

DHERN August 2025 Newsletter

DHERN Announcements

- **Save the date for the annual DHERN 2025 conference** on September 16th from 10 AM to 2 PM EST. We are thrilled to announce the theme of this year is Global Perspectives on Disability Equity. [Register for our conference now!](#) See the attached flyer for more details. The agenda will feature a keynote address and the following session topics:
 - a. Advancing Global Disability Data Equity
 - b. How Data Informs Global Disability Rights
 - c. Participation and Disability, Global Development, and Systems Change
- Funding for the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) is in serious jeopardy amidst the [proposed restructuring of HHS](#). The administration is proposing eliminating NIDILRR. NIDILRR is part of the Rehabilitation Act and for over 46 years has provided the infrastructure for applied disability research across all populations and the lifespan. NIDILRR plays a unique role in supporting research that promotes health, employment, and community living. Much of the data and research the disability and aging community uses to inform and advance policy and practice comes from NIDILRR. To support NIDILRR advocacy efforts:
 - a. Use NIDILRR advocacy materials in any conversations or posts you may be having. The American Association on Health & Disability has created an easily accessible [NIDILRR Support Toolkit](#) with flyers and graphics pre-formatted for Instagram and Bluesky.
 - b. Send a pre-written message to your representatives about NIDILRR funding using this [action alert](#). Feel free to tweak it to make it your own!
- If you would like to contribute to our work advancing disability health equity research, connecting researchers and trainees, and fostering the inclusion of disabled people in these efforts, you can [make a donation](#) to help sustain DHERN's mission.
- Share your recent publications, upcoming events, job opportunities with the DHERN community! To contribute to the next newsletter, please send details to us at dhern@jh.edu by the 28th of June.

Study Recruitment

- Researchers at Stanford University are seeking participants for a study about how different groups of people perceive the potential benefits and potential harms of emerging precision medicine research on cerebral palsy (PMR-CP). These studies aim to gather evidence that may inform future medical interventions for CP. This study is also interested in the priorities

different groups think should drive PMR-CP in the future. Individuals who are adults with CP, primary caregivers of adults with CP incapable of consenting to research, parents/guardians of minors with CP, healthcare providers with experience with CP patients, or researchers/PIs who have done genetics research involving CP may be eligible. Participation involves a 1-to-2-hour interview via Zoom, and participants will receive a \$50 gift card for their time. For questions, contact pmr-cerebralpalsy@stanford.edu.

- The Georgia Institute of Technology, in collaboration with the Center for Advanced Communication Policy, is conducting a research study to explore how individuals with functional disabilities — including paraplegia, quadriplegia, or upper/lower body mobility disabilities — currently use or would like to use digital virtual assistants (such as Alexa, Siri, or Google Assistant) in their daily lives and rehabilitation routines. Individuals aged 18 or older with functional disabilities may be eligible. Participation involves completing a [short online survey](#), which takes approximately 10–15 minutes. This study is led by Rayele Moreira at Georgia Tech. For questions, contact rsantos43@gatech.edu.

JOBS

- [The Center for Democracy & Technology Academic-year Externship](#)
 - a. The Center for Democracy & Technology is seeking an extern for their [Disability Rights in Technology Policy](#) project. Graduate-level students (master's, PhD, or law) interested in disability rights, tech policy, civil liberties, or human rights—and who are able to receive academic credit for the fall or spring semester—are eligible to apply. Positions are available across legal, policy, research, tech, and nonprofit communications roles. Students from all majors and degree programs are encouraged to apply.
- [Disability Policy Research Fellowship](#)
 - a. Northwestern University is accepting applications for a one- or two- year Post-Doctoral Fellowship on Disability Policy Research (DPR). The fellowship provides experiential training, knowledge, and skills in disability policy research with the goal of developing a cohort of experts capable of advancing policies that improve the lives of people with disabilities. Applications are reviewed on a rolling basis. For more information, contact ryan.splitt@northwestern.edu.

[Disability Data Equity Research Working Group](#) Featured Article

- Landes, S.D., Swenor, B.K., Hall, J.P., Forber-Pratt, A.J., Vaitisakhovich, N., Caldwell, K., Kakara, M., Lefkowitz, D., Myers, A., Popkins, S.J., Reed, N.S., Rothman, E.F., & Salinger, M. (2025). [The Disability Mismatch: The Case for a Comprehensive Disability Status Measure](#). *Health Affairs Scholar*, 3(7)
 - a. Using nationally representative survey data, this study found that nearly half of disabled adults identified through a comprehensive disability question were excluded by the current federal standard (ACS6) that measures only functional limitations. The authors argue that disability identity and experience extend

beyond functional impairments, and call for adopting a single, comprehensive disability status question to more accurately and inclusively identify disabled individuals in U.S. federal surveys.

Disability and Health Journal Featured Article

- Morris, M., Lockhart, S., Eberle, K., & Oshita, J. (2025). [Incentivizing, Enforcing and Improving Disability Accessible Health Care: Current Gaps and Potential Solutions](#). Disability and Health Journal, 101933.
 - a. This study explores why healthcare for people with disabilities remains inaccessible despite decades of federal legal requirements. Through 55 interviews with stakeholders—including disability advocates, researchers, and policymakers—the authors identified three key themes: (1) laws are necessary but not enough to drive systemic change, (2) healthcare organizations need education on disability as an equity issue, and (3) organizations are largely motivated by cost, quality, and competition. Many leaders are unaware of their legal responsibilities or the needs of patients with disabilities. The authors call for alternative strategies—beyond legal mandates—that align with institutional incentives and provide education to healthcare leadership to advance equitable care.

DHERN Member Submissions

- We are excited to share that Dr. Mustafa Rfat received the 2025 Career Enhancement Scholarship from the American Public Health Association (APHA) Disability Section. He has also been appointed to serve on the Accessibility Committee of the Disability Section, where he will contribute both his lived experience and academic expertise to promote inclusion and equitable access across public health spaces.

From,

The DHERN Team

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