

Editorial

Medical delivery without representation?: Examining disability representation within the healthcare community

Justin Ramsey^{a,*} and Christopher Raffi Najarian^b

^a*Bethany Children's Health Center, Bethany, OK, USA*

^b*Akron Children's, Akron, OH, USA*

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Abstract. Individuals with disabilities comprise approximately 13% of the overall population. This editorial explores recent events that may involve ableism. The recent COVID pandemic created a rapid need and pressure to develop ventilator allotment policies. Many concluded several state policies were discriminatory in nature toward persons with disabilities (PWD). Lack of disability representation in medical fields may contribute to such discrimination within state and hospital medical policies. The underrepresented numbers of PWD in medical fields are explored. We conclude that improved education for all medical providers is needed. Possible strategies for improving healthcare representation and delivery within the United States are discussed.

Keywords: Equity, inclusion, healthcare

Does representation of persons with disabilities in medicine and other healthcare matter? Individuals with disabilities represent 13–15% of the overall population [1]. The Centers for Disease Control and Prevention reports that 26% of adults have a disability and 13% of the population demonstrates mobility-related physical impairments and/or disabilities [1, 2]. We will explore the topic of representation of disabled individuals and their healthcare through our perspective as two physicians with cerebral palsy.

One striking and recent example of the marginalization of the disabled community occurred during the COVID-19 pandemic. The utilitarian policies regarding potentially life-saving ventilator treatment represent the height of ableism in the 21st century

United States. For the purposes of our discussion, ableism is defined by the Oxford English Dictionary as “discrimination in favour to of able-bodied people” [3]. Multiple states initially employed such policies that posited rationing of care based on the presence of intellectual and physical disability, which many thought were illegal according to the Americans with Disabilities Act, the Rehabilitation Act, and the Affordable Care Act. While decisions have to be made when resources are scarce, these policies were inequitable in that they prioritized those who were younger and healthier [4]. The Washington State Department of Health suggested that patient triage should consider “loss of reserves in energy, physical ability, cognition, and general health,” [4, 5] which largely ignored the benefits those with disabilities could receive from receiving intensive care and seemed to make discriminatory judgements based on perceptions of “quality of life.” Other states held

*Corresponding author: Justin Ramsey, MD, Bethany Children's Health Center, Bethany, OK, USA. E-mail: JRamsey@bethanychildrens.org.

similar policies, including Alabama, Pennsylvania, Kansas, Utah, and New York [4]. Complaints were filed with the Office for Civil Rights (OCR), with resolution often leading to policy change with more general guidance being issued [4]. The lack of specificity in some policies may have opened the door to possible reallocation of ventilators from chronic users. The delay in releasing the finalized New York State Ventilator Allocation Guidelines lead to concerns from members of the task force itself about lack of universal adoption of the guidelines across New York state hospitals [6]. This was a set-up for the introduction of bias and inequity. As stated by Ellison and Ballan, “The most effective way to reduce bias with the New York State Allocation Guidelines would have been to incorporate the voices of PWD [persons with disabilities], those most directly affected and likely to be.” [6] As physicians with developmental disabilities, we have grown up with friends, who have both physical and intellectual disabilities. It is clear based on conversations with those individuals that there is an awareness that they are viewed as “less” than the general population. One of us, prior to his medical training, was told by a group of physically and intellectually disabled adults in a service organization: “Remember us. You are one of us, and we need people [like us] to have a voice.” In a time of medical scarcity, it is so important to make sure that individuals with physical and intellectual impairments have a voice. There are infamous historical examples of disability-based discrimination and eugenics throughout human history. The COVID ventilator allotment discussion is a modern example of disability discrimination and ableism. Philosophers over time have warned about the lack of knowledge contributing to history repeating itself.

Current physician perceptions related to the dual questions of improved representation and improved access are a key uncertainty that has been recently studied. In a survey of over 700 physicians, Iezzoni et al. found that over 80% perceived the quality of life of individuals with disabilities to be less than that of nondisabled individuals [7]. The same survey indicated that only 40% of the same physicians felt “very qualified” to treat individuals with physical disabilities [7]. Another major conclusion of the study found that only 56% indicated that they would “strongly agree that they welcome individuals with disabilities into their practices” [7].

In the article, “I Am NOT The Doctor For You: Physicians Attitudes For Caring With Individuals With Disabilities,” perceptions about treating

individuals with disabilities were recorded from 14 practicing physicians [8]. Several practical and monetary barriers were noted, relating to physical architecture of office space and the cost of specialized equipment such as a wheelchair scale [8]. Billing and reimbursement were other barriers that were cited. One physician reported that the cost of hiring an interpreting service to accommodate patients who communicate using sign language was higher than the reimbursement for those patient visits [8]. We acknowledge that there are very real restrictions with regard to appropriate equipment and financial constraints that hinder many physicians from providing access for the disabled population. Based on our own personal histories as patients with physical disabilities, well-meaning treating physicians have often asked for advice on what test to order or medications to prescribe based on our own knowledge set. We, as physicians, are concerned that if we struggle finding individuals with appropriate knowledge or equipment, the task may be overwhelming for others with less medical training. This also manifests itself within our professional practice settings. We have personally seen and heard stories from other healthcare professionals with physical disabilities regarding physical barriers to accessibility within hospitals. Even in these institutions, which state their core values of diversity and inclusion, it is common for accessibility concerns to be pointed out with little response from facility authorities. For example, security doors (accessibility barriers) have been left in place, which has limited access to main transition points. Security alternatives, such hydraulic doors with card access, have not been examined, and access by individuals with disabilities remains limited. Also, individuals who benefit from wheelchairs have been placed in second-story offices without elevator access as opposed to more accessible work areas.

It is known that disability is more prevalent among those with heart disease and that the risk of cancer is higher for individuals with physical disabilities. In a study researching cancer, disability, and patient experience, certain patterns were evident. Architectural and physical barriers were listed as obstacles for appropriate physical examinations [9]. There were also concerns that signs and symptoms were falsely attributed to the disability rather than to the underlying oncologic process [9].

We suggest that these discrepancies could be improved by boosting the low number of disabled students and learners in medical schools and other healthcare-related fields. By amplifying disabled

voices in healthcare, greater opportunities will arise for those voices to achieve the leadership positions that are directly involved in the medical system level of decision making, which has a powerful influence on the disabled community at large, in a manner that comprehensively captures their diverse experiences.

There has been at least a small group of individuals who have researched the inclusion of individuals with physical disabilities into medical school and other forms of medical training. In 2016, individuals who reported a disability to medical schools were approximately 2.7% of all applicants [10]. A follow-up study indicated an overall increase to 5.9% in 2021 for allopathic schools [11]. An important study limitation that was discussed was non-disclosure rates of disability from medical students. Most of the disabilities recorded included attention-deficit/hyperactivity disorder, learning disabilities, or psychological disabilities [11]. In the 2021 study, approximately 27% of recorded disabilities were categorized as the following: deaf/hard of hearing, visual impairments, mobility-related disabilities, chronic health conditions, and other functional disabilities [11]. A separate study regarding technical standards examined 15 newly formed medical schools and their technical standards requirements. Most did not include easily located technical standards requirements online [12]. Thirteen percent of the 15 medical schools included discussion of accommodation in their technical standards language, and 73% included language that was restrictive for individuals with “physical or sensory disabilities” [12].

From our conversations with deans of student affairs and admissions from two separate medical schools, it is our impression that they feel their schools do reasonably well assisting disabled students with accommodation requests. Diversity, equity, and inclusion are frequently discussed, and this leads to searching for unique applicants. One dean discussed his school’s formal efforts to enroll first generation, veteran, and rural-based applicants, though there were not similar efforts directed at disabled applicants. Both deans supported the idea that representation of diverse student backgrounds does ultimately enhance patient care. While many medical school websites do not contain easily visible disability inclusive language, these deans felt their school’s technical standards documents were generally open and inclusive of disabled applicants. The other dean noted that admissions decisions are voted on anonymously in his institution, leaving the

possibility that unconscious biases may still influence those decisions. But do these generally positive thoughts bear themselves out when data is held under scrutiny?

We had the opportunity to have a discussion with Dr. Lisa Meeks, Ph.D., who was a lead researcher in the reviewed studies. She believes most medical school representatives are well-intended and that there may be a lack of awareness of methods that have already been created to help improve inclusion for those with disabilities into medical school training. Regarding actions medical schools could take to encourage inclusion of individuals with disabilities, she advises making technical standards easily accessible on admission websites. She also suggests ensuring that links to the disability and inclusion office page are readily visible. By making these resources difficult to find, prospective disabled applicants may think that schools are not interested in inclusion. Additionally, based on her experience working with medical schools, she advises individuals with visible disabilities to make a disclosure and describe how their disability may be addressed technically. Individuals anticipating a need for accommodations should be proactive and demonstrate a solutions mindset by sharing ideas and literature about what is possible. In this way, they lower the burden for admissions departments who may not be as familiar with accommodations or technology.

We believe that the inclusion of disabled individuals in the representation of healthcare is not limited to discussions of medical schools or physicians. We spoke with representatives who are trained in physical therapy (PT) who felt there is generalized acceptance of inclusion as a principle for the larger PT society. When interested parties have reviewed technical standards, there are still significant physical restrictions for admission to training programs. Some have suggested that the evolution of roles for physical therapists such as in care coordination, coaching, and telehealth programs should be considered when reviewing technical standards for PT programs. Published studies indicate that similar concerns exist between medical school and PT programs. A 2015 study showed that as many as 5–7% of individuals in therapy programs may have disabilities, of which many may be sensory in nature [13]. The same study noted “only 43.5% of faculty and 38.6% of students believed that PTs and PTAs with physical disabilities should have an unrestricted license to practice; more than half of respondents in each group favored

some type of restricted practice, or a stipulation that required accommodation, to ensure safe practice” [13]. In a UK study reviewing the experiences of 15 students with learning disabilities, anxiety around disclosure and lack of a consistent accommodation process was noted [14].

The same could be said for the nursing field. For instance, there are often lifting restrictions that are considered standard for most hospital job descriptions. There are several nursing roles including care coordination and education which may not require adherence to such standards which are nevertheless are considered baseline expectations at many hospitals around the country.

It is apparent upon reviewing literature and discussion with our interviewees that expanding resources would improve patient care for individuals with disability. Better inclusion of disabled students in healthcare training programs is part of the solution and may be achieved in part by increasing the number of scholarship opportunities for those individuals. Many conditions that we treat as physicians, such as cerebral palsy and spina bifida, are considered “pediatric” in nature but actually comprise a larger percentage of the affected adult population. Many adult or “general” training programs provide little to no exposure to such individuals, which may contribute to healthcare gaps. Developing appropriate curricula and medical training for all providers may improve the understanding of the medical community as well. We would encourage future studies funded by interested organizations, and perhaps the government, on the subject. Grants for appropriate equipment and accessible architecture will facilitate higher quality care for people with physical disabilities.

Individuals with disabilities represent a significant portion of the general population. These individuals add to the diversity of thought and practice in healthcare and represent important perspectives and experiences that would benefit larger policy conversations. There is evidence that the healthcare system has room to improve care delivery to people with disabilities. As long as there remain obstacles to entering healthcare fields for physically disabled individuals, important voices will continue to be stifled. We acknowledge that this editorial is being placed in the *Journal of Pediatric Rehabilitation Medicine*, which has a sympathetic audience. The discussion should be expanded to additional journals representing the broader medical and academic communities.

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Evelyn Kostiniuk, BKin, MSc Student, Rehabilitation Science, Faculty of Rehabilitation Medicine, University of Alberta.

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