

*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” <i>Moderator: Stephen M. Shore, Ed.D., Adelphi University</i> <ul style="list-style-type: none"><li>• J-Jaye Hurley, Parent Advocate and Autism Response Team Coordinator - Autism Speaks</li><li>• Jill Plevinsky, M.A., Founding Chair, Patient Advisory Council, ImproveCareNow</li><li>• Victoria Costello, M.F.A., Parent Advocate, Science Journalist, and Public Library of Science (PLOS)</li></ul>
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"><li>• Maureen S. Durkin, Ph.D., Dr.P.H., M.P.H., University of Wisconsin-Madison</li></ul>
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"><li>• Anne E. Kazak, Ph.D., ABPP, Nemours Children’s Health System and Sidney Kimmel Medical School of Thomas Jefferson University</li><li>• Robin S. Everhart, Ph.D., Virginia Commonwealth University</li><li>• Amy J. Houtrow, M.D., Ph.D., M.P.H., Children’s Hospital of Pittsburgh of UPMC</li><li>• Torrie Dunlap, CPLP, Kids Included Together</li></ul>
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"><li>• Heather Johnson, DNP, FNP-BC, FAANP, Uniformed Services University of the Health Sciences Graduate School of Nursing</li><li>• Nathan A. Call, Ph.D., BCBA-D., Marcus Autism Center, Emory University School of Medicine</li><li>• Connie Kasari, Ph.D., University of California, Los Angeles</li><li>• David S. Mandell, Sc.D., University of Pennsylvania School of Medicine</li></ul>
3:00-3:15	Break

3:15-4:45	Panel Three, "Early Identification and Interventions for Youth and Adolescents with Serious Behavioral Health Conditions" <i>Moderator: Kirsten Beronio, J.D., Office of the Assistant Secretary for Planning and Evaluation</i>
	<ul style="list-style-type: none"> <li>• Mary Fristad, Ph.D., ABPP, Ohio State University Medical Center</li> <li>• Robert K. Heinssen, Ph.D., ABPP, National Institute of Mental Health</li> <li>• Lisa Dixon, M.D., M.P.H., Columbia University Medical Center &amp; New York State Psychiatric Institute</li> <li>• Shay Bilchik, J.D., Georgetown University Center for Juvenile Justice Reform</li> </ul>
4:45-5:30	Armchair Discussion/Reflections from Moderators (full group Q&A) <i>Moderator: Maureen S. Durkin, Ph.D., Dr.P.H., M.P.H., University of Wisconsin-Madison</i>
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" <i>Moderator: Andy Shih, Ph.D., Autism Speaks &amp; Donald Werthlieb, Ph.D., American Orthopsychiatric Association and Tufts University</i>
	<ul style="list-style-type: none"> <li>• Steve Silberman, Science Writer and Author of <i>NeuroTribes: The Legacy of Autism and the Future of Neurodiversity</i></li> <li>• Susan M. Lanzoni, Ph.D., Historian of Science and Writer, Harvard University</li> <li>• Victoria Costello, M.F.A., Parent Advocate, Science Journalist, and Public Library of Science (PLOS)</li> <li>• Tony Foleno, M.A., The Advertising Council</li> <li>• Emily J. Willingham, Ph.D., Freelance Writer</li> </ul>
10:15-10:30	Break (transit to breakout groups)
10:30-11:30	Interactive Breakout Group Sessions (unavailable to webcast audience) <ul style="list-style-type: none"> <li>• Group 1: Considerations for when an evidence base is lacking <i>Moderator: C. Hendricks Brown, Ph.D., Northwestern University &amp; Emily Lichvar, Ph.D., Center for Mental health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services</i></li> <li>• Group 2: Community engagement and partnerships for development and implementation of solutions <i>Moderator: Kelly J. Kelleher, M.D., The Research Institute at Nationwide Children's Hospital &amp; Angela Lello, M.P.A., Autism Speaks</i></li> <li>• 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" <i>Moderators: Andy Shih, Ph.D., Autism Speaks &amp; Ed Schor, M.D., Lucile Packard Foundation for Children's Health</i></li> </ul>
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