# **DHERN** November 2024 Newsletter

#### **DHERN Announcements**

- 1. Send in your nominations for the DHERN 2024 Paper Award Competition!
  - a. We will provide two awards. The nominee must be the first author on the paper (co-authorship is permitted with student or faculty co-author(s)). The primary focus of the paper should relate to disability health equity, broadly defined. The paper must have been published or accepted for publication in a peer-reviewed journal in 2023 or 2024, and the nominee must have been at one of the following levels of education/training at the time the paper was published or accepted for publication: undergraduate student, graduate student, postdoctoral researcher.
  - b. Each awardee will receive \$500 and will present a summary of their paper at the DHERN meeting on Tuesday, January 28, 2025, 2:00-3:00pm ET.
  - c. One entry is permitted per nominee. Self-nominations will be accepted. **The** deadline for nominations is 5:00pm on Wednesday, December 4, 2024.
  - d. Email paper and nomination letter to sdlandes@syr.edu.
- 2. Mark your calendar for the Paper Award winners' presentations! Tuesday, January 28<sup>th</sup>, 2025, 2:00-3:00pm ET, each awardee will share a summary of their paper.
- 3. Recordings from the 2024 DHERN Conference, "Moving Disability Measurement Forward," are now live!
- 4. 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 <a href="mailto:dhern@jh.edu">dhern@jh.edu</a> 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. Assistant Professor of Education (Rehabilitation and Human Services) Tenure Track Opportunity at Penn State
    - The Department of Educational Psychology, Counseling, and Special Education (EPCSE), located in the College of Education invites applications for a tenure-track faculty member, whose research examines social and racial determinants of health and disability. The Rehabilitation and

Human Services (RHS) program educates and trains practitioners with applied knowledge and skills to improve quality of life, affect positive change, and facilitate life goals for persons with disabilities and associated social determinants of health. We seek candidates that can excel in teaching applied undergraduate courses in human services and have an associated research agenda. See attached flyer for more.

## b. 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.

## c. 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.
- d. 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. The <u>U.S. General Assembly Office has developed a survey</u> to obtain the lived experiences of people with disabilities regarding the barriers they've faced trying to access healthcare. Caretakers can also answer the survey on behalf of the person they care for. They plan to incorporate these stories into our report. The survey will be open until November 30, 2024.

- b. Participants Needed for a Qualitative Study About Healthcare Experiences of Pregnant People with Intellectual and Developmental Disabilities
  - The Rubenstein Lab at Boston University School is looking for participants for their new NIH-funded study, Policies for Reproductive Outcomes in Medicaid—Improving Services for Enrollees with Intellectual and Developmental Disabilities (PROMISE-IDD). The goal of our research study is to understand the health care experiences of pregnant people with intellectual and developmental disabilities (IDD). We hope this study will help improve the health care and health outcomes of pregnant people with IDD. Here is more information about the study.
  - We are actively recruiting people with IDD to participate in our study. We are looking for participants with a documented IDD diagnosis, age 18+, who speak and understand English, are or have been pregnant in the past 10 years in the U.S., and have been enrolled in Medicaid during pregnancy.
  - If you choose to participate, we will interview you for one to one and a half hours about your experience with pregnancy care. You will receive a \$50 Amazon visa gift card for your time.
  - If you are interested in participating, please fill out this interest form. If you have any questions about the study or want to discuss the study over the phone/Zoom, please email erubens@bu.edu or promidd@bu.edu.
- c. Stanford University is conducting a study to learn more about aging and Alzheimer's Disease for adults with Down syndrome. They are looking for adults with Down syndrome and their family members/caregivers to participate.
  - You are eligible for this study if you are an adult with Down syndrome (18 years old or older) or a caregiver/family member of an adult with Down syndrome (18 years old or older).
  - In this study, you will attend a 90-minute focus group with up to 5 other participants over Zoom. You will also tell the research team about your experiences with and perspectives on aging and Alzheimer's for adults with Down syndrome. Participants will receive a \$30 gift card.
  - For more information or to express interest in participating, contact Megan Cvitanovic at mcvitano@stanford.edu or call 650-497-0938.
  - For complaints, concerns, or participant's right questions, contact 1-866-680-2906.

## **Health Affairs** Featured Article

- Hoffman, A. K., Rhode, K., Coe, N. B., & Miller, K. (2024). <u>Addressing Problems with</u>
  <u>Medicaid Home & Community-Based Services in the Age of Rebalancing</u>. Health
  Affairs, 1438.
  - a. The needlessly complex Medicaid HCBS system is the result of Congress failing to craft a nationwide long-term care plan for "rebalancing." Constructing a more

cohesive path forward could ensure that Medicaid funds the long-term care that beneficiaries need, in an administrable and equitable way.

## **<u>Disability and Health Journal</u>** Featured Article

- Ipsen, C., Sage, R., & Standley, K. (2024). "Too few, too far away, for what is paid": Consumer voices about the personal assistance worker crisis. Disability and Health Journal, 101721.
  - a. This paper explores how peronal assistance service worker (PAS) shortages manifest themselves in the daily lives of people with disabilities using or needing PAS services in the United States. We used thematic coding of qualitative data from the 2022 National Survey on Health and Disability. Three themes emerged regarding consumer perspectives and experiences with worker shortages (1) low pay, few benefits, and undervalued work, (2) demanding working conditions and logistics, and (3) low quality workers. In combination, these themes informed a fourth theme (4) impacts for PAS consumers characterized by substandard care and additional stress and workload for those who direct their own care. Without tangible steps to resolve these problems at the policy level, such as improved worker pay and protections, hope for resolution to these issues remains elusive.

From,

The DHERN Team

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