

# Improving Accessibility And Quality of Care for Patients with Disabilities

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*“My brother, Jason, spent his days in a bed or wheelchair. He required 24-hour care, and my mother, Gail, was the primary person who carried out that dependency work over his 23 years on earth. Jason was visibly disabled, and Gail is invisibly so. For each, ‘being disabled’ could hardly be more different. My mother faces a host of distinct stigmas due to being a woman, due to the invisibility of her disability, and due to its concomitant pain. Doctors, both male and female, often discount what she says or simply refuse to take her as a patient. Her doctors don’t see her on the days she cannot get out of bed because on those days she must cancel. When she can finally make the appointment, she walks in, and much is assumed. To get the type of care she needs, my mother often finds herself in the opposite situation of my brother: she has to emphasize her ‘disabilities’ to get care. With Jason, we often had to deemphasize his ‘disabilities’ so people would see his life as one worth living and thus one worth care.”<sup>1</sup> — JOEL MICHAEL REYNOLDS*

In 2013, approximately 1 in every 5 adults in the U.S. reported a disability.<sup>2</sup> In the health care sector, the percentage of patients with disabilities or patients who will soon have disabilities is far higher. Despite this fact, the education and training health care professionals receive concerning disability and working with patients with disabilities is often insufficient.<sup>3</sup> While it is unreasonable to expect health care administrators or providers to be experts on every facet of disability, there are steps that anyone involved in health care can take in order to improve the health outcomes of disabled patients and ensure they receive accessible and quality care across medical specialties and institutions.

In fact, it is especially crucial for health care workers to better understand the experiences of patients with disabilities because it is too often the social, not medical, facets of disability that most directly impact quality of life and overall health outcomes for people with disabilities.<sup>4</sup> Social determinants of health for people with disabilities include unemployment, poverty, social isolation, lack of access to both basic and specialized care.<sup>5</sup> These factors contribute to the development and exacerbation of impairments and chronic diseases.<sup>6</sup>

## DISABILITY AND SOCIETY

People with disabilities are highly stigmatized within our society and across the globe.<sup>7</sup> The media often present disabled people through just two dominant narratives: tragedy and overcoming. The “tragedy narrative” depicts disabled people as pitiable because their lives have been ruined by their condition. The “overcoming narrative” builds upon that story, but then portrays disabled people as tenacious individuals who succeed “in spite of” their condition. In both cases, it is assumed that the obstacle and problem is

the mind or body of the individual unfortunate enough to be disabled.

These narratives centrally inform how the general public imagine what it is like to live as a disabled person. Yet, this image is considered misleading, if not simply false, in the view of many disability communities and all those across the globe who have fought for disability rights over the last 50 years. Such communities instead argue that “the social model” of disability is in many respects more accurate.<sup>8</sup> The social model suggests that while people indeed have various impairments, it is the societal response to such differences that often causes difficulty and disadvantage. It is society that by and large “disables,” not one’s impairments. To better understand this view, consider that disabled people face unjust discrimination across nearly every aspect of social life. They are more likely than non-disabled people to be unemployed, to be victims of crime, to live in poverty, and to lack equal access to adequate education, housing and transportation.<sup>9</sup> The Americans with Disabilities Act of 1990 was passed, in part, in recognition of the widespread social discrimination people with disabilities face. Through its passage, it also made disabled people the largest legally protected group in the country.<sup>10</sup> Although accessibility has certainly improved since the passage of the ADA, there is still significant progress to be made in recognizing the rights of disabled people and in remedying stigma and social discrimination, including in health care.

#### UNDERSTANDING ABLEISM

There is a word for the type of discriminations that people with disabilities face: ableism. “Ableism” refers to the assumption that disabled people are inferior to able-bodied people. It also refers to the results of that assumption, such as practices that “oppress, discriminate against, and stigmatize those who are not able-bodied.”<sup>11</sup> While it is increasingly common for medical educators to discuss the roles of racism and sexism, ableism currently gets less attention.<sup>12</sup> Yet, ableism is an essential concept for health care workers to understand if they wish to provide equitable

and just care for patients with disabilities and, by extension, all patients. As is the case with racism and sexism, it is entirely possible for someone with good intentions to unwittingly support ableist practices and ways of thinking.

Consider the difference between the phrases “confined to a wheelchair” and “uses a wheelchair.” The first sounds restrictive — as if the person is imprisoned — while the second provides a more neutral characterization, one that better fits the self-description of most wheelchair users. Or consider the phrase “Alzheimer’s patient” versus a “person with Alzheimer’s disease.” The former

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emphasizes the disease, while the latter centers on the person. Disability rights advocates in the United States have long called for the second approach, which is referred to as “person-first” language.<sup>13</sup> But language use is the tip of the ableist iceberg. Ableism is not just about how people talk about disability, but about how the world is, how we think it should be, and how we have set it up to be.

For example, consider the issue of accessibility. If you use a wheelchair and the entrance to a building you wish to enter has stairs, the very design of the building signals that it is not made for you. You are not welcome. From the developers to architects to construction workers to current people who own and run the building, the fact that anyone who cannot use stairs cannot get in is not an accident. It is part of the very logic of the building and those who maintain it. In a case like this, ableism fundamentally limits

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the possibilities of people with disabilities — not because of their bodies or minds, but because of how people have intentionally designed things to exclude them. While one might expect that accessibility would not be an issue in health care settings, patients report that it too often is. Examples of inaccessibility in health care include the lack of height-adjustable exam tables, inaccessible restrooms, videos without closed captioning, or doors that are too heavy for patients to open.<sup>14</sup>

While inaccessible buildings may seem uncontroversially problematic, consider quality-of-life assessments. Multiple studies have found that nondisabled people significantly overestimate the impact of impairment (disability) on quality of life. That is to say, able-bodied people expect the quality of life of someone who is disabled to be much lower, on average, than what disabled people actually report.<sup>15</sup> Some studies have found that health care providers estimated the quality of life of disabled people to be even lower than the estimates of members of the general public.<sup>16</sup> This may be due at least in part to the fact that many providers interact with disabled people primarily in times of crisis, for example, immediately after a severe injury or when experiencing an exacerbation of symptoms. Practitioners are less likely to encounter disabled people when their patients' lives are going well, and thus may not have a good understanding of how a patient's impairment or chronic illness fits into their everyday life and activities and how their disability may in fact be a positive component of their identity and community life. In many senses, it is easy to make unwarranted assumptions about how a health condition impacts a person's life and what they hope to accomplish through medical interventions. This is one of the reasons it is vital for providers to learn about the values, goals and actual lived experiences of their patients with disabilities. How well providers communicate with patients

plays a significant role in patient satisfaction and impacts patients' willingness to follow through on provider recommendations.<sup>17</sup>

### **IMPROVING HEALTH OUTCOMES FOR PATIENTS WITH DISABILITIES**

Having discussed how social factors impact the health and lived experience of people with disability as well as the powerful role that ableism plays in both the social and medical determinants of health for people with disabilities, we will now offer a few concrete recommendations.

#### **Connections with Disability Communities**

Given that disabled patients — like all patients — are likely to have difficulties that extend beyond what can be addressed by health care providers, it is important to be aware of community resources. For example, Centers for Independent Living, or CILs, are nonprofit agencies (whose board members and staff are constituted by at least 51 percent disabled people) that offer numerous services to disabled people. CILs are located in all 50 states and many U.S. territories, and they provide, at a minimum:

1. Information and referral
2. Independent living skills training
3. Individual and systems advocacy
4. Peer counseling
5. Transition assistance from nursing homes and other institutions to community-based residences
6. Assisting individuals to avoid institutional placement
7. Transition of youth with significant disabilities after completion of secondary education to postsecondary life.<sup>18</sup>

Many of these services are provided with no cost to participants. CILs may provide additional services, such as wheelchair recycling programs, personal assistance services and loans. Identifying your local CIL and learning about its services so that you are able to make referrals are simple actions you can take that may have a significant benefit for your patients.<sup>19</sup>

#### **Collaboration in Care**

Lisa I. Iezzoni, MD, MSc, professor of medicine at Harvard Medical School, and Bonnie O'Day, a researcher and policy analyst, conducted inter-

views with disabled people in the U.S. regarding their experiences related to health care. Their analysis concluded that “most people with disabilities know what works best for them — for effective communication and physical movements — and clinicians would likely benefit from asking their advice.”<sup>20</sup> This type of collaboration may be unfamiliar for clinicians, but, in some cases, it may be key for helping patients to feel safe, comfortable and supported during examinations and medical procedures. Tezzoni and O’Day concluded, “patients and clinicians should ideally function as partners during physical examinations.”

Another consideration is that it is important for clinicians to determine whether a patient’s disability has relevance for the current office visit. There are two ways in which it is possible to err: allowing a patient’s disability to eclipse their health concerns by paying disproportionate attention to it; or ignoring the person’s disability when it may matter for a diagnosis and recommendations.

For example, note the difference in the following two clinical experiences of Meena Dhanal Outlaw, a woman with a spinal cord injury. “When I got pregnant with Jamie, it was a shock! I had no idea that I could get pregnant. David and I had the understanding when we got married that I wouldn’t be able to have children. I had been told three days after my in-patient visit at TIRR that I should never think about having children again because I was now disabled.” Here Outlaw reports that health care providers assumed that having a spinal cord injury meant that she could not have children. While this is clearly false, it would also be a mistake to ignore that fact that she is paralyzed because it matters in practical ways for how an OB/GYN provides care. Contrast this with how her provider responded to the question of contractions: “That was the only thing that Dr. Hammill and I had to figure out — what were my contractions going to feel like? He had been doing this for over 30 years. He told me because your body over-compensates (you feel things in other areas of your body if you can’t feel them in the normal area), we would have to figure out what my contractions would feel like.”<sup>21</sup> Here, the physician and patient learned together what the implications of Outlaw’s spinal cord injury were for pregnancy and childbirth, and she was better supported and safer throughout the pro-

cess of giving birth due to this collaboration in care.

### **Disability Humility**

One important way to avoid the mistake of paying too much or not enough attention to a patient’s disability is to practice disability humility. “Disability humility” refers to learning about experiences, cultures, histories and politics of disability, appreciating that one’s knowledge and understanding of disability will always be partial, and acting in light of that fact.<sup>22</sup> Above all else, disability humility means recognizing that one does not know about the lived experience of patients with disabilities without respectfully talking to and carefully listening to them.

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While learning from patients is valuable for providers, it is also necessary to learn from existing research on best practices in regard to people with disabilities in specific situations. The Center for Research on Women with Disabilities is one organization that conducts research dealing with concerns that may be applicable to women with disabilities, and its website offers educational resources for clinicians and women with disabilities. For example, there is a page entitled “Practical Guidelines on Handling Abuse Issues in Clinical Settings,”<sup>23</sup> and there is information on their weight management program for those with mobility impairments.<sup>24</sup>

The idea that to be disabled simply means to be different in a bad way is often a guiding assumption within the practice of medicine. But that idea is misleading and contradicts the testimony of many people with disabilities as well as the social and political analyses offered by multiple communities of people with disabilities across the globe.<sup>25</sup> For many people with disabilities, they experience being disabled as merely being different from the “norm,” neither in a categorically

worse, nor categorically better way than being able-bodied. In other cases, people experience being disabled as being different in a better way, as so many examples from history attest.<sup>26</sup> Disability is an integral facet of being human. There will always be people with disabilities, and, we would argue, there always should be.<sup>27</sup> Because medical practice deals with the variability of the human body, clinicians will always be working with a high percentage of patients with disabilities and those on the way to becoming disabled or experiencing temporary impairment. This is part of the reason why more careful reflection on the meaning of disability and a better understanding of the social determinants of various disability experiences is so crucial for medical practitioners and administrators. Increasing equitable and just care for patients with disabilities requires many changes in practice and in thinking.<sup>28</sup> By connecting their patients to community resources, collaborating in care and practicing disability humility, clinicians can improve the care and health outcomes of people with disabilities and better shape their practice to address the social determinants of health they face.

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#### NOTES

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