

Critical Commentary

Social Work with Adults with Disabilities: An International Perspective

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Introduction

The longer life expectancy of the populations of developed countries, on the one hand, and poverty, poor working conditions, modern slavery and wars faced by people from poorer and rural countries, on the other, are conditions that dictate that the majority of the world's population will experience some kind of disability at some time in their lives. At the same time, the involvement of social work in rebuilding and recovery following the Tsunami catastrophes in different parts of the world and the recent earthquake in China have placed issues of disability at the very centre of social work. Now, more than ever, social work literature reflects the fact that most disabilities are not hereditary or present since birth, but constructed during the course of one's life, and that poverty and ethnic minority status in unjust societies produce different disabilities, including intellectual disabilities. Health and social work issues are again beginning to closely intertwine—a phenomenon reminiscent of the early days of the development of professional social work in rural areas of Europe (Hering and Waaldijk, 2006).

Rejection of the medical and popular/media gaze over the everyday life of people with disabilities, of the over-protectiveness and abusive nature of public care institutions and of unequal power relations between people with disabilities and welfare professionals has paved the way for a major shift based on *disability activists'* knowledge and *service users'* experiences known

as the move from the medical towards the social model of disability (Oliver, 1983; Fine and Asch, 1988; Hevey, 1992; Davis, 1997, 2006; Shakespeare, 1998; Oliver and Sapey, 1999; Priestley, 1999; Fawcett, 2000; Barnes *et al.*, 2002). Different authors since then have shown the interrelationship between embodied experiences, social contexts and personal agency and this has begun to serve as the foundation for understanding that changes in social policy and social work interventions are necessary and inevitable.

The impact of disability studies on social work and *vice versa*

Social work books written before the development of disability studies in the 1970s and 1980s are marked by the conspicuous absence of any approach to disability other than the medical-diagnostic perspective. Since then, in no other area have activists, parents and advocates had such a strong influence on social work (UPIAS, 1976; Finkelstein, 1980; Murphy, 1987; Oliver, 1990, 1996; Morris, 1991, 1992, 1993*a*, 1993*b*; Campbell and Oliver, 1996; Linton, 1998; Chimedza and Peters, 1999; Pečarič, 2002; Ishikawa, 2004). Paradoxically, these are often the same people who, until just recently, were perceived as the most dependent, weak and helpless. In some parts of the world, including Slovenia and other eastern European countries, legislation still refers to them as 'invalids', from the Latin 'invalidus', meaning weak, powerless or feeble.

Disability studies have given new dimensions to the inter-disciplinary perspective in social work by emphasising differences in historical and cultural contexts, and emphasising the rights for symbolic recognition. At the same time, these studies challenged academic research conducted without the collaboration of people with disabilities themselves (Groce, 1985; McCagg and Siegelbaum, 1989; Trent, 1994; Gilman, 1995; Mirzoeff, 1995; Ingstad and Reynolds, 1995; Mueller, 1996; Corbett, 1996; Garland Thomson, 1996; Wright and Digby, 1996; Wendell, 1996; Mitchell and Snyder, 1998; Gleeson, 1999; Swain *et al.*, 2003; Zaviršek, 2000; Turner and Stagg, 2006; Cree and Davis, 2007). The contribution made by social work perspectives to this knowledge includes several methods for assisting, encouraging and implementing governmental policies to provide extra resources and also redirect existing policies towards inclusionary transport, schooling, housing, supported employment and community-based services. Advocacy, citizenship rights, meaningful participation (especially in the field of work) and inclusion (especially in education) have become key concepts (Sayce, 2000; Gilbert *et al.*, 2005; Bollard, 2009).

While, for some researchers, 'disability studies' has become a brand name for critical thinking in social work, others have hardly heard of it. As a consequence, the conceptualisation, practice and teaching of disability issues

have taken place, based on a number of very different theoretical foundations, as reflected in the variety of titles used to describe this area, such as ‘social work with disabled people’, ‘rehabilitation’ and ‘disability studies’. In many academic environments, the fundamental conceptual distinction between the individual and the structural and between the deficit- and embodied-difference-perspectives still goes unnoticed (‘Oh, you teach disability studies: a lot of our colleagues at the department are in rehabilitation!’). Since different professionals claim expertise in this area, such as educational and occupational scientists, social workers in countries with modest disability activists’ movements and a weak tradition of political social work, which is the case in Eastern Europe and in most Asian countries, have found their niche mostly within ‘rehabilitation science’.

A difficult move and a meaningful difference

Over the past twenty years, the social model of disability has changed social work research and practice not only in the area of people with different impairments, but also in relation to their relatives and carers, as well as professionals. The most visible change has been the rejection of the spatial segregation of people with disabilities, which resulted in the de-institutionalisation of large-scale locations towards more humanising ‘locations of disability’ (a phrase borrowed from Snyder and Mitchell, 2006). In addition to the development of community-based services, social work research has acknowledged the damaging effects of deformity-based rehabilitation treatments, which brought about more ‘bodies in pain’ than relief and consequently made people into volatile patients without personal agency as they set out on an institutional career in boarding schools, special education, residential homes and sometimes even orphanages.

Research conducted by social workers has shown that in spite of the fact that disabled people were portrayed as asexual and therefore seemingly protected from sexual violence, they experienced *gendered violence* to a greater extent than non-disabled people (Brown and Craft, 1989; Sobsey, 1994). Furthermore, research on the victimisation of disabled people by non-disabled people at home or within public care institutions has deepened the understanding of some persons’ experiences (Stanlev *et al.*, 1999; McCarthy, 2000; Zaviršek, 2002). An important contribution was made by research that showed that many disabilities, including intellectual disabilities, are the consequence of early childhood violence or trauma in later life (Sinason, 1992). At the same time, injustice is caused by the fact that people with intellectual disabilities are not seen as political subjects (guardianship issues), not trusted to live independently and are not seen as being capable of testifying in court on behalf of themselves or others (Bowley *et al.*, 2005; Dickman and Roux, 2005).

Although invisible within the disabled people's movement for a long time, recent studies show that people with disabilities belonging to ethnic minorities face additional disadvantages because most welfare services are not culturally competent and cannot provide culturally sensitive brokering for disabled people of different ethnic backgrounds (Beresford *et al.*, 1996; Chamba *et al.*, 1999; Ali *et al.*, 2001; Stone, 2005; Burke and Parker, 2007). Social work research has acknowledged the interrelatedness of unemployment and pathologisation from an early age of some ethnic groups such as Roma, throughout Central and Eastern Europe, who are in high numbers labelled as 'intellectually disabled' (Zaviršek, 2007a). The diagnostic category of intellectual disability was seen by some professionals as a preventative measure against poverty in the case of Roma people, since many of them experience trans-generational unemployment. This type of false presupposition stems from the culturalisation of ethnic minorities, such as the belief that ethnic minority parents are less interested in using professional support (respite care) because they are able to rely on informal support networks (Fazil *et al.*, 2002).

In the last decade, social work research has demonstrated a greater effort by social workers in *discussing sexual matters* with disabled people in order to, first, increase awareness and safety, especially among people with intellectual disabilities, second, demystify the anxiety of those who believe that they are not able to or are not allowed to have intimate contacts, and, third, provide information about reproductive rights and give useful information about reproductive choices, including reproductive cell banking for those with long-term illnesses and disabilities, which can affect one's fertility possibilities (Crawshaw, 2006; Shakespeare, 2006). Research in this area has shown the importance of proper information and choices in order for the person to give informed consent on matters about which many other people do not need to make decisions. The fundamental value system underlying most of this research states that all people have the initial right to have a family of their own with children, including the right of intellectually disabled people to have children with proper support in the form of multi-agency practice and a holistic understanding of how the needs of children and parents are related, interrelated and conflicting (Jakob and Gumbrell, 2009). Research examining the needs of carers and family members has shown that care remains gendered and that families experience disablement because disability expands across the family members (Burke, 2004).

Employment issues—one of the most important social justice issues in developed and less developed countries—have been the subject of thorough research. Despite the mainstreaming of employment and success in this area in the UK, Germany and other (mostly Western) countries, people with disabilities face poverty more frequently than non-disabled people; conversely, children, adults and older people living in conditions of poverty can easily become disabled (Purdam *et al.*, 2008; Shima

and Rodrigues, 2008). In countries where the work ethic is strongly imbedded in the dominant value system, stigma is attached not only to poverty, but to the question of whether someone has a workplace or not (the newest national paper in the area of disability in Japan bears the slogan ‘We aim to create a “society for all” in which everyone will have a chance to contribute through work’, JEED, 2008). The notion of a person’s contribution through the nineteenth-century Western conception of work (not to mention other similar ethics like Confucianism) has recently been challenged by the Basic Income Earth Network (BIEN) activists and academics all around the world, who believe that instead of non-rewarding types of work and the stigmatising welfare cash transfers, basic universal income could be the future solution to increasing the meaningful participation of every person (van Parijs, 1992). While employment mainstreaming has been achieved in some European countries and for some disabled people, people with intellectual or multiple disabilities are being steered towards sheltered employment in greater numbers than ever before. In some countries, vocational rehabilitation laws dominate the disability debate and employment is framed within medical and needs-oriented laws that expect a number of professionals to evaluate the person with a disability during different stages of the mostly temporary employment processes (Zaviršek, 2007b). Sheltered employment as a form of welfare provision is, in some countries, partly organised and promoted as a form of respite care, to give some freedom to the relatives of the disabled persons. There is no evidence that this type of sheltered employment, where disabled people make embroideries while professionals get involved in social enterprise activities in order to sell them at social work conferences (as is the case in many Eastern European countries—but not only), increases a person’s choices and contributes to their meaningful participation in the community.

Following several UN initiatives, since 1981, another common development of great importance has occurred in the area of national legislation. In the EU, South Africa, Japan and several other countries, progressive legislation has been adopted, including policies for mainstreaming disability and, in some countries, anti-discrimination laws. The latest UN Convention on the Rights of Persons with Disabilities (adopted in 2006 and implemented in 2008) marks a big step towards making these achievements global. Nevertheless, an enormous gap still exists between the formal and everyday rights of people with disabilities in most of these countries (Barton, 2001; Philpott and Sait, 2001; Shima and Rodrigues, 2008).

In recent years, developments in biomedicine have become more evident in research on the impact of reproductive and pre-natal medical technology on people with disabilities. The options of disability ‘repairing’ and ‘preventing’, as Scully (2008) has named them, have increased research interest in the areas of eugenics, selective abortions and sterilisation, which, in some countries, are still seen as ‘protective’ measures against the reproduction of

people with disabilities and are carried out with the consent of carers and guardians (Alemdaroglu, 2006; Snyder and Mitchell, 2006). Not only the ethic of disability advocated by the pioneers of disability studies over the past decades, but also disability ethics—the ‘particular moral understandings that are generated through the experience of impairment’—are becoming a significant area of concern (Scully, 2008, p. 9).

Parallel values and practices

An international perspective clearly reveals the existence of parallel social work values and practices within the same country systems in Europe and beyond. In many countries, mainstream social work practice consists of single-task intervention and tends towards deficit-oriented rehabilitation. As such, it fails to take into consideration the holistic perspective of people’s lives and to view them in a time perspective (what Mark Priestley calls the life-course approach; see Priestley, 2001). In many cases, social work practice continues to be individualised and its focus remains on employment and sheltered workplaces, community residential care and the development of day centre facilities for people with various disabilities (including those with mental health problems). Recently, the resilience discourse popular in developed and less developed countries has replaced the more critical concept of empowerment. In less developed parts of the world, mainstream social work is dominated by a diagnostic-deficit perspective and dependency-oriented interventions, and people are sent to semi-closed institutions for life or cope at home with their relatives (especially in Eastern Europe and most parts of Asia) (Abu-Habib, 1997; Lewis, 1999; Zaviršek, 1999; Priestley, 2001).

Simultaneously, alongside mainstream social work theory and practice in most countries with social work education, other smaller-scale (both in terms of numbers and funding), sometimes marginal, research and practice exist almost as a kind of parallel system. Social workers, disability-led organisations and advocates have managed to shift a portion of the welfare resources and ideas towards centres for independent/integrated living, direct payment and personal assistance schemes and user-led services in some form or another almost all over the world (EUMAP Reports on ‘Rights of People with Intellectual Disabilities’, 2005; Hayashi and Okuhira, 2008). A discrepancy can be observed: even in countries where people with disabilities are still sent to large-scale institutions and young people are sent to old people’s homes, such as in Bulgaria and Slovenia, some non-governmental organisations and local municipalities provide funding for personal assistants employed by persons with disabilities (Shima and Rodrigues, 2008). Similarly, direct payment, which is still a long way from being a mainstream practice for people with disabilities, is known not only in the UK and Sweden, but also in Slovakia, where the national

scheme provides direct payment, including the option of the person with the disability selecting his/her own personal assistant and agreeing on how care is to be provided (Shima and Rodrigues, 2008). In Slovenia, this is addressed not by a national scheme, but by a disability-led activist organisation that promotes independent living and self-determination; in recent years, its efforts have enabled more than one hundred persons to avoid entering institutional care (Independent Living of Disabled People, 2004).

These parallel developments and practices challenge not only common-sense beliefs about disability, but also mainstream social work. The value system behind them underlines research that has revealed the unproductive distinction between impairment as a bodily dysfunction and the socially constructed discrimination that causes disability, since it produces methods and welfare interventions that subjugate persons with disabilities to a normative identity framed within a 'category' or 'diagnosis'. In order to embrace impairment and disability, more research needs to focus on the concepts of 'embodied difference' and disability as a 'site of resistance', a 'source of agency' and a 'way of being' (Mitchell *et al.*, 2006; Snyder and Mitchell, 2006; Scully, 2008). The question that remains to be addressed is to what extent is social work capable of being critical towards the buzzword of 'inclusion' and the idea of 'being different', which, in today's common-sense value system, still means 'being something less' (Rommelspacher, 1999)?

Against inclusionary exclusion

People with disabilities who are included in the system of community services (which are often managerial-based) and sheltered workplaces often find themselves excluded as active citizens and agents of their own lives by the very system that provides them with social benefits and sees to their everyday needs. Many authors have used Franz Kafka's famous story, *Vor dem Gesetz* [*Before the Law*], to illustrate the dynamic between exclusion and inclusion. The story is a fitting metaphor for the social limbo experienced by people with disabilities in many countries. Kafka's story describes a man from the country who goes to the open door of the Law, only to find that *der Tuerhueter* [the doorkeeper] will not allow him to enter. The man from the country does not give up; he waits there for years, observing and talking to the doorkeeper in order to understand the logic of entering the Law. Over the course of time, he grows old; just before he dies, he asks the doorkeeper 'If everybody wants to enter the Law why has nobody entered through this door?'. The story ends with the doorkeeper's reply: 'No one else could enter here, since this door was destined for you alone. Now I will go and shut it' (Kafka, 2003, pp. 162–3). A symbolic understanding of the story demonstrates the dialectic of inclusion and exclusion. The open door destined

only for the man from the country includes him as a citizen who spends his life waiting to be allowed to enter (the closed circuit between the sheltered work place and the community-based home) and, at the same time, excludes him by preventing him from entering (becoming an active citizen). This is the paradox that most consumers of social services encounter when they are included in the form of an exception, as Giorgio Agamben has pointed out: 'The exception is what cannot be included in the whole of which it is a member and cannot be a member of the whole in which it is always already included' (Agamben, 1998, p. 25). People with disabilities are included through the exclusion conferred by a disability category and a policy of inclusion marks their exclusion, as well as 'includes' them. This complex dynamic shows that the right to various social benefits turns people into welfare consumers while denying them certain basic rights. In keeping with this analogy, the question of why the man from the country did not just break the law and enter through the door arises. Not only internalised oppression, but also the fear that more active citizenship rights could put the welfare benefits that they currently enjoy in danger prevent disabled people from 'entering the Law'. Like the man from the country, the concept of 'inclusion' makes people neither free nor un-free if welfare interventions like 'independent living' or 'empowerment' are not led by disabled people themselves and do not transform the notion of disability as 'the difference' into one that sees it as 'just another way of being'.

All of these examples show that social work in the area of disability issues demands much more than an objective, problem-solving, positivist approach of 'inclusion' or 'accepting difference'. Some research has shown that disabled people who want to enter the social work profession face enormous discrimination (French and Swain, 2001). A recent example from central Europe is the social worker who stutters and was rejected by more than fifteen social work services seeking to fill a position for a social worker (personal communication, 2009).

Conclusion

In spite of the enormous changes that have taken place in research, legislation, social policy and social work practice, the structural deprivation experienced by people with disabilities in developing countries is difficult to comprehend. While in some developed countries, people with disabilities have achieved at least some fundamental rights, people with disabilities living in developing countries seem to be locked into death-wishes, experiences of oneself as a burden and a lack of hope for future change and to be living under the constant threat of violence. The last example comes from the Sichuan disaster area in China, where state social workers have been instrumental in helping individuals and communities get back to living an

ordinary life and are involved in rehabilitation activities, but fail to challenge the deep-rooted structural (societal and parental) rejection of people with disabilities. New institutions have been built for those who remain disabled (see Disaster Relief Conference, 2009). A boy from the region was nicknamed ‘The Coca-Cola hero’ when the media reported that the first words he uttered after being pulled from the rubble were a request for a ‘cold Coke’. A year later, he told a social worker that he tries not to drink in order to minimise situations where he needs help to use the toilet, as he is now physically impaired (Cecilia L. W. Chan, personal communication). Learning from the voices of people with disabilities, the question is where and who this boy will be when he grows up. What might be other social work responses—besides ‘the help for accepting the prosthesis’—towards increasing a person’s dignity as well as challenging structural inequalities, if the social work discipline is truly based on the universal human rights principles? Here, a similar gap to that between legislation and everyday experiences of disabled people can be found between the theory and professional practice. Some researchers claim that the gap is widening (Cree and Davis, 2007; Staub-Bernasconi, 2007). The story tells us that social work and welfare locations have a long way to go before respect, acknowledgement, personal dignity, recognition and normalisation of the difference embodied in disability become ordinary.

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