DOCTORS WITHOUT DISABILITY AWARENESS

The Role of Medical Training in a Profound Healthcare Barrier for People with Disabilities

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EXECUTIVE SUMMARY

People with disabilities (PWD) constitute the largest minority group in the United States (Bowen et al., 2020). An estimated 1 in 4 adults live with a disability (CDC, 2020). As the population of PWD grows, medical staff must meet their unique needs and provide them with the equitable, accessible, quality care afforded by their rights (ADA, 1990; CRPD, 2006).

To inform the development of disability-inclusive medical training standards, this review highlights physician bias as a profound barrier to healthcare for PWD. The vague cultural competency standards set by The United States Liaison Committee on Medical Education (LCME) lead to inconsistent, inadequate, and, in some cases, nonexistent disability awareness training. Consequently, physicians are ill-equipped to recognize personal prejudice or systemic medical field bias that views disability as an individual tragedy to be fixed or cured. Ultimately, healthcare disparities for PWD and evidence of physicians' and students' negative attitudes reveal the state of medical education in the United States, demonstrating the crucial role medical training plays in promoting equitable healthcare for PWD.

Methods

This report is based on a review of the literature on attitudinal barriers to PWD, physician bias, and the state of disability awareness training in United States medical schools. All included articles were required to come from reputable, peer-reviewed, or previously cited sources, clearly outline goals and methodology, and be published after 2000.

In addition to incorporating results from relevant literature, this report highlights the calls for better disability healthcare services and nondiscriminatory standards detailed in national and international statutes and medical school accreditation requirements.

Key Findings

Patient Experiences of Attitudinal Barriers

- PWD face healthcare disparities and negative interactions with the healthcare system.
    - PWD are less likely to receive cancer or STD screenings, Pap tests, cholesterol tests, tetanus shots, or dental cleanings (Pharr & Bungam, 2012).

Student and Physician Perspectives of Disability

- Physicians and trainees exhibit explicit and implicit negative biases against PWDs.
    - A recent survey of 714 physicians across 7 specialties found that 82% of participants reported that PWD live lower quality lives than people without disabilities when disability was the only factor considered (Iezzoni et al., 2021).
- Medical students and physicians desire more disability awareness training.
    - A survey of 376 family medicine doctors regarding the care of people with an autism spectrum disorder found that over 50% of the participants wanted more training in how to care for patients with developmental disabilities (Bruder et al., 2012). Only 36% of these providers previously received training in this area.

Rates of Disability Curriculum Inclusion

- A limited number of medical schools incorporate disability into their curriculum.
    - A 2017 study found that only 52% of medical schools (39/75) include disability awareness programs (Seidel & Scott, 2017).
- Schools with disability awareness training programs fail to center the voices of PWD.
    - 90% of medical schools with a program to teach trainees about disability were developed by physicians, not PWD (Seidel & Scott, 2017).

Benefits of Disability-inclusive Curriculum

- When medical schools adopt longitudinal, integrated approaches to disability awareness education, physicians and patients benefit.
    - Students who participated in a disability training program prioritized their patients' long-term health outcomes, whereas students without training only emphasized acute medical management (Santoro et al., 2017).

Recommendations

- Ensure health care professionals receive cultural competency training on disability
    - Set explicit disability inclusion requirements for medical school accreditation
    - Develop evidence-based curriculum that centers the voices of PWD
    - Implement evidence-based disability awareness curriculum to reduce bias
- Expand research on the role of medical training in attitudinal healthcare barriers to include intersectional experiences of PWD, including studies to understand the compounding effects of racial, gender, sexuality, and class bias
- Enforce legal nondiscrimination standards and require medical schools to ensure accessibility and opportunities for students and faculty with disabilities

INTRODUCTION

More than 1 in 4 people live with a disability in the United States (CDC, 2020). As chronic illness rates rise and the “baby boomer” population ages, the number of people living with a disability continues to grow (WHO, 2020). Currently, people with disabilities constitute the biggest minority group in the United States (Bowen et al., 2020). As a result, the medical field must prepare to serve people with varying abilities and needs. As Dr. Lisa Iezzoni contends, “Almost every physician providing direct patient care - from treating tiny neonates to centenarians - will likely see substantial numbers of persons with disabilities” (Iezzoni et al., 2012). This diverse patient population shares the challenge of finding healthcare services to meet their needs in a system where they face many disparities (Crossley, 2015).

People with disabilities (PWD) experience disparate health outcomes, in part, because health professional training fails to provide aspiring clinicians with appropriate ways to serve people with unique needs and conditions. The World Health Organization (WHO) found that “people with disabilities were more than twice as likely to report finding healthcare provider skills inadequate to meet their needs, four times more likely to report being treated badly, and nearly three times more likely to report being denied care” (WHO, 2020). To inform the development of disability-inclusive medical training standards, this paper investigates the pervasive discrimination against PWD resulting from attitudinal barriers created by biased healthcare professionals in the United States. The vague cultural competency standards set by the LCME lead to inconsistent, inadequate, and, in some cases, nonexistent disability awareness training. Consequently, physicians are ill-equipped to recognize personal prejudice or systemic bias that views disability as an individual tragedy to be fixed or cured. Ultimately, healthcare disparities for PWD and evidence of physicians' and students' negative attitudes reveal the state of medical education in the United States, demonstrating the crucial role medical training plays in promoting equitable healthcare for PWD.

METHODOLOGY

This report is based on a review of recent literature on attitudinal healthcare barriers to PWD, the prevalence of physician bias, and the state of disability-inclusive education in medical training in the United States. Recognizing that physicians interact with patients with varying physical, mental, and cognitive impairments, the literature review examined the inclusion of disability in medical school training broadly. To find relevant data on the state of disability training, the research employed the University of Washington Libraries Database, PubMed, and Google Scholar. Of the articles identified in this search, 28 were included in the final report. Each study selected for inclusion was published after 2000 to focus on relevant literature. Moreover, each article clearly outlined its goals and methodology and came from a reputable source, had been peer-reviewed, or had been cited by others. Recognizing the many stakeholders in clinical training and healthcare provision, articles included perspectives from patients, medical students, and medical professionals.

In addition to reviewing current literature, this paper includes an overview of medical school accreditation standards and national and international disability rights policies that advocate for equitable healthcare for PWD. The policy documents include the Americans with Disabilities Act of 1990 (ADA), the United Nations’ Convention on the Rights of Persons with Disabilities (CRPD), and the United Nations’ Sustainable Development Goals (SDGs). Articles about bias, discrimination, and access to quality healthcare were selected from these documents as a basis for the rights of PWD. Additionally, medical school accreditation requirements set by the LCME were analyzed for disability inclusion. These standards and policies were compared with statistics representing the current quality of care PWD receive in the United States.

Clarifications of Terminology

Disability:

"A disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions)" (CDC, 2020).

Medical model of disability:

The medical model views disability as inherent imperfection or brokenness: a problem for physicians to fix. It manifests in healthcare by forcing interventions, like drugs or surgeries, on people with disabilities. It assumes people with disabilities want a cure and implies people with disabilities need to conform to an able-bodied norm.

Ableism:

"Ableism is the discrimination of and social prejudice against people with disabilities based on the belief that typical abilities are superior. At its heart, ableism is rooted in the assumption that disabled people require 'fixing' and defines people by their disability. Like racism and sexism, ableism classifies entire groups of people as 'less than', and includes harmful stereotypes, misconceptions, and generalizations of people with disabilities." (Eisenmenger, 2019).

POLICY FRAMEWORK AND ACCEDITATION REVIEW

National and International Disability Rights Policy

Several national and international documents highlight the right to accessible, quality healthcare for PWD. For instance, the ADA ensures PWD have equal opportunities by prohibiting discrimination based on disability. Namely, Title II and Title III require healthcare entities to provide reasonable accommodations and make their facilities accessible to enable PWD to receive medical care (ADA, 1990; Pacific ADA Center, 2020). Mandated accommodations include providing patients with disabilities the right to choose communication options that fit their needs, such as hearing aids, a real-time translation device, braille, large fonts, or American Sign Language.

Beyond the national disability rights standards established by the ADA, international policy documents advocate for the rights of PWD, condemn discrimination based on ability, and support the importance of accessible, inclusive healthcare. For example, the Sustainable Development Goals (SDGs), 17 objectives adopted by United Nations Member States in 2015, include healthcare access and inclusion in the third global goal (UNDESA, 2020). By 2030, this goal aims to “ensure healthy lives and promote well-being for all at all ages” (UNDESA, 2020). Similarly, Article 25 of the CRPD prohibits healthcare discrimination based on disability (UNCRPD, 2006, Art. 25). The CRPD states that PWD deserve respect for their humanity, dignity, and autonomy. Health care professionals must provide PWD with the same quality of care as people without disabilities. Moreover, it asserts that “persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability” (UNCRPD, 2006, Art. 25). Unfortunately, although the U.S. signed the CRPD in 2009, it has not ratified it, limiting the legal role and benefits of the treaty (Pacific ADA Center, 2020; National Council on Disability, 2021).

Medical School Accreditation Standards

The LCME sets accreditation standards within the International Association of Medical Colleges for medical schools granting Doctor of Medicine (MD) degrees (LCME, 2003). These accreditation standards include curriculum requirements for the training of aspiring physicians that all institutions must document their compliance with. Clinical instruction must include “preventative, acute, chronic, continuing, rehabilitative, and end-of-life care” and “cover all organ systems” (LCME, 2003, ED-13). In addition to medical knowledge, medical school curriculum must “prepare students for their role in addressing the medical consequences of common societal problems” (LCME, 2003, ED-20). Recognition of disability implicitly surfaces in this standard because many of the disabling aspects of impairment, including inaccessible infrastructure and negative biases, arise from the social construction of disability.

Furthermore, medical schools must prepare students to address the consequences of common societal problems by prompting them to recognize their biases and “demonstrate an understanding of the manner in which people of diverse cultures and belief systems perceive health and illness” (LCME, 2003, ED-21 and ED-22). This standard suggests physicians need to recognize how the medical model of disability promotes medical paternalism and may force unwanted treatments on PWD in an attempt to “fix” them. PWD may not perceive their disability as a problem that needs fixing, especially if their condition is congenital or long-term (Shakespeare et al., 2009). For example, members of the Deaf community may refuse cochlear implants because, for them, deafness is a cherished piece of their identity, not a broken part to be fixed (Byrd et al., 2011).

Additionally, medical schools must teach aspiring physicians communication skills and ethics (LCME, 2003, ED-23). The LCME standards require that medical students demonstrate respectful patient care and receive evaluation and feedback regarding their performance during the progression of their curriculum. Teaching medical students to communicate and treat patients with dignity necessitates training them to interact with people, including those with disabilities, who communicate in unconventional ways. For example, physicians need training on how to interact with patients who use sign language or need an interpreter because it is their right under the ADA to be informed and included in their care. Therefore, the responsibility falls on medical schools to ensure physicians learn to treat PWD with dignity and respect.

ANALYSIS OF EVIDENCE

The State of Healthcare for People with Disabilities

> *"A perception of physician bias is not only likely to affect a patient's trust in a particular physician, but also may extend to decreased trust in the medical profession and the health care system more generally; especially if patients perceive the bias to be systemic, rather than confined to isolated individual providers" (Crossley, 2003).*

Despite the numerous documents that recognize their right to care, PWD experience prevalent healthcare disparities. Pharr and Bungam define a health disparity as "the preventable, population-specific differences in access to health care, disease presence and health outcomes'' (Pharr & Bungum, 2012). For example, PWD frequently face a lack or denial of care, discriminatory interactions with medical professionals, and low-quality services. Although only 18.1% of physicians agree that PWD receive inequitable care, further evidence from the WHO demonstrates that "[PWD are] more than twice as likely to find healthcare providers' skills inadequate to meet their needs" (WHO, 2020; Iezzoni et al., 2021).

Broken Trust and Low-Quality Care in a Biased System

Physician bias hinders essential patient-physician trust. If a patient perceives their healthcare provider as dismissive, ableist, or paternalistic, he or she may withhold private medical information, ignore physician recommendations, or stop following a treatment plan (Crossley, 2003). Moreover, as Mary Crossley observes, "a perception of physician bias is not only likely to affect a patient's trust in a particular physician, but also may extend to decreased trust in the medical profession and the health care system more generally" (Crossley, 2003). As a result, patients who perceive physician bias as a systemic issue are less likely to seek follow-up care because they feel excluded from the medical system. Therefore, bias erects an attitudinal barrier to care.

Aside from breaking patient-physician trust, provider bias leads to lower quality healthcare for PWD. When providers make assumptions about a patient's needs or life activities as a person with a disability, they may neglect elements of care they would regularly provide for people without disabilities. In severe cases, these assumptions put patient lives at risk. For example, at the intersection of gender and disability, physicians often assume women with disabilities are asexual (Shakespeare et al., 2009). Consequently, they fail to provide women with disabilities with the same resources and standard of preventative care as women without disabilities. Differences range from neglecting to provide information about contraceptives to omitting screenings for sexually transmitted diseases or cervical cancer (Pharr & Bungam, 2012). Likewise, physician bias, including assumptions about quality of life, against PWD can lead to other forms of healthcare discrimination. One study found that "[PWD] were less likely to have had their height or cholesterol checked, to have received a tetanus shot, or to have had their teeth cleaned" (Pharr & Bungam, 2012). These examples illustrate how negative provider bias can influence the healthcare PWD receive.

An Intersectional View of Attitudinal Healthcare Barriers

“The vulnerable in health-care are typically members of groups who are already disadvantaged on many levels” (Fitzgerald et al., 2017).

The biased, low-quality healthcare PWD face parallels the mistreatment of other marginalized groups. The medical profession, a historically white, heterosexual, non-disabled, and male field, discriminates against numerous identity categories, including disability, gender, sexuality, race, and class. As observed for disability, prejudice surrounding sexuality and gender present attitudinal barriers that adversely affect patient experiences. Patients are understandably unwilling to believe in a system that neglects their needs and oppresses their personhood. Similar to how physicians assume women with disabilities are asexual and do not require standard reproductive care, like STD screenings, providers often assume sexual minority women do not need these services either (Tarasoff, 2016). Moreover, sexual minority women avoid seeking care for fear of discrimination and heterosexist bias, echoing the breakdown of patient-provider trust seen for PWD.

The pattern of physician bias and broken trust is relevant for racial and ethnic minorities too. In the same way providers judge a person's life activities based on disability, providers tend to assume a patient's qualities and lifestyle based on race. Studies show that healthcare providers perceive Black patients as “less intelligent, less able to adhere to treatment regimens, and more likely to engage in risky health behaviors than their White counterparts'' (Hall et al., 2015). A similar bias against Hispanic patients assumes they are “unlikely to accept responsibility for their own care and more likely to be noncompliant with treatment recommendations'' (Hall et al., 2015). These attitudes influence the care these patients receive and raise additional attitudinal barriers to healthcare for PWD. Crossley recounts the story of one Black woman with diabetes that illustrates the intersection of race, gender, and disability in a biased healthcare system:

> “Over the course of more than two decades, a physician prescribed daily insulin injections for an African-American woman with diabetes. The physician prescribed only one injection per day for the woman, despite accumulating medical evidence that two or even more injections per day would better control the diabetes. . . he was concerned that the patient would not comply with a more demanding treatment regimen. As a result of the failure to control her diabetes, the patient ultimately lost both her legs below the knee to amputation” (Ridder, 2001, as cited in Crossley, 2003).

Despite the evidence suggesting the harm caused by physician bias, few, if any, studies look at these issues through an intersectional lens. The majority of studies examine race or class or gender or sexuality or disability as individual determinants of health, yet they do not elucidate their multiplicity for an intersectional identity. Consequently, the limited literature on disability bias in medicine as an intersectional issue restricts the understanding of how PWD experience the healthcare system.

Lack of Experienced Providers: Another Barrier to Care

People with disabilities necessitate physicians with expertise working with their unique needs or diagnoses; however, finding an accepting and qualified provider is difficult. Notably, the CDC suggests 1 in 3 adults with disabilities lacks a regular healthcare provider (CDC, 2020). Some experts propose the shortage of doctors with the expertise to treat adults with disabilities stems from inadequate exposure and training opportunities (Warfield et al., 2015). Medical education rarely includes sufficient information about the conditions and disease processes associated with common disabilities or the necessary communication skills to promote productive physician-patient interactions. Consequently, insufficient exposure to PWD and their needs limits the pipeline of physicians specializing in the care of this patient population.

The shortage of qualified physicians providing care to PWD makes transitioning from pediatric to adult care difficult. A 2010 study showed that youth with special healthcare needs cannot find medical teams prepared to continue their care once they reach adulthood (Patel & O'Hare, 2010). This disorganized transition leaves them stranded with no one to meet their medical needs, and many frustrated young adults with disabilities stop seeking healthcare services.

The ease of finding a pediatric or adult health care provider corresponds to disparate training on disability for pediatric residents and internal medicine residents. Namely, 73% of pediatric residents received training about supporting young adults with disabilities compared to only 13.8% of internal medicine residents (Patel & O'Hare, 2010). These statistics illustrate how exposure to disability contributes to the number of experienced physicians and, ultimately, whether patients with disabilities receive care.

Student and Physician Perspectives of Disability

Misconceptions About Quality of Life

> ***"Physician: So as of right now, his quality of life – he doesn't have much of one.***
> ***Melissa Hickson: What do you mean? Because he's paralyzed with a brain injury, he doesn't have quality of life?***
> ***Physician: Correct" (Doebirch et al., 2020).***

Physicians and medical students assume PWD live lower quality lives. On June 11, 2020, a 46-year-old Black man with quadriplegia and a brain injury named Michael Hickson died in a Texas hospital of COVID-19 after his physicians stopped treating his pneumonia (Doebrich et al., 2020). At the time of his death, St. David's South Austin Medical Center possessed the resources to continue Hickson's care, yet, by their definition, his medical team determined he did not have sufficient quality of life. In a conversation with one of his physicians, Michael's wife, Melissa Hickson, was told, "'his quality of life is different from [other patients]. [The other patients] were walking, talking people'" (Doebrich et al., 2020, p. 393). Some may argue that Hickson's death resulted from one ableist doctor or group of doctors; however, it derives from pervasive systemic biases in the medical field. Accordingly, his death is not an isolated case.

In spring 2020, months before Hickson's death, physicians at an Oregon hospital questioned providing life-saving measures to Sarah McSweeney, a young woman with an intellectual disability (Shapiro, 2020). McSweeney's caretaker recalls one doctor replying, "'Oh, she can walk? And talk?'" (Shapiro, 2020) when the caretaker advocated for McSweeney's continued care before her untimely death. These egregious incidents exemplify the repercussions when physicians fail to recognize and combat their own biases.

Beyond these tragic cases, numerous studies indicate that physicians consistently assume that PWD live lower quality lives than people without disabilities (Shakespeare et al., 2009). The COVID-19 crisis exposes the "structural racism, sexism, classism, and ableism" (Doebrich et al., 2020, p. 393) ingrained within the medical system that leads to substandard medical care for PWD, yet these are not new issues. In a recent national survey of 714 physicians across seven specialties, 82% of participants reported that PWD live lower quality lives than people without disabilities (Iezzoni et al., 2021). In contrast, research suggests 54.3% of people with severe disabilities report an excellent quality of life, a "disability paradox" that contradicts the overwhelming prejudice of medical professionals (Albrecht & Devlieger, 1999).

The disconnect between physician assumptions and the lived experiences of PWD may arise from poor disability education in medical training. Most medical school courses disregard the lived experience of PWD (Shakespeare et al., 2009). Consequently, Tom Shakespeare observes that "most [medical students] are sympathetic and display concern but have negative views about the experience of living with disability" (Shakespeare et al., 2009). Due to the normalized oppression and exclusion of PWD in society at large, healthcare professionals may not recognize their prejudice or its effects on the allocation of resources or their treatment of patients with disabilities (Crossley, 2003; Shakespeare et al., 2009). Therefore, health professional training must include cultural competency to raise awareness of ingrained biases, like assumptions about quality of life.

Ableism and the Coexistence of Health and Disability

The majority of physicians are subject to implicit bias, even if they report holding no explicit discriminatory attitudes against PWD. A survey of over 25,000 physicians found that 60.5% of providers are aversive ableists, meaning they possess high implicit bias against PWD despite demonstrating minimal explicit prejudice (VanPuymbrouck, Friedman, & Feldner, 2020). Another 10% of physicians are symbolic ableists, meaning they hold high implicit biases against PWD and exhibit explicit prejudice. Many of these physicians ascribe to the common misconception that disability can not coexist with health because it is an inherently broken state of existence.

In a traditional care dynamic, the physician is the assumed expert with the power to correct and cure defects while the patient passively complies. Reflecting the medical model of disability, "physicians viewed their goal as 'curing' persons with disabilities, explicitly eliminating or treating the very impairments or deficits that defined individuals as 'crippled' or 'handicapped'" (Iezzoni & Long-Bellil, 2012) until the 1970s. Residual medical model bias continues to influence physicians. They often assume what patients with disabilities want, feel, and need without considering their perspectives. Bowen and colleagues suggest that "without explicit disability training, health care providers are likely to view disability as a negative health outcome and to hold low expectations for the function and quality of life of [PWD]" (Bowen et al., 2020). Hence, ableist attitudes persist without purposeful intervention.

Fear, Anxiety, and Apprehension

Along with implicit and explicit ableist attitudes, numerous studies on the perspectives of healthcare providers serving patients with disabilities found that trainees and physicians felt fear, anxiety, lack of confidence, and apprehension about treating patients with physical and intellectual disabilities (Wilkinson et al., 2012; Satchidanand et al., 2012; Santoro et al., 2017; Symons et al., 2009). These attitudes do not support positive patient-physician interactions (Minihan et al., 2011). For instance, one primary care physician reflected that "'Sometimes I feel overwhelmed by the visits [with people with intellectual disabilities], like when my patient hit my computer and knocked it off the desk and broke the screen'" (Wilkinson et al., 2012). Another physician commented, "'Well, I definitely do not have the knowledge I need to take care of people [with intellectual disabilities], and I've had patients in my practice die because of it"' (Wilkinson et al., 2012). These views represent more than a handful of providers. In general, fewer than 50% of physicians feel confident about their ability to provide the same quality of care to patients with disabilities as patients without disabilities (Iezzoni et al., 2021).

Furthermore, providers' confidence in serving patients with disabilities predicts their inclusion of PWD in their practice. Only 56.5% of physicians (n = 714) reported strong agreement that they would welcome patients with disabilities into their practice (Iezzoni et al., 2021). The rates of inclusive attitudes were higher for physicians who reported feeling "very confident" about treating PWD and lower for those with less confidence. The connection between confidence and inclusivity highlights the importance of promoting positive physician attitudes towards disability.

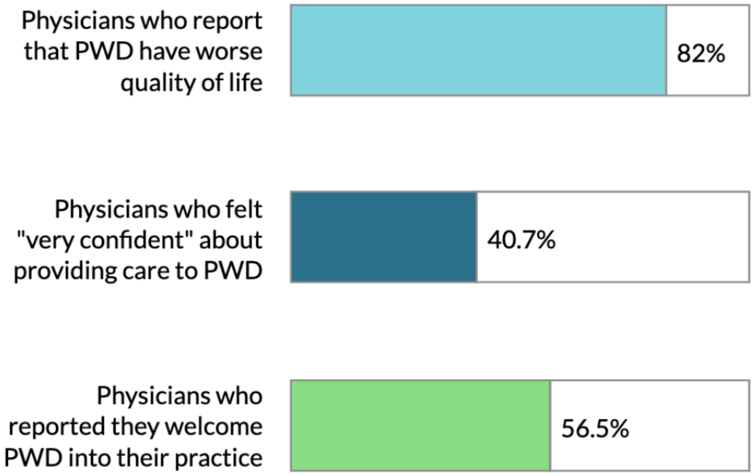

Figure 1. Physician Attitudes Towards Patients with Disabilities The majority of physicians contend that PWD have worse quality of life, less than 50% felt comfortable treating patients with disabilities, and only half welcome PWD (Iezzoni et al., 2021).

A Desire for Better Training

Medical students and healthcare professionals resoundingly crave better disability awareness training (Bruder et al., 2012; Santoro et al., 2017; Symons et al., 2009; Wilkinson et al., 2012). In a survey of 376 family medicine doctors regarding the care of people with an autism spectrum disorder, more than half of the participants wanted more training in caring for patients with autism or other developmental disabilities (Bruder et al., 2012). Notably, only 36% of the physicians in this survey previously received training about working with people with cognitive or developmental disabilities (Bruder et al., 2012). Trainees share this desire to prepare themselves to treat PWD. In a survey of medical and dental students, 75% of respondents expressed interest in serving patients with intellectual disabilities (DREDF, 2007). Institutions must meet the need for better disability education.

The State of Disability Inclusion in Medical Training

Number of Medical Schools Including Disability in Curriculum

Medical students, junior doctors, and practicing physicians report receiving inadequate training about disability in medical school (Shakespeare et al., 2009; Symons et al., 2009; Wilkinson et al., 2012; Bruder et al., 2012). One family medicine doctor reflected, '"I don't remember any specific curriculum directed towards people with intellectual disabilities. . . I feel like most of my training has been on the fly"' (Wilkinson et al., 2012). Low rates of inclusion of disability training support these views. As of 2011, only seven accredited medical schools used standardized patients with disabilities to teach students about disability (Santoro et al., 2017). Furthermore, a 2017 survey of 75 medical schools suggests only "fifty-two percent (39/75) of [medical] schools [have] a disability awareness program" (Seidel & Scott, 2017). However, the authors suspect the "actual rate [of disability awareness training] across all American medical schools may be as low as 23% if we assume that there was a selection bias where schools without programs were less likely to respond to the survey" (Seidel & Scott, 2017). Considering that the LCME accreditation standards went into effect more than a decade earlier in 2004, these rates are shockingly low. Therefore, the inclusion of disability awareness programs highlights the failure of the LCME to promote disability cultural competency in medical training.

Even when medical schools incorporate disability awareness training into their curriculum, they fail to center the voices of PWD. For 90% of the medical schools with a program to teach trainees about disability, physicians developed the training objectives, not PWD (Seidel & Scott, 2017). Disability rights advocates recognize that "having today's physicians, even when genuinely well-intentioned, retain control over designing disability-related training programs for future doctors may miss critical issues in caring empathetically and effectively for [PWD]" (Iezzoni et al., 2012). Consequently, the physician-developed curriculum may be less effective at teaching medical students disability cultural competency topics.

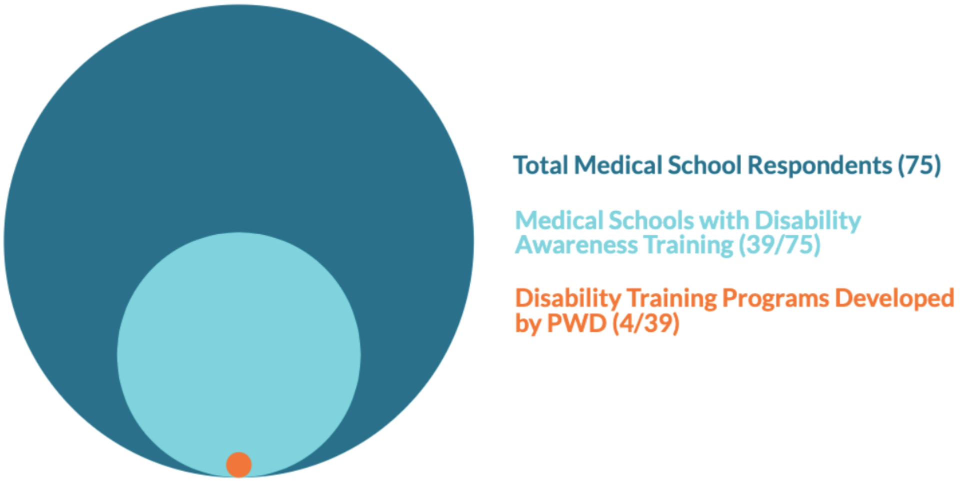

Figure 2. Number of Medical Schools with Disability Training Programs in 2017 Only 52% of medical schools reported providing disability awareness training programs (Seidel & Scott, 2017). 10% of those programs indicated their programs were developed by PWD.

Limited Disability Perspectives Represented in Medicine

The low rates of medical students, physicians, and faculty who identify as disabled limit the representation of disability rights perspectives in medical school and restrict interpersonal disability education. Learning alongside a classmate with a disability directly challenges negative assumptions and promotes positive attitudes about disability (Shakespeare et al., 2009). Unfortunately, despite nondiscrimination requirements set by the ADA, most medical schools fail to accommodate a full spectrum of disabilities, hindering many qualified PWD from entering the medical field (Marcelin et al., 2019). Studies show that less than 3% of medical students enrolled in accredited allopathic medical schools self-identify as disabled (Meeks & Herzer, 2016). The number of practicing physicians is barely higher at 2-10%, potentially due to disabilities acquired with age (DeLisa & Thomas, 2005). Of these professionals with disabilities, it is unclear how many of them hold positions as faculty, mentor trainees, or participate in the medical training process. Regardless, appalling disability representation rates in the medical field provide one explanation why paternalistic views of disability persist. Without peer-peer interactions or mentorship opportunities with PWD in medical training, attitudinal bias goes unchecked, and disability perspectives go unheard. This exclusion illustrates an additional way the medical field fails to prepare disability-inclusive physicians and may contribute to why disability topics are so often forgotten.

An Immediate Need for Better Curriculum

> ***“A training program might contribute a skill, such as the ability to position a patient with a physical disability for a physical examination, to a student's “toolkit.” That skill will only be put into practice, however, in the presence of attitudes that prompt the student to use it” (Minihan et al., 2011).***

Inconsistent Approaches to Disability Education

The evidence is clear: physicians and healthcare professionals need better training to serve PWD. The cultural competency standards in the LCME provide no explicit guidance on disability awareness education; therefore, the implementation of disability awareness training is inconsistent, ineffective, or nonexistent (Iezzoni et al., 2012; Crossley, 2015; Santoro et al., 2017). Most medical schools that include disability awareness present this content via conventional passive lectures, even though evidence shows this format reduces negative attitudes less effectively than interpersonal encounters with PWD (Anderson et al., 2010; Satchidanand et al., 2012; Shakespeare & Kleine, 2013; Seidel & Scott, 2017).

Along with employing ineffective delivery methods, the topics included in disability education vary and tend to ignore social aspects of disability. Echoing the medical model of disability, many medical training programs reduce disability to a deficit and focus on skills to examine, diagnose, or treat PWD (Anderson et al., 2010; Bowen et al., 2020; Shakespeare et al., 2009). While providing more technical skills training may reduce the anxiety and fear physicians report about treating patients with disabilities, it does not help physicians combat bias (Wilkinson et al., 2012; Satchidanand et al., 2012; Santoro et al., 2017; Symons et al., 2009). As Minihan and colleagues conclude, “technical competence is a necessary component of what the generalist physician should know about patients with disabilities, but technical skills alone are not sufficient to provide high-quality primary care” (Minihan et al., 2011).

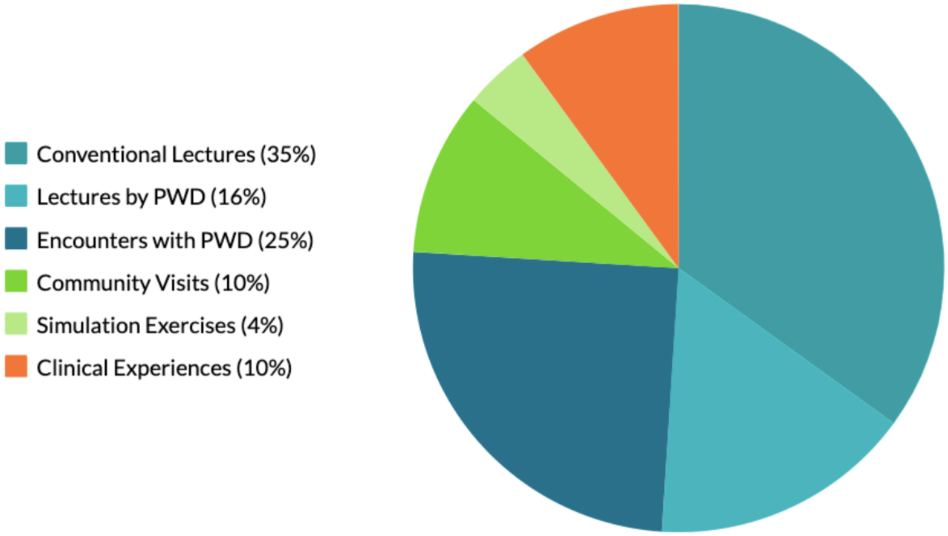

Figure 3. Distribution of Approaches to Disability Awareness Most medical schools with disability training programs use conventional lectures or host events where students can interact with PWD or their families (Shakespeare & Kleine, 2013).

In contrast to conventional lectures, interpersonal encounters with PWD in a community or clinical setting provide impactful experiences for professionals and trainees that reduce bias more effectively than the other common approaches to disability awareness training (Satchidanand et al., 2012; Shakespeare & Kleine, 2013; Bowen et al., 2020). These education methods center PWD. Examples of interpersonal learning methods include computer-based training approaches such as an interactive virtual module featuring a deaf-blind patient, seminars taught by PWD, service-learning with PWD, and other opportunities to engage with PWD (Shakespeare & Kleine, 2013). Unfortunately, less than 50% of medical schools that include disability in their curriculum take these approaches to disability awareness education (Shakespeare & Kleine, 2013).

The Interdependence of Knowledge and Attitudes

Physicians are unlikely to use their skills to treat PWD unless they also receive training to address explicit and implicit biases. Paula Minihan observes that “knowledge, attitudes, and skills do not act independently” (Minihan et al., 2011). Without teaching medical trainees about the social aspects of disability, medical training leaves out a crucial component to bias reduction. Hence, disability rights advocates argue that:

> “Education in disability should range from clinical information about specific conditions, practical issues about medical procedures, through to exploration of the human rights approach to disability. It is important for professionals to understand not just disease, but also the experience of living with disability” (Shakespeare et al., 2009).

Noting the overall low rates of disability awareness inclusion in medical school curriculum, this suggests few institutions provide appropriate training that includes both social and technical aspects of serving PWD. Moreover, in regards to disability, medical schools are not meeting the standards set by the LCME to teach medical students to recognize how social factors influence health (LCME, 2003, ED-20-22).

A Shift Towards Disability Inclusive Medical Training

> ***“Early and frequent encounters with people with disabilities aid student’s knowledge, skills and attitudes about providing care for such patients” (Santoro et al., 2017).***

A growing body of research supports the benefits of implementing disability into medical school training (Bruder et al., 2012; Minihan et al., 2011; Santoro et al., 2017). Evidence suggests “direct and positive exposure to a disfavored or marginalized group increases positive attitudes toward that group. . . these positive exposures can favorably influence even those deeply entrenched and implicit biases” (Minihan et al., 2011). Namely, encounters with PWD early in medical school provide medical students with essential knowledge, practical skills, and positive perceptions (Santoro et al., 2017). Moreover, spending time in a rehabilitation center, learning how to transfer a patient from a wheelchair, or visiting a patient with a disability in his or her home reduced bias and improved disability awareness (Santoro et al., 2017; Iezzoni et al., 2021). As disability rights gain recognition, medical training programs across the country are beginning to adopt disability-inclusive curricula that promote active interpersonal interactions with PWD. These programs contrast typical passive learning and better prepare aspiring physicians to treat this underserved patient population.

For example, the University at Buffalo School of Medicine offers one of the most in-depth, well-developed, and longitudinal programs for disability awareness (Santoro et al., 2017). The curriculum integrates education about disability into all four years of medical school training:

- The first year introduces students to disability studies through interactions with PWD in small group settings and traditional lectures.
- Students learn clinical examination skills with standardized patients with disabilities in year two.
- By the third year, the family and internal medicine rotations integrate disability topics.
- During their final year, students can participate in a four-week primary care elective serving PWD.

The curriculum designers at the University at Buffalo School of Medicine noted that “early and frequent encounters with people with disabilities aid student’s knowledge, skills and attitudes about providing care for such patients” (Santoro et al., 2017).

Similarly, a study on the effects of the disability education program at the University of Massachusetts Medical School also highlighted the importance and benefits of an integrated disability awareness curriculum. Before the program, each student filled out a survey about their experience with PWD. Most students indicated a lack of exposure to PWD and limited awareness of the ADA (Santoro et al., 2017). After participating in the program, students reported that it “helped better their skills for interviewing patients with disabilities and made them aware of the needs of [PWD]” (Santoro et al., 2017).

The Benefits of Integrated Disability Education

> *“It is important for professionals to understand not just disease, but also the experience of living with disability” (Shakespeare et al., 2009).*

Integrated disability education in medical school curriculum positively impacts physician attitudes towards PWD. A study conducted at the Stanford University School of Medicine found that students who participated in a disability training program prioritized their patients’ long-term health outcomes, whereas students without training only emphasized acute medical management (Santoro et al., 2017). This behavior change reflects a shift away from the medical model of disability and a move towards a social model that recognizes how constructed environments and social factors contribute to the lived experiences of PWD. Moreover, it exemplifies how education and exposure translate to better quality care. Once students learn about disability, they recognize the equal humanity of PWD and see their patients as more than people with impairments to be cured. Other studies repeat these findings, showing that students exhibit more professionalism, compassion, and competence in treating PWD after receiving disability training (Symons et al., 2009).

Beyond these behavioral and attitudinal benefits, exposure to disability through an integrated approach increases the number of students who envision themselves serving PWD in the future (Symons et al., 2009). After completing a family medicine clerkship in a specialized facility providing care for PWD, one student remarked, “‘Before this experience, I had reservations about disabled patients, but I am now more comfortable working with them in the future’” (Symons et al., 2009). Such evidence provides a path forward for overcoming the shortage of experienced professionals to care for PWD. By integrating disability education in medical training in a consistent and longitudinal approach, attitudinal barriers to care break down, and future physicians develop the skills, awareness, and confidence to provide quality care for the growing population of PWD.

RECOMMENDATIONS FOR FUTURE WORK

> *“. . . we believe that disability-related training is appropriate at all levels of health care education and practice and suggest that. . . these efforts would occur within a context of ‘substantial rethinking’ of physician training and not simply through the addition of a few disability awareness courses” (Minihan et al., 2011).*

- **Ensure health care professionals receive disability cultural competency training**
    - **Set clear accreditation requirements that explicitly acknowledge disability** Evidence indicates disability cultural competency training is inadequate in United States medical schools. Therefore, national medical school accreditation standards should include explicit requirements for medical schools to teach trainees about social factors and technical skills needed to serve PWD.
    - **Implement institutional changes to support disability cultural competence**
        - Medical schools must adopt evidence-based, integrated, longitudinal curriculum that promotes interpersonal engagement with PWD and reduces physician bias.
        - Medical training must provide students with mentorship, feedback, and assessment to promote bias recognition and establish skills to effectively and respectfully serve PWD
        - Medical training should expand training and specialization opportunities for healthcare professionals to pursue careers serving PWD and fill physician shortages for this patient population.

- **Develop evidence-based curriculum that reduces bias and centers the voices of people with disabilities** Medical schools need effective curriculum to teach trainees about disability. In line with the legal standards set by the CPRD, Kirschner and Curry determined six core competencies of disability awareness education:

> 1. “A conceptual framework of disability in the context of human diversity, illness, the life span, and the constructed social and cultural environments;
> 2. Skills for assessing the level of disability, the functional consequence of illness, and the social and physical environments of patients with disabilities along with considerations for treatment and management;
> 3. General principles and etiquette for interacting with persons with disabilities;
> 4. Appropriate knowledge about interdisciplinary care teams, the different roles and functions of various team members, and other disability-specific resources in both the health care system and the community;
> 5. The legal requirements of the Americans with Disabilities Act in health care and the concepts of universal design - not just for the built environment, but for all aspects of patient-related care, including medical equipment, staff procedures and training, and communication practices;
> 6. Patient-centered care and the importance of understanding quality of life from patients’ perspectives” (Kirschner & Curry, 2009).

- **Expand research on the role of medical training in attitudinal healthcare barriers to include intersectional experiences of PWD** Given the limited literature examining how intersectional identities compound attitudinal barriers to healthcare, more research must investigate the relationships between medical training and racism, sexism, ageism, and homophobia.

- **Enforce legal nondiscrimination standards and require medical schools to ensure accessible opportunities for students and faculty with disabilities** PWD are underrepresented in the medical field. Making the profession more accessible and inclusive will increase the recognition of disability rights perspectives.

CONCLUSION

This literature review synthesizes the available evidence of attitudinal barriers to healthcare for PWD and the role of medical education through the lens of multiple healthcare stakeholders. It provides a preliminary framework to understand how medical education impacts physician attitudes about disability, and ultimately, the quality of healthcare PWD receive.

Despite limited recent quantitative research and statistics on physician perspectives, rates of disability education in medical school, and the efficacy of current approaches to disability cultural competency training in the United States, this review reveals several emerging themes.

First, prevalent physician bias creates an attitudinal barrier to healthcare for PWD. Evidence indicates extensive ableism in the medical field and prevailing misunderstandings about quality of life for PWD. Consequently, provider bias breaks patient-physician trust and leads to lower-quality care.

Additionally, physicians and trainees desire more disability awareness training. Providers report feeling anxious and unprepared to serve PWD, yet many medical schools do not include disability awareness programs in their curriculum. Therefore, medical training requires better disability education.

Finally, interpersonal exposure to PWD reduces bias, improves provider attitudes, and promotes positive patient experiences. Moreover, longitudinal curriculum integrated over four years effectively reduces negative attitudes about disability, benefiting patients and physicians alike.

Overall, medical training fails to provide physicians with necessary cultural competency training for serving PWD, leaving them unconfident and unwelcoming towards this underserved patient population. As a result, PWD receive lower-quality healthcare. Given the success of disability awareness training programs to reduce prejudice and improve patient care, this report recommends that medical schools adopt disability-inclusive education programs, among other institutional changes.

Limitations

The inclusion of intersectional analysis in this report is limited by the current literature. During the literature selection process, few studies looked at physician bias through an intersectional lens. Instead reports tended to focus on one determinant or disparity.

Additionally, each study included in this report used varying definitions for disability. In some cases, the definition of disability was not explicitly stated. Due to this uncertainty and nonuniformity, some members of the disability community may not be represented in this analysis.

Furthermore, although they are beyond the scope of this report, economic and structural barriers to healthcare perpetuate inequities along with attitudinal barriers. Achieving equitable, quality care for PWD requires dismantling each barrier. Therefore, the call for better disability awareness education in medical training parallels the profound needs for affordable care, accessible facilities, and universally designed equipment.

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