

**Advancing Health Priorities that Matter to the IDD Community:  
Learnings and Future Directions**

Tuesday, June 10<sup>th</sup>, 2025 | 4:00PM-5:00 PM ET

**Webinar Agenda**

**Background and Objectives:**

Days in the community or “home time” is considered a patient-centered outcome measure reflecting clinical events impacting quality of life and patient preferences but has not been explored with the intellectual and other developmental disabilities (IDD) community. Including perspectives of the IDD community is essential to understanding how the concept of “home” and “home time” aligns with health priorities, particularly as adults with IDD age. This webinar will share learnings from the IDD community about health outcomes that matter to them and feature a panel with state and disability experts to explore opportunities to center the voices of the disability community in research and policy and co-create patient-centered outcome measures. This webinar is part of a project, “Engaging Adults with Intellectual and Developmental Disabilities to Inform a Patient-Centered ‘Home Time’ Outcome,” funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (EASCS-35236).

**4:00 PM**

**Welcome and Opening Remarks**

**Michelle Scotton Franklin, PhD, APRN;** Assistant Professor, Duke Psychiatry and Behavioral Sciences; Core Faculty Member, Duke-Margolis Institute for Health Policy  
**Rep. Zack Hawkins;** North Carolina State Representative (D, House District 31), Chairman of the IDD Caucus in the North Carolina General Assembly

*Objective:*

- Discuss the importance of centering the voices of the IDD community in research and policy.

**4:15 PM**

**Project Overview and Key Learnings**

**Montgomery Smith, MPH;** Policy Research Associate, Duke-Margolis Institute  
**Brystana Kaufman, PhD, MSPH;** Assistant Professor, Duke Population Health Sciences; Core Faculty Member, Duke-Margolis Institute for Health Policy; Research Health Scientist, Durham VA Medical Center

*Objectives:*

- Provide an overview of project goals and key learnings.
- Summarize priorities for patient-centered comparative effectiveness outcomes research that matters to the IDD community.

*This webinar is part of a project, “Engaging Adults with Intellectual and Developmental Disabilities to Inform a Patient-Centered ‘Home Time’ Outcome,” funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (EASCS-35236).*

4:25 PM

**Panel Discussion:**

**Moderator: Talley Wells, JD, M.Ed.;** Advisory Council Member and leader of a statewide disability advocacy organization

**Panelists:**

**Kenton Johnston, PhD;** Associate Professor of General Medicine and Geriatrics, Associate Director for Research Center for Advancing Health Services, Policy & Economics Research, Washington University in St. Louis School of Medicine

**Harold Pollack, PhD;** Helen Ross Distinguished Service Professor, Associate Faculty in Public Health Sciences, University of Chicago

**Sarah Triano;** Associate Director, Long-Term Services and Supports and Disability Policy, Center for Health Care Strategies

**Courtney Van Houtven, PhD;** Professor, Department of Population Health Science, Duke University School of Medicine; Core Faculty Member, Duke-Margolis Institute for Health Policy

*Objectives:*

- Discuss opportunities to center the voices of the IDD community in research and policy to co-create patient-centered health outcome measures.
- Explore health care strategies and policies intended to help adults with IDD achieve health priorities that matter most to them as they age.

4:55 PM

**Wrap Up**

*Objective:* Discuss takeaways from the discussion and where to find project learnings/materials.

5:00 PM

**Adjourn**