Introduction

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Disability before Disability (DbD) is an interdisciplinary research project about the hidden lives of disabled people in Iceland before the concept of disability existed culturally, socially, and administratively. The project focuses on Iceland from the Age of Settlement, traditionally considered to have taken place from 874 to 930, until the 1936 Law on Social Security (*Lög um almannatryggingar*), which is the first time that disabled people were referenced in Iceland as a legal or administrative category. DbD explored the seldom heard voices from the past by investigating “disability” through a colourful collection of sources available to the project: From the medieval Icelandic prose literature, through to archaeological remains, historical archives, folktales and legends, personal narratives, and museum displays in the contemporary period. A multidisciplinary team of experts working in Iceland in the fields of Disability Studies, History, Archaeology, Medieval Icelandic Literature, Folklore and Ethnology, Anthropology, Museum Studies, and Archival Sciences, along with a collection of post-doctoral and graduate students, provided the data and collaborated in the analysis in a series of meetings and workshops, along with select invited experts from outside of Iceland who shared an interest in the disability field. This volume provides an overview of the output of these collaborative endeavours. The project pursued several questions that were posed to the varied research strands. The overarching question was: What constituted disability in Icelandic society, culture, and history before the establishment of disability as a modern legal, bureaucratic, and administrative concept? This was followed with a series of related questions, inquiring into how disability figured in everyday life, such as: How did disability matter in terms of one’s social success? How was disability discussed and narrated? Pursuing these questions led to the collection of a large, and varied, body of data in different forms and from different times periods in Iceland. Interdisciplinary, collaborative analyses at times proved to be fruitful and exciting, and at other times challenging given the significant differences in some source material and time periods. What cemented the project together was the disability studies perspective provided by the project management, and the multidisciplinary input which demonstrated how disability studies could benefit

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from the knowledge and expertise provided by the diverse disciplines that comprised the research strands of DbD.

The project is grounded in critical disability studies. Disability studies rejects the traditional bio-medical understanding of disability as an individual deficit. Instead, disability is seen as a social phenomenon embedded in social arrangements and cultural conventions. Disability studies offers new avenues of scholarly inquiry whereby the dominant narrative of disability as an individual medical condition or deficit is replaced by an approach that recognises the multifaceted and complex nature of disability as embedded in culture and relations of power. The discipline emerged as a distinct field of research over the last three decades (Davis 2006a, Shakespeare 2014, Söder 2009, Watson *et al.* 2012). From its origins in the U.K., the Nordic countries, and North America, disability studies has since become global (Connell 2011, Grech and Soldatic 2016, Ingstad and Whyte 1995, 2007, Kakoullis and Johnson 2020), bringing into the fold the varied cross-cultural understandings that, in a way, provided some inspiration for DbD. From its inception, the discipline has been both an academic as well as a political project. Disability studies is rooted in political activism in North America and many European countries during the 1970s and 1980s. This era was marked by political turmoil, protest, and the fight for the civil rights of various social groups. It was in this political atmosphere that disabled people began to coordinate their efforts to fight against oppression, humiliation, discrimination, segregation, and poverty (Oliver 1990, Shapiro 1993, Traustadóttir 2006). Disabled activists protested the power that specialists and professionals wielded over their lives and fought for the right of disabled people to live independently in society, and the discipline of disability studies developed in relation with the everyday lives and political struggles of disabled people (Traustadóttir 2006). One key focus of the early academic work in this field centred on the institutional abuses of people with intellectual disabilities (Biklen and Bogdan 1977, Bogdan and Biklen 1977, Bogdan and Taylor 1976), while another was that of the cultural meaning and experiences of disability through the lens of stigma (Edgerton 1967, Goffman 1961, 1963). This research was very influential and contributed to the deinstitutionalisation movement that gained force in the 1970s and which led to the closing of institutions and the rethinking of how services were designed and implemented.

Disability studies is often presented through a number of approaches or “models.” What came to be known as the social model of disability developed out of the pioneering work of activists within UPIAS (Union of Physically Impaired Against Segregation) in the United Kingdom who radically redefined disability by shifting the emphasis from the individual and their impairments to that of society and societal barriers (Barnes 2012). The social model makes clear the distinction between impairment (biological dysfunction) and disability (a process of exclusion) (Barnes 2012, Oliver 1983, 1990). In North America, disability studies was heavily

influenced by the U.S. civil rights movement and the humanities, placing an emphasis upon concerns with normalcy, ableism, and the role of culture (Davis 2006b, Goodley 2011). The understanding of disability in the Nordic countries is not rooted in self-advocacy and activism as in U.K. and U.S. but arose in conjunction with service providers linked to the Nordic welfare systems. Progressive change was originally focused on the reform of service provision and its effects on the lives of disabled people (Traustadóttir 2004, 2006). The focus of this perspective is on the person-environment interaction and disability is conceptualised and defined as “a mismatch between the person’s capabilities and the functional demands in the environment” (Tøssebro and Kittelsaa 2004, p. 22). Disability is therefore not understood as “something caused or created by individual dysfunction or by barriers/oppressive social structures but as the result of a social, linguistic, discursive or cultural construction” and based on the complex interaction between individual and societal factors (Gustavson *et al.* 2005, p. 32).

In recent years, scholars in disability studies have become unsatisfied with the intellectual limitations of using one model or one approach for understanding the complexities of the disability concept. One response has been to criticise but also draw upon the strengths of these models (Shakespeare 2014, Vehmas and Mäkelä 2008, Vehmas and Watson 2014, 2016), or to refocus efforts on a critique of the larger society in terms of ableism and normalcy and how disability is intimately interwoven with other oppressive forms of power and knowledge such as gender, class, race, and sexuality (McRuer 2006, Mallett *et al.* 2016). Yet another has been to explicitly push the discipline beyond its original Euro-American framework (Meekosha 2011, Connell 2011, Grech and Soldatic 2016, Kakoullis and Johnson 2020) in order to include perspectives from the global south. A further development has been to emphasise the importance of expanding this multidisciplinary collaboration (Metzler 2006, Shakespeare 2014, Turner 2012, Southwell-Wright 2013). DbD continues this trajectory not only through multidisciplinary collaboration in terms of analysis, but also data sources and collection.

Disability studies, as it emerged in the global north, has had an arguably problematic relationship with history. Given the discipline’s activist roots, it followed that the initial focus of scholar-activists would be on the immediate concerns faced by disabled people at the time, such as deinstitutionalisation and independent living. Disability studies scholars were of course aware that disabled people – or at least people with impairments – existed throughout human history and that historically and culturally based narratives play some role in how disabled people in the present are viewed. However, in the early days of the discipline, consumed by the more immediate fights of deinstitutionalisation, accessibility, and human rights, the historical emphasis in terms of understanding disability was not placed too far into the past. Mike Oliver (1990), for example, linked disablement to the capitalist mode of production and the related socio-economic arrangements that produced

disability. Lennard Davis (2006b) focused on the emergence of the norm and the average, specifically referencing the emerging discipline of statistics and the work of Adolphe Quetelet in the 19th century as playing a key role in how “abnormal” bodies and minds were produced (Davis 2006b, p. 2). Bill Hughes (1999) argues that an understanding of disability, and a critique of the disablist rejection of impaired bodies and people, requires a criticism of modernity itself. What these approaches share is a collective focus on disablement as it emerged in early modern to present day European societies. This is understandable given the orientation of European disability studies at the time, and the situations faced by disabled people they addressed.

But there is also no question that people with impairments have existed throughout the entirety of human history, posing questions as to, among others, how disability was understood in the more distant past and the effects of impairment upon one’s social position and status within a given society. Disability studies scholars writing on issues prior the 19th century have produced somewhat mixed efforts, often referencing arguably simplistic or broad generalisations about the positions of disabled people at various points in more distant human history, such as the Middle Ages or the earlier Roman and Greek civilisations. Furthermore, given the extent to which the meaning and definitions of the disability concept are still discussed and debated in the current era, let alone the known problems of contemporary cross-cultural translation (Ingstad and Whyte 1995, 2007, Rice 2020), extending modern European understandings of disability into the more distant past is an exercise fraught with numerous challenges. Yet it is not unusual to find such broad assertions made within disability studies, seeking to posit how ancient societies’ understandings of disability/impairment are linked to contemporary views. For example, Barnes (1997) traces the contemporary negative views of disabled people to the societies of the ancient Greeks and Romans and cites cultural evidence in the form of the arts in support of this argument (Barnes 1997, p. 4–5). The validity of the analysis aside, these declarations emanating from within disability studies are often done by scholars who are not specialists in classical civilisations. Further, such statements are broad and difficult to sustain as they collapse centuries of history and assume a rather monolithic view of Europe in terms of its peoples, cultures and societies and the situations faced by those with impairments in different places and at different periods in time. Such arguments also run the risk of assuming that this data – be it in the form of writings, sculpture, or other forms of art – were perceived the same way as they appear to contemporary sensibilities. This has prompted some scholars with more specialised knowledge to respond. By way of example, Miles (2001) provides a somewhat sarcastic overview of this historical narrative sometimes found within disability studies: a history which starts with the exposure of ‘deformed’ infants by the ancient Greeks to Martin Luther’s advice to drown disabled children before coming to the rise of institutionalisation and the horrors of the Holocaust in modern times.

The point Miles is making is not to trivialise the sometimes horrific ways in which people with impairments or different bodies were treated, but to argue that this history is complex, and the evidence difficult to find and often ambiguous. What is required is a close collaboration with scholars who are specialists in different disciplines and areas working with different data sources. Looking at the time period of Martin Luther in particular, Miles points out that we not only need to consider the breadth of Luther's writings and theological positions, which are not always consistent, but also the specificity of the socio-cultural context of the 16th century in this part of Europe. Miles's point is that this complexity and ambiguity is often glossed over, and what is offered is more akin to a "caricature" of Luther's writings and the society in which he existed rather than any solid evidence pertaining to the lives and positions of actual people with various impairments at the time.

Some of these deficiencies in the data and the analyses of the lives and living conditions faced by disabled people of the past are some of the challenges that DbD was designed to engage. In many ways, Iceland is an ideal test case in which to confront these challenges. As a small island nation, existing on the fringes of Europe, Iceland's population in a way is somewhat young, some 30 generations in depth, but with a wealth of written records in the form of the Icelandic Sagas, and later archival records and census data. Iceland was originally inhabited in the 9th century primarily by Norse settlers, as well as via the Viking controlled areas of Ireland and Britain. The *landnám* (land-taking) generally concluded in the year 930 which corresponds to the establishment of the *Alþing*, the Icelandic general assembly or parliament (Byock 2001, p. 94). Even though the period from 870–1262 was known as the Commonwealth or Free State era, there was no centralized authority or any "state" structure in the modern sense, described as "a loose association of political assemblages, united by law and minimal agreement but without a centralized executive body" (Pálsson 1992, p. 3).

Despite being an island in the North-Atlantic, Iceland remained for much of its history an agrarian society in terms of economic production and social organisation. Towns remained a rarity throughout much of Iceland's history (Karlsson 2000, p. 44), as most of the population lived on coastal farms oriented towards the raising of sheep and cattle, as well as horses used for transportation, and the central highlands were generally uninhabitable (Gunnlaugsson 1988, p. 17). Fishing was a seasonal activity for subsistence, and later trade, but under the direction of farmers who long dominated Icelandic society and politics. As small coastal fishing villages began to emerge, they posed a threat to the labour supply needed on the farms. In order to protect the agricultural mode of production, those who were not engaged in farming had to enter into annual labour contracts as farmhands (Durrenberger and Pálsson 1989, p. 4, Karlsson 2000, p. 109). Up until the late 19th century, laws were passed in the interest of the landed farming class to prevent settlement on the coast. This was done in order

to protect the agricultural labour supply, as well as to prevent dependency on poor relief as fishing was not seen at the time as a stable occupation (Durrenberger 1997, p. 78). Another effect these laws had though was also to stall the process of urbanisation (see [Chapter 8](#) this volume).

Iceland gained its independence from Denmark in 1944, but still retained much of its rural orientation and generally lacked comparable institutions and social programmes aimed at vulnerable populations as found in mainland Europe. Elderly and disabled people, as well as poor and destitute, throughout most of Iceland's history were the responsibility of the household. In the event of the failure of a farm, or the inability to locate responsible kin, the *hreppur*, or local administrative unit, became the responsible party (Gunnlaugsson 1988, p. 53). The organisation of poor relief in Iceland has a long and durable history; it was codified in the *Grágás*, a law code from the early 12th century, but some elements of which have even earlier roots, for example with regard to the tithe law of 1096 which held that one quarter of the tithe collected from tax paying farmers had to be forfeited to the *hreppur* for the administration of poor relief (Gunnlaugsson 1988, p. 93).

Paupers – a mix of orphans, elderly people, disabled people, and those who could not, or would not, contribute their labour on the farm – were met with varying degrees of hostility and suspicion that would become sharpened during the times of economic hardships that were common throughout Icelandic history. Increasing numbers of paupers were a particular cause for concern, to the point where they were perceived as a threat to the very social order (Karlsson 2000, p. 252). Poverty, dependency on poor relief and suspicions of malingering extended in various ways into contemporary Iceland. As the historian Gisli Ágúst Gunnlaugsson notes, it was not until 1917 that prohibition on the right of paupers and those on poor relief to marry was lifted (Gunnlaugsson 1988, p. 94). Disability in Iceland was, and arguably still is in certain ways, partly intertwined with perceptions of social and economic marginalisation, dependency, stigma, and suspicion which appears to owe something to this history. In contemporary Icelandic society, fears about increasing numbers of *öryrkjar*, or disability pensioners, appear with a certain regularity in the Icelandic media and political discourses, linked to the belief that disabled people are dependent and not economically productive (Rice, 2012, Rice and Traustadóttir, 2011).

However, these broad statements do not capture well the contradictions, ambiguities, and nuances of disability from the perspective of lives-as-lived. One goal of the DbD project was to bring some of the stories of disabled people in Iceland to life, in some cases attempting to reconstruct lives from the distant past based upon only physical remains (see [Chapters 2](#) and [10](#) in this volume); Using diaries and archival documents to produce micro-historical accounts of individuals (see [Chapters 3–5](#) and [8](#) in this volume); Delving into museum displays for evidence (or not) of disabled people in the past (see [Chapter 6](#) in this volume); And using literary sources to see

how disability was discursively produced in different times and in different sources (see [Chapters 1, 7, and 9](#) in the volume). The project has found that there certainly was evidence of exclusion and harsh treatment, but there was also evidence of disabled people who were valued members of their society – and who were noted because of their impairment as well as their achievements, but also instances where their impairments were seen as only a minor part of the individual.

Each strand of the Disability before Disability project was led by a leading scholar in the respective fields, along with a team of post-doctoral scholars and graduate students, drawing upon the tools and traditions of each discipline but with the collective goal of understanding disability before disability. The edited volume that we are introducing here places an emphasis upon the contributions of these various strands. Some of the contributions represent the work of a sole author within his or her strand, reflecting on what their expertise and that of their discipline offers to a study of disability before disability, or else incorporating a disability studies approach upon the kinds of data they normally work with. An example of the former is Sigurður Gylfi Magnússon's *One Story, One Person – The Importance of Micro/Bio Research for Disability Studies*, which introduces microhistory and the value of researching individual lives. This work also serves as a preface to help contextualise the collaborative contribution by Guðrún Valgerður Stefánsdóttir (disability studies) and Sólveig Ólafsdóttir (history) in *The Peculiar Attitude of the People – The life and social conditions of one “feeble-minded” girl in the early 20th century* – the analysis of an autobiography of a woman born in north Iceland in 1927 who was labelled ‘feeble-minded.’ Writing from the perspective of Folklore but engaged with scholars working within the geography of disability, Ólafur Rastrick's *Physical Impairment and The Spatial Dimensions of Everyday Life in Rural Households in Pre-Industrial Iceland* addresses how design and layout of dwellings and home environment affected the quality of life of physically impaired individuals in preindustrial Iceland. Working at the other end of the historical spectrum, and from the perspective of archaeology, Haraldur Þór Hammer Haraldsson's *Fictive Osteobiographical Narrative – The Missing Puzzle Pieces* presents what he calls a ‘fictive osteobiographical narrative’ in order to analyse the excavated human remains of a man thought to have lived between 1000–1104. Arndís Bergsdóttir, working within the discipline of Museum Studies, in *Dis-labing Absence Absencepresence as Matters that Matter*, investigates the traces of disability in Icelandic museum collections through the cataloguing system to pose questions about presence and interpretation of histories and narratives of disability.

Other chapters within this volume represent collaborations between scholars working within their respective disciplines. Christopher Crocker, Yoav Tirosh, and Ármann Jakobsson, writing from the perspective of Medieval Icelandic literature, review some key methodological concerns

scholars must account for when exploring disability in the context of medieval Icelandic saga writing. In *Disability in Medieval Iceland: Some Methodological Concerns* they note some of these challenges but also point toward the more fruitful approaches scholars of the medieval sagas can take to gain a better understanding of how physical, mental, and sensory differences were experienced, communicated, represented, and interpreted in medieval Iceland. In *Beneath the surface: Disability in Archeological and Osteobiographical Contexts*, Steinunn Kristjánsdóttir and Joe W. Walser III discuss disability from a post-human angle in an archaeological and osteological context. Their work draws upon case studies of skeletonised individuals from a monastic site in East Iceland (1494–1554) to identify bodily impairments from skeletal remains to make inferences about how these individuals may have adapted to the biological limitations and potentially subsequent social marginalisation they may have experienced. Alice Bower, writing from the perspective of Folklore in *Guðmundur Bergþórsson as Creator and Creation: A Folk Narrative Study of a 17th Century Disabled Poet*, seeks to shine light upon the life and literary works of one of Iceland's noted poets. Guðmundur's impairments were well known and have become the most prominent theme of legends about him collected by folklorists during the 19th and 20th centuries. Finally, writing from Medieval Icelandic literature, Christopher Crocker and Yoav Tirosh explore issues of health, illness, and healing in medieval Iceland, in particular dealing with the corpus of texts known as the *Íslendingasögur* (Sagas of Early Icelanders). In *Health, Healing, and the Social Body in Medieval Iceland* they adopt a disability studies approach and seek to understand the lives and representations of those in the sagas who have sustained injuries, illnesses, and disease.

All of the chapters are interdisciplinary in that the authors engage with a disability studies perspective while applying their own disciplinary expertise and specialist knowledge. Some of the chapters, however, extend this further to produce collaborative work of two scholars from different disciplines. Guðrún Valgerður Stefánsdóttir (disability studies) and Sólveig Ólafsdóttir (history) analyse together the autobiographical writings of Bjargey Kristjánsdóttir (nicknamed Bibí) a woman with intellectual disabilities who grew up on a farm in North Iceland in the early 20th century. Bibí wrote her autobiography in secret from her family and neighbours and very few of them even knew that she could read and write. Bibí writes about her family and neighbours with a great sense of humour and irony within a socio-cultural and historical context in which it was seen as a great shame for parents to have a child with disabilities. Finally, Eva Þórdís Ebenezersdóttir (Folklore) and Sólveig Ólafsdóttir (History) consider the case of Sigríður Benediktsdóttir (known as Stutta-Sigga) who was a child minder and storyteller (1815–1900) with physical as well as cognitive or mental differences. Through analysing her “life-threads,” tracing Sigríður through various public sources, from birth to death, the findings are then compared to the narratives that have been preserved both during her lifetime and after

her death. The goal is to illuminate the life of Sigríður not as a subject of research but as an individual who acts, in a way, as a co-worker contributing to the research with her life stories. All of the contributions present partial, and often fractured and incomplete, pictures of disability before disability. However, the goal was not to produce a comprehensive story of the history of disability in Iceland but to demonstrate what can be done through a collaboration with different disciplines using different sources of data and to open a door upon an often overlooked history and to encourage more work to be done, either in Iceland or beyond.

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