

September 6, 2023

The Honorable Xavier Becerra
Secretary of Health and Human Services
U.S. Department of Health and Human Services
200 Independence Avenue SW
Washington, DC 20201


Dear Secretary Becerra:

We are writing to express our strong reservations about the recent (September 1, 2023) recommendation of the National Institute of Minority Health and Health Disparities (NIMHD) Advisory Committee to **not** designate people with disabilities as a “health disparity population.” This inaction is not consistent with the Administration’s commitment to people with disabilities; disrupts current NIH Diversity, Equity, Inclusion, and Accessibility (DEIA) efforts; fails to consider current models and theories of disability; and does not include the perspectives of people with disabilities. Specifically, we assert that:

- All required criteria have been met for the director of the NIMHD to designate people with disabilities as a health disparity population.
- The NIMHD Advisory Committee’s recommendation undermines current NIH DEIA initiatives and contradicts the Biden administration’s equity efforts.
- The NIMHD Advisory Committee’s stated reasons for not designating people with disabilities as a health disparity population are based on ableist assumptions and a biased view of disability.
- The NIMHD Advisory Committee did not include anyone with a disability, which is deeply problematic.

We explain these assertions in the attached policy analysis. In light of these concerns, we hope you will consider supporting a swift course correction on this issue and move to formally designate people with disabilities as an NIH health disparity population.

Sincerely,



Bonnielin K. Swenor, PhD, MPH, Director of The Johns Hopkins Disability Health Research Center



Jae Kennedy, PhD, Professor of Community and Behavioral Health, WSU College of Medicine

CC:

Tom Perez, Senior Advisor and Assistant to the President
Neera Tanden, Domestic Policy Advisor to the President
Mayor Stephen Benjamin, Senior Advisor and Director of the White House Office of Public Engagement
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Policy and Program Concerns Regarding the NIMHD Advisory Committee’s Recommendation to Not Officially Designate People with Disabilities as an NIH Health Disparity Population

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All required criteria have been met for the director of the NIMHD to designate people with disabilities as a health disparity population.

According to *The Minority Health and Health Disparities Research and Education Act of 2000* (P L. 106–525), the Director of NIMHD, in consultation with the Director of the Agency for Healthcare Research and Quality (AHRQ), is authorized to designate specific minority groups as US health disparity populations, if “there is a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality, or survival rates in the population as compared to the health status of the general population (SEC 485(d)(1)).” There is overwhelming evidence that this threshold has been met. The relevant statistical data have been outlined in a [2021 letter](#) from The National Council on Disability (NCD), a [2022 report](#) from a working group under the NIH Advisory Committee to the Director, and a [recent commentary](#) published in *the Disability and Health Journal* by Jae Kennedy and Bonnielin Swenor (both known experts in the field of disability research).

The NIMHD Advisory Committee’s recommendation undermines current NIH DEIA initiatives and contradicts the Biden administration’s equity efforts.

The National Institutes of Health (NIH) have made historic strides in addressing the deeply ingrained ableism that permeates much of biomedical research enterprise. Last December, the NIH Advisory Committee to the Director unanimously endorsed the recommendations of the Working Group on Diversity (WGD) Subgroup on Individuals with Disabilities, including a specific recommendation that the NIH formally designate people with disabilities as a health disparity population. This subgroup, comprised largely of scientists with disabilities, focused on improving the inclusion and equity of people with disabilities in research studies and in the research workforce. More recently, the NIH has released [a request for information \(RFI\)](#) on changes to the NIH mission statement to remove ableist language, and has also posted [a funding opportunity announcement \(FOA\)](#) focused on research addressing ableism as a cause of health disparities among disabled people. These actions have been widely lauded by leading disability community members and researchers.

However, the NIMHD’s Advisory Committee recommendation is inconsistent with these advances, and conflicts with [Executive Order 13985, Advancing Racial Equity and Support for Underserved Communities Through the Federal Government](#), which requires all federal agencies, including the NIH, to assess “whether, and to what extent, its programs and policies perpetuate systemic barriers to opportunities and benefits for people of color and other underserved groups.” The executive order explicitly and repeatedly includes people with disabilities as an underserved group requiring assessment.

Designating people with disabilities as an NIH health disparity population is more than a semantic exercise – centers, offices, and institutes across the NIH use these categories to develop research concepts and FOAs, particularly in the domain of health disparities research. They are also used to target training support and development funds for NIH employees and extramural grantees. Including people with disabilities is therefore essential to the broader health equity goals of the NIH and the US Department of Health and Human Services.

The NIMHD Advisory Committee’s stated reasons for not designating people with disabilities as a health disparity population are based on ableist assumptions and a biased view of disability.

Statements from the committee suggest a fundamental lack of familiarity with the disability field and an inappropriate reliance on the medical model of disability. For example, co-chair Dr. Neil Galman asserted that recent NIH funding for disability-related research “ranged from \$6.6 billion to \$11.8 billion,” suggesting that the NIH is already quite active in this research domain (and, presumably, that additional administrative action by the NIMHD is unnecessary). However, nearly all of this research focuses on prevention and treatment of specific disabling health conditions, while very few studies focus on the actual health disparities experienced by individuals with disabilities. It is a basic principle of our field that studying chronic illness or injury is not the same as studying people with disabilities.

Co-chair Dr. Lisa Barnes referred to the existence of “several definitions of disability” as another reason to reject designation, stating that it was “not clear who will be the population with health disparities that would be impacted by this designation.” In her presentation, she quotes from the [CDC’s “Disability and Health Overview” website](#), that “some disabilities are related to an injury, while others are associated with long standing conditions that cause disability.” However, a more inclusive definition of disability is provided at the top of the same CDC web page: “A disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions).”

This definition aligns with [the International Classification of Functioning, Disability, and Health \(ICF\)](#), which has been used globally by scientists, clinicians, and policymakers since its introduction by the World Health Organization in 2001. The scientific community has already produced several decades’ worth of thoughtful and rigorous research on how to appropriately define and measure disability for various research purposes and contexts. The existence of multiple definitions of disability does not present an insurmountable challenge to conducting or supporting health disparities research on this minority population.

The NIMHD committee did not include anyone with a disability, which is deeply problematic.

The NIMHD committee co-chair conceded that none of the committee members “openly declared a disability,” which stands in stark contrast to the NIH ACD WGD Subgroup on Individuals with Disabilities. In 2023, it is no longer considered acceptable to have a federal committee making policy decisions about an underserved and minoritized group when that group is not adequately represented on the committee.

Sincerely,

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- Adisa Sefic, Visual Design
- ADVION (formerly the National Association for the Support of Long Term Care)
- Advocates For Autism, Inc.
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