

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

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| 8:00-8:30 | Registration |
| 8:30-8:45 | Welcome & Workshop Overview |
| 8:45-10:00 | Introductory Session, “Perspectives from Individuals & Family Members”
<i>Moderator: Stephen M. Shore, Ed.D., Adelphi University</i> <ul style="list-style-type: none">• 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”
<i>Moderator: Deborah Klein Walker, Ed.D., Abt Associates</i> <ul style="list-style-type: none">• 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”
<i>Moderator: Mary Ann McCabe, Ph.D., ABPP, George Washington University School of Medicine, George Mason University</i> <ul style="list-style-type: none">• 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”
<i>Moderator: Craig J. Newschaffer, Ph.D., Drexel University</i> <ul style="list-style-type: none">• 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