

ABLEISM

Introduction

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WHAT IS A DISABILITY?

The Americans with Disabilities Act (ADA, 1990, amended 2008) considers a person to have a disability if she or he has a significant impairment that interferes with a major life activity, such as walking, seeing, hearing, learning, speaking, breathing, standing, lifting, or caring for one's self. The ADA covers both physical and mental impairments, such as mental retardation, orthopedic, hearing, visual, speech, or language impairments, emotional disabilities, learning disabilities, autism, traumatic brain injury, attention deficit disorder, depression, mental illnesses (such as bipolar disorder or schizophrenia), environmental illnesses, and chronic illnesses, such as diabetes, HIV/AIDS, cancer, and epilepsy. Disabilities are wide-ranging and impact the lives of many people worldwide. Approximately 10 percent of the world's population or 650 million people live with a disability and constitute the world's largest minority (United Nations Enable, n.d.). We must, however, understand the broadest sense of the word disability by expanding beyond the image of someone in a wheelchair or a person with a visual or hearing impairment in order to recognize that disability is a vast category; a category that includes an infinite number of possible experiences and realities that may or may not be visible to others.

ABLEISM AND DISABILITY OPPRESSION

Ableism or disability oppression is a term used to describe the all-encompassing system of discrimination and exclusion of people living with disabilities. Similar to other forms of oppression discussed in this book, ableism functions on individual, institutional, and cultural levels to advantage people who are temporarily able-bodied and disadvantage people with disabilities (Griffin, Peters, and Smith, 2007; see selection 4). We use the term *temporarily able-bodied* to raise consciousness that people who do not have disabilities may become disabled by illness, the process of growing older, accidents, and war, for example. Disability oppression also addresses how we as a society value "productivity" (Wendell, 1996). Economic productivity is a highly

valued standard in the United States, and this emphasis contributes to our undervaluing other social and material contributions while perpetuating socially constructed ideas about disability, dependence, and independence.

HISTORICAL TREATMENT OF PEOPLE WITH DISABILITIES

Historically, disability was perceived through a religious lens and considered an unchangeable condition that resulted from sin (Covey, 1998). In Western societies infants with disabilities were dropped off balconies to their death; children with disabilities were abandoned and left to live on the streets where they had no choice but to beg for food and money to survive (Wood, 1998). The term *handicapped* emerged in England from people with disabilities who used their cap in hand on street corners to plead for money. Many people with disabilities were placed in jails or asylums where they endured inhumane treatment. By the early eighteenth century, people with disabilities were seen as freaks, monsters, and less than human. In Europe and the United States, curiosity about people with severe disabilities made “freak shows” a very popular form of entertainment. Paradoxically, “freak shows” became one of the few viable ways for people with disabilities to earn a living (Vogtan, 1988).

In Western societies, as scientific and medical fields became more powerful, their guidelines began to shape the ways in which disability was perceived and understood. Early Western medical textbooks classified people with disabilities as genetically defective. The medicalization of disability fostered the belief that people with disabilities needed to be monitored and controlled by licensed physicians and medical specialists with authoritarian powers. The medical goal was to “cure” the disability, get rid of a deformity, fix the body, and/or numb the existing pain of the person who was described as the patient. This thinking and methodology resulted in solutions that were invasive usually by surgery or drugs, and which required submission from the person with a disability. The view that disabilities are deficiencies that require medical treatment and repair remains pervasive today.

During the 1880s and 1890s, people with “mental retardation,” as well as people who spoke English as a second language, were considered disabled or defective in the United States. For example, “medical imbecility” was attributed to people with mental retardation, as well as to paupers, prostitutes, immigrants, and others unable to express themselves in English (Longmore and Umanski, 2001). The power of the early-nineteenth-century Eugenics movement spurred policies to segregate and sterilize people considered to be hopelessly unredeemable because of their disabilities. “Eugenics” as a movement was coined in 1883 in England by Sir Francis Galton, a cousin of Charles Darwin. *Eugenics* is derived from the Greek word meaning “well born” or “of good origins or breeding,” and it became the “science” of supposedly improving qualities of a so-called “race” by controlling human breeding. Eugenics at its most extreme became the “scientific” rationale for Germany’s genocidal policies during World War II in which thousands of people with mental or physical disabilities (Gallagher, 1995) (as well as members of supposed “lower races,” for example Jews, Poles, and other groups, such as homosexuals) were shot, gassed, or left to starve to death.

Veterans returning with disabilities from World War II spurred medical fields to focus on rehabilitation and the development of devices to help soldiers return to work and live productive lives, rather than be restricted to hospitals or asylums. Although a new focus on rehabilitation emerged, many people with disabilities continued to be segregated and treated as patients who needed supervision and care from others who “knew best.” In the 1960s and 1970s, a social movement among people with disabilities and allies began to emerge, leading to the Independent Living Movement. On the heels of other civil rights and justice movements, disability activists organized and powerfully fought for their civil rights. This struggle resulted in the passage of Section 504 of the Rehabilitation Act of 1973, the Education for all Handicapped Children Act (PL 94-142) of 1975, Americans with Disabilities Act (ADA) 1990, Individuals with Disabilities Education Act (IDEA) 1990, 1997, and Individuals with Disabilities Education Improvement Act (IDEIA) 2004, all significant feats protecting the rights of people with disabilities.

On September 25, 2008, the ADA was amended, thereby expanding the definition of disability. The new regulation better defines the term "substantially limits" and expands the definition of "major life activities." For example, learning, reading, concentrating, thinking, communicating, and working are now recognized as major life activities. Also added to the law are major bodily functions, such as functions of the immune system. The amended ADA further states that conditions that are episodic or in remission may be labeled as disabilities when the active impairment can substantially limit a major life activity.

CURRENT ISSUES IN DISABILITY DISCOURSE

Many of the current issues presented here have been ongoing issues for years, but they have not received the amount of attention or debate that we are presently seeing. These issues include, but are not limited to, attention deficit hyperactivity disorder (ADHD) diagnosis and treatment for children and adults; traumatic brain injury (TBI) and post-traumatic stress disorder (PTSD) diagnosis and treatment for our veterans of war; and the disproportionality of students of color placed in special education programs. Newer developments include the controversial elimination of Asperger's syndrome from the *Diagnostic and Statistical Manual of Mental Disorders* (DSM; APA, 1994) and the inclusion of students with intellectual disabilities at some institutions of higher education.

Present debates relate to whether ADHD is a socially constructed disorder or a valid neurobiological disorder and whether youth are being overdiagnosed and unnecessarily medicated. While there is overwhelming scientific evidence to support that ADHD is a valid neurobiological disorder (National Institute of Health, 2002), research examining the possibility of overdiagnosis and overprescription of drug therapies presents inconclusive and conflicting information. The DSM outlines specific criteria for diagnosing ADHD, which includes a constellation of symptoms, such as inattentiveness, impulsivity, and hyperactivity with evidence of a clinically significant impairment in social, educational, or occupational performance. While there are set criteria for diagnosing ADHD, the consistency or lack of consistency across psychologists, psychiatrists, and other licensed clinicians is raising concern.

Discussions regarding PTSD and TBI are being brought to our attention as significant numbers of veterans of war have returned with PTSD and mild-to-severe TBIs. During World War I, veterans returning from war were diagnosed with "shell shock" including uncontrollable shaking, reoccurring nightmares, and imagined re-enactments of the horrific events. Today, these symptoms along with others are categorized as PTSD. Well over 1.5 million service personnel were deployed to Iraq and Afghanistan beginning in 2002 (Karney, Ramchand, Osilla, Calderone, and Burns, 2008), and PTSD is currently one of the enduring and invisible effects of the war. Veterans with PTSD are among the unnoticeably wounded. Veterans' hospitals and medical facilities around the nation are encountering staggering number of veterans who are not always able to get the full treatment they need to navigate the changed world. With a single trauma, PTSD generally lasts from three to five years (Kessler, Sonnega, Bromet, Hughes, and Nelson, 1995), although many experience multiple traumas in life, and a typical person with PTSD may experience symptoms that last more than twenty years (Breslau, Kessler, Chilcoat, Schultz, Davis, and Andreski, 1998; Kessler, 2000).

Related to the invisible and distressing consequences of war is traumatic brain injury (TBI). TBIs can result from any type of injury to the brain that causes it to swell, such as artillery fire, car crashes, explosions, and any non-war-related incidents, such as sports incidents. The manifestations of TBI include impaired cognition, sensory processing, communication, and mental health, and/or personality changes (National Institute of Neurological Disorders and Stroke, 2009). Although the incidence of TBI among veterans is on the rise, actual statistics are still unknown.

Another pressing issue within disability discourse brings our attention to the overrepresentation of students of color in special education. Since the 1960s, racial bias, cross-cultural misunderstanding, assessment bias, and teacher referral processes have contributed to the

overrepresentation of racial and ethnic minorities in special education (Dunn, 1968; Ford and Moore, III, 2004; Harry and Klingner, 2006, 2007; Losen and Orfield, 2002; Skiba, Simmons, Ritter, Raush, Cuadrado, Chung, 2008). In 2002, Donovan and Cross reported that African American students in particular are over two times more likely than white students to be labeled as mentally retarded. Recent research also points out that English language learners are similarly being disproportionately placed in special education programs (Harry and Klingner, 2006; Shepherd, Linn, and Brown, 2005). According to the U.S. Department of Education, in the late 1990s, only 25.5 percent of students with disabilities graduated with a standard diploma (U.S. Department of Education, 2000). Rendering a solution to this significant issue requires education reform that will minimally include overhauling educational processes and organizational structures, and stressing effective teacher preparation and professional development in multicultural education.

An additional matter in the arena of disability issues is that of autism and Asperger's syndrome. Autism and autism spectrum disorders (ASD) are complex developmental disabilities characterized by difficulties communicating and interacting with others and by restricted and repetitive thoughts and behaviors. Asperger's syndrome (AS), a mild form of autism, is described by symptoms such as repetitive routines or rituals, little or no eye contact, peculiarities in speech and language, difficulties interacting socially with peers, problems with non-verbal communication, and unusual facial expressions or postures. Colleges have seen an increase in the number of students with autism spectrum disorders and Asperger's syndrome and as such administrators and faculty are engaging in conversations about how to better support the social and academic success of this population. Meanwhile, the forthcoming American Psychiatric Association's DSM-V will eliminate Asperger's syndrome and instead include revised criterion for diagnosing autism spectrum disorders. This decision is causing a great stir, especially for many with Asperger's syndrome who express having developed a sense of pride, support, and community in relationship to their Asperger's diagnosis.

Another important topic receiving greater attention is the steadily growing number of students with intellectual disabilities attending programs at institutions of higher education. Intellectual disabilities are defined by significant limitations in intellectual and cognitive functioning and in adaptive behaviors required for everyday functioning. While students with intellectual disabilities have been historically excluded from higher education, college programs are providing an opportunity for such students to continue their academics, to socialize, to build career and technical skills, and to prepare for gainful employment. To date there are 110 officially registered college programs for students with intellectual disabilities across 28 states (CTC, 2012).

UNIVERSAL ARCHITECTURAL AND INSTRUCTIONAL DESIGN

Advocates for people with disabilities have called for an adaptation of architectural design, as well as instructional changes to curriculum and pedagogy, which will allow access for all people (Pliner and Johnson in selection 97). Universal Architectural Design (UAD) incorporates ramps, Braille signage, wider hallways and doorways, lower/adjustable desks and fixtures, and easy access door openers. The same principle of access for everyone is applied in Universal Instructional Design (UID). Both UAD and UID benefit all people with and without disabilities.

GLOBAL ISSUES

The global population of people with disabilities is growing because of aging, ethnic and sectarian violence, war, poverty, and the contamination of the environment (Harrison, 2004). It is estimated that there are 600 million people with disabilities in today's world. Many countries are passing

laws that recognize the rights of people with disabilities. Great Britain and Austria adopted the Disability Discrimination Act of 1995, while countries such as South Africa, Malawi, Uganda, the Philippines, Finland, Brazil, Austria, and Germany have adopted statutes that prohibit discrimination against people with disabilities (Harrison, 2004).

ABLEISM INTERSECTIONS

The complex social identities people occupy and the social context we live in largely shape how people with disabilities are treated and how one's disability is personally experienced. As people with disabilities represent various races, classes, genders, sexual orientations, ages, and religious backgrounds, people often simultaneously experience intersections with racism, classism, heterosexism, ageism, transgender oppression, religious oppression, and sexism.

The intersection between one's disability and classism is a glaringly important example of how the issues may be intertwined. People with disabilities, particularly low-income and people of color, face many barriers as the costs of health care, assistive technology, and digital hearing aids (to name a few) are often unattainable. This results in some receiving inadequate health care, limited employment opportunities, and significant learning disadvantages while attending school. On the contrary, people with disabilities who are born into families with greater financial means gain significant access to expensive medical treatment and diagnostic testing, assistive technology, personal care attendants, and other necessary resources.

Likewise, the intersection between disability and sexism further demonstrates how our complex identities and societal manifestations of oppression are overlapping. Unlike the current attention focusing on veterans returning from war with PTSD, there continues to be little consideration given to the reality that one out of nine women is diagnosed with PTSD symptoms, most often as a result of experiencing rape, sexual assault, domestic abuse, and/or violence (emedicinehealth.com, 2009). Sexual assault, for example, has wide-reaching effects on women, including an impact on physical and mental health, functionality, issues regarding basic needs, and difficulty reading social cues. With PTSD, a raised hand, a half-open door, a pointed object, or phraseology in a conversation can unconsciously set in motion intense reactions and the re-creation of the original traumatic incident. The continued cultural and institutional silencing of women being disproportionately and violently targeted perpetuates a cycle of abuse against women that is significantly tied to numbers of women being diagnosed with particular disabilities.

READINGS IN THIS SECTION

In this section, we have attempted to create a better understanding of the complexities of disability by including a representation of issues, ideas, and experiences of people with disabilities across multiple social identities. The section in no way represents every aspect of disability history, reform, treatment, and social, educational, or international issues and experiences. Rather, we present an overview of the issues that individuals, instructors, students, and others can refer to in their search for greater understanding and strategies regarding disabilities.

The articles in this section are as varied as the issues regarding disability. We begin our section with Willie Bryan's overview of the disability rights movement (selection 95) as a way of contextualizing the historical issues that were faced and the types of efforts that were led by people with disabilities. Another article that highlights historical developments is Janet Cerney's (selection 96) recounting of historical figures, events, and cultural shifts that have strongly shaped deaf education. Focusing on global issues, we have included two articles that address war and a third on neocolonialism and disabilities. David Grossman's piece (selection 101) shares stunningly

important information about the effects of war on the human body and the significant number of soldiers who become psychiatric casualties. Miguel Cyr (in selection 104 by Edward D. Murphy), an Iraqi veteran, gives a personal account of his struggles with post-traumatic stress disorder, how this invisible disability has impacted relationships with friends and relatives, and his ability to maintain steady employment. Cyr also discusses the difficulty of living with a psychological disorder because of the significant stigma attached to such disorders. On another global front, Nirmala Erevelles's article (selection 102) gives us more insight into how transnational capitalism and (neo)colonial institutions and policies have influenced the social construction of disability in Third World contexts and have particularly impacted the lives of Third World women.

Discussions on disability and hate crimes are often omitted by the media, and Lennard Davis (selection 99) draws our attention to this omission. Davis uses the lack of news coverage of a hate crime in which the murdered victim, James Byrd, is described only by his race, ignoring the fact that he was also a person with a disability. Davis asks that we deconstruct hierarchies of oppression by acknowledging intersections and the multiple identities that are targeted by oppression. Further, drawing upon intersections, Sumi Colligan's article (selection 100) explores the parallels between the cultural representations and everyday struggles of intersexed persons and people with disabilities with a particular focus on the medicalization of intersexed/disabled bodies and the construction of asexuality.

The personal narratives included in this section provide a glimpse into the many ways that people with disabilities, who live across multiple social identities, experience issues of oppression and liberation. Eli Clare's personal narrative (selection 103) about society's dehumanizing actions and reactions toward people with disabilities elicits the urgent need for better role models, heroes, and allies. As a genderqueer person with a physical disability, Clare describes the common use of demeaning language and belittling stares that play a significant role in the perpetuation of ableism and transgender oppression. In another personal account (selection 105), Jess Watsky describes both the relief and struggle of understanding her diagnosis of Asperger's syndrome in the article, "On the Spectrum, Looking Out." After learning how to navigate the world of academia and other life situations, Watsky shares that the very medical reference she's used to understand her life and make great strides is being eliminated from the DSM-V. Watsky's compelling story sheds light on how this change might have an enormous impact on her life and her ability to access suitable accommodations.

Another account of a child growing up with a disability is provided by Ashley and Deborah's story (selection 106) in "How to Curse in Sign Language." The article describes a mother and daughter's struggle for educational rights in the public school system, and acceptance with a religious institution and society in general. Jason Kingsley (selection 107) reflects on what he would tell parents and doctors about being born with Down syndrome. He reminds them not to set limitations on people with Down syndrome and their ability to learn, and to have relationships and participate in all kinds of life activities. In "In the LD Bubble," Lynn Pelkey (selection 108) shares her elementary and secondary public school experience in special education classrooms for students with learning disabilities. Her narrative describes her feelings of isolation and the hurtful effects this had on her self-esteem and her connection to her peers. Her message is one of overcoming institutionalized ableism and making progress in the college context.

The final part offers multiple ways to address the prejudice and discrimination toward people with disabilities on the individual, cultural, and institutional levels. Thomas Hehir (selection 109) opens this part by offering four suggestions to address ableist practices. Hehir asserts that we must challenge ableist assumptions in education that contribute to lower levels of success in educational pursuits and gainful employment. Also included in this section is an article by Heather Oesterreich and Michelle Knight (selection 110) that examines how the intersections of race, class, language, and disability inform the responsibilities of special educators to help students with disabilities. The overrepresentation of working-class students of African, Latino/a, and Native American heritages in special education have been a long-standing part of special education reform. Oesterreich and Knight provide "teacher tips" to educators in order to increase

the social and cultural capital of students with disabilities to support their prospective college-going and vocational identities. The authors are proponents of Universal Instructional Design, including use of assistive technology to meet the needs of particular students. Susan Pliner and Julia Johnson's article (selection 97) outlines the core principles and concepts of Universal Instructional Design necessary for achieving accessibility and inclusion in institutions of higher education. Critical for understanding how social conditions affect disability, Susan Wendell's article (selection 98) explores the physical, social, and cultural environments that cause disability.

Cheryl Howland and Eva Gibavic's article (selection 111) presents a learning disability identity development model that incorporates a discussion of several influential variables from dual diagnosis to support systems. Overall, this model helps individuals come to a greater understanding of the complex stages people with learning disabilities might encounter. Also included are additional influences of other identity development models, such as gender, race, and moral identity development. In "Creating a Fragrance-Free Zone" (selection 112), the Invisible Disabilities Advocate alerts us to the growing environmental illness identified as multiple chemical sensitivity. This article provides concrete practices that can be incorporated individually and institutionally to create safe and comfortable environments for all people. Finally, Madeline L. Peters, Carmelita (Rosie) Castañeda, Larissa E. Hopkins, and Aquila McCants (selection 113) provide examples of beliefs and practices that are ableist on individual, cultural, and institutional levels, followed by the actions people can take to eliminate these discriminatory practices and act as unified allies. For additional information on disabilities please refer to our section website.

See Companion Website for Additional Resources and Material

Note

- 1 We ask that those who cite this work always acknowledge by name both of the authors listed rather than only citing the first author or using "et al." to indicate coauthors. Both collaborated equitably on the conceptualization, development, and writing of this section.

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