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978-1-107-00047-6 - People with Disabilities: Sidelined or Mainstreamed?

Lisa Schur, Douglas Kruse and Peter Blanck

Excerpt

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Introduction

A. CHANGING VIEWS OF DISABILITY

People with disabilities have a long history of exclusion. In Babylon and ancient Greece, for example, children born with disabilities were often considered portents of evil or signs that their parents had displeased the gods, and infanticide was practiced against babies with congenital impairments in ancient Athens and Sparta (Rimmerman 2013: 13). In Europe in the Middle Ages, disabilities were often viewed as caused by the devil or demons, or as a punishment from God – a belief shared by early Puritans in America (Braddock and Parish 2001: 15, 17, 25).

People with disabilities have also been considered sources of ridicule and entertainment. For example, people of short stature were used as court jesters in ancient China and in the palaces of pharaohs in ancient Egypt. Slaves of short stature and slaves with intellectual disabilities were “kept” as fools by the wealthy during the Roman Empire and in Europe during the Middle Ages, while people with obvious physical or intellectual disabilities were frequently displayed as “monsters” in markets for profit during the Middle Ages and later in “freak shows” during the nineteenth and early twentieth centuries (Braddock and Parish 2001: 16; Chemers 2006; Bogdan 2009).

Along with provoking fear and providing entertainment, people with disabilities have often been subjects of pity and charity; for

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example, while some passages in the Old Testament portray disability as caused by divine retribution, other passages contain admonitions to be kind to people with disabilities (Rimmerman 2013: 11–12), and in ancient Athens (despite the practice of infanticide against babies with congenital disabilities) food was provided to people who developed disabilities and demonstrated economic need and the inability to work (Braddock and Parish 2001: 14, 16). Charity helped motivate the construction of early residential institutions for people with disabilities in the Arab world and Europe in the Middle Ages, such as hospices and schools for blind and deaf people (Braddock and Parish 2001: 17, 19–20; Hudson 2006: 855). However, the tremendous growth of mental asylums and other residential institutions in Europe and the United States in the eighteenth and nineteenth centuries often resulted in abusive and overcrowded conditions, and was fed by a desire to avoid people with disabilities and segregate them from mainstream society. Exclusion increased with the eugenics movement in the late 1800s and early 1900s. During this period people with disabilities were often portrayed as social deviants and menaces to society; many were prohibited from getting married and were sterilized (Trent 2006: 1501; Carey 2009: 52–82; Rimmerman 2013: 18–19). This movement reached its most extreme form in Nazi Germany in the 1930s and 1940s when more than seventy thousand people with disabilities were murdered (Shakespeare 2006: 1136).

Along with this medley of responses – fear, ridicule, pity, avoidance, and loathing – people with disabilities have sometimes been treated with great respect or even exalted. In some ancient Arab societies, mental disabilities were sometimes seen as divinely inspired, while some ancient Chinese texts claimed that people with disabilities were more likely than others to reach spiritual transcendence, and there are thousand-year-old records in Korea of blind people being viewed as having supernatural power (Braddock and Parish 2001: 16; Kim 2006: 859). Soldiers with disabilities caused by war injuries have

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been honored and given pensions in many societies, dating back to ancient Greece (D. Cohen 2006). Nevertheless, throughout history people with disabilities have been much more likely to experience stigma and exclusion.

Over the past forty years, there has been a widespread shift in attitudes and policies toward people with disabilities, driven by the rise of the disability rights movement (Shapiro 1993; Scotch 2001; Barnartt and Scotch 2001; Blanck 2004; Longmore 2009; Nielsen 2012). This movement has fought for equal rights and full access and inclusion of people with disabilities around the world. It has led to the development of the “social model” of disability (reviewed later in the chapter) and the idea that the obstacles faced by people with disabilities are caused largely by society, not by individual impairments.

This widespread shift has resulted in the adoption of important legislation and policy initiatives. A number of countries have enacted civil rights protections for people with disabilities, such as the 1990 Americans with Disabilities Act in the United States, the 1990 Law of the People’s Republic of China on the Protection of Disabled Persons, the 1992 Disability Discrimination Act in Australia, the 1995 Disability Discrimination Act in the United Kingdom, the 1998 Employment Equity Act in South Africa, and the 1998 Equal Rights for People with Disabilities Law in Israel. An important initiative took place in 2006 when the United Nations adopted the UN Convention on the Rights of Persons with Disabilities, which has now been signed by 153 countries. Legislative protections and initiatives will be discussed in Chapter 4.

The growth of the disability rights movement, and the passage of civil rights laws and the UN Convention, promote a new approach to disability – one based on rights, dignity, respect, and participation, rather than fear, pity, and exclusion. The question remains, however, to what extent these efforts have resulted in the full inclusion of people with disabilities in mainstream society. What are the current trends and prospects for greater inclusion?

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B. PLAN OF THE BOOK

The broad purpose of this book is to provide an overview of the economic, political, and social conditions of people with disabilities around the world and to discuss the barriers to and opportunities for greater inclusion that they face. We analyze a wide range of evidence from across the social sciences, including economics, political science, psychology, disability studies, law, and sociology. The disability literature has increased greatly in the past few decades – there are now literally thousands of publications; clearly, we cannot provide a comprehensive review of the entire vast literature. We have nonetheless searched widely for the important publications and evidence in this area, and will also present new findings from our analysis of U.S. datasets and interviews, in order to make the assessment as full and up to date as possible.

In the remainder of Chapter 1 we consider how to conceptualize disability by discussing the major models: “medical,” “social,” and “universalist.” We then review the thorny issues involved in measuring disability, along with recent estimates indicating that about one-sixth of the world’s population have disabilities.

Chapter 2 assesses the economic status of people with disabilities, focusing on their generally low income and employment levels and high poverty rates. We discuss the reasons for their low employment rates, distinguishing between factors that affect labor supply (the willingness of people to participate in the labor market) and those that affect labor demand (employers’ willingness to offer jobs to people with disabilities). We end the chapter by looking at the bad news and good news in current labor market trends that affect the prospects for increased employment among people with disabilities.

Chapter 3 delves more deeply into the critical area of employment. We first explore the issue of alternative work arrangements, including the growing use of technology for telecommuting and work-related online education and training, along with part-time, temporary, and flexible schedules that better meet the needs of many people with

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disabilities, but also have certain drawbacks. We then review evidence on pay, job characteristics, and worker attitudes, documenting a number of areas where workers with disabilities fare worse than do otherwise similar workers without disabilities. We discuss theories that help explain these disparities, including models of discrimination. This leads to a discussion of how corporate culture may shape policies and attitudes that affect experiences and opportunities for job applicants and employees with disabilities. The chapter concludes with a review of workplace accommodations and a discussion of policies that may promote better employment outcomes for people with disabilities.

In Chapter 4 we turn to political inclusion. We first examine the factors underlying disability activism, and then explore voter turnout and political participation in general among people with disabilities. We conclude by reviewing evidence on political interest and views of people with disabilities, providing insights into how their greater political participation might affect the formation of public policies.

Chapter 5 focuses on social inclusion among people with disabilities, starting with factors that are linked to isolation – stigma, institutionalization, low marriage rates, higher likelihoods of living alone, and transportation difficulties. We then review the value of computer and Internet access and the lower levels of access to these technologies among people with disabilities. Looking more broadly at technology and the physical environment, we discuss the value of universal design, which can increase the accessibility of buildings, products, and services for people of all abilities. Finally, we turn to the important topic of education, documenting the generally lower educational levels among people with disabilities, the strong benefits education can provide, and efforts to create more inclusive educational programs.

In Chapter 6 we explore how the experience of disability may differ by gender, race, and ethnicity. For example, disability status may combine with gender or minority status to create a “double handicap” or even “triple handicap,” leading to especially negative outcomes for women and members of disadvantaged minority groups. This includes

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a discussion of how disability may interact with traditional gender expectations in many societies and how it may create greater obstacles for members of disadvantaged racial and ethnic minority groups, who already face barriers and disparities related to stigma and prejudice.

Finally, in Chapter 7 we provide an overview of the progress and prospects for the full inclusion of people with disabilities. We do so, first, by reviewing the key points from the evidence in Chapters 1–6 along with an overview of implementation of the UN Convention and, second, by providing views from the disability community with a focus on 21 original interviews with disability leaders and scholars from the United States and the United Kingdom. The results from the qualitative interviews complement the findings from other studies and provide valuable perspectives on how people with disabilities may gain greater inclusion in the coming decades.

A note on language: there is a debate in the disability community over whether it is preferable to use the term “disabled” or to use “person-first” language. An argument for “person-first” language (saying “persons with disabilities” instead of “disabled people”) is that it makes it clear that disability may be an aspect of a person’s identity without being the defining trait, characteristic, or status (e.g., Perske 1988; Blaska 1993; Kailes 1985; Lynch et al. 1994). In this view, using the word “disabled” or placing the name of the medical condition before the word “person” or “people” places undue weight on people’s specific impairments and detracts from their humanity. As Joan Blaska writes:

The philosophy of using person first language demonstrates respect for people with disabilities by referring to them first as individuals, and then referring to their disability when it is needed. This philosophy demonstrates respect by emphasizing what people can do by focusing on their ability rather than their disability and by distinguishing the person from the disability. (Blaska 1993: 27)

This approach was developed in the 1970s and adopted by the Association for Persons with Severe Handicaps (Manus 1975; Bailey

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1991). Since that time, many disability groups and advocacy organizations have attempted to educate the public regarding person-first language, and some academic journals and organizations (such as the American Psychological Association) now require person-first language in their publications (Olkin 2002). The UN Convention on the Rights of Persons with Disabilities uses this approach.

An opposing view is that person-first language creates the impression that disability is an individual property of a person rather than the creation of external societal factors that “disable” a person: “The British civil rights movement has rejected the term ‘people with disabilities’, as it implies that the disabling effect rests within the individual person rather than from society” (Clark and Marsh 2002). This distinction between the individual property of impairment and the social property of disability is central to the social model. The term “disabled people” is also widely used by international organizations such as Disabled Peoples’ International.

Some people and groups have rejected person-first language for deafness, blindness, and autism. Those who identify with Deaf culture, for example, largely reject person-first language, along with the terms “disabled” and “disability”, since Deaf people (with a capital “D”) see themselves as a linguistic minority and being Deaf as a source of identity and pride (Clark and Marsh 2002; Padden and Humphries 2006). Vaughn, a scholar and advocate for the blind, maintains that person-first language may call “attention to a person as having some type of ‘marred identity’” (Vaughn 2009), while Sinclair argues that saying “person with autism” creates an overly negative view of autism and suggests that the person can be separated from the condition.¹

¹ autismmythbusters.com/general-public/autistic-vs-people-with-autism/jim-sinclair-why-i-dislike-person-first-language/ (accessed May 3, 2012). The U.S. National Federation for the Blind passed a resolution in 1993 dismissing the idea that “person” must come before “blind,” saying that it is “overly defensive” and “implies shame instead of true equality.” nfb.org/images/nfb/publications/bm/bm09/bm0903/bm090308.htm (accessed May 3, 2012).

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We recognize that person-first language is not universally accepted and agree with many of the points of those who question or reject it. In this book, we describe many ways in which people with impairments become “disabled” by inaccessible environments and negative attitudes. Nevertheless, we have to choose consistent terminology for use throughout this book, and as U.S. scholars we will follow the current and predominant convention in the U.S. disability community by using person-first language – emphasizing that disability is not the defining aspect but only part of an individual’s identity. The language debate has been divisive in the past, which disability advocate Irving Zola has said may not only “damage the unity so necessary to the cause of disability rights but also fail to see the forest for the trees. Our struggle is necessary because we live in a society which devalues, discriminates against and disparages people with disabilities” (Zola 1993: 171). We hope that our use of person-first language will not distract anyone reading our presentation and analysis of evidence on ways to increase the societal inclusion of people with disabilities.

C. MODELS OF DISABILITY

What do we mean by “disability”? How do we understand the complex relationship between individual impairments and environments? Three basic models have addressed these questions.²

² While there are clear distinctions among these models, they are not necessarily mutually exclusive. As will be seen, the World Health Organization proposes a “bio-psycho-social” model that combines elements of the medical and social models. Different government policies can reflect different models; for example, determination of disability benefits may rely on the medical model, while antidiscrimination laws may reflect the social model. A single law or policy can also contain elements of several models; for example, a person can be considered to have a disability under the Americans with Disabilities Act based on a physical or mental impairment (the medical model) or on how one is regarded by others (the social model).

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1. Medical Model

The traditional view of disability is based on the medical model, which focuses on functional impairments and health conditions. According to the medical model, disability is located within individuals and has little or no relation to the environment. The emphasis is on cure, without explicit awareness that many problems faced by people with disabilities are caused by social factors such as discrimination. The medical model is consistent with the value of individualism – it is up to the individual with a disability to “overcome” disability through hard work, determination, and a “positive attitude.” This is reflected in many books, news stories, movies, and television programs in which people with disabilities heroically overcome adversity and self-pity and eventually show the “triumph of the human spirit” over their disabilities (Shapiro 1993).

2. Social Model

The disability rights movement has developed, and been largely based on, the social model, which views disability as caused by society.³ People with disabilities are considered a distinct minority group with a shared experience of oppression. A defining statement of this model was articulated in 1976 by a British group called the Union of the Physically Impaired Against Segregation (UPIAS):

In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. (Quoted in Barnes and Mercer 2010: 31)

³ For a more detailed description of the social model, see Barnes and Mercer (2010: 29–36).

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A key aspect of the social model is the distinction made between “impairment,” which is an aspect of an individual, and “disability,” which is caused by social arrangements and thus subject to change through political means. Disability is not located within the individual (as maintained by the medical model), but in the interaction between an individual and his or her environment. According to this model, impairment alone is not disabling. Society creates disabilities by isolating, excluding, and stigmatizing people who have physical or mental impairments. For example, not being able to enter a building or not being able to enter it through the main entrance (e.g., through a back door) sends the message that people with disabilities are second-class citizens.

For advocates of the social model, the distinction between impairment and disability is fundamental because it identifies the source of discrimination and stigma, and reveals the appropriate targets for political action. Two strengths of the social model are that it identifies a political strategy – barrier removal – and helps empower people with disabilities by replacing a traditional focus on individual deficits with an understanding of social oppression (Shakespeare 2006: 30). The social model has been central to the development of the disability rights movement and has motivated generations of activists around the world:

It is about the victim refusing the label, and instead focusing attention on the structural causes of victimization. It is about the subversion of stigma: taking a negative appellation and converting it into a badge of pride. (Shakespeare 1993: 253).

Using the social model, stigmatized and powerless people can transform the negative identity attached to disability and claim it in a positive way to challenge traditional power relations:

Self-organization and direct action challenge prevailing stereotypes of powerlessness and objectification. This is important in the formation of disabled people’s own identity, just as it is in breaking