

DHERN August 2024 Newsletter

DHERN Announcements

1. We are thrilled to announce the details of our second annual virtual conference on September 17th, 2024, 11AM-3PM EST! This year centers on **Moving Disability Measurement Forward**, and we have fantastic guests joining us. [Register for our conference now!](#) See the attached flyer for more details.
 - a. **Keynote speaker: Robert Santos, Director of the US Census Bureau**
 - b. **Panel 1: Measuring Disability**
 - i. Jean Hall, PhD, Director, KU Institute for Health and Disability Policy Studies
 - ii. Sue Popkin, PhD, Co-Director, Disability Equity Policy Initiative, Urban Institute
 - c. **Panel 2: Disability Data Interagency Working Group (DDIWG)**
 - i. Adam Politis, Senior Policy Advisor for Disability and Equity, White House Office of Science and Technology Policy
 - ii. Bob Sivinski, Senior Statistician, Office of Management and Budget
 - iii. Invited: Other DDIWG Members
 - d. **Panel 3: Disability as Demographic**
 - i. Mary Lou Breslin, Senior Policy Advisor, Disability Rights Education and Defense Fund (DREDF)
 - ii. Silvia Yee, Public Policy Director, Disability Rights Education and Defense Fund (DREDF)
 - iii. Bonnielin Swenor, PhD, Professor and Director, Johns Hopkins Disability Health Research Center, DHERN Co-Founder
 - iv. Scott Landes, PhD, Associate Professor, Syracuse University, DHERN Co-Founder
2. Missed our May Careers in Disability Health Fireside Chat? Catch up with our [recorded conversation](#) with experts Silvia Yee, Corey Moore, Lisa Meeks, and Stephanie DeLuca!
3. Share your recent publications, upcoming events, job opportunities with the DHERN community! To contribute to the next newsletter, please send the following details to us at dhern@jh.edu by the 28th.
 - Name:
 - Email address for contact:
 - Details (for event or opportunity, include a brief description no more than 3 lines with dates and necessary links; for publication, include the full citation and an abstract):
 - Link for more information/publication:

Opportunities

- **JOBS**

- a. Post-Doctoral Fellow for Disability in All of Us - A Longitudinal Study of Health and Functioning (DIAL-HF).
 - We are interested in someone with experience in population health and/or disability studies, although other types of disciplinary backgrounds could be applicable. Please reach out to Elizabeth K. Rasch (Senior Associate and Chief, Epidemiology and Biostatistics Section at NIH Rehabilitation Medicine Dept) for more information: RaschE@cc.nih.gov

- **MEDIA**

- a. [One in Five: A podcast from Providence hosted by Sarah Quinto, MA and Angela Marith, MS](#)
 - At least one in five people have a disability. Health disparities for people with disabilities have a long and troubling history. In this podcast, we talk about common health disparities for people with disability, what needs to change to make healthcare more welcoming, and we explore how embracing disability strengthens our communities. [Transcripts, an opportunity to share your story, and more here.](#)

- **CALL FOR PAPERS**

- a. [Epidemiologic Reviews: Call for Papers on 2025 Theme: Health Equity for People With Disabilities.](#) The overall goal of this issue is to update and address critical research gaps relating to unmet health-care needs of individuals with disabilities. Topics may include, but are not limited to, prevalence; measurement; data gaps; health-care determinants; health-care access and experiences; health-care outcomes; access to and participation in research; impacts of structural ableism; and interventions and policy determinants. Reviews should focus on how to maximize inclusion and health for individuals with disabilities across the life course. Priority will be given to reviews that focus on the intersectionality with other minoritized identities (eg, race/ethnicity, gender identity, socioeconomic status) given stark health inequities for these individuals. Researchers should avoid ableist language and stereotypes; reviews that focus on disability solely as a condition to treat or cure will not be considered. All papers must be reviews of existing studies, though reviews may cite commentaries, frameworks, and empirical papers from public health, psychosocial sciences, and biological sciences. Reviews should discuss practical implication and potential implement of study findings to maximize health and equity for disabled individuals. Submissions due November 22, 2024.
- b. [BMC Health Services Research](#) is currently welcoming submissions of original research to the “Improving care for people with disabilities” Collection, Guest Edited by Dr Linda Long-Bellil.

but if you are unable to submit a manuscript before this date, please let us know as we may be able to be flexible. [Submission guidelines here](#). Authors should express their interest in the Collection in their cover letter.

- c. [Topical Collection on Disability and Women's Mental Health*](#). Co-Guest Editors Dr. Hilary Brown and Dr. Lesley Tarasoff are leading a call for papers for Archives of Women's Mental Health on disability and women's mental health. We are looking for original research, systematic reviews, and short communications investigating mental health outcomes and mental health care experiences among women with disabilities. We will consider quantitative study designs on populations with physical, vision, hearing, cognitive, and intellectual or developmental disabilities. We encourage the submission of studies that examine sex/gender differences in mental health in populations with disabilities; studies that examine mental health across the reproductive life course (e.g., related to pregnancy and parenting, the menstrual cycle, and the menopausal transition); studies that examine the intersecting impacts of ableism and other forms of oppression (e.g., racism) on disabled women's mental health; and studies from all global contexts. Submission deadline: September 30, 2024.
 - *Note that this is a revised call for the topical collection on Disability and Mental Health Across the Reproductive Life Course, which now has an expanded focus and extended submission deadline.
- **REQUESTS**
 - a. Participants Needed for Qualitative Research Study Exploring Structural Racism, Structural Ableism, and Intersectionality (flyer attached)
 - Researchers (PI: Amber Davis) are looking for participants who:
 - Are Black, Autistic, and between ages 16-35
 - Are willing to participate in a 60-minute interview by Zoom with availability of needed accommodations
 - Have at least one incident of:
 - Inpatient psychiatric hospitalization
 - Justice involved arrest
 - Misuse of prescription drugs and/or substance use
 - If you are interested in participating in this research project scan the QR code and complete the survey or email adavi212@jhu.edu. If you prefer to reach out by phone, please call/leave a message at: 410-502-7875
 - b. Participants needed for a study about how parents with developmental disabilities make decisions about feeding their babies (flyer attached)
 - We are looking for parents with developmental disabilities who are 18 years of age or older, have a baby 12 months old or younger, and live in the U.S. or U.S. Territory. We will ask you to take a 15- to 30-minute survey. After the survey, we may ask you to take part in an interview and

a group meeting. If you have questions: email slu47@jh.edu or call or text (410) 929-3598. If you'd like to take the survey, use the link: <https://redcap.link/IFDMstudy> or scan the QR code. This study has been reviewed and approved by the Johns Hopkins Bloomberg School of Public Health (IRB # 00028089). The principal investigator is Allison L. West, PhD, MSW.

- c. Volunteers with Disabilities Needed to Participate in a Research Study on Maternal Health
 - Researchers with the University of Virginia and the University of Montana are recruiting participants for a research study on maternal and infant outcomes among women with disabilities. This study will add to the limited understanding of how experiences of depression and/or interpersonal abuse around the time of pregnancy affect(s) the health and well-being of pregnant or new mothers with disabilities and their infants. Participants will be invited to participate in one confidential individual interview via ZOOM and asked to share information about their pregnancy and childbirth experiences.
 - To be eligible, participants must have a disability or a disabling condition (vision, mobility, intellectual, learning, or psychological) or are Deaf or hard-of hearing; be at least 18 years of age; be pregnant or have given birth in the last 24 months; and are experiencing or have experienced difficult intimate relationships and/or mood disturbances. Participants will receive a \$40 gift card for their time. For additional information, email disabilityandpregnancy@gmail.com or call 434-218-0242.

Health Affairs Featured Article

- Doctor, J. N., & Lakdawalla, D. N. (2024). [How To Advance The Debate Over QALYs: A Response To Kaplan et al.](#) *Health Affairs Forefront*.
 - a. The authors call for an alternative to QALYs, given issues with the underlying assumptions made in a previous *Health Affairs Forefront* article by Robert Kaplan and authors.

Disability and Health Journal Featured Article

- Desai, R. H., Choi, S., Wehmeier, A., Oxford, J. M., & Morgan, K. A. (2024). Advocating for transportation equity: A critical examination of paratransit service reductions in St. Louis and its impact on health and community social participation. *Disability and Health Journal*, 101666.
 - a. Our team recently reported in the *Journal of Disability and Health* that Missouri-dwelling adults aging with long-term physical disabilities who use paratransit services as their primary transportation mode are more likely to participate in social roles and activities outside the home compared to those who do not use

paratransit. In March of 2023, the paratransit company Metro Call-A-Ride that serves St. Louis announced major scale backs to their coverage zones due in part to staffing shortages. In this commentary, we will summarize the media coverage this decision has received, including the perspectives of disability rights advocates and individuals who have been directly affected. We will then present an overview of our original research findings in the context of these recent events and a brief synthesis of existing literature on paratransit services in the U.S. The commentary will end with proposed policy, research, and programming solutions for St. Louis's Metro Call-A-Ride and public transportation at large.

DHERN Member Submissions

- Landes, S. D., Swenor, B. K., Clark, M. A., Goddard, K. S., Hall, J. P., Hermans, A., ... & Vaitiakhovich, N. (2024). [A Research Roadmap Toward Improved Measures Of Disability](#). *Health Affairs Forefront*.
 - a. We are at a critical juncture regarding disability measurement in federal surveys. The disability measures currently used are not up to the task of inclusively and equitably counting the disabled population. But the path forward to creating new questions is not yet clear. To maximize the opportunity of this moment, members of the Disability Data Equity Research Working Group (DDERWG), inclusive of disabled and allied researchers with expertise in disability measurement, provide a roadmap for improving the measurement of disability. We recognize that the creation of new disability measures will take considerable time. Therefore, with this article, we articulate immediate, mid-range, and long-range goals for improving disability measures-as well as a clear rationale for pursuing these goals. As the process to determine the future of disability measurement in US population surveys moves forward, it is imperative to remember this key principle: nothing about disability measurement without us.

From,

The DHERN Team

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