After the ADA: The Salience of Stigma in the Lives of People with Disabilities

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People with disabilities comprise about 12% or more of the population in the United States, depending on which conditions disability is defined as to include (Annual Disability Statistics Compendium, 2010). They are one of the largest minority groups in the country. People with disabilities can be of any gender, race, ethnicity, religion, or sexual orientation, and due to injury or old age, the majority of us will experience disability at some point in our lives. Yet there is a stunning lack of awareness about this community's history and important issues that currently affect them. Like other minority groups, people with disabilities have come together to demand equal rights. And like other minority groups, they continue to battle a significant degree of social marginalization and stigma. In the first section of this paper, it is my goal to increase our understanding of people with disabilities as agents of social change. I will examine significant milestones in the Disability Rights Movement, including the development of the Independent Living model, the passage of Section 504 of the Rehabilitation Act of 1973, and a number of important protests and demonstrations, culminating in adoption of the Americans with Disabilities Act (ADA). In the second section, I will move to a detailed overview of how stigma continues to present significant barriers to the full inclusion of people with disabilities in society, despite the impressive civil rights they were able to secure through the ADA. Overall, I argue that it is social attitudes, misperceptions, and stigma that currently present the most fundamental challenge for people with disabilities and their efforts to achieve social equality.
Part One: History of the Disability Rights Movement in the United States

"The reason that people with disabilities are often thought to have had no history is really that they've had no recorded history. [...] It's been partly because society has denied that there was anything important to be learned. It was partly because, as with any minority group, the people were so of the Other that they were never given any of the tools to record any aspects of their history [...] So, people with disabilities have followed the paths of people of color, and women, of trying to reclaim what has long been lost." – Irving Zola

The Disability Rights Movement is rarely discussed as a part of American history, and yet it has brought life-changing benefits to millions of citizens. Activists led marches, coordinated government sit-ins, and invoked mass arrests. Parents demanded an end to segregated education for their children with disabilities. During the 1960s, some people even stole away in the middle of the night to chisel ramps into sidewalks (Shapiro 1993). Ultimately, the Disability Rights Movement led to major legal victories, such as the Americans with Disabilities Act (ADA), and began a shift in societal attitudes toward people with disabilities.

Before the Disability Rights Movement gained momentum, disabilities were often regarded as an affliction from God (National Public Radio 1998). People with disabilities were objects of pity, and charitable donations to institutions, where the majority were forced to live, were often used as a way to express religious faith. Children's stories introduced stereotypes about people with disabilities to Americans at a young age by portraying them as either objects of pity or brave and courageous for summoning the will to live in such circumstances (see Figure 1).

People with disabilities were also viewed as a threat, pushed to the margins of society to live in institutions where they routinely faced abuse and neglect such as forced sterilization, robbery, rape, and other forms of assault (Smart 2009, Shapiro 1993). During the late 1800s and early 1900s, the eugenics movement led to the legalized sterilization of thousands of institutionalized people with cognitive and
physical disabilities. Eugenics proponents also passed legislation which prohibited marriage among people with certain psychiatric disabilities, including those with schizophrenia, bipolar disorder, and depression (Pfeiffer 1993). In its most extreme form, these kinds of negative societal attitudes towards people with disabilities laid the foundation for the targeting of the disabled community by Nazi exterminators during World War II (Smart 2009).

At the same time that eugenicists were arguing for a society free of people with disabilities, factors such as World War I, World War II, and diseases such as the polio outbreak increased the population of individuals with disabilities in the United States. Major medical advances facilitated this population growth by making it possible for people to survive injuries that would have otherwise been fatal. For example, veterans of World War I and II were far more likely to return home paralyzed than their Civil War counterparts, who often died of their battle injuries. (Smart 2009, Shapiro 1993)

Successful medical advances led to a proliferation of charitable organizations which sought to raise funds to cure specific diseases. The March of Dimes, originally founded by President Franklin Delano Roosevelt in 1938 to eradicate polio, is one example (National Public Radio 1998). Other organizations were created by parents who sought to pool their resources and keep their children out of institutions, such as the United Cerebral Palsy Association founded in 1948 and the Muscular Dystrophy Association founded in 1950 (Shapiro 1993). These organizations played a unique and important role in shaping perceptions of people with disabilities through advertising and fundraising efforts. In their early decades, unfortunately, the images they presented were mostly negative (see Figure 2).
Cindi Jones, publisher and editor of the disability magazine *Mainstream*, was a poster child for March of Dimes in 1956 (Shapiro 1993). She was five years old and used crutches due to polio. During a telethon, she was made to walk across the stage and purposefully drop her crutches so that she would fall down after taking a few steps. The following year, Jones' first grade teacher distributed a flyer encouraging parents to vaccinate their children. It featured a picture of a young boy and girl skipping through a field with the caption "THIS," next to a picture of Jones' using her crutches with the caption "NOT THIS." Not only was this a psychologically scarring experience for Jones, it also shows how heart-wrenching, pitiable, even fearful images of people with disabilities were deliberately manufactured for public consumption. Such images were often assumed to be accurate by many who had little personal contact with people with disabilities.

Challenging the kinds of stereotypes that these charities helped perpetuate was at the heart of the Disability Rights Movement. Pity leads to lowered expectations, which in turn leads to institutionalization, segregated education, and discrimination in the workplace, with the economic consequence of trapping people with disabilities in poverty. In effect, these attitudes can be more "disabling" than physical and physiological impairments.

The philosophy that people with disabilities can and should integrate into their communities, living, learning, and working among their able-bodied counterparts, gave rise to the Independent Living Movement, a strand of the Disability Rights Movement that can be traced back to a man named Ed Roberts (National Council on Independent Living 2006). Roberts became paralyzed from the neck down as a teenager due to polio. Hospital staff told him he would never go to college, never get married, and never hold a job. In fact, he would do all three, but it was not easy. When he decided to apply to the University of California at Berkeley, he was initially denied financial aid from California's Department of Rehabilitation because they believed his disability was so severe that it was unlikely he would ever be able to work. After convincing them to fund his education, he faced another set of challenges: Berkeley's
admissions officials initially refused to admit him, the campus was inaccessible, and the dormitory floors were not strong enough to support his iron "lung," an 1800 pound contraption which helped people with quadriplegia breathe before portable ventilators were invented. He spent the first years living in the student hospital.

In 1967, while working on his doctoral degree, Roberts and several other students with disabilities formed a group called the "Rolling Quads" (Shapiro 1993). Using government and university funds, the Rolling Quads established the Physically Disabled Students' Program (PDSP) to help students with disabilities remain in school while living independently. Their office researched accessible living space in the community; maintained a list of potential personal assistants and carpoolers; and set up a wheelchair workshop to handle the frequent breakdowns common for wheelchairs of the time. Unlike other universities which had experimented with disability programs, the Rolling Quads' created a novel self-help approach that was ready to serve students with all kinds of disabilities, no matter how severe.

Due to increased demand from nonstudents, in 1972 the first Center for Independent Living (CIL) was opened to provide services to the rest of the community based on PDSP's principles of self-advocacy, equal access, and the right to make independent decisions (CIL of Berkley, California 2010). Roberts directed the CIL for 18 months before he was appointed director of the California Department of Rehabilitation—the very agency which told him he was not worth educating because he would never be able to work! He applied the CIL’s radical principles to his new position: instead of focusing on individuals who were most easily employable, Roberts insisted that every person with a disability deserved resources. His ideas began a transformation of American society and provided a philosophical platform for people with disabilities to assert their rights. Today, there are CILs in rural and urban areas across the United States (National Council on Independent Living 2006).

Several years after the first CIL was established, people with disabilities received their first civil rights legislation: Section 504 of the Rehabilitation Act of 1973 (Pfeiffer 1993, Shapiro 1993). It
prohibited any agency that receives federal funding, including public schools and universities, from discriminating based on disability. This law was largely an afterthought of a routine spending bill, one which hardly anyone noticed until after it was passed, but it would change the lives of people with disabilities. Fearing the financial costs of compliance, the Department of Health, Education, and Welfare (HEW) did not enforce the law immediately, and in 1977 Secretary Joseph Califano summoned a group of lawyers to rewrite the regulations.

Disability activists such as Judy Heumann, founder of the political advocacy group Disabled in Action; Frank Bowe, head of the American Coalition of Citizens with Disabilities; and Ed Roberts coordinated demonstrations and sit-ins at several regional HEW offices across the country to protest the proposed changes, which included exceptions to rules requiring ramps and separate (instead of modified) schools for some children with disabilities. In Washington DC, 300 people took over Califano's office for 28 hours, leaving only after the Secretary refused to allow food in to the building. In San Francisco, however, over 150 protesters remained for 25 days, surviving on food donations from local businesses and organizations (see Figure 3). It was the first time people with disabilities from across the spectrum—cognitive, physical, hearing, and visual—came together on such a massive scale. Cornered, Califano agreed to sign the law unchanged on April 28, 1977. (Shapiro 1993)

The passage of Section 504 gave the Disability Rights Movement a burst of momentum. Parents were now armed with legal protections to gain their children with disabilities access to a mainstream education. Activists with disabilities were organizing around the country. American Disabled for
Accessible Public Transit (ADAPT) was founded in 1983 with the aim to get all city buses equipped with wheelchair lifts. A more militant wing of the Movement, they relied on civil disobedience tactics such as disrupting American Public Transit Association conventions, and members were notorious for getting arrested (ADAPT 2011). The notion of Universal Design also gained wider appeal. Universal design promotes buildings and products that are accessible to people of all abilities (Center for Universal Design 2008). For example, ramped entrances can be used by everyone, unlike stairs. Door handles are easier than doorknobs for people with arthritis and others with limited dexterity.

Furthermore, people with disabilities were challenging social stigma. In 1981, disability activist Evan Kemp sparked controversy when he criticized the Muscular Dystrophy Association's annual Labor Day telethon in the New York Times. "By arousing the public's fear of the handicap itself, the telethon makes viewers more afraid of handicapped people," he wrote. "Playing to pity may raise money, but it also raises walls of fear between the public and us" (Kemp 1981, 19). Some organizations and commentators felt that people with disabilities were ungrateful to complain when many of them had benefited from research funded by these groups. But other organizations listened and began to pair disability advocacy with their fundraising efforts, using more adults in advertising and showing them as successful members of their communities. These progressive approaches paid off. For example, in 1985 Easter Seals raised $23 million; in 1992, after using more sensitive marketing techniques, they were up to $42 million, challenging the notion that the only way to convince people to donate is to capitalize on pity (Shapiro 1993).

Other segments of the disabled community began speaking out as well. The People First movement was a vehicle for individuals with intellectual disabilities (i.e. autism, down syndrome, closed head injuries, etc.) to demand the right to make their own decisions, such as living outside of institutions and nursing homes and working jobs with fair wages (People First of California 2008). And in March 1988, students at Gallaudet University, the most prestigious university for Deaf students in the US, made
national headlines during the Deaf President Now protests (Gallaudet University 2011). For the past century, Gallaudet had been run by hearing presidents. Furious over the Board of Trustees’ decision to appoint another hearing president at the expense of two qualified Deaf candidates, students shut down the school until their demands were met. After eight days of demonstrations, I. King Jordan became the first Deaf President (see Figure 4).

In 1988, the push for a sweeping civil rights bill for people with disabilities in the form of the Americans with Disabilities Act brought many activists together again (Shapiro 1993). The ADA would prohibit discrimination based on disability status in employment, transportation, public accommodations, and telecommunications (Smart 2009; Shapiro 1993). But getting this important legislation passed would be more difficult than other civil rights bills because of the perceived financial costs to businesses. Avoiding discrimination against people with disabilities often required architectural modifications or the provision of assistive technology, whereas avoiding discrimination against other minority groups usually provided economic benefits. Allowing African-Americans to dine in restaurants naturally results in more customers and is therefore arguably good for business. Still, the potential costs of inclusion for people with disabilities were routinely overestimated. Disability lobbyists focused on providing accurate data—for example, a 1982 Department of Labor study found that 30% of accommodations cost only between $100 and $500, far below previous estimates (Shapiro 1993). ADA supporters also pointed out that employing people with disabilities was better than forcing them to live on government welfare funded by taxpayers.

The ADA had several key supporters in Congress, many of whom had close friends or relatives living with disabilities. But disability activists grew impatient with the pace of action on Capitol Hill. While he was Vice President, George HW Bush had indicated that he was supportive of the ADA. But in March 1990, more than a year after his inauguration as president, the bill still hadn't reached his desk.
So activists mobilized, sending over 40,000 letters to the White House and demonstrating regularly. And they staged a major demonstration on the steps of Capitol Hill, with more than 600 participants, most of whom had disabilities. (Although this may not seem like a lot when compared to other major protests, people with disabilities often have fewer resources to travel to protests, especially considering the inaccessibility of much public transportation.) ADAPT’s national director Mike Auberger told the frustrated activists, "Twenty years ago, I walked up these steps a wholly equal American citizen. Today I sit here with you as less than second class citizens who are still legally discriminated against daily" (qtd. in Shapiro 1993). After Auberger’s speech, several dozen activists with disabilities threw themselves from their wheelchairs and dragged themselves up the steps of the Capitol, shocking viewers around the country and making it clear that they would wait no longer for their civil rights.

Meanwhile, activists on the inside, such as Evan Kemp Jr., chairman of the Equal Employment Opportunity Commission, continued to make the case for the ADA. Together, these civil rights leaders were able to push the most important piece of legislation for people with disabilities to date through Congress. The ADA was signed into law by President George H.W. Bush on July 26, 1990.

Today, people with disabilities face fewer physical barriers, and the ADA provides them with substantial legal recourse if they are openly discriminated against. Because of this law and laws that followed, Americans with disabilities have greater access to the workplace and society at large, and the United States is one of the most physically accessible countries in the world. But legislation cannot change popular attitudes. Combating stigma and ableism, or the belief that people with disabilities are
inherently different from and inferior to people without disabilities, continues to be an important item on the agenda of the Disability Rights Movement. This is the focus of the remainder of the paper.

Our waitress was fussing over me. After setting down my soup, she moved the placemat closer to me, unwrapped my silverware from the napkin, and handed me the spoon. She turned to my boyfriend, Nick, who sat across from me and asked if I was his sister. He informed her that I was his girlfriend. "Oh, how nice," she cooed, perhaps assuming I had an intellectual disability and he was indulging my heartwarming fantasy. Still talking to Nick, she said, "She's a sweet little girl."

Then she walked away. It was the summer of 2010.

Part Two: Combating Social Stigma

More than 20 years after the passage of the ADA, people with disabilities still experience pervasive social stigma. By stigma I am referring to a social disgrace experienced by an individual or group rooted in a collection of negative societal attitudes, misperceptions, and prejudice. Often it is society's assumption that disability is something to be feared or pitied that leads to the most damaging loss of opportunity for people with disabilities, regardless of their individual impairments. This section of the paper examines stigma faced by people with disabilities in the United States. At times I will draw from my own experiences (see above) as a woman who grew up with a disability which gradually caused me to use a wheelchair full time at the age of 17. I will examine the role of language and definitions of disabilities, sources of prejudice, and how people with disabilities are portrayed in film. All of these elements overlap to create an overall ableist understanding of disability, adversely impacting the self-esteem, sexuality, and the physical and financial well-being of individuals living with disabilities. In its most extreme and tragic form, stigma can even lead to death through the biased application of assisted
suicide. Ultimately, I would like to impress upon the reader that it is stigma, rather than impairment itself, that serves as the greatest and most dangerous obstacle for most people with disabilities.

**Disability Language**

One outcome of the Disability Rights Movement has been a shift in how we define terms such as "impairment" and "disability." Until 2001, the World Health Organization (WHO) defined impairment as "any loss or abnormality of psychological, physiological, or anatomical structure or function" and disability as "any restriction or lack (resulting from an impairment) of ability to perform an activity in a manner within the range considered normal for a human being" (qtd. in Oliver 1996, 30. Emphasis added). Thus, disability was seen as a direct result of impairment. According to this conception of disability, often referred to as the Biomedical Model or the Individual Model, there is no mention at all of socially constructed obstacles.

Mike Oliver, generally considered the father of the Social Model of Disability, advocates for a different understanding of disability that is separate from impairment. For example, he endorses the Disabled People's International definition, which defines impairment as "the functional limitation within the individual caused by physical, mental, or sensory impairment" and disability as "a loss or limitation of opportunity to take part in the normal life of the community on an equal level with others due to physical and social barriers" (qtd. in Oliver 1996, 31. Emphasis added). According to this view, impairment is a medical condition and disability is a social condition, and the responsibility for disability is placed squarely on the shoulders of society. As Oliver (1996, 36) points out, "[D]efining impairment or disability... is not simply a matter of language or science; it is also a matter of politics." The understanding of disability promoted by the Social Model was simultaneously a product of and a facilitator of the Disability Rights Movement, leading to important legislative and societal changes. For example, in 2001, WHO altered its definition to consist of the "interaction between features of a
person's body and features of the society in which he or she lives." Thus, in general, we are moving away from purely medical definitions in order to account for social barriers, including stigma, that have a significant impact on the experience of disability.

However, the exclusion of impairment from the definition of disability has come under significant criticism in the past few decades. Some scholars argue that disability as a loss of opportunity is necessarily linked to impairment because it is the impairment upon which society bases its denial of opportunity (Terzi, 2004). In other words, there would not be a loss of opportunity (disability) without impairment as a basis for prejudice and discrimination. Furthermore, some loss of social opportunities are directly tied to impairment. A Blind person cannot interpret body language, and there is nothing society can do differently to change this particular situation. Therefore, critics of the Social Model call for a definition of disability that is more inclusive of the experience of impairment and the associated psychological and physical pain (Terzi, 2004).

In addition to how we define disability, language used to describe people with disabilities also has an impact on society's perceptions. Most disability etiquette guidelines emphasize the use of person first language (Michigan Commission on Disability Concerns, National Service Inclusion Project). It is correct to say "person with a disability" instead of "disabled person," or "person with epilepsy" instead of "epileptic." This is to emphasize the individual's personhood over his or her specific condition. Person first language is not universally accepted. Some people consider their disability to be such an important part of their identity that they prefer the term "Disabled Person." Similarly, people who are deaf tend to prefer to be called "Deaf persons" because they believe Deafness is a cultural attribute. However, for most others with disabilities, the most respectful terminology uses person first language. (Smart 2009)

Sensationalist language, or describing someone as "an invalid," "wheelchair-bound," "a victim of," or "suffering from" a disability, should also be avoided because it inaccurately portrays life with a disability as excessively restrictive, unfulfilling, and sad. Terms such as "special," "differently-abled," or
"mentally challenged" are considered euphemistic and condescending, reflecting an attitude that views people with disabilities as pitiable and childlike. And other terms that were not originally intended to be used as pejoratives are now considered outdated and offensive due to their historical application. "Handicapped," "crippled," and "retarded" are some examples. (Smart 2009)

Monitoring the language we use to describe disabilities and people with disabilities may seem cumbersome, but it is important. The words we use subtly reflect our understanding of and attitudes toward that which we are describing. Pejorative language simultaneously reflects existing prejudice and helps perpetuate stigma against the person or group it is describing. The best contemporary example of the significance of language in perpetuating stigma is the popular use of the word "retarded" (see Figure 6). This word has become a trendy insult across race, gender, and age, to describe people with and without disabilities, even though "Mental Retardation" is still the medically proper term to describe individuals with significantly low IQs (Smart 2009). It is often paired with extremely offensive gestures or vocals to mimic someone with an intellectual disability. It should come as no surprise that people with intellectual disabilities are one of the most stigmatized groups within the disability community, second only to people with psychiatric disabilities (Smart 2009).

Whenever I encounter stigma in my social relations, it is almost always because someone has assumed I have an intellectual disability. In other words, it is a perceived intellectual disability, rather than my actual physical disability, that often results in stigma during my social encounters, such as the one described at the beginning of Part 2.

Figure 6: This image is widely available on the Internet. It shows how people with intellectual disabilities are acceptable targets of offensive jokes, especially among young people.
harmful stigma, and how it can also be used to challenge existing stigma. But why was pejorative, ableist language developed in the first place? Where does stigma come from? In her popular textbook on disability, entitled *Disability, Society, and the Individual*, Julie Smart identifies ten sources of prejudice and discrimination against people with disabilities.

**Julie Smart's 10 Sources for Prejudice and Discrimination**

The *economic threat* of people with disabilities refers to the perceived cost of making accessibility accommodations, particularly in the workplace, and the cost of providing state income and health care benefits for people with disabilities. These economic fears result in unemployment and underemployment for people with disabilities, as well as arguments to deny benefits rooted in a hierarchy of disability legitimacy (someone who acquired a disability after years on the job is more deserving than someone with a congenital disability). The *safety threat* of people with disabilities refers to the stereotype that certain individuals, especially those with psychiatric and intellectual disabilities, are particularly violent, or that a given disability is contagious. Ironically, this community has historically experienced more violence in the form of rape, assault, torture, forced sterilization, and robbery during periods of institutionalization. Studies suggest that people with psychiatric and intellectual disabilities are actually less violent than the general population (Smart 2009).

One of the most important sources of prejudice identified by Smart is the *ambiguity of disability*. For people who are misinformed or uneducated about various disabilities, encountering a person with a disability is an ambiguous situation, open to multiple possible interpretations and multiple possible appropriate or inappropriate social responses. People feel unsure of the

*When I talk to others about their thoughts on encountering individuals with disabilities and why some of us tend to say awkward or inappropriate things, the most common speculation is: “I think people just don’t know what to say.”*
nature of the disability and how they should interact with the person experiencing it. Smart describes the situation in the following way:

Learned responses and attitudes, which in the past were adaptive, may not be appropriate in ambiguous circumstances. Indeed, using learned responses...in a novel and ambiguous environment may actually be harmful. Frequently people make inappropriate responses and occasionally they are not aware that their responses have been inappropriate. Finally, an ambiguous environment is automatically assumed to be negative or hostile, even when it is not. This is often called "fear of the unknown." In short, we don't feel in control when our environment, and the people in it, are ambiguous. (Smart 2009, 141)

Ambiguity of disability occurs when able-bodied individuals avoid eye contact with people with disabilities and ask someone who is with them questions about them. This is likely because they feel that they are in an ambiguous situation. Learned responses—directing one's questions toward the person to whom the questions pertain—may actually result in harmful, perhaps embarrassing, consequences. The person may have an intellectual disability that prevents him or her from responding, or he or she may have a speech impairment that affects comprehension, creating an entirely new ambiguous situation. People feel it is better to avoid ambiguity and speak directly to the able-bodied person, whose response will be predictable and conform to learned responses. Often people without disabilities avoid people with disabilities in order to escape a stressful social situation.

The next source of prejudice, the salience of the perceived defining nature of the disability, shows why person first language is so important and why alternative descriptive language developed in the first place. This source of prejudice refers to the notion that the disability is the defining feature of the individual, the single most important trait informing his or her identity. Other traits such as gender, ethnicity, religion, education level, personal values, etc., are not even considered. Hence, an individual with epilepsy is labeled an "epileptic" and an individual with quadriplegia is labeled a "quadriplegic." In a similar vein, many Deaf people who believe Deafness is a cultural attribute are more likely to consider this a defining feature and are therefore comfortable with "Deaf person" as a label.
Closely related is the spread or overgeneralization of the effects of disability. This refers to the assumption that the effects of disability are more severe than they actually are. The fact that people assume people with physical disabilities also have intellectual disabilities is an example of spread. Terms such as "wheelchair-bound" and "invalid" are rooted in this source of prejudice.

The amount of stigma individuals face varies not only with the type of disability but also with the perceived moral accountability for the cause of the disability and the moral accountability for the management of disability. Those who acquired disabilities as a direct result of personal choices, such as smoking, using alcohol, riding a motorcycle without wearing a helmet, and so on, face a greater degree of stigma than those with congenital disabilities. Despite the fact that almost everyone engages in some form of risky behavior that may result in disability or illness—such as not exercising—society blames these individuals more because their behavior happened to lead to disability.

Growing up I was often told things like, "You are so inspiring. You never let your disability get you down. Some people go through life consumed with bitterness, but not you. It takes a special kind of person to have a disability." These were often well-intentioned comments meant to encourage me. But they also sent a clear message: you are obeying the rules, and others are not. Until only a year or two ago, I would become embarrassed when other people with disabilities complained openly about disability-related issues in the company of people without disabilities because subconsciously I knew they were breaking the rules.

Likewise, people with disabilities are expected to follow certain rules in managing their conditions. People with disabilities should be cheerful and ignore prejudice and discrimination. Those who openly discuss their disabilities, or those who showed sadness or anger, are viewed as disobedient. They are refusing to "accept" their situation and forcing others to acknowledge their disabilities. Naturally, these rules are enforced by an able-bodied society, and they can be taught to children at a young age. For instance, in 1997 Mattel produced a doll who used a wheelchair (see Figure 7). While it is perhaps an important step forward that Barbie's circle of friends includes someone with a disability, there were several problems. First, she was called "Share a Smile Becky," reinforcing the notion that people with disabilities are expected to maintain a positive
attitude, and others should reward this attitude with deliberate friendliness. Second, the box boasted that proceeds would benefit the National Parent Network on Disabilities and the National Lekotek Center, reinforcing the notion that disabilities are associated with charity. And third, Becky's wheelchair did not fit inside the elevator in Barbie's mansion!

Stigma against people with disabilities is also rooted in society's emphasis on health, fitness, and beauty. In general, beautiful people are more likely to find success and have more access to resources than plain people. In many cases, beauty is considered to be a result of individual effort. Those who do not meet society's standards of beautiful face more stigma because it is assumed that they are not making the proper effort to conform. For people with disabilities, a hierarchy of beauty and fitness exists. Often when people who use wheelchairs are portrayed in the media, they are attractive, symmetrical individuals who use manual wheelchairs which they are strong enough to push by themselves. In fact, people with facial disfigurement often face a high degree of stigma, even though this affect their level of functioning.

The inferred emotional consequence of the disability is another important source of stigma. This refers to the tendency of people without disabilities to assume that a person's disability is the worst, most tragic thing to have happened to them. This source of prejudice is rooted in another source: the fear of acquiring a disability. No one wants to experience a loss of function, and until we live this experience, we often imagine it is worse than it actually is. When encountering a person with a disability, a common reaction is to think, "I'm so glad it's not me" or "I don't know what I would do if that were my child." Smart argues people with disabilities serve as a reminder of our physical frailty and mortality. Because the acquisition of a disability is frightening, we assume having a disability is a tragic, traumatic experience. Thus, we use words such as "victim" and "suffering" to describe people with
disabilities, even though for most people managing a disability is simply another part of life, and in some cases is considered an important part of their identity.

The sources of prejudice identified by Smart form a complex array of attitudes that create the social stigma faced by people with disabilities. This stigma impacts our hiring practices, legislation, education, and our day to day interactions with people with disabilities. It also plays a role in how we choose to represent this community. Part 1 briefly discusses how charitable organizations have the power to reinforce or challenge stigma. The next section examines the impact of stigma on the portrayal of people with disabilities in film.

**People with Disabilities in Film**

To begin with, people with disabilities are generally absent from most movies and television. When a character does have a disability, they are typically the main character and the plot focuses extensively on their experience of disability, usually misrepresenting and sensationalizing it through an ableist lens. Most film portrayals are negative and reflect Smart's sources of prejudice (Smart 2009, Black and Pretes 2007). In 1993, Nelson exposed seven dominant stereotypes that occur in film representation of disability (Black and Pretes 2007).

According to Nelson, people with disabilities are portrayed as pitiable and childlike; "supercrips," or individuals who are courageous, determined, and obedient of the rules of managing disability; evil or criminal, rooted in Smart's safety threat of disability; better off dead (see Figure 8), rooted in inferred emotional consequences of disability; maladjusted, or bitter and incapable of managing disability; a burden to

Figure 8: In Million Dollar Baby, after the main character acquires quadriplegia, she attempts suicide a number of times. Finally, her coach helps her kill herself. According to this narrative, she is "better off dead."
family and caregivers, illustrating spread and overgeneralization of disability; and incapable of living a successful, fulfilling life, rooted in fear of disability as well as spread and overgeneralization of disability. This pattern of seven dominant stereotypes clearly shows how sources of prejudice and stigma are manufactured and reinforced in society.

A recent study by Rhonda S. Black and Lori Pretes (2007) builds on previous research exploring the portrayal of people with disabilities in film. Focusing exclusively on physical disability, the researchers reviewed films produced between 1975 and 2004 that were feature-length and available for widespread distribution. They screened for Nelson's seven stereotypes listed above, as well as E. Keith Byrd's important themes of portrayal: a fully developed personality not defined exclusively by the disability; integration within the community, including education, employment, and social activities; and a range of diverse and multidimensional interpersonal relationships. These themes were rated according to a rubric, with a 1 indicating the worst portrayal and a 4 indicating the best portrayal. More than half of the films reviewed (10 out of 18) had two or three stereotypes present, and all had at least one. The films generally did a good job portraying a fully developed personality, with the majority receiving a score of 3 out of 4. However, most films scored only a 2 or 3 in interpersonal relationships, and a significant minority received a score of 1 in community integration.

Overall, the researchers concluded that progress has been made over the past few decades and that there is a greater focus on the shared humanity between characters with disabilities and the viewing audience, but there is still a need for major improvement. Pity, particularly self-pity and embitterment, is still a common theme in film. "Feel-good" movies show people with disabilities overcoming obstacles and accomplishing goals. The authors note that this is problematic because "most movies... do not depict society as needing to change with respect to stigma and social discrimination; but rather disability is portrayed as an individual characteristic that can serve to build character. Therefore, audience members are blameless as to their role in perpetuating discrimination and
oppression of individuals with disabilities" (Black and Pretes 2007, 80). Stereotypes portraying individuals as unable to lead successful lives and as better off dead were also "disturbingly common" (Black and Pretes 2007). While more films portray people with disabilities as sexual beings, not one film reviewed showed a person with a disability initiating a relationship.

Film can have a powerful role in shaping our perceptions of certain issues or minority communities. Just as charitable organizations have a perceived authority when it comes to speaking for people with disabilities, movies are often assumed to be relatively accurate. As the authors of the above study point out, "Movies offer people a way to explore the unfamiliar in a safe environment. Therefore, if someone has not had direct experience with individuals with various disabilities, film depictions may be his or her primary source of information" (Black and Pretes 2007, 66). Thus, films contribute significantly to the pervasive social stigma experienced by people with disabilities. This stigma has very real consequences for individuals living with disabilities.

The Effects of Stigma

Smart recognizes that, "Holding false and unrealistic beliefs about disabilities limits any individual's view of the world, but if the person should acquire disability, then he or she literally becomes the object of his or her own prejudice and narrow views" (Smart 2009, 197). Even those who are born with their disabilities can internalize ableism, and this can be one of the nastiest effects of stigma. Like racism, sexism, and many other forms of "-isms," ableism is so saturated within our culture that it appears normal (Campell 2008). We are all a product of our respective cultures, and, especially as children, we are susceptible to their imprints regardless of our individual status. Accordingly, people with disabilities can harbor negative beliefs about their own community. Internalized ableism is especially difficult to deal with because, unlike race and gender, there can be negative aspects to having a disability that are not related to social constructs. If racism and sexism disappeared, race and gender
would simply be another attribute contributing to human diversity, on par with traits such as haircolor or height. But disability cannot always be separated from its health implications. In the absence of ableism, having a disability may still be undesirable due to chronic pain, shortened lifespan, and other reasons.

Internalized ableism is exacerbated by the belief that members of a stigmatized minority group should not associate with each other; rather, they should emulate the dominant group, conform to their standards, and assimilate into the mainstream (Campbell 2008). For people with disabilities, this has led to fewer opportunities to form a collective community. Campbell (2007) even suggests that integration into mainstream institutions and methods may have harmed people with disabilities because this process assumes that the mainstream is superior. While with this particular point is highly debatable—separation allows the mainstream to continue to exist without diversity, incubating lowered expectations and superior attitudes toward particular groups—it is interesting to note the strength of the Deaf community, which has experienced greater separation from the mainstream for centuries.

Pressure to conform to ableist standards prevents people with disabilities from accepting their true selves and from accepting their disabilities as another form of human diversity (Campbell 2008). This
bears some resemblance to Smart’s source of prejudice that people with disabilities are expected to manage their disabilities in a manner considered appropriate to people without disabilities. This has dire consequences for the identity-formation process. Campbell (2008, 157) writes, "Internalized ableism means that to assimilate into the norm[,] the referentially disabled individual is required to embrace, indeed to assume, an ‘identity’ other than one’s own." On top of this kind of fractured identity, people with disabilities often feel shame on two levels: shame of being associated with people with disabilities, and shame for being consciously aware of this shame.

Stigma also leads to important external consequences for people with disabilities. Studies show that, although this community has achieved de jure equality through the ADA and other legislation, de facto inequality persists, as people with disabilities continue to lag behind their able-bodied counterparts. The National Organization on Disability has partnered with Harris Interactive to monitor key areas of American life for people with disabilities compared to people without disabilities. Surveys are conducted every 4 to 6 years and indicators such as employment, poverty, financial situation, education, healthcare, transportation, socializing, satisfaction with life, and others are examined (GAP Survey 2010). The most recent study, conducted in 2010, shows that while there has been progress...
since the passage of the ADA, significant gaps still exist. I have summarized some of the findings in the following table:

Table 1 Kessler Foundation/NOD Survey of Americans with Disabilities, July 2010: Key Findings

<table>
<thead>
<tr>
<th></th>
<th>People with Disabilities</th>
<th>People without Disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment among all working age (18-64)</td>
<td>21%</td>
<td>59%</td>
</tr>
<tr>
<td>Household income of $15,000 or less (poverty level)</td>
<td>34%</td>
<td>15%</td>
</tr>
<tr>
<td>Living from paycheck to paycheck but not acquiring debt</td>
<td>58%</td>
<td>34%</td>
</tr>
<tr>
<td>Living from paycheck to paycheck and acquiring debt each month</td>
<td>21%</td>
<td>8%</td>
</tr>
<tr>
<td>Have not completed high school</td>
<td>17%</td>
<td>11%</td>
</tr>
<tr>
<td>Gone without needed healthcare at least once in the past year</td>
<td>19%</td>
<td>10%</td>
</tr>
<tr>
<td>Consider inadequate transportation to be a problem</td>
<td>34%</td>
<td>18%</td>
</tr>
<tr>
<td>Socialize with friends, family, or neighbors at least twice a month</td>
<td>79%</td>
<td>90%</td>
</tr>
<tr>
<td>Report that they are very satisfied with life in general</td>
<td>34%</td>
<td>61%</td>
</tr>
</tbody>
</table>

According to Smart (2007), writing before the 2010 survey was conducted, despite important advances made because of the ADA, people with disabilities are still at an overall disadvantage. This most recent study supports her claims. For every single indicator, people with disabilities are lagging (one minor exception is that people with disabilities between the ages of 18 and 29 had higher socialization scores) (GAP Survey 2010).

Employment is where we see the largest gap between people with and without disabilities: an alarming difference of 38 percentage points. Although the gap has been decreasing since 1998, change has come slowly, dropping only a single percentage point per year on average. Among people with disabilities who are unemployed, an overwhelming majority (73%) cite their disability as a reason that they do not have a job. Thirty-seven percent also mention that they are unable to get necessary accommodations in the workplace—even with the ADA in place—and 23% fear losing federal health benefits upon obtaining a job.
Some may argue that this latter statistic indicates overdependence, perhaps even abuse, of the
government welfare system. But let us remember that a job by no means guarantees healthcare
benefits. Because people with disabilities are more likely to have lower levels of education, they are also
more likely to be applying for jobs that either do not provide benefits at all or do not provide benefits
that cover all of their healthcare needs (for example, paying personal assistants who make
independence possible). Considering that people with disabilities in general have more healthcare
needs, anticipating the loss of state benefits is a reasonable fear when deciding to search for a job.
Depending on the outcome of the debate surrounding President Obama's health care reform, people
with disabilities may have less of a reason to fear losing their benefits upon obtaining employment.

Furthermore, people with disabilities are less likely to get hired in the first place. Twenty-six
percent report experiencing some form of job discrimination based on their disability in the past five
years—a number that used to be much higher, but despite improvements continues to create a
significant barrier to employment.

Low employment is clearly associated with other important problems, such as higher poverty
rates and an increased likelihood of incurring financial hardship. Fortunately, despite the gap that still
exists, major improvements have been made in access to education for people with disabilities, which
may provide a source of improvement in other areas. But people with disabilities also desperately need
comprehensive health care reform. And in spite of relatively strong civil rights and legal protections,
people with disabilities still experience a significant disadvantage in key areas compared to the general
population. This helps reveal the limits of the ADA: popular attitudes do not change overnight, and for
people with disabilities, stigma is still an obstacle.

The prevalence of ableist attitudes and stigma is best illustrated by the fact that so many people
with disabilities reported having experienced discrimination. Additionally, 26% of those who are
employed say they have experienced "discomfort or a negative reaction" from their fellow workers or
customers in their current job (GAP Survey 2010). It is important to remember that discrimination does not have to come in the form of denial of a job explicitly based on an individual’s disability. Rather, it can take the more subtle form of discomfort during an interview, or it can simply be a matter of perceived efficiency: if there are two equally qualified applicants, but only one requires accommodations, hiring the able-bodied applicant may just seem easier. Indeed, the applicant with the disability may never even know that he or she has been discriminated against.

Stigma can also play a role in the interpersonal relationships people with disabilities are able to form. Indeed, the lower rates of socialization and high overall satisfaction with life reported by the NOD study may be linked to the stigma people with disabilities face (although unemployment and financial stress can certainly cause these numbers to be higher, as well). A recent study conducted by Kenneth Hergenrather and Scott Rhodes (2007) examined social attitudes toward people with disabilities among undergraduate students. The survey posed questions exploring the willingness of participants to form relationships with people with disabilities in three specific social contexts: work, dating, and marriage. Although the majority of undergraduate students reported overall positive attitudes, the results supported previous research on theories of social distance as they relate to people with disabilities. Social distance refers to "the relative willingness of one person to participate in relationships of varying degrees of intimacy with a person who has a stigmatized identity" (Hergenrather and Rhodes 2007, 67). The more intimate the relationship, the less likely members of a non-stigmatized group will be willing to form it. In the study, participants were more likely to respond favorably to people with disabilities in the workplace than people with disabilities as partners for dating and marriage.

Of course, speculating on one’s own attitudes while filling out a questionnaire is quite different from actually living the described situation. The authors note that one of the limitations of this study is that respondents may have answered more positively because answering negatively would have been
uncomfortable. Furthermore, the study referred to disability in general. Disabilities which are more visible than others may have elicited more negative responses.

In fact, another study that explores physical disability and sexual esteem shows that while people with physical disabilities report high levels of interest in and enjoyment of sexual activity, many believe their disabilities make it more difficult to find a partner (Taleporos and McCabe 2001). Whereas respondents agreed and disagreed about equally with the statement "My disability interferes with my sexual enjoyment," and the majority disagreed with the statement "My disability is likely to prevent me from satisfying a sexual partner," the overwhelming majority agreed with statements such as "It is harder to find a sexual partner when you have a disability," "I feel that people are not sexually interested in me because of my disability," and "I often experience rejection from potential partners because of my disability." Some of these feelings may result from internalized ableism, which can make an individual less likely to try to initiate sexual relationships because they overestimate the chances of rejection. In fact, one participant alludes to this very thing:

Having acquired disability, you really notice how people treat you differently after the accident. It's very obvious. You can see how easily some people can become conditioned to feel negatively about their disability. (Qtd. in Taleporos and McCabe 2001, 139, emphasis added)

And in some cases, it is physical barriers that limit the formation of romantic relationships for people with disabilities, as exemplified in the following respondent’s comment:

It is hard to find a sexual partner when you have a disability BECAUSE of the disability. Things like: you just can't go back and have a bonk when you have to think about who's going to help you go to the toilet, or you can't go back to their place because it's not accessible. Practical considerations add an extra barrier to finding a partner in the first place. (Qtd. in Taleporos and McCabe 2001, 141)

But for many people with disabilities, stigma has a palpable impact on their ability to find a sexual partner:
Some people think that because you have a disability you are not interested in sex or that you are not able to have or enjoy sex. (Qtd. in Taleporos and McCabe 2001, 139)

No guy wants you if you're disabled. I can't compete with able-bodied girls. (Qtd. in Taleporos and McCabe 2001, 139)

I am interested in sex but I don't get opportunities... if I express that I'm seen as a dirty old man... as something "abnormal" (Qtd. in Taleporos and McCabe 2001, 144)

In a comment that supports the notion of social distance explored in the study on undergraduate attitudes, one participant said, "People may accept you as a friend but they won't ever consider a sexual relationship with you" (Qtd. in Taleporos and McCabe 2001, 139).

Respondents who were in committed relationships were more likely to respond positively to the questionnaire, and there were many positive comments on individuals’ sexuality and the ability to enjoy sex while having a disability. The ones recounted here are specifically relevant to the impact of stigma. Indeed, people with disabilities face a certain kind of stigma when it comes to their sexuality. Because members of this community are commonly viewed as childlike, and because of the effect of spread and overgeneralization of disabilities, it is assumed that people with disabilities are asexual.

Tepper (2000) notes that when able-bodied individuals do not experience orgasm, they are diagnosed with a medical condition. When people with disabilities do not experience orgasm, it is seen as unproblematic, an effect of the disability that cannot be mitigated. He blames this on an overall "neglect of the pleasurable aspect of the discourse of sexuality" and argues that the social aspects of "disability [are] perpetuated by the assumption that people with disabilities" are not sexual beings (Tepper 2000, 287).
It is interesting to note that, in the first study, able-bodied participants reported that they are open to forming romantic relationships with people with disabilities, and yet people with disabilities report difficulties actually forming romantic relationships with the able-bodied. Perhaps the truth lies somewhere in the middle—people without disabilities may be unwilling to acknowledge their own prejudices, and people with disabilities may be too quick to assume someone has judged them in the first place. In either case, stigma can be a barrier to interpersonal relationships by cultivating ableist attitudes among the able-bodied and creating internalized ableism among people with disabilities.

In addition to the negative impact of stigma on the self-esteem, social opportunities, and interpersonal relationships for people with disabilities, the most dangerous consequence is the misuse and misapplication of physician assisted suicide (Smart 2009, Shapiro 1993). For some, this includes using genetic testing to screen for certain disabilities or deciding to have an abortion if it is discovered that the fetus will develop a disability (depending on one's view on abortion, these acts may constitute murder based on disability). Infants are also at risk. In the United States, active euthanasia—meaning lethal injection—is illegal and expressly condemned by the American Medical Association (Sklansky 2001). Yet according to the Child Abuse Prevention and Treatment Act, in certain situations—where it is determined by doctors that an infant is irreversibly comatose or that treatment would "merely prolong dying"—parents may choose to deny life-support to an infant with a disability. This is problematic because doctors’ predictions of how long a patient will live or of a patient’s quality of life can be wrong. Additionally, parents’ decisions may be influenced by society's ableist attitudes and stigma. They may feel that they do not have time to adequately research what resources are available to parents raising children with disabilities, or how their child would live successfully with a disability. In the Netherlands, where assisted suicide has been legal for decades, in 1988 it was estimated that 300 babies each year are euthanized because they were born with disabilities that included spina bifida and down syndrome (Smart 2009).
But the first case of physician assisted suicide that caught the attention of disability rights activists involved an adult named Larry McAfee (Smart 2009, Shapiro 1993). He acquired quadriplegia in a motorcycle accident in 1989 at the age of 34. At the time of his injury, Medicare and Medicaid only paid for nursing home care. McAfee spent years moving from institution to institution, lying in bed, and his life was hardly stimulating. Sinking into a deep depression, he asked a lawyer to help him die. His case reached the Georgia Supreme Court, where his "right" to assisted suicide was upheld. However, in the meantime, disability rights activists had mobilized to pressure for bureaucratic change that would allow McAfee to hire personal assistants. He was also given a "sip-and-puff" wheelchair that he was able to control and he was shown assistive technology that would enable him to live independently outside of a nursing home and participate in recreational activities that he enjoyed before his injury. Eventually, McAfee decided that he no longer wished to die, and he became an outspoken critic of physician assisted suicide. If it had not been for stigma, policies that condemned young, healthy people with disabilities to nursing homes for the rest of their lives would never have been enacted. No Georgia Supreme Court would have permitted a man to commit suicide without thorough psychological treatment and without first researching whether significant attempts had been made to show him how it was possible to lead a fulfilling life.

In another case, Elizabeth Bouvia entered an emergency room in Los Angeles and told doctors she no longer wanted to live (Shapiro 1993). She had just suffered a miscarriage, a divorce, and her mother's death, and financial pressures had forced her to drop out of her Master's degree program. But the physicians who supplied her with the pills to take her own life knew none of this. They only knew that she had cerebral palsy. The fact that she may have recently gone through several traumatic experiences almost simultaneously were not even considered. Stigma and ableist attitudes convinced physicians that a woman who had recently been married, starting a family, and receiving a top-tier education, was better off dead simply because she had cerebral palsy.
In fact, studies show that physicians routinely underestimate the quality of life of people living with disabilities, despite findings that these individuals tend to rate their own quality of life around the same as people without disabilities.\(^1\) Doctors that harbor the most negative attitudes toward disability are more likely to agree to withhold treatment. For example, in a study of 273 Muscular Dystrophy Association clinic directors, 41% admitted that they would discourage ventilator use for patients facing respiratory failure due to “poor quality of life” (Gill 2000). The most frightening aspect of this finding is that the majority of these doctors—all but two!—were not up to date with the range of ventilator options available. This illustrates the extent to which stigma impacts the professional decisions of doctors and medical personnel. For their patients, these ableist perceptions could mean life or death.

Although physician assisted suicide is only legal in three US states and there are significant barriers to qualifying for the procedure (e.g., a prognosis of six months or less), there are prominent physicians and lawyers who argue that these laws should be more relaxed toward people with disabilities that are not terminal such as multiple sclerosis (Gill 2000). In the Netherlands, and in the United States at the hands of the infamous Dr. Jack Kevorkian, many people with disabilities have been "helped" to die. Thus, there is a legitimate concern among disability rights activists that laws protecting physician assisted suicide could be applied irresponsibly to people with disabilities. Clearly, stigma is not simply a matter of hurt feelings; in its most extreme and tragic form, it can be deadly.

**Areas for Further Research & Conclusion**

The purpose of this paper was to give a brief overview of the history of the Disability Rights Movement and to examine the role stigma continues to play in the lives and well-being of people with disabilities.

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\(^1\) This statement may seem inconsistent with the National Organization on Disability study cited earlier, which found that fewer people with disabilities rated their lives as "very" satisfying than people without disabilities. However, the word "very" is important to keep in mind, because others may have reported being just "satisfied." And, the study notes that these attitudes are likely in part related to financial hardship. Furthermore, Gill (2000) notes that other studies show results that are more equal between the two groups.
disabilities. Although the Americans with Disabilities Act provided landmark civil rights protections for this community, it was not my intention to imply that we have achieved legislative perfection. Buildings of a certain age are exempt from many of the law's accessibility standards, and access to healthcare and financial resources are still significant problems for people with disabilities. One area for further research would be an analysis of the strengths and weaknesses of existing legislation covering people with disabilities and a discussion of where improvement is specifically needed.

Furthermore, my study has been strictly limited to the United States. Another area for further research includes a look at what is being done internationally to advance the rights of people with disabilities, the majority of whom live in poverty. Particularly since the passage of the UN Convention on the Rights of Persons with Disabilities in 2006, people with disabilities have increasingly become a subject of human rights and are now firmly on the international agenda. NGOs run by and for people with disabilities had unprecedented influence on process of drafting this legislation, hopefully setting an exciting new trend in the process of the making of human rights law. Whether we should expect a significant amount of change as a result of this document is a question for future scholarship. An examination of how current organizations are monitoring its implementation—and why well-respected human rights organizations such as Amnesty International are silent on the matter—would also be welcome.

Finally, research on exactly how stigma affects people with different kinds of disabilities is underdeveloped. Someone with a visible disability likely experiences stigma in an entirely different way than someone with an invisible disability. Additionally, the presence of a service animal changes the dynamics of an individual’s day to day interactions and how he or she encounters stigma. Another area for possible further research involves an examination of how experiencing stigma and ableism varies depending on the nature of the disability, and whether and how service dogs actually mitigate the effects of stigma. These studies should draw heavily on first-hand accounts of people with disabilities.
The Disability Rights Movement has brought about sweeping legal and cultural changes for people with disabilities. Advocates have achieved many significant victories, but the struggle continues. Like other minority groups who continue to fight for equal rights and equal opportunities, people with disabilities are still striving for a shift in popular attitudes and perceptions. Fortunately, significant progress continues to be made. But living with a disability, one is often reminded of the pervasiveness of stigma and ableism. Now that the ADA provides significant legal support, it is stigma that leads to the greatest loss of opportunity for the disabled community. It is only by addressing our attitudes toward each other, and by increasing our understanding of each other's realities, that we as a society can achieve true equality.
References


