

Disability Studies

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(Revised, August 2015)

Disability Studies is an interdisciplinary academic endeavor that analyzes disability and the lived experiences of people with disabilities from the perspective of the humanities, social sciences, and arts, not the medical or applied fields (such as rehabilitation science or other related fields). Disability Studies has its political and intellectual roots in the disability rights movement that began in the United States and the United Kingdom in the mid-twentieth-century and expanded to include other countries such as Canada and Australia, various countries in Europe and South America, and countries in South and East Asia by the turn of the twenty-first century. One of the basic tenets held by disability studies researchers is that “disability” extends beyond individual bodies. Disability is not merely something that an individual has (I have cerebral palsy) or is (I am a paraplegic). Disability is created socially by built environments, cultures, and social norms that devalue, stigmatize, segregate, or discriminate against people who are considered “abnormal.” Disability Studies scholars have labeled their focus on the interactions among disabled people and the world around them the “social model” of disability, which they define in opposition to an older, well-entrenched “medical model” of disability that sees it in more negative and individualizing terms, as a deficit or defect that must be fixed, cured, or eliminated in order for an individual to function “normally” in society.

The institutional roots of Disability Studies can be traced to academics working in the United States during the early 1980s. In 1982, the Western Social Science Association created the Section for the Study of Chronic Illness, Impairment, and Disability, which became its own separate organization in 1984. In October 1986, the Board of Directors of the new organization renamed it the Society for Disability Studies (SDS). That same year, Irving K. Zola, university professor and first president of SDS changed the name of the organization’s main publication, the *Disability and Chronic Disease Newsletter*, to the *Disability Studies Quarterly* (DSQ). The DSQ grew from its humble beginnings as a newsletter in the early 1980s to one the most widely known and well-respected peer-reviewed academic journals in the field of disability studies by the turn of the twenty-first century. By 2015, the DSQ was publishing dozens of research articles, essays, reviews, and creative pieces each year, which it made available through an “open access” online journal produced in cooperation with the Ohio State University libraries. The *Disability Studies Quarterly* is unique among peer-reviewed

academic journals, because it is made available for free online (<http://dsq-sds.org>) to anyone with an internet connection who wishes to read it. The Society for Disability Studies experienced growth similar to that of the DSQ, going from a small collection of a couple dozen people during the early 1980s to a major international organization whose annual conference drew more than 500 participants in 2015. In addition to attending the annual meeting of the Society for Disability Studies, scholars, activists, and artists in countries other than the United States and Canada organized both formally and informally throughout the 1990s and into the twenty-first century, creating a global disability studies movement.

The number of degree programs and other initiatives that flourished at colleges and universities throughout North America, Europe, and the rest of the world are a direct measure of the institutional growth of disability studies as an interdisciplinary academic field. In a study they characterized as conservative in its findings, Cushing and Smith (2009) found that for the 27-year period between 1981 and 2008, disability studies course offerings in English-speaking North America grew a whopping 922 percent. Cushing and Smith found that in the five areas they referred to as the Western, English-speaking world – the United States, the United Kingdom, Canada, Australia, and New Zealand – there were in 2008, 36 “full” disability studies programs, which they defined as programs offering a Bachelors, Masters, or PhD in disability studies. There were an additional 31 “partial” disability studies programs that offered students modules, a minor, a diploma, a concentration, or a certificate. Disability studies degree programs, both partial and full, experienced a growth rate well over 200 percent from the late-1990s to 2008 (Cushing & Smith, 2009; Taylor & Zubal-Ruggieri, 2008). This phenomenal growth continued after 2008. A survey of disability studies degrees offered in the United Kingdom in 2015 revealed 40 different programs. Also in 2015, the University of Toledo, Ohio launched the first full undergraduate major in disability studies in the United States. Administratively, most Disability Studies programs are located in primarily three general areas within colleges or universities: independent disability studies departments (primarily in the U.S. and Canada), hybridized disability studies programs that are integrated with other fields, including the applied fields (common in the U.S., Australia, and New Zealand), and disability studies programs that are integrated into existing liberal arts programs and departments (common in the U.K. and the U.S.) (Cushing & Smith, 2009).

Although some schools – mostly in the U.S. – employ scholars with PhDs in disability studies, most programs recruit their faculty from a number of older, more well-established disciplines, such as

English, History, and Sociology, various Studies departments such as American, Cultural, Women's and Gender, Media, Design, and Science Studies, and fields such as architecture, occupational therapy, and education. The two elements that unite this diverse group of scholars are an overriding interest in disability and the lives of disabled people, and a strong commitment to using some variation of the social model of disability.

The Social Model of Disability

The social (occasionally called the socio-political) model of disability originated among disability rights activists in the United Kingdom in the early 1970s. Its primary purpose was to separate disability from impairment and say that disability was something that was socially created, while impairment was merely a biological fact with no cultural values attached to it. Under the social model, what became disabling for people was not their inability to walk, see, or hear (for example), but rather the inaccessibility of a physical, social, and cultural environment that remained hostile to their presence in it. As the British Union for the Physically Impaired Against Segregation (UPIAS) explained, disability is "a form of [socially created] disadvantage which is imposed on top of one's impairment, that is, the disadvantage or restriction of activity caused by a contemporary social organization that takes little or no account of people with physical impairments" (quoted in Tremain, 2006b p. 187). Put simply, the social model of disability makes a critical distinction between impairment (body) and disability (society) and roots disabled people's limitations in societal barriers that disable them, not in any individual embodied deficit. Disability studies scholars refer to this form of exclusion as "ableism." They argue that ableism and ableist attitudes are present in all societies that are built by and for nondisabled people (Goodley 2011; 2014).

For the next four decades (ca. 1975-2015), the social model of disability would form the core of the growing and evolving field of disability studies. Initially, primarily white male researchers who focused on physical and sensory impairments dominated disability studies in the United Kingdom and the United States. Throughout the late-1970s and most of the 1980s, sociologists and scholars using sociologically oriented methodologies sought to document and analyze both the causes and the effects of the structural exclusion of disabled people from society in areas such as employment, education, housing, and transportation. Over the remainder of the twentieth century and into the twenty-first century (ca. 1985-2015), disability studies scholars went from focusing almost exclusively on examining the effects of various social forces in the lives of people with physical and

sensory impairments to including a much broader range of impairments and a much larger evidence (i.e. archival) base in their research. Disability studies scholars trained primarily in English and History, as well as other studies programs (e.g. American, Media, Women's and Gender) built on the foundational literature developed in the field's first decade (ca. 1975-1985) by exploring not only the representation of disability and disabled people in culture (e.g. literature, film, art, popular culture), but also the lived experiences of disabled people throughout history. This new generation of scholars, many of whom were women, racial/ethnic minorities, and disabled, and were influenced by feminist, queer, and critical race theory expanded the range of impairments under their purview to include "mental illness" – often referred to as madness by disability studies scholars – learning and developmental disabilities, and chronic illnesses (Goodley 2011; 2014). By the first decade of the twenty-first century, the social model of disability had not only proven incredibly powerful in securing civil and human rights for people with disabilities (e.g. ADA, 1990; 2008 & UNCRPD, 2008), it also revolutionized the ways in which a growing group of academics, artists, and activists thought about impairment and disability. As Bonnie Smith, professor of women's and gender studies at Rutgers University (USA), noted (2004 p. 1), "Gone are the days of a simple and dominant physiological or medical definition of disability."

By redefining disability as something created in the social world and not through biology (or genes or neurochemistry), the social model of disability enabled scholars (and activists and artists) to move disabled people away from their historical place in society as individuals in need of medical, rehabilitation, welfare, and other services and interventions to that of an oppressed social minority in need of recognition of its civil and human rights. By discarding the notion that disability is negative and rooted in the individual, and by thinking critically about the power of various social arrangements to disable, social model theorists have been able to develop a powerful understanding of what it means to live differently in the world. Part of the success of the social model derives from its ability to expand the definition of disability to include a broad range of impairments, illnesses, and conditions, and to show that disability will touch everyone at some point in their life. Whether we become disabled or not, all of us at some point in our lives will feel the effects of disability, as we age, as we interact with co-workers, friends, lovers, clients, students, or customers, and as we care for the ones we love. The tremendous diversity among the world's disabled population and the broad range of experiences we all have with disability have been a source of empowerment for disability rights activists and academics alike.

While all disability studies scholars agree on the basic premise of the social model – that disability exists outside of the human body; that it is mediated through the environment and social relations – there are scholars who offer important critiques of some of the social model's finer points. These critiques can be broken down into three general categories, none of which are mutually exclusive (they all overlap). The first seeks to revise our understanding of the social model by critiquing the ways in which it defines impairment. The second values identity politics – as opposed to the more structural approaches of “strict” social model theorists – and urges us to recognize the critical role of class, race, gender, sexuality, and other categories in the formation of disabled people's identities and experiences. A third group of disability studies scholars who focus their work on “Global Disability Studies” question the usefulness of the social model outside of the five areas that Cushing and Smith (2009) referred to as the Western, English-speaking world – the United States, the United Kingdom, Canada, Australia, and New Zealand. In the next section I will briefly address each one of these critiques of the social model of disability.

Critiques of the Social Model

As stated above, the social model defines impairment as neutral, as a biological reality that exists outside of social relations, politics, and the pathologizing discourses of Western medicine. Initially, disability studies theorists drew an analogy with feminist thinking about sex and gender to describe the difference between impairment and disability: *impairment is to sex as disability is to gender*. Early disability studies theorists held that impairment, like our biological sex, is fixed in our bodies. We have little if any power to control or alter our impairment. It is part of our being, part of who we are; it is real. Disability, on the other hand, is like gender. It is socially created and historically contingent. Because disability emerges out of the built environment and the social milieu within which we live, it changes over time. Disability like gender is fluid; we have the power to control what becomes disabling in society by altering the built environment, as well as dominant social relations and cultural perceptions. Disability studies theorists through their research and writing sought to promote change in all three areas related to disability.

By the 1990s, feminist and queer theorists from a number of academic backgrounds, including those in disability studies, began challenging the taken-for-granted nature of both sex and impairment. Neither is as fixed or as value free as we might assume, they argued. Ideas and definitions of both sex and impairment change over time and among cultures. A mental illness in

one time and place might be a blessing from the gods in another time and place. Missing limbs or a lack of sensory perception could evoke stigma and feelings of shame and guilt in one setting and be completely normative in another. One need only look at the shift from “mental retardation” to learning and developmental disability in the mid- twentieth century, or the astronomical rise in psychiatric “disorders,” such as autism in the late-twentieth century to see the fluidity of impairment categories. A person could be defined as impaired in one historical moment and considered unimpaired in another historical moment. People with certain types of impairments might also only experience them sporadically and in varying degrees over the course of their lifetime. Think for example of someone with multiple sclerosis, lupus, chronic fatigue, or another chronic condition who might have days or weeks in which they are relatively “symptom-free.” Finally, disability studies theorists declared that impairment, in most cases, has very real disabling affects in the lives of those individuals who live with it. They urged social model theorists and all disability studies scholars to reconcile themselves with the fact that impairment imposed very real restrictions on people’s lives and in some cases could be deadly. No amount of social activism could alter either of those realities. Scholars in disability studies refer to these lived realities as the effects of impairment, or impairment effects.

The second critique of the social model has its roots in a particular form of US identity politics (Rembis, 2010). Authors writing primarily in the United States argue that a stigmatized and devalued disability identity is one of the powerful legacies of the individualization, medicalization, and pathologization of impairment (Siebers, 2008). Disabled people are divided, the argument goes, by their impairment; by medical and rehabilitation professionals, social workers, educators, and a larger society that sees them as nothing more than their own individual impairment(s) and treats each one of them as an individual case, patient or client, different from all the other cases, patients or clients. The professionals, of course, can find similarities in disabled people’s physiology, their neurochemistry, their symptoms, but disabled people remain isolated and alone, trapped by their own internalization of a depoliticized, pathologized, individualized, and ultimately devalued sense of themselves. Only when they shed this stigmatized identity can disabled people become free to see the ableist world and their place in it for what it really is – only then can they see the discrimination, segregation, isolation, and outright violence and oppression that they face every day.

According to this liberal form of identity politics, disabled people become empowered when they embrace their disabled identity and make it their own; when they begin to associate, demonstrate, and identify with other folks who have done likewise. Once they have experienced this consciousness raising, they are (in most situations) able to live life on their own terms. Some of them choose to “let their freak flags fly.” Some flaunt their (disabled) bodies and revel in their sexuality. Others among them choose to “pass;” to minimize the extent of their impairment or mute their disabled identities (usually when in the presence of mixed company). Most disabled people, however, choose to live what Siebers (2008) calls a complex embodiment, which is some mix of all of these extremes. Within this framework, everything disabled people choose to do, every utterance they make, and every cultural artifact they produce gets politicized. The personal lived experience of disability becomes a politicized identity that can be used to enact social and legal change (Siebers, 2008).

Critical to this identity-based disability politic and to its attendant theorizing within disability studies is the notion of “intersectionality.” As prominent disability studies theorist Tobin Siebers argues, disabled people experience a “complex embodiment” (Siebers, 2008). Their embodied experience in the world is influenced not only by their impairment or the disabling effects of an ableist society, but rather the by complex interactions – intersections – of impairment, disability, race, class, gender, sexuality, religion, and other important social and cultural categories. Disability studies scholars interested in identity and identity politics argue that all disability studies research must take into account these important and sometimes conflicting subjectivities when documenting and analyzing disability history and culture, and the daily lives, loves, and experiences of disabled people.

The final major critique of the social model to emerge within disability studies comes from scholars interested in global disability studies. Put simply, disability studies scholars working outside of the Western English-speaking world, or what they alternatively refer to as the global North, are finding that disability studies theories that are dominant in the West or global North, including the social model, are often ineffective, or in some cases only partially effective, in helping to explain the lived experiences of disabled people in other parts of the world, or what they call the global South. Global disability studies theorists make strong arguments for avoiding the uncritical exportation of global North disability studies theories to the global South, and for situating analyses of the lived experiences of disabled people in their own local cultural and historical contexts, social relations,

and governing structures, as well as larger international political and economic systems. Rather than dismiss global North disability studies, global South scholars encourage collaborative and constructive dialogue between North and South, which they argue will build stronger disability studies analyses and more powerful disability politics in both parts of the world (Mehrotra, 2013).

Conclusion

Disability Studies experienced tremendous growth in its first forty years. Born out of the disability rights movement primarily in the United Kingdom and the United States, Disability Studies took the social model of disability as its basic tenet. A direct critique of the older medical model of disability, the social model separated impairment from disability and stated that the built environment, social relations, and dominant cultures disabled people, not necessarily their own bodies. Disability Studies scholars raised important and influential critiques of the social model that served to broaden the reach of the field to include a greater number of disability experiences and strengthen the theoretical and methodological foundations upon which arguments were built. As Disability Studies entered the twenty-first century, scholars from a number of areas within the field increasingly critiqued its primary focus on white citizens of the Western, English-speaking world, giving rise to a growing global disability studies movement. Given the robustness of research emerging from Disability Studies and the impressive institutional growth of the field in most parts of the world, there is little doubt that it will continue to be influential in a number of academic, social, political, and cultural areas in the future.

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