DHERN October 2024 Newsletter

DHERN Announcements

- 1. Thank you to our speakers and attendees for making the 2024 DHERN Conference, "Moving Disability Measurement Forward," a success! Recordings of our fantastic panels will be available on our website soon. Stay tuned!
- 2. 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

- GRANTS
 - a. Community Champions for Disability Health Challenge
 - This Administration of Community Living prize competition seeks to engage community groups and support their initiatives to improve health equity for people with disabilities. Phase 1 open until 11/01/24 05:00 PM EDT. Total cash prizes: \$485,000.
- JOBS
 - a. The Ohio State University Nisonger Center Postdoc Opportunity
 - The Ohio State University Nisonger Center offers a postdoctoral research training opportunity in community-engaged disability research with the autistic and/or intellectual and developmental disability community. Funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), this program provides two-years of funding to partner with the disability community to answer research questions that matter to the disability community. In addition to community-engaged research opportunities, fellows are mentored by Susan M Havercamp, PhD, Katie Walton, PhD, and other interprofessional faculty. We are committed to increasing the diversity of researchers in the disability field and strongly encourage candidates with disabilities and diverse racial and ethnic identities to apply.
 - b. 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.
- c. 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

CALL FOR PAPERS

- a. <u>Epidemiologic Reviews: Call for Papers on 2025 Theme: Health Equity for</u> 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. <u>Submissions due</u> 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. <u>Submission guidelines here</u>. Authors should express their interest in the Collection in their cover letter.

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

- Landes, S. D. (2024). <u>Disability Mortality Disparity: Risk Of Mortality For Disabled</u>
 <u>Adults Nearly Twice That For Nondisabled Adults, 2008–19: Article examines the risk</u>
 <u>for mortality among disabled adults compared with nondisabled adults.</u> Health Affairs,
 43(8), 1128-1136.
 - a. Addressing the disability mortality disparity will require continued efforts to improve access to evidence-based, high-quality health care for disabled adults, as well as the development of inclusive and equitable measures of disability and ableism in population health surveys.

Disability and Health Journal Featured Article

- Kessler, A., Schroth, S. L., & Rydberg, L. (2024). <u>Disability's absence from admissions</u> <u>nondiscrimination and recruitment initiatives in Top-Tier US allopathic medical</u> <u>schools.</u> Disability and Health Journal, 101679.,
 - a. Disability is often overlooked and there are potential examples of discrimination in US medical schools. In this descriptive study, the authors reviewed publicly available data from websites of the top ranked 51 US allopathic medical schools to assess inclusion of disability in recruitment efforts or antidiscrimination statements. The results showed that just under one third of these schools (31 %) mention disability within their DEI or published recruitment efforts. Most commonly (27.5 %), disability is mentioned in a general diversity statement. These findings suggest that there is a need for greater inclusion of disability in US medical schools' recruitment efforts. This is essential to ensure that people with disabilities are not discriminated against in medical school applications and is

one of many factors that will contribute to future physicians being prepared to care for patients with disabilities.

Disability Data Equity Research Working Group Featured Article

- Hall, J. P., Goddard, K. S., Ipsen, C., Myers, A., & Kurth, N. K. (2024). <u>Counting Everyone:</u>
 <u>Evidence for Inclusive Measures of Disability in Federal Surveys.</u> *Health Affairs Scholar*.
 - a. The US Census Bureau has used the American Community Survey six-question set (ACS-6) to identify disabled people since 2008. In late 2023, the Census Bureau proposed changes to these questions that would have reduced disability prevalence estimates by 42%. Because these estimates inform funding and programs that support the health and independence of people with disabilities, many disability researchers and advocates feared this change in data collection would lead to reductions in funding and services. While the Census has paused but not ruled out—the proposed changes, it is critical that alternate, more inclusive disability questions be identified and tested. We used data from the 2023/2024 National Survey on Health and Disability to explore alternative questions to identify disabled people in national surveys. A single broad question about conditions identified 11.2% more people with disabilities, and missed significantly fewer people with psychiatric disabilities compared to the current ACS-6 questions. A combination of a broad question and the existing ACS-6 questions may be necessary to more accurately and inclusively identify people with disabilities.

DHERN Member Submissions

- Davis, A. M., Telfer, N. A., Artis, J., Abubakare, O., Keller-Bell, Y. D., Caruthers, C., Jones, D. R., & Pierce, N. P. (2024). Resilience and strengths in the Black autism community in the United States: A scoping review. Autism Research, 1–25. https://doi.org/10.1002/aur.3243
 - a. A scoping review was conducted to explore quantitative, qualitative, and mixed methods studies that investigate resiliency factors and related strengths in the Black autism community in the United States. A total of 436 articles were identified, with 28 studies included in the final review. Results demonstrated that (1) strengths of Black autistic persons across the life course have been disregarded in research; (2) Black caregiver advocacy, while common, is also a developmental process that can be supported by community-based interventions; (3) informal supports including family and friends play an instrumental role in supporting the well-under investigated being of Black parents of autistic children; and (4) spirituality is often endorsed by Black caregivers of autistic children, such as playing a role in acceptance of the autism diagnosis and with coping with difficult life situations.

From,

The DHERN Team

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