

# DHERN November 2023 Newsletter

## DHERN Announcements

1. **TUESDAY!** Dr. Kathleen Bogart joins us **for our upcoming meeting on November 7<sup>th</sup>, 2-3pm Eastern!** Don't miss her talk, "Rare in common: Mental and physical health disparities in diverse rare disorders" and register here:  
<https://syracuseuniversity.zoom.us/meeting/register/tJlqdu6rqT4vGdyfSaeVNW5hb5CZxenicrFM>
  - a. Dr. Bogart is an Associate Professor of Psychology and Director of the Disability and Social Interaction Lab at Oregon State University. She is a social/health psychologist specializing in disability, ableism, and rare disorders such as facial paralysis. Passionate about disability community-building, she is the co-founder of the Disability Advocacy and Research Network (DARN) for psychologists who have and/or specialize in disability. She is an Associate Editor of *Personality and Social Psychology Review* and *Rehabilitation Psychology*. Her work has been featured in *The Atlantic*, *The New York Times*, *Time*, and *Science*. Dr. Bogart presents to international academic, general, and TEDx audiences about disability as diversity, and she blogs about this topic for *Psychology Today*.
2. Nominate an undergrad, grad student, or post doc researcher for the **DHERN 2023 Paper Award Competition!**
  - a. We will provide two awards to papers related to disability health equity, broadly defined. The nominee must be an undergraduate student, graduate student, or a postdoctoral researcher at the time of paper acceptance or publication, and must be the first author on the paper (co-authorship is permitted with student or faculty co-author(s)). The paper must have been published or accepted for publication in a peer-reviewed journal in 2022 or 2023.
  - b. Each awardee will receive \$500 and will present a summary of their paper at the DHERN meeting on Tuesday, January 23, 2024, 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 Friday, December 1, 2023. Email paper and nomination letter to [sdlandes@syr.edu](mailto:sdlandes@syr.edu).
3. **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%.**
  - 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:
  - i. Submit a public comment to the [upcoming Census National Advisory Committee Meeting](#)
  - ii. 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!**
- 4. [The DHERN website](#) is now live! Visit to view our recorded conference, previous years' newsletters, and information about our leadership.
- 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](mailto: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 5<sup>th</sup>, 2024.
  - b. [Understanding and Mitigating Health Disparities experienced by People with Disabilities caused by Ableism](#) (R01 Clinical Trial Optional). The goal of this NOFO is to encourage research to understand the impact of ableism on health outcomes. Research on the underlying mechanisms by which ableism adversely

influences the health of persons with disabilities (PWD), as well as developing and/or testing interventions at a community or health systems level to mitigate adverse health effects of ableism are high priority.

- **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:
  - Submitting a public comment to the [upcoming Census National Advisory Committee Meeting](#)
  - Responding to the [current Federal Register request for comment](#)
- b. Provide a Public Comment for the proposed rule from HHS, [Nondiscrimination on the Basis of Disability](#), which clarifies Section 504 of the Rehabilitation Act to make clear that discrimination does not belong in health care, child care, and other federally funded spaces.
  - The Center for American Progress has [compiled this toolkit](#) to support all to draft a Comment.
- c. Respond to the Request for Information from the National Institutes of Health titled, [“Inviting Comments and Suggestions on Updating the NIH Mission Statement.”](#) The proposed revised mission statement will remove the aim to “reduce... disability.”

- **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. [Generation Patient is looking for a new Executive Director!](#) They are looking for a values-driven leader as a nonprofit that aims to empower adolescents and young adults with chronic, rare, and undiagnosed conditions. Apply by November 30<sup>th</sup>, 2023.

- **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. Drs. Lesley Tarasoff and Hilary Brown are Co-Guest Editors for a special collection for [Archives of Women's Mental Health](#) on Disability and Mental Health Across the Reproductive Life Course. [The call for papers can be found here](#). The submission deadline is November 30, 2023.
    - Seeking original research, systematic reviews, and short communications investigating mental health outcomes and mental health care experiences among women with disabilities related to the menstrual cycle, fertility/conception and pregnancy, postpartum and parenting, and the menopausal transition. We will consider quantitative study designs on populations with physical, vision, hearing, and intellectual or developmental disabilities. We encourage the submission of interdisciplinary studies, studies that examine the intersections of ableism and other forms of oppression such as racism, and studies from all global contexts.
  - c. [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.

## DHERN Member Publications

- Lérias, Pedro and Heather Sue Rosen. 2023. "[Accuracy of Excess Mortality Statistics Under Threat in UK.](#)" *WHN Communications* 4 (9): 1-1.
  - We demonstrate that actual excess mortality during COVID-19 in the United Kingdom is higher than is being reported by the UK Office of National Statistics (ONS). Changes in 2023 to the UK ONS' method of calculating excess mortality during COVID-19 allow for an underestimation of excess death, and thus, serve to normalize a mortality rate which was considered unacceptably high prior to the pandemic.

## [Disability and Health Journal](#) Featured Article

- Blanca Lorena Rojo, Sarah Brown, Hannah Barnes, Jacqui Allen, Anna Miles, [Home-based oral health program for adults with intellectual disabilities: An intervention study](#), *Disability and Health Journal*, 2023.
  - This prospective longitudinal experimental mixed methods study evaluated the efficacy of an oral health program aimed at improving knowledge and behaviors in adults with intellectual disabilities living in supported housing. 24 (63%) residents had significantly improved plaque scores at 3 months ( $p < .001$ ). Resident interviews were restricted by communication competency but supported interviews indicated positive responses to 3-sided toothbrush 91%, interdental brush/flosser 60%, and mouthwash 100%. Support worker interviews revealed perceived health and social benefits including fresher breath and benefits of routines.

From,

The DHERN Team

If you want to stop receiving the DHERN newsletter, please email [dhern@jhu.edu](mailto:dhern@jhu.edu) with the subject line "unsubscribe." Thank you!