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Disability

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In the 2009 documentary film *Monica and David*, Monica, a woman with Down syndrome, is asked to define the word "handicap." She responds, "When someone is in a wheelchair," adding that the term may also apply to people who cannot hear or walk. "It's a sickness," she concludes. When presented with the same question, her husband, David (who also has Down syndrome), says he does not have a handicap. Asked if he has Down syndrome, he answers, "Sometimes." In this brief exchange, Monica and David exemplify the challenges of defining disability as a coherent condition or category of identity. Yet David's assertion that "sometimes" he has Down syndrome suggests that he understands a central tenet of disability studies: that disability is produced as much by environmental and social factors as it is by bodily conditions. While Down syndrome may prevent David from driving a car or managing his own finances, for example, his genetic condition is not a defining feature of his home and family life.

These insights by Monica and David remind us that the meanings we attribute to disability are shifting, elusive, and sometimes contradictory. Disability encompasses a broad range of bodily, cognitive, and sensory differences and capacities. It is more fluid than most other forms of identity in that it can potentially happen to anyone at any time, giving rise to the insiders' acronym for the nondisabled, TAB (for temporarily able-bodied). As David suggests, disability can be situational;

it can also wax and wane within any particular body. Disability brings together people who may not agree on a common definition or on how the category applies to themselves and others. Yet those same definitional challenges are precisely what make disability such a rich concept for scholars, activists, and artists. Because “disability” is this volume’s organizing term, it is important that we explore how it became attached to such diverse experiences and meanings, and produced such a wide range of social, political, and personal consequences.

The word “disability” has been part of the English language since at least the sixteenth century. According to the *Oxford English Dictionary*, the current sense of “a physical or mental condition that limits a person’s movements, senses, or activities [or] the fact or state of having such a condition” was first used in 1547. But the term also covered a broad range of “inabilities” or “incapacities” that included inability to pay a debt or to worship God with a full heart, while some conditions currently treated as disabilities were not regarded as such. Some—like autism or chronic fatigue syndrome—had not been discovered (or invented, depending on one’s perspective); others, like chronic pain or various disfigurements, were simply considered inevitable facts of life.

For much of its historical run, “disability” has brushed up against words like “infirmity” and “affliction,” both of which held connotations usually ascribed to disability today, as well as phenomena like poverty, ugliness, weakness, sickness, or simply subjection to an unfortunate experience (Baynton 2011). Disability also shared ground with the early modern term “monstrosity” and the classical-era term “deformity”—the former having supernatural overtones and the latter representing a falling away from godliness into a particular kind of moral and physical ugliness (see Helen Deutsch’s entry on “Deformity” in this volume). By contrast, the

word “cripple,” which derives from the idea of one who creeps, represented an attempt to characterize various physical impairments that impeded mobility. Similarly, “invalid” was an early medical shading of a broad range of infirmities resulting from injury or illness.

It was in the nineteenth century that disability became firmly linked, through the discourses of statistics, medicine, and law, to words such as “deviance,” “abnormality,” and “disorder.” Lennard Davis (1995) argues that during this time the modern conception of disability emerged as a by-product of the concept of normalcy. Earlier human bodies were measured against idealized and often spiritual standards of perfection and ability that no earthly individual could match. With the development of statistical science and the bell curve, human ability came to be understood as a continuum, with disability and disabled people occupying the extreme and inferior end of the spectrum.

During the late nineteenth and early twentieth centuries, protecting the normal from the abnormal became a broad medical and social imperative undertaken in the name of progress. Vocabulary terms associated with disability reflect these shifts. Just as the eugenics movement attempted to rid the world of many disabilities through sterilization and segregation, disability terminology emphasized backwardness, atavism, and interruption: people with disabilities were said to be “slow,” “retarded,” or in a state of “arrested development.” Hereditary explanations stressed the degenerate threat disability posed to the white race. People with intellectual disabilities (classified under the broad term “feeble-minded”), in particular, were said both to exemplify the debilitating effects of modernity and to represent instances of exceptional regression (Valente 2013). At a time when the industrialized world prized speed and efficiency, the temporal lag associated with disability amounted to being “handicapped in the race for life.”

Many of these terms remain as residual signifiers for disability in contemporary society. As Douglas Baynton argues, by the early twentieth century, one had only to say “handicapped” to indicate disability, while in France the primary translation for disabled remains *handicapé* (Baynton 2011; Stiker 1999). On a global scale, however, “disability” has now become the preferred term. It began its ascent in the United States during the Civil War, when “disability” measured one’s capacity to serve in the armed forces or one’s right to compensation from injuries incurred in military service. As the welfare state developed in the twentieth century, the term came to incorporate chronic illnesses and conditions of impairment that impeded one’s ability to work (Linker 2013, 503–505). But paradoxically, as “disability” has muscled out older competitors, it has also grown more ambiguous and unstable in its meanings. This is because as the term has expanded to include new categories of experience and perception as well as phenomena once labeled by other terms, those meanings have simultaneously been challenged by scholars and activists (Kudlick 2003).

Although now someone with a visual impairment may recognize “disability” as the structure that links her to a wheelchair user or a person labeled as autistic, it thickens our sense of such alliances to study how people in earlier times understood—or, alternately, did not understand—their connections to each other. The historical record provides glimmers of cross-disability awareness but also of obstacles to finding common ground or shared values. A 1641 law in colonial Massachusetts, for instance, provided exemptions from public service for settlers who could claim “greatness of age, defect in mind, failing of senses, or impotency of Limbs” (Nielsen 2012, 21). Such unfitness for work ultimately led to organized systems of charity—and, by the nineteenth century, institutional quarantining and attempts

at medical “correction” for people with a wide range of impairments.

Paradoxically, such quarantining sometimes promoted social cohesiveness within and even across different types of institutions. In nineteenth-century asylums and other specialized “total institutions,” blind and deaf people, people defined as mentally ill or deficient, and other disabled people often came into contact with large numbers of other members of their group for the first time. Thomas Gallaudet, the cofounder of the American Asylum for the Deaf, characterized the typical student at his school as “among his countrymen, for [they] use his native language.” Occasionally, this fellow feeling extended across categories of impairment. A patient-run literary journal published in a public nineteenth-century asylum for the insane, for example, records a visit by students from a school for the blind; another article in the journal speculates on the increased susceptibility of blind and deaf people to mental illness, showing an appreciation for the shared social vulnerability of all of these groups. Such institutional dispatches suggest a flickering awareness of institutionalization as the grounds for identifying a common set of experiences. Such connections were the grounds for political activism. Early American deaf-rights activist John Jacobus Flournoy, for instance, was one of the first to use the word “disability” in relation to deafness among a range of physical and mental differences when he wrote in 1855: “The old cry about the incapacity of men’s minds from physical disabilities, I think it were time, now in this intelligent age, to *explode!*” (Krentz 2007, 155).

As with segregation, colonialism, and apartheid, shared experiences of social separation and political disenfranchisement ultimately galvanized many people with disabilities and their supporters toward a common purpose. However, before the 1960s, politicized protests

against the oppressive features of institutionalization and discrimination were scattered and generally did not speak for broad categories of disability. For instance, in the United States during the 1930s, when the League of the Physically Handicapped decried the Works Progress Administration's policy of failing to employ people with physical disabilities, it did not include people with mental or developmental disabilities in its list of those who had suffered discrimination (Nielsen 2012, 132). And when the league approached leaders of the Deaf community to make common cause, they were rebuffed on the grounds that the Deaf were not disabled or unemployable (Burch 2002, 126). (Today, the Deaf community tends to regard deafness as a culture; whether it is also a "disability" is a contentious point.)

In this volume, the entry by Denise Nepveux on "Activism" tells how isolated protest movements cohered into the broad disability rights movement, which, by the late 1960s, was agitating for inclusion and access on many fronts, and which strengthened the sense of disability as a positive identity category rather than a stigmatized designation of inferiority or lack. Political organizing within the incipient disability rights movements of the 1960s and 1970s attempted to shift "disability" from an exclusively medical concern to a broadly social one, an effort that eventually won important battles. Major legislation and policy initiatives in the United States and worldwide reflect this shift, with profound implications for governments, businesses, and citizens—disabled and nondisabled alike. For example, the first two definitional prongs of the Americans with Disabilities Act (ADA; 1990; amended 2008) locate the meanings of disability within the body: "A physical or mental impairment that substantially limits one or more major life activities of such individual; a record of such an impairment." These definitions are surprisingly similar to the long-standing dictionary definition

of "a physical or mental condition that limits a person's movements, senses, or activities" or "the fact or state of having such a condition." However, the third definitional prong of the ADA, which adds "being regarded as having such an impairment," put perceptions and social attitudes squarely in focus (Emens 2013). The UN Convention on the Rights of Persons with Disabilities (2008) goes even further in defining disability's social dimensions. Disability, according to the convention, "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." Perhaps most expansively, the vision of accessibility propounded by Ron Mace and the universal design movement since the late 1980s was born out of a belief that particular physical or sensory differences only become disabling when the environment creates barriers to access. These recent developments all emphasize meanings of "disability" that are external to the body, encompassing systems of social organization, institutional practices, and environmental structures. Disability studies scholars refer to this approach as the "social model," which challenges the medical understanding of disability as located exclusively in an individual body, requiring treatment, correction, or cure (Shakespeare 2006b).

Although the social model predominates, in much recent scholarship, disability refers to a subjective state, the condition not only of *identifying* as disabled but also of perceiving the world through a particular kind of lens. As Sharon Snyder and David Mitchell (2006) note, narratives of disability history that focus on legislative triumphs, social inclusion, and the breakdown of stigma risk losing sight of the distinct, individual, and subjective experiences that make up disability's history. Disability subjectivity, they argue, does not come either from bodily impairment or from the socially

constructed world outside; instead, they argue for a “cultural model” of disability that explores the disabled body’s interface with the environments in which the body is situated. While it may be true that to lose one’s leg, or to be visually impaired, or to have a chronic illness in the twenty-first-century United States is incommensurate with what those impairments or conditions meant in eighteenth-century Europe or ancient Egypt, disability itself always begins and ends with the subjective impressions of the individual who experiences the world through her body. Despite the lingering popular sense that disability represents deficiency or defect of body or mind, the cultural (or, alternately, biocultural) model of disability as a relationship between body and society is gaining increasing legitimacy in law, policy, and the social environment worldwide.

Part of the transformation of “disability” from stigma and object of medical correction to source of knowledge reflects this new attention to inwardness. Disability becomes a mode of situating one’s understanding of self rather than a marker of isolation, what the late disability historian Paul Longmore (2003, 246) called the “social death” sometimes experienced by people with disabilities. Whereas too often the experience of disability entered the historical record only through the words of those who tried to cure, tame, correct, or end it, disability studies scholarship is now focused on building—as well as excavating from the past—a rich and self-conscious record of the perspectives of disabled people themselves. Memoirs, films, journals, performance spaces, and online social networks promoting what is sometimes defiantly referred to as “crip” culture are all regular features of this new landscape of disability; meanwhile, academic conferences, journals, and degree programs have made disability studies a prominent force on many campuses. Such new developments parallel feminist epistemologies—including

what used to be called “women’s way of knowing”—as well as postcolonial and critical race theorists’ critiques of hybrid identities and psychic displacements, and queer theory’s blending of social analysis and subjective expression. Each of these political-cultural-academic movements began with a first wave of identifying and resisting oppressive structures, which was followed by attempts to recover a cultural heritage as a backdrop for individual and collective expression in the present.

Intersectional modes of analysis point to the common interests, struggles, and pleasures these movements can promote. Deaf artist and activist Joseph Grigely (2005) works in this vein when he speaks of a “proactive” disability studies: one that is focused not just on attaining rights and accommodations for people with disabilities but also on developing dynamic, interactive, and collaborative projects that challenge the tyranny of “normal” in all areas of social and political life. To this end, the subjective experiences of people on the wrong side of “normal” can be used, in the words of the Dutch educational philosopher Pieter Verstraete, “to expose the self to the other,” rather than merely to “reduce the other to the self” (2007, 63). Vivid examples of this work of mutual “beholding” rather than objectifying “staring” can be found in Rosemarie Garland-Thomson’s (2009) discussion of disabled artists who turn the unwanted attention of others into the subject of their own work.

While some scholars and activists claim or assume that disability is a category that cuts across cultures, others have noted that disability studies rests on assumptions derived from and specific to the Western world, and that its histories and archives continue to have a strongly Euro-American orientation. Disability scholarship and activism in Europe and North America have long sought independence for people with disabilities, a demand that arose in reaction against being

treated as passive, voiceless, and dependent. In the 1970s, the independent living movement was born in Berkeley, California, and quickly took hold throughout the United States and Europe, with the goal of achieving greater autonomy and inclusion by providing people with disabilities with personal assistants and adaptive technology. However, as Eva Kittay (1999) has noted, largely overlooked in the quest for autonomy is the fact that the independence of disabled consumers is contingent on the labor of personal assistants who are almost always immigrant women, sometimes with unclaimed disabilities of their own. “Independence” and “autonomy” are concepts that are deeply embedded in the Western philosophical and political traditions of liberalism and are not universally desirable goals in all cultural contexts (Nussbaum 2006).

The global ambitions of the universal design movement, which upholds the worthy goal of a barrier-free environment, also sometimes founder on the realities of global inequalities: this approach relies on architectural innovations and the use of technologies that may be too costly to be realistically implemented in many areas of the developing world. Moreover, the technologies that enable people with disabilities in the Western world are often manufactured by workers who cannot afford to use them, and who may themselves be disabled. For example, the smartphones and computer tablets that give students with disabilities in the West tools to learn alongside their nondisabled peers and that supply increasingly ingenious apps to allow blind, deaf, and mobility-impaired people to navigate their environments are likely to have been assembled under harsh and potentially disabling conditions in China. Michael Davidson argues that a more global disability studies must refine the concept of universal design to account for variations in resources and cultural values. In this way, disability studies can prompt us to consider

how “many aspects of modernity are founded upon unequal valuation of some bodies over others” (Davidson 2008, 171).

Some scholars have offered the concept of “debility” as a supplement to disability, which they see as entangled with Western ideas about individuality, autonomy, and bodily integrity. The dictionary meaning of “debility” overlaps with “disability”: it is the “condition of being weak or feeble,” in either physical or mental capacity. But a secondary meaning—“political, social, or pecuniary weakness”—makes it useful for scholars attuned to populations made vulnerable by political and economic forces globally: For instance, Jasbir Puar uses the term to signify an “aggregate” condition in which some bodies worldwide are made to pay for “progress” that others enjoy. “Debility,” she writes, “is profitable for capitalism” (2012, 153). Like Puar, Julie Livingston uses the term “debility” to supplement the concept of disability and its attendant assumptions about a liberal, rights-based understanding of personhood. In Botswana, for instance, AIDS activists have sought the equal participation of persons with disabilities in the public sphere, but Livingston shows how the liberal model of personhood at the heart of their activism is undercut by Botswanan notions of moral sensibility, which include both an ethos of communal care and an intense aversion to certain types of bodily disfigurement or unruliness. While Euro-American versions of disability rights focus on “enabling persons to participate equally in rational-critical discourse in the public sphere regardless of the vagaries of any individual’s particular bodily state,” such goals collide with cultural systems that shape the circulation of bodies, emotions, and values differently (Livingston 2008, 289).

Obscuring these different constructions of disability and debility, human rights activists and policy makers around the world tend to idealize Western—and often

specifically American—attitudes and practices concerning disability, while labeling those in the “developing” world as “backward” (Kim 2011). Certainly, the United States has done much to bring forward disability rights as a concept to be emulated elsewhere, but the social situation of people with disabilities is by no means uniformly secure. In the United States, health and physical beauty are marketed as commodities more aggressively than in any other culture. The rhetoric of the beauty, fashion, diet, and fitness industries, illustrated by the allure of cosmetic surgery, equates falling from these ideals with moral failure. So, too, in times of economic scarcity in the United States and other market-driven societies, people with disabilities and their supporters are often seen as a burden on public resources. Programs for education, transportation, and public services for people with disabilities are often the first to be cut by budget-conscious politicians. A backlash against civil rights accomplishments blames disability legislation for, in effect, “crippling” the economy. And many who claim accommodation or compensation under the law are viewed with suspicion of malingering—especially those whose disabilities are not immediately visible. The mapping of the human genome has also had ambivalent consequences for disability. Research that promises to cure or prevent disease and to bring new understanding of human character and potential often does little more than succeed in producing a new class of people whose genes tell us that they may someday become disabled by diseases like breast cancer, cystic fibrosis, or Huntington’s disease—thereby creating a pervasive anxiety about disability as a future risk. So, too, new technologies for prenatal testing seek to eliminate some types of genetic disability through the termination of fetuses. Such tests further stigmatize genetic conditions by making them seem like preventable mistakes. And in the eyes of many disability rights advocates, they augur

a new era of eugenics, in which disability is eradicated before it comes into the world.

Our understanding of disability is enhanced by awareness of the term’s complex genealogy, as well as by the enormously varied experiences of embodiment across cultures and socioeconomic locations. If history is any indication, the meanings of disability and the words we use to describe its various manifestations will no doubt undergo profound shifts as a category of identity; a social, legal, and medical designation; and an embodied condition. As a way of perceiving the world, it will help us to understand—and to influence—the way that future takes shape.