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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.

Sanela Bašić je docentka na Fakulteti za politične vede v Sarajevu. Na tej fakulteti je pridobila doktorat s področja socialnega dela, znanstveni magisterij pa je opravila na področju medkulturnega dela in upravljanja s konflikti na Univerzi uporabnih znanosti Alice Salomon v Berlinu. Leta 2013 je bila znova izvoljena v izvršni odbor Evropske zveze šol za socialno delo. Ima štipendijo raziskovalnega programa Open Society Foundation. Njeni raziskovalni interesi so: socialna politika, družina in zaposlovanje, revščina in socialno izključevanje, nasilje v družini, spol, duševno zdravje in socialna pravičnost, družbena neenakost in pokonfliktna obnova miru. Kontakt: basics@fpn.unsa.ba.

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.

[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

[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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