

The Politics of Disability Identity

1. Introduction

Disability is one of the clearest predictors of social marginalization and an enduring problem for global sustainable development. Although disability has in recent decades become enshrined in the framework and discourse of human rights, progress has been slow or absent in socioeconomic terms. There is a gap between rhetoric and results in policy: Disability remains correlated with poverty, low levels of education and employment, and relatively poorer life outcomes in affluent as well as less affluent societies. In this project we ask **whether current political, legal and cultural understandings of disability amount to a misrecognition that actually hinders material progress.**

We hypothesize that contemporary human rights-based framings of disability – in much of academia as well in policy – effectively equate it with other identity-defining characteristics such as gender, skin color, and sexual orientation. We further hypothesize that these framings are misleading and produce an ideal that is unattainable for the majority of people with disabilities, while serving mainly to include only the most resourceful members of this large and diverse category. **In this project we will critically investigate the history and consequences of the human rights framing of disability. We will provide a knowledge base for sustainable disability policies while advancing the field of disability studies.**

1.1. State of the field knowledge needs and project objectives

The main project objective is to answer three interrelated knowledge needs that connect disability policy to academic disability studies. We posit that there is a need for knowledge about:

- how disability is **normatively framed** in the fields of education, employment, culture, and the public sphere,
- what characterizes the **relative progress of different groups of people with disabilities** in these fields, and
- how normative **framings enable or hinder progress for different groups of people with disabilities.**

There is extensive work in disability studies on framings and representations of disability; however, the focus is often on the negative or the stigmatizing. Our project will advance the state of the field by investigating *ostensibly positive* framings of disability: the construction of disability as a publicly recognized identity and the normative constraints that follow from this identity. Since there is already a consensus in policy circles that negative or stigmatizing framings should be avoided, this approach better serves the knowledge needs by a) recognizing the progress that has been made and b) account for ongoing shortcomings.

The knowledge needs emerge from the state of the connected fields of disability policy and disability studies, where **increased recognition of disability identity** is the main historical trend over the last half-century. Following a surge in activism and political pressure from the 1970s onward (Driedger, 1989), the United Nations' International Year of Disabled Persons in 1981 and Decade of Disabled Persons (1983-1992) was accompanied by disability rights' legislation in numerous nation-states, territories, and supranational entities. These include the United States (Americans with Disabilities Act of 1990, n.d.), Australia (Disability Discrimination Act 1992 [Australia], n.d.), the United Kingdom (Disability Discrimination Act 1995, n.d.), the European Union (Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation, 2000), Sweden (Act (2003:307) prohibiting discrimination, n.d.), and Norway (Barne- likestillings- og inkluderingsdepartementet, 2008). The tendency arguably culminated in the **CRPD, i.e. the Convention on the Rights of Persons with Disabilities** (United Nations, 2007), which currently has 160 signatories. The white-on-blue wheelchair has become a global symbol of the recognition of disability. These developments have been hailed by activists, pressure groups, and researchers (Harpur, 2012; Kayess & French, 2008), as epochal and potentially transformative.

But there are problems with this progress narrative, evident from the **lack of material progress** for many disabled people. Generally, rates of employment for disabled people are much lower than for the general population, the situation has been unchanging for a long time, and to the extent that global statistics are available, the picture is not very bright either in developing or

developed countries (WHO, 2011). These problems directly inform the UN sustainable development goals, particularly goal 4 (quality education), goal 8 (decent work), and goal 10 (reduced inequality).

Our project hinges on the question of **the politics of disability identity**. While disability is now in many countries an identity that is **recognized** (Honneth, 1996) and **protected** – another phase in the expansion of the discourse of identity politics (Fukuyama, 2018). This strategy is embraced by much of the global disability movement, which has borrowed the vocabulary and strategies of other minority identities, including pride marches, and an emphasis on the connection between disability and rights anti-discrimination measures. In this logic, life will become better for disabled people if they publicly identify and are recognized as such.

However, **disability may not be claimable** in the same way as other identities. One reason is that disability is **extremely heterogeneous**. Approximately one seventh of humanity falls within one definition of disability, but far fewer identify or understand themselves as disabled. The CRPD opts for a non-exhaustive and imprecise definition, leaving open the issue of exactly **who is to be the protected class of persons, and how they are to be recognized**. Politically, then, disability becomes an identity that **has to be claimed**. But it has long been known that disability is a highly stigmatizing «master» identity or status (Goffman, 1963; Hughes, 1945), and the costs of being publicly recognized as disabled will for many people outweigh the benefits (Puar, 2017).

If this is the case, then it is very problematic to establish a political order based around disability as a distinct minority identity. Appiah (2018) points out that identity is inherent complex and unstable, but that categories can easily be reified. This may exacerbate marginalization. The structural causes of disability have traditionally been even harder to identify in policy, and so have often been elided. The CRPD, too, frames disability as individual identity that has to be claimed (Grue, 2019).

The field of disability studies, at the intersection of the humanities and social sciences, is partly constituted around these problematics. Disability studies has matured over the last several decades into a vibrant multidisciplinary field (Davis, 2016; Vehmas & Watson, 2019). Among its core concerns are global challenges relating to social justice, equality, public health, and political agency.

Disability studies contributes to the forefront of research on these challenges, but the field is split over how to approach its constitutive problems. On the one hand, there have been attempts to solve the problem of stigma through attempts to *revalorize* disability as value-neutral or positive identity, one that can be claimed with less attendant stigma (Garland-Thomson, 2012; Goodley, 2010). This research tradition is associated with the *cultural minority model* of disability and owes much to work in US social sciences (Goffman, 1963; Hahn, 1984; Zola, 1993) and humanities (Garland-Thomson, 1997; Snyder & Mitchell, 2006).

The project will advance the state of the field by investigating the politics of disability identity. For much of disability studies, it is tempting to have disability recognized by being codified as a political and legally protected identity. Socially constructed oppression, aka. *ableism* (Goodley, Hughes, & Davis, 2012; Goodley, Lawthorn, & Runswick Cole, 2014), is perceived as an ideology that privileges some forms of ability. To counter marginalization, disability must then be presented as one form of difference among many – an *a priori* neutral identity in search of recognition. Just as identities of ethnicity, race, gender and sexual orientation search for recognition in the face of racism, sexism, transphobia, and other oppressive ideologies, disability is an identity that ought to be socially and culturally validated. Disability studies is then directed at the exploration of what disabled identity means, of how it is constituted, and of how the marginalization of disabled people can best be countered by means of de-stigmatization, anti-discrimination measures, and measures of recognition.

However: Other research in disability studies is highly critical of the sustainability and desirability of *the category of disability as such*. This research, which owes much to the thought of Michel Foucault (Stiker, 1999; Tremain, 2005) is often concerned with the social and political construction of disability and its discourses (Corker & French, 1999; Shildrick, 2009), and the ways in which “disability” can become doubly repressive. One mechanism for this is that **publicly recognized disability only represents the experiences of some disabled people**.

The history of disability is a *hidden history* (Longmore, 1987), partly because the predicament of disability (Shakespeare, 2013) is very complex. A large part of humanity has always been *what we today term disabled*. But they have been understood under other signifiers of marginality, including, disease, poverty, or, with, the pejorative vocabulary of earlier times, as cripples, idiots, and outcasts. To counteract these stories and make disability a positive and claimable political identity is an

incredibly ambitious project historical, one whose ramifications we do not yet understand. In sum: The modern recognition of disability in global policy discourse is unprecedented, and may well amount to a *misrecognition* (Fraser, 2000) of disabled experience. This project stems from **the clear need for knowledge about the consequences and implications of the legal and political framing of disability as a minority identity that must be claimed.**

1.2. Primary research questions and hypotheses

We will ask two overarching research questions of our material:

1. Which groups of people with disabilities are construed as **recognized and includable**?
2. Which groups are **actually experiencing progress in terms of inclusion**?

We hypothesize a) that there is a *limited range of disabilities* that appear as recognized and includable in different areas of society, and b) the *people with disabilities who are recognized* are also the *people who experience decreasing marginalization*. The second part of our hypothesis may appear obvious, so it is important to remember that global disability policy is ostensibly *universalist*, aiming at the recognition and inclusion of *all* people with disabilities. That makes it important to identify anti-universalist factors in society's framing of disability, even if these are unintentional.

This hypothesis builds on cutting-edge work in disability theory. It is well-established that not all people with disabilities are considered or treated equally, and that there is a hierarchy of impairments (Deal, 2003) in which certain forms of (dis)ability are privileged over others. Recent research theorizes that, in neoliberal societies, such hierarchies are linked to *productive potential*, so that here emerges a subcategory of people with disabilities, the "able-disabled" (Mitchell & Snyder, 2015, 2019; Titchkosky, 2011). They are distinguished by being capable of studying, working, and otherwise participating in society as "productive" citizens *without requiring systemic change*. The category of the "able-disabled" therefore serves a double function in becoming a publicly acceptable "face of disability" and by making it *harder* to argue that systemic change is necessary. The "able-disabled" become icons of "good" disability, much as the blue-and-white wheelchair symbol has become a global symbol of effective inclusion, even as the *majority* of actual disabled people are excluded from these representations (Grue, 2017).

1.3 Data and materials

In order to achieve our objectives within the constraints of this project we will delimit ourselves to **a case study of Norway in recent decades**. The choice of Norway as a case is motivated by **opportunity**, its value as an **exemplar**, and the possibilities for **comparative analysis**. Although the Norwegian state is arguably among the most progressive in the world, Norway shows the same shortcomings with regard to disability inclusion as most other countries, with disabled people marginalized in most if not all fields. While Norway has been criticized for not living up to its commitments (Devandas, 2019), comparatively little attention has been paid to the *whether these commitments are framed and implemented in the best way*.

Norway, moreover, presents a unique historical case because of its distinct history of conceptualizing disability not as a matter of human rights, but as a problem of socio-economic inequality – a history that goes back at least to the 1960s (Sosialdepartementet, 1966) and arguably to the 1930s (NOU, 2001). The shift towards a human-rights framings is a fairly recent development, and can be observed alongside changes as well as the lack of change in the situation of people with disabilities. This allows us to analyse whether this normative shift correlates with substantive change.

For our **materials** we will examine a wide range of **discourse objects**. In Norway, a relatively small and culturally homogeneous country, this corpus will be relatively easily generated through **government archives, the National Library's archives, and the media service Retriever**. We will ask how disability has historically been encoded in policy in Norway (NOU, 2001; Sosialdepartementet, 1966) over time, with comparisons with the UK and US. In the fields of education (WP2) and employment (WP1), we will include comparable media material, including reportage, portrayals of individuals, and other "success stories", but also job listings and comparable documents, and corporate programs aimed at disability inclusion. We will focus here on normative representations of *includable disabled pupils, students, and employees*. We will ask what assumptions

are made about the value, contributions, and productivity of people with disabilities, what normative framing is established, and what the implications are for the recognition of disability (WP4).

We will proceed on the assumption that disability is ubiquitous in every social field, and cast a wide net, including a **corpus of cultural texts that have salience in Norwegian society**, including popular film and television, media events and sports events, and literary texts, including memoirs (WP3). Media events will include the 2012 and 2016 Paralympic Games, as well as the representation of disabled athletes like Birgit Skarstein in various media contexts, including the promotion of the Norwegian VI (“we”) foundation. Memoirs include critically acclaimed texts like Bjørn Hatterud’s *Mot normalt* and Ola Henmo’s *Hemningløs*. All discourse objects in our corpus share the quality of thematizing *identity formation* in encounters with non-disabled majority society; the analytical focus will be on the construction of the “includable person with a disability”. As intersectional work on disability has demonstrated how gender perspectives, alongside class and ethnicity perspectives, are essential to understanding the complex phenomenon of disability. We will ensure that all three of these perspectives are foregrounded in selection of empirical materials as well as in analysis (WP1-4).

We will also examine **register data** (WP1,2). By drawing on the unique possibilities offered by Statistics Norway, it is possible to tell a detailed story about determinants of inclusion and exclusion not attempted previously. The registers offers opportunities to identify groups of children with specific conditions defined by a physician, also including measures of severity of the condition. In exploring the implications of having a disability or chronic condition, the focus is on five specific conditions: Physical disabilities, sensory losses (sight and hearing), severe asthma and childhood diabetes. Longitudinal register data will be constructed in order to analyse and compare life trajectories for diagnostic groups as well as the overall population for individuals born from the late 1970s to the mid-1990s, a period that coincides with the advent of human-rights discourse on disabilities. We will also evaluate the educational attainment and employment situation of disabled people based on the European Union Statistics on Income and Living Conditions (EU-SILC) and the European Social Survey (ESS). A time series exist for the Norwegian sample in EU-SILC from 2003 and onwards; we will analyse these two data sources and compare with the situation in the United Kingdom.

Since much of our material will be publicly available and relate to public persons, our main challenge in terms of **research ethics** will be **the handling of the large and detailed information on inhabitants' educational attainments, diagnostic conditions and other relevant characteristics**. The management of these data presupposes rules of conduct that ensure data security and anonymity, as stipulated by Norwegian Data Protection Services (NSD) and the Norwegian Data Inspectorate

1.4 Project organisation and management

The empirical work is structured in three work packages:

WP1: Disability and employability.

Both the public and private sectors in Norway are putting a premium on diverse workplaces, stressing the need to recruit people with disabilities, yet the persistent, disproportionately low employment rates contribute hugely to the social marginalization of people with disabilities. This may seem surprising, given that systematic literature reviews have repeatedly shown that employers now hold positive global attitudes toward workers with disabilities, and often indicate a willingness to hire them (Hernandez, Keys, & Balcazar, 2000). Hence it is crucial to move from investigating disability-specific prejudice to examining generalized images of productivity and visions of the “ideal worker” (Foster & Wass, 2013) that may not deal with disability specifically. We will explore how images of disability interact with such images to produce normative representations of *good disabled employees*. Given that these representations of ‘good’ or ‘desirable’ employees with disabilities on different levels, we will investigate the following categories of data:

- To explore *macro-level* production, that is, representations of employment and disability that claim to be somehow independent of localized context, we will interpret globally popular textbooks in human resource management, management theory and similar fields of knowledge. On the one hand, we will pay particular attention to how key terms like ‘disability’, ‘inclusion’, ‘diversity’ and ‘accommodation’ are understood. On the other hand,

we will also emphasize “generalized” terms such as ‘flexibility’, ‘productivity’, ‘dynamic’ and ‘change’.

- To explore *meso-level* production, it is important to interpret the voice of large, somewhat cross-contextual employers. It is likely that organisational discourses are crucial to the processes in questions. Hence, we will also explore (a) job adverts, (b) corporate documents that has to do with so-called diversity strategies and (c) documents or public statements that have to do with corporate social responsibility.
- To explore *micro-level* production, we will also explore individual portrayals. After all, the images of *good disabled employees* are not only produced as intersections between larger narratives, but also as biographical narratives. We will analyse individual “success stories”, as they emerge in (1) mass media publications, (b) autobiographies, and (c) movies.

WP2: Pathways through education

Despite a number of legislative efforts and measures to increase the participation of disabled people in the workforce, participation rates have remained relatively stable over time (Petter Bø & Håland, 2015). For groups with specific disabilities, significant parts of the population have not managed to complete a secondary education (Finnvold, 2018), increasing their risk of marginalization in later phases of the life course. Another indicator of the difficulties facing inclusive policies is the sharp increase during the last decade in the number of young adults that receive disability benefits. The objective of this WP is to assess the Norwegian welfare state’s capacity to include disabled people, to determine whether this capacity have increased or decreased over time, and to explore how various enabling and constraining factors interact with different types of disability. The data will enable us to assess the degree of inclusion for outcomes such as income, labour market participation, educational attainments and uptake of disability benefits at different times, related to different types and severities of disability. We will account for enabling and constraining factors, such as class background, educational achievement, and whether the significance of parental educational background have changed over time.

WP3: Cultural citizens with disabilities

Disability is highly visible in the public sphere, creating both *opportunities* and *standards* for access. In this WP we will examine single-authored and multi-authored public personae for people with disabilities, drawn from literature, film, and the media, including sports events and campaigns. We will generate a typology of publicly recognized forms of disability identity. Our corpus will have a historical-comparative dimension that includes representations that predate the advent of human-rights discourse in Norway, and recent, highly salient representational forms.

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