

# DHERN June 2024 Newsletter

## DHERN Announcements

1. We are thrilled to announce the details of our second annual virtual conference on September 17th, 2024, 11AM-3PM EST! This year centers on **Moving Disability Measurement Forward**, and we have fantastic guests joining us. [Register for our conference now!](#) See the 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
    - ii. Bob Sivinski, Senior Statistician, Office of Management and Budget
    - iii. Invited: Other DDIWG Members
  - 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. Missed our May Careers in Disability Health Fireside Chat? Catch up with our [recorded conversation](#) with experts Silvia Yee, Corey Moore, Lisa Meeks, and Stephanie DeLuca!
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](mailto: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

- **EVENTS**

- a. [Webinar: Equity and Inclusion in Pregnancy Care \[Register\]](#)

- On June 18th from 3 – 4:30 p.m., join us for a webinar! The research team will describe the findings of the Disability and Pregnancy Study, which showed avoidable pregnancy-related health disparities and barriers to care for people with disabilities. With an expert panel that includes researchers, people with lived experience of disability, and health and social service providers, the team will discuss next steps in creating an accessible pregnancy care system that considers the needs of people with disabilities.

- **POLICY**

- a. [Request for Information: Federal Evidence Agenda on Disability Equity](#)

- Through this Request for information (RFI), the White House Office of Science and Technology Policy (OSTP) seeks input from the public to help inform the development of the Federal Evidence Agenda on Disability Equity. Executive Order 14091 on Further Advancing Racial Equity and Support for Underserved Communities Through the Federal Government (February 16, 2023) directed the OSTP National Science and Technology Council Subcommittee on Equitable Data (SED) to coordinate implementation of recommendations of the Equitable Data Working Group. To address the recommendations relevant to disability, the SED established the Disability Data Interagency Working Group (DDIWG). The DDIWG is tasked with the development and release of a Federal Evidence Agenda on Disability Equity, in order to improve the Federal government's ability to make data-informed policy decisions that advance equity for the disability community.
    - Comments are due by July 15, 2024. For further information or questions, please contact us at [disabilitydata@ostp.eop.gov](mailto:disabilitydata@ostp.eop.gov).

- **CALL FOR PAPERS**

- a. [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.

- \*Note that this is a revised call for the topical collection on Disability and Mental Health Across the Reproductive Life Course, which now has an expanded focus and extended submission deadline.

- **REQUESTS**

- a. Volunteers with SCI Needed to Participate in a Research Study

- Researchers with the Spinal Cord and Disability Research Center at TIRR Memorial Hermann in Houston and the University of Montana in Missoula are recruiting people with spinal cord injury (SCI) to participate in a study entitled, "Understanding Interpersonal Violence Against People with SCI and its Psychosocial Impacts." This research will add to the limited understanding of interpersonal violence (IPV) and its consequences in people with SCI. Participants will be invited to participate in individual interviews via ZOOM and asked to share information about their experience with post-injury IPV, help-seeking experiences, and perceptions of the social and psychological effects of IPV.
    - To be eligible, participants must have lived with a traumatic SCI for at least one year; be at least 21 years of age; and have experienced difficult relationships, mistreatment, or neglect since sustaining their SCI but not in the past 12 months. Participants will receive a small payment for their time. For additional information and to learn if eligible, email [SCIPStudy@uth.tmc.edu](mailto:SCIPStudy@uth.tmc.edu) or call 713-797-7245.

### **Disability and Health Journal Featured Article**

- Julie H. Levison, Vicki Fung, Anna Wilson, David Cheng, Karen Donelan, Nicolas M. Oreskovic, Ronita Samuels, Paula Silverman, Joey Batson, Ahmed Fathi, Stefanie Gamse, Sibyl Holland, Jessica E. Becker, Kenneth A. Freedberg, Lisa I. Iezzoni, Amy Donohue, Mark Viron, Carley Lubarsky, Terina Keller, Jean-Louise Reichman, Bettina Bastien, Elizabeth Ryan, Alexander C. Tsai, John Hsu, Cindy Chau, David Krane, Hao D. Trieu, Jessica Wolfe, Kim Shellenberger, Elizabeth Cella, Bruce Bird, Stephen Bartels, Brian G. Skotko, [Predictors of COVID-19 Infection and Hospitalization in Group Homes for Individuals with Intellectual and/or Developmental Disabilities](#), Disability and Health Journal, 2024, 101645, ISSN 1936-6574.
  - This study aimed to identify correlates of COVID-19 and related hospitalizations among people with ID/DD in group homes in Massachusetts. We collected data during March 1, 2020–June 30, 2020 (wave 1) and July 1, 2020–March 31, 2021 (wave 2) from the Massachusetts Department of Public Health and six

organizations administering 206 group homes for 1,035 residents with ID/DD. The main outcomes were COVID-19 infections and related hospitalizations. Compared with Massachusetts residents, group home residents had a higher age-adjusted rate of COVID-19 and COVID-19 hospitalizations in wave 1 and wave 2. COVID-19 infections and hospitalizations were more likely among residents aged 65+ and in group homes with 6+ resident beds and recent infection among staff and residents. Aggressive efforts to decrease resident density, staff-to-resident ratios, and staff infections through efforts such as vaccination, in addition to ongoing access to personal protective equipment and COVID-19 testing, may reduce COVID-19 and related hospitalizations in people with ID/DD living in group homes.

### **Health Affairs Featured Article**

- Al Janabi, Angelica L. (2024) [My Story Of Trauma And Reproductive Health](#). Health Affairs 43(4), 597-601.
  - a. Trauma-informed care is essential—and currently lacking—in reproductive health care. The author describes her pregnancy experiences as a person with mental health diagnoses and past trauma.

### **DHERN Member Articles**

- Report: [Advancing Accessible Communication for People with an Intellectual Disability](#)
  - a. For the past three years, Inclusion Canada, People First of Canada, and the CAMH Azrieli Adult Neurodevelopmental Centre have been exploring ways to make information more accessible for people with intellectual disabilities and their families. In addition to a published report outlining recommendations for the Canadian government, they created Best Practice Guidelines for producing information in different formats useful to anyone who wants to ensure their materials are accessible to people with intellectual disabilities. Available in easy read in French and English.
- [Equity and inclusion in pregnancy care: report on the pregnancy outcomes and health care experiences of people with disabilities in Ontario](#) Brown HK, Saeed G, Tarasoff LA, Proulx L, Welsh K, Fung K, Qureshi S, Guttman A, Haverkamp SM, Parish SL, Ray JG, Vigod SN, Lunsky Y. Toronto, ON: ICES; 2024.
  - a. Over the last 7 years, researchers at the University of Toronto and the Centre for Addiction and Mental Health have undertaken the largest study on disability and pregnancy in Canada. They analyzed data on almost 150,000 births to people with disabilities, talked to 62 people about their experiences of pregnancy care, and worked with a committee of people with disabilities, service-providers, and decision-makers to develop a set of recommendations to improve equity and inclusion in pregnancy care for people with disabilities. The full report, executive summary, and easy read summary are available.

From,

The DHERN Team

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