

EDITORIAL

Editorial Review: Touring the Archive 1999–2017 and Mapping the Future of *Scandinavian Journal of Disability Research*

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The *Scandinavian Journal of Disability Research* is now an Open Access Journal from this issue onwards. We are particularly pleased that not only new articles, but also our full archive are included in the publishing agreement with Stockholm University Press. To celebrate this turning point in the Journal's history, we have revisited trends in its development, considered what recent and newly published articles say about its direction, and have explored what we see as important possibilities for our future. This editorial is our reflections on what we have found.

Very Brief History of the Journal

The Journal emerged out of, and still operates as an important wing of, the Nordic Network of Disability Research. From its beginning, therefore, a key aim of the Journal has been to be a home for *research on disability* being done across the Nordic countries. The studied areas include childhood and family life, welfare provision, social participation, and modes of intervention in areas such as rehabilitation, healthcare, training and education. In this way, the Journal provides a visibility to Nordic disability research activity, creating possibilities for dialogue between international and Nordic discourses on disability. The Journal has captured important changes that have affected disabled people in Nordic countries and beyond. For example, new techniques and philosophies in rehabilitation practice, reductions in the availability and purpose of welfare services, debates on inclusion, integration and specialist provision in education, and approaches to challenging barriers to employment and social participation.

The Journal has provided the forum for discussion and development of the *Nordic Relational Approach to Disability* or the *Nordic model of disability* (Gustavsson et al., 2005). The Nordic model connects disability studies to disability research in order to provide a political dimension to research; a dimension looking to generate social change. The Nordic model does this by:

- 1) Emphasising a relational understanding of what produces disability: that is how the environment interacts with the individual and the range of personal factors that affect them (i.e. both impairments and other factors such as gender, sexuality, race and ethnicity).
- 2) Being deeply and critically embedded in the human rights framework of the United Nations Convention on the Rights of Persons with Disabilities.

The Journal has always been a site where researchers working with the Nordic model, including locations others than the Nordic countries, present their work. This has been and remains one very important reason why work outside of the Nordic countries has always been welcome in the Journal.

We are currently in an expansive era of disability studies work internationally. This expansion is leading to new work in sub-fields such as Mad Studies and Critical Autism Studies. From the Global South new voices and perspectives are emerging that examine the problematic relationship between international capitalism, development agendas and disability. Critical Disability Studies is a term now commonly used to draw some of these different streams of disability work together. Looking at the papers that begin our new residence at Stockholm University Press we are beginning to see some of these ideas come into the Journal, alongside the continuation of important areas of concern

in Nordic disability research. This combined profile of work is something we very much want to encourage going forward. Below we discuss some of the recent and current work in the Journal and what it indicates for continuity and change.

Where We Are Now

The “normalization framework” has been a dominant approach to examining disability in Nordic research for many years (Nirje, 1969). Normalization advocates that support and interventions provided for disabled people should enable them to live “like any other” and have citizenship rights. This ideology has informed both research connected to citizenship and the life course. The normalization approach is increasingly critiqued for the way it appears to privilege non-disabled ways of being and in doing so reproduces disabled people as Othered “deviants.” It, perhaps unintentionally, implies that for disabled people to be seen as acceptable human beings and citizens, they must appear to be “normal.”

Recent work on citizenship in the Journal is expanding beyond the normalization framework to consider different ways to advocate for the rights of disabled people – drawing in many instances from the advocacy of disability groups led by disabled people. Particularly visible are human rights-based approaches (Katsui & Kumpuvuori, 2008) influenced by Marshall's (1950) account of citizenship, which emphasises the importance of social welfare and societal participation for people to have active citizenship rights. From this perspective several studies have explored how to strengthen disabled people's “membership of society” through social rights (Christensen et al., 2014), enabling them to actively participate in society – rather than being passive receivers of support (Umb-Carlsson & Lindstedt, 2011). This work stresses factors such as social adult status, control of life, personal safety, social belonging and self-chosen solitude in producing varied forms of active citizenship (Umb-Carlsson & Lindstedt, 2011). In new pieces coming through the Journal now we are seeing this expansive discussion of citizenship requirements continue. For example, Ursin and Lotherington (2018) extend discussions around citizenship for disabled people by arguing that people with dementia can still be thought of as having citizenship rights through a “relational understanding” of citizenship, including the intricate net of practices of the person with dementia, the illness and the support workers around the person.

Another area of citizenship debate currently in the Journal is focused on the implications for disabled people of being a worker to having rights and recognition. In some ways in Nordic countries, and elsewhere, being a worker is increasingly seen as central to being a good citizen. This clearly has implications for disabled people who may face, both significant barriers to being workers and who also may instead be recipients of welfare services. Articles in the Journal are exploring both the barriers to work for disabled people (Mik-Meyer, 2017) and also the appropriateness of making work the marker of a good citizen (Holmqvist, 2008). This work does not deny that employment can be associated with well-being (Clifton, 2014) and a successful transition into adulthood (Båtevik & Myklebust, 2006). However, it also stresses the need for support to be there for work to be both enriching and stable (Roulstone et al., 2014).

Taking these debates forward several pieces in our first open access set of papers look at the issues of gaining and staying in work. Bliksvær (2018) discusses the impact of education for employment, arguing for more complex and deeper analyses than what is commonly carried out by Nordic disability policy, which tends to be dominated by simplistic claims that higher education is the route to reducing inequalities and enhancing societal inclusion for disabled people. Similarly, both Östlund and Johansson (2018) and Gustafsson et al. (2018) explore barriers against and possible support for disabled people to remain at work. Criteria for what is needed to be a worker, shape who is defined as work able or work disabled. Angelov and Eliason (2018) critically explore discursive framings of both disability and workability within Swedish Public Employment Service's classification of occupational disability. They argue that demographic characteristics, socioeconomic position, and health-related conditions are associated with higher risks of being classified as occupationally disabled. The emphasis on work in contemporary society leads to a narrow account of what are appropriate day to day activities for disabled people. Luthra et al. (2018), in their paper focused on people with intellectual disabilities, argue that there are two options for them that are judged as socially appropriate: employment or being involved in some kind of daily activity (for example attending day centers). Their paper goes beyond these two categories by researching what people with intellectual disabilities are actually doing post-upper secondary school to recognize other ways of being in society that could be valued.

As we highlighted earlier the normalization framework is also interested in the life course, in particular that disabled people should, as much as possible, go through the same life transitions as non-disabled people. However, we know that many disabled people still live in separate social spaces and networks to others (Löfgren-Mårtenson, 2008). How disabled people can go through “normal” transitions in the life course, while living separated lives has long been a theme in the Journal. For example, Elstad & Kristiansen (2009) have pointed out how confinement to specific spaces produce a lack of opportunities for participation and recognition in the wider society. While Bjarnason (2005) highlights how important mainstream schools are in placing young people on vastly different tracks, independent of their disability labels; either on a track that leads them to an interdependent adulthood or on a track within a special world for “eternal children.” Østvik et al. (2018) pick this theme up in the new issue, exploring how friendships between disabled children using augmentative and alternative communication and non-disabled children

can be facilitated or inhibited in mainstream primary school settings. The problems of institutional segregation to lack of opportunities for privacy (Fish, 2018), or lack of social participation and exclusion from the surrounding community (Sondenaa et al., 2018) is also present in the new issue.

Finally in this overview of recent and current debates in the Journal, we want to highlight a number of important areas of investigation, which we believe are important to this push to examine more fully the opportunities and challenges for disabled people to live full and varied lives of their own making. First, is work exploring the spaces and opportunities to explore one's sexual identity and participate in sociosexual relationships (Löfgren-Mårtenson, 2008). This is taken up in the new issue by Shakespeare and Richardsson (2018), who discuss ways in which social changes in the last twenty years may be both opening up spaces for people with disabilities to imagine a sexual life and explore their sexual identities. However, they also stress the continued contextual restraints on disabled peoples' sexuality. A second area is looking at questions of ageing across the life course and the issues created by disabled people not matching normal milestones maintained in developmental trajectories from childhood to adolescence, and from adolescence to adulthood. Articles in the Journal have explored both the different risks associated with disrupted or failed transitions from childhood to adulthood, as well as the problems created by early retirement due to disability (Törnbohm et al., 2011). This theme is explored in the new issue by Engeland et al. (2018) who look at experiences of transition into retirement among older people with intellectual disabilities.

A final area of current concern in the Journal is how people live with disability and/or chronic illness and the influence this has on their sense of identity. We have seen work examining aspects of *self-understanding* among disabled people, including the challenges this can create to identity-formation and dilemmas around disclosure practices/strategies (Asbjørnslett et al., 2014). Such work also considers how other aspects of people's social position and identity influences the relationship between illness and self-identity, in particular gender (Diesen & Grut, 2017). Research in this area is also looking at *self-management* in relation to the demands of everyday life (Asbjørnslett et al., 2014). Jonsson and Hedelin (2018) explore meanings of a moderate hearing loss in daily life among middle aged women, where experiences of responsibility for communication may be illustrative of (both internalized and external) assumptions of self-management of impairment. A final area being explored within work looking at living with disability and chronic illness, which reflects some of the shifts in understanding associated with critical disability studies, is exploring how the embodiments associated with disability and chronic illness can be lived as different but not lesser. This work argues that people can develop productive and positive identities through (rather than despite) their different embodiments (Magnusson & Karlsson, 2008). Within research focusing on phenomenological understandings of disability, experiences of the disabled body is produced as an alternative bodily experience, rather than as obviously a deficit. In this issue this is explored by two papers. Lamont-Robinson et al. (2018) explore experiences of disabled sailors on board a tall sailing ship, adapted for accessibility. They discuss how the particular embodied activities on the ship, created new possibilities for positive and relational identities through their interactions with others. Flodin (2018) explores, from a longitudinal case study, the meanings of standing for a young woman born with Spinal Muscular Atrophy II and through the account provides a rich analysis of disabled embodiment outside the norm.

This whirlwind tour round the recent archive and the first papers that will appear in the new Open Access format, indicates that the Journal is a space of lively debate. It is not that ideas and practical strategies focused on how disabled people can lead a normal life are no longer welcome. Instead, it is about balancing such accounts, with more critical interventions that ask what alternatives may there be that enable different ways of living, ways of living which value disabled people for who they are, rather than how similar they are to non-disabled people. We suspect that balance between the two areas of work will continue in the Journal in the future. For now, we want to end by highlighting some immediate priorities for us in this new Open Access era.

Mapping the Future

What we have outlined above is a snapshot of the approaches to disability that have been observed in the Journal, as well as newer areas of development. The Open Access archive will increase visibility and accessibility to the rich resource of information we have accumulated. Open Access has also provided an opportunity to reflect on the changes that have developed across disability research and disability studies in Nordic countries. The Journal remains a forum where a broad range of research on disability is included.

Based on the review of the archive, as well as a conducted on-line survey (which we will discuss in more detail in a later editorial) and ideas presented to the Editors during the last NNDR conference in Örebro, we have identified 3 priorities in continuing to develop the Journal and give it a clear and visible identity:

1. The Nordic model of disability continues to be important in the Journal. Alongside, we would also like to see papers that create further dialogue between the model and other useful frameworks for critically examining and (re)defining disability. Areas such as the cultural production of disability, Global South perspectives, science and technology studies, and new considerations of mind and body differences outside the 'normal.' These are all areas we would like to expand more in the Journal.

2. The Journal has been a place where early career researchers have been well represented. To support their presence in the Journal we will further strengthen the review process. This will also ensure the work of both early career researchers and more established scholars in the Journal are all of a high quality, making a new and valuable contribution to our understandings of disability.
3. We ask for papers to reflect on the social impact of disability studies and disability research. We believe that papers published in the Journal should give some consideration to issues such as the social production of disability, the role of disabled people in research, and the principles expressed in the United Nations Convention on the Rights of Persons with Disabilities, and social and political change.

Competing Interests

The authors have no competing interests to declare.

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