# ZEITSCHRIFT FÜR DISABILITY STUDIES ZDS JOURNAL OF DISABILITY STUDIES

Februar 2022 | innsbruck university press, Innsbruck ZDS | ISSN 2791-4313 | www.zds-online.org Nr. 1/2022 | DOI 10.15203/ZDS\_2022\_1.07 | internes Review Lizenz: CC BY 4.0 (Namensnennung)



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# Models of Disability: Connecting the Past to the Present

### **Abstract in English**

This article reviews the status of disability studies, in particular historic disability studies, models of disability to date, and how those models have been used or altered to fit premodern disability studies. It also examines new ideas and models for a broader look at how disabled people are part of larger society, namely Mounsey's model of "Variabilities," Booth's concept of "Information Streams," and Turner's own "environmental model" for disability studies in which there is no sovereign among humans, the environment, and disabilities. The article concludes with an overview of the future of disability studies, calling scholars to begin to examine social "attitudes", barriers to inclusion, and chronic impairment.

Keywords: disability studies, impairment, barriers, chronic impairment, long-term impairment, mental health

# Modelle der Behinderung: Die Verbindung zwischen Vergangenheit und Gegenwart

#### Zusammenfassung

Der Beitrag gibt einen Überblick über den Stand der Disability Studies, insbesondere ihrer historischen Dimensionen sowie über die Modelle von Behinderung und wie diese verwendet oder verändert wurden, um den vormodernen Disability Studies zu entsprechen. Er fragt zudem nach neuen Ideen und Modellen für einen erweiterten Blick darauf, inwiefern behinderte Menschen Teil einer größeren Gesellschaft darstellen. In diesem Rahmen werden Mounseys Modell der 'Variabilitäten', Booths Konzept der 'Informationsströme' angeführt sowie Turners eigenes 'Umweltmodell' für die Disability Studies dargestellt, nach dem es keine Souveränität zwischen Menschen, der Umwelt und Behinderungen gibt. Der Artikel schließt mit einem Ausblick zur Zukunft der Disability Studies, in dem Wissenschaftler\*innen aufgefordert werden, soziale 'Einstellungen', Inklusionsbarrieren und chronische Beeinträchtigungen zu erforschen.

Schlüsselwörter: Disability Studies, Beeinträchtigung, Barrieren, Chronische Beeinträchtigung, Langfristige Beeinträchtigung, Psychische Gesundheit





Scholars of the history of disability studies often use models to describe patterns in the records because for early history there were no overarching terms for "disability" and, even in modern history, there is little evidence to suggest that all disabling conditions were described within a medical, social, or philosophical category until the twentieth century. The closest arc-terms in premodern Europe might be "healthy" and "unhealthy" in Old English (hale, unhale) (Lee, 2018). Past peoples considered disabling and impairing conditions as specific situations, meaning not under one umbrella, for example, deafness, blindness, or lameness (in Latin: surditas, caecitas, vel claudum) rather than "disabled-ness."

To put the history of disabilities into context, it is important to understand that most scholarship on contemporary disabilities concentrates on physical impairment and motion as a central element of "dis-ability," with mental health conditions as well as intellectual or emotional disabilities studied separately. In historical studies, the same was true in the twentieth century—the history of physical disabilities were treated apart from studies of mental health and other intellectual or emotional impairments. In recent years, though, the history of disability studies has expanded the general umbrella to include mental, emotional, and intellectual impairment studies as part of the overall scope of disability or impairment studies. This shift is a good one and has potential to influence the contemporary discussion of disabilities and abilities generally—in terms of context, meaning, and healthcare. With this in mind, this paper intends to take a close look at the recent use of models within the field of historical disability studies and suggest how those models figure in influencing contemporary studies as well as where the field of the history of disabilities might go from here.

# 1. Definitions

Many questions arise when trying to define terms such as "disability" or "ability." Moreover, scholarly groups, like the Creative Unit: *Homo Debilis* at the University of Bremen<sup>1</sup>, have spent years discussing and debating the meaning of those words. They ask questions like what does it mean to "be able" and will that help researchers get closer to defining "disability"? Could someone have a temporary disability, such as a broken leg? Is pregnancy a disability? Those are all good questions that unpick the heart of the matter, but none answers the fundamental question of "what does the term 'disability' mean, exactly"?

Perhaps a start of an answer to the question of what researchers should mean by the term "disability" is to learn how the global disability community defines itself. The United Nations under its Department of Economic and Social Affairs has a division working on disability. They in-part ratified the "Convention on the Rights of Persons with Disabilities" (CRPD) in 2006.<sup>2</sup> The UN CRPD acknowledges that the term "disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others" (United Nations Department of Economic and Social Affairs, n.d.-b).<sup>3</sup> A few things stand out here—they are not talking about any sort of medical definition of "disability," and they are pointing out that disabilities occur "between persons." This means that there is a social element to being or becoming disabled. But the UN statement also says that disabilities happen when "attitudinal and environmental barriers" hinder the disabled person. Their use of the term "environment" might be in reference to a "social" environment, but it could also be in reference to lived space, which would add a component that would be outside of human interaction. The other interesting and important addition in the UN definition is the term "attitude"; a broad term, "attitude" could refer to the character of and treatment/perception by individuals or institutions or governments and would bring in other factors that impinge on the lives of disabled people.

The UN Committee on Rights of Persons with Disabilities also states in Article 1 of the "Convention" that "[p]ersons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (United Nations Department of Economic and Social Affairs, n.d.-b). This section embraces parameters for "disability" to include only long-term conditions that affect "physical, mental, intellectual or sensory impairments" (United Nations Department of Economic and Social Affairs, n.d.-b). Their statement in Article 1 goes on to point out, differently from the wording in the Preamble, that "in

interaction with various barriers"—rather than a social interaction with an attitudinal or environmental barrier—might "hinder the full and effective participation in society [...]" (United Nations Department of Economic and Social Affairs, n.d.-b). In other words, barriers of all kinds, be they physical or environmental or technological or human, might bar the impaired person from fully participating in society on an equal footing with other humans.

This might be a helpful way of thinking about historic disabilities; to ask of the evidence: what barriers disabled the impaired person of the past and if those barriers were human, environmental, or social attitudes, or were they something else? Most definitions from disability studies' historians to date have focused on the condition, and, while rejecting the medical "model," these studies have in some ways focused on impairments and not on people. To be fair, this is often because of a lack of first-person accounts in history; historians of disabilities have "found" persons with disabilities often mentioned almost as an afterthought among medical or legal or other documents, which have as their focus something else entirely.

# 2. Early Models

Most scholars of disabilities in the later twentieth century centered their studies, as explained above, on materials from outside the point of view of the disabled individual and wrote about the "group," using a sociological methodology to analyze a particular time and place in terms of its treatment of disabilities. For historical studies of impaired and disabled people, whether physical, mental, or emotional, many scholars continue to use a social approach to disability studies because it describes more of what they are seeing in the records than other models and, since the 1960s, has been more respectful to the contemporary disability community (Mitchell & Snyder, 1997). While arguments have been made for ecclesiastical models for the Middle Ages (Wheatley, 2010) or cultural models for premodern societies (Eyler, 2010), the ideas remain that to "be disabled" is describing a condition of being un-able and un-permitted to do something. Models will not help us find the answer to questions like "what is ability?" or "what is disability?" but they might help us organize datum around those questions. Certainly, scholars need a way to communicate their findings to one another whether working on the past or on the present and to research productively toward answers and illustrations that are relevant to the disability community as much as it is informative to the academy.

The dominant model for studies of disability in a premodern setting is the "social model," which was coined as a specific phrase in 1983 by Mike Oliver<sup>5</sup>, but seems to have been a framework as early as the 1970s, if not yet formally named (Shakespeare, 2004). According to Oliver, he never intended this model to explain all aspects of disability, which is complex, multifaceted and a most individualized experience (Oliver, 2013). Oliver later refined his "model," which was also adopted and expanded by Tom Shakespeare as well as David T. Mitchell and Sharon L. Snyder among others. Several of these authors illuminate the fact that while the medical community might categorize a disabled individual with this or that label of "otherness," it is society that is the greatest challenge for the impaired person (Mitchell & Snyder, 1997). Rosemarie Garland-Thomson (2009) explains this phenomenon most directly through art in her work on *Staring: How we Look*.

For premodern studies, work on disabled persons is difficult at best and impossible at worst. Often only hinted at in the records, disabilities might be described but apart from the disabled person. The social model gave scholars of premodern societies a path forward by examining the records not for disabled people, who were often absent, but rather for social reactions, laws, or accommodations. Irina Metzler adopted the social model in her foundational work on medieval disabilities, *Disability in Medieval Europe: Thinking about Physical Impairment in the High Middle Ages, c. 1100-c. 1400,* in 2006, and later developed her theories further in *A Social History of Disability in the Middle Ages,* in 2013 (Metzler, 2006, 2013). She writes that "a boy with multiple orthopaedic impairments is also portrayed [in the medieval record] as 'dreadfully and horribly' disfigured by the witnesses" (Metzler, 2006, p.154). In this passage and throughout her work, she is both using the translated terminology of the period as she finds it and pointing to the social reaction, not that the disabled person looked or felt "dreadful" or "horrible." In this way, Metzler used the social model to get at medieval prejudice, misconceptions, and understandings as they were. Premodern scholars who proposed new

models in the last fifteen years have done so in reaction to Metzler's work or to expand the concept laid out there (Eyler, 2010; Wheatley, 2010). Most premodern scholars of disabilities reject the "medical model" because it cannot expand far enough to encompass early vocabulary or early experiences without the scholar-ship becoming grossly inaccurate or wholly unsound.

The medicalization of a disabled individual reduces the person to the disability, which is why there has been such a strong rejection by many academics and political advocates. Disability study scholars do not study disabilities in and of themselves, but the people and the social or communal reaction to impaired people. In the past, especially the premodern past, contemporary medical terms do not work as an overlay for early terms. Patients cannot be interviewed or examined. This does not mean that scholars have not looked at the medical understanding or care for the disabled in historic communities; they have. But the "model" that is prominent in contemporary medical scholarship of disabilities—a model of reduction—is not viable or appropriate for historical studies because in so many ways that would be "back diagnosing," "retro diagnosing," or assuming a condition without having evidence.

Metzler and other medieval scholars, therefore, have used the social model to understand and explain the people they study within their social group, their community. Other scholars such a Bianca Frohne, Jenni Kuuliala, Tory Vanderventer Pearman, and Wendy J. Turner, have studied early disabilities without a model, relying entirely on the terms and definitions from premodern sources (Frohne & Kuuliala, 2018; Turner, 2013; Turner & Pearman, 2010). Kuuliala (2016), for example, writes of a boy as he was recorded in a canonization record of attributed miracles:

Thoumas de Voudai, who had to beg because of his blindness, was also occasionally beaten by three boys of his village. Guillaume de Saint-Pathus's text does not reveal their motives, or whether their actions had anything to do with testing Thoumas's blindness or were just a way of tormenting the beggar boy. However, the narrative also reports that sometimes Thoumas walked alone and fell into the mud, and in another instance it is reported that one of those who had been beating him left him to walk alone, and as a result he almost fell into a ditch (p. 161).

Kuuliala is not simply reporting the blindness of his child but the social, and very real, reaction to their neighbor and his impairment. This type of research works so long as authors are talking and discussing findings with other premodern scholars. For example, Aleksandra Pfau (2010) researching mental health in medieval France writes that,

According to a French remission letter composed on behalf of Jacques Mignon in 1458, Jacques was known to be 'perturbed and altered in his senses,' but was well-loved by his neighbors in the small town of Richardère in Poitou, because he would entertain them by doing 'cartwheels' (p. 93).<sup>6</sup>

Wendy J. Turner (2013), also writing on mental health, describes the mentally ill using the Latin terminology, such as when "Authorities bound John Faytour of Weston with a handcuff (manica) after he killed his father when he was 'out of his mind' (demens) during a spell in which he could not see reality ('amens existit [...] in tali demincia et furore')" (p. 134). These types of studies become less portable when trying to prove (or disprove) contemporary concepts—in those cases, models can be useful tools.

Premodern disability studies scholars in the first decades of the twenty-first century began exploring how to model what they could see in the premodern sources and comparing those ideas against contemporary ones. In 2010, Edward Wheatley suggested that religion permeated the lives of premodern peoples and that a "religious model" of disabilities would help bridge the gap between early understanding of disabling conditions and modern ones. At the same time, Joshua Eyler in response to Metzler and thinking similarly to Wheatley, suggested a "cultural model" in his 2010 edited collection, *Disability in the Middle Ages: Reconsiderations and Reverberations* (Eyler, 2010). Eyler's cultural model is a modified version of the social model, adding religion as a factor.

## 3. New Models

In 2013, a new conference was formed by Chris Mounsey, a professor at the University of Winchester, called "Variabilities," which took as its basis the idea "that all people are 'the same only different' from one another" (Mounsey, 2019, p. 4). The concept of everyone being on a scale of ability allowed the community or disabled people to at last discuss gradations in other ways – economic or access – as much as physical, mental, or emotional. As Mounsey (2019) proposes:

[A]bove all, Variability would not suggest that difference was binary and define disability against its absence in a term such as 'compulsory able-bodiedness.' [...] Variability would expect that every 'normal' person was as different (Variable) as every other 'normal' person (p. 4).

If then, all people are on a scale of ableness, scholars could look at difference in all people, which would be inclusive rather than exclusive; furthermore, it would open the doors wider for premodern scholarship of disability studies since all people have the potential to be disabled or abled within a lifetime.

I, too, and at nearly the same time as Mounsey, discussed and later published a model, which I called the "environmental model." This idea came from the 2001 WHO report, which said in part, that a "key finding is that human behaviour is partly shaped through interaction with the natural or social environment," (World Health Organization, 2001, p.12) and, in my mind, both the lived environment and the social element of that environment impinges on the impaired person. A few years later, environmental historians came out with a new theory, also called the "environmental model," which states that in studies of the environment, neither humans nor the environment should be sovereign over the other. I suggest that the same is true in disability studies: neither the humans, nor the environment (social, cultural, political, or physical), nor the disability should be treated as sovereign. Each plays a role of influence over the other and each—environment, human, and impairment—helps define and shape the others (Turner, 2017).

Along with this newer idea around the "environmental model," I introduce a concept I call "parallel diagnosis," which allows scholars to compare symptoms, terminology, and impairments so long as the time and context of both sides of the comparison are respected and recognized (Turner, 2020). This allows for comparison of contemporary symptoms, terminology, and impairments to similar components of the past with their social, cultural, or religious features recognized, while at the same time preserving and respecting the historic humans, environments, terminology, and impairments so long as the context and time periods of both sides of the comparison are acknowledged and maintained. In other words, historic persons can be compared to contemporary ones, so long as the scholar does not use the present to guess at the past (retro diagnose). In this light, scholars can talk about disabilities of the past considering what we know of contemporary conditions, describing symptoms or discussions that seem the same without fear of trying to diagnose using contemporary measures. While this theory has broad implications for use in the whole of medical history, my current hope is to begin a larger dialogue between the contemporary disabled community and the disabled of the past.

Stan Booth introduced a concept that would work well with the idea of parallel diagnosis; he calls this new idea "information streams." He is concerned that often the lives of some historic individuals are only known through the fragments of information left behind and scholars never quite get a full picture. This is especially true of impaired persons. Booth explains that "Information Streams separate out different narratives that tell different stories. But each is an aspect of one person," and, even if those narratives come from unlikely sources, when put together the streams of information form a larger picture of the complex narrative about the given individual that is left in the historical record (Booth, 2019, p. 135). Each individual is part of the particular time and place they came from and, as scholars study them, a "total picture" of that individual can only be perceived "if the various information streams are read together like the fibers that make up a rope" (Booth, 2019, p. 135). In other words, to understand a person or group of people, they must be understood within the time and place they lived and died (Mounsey & Booth, 2019, p. 4). This is true for all people, impaired or otherwise.

# 4. The Future of Historical Disability Studies

Future work on the history of disability could use the terminology and understanding of the time period in question or a combination of the environmental model, parallel diagnosis, information streams, and Variability to compare ideas across time or space. These studies could also turn toward a few things mentioned in the UN report—barriers, long-term impairment, environment, attitude, and interactions between the impaired and society and government, the lived environment, and interpersonal relationships.

One group that is looking at long-term conditions and the role of pain is the Pain Network, chaired by Bianca Frohne at Kiel University<sup>8</sup> and David Turner at Swansea University.<sup>9</sup> This international team is asking crucial questions of the historic record: how is pain described in the past and what role does it play (if any) in the care, treatment, and lasting effect of impairments?

Historical disability studies have grown tremendously in recent years, but there is more work to be done. Using tools, such as models, gives us a way of talking about historical disabilities that can become relatable to contemporary studies. Coupled with other tools, such as the concept of Variability or the environmental model of disabilities, some findings might become not just relatable but influential, affecting current ideas about the disability community and how disabled individuals are a normal part of the variety of humans in the environment and the world.

#### **Notes**

<sup>&</sup>lt;sup>1</sup> This Creative Unit was under the direction of Prof. Dr. Cordula Nolte from 2013-2016 and culminated in the publication of: *Dis/ability History der Vormoderne*. *Ein Handbuch*. (*Pre-Modern Dis/ability History*. A Companion), edited by Nolte and others (2017).

<sup>&</sup>lt;sup>2</sup> The current website states that 164 out of 182 have signed the document, agreeing to the "Convention" and its optional protocol (United Nations Department of Economic and Social Affairs, n.d.-a).

<sup>&</sup>lt;sup>3</sup> See both the UN website explanation of their mission and the documentation for the Preamble and Article 1 of the Convention.

<sup>&</sup>lt;sup>4</sup> More on this concept below.

<sup>&</sup>lt;sup>5</sup> Oliver distinguished between the ideas of what he called the "individual model" (now widely referred to as the medical model) and the "social model" of disabilities. While he announced this new model at a meeting of the UPIAS (Union of the Physically Impaired Against Segregation, formed in 1975) in 1983, his book, *The Politics of Disablement* (Oliver, 1990), fleshed out some of this idea for a much wider audience.

<sup>&</sup>lt;sup>6</sup> See also Pfau (2021).

<sup>&</sup>lt;sup>7</sup> I first spoke of this model in a keynote address in 2014 at the University of Bremen, "Public-Environment: A Working Model for the History of Disability," Creative Unit: *Homo Debilis*, University of Bremen, Germany. Later this concept was published: "The Environmental Model" (Turner, 2017).

<sup>&</sup>lt;sup>8</sup> Examples of her work include Frohne (2014, 2015, 2020, 2021).

<sup>&</sup>lt;sup>9</sup> Examples of his work include Turner (2012), Turner and Blackie (2018).

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