

DHERN September 2024 Newsletter

DHERN Announcements

1. The second annual DHERN conference is THIS MONTH! [Register for our conference now](#), held September 17th, 2024, 11AM-3PM EST. This year centers on **Moving Disability Measurement Forward**, and we have fantastic guests lined up! 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
 - 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. Interested in learning about disability data equity? Here are some suggested by the [Disability Data Equity Research Working Group](#):
 - a. Hall, J. P., Kurth, N. K., Ipsen, C., Myers, A., & Goddard, K. (2022). Comparing Measures Of Functional Difficulty With Self-Identified Disability: Implications For Health Policy: Study compares measures of functional difficulty with self-identified disability. *Health Affairs*, 41(10), 1433-1441.
<https://doi.org/10.1377/hlthaff.2022.00395>
 - b. Hermans, A., Morriss, S., & Popkin, S. J. (2024). [An Opportunity for the Census Bureau to More Accurately Estimate the Disabled Population in the US. Urban Institute.](#)
 - c. Ipsen, C., Chambless, C., Kurth, N., McCormick, S., Goe, R., & Hall, J. (2018). [Underrepresentation of adolescents with respiratory, mental health, and developmental disabilities using American Community Survey \(ACS\) questions.](#) *Disability and Health Journal*, 11(3), 447-450.

- d. Karpman, M., & Morriss, S. (2024). [Current Approaches to Measuring Disability Status in Federal Surveys May Limit Understanding of Economic and Health Disparities](#). Urban Institute.
 - e. Landes, S. D., Swenor, B. K., Clark, M. A., Goddard, K., S., Hall, J. P., Hermans, A., Ipsen, C., Karpman, M. Kurth, N. K., Myers, A., Popkin, S.J., Salinger, M.R., & Vaitsiakhovich, N. (2024). [A Research Roadmap Toward Improved Measures Of Disability](#). *Health Affairs Forefront*.
 - f. Landes, S. D., Swenor, B. K., & Vaitsiakhovich, N. (2023). [Counting disability in the National Health Interview Survey and its consequence: Comparing the American Community Survey to the Washington Group disability measures](#). *Disability and Health Journal*, 17, 1-9.
 - g. Salinger, M. R., Feltz, B., Chan, S. H., Gosline, A., Davila, C., Mitchell, S., & Iezzoni, L. I. (2023). [Impairment and Disability Identity and Perceptions of Trust, Respect, and Fairness](#). *JAMA Health Forum*, 4(9), e233180-e233180.
 - h. Schulz, J. A., Hall, J. P., West, J. C., Glasser, A. M., Bourne, D. E., Delnevo, C. D., & Villanti, A. C. (2024). [Measuring disability among U.S. adolescents and young adults: A survey measurement experiment](#). *Preventive Medicine Reports*, 43, 102770.
 - i. Swenor, B. K. (2022). [A Need For Disability Data Justice](#). *Health Affairs Forefront*.
 - j. Ward, B., Myers, A., Wong, J., & Ravesloot, C. (2017). [Disability Items From the Current Population Survey \(2008–2015\) and Permanent Versus Temporary Disability Status](#). *American Journal of Public Health*, 107(5), 706-708.
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. Ph.D. student recruitment opportunity - braille and vision rehabilitation focus
 - We are looking for a highly motivated candidate with strong interest and experience in the domain of braille and assistive technologies for people who are blind, deafblind or who have low vision. The candidate will join the research laboratory of Dr. Natalina Martiniello and complete a Ph.D. in Vision Science (Specialization: Visual Impairment Rehabilitation) in the

School of Optometry at the Université de Montréal, in Montréal, Québec, Canada.

- The individual will work on research to develop evidence-based indicators to guide the selection of braille display technologies for diverse reading and user needs across adulthood. This research will explore the influence of braille display characteristics (e.g. line length, single vs. multiline design, ergonomics, complexity) on reading performance across a range of linear and non-linear reading tasks for education, employment and independent living. This research will also explore the potential impact of age-related declines on the ability to use braille display technologies, and factors to maximize usage for working-age and older adults with acquired vision loss. Visit these sites for more information in [English](#) or [French](#).
- b. 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](#)**

- Currently welcoming submissions of original research to the “Improving care for people with disabilities” Collection, Guest Edited by Dr Linda Long-Bellil. [Submissions due](#) until the end of 15 March 2025, 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.

• **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

- Husain, N. (2024). [Reconsidering Pharmacy Methadone Distribution for Opioid Use Disorders](#). Health Affairs Forefront.

- a. Policy makers, consumer groups, and advocates must work together to compel retail pharmacies to fully staff their stores at levels necessary to meet demand.

Disability and Health Journal Featured Article

- Schwartz, A. E., McDonald, K., Ahlers, K., Anderson, E., Ausderau, K., Corey, J., ... & Vetoulis-Acevedo, M. (2024). [Research ethics for all: Development of a social-behavioral research ethics education program for community research partners with developmental disabilities](#). Disability and Health Journal, 101675.
 - a. In collaboration with collaborated with people with developmental disabilities, a disability service provider, health researchers, and human research participant protections experts , we developed a social-behavioral research ethics training that leads to certification tailored to the accessibility needs and roles of community research partners with developmental disabilities. To identify potential training content, we conducted a rapid scoping review of ethical, legal, and social issues in social-behavioral research with adults with developmental disabilities and reviewed national research ethics curricula. Research Ethics for All is a freely available training that includes 5 units, delivered via didactic and active learning, and assessment activities to verify understanding. Research Ethics for All should be facilitated by an experienced researcher. Research Ethics for All includes foundational social-behavioral research ethics content designed to support community research partners with developmental disabilities to take on new research responsibilities.

DHERN Member Submissions

- [The Dementia Datahub](#)
 - a. Have you ever needed to know how many Medicare beneficiaries are diagnosed with dementia in your state or county? Produced by NORC at the University of Chicago and Funded by the National Institute on Aging, The Dementia Datahub provides maps and dashboards to explore Dementia outcomes by geography, demographics, Medicare insurance category, dementia diagnosis category, and provides data on prevalence, incidence, mortality and COVID-19 infections among prevalent cases, and all-cause Medicare payments among fee-for-service beneficiaries. Particularly relevant to the DHERN audience, The Dementia Datahub contains information on diagnosed dementia among Medicare beneficiaries ages 64 and younger, many of whom qualified for Medicare via the disability pathway.

From,

The DHERN Team

To receive the DHERN newsletter, please email dhern@jhu.edu with the subject line “subscribe.” To stop receiving the DHERN newsletter, please email dhern@jhu.edu with the subject line “unsubscribe.” Thank you!