Disability Studies in Iceland: past, present and future

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Disability Studies is a new interdisciplinary academic field that has developed over the past two decades. The aim of this paper is to introduce Disability Studies in Iceland including its roots, context, development, main characteristics and future prospects. Icelandic Disability Studies has developed in Nordic and international contexts and shares theoretical origins and location in the academic landscape. Early beginnings of Disability Studies in Iceland can be traced back to the mid-1990s but the first and only academic programme in Disability Studies was launched at the University of Iceland in 2004, providing this young field with an institutional base and academic recognition. Main characteristics of Disability Studies in Iceland are its growing interdisciplinary nature and close cooperation with disabled people and the disability movement, parents, professionals and policy-makers. Today, Disability Studies is a well-established field within Icelandic academia and operates in the context of extensive international ties and connections.

Keywords: Disability Studies; Iceland; interdisciplinary scholarship; collaborative research

Introduction

Before the formal establishment of a Disability Studies programme at the University of Iceland in 2004, a small group of scholars had been teaching and researching disability using the social approach that is central to Disability Studies. These scholars were the pioneers in paving the way for Disability Studies and the first scholarly writings based on Icelandic disability research were published in the 1990s. Some of this research was initiated by the disabled people's movement and the parents' movement, reflecting a collaboration between disability scholars and activists; these are characteristics of Icelandic disability research that have continued. Today, Disability Studies in Iceland is a vibrant and diverse area of scholarly inquiry. It is interdisciplinary and employs various theoretical perspectives. In Iceland, like in other countries, it is informed by scholarship in social sciences, humanities, education, health sciences, arts and applied fields.

This article traces the historical roots, early beginnings and international context of Disability Studies in Iceland. It outlines, among other things, the importance of Nordic collaboration for the development of disability research in Iceland, in

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particular the supportive context of NNDR, the Nordic Network on Disability Research. The article describes events leading up to the formal launch of a Disability Studies programme, outlines the major characteristics of the field today and concludes with a discussion of the future prospects of Disability Studies in Iceland.

Historical roots

Iceland is a small country with a population of 320,000 people. Until about two decades ago university education in most academic disciplines was at the BA level only and those pursuing master's or doctoral degrees received their education abroad. As a result, the majority of academics in Iceland have graduated from a wide range of universities, mostly in the Nordic and other European countries and North America, providing the Icelandic academic community with a variety of international experiences, contacts and knowledge of disciplines, scholarships and traditions. This is one of the major characteristics of Icelandic academia as well as being regarded as one of its strengths.

This international educational background is also true for scholars in Disability Studies who have studied abroad and brought to Iceland knowledge of disability research and Disability Studies from a range of countries. The three authors of this article are a case in point having studied disability in Denmark, Norway, Britain and the USA. Thus, Disability Studies in Iceland is influenced by international scholarship and diverse approaches to disability. Icelandic Disability Studies has been inspired by US understanding of disabled people as a minority group and where the humanities are currently influential aspects of an interdisciplinary Disability Studies community (Albrecht 2002; Davis 2006; Snyder, Brueggemann, and Thomson 2002; Taylor 2006). Disability scholars in Iceland have also been informed by the British 'social model of disability' and its distinction between the biological (impairment) and the social (disability) and which provides a social science foundation for Disability Studies (Barnes, Oliver, and Barton 2002; Shakespeare 2006) but with a growing interdisciplinary approach (Goodley 2011). However, being one of the Nordic countries, Iceland is the most strongly influenced by Nordic scholars and shares the Nordic relational and relative understanding of disability (Gustavsson et al. 2005; Tøssebro 2004).

In Iceland, as in other Nordic countries, the development of a social understanding of disability was closely related to fundamental ideas about citizenship and equality which are long-standing basic principles and values of the Nordic welfare states. A central aspect of this understanding can be traced back to the 1960s when Nordic authors were formulating the principle of normalization (Bank-Mikkelsen 1964, 1969; Nirje 1969), demanding that welfare provisions and citizenship rights be extended to the entire population, including groups previously excluded such as disabled people (Grünewald 1989; Kristiansen 1993; Stangvik 1987). These new perspectives were accompanied by a challenge to the dominant biomedical/ therapeutic perspective and led to a rethinking of disability, disability policy and disability scholarship, shifting the attention away from the individual and the impairment to the environment and the impact of cultural, social and physical barriers. In Iceland, as in the other Nordic countries, this shift created the foundation for a new social approach to disability research and paved the way for Disability Studies. At the outset the new perspective on disability research in Iceland was strongly influenced by social sciences and the historical roots of Icelandic Disability Studies share a common international history that can be traced back to sociological theories of 'stigma' and the labelling theory of deviance which focused on how society creates deviants by labelling certain groups as 'outsiders' (Becker 1963). Goffman's (1961) analysis in his book *Stigma* and his exploration of the devastating effects of mental hospitals and other 'total institutions' on those living there in *Asylums* (Goffman 1963) were extremely influential. These theories directed the view away from the presumed deficits of disabled people to the social and cultural contexts in which disability is constructed. Goffman's work led to a critical view of institutions as well as a rethinking of the meaning of disability. The critical engagement of many disability scholars with these theories has greatly influenced the development of Disability Studies in the USA (Conrad and Schneider 1992), the UK (Barnes and Mercer 2003) and elsewhere. Icelandic Disability Studies shares these international theoretical roots.

Early beginnings

Before the formal establishment of Disability Studies as an area of scholarly inquiry, a small number of scholars had been teaching and researching disability, using the social approach that characterizes Disability Studies. These scholars were in the Faculty of Social Sciences at the University of Iceland and the Iceland University of Education. The early scholarly writings based on Icelandic disability research were published in the 1990s. At the outset much of this research was focused on children and inclusive education (Bjarnason 1997; Marinósson and Traustadóttir 1993), disability and family life with a focus on both families of disabled children (Traustadóttir 1995) and families of disabled parents (Sigurjónsdóttir and Traustadóttir 1998). Some of this research and writings were initiated by the disabled people's movement and the parents' movement, reflecting an early collaboration between Icelandic disability scholars and disability activists.

These scholarly publications were important steps in the early development of disability research and Disability Studies. These were, however, not the first writings in Icelandic introducing disability research and the social approach to disability. As early as the 1980s a number of short articles by Icelandic scholars appeared in the journal Throskahjálp published by the parent's movement The National Association for Intellectual Disability. These articles were aimed at professionals, parents, disabled people and others interested in issues of disability, and were intended to introduce and discuss new perspectives in disability and disability services. A wide range of issues were addressed in these articles including self-advocacy, family support services, gender and disability, new approaches to residential services, individualized supports, inclusive schools, integrated employment and deinstitutionalization. Some of the articles also provided information about disability affairs in other countries. These accessible short articles were no less influential than the more scholarly publications as they provided many people in the grassroots movement and service professionals with information about innovative issues and international developments in the field of disability. These articles were also widely read by students in various fields that addressed disability. The journal *Glæður*, published by the Icelandic Organization of Special Educators, also published important articles on

inclusive education in the 1990s (Bjarnason 1995; Marinósson 1995; Marinósson and Traustadóttir 1994).

Courses in Disability Studies were taught at the University of Iceland in the Faculty of Social Sciences in the 1990s at a similar time when the first academic writings were published. Rannveig Traustadóttir (1992) had conducted her doctoral studies at Syracuse University, a pioneering university in the USA in Disability Studies. Upon completing her dissertation in 1992, she returned to Iceland and soon became a leader in Disability Studies in Iceland. Starting in 1994 she taught courses with a Disability Studies focus in the Faculty of Social Sciences at the University of Iceland. At a similar time Disability Studies was also introduced in courses taught by Dóra S. Bjarnason at the Iceland University of Education where an emphasis on inclusive education has been strong.

These early beginnings were important as they introduced a new field of inquiry within the academia. The courses offered provided a social understanding of disability within academia, challenging traditional approaches and providing students with an alternative view of disabled people. Many of the students had disabled family members or had worked in disability services. Some of them were disillusioned with the way disabled people were treated and the Disability Studies approach provided a welcomed new perspective. The experiences of the early courses demonstrated an interest among students and the scholarly contributions by academics promoting this young discipline earned respect within the research community.

The first steps towards Disability Studies in Iceland were similar to the development in other countries where many of the fundamental aspects of Disability Studies existed 'before it had a name' as Steve Taylor (2006) phrases it and can be traced back many years before it became identified formally as an independent area of inquiry. Although the major characteristics of Disability Studies were far from being fully developed in Iceland in the 1990s when the first scholarly publications appeared and the first courses were taught, the core idea – the social perspective on disability – was firmly in place as reflected in the writings of the contributors to the first edited volume introducing Disability Studies in Iceland (Traustadóttir 2003).

Disability Studies - a new academic field

The first academic programme in Disability Studies in Iceland was formally launched in the fall of 2004 at the University of Iceland. It was a part of the Faculty of Social Sciences and was, from the start, defined as interdisciplinary. The programme was on a graduate level offering MA and Ph.D. programmes as well as a Graduate Certificate in Disability Studies. The establishment of the programme was made possible by a five-year grant from the Ministry of Social Affairs. Árni Magnússon, who came into office as the Minister of Social Affairs in 2003, officially declared his political interest in the affairs of disabled people and this included improving services, research and development in order to support change. This led to an agreement between the Ministry of Social Affairs and the University of Iceland stipulating that the Ministry provided a five-year grant for an academic position in Disability Studies to enable the University of Iceland to establish a Disability Studies programme. This was the first academic position in Iceland that was formally defined in Disability Studies. In May of 2004 Hanna Björg Sigurjónsdóttir was hired to fill this historical post. The launch of the programme in Disability Studies formally acknowledged it as an academic field of inquiry and provided an institutional base for Disability Studies in Iceland.

Two years later, in 2006, the Centre for Disability Studies was established as an interdisciplinary site for disability research with the goals to increase research, attract scholars to work in the field and provide graduate students for a base to work from. Rannveig Traustadóttir was the founding Director of the Centre which operates in close collaboration with the Disability Studies programme. Together with Hanna Björg Sigurjónsdóttir, Rannveig has been instrumental in developing Disability Studies as an academic field in Iceland.

There are four core courses in the Disability Studies programme which includes theories and perspectives in disability, cultural representation of disability, life course approach to disability and the intersection of disability with other social categories. One of these courses is taught in English. Research methods are also a requirement and a research-based thesis is a part of the master's programme. Reflecting the interdisciplinary nature of the programme, students are encouraged to take elective courses in fields of their interest and many combine Disability Studies with a variety of academic disciplines. In addition to the core courses, short intensive courses are offered most years. These courses are, as a rule, offered by international guest lecturers and have focused on a variety of topics such as inclusive research, sexuality and disability, independent living, disability and identity and parenting with intellectual disability.

The Disability Studies programme at the University of Iceland was from the beginning identified as belonging to multidisciplinary fields of studies such as gender studies, lesbian and gay studies and ethnic minority studies, all of which challenge inequality and marginalization. This scholarship shares many core characteristics with these allied disciplines including the roots in social movements aimed to end oppression, opposition to hegemonic normalcy, critique of dominant theories, challenging key concepts, the development of innovative and collaborative research methods and the equalization of the relationship between the researcher and the researched.

There is a strong commitment within the Disability Studies programme to collaborate with disabled people and the disability movement, including the parent's movement. Disabled people are among regular guest lecturers in the programme's core courses and students are encouraged to conduct inclusive, participatory or collaborative research, and are supported to include disabled people in research projects in meaningful ways. This is particularly true for those doing doctoral research.

Each year between 15 and 25 students start the programmes in Disability Studies (Graduate Certificate, MA and Ph.D. programmes combined). This is a highly diverse group with an educational background that covers most academic disciplines in the social sciences, education, humanities, health sciences and applied fields. Many have personal experiences of disability as disabled people or as family members or friends, and a large number has worked with disabled people in services ranging from institutions to independent living. In addition to the students enrolled in the Disability Studies programme, students from other disciplines also seek individual courses. Most of them are not only students from applied fields such as social work, social pedagogy, career and educational counselling but also students from academic disciplines as varied as anthropology and theology. The diversity of the student group is an important aspect of the interdisciplinary nature of the programme in

Iceland with students bringing diverse perspectives to their studies and to discussions within the student group.

The doctoral programme is the most important in terms of creating and developing Disability Studies as an academic field in Iceland. Many of those enrolled in the doctoral programme are mature students, including a number who already are university teachers in fields such as social pedagogy, education and occupational therapy. These are individuals who, for various reasons, did not go abroad for doctoral training and seized the opportunity when a doctoral programme was available in Iceland. Thus, the Disability Studies programme at the University of Iceland has supported disability research at other universities such as the University of Akureyri where a course in Disability Studies is taught in the School of Health Sciences. As well, the Iceland University of Education (which merged with the University of Iceland in 2008 to become its School of Education) offers a course in Disability Studies within the programme in Social Pedagogy as well as a two-year Vocational Diploma Studies course at the undergraduate level for people with intellectual disabilities.

In addition to the mature students already established within academia, young people show increasing interest in the doctoral programme. Among the six doctoral students in the Disability Studies programme, at the time of writing this article, are two international students recruited as a part of a larger Marie Curie Initial Training Network for Early Stage Researchers to educate future leaders in implementing the UN Convention on the Rights of Persons with Disabilities (United Nations 2006).

While it is important to provide training in Disability Studies in Iceland, it also has its dangers to have 'home grown' scholars in a country of the size of Iceland. The challenge is how to secure an international context and experience of doctoral students. This has been met with the development of new forms of international collaboration centring on the training of doctoral students and the installation of rules meant to ensure international components of the doctoral training. Each doctoral student has a Ph.D. committee that consists of a minimum of three members and there is at least one international scholar on each committee. It is also a requirement that each doctoral student spend a semester at a university abroad, most often at the university where their international committee member is placed. The Ph.D. dissertation is considered a contribution to the international scholarship and students are required to write it in English.

These aspects of the doctoral programme have encouraged increased student and teacher exchange and have solidified collaboration with a number of universities, mostly in Europe. Thus, while it is important to make it possible for people to study for a Ph.D. degree in Iceland it is essential to make sure that future disability scholars have the international overview, contacts and experiences that increasingly characterizes academic life in any field. The international aspects of Disability Studies in Iceland is further strengthened by the active participation of Icelandic scholars in Nordic, European and international research projects and training in Disability Studies and related fields, which also provides graduate students with opportunities to take part in such collaborations.

As an area of inquiry disability is not a new topic within academic institutions. Indeed, disability has been studied within psychiatry, psychology and medicine, as well as in special education, rehabilitation and other similar clinical or instructional areas. Within sociology, disability has traditionally been addressed in courses on social problems and deviance (along with gender, ethnicity and sexuality). These academic disciplines have viewed disability as a negative characteristic, an abnormal condition in need of cure, correction or treatment. Icelandic universities share this history. Thus, studying disability is not new; rather, it is *how* disability is approached that is a new characteristic brought about by Disability Studies. Influenced by international scholarship from the beginning, Icelandic Disability Studies views disability as a social, cultural and political phenomenon, and examines how disability is defined and represented in society. These key characteristics of Disability Studies have been central in the development of this young discipline from the outset in Iceland (Traustadóttir 2004).

Disability Studies in Iceland today

As was the case in other academic fields, the first scholars using social and cultural approach to disability research had to go abroad for their doctoral studies. First to complete such studies was Rannveig Traustadóttir (1992), who combined issues of gender and disability in her dissertation analysing the social reform of deinstitutionalization. A decade later Gretar L. Marinósson (2002) wrote a Ph.D. thesis addressing how mainstream schools respond to diversity among pupils. This was closely followed by Dóra S. Bjarnason's (2003) dissertation on disability and young adulthood, and Hanna B. Sigurjónsdóttir's (2005) thesis focusing on families headed by parents with intellectual disabilities. The first Ph.D. candidate to defend her dissertation in the field at the University of Iceland was Snæfrídur T. Egilson (2005), who studied the participation of students with physical impairments in regular schools. Other doctoral studies at the University of Iceland have included a historical analysis of deinstitutionalization and community living using a life history approach (Stefánsdóttir 2008) and identity formation and social participation of young adults with intellectual disabilities (Björnsdóttir 2009). Ongoing doctoral studies focus on a wide range of issues. Inspired by the UN Convention on the Rights of Persons with Disabilities there is an increased focus on human rights approach and the inclusion of disabled people in all aspect of community life.

The major areas of the early Icelandic disability research and writings of the 1990s - education, childhood and families - continue to be among those that still occupy scholars in Disability Studies as evident in recent publications (Bjarnason 2008a, 2008b, 2011; Egilson 2011, Egilson and Hemmingsson 2009; Egilson and Traustadóttir 2009a, 2009b, 2009c; Llewellyn et al. 2010; Traustadóttir, Sigurjónsdóttir, and Gunnarsson 2010). However, in the last two decades Disability Studies and disability research in Iceland have expanded and become considerably more interdisciplinary than in the early days when it was largely dominated by social science and education. Today, the humanities have gained ground with scholars examining the cultural representation of disability (Jakobsson and Sigurjónsdóttir 2007; Sigurjónsdóttir, Jakobsson, and Björnsdóttir 2013) and the images of disability in folklore (Jakobsson and Sigurjónsdóttir 2008) as well as images of disability in the media (Sæmundsson and Björnsdóttir 2011). Disability Studies scholars have explored social structural issues such as poverty, charity and disability (Rice 2007, 2011; Rice and Traustadóttir 2011) while others have looked closely at individual lives through life history work (Björnsdóttir 2010; Björnsdóttir and Jóhannesson 2009; Geirsdóttir and Stefánsdóttir 2005; Stefánsdóttir 2004). A gender perspective has been commonly used (Björnsdóttir 2011; Kristiansen and Traustadóttir 2004; Mayers and Sigurjónsdóttir 2010; Rice 2009; Sigurjónsdóttir 2004; Sigurjónsdóttir

and Traustadóttir 2000) and attempts have been made to combine Queer Studies, Crip Theory and Disability Studies (Björnsdóttir and Kjaran 2011; Rice 2012). Intersectional approaches to disability have also gained increased attention (Björnsdóttir and Traustadóttir 2010) and the growing emphasis on human rights is reflected in published works (Baldvins-Bjargardóttir and Sigurjónsdóttir 2011; Sigurjónsdóttir, Baldvins-Bjargardóttir, and Traustadóttir 2009). The interest in disability within various academic disciplines is also evident in health sciences with scholars critically reviewing existing health and social services, often in partnership with users and professionals (Árnadóttir and Egilson 2012; Pálmadóttir and Egilson 2011).

This quick overview of some of the trends in Disability Studies in Iceland today reflects a remarkable expansion of this young field in a relatively brief period. An annotated volume was first published in Iceland in 2003 introducing Disability Studies as a new field of study and presenting contemporary research in accessible case study formats (Traustadóttir 2003). This was followed by a more scholarly book outlining theoretical and methodological issues in Disability Studies and disability research (Traustadóttir 2006).

The main research activities are at the University of Iceland at the Centre for Disability Studies which operates in close collaboration with the Disability Studies programme. Disability research also takes place at the Centre for Inclusive Education and the recently established Centre for Social Pedagogy, both operating within the School of Education, University of Iceland. In addition, disability research is conducted in the Faculty of Health Sciences at the University of Akureyri.

Most Icelandic disability scholars have considered it important to publish their work in Iceland in order to disseminate locally the results of Icelandic disability research. Publications in Iceland are an essential aspect of creating the foundation for and development of Disability Studies in Iceland. It has been equally important to publish internationally, to introduce Icelandic disability research to an international audience and disseminate the findings from the many Nordic, European and other international projects Icelandic scholars have taken part in.

Disability Studies is interdisciplinary in that it crosses traditional boundaries between academic disciplines and schools of thought, and employs various theoretical perspectives. In Iceland, like in other countries, it is informed by scholarship as varied as sociology, political science, law, history, literature, education, anthropology, philosophy, cultural studies, theology, media studies, folklore, museum studies, the arts, gender studies, queer studies and more. No single academic discipline can claim Disability Studies.

Characteristics of Disability Studies in Iceland

There is a close collaboration within the small Disability Studies community in Iceland. Disability researchers have also reached out to collaborate with scholars in a wide range of disciplines, as outlined above, creating an interdisciplinary field. Although it is important to have a separate Disability Studies programme, it is also vital to introduce and integrate disability within the wider academia. Among the ways this has been achieved is to give guest lectures in courses in other disciplines and to offer lecture series and the like. In addition, symposia in Disability Studies have been an integral part of the annual Research Conference in Social Sciences at the University of Iceland since 2003.

One characteristic of disability research in Iceland is an expertise in qualitative research with Disability Studies scholars frequently teaching methodology in their respective faculties. There is a commitment to collaborative, inclusive, participatory and empowering research emphasizing the perspectives of disabled people and their active inclusion in research projects. As a result, many studies are carried out in cooperation with disabled people as individuals or with their organizations. A number of Icelandic disability researchers also have strong ties to the service system and many worked as professionals before embarking on academic training. This has facilitated collaborative research on various aspects of disability services and resulted in efforts to improve services and supports available to disabled people.

A collaborative spirit has also characterized efforts to reach out to community groups, professionals, parents and disabled people by offering public lectures, workshops, courses and conferences on various issues related to disability. Such events have frequently been planned in collaboration with the disabled people's movement, municipalities and ministries. An emphasis is on making these events accessible to a wide range of audiences. On many occasions international scholars are keynote speakers at such events.

As mentioned above, Disability Studies in Iceland has been developed in and influenced by Nordic and international contexts. A significant aspect of Icelandic Disability Studies is the wide ranging international connections and collaborations with scholars and academic institutions in the Nordic Countries as well as in a number of other European countries, Canada, the USA, Australia and New Zealand.

INDR, Icelandic Network on Disability Research

Established in November 2006 by a group of academics and disability activists, the Icelandic Network on Disability Research, INDR, has been one of the rallying points of people interested in disability research in Iceland. Reflecting this, the founding conference, attended by about 80 people, was chaired by Sigursteinn Másson, then president of the Organization of Disabled People in Iceland and featured Tom Shakespeare (a disability scholar and activist) as a keynote speaker. At the conference, Rannveig Traustadóttir was elected president and the six additional board members included scholars, leaders from the disabled people's movement and a graduate student in Disability Studies. This combination of the board reflects how the Network brings together a range of people interested in disability research including scholars, students, disabled people, parents, professionals and policy-makers, which is reflected as well in those who attend events organized by the Network. There is no membership fee for joining the INDR, and people can register as members online and receive information about the Network, its events and related issues of interest. Currently the Network has about 200 members.

The INDR's major activity is a bi-annual conference, held on alternate years to the conferences organized by NNDR, the Nordic Network on Disability Research. Themes of the INDR conferences have included 'Disability, Self and Society' for the 2008 conference and 'Human Rights and Independent Living' in 2010. INDR has hosted seminars on methodology and disability research, independent living and user-led personal assistance. In addition, the Network has co-hosted a number of other seminars and public lectures, often featuring international speakers. INDR events have been well attended reflecting an interest in disability research and the perspectives provided by Disability Studies.

NNDR, Nordic Network on Disability Research

The NNDR has been an important and supportive context for disability research in the Nordic countries. This was particularly true for Icelandic disability researchers at the outset in the 1990s when scholars in Iceland were few and Disability Studies was unheard of. The NNDR conferences were an important place for Icelandic disability researchers to meet colleagues and for the development of Disability Studies in Iceland.

Disability Studies in Iceland has been strongly influenced by participating in the NNDR and Icelandic scholars share the fundamental belief that a diversity of approaches and interdisciplinary perspectives are essential for the continuing development of Disability Studies as a field. While it is important to acknowledge the important influence of the NNDR on the development of disability research in Iceland, it should also be mentioned that the NNDR was also influenced by Icelandic scholars, particularly by Rannveig Traustadóttir who was the president of NNDR for seven years (2000–2007).

The group of scholars and activists who initiated the establishment of the INDR had previously worked together on various issues related to disability research, not least in the context of the NNDR. Among other tasks this group organized the 6th NNDR conference in Reykjavík in 2002. This was the first time a NNDR conference was held in Iceland and it was a major undertaking for a small group of people to organize such a large conference. One of the major goals of the conference organizers was to bring together Nordic and UK disability scholars to discuss 'understanding of disability'. A plenary symposium on this topic was organized as a part of the conference. It was chaired by Rannveig Traustadóttir and participants were Tom Shakespeare and Carol Thomas from the UK, and Märten Söder and Jan Tøssebro from the Nordic countries. Other keynote speakers were Colin Barnes (UK) and Kristjana Kristiansen (Norway). The conference was attended by 300 people which at that time was the largest NNDR conference. The conference also marked the beginning of fruitful collaborations between UK and Nordic scholars. Since the 2002 NNDR conference. Icelandic academics have had close contacts with UK scholars from various universities and research institutes. This collaboration has been of significant importance for the development of Icelandic Disability Studies and research.

The 2002 NNDR conference was important for Icelandic disability research in more than one respect. It was a critical moment as the first international Disability Studies conference to be held in the country, thus introducing to a substantial group of Icelanders the larger landscape and multidisciplinary scope of disability research. For most of the about 70 Icelandic participants, this was the first time they were exposed to Disability Studies as an independent academic field of inquire. It was also a revelation for many to see the important collaboration between the disability movement and academics, and the potential of Disability Studies for social change. The success of the 2002 NNDR conference encouraged and inspired the group of scholars and activists who organized the conference to continue the development of Disability Studies and disability research in Iceland.

In 2011 Iceland again hosted the NNDR conference. The conference's major focus was on the UN Convention on the Rights of Persons with Disabilities and Independent Living. One of the goals of the conference was to bring together disability and human rights scholars to discuss the significance of the UN Convention and its implementation. This turned out to be the most international of the NNDR conferences with over 400 participants from 29 countries. Keynote speakers were Anna Lawson (UK), Ron McCallum (Australia), Steven J. Taylor (USA), Adolf Ratzka (Sweden) and Freyja Haraldsdóttir (Iceland). The emphasis on human rights at the 2011 NNDR conference reflected the influence the UN Convention is having on disability research in Iceland and internationally, high-lighting yet again the strong international context of Disability Studies in Iceland.

Future of Disability Studies in Iceland

Although Disability Studies is a well-established field of inquiry in Icelandic academia, the Disability Studies programme at the University of Iceland is struggling to survive due to the funding mechanism of the programme and the relatively few students enrolled. Funding is based on the number of students completing each course and finishing MA and Ph.D. degrees. Most of the students are part-time, taking courses while doing research and writing alongside employment. As a result, many take a long time to complete their studies. The fact that students do a research thesis at the MA or Ph.D. level requires individual advice and supervision that is more intensive than required for BA students. Most academic fields generate their income through undergraduate programmes. The Disability Studies programme has no BA level courses, making the financial base of the programme vulnerable and, so far, the programme has not been able to survive without grants to supplement its income. These grants have all come from outside the University of Iceland, including the five-year grant mentioned above from the Ministry of Social Affairs (2004–2009) and a two-year grant from the largest disability umbrella organization, The Organization of Disabled People in Iceland (2010-2012). An additional source of income has been through research grants secured by the two full time academics in the Disability Studies programme.

Thus, while Disability Studies is established as a scholarly field in Iceland, the financial insecurity of the only Disability Studies programme makes the future insecure. It would be of great significance if the University of Iceland made a commitment to sustain the programme and make sure Disability Studies continues to be a part of its academic landscape. This raises the question: Why should the University support the Disability Studies programme? Disability is a part of human diversity and the human condition. It will touch each and every person at some time in their lives. Many have a family member or a friend who is disabled and those who live long enough will experience a functional limitation. Human bodies and minds are vulnerable and an accident or illness can cause impairments of various kinds. For disabled students, Disability Studies is particularly important as it can assist them place their personal experiences in a social, cultural and political context. As a scholarly field, it provides a new perspective to examine a range of phenomena such as culturally constructed ideas of normality and beauty and an understanding of stereotyping, exclusion and discrimination.

By supporting the Disability Studies programme, the University of Iceland can demonstrate a commitment to diversity. Disability Studies have complemented the services offered to disabled students at the University of Iceland. It has helped create knowledge about disability, has taken active part in developing anti-discrimination policies and equal opportunity practices. And it has assisted in making the University more inclusive and accepting of disabled students by helping break down the attitudinal barriers that can isolate and marginalize disabled students.

The academics associated with the Disability Studies programme have actively disseminated knowledge and information on disability-related issues to a range of audiences outside the academia. Such activities are particularly relevant in the near future in order to educate people about the new UN Convention on the Rights of Persons with Disabilities, including its contents, relevance, implementation and monitoring. Countries ratifying the Convention have a responsibility to implement it. This will not be achieved without wide ranging knowledge of the significance and demands of the Convention. The Convention itself calls for awareness raising and the collection of appropriate information, including statistical and research data, to enable countries to formulate and implement policies that are in accordance with the Convention. A strong Disability Studies programme is crucial in making sure that there is competence within Iceland to carry out this knowledge production and its dissemination.

Thus, the future of Disability Studies will, in part, be directed towards the continuing emphasis on knowledge production that can support the full and equal rights of disabled people, barrier removal and an inclusive society that welcomes the whole range of human diversity. Part of this endeavour is the increasing emphasis on the exploration of the construction and representation of disability in Icelandic society and culture. These and many other exciting projects await Icelandic Disability Studies scholars in the future.

Conclusion

The quick overview in this article of the development of Disability Studies and disability research in Iceland reflects a remarkable expansion of this young interdisciplinary field in a relatively brief period. At the outset, Disability Studies was dominated by the social sciences and education but the humanities are gaining ground and the connection with law and political science has increased since the UN Convention on the Rights of Persons with Disabilities came into force. Today, Icelandic Disability Studies scholars use an interdisciplinary approach and a major characteristic is the close collaboration with disabled people and the disability movement. A number of Icelandic disability researchers also have ties to the service system and their research on various aspects of disability services has resulted in efforts to improve services and supports offered to disabled people. The community of Disability Studies scholars is small but it is an active network of individuals that work closely together. Disability Studies in Iceland have been developed in and influenced by Nordic and international contexts. A significant aspect of Icelandic Disability Studies is the wide ranging international connections and collaborations with scholars and academic institutions in many countries.

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