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## Prestige rankings of chronic diseases and disabilities. A survey among professionals in the disability field



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### ABSTRACT

Disabled people constitute the world's largest minority; too little is known about the internal structure and valuations of that minority. We investigate whether prestige rankings of different chronic diseases and disabilities can be elicited from a community of disability non-governmental organizations (NGOs). A survey was performed in a sample of NGO professionals in Norway in late 2013 and early 2014. Two copies of a questionnaire was sent to 92 national and regional offices of disability NGOs requesting a response from either senior employees or elected officials, preferably one of each. Outcome measures were ratings on a 1–9 scale of the prestige these respondents believed most professionals in their field would accord to a sample of 38 different conditions. We find that there is a prestige hierarchy of chronic diseases and disabilities in the disability field. In this hierarchy, somatic conditions that are strongly associated with medical treatment were placed higher than either conditions that are characterized by permanence, or conditions are associated with psychosomatic etiologies. The elicited prestige hierarchy is at odds with prevalent normative positions in the disability field; there is a lack of fit between some of the field's central political goals and its internal evaluations. We propose that its structure can be explained through a) influence from the medical field, b) organization history, size, and prominence, and c) issues of credibility, shame and blame. Further research should be conducted into the structure and valuations of the disability field in general and people with disabilities and chronic diseases in particular.

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### 1. Introduction

Disability is a complex phenomenon involving social, relational, and biological causes. According to the World Health Organization (WHO, 2011), 1 billion people worldwide count as disabled, making disabled people the world's largest minority. Among the attempts to theorize disability are: the so-called British social model (Oliver, 1990; Oliver and Barnes, 2012), which focuses on external socio-economic and political causes of disablement; the North American minority model (Davis, 2013; Longmore, 1985; Linton, 1998), which especially emphasizes socio-cultural causation; and the Nordic relational model (Tøssebro, 2004), which stresses the relationship between individuals and states.

Too little is known, however, about the social structures and valuations of the disability minority. There is little research on how groups of people with different chronic diseases and disabilities relate to each other, and on how the larger group of disabled people

is constituted. In a literature review, Deal (2003) calls for research that investigates how different disabilities are viewed within the disability field. He notes that there may be a hierarchy of disabilities, and that the existence of such a hierarchy may contribute to divisions and conflicts among disabled people.

Following Deal, our research question is whether a prestige hierarchy of chronic diseases and disabilities can be elicited from the disability field, and what properties such a hierarchy has. *Prestige* is a measure of regard or esteem (Nørredam and Album, 2007: 655) that can be used to elicit positive, neutral and negative valuations that are shared among individuals (Zhou, 2005: 97–98), and so can reflect the standards and values of a community or cultural group. Since a fundamental motivation for human conduct is to gain public recognition of one's social worth (Ridgeway, 2014: 2), prestige matters. People strive for prestige as well as for money and power, and notions of what is prestigious and what is not have a significant influence on the aspirations, strategies and actions of agents in social fields (Bourdieu and Wacquant, 1992).

The disability field is, in part, constituted by non-governmental organizations (NGOs) that coordinate the political, economic, and

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medical interests of a highly diverse group of people. We therefore approach the matter of hierarchies in the disability field through the attitudes of *disability professionals* (“professionals” in the sense of being professionally engaged in the management of NGOs for people with different chronic diseases and disabilities, but not in the sense of being part of a profession, see e.g. [Abbott, 1988](#)). We use ‘chronic diseases and disabilities’, instead of e.g. ‘illnesses’ or ‘impairments’, in line with the wording that is current both in the Norwegian disability field ([FFO, 2014a](#)) and with the [WHO \(2011\)](#). The salient distinction for our purposes is that chronic diseases have a minimum duration of three months while disabilities are permanent; organizations based around both categories commonly define themselves as part of the disability field.

Our research question will be answered within the theoretical framework of disability studies. By drawing on sociology, history, anthropology, and social theory, among other academic specialties ([Davis, 2013](#); [Linton, 1998](#); [Siebers, 2008](#)), the discipline seeks to establish that disability is not simply a property of individuals, but that individual properties that are variously termed illness, chronic disease, and impairment are commonly represented as the all-but-exclusive causes of disablement. In this analytical framework, the constructions, perceptions, and valuations of illness, chronic disease, and impairment in any given society are analyzed as deriving from that society’s implicit standards, norms, and expectations for individuals’ abilities and functional capabilities. The exploration of various ways in which both disability in general and specific disabilities are socially constructed and evaluated is therefore central to the field.

## 2. Hierarchies of diseases and disabilities

The somewhat counterintuitive notion of discussing somatic and mental conditions in terms of hierarchies goes back at least to [Canguilhem \(1991 \[1966\]: 39\)](#), who proposed that diseases are ordered in a “vulgar hierarchy [...] based on the extent to which symptoms can – or cannot – be readily localized [...]”. Diseases at the top of such a hierarchy were “more of a disease” ([Canguilhem, 1991 \[1966\]: 39](#)) than those at the bottom.

There are several studies that show how members of the public value different conditions associated with disability. Some have analyzed culturally salient stereotypes, including the blind person imbued with compensatory sensory or mystical abilities ([Scott, 1969](#); [Weygand, 2009](#)), the malicious or evil person with restricted growth, and the scheming, manipulative wheelchair user ([Norden, 1994](#)). Others have elicited ordered hierarchies of conditions ([Harasymiw et al., 1976](#); [Tringo, 1970](#); [Yuker, 1983](#)). For instance, [Tringo \(1970\)](#) had 455 respondents rank a selection of “disabilities” on a scale of one to nine, according to the closest relationship they felt towards people with various chronic diseases and permanent disabilities, but also those who were in the predicaments of being “ex-convicts” or suffering from “old age”. [Tringo’s](#) scale ranged from the extremes of “Would marry” (1) to “Would put to death” (9), with milder (though mostly negative) options such as “Would accept as a casual friend” (4) and “Would keep away from” (6) in between. Respondents displayed the most negative attitude towards people with mental illness, alcoholism, and mental retardation, i.e. typical categories of social stigma ([Goffman, 1968](#)), while displaying the least negative attitudes towards people with ulcers, arthritis, and asthmas, i.e. relatively minor and predominantly somatic medical conditions. Three conditions that are “classically” associated with disability ([WHO, 2011: 7](#)), namely blindness, deafness, and paraplegia, were found to be in the middle range of social distance. Follow up studies found the hierarchy of preference to be fairly stable over time ([Horne and Ricciardo, 1988](#); [Thomas, 2000](#)). [Horne and Ricciardo \(1988: 84\)](#)

sum up the hierarchy of preferred “disabilities” from most to least acceptable, with physical disabilities on top, followed by sensory, psychological, and social disability.

The hierarchy of conditions presented by [Tringo](#) is defined in negative terms; only one statement out of nine proposed to respondents is positive (“Would marry”), the others suggest negative feelings (“Would accept as [social role]”) or outright hostility (“Would send out of my country”). It could thus be viewed as priming respondents for negative evaluations. Other studies have elicited hierarchies of *prestige*, which include both positive, neutral and negative valuations. For instance, [Album](#) coined the term *disease prestige* ([Album, 1991](#); [Album and Westin, 2008](#)) to investigate the informal rankings of diseases among medical doctors. The investigation is grounded in a research tradition that has occupational prestige as the main unit of analysis ([Treiman, 1977](#)), but which also deals with intra-occupational hierarchies such as the prestige of medical specialties ([Matteson and Smith, 1977](#); [Rosoff and Leone, 1991](#); [Schwartzbaum et al., 1973](#); [Shortell, 1974](#)). In line with this, disease prestige is seen to derive at least in part from specialist occupational prestige. [Album and Westin \(2008\)](#) find that a number of mutual factors seem to structure the disease prestige hierarchy. High prestige typically implies specialty or disease association with technologically sophisticated equipment and intervention, with specific bodily organs (particularly in the upper body), and with relatively young patients. Low prestige typically implies “diseases and specialties associated with chronic conditions located in the lower parts of the body or having no specific bodily location, with less visible treatment procedures, and with elderly patients” ([Album and Westin, 2008: 182](#)).

[Deal \(2003: 898\)](#) argues that there are hierarchical assessments that are unique to the disability field. Rather than reflecting the attitudes of society at large, they reflect notions of what constitutes a “genuine” chronic disease or disability, i.e. that whatever condition is perceived by disabled people as being the most representative of the category of disability will be at the top of the hierarchy. He concludes, however, that such hierarchies have not been conclusively shown to exist within the disability field.

The research literature makes it difficult to predict what logics will structure such a hierarchy. Cultural valuation plays a considerable part in shaping the expectations and valuations of particular conditions in many contexts ([Thomson, 1997](#)). Disabilities and diseases may therefore be ranked according to many criteria that are primarily dependent on social meaning ([Shakespeare, 1994](#); [Shakespeare et al., 1996](#)). Preliminary, informal discussions with professionals in the field suggested to us that high prestige might be accorded to conditions that are traditionally associated with what the [WHO \(2011\)](#) has termed “classic” disabilities, i.e. vision impairment, hearing impairment, and the various mobility impairments of “typical” wheelchair users. This would be in line with [Canguilhem’s](#) position; the “classical” types involve symptoms that can be “readily localized”. Furthermore, clearly visible signifiers of disability such as white canes, wheelchairs, or using sign language may lessen the risk of stigmatizing responses from others, and accusations of fakery or malingering ([Siebers, 2008](#)). The modern disability rights movement, with which our sample is at least nominally associated, has historically concentrated its attention on such “classic” disability groups. One highly influential ([Shakespeare, 2013](#)) model of disability, the so-called British social model ([Oliver, 1990](#); [Oliver and Barnes, 2012](#)), has contributed to analyzing physical, social and political causes of disablement largely in terms of the requirements and abilities of such groups ([Thomas, 1999](#)). This would lead us to expect a hierarchy of diseases and disabilities where what is most highly rated are the classic conditions with readily available signifiers of disability.

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