

Disability groups win fight to be included in health equity research

The designation of disabled people as a 'health disparity population' allows for more funding and research into the health equity barriers disabled people face



By [Amanda Morris](#)

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For years, the National Institutes of Health has funded research on health inequities faced by racial, gender and other underserved communities. But one notable group was left out: people with disabilities.

Now, in a major victory for disability health advocates, the NIH announced today that it has designated people with disabilities as a "health disparity population."

The term, which is used to describe a disadvantaged group that experiences preventable differences in health, dramatically expands access to funding and resources for studying and helping disabled populations. The NIH is the largest single public funder of biomedical research in the world.

Disability advocates say the change reflects an ongoing shift in medicine from trying to "fix" or cure disabled people toward viewing them more holistically, as a demographic group with its own unique socioeconomic challenges.

"This is a big deal," said Peter W. Thomas, co-coordinator of the Disability and Rehabilitation Research Coalition, which focuses on improving disability research. "This is going to focus more attention on getting people with disabilities the care they need and hopefully result in better outcomes for people with disabilities across the board."

Earlier this month, the National Advisory Council on Minority Health and Health Disparities recommended against the move, citing concerns over the lack of a standardized definition for disability and the broad nature of the disability population which they said could overwhelm existing staff and budgeting at the NIH. However, there was immediate pushback from hundreds of disability organizations, advocates, researchers and health-care professionals and the council did not include that recommendation in their final report, which did not take a position on a designation.

Disability researchers disagreed with the initial logic of the council, noting that while it can be tricky to define disability, other already designated groups have their fair share of complexities too, said Jae Kennedy, professor of health policy and administration at Washington State University.

"Race is really complicated. Gender identity is really complicated," he said. "And that is certainly not a good reason to ignore the population. If we want to be a healthier country and a more inclusive country we need to understand and develop policies to support this frequently ignored minority population."

He expects the new designation to have ripple effects across universities and organizations that vie for NIH funding by encouraging them to think more about how to make their own workplaces and research projects more inclusive of disability.

Disadvantages faced by the disability community

Disability advocates say there has been too little research on the challenges disabled people face in getting health care. Based on an analysis conducted by the National Institute on Minority Health and Health Disparities, about 3 percent of disability-related research grants across all NIH institutes from 2018 to 2022 also addressed health disparities.

This is despite “mountains of data” showing that people with disabilities have poorer health outcomes than those without disabilities, said Bonnielin Swenor, director of the Johns Hopkins Disability Health Research Center, including higher rates of mortality, chronic pain and emotional distress.

And while a disability itself can negatively impact someone’s health, there are a number of socioeconomic factors that also contribute, she said. For example, disabled people experience higher rates of poverty, incarceration and homelessness along with lower rates of employment — all of which can serve as a barrier to getting health insurance or health-care services, she said.

Other factors that can contribute to worse health for people with disabilities include limited transportation access, physical barriers to entering health-care facilities and a lack of accessible equipment — such as scales that can weigh someone who uses a wheelchair.

For a long time, Swenor, who is disabled herself, found it difficult to get NIH funding to better understand these barriers or address the inequities.

“I live those inequities, I see them in the data and it’s frustrating to not have the funding to do anything about it,” she said. “For the first time, it feels like we’re getting somewhere.”

The pandemic may have created a greater sense of urgency to address the issue because of how disproportionately disabled people were affected by covid-19. Some groups, such as those with intellectual disabilities, were at higher risk of contracting the virus and were more likely to die from it, whereas others couldn’t access critical covid testing tools. And, some dealt with shortages in the medication and supplies they needed to survive.

“The impact that COVID-19 had on disadvantaged populations, including people with disabilities, was enormous and demonstrates the critical importance of health disparities research,” Eliseo Pérez-Stable, director of the National Institute on Minority Health and Health Disparities at the National Institutes of Health, said in an email.

A shift in focus from ‘fixing’ disability

The effort for disabled people to be recognized as a health disparity population is part of a broader push to improve health outcomes for people with disabilities and change the way that disability is treated by medical institutions, said Andrés Gallegos, chair of the National Council on Disability, an independent government advisory agency.

For a long time, he said, doctors and researchers have only focused on efforts to “fix” or cure disabilities, rather than improving their overall well being.

“Having a disability and being healthy are not mutually exclusive,” he said.

This sentiment is reflected in a National Institutes of Health effort to change its mission statement, which current states that one goal is to “reduce illness and disability.”

Following a recommendation from members of an NIH advisory committee, the agency has proposed a change which would eliminate the goal of reducing disability specifically and focus more on a goal to “optimize health and prevent or reduce illness for all people.” The agency is inviting feedback on the proposed change.

Other changes that disability advocates are seeking include greater representation of disabled researchers and health-care professionals across the industry, better training in medical schools on how to properly treat people with disabilities and more accessible medical equipment in hospitals and health care facilities across the United States.