



TESTIMONY FOR THE WRITTEN RECORD

FROM THE

DISABILITY AND REHABILITATION RESEARCH COALITION (DRRC)

**SUBCOMMITTEE ON HEALTH
COMMITTEE ON WAYS AND MEANS
UNITED STATES HOUSE OF REPRESENTATIVES**

LEGISLATIVE HEARING ON

**“BRIDGING HEALTH EQUITY GAPS FOR PEOPLE WITH DISABILITIES AND
CHRONIC CONDITIONS”**

FEBRUARY 3, 2022

Disability and Rehabilitation Research Coalition (DRRC)
www.drcc-coalition.org

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Chairman Doggett, Ranking Member Guthrie, and Members of the Health Subcommittee:

On behalf of the Disability and Rehabilitation Research Coalition (DRRC), we appreciate the opportunity to submit this statement for the record regarding the Subcommittee's hearing on addressing health equity gaps for people with disabilities and chronic conditions. This hearing underscores the Subcommittee's recognition of the health disparities and inequities faced by people with disabilities, and we look forward to working with you to develop systemic solutions to this persistent problem.

The DRRC is a coalition of 25 national non-profit organizations committed to improving the science of medical rehabilitation, disability, and independent living. The DRRC seeks to maximize the return on the federal investment in disability, independent living, and rehabilitation research and development with the goal of improving the ability of Americans with disabilities to live and function as independently as possible, in keeping with the promises of the Americans with Disabilities Act.

The DRRC and its members are well aware of the myriad inequities faced by people with disabilities, not only in health status, but access to health care, employment, education, community participation and integration, and much more. In order to develop actionable solutions, it is critical to first understand the scope of these problems. The DRRC has long supported expanded research into not only the biological mechanisms and treatment of disability, but the broader impacts of disability into individuals' daily lives. Unfortunately, data on people with disabilities has long been lacking, due to inconsistent collection, a lack of appropriately standardized measures, and patchwork information sharing systems. **We urge the Committee to work with your colleagues in Congress and the Administration to support enhanced disability data collection across all federal initiatives.**

Congress has already 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 of 1990, as amended*, the *Rehabilitation Act 1973, as amended*, and the *Individuals with Disabilities Education Act, as amended*) to protect this population. It should also require federal agencies like the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH) to measure and address the health and health care disparities experienced by people with disabilities.

Research demonstrates that adults with disabilities, compared to those without disabilities, are much less likely to be employed, less likely to graduate from high school, more likely to live in poverty, and much more likely to be in fair or poor health.¹ They also use more health care than their nondisabled counterparts and are much more likely to report difficulties in obtaining and paying for their health care. Populations with physical, cognitive, psychiatric, or communication

¹ 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](#)).

disabilities have limited access to preventative care, including wellness, fitness, smoking cessation, and weight loss interventions. Deaf populations, for example, are 7 times more likely to have low health literacy compared to hearing populations; people with disabilities are 30% more likely to be obese, are over 2 ½ times more likely to develop diabetes and are around 3 times more likely to develop cardiovascular disease. People with disabilities face negative attitudes and biases; inaccessible environments and equipment; inaccessible written, verbal, and electronic health care communication; and a lack of accommodations and other modifications to policies, practices, and procedures.

The COVID-19 pandemic has only underscored and exacerbated the disparities faced by people with disabilities. Additionally, so-called “Long COVID” is causing an enormous influx of people into the disability population, making the need to address health equity for people with disabilities all the more urgent and impactful. Given the cited disparities data, it would be expected that people with disabilities would have higher rates of COVID-19 exposure, infection, serious symptoms, hospitalization, and death. They may also face significant barriers to vaccination or be at higher risk of developing so-called “Long COVID.” But we do not know for sure, because the data simply has not been collected appropriately. We do know that death rates among nursing home residents (nearly all of whom have significant disabilities) jumped by 32% in 2020.² While most people with disabilities do not live in institutions, they do share many of the same COVID-19 risk factors. All people with disabilities, regardless of their living circumstances, require accessible and affordable health and support services, particularly during a public health crisis.

Many stakeholders, including the DRRC and many of your colleagues in Congress, have long called for improved demographic data collection relating to COVID-19.³ However, the pandemic has laid bare the inadequacies of the current data collection regime at the federal, state, and local levels regarding disability. For too long, there has been a lack of reliable information on how people with disabilities are impacted by any number of factors. Real-time data collection and disclosure of disability disparities in health and health care is the first step towards developing appropriate and equitable public health programs and policies to support this vulnerable population. Whenever possible, this should include standardized utilization and increased interoperability of existing data sources to minimize burden on providers.

Under the President’s Executive Order 14035, the federal government has a new charge to collect and analyze data to advance equity across underserved populations.⁴ Unfortunately, we have seen many efforts arising within Congress and the Administration that omit or de-emphasize specific acknowledgement of disability status data as a key demographic component

² U.S. Department of Health and Human Services Office of Inspector General (HHS OIG), OEI-02-20-00490: *Data Snapshot: COVID-19 Had a Devastating Impact on Medicare Beneficiaries in Nursing Homes During 2020* (June 2021). Available [here](#).

³ See, e.g., *May 13, 2020 letter to HHS from Sens. Elizabeth Warren and Bob Casey and Reps. Jim Langevin and Ayanna Pressley* (available [here](#)); *January 25, 2022 letter to CDC from Reps. Ayanna Pressley and Don Beyer* (available [here](#)).

⁴ Exec. Order No. 14,035, *Diversity, Equity, Inclusion, and Accessibility in the Federal Workforce*, 86 Fed. Reg. 34,593 (June 30, 2021). Available [here](#).

in existing or newly proposed data collection efforts. A focus on standardizing and collecting uniform measures of race and ethnicity in federal data collection efforts is critical and clearly necessary to document the disproportionate impact of the pandemic and pre-existing inequities on people of color, and to develop appropriate federal policies to mitigate immediate and long-term health disparities. But disability rates also vary by race and ethnicity, as well as by age, gender, and geographic area. Understanding these intersectional relationships will be critical to building a more resilient and responsive health system for all Americans.

As Congress considers new legislative efforts to enhance demographic data collection relating to COVID, other public health initiatives, or in other areas, ***we urge the explicit inclusion of disability status as a mandated component of all collections.*** We also urge that Congress recommend the government-wide collection, analysis, and public reporting of data on COVID-19 testing and diagnoses, treatment, and outcomes (including rates of recovery and long-term illness) disaggregated by disability status. Finally, we encourage Congress to recommend that the National Institutes of Health and the National Institute on Minority Health and Health Disparities recognize and designate people with disabilities as a health disparity population for purposes of federal research and collaborations, as has been requested recently by the National Council on Disability.⁵ These recommendations are critical first steps to developing a more equitable policy agenda to address the serious disparities faced by people with disabilities.

Thank you for the opportunity to submit a statement on the health equity gaps faced by people with disabilities. If you have any questions about the information in this statement, please do not hesitate to contact the DRRC coordinators, Bobby Silverstein, Peter Thomas, and Joe Nahra, at 202-466-6550 or by email at Peter.Thomas@PowersLaw.com, Bobby.Silverstein@PowersLaw.com, and Joseph.Nahra@PowersLaw.com.

Sincerely,

The Undersigned Members of the Disability and Rehabilitation Research Coalition

American Academy of Orthotists and Prosthetists
American Academy of Physical Medicine and Rehabilitation*
American Association on Health and Disability
American Congress of Rehabilitation Medicine*
American Medical Rehabilitation Providers Association
American Music Therapy Association
American Occupational Therapy Association*

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⁵ See December 7, 2021 from the National Council on Disability to the National Institute on Minority Health and Health Disparities (NIMHD) and the Agency for Healthcare Research and Quality (AHRQ), available [here](#).

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

National Association for the Advancement of Orthotics and Prosthetics

National Association of Rehabilitation Research and Training Centers*

National Association of State Head Injury Administrators

Paralyzed Veterans of America

Rehabilitation Engineering and Assistive Technology Society of North America

United Spinal Association

**** DRRC Steering Committee Member***