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THE IDEOLOGY OF WORK AND THE LIMITS OF ITS EMANCIPATORY POTENTIAL IN THE LIVES OF PEOPLE WITH DISABILITIES IN EASTERN EUROPEAN: A COMPARATIVE PERSPECTIVE*

Сажетак

Међудржавна компаративна анализа права особа са инвалидитетом да раде и остваре своја грађанска права представља циљ овог истраживања. Под окриљем социјалистичке државе, особе са инвалидитетом нису биле препознате као сиромашне, будући да су као „деца државе“ били заштићени великом мрежом социјалних институција. Након распада државне социјалистичке привреде у региону, дошло је до повећања сиромаштва особа са инвалидитетом, што је нарочито било изражено у земљама у којима су социјални трансфери ниски или готово да не постоје и где се социјална димезија здравља не схвата озбиљно. Особе са инвалидитетом су несразмерно заступљене међу онима који живе у екстремном или дугорочном сиромаштву, будући да сиромаштво узрокује инвалидитет и обрнуто, инвалидност може да узрокује сиромаштво. У исто време, они се одређују као неспособни за рад, без да им је заиста дата могућност да се укључе у процес плћеног рада. Стога, активисти за права особа са инвалидитетом виде право на рада као основно средство за остваривање веће правде. Колико год да се поједини залажу за право на рад, други пак критикују идеологију рада у ери када одређени облици рада нестају, друге замењује висока

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технолозија, а поједини послови стварају нову армију сиромашних запослених. Амбивалентност између краја неолибералне ере и разумевања рада и једнакости рада особа са инвалидитетом једна је од етичких дилема данашњице.

Кључне речи: особе са инвалидитетом, право на рад, дискриминација, сиромаштво, социјална правда, источна Европа, активности за права особа са инвалидитетом, неолиберализам.

DISABILITY AND POVERTY

Disability has historically been connected with poverty given that physical impairments, mental health problems and the loss of health are associated with the loss of paid work, low social status and stigma around the world. Disabled people have been simultaneously constructed as unable to work without really being given the opportunity to be involved in paid employment (Shakespeare 1998). Under state socialism people with disabilities from Central and Eastern Europe were not defined as poor, but rather as the 'children of the state', since they were protected by a wide net of large social institutions and perspectives such as the quality of life, independent living and the life course did not count (Zaviršek 2006). Poverty in the region increased dramatically after the disintegration of state socialist economies and governments and is especially sharp in countries where social transfers are low or hardly exist and where the social dimensions of health are not taken seriously, for example in Ukraine, Russia, Romania and Georgia (UNDP Ukraine, 2008; Mete 2008; Mitra, Posarac and Vick 2011). People with disabilities¹⁾ are therefore disproportionately represented among those living in extreme or chronic deprivation since poverty causes disability and conversely disability can cause poverty.

It is therefore no wonder that disability activists, some experts and policy makers frequently see the right to work as the primary means of achieving greater justice and moving beyond individualistic explanations of poverty and exclusion. Yet can the solution be so simple when disability is not only connected to social and economic inequalities, but also to negative cultural beliefs and medicalist, pathological and

1) The expression 'people with disabilities' is based upon the People First Language (PFL) principles defined by people with impairments themselves. They stressed that disability is a descriptor for a medical diagnosis and should be placed after the 'person'. In the PFL formulation, 'person' comes always before disability. See more on that:

<http://www.disabilityisnatural.com/explore/pfl>;

<http://www.familytofamilynetwork.org/parent-resources/people-first-language> (accessed 06.02.2012).

patronising attitudes of caring professionals who invest their expertise and fantasies in helping ‘cripples,’ ‘invalids’ and disabled people? In Eastern Europe people with disabilities are excluded from ordinary life by their disability label in order to be “re-included” through welfare provisions that encompass not only paid workplaces, but also quasi-employment and occupational activities (Zaviršek 2002, 2006, 2010). Most forms of work and societal participation for people with disabilities are exclusionary and based on negative images and stereotypes of ‘not-entirely-normal’ subjects. The continuous production of the ‘Other’ is packed into the discourse of “being different” (Turner and Stagg 2006; ethnographic fieldnotes 2000-2012).

Actual figures about the poverty of people with disabilities and their families depend on many different factors such as the type of disability, social transfers, the symbolic representation of disability in a given society and whether poverty is defined solely in material terms or also in terms of quality of life, choices and life satisfaction. For example, the relationship between poverty and disability in Uzbekistan changes depending on the threshold for what constitutes a disability (Scott and Mete, 2008). When minor and moderate disabilities (either physical or intellectual) are included there is no significant relationship between poverty and disability, however, there is a strong positive correlation when a higher threshold is used so that only significant disabilities are counted. Another study from the post-socialist region shows that the employment rates of people with disabilities and the employment rate of non-disabled individuals are not correlated (Mete, 2008). In Moldova for instance adult persons with disabilities are 60 percent less likely to work in paid employment than those who have no impairments and in Bosnia and Herzegovina 20 percent less likely (ibid.: xiv).

This chapter offers a critique of the ideology of work as it relates to people with disabilities in the era defined by Jeremy Rifkin as the ‘end-of-work’ period where some types of work are disappearing due to globalisation and some are replaced by high technology. It will demonstrate that in relation to people with disabilities exclusionary practices and segregation in workplaces prevail despite new laws and regulations in the countries of Eastern Europe which have joined the European Union in recent years. The workfare ideology has contributed to the creation of more short-term welfare jobs and growing number of placements in sheltered workplaces without a work contract. However, there has been no fundamental shift in societal beliefs about the ‘normal’ and the ‘abnormal’ in the region and indeed most parts of the world.

THE MEANING OF WORK: HISTORY, IDEOLOGY AND POLICY

Historically, the employment, economic and profit-oriented activities of people with disabilities have been viewed with suspicion in society and politics. It was not actual ability, but stigma and prejudices, which excluded and kept disabled people from paid employment, creative work and innovation.²⁾

Early Christian ideas saw work as both a consequence of original sin (the Fall) and as a joy and moral responsibility (Granter 2009). The idea of a moral obligation to work – something that was not widespread prior to the early European industrialisation of the 18th century – viewed work as a charitable activity for the needy and as something to occupy the mind, which might otherwise be distracted by improper thoughts. The tendency to regard paid employment as a moral obligation was greatly influenced by Protestant ethics, but gained force throughout Europe in the nineteenth century. In the region of Slovenia, for instance, the well-known priest and educator Anton Martin Slomšek (1800-1862) wrote in his book Blaže and Nežica in the Sunday School (Blaže and Nežica v Nedeljskej šoli) that “Saint Paul commanded ‘Those who do not work shall not eat!’” (2006:49 [Orig.: 1857]). This slogan not only became a part of the moral and religious education for young people who visited Sunday schools in Slovenia, but also a widely used Slovenian proverb throughout the nineteenth and the twentieth Centuries.

The religious belief that work is an obligation to God was transformed into the capitalist work ethic of the nineteenth and twentieth centuries. In the industrialised secularising states, the obligation to work spread through all social professions, affecting the social construction of healthy bodies and the design of asylums and residential institutions (Foucault 1988; Garland Thomson 1996; Davis 1997). In Europe and the USA, especially those who were poor or homeless, were seen as dishonest, responsible for their own miserable situation, lazy and consequently worthy of punishment. Some people with disabilities tried to reject the stigma of the “undeserving poor” by carrying signs that read “I was born a cripple” to avoid being forcibly removed from public spaces (Gleeson 1999).

- 2) For evidence of this tendency one need only look at the revolutionary work of Louis Braille (1809-1852), who developed a tactile system of writing for people with visual impairments in France. Prior to the formal recognition of the Braille system, disabled children and adults who advocated for, or even used it were punished and ostracised. It took twenty years for the French authorities to officially recognise Braille’s system (in 1844) and more than fifty years for other European countries to implement the script he invented (in 1878). The United States began using Braille nearly a century after its invention in 1917 (Bavčar 2009: 10).

Work was used as a means of improving and re-socialising disabled people and keeping them under control. While emerging economic elites used the work ethic to discipline and educate workers in order to achieve modern production relations and profit, work in workhouses and asylums was used as a supposedly therapeutic tool to control disabled people. Work was a way of measuring time and breaking institutional tedium into sequences of monotonous activities. People who were seen as unable to work or who refused to work were perceived as irrational and were forced to work not for money but as a part of the medical therapeutic cure. The asylums proclaimed that they were protecting people from their own irrationality and consequently from criminality. Occupational and work therapies in these spatially segregated places became part of scientifically justified practices of healing, care and control (Mitchell and Snyder 1998; Albrecht, Seelman and Bury 2001).

While in religious conceptualisations work was seen as a tool for occupying minds which might otherwise drift towards immoral ideas, in secular thought the very same morality of work underpinned professional interventions such as occupational therapy and re-socialisation. This was in line with the view that disabled people and/or their families were morally responsible for their impairment. While the work of people with disabilities was not seen as potentially profitable, it was benevolently defined as an activity of moral improvement and medical therapy (Stiker 2000).

From a historical perspective, the majority of people with disabilities had always worked. However, medical classification and spatial segregation meant that their economic activity lost some of the fundamental characteristics normatively associated with work: a reward in the form of a salary, public recognition, increased choices and liberation in the form of self-determination.

For the past 300 years, then, people with disabilities have been caught in a conflict: as work became a societal imperative of normality, they were deprived of the ability to conform to this norm, consequently becoming morally suspect and outcasts. The normativity of paid work causes social exclusion, especially in countries with a pronounced work ethic, such as developed western countries and some Asian countries (Engel, 1985; Foucault 1988). This historical background is helpful in understanding why the right of work that was denied to people with disabilities in the past has become so vitally important in the struggle of disability activists across the world. It has become a fundamental part of the ethics of disability, as exemplified in the UN Convention on the Rights of Persons with Disabilities (2008) that many Central and

Eastern European countries have signed and even ratified. The right to work has also guided national campaigns around the Decade of Persons with Disabilities in the USA, Europe, Asia and Africa in the last twenty years. The fight for the right to work and paid employment in ordinary environments has therefore become one of the crucial goals and principles of the ethics of disability as defined by disabled people themselves from their own lived experiences.

STRIVING FOR EMPLOYMENT

Despite the fact that employment is one of the most socially accepted rights for adult citizens, there is a jarring discrepancy in the world: in some countries, people with disabilities can work and earn money, while in others there are hardly any jobs available to them. In Sri Lanka, approximately 8 percent of the population are classified as disabled and about 90 percent of them are unemployed and dependent on their families (Yeo and Moore 2003: 579). Estimates for Georgia, Kosovo, Rwanda and some Asian counties suggest that less than one percent of people with disabilities are employed. In Ukraine the employment among people with disabilities has increased from 14.5 percent of employed disabled persons out of all people estimated to be disabled in the 2002 up to 22 percent in the year 2007 (Phillips 2011:30). Some studies show that people with disabilities are excluded from micro-credit programmes because they lack assets as collateral and are seen as a bad risk, for example in Rwanda (Thomas 2005b). Disabled people are often not told about development activities in their communities in the first place and are deliberately excluded when they try to get involved.

Simultaneously, principles of redistributive justice and mainstream employment have become an important part of social policies in countries of the European Union. Mainstreaming the right of work among people with disabilities has undoubtedly produced a number of positive outcomes by increasing the visibility of the persons with disabilities and diminishing their spatial segregation, including:

- More people with disabilities work in ordinary environments;
- More people with disabilities work in mixed groups without medical compartmentalisation;
- Many people have overcome social isolation and developed their social networks;

- In some places stigma has declined and people with disabilities have become part of the social capital of societies;
- Paid work has become an important stabiliser for people with mental health concerns.

In 2008 the National Board of Persons with Disabilities in the Czech Republic conducted a survey on the employment of people with disabilities in the public sector. The survey showed that most ministries, regional authorities and municipalities fulfilled their legal duties to employ persons with disabilities directly or indirectly and that the public employment of this group is constantly increasing (Šiška 2009).³⁾ At the same time, it is worth noting that in the Czech Republic as well as in Slovenia, public enterprises try to find ways of meeting employment quotas⁴⁾ other than through the actual employment of people with disabilities. Slovenian firms sometimes award work contracts to the so-called “invalid companies” (*invalidska podjetja*), which are enterprises where at least 40% of all employed are people with disabilities. These are segregated workplaces subsidized by the government in the form of a tax reduction. Similarly, in the Czech Republic goods are purchased from sheltered workshops in order to fulfil legal quotas on disabled employees (Šiška 2009, Zaviršek 2010). In Slovakia employers, while seeking to fulfil the quota system and employing people with disabilities, prefer to hire people with less severe degrees of disability, which excludes people with multiple disabilities and especially those with intellectual disabilities and mental health problems from paid employment (Hanzelova *et al* 2009). In Lithuania, EU-supported programmes have provided opportunities for inclusive market-based initiatives like social enterprises, regional business development centres for disabled people and centres for professional rehabilitation. However, semi-closed initiatives prevail and people with mental health problems, still have the lowest chances of gaining employment (Ruškus 2009). These examples show that mainstreaming work does have some positive effects for a minority of people with disabilities, but this does not mean that employment contributes towards wider equality in different areas of life.

In some countries people with disabilities have been encouraged to assume more promising types of jobs such as social enterprises, credit unions, cooperatives, employee-owned businesses, development trusts and social firms. In Hong Kong, more than 50 WISEs (work-in-

3) Act No. 435/2004 Coll. on Employment stipulates that employers with more than twenty-five employees must employ 4 percent of people with disabilities.

4) In Slovenia the quota is between 2 and 6 percent regarding of the type of the organisation or enterprise; the smallest quota is for governmental jobs and the largest for industry.

tegration social enterprises) have been established since 2001. They all have the “dual aim of providing social improvement and generating economic profit to help to move people from welfare dependency to self-reliance by giving them the capacity for independent wage-earning” (Po-ying Ho, Kam-tong 2010). Poland is known for its cooperative movement with a long tradition dating from the end of the Second World War, although partially destroyed during the communist period, which provides employment for people with disabilities. In 2004 new social cooperatives were introduced into the Polish legal system⁵⁾ and defined more fully in 2006 with the Act on Social Cooperatives. Stimulated by non-governmental organisations with the support of the Ministry of Labour, the cooperatives are part of government policies to create jobs and limit social exclusion for people defined as disadvantaged including those with disabilities. The objective of social cooperative activity is to run a common enterprise based on personal inputs from its members with the goal of supporting the occupational and social integration of its members. In 2008 there were 187 social cooperatives across the country, most of them involved in the service sector (repair and building services, catering and care services) and 12 percent are involved in production (e.g. fruit and vegetables processing, production of candles and garden decorations) (Wapiennik 2009).

The new enterprises promise that people can increase individual independence and responsibility, but the question of whether employment really reduces stigma and to what extent it challenges the dominant meritocracy myth⁶⁾, trans-generational privileges and ideology of the able body, remain unanswered. The seemingly promising figures fail to demonstrate that the majority of people with disabilities occupy less socially valued and lower-paying jobs in developing as well as in the developed countries. The Integrated Service Solution (ISS) in several western European countries provides mostly cleaning jobs for people with disabilities: cleaning train stations and airports, industrial cleaning, window and office cleaning, cleaning of cooling and heating systems. In France, for instance, 45 percent of all jobs for people with disabilities are in cleaning, landscaping, waste removal and pest control (personal visit, project Equal, Paris, 17 May 2006). These jobs require very few qualifications and employees do not even need to be able to

5) See: Act on Promotion of Employment (Wapiennik 2009).

6) I refer to McNamee and Miller (2004), who showed that societal resources are not distributed primarily on the basis of individual merit (intelligence, high work ethic, moral, personal attitudes, integrity, abilities etc.), and that non-merit factors such as inheritance, social and cultural advantages, discrimination, unequal educational opportunities and prejudices highly influence a person's economic, social and symbolic status in society. They call it the ‘meritocracy myth’ and show that there is a gap between the person's merit and his or her actual success.

read and write. In Hungary, where lot has been done to encourage people with intellectual disabilities to enter some employment activities, persons living with Down's syndrome are largely employed in service industry jobs as cleaners and in the handicraft industry. Among 80,000 people with disabilities, more than half were employed in the processing industry where hard repetitive work is common (Könczei and Horváth 2009). In Slovenia too, the majority of people with impairments working in ordinary environments work in processing industries. Yet, discourses about the right of people with disabilities to work fail to question the limited types of jobs and semi-jobs available. The reality of low-paying and repetitive jobs, symbolic payment in so-called welfare jobs (short-term workplaces in state-financed employment centres during which the person is assessed about his or her working abilities), and sheltered workplaces (without work contracts) is accepted as a given fact that does not need to be questioned.

Additionally, few studies highlight that people with disabilities who work for pay are highly represented among the working poor, a term that highlights the relationship between a worker's income and their everyday material needs as well as the number of household members who depend on their salary. Employment does not always protect persons with impairments from deprivation, for instance in Romania where monthly wages do not prevent people with disabilities from poverty (Mete, 2008). These precarious conditions are glossed over by an ideology that views work as a sufficient condition for the inclusion of people with disabilities. The Japanese Organisation for the Employment of Older and Disabled People claims that *"We are aiming to create a 'society for all' in which everyone has a chance to contribute through work"* (JEED 2008). Work has become the major contribution that a person can make to a given society and thus an end in itself.

In Slovenia one can read media coverage such as "With the work toward the societal integration" (Finc 2010), which reproduces the same discourse of work as a major factor of "societal inclusion". In Portugal too, employment is seen as the major vehicle of social integration, and as claimed by Pinto, people with disabilities (even those who are unemployed, but in training programmes) become a "reserve army" of labour to serve the needs of the capital (2010: 127). Despite the fact that paid work provides some payment and an ordinary life style, the undesirable nature of these jobs shows that not only unemployment, but also work itself, may cause social exclusion and create social outcasts. People with disabilities are excluded from socially respected statuses by being included in paid employment. These types of jobs and the social positioning they imply can be symbolically compared to those of the

Untouchables in India or the Burakumin in Japan, who are constructed as the holders of polluted identities and stigmatised as a group because of their socially undesirable jobs which pollute their identity in the eyes of the others (Nakamura 2006).

‘WELFARE EMPLOYMENT’ AS THE REVIVAL OF MEDICAL PERSPECTIVES ON DISABILITY

The Eastern European countries which entered the European Union in 2004⁷⁾ and 2007⁸⁾ adopted new laws on employment which formally ensure equal access to the labour market for people with disabilities and introduced new types of welfare employment. Welfare employment is defined here as a short term work placement primarily financed by the state in order to offer short-term rehabilitation and assessment of person's work abilities⁹⁾. Even though some data show that the quota system has a positive effect and some disabled people have found paid employment, no empirical research confirms that workfare discourses and programmes have really improved their quality of life, diminished stigma and ensured independent living. This is because the new laws on employment and vocational rehabilitation – which were designed to bring more people into ordinary employment through supported and protected workplaces – did not increase jobs in mainstream settings. The opposite in fact occurred whereby the employment laws legitimated a medical view of disability and increased ‘welfare jobs’ and rehabilitation activities with an army of rehabilitation, social and medical professionals who assess, monitor and categorise disabled people's work performances whilst making the empty promise that this is done for their “own good” and will eventually bring them into paid employment.

In most Eastern European countries, an interdisciplinary, but largely medically oriented, review of a disabled person's “remaining ability to work” is conducted in order to produce a rehabilitation plan for future employment success.¹⁰⁾ The harmonious similarity of these laws

7) Czech Republic, Estonia, Hungary, Lithuania, Latvia, Poland, Slovakia, Slovenia.

8) Bulgaria, Romania.

9) In Slovenia the monthly payment is 70 percent of the minimum wage, which is much below the poverty line.

10) For instance: Law on Employment 2004 in Czech Republic; Employment Strategy of the Republic of Bulgaria for 2008 – 2015; Social Welfare Act 2009 and The Labour Market Services and Benefits Act 28 from 2006 in Estonia; Rehabilitation Allowances Act of 2007 in Hungary; Vocational Rehabilitation and Employment Act 2004 in Slovenia; The Labour Code in Latvia;

in all of these countries which are now part of the EU suggests the legacy and a specific continuity from the state socialist period. Vocational rehabilitation dominates debates over disability policy and employment is framed within medical and needs-oriented laws which expect a number of professionals to evaluate the person with a disability during different stages of largely temporary employment.

Across the Eastern European region, employment programmes for people with disabilities are problematic if evaluated according to principles of social justice and genuinely improving life chances. In Slovenia the Employment and Vocational Rehabilitation Act from 2004 introduced the quota system discussed above, vocational rehabilitation, employment companies and protected and supported workplaces. Yet, these types of employment did not necessarily bring about greater inclusion and challenge negative images of people with disabilities. Large number of persons with disabilities work in disabled companies, employment centres, centres for vocational rehabilitation and social inclusion programmes which are segregated workplaces, while protected and accommodated work places hardly exist in the laws mentioned above. Slovenian disability companies employ nearly a fifth of all persons with disabilities and more than half of employees are non-disabled even though the enterprises still receive considerable state support – a legacy of state socialism (Zaviršek 2010). As in many other countries, Slovenian employers are keener to employ disabled staff if there are added incentives, for example state subsidies for salaries or tax reductions. Table 1 shows the growing unemployment rate against the largely stable number of disability companies and welfare jobs companies.

The precariously low salaries and the limited amount of time people with disabilities are allowed to work in short-term welfare jobs (from 6-12 months) are worrying. Disabled workers involved in Slovenian programmes of social inclusion receive 62 Euros per month for a forty-hour working week. This amount is given to disabled people who are categorised as having thirty percent of the working abilities of a “healthy” person. Even a person without disabilities employed in the social inclusion programme would only get 200 Euros per month. The economic vulnerability instead of autonomy only becomes obvious when the sum is compared with the monthly minimum wage, which was 562 Euros in 2010 while the poverty line was 593 Euros per month.

Law on Social Integration of Disabled People 2004 and the Law on Support for Employment 2006 in Lithuania; Act on Vocational and Social Rehabilitation and Employment of Persons with Disabilities in Poland 2004 (Zaviršek and Gorenc 2009, Šiška 2009, Panayotova 2009, Kóncei and Horváth 2009, Sakkeus, *et al* 2009, Calite 2009, Ruškus 2009).

Table 1: Slovenian figures on employment and people with disabilities¹¹⁾

Year	Total registered unemployed	Number of persons with disabilities in paid employment	Registered unemployed persons with disabilities	Disability companies	Number of persons with disabilities in disability companies	Number of employment centres	Number of vocational rehabilitation services
2008	6.7%	33,901	11,025 persons	167	6,400 persons with disabilities	27	13
2009	9.1%	34,000	12,537 persons	166	5,708	27	13
2010	10, 6% (97,908 persons)	No data	14,038 persons	165	No data	27	13

State subsidised workplaces for persons with disabilities paradoxically show a new form of privatisation of the welfare system. Of the twenty-seven employment centres that employ 249 disabled people throughout Slovenia, the majority of them are licensed private organisations. Like the disability companies during state socialism, these centres provide semi-segregated jobs, low wages and limited employment hours. Similarly, among thirteen organisations providing vocational rehabilitation services only one is public institution, while the remaining twelve are licensed private organisations. While they offer poorly paid short-term jobs for persons with impairments, they have created new long-term stable jobs for [non-disabled] professionals such as social workers, occupational therapists and education specialists. These welfare professionals are employed to assess and monitor persons with

11) The table uses the figures from different sources: Institute of Macroeconomic Analysis and Development (UMAR) (2011), *Pregled gospodarskih kazalcev ob koncu leta 2010* ; Slovenian Unemployment Service, Monthly Statistics ; Action Programme for Invalids Report, 2008 [Akcijski program za invalide, 2008].

disabilities during their vocational rehabilitation even though the latter have little or no chance of entering ordinary long-term employment.

Overall, the implementation of Slovenia's new law on employment expanded the number of welfare jobs instead of ordinary workplaces. Even the fulfilment of quotas monitored by the Fund for the Encouragement of Employment of Disabled People reflects a paternalistic approach towards people with disabilities. At the end of 2008, there was a 9 percent increase in the employment of disabled people compared to 2006 when the quota system was introduced. Nevertheless, in the same year of 2008, more than 50 percent of all Slovenian companies to which the quota applies (those with more than twenty workers) opted to pay a fine for not meeting the quota instead of actually employing people with disabilities. As in Poland, employers in Slovenia have the option of entering into business contracts with disabled companies or employment centres to fulfil quotas instead of employing workers with disabilities at their companies. In 2009 around one third of the nearly 3,000 employers who fulfilled the quota opted to do so by entering into a business contract with a disabled company or employment centre. Nevertheless, prior to the onset of the economic crisis in 2008, the quota system had increased the employment of people with disabilities, albeit often in unsatisfactory or segregated workplaces (Zaviršek and Gorenc 2009).

It is obvious that an ideology that glorifies work as the major factor of social inclusion needs to be challenged because workfare and welfare jobs neither protect disabled people from poverty nor ensure inclusion, but preserve the hegemonic division between the normal and abnormal. In such schemes even successful employment may be treated as strange and unexpected, as shown by attitudes that "One of our staff performed so well that we promoted him to a position that is traditionally filled by a 'normal' person" (administrator of a welfare organisation, Po-ying Ho, Kam-tong 2010: 41). In this case, the stigmatising attitudes of staff undermine the repositioning of the disabled person in the world of the 'normal.'

OVERLOOKED DISCREPANCIES

The focus of political discussion on the right of people with disabilities to work inevitably overlooks practices that perpetuate traditional inequalities and power imbalances. Mainstreaming work has become more important than other human rights issues given the fact that so many people with disabilities still live in large institutions where they

are prevented from making self-determined choices, infantilised through media coverage and unable to obtain high-quality education. Many of them are entitled to work in institutions, but not to live a dignified life in ordinary environments. One of the leading disability activists from Bulgaria has commented: "They make us talk about employment to prevent us talking about more important things!" (personal communication, ENIL conference, Ljubljana 2010).

A 2007 study on the EU member states and Turkey found out that at least 1,2 million children and adults with disabilities are registered as living in long-term residential institutions, but that the number would be much higher if all countries kept accurate data on this type of welfare incarceration.¹²⁾ Institutionalisation is not declining, but affects new generations of children. It is estimated that across the EU at least 150,000 children live in residential care settings, including special schools, infants' homes, homes for mentally and physically disabled people, homes for children with behavioural problems, institutions for young offenders and homes for careleavers.¹³⁾ In Slovenia alone in 2009 21,730 persons resided in different long-term closed and semi-closed institutions, boarding schools and old people's homes and in 2010 the number increased 3 percent up to 22,254 persons¹⁴⁾. A large proportion of disabled people living in institutions have intellectual disabilities or diagnoses of multiple impairments.

Media representations in the region portray the happy faces of disabled children in residential settings. One recent article in Slovenia was titled "Happy to work" (Petek 2010) and reported on young people from a sheltered workplace who make candlesticks and souvenirs for paltry rewards (20 – 100 Euros per month). A recent study from Romania showed that the media still portrays people with disabilities at polar extremes where some are helpless and inferior victims whilst others are heroes with superior qualities (Ciot and Michailidis 2008). Societal perceptions and awareness of disability continue to be dominated by medical and charitable models of mercy and support that diminish citizenship rights. Such messages do not support the inclusive employment of disabled people.

One reason for the poorly paid jobs endured by persons with disabilities is the lack of educational opportunities and prejudices which have shoved them into spatially segregated environments. Current data

12) Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care. European Commission. September 2009, p. 10.

13) Ibid.

14) Public Welfare Institutions in Slovenia 20102. www.stat.si (27. 09. 2011).

show that children with disabilities living in East Europe are significantly less likely to enrol in schools (Mete 2008). They are often prevented by law from entering mainstream education and completing more than the obligatory minimum of primary education. Social workers and teachers in such institutions focus on disabled children's 'defects' or 'impairments' rather than their strengths and potential to succeed in school and continue education.

Educational disadvantages have different forms, ranging from total exclusion from the school system to segregated classes undermined by the low expectations, motivation and support for people with disabilities during primary education.¹⁵⁾ A lack of education (or the assumption that people with disabilities are ineducable) is a major reason why only about 13,000 people with disabilities have paid employment in Romania, which represents just 2.93 percent of the total number of disabled people (Ghergut and Gavrilovici 2009). In Slovenia for instance any person with a categorisation of intellectual disability (mild, moderate, severe or profound) is deprived of the right to study in an ordinary primary school. They will be taught in special schools, special classes of ordinary schools or large institutions (Zaviršek and Gorenc 2010). In Bulgaria almost half of disabled people do not have professional training or qualifications at all. Among those who are registered as unemployed, 45.6 percent have only completed basic education and just 8.7 percent have a university degree (Panayotova 2009). Focusing specifically on people with intellectual disabilities, they have no access to proper education and training, which results in a near-100 percent unemployment rate in Bulgaria and Slovenia (Panayotova 2009, Zaviršek and Gorenc 2010). The situation is very similar in Hungary: poor educational opportunities for persons with disabilities mean that only 9 percent are in paid employment and most are employed through 'special' or 'sheltered' arrangements (Könczei and Horváth 2009). Narratives of young persons with disabilities who finished social work education show that the higher the educational level of a person with disability, the greater the struggle to find work at a corresponding skill and qualification level (ethnographic fieldnotes 2008-2012).

15) This fact goes beyond the region presented in this chapter. In Turkey, for example, more than half of the 9 million people classified as disabled are illiterate and only 21.7 percent of them participate in the labour force (Tufan *et. al.* 2007).

ETHICAL DILEMMAS PERTAINING TO THE IMPERATIVE OF WORK FOR PEOPLE WITH DISABILITIES

Although the right of disabled people to work is one of the most important values within disability and rights discourse, the desirability of an ideology that glorifies work as the major facilitator of social inclusion has to be questioned. Workfare and welfare jobs do not automatically protect people from poverty or ensure inclusion. The vocational rehabilitation favoured by traditional disability organisations and policy makers who prioritise protection over human rights needs to be critically analysed from the viewpoint of the actual changes made by these state interventions in people's lives. Many people with disabilities have been included in paid employment, but thereby isolated from society and excluded from socially valued statuses. Even more people have experienced vocational rehabilitation, but have never had proper work in the full and positive sense of this term. Discourses of workfare fail to address these issues and do not contribute towards the right of disabled people to live a dignified life as well as their rights around housing and material well-being. More broadly, welfare jobs do not instantiate the right of disabled people to be respected as part of human diversity.

This idea comes close to what Scully (2008) calls 'disability ethics.' In her view disability ethics looks at how the "embodied effect of impairment" affects the everyday life of disabled people and how people with disabilities see the world. From this perspective, work would need to have three characteristics. Firstly, it needs to be defined as an activity that is carried out for remuneration. This constitutes an indictment of all sheltered workplaces and other semi-work contracts where workers do not receive a monthly salary and where salaries are below the poverty line or minimum wage. Next, work needs to have a creative component instead of being just repetitive labour. The distinction between labour and work can be traced back to ancient Greece and the ideas of some modern philosophers (Hannah Arendt, for example), where only work humanises and enriches the subject (Granter 2009). Third, people with disabilities should be actively supported and welcomed should they wish to obtain respected and intellectually demanding jobs in line with their skills, qualifications and level of education.

It is a paradox that work today is seen as the major criterion for including disabled people in society when between nine and twenty percent of the population in EU countries – and as much as seventy percent in other countries and communities, such as the Roma and Shinti in Kosovo – are unemployed. Can full employment be ever achieved if

today we face the export of jobs, mass unemployment and the massive phenomena of the working poor and the creation of precarious jobs? Such developments have prompted international discussions about the 'end of work' (Rifkin 1995) based on the idea that highly developed technology is eliminating the need for many traditional types of work such that industrial jobs are slowly disappearing. People with disabilities are most often employed in these disappearing types of industrial workforce labour.

Zygmunt Bauman has shown that we live in a global society that praises "[...] full employment as not just a desirable and attainable social condition but also its own ultimate destination; a society which therefore cast employment as a key – the key – to the resolution of the issues of, simultaneously, socially acceptable personal identity, secure social position, individual and collective survival, social order and systemic reproduction" (2004: 11). The obsession with full employment has also spread into the disability arena such that disabled people are being steered towards welfare employment in greater numbers than ever before. Despite employment mainstreaming and the success achieved in this area in mostly Western countries, people with disabilities are still more likely to face poverty than non-disabled people. In countries where a work ethic is strongly imbedded in the dominant value system, stigma is attached not only to poverty, but also to the question of whether someone is employed or not. The framing of a person's contribution and work through a nineteenth-century Western conception of work (or similar ethical concepts – Confucianism, for example) has been challenged by Basic Income Earth Network (BIEN) activists and academics from around the world who believe that, instead of non-rewarding types of work and stigmatising welfare cash transfers, a basic universal income could increase the meaningful participation of every person (van Parijs 1992).

There is therefore a need for disability policy and professionals to adopt four layers of commitment, advocacy and change in relation to disabled people's employment. First, there is a need for economic redistribution to ensure that people with disabilities can obtain paid employment and gain "a good life" from it. Second, societal recognition in addition to economic redistribution is important to ensure that people with disabilities are seen as equal human beings with a variety of embodiments and human specificities. Third, there is a need to transform narrow concepts of productive work that currently divide human bodies into what Bauman (2004) calls "producers" and "waste". Instead, a wider definition of work as the means for a holistically "good life" that enhances and supports the diversity of people's everyday lives is part of

disability ethics and concepts of social justice. Fourth, funds should be redirected from vocational rehabilitation programmes into real jobs and schemes for monitoring the effectiveness of vocational rehabilitation in particular countries.

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Resume

There is no doubt that paid employment can be effective at tackling poverty among people with disabilities. The right to work that was long denied to people with disabilities is one of the largest achievements of the disability people's movement across the world. At the same time the chapter has argued that neoliberalism dominates contemporary disability discourse and that notions of 'dependency' and 'care' have been partially replaced by the ideology of work, where every adult person is made into an income earner. Given that hegemonic workfare discourses claim that jobs for persons with disabilities contribute to independent wage earning and an enhanced self-image, research must interrogate the well-being and satisfaction of people with disabilities with their employment. How much does work really affect people's lives? How much do people with disabilities earn, how are the earnings spent, how many friends did they make, how assertive have they become and how many of them have really moved from welfare to general employment? Posing these questions will help to breach the symbolic and actual divisions between the 'normal' and 'abnormal' and will bring us closer to understanding that there are different ways of experiencing the world in line with different embodiments and social positioning. The mystification of work – the promise of economic security and a good life for those who produce – versus the reality of low-paid, repetitive, unsatisfying and sometimes unpaid work needs to be addressed by critical researchers and welfare professionals.

Today's policies and schemes for mainstreaming employment in Eastern European countries are too often just another way of drawing a line between the normal and abnormal since their entire discourses are based on the idea that people with disabilities should be steered into welfare employment rather than broader goals of self-determination and independent living. There is little interest in whether these types of work and "rehabilitation" really improve the everyday lives of indi-

viduals. Instead of looking at different types of discrimination, many professionals working with persons with impairments propagate this ideology of work rather than challenging the medical and rehabilitation model of disability. The latter may provide job opportunities, but it relies predominantly on semi-segregated and precarious work places and occupational activities, thus turning discussion away from human rights, diversity and an understanding of disability as a particular element of humanity.

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