



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service
National Institutes of Health

National Institute on Minority Health
and Health Disparities
6707 Democracy Boulevard
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Bethesda, Maryland 20892-5465

May 2, 2022

Joe Nahra
Co-Coordinator, Disability and Rehabilitation Research Coalition
Director of Government Relations
Powers Pyles Sutter & Verville PC
1501 M Street NW, Seventh Floor
Washington, DC 20005-1700

Dear Mr. Nahra,

Thank you for your letter dated April 7, 2022, to Drs. Lawrence Tabak and Robert Valdez on behalf of the Disability and Rehabilitation Research Coalition regarding the designation of individuals with disabilities as a National Institutes of Health (NIH) health disparity population.

With the establishment of the National Center on Minority Health and Health Disparities in 2000, Congressional language designated racial and ethnic minority groups as defined by the Census (American Indians/Alaska Natives, Asian Americans, Blacks/African Americans, Hispanics/Latinos, Native Hawaiians, and other Pacific Islanders) socioeconomically disadvantaged populations, and underserved rural populations were designated as health disparity populations. In 2016, sexual and gender minorities were designated as a health disparity population for NIH purposes after consultation with the Department of Health and Human Services. While not designated as a health disparity population, a retrospective cross-sectional study based on the National Health Interview Survey (NHIS) indicated that approximately 30% of individuals with severe disability are racial/ethnic minorities which is lower than the 37% identified in the entire population in the 2020 Census. However, a disproportionate number of individuals with severe disability would also be considered socioeconomically disadvantaged independent of their self-identified race or ethnicity.

As mentioned in your letter, the Minority Health and Health Disparities Research and Education Act of 2000 (P.L. 106-525) authorizes the Director of NIMHD, in consultation with the Director of the Agency for Healthcare Research and Quality to determine a health disparity population 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.” It is incontrovertible that individuals with disabilities experience challenges with access to appropriate healthcare and have poorer health outcome for many additional disease conditions. Furthermore, there is agreement that there are clear data gaps, and a reconfiguration

of Federally supported data collection instruments can play an important role in creating the knowledge base necessary to fully understand health disparities and individuals with disabilities.

The NIH has funded numerous research projects related to individuals with disabilities in extramural academic institutions as well as within the NIH Intramural Research Program. For example, the *Eunice Kennedy Shriver* National Institute of Child Health Development (NICHD) is supporting the project *Understanding and Supporting Reproductive Decisions Among Women with Developmental Disabilities that Affect Cognition* at the University of Wisconsin Madison. In addition, attention has been given to the career development of investigators interested in disability research through programs such as the *Research Training in Rehabilitation for Brain Injury and Neurological Disability* at the Kennedy Krieger Institute and the Johns Hopkins University, Department of Physical Medicine and Rehabilitation. Furthermore, the National Center for Medical Rehabilitation Research (NCMRR) aims to foster development of scientific knowledge needed to enhance the health, productivity, independence, and quality of life of people with physical disabilities. When one considers the definition of a disability, NIH has several other Institutes such as the National Eye Institute, National Institute on Deafness and Other Communication Disorders, the National Institute of Mental Health, and the National Institute on Aging with major investments in research for persons with visual impairment, deaf and hard of hearing persons, persons with severe mental disorders, and the broad spectrum of cognitive impairment.

However, much more can be accomplished to identify pathways of care and importantly develop interventions designed to improve the health of individuals with disabilities and reduce concomitant disparities. NIMHD and AHRQ leadership are planning to meet with the National Council on Disability to discuss the issue of health disparity population designation of individuals with disabilities and have taken steps to determine a time of mutual convenience.

Thank you for your strong support of NIH and NIMHD's efforts to improve minority health and reduce health disparities.

Sincerely yours,

A handwritten signature in black ink, appearing to read "Eliseo J. Pérez-Stable". The signature is fluid and cursive, with the first name "Eliseo" and last name "Pérez-Stable" clearly distinguishable.

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