Moderator and Speaker Biographies

Opening Plenary: Are We There Yet?

Speakers:

Rebecca Hines, *PhD – Administration on Disabilities, Commissioner*

Rebecca Hines is Commissioner of the Administration on Disabilities where she leads programs and initiatives that advance inclusion, independence, employment, financial well-being, and self-determination for people with disabilities. She brings extensive experience in disability research, program administration, workforce development, and special education. Before joining ACL, she was a tenured associate professor at the University of Central Florida, where she led academic programs and federally funded projects focused on personnel preparation, inclusive practices, technology, and artificial intelligence. Rebecca holds a PhD in Curriculum and Instruction, specializing in teacher education and special education, from the University of South Florida.

Jennifer Johnson, *EdD, MA – Administration on Disabilities, Deputy Commissioner*

Dr. Jennifer Johnson is Deputy Commissioner of the Administration on Disabilities at the U.S. Department of Health and Human Services' Administration for Community Living. She helps lead national efforts to advance independence, inclusion, and self-determination for people with disabilities. Dr. Johnson has more than two decades of federal service and holds a doctorate in special education and a master's degree in early childhood special education from The George Washington University.

Kathy Cargill-Willis *– Administration on Disabilities, Program Specialist*
Kathy Cargill-Willis has been a program specialist with the Administration on Disabilities at the U.S. Department of Health and Human Services' Administration for Community Living for more than 20 years. She has managed the I/DD Counts project for about 10 years and is passionate about people communicating with their doctors in a real way. Kathy, her husband, and their two dogs live in Manassas, Virginia.

Panel 1: IDD Survey Data at a Crossroads

Moderator:
Colleen Roche *– New Jersey Statewide Independent Living Council, Chairperson*
Colleen Roche is a consultant at the intersections of disability, violence and public health. She served on both Gov. Sherrill's Transition Interdisciplinary Advisory Task Force and the NJ Coalition Against Sexual Assault's Community Council. Currently, she is the board chair of both the Alliance Center for Independence and the NJ Statewide Independent Living Council. She holds degrees in Biology and Spanish and is a NJ LEND Fellow and Partners in Policymaking Advanced Leadership Academy graduate.

Panelists:
Alexandra (Alixe) Bonardi, *MS – Human Services Research Institute (HSRI), Vice President*
Alixe Bonardi has led work to improve national IDD and health data for over 15 years, working with Administration for Community Living, Centers for Disease Control and Prevention, and other federal agencies on developing and advancing the I/DD Counts Roadmap. She co-leads HSRI's contract with ACL to support I/DD Counts and supports several working groups as part of that project. She is an occupational therapist and assistant professor at UMass T.H. Chan Medical School, where she is also a faculty member of the Shriver Center's LEND program.

Alicia Dixon-Ibarra, *PhD, MPH – Special Olympics International, Director, Fitness and Health Research*

Alicia Dixon-Ibarra is the Director of Fitness and Health Research at Special Olympics International, where she leads research and evaluation efforts focused on improving health outcomes for people with IDD. With training in epidemiology and kinesiology, her work focuses on strengthening disability health surveillance, advancing inclusive health research, and building data systems that better represent people with IDD.

Ari Ne'eman, *PhD – Harvard T.H. Chan School of Public Health, Assistant Professor of Health Policy and Management*

Ari Ne'eman is an Assistant Professor of Health Policy and Management at the Harvard T.H. Chan School of Public Health. Prior to entering academia, he served as executive director of the Autistic Self Advocacy Network and served as a Senior Disability Advisor in the Department of Health and Human Services Office of Civil Rights. He is the author of the forthcoming book, "The Right to Live in This World: The Long Struggle for Disability Equality in America" (Simon & Schuster, 2027).

Julie Weeks, *PhD – National Center for Health Statistics (CDC/NCHS), Lead Health Statistician and Chief, Measures Research and Evaluation*

Dr. Julie Weeks' work focuses on improving and promoting methodologies and the use of statistical data to inform all aspects of aging, functioning and disability, including measurement, evaluation and implementation of the data collection standards currently used throughout the US federal statistical system. Under the auspices of the UN Statistical Commission, she works extensively with National Statistical Offices, Non-Governmental Organizations and Organizations of Persons with Disabilities to advance the availability and quality of disability data internationally.

Panel 2: Maintaining Momentum with Administrative Data

Moderator:

Jennifer Kucera *– Center for Disability Empowerment, Director of Policy, Advocacy and Outreach*

Jennifer was born with spinal muscular atrophy and currently lives in her own apartment with her emotional support dog Sissy. She works at a Center for Independent Living, and is chair of the statewide advocacy coalition called the Ohio Olmstead Task Force and chair of Ohio's DD Council. She is a tireless systems change disability rights advocate who has expertise in voting rights, independent living, Medicaid, accessible housing, and public policy that affects people with disabilities.

Panelists:

Leanne Candura, *MPH – Human Services Research Institute, Vice President, Director Population Health*

Leanne Candura is Vice President at HSRI and Director of its Population Health team, leading efforts to improve the quality, availability, and use of population health data for states, providers, policymakers, researchers, and consumers. She also directs consulting and data architecture initiatives for state all-payer claims databases, integrating these and other health data assets to support population health improvement and more effective health care.

Rhonda Eppelsheimer, *MSW – The University Center for Excellence in Developmental Disabilities at Oregon Health & Science University, Director*

Rhonda Eppelsheimer is Director of the UCEDD at Oregon Health & Science University. She provides leadership for initiatives that improve health, policy, and systems for people with IDD. Rhonda directs Oregon's Medicaid Administrative Data Project and leads the state's National Core Indicators surveying and workforce data initiatives, using data to identify health disparities, inform policy, and improve services and outcomes for people with IDD.

Jeffrey Galecki, *MS, LCADC, LCPC – Centers for Medicare & Medicaid, Social Science Research Analyst*
Jeffrey Galecki joined the Centers for Medicare & Medicaid Services, Data System Group, Division of Business and Data Analytics in 2015 as a Social Science Research Analyst. In this role, he has worked with various enterprise data systems. He supports annual reports on mental health, substance abuse, and per capita work.

Chip Haltermann, *MPP – Office of the Assistant Secretary for Planning and Evaluation, Social Science Analyst*
Chip Haltermann is an analyst in the Office of the Assistant Secretary for Planning and Evaluation (ASPE) at the U.S. Department of Health and Human Services. At ASPE, he conducts research and analysis to support the independence, health, and well-being of people with disabilities and older adults. Much of his research focuses on the use of long-term services and supports and end-of-life care.

Eric Rubenstein, *PhD, ScM – Boston University, Associate Professor*
Eric Rubenstein is an Associate Professor in the Department of Epidemiology at Boston University. His research focuses on improving health and well-being in the population with intellectual and developmental disabilities. Dr. Rubenstein's research is motivated and continually inspired by his friends, Special Olympics athletes, and fellow advocates in the IDD community.

Panel 3: Merge Ahead? Opportunities to Enhance Research Capacity

Moderator:

Richard Chapman, *PhD, LMHC*

Richard Chapman is a researcher and licensed mental health counselor whose work centers on self-determination among people with IDD. Grounded in Causal Agency Theory, his research spans psychometrics and measurement, including co-development of the Self-Advocacy Skills Inventory, mental health interventions that promote self-determination.

Panelists:

Kayte Barton *– Special Olympics, Athlete Leader, Health Messenger*

Kayte Barton is a Special Olympics Health Messenger, Athlete Leader, and passionate advocate for inclusive health research. Drawing from her own experiences, she works to ensure that people with IDD are included in research and have a meaningful voice in decisions that affect their health. Kayte is committed to making health care and research more accessible, equitable, and inclusive for everyone.

Lindsay DuBois, *PhD, MPH – Human Services Research Institute, Research Associate*

Lindsay DuBois is a Research Associate whose work is driven by a passion for collaborative, inclusive research to promote equity and support people to thrive in their communities. Lindsay is particularly dedicated to working with disability service systems staff to identify opportunities for improving the quality of services. Lindsay is also highly skilled in communicating research findings in accessible and meaningful ways to different audiences.

Susan Havercamp, *PhD – The Ohio State University Nisonger Center, Professor, Director of Health Promotion and Healthcare Parity*
Susan Havercamp is a professor of psychiatry and behavioral health at the Ohio State University Nisonger Center. She partners with people with IDD to conduct health and mental health research. She believes that the voice of people with disabilities should be centered in disability research and policy. She is excited that I/DD Counts will make sure that data about people with IDD benefits people with IDD.

Sheryl Larson (Sherri)*, PhD, MA – University of Minnesota, Institute on Community Integration, Research Manager 3*
Sheryl Larson is Principal Investigator of the Residential Information Systems Project and the U of MN's RTC on Community Living. She has been involved in 51 federal, state, and local grant funded research, training or TA projects on people with IDD. She works on Medicaid LTSS, deinstitutionalization, staff recruitment and retention, disability statistics and demographics, health care, and quality assurance, and used national data sets such as: NHIS, CMS CASPER and Minimum Data Sets, and NCI.

Margaret Nilz, *MPH CPH – Association of State and Territorial Health Officials, Senior Analyst, Preparedness*
Margaret Nilz is a Senior Analyst with the Association of State and Territorial Health Officials, where she leads national initiatives focused on emergency preparedness, disability inclusion, and public health systems. Through recent CSTE-funded projects, she works with state and territorial partners to strengthen disability data infrastructure, data linkage, and public health surveillance to improve decision-making and health outcomes.

Panel 4: Navigating Challenges to Increase Data Use and Dissemination

Moderator:

Tia Nelis *– TASH, Coordinator Self-Advocacy Engagement*

Tia Nelis is a strong advocate who has led groups of people with disabilities. Tia works as a Self-Advocacy Coordinator at TASH. She used to be in charge of Illinois People First and Self-Advocates Becoming Empowered. She also helped guide a national group that supports people with disabilities to vote. Tia was the first person with a disability to become a certified leader by the Franklin Covey Institute.

Panelists:

Jules Good, *MPP – Autistic Self Advocacy Network (ASAN), State Advocacy Manager*

Jules Good (they/them) is a multiply-disabled autistic person, disability policy professional, and grassroots activist. They currently serve as the State Advocacy Manager at the Autistic Self Advocacy Network, a 501c(3) national nonprofit created by and for autistic people. Jules is extremely passionate about supporting other autistic people in our common fight for civil rights and for the opportunity to not only survive but thrive.

Katie McDonald, *PhD – Syracuse University, Associate Vice President for Research; Professor*

Katherine (Katie) McDonald works in partnership with people with developmental and other disabilities to create new tools so people with developmental disabilities can not only participate in research but also serve as full members of research teams and as research participants. These new tools are designed to help generate new information that can improve the health and well-being of people with disabilities.

Teresa Moore *– Self Advocates Becoming Empowered, Self Advocacy Resource & Technical Assistance Center Project, SARTAC Project Co-Director*
Teresa Moore is the Co-Director of the Self Advocates Becoming Empowered Self Advocacy Resource and Technical Assistance Center or SABE SARTAC. Teresa has over 30 years of experience working with individuals with IDD. In addition to SABE SARTAC, she has engaged in the SABE GoVoter Project as a creative team member, trainer, and director.

Shea Tanis, *PhD – University of Kansas, Associate Research Professor*
Shea Tanis is an Associate Research Professor at the University of Kansas Life Span Institute and Principal Investigator for the State of the States in IDD Longitudinal Data Project, tracking public spending on disability services. She is a national expert on technology and information access for people with cognitive disabilities, focusing on self-determination, accessible data visualizations, cognitively accessible technology, and Technology First systems change.

Panel 5: Accelerating Improvements in IDD Data to Inform System Change Efforts

Moderator:
Christine Brown *– The Ohio State University Nisonger Center*
Christine Brown is a Clinical Research Assistant and Self Advocate Faculty at The Ohio State University Nisonger Center. She is a lifetime Advocate for people with disabilities. She co-chairs the Disability Experience Expert Panel and is an author in various research and brochures.

Panelists:

Nikolas Koscielniak, *PhD, MPH, MSOT – PCORI, Program Officer 2*

Dr. Nikolas Koscielniak is a Program Officer at PCORI in the Division of Research Infrastructure and Innovation. He currently manages a portfolio of awards that includes the PCORnet program, research projects and methodological science projects. His work focuses on leveraging and improving health research infrastructures to create a more efficient research ecosystem. He completed his PhD at the University of Michigan in Health Infrastructures and Learning Systems. He is also an occupational therapist.

Nassira Nicola, *MA, ADACC – Massachusetts Department of Public Health, Office of Health Equity and Community Engagement, Deputy Director for Access and Inclusion*

Nassira Nicola (she/they) works at the Massachusetts Department of Public Health (MDPH), helping all of the Department's programs understand how to serve people with disabilities and people who speak languages other than English. Nassira leads MDPH's Disability Data Standards Working Group, is the Program Director for DPH's Health and Disability Program and serves on the Massachusetts Governor's Special Advisory Commission on Disability Policy.

Melissa Parisi, *MD, PhD – NICHD/National Institutes of Health, Chief, Intellectual and Developmental Disabilities Branch*

Melissa Parisi is chief of the Intellectual and Developmental Disabilities (IDD) Branch at the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), NIH. She oversees the IDD Research Centers program and the NIH-wide INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndromE (INCLUDE) Project. Her goal is to advance basic, clinical, and translational research to improve the lives of those with developmental disabilities.

Hoangmai (Mai) Pham, *MD, MPH – Institute for Exceptional Care, President and CEO*
Dr. Mai Pham is a physician and health policy expert who is also parent to an autistic young adult. She worked clinically with underserved populations; researched healthcare payment policy and how it affects health disparities and quality; and ran national care delivery and payment programs for the Center for Medicare & Medicaid Innovation at CMS, and for Elevance. She lives and works in Washington, DC, where she bakes like a madwoman and just published a memoir, "Bridge from Saigon."

Closing Plenary: The Next Leg of the Journey

Moderators:
Nicole LeBlanc *– Human Services Research Institute (HSRI), Policy Assistant*
Nicole LeBlanc has a keen ability and interest in public policy and excels at communicating the needs of people DD to public officials. She has almost 20 years of experience in the disability field at the state & federal level. Nicole has a certificate of professional studies from UVM. In 2016, Nicole moved to the Washington, DC region and has served as a budget watchdog guardian of inclusion ever since.

Heather Young *– Human Services Research Institute (HSRI), Project Coordinator*
Heather Young is a Project Coordinator at HSRI and serves as the coordinator for the I/DD Counts project. Her work is driven by a passion for person-centered approaches, innovative services and improving the quality of supports for people with disabilities and their families. She brings a deep understanding of policymaking, HCBS waiver services, and grassroots advocacy. Heather is committed to translating complex information into clear, accessible, and meaningful resources for diverse audiences.

Panelists:
Rebecca Hines *(see opening plenary)*

Alixe Bonardi *(see Panel 1)*

Gloria Krahn, *PhD, MPH – Oregon State University, Adjunct Professor; disability and public health consultant*
Gloria Krahn is adjunct professor at Oregon State University and consultant on disability and public health. She previously served as UCEDD Director and RRTC Director in Oregon, and in the federal government as Division Director at the Centers for Disease Control and Prevention. She has worked for decades to improve health data for people with disabilities and has been involved with I/DD Counts since its inception.