Doctors and Disability: Improving Inclusion in Medical Education

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Abstract

Description
Disability is extremely common in the United States with 26% of adults identifying as having some type of disability. Oftentimes, people with disabilities need to access health care services frequently in order to receive adequate care and support. However, despite this need, medical students receive limited, if any, education about people with disabilities and how to appropriately provide medical care and interact with them. This lack of education exacerbates health care disparities experienced by people with disabilities. This article highlights these disparities as well as the history of disability and health care. Current advancements in medical education regarding people with disabilities are reviewed with suggestions for medical schools looking to improve or begin programming focused on people with disabilities. By covering the history and current difficulties experienced by people with disabilities accessing health care, as well as the best practices for educating medical students, this article takes steps to fill an important gap in the literature.

Keywords
disability; healthcare disparities; delivery of healthcare; intellectual disability; disabled persons; disabled children; persons with mental disabilities; developmental disabilities; social discrimination; medical ethics; medical education; graduate medical education; patient care

Disability and Health Disparities in Modern Medicine
Disability is defined by the World Health Organization (WHO) as an “interaction between individuals with a health condition (eg, cerebral palsy, Down syndrome and depression) and personal and environmental factors (eg, negative attitudes, inaccessible transportation and public buildings, and limited social supports).” Disability is a broad term that can include physical, intellectual, psychological, and communicative limitations. Examples can include sensory disabilities (eg, visual impairment, Deafness), physical disabilities (eg, paraplegia), developmental disabilities (eg, autism spectrum disorder, intellectual disability), and acquired disabilities (eg, stroke, traumatic brain injury). While some disabilities may be immediately evident, other disabilities, such as autism spectrum disorder, traumatic brain injury, and cognitive impairments, are often referred to as “invisible disabilities” and might not be readily apparent.

It should be noted that disability, as defined above, is not rare. In the United States (U.S.), 26% of adults have some type of disability. Although disability is very common, many barriers to adequate healthcare persist for people with disabilities (PWD). These barriers include physical barriers and barriers related to knowledge and attitudes of healthcare providers. Overall, PWD have reduced access to health care services, lower rates of preventative care screenings, and worse health outcomes than the general population. Additionally, PWD have reported being distrustful of the medical field.

Discrimination and Disability in the History of Medical Practice
The relationship between PWD and health care is long and complicated. PWD have faced historical discrimination in society for centuries, and this discrimination includes treatment...
within the medical system. Beginning in the nineteenth century, PWD were routinely removed from their families and institutionalized, often with no cause. In 1927, the U.S. Supreme Court ruled that the forced sterilization of PWD was constitutional in Buck v. Bell. The abuse and horrid conditions in institutions for PWD were famously revealed in a 1972 exposé by Geraldo Rivera entitled Willowbrook: The Last Great Disgrace. Since then, these institutions have largely been dismantled, but individuals with disabilities continue to face discrimination within the medical system. A full history of disability in healthcare is outside the scope of this article, but physicians should take steps to educate themselves on the historical interactions between doctors and PWD as well as how these interactions manifest in modern healthcare. Relevant resources include: “On the Borderland of Medical and Disability History: A Survey of the Fields”, “Social History of Medicine and Disability History” in The Oxford Handbook on Disability, an article titled “Disability, Medicine, and Ethics”, the guide “Three Things Clinicians Should Know About Disability”, and a recent article on the discrimination of PWD in healthcare during COVID-19.

Disability Is Central to the Patient Experience

PWD have reported fundamental problems regarding how healthcare is currently administered. A study on patient experiences revealed that healthcare professionals assume the quality of life to be low in PWD; however, that is often not the case as expressed by PWD themselves. Additionally, PWD report a lack of sensitivity and a hyper-focus on their disability from their healthcare providers rather than a focus on the reason for the visit. PWD also consistently report having to educate medical providers, staff, and trainees about basic aspects of disability. In pediatrics, parents of children with disabilities must often dedicate a significant amount of time and resources to advocating for their children and their needs.

In addition to these challenges with medical providers, PWD experience other barriers to healthcare related to their disability. For example, PWD report having difficulty understanding what their provider is communicating, which can be especially difficult for patients with communication disorders. Physical access and transportation barriers also frequently make it difficult for PWD to access healthcare appointments as needed. As of late, the COVID-19 pandemic has further exposed the barriers PWD face across the healthcare system as they have been deprioritized for lifesaving care for COVID-19.

Many Providers Feel Unprepared to Support PWD

PWD are not the only party reporting concerns regarding the relationship between disability and healthcare. Physicians and medical students routinely report being under-educated about treating PWD and uncomfortable treating them. It should be noted that some physicians, such as those specializing in physical medicine or rehabilitation, may be well versed in treating PWD. However, many other physicians including family practice physicians are not. In a 2012 study by Wilkinson and colleagues, primary care physician participants compared interacting with patients with intellectual disabilities to “operating without a map.” Similarly, a 2015 review by Sharby and colleagues found that health professionals and healthcare students are often unsure of how to interact with PWD. Additionally, physicians often believe that barriers to healthcare experienced by PWD are only related to access, and they fail to consider attitude- or knowledge-related barriers such as implicit bias against PWD or a lack of understanding/awareness of disability on the part of healthcare providers. Symons and colleagues (2009) conducted a needs assessment with medical students, medical educators, and community stakeholders as part of the development of a curriculum at the State University of New York (SUNY) Buffalo to teach medical students to care for PWD. Critically, fourth-year medical students in a family medicine sub-internship reported that care for PWD had not been addressed during their medical school experience. Residents reported that while they routinely care for PWD, they did not feel prepared to do so. Furthermore, the faculty identified a lack of attention in the curriculum to issues related to caring for PWD. Based on these alarming reports by PWD and medical providers alike, it is important to examine the current state of medical education as it relates to disability.
Disability Is an Afterthought in Medical Education

The U.S. Surgeon General, WHO, and the American Association of Medical Colleges have all called for increased training on disability for physicians. Despite this request, only about half of U.S. medical schools report having any type of disability awareness program as part of their curriculum. While it is important to consider whether physicians are being educated about PWD, it is also important to consider how they are being educated.

Historically, disability has been viewed and taught within healthcare using the medical model of disability. The medical model defines disability as “...a product of biology, in which a congenital or chronic illness, injury, or some other departure from ‘normal’ biomedical structure or functioning has consequences for an individual’s activities of daily living and, ultimately, for that individual’s ability to participate in society...” The medical model conceptualizes disability as a long-term or permanent illness or injury, and proposes to ‘fix’ it, or at least ameliorate its effects at the level of individual functioning. It is a model based on deficit, with the assumption that an individual’s impairment(s) affects every aspect of the life of people with disabilities, invariably in a negative manner. Thus, having a disability is associated with the need for medical treatment, financial help, and psychological and social support. This model is the lens through which disability is viewed in most medical schools and healthcare facilities. However, a criticism of this model is its hyper-focus on the deficits of PWD, its omission of their abilities, and its failure to recognize how society contributes to the difficulties experienced by PWD. Many assume that PWD have a lower quality of life or that their life is not as valuable as those without disabilities. This erroneous belief is in many ways supported by the medical model.

The medical model can be viewed as in opposition to the social model of disability. The social model of disability was first defined in 1976 by a group of disability rights activists who asserted, “In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. It follows from this analysis that having low incomes, for example, is only one aspect of our oppression. It is a consequence of our isolation and segregation, in every area of life, such as education, work, mobility, housing, etc.” This model is sometimes preferred by PWD as it recognizes the role of society in shaping disability, and it removes the focus from PWD’s deficits. Although historically, the social model of disability has been most well-known within the disability community, it is starting to gain recognition in other circles, including some health professions.

There is a clear need for increased and improved education on disability for physicians in training. In order to improve medical education regarding PWD in the U.S., it is necessary to review the literature to determine the current state of disability training within medical education and evaluate existing curricular options and their effectiveness.

Review of the Literature: Disability Training in Medical School

While opportunities for education on disability exist in both medical school and post-graduate training, medical school is a natural time to begin this education, as physicians in training are just beginning their careers. Below is a brief review of current methods of teaching medical students about PWD and how to care for them. While readers may be familiar with methods that are more commonly used in medical training, such as standardized patient encounters, it is still helpful to review how these methods can be adapted for teaching about PWD. Additionally, other methods, such as a flipped classroom, are more recent developments in pedagogy and necessitate a more detailed explanation. The studies below can also serve as examples for medical schools seeking to begin educational experiences focusing on PWD.

Standardized Patient Encounters

A common method used to teach clinical skills to medical students is the standardized patient encounter. This method holds true when
teaching about PWD. In some instances, PWD participate in the encounter; in other instances, able-bodied people act as PWD.

A 2011 review of the literature explored the benefits of using standardized patients to teach medical school students how to treat PWD competently. The authors discuss 7 programs that used standardized patients to teach their students about disability. Some programs used standardized patients who did not have disabilities to portray patients who did, whereas others recruited actual PWD for the encounters. The common goals of the programs were to teach students how to communicate with PWD, to provide students an opportunity to interact and increase their comfort level with PWD, and to debunk common notions that PWD cannot speak for themselves or have a low quality of life. The 3 schools that had evaluative standardized patient programs used checklists to assess performance. The authors concluded that standardized patients provide an opportunity to meet the goals of medical education in developing students’ clinical skills and improving and evaluating students’ understanding of and attitude toward PWD. Based on their findings, the authors suggest that medical schools seeking to incorporate disability into their curriculum should consider using standardized patient encounters to achieve this goal.

A more recent article by Crane and colleagues (2021) evaluated the effectiveness of a standardized patient encounter with PWD in increasing medical students’ comfort level in treating patients with disabilities. The 169 third-year medical students who participated in this study completed a standardized patient encounter with a PWD. During this interaction, they took a social and medical history. The researchers measured the students’ comfort level caring for PWD before and after the encounter as well as 1 year later. Results showed that the encounter resulted in a significantly improved comfort level treating PWD. Students reported being satisfied with this exercise, and 1-year follow-up data suggested that students desired more content on disability during their medical education.

In summary, multiple studies have shown that standardized patient encounters are effective at teaching medical students to care for and interact with PWD. It is worth noting that there are inconsistencies across curricula regarding whether PWD participate in these encounters or if able-bodied actors portray PWD instead. To ensure the most realistic experience possible, and to move toward involving PWD directly in the development of medical school education, it is this author’s recommendation that PWD participate in these encounters, as opposed to able-bodied people portraying PWD, as PWD can draw on their experiences with physicians to inform the activity and accurately answer questions.

Modules
Another popular way to teach about PWD is using a module, sometimes also called a workshop. Modules vary in length and depth with some lasting a few hours and some spanning a semester. Agendas for these modules can look drastically different based on length and focus, but they have been shown to benefit medical students by teaching them about PWD and about how best to treat them in the clinical setting.

Bu et al. (2016) investigated the effect of a 2.5-hour module on medical students’ attitudes toward physical disability. The module included lectures, panel discussions with PWD, and video presentations. Of the students, 237 were surveyed after the module, and their results were compared with a control group (n=251) that did not participate in the module using the Disability Attitudes in Health Care (DAHC) scale. The intervention group exhibited significantly more positive attitudes on 6 of the 17 DAHC items. These results further support that even brief modules can positively impact medical students’ attitudes toward PWD, which is critical to reducing healthcare disparities for this population.

Additionally, Lynch et al. (2019) evaluated the outcome of a longer, 12-week module called “Understanding Disability”. Students completed an online survey at the beginning, middle, and end of the module. The module included lectures from allied health professionals, academics, and advocates with disabilities. It also featured anatomy laboratory sessions related to disability, a visit to a rehabilitation hospital, and case presentations. The module
also included an overview of WHO’s International Classification of Function, Disability, and Health, which is a classification of health domains that measure disability at the individual and population levels. During the hospital visit, students were provided an opportunity to interact directly with PWD. A total of 65 students completed all 3 data collection points (beginning, middle, and end of the module). Data collection included measures on anxiety, attitude, competency, and empathy. Results showed that there were significant changes in mean scores from the beginning to the end of the module across all four construct measures. The authors note that direct contact with PWD had a specific impact on the students’ levels of anxiety and empathy. This study supports the implementation of disability-focused modules in medical education and the inclusion of PWD in the development and delivery of those modules.

A variety of module types have been shown to effectively improve the understanding of and attitudes toward PWD by medical students. Because modules are easily adjustable to fit the needs of a medical school and the existing curriculum, these might be a good first step for medical schools interested in introducing disability into their program.

**Flipped Classroom**

A flipped classroom is an educational technique in which students read and study material before discussing the topic at hand and participating in related activities. This exercise allows students to come to the table with background information and can lend itself to deeper, more meaningful educational experiences in the classroom.

In a 2017 study, researchers used a flipped classroom, including an online module, a panel of parents of children with disabilities, and an online discussion. Medical students completed pre-and post-assessments to evaluate their knowledge of special education law and practices, which are crucial in treating children with disabilities as children often rely on these resources for rehabilitation and support services. Participants in this study consisted of second-year medical students enrolled in a pediatric medicine course. A total of 118 students completed the pre-and post-assessment, which was optional and anonymous. As a result of the flipped classroom approach, students showed an increased understanding of special education laws and practices. Qualitative analyses showed that students also recognized the importance of learning the content in order to support their patients and their families.

Although the use of a flipped classroom module appears to be gaining steam in pedagogy, including in medical school, there is relatively little research on its effect on the attitudes of medical students toward PWD. More research is needed to determine if using a flipped classroom is a preferred approach to teaching students to better care for PWD, though it has shown great promise for increasing depth of understanding and comfort level in other areas of medical education.

**Clinical Placements/Exposure**

Clinical placements centered around PWD may take place as part of a module, as noted by Lynch et al. They can also be incorporated into the medical school curriculum alongside other standard clinical placements.

A 2012 study by Woodard and colleagues detailed the integration of clinical exposure to PWD within the disability curriculum at the University of South Florida Health, Morsani College of Medicine (USF). Medical students spent 1 to 2 half-days per week for 12 weeks in clinical exposure activities. These included community site visits such as at a Shriner’s Hospital, a VA Hospital spinal cord unit, and an Easter Seals preschool program. Some students also presented health topics (eg, first aid) to community groups with intellectual disabilities. This helped the medical students learn how to best communicate and interact with this population. Students also visited PWD in their homes to dispel common negative assumptions about the quality of life of PWD. The medical students who participated in these activities, along with classroom-based learning about disability, exhibited improved knowledge, attitudes, and comfort in caring for PWD as measured by pre-and post-assessments. This curriculum is quite comprehensive and makes excellent use of first-hand interactions with PWD.

In a 2008 needs assessment by Mayer et al., the authors suggested, among other methodologies, that clinical experiences with PWD in
rehabilitation units, outpatient clinics, home visits, community centers, and skilled nursing facilities be incorporated into the curriculum.\textsuperscript{39} Because many other skills are taught through clinical exposure in medical school, incorporating exposure to PWD could be an effective teaching method. Additionally, this type of exposure has the added benefit of providing students with the opportunity to build real-world relationships with PWD to better understand the lives they lead.

Because many clinical skills within the health professions are taught via clinical placements, and because these placements expose learners to a variety of real-world patients and situations, medical schools should consider incorporating clinical placements focused on PWD into their programming. Medical schools should prioritize physical medicine and rehabilitation rotations in order to give students access to physicians who specialize in treating individuals with disabilities.\textsuperscript{40} Look to the rehabilitation professions (eg, occupational therapy, physical therapy, and speech-language pathology) as a model for this as these programs routinely prioritize these types of placements as a part of their curricula. Additionally, these programs have identified how to provide quality interactions with PWD that result in meaningful interactions and relationships that can in turn improve the clinical practice of healthcare professionals. Such interactions are often guided by a professional who is experienced interacting with PWD in a respectful and skilled manner.

**Conclusions**

It is clear that there is a need for increased and consistent education about PWD in medical schools. Both the healthcare and disability communities have been calling for this for some time, and research is beginning to catch up by detailing effective curricular methods. These needs include standardized patient encounters, modules, and direct clinical exposure. Standardized patient encounters appear to have the most backing in the literature, though modules are also a popular, low-resource, and effective method. The concern with both of these methods is that they do not necessitate direction interaction with a PWD as some standardized patient encounters use able-bodied actors and modules do not always include PWD. Therefore, there is a need for more research on the effectiveness of direct clinical exposure to PWD as part of the medical school curriculum. Additionally, medical schools could use more guidance as to how they can feasibly prioritize this type of placement and carry it out consistently for all students. It may be helpful to prioritize placements with physicians who specialize in physical medicine or rehabilitation as well as borrow from other allied health professions who incorporate these types of placements routinely (eg, speech-language pathology, occupational therapy, and physical therapy).

While more research is needed, studies across the past decade have provided examples of a variety of methods to incorporate teaching on and with PWD into the medical school curriculum. Since the inclusion of disability programming in medical school is meant to benefit PWD, it is absolutely crucial that their input be prioritized when designing this type of programming.

**Resources**

Presently, there are a variety of resources available for medical students or physicians interested in improving their knowledge and practice around disability.

**General resources:**

- The Association for University Centers on Disabilities (AUCD) is an excellent resource on all things disability.\textsuperscript{41} Additionally, AUCD has centers called Leadership Education Neurodevelopmental and Related Disabilities (LEND) programs at universities across the country that train health professionals, including physicians, on how best to support PWD.
- The Alliance for Disability in Health Care Education is a non-profit organization that focuses on integrating disability content and experiences into healthcare training programs.\textsuperscript{42} Their website includes a wealth of resources for both students and practitioners.
- As mentioned previously, it would also be beneficial for physicians to educate themselves on the history of disability and the disability rights movement as well as how
PWD have experienced and interacted with the medical profession. Understanding this history can provide meaningful context to clinical interactions with PWD. For experience with advocacy for and by PWD, consider contacting your local Protection and Advocacy (P&A) organization. Each state in the U.S. has a P&A that is part of the National Disability Rights Network, which provides legal and advocacy services for people with disabilities. These organizations may have resources on disability and information on how to get involved in advocating for PWD in your area.

Resources geared towards physicians:
• The Health Care for Adults with Intellectual and Developmental Disabilities Toolkit for Primary Care Providers is hosted by the Vanderbilt University Kennedy Center. It provides a wide range of information, including a guide to communicating effectively with patients with disabilities, gathering informed consent, physical health issues, behavioral and mental health issues, and tables that provide information about diagnosing and treating certain conditions.

• The Centers for Disease Control and Prevention offers a website that provides disability and health information for health-care providers. It provides suggestions for interacting with each patient, as well as a lengthy list of helpful resources.

• Mount Sinai provides tips for treating patients with physical and sensory disabilities. These tips include general suggestions as well as specific suggestions for treating patients who are blind or have low vision, those who are Deaf or hard of hearing, and wheelchair users. All of these resources are excellent places to begin for physicians wishing to improve their care of PWD.

• For medical students, there is a primer by Bosques et al. that addresses how to be a “disability education champion” in your medical school. This article would be an excellent resource for those who wish to advocate for PWD while still in medical school.

Conflicts of Interest
The author declares she has no conflicts of interest.

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