

Ableism in Medicine and Clinical Research Workshop: Executive Summary

April 27–28, 2023

Virtual Meeting Sponsored by the National Institutes of Health (NIH)¹

The National Center for Medical Rehabilitation Research (NCMRR) in the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) hosted a 2-day virtual workshop on ableism in medicine and clinical research on April 27–28, 2023. The primary goal of the workshop was to elevate the conversation at NIH about ableism and provide a platform to hear about the work, advocacy, and lived experiences of researchers and people with disabilities (PWD).

The [World Health Organization \(WHO\) World Report on Disability](#) estimates that globally more than 1 billion people experience disability. Across the world, 970 million people need glasses and low-vision aids, 75 million need a wheelchair, and 466 million have disabling hearing loss. These needs are far from being met, however, in large part because of inaccessibility. According to the Centers for Disease Control and Prevention, [approximately 61 million adults in the United States](#)—equivalent to one in four or 25 percent of the adult population—are living with some type of disability and comprise the largest minoritized group in this country. PWD have the same general healthcare needs as others, but they are twice as likely to find healthcare providers' skills and facilities inadequate, three times more likely to be denied healthcare, and four times more likely to be treated badly in the healthcare system. Overall, approximately one-half of PWD cannot afford healthcare, and PWD are 50 percent more likely than non-disabled people to experience catastrophic health expenditures. These out-of-pocket healthcare costs can push a family into poverty.

Underlying these health disparities is the concept of “ableism”—defined by the American Psychological Association as “prejudice and discrimination aimed at people with disabilities—in both clinical care and the biomedical and behavioral research enterprise.” Ableism has also been defined as “[being rooted in the assumption that non-disabled are the ideal](#).” Framing non-disabled people as the ideal outlines how ableism shapes and underlies societal and individual views of health.

The concept of ableism and the movement for disability justice are not new. The fight for civil rights by the U.S. disability community is long-standing and led to the passage of the Rehabilitation Act of 1973, which prohibits discrimination on the basis of disability in programs and activities that receive federal funding and in federally conducted programs. Even with the passage of this landmark legislation 50 years ago and the legislation that has followed, including the Americans with Disabilities Act (ADA) of 1990, there is more work to be done.

The workshop looked at not only the past and present but also to the future and how multiple forms of ableism—interpersonal, structural, and systemic—impact health and workforce disparities for PWD and the lived experience of disabled people. Interpersonal ableism, which includes individual-level attitudes and behaviors that create and perpetuate ableism, does not tell the full story of experiences of PWD within the healthcare system, and fixing the perceptions of healthcare providers alone will not

¹Recordings from [Day 1](#) and [Day 2](#) of the workshop are available via the NIH VideoCast site.

eradicate ableism. Structural ableism, which emphasizes the roles of structures and includes ableism in institutions, laws, policies, and entrenched norms, and systemic ableism, which emphasizes the involvement of whole systems and often all systems, must also be taken in account and addressed. This requires consideration of embedding interpersonal, structural, and systemic ableism in society through a historical lens, including acknowledging eugenics in our history, to change the attitudes, behaviors, and assumptions about and toward PWD that persist to this day.

The Ableism in Medicine and Clinical Research Workshop focused on awareness and research opportunities to mitigate the effect of ableism in the medical and clinical spaces. Scientific sessions over the course of the conference addressed ableism across multiple dimensions, including:

- Ableism as a barrier to clinical care and a contributor to health disparities experienced by PWD
- Ableism in the biomedical and behavioral scientific workforce and graduate education system
- Accessibility in biomedical and behavioral research
- Research opportunities addressing structural and cultural barriers created by ableism

The workshop was intended to inform future research areas in this complex area of public health.

The conference included four topical sessions, three keynote speeches, a panel discussion, and a musical performance. The disability community brought a broad range of perspectives to the conference. Presentations and discussions focused on data and lived experiences that documented, challenged, and debunked interpersonal, institutional, and societal ableism. The theme of “nothing about us without us”—that no policy should be created without the full and direct participation of those it affects—was emphasized throughout the conference. This idea was adopted by the disability rights movement in the 1990s as a clarion call around the passage of the ADA and has been advanced by patient communities seeking broader involvement with the healthcare system. While the push for patient involvement has come from the disability community, the medical community has much to learn and gain from their disabled patients.

The workshop opened with a keynote presentation and call to action to advance health equity for PWD and promote disability inclusion in higher education; science, technology, engineering, mathematics, and medicine (STEMM); public health; and research. The opening keynote speech was followed by Session 1, in which the speakers defined ableism and described how it manifests in research and healthcare. Session 2 speakers focused on disability and health disparities research, including disability as a health disparities population, disability and reproductive health, and ableism through an intersectional lens. Day 1 wrapped up with a panel of experts—people with lived experience who are engaging in biomedical research to make that research more impactful to people with disabilities.

Day 2 opened with an interview and performance by disability rights advocate and musician Gaelynn Lea and a keynote presentation on the historical experiences of deaf people and how cultural pressures of normalcy stigmatize deafness. Session 3 of the workshop focused on ableism in the scientific workforce and included a student perspective, medical school education and disability, and approaches to building a research career. Session 4 addressed navigating ableism in the biomedical research community, with presentations on opportunities for inclusion of PWD in research, making research accessible, and legal protections and tools to create and sustain more effective and inclusive work environments.

The closing keynote address revisited the recent history of the disability rights movement and paid tribute to Judy Heumann—an internationally celebrated civil rights advocate for the disability community often referred to as “the mother” of the disability rights movement—who passed away on March 4, 2023.

The workshop identified multiple barriers to access to healthcare that PWD face in addition to the barriers for non-disabled people. These barriers fall into three major categories:

- **Environmental**
 - Lack of facilities that meet accessibility guidelines
 - Lack of affordable and accessible transportation
 - Lack of knowledgeable healthcare providers
 - Lack of financial resources
- **Programmatic**
 - Lack of sufficient appointment times to accommodate patients with speech limitations and other disabilities
 - Lack of accessible online systems
 - Lack of health information in plain language and alternate formats
- **Attitudinal**
 - Lack of understanding that PWD can live high quality and healthy lives

As pointed out throughout the workshop, attitudinal barriers affect not only the health but the lives of PWD. There is a belief among healthcare providers that PWD cannot be healthy or that they have such a low quality of life that their health is less important than that of non-disabled people. One study of more than 700 physicians indicated that 82 percent believed that people with significant disability have a worse quality of life than non-disabled people. Only 40 percent of the surveyed doctors were very confident in their ability to provide the same quality of care to PWD as to non-disabled people, and just 56 percent strongly agreed that they welcomed patients with a disability into their practices. However, statistics about perceived quality of life contradict many studies showing that PWD do not share these views and report similar levels of quality of life as people without disabilities. Understanding the assumptions of healthcare providers and researchers and the underpinnings of their misperceptions can better address these issues.

The impact of ableism extends to the training and practice of disabled healthcare providers and researchers, as exemplified by the low representation of PWD among medical students (4.6 percent) and practicing physicians (3.1 percent) in the United States. These numbers are in stark contrast to the 20 percent to 25 percent of adults in this country with some form of disability. Data also suggest underrepresentation of PWD not only in academic leadership positions but across the pipeline of STEMM training. The National Center for Science and Engineering Statistics/National Science Foundation found that 19 percent of undergraduate students in STEMM-focused areas reported having a disability, whereas only 9 percent of doctoral students and 8 percent of postdocs identified as PWD. A slightly higher percentage (10 percent) of assistant professors and professors reported having a disability. PWD accounted for approximately 8 percent of leaders in academic spaces, including deans, chairs, department directors, presidents, provosts, and chancellors. Disclosure of disability in medicine and science is risky and very personal, and it remains a barrier for healthcare providers and scientists. Many physicians and researchers do not disclose their disability because of the cultural and other personal and professional risks that are at play.

The workshop showed how the legacy of devaluing the lives of PWD as part of institutional and government policies continues to this day and was exacerbated during the COVID-19 pandemic. For example, review of the current crisis standards of care (CSC) across the country during the pandemic identified eight states with plans that deprioritized PWD, including four states that explicitly instructed hospitals to consider baseline functional status in CSC decisions and to “not offer mechanical ventilation support” for patients with severe or profound intellectual disability, dementia, or traumatic brain injury. Such provisions embedded norms that influence healthcare decisions for PWD at the individual level. These plans were determined by the Department of Health and Human Services to be in violation of the ADA because they discriminated against PWD.

The workshop also explored the impact of ableism through the lens of intersectionality—when discrimination against disability joins with additional aspects of a person’s identity, such as race, gender, economic status, and educational background—and how those experiences of identity intersected resulting in a completely different experience. Research shows how the assets and knowledge of PWD and other marginalized groups translate into tools for developing strong skills to build capacity, navigate healthcare and educational systems, and advocate for themselves and their families and communities.

The ADA and other legislation guarantee protection of the rights of individuals with disabilities in a broad array of activities. The real goal of these laws is not just to change the behavior toward a particular person or group with disabilities, but also to lead to greater inclusion of PWD in all aspects of society. By working, studying, playing, and interacting with PWD, societal and individual ableist attitudes are reduced.

The workshop also identified areas where progress is being made. Multiple tools and resources are available for institutions to apply in developing and implementing diversity programs that address ableism and the disability community. Some medical and graduate schools are partnering with disabled educators and researchers and are including disabled people in the design of disability-focused or -centered curricula for students and residents. Some schools are developing or have established mentoring programs for trainees and faculty to connect with other disabled people for educational purposes and to see that it is possible for disabled people to have successful careers in academia or the clinical practice setting. More opportunities are being made available for continuing medical education for residents and practicing clinicians.

The next generation of students is paving the way for a more inclusive future in medical and graduate school education. As social media has grown and education has expanded to include more virtual options and opportunities, it has become much easier to find and connect with each other across the country and form organizations. Some of these groups include [Medical Students with Disability and Chronic Illness](#), [Disabled in STEM](#), and the [Disability Advocacy and Research Network](#), a community for disabled psychology scholars and allies. Many of these organizations also have mutual mentorship programs. As these efforts take hold and grow, students are increasingly able to push for change.

Many in the disability community are focused on building capacity and developing tools for meaningful engagement with the medical and scientific research communities, so that PWD collectively can be more effective advocates in advancing their priorities and being an integral part of the healthcare and biomedical research enterprises.

The federal government and NIH are committed to eliminating ableism and increasing diversity in the healthcare and biomedical research spaces. Two Executive Orders (EO), [EO 13985](#) and [EO 14035](#), and current NIH diversity, equity, inclusion, and accessibility (DEIA) efforts have served as the foundation for reforms. The NIH established the Subgroup on Individuals with Disabilities of the Advisory Committee to the Director (ACD) Working Group on Diversity as part of this effort. The group met for a year to develop recommendations for increasing the inclusion of PWD in the biomedical workforce, which was extended to include PWD in research studies. The group developed the following recommendations that were endorsed by the ACD:

- **Anti-ableist communication and policies**
 - Update the NIH mission statement to remove “reducing disability.”
 - Review policies, culture, and structures to promote disability inclusion.
- **Coordination**
 - Establish an NIH Office of Disability Research.
 - Develop an effort to combat structural ableism across NIH and NIH-funded institutions.
- **Disability inclusion**
 - Establish an NIH Disability Equity and Access Coordinating Committee.
 - Expand ways to include the perspectives of disabled people in NIH efforts.
- **Disability equity research**
 - Designate PWD a “health disparity population,” which is critical for providing funding to address health disparities among PWD.
 - Increase funding for disability research, disability data collection, and inclusion of disabled people in research studies.
- **Accountability**
 - Conduct continuous, transparent practices.
 - Share accessible data publicly to provide an opportunity for the community to continue working with NIH to inform and guide changes.

The [report and recommendations from the working group](#) were released in December 2022. The [NIH DEIA Strategic Plan for 2023–2027](#) was released in March 2023 and sets forth three objectives: growing and sustaining DEIA through structural and cultural change, implementing organizational practices to center and prioritize DEIA in the biomedical and behavioral research workforce, and advancing DEIA through research. These recommendations and plans present landmark opportunities for change and for setting the tone to make the NIH more inclusive of PWD.

As noted throughout the workshop, the disability community is the only minority group that any person can become a member of due to an illness, accident, or other life event, underscoring that the community is not only “other people” or “someone else.” The call to action for people with disabilities, advocates, and their allies in addressing ableism and other forms of discrimination and prejudice is to:

- **Be anti-ableist.** Everyone has a role and responsibility in addressing ableism in medical research and biomedicine.
- **Advance disability equity.** Ableism is a formidable threat to health equity and diversity.
- **Include disabled people.** PWD are part of all communities, and all issues are disability issues.
- **Act now.** Success comes from approaching this work with humility, a growth mindset, and the understanding that it is a journey.