

DHERN April 2025 Newsletter

DHERN Announcements

- Join us for our June DHERN meeting, “At the Margins of Care: Uncovering Health Inequities Faced by Refugees with Disabilities Living in the U.S.,” featuring Mustafa Rfat, PhD! Dr. Rfat is a Ph.D. candidate in Social Work at Washington University in St. Louis and a McDonnell Scholar. His research focuses on the intersection of forced displacement, disability, and structural inequities. CART and ASL interpretation will be available. [Register now](#) to attend on June 24th, 2-3pm ET.
- The Institute for Health and Disability Policy Studies at the University of Kansas is recruiting adults in the U.S. with physical, mental, emotional, or other health conditions to take the [2025 National Survey on Health and Disability](#). The goal of this survey is to better understand how access to health care services and types of insurance coverage affect the daily life, health, and community participation of people with disabilities. Responses will help shape future policies and resources. This survey is available in English, Spanish, and ASL, —online, by phone, or via Zoom. For questions, contact healthsurvey@ku.edu.
- Recordings from our March DHERN meeting, “[Designing Digital Health and Broader Structures with the Disability Community](#),” featuring Rupa Valdez, PhD, are now live!
- 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.

AWARDS

Congratulations to Scott D. Landes, Bonnie K. Swenor, and Natassia Vaitiakhovich for receiving the IPUMS Excellence in Research Award for their paper, “[Counting Disability in the National Health Survey and its Consequence: Comparing the American Community Survey in the Washington Group Disability Measures](#)”. This study leverages a unique feature of the 2011–2012 NHIS, which included both the ACS and WG-SS disability measures. By comparing individual responses across the two, the authors found that the WG-SS—adopted by the NHIS—substantially undercounts people with disabilities, capturing primarily those with multiple disabilities. The paper also demonstrates that the WG-SS overestimates disability-related mortality risk compared to the ACS measures.

JOBS

Senior Research Associate, University of Kansas

The Institute for Health and Disability Policy Studies (IHDPs) is hiring a half-time Senior Research Associate to lead the design, planning, and implementation of research and evaluation projects related to health, health policy, employment, and community participation for people with disabilities. The position involves supporting grant projects, developing proposals for external funding, conducting mixed methods research, and disseminating project findings.

STUDY RECRUITMENT

- We are seeking volunteers for a research study to improve the experience and accessibility of making healthcare appointments online. Individuals with one or more disabilities or chronic illness and are 18+ years old may be eligible. If you are interested, complete our [short screening survey](#). For questions, contact tbernst4@jh.edu. The Principal Investigators for this project are Dr. Theodore J. Iwashyna and Dr. Bonnielin Swenor. The Johns Hopkins Medicine Institutional Review Board has approved of this project under IRB#00463432.
- The Rubenstein Lab at Boston University School of Public Health is conducting a study, [Policies for Reproductive Outcomes in Medicaid—Improving Services for Enrollees with Intellectual and Developmental Disabilities](#), to better understand the healthcare experiences of pregnant people with intellectual and developmental disabilities, with the goal of improving care and health outcomes of pregnant people with IDD. Individuals who have an intellectual and/or developmental disability and were pregnant in the last ten years may be eligible. For questions, contact promidd@bu.edu.

Disability Data Equity Research Working Group Featured Article

- Goddard, K.S., Hall, J.P. (2025). [Limitations of the Washington Group Short Set in Capturing Moderate and Severe Mobility Disabilities](#), Health Affairs Scholar, 3(2).

The Washington Group Short Set (WG-SS) is commonly used in U.S. federal surveys to identify disability status—but growing research suggests it misses large segments of the disabled population. Using NHIS data from 2010–2018, researchers found that 54% of

respondents who reported using mobility aids were still categorized as nondisabled by the WG-SS. These findings raise serious concerns about the WG-SS's validity and suggest that current disability measures may significantly underrepresent people with mobility-related disabilities. The study reinforces the urgent need to revise how disability is measured in federal surveys, calling for more inclusive approaches that reflect a wider range of disability experiences and severity levels.

Health Affairs Featured Article

- Stein, R. I., Ma, Y., Phelan, J., Roberts, E. T., Johnston, K. J., Orav, E. J., & Figeroa, J. F. (2025). [Growth of Chronic Condition Special Needs Plans Among Dual-Eligible Beneficiaries](#), 2011-24. Health Affairs, 44(3), 304-312

Full-benefit dual-eligible enrollment in plan types like the Chronic Condition Special Needs Plan (C-SNP) has grown during the past decade. Nationally, nearly one in four full-benefit dual eligibles newly enrolling in C-SNPs in 2024 were previously enrolled in plans with some form of Medicare-Medicaid integration. In several states, there are notably large proportions of full-benefit dual eligibles among C-SNP enrollees. These results indicate that dual-eligible beneficiaries are increasingly enrolling in C-SNPs that may address their chronic condition needs yet not provide them with optimal levels of Medicare-Medicaid integration

Disability and Health Journal Featured Article

- Agaronnik, N.D., Park, E.R., Iezzoni, L.I (2025). [Discretionary exclusion criteria in oncology clinical trials and exclusion of people with psychiatric and cognitive disabilities](#). Disability and Health Journal

A review of Phase III and IV interventional oncology clinical trials listed on ClinicalTrials.gov between 2019 and 2023. Among 96 eligible trials, 85% included broad discretionary eligibility criteria, often allowing investigators to exclude participants based on perceived safety risks, adherence concerns, or ability to provide informed consent. Qualitative analysis revealed that such criteria may disproportionately exclude individuals with psychiatric or cognitive disabilities. The findings raise important questions about equity in clinical trial access and call for greater scrutiny of how and why these populations are excluded from oncology research.

From,

The DHERN Team

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