goal of increasing social inclusion. It is important to emphasize that the institutional form of care leads to social exclusion of children with intellectual disabilities because they are separated from their families and their natural social environment.

The parents' initiative for rights implementation and system changes

The parents from the life stories are familiar with their guaranteed rights, included in non-governmental organizations and active in improving the quality of service support (Lisak 2013). Due to the experience of discrimination and exclusion from the community, parents become aware of the distinction of their own children and family. Raising public awareness on diversity (Kasnitz 2001) becomes a driving force of activism and struggle in the lives of parents, and it encourages parents to associate with other parents of disabled children.

The system does not provide relevant information about the guaranteed rights, which is the reason for getting information from other involved parents.

The activism of the non-governmental sector is an important determinant of the social context that shapes the quality of life for families with children with intellectual disabilities (Lisak 2013). Professionals and parents work together in creating new models of support for children from the earliest age – an inclusive environment in the educational system and independent living in the community. On the positive side, the non-governmental sector does promote better quality of life for people with disabilities, taking into account the needs of children and their families through their social action. But the question remains, where is the state responsibility for the social change and development of service support? A process called 'NGO-ization' (Zaviršek 2007) indicates the emergence of a large number of non-governmental organizations in the ex-socialistic countries and it seems that they have become the only 'responsible' holders and agents of social change.

The active role of mothers in everyday family life and supportive family relationships

Supportive family relations were present in all life stories and family values were fellowship, love and happiness (Lisak 2013). Supportive family relations represent collaboration between partners and getting support from grandparents (*ibid.*). These kinds of supportive family relations empower the parents to cope with everyday life challenges. Even though family relations were a great support in everyday life, it is important to consider the need for organizing professional support for family members to stay empowered.

The role of mothers in providing everyday support for their children, especially in the first years of a child's life, is an important context that shaped the families' life course (*ibid.*). The role of the mother is connected with a social role of a woman on gender level that is present and expected in the Croatian society. Mothers are overstrained in the process of taking care of a child and do not have free time to consider their own needs. It is necessary to empower mothers of children with intellectual disabilities through professional support and counselling to cope with expectations, advocacy for their needs and to make choices.

Conclusion

Some recommendations are given for improving the quality of life for families with children with intellectual disabilities in accordance with the explained social context: organization of a multidisciplinary team for assessment and support in all systems and in one location; the transparency and availability of information about guaranteed rights and support from the health, education and social welfare systems; awareness of acceptance of every person and respect for diversity in order to prevent rejection and exclusion of children with disabilities from organized systems in the Catholic Church; empowerment of medical doctors for appropriate correspondence with parents of children with intellectual disability and respect for the parents' perspective; empowerment of teachers for supporting inclusion in the regular preschool and school system; organizing systematic support for educational inclusion; supervising professional work in health, education and social welfare systems; supporting the constancy of NGO program funding, which improves the quality of social services on local and regional levels; improving the quality of support systems; organizing systematic support for independent living in the community through organized housing and multidisciplinary teamwork and raising community awareness of children with disabilities and their families through social action and giving positive examples.

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Ana M. Sobočan

OTROCI S POSEBNIMI POTREBAMI V SISTEMU REJNIŠTVA

V prispevku je predstavljena prva faza raziskovanja na področju rejništev in posvojitev otrok z ovirami oz. otrok s posebnimi potrebami v Sloveniji: pogled socialnih delavk in delavcev (načrtovane naslednje faze so raziskovanje s pomočjo posameznic in družin, ki opravljajo rejniško dejavnost, posameznic in družin, ki so posvojili otroke z ovirami in mladih in odraslih z izkušnjo rejništva in posvojitve). Avtorica je v raziskavi, opravljeni na centrih za socialno delo, ugotavljala, kakšni so elementi rejniške prakse in strokovnega dela z rejniškimi družinami, biološkimi družinami in otroki s posebnimi potrebami (ali oz. kako se razlikujejo od pristopov in metod, uporabljenih pri delu z otroki, ki niso opredeljeni kot otroci s posebnimi potrebami). V kontekstu etike hendikepa so avtorico še posebej zanimale vrednote in stališča strokovnih delavk in delavcev na tem področju, njihovo razumevanje in konceptualiziranje dela na tem področju , njihova morebitna skrb za dodatne storitve in podporo, izobraževanje in vodenje, njihove usmeritve in motivacije pri zagotavljanju trajnih oblik namestitve (posvojitev ali vrnitev v biološko družino) ipd. Področje rejništva in otrok s posebnimi potrebami je prikazano tudi s pomočjo tujih raziskav, vpogledov in relevantne literature (avstralskih, kanadskih, ameriških in angleških avtorjev).*

Ključne besede: rejništvo, otroci s posebnimi potrebami, šole s prilagojenim programom, posvojitev.

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CHILDREN WITH SPECIAL NEEDS IN THE FOSTER CARE SYSTEM

The paper presents the first phase of the research in the system of foster care and adoptions of children with disabilities or children with special needs in Slovenia: the perspective of social workers (the planned next phases of the research are: research with participation of individuals and families who are foster carers, individuals and families who adopted children with disabilities, and youth and adults with the experience of foster care and adoption). The research, conducted in Social Work Centers in Slovenia disclosed, what are the elements of foster care practice and professional work with foster families, biological families and children with special needs (and whether these are different from approaches and methods applied in work with children who are not labeled 'special needs children'). In the context of disability ethics the author was especially interested in the values and beliefs of professional workers in this field, their understandings and conceptualizations of work in this field (including identifying the gaps and introducing innovations), their possible effort to implement additional services and support, education and guidance, their aims and motivations in working towards permanents placements (adoptions or returns to the biological family), etc. In the paper, the topic of foster care and special needs children is discussed also with the help of international research, insights and relevant literature (by Australian, Canadian, American and English authors).

Key words: foster care, special needs children, special programme schools, adoption.

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Uvod

Maja 2014 je v Sloveniji v rejništvu živelo 1020 otrok oz. oseb; ena od rejniških pogodb je sklenjena za rejništvo ob vikendih, 50 rejniških pogodb za rejništvo ob vikendih in počitnicah, 5 rejniških pogodb je sklenjenih zaradi usposabljanja (po drugem odstavku 157. člena Zakona

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* V tem prispevku uporabljam izraz »otroci s posebnimi potrebami« kot sinonim za izraz »otroci z ovirami« (čeprav izraza sama nista sinonimna v vseh kontekstih); gre za otroke, ki jim je bila izdana odločba o usmeritvi na podlagi Zakona o usmerjanju otrok s posebnimi potrebami (ZUOPP-1), podzakonskih aktov s področja usmerjanja otrok s posebnimi potrebami in Zakona o splošnem upravnem postopku. Tovrstno poimenovanje sem izbrala predvsem zaradi metodoloških razlogov – potrebno je bilo postaviti formalni okvir za podskupino, ki jo raziskujem – na podlagi česar lahko merimo tudi to, v kolikšni meri je razumevanje posebnih potreb skladno med zakonodajo in prakso in na kakšen način diferencirano od zakonodajnega okvira.

o zakonski zvezi in družinskih razmerjih 2004), 964 otrok/oseb pa je v rejništvu ves čas.[1] Dovoljenje za izvajanje rejniške dejavnosti pa ima 737 oseb.[2] V okviru podatkov o rejništvu in otrok/oseb, ki živijo v rejništvu, je mogoče pridobiti tudi podatke o zdravstvenem stanju,[3] ki se iz medicinskega vidika približa oznaki oseba z oviro.

Preglednica 1: Podatki o zdravstvenem stanju oseb v rejništvu.

	2012	2013
Otrok nima posebnih zdravstvenih težav	616	616
Otrok s hudimi prilagoditvenimi težavami	12	12
Otrok s čustvenimi motnjami	166	169
Vedenjsko in osebnostno moten otrok	36	38
Zlorabljen otrok	27	26
Hudo bolan otrok	10	9
Manjša motnja v duševnem razvoju	32	32
Zmerna motnja v duševnem razvoju	45	28
Hujša motnja v duševnem razvoju	9	5
Huda motnja v duševnem razvoju	1	1
Gibalno oviran otrok	13	11
Slep ali slaboviden otrok	2	3
Gluh ali naglušen otrok	12	11
Drugo	60	62
SKUPAJ	1041	1023

Da bi lahko zagotavljali primerne storitve za otroke in njihove družine oz. tiste, ki zanje skrbijo, je, kot ugotavljajo tudi tuji raziskovalci (npr. Lightfoot *et al.* 2011), nujno vedeti, koliko je otrok z ovirami v sistemu rejništva, kakšne so njihove specifične potrebe in kako poteka skrb zanje. Naša raziskava sicer omogoča nekatere vpoglede v skrb za otroke z ovirami v rejništvu, vendar le iz perspektive socialnih delavk, ki delajo z njimi. Prihodnje raziskave bodo morale poglobljeno raziskati tudi izkušnje staršev, rejniških staršev in otrok z ovirami, kakor jih doživljajo sami. Hkrati bo treba natančneje zbrati tudi različne kvantitativne podatke o otrocih v rejništvu in njihovih značilnostih, tudi podatke o različnih oblikah ovir in njihovo korelacijo z obravnavo, šolanjem, nasiljem ipd. Tudi v ZDA, tam je bilo leta 2012 v rejništvu 397.000 otrok (Trends in foster care and adoption 2013), kot poročajo Lightfoot *et al.* (2011), ni standardiziranega poročanja oz. zbiranja podatkov o tem, kakšne ovire so imeli otroci, ki so (bili) v rejništvu. Podobno ugotavljajo tudi Shannon in Tappan (2011), Bonner *et al.* (1997) za Združene države Amerike, čeprav se tam različni podatki zbirajo v sistemu za poročanje in analizo posvojitev in rejništva (*The Adoption and Foster Care Analysis and Reporting System).* Sainero *et al.* (2013), ki so sicer raziskovali potrebe otrok z ovirami v rejništvu v Španiji, ugotavljajo, da je kljub velikemu številu otrok v rejništvu in drugih oblikah oskrbe to področje še vedno zelo neraziskano, še posebej kakšen je njihov položaj ter kakšne so specifične lastnosti in parametri oskrbe in storitev, ki jih prejemajo. Uradni statistični podatki, ki specifično

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[1] Podatek MDDSZEM, Direktorat za družino, maj 2014.

[2] Podatki Ministrstva za delo, družino, socialne zadeve in enake možnosti; dostopno na: http://www.mddsz.gov.si/si/uveljavljanje_pravic/statistika/rejnistvo/ (7. 4. 2014).

[3] Podatki se nanašajo na stanje decembra vsako leto. Vključujejo tudi osebe, starejše od 18 let, ki jim je bilo bivanje v rejniški družini podaljšano zaradi nadaljevanja šolanja ali nezmožnosti samostojnega življenja (zaradi motenj v telesnem ali duševnem razvoju). Vir: MDDSZEM, Direktorat za družino, maj 2014.

prikazujejo to področje, večinoma ne obstajajo (Hill 2012), strokovne delavke in delavci, ki delajo z rejniškimi družinami in otroci, pogosto niso usposobljeni za prepoznavanje različnih oblik hendikepiranosti (Shannon, Tappan 2011), pogosto pa je okrnjen tudi dostop do ustrezne pomoči, npr. na področju duševnega zdravja (Burns *et al.* 2004, Farmer *et al.* 2001, Romanelli *et al.* 2009, Tarren-Sweeney 2010). Kot še pišejo Sainero *et al.* (2013), je raziskovanje na tem področju oteženo tudi zaradi heterogenosti vzorcev, metodologije in meril o tem, kdo vse so otroci z ovirami.

Članek temelji na kvalitativno podkrepljeni raziskavi – intervjujih, ki sem jih opravila s socialnimi delavkami, ki delajo na področju rejništev in posvojitev na različnih centrih za socialno delo po Sloveniji. Opravljenih je bilo 22 poglobljenih polstrukturiranih intervjujev s socialnimi delavkami; vsi so bili opravljeni v njihovih pisarnah. Poleg pripovedi o praksi rejništva pri nas – o tem, katere so najpogostejše težave, s katerimi se starši, otroci in strokovne delavke srečujejo v sistemu rejništva, o predlogih in primerih dobrih praks ipd. – je bil raziskovalni cilj raziskave zbrati tudi kvantitativne podatke z vseh centrov za socialno delo po Sloveniji o tem, koliko otrok z ovirami je zdaj v rejništvu, za kakšne ovire gre, kako dolgo ostajajo v rejništvu, kako pogosto prehajajo nazaj v biološko družino, posvojitev ali institucije. Zbiranje kvantitativnih podatkov (s pozivi CSD-jem za izpolnjevanje preproste razpredelnice z navedenimi kategorijami) je potekalo več kot pol leta (od oktobra 2013 do marca 2014) in še ni končano (zbiranje podatkov še vedno poteka, predvsem zaradi neodzivnosti nekaterih institucij).

Podskupino otrok v rejništvu, ki me je še posebej zanimala, sem zaradi jasnosti poimenovala otroci s posebnimi potrebami in kot dodatno merilo oz. oznako navedla, da raziskujem področje otrok in mladih, ki so kategorizirani kot otroci s posebnimi potrebami (in imajo odločbo o usmerjanju, po Zakonu o usmerjanju otrok s posebnimi potrebami 2011) ali so otroci, ki potrebujejo posebno nego in varstvo – pravico pridobijo na podlagi mnenja zdravniške komisije (imajo odločbo CSD o dodatku za nego v skladu z Zakonom o starševskem varstvu in družinskih prejemkih 2014). V intervjujih sem pogovor začela z izrazom »otroci z ovirami«: socialne delavke so se na različne načine odzivale na to, da naj spregovorijo o otrocih z ovirami, primanjkljaji, hendikepom ali posebnimi potrebami. Čeprav so socialne delavke izraz razumele predvsem v pomenu telesnih, duševnih in intelektualnih ovir, se jih je večji del (17/22) odzval tudi tako, da so naprej opozorile, da same verjamejo, da je večina otrok v rejništvu pravzaprav otrok s posebnimi potrebami:

> Lahko pa bi pravzaprav rekla, da imajo vsi ti otroci posebne potrebe. So zelo ranjeni, večinoma. Nekateri sicer bolj odporni, bolj opremljeni, trdnejši, drugi pa zelo ranjeni – vsi imajo kakšne zelo slabe izkušnje, rabijo morda več kot kakšen čisto običajen otrok. (Breda, 8.)[4]

Zakon o zakonski zvezi in družinskih razmerjih (2004) otroke, ki jih je država umaknila iz matične družine (v rejništvo ali zavodsko oskrbo), imenuje otroci, prikrajšani za normalno družinsko življenje. Po Zakonu o usmerjanju otrok s posebnimi potrebami (2011) so t. i. otroci s posebnimi potrebami: *otroci z motnjami v duševnem razvoju, gluhi in naglušni otroci, slepi in slabovidni otroci oziroma otroci z okvaro vidne funkcije, otroci z govorno-jezikovnimi motnjami, gibalno ovirani otroci, otroci s primanjkljaji na posameznih področjih učenja, dolgotrajno bolni otroci, otroci s čustvenimi in vedenjskimi motnjami in otroci z avtističnimi motnjami.* Nekateri menijo, da bi bilo klasifikaciji treba dodati še kategorijo otrok s primanjkljaji na posameznih področjih socialnega funkcioniranja. Skoraj večina intervjuvanih socialnih delavk razširi navedeno kategorizacijo – vključi tudi otroke, ki nimajo odločbe o usmerjanju ali odločbe o dodatku za nego: v skupino vključijo vse otroke, ki imajo izkušnjo, da so morali zapustiti svojo matično družino.

Kot piše Smith (2002), so po navadi definicije ovir pri otrocih oblikovane na podlagi medicinskih in funkcionalnih modelov, vendar te pogosto ne vključujejo dimenzije interakcije z

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[4] Imena so izmišljena; številka označuje število let, kolikor socialna delavka dela v praksi.

okoljem in perspektive življenjskega poteka, to pa pomeni, da te definicije zanemarjajo področja, kot so učenje v šoli, ali družinske vloge (Simeonsson *et al.* 2000). V literaturi so ovire pri otrocih včasih konceptualizirane kot oblike ali kategorije bolezni (Gortmaker, Sappenfield 1984, Weiland *et al.* 1992), včasih pa kot funkcionalne omejitve. Newacheck in Halfon (1998) na primer oviro definirata kot dolgotrajno zmanjšanje zmožnosti za izvajanje dejavnosti, povezanih z družbenimi vlogami, npr. v šoli ali med igro, zaradi kroničnega fizičnega ali mentalnega stanja. Takšna definicija poudarja funkcionalne zmožnosti otrok pri odzivanju na pričakovanja glede njihovih družbenih vlog, npr. učenje v šoli ali vključenost v igro (saj igra vpliva tudi na razvijanje socialnih spretnosti).

Socialne delavke so sicer klasično razumevanje oviranosti razširile še s pojmovanjem, da imajo zaradi posebnih življenjskih okoliščin, izkušenj, dogodkov, odnosov ipd. posebne potrebe vsi otroci, ki ne morejo živeti v svoji matični (navadno biološki) družini, ampak živijo v rejništvu ali institucionalni oskrbi. Skupina socialnih delavk, ki sem jih intervjuvala, »posebne potrebe« večinoma razume v povezavi s čustvenimi, vedenjskimi, učnimi ali podobnimi težavami in potrebami kot posledicami njihovih življenjskih (družinskih) izkušenj. Posebne potrebe tako konceptualizirajo kot posledico tistega, kar pogosto na primer imenujejo »ranjenost« ali »prikrajšanost«, in kot sporočilo, da ti otroci potrebujejo posebno, predvsem občutljivejšo oskrbo. S tem se socialne delavke približajo razumevanju potreb v najširšem pomenu, povezanih s travmatičnimi dogodki, ki so jih osebe doživele ali jim bile izpostavljene (Zaviršek 2012: 159). Zaviršek piše o travmatičnih izkušnjah kot kompleksnih, saj se nanašajo na telo (zanemarjanje, nasilje), interakcijo s pomembnimi osebami, prekinitev znanega in kombinacijo vsega tega (*op. cit.*: 160–165). Zaviršek (*op cit.*) travmatične situacije sicer opisuje na primeru izkušnje posvojitve, vendar je mogoče podobna travmatična življenjska obdobja prepoznati tudi v življenjskih potekih otrok in mladih z izkušnjo bivanja v zavodu ali rejništvu.

Otroci z ovirami v sistemu rejništva

Položaj otrok z ovirami v sistemih oskrbe, predvsem rejništva, je v nekaterih zahodnih državah veliko bolje raziskan kot v Sloveniji. Raziskave se tematike lotevajo iz različnih izhodišč: v ospredju sta dva pristopa – raziskovanje položaja otrok v rejništvu in vpliv tega na ovire (povezava med rejniškim statusom in oviro) in raziskovanje položaja otrok z ovirami, ki potrebujejo državno oskrbo (vpliv ovire na življenjski potek in s tem tudi na to, ali oz. kako živijo v rejništvu).

Raziskave, ki se ukvarjajo z otroki v rejništvu in njihovim življenjskim potekom, v zvezi z ovirami ugotavljajo, da so otroci, ki morajo živeti v rejništvu ali institucionalni oskrbi, pogosteje bolj prikrajšani, usmerjeni v posebne vrste izobraževanja ipd. Pri tujih raziskovalcih je mogoče najti več raziskav s področja otrok v rejništvu, ki preučujejo, koliko so otroci pogostejši uporabniki socialnovarstvenih storitev oz. posebnih programov šolanja.

Scherr (2007) preuči 31 raziskav in ugotavlja, da je neprimerljivo večji delež otrok iz rejništva tudi v posebnih programih šolanja; Smithgall *et al.* (2005) pa so ugotavljali, da se pri otrocih v rejništvu pojavlja več oviranosti, še posebej na področju duševnega zdravja. Ameriško poročilo o mladih z ovirami v sistemu rejništva (Youth with disabilities in the foster care system 2008) poroča o študiji, ki je raziskovala položaj oseb, ki so odraščale v rejništvu: več kot polovica jih je imela težave z duševnim zdravjem (v primerjavi z 22 % oseb v splošni populaciji); od teh jih je 25 % trpelo za posttravmatskim sindromom (v primerjavi s 4 % splošne populacije), 20 % pa jih je doživelo vsaj eno epizodo klinične depresivnosti (v primerjavi z 10 % splošne populacije) – v ospredju so bili tudi sociofobija, napadi panike in generalizirana anksiozna motnja. Kar zadeva izobraževanje, je študija pokazala, da je med 30 % in 40 % otrok v rejništvu vključenih v šole s prilagojenim programom (*ibid.*). Diaz *et al.* (2004) poročajo, da so otroci v rejništvu v ZDA skupina otrok, ki imajo največ zdravstvenih težav; dvakrat pogosteje trpijo za kroničnimi boleznimi in imajo skoraj petkrat pogosteje težave na intelektualnem področju ali področju duševnega zdravja; kar 58% otrok v rejništvu naj bi imelo resne zdravstvene težave.

Romney *et al.* (2006) kot razloge za to navajajo, da je pogost razlog za umik otrok iz primarne družine zanemarjanje, zato ni nepričakovano, da se otroci srečujejo z več zdravstvenimi težavami, saj zanemarjanje vpliva na fizično in duševno zdravje, odnose z vrstniki in uspešnost pri učenju (Gaudin 1993, Kendall-Tackett, Eckenrode 1996). Po drugi strani je del razlage tudi to, da otroci z ovirami pogosteje doživljajo zlorabe in zanemarjanje kot otroci brez težav (raziskovalci poročajo o slabši navezanosti med primarnim skrbnikom, npr. mamo in otrokom, povečani ranljivosti otroka, »starševskem stresu« pri oskrbi otroka z oviro ipd.), čeprav je treba poudariti, da povezava med vzroki in posledicami (med zlorabo in oviro) še vedno ni popolnoma pojasnjena (Romney *et al.* 2006). Raziskave kažejo več težav z duševnim zdravjem, težave s pozornostjo in agresijo (Casey *et al.* 2008, Tarren-Sweeney 2008, Trout *et al.* 2009) ter težave, povezane z učnim uspehom oz. učenjem (Zetlin 2006). Podobno kot ameriški raziskovalci (na tem področju je največ raziskav v ZDA) so tudi avtorji v Španiji ugotovili, da ima skoraj polovica otrok, ki živijo v rejništvu ali instituciji, težave z duševnim zdravjem (Sainero *et al.* 2013) in da je eden od osrednjih problemov, s katerimi naj bi se srečevali otroci v rejniški ali zavodski oskrbi, razmeroma visoka raven konfliktnih situacij v vsakdanjem življenju (Bravo, del Valle 2009).

Iz perspektive otrok z ovirami tako raziskave kažejo, da so ti pogosteje kot otroci brez težav uporabniki sistemov oskrbe, rejništva ali institucionalne namestitve in so tako ranljivejši in bolj deprivilegirani. Raziskave kažejo, da so otroci z ovirami pogosteje prejemniki ukrepov, ki vključujejo ločitev od biološke družine (Lightfoot *et al.* 2011, Rosenberg, Robinson 2004), in da so izpostavljeni manjši permanentnosti, t.j. manjši stalnosti (večkrat zamenjajo namestitev) na svoji poti skozi sisteme oskrbe, več prekinitvam oz. premestitvam in da ostanejo v rejništvu dlje kot otroci, ki nimajo ovir (Chmelka *et al.* 2011, Hill 2012, Slayter, Springer 2011, Trout *et al.* 2008). Rosenberg in Robinson (2004) sta ugotovila, da so otroci z ovirami pogosteje nameščeni v različne oblike oskrbe, dlje časa ostajajo v rejništvu in se manj verjetno vrnejo v svojo biološko ali primarno družino. Otroci z ovirami imajo več izkušenj nasilja, predvsem pa pogosto doživljajo več zanemarjanja (nekatere raziskave kažejo, da tudi desetkrat več), kot na podlagi obsežnega pregleda raziskav (predvsem ameriških in avstralskih) pokažejo Lightfoot *et al.* (2011).

Sullivan in Knutson (2000) sta ugotovila, da so otroci z ovirami skoraj štirikrat pogosteje žrtve zanemarjanja kot otroci brez ovir, hkrati pa tudi, da so otroci z ovirami skoraj štirikrat verjetneje žrtve fizičnega nasilja, več kot trikrat pogosteje žrtve spolnega nasilja in skoraj štirikrat pogosteje žrtve čustvenih zlorab. Ob tem pa so otroci z ovirami pogosteje izpostavljeni več oblikam zlorab naenkrat (v primerjavi z otroci brez ovir), znotraj skupine ovir pa so v najslabšem položaju otroci z intelektualnimi ovirami (Zaviršek 1998, 2000, 2005). Nekatere raziskave (npr. Jonson-Reid *et al.* 2004) so pokazale tudi na povezave med vključenostjo v posebne programe izobraževanja in tveganjem za zlorabe ali starševsko zanemarjanje (Zaviršek 2000, 2005).

Jonson-Reid *et al.* (2004) so preiskovali povezavo med vključenostjo v posebne programe izobraževanja in zlorabami med otroki, ki živijo v družinah z nizkimi prihodki. Raziskava je obsegala 7940 primerov otrok, starih med 7,5 in 16 let (na področju St. Louisa v ZDA), rezultati pa so pokazali dvostransko povezanost med prilagojenim izobraževalnim programom in zanemarjanjem oz. zlorabo. Otroci z izkušnjo zlorabe so pogosteje vključeni v posebne programe izobraževanja, najpogosteje tisti, ki so doživeli ali doživljali telesne zlorabe. Pokazalo se je tudi, da so otroci, ki bo bili vključeni v posebne programe za otroke z intelektualnimi ovirami, zaostankom v razvoju, hudimi vedenjskimi težavami, najpogosteje imeli tudi izkušnjo starševske zlorabe (*op. cit.*).

Hershkowitz *et al.* (2007) poročajo, da otroci z ovirami pogosteje kot drugi otroci ne razkrijejo zlorab, ki jih doživljajo, in pri razkrivanju v povprečju to storijo najmanj mesec pozneje kot drugi otroci; najmanj pogosto razkrijejo spolne zlorabe. Otroci z ovirami težje spregovorijo o zlorabah in zanemarjanju zaradi svoje odvisnosti od skrbnikov, zaradi želje, da ravnajo v skladu z željami skrbnikov, zaradi občutkov izolacije in ker ne razumejo, kaj se jim dogaja. V zvezi s tem Zaviršek (2000) poudarja tudi, da otroci z ovirami nimajo znanja o svojem telesu in ne vedo, da bi se morali zlorabljanju upreti. Še posebej otroci z ovirami v intelektualnem razvoju niso prepoznani kot zanesljive oz. verodostojne priče v morebitnih kazenskih postopkih (Aarons *et al.* 2004).

Skrb za otroke v rejništvu

Zaradi skrbi za vse otroke v rejništvu in morda zaradi zahtevnejših okoliščin še posebej tudi za otroke z ovirami je izjemno pomembno, kdo in kakšni so rejniški starši kot tudi strokovni delavci in delavke, ki delajo na tem področju. Orme *et al.* (2006) so zapisali, da veliko število otrok v rejništvu in specifika oskrbe otrok s številnimi težavami zahtevata visoke standarde in usposobljene rejniške starše, vendar so, zaradi pomanjkanja kandidatov, pogosto vključeni tudi rejniški starši, ki niso primerni za starševsko skrb. V novejši raziskavi Shannon in Tappan (2011) za ZDA poročata, da večina rejniških staršev, ki sprejmejo otroke z ovirami, pove, da niso pripravljeni za starševstvo in skrb za otroke s kognitivnimi, fizičnimi ali čustvenimi potrebami, povezanimi z njihovo oviro. Pogosto za otroke ni mogoče najti namestitve v rejniški družini, saj rejniki menijo, da niso kos nalogi, zato gredo otroci v zavodsko oskrbo (*op. cit.*: 1471). Po drugi strani pa so rejniški starši poročali, da po zaslugi dela strokovnih delavk in delavcev prepoznavajo, da posvojitev ali vrnitev v matično družino sploh ni del načrta ali strokovnih ciljev pri otrocih z ovirami (*ibid.*).

Hkrati pa so raziskovalci v različnih državah pokazali, da rejniški starši nimajo dovolj podpore in niso usposobljeni skrbeti za otroke z različnimi potrebami, še posebej kadar gre za ovire na intelektualnem področju ali področju duševnega zdravja. Murray *et al.* (2011) poročajo o razhajanju med ravnijo podpore in usposabljanj, ki so na voljo rejniškim staršem, in razsežnostmi skrbi za otroke s kompleksnimi čustvenimi, vedenjskimi, medosebnimi in drugimi težavami. Tarren-Sweeney (2008) pa opozarja, da rejniški starši doživljajo situacije, povezane s težavami z duševnim zdravjem, ki presegajo običajne starševske izkušnje ali znanje. Kot priporočajo avtorji, je še posebej pomembno, da imajo starši primerna pričakovanja glede razvoja in intelektualnih sposobnosti otrok, ki odraščajo pri njih, saj, kot piše Bavolek (2000), neprimerna pričakovanja pomenijo tudi več tveganj za zlorabe. Sanders in Morawska (2008) sta v svojem pregledu raziskav ugotovila, da so matere, ki imajo ustrezna pričakovanja glede razvoja, bolj kompetentne v starševski vlogi in manj stroge pri discipliniranju. Previsoka pričakovanja od otrok v rejništvu, katerih zgodovina in izkušnje imajo morda za posledico počasnejši razvoj spretnosti in kompetenc, imajo lahko rušilen vpliv na otroke, ki so že sicer doživeli zavrnitve in zlorabe, po drugi strani pa lahko prenizka pričakovanja zavirajo njihov trud in dosežke (Combs-Orme, Orme 2014).

Otroci s posebnimi potrebami in šola

V raziskavi so skoraj vse intervjuvane socialne delavke same spregovorile o vzrokih za previsoka pričakovanja v rejniških družinah in posledicah zanje. Osrednjega pomena v pripovedovanjih je bila vloga otroka kot učenca oz. učenke.

Vse so poročale o tem, da je učni uspeh otrok v rejništvu zelo pomemben za rejniške starše: če ima otrok dobre ocene v šoli, naj bi to kazalo, da ga starši dobro vzgajajo, da dobro skrbijo zanj, da otroku dobro gre, da je torej otrok uspešen v eni svojih poglavitnih vlog v tem obdobju – kot učenec oz. učenka.

> Problem, poseben problem je potrjevanje rejnikov preko šole – to je velik problem, kadar so otroci s posebnimi potrebami. Dober rejnik sem, če ima otrok dober šolski uspeh. In ti otroci niso takoj usmerjeni, in veliko let jih mučijo v šoli, ne znajo prepoznati, kje so meje. Rejniki mislijo, da otrok noče razumeti, da se noče učiti, da je len – ampak morda gre samo za to, da nima koncentracije, da ne zmore intelektualno. In rejniki se hočejo potrjevati skozi uspeh otroka, to je zunanji feedback, ki priča o njihovi uspešnosti. (Janja, 24.)

Kot je poudarila Janja, je pozitivni odziv na uspeh v šoli tisto sporočilo iz okolice, ki potrjuje, da rejniki dobro opravljajo svoje delo. To je mogoče interpretirati predvsem tako, da ne prepoznavajo vseh dimenzij rejniške-starševske skrbi in predvsem ne, katere so bolj temeljne in pomembnejše od podpore pri tem, da bi otrok imel dober učni uspeh[5]. Še pomembneje je, da očitno ni razumevanja za vse plasti življenjske situacije ter travmatičnih in drugih izkušenj otroka, ki lahko vplivajo tudi na zmožnosti učenja, zbranosti ipd. V še posebej slabem položaju so otroci, ki imajo zaostanke v intelektualnem razvoju ali so tudi drugače prikrajšani – kot je povedala Janja, ker ni razumevanja zanje, ker starši, očitno pa predvsem tudi strokovne službe, ki bi lahko posredovale o tem informacijo, ne prepoznavajo, da ima otrok težave in kakšne so te težave.

Neustrezna pričakovanja, pomanjkanje razumevanja, informacij in usposobljenosti ter gotovo po drugi strani tudi zahteve okolice se pogosto stopnjujejo do nasilja nad otroki, ker ne ustrezajo pričakovanjem. Otroci z različnimi prikrajšanostmi in ovirami so torej ranljivejši tudi za nasilje.

> Eno deklico s posebnimi potrebami je rejnik udaril. V šoli so opazili buško na čelu, ona pa ni hotela povedati. Jaz sem takrat z njo zelo veliko delala in smo skupaj s šolsko svetovalno delavko in učiteljico prišli do tega, da je ona narisala, kaj se je zgodilo. In potem smo predvidevali, da je bil rejnik, ker ona ni nikoli povedala. Ona je bila takrat že veliko let pri tej družini. Kaj zdaj narediti? Premestitev je bila skoraj nemogoča. Potem smo veliko delali s to družino, da je tudi on povedal, da mu je težko, in potem smo delali z družino. (Ela, 16.)

Kadar se zgodi nasilje, se strokovni delavci, rejniki in drugi različno odzivajo nanj. Ela je tako pripovedovala o deklici, ki je najverjetneje želela zavarovati svojega rejnika, predvsem pa ne ogroziti svojega položaja v družini ali vplivati na to, da bi jo (spet) premestili. Kot kaže, je bilo veliko lažje prenesti telesno nasilje kot pa vse druge oblike nasilja in zlorab, ki jih morda deklica doživlja. Tudi socialne delavke so bile v dilemi, kako nadaljevati; odločile so se, da bi bilo za deklico težje, če bi morala spet v novo družino (in hkrati tudi negotovo, ali bo tokrat kaj drugače), zato so več pozornosti namenile delu z rejniki in skrbi za njihovo duševno zdravje in počutje, zmožnosti za skrb in spoprijemanje s svojo rejniško vlogo.

> Deklica je bila prav pretepena, ker se potem ni hotela več učiti, ker ji je šlo tako težko. Ko se ni učila, jo je oče pretepal – čeprav je imela cele dneve šolo, popoldanski pouk z inštruktorji in še doma se je morala neprestano učiti. Ko je prišla v šolo s prilagojenim programom, je končno zaživela. Pokazalo se je, da so jo v običajni šoli zadrževali tudi zato, ker je bila majna šola, in so potrebovali vsakega učenca. Potem pa je bila vesela, je tudi rekla – končno sem dobila petice. Njena sestrica je že bila v prilagojenem programu, se nič ni učila in imela petice, ona pa je trpela, ker ni zmogla niti dvojk. Potem se je končno začela potrjevati, okrepila je svojo samozavest. (Milena, 18.)

Zgodbe o nasilju v pripovedih socialnih delavk niso redkost, so pa pogosto povezane z nerazumevanjem ali pomanjkanjem informacij, kako ravnati. V primeru otrok s posebnimi potrebami, kot je povedala ena od socialnih delavk, »še najbolj nastradajo tisti mejni, ki so vedno nekje vmes« (Alma, 5). Pogosto je za otroke še težje, saj nikakršna pomoč otrokom, ki ni prilagojena njihovim potrebam, ne da pričakovanih rezultatov. Pripovedim o prizadevanjih otrok, da bi se odzvali na želje rejniških staršev, se je v intervjujih pridružil tudi diskurz o prednostih in slabostih šolanja v šolah s prilagojenim programov. Socialne delavke, ki so govorile o integraciji vseh otrok v običajne šole in šolanju v prilagojenih programih, so izražale mnenje, da je za otroke s posebnimi potrebami pogosto boljše, da obiskujejo zadnje.

> Jaz tudi ne vem, če je dobro, da vse tako integrirajo. En otrok, ki je mejni, ne zmore toliko – ves čas se počuti samo nesposobnega, otroci ga šikanirajo, vedno je najslabši, drugi sprašujejo, zakaj ima on najlažje naloge, zakaj ima posebne pogoje – to je za otroka tudi težko, slabo, veliko težje, kot če bi bil v skupini, kjer bi lahko kdaj bil tudi zelo dober. (Irena, 28.)

Socialne delavke so menile, da so otroci s posebnimi potrebami, ki so vključeni v običajne programe šolanja, še ranljivejši in bolj prikrajšani, saj iz svojega okolja ne dobivajo spodbud,

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[5] To je morda mogoče povezati s splošno težnjo v slovenski družbi po učnem uspehu kot splošnem in temeljnem kazalcu (starševske) uspešnosti.

pohval in ne morejo dobiti sporočil, da dobro opravljajo eno svojih osrednjih socialnih vlog, to je vlogo učenca ali učenke. Nekatere socialne delavke so tudi prepoznavale, da so otroci s posebnimi potrebami tako prikrajšani v šoli zato, ker ni poskrbljeno za zadostno podporo, ker starši in strokovni delavci (socialne delavke, psihologinje, učiteljice) otrok ne zmorejo okrepiti in ne razumejo, kaj vse otroci potrebujejo za vključenost oz. niso dovolj občutljivi za vse dimenzije njihove prikrajšanosti v običajnem šolskem okolju. Šele v šoli s prilagojenim programom, »med sebi enakimi« (Breda, 8), naj bi našli dovolj varno okolje, da se lahko okrepijo in izboljšajo svojo samopodobo (skupaj z učnim uspehom).

Usposobljenost rejniških staršev za skrbstveno vlogo

Pri pričevanjih o pričakovanjih in potrjevanju nekaterih rejniških staršev s pomočjo šolskega uspeha otrok je izjemno pomemben tudi razmislek o usposobljenosti tako staršev kot tudi strokovnih delavcev na tem področju in o primernosti rejniških staršev za skrbniško vlogo. Socialne delavke so pogosto govorile o tem, da je nemogoče zagotavljati visoke standarde tudi zato, ker je rejniških staršev malo. Ta hip je sicer prostih mest pri rejniških starših 171: ali to pomeni, da zdaj rejništvo poteka pod visokimi standardi – in ali so »prosti« starši zares tisti, ki so manj kakovostni skrbniki (če to drži, se je ob tem treba tudi vprašati, zakaj imajo dovoljenje za opravljanje rejniške dejavnosti)?

Rezultati raziskave sprožajo pomembni vprašanji, ki bi ju bilo treba natančno raziskati, saj se morda otroci s posebnimi potrebami srečujejo z dvojno prikrajšanostjo (pomanjkanjem usposobljenih rejniških staršev in torej zmanjševanjem standardov pri strokovnem delu). Na podlagi intervjujev s socialnimi delavkami se namreč kaže, da naj bi večji del rejniških staršev (in še posebej posvojiteljskih staršev) težje sprejel otroke z (več) ovirami. Hkrati pa socialne delavke menijo, da nimajo velike izbire (tudi zaradi pomanjkanja rejniških družin) pri namestitvah, zato so morda včasih prisiljene standarde svojega dela in strokovnih presoj znižati pri zagotavljanju namestitve otroku (čeprav morda vedo, da družina za otroka ni najboljša, mu morajo namestitev kljub temu zagotoviti).

> Vsaka družina ni pripravljena sprejeti kogarkoli. (Nadja, 7.)

Rejniški starši lahko zavrnejo otroke, za katere ne želijo skrbeti (z vidika blaginje otroka je morda boljše, da se avtoselekcija zgodi že pred namestitvijo), najverjetneje predvsem zato, ker se take situacije bojijo ali menijo, da zanjo niso usposobljeni. Hkrati pa včasih rejniki odpovejo rejništvo, ko otrok že nekaj časa živi pri njih, ter s tem pripomorejo k večji nestabilnosti in zmanjšanim občutkom stalnosti in varnosti pri otrocih.

> Gre za zahtevno delo, še posebej če gre za intelektualne težave. Pomembno je, da rejniki razumejo. Da razumejo, kaj so specifične potrebe otrok. Imela sem primer rejnice, pri kateri je živela deklica s posebnimi potrebami, in ni zmogla več, je odpovedala rejništvo. Ker ni mogla sprejeti, ni prenesla, da je deklica malo drugačna, da je bolj zgovorna, da je bolj radovedna, da rabi več fizične bližine, da je bolj počasna v razumevanju. (Milena, 18.)

Socialne delavke so poročale, da rejniškim staršem niso zagotovljena izobraževanja o otrocih s posebnimi potrebami ali specifičnimi vrstami oviranosti, saj je v kratkem (12-urnem) izobraževanju premalo časa še za to temo. Tako se, po pripovedovanjih socialnih delavk, rejniški starši srečujejo s pomanjkanjem informacij, znanja in spretnosti za delo z otroki z ovirami, še posebej s tistimi, ki imajo vedenjske ali intelektualne težave. Ti so, kot so povedale, v še bolj neprivilegiranem položaju kot drugi otroci in tudi kot drugi otroci s telesnimi ovirami.

> Pri telesnih invalidih je drugače, zanje naredijo več, nekateri rejniki iščejo vse žive možnosti, da bi jim pomagali. Tu je več razumskega odziva, ker so intelektualno normalno razviti, rejniki dobijo od njih drugačen odziv, mogoče jim je zato najlažje. (Jana, 16.)

Jana je pojasnila, da imajo po njeni oceni manj težav kot otroci z čustvenimi, vedenjskimi in intelektualnimi težavami tisti, ki imajo gibalne ali senzorne ovire. V tem kontekstu se lahko rejniško skrbstveno delo potrjuje tudi prek premagovanja ovir za otroke v dnevnem življenju.

Kot so menile socialne delavke, je identificirana in kategorizirana težava ali diagnoza nekaj, kar rejniškim staršem (pa tudi strokovnim delavkam) pomaga pri umeščanju ali predpostavljanju otrokovih zmožnosti in potreb. Starši z diagnozo pridobijo tudi »orodje« za razumevanje otroka, to pa sicer nikakor ne pomeni, da poznajo vse otrokove težave, zgodovino, izkušnje, specifične potrebe ipd.

> Najtežje je pri mejnih, dokler se ne ugotovi diagnoza, je zares težko. Dokler ga obravnavajo kot zdravega otroka brez posebnih potreb, on pa ne zmore. Vsi imajo drugačna pričakovanja – doma in v šoli, on pa ne zmore. (Ema, 22.)

Rejniški starši in strokovni delavci sicer tako bolje razumejo otroka in njegova stanja, vendar v primeru posameznih diagnoz to lahko tudi pomeni, da je to razumevanje zelo poenostavljeno, premalo individualizirano in preveč enodimenzionalno.

> Potem pa, da se ne bo kaj zgodilo, da jih zaščitijo, jih nikamor ne pustijo, nimajo družbe, nimajo življenjskih izkušenj … predvsem pa, kadar gre za zavod, nikoli nimajo možnosti izbire, kje bodo. (Ema, 14.)

Kot je še povedala Ema, otroci s posebnimi potrebami pogosto ne morejo krepiti svoje neodvisnosti ali se razvijati v samostojno odraslo osebo, saj se okrog njih lahko oblikuje zelo velik ščit rejniških staršev, posledici tega pa sta lahko popolna socialna izključenost in pomanjkanje priprav na samostojno življenje.

Posebej velike težave se pokažejo na ravni vsakdanjega življenja, med vsemi člani družine – socialne delavke so opozarjale na to, da bi morali pozornost nujno namenjati tudi pogovarjanju, izražanju in naslavljanju. Vse to se zdi zelo običajno, a lahko otroke v rejništvu nepopisno rani.

> Premalo smo pozorni tudi na to, kako se razumejo biološki ali drugi otroci rejniških staršev in otroci v rejništvu; kaj biološki govorijo o rejniških, »ta je neumen« in take slišijo … Ključno bi bilo tudi, da rejniki pred otroki ne razlagajo zgodb o njihovem življenju, starših ipd. – njim samim ali pa drugim, komurkoli. (Tanja, 30.)

Rejništvo kot dolgotrajni ukrep in prehodi v posvojitev

Odločitve o namestitvi so predvsem del subjektivnih interpretacij, kaj je najbolje za otroka (McConnell *et al.* 2006), poleg tega pa osebna mnenja in prepričanja o oviranosti lahko povzročijo, da se za otroke z ovirami priporoča predvsem dolgotrajno skrbništvo in institucionalno skrb, ne spodbujajo pa se posvojitve ali delo z družino s ciljem vrnitve. V Sloveniji za zdaj raziskav o praksi socialnih delavk, o odločanju, še ni.

Romney *et al.* (2006) so ugotavljali povezave med specifičnimi ovirami otrok in vrsto njihove namestitve zunaj matične družine: zanimalo jih je, ali način, kako skrbniki dojemajo otrokovo oviro, vpliva na to, kje bo otrok živel in kako se načrtuje njegova namestitev; in ali določene vrste ovir vplivajo na namestitev otrok. Raziskava, ki je potekala na vzorcu 1221 otrok do šestnajstega leta (s fizičnimi, vedenjskimi, kognitivnimi ali komunikacijskimi ovirami), je pokazala, da se otroci z ovirami manj pogosto vrnejo v primarno družino in pogosteje kot otroci brez ovir ostanejo v rejništvu (še posebej v nesorodniškem rejništvu) (*ibid.*).

Wells in Guo (1999) sta na vzorcu 2616 otrok v ameriški zvezni državi Ohio pokazala, da se otroci z zdravstvenimi težavami kar za 39,8 % manj pogosto vrnejo v svojo primarno družino. Schmidt-Tieszen in McDonald (1998) sta z regresijsko analizo preučila več dejavnikov, tudi različne vrste oviranosti, in ugotavljala, kako so ti dejavniki povezani z načrtovanjem posvojitve ali dolgotrajnega skrbništva; ugotovila sta, da je ključna storitev za otroke z ovirami štirikrat pogostejša namestitev v rejniško družino ali zavod, da otroci z ovirami v rejništvu ostajajo dlje in da večkrat zamenjajo rejniško družino. Ugotovila sta, da je še posebej pri otrocih z vedenjskimi ali razvojnimi ovirami verjetneje, da bodo ostali v rejništvu, za otroke s fizičnimi ovirami ali zdravstvenimi težavami pa je verjetneje, da bo vloženega veliko truda v njihovo posvojitev (*ibid.*) Tudi Connell *et al.* (2007) pišejo, da se otroci z ovirami manj pogosto lahko vrnejo v svojo matično družino in se pogosteje vedno znova vračajo v rejniško. Rosenau (2005: 3) to stanje opiše takole: preveč otrok z ovirami gre v namestitev (rejniško ali zavodsko), premalo jih sistem zapusti in pogosto so nameščeni v zanje neprimerno obliko oskrbe. Shannon in Tappan (2011: 1474) na podlagi lastne in sorodnih študij ugotavljata, da otroci z ovirami nimajo dostopa do enakih in enako kakovostnih storitev kot drugi otroci.

Tudi v raziskavi, ki so jo izvajali v Španiji, so Sainero *et al.* (2013) ugotovili, da otroci z ovirami v rejništvu pogosteje menjajo rejniško družino ali obliko bivanja (npr. prehajanje med institucionalno oskrbo in rejniško družino) kot pa otroc brez ovir. To pomeni pomemben destabilizacijski element v njihovem življenju, kot pišejo tudi drugi avtorji v Španiji (del Valle *et al.* 2008) in ZDA (Hill 2012, Lightfoot *et al.* 2011). Sainero *et al.* (2013) opozarjajo, da bi bilo treba rejniške starše bolje pripraviti, da bi se izognili premestitvam: kot enega od razlogov zanje namreč vidijo tudi nezmožnost rejniških staršev za ravnanje s kompleksnimi čustvenimi in vedenjskimi stanji in izkušnjami otrok, to pa spodbudi (še posebej v njihovi puberteti) zahtevo za premestitev.

Koh (2014: 44) je v raziskavi primerjal skupino otrok v rejništvu z več premestitvami in zelo stabilno skupino: rezultati so pokazali, da je kar 31,2 % otrok v skupini s premestitvami v času poteka študije pridobilo novo diagnozo na področju duševnih težav, rezultat za primerljivo skupino otrok s stabilnim rejništvom pa je bil le 5 % (skupini sta na začetku študije vključevali enako število otrok z diagnozo na področju duševnega zdravja, številke so divergirale v času raziskovalnega obdobja). Podobne izsledke so dobili raziskovalci v starejših študijah, ki so raziskovale razmerje med nestabilnostjo namestitve ter čustvenimi in vedenjskimi težavami (Barth *et al.* 2007, Chamberlain *et al.* 2006, James *et al.* 2004, Leathers 2006) ter vpliv na razvoj zlorabljenih/zanemarjenih otrok (Festinger 1983, Newton *et al.* 2000, Rubin *et al.* 2007, Wulczyn *et al.* 2003).

Prva in edina raziskava, ki v Sloveniji obravnava življenjske poteke ljudi z izkušnjo posebnih oblik varstva, s poudarkom na tem, kaj se zgodi, ko se bivanje v posamezni obliki varstva konča, je bila opravljena leta 2012 (Boškić *et al.* 2012). Tudi avtorji te raziskave opozarjajo, da podatki, ki so jih pridobili s pomočjo anketiranja socialnih delavcev in delavk na centrih za socialno delo po Sloveniji, niso reprezentativni in gre v resnici zgolj za oceno stanja na področju (*op. cit.*: 36).

Posvojitve otrok z ovirami

Tudi v naši raziskavi se je pokazalo, da prehodov v posvojitev za otroke s posebnimi potrebami pravzaprav ni ali skoraj ni. Tudi Marijan (2011), ki navaja gibanje otrok v rejništvu (med letoma 2004 in 2011 sta bila od skupaj 2122 otrok v rejništvu 202 premeščena iz ene rejniške družine v drugo, 43 pa iz rejniške družine v zavod), ne omenja posvojitev. Sama nisem našla raziskav, ki bi poročale o prehodih in izidih izhodov iz rejništva, niti na splošno niti posebej za področje otrok s posebnimi potrebami. Po podatkih MDDSZEM je bilo od leta 2003 do 21. 5. 2014 48 oseb iz rejništva premeščenih v vzgojni zavod, 23 pa v zavod za usposabljanje.[6]

V raziskavi so socialne delavke kot izhod iz rejništva, poleg morebitne vrnitve v matično družino, navajale le premestitev v drugo rejniško družino ali zavod. Najpogostejši odgovor med intervjuvanimi socialnimi delavkami je bil, da so taki primeri izjemno redki:

> Ne spomnim se primera, da bi šel kdaj kakšen otrok s posebnimi potrebami v posvojitev. (Irena, 8.)

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[6] MDDSZEM, Direktorat za družino; ISCDS-rejništvo, maj 2014.

> Že rejniško družino je težko dobiti, kaj šele posvojiteljsko. Težko je že, če je otrok starejši, če pa ima še posebne potrebe, potem je nemogoče. (Maja, 18.)

Le ena od socialnih delavk je povedala:

> Imeli smo en primer, deklica z avtizmom, so jo rejniki posvojili. (Majda, 24.)

Socialne delavke so pojasnjevale, zakaj otroci s posebnimi potrebami ostajajo v rejništvu in se le izjemoma vrnejo v matično družino ali gredo v posvojitev. Posebne potrebe so večinoma poudarile kot dejstvo, ki se ga posvojiteljski starši bojijo – »vsakdo hoče zdravega otroka« (Alenka, 6). Hkrati pa gre pogosto pri otrocih tudi za višjo starost – to so socialne delavke navedle kot dodatno oviro. To je povezano z dejstvom, ki je bilo v tem prispevku že omenjeno – da pri velikem deležu otrok s posebnimi potrebami (intelektualnimi in telesnimi ovirami) te niso bile dovolj zgodaj prepoznane, zato tudi obravnava ni ustrezna.

> Premalo, premalo strokovnjakov je za to področje, psiholoških in podobno; predolgo se čaka [na diagnoze]. (Alenka, 6.)

Zaradi neodzivnosti strokovnih služb se odlaga tako odločitev glede možnosti za vrnitev v matično družino kot tudi razmislek o možnostih za posvojitev: Alenka je povedala, da »nas psihologi in drugi strokovnjaki zares premalo informirajo« (Alenka, 6), zato se težje in pozneje odločajo glede tega, ali bo vrnitev v matično družino sploh še možna ali pa naj raje iščejo posvojiteljske starše ali namestitev v institucijo. Kot ugotavljajo tudi Rakar *et al.* (2010) v obsežni raziskavi o standardih in postopkih na področju rejništva v Sloveniji, tako otroci ostajajo v dolgotrajnem rejništvu. To na več primerih pojasni Adam (2010). V Sloveniji rejništvo traja povprečno 7,6 leta, polovica vseh otrok v rejništvu ostane več kot 5 let, skoraj četrtina otrok pa je v rejništvu več kot 10 let (Gajšek 2011). Kot kažejo odgovori socialnih delavk v naši raziskavi, so v dolgotrajnem rejništvu še posebej otroci z ovirami.

Zdi se, da so socialne delavke glede posvojitve ali vrnitve vdane v usod oz. je ne pričakujejo, kadar gre za otroke z ovirami, zato zanje po navadi priskrbijo zavodsko namestitev, če otroci ne morejo živeti pri rejniški družini.

> Uspešnost svojega rejništva je hotela dokazovati z učnim uspehom deklice, deklica pa tega ni zmogla. Začelo je prihajati do nasilja in mi smo začeli iskati novo namestitev, tudi posvojitev. Nismo našli posvojiteljev in dejansko ni bilo druge rešitve, kot da gre v zavod, čeprav nima vzgojnih težav, samo neke intelektualne primanjkljaje. (Janja, 24.)

V takšnih primerih namestitve v vzgojni zavod gre za to, kot je ugotavljala tudi Marijan (2011), kdo so ti otroci (otroci s posebnimi potrebami), ne pa, kaj počnejo oz. kakšne vzgojne ali vedenjske težave imajo. Otroci so s tem vsaj dvojno prikrajšani, saj s tem ne prejemajo ustrezne oskrbe in podpore, prilagojene njihovim potrebam, ampak so vključeni v še en sistem, v katerem doživljajo, da so »tujci«: z vidika oskrbe in odgovornosti strokovnih služb za otroka gre torej za zlorabo. Na nekaterih centrih za socialno delo v takšnih primerih ravnajo tako, da pri namestitvi v zavod poskušajo poskrbeti vsaj za rejništvo za konec tedna (to je, kot kažejo izkušnje, po navadi sorodniško).

Socialne delavke so ob razpravi o prehodih med posvojitvami in rejništvom omenjale še eno oviro: materialna sredstva in visoke stroške za zagotavljanje (ustreznejše) skrbi in podpore otrokom z ovirami.

> Ostajajo otroci v rejništvu, jih ne posvojijo – tudi zato, ker potem ne bi bilo niti te minimalne finančne podpore, ki jo dobijo s pomočjo rejništva. Ker pri otrocih s posebnimi potrebami, če so kakšne invalidnosti, bolezni, to je treba voziti na preglede, tudi v Ljubljano, to so veliki stroški. (Elza, 23.)

Konec rejništva za otroke z ovirami

V praksi tako otroci z ovirami ostajajo v dolgotrajnem rejništvu ali pa živijo v zavodih; vanje so nameščeni načelno glede na potrebe (vzgojni zavod, vzgojno-izobraževalni zavod in mladinski dom). Iz same prakse so prišli tudi predlogi, da bi se vzpostavile stanovanjske enote ali bivalne skupnosti za mlade, ki po koncu rejništva nimajo drugih možnosti za reševanje svoje bivalne situacije (Mali 2012). Med letoma 2004 in 2011 se je rejništvo končalo za 645 otrok – od tega se je v matične družine vrnilo 220 otrok ali 34 % (Gajšek 2011).

Kot so socialne delavke povedale v intervjujih, pomeni konec rejništva veliko negotovost za mlade, ki so odrasli v rejniški družini (prim. tudi Rakar *et al.* 2010), še posebej pa to velja za mlade z ovirami. Pomembno je tudi, da strokovni delavci nimajo zakonske podlage za spremljanje oseb po izhodu iz rejništva ali zavodov, zato vsakršni morebitni podatki o tem v Sloveniji temeljijo predvsem na ocenah (prim. tudi Boškić *et al.* 2012); sistematičnega zbiranja podatkov ni. Socialne delavke podatke o tem, kaj se dogaja z mladimi, potem ko zapustijo sistem rejništva ali zavodske oskrbe, pridobivajo (in posredujejo) predvsem na podlagi tega, ali se mladi sami pozneje še oglasijo pri njih, ker npr. pridejo po pomoč ali storitve ali zaradi drugih razlogov. Informacijski sistem namreč ne omogoča vnašanja/pregleda podatkov o tem, koliko oseb ostane v družinah, v katerih so bivali, tudi po koncu rejništva.[7]

> Tudi moj »strokovni« strah je bil vedno precej večji za otroke s posebnimi potrebami; kam ga bomo vključili, kako bomo zaključili, kam naprej. Težje jim je, veliko težje, bolj negotovo, kot pa morda kakšen otrok, ki je bolj opremljen, je končal šolo, se znajde. (Zvonka, 30.)

Socialne delavke so prepoznale, da so mladim z ovirami veliko bolj zaprta vsa vrata, da imajo manj možnosti za samostojnost, zaposlitev, nadaljnje izobraževanje ipd. in da so zato še ranljivejši, prepuščeni »dobri volji« posameznikov (npr. predvsem rejniških staršev, ki se lahko strinjajo s tem, da mladi ostanejo pri njih – brezplačno – tudi po koncu rejništva).

> Ja, seveda so tudi podaljšana rejništva, ampak tudi ta se zaključijo. Kaj pa potem? Kako jih pripravimo na vstop v življenje? In v današnjih časih, ko ni služb … nekateri sicer ostanejo v družini, z denarno pomočjo in potem, ko se zaključi, so pač obravnavani kot vse druge odrasle osebe. (Zvonka, 30.)

Sistemsko so mladi z ovirami obravnavani enako kot preostali, kljub specifični situaciji, iz katere izhajajo. Še bolj skrb zbujajoče pa je, da so zato, ker so pravzaprav prepuščeni sami sebi, »dobrodelnosti«, rejniških družin in osebni angažiranosti posameznih strokovnih delavk, še toliko bolj izpostavljeni zlorabi, revščini in drugim prikrajšanostim.

> Glavno je, nimajo potem kam. Včasih ostanejo pomožna delovna sila na kmetiji. Ampak potem se njihov socialni svet zapira, tudi veščine, ki so jih že osvojili, zbledijo. (Majda, 24.)

Že sicer pomanjkljiv vpogled v dogajanje v rejniških družinah, počutje, varnost in skrb za otroke se s koncem rejništva popolnoma izgubi. Mladi z ovirami postanejo popolnoma prepuščeni sebi oz. rejniški družini, njihova nadaljnja pot in preživetje sta odvisna predvsem od »sreče«, angažiranih posameznikov in posameznic, vsekakor pa ne od organizirane oskrbe oz. strokovnih služb, ki bi jih lahko podpirale in spremljale.

> Potem iščemo neke rešitve, ki so izredne in tudi mimo pravil včasih. Smo imeli enega fanta, ki je bil v zavodu v Levcu in so ga po dopolnjeni starosti potem še vzeli za par mesecev nazaj noter, ne vem, morda ga sploh ne bi smeli. Potem so mu tudi pomagali in ga še vzeli v neko službo pri njih. (Zvonka, 30.)

V okviru rejništva je pomembno opozoriti še na ugotovitev, ki jo v svoji raziskavi navajajo Boškić in drugi (2012): navajajo izjavo strokovne delavke, ki je opozorila na pojav, ki ga zaznava – rejniki naj bi pred 18. letom, ko se začnejo mladostniške težave, ne zmogli več dela z mlado osebo, predvsem pa naj bi se bali

> moralne odgovornosti, kaj bo, ko bo mladostnik star 18 let, in to etično odgovornost potem preložijo na zavod. (Op. cit.: 45).

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[7] Podatek MDDSZEM, Direktorat za družino, maj 2014.

Priporočila

Področje rejništev bi potrebovalo več raziskovalnih vpogledov in predvsem kakovostne empirične študije, skupaj s kvantitativnim zbiranjem podatkov, da bi se lahko oblikovali prepotrebni predlogi za izboljšave. Kljub temu pa avtorji pogosto predlagajo različne izboljšave na področju rejniške prakse oz. opozarjajo na pomanjkljivosti, s katerimi bi se bilo treba spoprijeti (*cf.* Rakar *et al.* 2010, Zaviršek 2012). Kot izhodišče je ključno, da so socialne delavke dobro usposobljene z delo z rejniškimi starši, biološkimi starši in otroci ter da poznajo posebnosti in potrebe na področju različnih vrst ovir, hkrati pa morajo tudi odlično poznati pravice otrok in staršev, te pravice upoštevati in informacije o njih tudi posredovati staršem.

Na področju otrok s posebnimi potrebami in oseb, ki so jim bile dodeljene različne kategorije invalidnosti, imamo v Sloveniji zapleteno, v nekaterih primerih tudi nasprotujočo si zakonodajo, ki jo morajo socialne delavke zelo dobro poznati, da bi lahko svetovale in podprle družine in otroke pri uveljavljanju pravic. Zaplete se že pri najosnovnejših stvareh – pri urejanju stalnega bivališča in zdravstvenega zavarovanja za otroke v rejništvu, varčevanju denarja, odpiranju hranilnih knjižic, urejanju osebnih dokumentov ipd., čeprav je novela Zakona o izvajanju rejniške dejavnosti (2002) že rešila nekaj teh stvari, vendar imajo določeni rejniki še vedno težave, ker je novela nedorečena oziroma jo različni občinski uradi različno razumejo. Tudi Murgel (2014) navaja dilemo glede statusa »invalid« pri osebah, ki v otroštvu ali mladosti niso bile usmerjene v skladu s pravili Zakona o usmerjanju otrok s posebnimi potrebami (2011). Poznavanje teh je pomembno tudi zato, ker bi bilo mogoče včasih tako tudi biološke starše bolje podpreti (materialno in psihosocialno) pri tem, da bi otroci lahko ostali v matični družini in namestitev v rejniško družino ne bi bila potrebna (najpreprostejši primer tega bi bil, kadar je otrok z določeno oviro nameščen v rejništvo zato, da je bližje ustreznemu programu šolanja).

Poleg tega je znanje s področja dela z ljudmi z ovirami ključno za to, da lahko socialne delavke podprejo biološke in rejniške starše v njihovih skrbniških vlogah, jim pomagajo pri razumevanju otroka z ovirami, prepoznavanju njegovih potreb in ustrezni skrbi zanj. Kot meni Zaviršek (2012), gre pogosto tudi za hitre namestitve otrok, pri katerih rejniški starši niso bili prej usposobljeni ali pripravljeni in tako le slabo razumejo otrokove potrebe, doživljanje in ravnanje. Takšno znanje in podpora bi bila koristna tudi z vidika zmanjševanja pojava premestitve, saj ima za otroka travmatične in druge posledice. Uspešne namestitve so, kot poroča Crum (2010), namreč pozitivno povezane s količino čustvene in socialne podpore, ki jo prejemajo rejniški starši. Vendar mora biti ta podpora zelo dobro povezana z izobraževanjem in usposabljanjem (to je zdaj zelo borno) že pred rejništvom, sicer utegne biti velik del vse podpore, ki je na voljo, namenjen samo staršem:

> Ves čas se ukvarjamo z različnimi problemi, ki jih imajo starši, rejniški starši ipd., na otroke pa ves čas pozabljamo; ne pozabljamo, ampak zmanjka časa. Ne opazimo jih, nismo dovolj pozorni nanje. Najprej, otroci si ne upajo povedati slabih reči; potem pa se dogaja, da otroci celo povejo, povejo v šoli npr., pa nihče ničesar ne naredi. (Zvonka, 30.)

Vsekakor je delo z matično in rejniško družino ključno, vendar je pri tem pomembno, da se tudi vzpostavi ali ohrani stik z otrokom, ki je po navadi najmanj slišan in se v nasprotju z odraslimi veliko težje postavi v ospredje. Pogosto ga jemljejo manj resno in kot neenakopravnega sogovornika. Ena od socialnih delavk je izjavila, da je v procese treba vključevati vse otroke:

> Mislim, da je treba vse otroke vključevati; še posebej ti mejni, teh je veliko, če jim razložimo, je še lažje z njimi vzpostaviti kontakt, lažje sprejmejo na neki ožji način, in njih je potrebno tudi vključevat. Jaz vključujem vse. Meni se ne zdi toliko zahtevno delo z njimi, še manj zahtevno – so bolj odprti, bolj direktni, prej povejo. (Tanja, 30.)

Vsekakor pa je ključna tudi usposobljenost rejniških staršev, ki so v vsakodnevnem stiku z otroki s posebnimi potrebami, ki so pri njih v rejništvu. Rejniške starše bi bilo treba dobro pripraviti in usposobiti – za zdaj še ni posebnih izobraževanj, ki bi bila usmerjena v področje otrok s posebnimi potrebami, ampak so informiranost, znanje in pripravljenost rejniških staršev odvisni predvsem od angažiranosti posameznih socialnih delavk oz. centrov za socialno delo (kolikor jih zmorejo podpreti) in seveda od angažiranosti staršev. Posebej bi bilo treba dodatno usposobiti nekaj družin, ki bi lahko sprejele otroke z veliko slabih izkušenj oz. več ovirami in ustrezno poskrbeti zanje.

Treba je poskrbeti tudi za nenehno dobro sodelovanje med vsemi strokovnimi službami, ki so vključene v življenjski potek otrok in mladih s posebnimi potrebami: tako zdravstvenimi profili, pedagoškimi profili, socialnimi delavkami, pozneje tudi strokovnjaki s področja zaposlovanja idr.

Strokovnemu delu se morajo seveda pridružiti tudi sistemske izboljšave, ki bodo omogočale več podpore, materialne in v storitvah, prožnejšo ureditev formalnih pravic (da bi tako rejniški starši lahko več uredili za otroke), dobre sistemske rešitve, povezane s pravicami otrok (s posebnimi potrebami), in še posebej v rejništvu, spodbude za hitrejše, bolj strokovno in ustreznejše ugotavljanje pogojev in potreb ter učinkovitejše zagotavljanje boljšega položaja otrok, z več varnosti, stalnosti in ustrezne oskrbe.

To se nanaša tudi na potencialne prehode v posvojitev. Pri tem je treba zagotoviti dobre strokovne ocene in ustrezno podporo odraslim in otrokom. Lightburn in Pine (1996) poročata o raziskavi, ki je merila izide v primerih posvojitev otrok z ovirami: raziskava je pokazala zelo nizko število prekinitev posvojitve, visoko stopnjo starševskega zadovoljstva, seveda pa tudi potrebo za storitve po sami posvojitvi (npr. finančno podporo, svetovanje). Ugotovila sta, da je pri posvojitvah otrok z ovirami izjemno pomembno, da imajo dostop do storitev in tehnično-medicinskih pripomočkov, ki jih potrebujejo. Hkrati bi bilo sistemsko treba poskrbeti za tiste mlade, ki se niso imeli možnosti vrniti niti v matično družini niti niso prešli v posvojitev in so ob koncu rejništva prepuščeni sami sebi ali »milosti« drugih. Poleg tega, kot navajajo Boškić *et al.* (2012), se pri prenehanju podpore oz. izhodu iz rejništva ali zavodske oskrbe mladi srečujejo z več problemi naenkrat: prehod iz rejništva ali zavoda v neodvisno življenje, prehod iz sistema izobraževanja na trg dela – oboje pa povečuje tveganja za izključenost. Otroci z ovirami so v takšnih okoliščinah v najtežavnejšem položaju.

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Anja Pirec Sansoni

VPLIV STANOVANJSKE IZKLJUČENOSTI IN BREZDOMSTVA NA ZDRAVJE

Socialni dejavniki so pomemben vidik vplivov na zdravje ljudi, kajti stanovanjske in bivanjske razmere zelo vplivajo na telesno in duševno zdravje. Število brezdomnih oseb se povečuje v večini evropskih držav, prav tako se slabšajo stanovanjske razmere, v katerih ljudje bivajo. Izkušnje brezdomnih oseb ter strokovnih delavk in delavcev na področju brezdomstva in socialne izključenosti kažejo, da so zdravstvene težave brezdomnih oseb večkrat spregledane, razvijajo se v trajno oviranost. V Sloveniji se srečujemo s pomanjkanjem specializiranih služb za brezdomne osebe z ovirami ali hudimi zdravstvenimi težavami, prav tako se s težavami srečujejo izvajalci programov na področju brezdomstva, saj niso usposobljeni za izvajanje zdravstvene oskrbe, hkrati pa se spoprijemajo z ovirami pri iskanju možnosti za namestitev uporabnikov storitev.

Ključne besede: socialni dejavniki, zdravstvena neenakost, revščina, storitve, oviranost.

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THE EFFECT OF HOUSING EXCLUSION AND HOMELESSNESS ON HEALTH

Social factors have important effect on people's health, since housing and living conditions greatly affect the physical and mental health of people. The number of homeless people is increasing in most European countries and living conditions are also getting worse. Experience of homeless people and professional workers in the field of homelessness and social exclusion suggests that health problems of homeless people are often overlooked and evolve into permanent disability. In Slovenia, we are facing a lack of specialized services for homeless people with disabilities or serious health problems. Professional and other staff working in the field of homelessness are not trained to perform medical care, although they are faced with obstacles in finding a way to accommodate service users.

Key words: social factors, health inequality, poverty, services, disability.

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Uvod

Problematika stanovanjske izključenosti in brezdomstva v Sloveniji kaže, da je pri odzivih na potrebe ljudi pomembno in potrebno povezovati socialno in zdravstveno stroko. Socialni dejavniki vpliva na zdravje, predvsem stanovanjske razmere, so ključni pri razumevanju zdravstvene problematike brezdomnih oseb. V teoretskem uvodu želimo s kompleksno definicijo brezdomstva in stanovanjske izključenosti, prikazom socialnih dejavnikov vpliva na zdravje in analizo sprememb stanovanjskih razmer v Sloveniji prikazati koncepte razumevanja kompleksnosti situacij brezdomnih oseb.

V empiričnem delu prikažemo izkušnje izvajalcev socialnih storitev na področju brezdomstva v Sloveniji in izkušnje brezdomnih oseb. Brezdomci se večkrat srečujejo z izključevalno in diskriminatorsko politiko zdravstvenega sektorja. Ta se namreč pogosto ne zmeni za njihov socialni kontekst, to pa kaže na medicinski model obravnave in trdovratne predsodke do oseb z izkušnjo brezdomstva. Pričevanja brezdomnih oseb smo zbirali pri socialnem delu na tem področju od leta 2009, predvsem v osebnih pogovorih in v procesu pomoči pri reševanju njihovih situacij. V članku navajamo ali povzemamo zgolj nekatere izstopajoče primere, ki najbolj slikovito prikazujejo njihov boj z mlini zdravstvene birokracije.

Predstaviti želimo ključne povezave med neenakostjo in zdravjem, hkrati pa prikazati neustreznost institucionalnega odziva na zdravstvene težave brezdomnih oseb. Poleg že omenjenega medicinskega modela, ki ga razumemo kot del problema, gre tudi za pomanjkanje specializiranih služb za brezdomne osebe z ovirami ali kroničnimi zdravstvenimi težavami in za preobremenjenost obstoječih služb.

Opredelitev stanovanjske izključenosti in brezdomstva ter podatki za Slovenijo

V Sloveniji se število brezdomnih oseb povečuje po letu 1990, torej sočasno s slabljenjem in razkrajanjem številnih formalnih in neformalnih varovalnih sistemov (Razpotnik 2009). Dejavniki, ki vplivajo na večanje števila brezdomnih oseb, so: višanje cen stanovanj v zadnjih 15 letih, radikalna privatizacija, gentrifikacija[1], zmanjševanje dostopnosti vseh zdravstvenih storitev (brezdomci so redkeje in manj obravnavani v psihiatričnih bolnišnicah in verjetno tudi slabše) (Razpotnik, Dekleva 2007).

Maša Filipovič (2007) opozarja, da so podatki o brezdomstvu in stanovanjski izključenosti v Sloveniji izjemno pomanjkljivi. V Sloveniji je namreč brezdomstvo še vedno obravnavano v kontekstu socialne politike in ne v kontekstu stanovanjske politike oziroma je stanovanjska politika ločena od socialne, to pa precej vpliva na javno percepcijo in predlagane rešitve te problematike.

> Tako je brezdomstvo najpogosteje obravnavano kot stranski produkt drugih socialnih problemov, kot so, na primer, nizek osebni dohodek, osebne težave, družinski konflikti. (*Ibid.*: 193.)

Evropska tipologija brezdomstva in stanovanjske izključenosti (ETHOS 2006) temelji na razumevanju kompleksnosti pojava brezdomstva. Brezdomstvo definira na treh ravneh: fizični, družbeni in pravni. Fizična dimenzija vključuje fizični prostor za bivanje, pravna označuje zakonito pravico do bivanja na določenem prostoru, družbena pa pomeni imetje zasebnega prostora, v katerem lahko potekajo družbeni odnosi. Izključenost iz vseh treh dimenzij tako pomeni brezdomstvo, izključenost iz enega ali dveh področij pa izključenost in potencialno brezdomstvo.

Na podlagi definicije ETHOS (*ibid.*) lahko osebe uvrstimo v štiri kategorije brezdomstva in stanovanjske izključenosti:

- *Osebe brez strehe nad glavo*

Navezuje se na posameznike, ki jih v javnosti najpogosteje povezujejo z brezdomstvom, torej tiste, ki spijo na javnem prostoru, na ulicah, ali pa občasno v nujnih nastanitvah za brezdomce (vendar gre predvsem za omejene nastanitve, na primer le čez noč). Gre za najhujšo obliko izključenosti, saj so v takem primeru osebe izključene z vseh treh področij. Brezdomne osebe, ki jih opisujemo v tej kategoriji, so najvidnejše in jih družba tudi največkrat stigmatizira in označi kot brezdomne. Ocene (Dekleva *et al.* 2010) za Slovenijo kažejo, da je od nekaj sto do več kot tisoč ljudi brez strehe nad glavo. Ta skupina je najbolj izpostavljena različnim dejavnikom tveganja, vpliv na njihovo zdravje je odvisen od njihovega splošnega zdravstvenega stanja, časa trajanja življenja brez strehe nad glavo in uporabe različnih strategij preživetja in skrbi za zdravje. Zaradi vidnosti brezdomstva imajo slabši dostop do zdravstvenih storitev in slabšo zdravstveno oskrbo, večkrat so zaradi specifične situacije tudi brez osnovnega in dodatnega zdravstvenega zavarovanja. Izkušnje iz prakse kažejo, da se veliko brezdomnih oseb zateče po pomoč v zavetišča in druge oblike storitev, ko se njihovo zdravstveno stanje tako poslabša, da ne zmorejo več živeti zunaj institucije, večkrat so napoteni v zavetišča tudi ob odpustu iz različnih zdravstvenih ustanov ali pripeljani z rešilcem iz ambulante nujne medicinske pomoči.

- *Osebe brez stanovanja*

Kategorija označuje različne življenjske situacije, večinoma vanjo uvrščamo osebe, ki živijo v določenih institucionalnih oblikah pomoči. Ti sicer niso izključeni s fizičnega področja, temveč

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[1] Gentrifikacija je rekonstrukcija določenega območja v mestu. Gre za proces socialne preobrazbe delov mesta, praviloma z nižjim socialnim in ekonomskim položajem, vendar zaradi lege, nizkih cen in bivalnega okolja pomeni velik potencial. Obnova in sanacija stavb tako povzročita višje cene nepremičnin in priseljevanje premožnejše populacije, zato se revnejši prebivalci odseljujejo (Rebernik 2004).

z družbenega in pravnega (npr. v njem nimajo zasebnosti in ne morejo prijaviti stalnega bivališča ali pa nimajo pravne podlage za samostojno rabo bivališča). V tej kategoriji prepoznamo ljudi, ki živijo v zavetiščih za brezdomce, azilnih domovih, materinskih domovih in varnih hišah za ženske in osebe, ki so pred odpustom iz institucij (npr. bolnišnice, zapora) in nimajo doma, kamor bi se lahko vrnili. Ljudi brez stanovanja je v Sloveniji po zadnjih ocenah (Dekleva in drugi 2010) od dva tisoč do nekaj tisoč, veliko jih ostaja skritih, neregistriranih in neslišanih.

- *Osebe z negotovo nastanitvijo*

Bivanje brez zagotovljene trajnosti pomeni predvsem izključenost na pravnem področju bivanja oziroma negotovost glede prihodnosti, saj ima oseba več možnosti, da bo nastanitev izgubila. Te situacije so lahko: najem brez zakonite pogodbe ali za določen čas, bivanje pri sorodnikih in prijateljih, grožnja prisilne izselitve, nezakonita naselitev in bivanje z grožnjo nasilja. Ocena raziskave (*ibid.*) kaže na to, da v negotovi nastanitvi v Sloveniji biva več tisoč ljudi. To je zaradi nedostopnosti podatkov zelo groba ocena, številka vseh je po mnenju avtorjev zagotovo veliko višja. Zaradi specifičnih življenjskih situacij (ogroženo, stresno življenje, nezakonita naselitev ipd.) imajo ljudje, ki bivajo v negotovi nastanitvi, več zdravstvenih težav kot tisti, ki imajo varno nastanitev trajno zagotovljeno.

- *Osebe v neprimernem stanovanju*

V tej kategoriji imajo osebe fizično stanovanje, torej streho nad glavo, vendar so razmere neprimerne za bivanje. Za neprimerno stanovanje veljajo mobilni domovi, nelegalno bivanje na posestvu in nelegalno bivanje v stavbi (skvoti), bivanje v prostorih, ki so označeni kot neprimerni po nacionalnih standardih (npr. brez sanitarij, vlaga, plesen) in bivanje v okoliščinah ekstremne prenaseljenosti. Raziskovalci ocenjujejo (*ibid.*), da v neprimernem stanovanju v Sloveniji biva skoraj 80.000 ljudi, vendar je ta številka verjetno podcenjena. Življenje v neprimernem stanovanju, predvsem dolgotrajno, ima lahko hude in trajne posledice za zdravje.

Klasifikacija ETHOS je izjemno kompleksna, a statična, zato ne more upoštevati procesne, spremenljive narave brezdomstva, zaradi katere je velik del brezdomstva manj viden ali celo skrit. Za brezdomstvo je namreč značilno prehajanje med oblikami v različno dolgih obdobjih. Pomembni pa sta zavedanje kompleksnosti problematike brezdomstva in prepoznavanje različnih poti v brezdomstvo, to pa opozarja tudi na stanovanjska tveganja (*ibid.*).

Socialni dejavniki vpliva na zdravje

Coleen Reid (2004) kot pomembne socialne determinante zdravja opredeljuje revščino, spol, barvo kože, etničnost in življenjske navade. Zdravje razume veliko širše samo stanje posameznika, predvsem pa upošteva tudi posledice materialne prikrajšanosti, slabih stanovanjskih in delovnih razmer. Socialni diskurz prepoznava družbene razlike v zdravju in opozarja, da socialni, politični, kulturni in ekonomski dejavniki vplivajo na pojavnost večine bolezni in oviranosti. Diskurzi revščine in zdravja so izraz ideoloških agend, ki so zgodovinsko specifične in odvisne od družbe. Za razumevanje zdravja in bolezni moramo namreč razumeti socialne razmere, v katerih se zdravje in bolezen ustvarjata, identificirata in nadaljujeta (*ibid.*). Zdravje poznamo kot eno izmed osnovnih človekovih pravic, kljub temu pa socialna in ekonomska struktura družbe ter socialna izključenost pomenijo enega izmed poglavitnih razlogov za bolezni in smrt ljudi. Zdravje moramo tako razumeti tudi kot problem socialne politike; večanje revščine in razlik v dohodkih gospodinjstev pa pomeni večanje zdravstvenih neenakosti. »Pomanjkanje moči na individualni, skupnostni in družbeni ravni je glavni dejavnik tveganja za težave z zdravjem« (*ibid.*: 4).

Buzeti *et al.* (2011) opredelijo pet ključnih mehanizmov, ki vplivajo na pojav neenakosti v zdravju. Prvi izvira iz različne porazdelitve moči in virov; neenakosti lahko povzročajo družbene norme, politike in prakse, saj sistematično vplivajo na porazdelitev moči, blaginje in drugih potrebnih družbenih virov.

Razlike v socialnem položaju kot drugi identificirani mehanizem na področju zdravja povečujejo izpostavljenost dejavnikom tveganja (materialnim, psihološkim in vedenjskim). S slabšanjem socialnega položaja se tveganja večajo.

Tretji mehanizem vpliva na zdravje avtorji vidijo v tem, da lahko enaki dejavniki tveganja različno vplivajo na različne skupine oziroma posameznike, saj je njihov vpliv odvisen od trajanja in moči, predvsem pa od številčnosti dejavnikov. Vsekakor so ob daljšem, pogostejšem ali večjem tveganju posledice usodnejše, kot če neki negativni dejavnik vpliva le občasno. Prav tako več dejavnikov tveganja za zdaj na zdravje vpliva slabše kot posamezni dejavnik.

Četrti ključni mehanizem je vpliv socialno-ekonomskih determinant zdravja v celotnem življenjskem obdobju. Učinki se v življenju namreč seštevajo, kopičenje negativnih vplivov oziroma dejavnikov tveganja pa pomembno vpliva na razlike v zdravju med skupinami prebivalstva. Dogodki v zgodnjem otroštvu (npr. pogostejše bolezni), revščina in materialna prikrajšanost (slabe stanovanjske razmere, slabša prehrana ipd.) pomembno vplivajo na zdravje v poznejšem obdobju. Ne smemo tudi zanemariti, da socialno-ekonomski položaj staršev zelo vpliva na otroke, ne samo na njihovo zdravje, temveč tudi na izobraževanje in pozneje na zaposlovanje, posledica tega pa je začaran krog revščine. Slabo zdravstveno stanje in oviranosti pa lahko vplivajo na posameznikovo življenje, saj ima zaradi omenjenih dejstev slabši položaj na področju izobraževanja, zaposlovanja, stanovanja, zato se večkrat doživlja socialno izključenost.

Razpotnik in Dekleva (2009) razumeta zdravstveno problematiko kot eno izmed ključnih tematik, povezanih z brezdomstvom, saj imajo brezdomne osebe precej slabše zdravstveno stanje kot splošna populacija. Večkrat se pogoste zdravstvene težave zaradi nezadostne zdravstvene oskrbe tako poslabšajo, da imajo trajne posledice (npr. oviranosti). Težave z zdravjem lahko vplivajo na ustvarjanje novih in omogočajo povečevanje začaranega kroga socialne izključenosti, to pa vpliva tudi na izključenosti iz sistemov zdravstvene oskrbe. Zdravstvene potrebe brezdomnih ljudi so odvisne od več dejavnikov – čas trajanja brezdomstva in starost posameznika sta izmed najpomembnejših, saj se zdravje slabša z daljšanjem časa trajanja brezdomstva in s staranjem posameznika. Zdravstvene težave so posledica množice dejavnikov, ki izhajajo iz okolja. Avtorja (*ibid.*) poudarjata, da so na primer posledice spanja na prostem in neprimerne obutve okužbe, ozebline, bolezni ožilja (tromboza) ipd. Poudarjata tudi, da so bolezni in poškodbe zaradi nezdravljenja pogosto zanemarjene in zastarane, pojavljajo se okužbe in zastrupitve, tudi gangrena.

Revni ljudje doživljajo več dejavnikov tveganja, večkrat živijo v slabih stanovanjskih razmerah (vlaga, mraz, plesen), imajo slabe delovne razmere, živijo v prenaseljenih stanovanjih. Healy (2004) ugotavlja, da imajo ljudje, ki ne morejo dovolj ogreti stanovanja, več težav z zdravjem. Slabše zdravje imajo tudi družine, v katerih je proračun zelo obremenjen zaradi stanovanjskih stroškov ali pa težko poravnajo tekoče stroške (elektrika, plin, komunala).

Analize kažejo, da v Sloveniji socialno-ekonomske razmere zelo vplivajo na življenjske navade prebivalcev in to se kaže tudi na njihovem zdravju (Buzeti *et al.* 2011). Otroci v revnejših družinah uživajo manj sadja in zelenjave ter so manj pogosto telesno dejavni, prav tako je delež čezmerno hranjenih in debelih odraslih večji med prebivalci z nizkim socialno-ekonomskim položajem. Ti podatki kažejo, da revnejši za zagotovitev preživetja jedo bolj kalorično in manj kakovostno hrano, to pa se kaže na njihovem zdravju. Delež kadilcev je pri obeh spolih večji v skupini prebivalcev s poklicno, osnovno ali nižjo izobrazbo – to je lahko edina pregreha, ki si jo lahko privoščijo, in strategija preživetja v stiski. Prav tako se pojavljajo razlike v obolevnosti med revnejšim prebivalstvom in splošno populacijo (pogostejša arterijska hipertenzija, bolezni srca, rak), višja je tudi stopnja zgodnje umrljivosti zaradi omenjenih bolezni pri revnejšem prebivalstvu. Ugotovljene razlike so primerljive z neenakostmi v zdravju v drugih državah EU.

Luj Šprohar (2010) opozarja, da postajajo problemi ogroženih skupin prebivalstva povezani z njihovim zdravjem, vse pomembnejši javnozdravstveni problem ter veliko breme za posameznika, njegovo družino, skupnost in državo. Po njegovem mnenju ogrožene skupine potrebujejo posebno pozornost, pomoč, predvsem pa zakonsko zaščito in vključenost v sistem javnega zdravstva. Ugotovitve na podlagi opravljenih raziskav kažejo, da je treba razviti veliko različnih programov, diferenciranih tako geografsko kot sektorsko in vsebinsko, na področju nastanitve, vključevanja na področja dela, zdravstva, kulture, izobraževanja, javnega dialoga, potrebna pa je tudi ustrezna sistemska umestitev. Programi morajo biti prilagojeni različnim skupinam in upoštevati dejavnike, kot so spol, starost, etničnost, med seboj se morajo dopolnjevati. Okrepiti je treba tudi nemoteno delovanje organizacij, ki že delujejo na področju brezdomstva in zdravstva, še posebej pomembni pa sta izobraževanje različnih strokovnih profilov in medsebojno sodelovanje med različnimi resorji (zdravstvo, socialno varstvo, šolstvo) ter med organizacijami na več ravneh: javne in nevladne, nizkopražne in visokopražne.

Število brezdomnih oseb se povečuje, stanovanjske razmere se slabšajo

Poročilo, ki ga je izdala FEANTSA (2012), evropska federacija organizacij, ki delujejo na področju brezdomstva, kaže, da se število oseb v času krize povečuje. Evropski letni pregled rasti (Evropska komisija 2012 a) potrjuje, da se je število brezdomnih ljudi povečalo v nekaterih članicah EU zaradi gospodarske krize. V četrtletnem poročilu EU o zaposlovanju in socialnih razmerah (Evropska komisija 2012 b) je pisalo, da se je število brezdomnih oseb povečalo po vsej Evropi zaradi povečanja brezposelnosti in izgube dohodkov, zlasti v državah članicah na obrobju EU. Poudarja, da se je tistim državam članicam, ki vodijo učinkovite politike reševanja brezdomstva, kljub recesiji in propadu stanovanjskih balonov uspelo izogniti občutnejšemu povečanju števila brezdomnih oseb (*ibid.*). Razpoložljivi podatki o obsegu brezdomstva v EU so sicer omejeni, saj le malo nacionalnih vlad sistematično meri obseg brezdomstva. Pomanjkanje primerljivih kvantitativnih in kvalitativnih podatkov o brezdomstvu, še posebej o specifičnih skupinah brezdomnih oseb (ženske, otroci, osebe z oviranostmi) v vseh državah EU je eden izmed poglavitnih izzivov, in to kljub napredku, ki smo mu bili priče v zadnjih letih.

Povečanje obsega brezdomstva v zadnjih petih letih so zaznali v kar 15 državah članicah EU: poleg Slovenije še v Avstriji, na Češkem, v Franciji, Nemčiji, Grčiji, na Madžarskem, Irskem, v Italiji, Litvi, na Portugalskem, Poljskem, v Španiji, na Švedskem in v Združenem kraljestvu (Angliji, Severni Irski in Walesu). Zmanjšanje obsega brezdomstva v zadnjih petih letih pa ugotavljajo: Finska, Nizozemska, nemška zvezna dežela Severno Porenje-Vestfalija in Škotska. Izkušnje kažejo na to, da celostne politike, ki vključujejo raznolike oblike storitev in podpore, pripomorejo k zmanjševanju obsega brezdomstva (*ibid.*).

Slovenija torej sodi v skupino držav, v katerih se brezdomstvo povečuje ne samo v zadnjih petih, temveč dvajsetih letih. Priče smo stalni rasti, zato ta hip težko ocenimo moč vpliva gospodarske krize na povečanje števila brezdomnih oseb. Vsako leto je brezdomnim na voljo več storitev (zavetišča, prenočišča, druge oblike nastanitve). Evalvacija storitev za brezdomne kaže, da je bilo leta 2012 v programih 2243 različnih uporabnikov. Število uporabnikov se je v zadnjih letih zelo povečalo: leta 2008 jih je bilo 904, leta 2009 1637, leta 2010 1974, leta 2011 pa 2228 (Smolej *et al.* 2013).

Zdajšnja gospodarska kriza je skupaj z drugimi dejavniki (npr. stanovanjsko in socialno politiko) povečanje brezdomstva okrepila, postalo je vidnejše, ni pa ta kriza edini dejavnik vpliva. Trend zniževanja javne porabe in krčenja socialne države se je pojavil že pred krizo, v času krize pa se je še okrepil kot oblika reševanja posledic gospodarske krize (FEANTSA 2012).

Profil brezdomnih se v Evropi razlikuje glede na demografske in nacionalne značilnosti posamezne države, raziskave pa kažejo, da so se značilnosti brezdomnih oseb v zadnjih letih v večini evropskih držav spreminjale. V 14 državah se je povečalo število brezdomnih med priseljenci, v 10 državah se je povečal delež brezdomstva med mladimi in prav tako v 10 državah brezdomstvo med ženskami. V šestih državah ugotavljajo, da se je povečal delež brezdomnih družin. Na Poljskem in na Severnem Irskem ugotavljajo, da se brezdomna populacija stara – posledica širših demografskih sprememb (*ibid.*).

Slabšajo pa se tudi stanovanjske razmere. Podatki o stanovanjskih razmerah v 27 članicah Evropske unije (Eurostat 2009) kažejo, da v izjemno slabih stanovanjskih razmerah živi 6 %

Evropejcev ali 30 milijonov ljudi. Najpogostejši problemi, s katerimi se srečujejo ljudje v svojih naseljih in stanovanjih, so: hrup (22,2 %), stanovanjska prenaseljenost oziroma površinska neustreznost stanovanja (17,8 %) in onesnaženost (16,5 %). V Sloveniji je o stanovanjski prenaseljenosti leta 2010 poročalo 45 % najrevnejših prebivalcev, ocena stanovanjske prenaseljenosti za splošno populacijo pa je 35 %, več od evropskega povprečja. Med najemniki je stanovanjska prenaseljenost veliko večja kot med lastniki stanovanj, predvsem med najemniki po tržni ceni, pri tem je bila stopnja stanovanjske prenaseljenosti leta 2010 kar 82 %, se pravi, da so cene stanovanj v Sloveniji zelo visoke in si ljudje ne morejo privoščiti dovolj velikih stanovanj za svoje potrebe (SI-STAT 2012). Leta 2009 je kar 67 % prebivalcev EU menilo, da v svojem okolju nimajo dostopa do ustreznega stanovanja (Eurostat 2009).

Stanovanjske razmere se v Sloveniji v zadnjih letih slabšajo, predvsem po začetku krize je po podatkih Slovenskega statističnega urada (SI-STAT 2012) opaziti tak trend. Leta 2005 je namreč o slabi stanovanjski situaciji poročalo 20 % prebivalcev, leta 2008 je bilo takih 31 %, leta 2011 pa že 35 %. Podatki kažejo, da se stanovanja slabšajo, saj ljudje nimajo sredstev za vzdrževanje. Med najrevnejšim prebivalstvom je bilo takih, ki so poročali o slabem stanju stanovanja, leta 2011 46 %, med najemniki pa je delež 42 %.

Povečuje se tudi število ljudi, ki v stanovanjih nimajo primernega ogrevanja, saj jih je bilo leta 2005 3 %, delež pa je do leta 2011 povečal na 6 % (odstotek je pri revnejših ali najemniških gospodinjstvih še večji). Povečuje pa se tudi število ljudi, ki so jim stanovanjski stroški veliko breme, saj je bilo leta 2009 v EU 12,2 % (61 milijonov) ljudi, ki so za stanovanjske stroške porabili več kot 40 % svojih dohodkov (Eurostat 2009), odstotek teh pa se je leta 2010 povečal na 19 %. Kar dvakrat več (38 %) pa je ljudi, ki živijo pod pragom revščine in porabijo več kot 40 % za stanovanjske stroške (Svet Evrope 2010). V Sloveniji po statističnih podatkih (SI-STAT 2012) o stanovanjskih stroških kot velikem bremenu poroča leta 2011 kar 58 % najrevnejših gospodinjstev (2005: 48 %), v splošni populaciji je takih gospodinjstev 40 %. Stanovanjski stroški so bili leta 2011 veliko breme za kar 59 % najemnikov in za 58 % enostarševskih gospodinjstev z vsaj enim vzdrževanim otrokom. Z vsaj enim elementom stanovanjske prikrajšanosti se je leta 2011 spopadalo 40,7 % gospodinjstev pod pragom tveganja revščine (2005: 23,1 %), v splošni populaciji je takih gospodinjstev 34 % (2005: 18,4 %).

Na podlagi statističnih podatkov lahko razberemo, da so se stanovanjske razmere v Sloveniji v letih krize na nekaterih področjih zelo poslabšale tako za splošno populacijo kot za ljudi, ki živijo pod stopnjo tveganja revščine, posebej ogrožene skupine so najemniki in enostarševske družine z vsaj enim vzdrževanim otrokom. V primerjavi s povprečjem v EU lahko ugotovimo, da so stanovanjske razmere v Sloveniji slabše, saj so deleži stanovanjske izključenosti in prikrajšanosti večji. Slabše stanovanjske razmere povečujejo možnost za hude trajne zdravstvene težave, tudi za oviranosti, zato je nujno treba sprejeti ukrepe, ki bodo ljudem omogočili boljšo kakovost njihovih bivalnih prostorov, hkrati pa je treba omogočiti dostop do stanovanj, ki si jih bodo ljudje lahko privoščili, prav tako njihovo vzdrževanje in primernost za bivanje (dovolj velika, varna in predvsem trajna).

Revščina in slabe stanovanjske razmere povečujejo možnosti za oviranost

Oviranost in revščina sta dvosmerno povezana: hendikep veča tveganje revščine in revščina veča tveganje za oviranost. Za osebe z oviranostmi je verjetneje, da bodo brezposelne ali pa bodo zaslužile manj, če bodo zaposlene, nezaposlenost ali nižanje dohodka se povečujeta glede na stopnjo oviranosti, kot poroča Svetovna zdravstvena organizacija (WHO 2011). Zaradi vseh teh dejstev so gospodinjstva, v katerih biva oseba z ovirami, revnejša od drugih. Prav tako je za ta gospodinjstva verjetneje, da se spopadajo z materialno ogroženostjo; to vključuje negotovo preskrbo s hrano, slabše stanovanjske in higienske razmere, slabši dostop do pitne vode in neustrezen dostop do zdravstvenih storitev, kot na globalni ravni ugotavlja Svetovna zdravstvena organizacija (*ibid.*). Revščina ljudi z ovirami ne temelji zgolj na materialni izključenosti, temveč na družbeni izključenosti in nemoči, pomanjkanju uresničevanja njihovih potreb.

Revščina torej poveča možnost za pojav oviranosti. Povzroči lahko več zdravstvenih težav, predvsem pa se lahko zdravstvene težave v revščini poslabšajo do stopnje trajne oviranosti (zaradi nedostopnosti zdravstvenih storitev, stanovanjskih razmer). Položaj revnih oseb se s slabšanjem zdravstvenih težav oziroma s pojavom hendikepa še poslabša, osebo pahne v še večjo socialno izključenost. Oseba z izkušnjo revščine in hendikepa se hkrati znajde v začaranem krogu izključenosti, gre za večdimenzionalno izključenost.

V zadnjih letih se v skladu s povečevanjem števila brezdomnih in najrevnejših oseb povečuje tudi število oseb, ki obiskujejo ambulante in posvetovalnice za osebe brez zdravstvenega zavarovanja. V Ljubljani se je število uporabnikov od leta 2002 (89) povečalo za desetkrat, saj so jih v letu 2012 našteli več kot 900, številka pa je v letu 2014 presegla 1000.

Spreminja se tudi populacija uporabnikov, saj je vse več nekdanjih samostojnih podjetnikov, ki zaradi krize niso mogli plačevati socialnih prispevkov, nam je povedal zdravnik dr. Aleksander Doplihar, vodja ambulante v Ljubljani (osebni pogovori, september 2012–marec 2014). V ambulanti so opazili povečano število uporabnikov, ki niso slovenski državljani, povečuje se tudi število otrok. Zaradi neurejenih stanovanjskih razmer, pomanjkanja kopalnic in umivalnic veliko uporabnikov ne more vzdrževati niti osnovne osebne higiene. Doplihar poudarja, da so posledice težav večkrat tako hude, da uspešno zdravljenje ni več možno. Srečujejo se tako s hudo zanemarjenostjo (tudi z gnojnimi vnetji, zajedavci, nalezljivimi boleznimi) kot s podhranjenostjo, fizično izčrpanostjo in hudo okrnjenostjo imunskega sistema. Hude zdravstvene težave se pri brezdomnih osebah razvijejo v trajne, neozdravljive bolezni in okvare, ki so posledica tudi kronične zasvojenosti z alkoholom (okvara možganskega tkiva, tresavica, prizadetost živcev ipd.). Podobno ugotavljajo pri brezdomnih osebah, ki so zasvojene s tobakom, saj so posledice večkrat neozdravljive (kašelj, rakasta obolenja, astma, zamašitev ožilja). Izkušnje iz prakse tako kažejo, da pomanjkanje obravnave in nedostopnost zdravstvenih storitev zelo vpliva na zdravstveno stanje brezdomnih oseb. Bolezni in težave, ki jih splošna populacija preboli brez večjih zapletov, se pri brezdomnih osebah lahko hitro zapletejo in poslabšajo (osebni pogovori, september 2012–marec 2014).

Glas z družbenega obrobja

V kontekstu razumevanja povezave med izkušnjo brezdomstva in oviranostmi so izjemno pomembne osebne izkušnje brezdomnih. Zaradi specifične situacije večkrat ostanejo brez osnovnega in dodatnega zdravstvenega zavarovanja, to pa zelo vpliva na njihov dostop do storitev. Dostop do storitev je omejen tudi zaradi diskriminacij, ki izhajajo iz stigme brezdomne osebe, zato uporabljajo različne strategije za prikrivanje brezdomstva.

Če oviranosti definiramo v okviru zakonsko opredeljene invalidnosti na treh stopnjah, lahko pridobimo določene podatke o številu brezdomnih, ki se srečujejo s trajnim hendikepom. Uradne številke so vsekakor podcenjene, saj veliko brezdomnih nikoli ne začne pridobivati status invalida ali pa statusa zaradi različnih razlogov ne pridobijo, zato so ti podatki zgolj opis situacije na tem področju. Nekaj podatkov sta zbrala Špela Razpotnik in Bojan Dekleva v raziskavi o zdravstvenem stanju brezdomnih (Razpotnik, Dekleva 2009). Ugotovila sta, da je v vzorcu raziskave (122 brezdomnih iz celotne Slovenije, starih od 22 do 77 let, 84 % moških) invalidov prve stopnje 4,9 %, druge stopnje 1,6 % in tretje stopnje 13,9 %. V postopku pridobivanja statusa je bilo takrat 2,3 % brezdomnih, brez statusa pa je bilo takrat 76,2% udeležencev v raziskavi. To pa ne pomeni, da se niso srečevali s hudimi zdravstvenimi težavami ali oviranostjo.

Ko se brezdomni obrnejo na zdravstvene službe po pomoč, doživljajo različne odzive. Tisti, ki prejemajo denarno socialno pomoč ali druge prejemke (npr. invalidska pokojnina), imajo po zakonu urejeno tudi osnovno in dodatno zdravstveno zavarovanje (plačilo iz proračuna RS), zato se večinoma lahko obračajo na svoje osebne zdravnike in so napoteni tudi k specializiranim zdravnikom. Kljub urejenosti zavarovanja so na podlagi informacije, da bivajo v zavetišču oziroma nimajo urejene nastanitve, večkrat drugače obravnavani oziroma se odnos spremeni, ko ta podatek postane znan. Tako nam je poročal tudi Janez, eden izmed stanovalcev zavetišča v večjem slovenskem mestu:

> K zdravniku sem šel vedno urejen, umit, na zunaj se ni videlo, da sem brezdomec ali da sem v zavetišču. Enkrat pa je zdravnik slišal, da živim v zavetišču, in mi ob prihodu rekel, da naj grem pred pregledom najprej pod tuš. Bil sem čist in urejen, ampak sem to vseeno storil, ker me drugače ne bi hotel pregledati. (Janez, brezdomen uporabnik zavetišča, 60+ let, osebni pogovor, maj 2012.)

Podobno izkušnjo je imela tudi strokovna delavka, ki je v pogovoru o zdravstveni oskrbi brezdomnih povedala:

> Z njo sem morala prav do vrat zobozdravnika, jaz sem potrkala, saj so njej nazadnje zaloputnili vrata pred obrazom. Vprašala sem, če lahko koga sprejmejo, in dobila pritrdilni odgovor, nato sem pred sebe potegnila uporabnico in ji rekla, naj vstopi. Obrazi zdravstvenega osebja so bili zaprepadeni, vendar jim ni preostalo drugega, kot da jo sprejmejo. (Neobjavljen dnevniški zapis, december 2009.)

Izkušnje sogovornikov kažejo, da kljub hujšim zdravstvenim težavam ne dobijo dovolj zdravniške pomoči, saj naj je ne bi bili vredni toliko kot drugi. Večkrat je odziv zdravstvenega osebja, da so si za zdravstvene težave krivi sami, ker so se odločili za tak življenjski slog, prav tako se ob ponavljajočih se poškodbah ali težavah z uporabnikom ukvarjajo manj kot ob prvi poškodbi ali težavi. Takšna je izkušnja Štefana, uporabnika zavetišča v večjem slovenskem mestu:

> V zadnjem letu se mi je zdravje poslabšalo, večkrat sem padel in imel več zlomov na okončinah, zlomljeno sem imel ključnico, nogo. Od prve poškodbe naprej moram uporabljati bergle za pomoč pri hoji, zaradi zdravstvenih težav sem tudi prišel v zavetišče, saj ne morem več drugače. Zdravniki se z mano ukvarjajo manj, ker vejo, kdo sem, osnovno so mi pomagali, več pozornosti mi pa ne dajo. Rad bi šel v dom za stare, čeprav sem star nekaj čez 50 let, ampak mi občina noče doplačevati oskrbe, ker sem premlad, moje zdravstveno stanje pa naj ne bi bilo tako slabo, da bi moral v dom. (Štefan, brezdomen uporabnik zavetišča, 50+ let, hude zdravstvene težave, gibalna oviranost, osebni pogovor november 2012.)

Na podlagi povedanega lahko potrdimo, da ima veliko brezdomnih, ki imajo izkušnjo dolgotrajnega brezdomstva in življenja na cesti, hujše zdravstvene težave kot drugi ljudje enake starosti, ki teh izkušenj nimajo. Kljub izkušnjam, da je takih brezdomnih oseb več, se težko najdejo rešitve, ki bi jim omogočale varno namestitev, ki bi zagotovila izboljšanje zdravstvenega stanja. Zavetišča so tako prevečkrat »zadnja postaja« za veliko bolnih oseb oziroma, kot se je izrazil vodja enega izmed zavetišč v Sloveniji (Mirenski grad, 7. 3. 2013, srečanje mreže izvajalcev, neobjavljeno):

> Zavetišča postajajo hiralnice, saj drugih možnosti za namestitev hudo bolnih brezdomnih ni. Včasih dobimo primer, ko nekoga hospitalizirajo za en teden, potem ga pa zopet odpustijo in se vrne v zavetišče, po enem tednu ga zopet hospitalizirajo in to se vleče, dokler človek ne umre. V takih primerih si samo želim, da ne bi umrl pri nas.

Eden izmed paradoksov, s katerimi se srečajo brezdomni, predvsem tisti, ki nimajo strehe nad glavo, je odpust iz bolnišnice v »domačo nego«, svetujejo jim počitek, redno jemanje zdravil in zdravo prehrano. Gre za popolno prevlado medicinskega modela, ki spregleda posameznikovo konkretno situacijo. Vključuje zgolj redno jemanje zdravil in primeren življenjski slog, ta pa za večino brezdomnih oseb ni mogoč.

Podobno o tem piše tudi Uršula Lipovec Čebron (2007), saj pri interpretiranju zdravstvenih posledic izbrisa ugotavlja, da zdravstvene institucije reproducirajo vladne politike izključevanja. Primerjava pričevanj oseb z izkušnjo izbrisa in pričevanj brezdomnih oseb pokaže ne le podobno ranljivost za razvoj bolezni, temveč tudi podobnost mehanizmov izključevanja v zdravstvenem sistemu. Čeprav so izkušnje izključenosti podobne, pa je razlog za izključenost različen.

Brezdomne osebe pogosto imajo zdravstveno zavarovanje, saj do njega dostopajo prek pravice do denarne socialne pomoči, vendar pa se srečujejo z birokratiziranim zdravstvenim sistemom, ki se ne odziva na njihove življenjske situacije.

Ena izmed nekdanjih stanovalk v zavetišču za brezdomce v večjem slovenskem mestu je poročala o več zdravstvenih težavah, vendar si vseh zaradi finančne zdravil stiske ni mogla privoščiti. Zdenka je bila med najstarejšimi stanovalkami zavetišča (65+ let), tam je živela z zunajzakonskim partnerjem, ima pet otrok, vendar z vsemi zelo slabe stike, najmlajši je prav tako brezdomen kot ona, vendar ne živijo skupaj. V življenju je doživela veliko nasilja, že v otroštvu, pozneje so bili do nje nasilni partnerji, problem je bil tudi alkohol. Vse to je zelo vplivalo na njeno zdravje. Ima težave s čezmerno težo, sladkorno boleznijo, povišanim krvnim tlakom, zdravnikovih navodil glede spremembe življenjskega sloga, predvsem prehrane, ne more upoštevati, saj finančno ne zmore. Naporno delo na kmetiji in v tovarni je na njej pustilo veliko posledic, prav tako pet porodov. Zdenka tudi po selitvi v najemniško nastanitev ne more dovolj skrbeti za svoje zdravje, zato se ji stanje ne izboljšuje, jemlje zdravila, ki jih dobi na recept. Po spremembi zakonodaje o socialnih prejemkih leta 2012 pa je izgubila še del dohodkov, ker s partnerjem kljub nizkim pokojninam presegata cenzus, zato se je njena situacija še poslabšala.

Pretresljiva je tudi izkušnja starejše stanovalke, ki je v zavetišče prišla iz bolnišnične oskrbe po poškodbi, vendar doma ni imela možnosti kakovostne oskrbe – doma ni mogla živeti, ker zaradi poškodbe ne bi mogla skrbeti zase, saj živi v odročnem kraju, kuri na drva, ki jih mora vsak dan prinašati v stanovanje, skupnostne službe in sorodnikov, ki bi ji pomagali v tem obdobju, nima oziroma jih zavrača (Pirec Sansoni 2011). Njeno zdravstveno stanje se slabša, leta 2013 je bila spet hospitalizirana, vendar namestitev v zavetišče zanjo glede na zdravstveno stanje ni mogoča.

V pogovorih z brezdomnimi osebami pa slišimo tudi pozitivne izkušnje. Včasih se zdravstveno osebje še posebej zavzame, da je storitev kakovostna in da se zdravstveno stanje izboljša, pozitivne izkušnje imajo tudi s socialnimi delavkami in delavci v zdravstvenih ustanovah. O taki izkušnji nam je povedal Dani, eden izmed stanovalcev zavetišča, ki je invalidsko upokojen (star 50+ let) po dolgoletni uporabi nedovoljenih drog, s hudimi zdravstvenimi težavami:

> Po odhodu iz zapora sem bil zaradi slabega zdravstvenega stanja hospitaliziran, nabralo se mi je veliko stvari. Socialna delavka mi je predlagala, da bi šel v zavetišče, saj me doma niso hoteli vzeti k sebi. Dogovorila se je, da sem bil sprejet v zavetišče, saj zaradi slabotnosti ne bi mogel živeti sam, tudi dohodkov ne bi imel dovolj, da bi živel sam. (Osebni pogovor, avgust 2012.)

Njegova in še številne druge izkušnje kažejo, da je za zdravstveno najšibkejše brezdomne pot med zdravstvenimi ustanovami in zavetišči za brezdomce dokaj pogosta, ob izpolnjevanju pogojev pa se pozneje v veliki meri nastanijo tudi v domovih za stare.

Dani je poročal tudi o izkušnji postopka za odobritev operacije:

> Zdravnica me je napotila v bolnico na pregled k ortopedu in ta je ugotovil, da bi bila možna operacija. Po vseh pregledih so mi sporočili, da je zaradi slabega zdravstvenega stanja ne želijo opraviti, ker ne vedo, kakšne bodo posledice. Nisem bil prepričan, v čem je vzrok za nenadno odločitev. Kljub temu so mi čez nekaj dni sporočili, da operacija bo. Medicinska sestra je vložila veliko truda, da je šlo vse dobro, za to sem ji res hvaležen. Tudi na metadonski (metadonska ambulanta, kamor vsak dan hodi po nadomestno metadonsko terapijo; op. a.) so zelo prijazne, držim se dogovorov, zato mi veliko pomagajo. (Dani, invalidsko upokojen, 50+let, hude zdravstvene težave, osebni pogovor, avgust 2012.)

Izkušnje zaposlenih v organizacijah za brezdomne osebe v Sloveniji

Mreža izvajalcev na področju brezdomstva in socialno ranljivih skupin, ki deluje v Sloveniji, ugotavlja, da se prav v vseh organizacijah srečujejo z brezdomnimi osebami, ki bi nujno potrebovale prilagojeno obliko nastanitve zaradi svojih zdravstvenih težav, oviranosti in starosti. Večina se srečuje s problemom, da brezdomnih oseb v dom za stare ne sprejmejo, saj ne ustrezajo zahtevani starosti. A njihovo fizično stanje je tako šibko, da je to večkrat razlog, da jih domovi kljub temu sprejmejo. Taka rešitev je odvisna od posluha lokalne skupnosti (doplačevanje namestitve) in angažmaja strokovnih delavk in delavcev. V društvu Kralji ulice eno hišo namenjajo samo nastanitveni starejših, žal pa se pojavlja konkreten problem, saj strokovni delavci in delavke na področju socialnega varstva načelno niso usposobljeni za opravljanje zdravniške oskrbe in nege, kot poročajo strokovne delavke in delavci iz celotne Slovenije. Večkrat oseba prej umre, preden se njen status vsaj delno uredi. Položaj brezdomnih oseb z oviranostmi in hudimi zdravstvenimi težavami v Sloveniji se zdi veliko slabši za tiste, ki se znajdejo na ulici, kot za osebe, ki so nastanjene v različnih podpornih oblikah namestitve. Strokovne delavke in delavci ugotavljajo, da se osebe večkrat odločijo za namestitev v zavetišče, šele ko je njihovo zdravstveno stanje tako slabo, da ne morejo več bivati na ulici ali v drugih netrajnih oblikah namestitve (osebni pogovori s strokovnimi delavkami in delavci na področju brezdomstva, januar 2013–marec 2014).

Strokovni in drugi delavci in delavke v slovenskih zavetiščih poročajo o različnih izkušnjah dela z brezdomnimi, večina ima hujše zdravstvene težave, nekateri imajo tudi trajen hendikep. Skupne so jim težave pri nastanitvi oseb, ki potrebujejo še posebej intenzivno nego in zdravstveno oskrbo, saj nimajo zaposlenega zdravstvenega osebja, sami pa nimajo znanja, ki bi jim omogočalo izvajanje nege. Večina storitev za brezdomne (nastanitvenih in drugih) se srečuje s kadrovskimi težavami, zato je zanje ne/zaposlitev zdravstvenega osebja velika ovira. Težave rešujejo s sodelovanjem z zdravstvenimi ustanovami (npr. patronažna služba). To sodelovanje je vzajemno, saj v veliko primerih zavetišča sprejmejo uporabnike po odpustu iz bolnišnic. S kakovostnim sodelovanjem med organizacijami, ki delajo z brezdomnimi in zdravstvenimi ustanovami, se povečuje tudi ozaveščenost zdravstvenega osebja o specifičnih potrebah brezdomnih ljudi, zato strokovni delavci večkrat delujejo v vlogi zagovornika za brezdomno osebo. Slabšo ozaveščenost in v nekaterih primerih tudi strah zdravstvenega osebja kaže anekdota, ki se je zgodila v enem izmed slovenskih zavetišč. Strokovna delavka nam je v osebnem pogovoru (oktober 2012) povedala:

> Za stanovalca [zavetišča za brezdomne], ki je bil odpuščen iz bolnišnice po operaciji, smo poklicali patronažno službo, saj je bilo potrebno rano prevezati, zaposleni pa tega znanja nimamo. Na naše presenečenje je prišel medicinski tehnik, ki nam je povedal, da so sestre poslale njega, ker same niso upale priti. Po njegovi pozitivni izkušnji je čez nekaj dni prišla tudi patronažna sestra.

Ta izkušnja kaže, da sta delo z zdravstvenimi delavci in refleksija o njihovih stereotipih ter strahovih pri delu z brezdomnimi in drugimi ranljivimi skupinami nujno potrebna. Uporabnik zavetišča za brezdomne Dani nam je namreč poročal tudi o neprijetni izkušnji, ki jo je imel s svojo osebno zdravnico. V ambulanto je poklicala varnostnika, ker se kot pacient ni strinjal z njeno odločitvijo o koncu zdravljenja in se ga je ob nestrinjanju ustrašila. Varnostnik ga je potem odpeljal iz ambulante, čeprav je izjemno šibkega zdravja, pri hoji uporablja bergle in je na sploh izjemno miren (osebni pogovor, avgust 2012).

Strokovni delavci in delavke poročajo tudi o težavah z dostopnostjo in uporabo prostorov za stanovalce z oviranostmi. Vodja enega izmed zavetišč opaža problem pri dostopu do pogradov:

> Večina ima zdravstvene težave v tej meri, da ne morejo dostopati do vrhnjega ležišča na pogradu, zato se trudimo, da ležišča kar najbolj prilagodimo, da lahko dostopajo tudi tisti, ki so gibalno bolj ovirani. (Osebni pogovor, oktober 2012.)

Brezdomne osebe z oviranostmi so še bolj socialno izključene kot drugi brezdomni, težje dostopajo do zdravstvenih in socialnih storitev, tudi do storitev za brezdomne, saj obstajajo tako kadrovske kot arhitektonske ovire. Ocenimo lahko, da se vzpostavljene storitve trudijo prilagoditi raznovrstnosti potreb uporabnikom, kljub temu pa zaradi različnih omejitev ne morejo ugoditi vsem, prav tako iščejo rešitve, da bi brezdomnim osebam omogočili čim bolj prilagojeno namestitev.

Kako naprej?

Brezdomne osebe in osebe, ki živijo v stanovanjski prikrajšanosti, so zdravstveno bolj ogrožene kot splošna populacija, njihovo zdravje je slabše od zdravja splošne populacije. Še posebej ogroženi so otroci in ženske, med brezdomnimi pa tisti, ki imajo izkušnjo dolgotrajnega življenja na ulici oziroma v nastanitvah, ki niso trajne. Stanovanjske razmere v Sloveniji so slabše od povprečja Evropske unije, s posledicami krize se situacija še slabša. Posledice krize vplivajo tako na stanovanjske razmere ljudi, njihovo sposobnost za plačevanje stanovanjskih in drugih stroškov kot na njihovo zdravje. S krizo se število brezdomnih oseb povečuje, a trend povečevanja brezdomstva v Sloveniji je opazen že od leta 1990. Revnejši in stanovanjsko izključeni ter brezdomni imajo slabši dostop do storitev, verjetnost, da se bo njihovo zdravstveno stanje izboljšalo, je manjša kot pri splošni populaciji. Na njihovo zdravje vpliva več dejavnikov tveganja, prav tako so jim izpostavljeni dlje časa kot splošna populacija.

Pri zagotavljanju zdravstvene oskrbe ranljivim skupinam je treba izhajati iz njihovih potreb in dejanskega življenjskega okolja. Za izboljšanje zdravstvenih storitev sta potrebni ozaveščanje zdravstvenega osebja in izobraževanje za delo z brezdomnimi. Sodelovanje med socialnim in zdravstvenim sektorjem je treba tako okrepiti, da se bodo storitve dopolnjevale, saj poleg zdravstvene oskrbe večina brezdomnih potrebuje tudi druge oblike pomoči, kot zelo dobro pokažejo izkušnje Ambulante Pro bono v Ljubljani.

Na sistemski ravni je treba razmišljati v smeri organizacije specifičnih služb za posebej ranljive skupine brezdomnih in drugih skupin prebivalstva. Nujno je treba uvesti spodbude za ljudi, ki želijo izboljšati stanovanjske razmere, saj bo to pozitivno vplivalo tudi na njihovo zdravje. Slovenija potrebuje tudi strategijo za reševanje brezdomstva, ki bo vključevala celostno analizo in načrt storitev, tako kratkoročnih namestitev kot trajnejše namestitvene podpore. Pomemben korak k celostni obravnavi problematike stanovanjske izključenosti in brezdomstva v Sloveniji je formalizacija mreže izvajalcev na področju brezdomstva in socialno ranljivih skupin.

V okviru stanovanjske politike je treba omogočiti večjo dostopnost ugodnih stanovanj, povečati število neprofitnih stanovanj in omogočiti lažji dostop do njih tudi skupinam prebivalstva, ki zdaj niso opredeljene na prednostnem seznamu za neprofitna stanovanja. Omogočiti je treba spodbude tudi za trg tržnega najema, na primer uvesti olajšave za najemodajalce ranljivim skupinam.

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PEOPLE WITH DISABILITIES AT THE EUROPEAN SEMI-PERIPHERY

The case of Bosnia

The right to full participation in society shall theoretically apply to all citizens. However, segments of society, such as people with disabilities, are often denied full participatory citizenship through different mechanisms of social exclusion. The article will outline major sources and mechanisms of social exclusion of people with disabilities in a post-conflict, transitional post-socialist country at the Europe's semi-periphery.

Key words: poverty, social exclusion, disabled people, Bosnia-Herzegovina.

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LJUDJE Z OVIRAMI NA EVROPSKI POLPERIFERIJI: PRIMER BOSNE

Pravico do sodelovanja v družbi naj bi imeli vsi ljudje. Vendar pa je določenim skupinam, kot so ljudje z ovirami, to participativno državljanstvo onemogočeno. Članek opiše poglavitne vire in mehanizme družbenega izključevanja ljudi z ovirami v pokonfliktni, tranzitni posocialistični državi evropske polperiferije.

Ključne besede: revščina, socialna izključenost, hendikep, Bosna in Hercegovina.

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Introduction

Bosnia-Herzegovina is a small country located in the western part of the Balkan Peninsula. Historians agree that Bosnia is the country in which the 20th century started (with the assassination of Archduke Franz Ferdinand in 1914) and ended, with the siege of Sarajevo (1992–1995). Since the fall of the Berlin Wall, South-Eastern Europe – Europe's semi-periphery – has been subject to transition, westernization and Europeanization. Among these countries, the Bosnian transitional experience is a very unique one: the societal crisis has been a permanent state of affairs for the last two decades. Initially, the crisis was triggered by destructive nationalist political ideologies in the context of dissolution from Yugoslavia, which culminated in the war against Bosnia 1992–1995. Instead of putting an end to the crisis, the Dayton Peace Agreement of 1995 cemented ethnic divides in political and everyday life, leading to the state which psychologists would inevitably label the 'crisis of exhaustion'.

The lack of social cohesion is probably the most defeating consequence of this prolonged crisis. Contemporary Bosnian society faces many lines of division. They are structured around ethnic, political, economic, educational, religious, age, gender, and even residential divides. Until recently, the one relating to disability has been hidden, almost invisible, even though according to estimates 10% of Bosnian citizens face physical, sensory, developmental, mental or emotional disabilities, while an additional 30% of the population are directly or indirectly affected by consequences of disability (Governmental Office 2008). The total number of people with disabilities is not known, but for the a country of an estimated 3.4 million inhabitants, it is a number that cannot be ignored or overlooked.

The following article looks at how such an over-burdened post-conflict and transforming society deals with discriminating, ghettoizing and excluding politics and practices towards people with disabilities.

Disability studies in Bosnia-Herzegovina

Is there something like 'disability studies' in Bosnia? The answer to this question is rather ambiguous. Practically, the heritage of the psycho-medical approach to disability which dominated scientific discourse and the practical approach of many disciplines which routinely encountered people with disabilities (medicine, psychiatry, pedagogy, psychology, and social work) during the socialist era is still present. However, it would be untrue to assert that nothing has changed in the past two decades.

We bear witness to diverse and, to a certain degree, fruitful attempts which promote questioning of the legacy of the psycho-medical paradigm of disability, emphasising impairment itself and the various ways it limits the capability of an affected person, while neglecting the societal input in the construction of disability and the creation of a wide range of often insurmountable physical, normative, and socio-cultural obstacles contributing to the exclusion of people with disabilities from the rest of society.

Initially, it was not a genuine, intrinsic societal transformation towards embracing diversity. New rhetoric, new ideas and approaches promoting a social constructionist perspective on disability were introduced from outside: they were brought by numerous international organizations involved in the peace-building process in the aftermath of the conflict. Namely, the Dayton Peace Agreement, which ended the conflict in 1995, paved the way for the country's development in the framework of a semi-protectorate. Without a precedent in the modern history, the peace-building process (and subsequently transition to democracy and market economy) was to be sustained by many international governmental and non-governmental actors involved in (de) construction of every aspect of the former institutional framework for functioning of the society. Thus, the organizations involved in the process of reform in the fields of education, social welfare and health care inaugurated innovative theoretical approaches and scientific discourses, and introduced new models of practice which were almost instantly transposed in different scientific fields, disciplines and professions. By combining recent theoretical frameworks (social model of disability, social-constructionist theory, community care approach) with high quality empirical research in different aspects of disability in a national context, it can be claimed that all these processes give impetus to growing resistance against oppressive and exclusionary institutions and practices.

Taking into consideration the enormous consequences of the war on diverse population groups, it is understandable that what might be defined as the disability studies dealt with the effects of war-related trauma on mental health in refugees, disabled war veterans and children (Mollica *et al.* 1999, Mollica *et al.* 2001, Hastie 1997). By linking trauma to disability, these studies paved the way for the reform of mental health care, which was introduced as early as 1996 in the context of the war-related collapse of former psychiatric institutions and the shift to community mental health. In the course of this transition, the focus of the international community has shifted from adult people with intellectual disabilities towards children with disabilities, especially children with intellectual disabilities. For almost half of the century during state socialism, social exclusion of these children was institutionalized and sustained through their exclusion from the ordinary education system.

Therefore, a new educational paradigm was developed which criticized the prevalent practice of separate schooling systems for disabled and non-disabled children. Educational scientists started advocating for the rights of children with intellectual disabilities to inclusive education (Pašalić-Kreso 2003, Cerić, Alić 2005, Cerić 2008). Critical voices were raised also from a social work perspective. Informed by the premises of a social model of disability and new concepts of community care, existing practices of institutionalized care have been questioned and preventive approaches promoted (Miković 2011). Further, the importance of service user's involvement, including people with disabilities, in social work practice has been emphasized (Basić 2009).

Large international organizations interested in (child) wellbeing – particularly Unicef BiH and Save the Children UK – contributed extensively to ongoing academic debates and advocacy campaigns by providing empirical data linking child disability to particular aspects of life like for instance:

- the data on the quality of life (PRISM 2006, UNDP 2007, Unicef 2008, Institucija ombudsmana za ljudska prava BiH 2010, Svraka *et al.* 2011);
- educational issues (Save the Children 2008, Unicef BiH & Save the Children UK 2009);
- social attitudes towards children with disability in society (Unicef 2013);
- the representation of children's disability in the media (Unicef 2010) and more.

In addition, there was some research focusing on the situation of adult people with disabilities within the labour market (Fondacija za socijalno uključivanje 2014), and their situation within the social protection system (OSCE 2012). In recent years, it became quite common to use a regional perspective in shedding light on how disability is presented in the media (Adams 2008 a); how to promote community living for people with disabilities (Adams 2008 b); what is the role of diverse social institutions such as family in securing full and participatory citizenship, freedom and equality to all (Bećirević, Dowling 2012).

At the advocacy level, the participation of evolving organizations of people with disabilities – especially non-traditional ones, such as associations of parents of children with autism or learning disabilities – equipped with new communication technologies (Internet, social media) started creating space and opportunities to express non-dominant perspectives in relation to issues of marginalization and stigmatization, and put forward an agenda for inclusion.

Poverty and social exclusion among Bosnians – brief overview

The most painful implication of social transformation to a neo-liberal market economy at the European semi-periphery has been impoverishment. In Bosnia, a complex interface of factors in the realm of political, economic and social, and among the most important, growing unemployment, continuing political and social obstruction, inadequate organization of social state, poorly performing education and health system as well as widespread corruption has led to ever growing poverty among Bosnian citizens. This in turn has produced strong tendencies towards social exclusion among elderly, children and youth, women and displaced persons, but especially among people with disabilities.

It might appear quite optimistic that if assessed by using the Human Development Index – a three-composite measure of life expectancy, education and standard of living, Bosnia-Hercegovina is ranked in 74th place of 172 included countries worldwide. Nevertheless, looking from the South-Eastern Europe perspective, the country is lagging far behind other countries in the SEE region.[1]

More realistic and detailed indicators of the extent and structure of poverty, as well as the relative vulnerability of groups at risk of poverty, are provided by the Living Standard Measurement Survey (Agency for Statistics of FBiH 2001) conducted jointly by the World Bank and UNDP in 2001, and lately by domestic statistic offices in 2004 and 2007.

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[1] Most developed in the region seems to be Slovenia placed in 21nd position, followed by Croatia (46), Montenegro (54), Serbia (59) and Albania (70).

Empirical data on the extent of impoverishment was shocking: it showed that in 2001, 19.5% of the Bosnian population lived under the general poverty line[2], while an additional 30% of the population were slightly above the general poverty line and greatly vulnerable to induced economic reforms. According to the last available LSMS data from 2007, 639,781 out of approximately 3.4 million inhabitants, or 18.56% live under the general poverty line[3]. Additionally, 22.9% of the population is at risk of poverty. Poverty is frequently present in families with 3 or more children, unemployed and working poor, and people with disabilities which together form 40% of those living in poverty. Actually, people with disabilities are one of the largest groups to experience poverty, as disability increases the probability of being poor by 18% (Governmental Office 2010). Indeed, poverty seems to be not only economically, but also socially connoted: lack of economic resources is accompanied by a sense of dependency, hopelessness and powerlessness, as reflected in the research on social exclusion published in 2007 by UNDP.

Based on seven Laeken indicators (these are European statistical indicators) in the areas of living standards, health, education, participation in society and access to services, indices of general, extreme and long term social exclusion have been calculated. The results obtained were alarming: the general social exclusion index was 52.32%, meaning that half of the population is socially excluded in at least one of the measured areas, out of which 21.85% were being extremely excluded from the most basic processes and needs, while 47.31% are facing long term exclusion (UNDP 2007).

The ‘excluded’ in Bosnia are a heterogeneous group made up of elderly, youth, displaced, Roma and people with disabilities. The intersection of two or more cumulative factors (such as being an old woman with disability) leads to multiple discrimination with lasting and devastating effects on quality of life. The most deprived seem to be women, children and Roma with disabilities.

The drivers of social exclusion of people with disabilities

Social exclusion of people with disabilities takes very practical forms visible in the limited access of this population to key areas of social life, such as social welfare, health care, education and employment. The major source of exclusion at the societal/state level is discriminatory legislation which enables different, unequal level of social rights not only for different populations (disabled and not-disabled), but also for members of the same group/population, as will be shown in the following analysis.

The partial transformation of the social protection system

The most peculiar feature of social welfare provisions applicable to people with disabilities in Bosnia is institutionalized discrimination based on the origin or cause of the disability. It divides people with disabilities in three groups: disabled war veterans from the war for independence which took place in the 1990’s, disabled civilian war victims and people with non-war related disabilities. Depending on their status, different levels of social rights are provided to beneficiaries: the most favourable position is enjoyed by the group of disabled war veterans. The position of civilian war victims is less favourable than that of war veterans, but nevertheless more favourable than that of non-war related disabled people. The discriminatory treatment is visible at the level of benefits, eligibility criteria and administration

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[2] In 2001, the general poverty line was set at the consumption of less then cca. 2000 KM (app. 1000 EUR) per household member per year.

[3] In 2007, the general poverty line was equivalent to consumption of less then 2857,31 KM (cca. 1465 EUR) per household member yearly.

of social assistance. For example, financial assistance/in-cash benefits for the same form and level of disability can vary between 41 KM (31.72 US Dollars) and 1700 KM (1,147.37 US Dollars) depending on the status of the person with a disability.

In addition to financial assistance, the social protection system offers two additional forms of benefits: institutional care and placement in another family. In the last two decades, social workers employed in centres for social work – key institutions of social welfare at municipality level – made tremendous efforts to move beyond the medical model of disability and towards new approaches to (social) work with people with disabilities. New types of social services are being developed, such as in-home care, personal assistants schemes, day centres for children and adults, psychosocial support to children and youths with developmental problems, etc. However, the fact that most disabled people still face institutional care cannot be ignored or overlooked. The trend to deinstitutionalisation progresses slowly, alternative forms of care, such as community living, are not sufficiently available and even if present, have very limited financial capacity.

Problematic health care

Despite the nominal coverage of Bosnian citizens by the compulsory health insurance scheme, there are estimates that 19% of the population is not covered by health insurance (ICVA 2010). Given that access to health care depends on the form of insurance, a large proportion of the population, especially vulnerable groups, face difficulties in accessing proper health care. Again, within the health care system we find the same mechanism of unequal treatment based on the origin or cause of disability, which favours one group of disabled people over others, as described above.

Consequently, persons with disabilities have varying degrees of health protection, from full access, to highly limited access to the health care system for non-war related disabled persons. Moreover, there are also many (architectural) barriers which prevent persons with disabilities from enjoying the same level of health care as the rest of the population, such as inaccessible buildings, nurses stations which are inaccessible for people using wheelchairs, no sound signals for the visually impaired, no written signs for the hearing impaired, and general unavailability of equipment for gynaecological treatment of women in wheelchairs, etc.

Towards inclusive education

Prior to reforms started in 2006, education for children with disabilities was provided either through the regular school system, for children with physical disabilities, or through ‘special education’ for all other disabled children. In 2006, an ‘Action Plan for Inclusion of Children with Special Needs in Regular Education’ was adopted, paving the way for inauguration of a model of inclusive education for all children. It was a huge step forward in securing a higher degree of social integration for children with disabilities through access to education, yet coupled with serious challenges in the realm of pedagogical and infrastructural dimensions. As reforms have been introduced, primary and secondary school teachers generally have not been adequately prepared to work with disabled children. In addition, school buildings had not been adapted to suit the needs of this population. The issue of inaccessible school buildings is compelling even today, especially in secondary schools in remote rural areas. Pedagogical deficiency has been to a certain degree addressed by formal and informal education of teachers and other professionals in the schools. Additionally, for the past few years, schools have tended to take on interns – social workers to serve as personal assistants to children with special needs. As the official evaluation of these programs has not yet been conducted, for now we can only rely on informal feedback received from our students. In their experience, children covered by the program achieve better learning outcomes, experience less stress resulting from often inaccessible and not-understandable teaching content, and are more successful in socialising with classmates and better integrated in the classrooms.

Limited access to employment

Until 2008, Bosnia experienced steady, but jobless, economic growth, giving rise to massive unemployment, which is today the most difficult economic, social and developmental problem facing the country. According to official statistics, activity rate in 2013 was 43.6%, employment rate 31.6% and unemployment rate 27.5% (Agency for Statistics 2013). As labour market statistics do not include disability as a parameter, there are no data on employment and unemployment rates among this population.

In theory, access to employment – in terms of paid work – is considered to be the first and foremost barrier to poverty and social exclusion. In order to strengthen the capacity of labour markets to absorb actual and incoming labour forces, which would be inclusive towards people with disabilities, the government adopted legal frameworks (such as laws on professional rehabilitation, education and employment of people with disabilities) and created corresponding institutions. However, the results are rather modest: in 2012, research with employers in the Federation of Bosnia and Herzegovina showed that people with disabilities are the least employable population – only 14.22% of employers would employ an individual with disabilities (Federal Employment Office 2012).

Stigmatisation and social isolation

Traditionally, one of the key features of societal attitudes towards people with disabilities has been the persistent degree of their isolation and stigmatisation. Bosnian society had an ambivalent attitude to disability: on the one hand, there was a sense of obligation to provide support, and, on the other hand, the programs of social support have been repressive, isolating, and segregating in effect. Disability has been considered as abnormal, and deviant. Given the social stigma which surrounded disability, it is no wonder that families kept their disabled children hidden. When disability was identified – sometimes as late as when the child reached school age, they were ordinarily referred to special schools, closed communities of like-minded children, seen rarely and even then only on carefully chosen occasions. As adults, they continued living within the narrow confines of family and school or work environments, not daring to ask for more inclusionary life opportunities. In this way, cultural norms and social barriers rendered them invisible solely on the ground of their personal characteristics. Consequently, patterns of internalized oppression are still found in the realm of linguistics: many associations of people with disabilities even today bear the designation ‘invalid’ in their official titles, even though it disappeared from public discourse long ago.

Looking forward

In 2008, the government adopted a document called ‘Disability Policy in Bosnia-Herzegovina’. By describing exclusion as the denial or non-realisation of political, economic, cultural, and social rights, the document promotes a rights-based approach to disability. In 2009, the Ministry of Civilian Affairs finally put forward the proposal to ratify the UN Convention on the Rights of People with Disabilities. The Convention and the Optional Protocol were ratified in March 2010 (12/03/2010).

If implemented properly, in the next decade it might bring equal freedoms and rights for all people with disabilities. As social workers we should insist that the main catalyst in promoting a socially inclusive approach should be empowered disabled people themselves who are very capable of using available social resources in order to actively engage, participate and influence decision-making processes affecting their lives.

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Michael Rasell, Elena Iarskaia-Smirnova (ur.) (2014)

Disability in Eastern Europe and the Former Soviet Union

History, policy and everyday life

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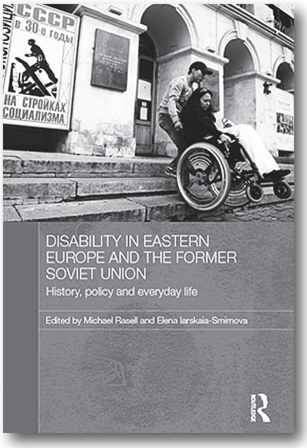
Koristnost perspektive, ki jo prinaša preučevanje koncepta hendikepa za napredek razumevanja Vzhodne Evrope, skoraj vsake njene regije, postane jasna šele, ko pojem hendikepa razumemo kot kompleksen družbeni in kulturni konstrukt (str. 3).



Petnajst avtoric in avtorjev, ki so prispevali članke v knjigi *Disability in Eastern Europe and the Former Soviet Union: History, policy and everyday life*, je v monografiji predstavilo nabor raziskav vzhodnoevropske regije. Regija, v katero urednika uvrščata države nekdanje Sovjetske zveze in Jugoslavije, ki zdaj vključujejo vzhodnoevropske članice Evropske unije, Balkan, Rusijo in zahodni Kavkaz ter srednjeazijsko regijo, ima številne skupne značilnosti, kot najpomembnejšo pa omenjata obdobje socializma in za njim postsocializma ter izhodiščno sorodne usmeritve politik, ki urejajo življenja ljudi z ovirami. Kljub nekaterim zgodovinskim podobnostim urednika poudarjata, da države v vzhodni regiji kljub socialistični zapuščini nimajo le enega modela za obravnavanje hendikepa, temveč, prav nasprotno, da je bilo teh modelov tako v zgodovini kot tudi danes več.

Knjiga daje glas več kot 30 milijonom oseb z ovirami, ki bivajo v Rusiji in Vzhodni Evropi. Iz zgodovinske perspektive odkriva izvor zapuščin, ki še danes vplivajo na vsakdanje življenje ljudi z ovirami v regiji. Avtorice in avtorji razpravljajo o družbenih vidikih hendikepa, pri tem pa še posebej poudarjajo družbene predpostavke, ki konstruirajo hendikep in na podlagi katerih ljudje z ovirami v regiji izoblikujejo lastno identiteto in vlogo v družbi. Avtorice in avtorji so predstavili tudi poglobljene biografije oseb, ki prikažejo vsakdanje življenje ljudi z ovirami v regiji, in preučijo posege v lokalno zakonodajo in zunanje vplive nanjo, najnovejše reforme in težave pri implementaciji inkluzivne, skupnostno usmerjene podpore.

Novejši vplivi – na primer neoliberalne socialne politike in ideje o socialni inkluziji – se v regiji prepletajo z nekdanjimi socialističnimi socialnimi programi, institucijami in stališči, a v vsaki državi so okoliščine nekoliko drugačne. Urednika tako raje kot o neposrednih zapuščinah socializma pišeta o rekombinaciji ostankov starega reda. Opozarjata na odstopanja od tradicije, na primer od zaprtja »posebnih« šol v Armeniji, in na procese dezinstitucionalizacije v nekaterih drugih državah v regiji. Nabor prispevkov, zbranih v knjigi, prikaže raznovrstne vidike študija hendikepa v državah Vzhodne Evrope in nekdanje Sovjetske zveze, kritično pa se oddalji od metaanalize ali sistematične primerjave »postsocialistične« perspektive hendikepa, saj bi tak pristop po mnenju urednikov preveč posplošil in poenostavil kompleksno dinamiko dogajanja na področju ljudi z ovirami v regiji.

Urednika sta poskrbela, da je v naboru avtoric in avtorjev zastopano zelo veliko držav iz regije, še pomembneje pa je, da so predstavljeni različni vidiki in razvoji na področju hendikepa.

Michael Rasell in Elena Iarskaia-Smirnova opozorita na to, da sta vzhodnoevropska regija in nekdanja Sovjetska zveza nehomogeni območji. Koncept hendikepa se je v vsaki izmed držav v obdobju postsocializma dograjeval na svojevrsten način, najpogosteje pod velikim vplivom in pokroviteljstvom zahodnih institucij in finančnih virov. Poudarjata tudi, da v regiji kljub številnim programskim in političnim spremembam prevladuje medicinski model obravnave hendikepa kot del socialističnega izročila, ki normira posameznikovo telo. Uvodno poglavje, ki ga prispevata urednika, se ukvarja z raznovrstnimi predstavami o zdravju, estetiki in telesu, ki so razširjenje v vzhodnoevropskem družbenem in političnem diskurzu. Državne zdravstvene in socialne institucije z začetka 18. stoletja avtorja uvrščata v širši sistemi »bio-oblasti«, kot ga prvotno zastavlja Michael Foucault. Institucije so prostori diskurzov, kjer država izvaja oblast nad telesi in prostori, v katerih se ohranjajo načini, na katere razmišljamo o človeški (ne)normalnosti, manifestirani v telesih ljudi z ovirami.

V drugem poglavju Beate Fieseler preuči sovjetsko socialno politiko skozi prizmo materialne skrbi za vojne veterane. Razišče, koliko je Sovjetski zvezi uspelo zagotoviti »vseobsegajočo skrb« veteranom (to je veljalo za »sveto dolžnost«), kako je zadovoljevala pričakovanja in kako je pripravila vojne veterane z ovirami, da kljub svoji oviri izpolnijo dolžnost do države (str. 18). Avtorica evidentira več prizorišč, na katerih se dogajajo stiki med državo in vojnimi veterani: proces uradnega priznanja hendikepa; pokojnine in denarni dodatki za vojne veterane; proces reintegracije vojnih veteranov s hendikepom v delovno življenje; njihovo (ne)zadovoljstvo s sovjetskim socialnovarstvenim sistemom. Ugotavlja, da v sovjetskem socialnovarstvenem sistemu vsi ljudje nimajo enakega dostopa do socialnovarstvenih storitev, saj daje prednost tistim osebam, ki so kljub svoji oviri zmožne opravljati pridobitno delo, s tem pa ustvarja hierarhijo med prejemniki socialnovarstvenih storitev.

V naslednjem poglavju Frances Bernstein opiše primer praktične in zlasti simbolne funkcije protetičnih okončin, ki so po drugi svetovni vojni veljale za eno ključnih tehničnih iznajdb takratne dobe. Zlasti protetične roke so bile upodobljene kot moški objekt, ki predvideva moškega prejemnika. Hendikep je bil tesno povezan z grožnjo feminizacije, torej je proces rehabilitacije vseboval tudi elemente vnovičnega uveljavljanja tradicionalnih spolnih vlog. Avtorica zapiše tudi, da so ženske, kljub enakim telesnim poškodbam kot moški, prejele in uporabljale neprimerno manj protetičnih okončin. K pomembnosti teme pripomore tudi simbolni pomen roke in dlani; zanj avtorica trdi, da je bil v poznostalinistični Rusiji ključni propagandni simbol, ki je ponazarjal boljševiške vrednote in moralo.

Elena Iarskaia-Smirnova in Pavel Romanov v tretjem poglavju pojasnita vpliv ikonografije hendikepa v sovjetskem filmu. Razkrijeta sporne in hitro izmenjujoče se pomene, povezane z vizualnimi podobami teles z ovirami, ki so vplivale na politični diskurz sovjetske družbe, ki je delil državljane na običajne in neobičajne. Vpliv, ki ga je imel film na celotni družbeni diskurz, pa je bil še toliko večji, ker je bil film po oktobrski revoluciji sredstvo za vzgojo državljanov, uporabljeno za državno propagando (str. 73).

Agita Lūse in Daiga Kamerāde v četrtem poglavju pišeta, da so v zadnjih dveh desetletjih psihiatri, zaposleni v Latviji, zaradi želje po bolj uveljavljenem mednarodnem statusu in privlačnejši podobi v očeh domače javnosti občutno razširili meje svoje stroke in vključili bolj inkluzivne koncepte duševnega zdravja. Avtorici navajata, da je posledica takšnega pristopa nova opredelitev koncepta duševnega zdravja, ki vključuje veliko širši nabor duševnih stanj (str. 100). Pišeta, da psihiatri zdaj lastno ekspertno znanje zastavljajo precej širše: ne vključujejo le znanja o dolgotrajnih in hudih duševnih stanjih, temveč tudi o vsakodnevnih, prehodnih in razširjenih duševnih stiskah. Tako se želijo oddaljiti od sovjetskega izročila, ki temelji zlasti na institucionalizaciji, in se približati zahodnim modelom duševnega zdravja. Svoje izsledke utemeljujeta s pregledom strokovne literature, intervjuji in vsebinskimi analizami tiskanih medijev.

Eszter Gábor obravnava življenje z oviro na Madžarskem in ugotavlja, kako mladi ljudje z ovirami na Madžarskem doživljajo vsakodnevno življenje z oviro in kako ta vpliva na oblikovanje osebne identitete. V kritičnem pregledu življenjskih zgodovin študentov in študentk z ovirami na Madžarskem avtor prepozna tri teoretske načine, na katere se hendikep vključuje v posameznikovo biografijo, vrste biografij pa deli na tri zglede: (a) *v cilj usmerjena borec in borka*, ki v življenju doživljata nestabilne medčloveške odnose, ključni ljudje pa ključnih želja ne podprejo; (b) *delovanje in prilagajanje,* pri katerem je posameznikovo življenje zelo zaznamujejo bolezen ali izguba in občutki krivde, v lastnem življenju pa si želijo običajnosti; (c) *podpornik in aktivist/aktivistka* – oseba ni ujeta v vlogo žrtve, temveč je aktivna, čeprav je posameznikova ovira eden izmed poglavitnih delov osebne zgodbe. V razpravi poudari tudi, da je bil za študente z ovirami, ki so sodelovali v raziskavi, ključen tudi sam študij na terciarni ravni, saj je občutno pripomogel k razvoju pozitivne samopodobe.

Teodor Mladenov v sedmem poglavju obravnava predmet spolnosti ljudi z ovirami v sodobni Bolgariji. Zapiše, da se je v zadnjem desetletju pojavilo veliko poročil o neenakopravnosti, segregaciji in zatiranju, ki jih doživljajo ljudje z ovirami v Bolgariji. Skupaj z burnimi spremembami, ki so se dogajale v Bolgariji ob prehodu iz enopartijskega sistema v parlamentarno demokracijo, so bile (zgolj na videz) ogrožene tudi do takrat jasno določene ločnice, ki so utemeljevale narod, ideologijo in kulturo. Avtor v prispevku ugotavlja, da so negativni in stereotipni odnosi do vprašanj etničnosti, spola, spolnosti in hendikepa ostali večinoma nespremenjeni, čeprav so postali kulturni viri (dostop do informacij, potovanja v tujino, internet), ki so bili v prejšnjem političnem sistemu redki ali celo prepovedani, širše dostopni.

Sarah Phillips se v osmem poglavju ukvarja s povečevanjem števila gibanj oseb z ovirami skozi prizmo aktivnega državljanstva v postsovjetski Ukrajini. S prispevkom želi pojasniti kompleksne procese, v katerih se ljudje z ovirami spreminjajo v določene vrste državljanov v spreminjajoči se državi blaginje (str. 174).

Njena raziskava pokaže, da mnogi aktivisti in aktivistke v Ukrajini dosežejo svoje cilje s pomočjo neformalnih sredstev, respondenti v raziskavi pa poročajo tudi, da je meja med državo, trgom in neprofitnim sektorjem zamegljena, zato številni aktivisti ter organizacije pogosto prehajajo med sferami.

Darja Zaviršek se v prispevku ukvarja z ideologijo dela. Začetke poišče v zgodnjekrščanskih idejah. Takrat so o delu razpravljali kot o posledici izvirnega greha, delo pa je postalo univerzalna vrednota in merilo za vrednotenje človeka (*kdor ne dela, naj ne je*). Opozarja, da vključitev v delo posameznika samodejno ne reši pred revščino in prav tako ne zagotovi socialnega vključevanja. Diskurz, ki je opazen v Vzhodni Evropi, je usmerjen tako, da je (vnovična) vključitev v delo poglavitni namen skrbi za ljudi z ovirami. To avtorica ponazori s številnimi primeri predpisov, zakonodaje in praktične ureditve dela ljudi z ovirami v regiji (str. 186). Kljub plemenitemu poslanstvu pa sistem ostaja zlasti orodje nadzora. V prispevku avtorica argumentira, da vključevanje v delo še ne pomeni uveljavitve načela enakosti oseb z ovirami, pokaže pa tudi, da je bil hendikep vedno tesno povezan z revščino.

V desetem poglavju Hisayo Katsui obravnava izzive operacionalizacije človekovih pravic na področju ljudi z ovirami v srednjeazijski regiji. Zapiše, da so bile politične entitete v Srednji Aziji v obdobju Sovjetske zveze kot tudi po nagli osamosvojitvi v devetdesetih letih skrit del sveta. Kot enega izmed poglavitnih razlogov za to, da se ohranja sistemski *status quo* na področju oskrbe ljudi z ovirami, navaja, da socialne politike dajejo prednost ekspertnemu znanju, osredotočenemu na posameznika, širši elementi, ki generirajo in ohranjajo neenakosti pa ostajajo zanemarjeni. Avtorica opiše napetosti, ki jih države Srednje Azije občutijo pri oblikovanju politik, zlasti kako uravnotežiti mednarodne (zlasti zahodne) modele človekovih pravic in vključevanja ter lokalno politično in ekonomsko stvarnost (str. 211).

Razpravo nadaljujeta Majda Bečirević in Monica Dowling v poglavju o inkluzivni pedagogiki na Balkanu. Preučita številne zunanje vplive na socialno politiko v Bosni in Hercegovini ter Bolgariji. Primerja lokalne značilnosti in širše dejavnike, ki vplivajo na razvoj socialnih politik na področju ljudi z ovirami v regiji.

Victoria Shmidt v zadnjem, dvanajstem poglavju prispeva eno izmed redkih analiz socialne politike v kavkaški regiji, ki so dostopne v angleškem jeziku. Razpravlja o različnih usmeritvah Armenije, Azerbajdžana in Gruzije v povezavi z inkluzivno pedagogiko in vključevanjem otrok v posebne oblike vzgoje in izobraževanja. Pri tem opozori zlasti na različne razvoje, kljub podobnim izhodiščem v vseh treh državah.

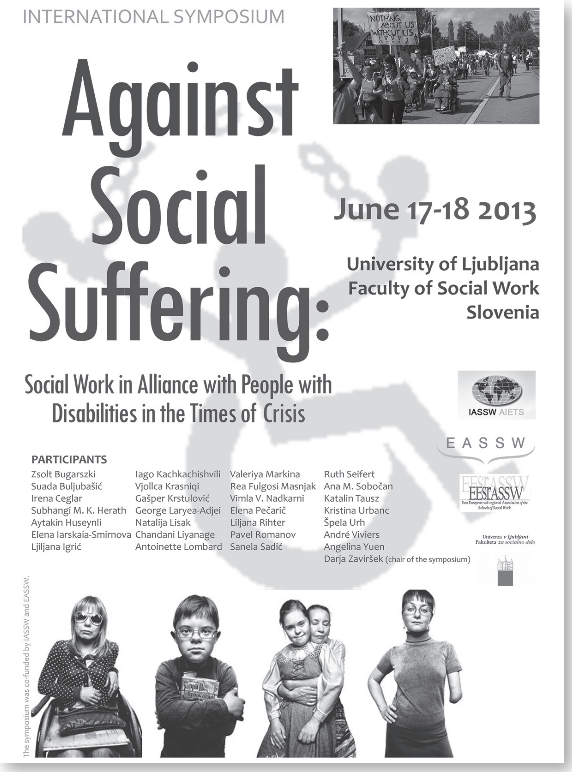
Knjiga opisuje raznovrstnost življenjskih izkušenj ljudi z ovirami v postsocialističnih državah. Čeprav so poglavja tematsko široko zastavljena, ostajajo številna področja študija hendikepa v Vzhodni Evropi premalo raziskana. Zdi se, da so druge oblike ovir poleg fizičnih, torej intelektualne in senzorne, v vzhodnoevropskem diskurzu predmet razprav še toliko manj. Čeprav so raziskovalci vrste ovir, o katerih pišejo, izbrali sami, zaradi lastnih raziskovalnih interesov in delno na podlagi dostopnega raziskovalnega gradiva, je jasno, da intelektualne in senzorne ovire ter duševno zdravje niso teme, ki bi bile v vzhodno evropskem diskurzu obravnavane tako pogosto in podrobno kot fizične ovire. Zelo malo je znanega tudi o ljudeh, ki še vedno bivajo v številnih institucijah v Vzhodni Evropi, čeprav so v literaturi pogosto kritizirane.

Knjiga ponuja dragocen vpogled v stanje družbenega diskurza o ljudeh z ovirami v Vzhodni Evropi in Rusiji ter skrbno preuči prispevek, ki ga imajo vzhodnoevropske raziskave in avtorice ter avtorji pri razvoju teorije hendikepa, čeprav v njem vsekakor prevladuje zahodni diskurz. Avtorji in avtorice v knjigi prikažejo, da je pojem hendikep kompleksen družbeni konstrukt, ki ga moramo razumeti v skladu z lokalnim političnim, družbenim in zgodovinskim kontekstom. Knjigo moramo v slovenskih razmerah ekonomske krize in tanjšanja socialne države brati kot refleksijo o zgodovinskem dogajanju in kompleksnem razvoju politik v regiji, hkrati pa kot pomemben premislek o vplivu, ki ga ima dominantni zahodni diskurz na oblikovanje lokalnih politik ter na preoblikovanje strukture nosilcev socialne varnosti, ki počasi, vendar vztrajno vse bolj prehaja v zasebni sektor. Prehod pa se, kot pokažejo avtorji, dogaja tudi zaradi nepremišljenega ohranjanja socialnih politik, ki ne upoštevajo razvoja strokovnega področja, pobudo napredka pa morajo prevzemati uporabniki storitev sami.

Knjiga je namenjena vsem, ki želijo bolje razumeti družbene procese, ki generirajo družbene neenakosti na področju ljudi z ovirami v Vzhodni Evropi in v dialogu z vzhodnoevropskimi avtorji razširiti obzorje znanstvenega področja, v katerem navadno prevladujejo zahodni diskurzi. Namenjena je strokovnjakom, ki delujejo na področju hendikepa in želijo bolje razumeti zgodovinske procese, na podlagi katerih se je izoblikovala socialnovarstvena politika, ki velja še danes. Za strokovnjake so dragoceni številni primeri razvojev socialnih politik in še zlasti številni primeri vsakodnevnega življenja ljudi, na katere socialna politika vpliva. Te vsebine so pomembne tudi za študente, da se naučijo razumeti sodobni položaj socialne politike v zgodovinskem razvoju regije in povečajo znanje o vplivu med politiko in vsakdanjim življenjem.

Gašper Krstulović

INTERNATIONAL REGIONAL SYMPOSIUM ‘Against Social Suffering: Social Work in Alliance with People with Disabilities in Times of Crisis’, of the International Association of Schools of Social Work (IASSW), the European Association of Schools of Social Work (EASSW) and the East European sub-regional Association of the Schools of Social Work (EEsrASSW).



INTERNATIONAL SYMPOSIUM

Against Social Suffering:

Social Work in Alliance with People with Disabilities in the Times of Crisis

June 17-18 2013

University of Ljubljana
Faculty of Social Work
Slovenia

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IASSW AIETS

EASSW

EEsrASSW
East European sub-regional Association of the Schools of Social Work

Univerza v Ljubljani
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The symposium was co-funded by IASSW and EASSW.

From 17th June to 19th June 2013 the University of Ljubljana, Faculty of Social Work hosted the International regional symposium titled ‘Against Social Suffering: Social Work in Alliance with People with Disabilities in the Times of Crisis’. The symposium was funded by the IASSW and EASSW and symbolised a joint collaboration between the sub-regional (EEsrASSW), regional (EASSW) and global associations (IASSW). Regionally, it was of key importance that the symposium was organized under the lead of the sub-regional organization, EEsrASSW, and that it focused on the issue of disability, which is one of the pertinent issues in the region. The organisation of the regional symposium was taken over by the Department of Social Justice and Inclusion under the leadership of Prof. Darja Zaviršek.

Disabled people internationally, including people from the East European region, suffer great inequalities, but their personal experiences often remain silent and invisible. Poverty, social isolation, poor health conditions, experiences of violence and the denial of their competencies often intertwine and cause disabling conditions and more inequalities. The purpose of the symposium was to reflect today’s social movements, recent changes towards greater dispossessions of disabled people, and social work responses towards these processes, in order to put the wider notion of disablement caused by social inequalities and human rights violations into the focus of research. Speakers from different countries explored the experiences of physical, sensory and intellectual disabilities, mental health problems and civic disability and focused on the local, the national and the global levels. The symposium engaged prominent researchers and social work educators from the region and from the wider academic community for a global exchange of ideas, concepts and visions for a just society. Among others, the speakers addressed the following topics: recovery oriented mental health services, de-institutionalization, motherhood of women with intellectual disabilities, cultural construction and social conceptions of disability, inclusion of children with disabilities, disabled people’s movement in times of crisis, palliative care, disability in the media, politics of gender and disability, transitions into adulthood of youth with disabilities, everyday life of families of children with disabilities, well-being and being-ill paradigms, disability and inequality, stigmatization of people, personal assistance, employment of people with disabilities, deconstructions of inclusion, children with disabilities in adoption and foster care, access to social rights, community support research programs, students with disability, disability and the Roma, social work education, and east-European perspectives on disability.

Other important purposes of the symposium were: to establish and strengthen the connections and networks among social work agents (researchers, academics, practitioners, service users, students etc.) in Eastern Europe, wider Europe and also globally; exchange and transfer of knowledge among these agents and regions; capacity building in the region; identification of challenges in the field of disability and providing suggestions to address these challenges.

The symposium was opened by Prof. Vimla V. Nadkarni, president of the International Association of Schools of Social Work, Prof. Susan Lawrence, president of the European Association of the Schools of Social Work and Prof. Darja Zaviršek, president of the East European sub-regional Association of the Schools of Social Work. Importantly, this symposium brought together a really international community of social work educators and researchers: including guests from Azerbaijan, Sri Lanka, South Africa, China, Georgia, Russia, Greece, Ukraine, Kyrgyzstan, Croatia, UK, Germany, Bosnia and Herzegovina, Hungary, Hong Kong, etc.; altogether around 120 people in two days. The audience was diverse, both regionally as well as professionally. The symposium brought together: social work researchers, students, professionals, public health practitioners, social policy officers, policy makers, pedagogues, sociologists, alumni of the faculty, social workers working in the public sector, private sector and in governmental organisations, service users, parents and people with experiences of bodily or civic disability themselves.

The event contributed to awareness raising, sharing academic knowledge, creating new and stronger professional links, all in the field of social work in the area of disability studies including the studies of disablement which does not necessarily come from impairment itself.

To secure sustainability of the debates, the results of the symposium were published as an open source text and audio e-book (easily accessible at: https://www.dropbox.com/s/57z2nrhn3km5mk0/Against_Social_Suffering-EBOOK.pdf).

Ana M. Sobočan

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ŠTUDIJ HENDIKEPA V DRŽAVAH POSTSOCIALIZMA IN JUGOVZHODNI AZIJI

Gostji urednici: Darja Zaviršek, Jelka Zorn

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