

## **Panel I: When Should I Be Concerned?**

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### ***Clinical Experts:***

#### **Geraldine Dawson, Ph.D.**

*Chief Science Officer, Autism Speaks*

Dr. Geraldine Dawson became Autism Speaks' first Chief Science Officer in January of 2008. In this role, Dr. Dawson serves as the scientific leader of Autism Speaks, working with the scientific community, stakeholders, and science staff, to shape, expand, and communicate Autism Speaks' scientific vision and strategy. Dawson also holds the positions of Research Professor of Psychiatry at the University of North Carolina at Chapel Hill, Adjunct Professor of Psychiatry at Columbia University, and Professor Emeritus of Psychology at University of Washington.

Dr. Dawson received her Ph.D. in Developmental Psychology with a minor in Child Clinical Psychology from the University of Washington and was a post-doctoral fellow specializing in neurodevelopmental disorders at the Neuropsychiatric Institute at UCLA. She has been licensed as a clinical psychologist since 1980. Prior to joining Autism Speaks, Dawson was Professor of Psychology and Psychiatry at the University of Washington (UW) and Founding Director of the UW Autism Center, which has been designated an NIH Autism Center of Excellence since 1996. While at the University, Dr. Dawson led a multi-disciplinary autism research program focusing on genetics, neuroimaging, diagnosis, and treatment.

Dr. Dawson's own research has been in the areas of early detection and intervention, early patterns of brain dysfunction (electrophysiology), and more recently, development of endophenotypes for autism genetic studies. In collaboration with Sally Rogers, Dawson developed and empirically-validated the *Early Start Denver Model*, a comprehensive early intervention program for young children with autism. Dr. Dawson received continuous NIH funding for her research from 1980 until 2008 when she left UW to join Autism Speaks.

Dr. Dawson has published over 180 scientific articles and chapters and co-edited or authored a number of books about autism spectrum disorder and brain development, including *The Early Start Denver Model for Young Children with Autism*; *Autism Spectrum Disorders*; *Human Behavior, Learning, and the Developing Brain*; and *A Parent's Guide to Asperger Syndrome and High-Functioning Autism*. From 2000 to 2007, Dawson founded and directed University of Washington Autism Center's multi-disciplinary autism treatment program, which is the largest of its kind in the northwestern United States. Dawson has testified before the U.S. Senate on behalf of individuals with autism and played a key role on the Washington State Autism Task Force.

#### **Rebecca Landa, Ph.D., CCC-SLP**

*Founder & Director, Kennedy Krieger's Center for Autism & Related Disorders*

Dr. Rebecca Landa is the founder and director of Kennedy Krieger's Center for Autism and Related Disorders. She is an associate Professor of Psychiatry in the Johns Hopkins University School of Medicine. Dr. Landa obtained her master's degree at the Pennsylvania State University and her doctorate at the University of Washington. She completed post-doctoral training in Psychiatric Genetics at Johns Hopkins. She is the recipient of the NIMH Shannon Award for excellent and innovative research, as well as the Rita Rudel Prize for Developmental Neuropsychology. Dr. Landa is

the recipient of the 2009 Alumni Recognition Award from the College of Human Health and Development of the Pennsylvania State University.

Dr. Landa's research has focused on neuropsychological, learning, and communication processes in autism across the lifespan. She was the principal investigator of an NIH STAART Center of Excellence, through which she developed and defined the evidence-base for the Early Achievements intervention for toddlers with autism spectrum disorders. She has pioneered research aimed at identifying the earliest signs of autism through the study of infant siblings of children with autism.

Dr. Landa is the author of the Pragmatic Rating Scale, used internationally in autism-related research and clinical practice. Her current research focus is on learning processes in autism, as well as early detection of and intervention for autism spectrum disorders (ASD).

## **Research Experts:**

### **Deborah Fein, Ph.D.**

*Distinguished Professor of Psychology, Professor of Pediatrics, University of Connecticut*

Dr. Deborah Fein is currently Board of Trustees Distinguished Professor of Psychology and Professor of Pediatrics at the University of Connecticut. She received her Ph.D. in Clinical Psychology from Rutgers University and her training in neuropsychology at Boston University and the Boston VA Medical Center. She is a Diplomate in Clinical Neuropsychology (American Board of Professional Psychology). She served on the Board of Directors of the American Association for Clinical Neuropsychology from 2005-2009, is on the Science Advisory Board of Autism Speaks, is Associate Editor of the journal *Neuropsychology*, and was recently elected Secretary of the International Society for Autism Research.

Dr. Fein's main research interests have involved the neuropsychology of autistic spectrum disorders, as well as issues in child and adult neuropsychological assessment. She has published over 100 articles and chapters, mostly on autism-related topics, focusing on language, memory, attention, social interaction, and early detection, as well as some biological studies (evoked potentials, oxytocin blood levels). She is the co-author of a recent book for teachers, "Autism in Your Classroom" and is the co-author of the widely used "Modified Checklist for Autism in Toddlers." She is currently investigating early detection of autism and conducting a neuropsychological and fMRI study of language in children whose autism has resolved.

### **Catherine Lord, Ph.D.**

*Director, University of Michigan Autism & Communication Disorders Center (UMACC)*

Dr. Catherine Lord is the Director of the University of Michigan Autism and Communication Disorders Center (UMACC) and a Professor of Psychology, Psychiatry and Pediatrics. She is a clinical psychologist who has worked in Canada and the United Kingdom, and at various universities in the United States, including the TEACCH program. She was involved in developing standardized diagnostic instruments for ASD (the Autism Diagnostic Observation Schedule [ADOS], an observational scale, and the Autism Diagnostic Interview – Revised [ADI-R], a parent interview), considered the gold standard for research diagnoses. She was the Chair of the Committee on Effectiveness of Early Intervention in Autism for the National Research Council.

As Director of UMACC, she provides clinical evaluations and consultations and trains university students and professionals in the diagnosis of ASD. Current projects include the development of a toddler module for the ADOS and use of it in longitudinal follow-up of very young children with possible ASD; organization of the Simons Simplex Collection, a repository of cell lines and phenotypic data for families with a child with autism and a typical child; the development of a measure of spontaneous, functional language in children with ASD; two studies of different interventions with very young children; and a longitudinal study of children followed from age 2 who are now in their teens. The UMACC website is: [www.umaccweb.com](http://www.umaccweb.com)

## ***Family/Personal Experts:***

### **Paula C. Durbin-Westby**

*Board of Directors, Autistic Self-Advocacy Network*

Paula C. Durbin-Westby serves on the Board of Directors of The Autistic Self-Advocacy Network. The Autistic Self-Advocacy Network is the leading non-profit organization run by and for autistic people. ASAN seeks to advance the principles of the disability rights movement in the world of autism. Ms. Durbin-Westby works with ASAN on public policy advocacy, educational issues, media and community outreach. Ms. Durbin-Westby is also an autistic community member of the Academic Autistic Partnership In Research and Education (AASPIRE). She is also a graduate of the Virginia Board for People with Disabilities' Partners in Policymaking Class of 2009.

Ms. Durbin-Westby has testified at numerous Interagency Autism Coordinating Committee (IACC) meetings, calling for research into supports and services throughout the lifespan, urging NIMH to include autistic individuals as full partners in research projects. She gave an invited presentation to the IACC full committee on "Ethical Concerns in Autism Research" on November 21, 2008.

Ms. Durbin-Westby has been self-employed in the publishing industry for 15 years, as an indexer of scholarly monographs, primarily in the fields of political science, international relations, labor relations, and philosophy. Ms. Durbin-Westby is also employed as a choir director and organist.

Ms. Durbin-Westby holds a Bachelor of Music in organ performance from the University of Richmond and a Bachelor of Arts in English literature from University of Maryland, College Park.

### **Nancy D. Wiseman**

*Founder & President, First Signs, Inc.*

Ms. Nancy Wiseman is founder and president of First Signs, Inc., a national nonprofit organization dedicated to educating parents and professionals about the early signs of autism and related disorders. Since 1999, Ms. Wiseman has made a significant contribution to changing policy, improving awareness, and changing pediatric practice in how we screen, refer, and detect young children today. She has launched statewide public awareness and training programs in 8 states and has trained more than 15,000 professionals. Before devoting herself to First Signs, Ms. Wiseman worked in corporate communications for over 20 years where she led award-winning advertising, public relations, and direct marketing campaigns for international corporations.

Ms. Wiseman holds a B.S. in Mass Communication from Boston University. She has appeared in interviews with USA Today, Parents Magazine, NBC's *Today Show*, and CNN's *Larry King Live*. Nancy

is the author of *Could It Be Autism? A Parent's Guide to the First Signs and Next Steps* (Broadway Books, 2006) and *The First Year: Autism Spectrum Disorders: An Essential Guide for the Newly Diagnosed Child* (Da Capo Press, 2009). She is the mother of Sarah, who was diagnosed with autism at the age of two. Today—at age 13—Sarah stands as a powerful example of the impact that early identification and intensive intervention can have on young children with autism and related disorders. Nancy is the 2006 recipient of the American Academy of Pediatrics' Dale Richmond/Justin Coleman Award for her outstanding achievement in the field of child development.

## ***IACC Liaisons:***

### **Yvette Janvier, M.D.**

*Medical Director, Children's Specialized Hospital and IACC Member*

Dr. Janvier is board-certified in Pediatrics, Neurodevelopmental Disabilities, and Developmental - Behavioral Pediatrics, and has been practicing neurodevelopmental pediatrics for the past 19 years. Her clinical and research focus is on the early identification of autism. She completed a two-year fellowship in Developmental - Behavioral Pediatrics at Cornell Medical Center in June of 1990 and has served as the Medical Director of Children's Specialized Hospital - Toms River since its opening in March 1992.

Dr. Janvier is a public member of the Interagency Autism Coordinating Council (IACC) and is a co-investigator on the NIMH study: A Clinical and Immunologic Investigation of Regression in Autism. Dr. Janvier is also the principal investigator for a clinical enhancement grant to expand and improve services for children on the autism spectrum at Children's Specialized Hospital. She is a member of the New Jersey Governor's Council on Medical Research and Treatment of Autism and serves on the Board of Directors for Autism New Jersey.

The recipient of many awards, Dr. Janvier recently received the New Jersey Community Service Award given by Autism Family Services and the Wynona Lipman Innovation Award given by the New Jersey Department of Community Affairs Division on Women and the New Jersey Advisory Commission on the Status of Women. She was also named a finalist for "Physician of the Year" from the NJBIZ 2008 Healthcare Hero Award. Dr. Janvier works and resides in central New Jersey.

### **Jennifer G. Johnson, Ed.D.**

*Supervisory Program Specialist and IACC Member*

Dr. Jennifer Johnson is a Supervisory Program Specialist with the Administration on Developmental Disabilities, Administration for Children and Families, U.S. Department of Health and Human Services, where she oversees the University Centers for Excellence in Developmental Disabilities and State Developmental Disabilities Councils grant programs. Her other responsibilities include managing ADD's monitoring process and the ADD independent evaluation of the Councils, Protection and Advocacy Systems, and University Centers, working with an outside contractor to develop and implement a national study to examine the impact of ADD-funded programs.

Prior to joining ADD, Dr. Johnson worked at The George Washington University on a variety special projects, including those related to the National Board for Professional Teaching Standards. She also served as an Adjunct Lecturer teaching master's level coursework in research methodology and public policy. She also has consulted to a variety of national organizations providing expertise on

issues related to special education, early childhood, disabilities, and research design. Dr. Johnson earned her doctorate in education from the George Washington University.

Dr. Johnson's most direct experience with autism is working with young children on the autism spectrum, delivering intervention and educational services and supporting their inclusion in classroom-based settings.

## **Panel II: How Can I Understand What is Happening?**

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### ***Clinical Experts:***

#### **Pauline A. Filipek, M.D.**

*Professor of Pediatrics, University of Texas Health Science Center at Houston*

Dr. Pauline Filipek received her B.S. from Georgetown University and her M.D. from Georgetown University School of Medicine. She completed a pediatric residency, including a year as Chief Resident, at the University of Massachusetts Medical School. She then completed a three year child neurology residency, followed by a Fellowship in MRI Morphometry, at Massachusetts General Hospital/ Harvard Medical School, where she remained on faculty until 1994. While in Boston her research interests were focused on the use of MRI morphometry to identify subtle changes in the brain structures of children with developmental disorders, including autism. In 1994 she moved to UC Irvine, where her clinical and research focused predominantly on screening and diagnosis of autistic spectrum disorders, particularly on the early identification of red flags for the diagnosis.

She founded the *For OC Kids Neurodevelopmental Center* at UC Irvine with a grant from First Five California which is dedicated to diagnosis and advocacy for children with autism, empowerment of their families, and education of professionals and the general public of the earliest signs of autism in children. In July 2009, she was recruited to the University of Texas Health Sciences Center at Houston to develop an Autism Center of Excellence for individuals with ASD and their families in the greater Houston area. Her research focus continues to be the identification of the earliest signs of autism in infants and toddlers to implement effective intervention strategies as soon as possible.

#### **Sarah Spence, M.D., Ph.D.**

*Pediatric Neurologist, National Institute on Mental Health*

Dr. Sarah Spence is a board certified child neurologist with a doctorate in neuropsychology. She completed her undergraduate education at Harvard-Radcliffe, her Ph.D. at UCLA and her M.D. at UCSF. After residency training in general pediatrics and neurology, she completed a fellowship in child neurology at UCLA. She then did a post-doctoral fellowship working with the Autism Genetic Resource Exchange (AGRE), a large shared resource for the study of autism genetics supported by Cure Autism Now, Autism Speaks and the National Institute of Mental Health (NIMH). After joining the UCLA Medical School faculty she served as Medical Director of the UCLA Autism Evaluation Clinic with an active clinical practice specializing in comprehensive medical evaluation and treatment of children with ASD. In 2006 she was recruited to join the intramural autism research program in the Pediatrics and Developmental Neuropsychiatry Branch at the NIMH in Bethesda, MD.

There she is involved in a number of studies including the intensive investigation of the subtypes of autism and several novel treatment trials. She has continued working with the advocacy groups Cure Autism Now and Autism Speaks with roles on steering committees for a number of programs including the AGRE program, the Autism Treatment Network, and the High Risk/High Impact research initiative. She currently serves on the DSM V Work Group for Neurodevelopmental Disorders. Her research interests include exploration of the medical aspects in autism including the role of epilepsy and EEG abnormalities, sleep disorders, metabolic dysfunction, and genetics.

## **Research Experts:**

### **David G. Amaral, Ph.D.**

*Distinguished Professor of Psychiatry & Behavioral Sciences; Research Director, Beneto Foundation; Chair, The M.I.N.D. Institute (Medical Investigation of Neurodevelopmental Disorders) University of California, Davis*

Dr. David Amaral received his undergraduate education at Northwestern University and graduated with a degree in Psychology. He then moved to the University of Rochester where he received a joint Ph.D. in Neuroscience and Psychology. He conducted postdoctoral research at the Department of Anatomy and Neurobiology at Washington University. He then moved to the Salk Institute for Biological Studies where he remained for 13 years. During this period, he was also an adjunct professor in the Department of Psychiatry at UC San Diego.

Dr. Amaral joined the University of California, Davis in 1995, as a Professor in the Department of Psychiatry and Behavioral Sciences and the Center for Neuroscience. He is also a staff scientist at the California National Primate Research Center. Dr. Amaral was named the Beneto Foundation Chair and Research Director of the M.I.N.D. (Medical Investigations of Neurodevelopmental Disorders) Institute in 1998. The M.I.N.D. Institute is dedicated to understanding the biological basis of autism and other neurodevelopmental disorders with the goal of developing preventative measures and innovative treatments. Dr. Amaral was a founding member of the M.I.N.D. Institute and has been charged with guiding the overall research mission of the Institute.

Dr. Amaral's laboratory pursues research programs dealing with the neurobiology of primate social behavior and with the development and neuroanatomical organization of the primate and human amygdala and hippocampal formation. He has also carried out a longstanding program designed to understand the organization of brain regions involved in memory. His research now also includes postmortem studies of the autistic brain and magnetic resonance imaging studies of children with autism spectrum disorders.

As Research Director of the M.I.N.D. Institute, he is currently coordinating a comprehensive and multidisciplinary analysis of children with autism called the Autism Phenome Project to define biomedical characteristics of different types of autism. This project will lead to more effective hypothesis driven research on the causes of each type of autism and ultimately to more effective treatments. Dr. Amaral has also spearheaded efforts to establish animal models of autism and has been evaluating the potential immune basis of certain forms of autism.

Beginning in 2009, Dr. Amaral was appointed to the National Mental Health Advisory Council of the National Institute of Mental Health. In May of 2009, he was elected President of the International Society of Autism Research.

## **Emanuel DiCicco-Bloom, M.D.**

*Professor of Neuroscience & Cell Biology & Pediatrics, Robert Wood Johnson Medical School*

Dr. Emanuel DiCicco-Bloom is Professor of Neuroscience & Cell Biology and Pediatrics (Child Neurology & Neurodevelopmental Disabilities) at Robert Wood Johnson Medical School (RWJMS), and member of graduate programs in Cell & Developmental Biology, Neuroscience and Toxicology at UMDNJ and Rutgers University. He graduated summa cum laude from Princeton University, received his M.D. from Cornell University Medical College, and trained in Pediatrics and Neurology at New York Hospital-Cornell Medical Center, joining RWJMS in 1990.

Dr. DiCicco-Bloom's research focuses on defining molecular pathways that regulate production of neuronal cells (neurogenesis) during brain development, and how related abnormalities contribute to developmental disorders including autism and schizophrenia. He investigates how neuropeptides, growth factors and environmental toxins impact cell cycle and survival mechanisms that control neurogenesis, studying neural precursor cells in culture and in developing embryos and newborns. Recent studies of the autism-associated gene, *Engrailed 2*, a critical regulator of cerebellar development, indicate that it regulates neurogenesis and differentiation, as well as forebrain monoamine neurotransmitters that are targets of neuropsychiatric drugs.

Dr. DiCicco-Bloom has long served the autism community, providing scientific expertise to National Alliance for Autism Research; Autism Speak's Board of Directors and Scientific Advisory Committee and current Scientific Advisory Board (SAB); the SAB of the Autism Science Foundation; and Executive Committee and Tissue Advisory Board of Autism Tissue Program. He was Chair of Scientific Program Committee of the 2008 IMFAR meeting and is Co-Chair for 2010. He served N.J. Governor's Council on Autism Research; is current Chair of N.J. Commission on Brain Injury Research; on SAB of International Rett Syndrome Foundation; and Public Education and Communication Committee of Society for Neuroscience.

Dr. DiCicco-Bloom has worked closely with the many families (especially Karen and Eric London, and son Zac) who created and supported the National Alliance for Autism Research (NAAR).

## ***Family/Personal Experts:***

### **Ashura Williams Buckley, M.D.**

*Research Clinical Fellow, National Institute on Mental Health*

Dr. Ashura Buckley is a board certified child neurologist, fellowship trained in sleep medicine. She received her undergraduate degree from Harvard University, her M.D. from the State University of New York at Stony Brook and completed her training in pediatric neurology at Massachusetts General Hospital. Since 2006, Dr. Buckley has been a Research Clinical Fellow at the National Institute of Mental Health (NIMH) where she focuses on dysregulated sleep patterns in autism. She is interested in the normal developmental trajectory of sleep architecture and how abnormal sleep patterns in autism may reflect underlying disorders in neurotransmission. She also holds a Research Assistant Professorship at the Child Study Center at New York University. Dr. Buckley has a younger, adult brother with Pervasive Developmental Disorder.

## **Denise D. Resnik**

*Co-founder, Southwest Autism Research & Resource Center; President, Denise Resnik & Associates*

Ms. Denise Resnik is the co-founder and board development chairman of the Southwest Autism Research & Resource Center (SARRC), which is dedicated to autism research, education and community outreach and the support of individuals with autism and their families throughout their lifetimes. She served as Board Chairman from 1997-2007, and now chairs SARRC's Board Development and Vocational & Life Skills Committees, and serves on its Research & Medical Affairs Committee.

SARRC's 18,000-square-foot Campus for Exceptional Children and 10,000-square-foot Vocational & Life Skills Academy serve as hubs for its research and programs, which range from parent empowerment, early intervention and educator training to Hispanic outreach, physician education and vocational/life-skills development.

SARRC participates in pharmaceutical trials, directs its own clinical studies and has been advancing its molecular and genetic studies in collaboration with the Translational Genomics Research Institute (TGen). SARRC consistently emerges as a leader in the recruitment and enrollment of subjects in multi-site studies, and proudly partners with the Autism Genetic Resource Exchange, Autism Trials Network and the Organization for Autism Research. Ms. Resnik is a member of the Autism Speaks Family Services Committee and Advancing Futures for Adults with Autism (AFAA) Steering Committee, and has served as a managing partner of Autism Cares and members of the 2006 NIMH Autism Matrix Review Committee and 2007-08 NIH Autism Strategic Plan Workgroup.

Ms. Resnik is the mother of an 18-year-old son with autism. She is also the founder and president of a strategic marketing and public relations agency, Denise Resnik & Associates. The agency provides significant in-kind support to SARRC.

## ***IACC Liaisons:***

### **Alison Singer, M.B.A.**

*President, Autism Science Foundation and IACC Member*

Ms. Alison Singer is Co-Founder and President of the Autism Science Foundation, a not for profit organization launched in April 2009 to support autism research. From 2005-2009 she served as Executive Vice President and a member of the Board of Directors at Autism Speaks.

The Autism Science Foundation supports autism research by providing funding and other assistance to scientists and organizations conducting, facilitating, publicizing and disseminating autism research. Founded by parents of children with autism, ASF also provides information about autism to the general public and serves to increase awareness of autism spectrum disorders and the needs of individuals and families affected by autism. The organization adheres to rigorous scientific standards and values.

As the mother of a child with autism and legal guardian of her adult brother with autism, she is a natural advocate. In 2007, Ms. Singer was appointed by HHS Secretary Michael Leavitt to serve as one of six public members of the Federal Interagency Autism Coordinating Committee (IACC) which is charged with writing a strategic plan to guide federal spending for autism research. Within the IACC, she serves on the services subcommittee and on the subcommittee for strategic plan review.

Ms. Singer also currently serves on the Executive Board of the Yale Child Study Center Associates Committee, on the external advisory board of the Autism Baby Siblings Research Consortium, on the external advisory board of the CDC's Center for Birth Defects and Developmental Disabilities, on the board of directors of Mental Health News, as a member of the American Academy of Pediatrics' New York State Immunization Coalition, and as a member of the program committee for the International Meeting for Autism Research (IMFAR). Ms. Singer graduated magna cum laude from Yale University with a B.A. in Economics and has an M.B.A. from Harvard Business School.

## **Edwin Trevathan, M.D., M.P.H.**

*Director, National Center on Birth Defects and Developmental Disabilities, CDC and IACC Member*

Dr. Edwin Trevathan serves as Director of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at CDC. Dr. Trevathan's first experience at CDC was as a graduate and medical student in the late 1970's and early 1980's. He returned to work at CDC in 1987 as an Epidemic Intelligence Service (EIS) officer in the Division of Birth Defects and Developmental Disabilities. A pediatrician and neurologist, Dr. Trevathan has spent most of his career in clinical medicine, caring for people with neurological and developmental disorders, conducting clinical and epidemiologic research, and serving as a leader in clinical academic medicine. Prior to his return to CDC in 2007, he was Professor of Neurology and Pediatrics, and Director of the Division of Pediatric and Developmental Neurology at Washington University in St. Louis, and Neurologist-in-Chief at St. Louis Children's Hospital.

Dr. Trevathan has conducted epidemiologic studies of childhood epilepsy and developmental disabilities, has directed multi-center clinical trials, and has authored or co-authored over 100 clinical and scientific publications. He serves on the editorial boards of *Neurology*, the *Disability and Health Journal*, and the *Journal of Developmental Origins of Health and Disease*. He is a regular reviewer for other journals including *Pediatrics*, *Epilepsia*, and *The Lancet*, and lectures nationally and internationally.

Dr. Trevathan obtained his B.S. (Chemistry and Mathematics) from the Lipscomb University in Nashville, TN. He received his M.D. and M.P.H. at Emory University, where he was elected to *Alpha Omega Alpha*. He completed his residency training in pediatrics at Yale University School of Medicine, and in neurology and child neurology at Massachusetts General Hospital. He was a fellow in clinical neurophysiology at Boston Children's Hospital. He is board-certified in pediatrics, neurology with special qualification in child neurology, and in clinical neurophysiology.

Dr. Trevathan's prior experience includes co-founding a private child neurology group practice in Atlanta, working with state health departments, and serving as a professor at the University of Kentucky College of Medicine and at Washington University in St. Louis. He continues to enjoy his work as an Adjunct Professor of Neurology at Washington University in St. Louis, and as an Adjunct Professor of Epidemiology at Rollins School of Public Health of Emory University.

Dr. Trevathan's first experience with autism was as a child in the early to mid-1960's. His mother was a special education teacher. He frequently played with her students - some of whom had what we now diagnose as one of the autism spectrum disorders. Only years later did he realize the powerful impact this early life experience had on his career choices.

## **Panel III: What Caused This to Happen and Can It Be Prevented?**

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### ***Clinical Experts:***

#### **Robin Hansen, M.D.**

*Professor of Pediatrics, Director, Center for Excellence in Developmental Disabilities  
Director of Clinical Programs, UC Davis M.I.N.D. Institute*

Dr. Robin Hansen is Professor of Pediatrics, Director of the Center for Excellence in Developmental Disabilities, and Director of Clinical Programs at the UC Davis M.I.N.D. Institute. She is a board-certified developmental-behavioral pediatrician who heads a multidisciplinary clinic that diagnoses children with neurodevelopmental disorders, plans/initiates intervention strategies, and works closely with patient families. Dr. Hansen has developed services for families affected by parental substance abuse, infant mental health programs, and programs for children in foster care and children with externalizing behavior disorders within school settings. Dr. Hansen also facilitates the California Interagency Autism Planning Group through the Center for Excellence in Developmental Disabilities.

Her clinical research has focused on children's temperament and its effects on parenting, long-term effects of prenatal drug exposure, gene-environment interactions related to causes and early identification of autism spectrum disorders, and evidence based treatments for neurodevelopmental disorders such as autism. She is a faculty member of the UC Davis Center for Children's Environmental Health and a co-investigator on the Center's Childhood Autism Risks from Genetics and Environment (CHARGE) and Markers of Autism Risk in Babies - Learning Early Signs (MARBLES) studies.

Dr. Hansen received her undergraduate degree in Human Biology from Stanford University and her medical degree from the University of California, Davis. She completed her pediatric residency at Children's Hospital, Oakland, CA, and her fellowship in developmental behavioral pediatrics at the University of Colorado Health Sciences Center. She is currently President of the Society for Developmental Behavioral Pediatrics, Associate Editor for the Journal of Developmental Behavioral Pediatrics, a fellow of the American Academy of Pediatrics, and serves on the Developmental Behavioral Pediatrics sub-board of the American Board of Pediatrics. Her work is dedicated to providing collaborative opportunities for expanded interdisciplinary training, community partnerships, translation of research into practical applications and advocacy for individuals with developmental disabilities across the lifespan.

#### **Susan Swedo, M.D.**

Dr. Susan Swedo is Chief of the Pediatrics & Developmental Neuropsychiatry Branch, NIMH. She is a board-certified pediatrician, who trained at Northwestern University's Children's Memorial Hospital in Chicago, Illinois. Dr. Swedo has authored/co-authored over 100 research publications since joining the NIMH in 1986. Her research has focused on diagnosis and treatment of childhood neuropsychiatric conditions, including Sydenham's chorea, Tourette Syndrome, Obsessive-Compulsive Disorder (OCD), and autism spectrum disorders. Dr. Swedo and colleagues were the first to describe a post-infectious etiology for OCD and define criteria identifying the PANDAS subgroup (Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections).

Current research efforts are directed at identifying biological causes for behavioral syndromes and developing new and more effective therapies. Dr. Swedo received her B.A. degree from Augustana College in 1977 and her M.D. from Southern Illinois University in 1980.

## **Research Experts:**

### **Craig Newschaffer, Ph.D.**

*Professor & Chairman, Dept. of Epidemiology & Biostatistics, Drexel University School of Public Health*

Dr. Craig Newschaffer is Professor and Chairman of the Department of Epidemiology and Biostatistics at the Drexel University School of Public Health. Previously, Dr. Newschaffer founded and directed the Center for Autism and Developmental Disabilities Epidemiology at the Johns Hopkins Bloomberg School of Public Health. Dr. Newschaffer now leads an NIH Autism Center of Excellence project studying a large cohort of mothers of children with autism at the start of subsequent pregnancies. This project, known as the EARLI Study, is designed to study pre-, peri- and neonatal autism risk factors and biomarkers. He is also a PI on other autism epidemiology initiatives, including the CDC-funded SEED study and ADDM network.

He has worked on autism internationally, leading a pilot project funded by the NIH to develop capacity for, and assess the feasibility of, conducting epidemiologic research on autism in China. Dr. Newschaffer is a co-investigator on the Baltimore site of the National Children's Study, a prospective epidemiologic study of a representative sample of 100,000 U.S. pregnancies, serving on that study's Mental Health working team. He is an Associate Editor of the *American Journal of Epidemiology* and a member of the editorial boards of *Autism Research* and *Developmental Epidemiology*. He sits on the Science Advisory Board for *Autism Speaks* and on advisory boards for the Commonwealth of Pennsylvania's Bureau of Autism Services and the Delaware Birth Defects and Autism Registry. Dr. Newschaffer holds a master's degree in health policy from Harvard University and a doctoral degree in epidemiology from Johns Hopkins University.

### **Matthew State, M.D., Ph.D.**

*Yale University School of Medicine*

Matthew State, MD, PhD is both a Child Psychiatrist and Geneticist. He received his undergraduate and medical degrees from Stanford University, and completed his residency and child psychiatry fellowship training at the UCLA Neuropsychiatric Institute. He received his PhD in Genetics from Yale University and joined the faculty there in 2001. He is currently the Donald J. Cohen Associate Professor of Child Psychiatry, Associate Professor and Deputy Chair for Research in the Department of Psychiatry, and Associate Professor of Genetics. He co-directs the Yale Program on Neurogenetics.

Dr. State's lab has been had a long-standing interest in the contribution of rare genetic variation to Autism and related syndromes. In 2004, his lab identified the contribution of the *Contactin 4* to developmental disorders and social disability and more recently was among several groups simultaneously highlighting the role of *Contactin Associated Protein 2* in Autism Spectrum Disorders (ASD). Dr. State is currently leading a multi-site genome wide study of ASD funded by the Simons Foundation. He is principal investigator on several NIH grants focusing on Autism as well as Tourette syndrome. Clinically, he serves as a consultant to a residential facility for young adults with ASD and

he serves on the Steering Committees of the Autism Genetics Resource Exchange (AGRE) and the High Risk-High Impact Initiative at Autism Speaks, the Scientific Advisory Board of the Autism Science Foundation, and on the editorial boards of the journals *Autism Research and Molecular Autism*.

### ***Family/Personal Experts:***

#### **Lars Perner, Ph.D.**

*Assistant Professor of Clinical Marketing, Marshall School of Business, University of Southern California*

Dr. Lars Perner is an Assistant Professor of Clinical Marketing at the Marshall School of Business at the University of Southern California. He holds a Ph.D. in marketing from the University of Southern California and an M.B.A. and a B.A. in political science and psychology from California Polytechnic State University, San Luis Obispo. Dr. Perner serves on the Autism Society's Panel of People on the Spectrum and has written extensively about issues such as the paradoxes of autism, cognitive functions, college education, and special interests. He illustrates how, ironically, using special interests as a context of teaching may actually facilitate the development of generalization skills due to reduced cognitive overhead and denser network of knowledge associated with these interests. Dr. Perner is a strong supporter of autism subtype research given the considerable heterogeneity within the autism population as a means to identify suitable treatment for disparate individuals and reducing the impact of aggregation bias on autism research.

Dr. Perner became interested in the autism spectrum after being diagnosed with Asperger's syndrome in 1996. His research focuses on consumer behavior, branding, consumer price response, "win-win" deals, sponsored fundraising, and non-profit marketing. Prior to returning to his alma mater at USC, he held faculty positions at the University of Maryland, The George Washington University, the University of California at Riverside, and San Diego State University.

#### **Jeff Sell, J.D.**

*Vice President, Advocacy & Public Policy for the Autism Society of America (ASA)*

Mr. Jeff Sell has been blessed with four children, Natalie (16), Ben and Joe (15 year-old twins with autism), and Gracie (12).

Mr. Sell is the Vice President, Advocacy & Public Policy for the Autism Society of America (ASA). He has served as the first Vice Chairman of ASA's Board of Directors, Chairman of ASA's Government Relation Committee and Director of Chapters & Membership. Mr. Sell presently serves on the Professional Advisory Boards of New York Families for Autistic Children (NYFAC) and he is the Vice President of the World Autism Organization (WAO).

Mr. Sell graduated from Lamar University and earned his Juris Doctorate degree from South Texas College of Law. In addition to being a member of several professional societies and organizations, Mr. Sell serves on the Board of Directors for the Houston Trial Lawyers Association and was a founding partner of Patterson & Sell, L.L.P. in Houston, Texas. He is a certified mediator and a co-founder of the Vaccine Injury Alliance and he served as Public Liaison Counsel on the Petitioner's Steering Committee for the Autism Omnibus case in the U.S. Court of Federal Claims in Washington, DC.

## **IACC Liaisons:**

### **Lee Grossman**

*President/CEO, Autism Society of America (ASA) and IACC Member*

Mr. Lee Grossman is currently the President and CEO of the Autism Society of America (ASA) and the President of the Autism Society of America Foundation, publisher of the Autism Advocate journal, as well as a member of the United States Interagency Autism Coordinating Committee (IACC), which coordinates federal efforts in autism research and services amongst all Federal agencies. He was appointed to the IACC by Health and Human Services Secretary Mike Leavitt and is the Co-Chair of the IACC's Services Subcommittee. Mr. Grossman oversees the nation's largest grassroots autism organization, with over 190,000 members and supporters and 160 chapters across the United States. In 2007, Lee initiated strategic partnerships with Easter Seals, the Autism Research Institute, and the Celtic Nations for Autism, the Autism Society of the Philippines and the Autism Society of Parents in Hong Kong, as well as forming coalitions in the United States to deal with disability services issues.

Lee was born and raised outside of Pittsburgh, PA, and attended college at the University of Pennsylvania in Philadelphia. He completed his senior year at Hawaii Pacific University in Honolulu, Hawaii, earning his Bachelors of Science in Business Administration. Currently, Mr. Grossman is enrolled in the Georgetown University McDonough School of Business Master's of Leadership program where he is expected to graduate in April 2010.

Mr. Grossman has served on the Board of Directors of the ASA since 1995 and is a past President of the Autism Society of Hawaii. While on the Board of ASA, Lee has been served in numerous capacities including Chair of National Autism Awareness Month, Nominating Chair, Development Chair and Public Relations Chair.

Mr. Grossman and his wife Nina have three sons, one of whom has autism. He spends his leisure time doing sports conditioning, reading, and speaking on all topics related to business or autism and enjoying the company of his family and friends.

### **Story Landis, Ph.D.**

*Director, National Institute for Neurological Disorders & Stroke (NINDS) and IACC Member*

Dr. Story Landis has been Director of the National Institute for Neurological Disorders and Stroke (NINDS) since 2003. A native of New England, Dr. Landis received her undergraduate degree from Wellesley College in 1967 and her Ph.D. (1973) from Harvard University. After postdoctoral work at Harvard University, she served on the faculty of the Department of Neurobiology there. In 1985, she joined the faculty of Case Western Reserve University School of Medicine, where she created the Department of Neurosciences that achieved an international reputation for excellence. Throughout her research career, Dr. Landis has made fundamental contributions to the understanding of nervous system development. She has garnered many honors, is an elected fellow of the Academy of Arts and Sciences, the American Association for the Advancement of Science, and the American Neurological Association, and in 2002, was elected President of the Society for Neuroscience.

Dr. Landis joined the NINDS in 1995 as Scientific Director and worked to re-engineer the Institute's intramural research programs. Between 1999 and 2000, she led the movement, together with the NIMH Scientific Director, to bring a sense of unity and common purpose to 200 neuroscience laboratories from eleven different NIH Institutes. As NINDS Director, Dr. Landis oversees an annual

budget of \$1.5 billion that supports research by investigators in public and private institutions across the country, as well as by scientists working in its intramural program. With NIMH Director, Dr. Thomas Insel, she chairs the NIH Neuroscience Blueprint, a roadmap-like effort to support trans-NIH activities in the brain sciences. In 2007, Dr. Landis was named Chair of the NIH Stem Cell Task Force

## **Panel IV: Which Treatments and Interventions Will Help?**

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### ***Clinical Experts:***

#### **Robert L. Hendren, D.O.**

*Professor of Psychiatry & Behavioral Science, Director of Child & Adolescent Psychiatry  
Vice Chair of the Department of Psychiatry, University of California, San Francisco*

Dr. Robert Hendren is Professor of Psychiatry and Behavioral Science; Director of Child and Adolescent Psychiatry and Vice Chair of the Department of Psychiatry at the University of California, San Francisco. He is also the current (2007-2009) President of the American Academy of Child and Adolescent Psychiatry. Dr. Hendren is board-certified in General, as well as Child and Adolescent Psychiatry. His current areas of research and publication interests are translational clinical pharmacology and nutritional trials using biomarkers (MRI, measures of inflammation, oxidative stress, immune function and pharmacogenomics) in neurodevelopmental disorders. He has published over 100 scientific papers and four books and has been listed in "The Best Doctors in America," each year since it was published in 1996.

Dr. Hendren took his residency in general psychiatry at the Mayo Graduate School of Medicine and his child and adolescent psychiatry fellowship at the Yale Child Study Center. After training, he was on the faculty at the George Washington University School of Medicine and the University of New Mexico, School of Medicine. He was Professor of Psychiatry and Pediatrics and Director of Divisions of Child and Adolescent Psychiatry at UMDNJ-Robert Wood Johnson and New Jersey Medical Schools and Director of the Behavioral Research and Training Institute at UMDNJ-University Behavioral HealthCare, RWJMS, NJMS. He was Professor of Psychiatry and Behavioral Science; Executive Director and Tsakopoulos-Vismara Chair, M.I.N.D. Institute (Medical Investigation of Neurodevelopmental Disorders); and Chief, Division of Child and Adolescent Psychiatry at the University of California, Davis from 2001-2009.

#### **Eric Samstad, M.D.**

*Lead Psychiatrist, Autism and Special Needs Clinic of Johns Hopkins*

Dr. Samstad received his M.D. from the University of Maryland in 2000. He completed his internship and residency in Psychiatry at Johns Hopkins in 2004. He is board-certified in Psychiatry by the American Board of Psychiatry and Neurology. His work has involved clinical care of ID and DD patients in outpatient, inpatient, and institutional settings. His research interests include the use of anti-Alzheimer's medications in autism spectrum disorders and the study of non-pharmacologic treatments (e.g., EEG neurofeedback).

## **Research Experts:**

### **Edwin H. Cook, Jr., M.D.**

*Professor of Psychiatry/Director of Autism & Genetics, University of Illinois at Chicago*

Dr. Edwin Cook received his bachelor's degree from Southern Methodist University and later, his medical degree from the University of Texas Medical Branch at Galveston in 1981. He trained in psychiatry and child and adolescent psychiatry at the University of Chicago from his internship through appointment as Professor in 2000. In 2005, he moved to the Institute of Juvenile Research (IJR) at the University of Illinois at Chicago where he is Professor of Psychiatry and the Director of Autism and Genetics. He is principal investigator of an Autism Center of Excellence funded by NIH with a focus on neurochemistry, genetics, pharmacogenetics, systems neuroscience of what Kanner originally described as an "anxiously obsessive desire for the maintenance of sameness." The overarching research focus is on more effective use of existing pharmacological treatments for symptoms related to ASD and the development of new treatments. Dr. Cook's younger brother, Kenneth Wade Cook, had ASD, intellectual disability, and epilepsy. He was continuing to learn to speak more fluently in his late 20s, when he died suddenly and unexpectedly. He is greatly missed for his warmth, giving spirit, and love of life.

### **Bryan H. King, M.D.**

*Professor/Vice Chair of Psychiatry & Behavioral Sciences, Director of Child & Adolescent Psychiatry University of Washington, Seattle Children's Hospital*

Dr. Bryan King is Professor and Vice Chair of Psychiatry and Behavioral Sciences and Director of Child and Adolescent Psychiatry at the University of Washington and Seattle Children's Hospital. He joined the University from Dartmouth Medical School where he held a similar position, as well as serving as the Medical Director for New Hampshire's Division of Developmental Services.

Dr. King completed his medical training at the Medical College of Wisconsin, and subsequently did his medical internship and psychiatric training at the UCLA Medical Center and Neuropsychiatric Institute. He obtained his clinical and research training in Child and Adolescent Psychiatry at UCLA and at the Merck Neuroscience Research Center in England with sponsorship of the National Institutes of Health.

Dr. King's clinical and research interests have been focused on psychiatric aspects of developmental disorders, repetitive movements, and upon the pathogenesis and treatment of behavioral disturbance in autism. He currently chairs a multi-site clinical trial by the National Institutes of Health funded STAART (Studies to Advance Autism Research and Treatment) Centers examining the potential role for an antidepressant medication in the treatment of children with autism who have significant problems with repetitive behaviors. He is also Director of the NIH funded UW Autism Center of Excellence.

Dr. King is a co-author on the practice parameters for children and adults with developmental disorders and mental illnesses by the American Academy of Child and Adolescent Psychiatry. He has written extensively in the medical literature relating to this field, and has received lifetime achievement awards from the American Academy of Child and Adolescent Psychiatry, and from the American Psychiatric Association, for his work in the field of Developmental Disabilities. He was honored for his clinical care by the nursing staff of the UCLA Neuropsychiatric Institute with its

annual Outstanding Physician Award, and by families at Seattle Children's with the annual Family Choice Award.

### ***Family/Personal Experts:***

#### **Joyce Y. Chung, M.D.**

*Professor of Psychiatry, Georgetown University Medical School*

Dr. Joyce Chung is Associate Professor of Psychiatry at Georgetown University Medical School. She received her undergraduate and medical degrees from Northwestern University. She completed psychiatry residency at the Massachusetts General Hospital in Boston, and a research fellowship in medical anthropology at Harvard Medical School. Her research interests include the study of sociocultural barriers to mental health care, treatment interventions for mental health problems in minority and underserved populations, ethnographic/mixed research methods, and patient-provider discourse. She is the recipient of several research grants.

Dr. Chung has expertise in the area of HIV psychiatry and was the chief writer for the American Psychiatric Association's Practice Guidelines for the Treatment of Patients with HIV/AIDS. During her 17-year affiliation with Georgetown, Dr. Chung has served as Chief of the Consultation-Liaison service at the Washington VA, Medical Director of the Mental Health Care Unit at Georgetown University Hospital and Director of Psychiatric Research Training. In 2007, she served for a year as the Autism Coordinator in the Office of the Director at the National Institute of Mental Health where she helped manage the activities of the Interagency Autism Coordinating Committee of the Department of Health and Human Services. In that role, she facilitated the development of the first national strategic plan for autism spectrum disorder research. She is the mother of a 17-year-old daughter with an autism spectrum disorder.

#### **Sharisa Joy Kochmeister**

*President, The Autism National Committee*

Ms. Kochmeister is the President of The Autism National Committee (2007-2009) and a member of the Executive Committee for the Colorado Developmental Disabilities Council. She is also a member of Watch Our Words and Panel of Spectrum Advisors of the Autism Society of America, as well as creator, publisher and editor-in-chief of *"The Voices and Choices of Autism"* magazine with over 1,000 worldwide subscribers.

Ms. Kochmeister is a professional author of poetry and essays, a published and performed composer/lyricist, a professional speaker (dozens of keynotes, workshops and panels in the USA and Canada), a consultant/advocate, a high school and college literary magazine writer/editor and President of college Pre-Law/Political Science Association, and a former member board of advisors member and editor-in-chief for *"The Autism Perspective"* magazine.

Ms. Kochmeister: "I have multiple other disabilities, including Cerebral Palsy, epilepsy, being non-verbal, and requiring a keyboard to communicate and a trusted assistant to ease my way. I have written a fairytale about autism to try to help people understand, am writing my autobiography 'My Life As A Zero And My Life As A Hero,' and have won awards for my poetry."

"I visited the White House and met President Clinton, was one of 500 college students from around the country invited to an annual conference of The Center for the Study of the Presidency, and

received Presidential, state, county, local, university and private awards for advocacy, community service and influencing public policy.”

Ms. Kochmeister holds an A.S. in Humanities and Social Sciences from SUNY Rockland and a dual B.A. in Sociology and Psychology from Denver University.

## ***IACC Liaisons:***

### **Thomas Insel, M.D.**

*Director, National Institute of Mental Health and Chair of the IACC*

Dr. Thomas Insel is Director of the National Institute of Mental Health (NIMH), the component of the National Institutes of Health charged with generating the knowledge needed to understand, treat, and prevent mental disorders. NIMH is home to a large autism research program, covering a wide variety of topics, including: diagnosis, basic biology; behavioral, cognitive and motor learning; genetics; treatment; prevention; epidemiology; health services research and outcomes of autism across the lifespan. The program emphasizes studies that will lead to improved and earlier diagnosis, a better understanding of the neurobiology of autism, identification of genetic and environmental risk factors, and the development of novel or improved treatments and intervention strategies. In addition to directing the NIMH, Dr. Insel also chairs the Interagency Autism Coordinating Committee, a federal advisory panel that provides advice and coordination to the federal autism research effort.

Prior to his appointment as NIMH Director in the Fall 2002, Dr. Insel was Professor of Psychiatry at Emory University. There, he was founding director of the Center for Behavioral Neuroscience, one of the largest science and technology centers funded by the National Science Foundation and, concurrently, director of an NIH-funded Center for Autism Research. From 1994 to 1999, he was Director of the Yerkes Regional Primate Research Center in Atlanta. While at Emory, Dr. Insel continued the line of research he had initiated at NIMH studying the neurobiology of complex social behaviors. He has published over 250 scientific articles and four books, including the *Neurobiology of Parental Care* (with Michael Numan) in 2003.

Dr. Insel has served on numerous academic, scientific, and professional committees and boards. He is a member of the Institute of Medicine, a fellow of the American College of Neuropsychopharmacology, and is a recipient of several awards including the Outstanding Service Award from the U.S. Public Health Service. Dr. Insel graduated from the combined B.A.-M.D. program at Boston University in 1974. He did his internship at Berkshire Medical Center, Pittsfield, Massachusetts, and his residency at the Langley Porter Neuropsychiatric Institute at the University of California, San Francisco.

### **Stephen Shore, Ed.D.**

*Professor, Adelphi University and IACC Member*

Diagnosed with "atypical development and strong autistic tendencies" and "too sick" for outpatient treatment, Dr. Shore was recommended for institutionalization. Nonverbal until four, and with much support from his parents, teachers, wife, and others, Stephen is now a professor at Adelphi University where his research focuses on matching best practice to the needs of people with autism.

In addition to working with children and talking about life on the autism spectrum, Stephen presents and consults internationally on adult issues pertinent to education, relationships, employment, advocacy, and disclosure as discussed in his books *Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome*, *Ask and Tell: Self-advocacy and Disclosure for People on the Autism Spectrum*, and the critically acclaimed *Understanding Autism for Dummies*.

Dr. Shore serves on the Interagency Autism Coordinating Committee and for the Board of Directors for Autism Society of America Unlocking Autism, and other autism related organizations.

## **Panel V: Where Can I Turn for Services? & What Does the Future Hold?**

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### ***Clinical Experts:***

#### **Tec Chapman**

*Deputy Director, Missouri Division of Developmental Disabilities*

Mr. Tec Chapman is the Deputy Director of the Missouri Division of Developmental Disabilities. He has over 25 years of experience supporting individuals with disabilities, their families, and working with federal, state, and local agencies. He has worked as a direct support professional, director of community based support services, researcher, and consultant, and has directed projects of national significance.

In 1999, he received the Anne Rudigier Award from the Association of University Centers for Excellence on Developmental Disabilities (AUCD) for his demonstrated dedication and commitment to enhancing the lives of families and individuals with developmental disabilities.

Mr. Chapman was a 2005 Joseph P. Kennedy, Jr. Foundation Public Policy Fellow working in the United States Senate for Mike Enzi, Chairman, Health, Education, Labor, and Pensions committee. At the completion of his fellowship, he was hired by the Chairman with a legislative portfolio that included disability policy (IDEA, Rehabilitation Act, Developmental Disabilities Act, Combating Autism Act), K-12 education (NCLB), the Head Start Act, Title II of the Higher Education Act, and childcare issues.

Mr. Chapman's doctoral program at the University of Kansas focused on issues of public policy, disability, and interdisciplinary practice.

#### **Cathy Pratt, Ph.D.**

*Director, Indiana Resource Center for Autism, Indiana Institute on Disability & Community, Indiana University*

Dr. Cathy Pratt is the Director of the Indiana Resource Center for Autism at the Indiana Institute on Disability and Community located at Indiana University. Dr. Pratt is on faculty at Indiana University, and presents internationally. She currently serves as Chair of the Board for the National Autism Society of America. Dr. Pratt also serves on the advisory board for the National Professional Development Center on Autism Spectrum Disorders grant funded through the US Department of Education. She has been involved with the Institute on Rehabilitation Issues focused on Autism; the Interagency Autism Coordinating Committee as a member of the Expert Working Group on Services; and served on the Scientific Advisory Board for IMFAR (International Meeting for Autism Research).

She also served as a member of the public review committee for the Research Roadmap of the Interagency Autism Coordinating Committee.

Dr. Pratt has been honored by the Autism Society of America with the Individual Achievement Award, with the 2005 Princeton Fellowship Award, and with various awards through New York Families for Autistic Children, including recognition from the United States House of Representatives. In 2008, Dr. Pratt was awarded with the Distinguished Service Award by the Indiana Council of Administrators of Special Education. She has written articles and presents on the following topics: autism spectrum disorders, functional behavior assessment/positive behavior supports, instructional approaches, systems change, and policy. Prior to pursuing her doctorate at Indiana University, Dr. Pratt worked as a classroom teacher for students across the autism spectrum and with other disabilities.

## **Research Experts:**

### **Peter F. Gerhardt, Ed.D.**

*President & Chair, Scientific Council, Organization for Autism Research*

Dr. Peter Gerhardt is President, and Chair of the Scientific Council, for the Organization for Autism Research, a nonprofit organization dedicated to funding intervention research in support of individuals with an autism spectrum disorder (ASD) and their families. Dr. Gerhardt has over 25 years experience utilizing the principles of Applied Behavior Analysis in support of adolescents and adults with an ASD in educational, employment, and community-based settings. He is the author or co-author of articles and book chapters on the needs of adults with autism spectrum disorder, the school-to-work-transition process, assessment of social competence, and analysis and intervention of problematic behavior. He has presented nationally and internationally on these topics. Dr. Gerhardt received his doctorate from the Rutgers, the State University of New Jersey Graduate School of Education.

### **David S. Mandell, Sc.D.**

*Assistant Professor of Psychiatry & Pediatrics, University of Pennsylvania School of Medicine's Center for Mental Health Policy; Services Research & Associate Director, Penn/CHOP Center for Autism Research*

Dr. David S. Mandell is Assistant Professor of Psychiatry and Pediatrics at the University of Pennsylvania School Of Medicine's Center for Mental Health Policy and Services Research and Associate Director of the Penn/CHOP Center for Autism Research. His research focuses on the organization, financing and delivery of services to children with autism, and provides the basis for the development of interventions at the individual, provider and system levels to decrease the age at which children with autism are recognized and enter treatment, and to improve the services and supports available to them and their families.

Dr. Mandell's current funded research includes a study examining the relationship between states' policies and their delivery of health services to children with autism. He also is conducting, in partnership with the School District of Philadelphia, a large randomized field trial of a behavioral intervention for children with autism, with the goal of determining the best strategies for moving efficacious practices into communities so that they are effective and sustain. Dr. Mandell co-chaired the Commonwealth of Pennsylvania's Autism Task Force from 2003 to 2006 and consults with the

Department of Public Welfare to help them develop appropriate policies to meet the needs of families of children with autism. He also served as a member of the planning team for the Philadelphia Mayor's Blue Ribbon Commission on Children's Behavioral Health in 2007. He holds a bachelor of arts in psychology from Columbia University and a doctorate of science from the Johns Hopkins School of Public Health.

### ***Family/Personal Experts:***

#### **Ann Boeker Gibbons, J.D.**

*Executive Director, Autism Speaks National Capital Area*

Dr. Gibbons currently serves as Executive Director of Autism Speaks' National Capital Area chapter. Previously she served as a volunteer on the national board of Autism Speaks, before which she served as the Chairman of the Board of the National Alliance for Autism Research. Ms. Gibbons also formed a small charity and raised seed money for the Ivymount School Autism Program, which was founded in 1998. Before staying home to raise her children, she was a securities lawyer and investment banker. Her son Philip, now 21, has autism. Dr. Gibbons graduated from the University of Michigan with a B.A. and received her J.D. from the New York University School of Law.

#### **Marjorie Solomon, Ph.D.**

*Assistant Professor of Clinical Psychiatry, Dept. of Psychiatry & Behavioral Sciences, UC Davis*

Dr. Marjorie Solomon is an Assistant Professor of Clinical Psychiatry in the Department of Psychiatry and Behavioral Sciences at UC Davis. She is on the Faculty of the M.I.N.D. Institute and of the Autism Research Training Program. She received her B.A. at Harvard College, an M.B.A. at Stanford Graduate School of Business, and a Ph.D. in Psychology from U.C. Berkeley in 1999.

In 2000, she was awarded a Fellowship from M.I.N.D. Institute to conduct a study of a social skills training group intervention for high functioning children with autism spectrum disorders. This program incorporates parents and siblings into the treatment model. In addition to providing high quality services to over 200 children and families over the past ten years, the program has supplied training in to multiple psychologists, psychiatrists, pediatricians, social workers, speech and language pathologists and educators in northern California. The intervention model has been studied empirically, and is considered one of the few empirically validated treatments for children and families with high functioning autism spectrum disorders.

In the coming year, an adaptation of the curriculum will be piloted as part of a college orientation and socialization program for undergraduate students at U.C. Davis. Dr. Solomon and colleagues also have implemented and studied a parent coaching intervention to help parents work with their children with autism spectrum disorders to improve language and social skills and to decrease problem behaviors. This intervention also has been published in the empirical literature, and has been shown to enhance the quality of parent-child relationships. In addition to her clinical research work, Dr. Solomon studies cognition and learning in high functioning individuals with autism spectrum disorders using cognitive neuroscience methods.

***IACC Liaisons:***

**Ellen W. Blackwell, M.S.W.**

*Social Worker/Health Insurance Specialist, Centers for Medicare & Medicaid Services (CMS) and IACC Member*

Ms. Ellen Blackwell is a social worker specializing in geriatrics, and a Health Insurance Specialist at the Centers for Medicare & Medicaid Services (CMS). She joined the Federal service in 2001 as a Presidential Management Fellow. Working primarily on long-term care issues, Ms. Blackwell helps states improve the quality and consistency of community based services, and mental health services delivered through managed care delivery systems. Previous to joining CMS, Ms. Blackwell worked at The Horizon Foundation, a philanthropic organization that promotes local health and wellness. She interned as a graduate student at The Hilltop Institute, a health research center at the University of Maryland, Baltimore County, and the Howard County Maryland Office on Aging. Ms. Blackwell founded the Howard County chapter of the Autism Society in 1992, and has a 22-year-old son with autism spectrum disorder. She graduated from the University of Maryland - Baltimore, and the University of Wisconsin - Stout.

**Christine M. McKee, J.D.**

*IACC Member*

Ms. Christine M. McKee graduated from the University of Notre Dame Law School in 1991. She worked as a Labor and Employment defense attorney in Kansas City, Missouri, and as a career law clerk for the Honorable Nanette K. Laughrey, United States District Court for the Western District of Missouri. She served as judge pro tem for the Municipal Court of Prairie Village, Kansas, and volunteered for the American Red Cross of Kansas City, Missouri's human resources committee.

As the parent of a child with an autism spectrum disorder, Ms. McKee currently serves as a public member of the Interagency Autism Coordinating Committee (IACC) and as a member of the IACC Services Subcommittee. This past summer, Ms. McKee participated in the National Institute of Mental Health (NIMH) review panel relating to the appropriation of the American Recovery and Reinvestment Act (ARRA) funds dedicated to ASD research.