

The National Academies of
SCIENCES • ENGINEERING • MEDICINE

WORKSHOP ON ENSURING QUALITY AND ACCESSIBLE CARE FOR
CHILDREN WITH DISABILITIES AND COMPLEX HEALTH AND EDUCATIONAL NEEDS

December 9-10, 2015

The National Academies Keck Center
500 Fifth Street, NW, Room 100
Washington, DC 20001

Agenda

Day 1 – Wednesday, December 9, 2015

- 8:00-8:30 Registration
- 8:30-8:45 Welcome & Workshop Overview
- 8:45-10:00 Introductory Session, “Perspectives from Individuals & Family Members”
Moderator: Stephen M. Shore, Ed.D., Adelphi University
- J-Jaye Hurley, Parent Advocate and Autism Response Team Coordinator - Autism Speaks
 - Jill Plevinsky, M.A., Founding Chair, Patient Advisory Council, ImproveCareNow
 - Victoria Costello, M.F.A., Parent Advocate, Science Journalist, and Public Library of Science (PLOS)
- 10:00-10:45 Keynote Presentation, “Disability Names and Numbers: Challenges and Opportunities in Nosology, Epidemiology, and Equity/Disparity”
Moderator: Deborah Klein Walker, Ed.D., Abt Associates
- Maureen S. Durkin, Ph.D., Dr.P.H., M.P.H., University of Wisconsin-Madison
- 10:45-11:00 Break
- 11:00-12:30 Panel One, “Children with Serious Medical Conditions and the Behavioral Health Implications”
Moderator: Mary Ann McCabe, Ph.D., ABPP, George Washington University School of Medicine, George Mason University
- Anne E. Kazak, Ph.D., ABPP, Nemours Children’s Health System and Sidney Kimmel Medical School of Thomas Jefferson University
 - Robin S. Everhart, Ph.D., Virginia Commonwealth University
 - Amy J. Houtrow, M.D., Ph.D., M.P.H., Children's Hospital of Pittsburgh of UPMC
 - Torrie Dunlap, CPLP, Kids Included Together
- 12:30-1:30 Lunch
- 1:30-3:00 Panel Two, “Early Identification and Interventions for Developmental Disabilities Emerging in Childhood”
Moderator: Craig J. Newschaffer, Ph.D., Drexel University
- Heather Johnson, DNP, FNP-BC, FAANP, Uniformed Services University of the Health Sciences Graduate School of Nursing
 - Nathan A. Call, Ph.D., BCBA-D., Marcus Autism Center, Emory University School of Medicine
 - Connie Kasari, Ph.D., University of California, Los Angeles
 - David S. Mandell, Sc.D., University of Pennsylvania School of Medicine
- 3:00-3:15 Break

- 3:15-4:45 Panel Three, “Early Identification and Interventions for Youth and Adolescents with Serious Behavioral Health Conditions”
Moderator: Kirsten Beronio, J.D., Office of the Assistant Secretary for Planning and Evaluation
- Mary Fristad, Ph.D., ABPP, Ohio State University Medical Center
 - Robert K. Heinssen, Ph.D., ABPP, National Institute of Mental Health
 - Lisa Dixon, M.D., M.P.H., Columbia University Medical Center & New York State Psychiatric Institute
 - Shay Bilchik, J.D., Georgetown University Center for Juvenile Justice Reform
- 4:45-5:30 Armchair Discussion/Reflections from Moderators (full group Q&A)
Moderator: Maureen S. Durkin, Ph.D., Dr.P.H., M.P.H., University of Wisconsin-Madison
- 5:30-5:45 Closing Remarks & Adjourn

Day 2 – Thursday, December 10, 2015

- 8:00-8:30 Registration
- 8:30-8:45 Welcome, Brief Recap of Day One, & Overview for Day Two
- 8:45-10:15 Panel Four, “Media & Public Perceptions/Misperceptions of Children with Disabilities”
Moderator: Andy Shih, Ph.D., Autism Speaks & Donald Wertlieb, Ph.D., American Orthopsychiatric Association and Tufts University
- Steve Silberman, Science Writer and Author of *NeuroTribes: The Legacy of Autism and the Future of Neurodiversity*
 - Susan M. Lanzoni, Ph.D., Historian of Science and Writer, Harvard University
 - Victoria Costello, M.F.A., Parent Advocate, Science Journalist, and Public Library of Science (PLOS)
 - Tony Foleno, M.A., The Advertising Council
 - Emily J. Willingham, Ph.D., Freelance Writer
- 10:15-10:30 Break (transit to breakout groups)
- 10:30-11:30 Interactive Breakout Group Sessions (unavailable to webcast audience)
- Group 1: Considerations for when an evidence base is lacking
Moderator: C. Hendricks Brown, Ph.D., Northwestern University & Emily Lichvar, Ph.D., Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services
 - Group 2: Community engagement and partnerships for development and implementation of solutions
Moderator: Kelly J. Kelleher, M.D., The Research Institute at Nationwide Children’s Hospital & Angela Lello, M.P.A., Autism Speaks
 - Group 3: This breakout group is offered to participants of both the December 7-8 “National Symposium on Designing Systems That Work for Children with Complex Health Care Needs” and the December 9-10 “Workshop on Ensuring Quality and Accessible Care for Children with Disabilities and Complex Health and Educational Needs”
Moderators: Andy Shih, Ph.D., Autism Speaks & Ed Schor, M.D., Lucile Packard Foundation for Children’s Health
- 11:30-11:45 Break – reconvene in large group
- 11:45-12:45 Report-back from breakout groups
- 12:45-1:00 Workshop Reflections
- 1:00 Adjourn