Introduction

Rachel Adams, Benjamin Reiss, and David Serlin

In 2005, Gallaudet University—the premier research and teaching institution for Deaf and hearing-impaired students in the world—began designing a new building, the James Lee Sorenson Sign Language and Communication Center. Instead of simply commissioning an architectural firm to do its work, administrators invited faculty and graduate students in the social sciences and humanities to help design the building, which was eventually completed in 2008. To this end, Dirksen Bauman, a Gallaudet faculty member who studies linguistics and critical theory, held a graduate seminar in 2006 entitled "Deaf Space."

Bauman worked with students to think about the political and experiential ramifications of Deaf space rather than simply giving administrators or architects of the new building a laundry list of "needs" that could be incorporated or added on to an existing design. Would a building designed entirely by and for Deaf people look, feel, and be experienced differently from other buildings—and, if so, how might it work? Alternately, because Deaf people already live in the world without specially designated spaces, could there be something fundamentally problematic and even essentialist about creating an identifiable "Deaf" space? Does designing a building for "the Deaf" undermine the goals of the universal design movement, which is intended to provide accommodations and access for all users rather than for a singular population?

By the end of the course, the students had raised these and dozens of other questions about how to construct a new vocabulary for thinking in concrete and useful ways about this seemingly abstract thing called "Deaf space" (Byrd 2013). Such a project, ultimately, was intended to question the results-oriented goals of architects for whom compliance with the law—via the installation of a wheelchair ramp or a chirping elevator—often represents the full extent of their critical vocabulary concerning disability. And many of the lessons learned could be applied to other projects beyond Deaf space.

The questions undergirding Bauman's course have much in common with the project we have undertaken in *Keywords for Disability Studies*. At the most basic level, both are collaborative, interdisciplinary attempts to revisit the categories, concepts, and assumptions that define disability and the experiences of people with disabilities more broadly. Both also question fundamental terms and concepts that may seem settled in order to understand how and why they were used in the first place and how they might evolve in the future. But while Bauman taught his students to think about architecture as a kind of language that resonates with Deaf linguistics and experience, the medium for this book is language itself.

As the editors of this book, we worked with a group of more than sixty authors to produce a collection of essays that explore the conceptual vocabulary of disability

studies as it is understood, practiced, and taught in the early twenty-first century. For newcomers seeking a very basic definition of this area of scholarship and research, disability studies explores the social, cultural, and political dimensions of the concept of disability and what it means to be disabled. It grew out of a quest for civil rights, equal access, and inclusion for people with disabilities that began in the 1960s and 1970s. This "first wave" of disability rights activism sought to affirm basic human rights of dignity and respect by tying them to concrete goals like access to education, employment, housing, and transportation. Such activism has led to landmark legislation such as the passage of Section 504 of the Rehabilitation Act of 1973 in the United States, the Declaration of Rights of Disabled Persons in the United Kingdom (1975), the Americans with Disabilities Act (1990), the British Disability Discrimination Act (1995), and the United Nations Convention on the Rights of Persons with Disabilities (2008). Spurred by these developments in the legal and political realm, scholars in the humanities and social sciences began to conceive of disability as a form of embodied difference that could be studied similarly to race, gender, ethnicity, and sexuality. They viewed disability not just as a legal designation but as an arena of social contestation and an identity category in need of analysis across time, geographies, and cultures.

One core tenet shared by scholars of disability studies is opposition to the "medical model" of disability, which sees disability in terms of individual impairments to be corrected and cured. As an alternative, scholars and activists define disability as a social and environmental phenomenon. In the "social model," one is disabled because of the body's interaction with the social and physical environment rather than because of individual pathology or "lack." The social model asks how certain kinds of bodies are disabled by physical barriers, social stigma, lack of legal recognition, adaptive technologies, and economic resources.

Many of our entries—especially Sayantani Das-Gupta's "Medicalization"—expand upon and even challenge this neat distinction between medical and social models. Not all aspects of disability, they argue, can be attributed to social or environmental barriers. Yet despite its limitations, the social model represented a crucial stage in the development of disability theory and activism because it links disability to other major vectors of identity, such as race, class, gender, sexuality, and citizenship, that are understood as socially produced. As a result, some disability studies scholars have shown how identifying the body as *either* disabled *or* nondisabled is fundamental to many forms of social discrimination based on supposedly innate and "natural" forms of bodily difference. For example, hierarchies of race, class, gender, and sexuality proceed in large part from a set of presumptions about "normal" mental and physical capacities. Indeed, the study of disability often shows quite vividly how the dialectical concepts of "normal" and "abnormal" are responsible for structuring basic aspects of society and culture. The study of disability thus engages some of the most pressing debates of our time: about the beginning and end of life; about prenatal genetic testing, abortion, sterilization, euthanasia, and eugenics; about accommodation in public schools, public transportation, housing, and the workplace; about technologies intended to correct and "cure" the nonnormative bodies of infants, children, and adults; and about the complex relationships between wartime injuries, post-traumatic stress, health care, and citizenship. These questions could not be more relevant, given that people with disabilities are the world's largest minority group and that anyone can potentially become disabled.

Over the past three decades, disability studies as an interdisciplinary field has had far-reaching effects, as

evident in the formation of interest groups and caucuses within major scholarly organizations, in the growth of disability studies programs at the undergraduate and graduate levels, and in the publication of countless books, articles, and course offerings. As it has moved out of the humanities and social sciences, disability studies has also begun to challenge core assumptions of professional arenas like law, medicine, and economics, which in some ways mark a return to the field's origins among disability rights activists. Yet despite all of this intellectual and institutional activity, the field is at something of an intellectual crossroads. As it has moved into new terrains, disability has become a remarkably heterogeneous category. The diversity of work currently conducted under the rubric of disability represents varied and sometimes competing interests, and different areas of scholarship have not always been in productive dialogue with each other.

Keywords for Disability Studies is intended both to highlight debates and differences within disability studies and to provide a conceptual architecture that holds together the field's sometimes fractious components. Our goal in designing this volume was not simply to define terms but to use them to delineate the field's debates and problems, while also establishing their importance to many other areas of inquiry across the disciplines. We modeled our project after Raymond Williams's classic book *Keywords: A Vocabulary of Culture and Society*, originally published in 1976. Williams viewed his book as "a way of recording, investigating and presenting problems of meaning in the area in which the meanings of *culture* and *society* have formed." While he offered a certain amount of etymology, unlike a dictionary, his book never attempted to get at "original" or "true" meanings. Meaning for Williams was always in flux, always subject to the forces of history. Shifts in linguistic connotation and usage did not simply *reflect* historical change;

rather, given that "some important social and historical processes occur *within* language" (Williams 1985, 15, 22), linguistic shifts might in fact also drive social change.

Like Williams's project, *Keywords for Disability Studies* seeks to view concepts and the language that gives them shape as matters of social contestation and historical change. This framework is especially appropriate in a field that was born out of an attempt to widen the meanings of disability beyond the scope of the medical practitioners who so often laid claim to them. Despite the field's resistance to the medical model, we have avoided a reflexive opposition to approaches grounded in the health sciences and policy out of a belief that it is time to move past such easy oppositions. Recognizing that there is considerable potential for dialogue and collaboration, we hope that readers in those fields will use our book much as the architects at Gallaudet used the ideas of Bauman and his students: as a way to expand their understanding, rather than as a challenge to their expertise.

Many of our entries cover topics that are largely internal to the field of disability studies, such as "Prosthesis," "Deafness," "Crip," and "Deformity." However, we have avoided specialized terms like "neurodiversity," "dismodernism," or "posthumanism," which have gained currency within the field but might be perplexing to newcomers. Such vocabulary is clearly explained where appropriate within the essays themselves. Given the collective and heterogeneous nature of our subject, we have also tried to avoid terms that isolate specific disabilities wherever possible. Sander L. Gilman's entry on "Madness," for instance, references a range of experiences that are now medicalized as mental illnesses or neurological conditions, but it also suggests the elasticity and porousness of stigmatized realms of psychological, emotional, or developmental difference. Gilman shows how homosexuality and epilepsy were

once considered forms of madness, and how new categories of psychiatric or mental disability may be called into question as soon as they are identified. The term also suggests intersections with various forms of embodied difference, such as the fact that in the nineteenth century the Deaf were often presumed to be mentally deficient.

We have also included many entries that one might find in a book addressing keywords in the humanities and social sciences more broadly. This is because we believe that a consideration of disability has the potential to transform the critical terms from nearly any discipline. Indeed our book shares several terms with Williams's, including "Aesthetics," "Communication," "Family," "History," "Institution," "Technology," and "Work." However, it would be misleading to suggest that these entries are conceived according to a neat logic of inside/outside the field. Douglas Baynton's entry on "Deafness," for instance, is in direct conversation with Carol Padden's entry on "Communication," which analyzes sign language as one of many alternatives to speech that people who are considered disabled have found or invented in order to communicate linguistically. Entries on topics like "Race" and "Sexuality" show how such concepts have functioned to construct particular disabilities, how imputed disability has been used to stigmatize racial groups and sexual practices, and how historical processes of colonialism, eugenics, and the ascription of sexual "abnormality" have linked ideologies of race and sexuality to disability. Because our book is conceptually driven rather than encyclopedic, it does not offer entries on important historical or social phenomena like universal design or the Americans with Disabilities Act of 1990. Instead, such topics are threaded through relevant entries like "Access," "Space," "Rights," and "Design." By working conceptually rather than categorically, we hope to combat the isolation and

stigmatization so often associated with disability, instead bringing it into a wider realm of social, cultural, and political circulation.

One important difference between our volume and Raymond Williams's foundational work is that each essay is written by a different author—a format that follows Bruce Burgett and Glenn Hendler's *Keywords for American Cultural Studies* (2007). While we encouraged our authors to write broadly for readers from a range of backgrounds, we also wanted them to acknowledge how their respective disciplinary positions informed their critical perspectives on their chosen topics. One of the key assumptions of disability studies is that there is no neutral or objective position from which to regard the human body and its differences, just as the "normal" body is a fantasy belied by the wondrous spectrum of human difference. In fact, disability was often seen as incommensurate with objectivity, which was reserved for those who decided the fate of the disabled. Therefore, a stance of neutrality or false objectivity would only replicate the conception of disability as a problem to be solved or banished, rather than as a perspective worth considering. And yet we also wanted the book to be more than a collection of individual voices. During the process of writing and editing their entries, contributors were encouraged to share drafts via an editorial wiki web page. Our editorial interventions were often more extensive than usual, with the goal of creating complementarity among entries while maintaining the particularities of a given author's voice and perspective. We see this collaborative spirit as a means of combating some of the divisions that have emerged within the field and within the broader community of people with disabilities.

The capaciousness of our terms stems from our belief that disability studies opens a new lens on the full spectrum of human activity. How cultures draw the

line between "normal" and "abnormal" has broad consequences for everyone. Accordingly, we hope that the volume will help crystallize debates and problems internal to disability studies, as well as establish their importance to many other areas of inquiry across the disciplines. And we hope that, as with Bauman's project, the structure we have created together will inspire others not only to build new structures but also to think more creatively and more inclusively about the people who will interact with them.

Editors' note: In the time since we first drafted this introduction, the field of disability studies suffered two great losses with the deaths of Adrienne Asch in November 2013 and Tobin Siebers in January 2015. Their work left its mark on so many of the ideas expressed in this volume. If we imagine disability studies as a collaborative design, its structure was immeasurably enhanced by the wisdom, courage, and insight of Adrienne and Tobin. We hope that our future work in the field will be a tribute to their legacies, and we dedicate this volume to their memory.

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Disability

Rachel Adams, Benjamin Reiss, and David Serlin

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;