Health care in the US is at a watershed moment concerning disabled people. Last April, the National Center for Medical Rehabilitation Research, part of the National Institutes of Health (NIH), hosted the first federally funded conference identifying ableism as a problem in medicine. In just the past year, multiple leading medical journals published pieces on the same topic. On August 14, 2023, for the first time in the history of NIH, a grant request appeared that explicitly named and sought out research on ableism, "Understanding and Mitigating Health Disparities experienced by People with Disabilities caused by Ableism." Then, just more than a month later, the most significant event for disabled peoples' health as it relates to the NIH occurred: the National Institute on Minority Health and Health Disparities (NIMHD) officially designated disabled people as a health disparity population.

This decision was not without controversy. In December 2022, the Subgroup on Individuals with Disabilities for the Advisory Committee to the NIH Director Working Group on Diversity (ACDWGD) presented its findings. It put forward multiple suggestions to support the inclusion of disabled people in the scientific workforce and in the research enterprise, including formal designation of disabled people as a health disparity population, an effort for which disability researchers had been pushing for more than a decade. Yet, on September 1, 2023, the NIMHD rejected that designation request. Disability researchers and advocates then initiated a letter writing campaign to secretary and director of the US Department of Health and Human Services demanding reconsideration of the NIH designation, which in less than 3 days garnered more than 1200 signatures from prominent state- and federal-level disability organizations, health disparity scientists, health service professionals, and advocacy groups.

The NIMHD decision to name disabled people as a health disparity population is a monumental step in the right direction. But it is important to understand the larger context of this decision as well as the clinical import of the research leading up to it. Over the past 20 years or more, medical and public health organizations increasingly recognized that disability is not merely and never solely medical, but also—and often more so—social in nature. As Christakis and lezzeno note, the latter of whom sat on the ACDWGD, the Centers for Disease Control and Prevention’s Healthy People Initiative first recognized disabled people as experiencing health and health care disparities in 2000. Appendix C of the ACDWGD report details more than 92 research studies that quantify disability health disparities. From the perspective of those who gathered and interpreted the data of those studies and others like it, the issue for the NIMHD for decades now should not have been whether to add disabled people to their population-level mission, but how much to fund to mitigate and eliminate the health disparities they face.

Long before such federal research and recognition, disability rights organizations and activists fought to change how people view disability. Following the model of civil rights activism and legislative strategies, disability rights in the US were achieved not just through changing laws, but through changing minds with evidence and argumentation. Just as it had to be argued that Black people face worse health outcomes not because of how their bodies or minds are but due to segregationist and other racist policies, it had to be argued that disabled people face worse health outcomes not because, or at least not solely because, of how their bodies or minds are but due to segregationist, discriminatory, and other ableist policies.
As it always is when combating ignorance and prejudice, an uphill battle ensued. Most people are incorrectly taught from childhood that disability simply means that something is medically wrong with an individual person's body and/or mind. Since the 1960s, disability activists and scholars across the globe demonstrated that a more accurate way to understand the lived experiences of disabled people is by using a social model. On a social model of disability, one distinguishes between a person's impairments, the way one's body and/or mind is different, and disability, the social responses to one's impairments. As the disability studies 101 example goes, you may use a wheelchair because of a spinal impairment, but what disables you is a world without ramps and lifts, with stigma and discrimination in education, labor, and so on. It was a social model understanding of disability that led to Section 504 of the 1973 Rehabilitation Act and that paved the way for the Americans with Disabilities Act of 1990. It is not an exaggeration to say that a social model approach to disability underwrites every major legal, social, and political advance for disabled people in the US as well as across the globe. Following on the heels of such advances, research in social epidemiology, public health, and qualitative and quantitative work spanning the social sciences and humanities continues to bolster the claim that a central reason why disabled people face worse health outcomes is due in large part to socially controllable factors, as the ACDWGD report demonstrated.

Crucially, recognition of the health disparities that disabled people face is an integral component of addressing the health disparities of historically marginalized people more broadly. Further research is needed to understand, for example, the intersections of disability and race that lead 55.2% of Hispanic persons, and 46.6% of African American individuals to report fair or poor health, compared with 36.9% of White individuals. The NIMHD decision marks an opportunity to call for such research on the relationship between and across distinct health disparity populations, including further theoretical and empirical work concerning intersectionality in health disparities science.

Recognition of disabled people's health disparities also paves the way for applications that reach from the level of the population down to that of the individual patient. A widely cited 2021 study of 714 physicians reported that 82.4% believe that people with "significant disability" have worse quality of life (QoL) than people without disabilities. This is a troubling finding because social scientific research on the relationship between disability and QoL since the 1990s has shown that people with disabilities, significant or not, have similar levels of QoL as those without. The ableist conflation of disability with pain and suffering can mislead practitioners into believing that disabled patients are, on the whole, living terrible lives. A health disparities lens suggests to the contrary that most disabled people instead face adversity because of the misfit they experience in the discriminatory, stigmatizing, inaccessible, and ableist environments they find confronting them day in and day out. As the NIMHD health disparity designation signifies, being disabled results in societally caused, and thereby preventable, effects on an individual's health status.

A watershed moment marks a turning point, a beginning, and medicine is indeed at the beginning of appreciating the problem of ableism in medicine, the beginning of making equity of care for disabled patients a priority, and the beginning of not just acknowledging, but mitigating and eliminating the health disparities faced by disabled people. This beginning promises a future that improves quality and equity of care across patient populations, builds better health care systems, and makes a world that is a better fit for all.

ARTICLE INFORMATION
Published: June 14, 2024. doi:10.1001/jamahealthforum.2024.1185
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Conflict of Interest Disclosures: Dr Reynolds reported funding from the Greenwall Foundation as part of a faculty scholar career development award for Addressing the Roots of Disability Health Disparities during the conduct of the study.

REFERENCES