August 2, 2023

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Re: Designating People with Disabilities as a Health Disparity Population

Dear Drs. Pérez-Stable and Valdez:

On December 9, 2022, the Advisory Committee to the Director (ACD) of the National Institutes of Health (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] The Disability and Rehabilitation Research Coalition (DRRC) writes in strong support of NIH officially recognizing people with disabilities as a "health disparity population."

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. We seek 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. We therefore enthusiastically endorse all of the recommendations of the ACD in the December 2022 report, including Recommendation 7a. Recognition of people with disabilities as a health disparity population is among the most important recommendations in the ACD report.

When President Biden issued Executive Order 13985 on the day he took office, he signaled that one of this administration's highest priorities is to advance health equity for underserved populations and made clear that people with disabilities are included in these efforts. 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, including disabled people from racial and ethnic minority groups who often have higher rates of

[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

disability. It is also consistent with more than 30 years of civil rights law, including the Rehabilitation Act and the Americans with Disabilities Act.

The Minority Health and Health Disparities Research and Education Act of 2000 (P.L. 106-525) authorizes 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), 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." In a letter to the DRRC, dated May 2, 2022, Director Pérez-Stable acknowledged that "It is incontrovertible that individuals with disabilities experience challenges with access to appropriate healthcare and have poorer health outcomes." We strongly agree with his statement and, therefore, question whether the NIMHD and AHRQ need additional evidence to designate people with disabilities as a health disparity population. However, the scientists and researchers associated with DRRC member organizations stand ready to assist (or even help lead) a systematic review of the disparities literature if this would help expedite administrative action.

In a follow-up meeting with the DRRC and NIMHD administrators on August 9, 2022, Director Pérez-Stable expressed concerns that officially designating people with disabilities as a health disparity population could lead to a significant expansion of the NIMHD's research responsibilities and a strain on the Institute's research budget, particularly given the large discrepancies in disability prevalence estimates cited by advocates and policymakers.[2]

We readily acknowledge the budgetary constraints faced by the NIMHD and other Institutes, Centers, and Offices within the NIH. The DRRC has consistently advocated for increased funding to NIH and other federal research agencies. Given NIMHD's mission to lead scientific research to improve minority health and eliminate health disparities presupposes additional budgetary needs as new populations are discovered and their health research needs are addressed. We will not hesitate to point out this fundamental fiscal reality to policy makers. We also recognize that estimating population prevalence is a challenge, particularly given the constraints of public disability data in the US. However, that measurement challenge has been faced previously by researchers in defining all other health disparity populations, including American Indians/Alaska Natives, Asian Americans, Blacks/African Americans, Hispanics/Latinos, Native Hawaiians, and other Pacific Islanders, sexual and gender minorities, socioeconomically disadvantaged populations, and underserved rural populations.

Dr. Jae Kennedy and Dr. Bonnie Swenor have looked specifically at this potential expansion of NIMHD's research responsibilities in a recent commentary.[3] Using data from the 2019 National Health Interview Survey, they calculate that more than half of noninstitutionalized adults in the US already identify with one or more currently recognized health disparity groups. Recognizing people who consider themselves disabled (but do not identify with any of the other currently designated health disparity populations) would increase the hypothetical target population covered by the NIMHD by roughly 8%, (from an estimated 118 million noninstitutionalized adults to an estimated 127 million noninstitutionalized adults).

We would also note that the designation of people with disabilities as a health disparity population should help the Institute solicit responsive grant proposals under the research concept titled *Health Disparities*

[2] For instance, one widely cited statistic, derived from the CDC's 2016 Behavioral Risk Factor Survey, estimates that 25% of American adults have a disability, while a different and less widely-cited statistic, derived from the 2021 American Community Survey, estimates that 15% of American adults have a disability.

[3] 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.

Experienced Among People with Disabilities, approved by the NIMHD advisory council on September 2, 2022. This concept paper acknowledges "the need for targeted research to better understand the range of intersectional factors and mechanisms influencing unique health disparities, and to develop actionable strategies to mitigate their impact on health outcomes and QoL."

Disparities research that fully embraces the framework of intersectionality must acknowledge the distinct identities of different minoritized groups, and systematically investigate how these different identities interact at the individual level. Such research must include people with disabilities.

Different Institutes, Centers, and Offices within the NIH will need to respond in different ways to the recommended changes in disability inclusion endorsed by the ACD, but the specific responsibilities placed on the NIMHD and AHRQ with regards to Recommendation 7a are quite clear. We urge you to take prompt action on this matter and thank you for your consideration of our views.

Sincerely,

The Undersigned Members of the Disability and Rehabilitation Research Coalition

American Academy of Physical Medicine and Rehabilitation*
American Association on Health & Disability
American Congress of Rehabilitation Medicine
American Medical Rehabilitation Providers Association
American Music Therapy Association
American Occupational Therapy Association*
American Physical Therapy 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
The Lakeshore Foundation
National Association for the Advancement Orthotics & Prosthetics
National Association of Rehabilitation Research and Training Centers*
National Neurotrauma Society
Paralyzed Veterans of America
Rehabilitation Engineering and Assistive Technology Society of North America
Spina Bifida Association
United Spinal Association

****DRRC Steering Committee Member***

CC:

DHHS Secretary Xavier Becerra
Dr. Lawrence Tabak, Acting Director, National Institutes of Health

Dr. Diana Bianchi, Director, National Institute on Child Health and Human Development
Dr. Alison Cernich, Deputy Director, National Institute on Child Health and Human Development
Dr. Theresa Cruz, Director, National Center for Medical Rehabilitation Research