



August 30, 2023

Eliseo J. Pérez-Stable, MD

Director

National Institute on Minority Health and Health Disparities

National Institutes of Health

6707 Democracy Boulevard, Suite 800

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Robert Otto Valdez, PhD, MHSA

Director

Agency for Healthcare Research and Quality

5600 Fishers Lane

Rockville, MD 20857

## Re: Designating People with Disabilities as a Health Disparity Population

Dear Drs. Pérez-Stable and Valdez:

The Leadership Conference on Civil and Human Rights, a coalition charged by its diverse membership of more than 240 national organizations to promote and protect the civil and human rights of all persons in the United States, and the American Association of People with Disabilities are writing to strongly recommend that you adopt the recommendation already endorsed by the Advisory Committee to the Director (ACD) of the National Institutes of Health (NIH) and formally designate people with disabilities as a health disparity population. The Leadership Conference is the nation's oldest, largest, and most diverse civil and human rights coalition and provides a powerful unified voice for the many constituencies we represent. Our coalition is made up of a breadth of organizations committed to advancing civil and human rights for people of color, low-income people, children, older adults, people with disabilities, LGBTQ people, women, immigrants, students, workers, and so many others whom our society has often forced through law and policy to live at the margins. The American Association of People with Disabilities (AAPD) is a national disability-led and cross-disability rights organization that advocates for full civil rights for more than 60 million Americans with disabilities. AAPD works to increase the political and economic power of people with disabilities. Through advocacy and outreach, our organizations work toward the goal of a more open and just society — an America as good as its ideals.

On December 9, 2022, the Advisory Committee to the Director (ACD) of the National Institutes of Health (NIH) unanimously endorsed the report and recommendations drafted by the Working Group on Diversity (WGD) Subgroup on Individuals with Disabilities. This

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included Recommendation 7a, “formally designating people with disabilities as a health disparity population.”<sup>1</sup>

When President Biden issued [Executive Order 13985](#) on his first day of office, he signaled that one of this administration’s highest priorities is to advance health equity for underserved populations. The executive order specifically recognizes that people with disabilities are included in these efforts. In NIH’s work, specifically designating people with disabilities as an NIH “health disparity population” aligns with the administration’s goals. Further, it would acknowledge the well-documented health and health care inequities that people with disabilities face. It is also consistent with both longstanding and newer civil rights law, including the Rehabilitation Act, the Americans with Disabilities Act, and Section 1557 of the Affordable Care Act.

As recognized by the Minority Health and Health Disparities Research and Education Act of 2000 (P.L. 106-525), the director of the National Institute of Minority Health and Health Disparities (NIMHD), in consultation with the director of the Agency for Healthcare Research and Quality (AHRQ), is authorized to designate new populations as “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.”

While we recognize that officially designating people with disabilities as a health disparity population could lead to an expansion of the NIMHD’s research responsibilities, we do not believe this is a reason to delay this designation. In particular, NIMHD’s designations already include racial and ethnic minority groups, people with lower socioeconomic status, underserved rural communities, and sexual and gender minority groups. We believe adding people with disabilities is critical not only to advance research specific to people with disabilities, but also to identify and address intersectional issues between health disparity groups. Research that embraces the framework of intersectionality must acknowledge the distinct identities of different groups and systematically investigate how these different identities interact at the individual level. Specifically excluding people with disabilities, many of whom may also be in one of NIMHD’s other designated health disparity groups, negates the importance of conducting research specific to disability in addition to recognizing intersectional issues.

NIMHD’s (and NIH’s) work would directly benefit from adding people with disabilities as a designated health disparity population. Improving health care access for people living with disabilities is critical to reducing racial health disparities. Recent estimates found that more than half of noninstitutionalized adults in the United States already identify with one or more currently recognized health disparity groups.<sup>2</sup> With regard to particular population groups, Black people are more likely to have a disability relative to White people in every age group, and according to the [National Disability Institute](#), 14 percent of Black people live with disabilities compared to 11 percent of non-Hispanic White people and 8 percent

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<sup>1</sup> National Institutes of Health. Advisory Committee to the Director Working Group on Diversity, Subgroup on Individuals with Disabilities. Report. Dec. 1, 2022.

[https://acd.od.nih.gov/documents/presentations/12092022\\_WGD\\_Disabilities\\_Subgroup\\_Report.pdf](https://acd.od.nih.gov/documents/presentations/12092022_WGD_Disabilities_Subgroup_Report.pdf).

<sup>2</sup> Kennedy, Jae, Swenor, Bonnielin. It's time for the NIH to formally designate people with disabilities as a US health disparity population, *Disability and Health Journal*, Volume 16, Issue 3, .2023.

of Latinos. People with disabilities who are pregnant or planning to become pregnant may face additional disparities compared with people who do not have disabilities. A transgender person with a disability may experience disparities due to the intersection of sex (gender identity) and disability (diagnosis of gender dysphoria) that are different than those based on sex alone. To the extent that religious exemptions have been [used to discriminate](#) against sexual and reproductive health care, LGBTQ+ competent care, and actively exacerbate health disparities, people with disabilities who seek reproductive and sexual health care may face additional barriers to accessing care that research should identify.

We readily acknowledge the budgetary constraints faced by the NIMHD and NIH itself. Yet we do not believe the answer is to exclude a significant health disparity group both for the importance of research related to that group directly as well as addressing intersectional issues. Rather, we believe in advocating for additional funding to ensure NIMHD has the resources it needs to conduct critical research on all relevant disparity populations.

We thank you for considering our comments and strongly recommend NIMHD move forward to designate people with disabilities as a health disparity group. If you have any questions, please contact Peggy Ramin ([ramin@civilrights.org](mailto:ramin@civilrights.org)).

Sincerely,

Maya Wiley  
President and CEO  
The Leadership Conference on Civil  
and Human Rights

Maria Town  
President and CEO  
American Association of People with  
Disabilities