CHAPTER SIX

Navigating with Disabilities in the U.S. Health Care System

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Introduction

Individuals with disabilities[1] comprise the largest minority group in the world, with over a billion people having some form of disability.[2] In the United States alone, nearly one in five people have a disability.[3] In 2010, the U.S. Census Bureau reported that about 56.7 million Americans had a disability, with almost half of those reporting their disability as being severe.[4] Despite their large numbers, individuals with disabilities are the most vulnerable to health care deficiencies and face a slew of institutional and physical barriers to health care. For many, the consequences of these unmet needs have been devastating.[5]

Rates of disability are rising sharply due in part to increases in chronic health conditions and an aging population.[6] Advances in technology are allowing people with disabilities to live longer and healthier lives than in the past. However, the health care delivery system still struggles to provide these technologies and services to individuals who fall on the disability spectrum.[7] Problems in the current health care delivery system include miscommunication between patient and clinicians, inadequate health insurance, and inaccessibility to buildings and physical spaces.[8] Unfortunately, many people in the nondisabled population are unaware of the obstacles facing the individuals with disabilities. The struggles that disabled communities[9] face

are very real, both financially and systematically through policy changes and treatment costs. These costs are incurred not only by individuals with disabilities but also by caregivers and taxpayers at large.

While the disabled community may seem unfamiliar or absent to many, the reality is that increased life expectancies have led to an increased chance of becoming disabled within an individual's lifetime. The Council for Disability Awareness predicts that one in four of today's 20-year-olds will become disabled before they retire.[10] Back injuries, heart disease, cancer, and other illnesses—many of which are chronic or potentially chronic—have led to an increase in disability, a cause for concern among health care policy makers.[11]

Individuals with disabilities have medical needs that are different than for those without disabilities. However, it is difficult to generalize the ongoing needs for individuals with disabilities because different conditions have varying consequences. Further, most medical research excludes people with disabilities, making it more difficult to identify those needs. The lack of data on disability and health care access means that medical professionals often lack proper training regarding disability competency.[12]

Historically, little attention has been paid to the medical needs of the disabled population. While the implementation of the Americans with Disabilities Act of 1990 (ADA),[13] the Rehabilitation Act of 1973,[14] and the Civil Rights of Institutionalized Persons Act,[15] among others, have increased the visibility of health disparities among the disabled community, more action is still needed to improve the current state of awareness.

In the United States, health care policy changes have made access to health care services more difficult for people with disabilities. The World Health Organization (WHO) has found that people with disabilities report seeking more health care than those without disabilities and are less likely to receive treatment.[16] In several recent surveys, WHO found that among people with serious mental disorders, 35 percent and 50 percent of people in developed countries received no treatment in the year prior to the study.[17] The statistics are even more devastating in developing countries, where 76 percent and 85 percent of individuals with mental disorders went untreated.[18]

In addition to economic and bureaucratic factors, interpersonal difficulties and biases may block access to health care for people with disabilities. Health care practitioners tend to be more uncomfortable, less certain, and may spend less time with patients with disabilities, as opposed to those without.[19] In some instances, abusive and patronizing attitudes have led patients with disabilities to distrust health care professionals.[20] Current levels

of distrust toward the medical community need to be addressed, which in turn necessitates the adaptation of current testing procedures, treatments, therapeutic interventions, and equipment for people with disabilities by health care professionals and medical staff.

This chapter will address the health care needs of people with disabilities and the disabled by offering suggestions for adapting current health care policy. The authors of this chapter will also address the history of health care policy designed for people with disabilities in the United States, and the Patient Protection and Affordable Care Act[21] relevant to disability policy development. Our hope is that this chapter will shed light on current health care policy issues, which impact those within the disabled community.

Uncertainty and Avoidance in Health Care Settings

David "Isaac" Valencia, who has been blind since birth, does not necessarily consider himself a person with a disability.[22] Isaac states that people with impaired conditions just want to be treated like anyone else, and they do not want to be referred to as "disabled" or pitied.[23] Isaac explains that labeling and disability terminology should not be used to define what can and cannot be done as a person with a disability.[24] Even though Isaac does not consider himself disabled, he claims that in the eyes of the law and in the eyes of health care professionals, he is "100 percent disabled."[25] In order to qualify for a handicap-parking pass, to get accommodations from his university, and to fill out Social Security forms, he must classify himself as disabled.

The negative language associated with disability can lead to many unintended consequences, though it is most knowingly associated with avoidance.[26] There is inconsistency with labels used to define disability (as in Isaac's case), and this is partly to blame for the uncertainty health professionals have in initiating conversation with those in the disabled community.[27] Most avoidance literature is linked to the effects of communication apprehension, or the anxiety associated with real or anticipated communication with another person.[28] The person who experiences communication apprehension often avoids initiating communication entirely. In health care settings, doctors and clinicians are uncertain about how to interact with patients with disabilities, and individuals with disabilities are uncertain of how they will be treated by their health care professionals.[29] These difficult interactions further impede patients' access to quality health care. As such, the following section addresses the role of communication apprehension and miscommunication in physician malpractice toward the disabled community.

History of Malpractice

Physician malpractice can be defined as denying someone treatment, withholding information, violating the standards of care, and/or an injury caused by negligence. This can include prescribing improper medication or dosing, poor follow-up or aftercare, disregarding or not taking appropriate patient history, and failure to recognize symptoms.[30]

Malpractice is not necessarily intentional or criminal. Extensive research suggests that encounters and/or interactions between individuals with disabilities and health care professionals may be experienced as demeaning and oppressive.[31] People with disabilities are often regarded by health care professionals as passive recipients with limited emotional resources or capacity for self-care.[32] Furthermore, health care professionals' communication with people with disabilities is often either poor or inefficient.[33] Together, these factors can lead to disabled patients receiving inappropriate medical advice or substandard care.

Physicians are the gatekeepers to treatment and information, and they are crucial in helping people appraise how the individual's disability is likely to affect them. Additionally, physicians are in control of eligibility requirements for accommodations and support services and play a role in validating an individual's needs in legal or bureaucratic contexts. Some individuals with disabilities are concerned that the clinicians' attitudes toward disability perpetuate negative stereotypes and exacerbate the "difference" of disability."[34] Stereotypes and discrimination are related to malpractice because they can result in prejudice—defined as a negative attitude toward a specific group—which can be directly related to making improper decisions about the treatment and health care of a person with a disability.

In the United States, it is generally held to be socially unacceptable to discriminate overtly against another group or to deny someone service because they belong to that group. This phenomenon is evident in studies of health care professionals, where it was found that it was difficult for health care professionals to cope with the needs of people with disabilities and that as a result, the professionals actually discriminated against disability.[35] Similarly, medical students are more uncomfortable, uncertain, and spend less with individuals with disabilities than with patients who do not have disabilities.[36]

The social and legal pressures against discrimination have led to the evolution of something more covert and subtle, making it difficult to prove that such behavior was intentional. Further, it is important to note that prejudice can be implicit, that is, outside of the individual's awareness. Implicit attitudes are unidentified traces of past experience that facilitate "attributions

of qualities to members of a social category."[37] Since people do not have control over their mental processes of perception, they are unaware of how implicit bias can affect their actions with other groups of people. Implicit bias is partly responsible for some of the physician malpractice that occurs in the United States. For example, research has shown that a consistent pattern of moderate to strong negative implicit attitudes toward individuals with disabilities exists.[38] Evidence suggests that attitudes of mainstream health care providers are more negative toward people with intellectual disabilities than those providers who specialize in intellectual disabilities.[39] These negative attitudes have a detrimental impact on service provision and even referrals to proper specialists. Implicit attitudes have been measured by Greenwald and colleagues with the Implicit Association Test (IAT). This test involves a reaction-time measure that captures the strength with which certain social groups (such as people with disabilities) are implicitly or automatically associated with bad evaluations.[40]

As discussed, physicians often play a significant role in the life of an individual with a disability and serve as a potential gatekeeper to treatment and accommodation services.[41] Given that the physician plays such a significant role in providing care, we consider a number of ways in which physician malpractice can be reduced in regards to treating people with disabilities. These methods for reducing malpractice include:

1. **IAT for Diversity Training:** The disability IAT identifies the unknown biases others have toward the disabled community. Research aimed at reducing implicit bias has suggested that the IAT should be used for diversity sensitivity training in police academies and other high-stakes groups where prejudice is involved in decision making.[42] These same conditions exist for medical personnel and their patients with disabilities.
2. **Physician Etiquette:** Training for those who provide services for individuals with intellectual disabilities has been suggested, given that mental health deficits in mainstream health care exist.[43] Physicians can undergo specialized training to address conditions such as poor memory, low cognitive functioning, impaired verbal skills, paranoia, or other intellectual disabilities. Training should focus on gaining compliance and effectively communicating information, as well as learning how to help individuals with intellectual disabilities and allowing them to take an active role in their own health-related choices.
3. **Addressing Caretaker Needs:** Increasing social services and physician training to address caretakers' needs may actually improve a disabled person's health.[44] Concerns such as caregivers' perceived financial hardship, psychological distress, and the disease activity of individuals with disabilities are associated with decrease in health of the individual with a disability.[45] In addition to potentially improving the welfare of individuals with disabilities, physician

training can improve caretaker well-being. Caretaker stress is the emotional and physical strain caused from caregiving. Caretakers typically report lower quality of life and are at increased risk for internalizing disorders.[46] The relationship between the caretaker and their loved one may also be strained, and people with disabilities are at elevated risk of being abused by a caretaker.[47] By providing training, physicians will be more qualified to provide psychological help to caretakers and potentially will be able to offer information about financial resources and ways to prevent or relieve stress.[48] This training has the potential to improve the health outcome of individuals with disabling impairments and/or their caretakers.[49]

Defining Disability

Part of the reason that defining "disability" is difficult is due to its context-dependent and heterogeneous nature. There is no one single definition of disability that fits all circumstances and situations.[50] Due to this lack of consistency, individuals may be labeled as disabled in one context but not in another.[51] For example, Isaac is granted certain accommodations by the university for his disability but is denied disability-related benefits by his employers or health insurance provider. To increase individuals' access to services, there is a need to have a more inclusive and operational definition that ties legal, clinical, and scholastic definitions together. Awareness of this need is not new and continues to puzzle researchers from around the world.[52]

Scholars have identified two overarching perspectives on disability: the medical and social models.[53] The medical model is observed by insurance agencies and health care providers. Within this model, physicians are seen as arbiters, in that they are able to determine if an individual meets the established disability criteria.[54] The medical model sees disability as a physical or mental impairment that is a problem of the person.[55] Within the medical model, limitations faced by people with disabilities are caused by health conditions or disease, and these conditions require medical care in order to be fixed.[56]

This medical model of disability can be contrasted with the social model of disability, which challenges the medical model's focus on an individual's limitations. The WHO explains that the social model sees the issue of disability as a social problem rather than an attribute of the individual.[57] In this way, the social model, unlike the medical model, positions interpretations of disabling conditions as a product of the social environment[58] and not a flaw on behalf of the individual. Where the medical model is essentialist, the social model is contextual. By identifying systemic barriers and negative attitudes toward the disabled community as a main factor in these

disabling conditions, the social model can promote social change.[59] It is partly because the social and the medical models have both been advocated by members of the research community that disability has not been defined consistently in the literature.

There are numerous laws and statutes that have their own interpretation of disability based on when they were written and the organization they represent. Some organizations have more comprehensive and universally inclusive definitions of disability, while others are more influenced by a medical model of disability. Definitions of disability and impairment vary to the extent that they align with the social versus the medical model of disability. We argue that the social model of disability is more empowering than the medical model. In addition to avoiding the medical model's essentialism, the social model serves to critique disabling and discriminatory features of the environment and motivate social change. Despite these advantages, the medical model is still widely accepted in large part because of the importance that is placed on health professionals and clinicians in determining disability eligibility for health insurance and social security. The categorization of the body or brain as "disabled" serves as the gateway to resources that are necessary for survival. Since the medical model is still widely used to define disability, it perpetuates a stigmatizing view of disability.

Patient Protection Act and Affordable Care Act (ObamaCare)

In 2000, the World Health Report stated that the U.S. health care system ranks 37th in the world and had left 48 million Americans without health care coverage.[60] In attempts to solve the health care disparity in the United States, President Barack Obama signed the health care reform bill in 2010.[61] This law consists of the Affordable Care Act and the Patient Protection Act, though these are often lumped together in the public's perception. It is very difficult to distinguish them, given that most often they are presented together in reports and articles.[62] Together, the Affordable Care Act and Patient Protection Act are often referred to as health care reform, ObamaCare, or the ACA.

Health care reform was intended to prevent insurance companies from engaging in medical underwriting (in which insurance plans refuse to cover their clients' newly acquired conditions) and excluding preexisting conditions. Before the implementation of the health care reform, insurers cited preexisting conditions to justify denying coverage to one in seven applicants.[63] Prior to the ACA, insurance companies were also allowed to deny coverage and set rates based on health status, medical condition, claims experience, genetic information, evidence of domestic violence, and other

health-related factors. Although the Act was designed to help end discrimination against people with disabilities, it did not protect individuals from discrimination by insurance companies, whereas the ACA has made it illegal to deny an individual coverage solely based on their condition.

Arguably, the ACA is not only a piece of legislature that has been created to improve the health of Americans, but it also functions as a civil rights law, and the ACA constitutes one of the most significant civil rights victories for the disability community.[64] One of the ways in which the ACA benefits people with disabilities is by including multiple provisions that expand Medicaid and public health insurance for ongoing care; it also eliminated the preexisting condition exclusions, created limits on health status–based rating, and it recognizes people with disabilities as a health disparities group.[65]

The Patient Protection and Affordable Care Act has already achieved some of its goals; for instance, the Congressional Budget Office (CBO) has determined that the Patient Protection and Affordable Care Act will cover more than 94 percent of Americans.[66] The health care reform contains nine titles, each of which addresses how individuals with disabilities may be impacted.[67]

In addition to the ACA, the United States has passed two key civil rights laws for people with disabilities: the Rehabilitation Act of 1973 and the ADA. The Rehabilitation Act requires that entities receiving federal funds provide equal access to their programs and services for people with disabilities.[68] The ADA, meanwhile, contains four substantive titles, which prohibit discrimination on the basis of disability within a variety of public domains. The ADA and the Rehabilitation Act have improved the life of people with disabilities by increasing employment opportunities and access to public accommodations and services, including transportation. The ADA, in particular, has been instrumental in improving access to transportation and buildings and in increasing inclusion in society for people with disabilities. However, the ADA and Rehabilitation Act have also been criticized for only superficially addressing the root cause of disabled persons' inadequate access to health care; that is, institutional and structural discrimination.[69] For example, the ADA does not adequately address key areas such as access to employment or health care, nor does it protect individuals from prejudice or interpersonal exclusion in institutional settings.[70] The survey also found that Americans with disabilities faced many barriers and obstacles to obtaining jobs, including inadequate education and training, lack of transportation, pay discrimination, lack of job counseling, and being denied health insurance or other work-related benefits.[71] Currently, policies under the ACA address the lack or the denial of employer-based health

benefits for people with preexisting conditions; however 19.8 percent of disabled Americans reported being denied health insurance or other work-related benefits.[72] There is an apparent disconnect between the spirit of these laws and what is practiced by businesses and government agencies. Collaboration between each of these institutions is key to breaking down the barriers between the disabled community and jobs, work-related benefits, and quality health care.

How Does the ACA Impact People with Disabilities?

In the following section, we will discuss the ACA's positive impact on people with disabilities in three areas of this health law, as described in Roberts's article.[73] Specifically, we will focus on the ACA's effect on Medicaid, Medicare, and public benefits; how the ACA impacted the private health insurance industry; and lastly, the importance of ACA's recognition of the disability community as a health disparity.

Public Health and Benefits

Medicaid and Medicare

Medicaid has been regarded as the single largest source of health insurance for individuals with disabilities.[74] Medicaid covers hospitalization costs, physician's services, lab and x-ray services, medical equipment, outpatient services, and prescription drugs.[75] In the United States, Medicaid provides coverage to more than 8.8 million people with disabilities but does not account for the majority of adults with physical and sensory disabilities who are not insured.[76] Medicaid has shortcomings that contribute to the health accessibility of the disabled community. Often, beneficiaries have trouble locating health care providers who will accept Medicaid payments. Even when a provider is found, Medicaid recipients with disabilities often report barriers to obtaining care because of improper referrals and accessibility. Medicaid-managed programs have also been criticized for limiting individuals' "ability to choose from and access medical care."[77] Lastly, Medicaid has limited coverage, if any, when it comes to essential services such as dental, vision, personal care, and durable medical equipment.[78] Since Medicaid does not cover everything, many people typically obtain private supplemental insurance with high premiums, and most of the time beneficiaries still face out-of-pocket co-pay expenses.[79]

After the implementation of ACA, several provisions were designed to improve and expand Medicaid and Medicare coverage. The ACA expanded

the Medicaid program (effective January 2014) by allowing coverage and eligibility to anyone under the age of 65 with an income at or below 133 percent of the Federal Poverty Level.[80] Since the health care reform, Medicaid and Medicare programs now provide better coverage for ongoing and at-home health services.[81] The expanded Medicaid program also provides support for individuals requiring long-term care; for example, with the creation of community living assistance services, Community First Choice Option (CFC) is a new, optional Medicaid benefit that offers community-based living and associated services to individuals with disabilities and people needing long-term inpatient care or a nursing home. Government-run community-based services for individuals with disabilities have to adhere to standards of integration and care in accordance with the Olmstead decision.[82]

People with disabilities may require more health services, and they have experienced more barriers to accessing those services.[83] Some individuals were not able to qualify for Medicaid prior to the ACA, and some that did qualify still encountered restrictions on the type of services accessible to them. Further, the ACA requires insurance companies to cover assistive technologies such as a motor-powered wheelchair, which was not previously guaranteed. Additionally, the ACA mandated multiformat informational access in order to facilitate health promotion and education.[84] Nonetheless, doctors have been reluctant to make changes in their service so that they are more accessible to the disabled population, such as the millions of Americans who are deaf or hard of hearing.[85] In addition, individuals with learning disabilities encounter barriers accessing medical information. Maria Truesdale-Kennedy and colleagues found that women with intellectual disabilities experience barriers such as embarrassment and lack of information for breast cancer screening.[86] Further, these women experience feeling more anxious, fearful, and uncertain about the future outcomes than women without intellectual disabilities. In summary, though the ACA has been successful in breaking down some of the accessibility barriers, work still need to be done.

Private Health Insurance

Modifications to private health insurers are also to take place and positively affect people with disabilities. Health insurers are no longer allowed to impose lifetime caps on benefits. This modification is significant to people with disabilities because of their increased use of health services.[87] Further, the ACA also does not allow insurers to deny or restrict an individual's health coverage based on their health status. Lastly, private health insurers

are not allowed to rely on an individual's health status in setting insurance rates.[88] This is clearly a significant improvement, given that individuals with disabilities often need more services and end up paying more for those services. Thus, as of 2014, private health insurance companies may only rely on the following four factors when setting insurance rates: individual versus family coverage, geographical location, age, and tobacco use.[89]

Public Health

Health care reform had set many goals, including reducing health disparities within the population.[90] The ACA is one of the first federal laws to recognize people with disabilities explicitly as a health disparity group.[91] Surprisingly, prior to the ACA, people with disabilities were not formally recognized as a health disparities population, even though by definition they should have been. Specifically, health disparities are defined as "differences in incidence, prevalence, mortality, and burden of disease and other adverse health conditions that exist among specific population groups in the United States."[92] The recognition of disability as a health disparity group has been an important step toward including people with disabilities in health disparities research, which in the past has focused almost exclusively on racial and ethnic minorities.

Moving Forward: Policy Suggestions to Promote Inclusivity

Differences in disability terminology help illuminate the fact that legal or formal definitions of disability are in constant flux, along with the types of services, programs, and accommodations offered to the disabled community. Disability policy legislation was designed to improve the conditions of those living with disabilities; unfortunately, many issues are still unanswered. In response to the current needs, we provide several suggestions to help improve health care policy in the hopes of promoting inclusivity among the disabled community.

1. **Using a Biopsychosocial Model:** In defining disability, we described two models used to define disability: the social and medical models. We argue that there needs to be a balance between these approaches to include what the International Classification of Functioning, Disability and Health (ICF) refers to as a biopsychosocial approach. The biopsychosocial approach provides a new and coherent view of health through social and individual perspectives.[93] In this view, patient care does not focus solely on the disease and cure of a person but also on the patient as an individual and the contexts surrounding the situation.[94] Further, evidence suggests that health care professionals who have been trained

in the social model of disability had more positive attitudes toward individuals with disabilities than physicians trained under the biomedical model. Traditionally, health care professionals have treated disability as a disease or condition that needs to be cured; however, many chronic disabilities are not currently treatable and do not fit under the medical model.[95] By definition, the social model recasts "disability" from a functional limitation to a limitation imposed by the interaction between a person's impairment and their physical and social environment.[96] By including this perspective in our conception of disability, we as a society can broaden our myopic focus from the individual body of the person to the structural shortcomings of the society at large. It is time that scientists and researchers work together to adopt a universal definition of disability that is sensitive to the variety of needs of those within the disabled community. We also argue that government agencies should include the perspectives of individuals with disabilities in the adaption or the creation of disability terminology.

2. **Improving Patient-Clinician Communication:** Miscommunication and misinformation about disabilities in a health care setting have the potential to lead to erroneous assumptions by both the patient and physician. Small steps can be taken by both parties to increase communication and improve the quality of health care individuals with disabilities receive. The Accreditation Council for Graduate Medical Education (ACGME) is an organization that accredits post-medical degree residency and fellowship training programs in six areas.[97] Training testing under the ACGME is dependent on the accrediting institution; this accounts for interpersonal communication and patient care inconsistencies. Institutions should use standardized testing procedures when testing doctoral students on core competencies. Physicians should also be required to be tested on the core competencies every five years. Supplemental training should be offered when additional testing is done.
3. **Informal Support Networks in Policy and Program Development:** People with disabilities often rely on the social and emotional support services available in their environment. Strong support networks such as family members and friends can help individuals with disabilities live longer and healthier lives.[98] Those suffering from severe or chronic disabilities require the help of formal and informal support networks to gain access to health care services and accommodations.[99] Family and friends can be trained to help individuals with disabilities assimilate into different environments. Support can also be found within communities. Family members and friends of individuals with disabilities should be included in policy implementation and program development discussion. Their perspectives are invaluable, as they represent a different side of the spectrum of needs for people with disabilities.

Inclusivity is possible for individuals with disabilities; however, effort from multiple parties is necessary for this to occur. Interventions to improve physician and patient communication and interventions to reduce stigma of disability are vital. While individuals may be *disabled* by their conditions,

they are often handicapped by social and physical structures, biases, and harmful stereotypes. Physicians and external/internal support services are largely untapped resources as disability advocates and must be included in policy decisions and program implementation. Ultimately, these groups can best promote the well-being and equality of people with disabilities, if given the proper resources.

Acknowledgment

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Notes

1. We use the term "individuals with disabilities" rather than "disabled individuals" to avoid defining the individual by their disability.
2. World Health Organization, "Disability and Health," *World Health Organization Fact Sheet,* last reviewed December 2014. http://www.who.int/mediacentre/factsheets/fs352/en/
3. Robert Bernstein, "Nearly 1 in 5 People Have a Disability in the U.S., Census Bureau Reports," U.S. Census Bureau, report released July 25, 2012. https://www.census.gov/newsroom/releases/archives/miscellaneous/cb12-134.html
4. Ibid.
5. Lisa I. Iezzoni and Bonnie L. O'Day, *More Than Ramps: A Guide to Improving Healthcare Quality and Access for People with Disabilities* (New York: Oxford University Press, 2006), 10–11.
6. World Health Organization. "World Health Organization Fact Sheet."
7. Iezzoni and O'Day, *More Than Ramps.*
8. Ibid., p. 11.
9. The term disabled communities is also used throughout this chapter to designate communities that are self-identified as disabled.
10. Council for Disability Awareness, "Chances of Disability," *Council for Disability Awareness Overview.* Accessed July 16, 2015. http://disabilitycanhappen.org/chances_disability/
11. World Health Organization. *World Health Organization Fact Sheet.*
12. Jessica L. Roberts, "Health Law as Disability Rights Law," *Minnesota Law Review* 97, no. 6 (2013): 1963–2035 (Accessed May 24, 2015). http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2027534
13. Americans with Disabilities Act of 1990. Public Law 101–336. 108th Congress, 2nd session (July 26, 1990). Accessed July 12, 2015. http://www.ada.gov/pubs/adastatute08.htm