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Putting Disability at the Center of Public Health Research

A summary of the Health Equity Collaborative's 2025 article in The Lancet

> **"Engaging disabled people as equal partners in health research makes for better science and is the number one way to achieve health equity."**
>
> —Susan Havercamp, Ph.D., The Ohio State University Nisonger Center

The September 2025 issue of *The Lancet Regional Health Americas* featured an article by members of the Health Equity Collaborative (HEC) about the importance of including disability in health equity research and policy. Here, we summarize the article and share how the HEC's innovative approach of including people with lived experience throughout the research process redefines (and exemplifies!) disability research.

A Summary of "A call to action to include disability in intersectional health equity research and policy"

Invisible No More: Why Disability Must Be Central to Public Health

People with disabilities make up about 16% of the world's population, yet they are often left out of health research and planning. This exclusion causes serious problems, such as fewer chances to get good healthcare, more people reporting poor health, and needs that go unmet. People with disabilities are also more likely to differ in race and gender identity, which means they often face overlapping barriers to care. Social factors like family income, education, and discrimination further shape these health gaps.

Who Is the HEC?

In 2022, leaders from 19 health and disability research institutions came together under the leadership of Susan Havercamp, Ph.D., of The Ohio State University Nisonger Center, with a vision to create a national plan for advancing health equity for people with disabilities. Meeting once a month for three years, the Health Equity Collaborative—formed initially to develop a proposal for a federally funded disability center—leveraging the experiences of people with disabilities fthroughout the entire research process. When the proposal was not funded, the HEC was undeterred. They transformed their efforts into this powerful article calling on researchers everywhere to keep people with disabilities front and center of public health research and policy.

To fix these inequities, health research must look at how different parts of a person's identity—like race, gender, and disability—interact and affect their lives. Ableism, the unfair treatment of people with disabilities, is built into many health systems and must be addressed to create real change.

From Subjects to Leaders: Centering Disabled Voices in Research and Policy

People with disabilities must be included in every step of health research and policy, not just studied from the outside. Their lived experience helps to:

- create better questions
- determine more precise data
- develop stronger solutions.

We cannot achieve health equity without fully including people with disabilities as leaders, partners, and decision-makers in shaping health systems.

THE HEALTH EQUITY COLLABORATIVE'S CALLS TO ACTION:

- Include disabled people in every stage of research and policy planning.
- Improve health data by making sure disability is always counted.
- Study how disability connects with other identities, like race, gender, and economic status.
- Ensure health systems and new tools, like artificial intelligence, are free from bias.

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