

## Educational Primer #2: Ableism in Health Care

This primer is part of the [2024-2025 AMA Organizational Strategic Plan to Advance Health Equity](#).

*This primer was created to center the perspectives of physicians and medical students with disabilities and highlight their experiences and priorities.*

Ableism is a root cause of health inequities. Like racism and sexism, ableism is a system of power that classifies entire groups of people as “less than” and structures opportunities to advantage some and disadvantage others.<sup>1</sup> In one of the first uses of the term, arachne rae described it as the “systemic oppression of a group of people because of what they can or cannot do with their bodies or minds.”<sup>2</sup>

Ableism can take many forms, including discrimination against people with disabilities based on the belief that non-disabled persons are normal.<sup>3,4</sup> Ableism appears in our language (for example, in “colorblind” terminology) and through inaccessible design in buildings, public spaces, technology, curricula, and more.

Ableism operates at many levels. Structural ableism, analogous to structural racism, operates through systems of hierarchical and discriminatory processes and policies.<sup>5</sup> Institutional ableism reflects discriminatory treatment, unfair policies, and inequitable opportunities within organizations and institutions based on one’s abilities. Ableism may also be expressed at the level of interpersonal interactions, and again, like racism, it may also be internalized by people with disabilities.

Our AMA’s 2021-2023 *Organizational Strategic Plan to Embed Racial Justice and Advance Health Equity* included ableism as one of the root causes of health inequities. Yet, the word “ableism” has only appeared in top-tier medical journals in the past few years, suggesting that the medical community is only beginning to recognize and discuss these issues openly. While papers related to racism are increasing,<sup>6</sup> ableism remains underexplored. This failure to recognize structural disadvantage embedded in our society and health care institutions prevents us from even seeing, much less addressing, the ways in which ableism perpetuates injustice.

For many decades, the dominant framework around disability has been the “medical model,” which frames disabilities as conditions to be prevented, treated, or cured. Medicine is steeped in pathology concepts of normal and abnormal, with ableist terms still common in International Statistical Classification of Diseases and Related Health Problems (ICD) diagnostic codes (e.g., wheelchair bound), and medicalized assessments required for people to access services, benefits, or accommodations.

More recently, the writings and advocacy of people with disabilities have shifted the conceptualization of disability towards the “social model,” in which societal restrictions and barriers are recognized and addressed as the causes of disability and exclusion.<sup>7</sup> In this view, a person’s activities are not limited by the impairment or condition itself, but by their environment, including institutional policies and systems.<sup>8</sup>

“Biopsychosocial” has emerged as a model seeking a holistic approach, acknowledging that there are biological sources of impairment, psychological coping strategies and sources of impairment, and social structures that turn impairment into disability.<sup>9</sup> This has formed the basis of the World Health Organization’s International Classification of Functioning, Disability and Health (ICF).<sup>10</sup> Unfortunately, the medical profession has continued to focus heavily on the medical aspect and delegitimizes impairment when no clear medical cause is found, situating disability predominantly in individual responsibility, with insurance corporations seizing on the model to reject claims and push for governmental policies that exclude people with disabilities from benefits.<sup>11</sup>

In the U.S., an estimated 27% of adults have a disability.<sup>12</sup> Disabilities may be apparent or not apparent to others, and their impact can shift based on the environment.<sup>13</sup> For example, access to routine preventive health care can vary greatly depending on access to transportation, the availability of assistive technology and services, accessible screening for accommodation and physical clinic design, as well as institutional- and policy-level incentives for health care systems to provide accessible care. Within medical practice, clinicians are established as both designators of disability and gatekeepers to care, a position of power that can harm patients if not approached with care.<sup>14</sup> Misconceptions and rigid thinking about disability, ineffective communication, and unwelcoming encounters may result in poor patient engagement and negative health outcomes.<sup>15,16</sup> Universal design can promote broad inclusion, but in many cases, full participation is context-specific. Further, accommodations for people with disabilities, such as closed captioning, benefit the broader population beyond their initial intended use.

An estimated 4.6% of medical students and 3.1% of physicians identify as having a disability.<sup>17,18</sup> Even though

accommodations benefit all persons within health care and medical education, ableist systems remain widespread in medicine. Within medical schools, unjust admissions processes and inconsistent and complex accommodation processes create significant obstacles for disabled applicants and students, denying people with disabilities entry to and advancement within the medical community.<sup>17,19-21</sup> Medical education itself retains centuries of ableist notions, which activists are only now beginning to dismantle within the formal and hidden curricula.<sup>22-24</sup> While some settings may limit a disabled physician's access, others allow them to outperform colleagues, demonstrating the benefits of this type of diversity. For example, proficiency in American Sign Language promotes language concordance between physicians and deaf and patients with severe hearing loss.<sup>25</sup> Nevertheless, practicing physicians with disabilities more often face mistreatment from patients and colleagues than their peers, including offensive remarks (about a variety of factors in addition to disability), threats and enacted physical harm, and unwanted sexual advances.<sup>26</sup>

**"Nobody feels empowered or incorporated when they're an afterthought. And there's nothing that proves you're an afterthought [more than] when there's no room for you, there was no voice for you, there's no protocol for you and it's clear that nobody even thought that you mattered."<sup>27</sup>**

**-Maurice G. Sholas, MD, PhD**

### Recent Developments

Despite obstacles within health care and medical education, disability activists and partners are expanding their presence with clear impact. Notable examples include:

- **Docs With Disabilities Initiative** works to create more inclusive educational environments for students with disabilities through policy-focused research, education, and media.<sup>28</sup> Their projects seek to define the prevalence of disabilities among medical students, to illustrate the experiences of medical students and residents with disabilities, as well as to create and disseminate innovative practices and technical standards for inclusive health professions instruction.
- **Hastings Center**, which has long worked to address social and ethical issues in health care, has made anti-ableism a cornerstone of their diversity, equity, and inclusion work by partnering with the Macy Foundation to develop anti-ableist medical and nursing educational resources that center disability justice.<sup>29</sup>
- **Medical Students with Disability and Chronic Illness** was founded in 2019 to unite health care trainees with disability organizations, researchers, and each other to increase inclusion and representation in health professions education and practice.<sup>30</sup>

## What We Build On

Our AMA recognizes the thought, writing, and advocacy of disabled people and disability advocates in their unflagging efforts to ensure that health care is just, equitable, and inclusive for all individuals. We commit ourselves to working explicitly to address ableism in medicine in 2024 and beyond.

Our initial efforts to amplify this work are described below:

1. Development of a disability advisory group, called for by new House of Delegates policy, which will guide AMA work related to disability. This group is required to be composed of AMA member physicians and medical students with disabilities supporting at least four domains: inclusion in all AMA activities, educational and training opportunities, tools for physicians and students to advocate in the workplace, and communication to employers on reasonable accommodation.
2. Publication of an online learning module featured on AMA Ed Hub™ entitled [Fighting Ableism: What Do You Need?](#). In this module, AMA member Joanna Turner Bisgrove, MD, describes the challenges faced by health care professionals and patients with hearing loss as well as how accommodations create inclusive health care environments. This module was launched under the AMA's new standard for accessible education.
3. Partnership with [RespectAbility](#), a national nonpartisan nonprofit organization dedicated to empowerment and self-advocacy for individuals with disabilities, as a founding collaborator of the [National Health Equity Grand Rounds](#). Their collaboration on this series has supported the creation of a new gold standard for inclusive and accessible virtual education.
4. Implementation of inclusive educational offerings and meeting services, with the AMA committing to ensuring that all of its meetings are accessible to staff, members, and leaders with disabilities. Live ASL interpretation is now offered in many virtual and in-person offerings.
5. Improved workspace accessibility, including installing auto-operators on doors in the Chicago and District of Columbia offices and reducing the size of conference room tables to improve accommodations for assistive mobility devices and other factors.
6. The 2023 Medical Student Section Annual Meeting was held piloting a novel hybrid format to ensure accessibility for all participants. New virtual voting features through the Lumi platform ensured that over 300 students participated.



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