



DRRC Applauds Landmark Decision by NIH to Designate People with Disabilities as a “Health Disparities Population”

The Disability and Rehabilitation Research Coalition (DRRC)—a coalition of 26 national research, clinical and consumer non-profit organizations committed to improving the science of rehabilitation, disability, and independent living—celebrates a huge victory for the disability community accomplished through years of advocacy and a massive letter “sign-on” campaign which energized a broad swath of stakeholders. On September 26, 2023, Dr. Eliseo Perez-Stable, M.D., Director of the National Institute on Minority Health and Health Disparities (NIMHD) at the National Institutes of Health (NIH), designated people with disabilities as a distinct “health disparities population.” This decision was a stunning reversal of NIMHD’s expected approach after receipt of a contrary recommendation from its Advisory Council and represents a major success by the disability community in addressing health inequities for people with disabilities.

The need to recognize people with disabilities as a distinct health disparity population is well-established in the clinical literature and has been a long-standing goal of the disability community. The COVID-19 experience highlighted the need for the federal government to make this formal designation. Since April 2022, the DRRC has written five letters to NIH urging NIMHD to designate people with disabilities as a health disparities population, most recently on August 2, 2023 ahead of the recommendation from the NIMHD working group.¹ Additionally, the DRRC met with NIMHD administrators on August 9, 2022 to advocate for the designation. A health disparities designation allows NIH funding for projects that include a focus on disability health disparities and enhances clinical research by incentivizing the recruitment of both researchers and clinical research participants with disabilities.

On September 1, 2023, the Advisory Council for the NIMHD recommended to **not** designate people with disabilities as a “health disparities population,” calling instead for additional research to better understand the impact of health disparities on this population. NIMHD is the lead institute on monitoring minority health and health disparities research for the NIH. The

¹ April 1, 2022 Letter: <https://disabilityandrehabilitationresearchcoalition.files.wordpress.com/2022/04/drrc-comments-on-nih-deia-strategic-plan-framework-4.1.2022.pdf>

April 7, 2022 Letter: <https://disabilityandrehabilitationresearchcoalition.files.wordpress.com/2022/04/drrc-letter-to-nimhd-ahrg-on-health-disparities-designation.pdf>

June 3, 2022: <https://disabilityandrehabilitationresearchcoalition.files.wordpress.com/2022/06/drrc-recommendations-for-implementing-coswd-strategic-plan-from-disability-perspective.pdf>

May 2, 2023 Letter: <https://disabilityandrehabilitationresearchcoalition.files.wordpress.com/2023/07/drrc-letter-on-nih-acd-disability-inclusion-recommendations.pdf>

August 2, 2023 Letter: <https://disabilityandrehabilitationresearchcoalition.files.wordpress.com/2023/08/drrc-letter-to-nimhd-and-ahrg.pdf>

NIMHD director is responsible for designating a health disparity population in consultation with the director of the Agency for Healthcare Research and Quality (AHRQ).

On September 6th, a [stakeholder letter](#) was submitted to the U.S. Department of Health and Human Services (HHS) urging the Agency to reconsider the NIMHD recommendation to not consider people with disabilities as a health disparities population. The letter was written by longtime advocates for this designation, Jae Kennedy, Ph.D., Professor of Community and Behavioral Health at the Washington State University College of Medicine and DRRC Steering Committee member, and Bonnie Swenor, Ph.D., M.P.H., Director, The Johns Hopkins Disability Health Research Center, on behalf of the DRRC and the disability community. This letter garnered the support of 1,291 healthcare providers, researchers, caregivers, organizations, and people with disabilities. In addition, former Congressman Tony Coelho, Chairperson of the Partnership to Improve Patient Care (PIPC), also sent a similar [companion letter](#) the same day to HHS that was signed by 175 additional stakeholder individuals and organizations.

In response to both letters, Dr. Perez-Stable issued a public statement on September 18, 2023, which noted that a final report was forthcoming, and that the Council's recommendation was advisory only and no official decision had been made. Dr. Perez-Stable stated that he would make the final decision in consultation with the AHRQ director based on the analysis that was conducted by NIMHD, stakeholder input, and a review of the science and evidence once a final report was delivered.

As a result of this review, as well as the massive advocacy effort by disability advocates, on September 26, 2023, the NIH and Dr. Perez-Stable decided to designate people with disabilities as a distinct health disparity population in a rejection of the Advisory Council's recommendation to the director. In the NIH press release, Acting NIH Director Lawrence Tabak, D.D.S., Ph.D., addressed the groundswell of support from the disability community by stating, "To the disability community, we hear you and thank you for sharing your lived experiences with NIH."

In addition to the designation, the NIMHD also announced a Notice of Funding Opportunity (NOFO) focused on the intersection of disabilities, race and ethnicity, and socioeconomic status in persons with developmental and physical disabilities. See link: <https://grants.nih.gov/grants/guide/pa-files/PAR-23-309.html>. The overarching goals are to support innovative research that focuses on the health (e.g., conditions, outcomes, trajectories, etc.) and healthcare (e.g., modalities systemic or structural factors, access/barriers, service delivery, care quality, utilization, etc.) of persons living with disabilities and the intersections with race and ethnicity, and socioeconomic status.

The NIH press release is available here: <https://www.nih.gov/news-events/news-releases/nih-designates-people-disabilities-population-health-disparities>

The Washington Post also published an article on the decision, in which the DRRC's Peter Thomas, Jae Kennedy, and Bonnie Swenor are quoted, and that article is available here: <https://www.washingtonpost.com/wellness/2023/09/26/disability-groups-win-fight-be-included-health-equity-research/>

The coalition will continue to support inclusion of people with disabilities at the NIH. In the near term, DRRC will submit comments on the pending Request for Information inviting feedback on a proposed update the NIH mission statement. See link:

<https://grants.nih.gov/grants/guide/notice-files/NOT-OD-23-163.html>.

More information about DRRC and its advocacy work is available at <https://drcc-coalition.org/>

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