DHERN December 2023 Newsletter

DHERN Announcements

1. Mark your calendar for **presentations from the DHERN Paper Award winners**! Tuesday, January 23rd, 2-3pm Eastern. CART will be available, email dhern@jhu.edu for additional access requests. **Register here.**

2. **CRITICAL POLICY ISSUE:**
   a. **The U.S. Census is changing the way disability data is collected, which will reduce national prevalence estimates of disability from 14% to 8%.** Read STAT News article by Drs. Bonnie Swenor and Scott Landes, "The next Census could undercount the number of disabled Americans by 20 million."
   b. These changes have moved forward **without the input of the disability community** and have far-reaching, negative implications for disabled people. As disabled scholars and scholars of disability data, we are also concerned with the **limited empirical evidence to support these changes** to the Census disability data methodology.
   c. Along with colleagues, we recently sent a letter to the Director of the U.S. Census, Robert Santo, as well as other leaders across the federal government outlining our concerns and requests.
   d. We are asking the Census to stop efforts aimed at changing disability data collection. **We urge you** to share your perspective and respond to the current Federal Register request for comment
   e. We are also asking the Census to:
      i. Make a plan to improve the inclusion of disabled people across the activities of the U.S. Census Bureau.
      ii. Support forming a National Taskforce on Disability Data to improve and expand disability data collections at the U.S. Census and across the federal government.
   f. **Please share this information with your networks!**

3. Missed our previous meeting featuring Dr. Kathleen Bogart? Catch up with the recording on our website.

4. See below for our latest addition: featured articles on disability health from the editors at Health Affairs!

5. 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 ccerill1@jhu.edu by the 28th.
   - Name:
   - Email address for contact:
   - Twitter handle for contact and/or organization:

- 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. With the NIMHD designation, they have also announced an R01 (Clinical Trials Optional) grant opportunity, [Health and Health Care Disparities Among Persons Living with Disabilities](). The NOFO is to support novel and innovative research that examines and/or intervenes on the underlying and multilevel causes, pathways, and factors adversely impacting the health and well-being of persons with disabilities at the intersections of race and ethnicity, and socioeconomic status. Open date is January 5th, 2024.

- **POLICY**
  a. [The U.S. Census is changing the way disability data is collected](), which will reduce national prevalence estimates of disability from 14% to 8%, without input from the disability community. Read [this letter]() by disability scholars to learn more about the issues the upcoming changes present. Stay engaged and share your perspective by responding to the [current Federal Register request for comment]()

- **MEDIA**
  a. The Providence "Health Equity in Action" Podcast is a new podcast focused on healthcare experiences in underserved and/or marginalized communities. An upcoming series will focus on disability and will explore the challenges people with disabilities face in healthcare. To better understand disability health equity, and to hear directly from people with lived experience, [we've designed a 1-question survey](). If you opt in, we may reach out for more information and/or to ask if we can record the story for our podcast. If recorded, participants will receive compensation for their time. Recordings will be conducted and edited in collaboration with people with disabilities.

- **JOB OPPORTUNITIES**
  a. **Post-doctoral training program**: The goal of this ARRT postdoctoral training program is to increase the number of researchers-especially researchers with disabilities-who are prepared to conduct high-quality rehabilitation research to improve community living and participation outcomes of people with intellectual and developmental disabilities (IDD). Project objectives focus on providing trainees from underrepresented populations the opportunity to: (1) develop and refine their research skills in both qualitative and quantitative research projects in areas with a paucity of research (i.e., community living and participation in IDD); (2) train and engage in stakeholder-engaged research in collaboration with individuals with disabilities; and (3) assume increasingly independent leadership

roles that will prepare them for careers as independent researchers and help to remove barriers for future researchers from underrepresented populations. Project outcomes are individualized and based on the career and training goals each postdoctoral scholar sets through their Individualized Development Plans (IDPs). As a part of their IDPs, trainees set specific and attainable goals to develop scientific work products by the end of their fellowship, including at least three publications submitted (≥1 first author) to peer-reviewed scientific journals; at least two scientific presentations to be submitted to professional conferences; a clear language community-facing product based upon their research findings; and a grant application to be submitted by the end of the postdoctoral training period.

- Candidates should contact Katherine Walton PhD for more information at Katherine.walton@osumc.edu. Applications can be sent to Manisha Khatiwada at Manisha.khatiwada@osumc.edu.

- **DATA COLLECTION**
  a. The fifth and most recent wave of the [National Survey Health and Disability](#) is NOW OPEN. We are looking for members of the disability community to [take the survey](#). Data from the fifth wave of NSHD will be available to researchers in the Spring of 2024. Learn more from this [video about the survey](#) and this [press release](#).

- **CALL FOR PAPERS**
  a. A team of Disability Advocacy and Research Network (DARN) members are editing a special issue of Teaching of Psychology on [Creating an Anti-Ableist Psychology Curriculum and Teaching Environment.](#) Deadline: February 1st, 2024.
     - People with disability represent roughly 1 in 6 of the population and comprise a large, yet understudied and underrepresented, minority group in psychology. There is an urgent need for pedagogical methods and techniques which challenge ableist systems and biases. Likewise, approaches to enhance the educational experience for both students and faculty with disabilities is an important topic for consideration.
  b. [Special Issue on Autism and Aging: A Lifespan Approach](#) in *Autism in Adulthood*. This special issue will address the dearth of published research on older Autistic adults by focusing on autism and aging. Authors are encouraged to explore Autistic experience in adulthood and later life from a variety of frameworks and approaches, including those that use a biopsychosocial perspective or build upon social or social relational models of disability, rights-based models, the neurodiversity paradigm, or models of social inclusion.
     - Submission deadline for this special issue is January 15, 2024, through the Autism in Adulthood online submission system. Visit the journal website

to view more on information for authors including manuscript guidelines, information on available author services, and publication costs.

[Disability and Health Journal](#) Featured Article

- Russell, L. A., Tinker, S. C., Rice, C. E., Ryerson, B., & Gonzalez, M. G. (2023). [**Variation in identifying children and adolescents with disability and developmental disability in population-based public health surveys**](#). Disability and Health Journal, 101556.
    - This project aimed to identify existing definitions of disability and DD and to determine the extent to which each definition could be operationalized to produce prevalence estimates. Disability (NHIS: 5.2–6.3%; NSCH: 9.2–11.9%) and DD prevalence (NHIS: 0.6–18.0% and NSCH: 0.2–22.2%) varied depending on the definition and data source. For the same definition, NSCH prevalence estimates tended to be higher than NHIS estimates. The substantial variability in estimated prevalence of disability and DD among children in the United States may be in part due to the surveys not representing all components of each definition. Different or additional questions in national surveys may better capture existing definitions of disability and DD. Considering the data collection goals may help determine the optimal definition to provide useful information for public health action.

[Health Affairs](#) Featured Article

- Cruz, T. H., Bonner, J., Bambrick, L., Donohue, C., King, R., King, T., ... & Wiggs, C. (2023). [**Ableism In Biomedical And Behavioral Research At NIH**](#). Health Affairs Forefront.
    - This article discusses issues with the National Institutes of Health's (NIH's) existing approach to disability and research. It highlights the positive steps forward the NIH is taking to address these issues. Additionally, it emphasizes the need for the NIH to combat ableism in all aspects of the biomedical and behavioral research ecosystem. Looking ahead, the authors predict that these efforts if undertaken by NIH can work to advance equity for people with disabilities.

From,

The DHERN Team