

INTRODUCTION

On the first day of class, I ask my students: “When you walk into any major chain bookstore, do you find any books about people with disabilities?” All of my students are smart, but it takes them a bit of time to think about this. Eventually, they answer: Helen Keller, Christopher Reeve, and the blind guy who climbed Mt. Everest. But all of these individuals are considered to be *disabled heroes*, individuals with many more resources than the typical person with a disability. Given the fact that nearly one fifth (18%) of the American population has a disability (NOD/Harris Survey, 2004), it is surprising that there isn’t a section in the bookstore devoted to “Disability History.”

I ask my students this question because I want them to think about the invisibility of people with disabilities in our society and culture. People with disabilities, and their experiences, knowledge, and accumulated wisdom, are invisible in our society and culture; furthermore, this invisibility is not noticed or discussed. No one questions why there are no books written by people with disabilities, or better stated, why books written by people with disabilities are not widely available.

John Hockenberry, a journalist with a spinal cord injury, describes the invisibility of people with disabilities in textbooks and the curriculum:

Why is it that a person would not be considered educated or privileged if he went through school and never learned there was a France or a French language? But if a person went through school and knew nothing about disability, never met a disabled person [*sic*], never heard of American Sign Language, he might be considered not only educated, but also lucky? (cf. Fleischer & Zames, 2001, p. 205)

In spite of this invisibility, disability is being redefined as a social construct; people with disabilities are developing a collective identity, and the number of those with disabilities continues to climb. Furthermore, “We want more disabled people [*sic*], not

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fewer” (Stalcup, 1997, p. 175). Perhaps most important, all of us have the possibility of acquiring a disability, or marrying someone with a disability, or having a child with a disability.

The Purpose of This Book

The threefold purpose of this book is to look at the disability experience from the perspective of the individual who has a disability, to discuss how disabilities are viewed by society, and to consider the relationship between these two viewpoints. As this book emphasizes, a perfect world is not a world without disabilities; it is a world in which accommodations for people with disabilities (PWDs) are provided and artificial barriers are removed. It is also a world that does not stigmatize or discriminate against those with disabilities, a world that accords basic human rights to PWDs. (Note: the acronyms PWD and PWOD, and their plurals, will be used throughout the book for the purposes of clarity and brevity. PWD denotes a person or people *with* disabilities, and PWOD denotes a person or people *without* disabilities.)

I wanted to write a book that, in a single place, would consider the overall, broad, comprehensive experience of disability. It was important for me that readers gain an introductory understanding of the way in which three broad areas relate to each other. These areas are as follows: definitions of disability, societal response to PWDs, and the experience of disability. To my knowledge, such a book has not been available. Of course, there are excellent books on each of the three broad areas, and I have used these works in my research and writing and have referenced each, to which the reader may refer for more depth and detail. Therefore, I have deliberately sacrificed detail and depth to provide a broad overview of the disability experience. Some sort of organization and conceptualization, even if artificial, is necessary. Hence, these three sections of the book (and the *sequence* of the sections) are provided to facilitate learning. Whenever possible, these interrelationships are noted.

Clearly, the most important section of this book deals with the experience of the PWD. It may appear counterintuitive that the most important section of the book is also the final section. After much consideration, I decided that it is impossible to understand the experiences of PWDs without first learning about the differing definitions and models of disability and how these affect the daily lives of PWDs. The services PWDs receive, whether they live in the community or in an institution, or whether they *live* at all, are all determined by definitions and models of disability. Hence, the first section defines disability. The second section deals with societal responses to disability. The PWD is greatly affected by the way in which society views him or her and the disability. Indeed, many PWDs declare that coping with prejudice and discrimination is a greater concern than the disability itself. Furthermore, because everyone’s self-identity is partially determined by one’s culture and society, it makes sense to consider the way in which society views (and has viewed) PWDs before discussing the experience of PWDs.

Do these well-defined sections represent the reality of any one person? Of course not. No book can truly communicate someone's experience. Moreover, there are no neat divisions between defining disability, society's response, and the individual's experience of living with a disability. Certainly, all three of these concepts interact with each other, and no one truly conceives of his or her life in these three neat, clean paradigms.

In contrast to most textbooks on disability, this book is not organized by the various diagnostic categories of disability, with each chapter discussing a specific disability, such as blindness, mental illness, paraplegia, or intellectual disabilities. Rather, broad similarities and differences across a wide range of disabilities are considered. There are many psychosocial issues, responses, and tasks required of PWDs; therefore, this book discusses these broad issues. Society's view of disability and PWDs are also discussed in terms of a wide spectrum of disabilities, rather than discussing society's view of and response to each disability type.

Section 1: Definitions of Disability

The first section defines disability and normality and the various models of disability. Normality and disability are defined in relation to each other, and the definition of neither is straightforward or clear-cut. (I recently saw a bumper sticker on a car that read, "Normal at our house is just a setting on the clothes dryer.") Some of this section is devoted to what a disability is *not*. Models of disability, at first glance, appear to be theoretical abstractions; however, these models determine the daily lives of PWDs. Six reasons why there are more disabilities than ever before are discussed in addition to the Americans With Disabilities Act (ADA). The ADA was passed in 1990, leading many in the Disability Rights Movement to term PWDs as the "last and least minority." Certainly, most other minority groups in the United States were accorded their civil rights before 1990. These first two chapters also present the rationale underlying the correct terminology for describing disability and PWDs. Much of the research for this section is focused on demographic data and legal scholarship.

Section 2: Society and Disability (or, the Best Way to Teach Social Justice Is to Teach the History of Social Injustice)

The second section of the book discusses society's responses to disability and PWDs—most of which have included prejudice and discrimination. Chapters 3, 4, and 5 discuss sources of prejudice and discrimination. Each PWD, regardless of his or her achievements, economic resources, or privilege, understands that he or she belongs to a devalued group. PWDs are often faced with the need to negotiate a relationship with a society that, in many cases, rejects them. The focus of these three chapters is on the

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effect of prejudice on PWDs; however, the way in which people without disabilities (PWODs) pay for their prejudice is also reviewed. Prejudice is expensive. Prejudice against any group costs the larger group, and eliminating prejudice against the minority group improves the economy. By systematically refusing to allow members of one group the right to fulfill their potential, the larger group forfeits economic benefits. Furthermore, PWODs pay for their prejudice by losing the creativity and diversity of ideas that PWDs could provide, if allowed. For example, most universities offer women's studies courses and African American (Black American) courses, but the incorporation into the undergraduate curriculum of disability history or disability studies lags far behind. Finally, PWODs pay for their prejudice against PWDs by losing an opportunity to grow because of the fear of acquiring a disability. If PWDs and their experiences were socially validated, PWODs could understand the disability experience and not fear it as much.

Some concepts in this second section are difficult to understand. First, as a society, we have never viewed disability as an ordinary human experience. Indeed, many PWDs report that they would not wish to be cured of their disability; instead, they would rather simply be treated as individuals whose disability does not make them unordinary or less than fully human. When the public views disability as heroic or tragic, not only is this an inaccurate perception of the lives of PWDs, but it also does not allow PWDs to be regarded as and judged like everyone else. Second, the idea that disability is a collective concern may appear illogical; nonetheless, these chapters attempt to show that disability concerns everyone. Finally, and most difficult, many readers have questioned my arguments against telethons, simulation exercises, and other "well-intentioned handicapism." I think it is important to think about the *results* of some of these practices. Without question, the *motives* of those who support telethons and simulations are well-intentioned; however, the costs to PWDs and the *results* have set the Disability Rights Movement back. Indeed, many PWDs point out that there are no telethon or simulation exercises for other minority groups. Many PWDs consider charity of any type, including telethons, to have relieved general society of any need to provide civil rights for PWDs. Titles of many books stress the contradiction between civil rights and charity, including Shapiro's (1993) *No Pity: People With Disabilities Forging a New Civil Rights Movement*; Fleischer and Zames's (2001) *The Disability Rights Movement: From Charity to Confrontation*; and Scotch's (1984) *From Good Will to Civil Rights: Transforming Federal Disability Policy*. Much of the literature for this section was taken from works on the sociological view of disability and books on disability rights.

Section 3: The Individual and Disability

The focus changes in Chapters 6, 7, 8, and 9. In these chapters, the individual's response to disability is considered, especially considering the factors of the disability

itself and factors in the environment. Types of onset, varied courses, levels of severity, degree of visibility, the presence of chronic pain, and the degree of stigma and prejudice directed toward that particular disability are all known to have an effect on the individual's response. Disability scholars recognize that factors in the environment have an important impact on the individual's response to the disability. Of course, most PWDs think of the disability as a personal attribute, not as a tragic problem. For many PWDs, the disability is not the single most important self-identifier. Furthermore, the only shared identity is the prejudice and discrimination PWDs experience. Other than this devalued position in society, it is safe to state that there is no single disability experience.

There are many blogs and YouTube sources that show PWDs relating their experiences and viewpoints and allowing viewers to see PWDs in many different settings: in their homes, in hospitals, at work, with their friends, or in school. Some of these videos follow a PWD for a long period of time, providing viewers with a long-term perspective of a disability. In other videos, family members, friends, and professional caregivers, in addition to the PWD, discuss their responses to the PWD and the disability. This provides a multifaceted picture of the disability experience. Some videos show historical scenes of hospitals and institutions that have been closed for decades, and two videos show the institutions in Nazi Germany where PWDs were murdered. In other videos, major players in the Disability Rights Movement recount their experiences and the difficulties in obtaining basic civil rights for Americans with disabilities. It is my hope that this book will provide the foundation and background for viewing these videos; moreover, it is clear that these videos will add richness, detail, and immediacy in understanding disabilities and the people who experience them. Sources include the magazine *Ragged Edge* (<http://raggededgemagazine.com>) and many others. The *Ragged Edge* blog consists of PWDs discussing their experiences with prejudice and discrimination and presents current disability rights information. In contrast, the second website is an academic, research-oriented journal, *Disability Studies Quarterly* (<http://dsq-sds.org/>), which provides articles on international disability law and policy.

As a society, we are increasingly understanding the pervasiveness, significance, and value of the disability experience. I hope that this book will lend support to a transformation of the way in which we view ourselves.