

International Encyclopedia of Rehabilitation

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This publication of the Center for International Rehabilitation Research Information and Exchange is supported by funds received from the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education under grant number H133A050008. The opinions contained in this publication are those of the authors and do not necessarily reflect those of CIRRIE or the Department of Education.

Disability Studies

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As an active, integrative, interdisciplinary academic endeavor, disability studies analyzes disability from the perspective of the social sciences, humanities, and arts, not the medical or applied fields. Though disability studies has its ideological roots in the broad-based mid-twentieth-century international disability rights and art and culture movements, its institutional roots can be traced to the United States in the 1980s. In 1982, the Western Social Science Association created the Section for the Study of Chronic Illness, Impairment, and Disability, which was renamed the Society for Disability Studies (SDS) in 1986. That same year, Irving K. Zola, university professor and the first president of SDS renamed the *Disability and Chronic Disease Newsletter* the *Disability Studies Quarterly*—one of the most widely known and respected peer-reviewed academic journals in the field.

Since its inception in the mid-1980s, disability studies programs, departments, initiatives, seminars, and projects have been flourishing in numerous universities and countries around the world (Cushing & Smith, 2009; Taylor & Zubal-Ruggieri, 2008). In a study they admittedly characterize as conservative in its findings, Cushing and Smith declared in 2009 that for the 27-year period between 1981 and 2008, disability studies course offerings in English-speaking North America grew a whopping 922 percent, a growth rate that they describe as exponential. Cushing and Smith found that in the five areas they consider 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 Bachelor, 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 in disability studies. Disability studies degree programs, both partial and full, have experienced a growth rate well over 200 percent from the late-1990s to 2008. Institutionally, Disability Studies has experienced growth in primarily three areas: independent Disability Studies departments (primarily U.S. and Canada), what Cushing and Smith call “hybridization” with other fields, including the applied fields (U.S. Australia, and New Zealand), and integration into existing liberal arts programs and departments (U.K. and U.S.). In addition to academic programs, organizations such as the U.S.-based Society for Disability Studies, the Canadian Centre on Disability Studies, the Canadian Disabilities Studies Association, the Asia-Pacific Disability Development Centre, the All Russia Society of People with Disabilities, the All Russian organization, New Choices, and the All Ukrainian Association of Disability Organizations are only a few examples of the types of organizations at the forefront of the global disability studies movement.

Disability Studies scholars have developed what has become known generally as the social or socio-political model of disability. Early on, disability rights activists, artists, and disability studies scholars abandoned what they referred to as a medical model of disability and began fashioning a socio-political model of disability. Put simply, the socio-political model of disability makes a critical distinction between impairment and disability and places the voices and experiences of disabled people themselves at the center of any analysis of their lives. It roots

disabled people's oppression in social, cultural, and environmental barriers that disable them, not in any individual deficit or impairment (Davis, 2002, 2006b; Oliver, 1990; Shakespeare, 2006; Thomas, 2002; Tremain, 2006a, 2006b). As the British Union for the Physically Impaired Against Segregation (UPIAS) explained, disability is "a form of [socially constructed] 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). Early, mostly white, mostly male, mostly spinal chord injured advocates of the socio-political model of disability focused almost exclusively on physical impairments. More recent disability studies scholars influenced by feminist, queer and critical race theory have expanded the socio-political model to include a broad range of impairments, such as mental illness, learning and developmental disabilities, and chronic illness (Barnes, Oliver & Barton, 2002; Davis, 2006a; Longmore & Umansky, 2001; Smith & Hutchison, 2004; Tremain, 2006a, 2006b). The advent of the disability rights movement and the socio-political model of disability have enabled activists, artists, and scholars to reposition the disabled subject and ultimately redefine disability itself. As Bonnie Smith, professor of women's and gender studies at Rutgers University (USA), has noted (2004), "Gone are the days of a simple and dominant physiological or medical definition of disability."

By discarding the notion that disability is negative and rooted in the individual, and by thinking critically about the taken-for-granted nature of various diagnoses, labels, categories, and conditions, disability studies scholars have been able to develop a powerful understanding of what it means to live differently in the world. While all disability studies scholars use their work to combat the stigma (Goffman, 1963) associated with disability and expand popular notions of what qualifies as the human and the livable (Butler, 2006), there are some scholars who take a more incisive approach to the study of disability. This latter group of scholars uses the socio-political model, along with other theoretical frameworks both to highlight and to analyze the oppression under which most disabled people live, and to reveal the central role of class, race, gender, and sexuality in the formation of disabled identities—something recent theorists refer to as intersectionality (Barnes, Oliver, & Barton, 2002; Charlton, 2000; Davis, 2006; a Longmore & Umansky, 2001; Smith & Hutchison, 2004; Tremain, 2006a, 2006b).

Disability studies scholars, and activists and artists, do not seek to deny or to minimize the existence of impairment. Rather they work to show that dominant ideas about disabled people and various disability categories (like learning disabled) are historically, culturally, socially, politically, and economically contingent; that they change over time and vary by culture, region, and social class. Activists, artists, and academics have shown, moreover, that the social, economic, and psychic costs of disability are increased exponentially in a society that ignores or greatly devalues its disabled citizens. The current move toward universal design in everything from curriculum and instruction to new housing construction is a direct result of the work done by disabled activists, artists, and scholars, as well as their allies, to teach the value of difference and force themselves into the consciousness of the larger society.

Part of the success of disability studies has been rooted in 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, clients, and 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. They have also been a point of contention. On one hand, a very broad definition of disability enables movement participants in the United States, for example, to claim that they are part of the largest minority group in the country. At about 54 million, people with disabilities make up about 20 percent of the U.S. population (Siebers, 2008). These numbers and percentages have been critical in making civil rights claims against the state. On the other hand, this broad definition of disability makes it difficult to think about and talk about a shared identity, a common culture, or a collective consciousness. The fact that only about 15 percent of disabled people are born with their disabilities—85 percent of disability is acquired—and that about 80 percent of the 500 million people with disabilities live in what is commonly referred to as the “developing” or “third” world only serves to complicate disability studies (Charlton, 2000; Siebers, 2008).

For years, scholars have been theorizing about the alienation that many disabled people feel. Most authors argue that it is one of the powerful legacies of the individualization, medicalization, and pathologization of disability (Siebers, 2008). We (disabled people) are divided, the argument goes, by our impairment; by medical and rehabilitation professionals, social workers, educators, and a larger society that sees us as nothing more than our own individual impairment(s) and treats each one of us as an individual case, patient or client, different from all the other cases, patients or clients. *They*, of course, can find similarities in our physiology, our neuro-chemistry, our symptoms, but *we* remain isolated and alone, trapped by our own internalization of a depoliticized, pathologized, individualized, and ultimately devalued sense of ourselves. Only when we shed this false consciousness can we become free to see the world and our place in it for what it really is, only then can we see the discrimination, segregation, isolation, and outright violence and oppression we all face every day.

According to this liberal ideology, we (the disabled) become empowered when we embrace our disabled identity and make it our own; when we begin to associate, demonstrate, and generally identify with other folks who have done likewise. Once we have experienced this consciousness raising, we are (in most situations) able to live life on our own terms. Some of us choose to “let our freak flags fly.” We flaunt our (disabled) bodies and revel in our (usually hetero-) sexuality. Others among us choose to “pass;” to minimize the extent of our impairment or mute our disabled identities (usually when in the presence of mixed company). Most of us, however, choose to live what Siebers (2008) calls a complex embodiment, which is some mix of all of these extremes. Within this liberal framework, everything we choose to do, every utterance we make, and every cultural artifact we produce gets politicized. The personal becomes political (Siebers, 2008).

While this is a very powerful and important analysis of the alienating effects of disability, disability studies scholars are increasingly considering alternative explanations. Disability Studies scholars based primarily in the UK, and more recent disability studies scholars in other parts of the world, argue that it is not necessarily a false consciousness that keeps disabled people isolated and alone, living on the margins of society, but rather a lack of access to much needed support and economic resources. Much of the world's disabled population lives in abject poverty. The rise over the last thirty years of a global neo-liberal economic order that favors

privatization, so-called free market economics, and military engagement has only served to deepen the plight of people with disabilities, especially those living on the periphery (Charlton, 2000; Holden & Beresford, 2002; Rioux, 2002). People who have no prosthesis cannot choose to pass. People who have no wheelchair cannot choose when or if they will use one. People who have no access to a screen reader or a Braille printer may be forced to live in ignorance. People who never learn to sign may never feel part of the larger deaf culture. And people who have no access to education, or are forced out of poverty to work from a very young age, may never have the opportunity to come out and identify as disabled. For a long time, disability studies scholars in the US and elsewhere have been talking about how disability is socially constructed (Liachowitz, 1988). Recently, however, a growing number of disability studies scholars are beginning to reconsider how disability is socially created—through war, famine, inadequate healthcare, fierce competition for scarce resources, as well as rising profit margins, and general neglect.

Despite difficult economic times during the first decade of the twenty-first century, the rate of growth of disability studies shows no signs of abating. As modern medical technologies make it increasingly possible for people with access to adequate healthcare to live longer more fruitful lives, as the world's population continues to age, and as much of the world continues to suffer the devastating effects of global capitalism, the need for disability studies will continue to grow.

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