



April 7, 2022

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National Institutes of Health  
9000 Rockville Pike  
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Robert Otto Valdez, PhD, MHSA  
Director  
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5600 Fishers Lane  
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**Re: Designating People with Disabilities as a Health Disparity Population**

Dear Drs. Tabak and Valdez:

On behalf of the Disability and Rehabilitation Research Coalition (DRRC), we write to urge you to consider designating people with disabilities as a “health disparity population” for purposes of federal research conducted at the National Institute on Minority Health and Health Disparities (NIMHD) and across the National Institutes of Health (NIH).

The DRRC is a coalition of 26 national research, clinical, and consumer non-profit organizations committed to improving the science of rehabilitation, disability, and independent living. The DRRC seeks to maximize the return on the federal research investment in these areas with the goal of improving the ability of Americans with disabilities to live and function as independently as possible following an injury, illness, disability, or chronic condition. Addressing the health and social disparities faced by underserved populations has long been a critical focus of the DRRC.

As you know, NIMHD, in consultation with AHRQ, has the authority under the Minority Health and Health Disparities Research and Education Act of 2000 (P.L. 106-525) to designate 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.” This designation allows NIMHD and the entire NIH to conduct prioritized and focused research on the causes of disparities and methods to prevent, diagnose, and treat such disparities among the target populations. Currently, several racial and ethnic minority groups (American Indians/Alaska Natives, Asian Americans, Blacks/African Americans, Hispanics/Latinos, Native Hawaiians, and other Pacific Islanders) are designated as health disparity populations, as are sexual and gender minorities, socioeconomically disadvantaged populations, and underserved rural populations.

**The DRRC strongly believes that people with disabilities meet the qualifications to be designated as a health disparity population by NIMHD and AHRQ, and we urge you to do so under your current legislative authority.**

*Federal Actions Recognizing Health Disparities Faced by People with Disabilities*

The Department of Health and Human Services has already separately designated disability status as a health disparity through the Healthy People 2030 initiative.<sup>1</sup> There is clear overlap between the health disparities identified by NIMHD and Healthy People; however, NIMHD does not recognize people with disabilities in its disparity efforts.

Further, the recently enacted *Consolidated Appropriations Act, 2022*, includes report language making clear Congress' intent that people with disabilities be recognized as a health disparity population.<sup>2</sup> Specifically, the agreement calls on NIH to fund disparities research impacting people with disabilities, as follows:

***Health Disparities for Persons with Disabilities - Despite being uniquely affected by COVID-19, people with disabilities experienced gaps and inequities in health care in the response to the COVID-19 pandemic. This illustrates that there is a need for increased data collection to provide policymakers with necessary information to improve pandemic planning and outcomes. The Committee strongly encourages NIH to examine health and health care inequities more broadly for people with disabilities, including those with physical, sensory, cognitive, intellectual and developmental, and psychological disabilities. The Committee strongly encourages NIH to fund research on identifying inequities in health and health care for people with disabilities and to support research that develops and evaluates interventions to reduce these disparities, including approaches that focus on addressing systemic and community-level barriers.***  
(emphasis added)

This charge was also accompanied by an increase of \$50 million for NIMHD to support research related to identifying and reducing health disparities.

Congress has recognized people with disabilities as a distinct minority group, subject to pervasive social stigma and institutional discrimination, and has passed significant civil rights laws (e.g., the *Americans with Disabilities Act*, the *Rehabilitation Act*, and the *Individuals with Disabilities Education Act*) to protect this population.

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<sup>1</sup> Healthy People 2020 (and the successor Healthy People 2030 initiative) defines a health disparity as “a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; **cognitive, sensory, or physical disability**; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion.” Available at <https://www.healthypeople.gov/2020/about/foundation-health-measures/Disparities>

<sup>2</sup> This language is included in House Report 117-96, which “carries the same weight as language included in this explanatory statement [accompanying the Consolidated Appropriations Act, 2022 (P.L. 117-103)] and should be complied with.” The language can be found here: <https://www.congress.gov/117/crpt/hrpt96/CRPT-117hrpt96.pdf#page=153>

We also note that the President’s Executive Order 13895, *Advancing Racial Equity and Support for Underserved Communities*, recognized people with disabilities as a target population for Administration-wide equity efforts, including advancing health equity. Designating people with disabilities as a health disparity population would align NIMHD’s research focus with other federal efforts and help carry out the charge in the President’s Executive Order.

### *Prevalence of Health Disparities Faced by People with Disabilities*

People with disabilities face pervasive disparities in health status and access to health care, not to mention employment, education, community participation, integration, and much more. People with disabilities use more health care than their nondisabled counterparts, are more likely to be in fair or poor health and are much more likely to report difficulties in obtaining and paying for their health care.<sup>3</sup>

Additional clinical evidence detailing such disparities is already fairly established, as laid out in the [recent letter](#) your offices received from the National Council on Disability (NCD) on December 7, 2021 (included as an attachment here). The NCD has included this designation as a critical part of their recently released [Health Equity Framework for People with Disabilities](#), which we strongly support.

The COVID-19 pandemic has underscored and exacerbated the disparities faced by people with disabilities, with death rates among nursing home residents (nearly all of whom have significant disabilities) jumping dramatically, individuals facing delayed or cancelled medically necessary care due to pandemic restrictions, and a higher risk of severe illness or death from COVID-19 as recognized by the Centers for Disease Control and Prevention (CDC). In many cases, people with disabilities are in more precarious and inequitable situations than ever.

### *Gaps in Federal Data and Research Reflect Health Disparities*

The COVID-19 pandemic has also highlighted the serious issues surrounding federal data on people with disabilities, as well as other demographic factors that often coincide with health disparity populations. The broader public health data ecosystem has significant and distinct gaps and inconsistencies on how people with disabilities are impacted by any number of factors. Disability status data is far too inconsistently reported and collected across nearly all federal data collections, and these issues are replicated at the state and local levels as well. This status quo has made it incredibly difficult to accurately gauge, for example, the extent to which people with disabilities are facing disproportionately higher risks of COVID-19 exposure, infection, serious and life-threatening symptoms, hospitalization, and death. Improved disability data collection is critical to better understand not only the disparities associated with disability, but the intersection of other identities as well.

The lack of reliable and equitable demographic data is an exceedingly broad problem, and not one solely within the scope of NIH to address. We also recognize that the White House has

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<sup>3</sup> Kennedy, J & EG Wood (2020). Disability-Based Disparities among Noninstitutionalized Working-Age Adults in the US: Evidence from the 2018 National Health Interview Surveys. Spokane WA: Collaborative on Health Reform and Independent Living (available [here](#)).

undertaken a significant interagency effort to address these issues and improve the federal data ecosystem. We believe that recognizing people with disabilities as a health disparity population will help ensure that the disability population is paid appropriate attention and care across federal efforts regarding data collection and other equity work.

*DRRC Request*

The DRRC and many in the disability and rehabilitation research community have long viewed the lack of a health disparities population designation for people with disabilities as a glaring omission that fails to recognize the significant health disparities people with disabilities face on a daily basis. By revising this omission, research conducted through NIMHD and NIH will better prioritize research into the causes of these disparities and how they interact and intersect with the disparities faced by other already recognized health disparity populations. Further, and perhaps most importantly, such action will help develop and inform critical policy solutions to reduce and eliminate health disparities and advance health equity for all populations.

**We strongly support and echo the request made by the National Council on Disability to remedy this omission and designate the disability population as a named health disparity population under NIMHD and AHRQ's existing authority.** We would welcome the opportunity to discuss these issues with you and your colleagues further and would be happy to connect you with some of our members who are leaders in the disability disparities research community.

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We thank you for your attention this request. We look forward to working with you and your colleagues to advance this designation and carry out research to better understand the significant health disparities and inequities impacting people with disabilities nationwide. If you have any questions, please contact the DRRC coordinators at [Peter.Thomas@PowersLaw.com](mailto:Peter.Thomas@PowersLaw.com), [Bobby.Silverstein@PowersLaw.com](mailto:Bobby.Silverstein@PowersLaw.com), and [Joseph.Nahra@PowersLaw.com](mailto:Joseph.Nahra@PowersLaw.com).

Sincerely,

**The Undersigned Members of the Disability and Rehabilitation Research Coalition**

Academy of Spinal Cord Injury Professionals  
American Academy of Orthotists & Prosthetists  
*American Academy of Physical Medicine & Rehabilitation\**  
American Association on Health and Disability  
*American Congress of Rehabilitation Medicine\**  
American Medical Rehabilitation Providers Association  
*American Occupational Therapy Association\**  
*American Physical Therapy Association\**  
American Speech-Language-Hearing Association  
American Therapeutic Recreation Association  
Amputee Coalition

***Association of Academic Physiatrists\****

Association of Rehabilitation Nurses

Association of University Centers on Disabilities

***Brain Injury Association of America\****

Christopher & Dana Reeve Foundation

National Association for the Advancement of Orthotics & Prosthetics

***National Association of Rehabilitation Research and Training Centers\****

National Association of State Head Injury Administrators

Paralyzed Veterans of America

Rehabilitation Engineering & Assistive Technology Society of North America

Spina Bifida Association

United Spinal Association

***\* DRRC Steering Committee Member***

**CC:**

Dr. Eliseo J. Pérez-Stable, Director, National Institute on Minority Health and Health Disparities

Dr. Diana Bianchi, Director, National Institute on Child Health and Human Development

Alison Barkoff, Acting Administrator, Administration for Community Living

Dr. Alison Cernich, Deputy Director, National Institute on Child Health and Human Development

Dr. Theresa Cruz, Director, National Center for Medical Rehabilitation Research

Dr. Anjali Forber-Pratt, Director, National Institute on Disability, Independent Living, and Rehabilitation Research