



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 Bethesda,
MD 20892

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:

On behalf of the undersigned members of the Consortium for Constituents (CCD) with Disabilities Autism, DD, and Family Support Task Force, we write to strongly support the proposal for the National Institutes of Health (NIH) to formally designate people with disabilities as a health disparity population.

On December 9, 2022, the Advisory Committee to the Director (ACD) of NIH unanimously endorsed the landmark report and set of recommendations drafted by the Working Group on Diversity, (WGD) Subgroup on Individuals with Disabilities, including Recommendation 7a, “formally designating people with disabilities as a health disparity population.”^[1]

CCD is the largest coalition of national organizations working together to advocate for Federal public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society. The DD Task Force focuses on federal public policies that directly relate to individuals with developmental disabilities, Autism, family supports, and the prevention of child abuse and neglect. One of our highest priorities has been to support legislation and other public policies that reduce health disparities and increases the training of interdisciplinary health professionals to provide quality health and behavioral health care to those with intellectual and developmental disabilities.

People with disabilities are among the population groups that experience significant health disparities; and yet, our public policies rarely include efforts to reduce their health disparities. This is reflected in the fact that although disability status is considered by the National Institute of Minority Health and Health Disparities to be a “fundamental characteristic” that may interact with health disparity populations, the disability community is not in and of itself recognized as a health disparity population. The disparities faced by disabled people are not the inevitable result of disability—they are the result of systemic failures.

People with developmental disabilities face tremendous barriers and discrimination in the current healthcare system. Healthcare disparities are compounded when disability intersects with race, ethnicity, gender identity, and age. It is for these reasons and more that we believe the NIH should designate people with disabilities as a health disparity population.

This action will also be in line with President Biden’s Executive Order 13985 to advance health equity for underserved populations. The President made clear that people with disabilities and disability status are central to the Administration’s definition and assessment of equity. The Executive Order directs federal agencies to establish an equitable data working group to address a persistent lack of disaggregated data on race, ethnicity, gender, disability, and other key demographic variables. Formally designating people with disabilities as an NIH “health disparity population” directly aligns with the Administration’s goals and acknowledges the well-documented health and healthcare inequities that people with disabilities face.

Again, the undersigned organizations urge you to take quick action to formally designate people with disabilities as a health disparity population. This action will positively impact thousands of individuals with Autism, intellectual and developmental disabilities. Please contact [Kim Musheno](#) or any of the other co-chairs of the [CCD DD, Autism, and Family Support Task Force](#) with any questions regarding this letter.

Thank you.

Sincerely,

Access Ready Inc.
American Association of People with Disabilities
American Network of Community Options and Resources
Association of University Centers on Disabilities
Autistic People of Color
Autistic Self-Advocacy Network
Autism Society of America
Autism Speaks
CommunicationFIRST
Family Voices
National Association of Councils on Developmental Disabilities
National Disability Rights Network
National Down Syndrome Society
National Respite Coalition
Perkins School for the Blind
RespectAbility

^[1] 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

The Consortium for Constituents with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for Federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society free from racism, ableism, sexism, and xenophobia, as well as LGBTQ+ based discrimination and religious intolerance.

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