THANK YOU!

The Gatlinburg Conference especially thanks the following institutions for their financial contributions and generous support of the 2013 Conference:

- The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development
  - The American Psychological Association–Division 33
- The Schiefelbusch Institute for Life Span Studies, University of Kansas
- The *Eunice Kennedy Shriver* Center, University of Massachusetts Medical School
  - The Waisman Center, University of Wisconsin-Madison
- The Vanderbilt Kennedy Center, Vanderbilt University

Cover Art: *United Through Colors* by Jorge Yances and families served by Vanderbilt Kennedy Center Multicultural Program
This volume contains abstracts for plenary sessions at the 46th Annual Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities. Abstracts of symposia and poster presentations may be found at http://kc.vanderbilt.edu/gatlinburg/program.html. Permission to quote or reprint any of these materials must be obtained from the author(s).
Award Recipients

**Laraine Masters Glidden Undergraduate Award**

- **Katherine Grein**
  University of Alabama at Birmingham
- **Scott Tillem**
  Case Western Reserve University

**David Zeaman Graduate Award**

- **Sarah Edwards**
  University of Alabama at Birmingham
- **Anne V. Kirby**
  University of North Carolina at Chapel Hill
- **Caroline Oates**
  University of Alabama at Birmingham
- **Darren Olsen**
  University of Hawaii at Manoa
- **Jessica E. Solomon**
  Vanderbilt University
- **Kelly Windsor**
  Vanderbilt University

**Dissertation Award**

- **Matthew Foster**
  Georgia State University
- **Nandita Golya**
  University of Oregon

**Theodore Tjossem Postdoctoral Award**

- **Marisa H. Fisher**
  Vanderbilt University
- **Sarah E. Schipul**
  University of North Carolina at Chapel Hill
- **Lauren M. Little**
  University of North Carolina at Chapel Hill
- **Laura J. Hahn**
  University of Kansas
- **Jason Wolff**
  University of North Carolina at Chapel Hill

**John G. Borkowski Diversity Travel Award**

- **Matthew Cuellar**
  University of Alabama
- **Susanna Luu**
  Loma Linda University
- **Danielle Henderson**
  University of Louisville
- **Ana Dueñas**
  San Diego State University
- **Yingying (Jennifer) Yang**
  University of Alabama

**American Psychological Association Division 33 Graduate Student Travel Award**

- **Allyson Davis**
  Loma Linda University
At the inaugural Gatlinburg Conference in 1968, John Borkowski gave his first major presentation on meditational processes in children with intellectual disabilities. His early research focused on strategy-based learning, executive functioning, and attributional beliefs, all guided by his theory of metacognition. During the past 25 years, Dr. Borkowski, his graduate students, and research colleagues have studied the causes of developmental delays in children born to teenage mothers, following their life course from birth to young adulthood. His 40-year training grant from NICHD brought a stream of young scholars to the Gatlinburg Conference. Dr. Borkowski, the Andrew J. McKenna Chair, contributed to the development of the Psychology Department at Notre Dame and founded the Center for Children and Families, a major research unit at the University.

Since graduate school days in the late 1960s, Dr. Laraine Glidden has engaged in research related to individuals with disabilities. Using a unique comparison group of families who adopted children knowing of their disabilities, she demonstrated a normative pattern of resilience for most families. The impact of her findings was recognized with the national Arc Career Research Award in 2008. In addition to more than 100 publications in the disability field, including 16 volumes of the International Review of Research in Developmental Disabilities published under her editorship, Dr. Glidden has served in numerous leadership positions, including as president of Division 33 (Intellectual and Developmental Disabilities) of the American Psychological Association and of the Academy on Intellectual and Developmental Disabilities. She has attended 39 Gatlinburg conferences, usually with one or more undergraduate students from St. Mary's College of Maryland who were presenters. Dr. Glidden retired in 2012 after 42 years of post-Ph.D. service.

A tireless advocate for biobehavioral research in intellectual disabilities, Dr. Ted Tjossem began his career at the University of Washington. There he served as a faculty member from 1949 until 1964, helping to lay the foundation for the creation of the University’s Center on Human Development and Disability in the 1960s. From 1966 until his retirement in 1987, Dr. Tjossem served as the chief of the Mental Retardation and Developmental Disabilities Research Centers branch at the National Institute of Child Health and Human Development, under the National Institutes of Health (NIH). His seminal book, Intervention Strategies for High Risk Infants and Young Children, published in 1976, contributed immensely to our understanding of the early development of children with Down syndrome and other disabilities.

Dr. David Zeaman contributed greatly to our understanding of individual differences in attentional processes in persons with intellectual disabilities. Along with his wife, Dr. Betty House, Dr. Zeaman hypothesized that persons with versus without intellectual disabilities differ in their respective abilities to select relevant dimensions from a stimulus complex. These theories, proposed in chapters to the first two editions of Norm Ellis's Handbook of Mental Deficiency (1963; 1979), influenced generations of attention researchers. A founding member of the Department of Psychology at the University of Connecticut, Dr. Zeaman served on its faculty from 1949 to 1984.
Invited Speakers

Rod Howell, M.D.
Professor and Chairman Emeritus of Pediatrics at the University of Miami Miller School of Medicine
“The 50th Anniversary of Newborn Screening: PKU 50 Years Later”
Wednesday, March 6, 2013 • 8:45-10:00 a.m. • Contessa A&B

Eighty years ago, Asbjørn Følling, an Oslo physician skilled in metabolism, made the dramatic discovery that certain children with profound developmental delay had an abnormality of phenylalanine metabolism, which he termed phenylpyruvic oligophrenia and we now call phenylketonuria (PKU). His research was sparked by observant parents who noticed an unusual odor in their affected children, which later proved to be due to the presence of an abnormal metabolite of phenylalanine. Bickel, a German scientist, discovered that removing phenylalanine (an essential amino acid) from the diet in a child with PKU produced great benefit, and it was postulated that it would be most beneficial when begun early. The development by Guthrie of a simple test for elevated phenylalanine concentrations in small dried blood spots, which could be simply performed on all newborn infants, opened the door to newborn screening. The spectacular benefit of treatment when begun in infancy led to the rapid adoption of newborn screening for PKU by the individual states as a public health measure, 50 years ago. In the intervening 50 years, we have learned an enormous amount about phenylketonuria: that the diet must be maintained throughout life, and that women with phenylketonuria must have rigid dietary control during pregnancy to avoid the severe in-utero fetal damage due to elevated concentrations of phenylalanine. Much remains to be done in PKU: the diet is difficult and cumbersome—better treatments must be found. The role of tetrahydrobiopterin co-factors must be clarified. However, today many adults with PKU treated since birth occupy responsible positions as physicians, nurses, teachers, and mothers and fathers, as opposed to living a long life dominated by profound developmental delay.

In the 50 intervening years, newborn screening has expanded greatly, erratically in the beginning and now in a more organized fashion. How and why this expansion has occurred will be reviewed, as well as an overview of the Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children, the congressionally mandated group that advises the Secretary of Health and Human Services on Newborn Screening, as well as other issues. Although many issues remain surrounding the entire newborn screening program, it has been remarkably successful, and the expansion of newborn screening has been recognized by the Centers for Disease Control and Prevention as one of the ten greatest public health accomplishments of the 21st century.

Christine Yoshinaga-Itano, Ph.D.
Professor of Speech, Learning, and Hearing Sciences and an Associate Professor of Communication Disorders and Speech Science at the University of Colorado–Boulder
“Evolution of Universal Newborn Hearing Screening: The Importance of Sensitive Periods of Development and High Quality Early Intervention Services”
Wednesday, March 6, 2013 • 1:30-2:45 p.m. • Contessa A&B

The first universal newborn hearing screening programs in the United States began in 1992 in Rhode Island, Hawaii, and Colorado. The path to universal screening of newborns for hearing involved individual state legislation and responses to the following issues: 1) the frequency of the disorder merits screening, 2) ability to detect accurately in mass screening, 3) acceptable rate of false positive screening, 4) screening programs do not cause harm, 5) effective treatment is available and ensured, 6) early intervention improves outcomes, and 7) costs are reasonable and justified. The essential component was demonstration that early intervention improves developmental outcomes. Colorado state population outcome statistics demonstrated that children with typical and delayed cognitive ability with hearing loss identified by 6 months and with early intervention initiated by 6 months from providers with specialized skills maintained receptive and expressive language development consistent with their nonverbal cognitive abilities as compared to children identified after 6 months who had significant developmental delays regardless of cognitive ability. Cortical evoked auditory potentials also provide evidence of a sensitive period of development for access to auditory spoken language. Current research indicates that language developmental benefits maintain throughout the first seven years of life.
Invited Speakers

Don Bailey, Ph.D.
*Distinguished Fellow in Early Childhood Development with RTI International*

“Newborn Screening for Fragile X: Reflections on a Multi-Year Pilot Investigation”
Thursday, March 7, 2013 • 8:45-10:00 a.m. • Contessa A&B

Fragile X syndrome (FXS) is the most common inherited form of intellectual disability. Since FXS is not obvious at birth, it must be “discovered” by watchful parents or clinicians, and typically is not diagnosed until around 3 years of age. By then, infants and toddlers with FXS have missed the opportunity to participate in early intervention programs, parents have incurred substantial expense and frustration in a diagnostic odyssey, and many (probably around 30%) have a second child with FXS before the first child is diagnosed. Although some data are now emerging about the phenotype of infants and toddlers with FXS, the variability and nonspecificity of clinical symptoms suggest that better developmental screening is unlikely to result in significant changes in age of diagnosis. Newborn screening would solve this problem but is complicated because there is no proven treatment that must be provided shortly after birth, and if a DNA test were used for newborn screening it would result in the detection of a large number of children who are carriers. In this presentation, I summarize the issues and challenges associated with fragile X newborn screening, report findings from a 5-year pilot screening program, discuss implications for public policy, and describe a needed research agenda for behavioral and social scientists interested in intellectual and developmental disabilities.

Jeff Brosco, M.D., Ph.D.
*Professor of Clinical Pediatrics at the University of Miami School of Medicine*

“Bedside Genome Sequencing: What History Tells Us About the Future of Newborn Screening”
Friday, March 8, 2013 • 9:30-10:45 a.m. • Contessa A&B

State newborn screening programs are among the most remarkable public health advances in recent history, in part because their origins lie in advances in laboratory science. We are on the verge of a new era in which the tools of lab science, such as whole genome sequencing, seem to be advancing faster than our ability to understand how to deploy them. This poses ethical issues for clinicians at the bedside, as well as for policy-makers eager to maintain the public health features of newborn screening programs. These issues are addressed from a historical perspective using autism as a salient example.

Special Presentations

Wednesday, March 6 • 3:30-4:10 p.m.
*NICHD: Reflections on Its 50th Anniversary and Update on Related NIH Activities*
Melissa Parisi, M.D., Ph.D., Chief, Intellectual and Developmental Disabilities Branch, and Tiina Urv, Ph.D., Program Director, *Eunice Kennedy Shriver National Institute of Child Health & Human Development*

Wednesday, March 6 • 4:10-4:30 p.m.
*Video Presentation: “Breakthroughs In Developmental Disabilities Research: What Do Our Leaders Have to Say?”*
Produced by Blythe Corbett and Tony Maupin, Vanderbilt Kennedy Center, Vanderbilt University, and introduced by Gatlinburg Conference Chair Elisabeth Dykens, this 18-minute video features commentary by Alan Guttmacher, Timothy Shriver, Melissa Parisi, and other heavy hitters in the field of disabilities research.

Thursday, March 7 • 1:45-2:45 p.m.
*Newborn Screening: Who Does What, and Where Do I Fit In? A Federal Perspective*
Tiina Urv, Ph.D., Program Director, *Eunice Kennedy Shriver National Institute of Child Health & Human Development*
2013 Gatlinburg Conference

WEDNESDAY

March 6, 2013

■ 8:30-8:45 A.M.
OPENING REMARKS
CONTESSA A&B
Elisabeth Dykens, Ph.D.
Gatlinburg Conference Chair
Vanderbilt Kennedy Center, Vanderbilt University

■ 8:45-10:00 A.M.
PLENARY SESSION 1
CONTESSA A&B
The 50th Anniversary of Newborn Screening: PKU 50 Years Later
Rod Howell, M.D.
University of Miami Miller School of Medicine

■ 10:30 A.M.-12:00 P.M.
SYMPOSIUM 1—MAGNOLIA
Infant Sensory Processing and Neurodevelopmental Outcomes
Chair: Nathalie Maitre, Vanderbilt Kennedy Center, Vanderbilt University
Discussant: Alexandra Key, Vanderbilt Kennedy Center, Vanderbilt University

Disorders of Sensory Modulation in Very Preterm Infants: Antecedents and Associations With Neurodevelopment in Infancy
Jessica E. Solomon *Zeaman Award Winner*
James C. Slaughter
Nathalie L. Maitre
Vanderbilt University

Cortical Speech Sound Discrimination in the Intensive Care Nursery Predicts Cognitive and Language Development Through 2 Years of Age
Nathalie Maitre
Warren E. Lambert
Judy L. Aschner
Alexandra F. Key
Vanderbilt University

Improved Nutrition and Respiratory Outcomes in Preterm Infants After Exposure to Recorded Maternal Sounds
Amir Lahav

SYMPOSIUM 2—CONTESSA A
Mindfulness-Based Stress Reduction in Intellectual and Developmental Disabilities
Chair: Elisabeth Dykens, Vanderbilt Kennedy Center, Vanderbilt University

Effects of Mindfulness-Based Stress Reduction on the Health of Mothers of Children With Autism and Other Developmental Disabilities
Elisabeth Dykens
Marisa Fisher
Nancy Miodrag
1Vanderbilt Kennedy Center, Vanderbilt University
2California State University–Northridge

Mindfulness and Skills-Based Training Programs for Parents of Children with Autism Spectrum Disorders: Feasibility and Preliminary Outcomes
Susannah Iadarola
Sandra L. Harris
1University of Rochester Medical Center
2Douglass Developmental Disabilities Center, Rutgers University

An Experimental Test of the Transactional Relationship Between Parenting Stress and Child Behavior Problems: A Pilot Study of the MAPS Project
Cameron L. Neece
Loma Linda University

SYMPOSIUM 3—CONTESSA B
Health and Behavior in Rett Syndrome: How Well Do We Understand the Behavioral Phenotype?
Chair: Frank Symons, University of Minnesota
Discussant: Sarika Peters, Vanderbilt Kennedy Center, Vanderbilt University
RTT and Functional Behavioral Assessment
Adele Dimian
Breanne Byiers
Frank Symons
University of Minnesota

Rett Syndrome and Functional Communication Training
Breanne Byiers
Adele Dimian
Frank Symons
University of Minnesota

Rett Syndrome: Stress, Stereotypy, and Negative Affect
Kelsey Quest
Breanne Byiers
Ameante Lacoste
Frank Symons
1State University of New York at Genesco
2University of Minnesota

Rett Syndrome and Hypothalamic-Pituitary-Adrenal (HPA) Axis Function
Ameante Lacoste
Breanne Byiers
John Hoch
Michael J. Ehrhardt
Angela Panoskaltsis-Mortari
Frank Symons
University of Minnesota

Rett Syndrome and Pain Behavior
Chantel Barney
LaTosia Erikson
Tim Feyma
Art Beisang
Frank Symons
1University of Minnesota
2Gillette Children’s Specialty Healthcare

Self-Injury and Stereotyped Behavior in Young Children With and Without Developmental Delays
Lisa Spofford
Raymond T. Tervo
William MacLean
John Hoch
Frank Symons
1University of Minnesota
2University of Wyoming

1:30-2:45 P.M.
PLENARY SESSION 2
CONTESSA A&B
Evolution of Universal Newborn Hearing Screening: The Importance of Sensitive Periods of Development and High-Quality Early Intervention Services
Christine Yoshinaga-Itano, Ph.D.
University of Colorado–Boulder

2:45-3:15 P.M.
POSTER BLITZ
CONTESSA A&B
During the Poster Blitz, each presenter in Wednesday evening’s poster session will have a minute to share the content of their posters with conference attendees.

3:30-4:10 P.M.
NICHD WORKSHOP
CONTESSA A&B
NICHD: Reflections on Its 50th Anniversary and Update on Related NIH Activities
Melissa Parisi
Tiina Urv
Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), National Institutes of Health (NIH)

4:10-4:30 P.M.
VIDEO PRESENTATION
CONTESSA A&B
Breakthroughs in Developmental Disabilities Research: What Do Our Leaders Have to Say?
This 18-minute video, produced by Blythe Corbett and Tony Maupin of the Vanderbilt Kennedy Center, Vanderbilt University, features commentary from some of the world’s leading experts in developmental disability research.

5:00-7:00 P.M.
POSTER SESSION 1 RECEPTION
CEDAR & LAUREL
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<th>Poster No.</th>
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<td>Barton-Hulsey</td>
<td>Andrea</td>
<td>Georgia State University</td>
<td>Long-Term Reading Outcomes In Toddlers With Significant Developmental Delays</td>
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<td>Berke</td>
<td>Elizabeth</td>
<td>George Mason University</td>
<td>The Moderating Effects of Comorbid Anxiety Disorder and Problem Behaviors In Infants With ASD</td>
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<td>Burke</td>
<td>Meghan</td>
<td>University of Illinois-Chicago</td>
<td>Relations Between Maternal Stress and Parent, Child, and Parent-School Characteristics</td>
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<td>Dankner</td>
<td>Nathan</td>
<td>Vanderbilt University</td>
<td>Autism Spectrum Disorders and Symptoms of Psychosis In Prader-Willi Syndrome: A Story of Misdiagnosis?</td>
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<td>Zeaman</td>
<td>Edwards</td>
<td>University of Alabama-Birmingham</td>
<td>Evaluating Friendships and Social Status of Preschoolers With ASD</td>
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<td>Gerstein</td>
<td>Emily</td>
<td>University of Wisconsin-Madison</td>
<td>A Longitudinal Investigation of Parenting Stress, Intrusive Parenting, and the Development of Behavior Problems at Age 6 In Children Born Preterm</td>
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<td>Dissertation</td>
<td>Golya</td>
<td>University of Oregon</td>
<td>Variability in Adaptive Skills: The Role of Autism Symptom Severity and Family History</td>
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<td>Glidden</td>
<td>Grein</td>
<td>St. Mary's College of Maryland</td>
<td>It's Where You Look and When: The Value of Multiple Measures at Multiple Times</td>
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<td>Haebig</td>
<td>Eileen</td>
<td>University of Wisconsin-Madison</td>
<td>Assessing Autism Diagnostic Tools in Fragile X Syndrome</td>
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<td>Hahn</td>
<td>Laura J.</td>
<td>University of Kansas</td>
<td>Do Children With Fragile X Syndrome Decline in Adaptive Behavior Over Time?</td>
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<td>Hassenfeldt</td>
<td>Tyler A.</td>
<td>Virginia Polytechnic Institute &amp; State University</td>
<td>Anger and Aggression in Young Children With Autism Spectrum Disorders: Treatment Results From the Stress and Anger Management Program (STAMP)</td>
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<td>12</td>
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<td>Huddleston</td>
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<td>Emory University</td>
<td>Early Screening for Autism in Children With Down Syndrome</td>
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<td>Kaat</td>
<td>Aaron J.</td>
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<td>Parent-Rated Reactive and Proactive Aggression in Children Suspected of a Disability</td>
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<td>Klusek</td>
<td>Jessica</td>
<td>University of North Carolina-Chapel Hill</td>
<td>Cardiac Arousal in Idiopathic Autism and Fragile X Syndrome With and Without Autism</td>
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<td>Lloyd</td>
<td>Blair P</td>
<td>Vanderbilt University</td>
<td>An Application of Generalizability and Decision Studies to Plan for Observational Measurement in Classroom Settings</td>
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<td>Loveall</td>
<td>Susan J.</td>
<td>University of Alabama</td>
<td>Receptive Vocabulary Pattern Analysis in Down Syndrome</td>
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<td>Makiwala</td>
<td>Kenya T.</td>
<td>University of Oregon</td>
<td>Impact of Children With DD and Siblings With Behavior Problems on Family Well-Being</td>
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<td>Zeaman</td>
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<td>Life Satisfaction Among Mothers of Children With Prader-Willi Syndrome: A Correlational Study</td>
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<td>Zeaman</td>
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<td>Association of Family Interactions and Quality of Peer Relationships in Children With Intellectual Disabilities</td>
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<td>20</td>
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<td>Smith</td>
<td>Ashlyn</td>
<td>University of Wisconsin-Madison</td>
<td>Parent Perceptions of Communication Skills in Children With Cerebral Palsy and the Relationship to Receptive and Expressive Language Skills</td>
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<td>Spofford</td>
<td>Lisa</td>
<td>University of Minnesota</td>
<td>Self-Injury and Stereotyped Behavior in Young Children With and Without Developmental Delays</td>
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<td>Travers</td>
<td>Brittany</td>
<td>University of Wisconsin-Madison</td>
<td>Predicting Young Adult Executive Function From Maternal Well-Being: A Longitudinal Study</td>
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<td>Walious</td>
<td>Danielle M.</td>
<td>University of Louisville</td>
<td>Executive Function and Its Relations to Behavioral and Emotional Problems: Children With Williams Syndrome</td>
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<td>Zeaman</td>
<td>Windsor</td>
<td>Vanderbilt University</td>
<td>Effects of Enhanced Milieu Teaching on the Language Skills of Children With Down Syndrome and Children With Developmental Delays</td>
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<td>Tjossem</td>
<td>Wolff</td>
<td>University of North Carolina-Chapel Hill</td>
<td>Patterns of Repetitive Behavior and Associated Neurobiology in Fragile X vs. Idiopathic Variants of Autism</td>
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<td>Woodman</td>
<td>Ashley C.</td>
<td>University of Wisconsin-Madison</td>
<td>Group-Based Trajectories of Psychopathology in Adults With Autism</td>
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<td>27</td>
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<td>Borkowski</td>
<td>Yang</td>
<td>University of Alabama</td>
<td>Selective Attention in Implicit Contextual Cueing of Persons With Intellectual Disability</td>
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THURSDAY
March 7, 2013

8:45-10:00 A.M.
PLENARY SESSION 2—CONTESSA A&B
Newborn Screening for Fragile X: Reflections on a Multi-Year Pilot Investigation
Don Bailey, Ph.D.
Research Triangle Institute International

10:30 A.M.-12:00 P.M.
SYMPOSIUM 4—MAGNOLIA
Social Vulnerability of Individuals With Intellectual and Developmental Disabilities Across the Lifespan
Chair: Marisa Fisher, Vanderbilt Kennedy Center, Vanderbilt University Tjossem Award Winner
Discussant: Stephen Greenspan, University of Colorado

Exploring the Dyadic Relationship Between Bullying and Victimization Among Students With Disabilities
Chad A. Rose¹
Cynthia G. Simpson²
¹Sam Houston State University
²Houston Baptist University

Social Vulnerability of Adolescents With Autism Spectrum Disorders and Adolescents With Other Developmental Disabilities in Situations of Negative Peer Pressure
Ishita Khemka³
Linda Hickson⁴
Sarah Mallory¹
Ruth Zealand²
³Teachers College, Columbia University
⁴College of New Rochelle

Enhancing Parent-Infant Interactions With High-Risk Parents
John R. Lutzker
Katelyn Guastaferro
Megan Graham
Yamile Morales
Monica Aquilar
Georgia State University

Stranger Safety Training for Young Adults With Williams Syndrome
Marisa H. Fisher
Vanderbilt Kennedy Center, Vanderbilt University

SYMPOSIUM 5—CONTESSA A
Characterizing Sensory Features in Children With Autism Spectrum Disorders: Behavior and Physiology
Chair: Lauren M. Little, University of North Carolina-Chapel Hill Tjossem Award Winner
Discussant: James Bodfish, Vanderbilt University

Activity Participation Among Children With ASD: Associations With Sensory Features
Lauren M. Little¹
John Sideris¹
Karla Ausderau²
Grace T. Baranek¹
¹University of North Carolina-Chapel Hill
²University of Wisconsin-Madison

Sensory Subtypes in Children With ASD: Latent Profile Transition Analysis Using a National Survey of Sensory Features
Karla Ausderau¹²
Melissa Furlong²
John Sideris¹
John Bulluck²
Lauren M. Little²
Grace T. Baranek²
¹University of Wisconsin-Madison
²University of North Carolina–Chapel Hill

Dimensions of Sensory Interests, Repetitions, and Seeking Behaviors: Differences Among Diagnostic Groups
Anne V. Kirby Zeaman Award Winner
Lauren M. Little
Grace T. Baranek
University of North Carolina-Chapel Hill

Distinct ERP Responses During Auditory Processing in Young Children With Autism
Sarah E. Schipul¹ Tjossem Award Winner
Franc C.L. Donkers²
Grace T. Baranek¹
March 7, 2013

Katherine M. Cleary¹
Aysenil Belger¹
¹University of North Carolina-Chapel Hill
²Tilburg University

Tactile Defensiveness in Children With ASD: Effect of Stimulus Material and Bodily Location
Carissa J. Cascio¹
Jill Lorenzi²
Grace T. Baranek²
¹University of North Carolina-Chapel Hill
²Tilburg University

SYMPOSIUM 6—CONTESSA B
Down Syndrome: Identifying Targets for Intervention Across the Lifespan
Co-Chairs: Lisa A. Daunhauer, Colorado State University
Deborah J. Fidler, Colorado State University

Early Social Cognitive Skills and the Understanding of Intentionality in Young Children With Down Syndrome
Laura J. Hahn¹
Susan L. Hepburn²
Deborah J. Fidler³
¹University of Kansas
²University of Colorado
³Colorado State University

Everyday Executive Functioning in Children With Down Syndrome: Evidence for a Specific Profile and Convergence With Functional Performance
Lisa A. Daunhauer
Deborah J. Fidler
Colorado State University

Caregiver-Report of Structural and Pragmatic Language Skills in Down Syndrome: Evidence for a Syndrome-Specific Language Profile and Convergence with Direct Neuropsychological Testing?
Nancy Raitano Lee
Elizabeth I. Adeyemi
Jay N. Giedd
Child Psychiatry Branch, National Institute of Mental Health

Mortality and Hospitalization Use Among Adults With Down Syndrome
Anna J. Esbensen¹
Robert Hodapp²
Richard Urbano²
¹Cincinnati Children’s Hospital Medical Center
²Vanderbilt Kennedy Center, Vanderbilt University

■ 1:45-2:45 P.M.
SPECIAL PRESENTATION—CONTESSA A&B
Newborn Screening: Who Does What, and Where Do I Fit In? A Federal Perspective
Tiina Urv, Ph.D.
Program Director, National Institute for Child & Human Development, National Institute for Health

■ 2:45-3:15 P.M.
POSTER BLITZ—CONTESSA A&B
During the Poster Blitz, each presenter in Thursday evening’s poster session will have a minute to share the content of their posters with conference attendees.

■ 3:45-5:15 P.M.
SYMPOSIUM 7—MAGNOLIA
Life Course Trajectories of Adaptive Behavior and Vocational Achievement in Individuals With Autism and Other Developmental Disabilities
Chair: Marsha R. Mailick, Waisman Center, University of Wisconsin-Madison
Discussant: Frank Floyd, University of Hawaii

Early Childhood Predictors of Adaptive Behavior Development From Infancy Through Young Adulthood in Children With Developmental Disabilities
Ashley Woodman¹
Penny Hauser-Cram
¹Waisman Center, University of Wisconsin-Madison

A Longitudinal Examination of Adaptive Behavior in Adolescents and Adults With ASD
Leann E. Smith
Marsha R. Maillick
Jan S. Greenberg
Waisman Center, University of Wisconsin-Madison
Ten-Year Change in Vocational Outcomes for Adults With ASD
Julie L. Taylor¹
Marsha R. Mailick²
¹Vanderbilt Kennedy Center, Vanderbilt University
²Wisconsin Center, University of Wisconsin-Madison

SYMPOSIUM 8—CONTESSA A
Powerful Predictors: An Update on the Role of Family and School Experiences in the Development of Children with IDD
Chair: Cameron L. Neece, Loma Linda University
Discussant: Ann Kaiser, Vanderbilt Kennedy Center, Vanderbilt University

Maternal Self-Efficacy, Stress, and Depression in Families With Preschoolers With Autism and Other Developmental Disabilities
Laura Lee McIntyre
University of Oregon

Autism and Parenting Stress: The Role of Behavior Problems
Allyson Davis  APA Award Winner
Cameron L. Neece
Loma Linda University

Student-Teacher Relationships in Early Elementary School and Impact on Later Academic Engagement
Stacy Lauderdale-Littin¹
Jan Blacher²
¹Monmouth University
²University of California-Riverside

Resilient Parenting of Children With Intellectual Disability Across Middle Childhood
Ruth Ellingsen
Bruce Baker
University of California-Los Angeles

Student-Teacher Relationships in ASD: The Parent Perspective
Regan H. Linn¹
Sasha Zeedyk¹
Shana R. Cohen¹
Jan Blacher¹
Abbey Eisenhower²
¹University of California-Riverside
²University of Massachusetts-Boston

SYMPOSIUM 9—CONTESSA B
Early Identification of Children Most At Risk for Deficits in Spoken Language
Chair: Ann Kaiser, Vanderbilt Kennedy Center, Vanderbilt University
Discussant: Leonard Abbeduto, University of California-Davis

Using Language Comprehension Data to Refine Early Language Interventions for Young Children with Developmental Disabilities
Mary Ann Romski
Rose A. Sevcik
Georgia State University

Preverbal or Nonverbal? Predictors of Spoken Language In Toddlers With ASD
Amanda Gulsrud
Amy Fuller
Connie Kasari
University of California-Los Angeles

Identifying Functional Language Deficits in Young Children with Cleft Palate
Jennifer Frey¹
Ann Kaiser²
¹The George Washington University
²Vanderbilt Kennedy Center, Vanderbilt University

■ 5:15-7:15 P.M.
POSTER SESSION 2 RECEPTION
CEDAR & LAUREL
### Poster Session 2, 5:15-7:15 p.m., Cedar & Laurel Rooms

<table>
<thead>
<tr>
<th>Poster No.</th>
<th>Award Granted</th>
<th>Last Name</th>
<th>First Name</th>
<th>Institutional Affiliation</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td>Adeyemi</td>
<td>Elizabeth</td>
<td>National Institutes of Health</td>
<td>Triplets Discordant for Down Syndrome: An Analysis of Brain and Behavior</td>
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<td>Barker</td>
<td>R. Michael</td>
<td>University of Kansas</td>
<td>AAC Use In School Settings Predicts Language Outcomes for Young Children With Developmental Disabilities</td>
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<td></td>
<td>Belmonte</td>
<td>Colleen</td>
<td>Rider University</td>
<td>Differences in Knowledge of Autism, Down Syndrome, and Fragile-X Syndrome Across Parents, Teachers, and Students of Education</td>
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<td>Bryant</td>
<td>Julie D.</td>
<td>Vanderbilt University</td>
<td>Examining Differences in Language Use Between Parents of Children With Autism and Parents of Typical Children</td>
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<td>6</td>
<td></td>
<td>Channell</td>
<td>Marie Moore</td>
<td>University of Alabama</td>
<td>Autism Symptomatology in Youth With Down Syndrome Who Do Not Meet Criteria For Autism</td>
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<td>Borkowski</td>
<td>Matthew</td>
<td>University of Alabama</td>
<td>Phonological Memory in Down Syndrome: A Cross-Sectional Developmental Trajectory Approach</td>
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<td>8</td>
<td></td>
<td>Borkowski</td>
<td>Ana</td>
<td>San Diego State University</td>
<td>Culturally and Linguistically Diverse Families of Transition-Age Youth With ASD: Success, Family Involvement, and Stress</td>
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<tr>
<td>9</td>
<td></td>
<td>Dissertation</td>
<td>Matthew E.</td>
<td>Georgia State University</td>
<td>Longitudinal Precursors to Mathematical Achievement in Children With Mild Intellectual Disabilities</td>
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<tr>
<td>10</td>
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<td>Gotham</td>
<td>Katherine</td>
<td>Vanderbilt University</td>
<td>Psychosocial Predictors of Depressive Symptoms in Adolescents and Adults With Autism Spectrum Disorders</td>
</tr>
<tr>
<td>11</td>
<td></td>
<td>Grofer</td>
<td>Marjorie</td>
<td>University of South Carolina</td>
<td>Surgency Characteristics as Indicators of ADHD and Autism in Boys With Fragile X Syndrome</td>
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<td></td>
<td>Hampton</td>
<td>Lauren H.</td>
<td>Vanderbilt University</td>
<td>Understanding Vocabulary Composition in Children With Autism</td>
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<td>13</td>
<td></td>
<td>Borkowski</td>
<td>Daniella R.</td>
<td>University of Louisville</td>
<td>Emotional and Problem Behaviors in Children With Williams Syndrome: A Longitudinal Study</td>
</tr>
<tr>
<td>14</td>
<td></td>
<td>Hickey</td>
<td>Emily J</td>
<td>University of Wisconsin - Madison</td>
<td>Social Support for Fathers of Children With Autism Spectrum Disorders and Its Relation to Psychological Well-Being</td>
</tr>
<tr>
<td>15</td>
<td></td>
<td>John Thuman</td>
<td>Angela E.</td>
<td>MIND Institute, UC Davis</td>
<td>Mothers of Sons With Down Syndrome or Fragile X Syndrome: Maternal Closeness and Perceived Relationship Quality</td>
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<td>16</td>
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<td>Lorenzi</td>
<td>Jill</td>
<td>Virginia Tech</td>
<td>Early Developmental Trajectories of Respiratory Sinus Arrhythmia: Marker of Social Functioning</td>
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<tr>
<td>17</td>
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<td>Borkowski</td>
<td>Susanna</td>
<td>Loma Linda University</td>
<td>Mindfulness-Based Stress Reduction for Parents of Young Children With ASD: The Moderating Role of Parental Confidence</td>
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<td>McFaddin</td>
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<td>University of Wisconsin-Madison</td>
<td>Maternal Responsivity in Toddlers With Cerebral Palsy</td>
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<tr>
<td>19</td>
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<td>O'Brien</td>
<td>Katy H.</td>
<td>University of Minnesota-Twin Cities</td>
<td>The Development and Evaluation of a Personal Narrative Language Intervention for Adolescents With Down Syndrome</td>
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<td>Phillips</td>
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<td>University of Alabama</td>
<td>Matching Variables in Down Syndrome Research: Leiter Versus PPVT</td>
</tr>
<tr>
<td>21</td>
<td></td>
<td>Richardson</td>
<td>Shana</td>
<td>Children's Healthcare of Atlanta, Marcus Autism Center &amp; Emory University School of Medicine</td>
<td>The Longitudinal Course of Coparenting in Families Of Children With Intellectual Disability</td>
</tr>
<tr>
<td>22</td>
<td></td>
<td>Scherr</td>
<td>Jessica F.</td>
<td>University of South Carolina</td>
<td>A Longitudinal Investigation of Working Memory and Salivary Cortisol in Young Males With Fragile X Syndrome</td>
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<tr>
<td>23</td>
<td></td>
<td>Taylor</td>
<td>Cora</td>
<td>Vanderbilt University</td>
<td>&quot;Level of Support&quot; in DSM-5: Untangling the Relations Between Adaptive Behavior, Cognitive Skills, and Autism Severity Scores in Seeking to Assign a Diagnostic Severity Level</td>
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<td>24</td>
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<td>Glidden</td>
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<td>Case Western Reserve University</td>
<td>Functional Differences Between Prader-Willi Syndrome, Autism Spectrum Disorder, and Neurotypical Controls During a MRI-Based Facial Processing Task</td>
</tr>
<tr>
<td>25</td>
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<td>Unruh</td>
<td>Kathryn E.</td>
<td>University of Kansas</td>
<td>Visual Scanning and Pupillary Responses to Dynamic and Static Scenes in Young Children With Autism Spectrum Disorder</td>
</tr>
<tr>
<td>26</td>
<td></td>
<td>Wasserman</td>
<td>Melissa</td>
<td>The Help Group-UCLA Autism Research Alliance</td>
<td>Understanding the Relationship Between Friendship Quality and Peer Conflict Following the UCLA PEERS® School-Based Curriculum</td>
</tr>
<tr>
<td>27</td>
<td></td>
<td>Wright</td>
<td>Courtney</td>
<td>Vanderbilt University</td>
<td>Effects of Training Parents In a Naturalistic Sign Language Immersion Intervention</td>
</tr>
</tbody>
</table>

Full abstracts for all posters presented at the 2013 Gatlinburg Conference are available at [http://kc.vanderbilt.edu/gatlinburg/program.html](http://kc.vanderbilt.edu/gatlinburg/program.html)
FRIDAY
March 8, 2013

8:00-9:30 A.M.
POSTER BREAKFAST—CEDAR & LAUREL
This morning’s poster session consists solely of presentations by university faculty and research professionals.

9:30-10:45 A.M.
PLENARY SESSION 4—CONTESSA A&B
Bedside Genome Sequencing: What History Tells Us About the Future of Newborn Screening
Jeff Brosco, M.D.
Miller School of Medicine, University of Miami

11:15 A.M.-12:45 P.M.
SYMPOSIUM 10—MAGNOLIA
Biobehavioral Examination of Development in Infants and Toddlers Across the Fragile X Spectrum of Involvement
Co-Chairs: Jane E. Roberts, University of South Carolina
Heather Cody Hazlett, University of North Carolina, Chapel Hill, Carolina Institute for Developmental Disabilities
Susan Rivera, MIND Institute, University of California-Davis
Discussant: Don Bailey, RTI International

Heart Activity and Visual Attention in Infants at High Risk for Autism
Bridgette L. Tonnsen
John E. Richards
Sara Deal
Jane E. Roberts
University of South Carolina

Evidence of Visual Processing Impairments in Infants With the Fragile X Premutation
Susan M. Rivera
MIND Institute, University of California-Davis

Development and Behavior Profiles of Infants Identified With an FMRI Expansion During Newborn Screening
Anne Wheeler¹
Don Bailey¹
Christina Prescott²
Anna De Sonia²
Elizabeth Berry-Kravis³
Randi Hagerman³
Susan Rivera³
Flora Tassone³
¹University of North Carolina-Chapel Hill
²Rush Medical Center
³MIND Institute, University of California-Davis

An Examination of Early Brain Volume Development in Fragile X
Heather Cody Hazlett¹,²
Amy Lightbody³
Allan L. Reiss³
Joseph Piven¹,²
¹University of North Carolina-Chapel Hill
²Carolina Institute for Developmental Disabilities
³Center for Interdisciplinary Brain Studies Research, Stanford University School of Medicine

SYMPOSIUM 11—CONTESSA A
Which Came First? Anxiety, Repetitive Behavior, and Hoarding in PWS, ASD, ID, and OCD
Co-Chairs: Elizabeth Roof, Vanderbilt Kennedy Center, Vanderbilt University
Discussant: William MacLean, Jr., University of Wyoming

Anxiety and Other Psychiatric Features in Prader-Willi Syndrome
Elizabeth Roof¹
Carolyn Shivers¹
Lauren Deisenroth¹
Caroline Oates²
¹Vanderbilt Kennedy Center, Vanderbilt University
²University of Alabama-Birmingham
**Hoarding in Prader-Willi Syndrome**  
Elisabeth Dykens  
Elizabeth Roof  
Lauren Deisenroth  
Loren Tilson  
Vanderbilt Kennedy Center, Vanderbilt University

**Prader-Willi Syndrome: Does Repetitive Behavior Change With Age?**  
Evon Lee  
Carolyn Shivers  
Vanderbilt Kennedy Center, Vanderbilt University

**Repetitive Behaviors, Interests, and Reward in Autism and Anxiety Disorders**  
Jim Bodfish\(^1\)  
N. Sasson\(^2\)  
L. Turner-Brown\(^3\)  
Cara Damiano\(^3\)  
J. Richey\(^4\)  
A. Rittenburg\(^5\)  
S. Miller\(^1\)  
A. Sabatino\(^3\)  
E. Hanna\(^3\)  
M. Kovac\(^3\)  
\(^1\)Vanderbilt Bill Wilkerson Center  
\(^2\)University of Texas-Dallas  
\(^3\)Virginia Tech University  
\(^4\)University of North Carolina-Chapel Hill

**Symposium 12—Contessa B**  
Families of Children With Disabilities: A Focus on Resources and Adaptation  
Chair: Shelley Watson, Laurentian University

**Life Satisfaction Over Time Among Mothers of Children With Prader-Willi Syndrome**  
Carolyn M. Shivers  
Caroline Oates  
Elisabeth Dykens  
Vanderbilt Kennedy Center, Vanderbilt University

**Facilitators of Social Inclusion and Participation for Children With an Intellectual or Developmental Disability: Access Ramps Are Not Enough!**  
Claude Normand\(^1\)  
André C. Moreau\(^1\)  
Julie Ruel\(^2\)  
Thierry Boyer\(^2\)  
\(^1\)Université du Québec en Outaouais  
\(^2\)Pavillon du Parc Rehabilitation Center

**“It’s Like Being On a Bicycle, You Just Have to Keep Peddling and Do the Best You Can”: Adaptation in Families Raising Children With Fetal Alcohol Spectrum Disorder**  
Kelly D. Coons  
Alexandra Clement  
Elisa Radford-Paz  
Shelley L. Watson  
Laurentian University

**“I’m Hoping, I’m Hoping...”: A Comparison of Resiliency and Hope in Families of Individuals With Fetal Alcohol Spectrum Disorder and Autism**  
Shelley L. Watson\(^1\)  
Kelly D. Coons\(^1\)  
Stephanie A. Hayes\(^2\)  
\(^1\)Laurentian University  
\(^2\)University of Alberta

**12:45 P.M.**  
**Closing Remarks**  
**Contessa B**  
Elisabeth Dykens, Ph.D.  
Gatlinburg Conference Chair  
Vanderbilt Kennedy Center, Vanderbilt University
### Poster Session 3, 8:00-9:30 a.m., Cedar & Laurel Rooms

<table>
<thead>
<tr>
<th>Poster No.</th>
<th>Last Name</th>
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<tr>
<td>1</td>
<td>Anderson</td>
<td>Christa J.</td>
<td>University of Kansas</td>
<td>Pupil and Salivary Indicators of Autonomic Dysfunction in Autism Spectrum Disorder</td>
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<td>Brady</td>
<td>Nancy C.</td>
<td>University of Kansas</td>
<td>Aggressive Behaviors in Fragile X Syndrome</td>
</tr>
<tr>
<td>3</td>
<td>Courbois</td>
<td>Yannick</td>
<td>Université Lille Nord de France</td>
<td>Route Learning in Individuals With Down Syndrome: The Role of Landmarks</td>
</tr>
<tr>
<td>4</td>
<td>Crossman</td>
<td>Morgan K.</td>
<td>Brandeis University</td>
<td>Perspectives of Adult Physicians on Providing Care for Adults With Autism Spectrum Disorders</td>
</tr>
<tr>
<td>5</td>
<td>Derrington</td>
<td>Taletha M.</td>
<td>Brandeis University</td>
<td>Engaging Drug-Exposed Infants in Part C Early Intervention Services: Population-Based Screening and the Importance of Relationships and Communication With Hospitals</td>
</tr>
<tr>
<td>7</td>
<td>Henninger</td>
<td>Natalie A.</td>
<td>Vanderbilt Kennedy Center</td>
<td>Stability and Mobility in Vocational Activities For High-Functioning Adults With Autism Spectrum Disorder</td>
</tr>
<tr>
<td>8</td>
<td>Mitchell</td>
<td>Teresa</td>
<td>E. K. Shriver Center</td>
<td>Atypical Electrophysiology of Face Perception in Down Syndrome</td>
</tr>
<tr>
<td>9</td>
<td>Mitchell</td>
<td>Darcy B.</td>
<td>Colby-Sawyer College</td>
<td>Early Family Cohesion as a Predictor of Quality of Life and Self-Determination in Adolescents With Disabilities</td>
</tr>
<tr>
<td>10</td>
<td>Pitts</td>
<td>C. Holley</td>
<td>University of Louisville</td>
<td>Performance on the Kaufman Brief Intelligence Test-2 by Children With Williams Syndrome</td>
</tr>
<tr>
<td>11</td>
<td>Raspa</td>
<td>Melissa</td>
<td>RTI International</td>
<td>Family Communication and Cascade Testing for Fragile X Syndrome</td>
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<td>12</td>
<td>Richman</td>
<td>David</td>
<td>Texas Tech University</td>
<td>Contrasting Neuroimaging Patterns in Two Individuals With Autism Spectrum Disorder and Specific Phobia</td>
</tr>
<tr>
<td>13</td>
<td>Sanders</td>
<td>Eric</td>
<td>Pacific University</td>
<td>The Questions Preschoolers with Autism Spectrum Disorder Experience in the Inclusive Classroom</td>
</tr>
<tr>
<td>14</td>
<td>Schroeder</td>
<td>Stephen</td>
<td>University of Kansas</td>
<td>Early Distance Intervention and Follow-Up for Families of Infants and Toddlers at Risk for Developmental Disabilities and Severe Behavior Problems</td>
</tr>
<tr>
<td>15</td>
<td>Shogren</td>
<td>Karne A.</td>
<td>University of Illinois</td>
<td>Exploring Self-Determination and Its Predictors Using Data from National Longitudinal Transition Study-2</td>
</tr>
<tr>
<td>16</td>
<td>Stoneman</td>
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<td>University of Georgia</td>
<td>Latino Children in Early Intervention: Age of Entry, Referral Source, and Eligibility Diagnosis</td>
</tr>
<tr>
<td>17</td>
<td>Sudhalter</td>
<td>Vicki</td>
<td>New York State Institute for Basic Research in Developmental Disabilities</td>
<td>Neurobehavioral Development and Temperament: A Proposed Two-Factor Model of Inhibitory Control</td>
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<tr>
<td>18</td>
<td>Taylor</td>
<td>Cora</td>
<td>Vanderbilt University</td>
<td>Training for Educators of Students With Autism Spectrum Disorders</td>
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<tr>
<td>19</td>
<td>Valdivinos</td>
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<td>Drake University</td>
<td>Is There a Relationship Between Gastrointestinal Issues In Autism and Psychotropic Medication Effectiveness?</td>
</tr>
<tr>
<td>20</td>
<td>Vukoetsak</td>
<td>Jeannie</td>
<td>Emory University School of Medicine</td>
<td>Neurodevelopmental Outcomes of Children With Down Syndrome and Congenital Heart</td>
</tr>
<tr>
<td>22</td>
<td>Wheeler</td>
<td>Anne</td>
<td>University of North Carolina-Chapel Hill</td>
<td>Child and Family Outcomes of Newborn Screening in Fragile X</td>
</tr>
<tr>
<td>23</td>
<td>Wilson</td>
<td>Amy</td>
<td>Vanderbilt University</td>
<td>Regression Profiles and the Need for Early Screening Identifiers In MECP2 Duplication and Rett Syndrome</td>
</tr>
<tr>
<td>24</td>
<td>Yoder</td>
<td>Paul J.</td>
<td>Vanderbilt University</td>
<td>Bidirectional and Mediated Relations Among Parental Linguistic Mapping, Child Canonical Communication, and Child Spoken Vocabulary</td>
</tr>
</tbody>
</table>

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INFANT SENSORY PROCESSING AND NEURODEVELOPMENTAL OUTCOMES

Chairs: Nathalie Maitre, Vanderbilt Kennedy Center, Vanderbilt University

Discussant: Alexandra Key, Vanderbilt Kennedy Center, Vanderbilt University
Infant Sensory Processing and Neurodevelopmental Outcomes

Chair: Nathalie Maitre, Vanderbilt Kennedy Center, Vanderbilt University
Discussant: Alexandra Key, Vanderbilt Kennedy Center, Vanderbilt University

Disorders of Sensory Modulation In Very Preterm Infants: Antecedents and Associations With Neurodevelopment In Infancy
Jessica E. Solomon  Zeaman Award Winner
James C. Slaughter
Nathalie L. Maitre
Vanderbilt University

Cortical Speech Sound Discrimination in the Intensive Care Nursery Predicts Cognitive and Language Development Through 2 Years of Age
Nathalie Maitre
Warren E. Lambert
Judy L. Aschner
Alexandra F. Key
Vanderbilt University

Improved Nutrition and Respiratory Outcomes in Preterm Infants After Exposure to Recorded Maternal Sounds
Amir Lahav¹
Erin McMahon²
Emily Zimmerman²
¹Harvard University
²Harvard Medical School

A Random Clinical Trial of Mother’s Voice With a Pacifier-Activated Music Player to Improve Hospitalization and Feeding in Preterm Infants
Olena Chorna
Lu Wang
Nathalie Maitre
Vanderbilt University
Disorders of Sensory Modulation In Very Preterm Infants: Antecedents and Associations With Neurodevelopment In Infancy

Jessica E. Solomon (Zeaman Award Winner), James C. Slaughter, Nathalie L. Maitre
Vanderbilt Kennedy Center, Vanderbilt University
PMB 40, 230 Appleton Pl., Nashville, TN 37203
(jessica.solomon@vanderbilt.edu)

Background: Preterm infants experience multiple disruptions to brain development and abnormal sensory inputs in the neonatal intensive care unit (NICU). The establishment of early multisensory processing and modulation is essential to learning in infancy and the basis for later cognitive and behavioral development.

Objectives: To characterize the frequency and type of sensory processing disorders in very low birth weight (VLBW) preterm infants seen in a neonatal follow up clinic. We hypothesized that deficits in sensory processing are associated with perinatal characteristics and are directly correlated with neurodevelopment during the first year of life.

Methods: This was a prospective study of 102 infants 6-18 months chronologic age with birth weight < 1500g seen in the Vanderbilt NICU Follow-up clinic. Trained examiners blinded to the subject’s NICU course and gestational age at birth (GA) assessed all infants using the Test of Sensory Function in Infants (TSFI). Clinic personnel performed the Developmental Assessment of Young Children (DAYC). Analyses were performed using the proportional odds model to estimate the odds of worsening sensory processing and Wilcoxon-Mann-Whitney test was used to determine associations with DAYC scores.

Results: Specific deficits in sensory processing were detected in most VLBW infants. A difference of one week in GA resulted in a 1.33-fold (p = 0.002) increase in adverse reactivity to deep pressure and a 1.20-fold increase in adverse reactivity to vestibular stimulation (p = 0.016). Infants receiving less than 50% breast milk had 5 fold increased odds of having abnormal tactile deep pressure reactivity (99% CI: [0.07, 0.88]). Abnormal reactivity to vestibular stimulation on the TSFI was correlated with lower cognitive and motor developmental scores on the DAYC (p =0.05 and p = 0.02, respectively) even after correcting for GA.

Discussion: VLBW preterm infants have a high prevalence of sensory processing deficits, which are inversely related to their GA and affected by their consumption of human milk. Sensory processing deficits correlate with neurodevelopment during infancy. Given the importance of multisensory system development to higher order brain function in childhood, it is essential to further analyze the NICU factors contributing to poor sensory processing and to define how they affect the neural connectivity of sensory systems.
Cortical Speech Sound Discrimination in the Intensive Care Nursery Predicts Cognitive and Language Development Through 2 Years of Age

Nathalie Maitre, Warren E. Lambert, Judy L. Aschner, Alexandra F. Key
Vanderbilt University
PMB 40, 230 Appleton Place, Nashville, TN 37203
(nathalie.maitre@vanderbilt.edu)

Background: Preterm infants have high rates of neurodevelopmental delays in childhood, which are difficult to predict using conventional imaging or clinical variables, before infants leave the neonatal intensive care unit (NICU). There is a need for quantitative tools to measure cortical function in this vulnerable pre-verbal population to predict neurodevelopmental deficits when the potential for plasticity in response to interventions is greatest.

Objectives: We hypothesized that event-related potential (ERP) methodology characterizing the cortical discrimination of speech sounds in hospitalized infants would predict cognitive and language outcomes during early childhood.

Methods: We conducted a prospective, longitudinal study of 57 infants (gestational age (GA) at birth 24 to 40 weeks) prior to discharge from the NICU. Efficiency of speech perception was quantified as absolute difference in mean amplitudes of ERPs in response to vowel (/a/-/u/) and consonant (/b/-/g/, /d/-/g/) contrasts within 250-400 after stimulus onset. Standardized neurodevelopmental assessments were performed at 12 months (Developmental assessment of Young Children) and at 24 months of age (Bayley Scales of Infant Development Third ed., BSID).

Results: In a normative sample of NICU infants (N =50), both GA and PNA affected speech sound processing. These effects were more pronounced for consonant than vowel contrasts. Increasing PNA was associated with greater sound discrimination in infants born at or after 30 weeks GA, while minimal PNA-related changes were observed for infants with GA less than 30 weeks. In the entire sample of 57 infants, overall validity of predictive constructs using all ERP variables, gender, maternal education, GA and age at ERP was good, and allowed significant prediction of cognitive and communication outcomes at 12 and 24 months (R2 between 22-42%, p< 0.05). Quantitative models incorporating specific ERPs, GA, and age at ERP explained a large proportion of the variance in cognition and receptive language on the BSID at 24 months (R2 > 50%, p< 0.05).

Discussion: This study establishes ERP methodology as a valuable research tool to quantitatively assess cortical function in the NICU and to predict meaningful outcomes in early childhood.
Improved Nutrition and Respiratory Outcomes in Preterm Infants After Exposure to Recorded Maternal Sounds

Amir Lahav¹, Erin McMahon¹, Emily Zimmerman²
¹Harvard University, ²Harvard Medical School
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Background: Prematurity is associated with respiratory instability and a limited capacity for self-regulation. In addition, illness and immaturity often interfere with the infant’s ability to gain weight during the first weeks of life. The maternal environmental factors influencing respiratory and nutritional outcomes in preterm infants are still largely unknown.

Objectives: Our research aimed to examine whether providing preterm infants with routine exposure to biological maternal sounds, such as their mother’s voice and heartbeat, can reduce the time spent on respiratory support during the infant’s NICU stay and can increase daily weight gain.

Methods: Subjects: 68 preterm infants < 32 weeks gestational age were included. Exclusion criteria were surgical patients, patients with chromosomal anomalies, congenital infections, >grade II intraventricular hemorrhage, NEC, and maternal use of tobacco, alcohol, or illicit drugs. All infants were extubated at the start of the study.

Design: Two studies are reported: Study 1: Matched Case-Control (N=40); Study 2: Pilot Randomized Controlled Trial (N = 28).

Intervention protocol: Maternal vocalizations and heartbeat sounds were recorded from the infant’s mother soon after birth. The maternal recordings were played four times per 24-hour period via a micro audio system installed in the infant’s bed throughout the entire hospital stay.

Results: Study 1: Nutritional outcomes: Infants exposed to maternal sounds during their NICU stay showed improved daily weight gain (g/kg/day) in the first 28 days of life compared to historical controls, matched on their SNAPPE-II score who received standard care (p< 0.05).

Study 2: Respiratory outcomes: Infants randomized to receive maternal sounds were able to breathe room-air much sooner than control infants randomized to receive standard care (p< 0.05). Mean incidence of respiratory distress syndrome and chronic lung disease did not differ between the groups.

Discussion: Exposure to recorded maternal sounds during NICU hospitalization may improve daily weight gain in the first 28 days of life and reduce the time spent on respiratory support. These results suggest that respiratory regulation and the growth trajectory in preterm infants can be positively modulated by biologically-meaningful stimuli.
A Random Clinical Trial of Mother’s Voice With a Pacifier-Activated Music Player to Improve Hospitalization and Feeding in Preterm Infants

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Background: A newborn's ability to suck is critical to self-feeding, neurological developmental, and acquisition of later milestones. Preterm infants learn this skill in the intensive care unit (ICU) under altered environmental and medical conditions, often resulting in delays in hospitalization and disorders of feeding. Positive stimuli such as mother's voice and specialized music can improve infant development in the ICU.

Objective: We hypothesized that music using mother's voice in combination with a pacifier-activated music player (PAL) could improve the development of sucking ability in preterm infants, resulting in shorter hospitalizations.

Methods: This was a randomized clinical trial of mother's voice with, vs. control in 94 infants in the Vanderbilt ICU. Intervention was 5 consecutive daily 15 min sessions with PAL vs. mothers' voice randomly singing identical lullabies in controls. Inclusion criteria were gestational age (GA) at intervention 34 0/7-35 6/7 weeks, > 50% enteral feeds and <50% oral feeds in the 3 preceding days. Salivary cortisol was obtained before and after the intervention. Suck rate and clinical data were obtained from the medical record. Nursing staff was masked to the study group.

Results: In this abstract, we report results from ongoing data collection (N = 37). Infants in the intervention group had a doubling in the suck rate of oral feeds within 5 days (1.19 ml/min increase vs. 0.57 ml/min in controls, p =0.01). This corresponded to an average decrease of 17 minutes in oral feeding time per 28 ml feed. There was also a decrease in length of NICU stay not explained by difference in GA at birth (p =0.05). There was no measurable difference in discharge weight between the 2 groups. There was no measurable increase in adverse events or cortisol levels during the intervention, and no decrease in weight gain.

Discussion: PAL using mother's voice may improve oral feeding skills and decrease length of hospitalization in preterm infants without adverse effects on stress and growth.
SYMPOSIUM 2

MINDFULNESS-BASED STRESS REDUCTION IN INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Chair: Elisabeth Dykens, Vanderbilt Kennedy Center, Vanderbilt University
SYMPOSIUM 2

Mindfulness-Based Stress Reduction In Intellectual and Developmental Disabilities

Chair: Elisabeth Dykens, Vanderbilt Kennedy Center, Vanderbilt University

Effects of Mindfulness-Based Stress Reduction on the Health of Mothers of Children With Autism and Other Developmental Disabilities
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Marisa Fisher¹ Tjossem Award Winner
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Mindfulness and Skills-Based Training Programs for Parents of Children With Autism Spectrum Disorders: Feasibility and Preliminary Outcomes
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An Experimental Test of the Transactional Relationship Between Parenting Stress and Child Behavior Problems: A Pilot Study of the MAPS Project
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Effects of Mindfulness-Based Stress Reduction on the Health of Mothers of Children With Autism and Other Developmental Disabilities

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Introduction: Compared to the general population, parents of offspring with autism spectrum disorders or other developmental disabilities experience higher levels of stress, depression, and health and mental health problems. Most family interventions either provide brief respite or teach specific ways of enhancing child outcomes, without directly addressing high parental stress. In contrast, we recently completed a randomized clinical trial of two interventions specifically designed to reduce parental stress, depression and anxiety. Here we report on the health status of participants at baseline, after the 6-week intervention, and at 3 and 6 months follow-up.

Methods: Parents were randomly assigned to 6-weeks of either Positive Adult Development or Mindfulness-Based Stress Reduction (MBSR) classes led by trained and supervised peer mentors. Data from participants (202 mothers, 64 fathers) include standardized measures of depression, sleep, anxiety, well-being, and health self-perception, as well as medical history, medication use, and preventative health practices. Approximately 65% of the sample had children on the autism spectrum, and 35% with other disabilities. Biomarkers of stress, diurnal salivary cortisol and telomere length, are currently being assayed in a subsample of participants.

Results: Reporting on mothers only, mental health diagnoses were the most prevalent condition in their medical histories, with 48% having clinically diagnosed depression, 38% anxiety disorders, and 17% panic attacks. Frequent physical problems included headaches (39%), lower back pain (35%), high blood pressure (24%) and fatigue (22%). We also found relatively high rates of prescription pain medications (28%), anti-depressive or anxiety agents (53%), and sleep aides (30%) Although both interventions led to reduced anxiety and depression, and improved sleep, no changes in medical diagnoses were found. However, self-perceptions of health status improved over time in both treatment groups. Compared to the positive parenting program, mothers in the MBSR group engaged in more preventative health care practices at post-treatment and follow-up.

Discussion: Despite reduced maternal symptoms of anxiety and depression, medical status did not substantially change at post-treatment or follow-up. Relatively high rates of use were found for psychotropic, sleep, pain, and anti-inflammatory medications. We expect that chronic health problems will be reflected in aberrant diurnal cortisol patterns and shorter telomere length, underscoring the need for effective stress-reducing interventions in this medically and psychiatrically high-risk group of mothers.

The authors are grateful for support of this work from NIH NCAM RC1 1AT005612-01 and NICHD P30HD15052.
Mindfulness and Skills-Based Training Programs for Parents of Children With Autism Spectrum Disorders: Feasibility and Preliminary Outcomes

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Introduction: Autism Spectrum Disorder (ASD) is a complex, developmental disability characterized by core impairments in social communication and the presence of stereotyped behaviors and/or interests. Parents of children with ASD are documented to experience significantly more stress than parents of typically-developing children, children with chronic illness, and children with other developmental disabilities. The psychological well-being of parents is particularly paramount considering the bidirectional effects between parent emotion and child outcomes that have been highlighted in families of children with developmental disabilities. Despite this longstanding need, current parent training models have not been well-established in the literature, and those that are considered evidence-based primarily focus on changing child behavior, rather than reducing the stress of caregivers. The primary goals of this pilot project were to a) evaluate the feasibility of two parent training programs for parents of children with ASD, and b) preliminarily examine the effects of these programs on parenting stress and global health.

Method: Fifteen parents of children with ASD were matched on a pre-treatment measure of parenting stress and randomly assigned to one of two 8-week treatment groups: a mindfulness-based group or a behavioral skills group. Assessments of outcome measures (i.e., parenting stress and global health) were conducted at baseline (T1), post-treatment (T2), and 12-week follow-up (T3). Feasibility was evaluated with respect to recruitment, retention, fidelity, acceptability, and cost. Outcome measures were evaluated in two ways: a) repeated measures analyses were conducted to assess within-group response to treatment, and b) between group analyses were conducted to compare group differences at T1, T2, and T3.

Results: Both groups were conducted with good feasibility, including high fidelity, low cost, and recruitment and retention rates that were equal to or higher than those reported in other parent training studies. Additionally, qualitative and quantitative data indicated that parents found both treatment packages to be acceptable. The mindfulness group demonstrated significant reductions in parenting stress at T2 (p=.009) but not T3 (p=.221), and also showed significantly more change in parenting stress at T3 than the skills group (p=.011). With respect to global health, the mindfulness group demonstrated significant improvement in their scores at T2 (p=.032) and T3 (p=.011), as well as higher change scores than the skills group at both these timepoints (p=.015; p=.008).

Discussion: The results of this study support the feasibility of running two concomitant group-based interventions for parents of children with ASD in a university-based setting. Additionally, the data provide preliminary support for the efficacy of a mindfulness-based intervention for improving stress and global health in this population. Certainly, these results must be considered in light of several key limitations, including a small sample size and pre-treatment group differences (although these differences were accounted for in the analyses). However, the results of the current study provide initial support for the efficacy of a mindfulness-based approach to parent training and replicate findings supporting the use of parent training in general for parents of children on the autism spectrum.
An Experimental Test of the Transactional Relationship Between Parenting Stress and Child Behavior Problems: A Pilot Study of the MAPS Project

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Introduction: Parents of children with developmental delays (DD) typically report more parenting stress than parents of typically developing children (Baker et al., 2003; Emerson, 2003; Hauser-Cram, Warfield, Shonkoff, & Kraus, 2001). Additionally, there is consistent evidence that children with delays are more likely to have significant behavior problems and to develop psychopathology (Baker, Blacher, Cronic, & Edelbrock, 2002; Emerson & Einfeld, 2010; Merrell & Holland, 1997). Given the increased levels of both child behavior problems and parent stress among families affected by DD, it is likely that these variables have a reciprocal relationship over time whereby elevated levels of child behavior problems predict increased parenting stress which, in turn, results in even higher levels of behavior problems. However, despite evidence showing that parenting stress is an important predictor of child outcomes, it is rarely directly addressed in interventions targeting child problems. The current study is a pilot study examining the effectiveness of Mindfulness-Based Stress Reduction (MBSR), an evidence-based stress reduction intervention, for parents of children with DD. More specifically, we will investigate (1) whether MBSR is a feasible intervention for families of young children with DD, (2) whether MBSR leads to reductions in parenting stress, and (3) whether reductions in parental stress are associated with subsequent reductions in child behavior problems.

Method: The current study involves data from the Mindful Awareness for Parenting Stress (MAPS) Project, which included 51 parents of children, ages 2.5 to 5 years old, with DD. These parents participated in a randomized controlled trial examining the efficacy of Mindfulness-Based Stress Reduction (MBSR) in reducing parental stress and subsequent child behavior problems. Parents were assigned to an immediate treatment or a waitlist control group. Parenting stress was measured using the Parenting Stress Index (PSI, Abidin, 1990) and behavior problems were assessed with the Child Behavior Checklist (CBCL, Achenbach & Rescorla, 2000).

Results: Preliminary results suggest that MBSR is a feasible intervention for parents of young children with DD. 72.7% of parents attended the majority of sessions (defined as a minimum of 7 out of the 9 sessions including a daylong retreat), attrition was very low (about 3%), and 100% of parents participating indicated that they would enroll in the group again if given the chance. Additionally, MBSR appeared to be effective in reducing parental stress and child behavior problems. At intake there were no differences between the immediate (mean=36) and delayed (mean-36.11) treatment groups in terms of Parental Distress at on the PSI. However, after the first round of the intervention, the immediate treatment group has significantly lower stress (mean=31.29) compared to the delayed treatment group who had not yet received the intervention (mean=37.01); t=2.11, p<.05, d=1.28). Similarly, there were no group differences in child behavior problems at intake. However, after the intervention children of parents in the treatment group were reported to have significantly fewer externalizing behavior problems, specifically attention problems (t=1.78, p<.05, d=0.57) and ADHD symptoms (t=1.86, p<.05, d=0.61). Future analyses will examine changes in stress across the course of the intervention as well as teacher reports of child behavior problems.

Discussion: In addition to hopefully helping families cope with their children’s behavior more effectively, this study is critical because it is a rigorous, experimental test of the effectiveness of MBSR training on parenting stress and how that subsequently affects child behavior. We experimentally manipulated parenting stress and saw subsequent changes in child behavior problems. These findings provide stronger evidence that parenting stress has an effect on the development of children’s behavior problems. Other clinical implications and directions for future research will be discussed.
HEALTH AND BEHAVIOR IN RETT SYNDROME: HOW WELL DO WE UNDERSTAND THE BEHAVIORAL PHENOTYPE?

Chair: Frank Symons, University of Minnesota

Discussant: Sarika Peters, Vanderbilt Kennedy Center, Vanderbilt University
Health and Behavior in Rett Syndrome: How Well Do We Understand the Behavioral Phenotype?

Chair: Frank Symons, University of Minnesota
Discussant: Sarika Peters, Vanderbilt Kennedy Center, Vanderbilt University

RTT and Functional Behavioral Assessment
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Rett Syndrome and Functional Communication Training
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Rett Syndrome: Stress, Stereotypy, and Negative Affect
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Rett Syndrome and Hypothalamic-Pituitary-Adrenal (HPA) Axis Function
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Rett Syndrome and Pain Behavior
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Introduction: Rett syndrome (RTT) results in cognitive impairment, loss of functional and communication skills, and an emergence of idiosyncratic, often difficult to manage, behaviors. There is little behavioral research to date using functional analysis to examine the operant properties of behaviors exhibited by individuals with RTT (Iwata et al., 1986; Roane et al., 2001; Wales et al., 2004). Given the limited understanding of the functional properties of various idiosyncratic forms of behavior associated with RTT, there is a need for continued investigation into the behavioral features of the RTT phenotype, particularly because they may be relevant for improving our ability to target potential classes of communicative responses. The purpose of this study was to test whether functional analysis technology could be applied to a broad range of idiosyncratic behaviors observed in a clinical sample of girls and women living with RTT.

Methods: Following IRB approval, six girls and women (aged 4-47 years) clinically diagnosed with RTT participated in the study. Brief functional analyses (e.g., Iwata et al., 1994) were conducted to evaluate the influence of social reinforcement contingencies on target idiosyncratic behaviors exhibited by each participant (e.g., vocalizations, self-injurious behaviors, breath holding, hand mouthing, tantrums). A multielement design was utilized with each participant and all data were behaviorally coded with coding software (MOOSES; Tapp et al., 1995) from videos. Data were then visually inspected for differentiated data paths. Inter-observer agreement (IOA) was calculated for approximately 27% of all experimental conditions implemented across all six participants. The mean IOA across participants was 88% (85% to 100%).

Results: Based on visual analysis of the data, evidence of differentiated data paths was demonstrated in all six data sets. Four out of the six brief functional analyses conducted suggested that the individual’s idiosyncratic target behavior was maintained by negative reinforcement in the form of escape from demands. The other two participants’ targeted behaviors were maintained by positive reinforcement in the form of access to tangibles and social attention as indicated by elevated rates in responding.

Discussion: Results suggest that a wide range of idiosyncratic behaviors exhibited by this sample of girls and women with RTT were sensitive to social reinforcement contingencies. This study extends the limited empirical evidence about the influence of environmental contingencies on behavior in RTT. Based on this study, function-based interventions such as functional communication training could be developed targeting idiosyncratic behaviors. More generally, further research is warranted to examine how the functional properties of idiosyncratic behaviors exhibited by individuals with RTT play a role in the RTT behavioral phenotype.

References:

Supported, in part, by Eunice Kennedy Shriver NICHD Grant No. 47201.
Introduction: Language and communication are severely compromised in girls and women living with Rett syndrome (RTT). Some evidence suggests that intentional communicative acts rarely occur (e.g., Woodyatt & Ozanne, 1997). Currently, there are no effective communication interventions for this population (Sigafoos et al, 2009). One behavioral approach to improving communication, Functional Communication Training (FCT), involves replacing idiosyncratic or aberrant behaviors (e.g., vocalizations, body movements, problem behavior), that may have acquired functional (i.e., communicative) properties, with more specific responses (e.g., switch pressing) to improve the likelihood of being understood (Carr & Durand, 1985; Keen, Sigafoos, & Woodyatt, 2001). The purpose of this proof-of-concept study was to test whether FCT could be effectively used to replace idiosyncratic forms of behavior identified to be sensitive to reinforcement (positive, negative) with more conventional communicative behaviors in a small clinical sample of girls with RTT.

Methods: Three young girls (aged 5-8 years) diagnosed with classic RTT and with confirmed MECP2 mutations participated in the study. The FCT intervention involved differential reinforcement of the idiosyncratic behavior (e.g., vocalizing) and a functional alternative communicative response (e.g., activating a voice-output switch) in an ABA (reversal) single-subject design with each participant. Repeated direct observation was used to assess communicative responding (mean inter-observer agreement on 50% of session = 96% [80-100]). Each session consisted of five communication opportunities, and the first response (idiosyncratic behavior, functional alternative response) was counted for each opportunity.

Results: All participants learned to activate the voice-output switch within a single session. During Phase 1, when reinforcement was available for switch-pressing, but not idiosyncratic behavior, switch pressing was the first response attempted on at least 67% of the trials in each session for each participant. The pattern reversed in Phase 2 when reinforcement was only available for vocalizations. All participants resumed switch pressing in the final phase.

Discussion: The results suggest that girls with RTT are capable of learning novel communicative responses within the context of FCT, and will change their communicative behavior dependent on environmental contingencies. This study represents the first empirical evidence that the communicative behaviors of individuals with RTT are flexible and amenable to intervention. Given the paucity of empirical communication intervention research in RTT, the results represent an important step toward improving communication and ultimately quality of life for individuals with RTT and their families.

References:

Supported, in part, by Eunice Kennedy Shriver NICHD Grant No. 47201.
Introduction: Stereotypic hand movements are one of the core diagnostic criteria for RTT. MeCP2 deficient mice, which have been developed to recapitulate the core features of RTT, often show significantly higher levels of anxiety-like behaviors including limb clasping in behavioral assessments designed to test responses to stressful situations. Similarly, anxiety and stress-related issues are commonly reported by parents and other caregivers (e.g., ~74% of caregivers reported that their daughters experienced anxiety in unfamiliar situations). Although the relationship between hand stereotypy (i.e. hand wringing) and anxiety in RTT has not been studied directly and systematically, it has been reported that motor stereotypy increases or intensifies in response to stress. In this preliminary study, direct behavioral observation was used to quantify the frequency of hand stereotypy during presumed high and low stress conditions associated with controlled behavioral assessment conditions. The general research question was whether there would be increased hand stereotypies during a high-stress condition. We specifically hypothesized that the frequency of hand stereotypies would be greater in the high- vs. low-stress condition. We also tested whether non-verbal signs of negative affect varied by stress condition.

Methods: Three females aged 4, 7, and 47, with clinical diagnoses of Rett Syndrome, confirmed by Gillette Children’s Specialty Healthcare, participated in the study. Archived videos of prior functional analyses conducted with the three participants were used. Among the conditions conducted during the functional analysis (as described by Iwata et al., 1982/1994) were freeplay or a control condition (considered here as the ‘low-stress’ condition), during which participants had free access to attention and preferred activities, and escape or negative reinforcement condition (considered here as the ‘high-stress’ condition), during which participants were prompted repeatedly to engage in non-preferred or difficult activities of daily living consistent with individual family service (IFSPs) and education plans (IEPs). A partial-interval 10 s coding system was used to estimate frequency of hand stereotypies and negative affect signs (crying, facial grimacing, & trembling). Each participant was coded by by two independent coders for 20% of observation sessions (mean inter-observer agreement [IOA] = 92.3%, range = 90.0-94.9).

Results: Across all three participants, the percent of intervals that negative affect occurred was higher in the ‘high stress’ vs ‘low stress’ condition (χ² (1, N = 630) = 95.172, p < .001). The percent of intervals that hand stereotypy was expressed did not differ across the two conditions for the three participants (χ² (1, N = 617) = 0.14, p = .708). For each individual participant, the percent of intervals with negative affect was greater in the ‘high-stress’ condition than in the ‘low-stress’ condition (P₁ - χ²₁ = 22.736, p < .001, P₂ - χ²₁ = 79.552, p < .001, and P₃ - χ²₁ = 12.452, p < .001, respectively). The percent of intervals with hand stereotypy was greater for the low-stress than the stress conditions for one participant (P₃ - χ²₁ = 08.014, p = .018), but not significantly different for the other two participants (P₁ - χ²₁ = .031, p = .86, and P₂ - χ²₁ = .068, p = .795, respectively).

Discussion: These results showed a clear relationship between negative affect and condition, such that negative affect was more likely to occur during the high-stress condition versus the low-stress condition. On the other hand, the percent of intervals with hand stereotypy did not differ across conditions for two of three participants, and for the third, it was greater in the low-stress condition. Therefore, hand stereotypy may not reflect changes in arousal or stress for females with RTT as has previously been suggested.


Supported, in part, from NSF grant # SMA-1063006 (U of M REU); Eunice Kennedy Shriver NICHD Grant No. 47201
**Introduction:** Despite longstanding clinical observations that girls with RTT syndrome appear to have serious difficulties associated with anxiety and arousal, there has been limited investigation into neuroendocrine function vis-à-vis the hypothalamic-pituitary-adrenal (HPA) axis system. The major neuroendocrine endproduct of the HPA axis system is the steroid hormone cortisol. It is well established that basal cortisol levels follow a circadian rhythm with higher concentration values obtained in the morning and then decreasing throughout the day. Deviations in this pattern (AM > PM; diurnal variability) may be a useful biomarker for HPA axis dysfunction. In a prior study using urine cortisol samples, 47% of the sample with RTT were found to have evidence of altered HPA axis function. The current study was designed to investigate whether concentration values of salivary cortisol would show evidence of abnormal HPA axis function.

**Methods:** Participants were 20 girls and women with clinical diagnoses of RTT (M age = 13 years; 4-27). Parents/caregivers collected saliva samples (Salimetrics) at four pre-appointed times throughout the day (morning, midday, early evening, bedtime) across two typical days. Samples were assayed for cortisol concentration levels (assay sensitivity = 1.0 ng/mL, \( r = 0.99 \) duplicate values) and averaged across the two collection days. Caregivers completed questionnaires with items related to medications, sleep, and behavior. Each participant's diurnal pattern was examined for deviations from typical patterns, and average cortisol levels in the RTT sample were compared to previously published values from typically developing control samples.

**Results:** On average, diurnal cortisol patterns in the current RTT sample were consistent to some degree with a normal diurnal rhythm, in that the highest values were observed in the initial morning sample, and values decreased throughout the day. The overall diurnal pattern showed less of a decrease from the morning to evening in the RTT sample than has been previously observed in typically-developing samples (e.g., see Figure for child comparisons [ug/dL]). When a criterion of at least a 50% reduction in cortisol concentration from morning to bedtime was applied, 65% of the RTT samples showed less than the expected decrease. Similarly, 55% of the RTT samples showed an abnormal pattern as defined by a maximum cortisol concentration level at the morning collection and the minimum cortisol concentration level at bedtime. There were significant negative correlations between age and the difference between time point 2 and 4 (\( r = -.46, p < 0.05 \)).

**Discussion:** These results indicate that the diurnal basal activity of the HPA axis as indexed by salivary cortisol patterns in this RTT sample appeared to be blunted. Further research is needed to confirm these preliminary findings. It seemed that, as age increased, cortisol values showed less of a decline later in the day which could be related to chronic stress effects. Understanding the relationships between HPA axis functioning and the behavioral phenotype in RTT may have implications for the development of pharmacological and behavioral interventions for problems with anxiety and arousal. In particular, it is not clear whether behavior problems associated with RTT are related, in part, to HPA axis dysregulation.

**Key References:**


*Supported, in part, by Eunice Kennedy Shriver NICHD Grant No. 47201.*
Introduction: The scientific knowledge base concerning the clinical problem of pain among girls and women with RTT is limited and presents somewhat of a paradox. On the one hand, there are numerous health issues, many of them chronic (e.g., constipation, scoliosis), for which it would be reasonable to raise the index of suspicion regarding the possibility of recurrent and chronic pain, particularly among a vulnerable population with communicative, motor, and possible intellectual impairments. But, on the other hand, there is an apparent pain insensitivity or indifference reported among providers and caregivers and made clear by Hagberg’s description of the paradoxical case of a girl with RTT laughing while her hand was exposed to a candle flame.1 Atypical pain responses and apparent pain insensitivity are considered part of the supporting diagnostic criteria in the delineation of variant phenotypes (“diminished response to pain”)2 and also described and discussed as evidence of impaired pain perception or increased pain thresholds despite the fact that there has been no psychophysically-based study specific to pain thresholds among individuals with RTT.3 The purpose of this study was to investigate pain using multiple approaches (proxy report, standardized pain exam) in more detail (frequency, duration, intensity, expression, interference) among a sample of girls and women living with RTT.

Methods: Following informed consent, 18 females with Rett syndrome (mean age= 12.8 years, SD= 6.32 range 4-29) were characterized in terms of the type, intensity, and duration of pain experienced in the previous week, the degree to which pain interfered with daily living (Brief Pain Inventory [BPI4]), and the typical behaviors used to show pain (Non-Communicating Children's Pain Checklist - Revised [NCCPC-R5]). A brief pain exam was performed and participants were observed for signs of pain (Pain and Discomfort Scale [PADS6]).

Results: Of the 18 caregivers interviewed, 16 reported that their daughters/wards had experienced pain in the previous week. Participants most frequently reported gastrointestinal pain (n=7), musculoskeletal pain (n=5), and seizure related pain (n=5) that was intense (scored 0-10; M= 5.67, SD= 3.09; range 0-10) and long in duration (M= 25.22 hours, SD= 53.52; range 0-168 hours). Pain interfered to some extent with all aspects of daily living; however, ‘mood’ (scored 0-10; M= 4.0, SD=2.99) and ‘social activities’ (M=3.39, SD= 3.43) were most affected. Pain interference (BPI total score) was significantly correlated with pain expression (NCCPC-R total score; r=.58, p<.05). Facial behaviors were used most often by individuals with Rett syndrome to communicate their pain. This was the case both when parents reported typical pain behaviors their child used (NCCPC-R; [F(6,119)= 6.72, p<.01]) and also when researchers scored pain behaviors during the pain exam (PADS; [F(4,85)= 6.23, p<.01]).

Discussion: The results from this preliminary study suggest that pain was a problem for a significant subgroup of girls and women living with RTT - with 89% of the sample experiencing some form of pain in the week prior to evaluation. Among the pain sources, it is important to note visceral and musculoskeletal pain - pain originating here may be regulated by different mechanisms than more familiar acute nociceptive pain (i.e., acute noxious skin surface damage). Both parent rating (subjective) and standardized pain exam and scoring (objective) approaches showed that facial expression changes were important for signaling pain. From a clinical care perspective, the frequent health issues and communication impairments associated with RTT suggest an increased risk that the problem of pain may be overlooked or discounted in this vulnerable population but these findings suggest careful evaluation using non-verbal rating scales or standardized exam can reveal evidence for intact pain signaling.


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SOCIAL VULNERABILITY OF INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES ACROSS THE LIFESPAN

Chairs: Marisa H. Fisher, Vanderbilt Kennedy Center, Vanderbilt University

Discussant: Stephen Greenspan, University of Colorado
SYMPOSIUM 4

Social Vulnerability of Individuals With Intellectual and Developmental Disabilities Across the Lifespan

Chair: Marisa Fisher, Vanderbilt Kennedy Center, Vanderbilt University  *Tjossem Award Winner*
Discussant: Stephen Greenspan, University of Colorado

Exploring the Dyadic Relationship Between Bullying and Victimization Among Students With Disabilities
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Social Vulnerability of Adolescents With Autism Spectrum Disorders and Adolescents With Other Developmental Disabilities in Situations of Negative Peer Pressure
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²College of New Rochelle

Enhancing Parent-Infant Interactions With High-Risk Parents
John R. Lutzker
Katelyn Guastaferro
Megan Graham
Yamile Morales
Monica Aquilar
Georgia State University

 Stranger Safety Training for Young Adults With Williams Syndrome
Marisa H. Fisher  *Tjossem Award Winner*
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SYMPOSIUM 4

Exploring the Dyadic Relationship Between Bullying and Victimization Among Students With Disabilities

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Introduction: Given the recent high-profile media attention and the associated tragic outcomes, bullying has been thrust into the forefront of educational discussions, research, and political discourse. As a result, 49 states have adopted legislation related to the prevention of bullying and harassment (Maag & Katsiyannis, 2012). Unfortunately, research suggests that students with disabilities are overrepresented within the bullying dynamic (Rose et al., 2011). To compound the issue of bullying involvement among students with disabilities, several scholars have argued that bullying is not a static process, and roles have become contextually fluid (Espelage et al., 2012). Given the complexity of involvement and the overrepresentation of students with disabilities, it is imperative to explore the relationship between aggression (bullying, fighting, pro-bullying attitudes) and victimization (direct, online, social/relational).

Method: The University of Illinois and Wellesley College: Student Behavior Survey (Espelage & Stein, 2006) was used to assess bullying, fighting, direct victimization, online victimization, and relational victimization of middle and high school students. The sample included 2971 students without disabilities and 310 students with disabilities from two school districts in grades 6 - 12 with a mean age of 14.4 years. The sample was 47% female and 53% male with a racial breakdown of 61% white, 20% Latino/a, 11% African American, and 8% other or bi-racial. Data were examined using hierarchical linear regression, where bullying and fighting are dependent variables, and victimization (direct, online, relational) and victimization interactions (disability by direct, disability by online, disability by relational) serve as predictor variables.

Results: Given significant changes in F, significant interactions were probed and graphed based on ±1 standard deviation of the group mean. For bullying, the main effects of disability (B= -.24), direct victimization (B= .17), and online victimization (B= .10) were significant predictors (p < .05). Additionally, the interactions of disability by direct victimization (B= -.13) and online victimization (B= .16) were significant, where higher levels of direct victimization predicted higher levels of bullying for students with disabilities (t(308) = 12.95), and higher levels of online victimization predicted higher levels of bullying for individuals without disabilities (t(2969) = 5.73). For fighting, the main effect of disability (B= -.25), Gender (B= .21), victimization (B= .13), and online victimization (B= .11) served as significant predictors. For pro-bullying attitudes, the main effects of grade (B= .12), gender (B= .13), disability (B= -.16), victimization (B= -.05), online victimization (B= .06), and relational victimization (B= -.10) served as significant predictors. The interaction of disability by direct victimization (B= -.11), online victimization (B= .11), and relational victimization (B= .16) were significant, and suggested that direct victimization predicted lower pro-bullying attitudes, especially for students without disabilities, where online victimization predicted higher supportive bullying attitudes for both groups.

Discussion: The results from this study support extant literature that students with disabilities are uniquely involved within the bullying dynamic (Rose et al., 2011), and extend this literature base by suggesting that the roles are fluid for this population of students and rates of bullying behaviors may be partially predicted by type of victimization. Given these findings it is important to examine the unique predictive factors associated with specific subgroups of students with disabilities to discern the at-risk characteristics associated with diagnostic criteria (Rose et al., 2011) to prevent high levels of bullying and victimization among students with disabilities.

References:


Introduction: The findings of past studies suggest that the social vulnerability of youth with intellectual and developmental disabilities (DD) may be exacerbated by limited decision-making (DM) skills in complex peer situations (e.g., Khemka, & Hickson, 2006). Although little is known about how the DM of adolescents with autism spectrum disorders (ASD) may differ from that of adolescents with other DDs, it has been suggested that individuals with ASD may be especially vulnerable to peer victimization (e.g., Cappadocia, Weiss, & Pepler, 2012). The present exploratory study was designed to compare the DM performance of adolescents with ASD to that of adolescents with DD in situations involving negative peer pressure.

Method: Sixteen adolescents (fifteen male/one female) with ASD and 17 adolescents (ten male/seven female) with other DDs (i.e., intellectual disabilities, speech/language disorders, learning disabilities) participated in the study. All subjects received the following assessments: CREVT-2 (Pro-Ed, 2002), Decision-Making Competency Inventory (DMCI) (from Miller & Byrnes, 2001), and the Adolescent Decision-Making Scale (ADMS) (developed for this study). IQs were obtained from participants’ records. Subjects with ASD and subjects with DD did not differ significantly in age (ASD: M = 16.03, SD = 1.45; DD: M = 16.33, SD = 1.94), IQ (ASD: M = 72.38, SD = 9.90; DD: M = 67.76, SD = 17.41), or CREVT-2 Composite Raw Score (ASD: M = 46.56, SD = 18.12; DD: M = 56.47, SD = 17.31).

Results: Subjects with ASD did not differ significantly from subjects with DD on the DMCI, an overall measure of decision-making competence, (ASD: M = 18.53, SD = 2.29; DD: M = 18.47, SD = 2.92). However, the subjects with ASD were significantly more likely than the subjects with DD to make decisions on the ADMS recommending that the protagonist go along with negative peer pressure to engage in actions such as stealing, shirking responsibilities, risk taking, and substance use (ASD: M = 3.31, SD = 3.03; DD: M = 0.82, SD = 1.38).

Discussion: Despite comparable cognitive abilities, adolescents with ASD were more likely than adolescents with other DDs to acquiesce to negative peer pressure. Discussion will explore possible reasons for this vulnerability in light of the communication impairments and difficulties with understanding intentionality associated with ASD.


Enhancing Parent-Infant Interactions With High-Risk Parents

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Introduction: Parents with risk factors such as poverty, low education, being single and unemployed are at risk for engaging in child maltreatment. This is compounded if the parent has an intellectual disability. Parents with intellectual disabilities are at higher risk for having their children removed and often lack services or face poor service coordination. Parent training programs need to be tailored to parents with intellectual disabilities by using simple language, presenting concrete concepts, and simple technologies that may enhance outcomes.

Method: Presented here will be data from a number of single-case research design studies examining whether the use of digital frames enhances parent-infant interactions. The frames contain photos of mothers and their own babies in posed interactions that represent desired criterion performances from the parent-infant interaction module of SafeCare, an evidence-based program that reduces risk of child maltreatment. The use of the frames are based on the principle of self-modeling which has demonstrated that individuals with intellectual disabilities perform better when they are able to see themselves performing criterion behaviors. We have explored the use of the frames with a diverse range of mothers living in diverse circumstances.

Results and Discussion: It appears that the use of inexpensive digital frames enhances already good outcomes of the SafeCare parent--infant interaction module. Implications and design nuances will be discussed.
**SYMPOSIUM 4**

**Stranger Safety Training for Young Adults With Williams Syndrome**

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**Introduction:** Individuals with Williams syndrome (WS) are often characterized as overly friendly, socially disinhibited, and too trusting of others. These features are thought to be immutable in WS, and related to altered functioning in specific brain regions. These social personalities often lead individuals with WS to be indiscriminate towards strangers; often approaching strangers and engaging them in conversation. This increased sociability and desire to engage others may lead to social victimization. To date, no research has been conducted to determine whether individuals with WS can be taught to interact appropriately with strangers. This study used methods borrowed from stranger abduction interventions for typically developing children to teach young adults with WS the safety skills for appropriately responding to a stranger lure.

**Method:** Participants included 21 young adults with WS (4 female, 17 male); average age was 25.71 (9.67) and average full scale IQ was 70.90 (13.53). At the start of the study, all participants received a baseline in situ assessment. During this assessment, the participant was left alone in a community setting and a confederate stranger approached and delivered a lure. Safety ratings for each behavior of the in situ assessments were recorded as follows: 0 = went with the stranger, regardless of verbal response; 1 = stayed near the stranger with no refusal; 2 = stayed near the stranger but refused to leave with the stranger; 3 = walked away from the stranger (with or without a verbal refusal); 4 = walked away from the stranger and reported it to a trusted adult. If the participant did not walk away but later told an adult, 1 point was added to the score. Following the baseline in situ assessment, participants were separated into 2 groups. Group A participated in 3 consecutive days of behavior skills training (BST; instruction, modeling, rehearsal, feedback) in which they were taught and rehearsed the skills to say “no”, walk away, and tell an adult in response to a lure from a stranger. All participants then received another in situ assessment on day 3 (post-test 1). Following post-test 1, Group B received 3 days of BST while Group A did not receive any further stranger safety instruction. Following Group 2’s BST, all participants received a final in situ assessment (post-test 2).

**Results:** A significant main effect was found for time, F (2, 32) = 6.49, p < .01. Groups A and B did not differ in performance at baseline (M = 1.60 (1.17) and M = 1.09 (1.14), respectively). Participants in Group A demonstrated a significant increase in performance from baseline (M = 1.60 (1.17)) to post-test 2 (M = 2.90 (1.29)), t (9) = -2.25, p = .05. Group B significantly increased from post-test 1 (M = 1.36 (1.36)) to post-test 2 (M = 3.09 (0.70)), t (10) = -4.25, p < .01. At baseline, no participants achieved a score of 4, and 36% of participants agreed to go with the stranger. At post-test 1, 71% participants in Group A said “no” to the stranger (scored at least 2). At post-test 2, only 1 participant agreed to go with the stranger. Importantly, 86% of participants said “no” to the stranger following intervention.

**Discussion:** Following participation in 3 days of BST, individuals with WS significantly increased use of the safety skills when responding to a lure from a stranger. Individuals with WS are thought to be incapable of learning how to appropriately interact with strangers. At the start of this study, many participants were friendly with the confederate strangers and were willing to walk away with them. At post-test 2, the majority of participants said “no”, walked away, and reported the lure to a trusted adult. This is the first study to demonstrate that individuals with WS can learn to say “no” and walk away from a stranger. Clinical implications will be discussed.
CHARACTERIZING SENSORY FEATURES IN CHILDREN WITH AUTISM SPECTRUM DISORDERS: BEHAVIOR AND PHYSIOLOGY

Chair: Lauren M. Little, University of North Carolina-Chapel Hill

Discussant: James Bodfish, Vanderbilt University
SYMPOSIUM 5

Characterizing Sensory Features in Children With Autism Spectrum Disorders: Behavior and Physiology

Chair: Lauren M. Little, University of North Carolina-Chapel Hill  *Tjossem Award Winner*
Discussant: James Bodfish, Vanderbilt University

Activity Participation Among Children With ASD: Associations With Sensory Features
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Sensory Subtypes in Children With ASD: Latent Profile Transition Analysis Using a National Survey of Sensory Features
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Melissa Furlong2
John Sideris2
John Bulluck2
Lauren M. Little2  *Tjossem Award Winner*
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Dimensions of Sensory Interests, Repetitions, and Seeking Behaviors: Differences Among Diagnostic Groups
Anne V. Kirby  *Zeaman Award Winner*
Lauren M. Little  *Tjossem Award Winner*
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Distinct ERP Responses During Auditory Processing in Young Children With Autism
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Tactile Defensiveness in Children With ASD: Effect of Stimulus Material and Bodily Location
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SYMPOSIUM 5

Activity Participation Among Children With ASD: Associations With Sensory Features

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Introduction: Research suggests that children with autism spectrum disorders (ASD) participate in activities in the home and community less frequently than children with other developmental disabilities (DD) and typical development. Sensory features, highly prevalent among children with ASD, include hyperresponsiveness (HYPER; an exaggerated response to sensory stimuli), hyporesponsiveness (HYPO; a lack of response to sensory stimuli), sensory interests, repetitions, and seeking behaviors (SIRS; craving/ fascination with sensory stimuli), and enhanced perception (EP; enhanced discrimination of sensory stimuli). Large-scale empirical research has not tested the differential impact of sensory features on specific activities in the home and community. Therefore, this study addressed the following questions: 1) To what extent are sensory response patterns (HYPO, HYPER, SIRS, EP) associated with dimensions of participation among children with ASD ages 5-12 years?; and, 2) To what extent do child characteristics (i.e., chronological age, autism severity) moderate the associations between sensory response patterns and dimensions of activity participation among children with ASD ages 5-12 years?

Methods: The sample included 713 caregivers of children with ASD ages 6-12 years (mean=105.93 mos.; SD=26.02 mos.; range=60-155). This online survey study used the Home and Community Activities Scale (adapted from Dunst et al., 2002), an 83-item parent report instrument that measures the frequency with which children participate in home and community activities. Sensory features were assessed using the Sensory Experiences Questionnaire Version 3.0 (Baranek, 1999), a 105-item caregiver report tool that characterizes sensory features in children ages 2-12 years with ASD and/or DD. Mixed model regression was used to determine the extent to which sensory patterns were associated with dimensions of activity participation, as well as the moderating effects of child characteristics.

Results: HYPER negatively impacted children's participation across contexts [F(1,586)=9.25, p<.01] while EP supported participation in each activity dimension [F(1,586)=12.80, p<.001] regardless of autism severity. HYPO and SIRS differentially impacted activity participation based on children's chronological age. Specifically, younger children with high scores of HYPO participated more frequently in activities across contexts versus older children with high HYPO. Moreover, older children with high scores on SIRS participated less frequently in community activities versus older children with low SIRS.

Discussion: Findings from this study suggest that patterns of sensory response have differential effects on dimensions of activity participation. HYPER appears to particularly negatively impact activity participation for young children; however, for HYPO and SIRS, the association is largely a function of chronological age. The current findings suggest that children's sensory features impact their activity participation regardless of autism severity.

Key References:

Introduction: Sensory features are prevalent in children with ASD and will soon be associated with the core characteristics. The heterogeneity of sensory features has long been discussed (Baranek, et al., 2006; Ben-Sasson et al., 2009). However, lacking in the literature is the identification of homogeneous sensory phenotypes as well as assessing the stability of such identified subtypes over time. This study used latent profile transition analysis (LPTA) used to identify sensory subtypes, assess their stability over time, and association with child and family characteristics.

Methods: Data were collected from participants with ASD, ages 2-12, at two time points (Time 1, n= 1293, Time 2, n=884), one year apart as part of a national online survey. A confirmatory factor analysis (CFA), of the Sensory Experience Questionnaire-3.0 (SEQ-3.0) yielded four factors of sensory response patterns (i.e., hyporesponsiveness; HYPO, hyperresponsiveness; HYPER, sensory interests, repetitions, and seeking behavior; SIRS, and enhanced perception; EP). These scores were exported for an LPTA. Previous literature, latent profile analysis (LPA) from both time points, LPTA with multiple profile solutions, and assessing statistical fit (AIC, BIC, Lo-Mendell-Rubin test, entropy, and the Bootstrap Likelihood Ratio Test) were used to determine the appropriate number of distinct subtypes over time (Thompson, et al., 2011). The final LPTA (n=1069) was run with select child and family covariates (gender, autism severity, household income, IQ proxy, chronological age, and mother’s education).

Results: Four distinct sensory subtypes were supported by statistical measures and theoretical/clinical models. The majority of participants (n=971, 91%) remained stable in their sensory subtype across one year. The first subtype (n=283, 31%) described children who scored low on all sensory patterns, while the second subtype (n=189, 19%) showed the opposite profile, with high scores in all four sensory patterns. The third subtype (n=294, 30%) scored very close to the mean on all patterns, with a tendency to score low on HYPO and SIRS, but higher on HYPER and EP. The fourth subtype (n=191, 20%) had the opposite pattern of the third subtype with scores more extreme on HYPO and SIRS. In the group (n=98, 9%) that did transition between the two time points, about half (n=48) moved from the third subtype to the first subtype. The four sensory subtypes related differentially to demographic variables. For example, the third subtype was the youngest group and had the lowest proxy IQ while the second subtype had the highest SRS scores and lowest household income.

Discussion: The LPTA identified four distinct sensory subtypes that were stable over one year in a population of children ages 2-12 with ASD. The identification of homogenous sensory subtypes and characterization of children within their subtype will lead to improved assessment, treatment and potentially inform biological mechanisms. Further analysis will determine the relationships between the identified subtypes and outcome measures.

Key References:


Dimensions of Sensory Interests, Repetitions, and Seeking Behaviors: Differences Among Diagnostic Groups

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Introduction: Children with autism spectrum disorders (ASD) demonstrate sensory response patterns, which include sensory interests, repetitions and seeking behaviors (SIRS; i.e., a fascination with or craving of sensory stimulation that may be repetitive in nature) (Ausderau et al., in preparation). Research suggests that children with ASD may demonstrate SIRS behaviors at a higher frequency and with increased behavioral complexity (i.e., simultaneous occurrence of two or more SIRS behaviors) as compared to children with developmental disabilities (DD) and typical development (TD). Moreover, theoretical descriptions have associated enjoyment, or positive affect, with the presentation of SIRS behaviors. There is a dearth of observational research on the dimensions of SIRS behaviors (frequency, intensity, complexity, affect). Therefore, this study addressed the following research questions: 1) To what extent does the behavioral presentation (i.e., occurrence rate, complexity) of SIRS differ between diagnostic groups (ASD, DD, TD)?; 2) To what extent does facial affect associated with SIRS differ by diagnostic group?; and, 3) What specific SIRS behaviors significantly differentiate diagnostic groups?

Methods: A behavioral coding scheme was developed as a supplement to the Sensory Processing Assessment (SPA; Baranek, 1999) to measure occurrence rate, complexity, affect, and specific SIRS behaviors. Currently, data on 47 children (ASD=15, DD=16, TD=16) (mean age=52.0 mos., SD=23.9 mos.) has been coded. Coded data on the entire sample (n=105) will be available by March 2013. In order to analyze group differences on occurrence rate and complexity, ANOVAs were used. MANOVA was used to analyze specific SIRS behaviors, and a chi-squared test was used to analyze differences in facial affect during SIRS behaviors.

Results: Preliminary results of the ANOVA revealed significant group differences \[F(2,44)=7.80, p<.01\] for occurrence rate of SIRS between diagnostic group. Post-hoc analyses showed significant differences between ASD and DD groups (p<.05), ASD and TD (p<.001), but not between DD and TD groups on occurrence rate. Further results revealed that children with ASD demonstrated the highest complexity of SIRS as compared to children with DD (p<.05) and children with TD (p<.01). Additionally, children with ASD demonstrated significantly more sighting and spinning objects as compared to children with DD (p<.05) and TD (p<.001). No significant differences were found between positive, negative, and neutral affect during SIRS behaviors.

Discussion: The current findings suggest that children with ASD demonstrate increased rates and complexity of SIRS behaviors as compared to children with DD and TD. In the current sample, children with DD and TD did not differ on any dimension of SIRS behaviors. Moreover, results demonstrated that specific behaviors may be more likely to occur simultaneously (i.e., spinning and sighting) among children with ASD as compared to those with DD and TD. Although theoretical accounts associate SIRS with positive affect among children with ASD, results from the current analysis demonstrate that this assertion warrants further investigation.

Key References:

Distinct ERP Responses During Auditory Processing in Young Children With Autism

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Introduction: Autism Spectrum Disorder (ASD) is characterized by deficits in communicative language, social functioning, and restricted interests and behaviors. Many individuals with autism also have unusual sensory experiences, beginning in early childhood (Baranek et al., 2006). While the behavioral characteristics of sensory processing have been extensively studied, less is known about their neurobiological correlates. Electroencephalography (EEG) can be used to measure electrical activity in the brain during cognition, and its high temporal resolution is ideal for examining sensory processing. Therefore, EEG studies may be able to elucidate the temporal characteristics of aberrant sensory processing in individuals with autism. The current study measured event-related potential (ERP) effects during an auditory oddball task in young children with autism, in order to examine the sensory, perceptual, and cognitive processing of auditory information in the disorder.

Methods: Participants include 36 children with autism spectrum disorder (ASD) and 41 neurotypically developing children (NT), between 4 and 12 years of age, with a mean age of 7. ERPs were collected during a passive listening task, during which participants watched a video of their choice, while ignoring sounds played over speakers. The stimuli consisted of 2200 standard tones, 100 duration deviant tones, 100 pitch deviant tones, and 100 novel sounds, randomly presented. Data was collected from 11 electrode sites and was analyzed using EEGLab and FieldTrip MATLAB functions. ERP components examined include (1) the P1, reflecting early sensory processes; (2) the N1 and mismatch negativity - MMN, reflecting pre-attentive perceptual processes; and (3) the P3a, reflecting post-sensory attentional processes.

Results: Preliminary results suggest that children with ASD have atypical ERP responses during auditory processing. ASD children had a smaller N1 amplitude for standard sounds, reflecting atypical pre-attentive perceptual processes for baseline tones. ASD children also had a smaller P3a amplitude for the comparison of novel sounds to standard sounds. This component of the neural signal occurs relatively late (around 300 ms) and indicates post-sensory involuntary attention. Therefore, this finding suggests that the children with ASD show evidence of reduced attentional orienting to novel sounds in this passive listening paradigm.

Discussion: These preliminary findings suggest that sensory processing is disrupted at the neural level in children with autism, particularly in attentional processes. This may reflect abnormal attentional orienting to environmental novel stimuli, consistent with the prevalence of aberrant sensory sensitivities in many children with autism. Further analyses will examine correlations between these ERP components and clinical sensory features in the participants with ASD, to potentially identify a direct relation between neural characteristics and sensory dysfunction.

References:
SYMPOSIUM 5

Tactile Defensiveness in Children With ASD: Effect of Stimulus Material and Bodily Location

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Introduction: Negative emotional response to touch, or tactile defensiveness, is a commonly exhibited manifestation of aberrant sensory processing in autism spectrum disorders (ASD). It is unclear, however, how tactile defensiveness varies with the properties of the stimulus and the bodily site of stimulation. Recent neurophysiological, psychophysical, and neuroimaging work has described a distinct neural system for conveying social and pleasant emotional touch, mediated by slowly conducting, unmyelinated afferents (CT fibers) that heavily innervate the face and forearm, but are absent from the palm, where receptor type and distribution are optimized for discriminative touch. We were interested in the effects of sociality, pleasantness, and CT fiber innervation on defensiveness reactions in children with ASD.

Methods: We presented three textures (unpleasant: plastic mesh, pleasant non-social: soft fleece, and social: experimenter’s finger) at three bodily sites (perioral face, forearm, and palm) and observed defensiveness reactions from a group of children with ASD (n=27, mean age 7.8 years) and two comparison groups (one with developmental disability (DD) (n=13, mean age 7.5 years), one with typical development (TD)) (n=37, mean age 6.8 years) for each combination.

Results: Children with ASD and DD showed significantly more defensiveness reactions to all textures than the TD group, with higher variability of reactions. A closer inspection of the data suggested that the fleece material best distinguished ASD defensiveness from DD, and tended to correlate less with mental age. While all bodily sites showed trends for group differences, the elevated defensiveness in ASD was most heavily driven by reaction to regions with CT fiber innervation.

Discussion: Taken together, these data suggest that children with ASD do not simply show elevated responses to generally unpleasant tactile or social experiences, but also react to stimuli that are nonsocial and generally perceived as pleasant. These results warrant further investigation of the CT system as a neurobiological substrate of tactile defensiveness in ASD.
DOWN SYNDROME: IDENTIFYING TARGETS FOR INTERVENTION ACROSS THE LIFESPAN

Co-Chairs: Lisa Daunhauer, Colorado State University
           Deborah J. Fidler, Colorado State University
SYMPOSIUM 6

Down Syndrome: Identifying Targets for Intervention Across the Lifespan

Co-Chairs: Lisa A. Daunhauer, Colorado State University
Deborah J. Fidler, Colorado State University

Early Social Cognitive Skills and the Understanding of Intentionality in Young Children With Down Syndrome
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Everyday Executive Functioning in Children With Down Syndrome: Evidence for a Specific Profile and Convergence With Functional Performance
Lisa A. Daunhauer
Deborah J. Fidler
Colorado State University

Caregiver-Report of Structural and Pragmatic Language Skills in Down Syndrome: Evidence for a Syndrome-Specific Language Profile and Convergence With Direct Neuropsychological Testing?
Nancy Raitano Lee
Elizabeth I. Adeyemi
Jay N. Giedd
Child Psychiatry Branch, National Institute of Mental Health

Mortality and Hospitalization Use Among Adults With Down Syndrome
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Early Social Cognitive Skills and the Understanding of Intentionality in Young Children With Down Syndrome

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This study examined the relationship between early social cognitive skills and the development of the understanding of intentionality in young children with Down syndrome (DS) and developmentally matched children with developmental disabilities (DD). The study of intentionality focuses on how children come to understand the intentional actions of others (Meltzoff, 1995), and is an important precursor to the development of more complex social cognitive skills, such as theory of mind (Meltzoff, 2007; Trevarthen & Aitken, 2001). Past research on social cognition in DS has suggested that this domain may be compromised and that children with DS may overuse their social strengths to compensate during challenging tasks (Cebula & Wishart, 2008; Fidler, 2006). To examine whether it is possible that the competent development of the understanding of intentionality in children with DS is influenced by other skills related to intersubjectivity, we investigated the relationship between joint attention and affect sharing abilities, and the understanding of intentionality.

Participants were 16 children with DS and 16 children with DD. Children with DS had a mean CA of 40.38 months, a mean VMA of 23.28 months, and a mean NVMA of 25.38 months. Children with DD had a mean CA of 38.47 months, a mean VMA of 25.30 months, and a mean NVMA of 26.39 months. Meltzoff’s (1995) behavioral reenactment procedure was used to examine the understanding of intentionality. This is a nonverbal procedure that examines children’s ability to read a social partner’s intentional action on an object. Each child was shown 5 or 6 different presentations of novel toys that involved either: 1. a successful completion of a target action or, 2. a failed intention at completing the target action (e.g. trying, but failing to successfully complete the target action). At least 3 failed intentions were shown. Joint attention and affect sharing were examined using the Early Social Communication Scales (Seibert et al., 1982; Mundy et al., 1990).

For children with DS, higher levels of affect sharing predicted more imitations of the failed intention (F(2,11) = 9.73, p < .01). For children with DD, lower levels of affect sharing predicted more productions of the target action when viewing the failed intention (F(2,8) = 5.58, p < .05). These results suggest that although children with DS show strengths in joint attention and affect sharing, these skills may not be supporting the development of more complex social skills, like the understanding of intentionality. Children with DS were 18% more likely to produce the target action on the failed intention administration (relative likelihood = 1.18, 95% CI .79 to 1.77) than children with DD. These findings provide suggestive evidence of a small advantage in the ability to understand the intentions of others in children with DS. More longitudinal research with a larger sample is needed to examine the development of the understanding of intentionality in DS to help to clarify whether this is an area of strength. Further, more research is needed to explore the relationship between early social cognitive skills and the development of more complex social cognitive skills in DS.

Key References:

Introduction: Critical gaps persist in our current understanding of the Down syndrome (DS) cognitive phenotype. Recent evidence suggests that individuals with DS demonstrate deficits in adaptive, goal-directed behaviors known as executive function (EF) skills (see Lee et al. for a review). Using parent reports of everyday EF, our team previously found that even at young mental ages, children with DS were reported to have a specific EF profile. This profile included impairments in working memory and planning identified as “cool” EF deficits beyond those expected for their overall, delayed developmental level (Lee et al. 2011). However, this work was limited by the lack of a MA-matched comparison group. Characterizing the specific EF profile in individuals with DS will be critical in that EF skills are associated with school participation and behavior related to academic achievement in children with developmental disabilities (e.g. Zingerevich & LaVesser, 2009).

Methods: Young children with DS (n = 22, MA M = 48.88, SD = 7.79) and typically developing (TD) children (n = 23, MA M = 49.96, SD = 5.32) were matched for nonverbal mental age using the Leiter International Performance Scale-Revised Brief IQ composite. Both the children’s parents and teachers completed the Behavior Rating Inventory of Executive Function-Preschool (BRIEF-P; Gioia, Espy, & Isquith, 2003) to measure EF in everyday activities. Additionally, parents reported their children’s functional performance using the Pediatric Evaluation of Disability Inventory (PEDI, Hayley et al., 1992).

Results: Both parent and teacher reports indicated that the DS group presented with significantly higher levels of impairments in Working Memory and Planning when compared to TD children at equivalent mental ages. Additionally, parents of the DS group reported that their children had significantly more deficits in the area of Inhibitory Control than expected for their overall developmental level. Problems in Inhibitory Control in the DS group were less pronounced for the teacher report data. Furthermore, parent report of EF points to strong relationships with children’s functional performance. Specifically, for the DS group, better parent-reported performance on both Working Memory and Planning on the BRIEF-P was strongly correlated with better self-care skills (r=.60 and .56, p < .01 respectively) and less need for parental assistance in self-care (r=.63 and .64, p < .01 respectively) on the PEDI. Discussion: Results support and extend earlier findings indicating a specific “cool” profile of EF impairments in young children with DS featuring deficits in both working memory and planning with a possible subgroup of children experiencing challenges with inhibitory control. Future investigation is needed to understand how this profile may moderate developmental trajectories for children with DS.

Key References:


Caregiver-Report of Structural and Pragmatic Language Skills in Down Syndrome: Evidence for a Syndrome-Specific Language Profile and Convergence With Direct Neuropsychological Testing?

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Introduction: Increasingly, researchers studying the biological mechanisms underlying behavioral phenotypes associated with developmental disorders are capitalizing on cross-institution collaborations. This is particularly relevant for Down syndrome (DS) as efforts are made to establish a global patient registry and biobank. Consequently, there will be a greater need for standardized test batteries and caregiver-report measures that can characterize the cognitive characteristics of study participants across sites validly and efficiently. Furthermore, treatment studies are in need of ecologically-valid measures of language functioning to identify and track targets for intervention. Thus, the current study examined the use of a standardized parent-report measure of language functioning, the Children’s Communication Checklist-22 (CCC-2), to characterize the DS language profile and contrasted it with that found for typically developing youth matched on mental age (TD-MA) and youth with X-chromosome trisomies matched on chronological age. Two tests were used to evaluate the utility of the CCC-2 in describing the DS language phenotype: (1) the ability to discriminate between DS patients and those with either typical development or another chromosomal aneuploidy, and (2) an examination of correlations within the DS group between CCC-2 scores and direct neuropsychological testing.

Methods: Fifty-seven youth participated (DS: n=18; MA-TD: n=10; +1X: n=29) with a mean age of ~11 (range: 4-22). Caregivers completed the CCC-2, a norm-referenced questionnaire that evaluates nonsocial or structural (STRUCT) and social-pragmatic (PRAG) language using eight subscales: speech, syntax, semantics, coherence (STRUCT scales) and initiation, scripted language, context, and nonverbal communication (PRAG scales). All participants completed tests of intellectual functioning (Wechsler or Differential Ability Scales). Receptive vocabulary and short-term/working memory were also assessed in the DS group.

Results: (1) DS language profile specificity: When groups were compared on a raw CCC-2 composite score, both the MA-TD and +1X groups outperformed the DS group (ps<.001). However, when raw STRUCT and PRAG composites were considered separately, results were as follows: the MA-TD group outperformed the DS group on both domains (ps <.005) but the +1X group only outperformed the DS group on the STRUCT domain (p<.001). Furthermore, a mixed measures ANOVA revealed a group by STRUCT/PRAG domain interaction (F[2,54]=6.5, p<.004), such that the DS group showed a PRAG strength and the +1X group showed no differences between the STRUCT and PRAG composites. An examination of within domain age-referenced subscale scores revealed a relative strength on the Semantics subscale and weakness on the Speech subscale for the DS group in the STRUCT domain. In contrast, the +1X group demonstrated a relative strength in Syntax and weakness in Semantics. In the PRAG domain, both aneuploidy groups demonstrated a relative weakness on the Context subscale. (2) CCC-2 convergence with direct testing: Partial correlations controlling for age were completed within the DS group to examine relations among the CCC-2 scores and direct tests of receptive vocabulary and verbal short-term/working memory. Statistically significant correlations were found between receptive vocabulary testing and both the CCC-2 STRUCT language composite and Syntax subscale, but interestingly, not with the CCC-2 Semantics subscale. Similarly, significant correlations were found between tests of verbal short-term/working memory and the Syntax subscale (all rs >.48, all ps<.05).

Discussion: Taken together, there does appear to be support for the use of the CCC-2 as a measure of language functioning in DS. It documented an overall weakness in language skills relative to TD-MA controls, relative strengths on pragmatics and semantics and a relative weakness on speech. These results are consistent with findings in the broader literature and were distinct from those found for the +1X group, providing evidence for syndrome specificity. Lastly, there were modest correlations among direct vocabulary and verbal memory testing and the CCC-2 Syntax subscale in particular.

Mortality and Hospitalization Use Among Adults With Down Syndrome

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Introduction: African-Americans with Down syndrome experience significantly shorter lifespans than their Caucasian peers (Yang, Rasmussen & Friedman, 2002). There is a need to understand how racial disparities in health and hospitalizations contribute to these disparate life expectancies. Using Tennessee administrative databases, we linked hospitalization and death records over 1997-2009 in order to examine deaths and associated hospitalizations among adults with Down syndrome. We investigated racial and gender differences in mortality and contributing patterns of hospitalization prior to mortality among adults with Down syndrome.

Method: We identified over 2,500 adults with Down syndrome over 1997-2009 via notation of Down syndrome within their hospitalization or death records, of whom 17% were African-American. For deceased individuals, links were then performed between the person’s death record and all previous hospitalizations using social security numbers and dates of birth.

Results: We identified over 750 deceased adults with Down syndrome, of whom 19% were African-American. Consistent with previous findings, African-Americans died significantly younger than Caucasians, t(750) = 2.97, p < .01, and this discrepancy in life expectancy was more pronounced for males, with more African-American males with Down syndrome dying at younger ages, χ²(5) = 14.83, p < .05. While males and females in general were reported to die at similar ages, a greater proportion of females identified in these administrative datasets were deceased, χ²(1) = 4.38, p < .05. Regarding hospitalizations, there was no significant difference in the number of hospital visits within the last year, nor in the latency to the last hospital visit. When we examined the number of hospital visits through the entire study period by race and gender, we found that African-American males had the least hospitalizations and African-American women the most, F(1,748) = 4.61, p < .05. Further, African-Americans had, on average, longer hospital visits than Caucasians, F(1,748) = 15.89, p < .01, and African-Americans and males spent the most time in the hospital, F(1,748) = 9.30, p < .01 and F(1,748) = 6.25, p < .05, respectively. The primary cause of death differed by race and age of death χ²(13) = 23.38, p < .05, and χ²(65) = 83.78, p < .05, respectively. Circulatory and respiratory causes were the most common for African-Americans and Caucasians. However, neoplasms were more common among Caucasians and endocrine causes more common in African-Americans.

Discussion: This presentation provides the audience with detailed description of how large-scale databases can shed light on unexplored health issues among populations with Down syndrome in order to understand racial disparities found in this population.

Key References:
LIFE COURSE TRAJECTORIES OFadaptive behavior and vocational achievement in individuals with autism and other developmental disabilities

Chair: Marsha R. Mailick, University of Wisconsin-Madison

Discussant: Frank Floyd, University of Hawaii
SYMPOSIUM 7

Life Course Trajectories of Adaptive Behavior and Vocational Achievement in Individuals With Autism and Other Developmental Disabilities

Chair: Marsha R. Mailick, Waisman Center, University of Wisconsin- Madison
Discussant: Frank Floyd, University of Hawaii

Early Childhood Predictors of Adaptive Behavior Development From Infancy Through Young Adulthood In Children With Developmental Disabilities
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A Longitudinal Examination of Adaptive Behavior in Adolescents and Adults With ASD
Leann E. Smith
Marsha R. Mailick
Jan S. Greenberg
Waisman Center, University of Wisconsin-Madison

Ten-Year Change in Vocational Outcomes for Adults With ASD
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Early Childhood Predictors of Adaptive Behavior Development From Infancy Through Young Adulthood In Children With Developmental Disabilities

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Introduction: Harter’s (1978) model of effectance motivation describes the internalized system of self-rewards children gain from persisting at challenging tasks. Although much research has focused on such persistence, this has been less investigated in children with developmental disabilities (DD). In the present study, we investigated whether the extent of task persistence displayed by children with DD during the early childhood years sets children on different trajectories of skill development. In addition, we explored the impact of mothers’ sensitive and growth-fostering behavior during interactions with their young children as a predictor of children’s long-term skill development. Specifically, we investigated group-based trajectories of daily living, socialization and communication skills among children with DD from infancy (less than age 1) through young adulthood (age 23). We first tested the number and shape of such trajectories followed by tests of association between early childhood factors (mastery motivation, mother-child interaction) and membership in skill trajectory groups, controlling for cognitive skills and family income.

Methods: Data for this study were drawn from 182 families who participated in at least three waves of data collection in the Early Intervention Collaborative Study (Hauser-Cram et al., 2001), a longitudinal study of children with early-diagnosed disabilities (Down syndrome, motor impairment, other DD). Mothers completed the Vineland Scales of Adaptive Behavior (Sparrow et al., 1984; 2005) when their child was 1, 3, 5, 10, 15, 18, and 23 years old. Child cognitive skills were measured at age 1 using the Bayley Scales of Infant Development (Bayley, 1969). Mother-child interaction was assessed using the Nursing Child Assessment Teaching Scale when the child was age 2 (NCATS; Barnard, 1978). At age 3, children were given a series of mastery motivation tasks that involved persistence on cause-and-effect type tasks (Morgan et al., 1990). A semi-parametric group-method (Nagin, 2005) was used to identify distinct trajectories of skill development from children’s infancy through young adulthood. First, an unconditional model was fit to identify the number and shape of trajectory groups. Next, multinomial logistic regression was used to test the association between early childhood factors and trajectory group membership for each subscale.

Results: Three trajectory groups were identified for each of the adaptive behavior subscales. For daily living skills, the first group (33.3% of the sample) started with the lowest skills and displayed declining scores across the length of the study. The second group (30.7%) started with slightly higher skills than the first group that declined moderately through adolescence then increased through young adulthood. The final group (36%) displayed the highest initial skills, which steadily increased from infancy through young adulthood. Trajectories of socialization skills followed a similar pattern, with 24.3% in the low group, 46.3% in the middle group and 29.4% in the highest group. For communication skills, trajectories for the lowest and middle groups were similar to those for daily living and socialization (with 46.5% in the lowest group and 30.9% in the middle group). For the highest group (22.6%), communication skills remained stable across the study period, unlike the increasing skills observed for the highest group in socialization and daily living skills. Compared to the lowest skill trajectory, higher levels of mastery motivation in early childhood increased the likelihood of following the middle and highest skill trajectories across subscales. Children whose mothers displayed more sensitive and growth-fostering behaviors during early interactions were significantly more likely to follow the middle or highest trajectories of socialization. These associations were observed while controlling for family income and children’s cognitive skills.

Discussion: This is the first study we are aware of in which group-based modeling has been used to examine trajectories of skills in children with DD. The results suggest that early childhood persistence on challenging tasks has positive associations with trajectories of skill development. In addition, mothers’ behavior during early interactions with their child with DD was found to have long term associations with socialization skills. These results have valuable implications for early child and parent interventions that may impact long term development.
A Longitudinal Examination of Adaptive Behavior in Adolescents and Adults With ASD
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Introduction: Adaptive behaviors are skills necessary for age-appropriate, independent functioning in social, communication, daily living, or motor areas. Past research has indicated that adaptive behaviors are significantly delayed for children with autism spectrum disorders (ASDs) relative to typically developing peers. Adaptive behaviors likewise have been suggested to be an important predictor of adult outcomes. However, less attention has been given to studying adaptive behavior in individuals with ASD during adolescence and adulthood and how these behaviors may change over time. For the present study, we explored the level and change in adaptive behavior in three domains (communication, socialization, and daily living skills) in a sample of adolescents and adults with ASD.

Methods: Participants were 259 adolescents and adults with ASD drawn from an ongoing, longitudinal study, the Adolescents and Adults with Autism study (AAA). The present study focused on three points of data collection, Times 4, 7, and 8, covering a time period of almost 6 years. At Time 4, individuals with ASD were between the ages of 14 and 53 (M=26.0, SD=9.6) and 57.1% were coresiding with their family. Further, 68.7% of the sample had an intellectual disability (ID). Adaptive behavior was measured using the Vineland Screener (Sparrow, Carter, & Cicchetti, 1993), which provides standard scores (M=100; SD=15) analogous to the full Vineland Scales of Adaptive Behavior in three domains (communication, daily living skills, and socialization) in addition to an adaptive behavior composite score. Personal characteristics were measured as potential covariates including age, sex, ID status, and residential status.

Results: Results indicated that individuals with ASD, on average, had adaptive behavior scores in all domains significantly below norms at all three time points. For individuals with ASD without ID, average adaptive behavior composite scores were 67.3 (SD=13.3), 60.7 (SD=15.4), and 72.4 (SD=15.1) at Times 4, 7, and 8, respectively. For individuals with ASD and ID, average adaptive composite scores were 33.8 (14.20), 34.8 (14.9), and 34.0 (14.1) at the same time points. Similarly low scores were found for the individual domain scores, although daily living skills were the highest of the domains (at Time 4, M=87.7 for individuals without ID and M=45.1 for individuals with ID). When exploring the percent of individuals who evidenced a half standard deviation change or greater from Time 4 to Time 8, results suggested stability in adaptive behavior over time, particularly for individuals with ID. Specifically, for individuals without ID, 12% demonstrated a decline in adaptive behavior composite scores, 44% evidenced no change, and 44% showed improvements. For individuals with ID, 18% declined in adaptive behavior composite scores, 66% remained stable, and 16% improved. Differences between individuals without ID and those with ID were particularly striking in the area of daily living skills; those without ID gained, on average, over 10 points in daily living skills during the study period compared to only 2 points gained in the ID group. Next, latent growth curve models were used to explore trajectories of adaptive behavior for the sample across the study period. Models indicated significant improvements, on average, in the socialization domain as well as significant improvements in the daily living skills domain, particularly for individuals without ID. Notably, there was no significant change in communication scores even after controlling for possible covariates (ID, residential status, sex).

Discussion: On average, adolescents and adults with ASD had low adaptive behavior scores relative to norms. Adaptive behavior scores evidenced stability over time, particularly in the communication domain. Findings suggest that even for individuals without ID, autism continues to be a significant disability requiring supports for independence across the life course.

Key References:
Introduction: The transition from adolescence to adulthood is a time of amplified risk for individuals with autism spectrum disorders (ASD). It is unknown, however, whether problems in employment and educational attainment in the years immediately after high school exit represent “momentary perturbations” in development or a “turning point” in development with long-lasting effects throughout adulthood. The present study addressed this question by examining 10-year trajectories of vocational outcomes for adults with ASD, as well as the personal characteristics and environmental resources that predicted outcomes.

Methods: Participants were 161 adults with ASD (ages 18-52 at the start of the study, M=30.9 years) who were part of a larger longitudinal study, and who had all exited high school prior to the start of the study. Approximately three-fourths (72%) of the sample was male and 80.7% had an intellectual disability (ID). Data were collected at 6 time points over a 10-year period. Vocational Outcomes were measured at each time using the Vocational Index (Taylor & Seltzer, 2010). This index is composed of nine ordered categories, ranked on a scale from 1 to 9; ordering of categories reflects the independence necessary to achieve a vocational/educational activity, as well as whether the adult participated in activities for more than a minimal amount of time (range of 1 = no activities to 9 = competitive employment or degree-seeking, post-secondary education). Independent variables included indicators of personal characteristics (ID; sex; autism symptoms; maladaptive behaviors; independence in activities of daily living) and environmental resources (family income; number of services; unmet service needs; maternal support).

Results: Multi-level models were used to examine whether personal characteristics and environmental resources were related to 1) concurrent Vocational Index scores (Time 1 scores); 2) Vocational Index scores measured 10 years later (Time 6 scores); and 3) change in Vocational Index scores over time (slope). Changes in maladaptive behaviors, autism symptoms, and residential placement were controlled as time-varying covariates. Overall, Vocational Index scores were declining over the 10-year study period, $B = -.04$, $p < .05$, with less than one-quarter of the sample (24%) evidencing any improvement. Greater declines were observed for females relative to males, $B = -.09$, $p < .05$. On average, Vocational Index scores of females with ASD declined over 1 full point on the 9-point scale; this decline was 4 times greater than what was observed for males. Personal characteristics of the adult with ASD predicted higher Vocational Index scores at Time 1 and Time 6, including no comorbid ID ($Bs = 1.55$ and 1.10 for Time 1 and Time 6, respectively, $ps < .01$), more independence in activities of daily living ($Bs = .06$ and .06 for Time 1 and Time 6, respectively, $ps < .05$), fewer maladaptive behaviors ($B = -.04$, $p < .05$ for Time 6), and fewer autism symptoms ($B = -.11$, $p < .05$ for Time 6). Environmental resources were not related to Vocational Index scores.

Discussion: On average, adults with ASD were losing ground in their vocational and educational activities over the 10-year study period - particularly females. Discussion will focus on the role of sex, independence in activities of daily living, and behavior problems in the vocational activities of these adults.

Key References:
POWERFUL PREDICTORS: AN UPDATE ON THE ROLE OF FAMILY AND SCHOOL EXPERIENCES IN THE DEVELOPMENT OF CHILDREN WITH IDD

Chairs: Cameron L. Neece, Loma Linda University

Discussant: Ann Kaiser, Vanderbilt Kennedy Center, Vanderbilt University
Powerful Predictors: An Update on the Role of Family and School Experiences in the Development of Children With IDD

Chair: Cameron L. Neece, Loma Linda University
Discussant: Ann Kaiser, Vanderbilt Kennedy Center, Vanderbilt University

Maternal Self-Efficacy, Stress, and Depression in Families With Preschoolers With Autism and Other Developmental Disabilities
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Autism and Parenting Stress: The Role of Behavior Problems
Allyson Davis *APA Award Winner*
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Loma Linda University

Student-Teacher Relationships in Early Elementary School and Impact on Later Academic Engagement
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Resilient Parenting of Children With Intellectual Disability Across Middle Childhood
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Student-Teacher Relationships In ASD: The Parent Perspective
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Introduction: There is a robust body of evidence suggesting that parents of children with developmental disabilities (DD), including autism spectrum disorders (ASDs), report more psychological distress and depression than parents of typically developing children (Baker et al., 2003; Estes et al., 2009). The negative impact and burden is exacerbated by the presence of child problematic behaviors (Lecavalier et al., 2005). Furthermore, research suggests a bidirectional effect of behavior problems and stress over time (Neece et al., 2012). Parenting self-efficacy, or parental feelings of competence in their role as parents, has been associated with well-being and positive parenting outcomes (e.g., Kuhn & Carter, 2006). Understanding and promoting parenting self-efficacy may prove useful in supporting the well-being of parents and children with disabilities. The purpose of this study was to investigate predictors of parenting self-efficacy in families with preschool-aged children with ASD and DD.

Methods: This study was part of a larger investigation of family-based early intervention for families with pre-school-aged children with DD (McIntyre, PI). Families with children with DD (n = 58) and ASD (n = 40) were recruited from early intervention and early childhood special education programs. Children with DD ranged in age from 2-5 years (M = 46.81 months). Data were collected through extensive in-home interviews and assessments of family demographics, parenting stress and competence/self-efficacy (PSI-3; Abidin, 1995), depression (CES-D; Radloff, 1977), family impact (FIQ; Donenberg & Baker, 1993), and child functioning (Vineland Adaptive Behavior Scales; Child Behavior Checklist).

Results: Family demographic variables (maternal education, employment, and family income), child diagnosis (ASD vs. DD), child functioning variables (adaptive behavior and problem behavior), and parenting distress variables (family impact and depression) were entered in a hierarchical linear regression predicting parenting self-efficacy. The full model accounted for 55% of the variance on parenting self-efficacy. After controlling for family demographics, children’s adaptive behavior, negative family impact, and depression significantly predicted parenting self-efficacy. Although there was a significant relation between child behavior problems, problem behavior was no longer a significant predictor of parenting self-efficacy after accounting for the effects of the other variables in the model. Children’s diagnosis (ASD vs. DD) was not significantly related to parenting self-efficacy. Discussion: Results suggest that parental self-efficacy is related to a number of child and family characteristics. Interventions aimed at reducing child behavior problems and parenting stress and depression may be important for empowering parents and enhancing their feelings of competence and positive parenting behavior.

Key References:


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SYMPOSIUM 8

Autism and Parenting Stress: The Role of Behavior Problems

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Introduction: Parents of children with developmental disabilities (DD) have been shown to have very high levels of parental stress (Baker, McIntyre, Blacher, Crnic, Edelbrock, & Low, 2003; Webster, Majnemer, Platt, & Shevell, 2008), and the stress experienced by these parents appears to be better accounted for by elevations in child behavior problems rather than intellectual or developmental functioning (Baker, Blacher, & Olsson, 2005; Neece, Green and Baker, 2012). Among children with developmental delays, children with autism spectrum disorders (ASD) have been found to have the highest levels of behavior problems and, in turn, parents of children with ASD typically show the highest stress levels (Eisenhower, Baker, & Blacher, 2005; Jang, Dixon, Tarbox, & Granpeesheh, 2011; Kozlowski & Matson, 2012). The relationship between child behavior problems and parenting stress appears to be reciprocal such that child behavior problems lead to increases in parental stress which further exacerbate the child’s behavior problems (Baker et al., 2003; Pesonen et al., 2008; Neece et al., 2012).

Despite the host of research demonstrating a link between behavior problems and parenting stress among families of children with delays, little research has examined the specific behavior problems that are most common in this population and how these specific behavior problems relate to parental stress. In addition to knowing little about the specific behavior problems that are endorsed and their relationship to parental stress, we also do not know how these behavior problems impact changes in parental stress over time. The research questions we examined in the current study were: (1) Which behavior problems on the CBCL did parents of children with ASD most commonly endorse? (2) Among behavior problems most commonly endorsed by parents of children with ASD, which items were associated with parenting stress and, among those associated, which items uniquely predicted parental stress levels? (3) Did the behavior problems endorsed on the CBCL moderate changes in parenting stress as a result of a stress-reduction intervention?

Method: The current study involves data from the Mindful Awareness for Parenting Stress (MAPS) Project, which included 44 parents of children, ages 2.5 to 5 years old, with ASD. These parents participated in a randomized controlled trial examining the efficacy of Mindfulness-Based Stress Reduction (MBSR) in reducing parental stress and subsequent child behavior problems. Parenting stress was measured using the Parenting Stress Index (PSI, Abidin, 1990) and behavior problems were assessed with the Child Behavior Checklist (CBCL, Achenbach & Rescorla, 2000).

Results: Post-treatment PSI scores showed significant reductions after the MBSR intervention. Hierarchical regression analyses were used to predict parenting stress from the child behavior problems most frequently endorsed and to examine how those behavior problems moderated the effectiveness of MBSR in reducing parental stress. Two behavior problems, “doesn’t answer when people talk to him/her” and “temper tantrums or hot temper,” significantly predicted parenting stress levels, $B = 7.77, t(36) = 3.24, p < .01$ and $B = 3.47, t(36) = 2.26, p < .05$, respectively. Additionally, one behavior problem, “Doesn’t answer when people talk to him/her”, significantly predicted change in parenting stress as a function of the intervention, $B = -8.49, t(25) = -2.46, p < .05$, such that parents who endorsed this behavior problem at the highest level showed the greatest reductions in parental stress.

Discussion: Knowing which behavior problems are most difficult for parents allows for the tailoring of behavioral interventions to the needs of the parents. Those behavior problems that have the greatest negative impact on parental stress are ideal targets in interventions. Additionally, “doesn’t answer when people talk to him/her” is a core symptom of ASD, yet there is little intervention directed at helping parents deal with these internalizing behavior problems such as this one. Therefore, Mindfulness Based Stress Reduction may serve as a valuable intervention for parents of children with ASDs.
Aim: Teachers have many roles that make them influential in a child's overall development at school. The relationship formed between teachers and students early on may foreshadow adjustment and functioning of the student in later school years. This study aimed to assess the impact of student-teacher relationships in early elementary school and their impact on later academic engagement in middle school of children with typical development and those with intellectual disability.

Methods: A conditional latent curve model was fit to data from a subsample of the longitudinal Collaborative Family Study dataset (n=84) and used to examine the effects of the student-teacher relationship (STR) change over time (ages 6-9) in predicting academic engagement at age 13 for both typically developing (TD) children and those with intellectual delays (ID). This model was then expanded to include the child characteristics of social skills and behavior problems in predicting STR.

Results: Results indicated that age 6 STR's predicted academic engagement at age 13; students who experienced more positive STR's very early in elementary school had higher levels of academic engagement in middle school. In addition, the child characteristics of social skills and behavior problems were predictive of the STR, and accounted for more variance within academic engagement than the STR alone.

Conclusions: The results of this study are consistent with the literature and highlight the impact of social skills and behavior problems on STR and later academic engagement, especially in the early school years. The longitudinal impact of relationships formed at a young age is also emphasized within these findings underscoring its importance for later formative experiences. This impact speaks to the importance of providing target individuals with the tools to combat these deficit areas and potentially lead to more positive STR's and thus produce higher levels of academic engagement in years to come.
Introduction: Most resiliency research has focused on child outcomes, and across studies there is consistent evidence for positive parenting as a strong protective factor. Yet, while parenting is often examined as a predictor of children’s developmental outcomes, it is rarely focused on as the outcome domain of interest (Luthar, Sawyer, & Brown, 2006). Given the great benefits of effective parenting to child development, it is important to understand why some parents manage to be effective in their parent-child interactions in spite of formidable challenges. A previous study examined resilient parenting from child age 3 to 5, focusing on the risk factors of child intellectual disability (ID), child behavior problems, and low family income. Results suggested that mother education, optimism, and health act as protective factors for positive parenting in the face of risk (Ellingsen & Baker, in preparation). In the current study we expand upon these results by examining resilient parenting and its impacting factors through middle childhood.

Methods: Data were obtained from 156 families at child ages 5 and 8. Using an adapted ABCX model, we examined four risk domains, (A): child ID, child behavior problems, child poor health, and low family income. The outcome of interest is positive parenting behaviors in mothers (X). We hypothesized that each of these risk factors would predict poorer parenting (A - X), and that the effect on parenting behavior would be cumulative when more than one risk factor was present. We also hypothesized that higher levels of resources (B: mother education and health) and cognitions (C: mother dispositional optimism) would buffer the A-X relationship; i.e. they would, in the face of child risk, increase the likelihood of positive parenting (resilience).

Results: Child ID, child poor health, and low family income at age 5 predicted less positive parenting at age 8. Child behavior problems, however, were not associated with parenting. Therefore, child ID, child poor health, and low family income were combined into a risk index, and as the risk index rose from 0 to 3 risk factors, levels of positive parenting decreased accordingly (p<.05). Level of risk alone predicted lower levels of positive parenting (p<.01), but when the three protective factors were included in the model, higher level of risk was no longer a significant predictor of parenting. Higher levels of mother education (p<.05), health (p<.10) and optimism (p<.01) at child age 5 each predicted higher levels of positive parenting at child age 8. There were no significant interactions between risk and protective factors.

Discussion: The current study examined what factors lead to positive parenting in the face of risk across middle childhood, a realm that has been largely neglected in the literature (Luthar et al., 2006). The results provide important preliminary evidence in this area. Limitations, future directions, and implications for intervention will be discussed. For example, optimism appears to be an important protective factor for positive parenting and there is evidence that optimism can be learned (Seligman, 2002). Parents with the risk factors identified in this study (and possibly others illuminated by future research) should be targeted for such parenting interventions that shift the focus from problems to strengths and opportunities.

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SYMPOSIUM 8

Student-Teacher Relationships In ASD: The Parent Perspective

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Introduction: As a child's first teacher the academic, social and behavioral goals, set forth by the parent have long-term consequences, are established early on, and ideally carry forward as the child transitions to school (O'Connor & McCartney, 2006). However, if these goals are not aligned with those of the teacher, conflict between the parent and teacher may arise, which could negatively impact the student-teacher relationship and lead to suboptimal outcomes for the child (Powell, 2010). Furthermore, research indicates that teacher's perceptions of the student-teacher relationship may be strongly correlated with their perceptions regarding their relationship with the parent, especially for students who exhibit high levels of externalizing and internalizing behaviors (Thijs & Eilbracht, 2012). However, little is known about student-teacher relationships for young children with high-functioning autism spectrum disorders (ASDs). The aim of this study is to understand student-teacher relationships from the parent-perspective. A secondary aim is to determine whether parents' views of the student-teacher relationship maps on to the actual teachers' reports.

Method: This paper includes data from the first cohort of 50 children and their mothers. Child IQ scores were obtained from the WPPSI-III (Wechsler, 2002). All children had an ASD diagnosis confirmed for research purposes using the Autism Diagnostic Observation Schedule (ADOS; Lord, Risi, Lambrecht, Cook, Leventhal, et al., 2000). Child classroom placement and mother variables (e.g. age, education) were derived from the Family and Child Background Survey. Home-School variables were obtained from the following: 1) semi-structured parent interviews; 2) Parent-Teacher-Involvement Scale (NICHD, 2005); 3) Parent Perception Measure (MacMullin et al., 2010); 4) Child's School Experiences & Relationship with Teacher Scale (Eisenhower, 2008); 5) Student Teacher Relationship Scale, STRS (Pianta, 2001).

Results: Of the 50 children (M age = 5.8 years; M IQ = 91.7), 13 attended a special education class for more then 50% of the school day; 28 were enrolled in a general education classroom 76-100% of the time and received some special education services; 9 participants attended a general education classroom setting and received no specialized services. Classroom placement appeared to make a difference in parent-teacher and student-teacher relationships. Parents of children with ASD in special education classrooms reported that their child's teacher is more open to their concern's (p < 0.05), more knowledgeable about the child's disability (p< 0.05) and more willing to communicate about the child's specific needs (p < 0.05). Furthermore when all participants who received any special education services were included, parents reported that the teacher was more likely to meet the child's individual needs (p< 0.05). Finally, Cohen's Kappa revealed that the parents' and teachers' reports of the quality of the student-teacher relationship showed very poor levels of agreement.

Discussion: It appears that the quality of the student-teacher relationship is related to student placement for children with ASD. This may be due in part to the fact that special education teachers have more specific knowledge of their students' disability, have smaller class sizes and are able to adapt the pace of instruction to suit their students' needs. Further analyses will examine how child characteristics affect these relationships. The validity of the construct of student-teacher relationship will also be discussed.
EARLY IDENTIFICATION OF CHILDREN MOST AT RISK FOR DEFICITS IN SPOKEN LANGUAGE

Chair: Ann Kaiser, Vanderbilt Kennedy Center, Vanderbilt University

Discussant: Leonard Abbeduto, University of California-Davis
SYMPOSIUM 9

Early Identification of Children Most At Risk for Deficits in Spoken Language

Chair: Ann Kaiser, Vanderbilt Kennedy Center, Vanderbilt University
Discussant: Leonard Abbeduto, University of California-Davis

Using Language Comprehension Data to Refine Early Language Interventions for Young Children With Developmental Disabilities
Mary Ann Romski
Rose A. Sevcik
Georgia State University

Preverbal or Nonverbal? Predictors of Spoken Language In Toddlers With ASD
Amanda Gulsrud
Amy Fuller
Connie Kasari
University of California-Los Angeles

Identifying Functional Language Deficits in Young Children With Cleft Palate
Jennifer Frey¹
Ann Kaiser²
¹The George Washington University
²Vanderbilt Kennedy Center, Vanderbilt University
Introduction: Language comprehension serves as an important foundation for the development of expressive language for typically developing children and children with developmental disabilities (Bates, 1979; Benedict, 1979; Goldin-Meadow, Seligman, & Gelman, 1976; Sevcik, 2006). Children develop competency in the receptive domain prior to competency in the expressive domain (Benedict, 1979; Goldin-Meadow et al., 1976). By the time they are 12- to 15-months old, typically developing children often understand an average of approximately 50 words, but they usually produce only about 10 words (Benedict, 1979). Children generally take about twice as long to produce 50 words, when compared to comprehension. It is only with understanding of the communication of others that children can begin to produce meaningful communication and fully assume the roles of listener and speaker in the communication exchange. The purpose of this presentation is to explore how language comprehension data can serve as the basis for refining early language interventions for children with minimal language comprehension skills.

Methods: Romski, Sevcik, Adamson, Cheslock, Smith, Barker, & Bakeman (2010) compared the language performance of 62 young children with developmental delays who were randomly assigned to 1 of 3 parent-coached language interventions: augmented communication input (AC-I), augmented communication output (AC-O), or spoken communication (SC). Differences in performance on augmented and spoken word size and use, vocabulary size, and communication interaction skills were examined.

Results: All children in the AC-O and AC-I intervention groups used augmented and spoken words for the target vocabulary items, whereas children in the SC intervention produced a very small number of spoken words. Expressive vocabulary size was substantially larger for AC-O and AC-I than for SC groups. While we did not control for receptive language skills, in a follow-up study, Barker, Romski, Sevcik, Smith, Adamson, and Bakeman (2012) reported significant positive main effects of extant receptive language skills on all three outcome variables. Intervention focus was a moderator for expressive language age and target vocabulary size. Children in the AC-I intervention demonstrated a stronger positive relationship between extant receptive language and expressive language compared to children in the other interventions. Children in the SC intervention demonstrated no relationship between extant receptive language and target vocabulary size, while children in both of the augmented interventions demonstrated strong positive relationships.

Discussion: Using these data as a foundation, this presentation will articulate language comprehension measurement issues and how early language intervention protocols for young children with little or no speech comprehension can be refined to enhance their effectiveness.
Preverbal or Nonverbal? Predictors of Spoken Language In Toddlers With ASD

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Introduction: Developing spoken language during the preschool years is regarded as one of the primary goals of early intervention for children with an autism spectrum disorder (ASD) and a prognostic indicator of a positive social outcome (Rutter, 1978). However, nearly 30-40% of children enter primary school ‘nonverbal’ i.e., with only minimal verbal skills (Anderson et al, 2007). Over the past fifteen years, early intervention researchers have focused on better understanding the active ingredients necessary to improve spoken language outcomes for children with ASD. Much progress has been made. Kasari et al (2012) followed children in a previous randomized controlled trial to determine predictors of later language development. Initiating joint attention, play level, chronological age, expressive language scores, and whether or not children received one of two experimental interventions focused on joint attention and play were associated with better language outcomes. Thus, these data confirm the importance of early joint attention and play skills as targets for early intervention. The Kasari et al study assessed children between 3 and 4 years of age and followed them over five years. One important predictor was age with younger children performing better at the five-year follow up. Currently children are beginning early intervention at even younger ages. Thus, determining if the predictors of later language outcomes for toddlers are the same as those for older children is needed, as early intervention programs must adapt their interventions for these very young children.

Methods: In the current study 72 toddlers (22 to 36 months) diagnosed with ASD (ADI-R and ADOS) were measured at two time points across nine months to determine predictors of language outcome, as well as the numbers of children who changed from preverbal to verbal status over this time frame. All children were attending the same intensive early intervention ABA program for young children with autism. Children’s average chronological age was 31 months (3.21) and mental age averaged 20.5 months. The majority of children in the sample were Caucasian (60.5%) and male (80%) and most mothers had some college. Children were assessed on the Reynell and Mullen at entry to the study and approximately 9 months later. Other measures included social communication skills observed in a caregiver child interaction.

Results: Using a cutoff of 12 months expressive language age on the Reynell (corresponding to no single words), 36 of the 72 participants (50%) scored less than 12 months at entry. At the 9-month data point only 10 of these 32 children remained nonverbal, 13.9% of the entire sample. Stepwise multiple regression was utilized to select a minimum set of meaningful predictors. Significant predictors included non-verbal cognition (Mullen), ADOS Social Affective scores, and symbol-infused states of supported joint engagement, object engagement, and coordinated joint engagement (F(6,65)= 18.917, p<.01, R2=.61).

Discussion: Results suggest that over 85% of toddlers receiving intensive interventions achieve verbal ability over 9-months later suggesting that most are preverbal at these early ages. Nonverbal cognition, severity of autism diagnostic scores and symbol-infused engagement states predict children who remain minimally verbal at 4 years. Intensifying and altering interventions may be necessary to put all children on a positive course to spoken communication.

Key References:


SYMPOSIUM 9

Identifying Functional Language Deficits in Young Children With Cleft Palate

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Introduction: Cleft lip and/or palate (CLP) is the fourth most common birth defect and affects an estimated one in every 750 births in the United States (Cleft Palate Foundation, 1999; Kummer, 2008). Currently, most children with CLP have their initial palate repairs around 12 months of age. Although speech development may improve after surgery, delays in mastery of speech sounds still are observed. Children with repaired CLP continue to be at-risk for delays in speech sound acquisition and early language development following palate repair (Chapman & Hardin, 1992). The purpose of this study was to examine the speech and language skills of young children with and without CLP.

Methods: Thirty-eight children between 15- and 36-months-old participated in this study. Data for this study were selected from two samples: (a) 19 children with repaired CLP and (b) 19 children with typical language development (TL). Children participated in language evaluations in the clinic. Language skills were assessed using (a) standardized, norm referenced assessments; (b) play-based language samples with a clinician; (c) parent-child interactions of play, book reading, and snack; and (d) parent report. Assessment results across measures were compared for the CLP and TL groups.

Results: No significant differences were observed between the CLP and TL groups on standardized cognitive and language measures, and mean standard scores fell within the average range for both groups. Significant differences were observed, however, in the spoken language of children with and without CLP as measured by mean length of utterance in morphemes (MLUm), total number of words spoken (TNW), number of different words (NDW) used, and words spoken per minute (WPM) in language samples and parent-child interaction sessions. In language samples, no significant differences in MLUm were observed between the two groups (F (1, 36) = 2.085, p = 0.157), but significant differences in NDW and TNW were observed between children with and without CLP. Children with CLP had fewer NDW (F (1, 36) = 7.174, p = 0.011) and fewer TNW (F (1, 36) = 10.635, p = 0.002) compared to children with typical speech and language development. During play-based parent-child interaction sessions, there were significant differences in MLUm (F (1, 36) = 4.012, p = .053), TNW (F (1, 36) = 6.576, p = .015), and WPM (F (1, 36) = 4.074, p = .051) between children with and without CLP. Children with typical language had higher MLUm and spoke more WPM than children with CLP.

Discussion: The significant differences observed in the spoken language of children with and without CLP suggest a possible functional language deficit for young children with CLP. The results of this study have several implications for assessment and early intervention for young children with CLP. First, measurement context and type must be considered when evaluating language skills of children with CLP. Second, observed differences in spoken language of children with and without CLP suggest there may be a gap between language competence and language performance for children with CLP. To address this gap, increasing language productivity (e.g., TNW, WPM) and the complexity of spoken language (e.g., MLUm) should be targets of early intervention. Third, observed differences in child language use during the language sample and the parent-child interaction session suggest a need for cross setting support and intervention in multiple contexts to increase the verbal productivity with less familiar conversational partners. The target of early language intervention for children with CLP may be to close the gap between language competence and language production across partners and contexts as well as to address speech production skills.

References:

BIOLHEAVIORAL EXAMINATION OF DEVELOPMENT IN INFANTS AND TODDLERS ACROSS THE FRAGILE X SPECTRUM OF INVOLVEMENT

CoChairs: Jane E. Roberts, University of South Carolina

Heather Cody Hazlett, University of North Carolina-Chapel Hill

Susan Rivera, MIND Institute, University of California-Davis

Discussant: Don Bailey, RTI International
SYMPOSIUM 10

Biobehavioral Examination of Development in Infants and Toddlers Across the Fragile X Spectrum of Involvement

Co-Chairs: Jane E. Roberts, University of South Carolina
Heather Cody Hazlett, University of North Carolina, Chapel Hill, Carolina Institute for Developmental Disabilities
Susan Rivera, MIND Institute, University of California-Davis

Discussant: Don Bailey, RTI International

Heart Activity and Visual Attention in Infants At High Risk for Autism
Bridgette L. Tonnsen
John E. Richards
Sara Deal
Jane E. Roberts
University of South Carolina

Evidence of Visual Processing Impairments In Infants With the Fragile X Premutation
Susan M. Rivera
MIND Institute, University of California-Davis

Development and Behavior Profiles of Infants Identified With an FMR1 Expansion During Newborn Screening
Anne Wheeler¹
Don Bailey²
Christina Prescott²
Anna De Sonia²
Elizabeth Berry-Kravis²
Randi Hagerman³
Susan Rivera³
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An Examination of Early Brain Volume Development in Fragile X
Heather Cody Hazlett¹,²
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Joseph Piven¹,²
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Introduction: Atypical behavioral patterns of visual attention have been documented in both infant siblings of children with autism and infants with fragile X syndrome (FXS) and may serve as a robust early indicator of autism in high risk samples. Attention requires the integration of complex, co-occurring cognitive processes, thus overt eye gaze may not reflect underlying cognitive engagement in a stimulus. In non-clinical infant samples, patterns of heart rate (HR) variability have been used to supplement behavioral data by indexing infants’ engagement in environmental stimuli (e.g. Casey & Richards, 1988). Sustained attention is a period during which infants exert increased cognitive resources to process stimulus details, as reflected by maintenance of decelerated heart rate. Examining sustained attention may be particularly useful to examine autism in neurodevelopmental disorders, as previous studies have demonstrated an association between autistic symptoms and arousal modulation in FXS and idiopathic autism. However, no published studies have applied this method during computerized attention tasks to compare infants at high- and low-risk for autism. The present study examined mean levels and variability in heart rate during visual attention tasks in three groups at varied risk for autism: high-risk infant autism siblings (ASIB), high-risk infants with FXS, and low-risk (LR) typically-developing controls. We hypothesized that compared to LR controls, infants with FXS and ASIBs would demonstrate faster HR and less variability in HR during attention tasks. Infants with FXS and ASIBs will also spend less time in SA and exhibit shallower declarations in HR during SA.

Methods: Participants included infants with FXS (n=8), ASIBs (n=13), and low risk controls (n=15). Infants were tested at 6 (ASIB and LR only), 9, and 12m of age. Data were collected using a telemetry-based, noninvasive monitor. Heart activity was measured during two visual attention experimental tasks: (1) passive viewing of an engaging children’s video and (2) structured viewing of an experimental task designed to measure attention orienting.

Preliminary Results: We have examined HR during the experimental task in a subset of our sample (FXS=3, ASIB=8, LR=14). Descriptive statistics suggest that compared to LR and ASIB groups, infants with FXS display faster mean HR at 9m [FXS=418.11(20.58), ASIB=468.30(26.81), LR=463.14(33.20)] and faster mean HR and less variability in HR at 12m [FXS=461.86(15.68), ASIB=494.43(53.13), LR=478.78(31.55)]. Contrary to our expectations, ASIBs appear to demonstrate greater variability in HR at 12m and similar mean levels of HR to LR controls at each time point. Our presentation will examine these analyses in an expanded sample, as well as tease apart variability in heart rate by examining duration and depth of sustained attention in these groups.

Discussion: Previous studies have associated autism symptoms with atypical behavioral attention in high risk samples. Our data suggest examining variability in HR may further inform these relationships by indexing physiological indicators of engagement. Our results will be discussed in relation to theoretical models of self-regulation, attention, and autism in FXS. We will also apply our findings to early identification efforts.

References:
Evidence of Visual Processing Impairments In Infants With the Fragile X Premutation

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Introduction: Fragile X syndrome (FXS) results from a trinucleotide repeat expansion (full mutation > 200 CGG repeats) in the FMR1 gene, leading to a reduction or absence of the gene's protein product, FMRP, ultimately causing cognitive and behavioral impairments that are characteristic of the syndrome. In our previous work on infants and toddlers with the FXS, we have been able to describe much about their cognitive and visual processing abilities. We now know that they appear not to have low-level magnocellular pathway deficits (1); have intact ventral stream functioning (2, 3); that dysfunctions of the dorsal stream appear to be limited to those visual events that implicate attentive tracking mechanisms (2, 3); that the spatial resolution of visual attention in infants with FXS seems to be intact, while the temporal resolution of attention is affected (1). In light of recent work on the mild cognitive deficits and functional and structural brain differences that are present in adults with the FX premutation (4,5), in the present study we examined whether some of the low-level visual processing deficits we have observed in infants FXS would also be present in infants with the FX premutation (54-200 CGG repeats). Namely, we chose a contrast detection task using second-order motion stimuli on which infants with FXS showed significantly increased detection thresholds.

Method: Using a Tobii 1750 binocular eye tracker, we collected gaze data on 18 infants with the FX premutation, who came to our study in one of three ways: (a) they were identified through newborn screening (n=7); (b) they were the sibling or child of a proband who was seen in our Fragile X Research and Treatment Center (FXRTC) and identified through cascade testing (n=9); or (c) their parents self-referred to the FXRTC, having obtained a diagnosis for their child by some other means (n=2). Second-order motion stimuli were created with a dynamic random-dot Gabor pattern (each dot was 0.2 by 0.2 deg), modulated by a contrast-defined sinusoid, which was .35 cyc/deg that drifted at 4Hz. Contrast modulation was varied at 4 levels: 10, 21, 31, and 42%. Stimuli were presented within a 3 sec temporal Gaussian window (fading in and out of view).

Results and Conclusion: In this group of non-clinically referred infants with the FX premutation, we observed similar second order motion deficits to those we observed in infants with FXS (3). While a group of TD infants matched on mental age show the typical response we observed for second order motion in our published FXS study (i.e., a 75% detection threshold at 20% contrast and above) infants with the FX premutation, like those with FXS, exhibited a 75% detection threshold only at the highest contrast level (40%). These results, which are in keeping with a growing body of evidence on the mild cognitive deficits and functional and structural brain differences that are present in adults and older children with the FX premutation, underscores the pressing need to study and describe the processing capabilities of infants and toddlers with the FX premutation.


Farzin F, Rivera SM. Dynamic Object Representations in Infants with and without Fragile X Syndrome. Front Hum Neurosci.4:12.


Development and Behavior Profiles of Infants Identified With an FMR1 Expansion During Newborn Screening

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Introduction: Emerging literature on individuals with premutation FX suggests potential developmental and behavioral variations, including increases in risk for child psychopathology such as autism, ADHD and developmental and learning problems, beyond what would be expected for individuals without an FMR1 expansion (Bailey et al., 2008; Clifford et al., 2007; Farzin et al., 2006). However, very little is known about the early development of children with premutation FX, and to date, no studies have explored the early development of infants and toddlers with a premutation who are themselves the proband for the family. This study examined early development and behavior profiles of infants with the premutation who were identified as part of a study on newborn screening for fragile X (FX).

Methods: Families whose infants screened positive for an expansion of the FMR1 gene were invited to participate in a longitudinal study of outcomes of newborn screening. Matched control families whose infants screened negative were also recruited. Thirty two infants (16 with premutation FX, 16 controls) and their families participated in this study. Participants were recruited from three sites (UNC-Chapel Hill, UC Davis, Rush Medical Center) and participated in between 1-5 assessments between the ages of 6 months and 4 years of age. Data on the child’s early developmental skills, communication, adaptive behavior, temperament and sensory behaviors were collected.

Results: Preliminary results of the child assessments suggest differences as young as 18 months between the groups in early development. Scores on the Visual Reception and Fine Motor scales of the Mullen Scales of Early Learning were lower over time for the FX group, in contrast to the TD group whose scores stayed consistent and average over time. Further, differences in sensory sensitivity as reported on the Sensory Experiences Questionnaire were found for the FX group in comparison to their TD matches.

Discussion: Newborn screening for FXS will also identify infants with the premutation. This has implications for families as well as for the potential for early intervention for the children. Increased risk for later developmental and psychiatric challenges in individuals with the premutation, as well as the trends towards differences in very early development between the infants with and without the premutation in this study suggest a need for more research on outcomes for carrier infants.

Key References:


SYMPOSIUM 10

An Examination of Early Brain Volume Development in Fragile X

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Introduction: Our group has previously reported on a cross-sectional group of toddlers with Fragile X syndrome (FXS) (18-42 months old) with enlarged caudate nucleus (CN) and smaller amygdala (AMY) volume compared to controls, while the toddlers with idiopathic autism (iAUT) had only modest CN enlargement and significantly larger AMY. Voxel based morphometry (VBM) studies of this sample examined FXS compared to controls and found larger gray matter volume (GMV) in CN, thalamus, and fusiform gyrus and decreased GMV in cerebellar vermis present at both timepoints in the FXS group (2,3). White matter volume (WMV) was observed to be larger in frontal striatal regions in the boys with FXS compared to controls and became more pronounced over time (3). A cross-sectional comparison study using VBM (4) examined the FXS group compared to iAUT and observed different patterns of brain volumes in the iAUT and control group compared to FXS. In this report, we extend our previous work (1) by comparing the longitudinal brain volume data from this sample of boys with FXS to a sample of boys with iAUT.

Method: The study included 53 boys between 18-42 months of age with FXS, 68 boys with idiopathic autism (ASD), and a comparison group of 50 typically-developing and developmentally-delayed controls. We examined structural brain volumes using MRI across two timepoints between ages 2-3 and 4-5 years and examined total brain volumes and regional (lobar) tissue volumes. Additionally, we studied a selected group of subcortical structures implicated in the behavioral features of FXS (e.g., basal ganglia, hippocampus, amygdala).

Results and Conclusion: Children with FXS had greater global brain volumes compared to controls, but were not different than children with idiopathic autism, and the rate of brain growth between ages 2 and 5 paralleled that seen in controls. In contrast to the children with idiopathic autism who had generalized cortical lobe enlargement, the children with FXS showed a specific enlargement in temporal lobe white matter, cerebellar gray matter, and caudate nucleus, but significantly smaller amygdala. This structural longitudinal MRI study of preschoolers with FXS observed generalized brain overgrowth in FXS compared to controls, evident at age 2 and maintained across ages 4-5. We also find different patterns of brain growth that distinguishes boys with FXS from children with idiopathic autism. These findings have significance for expanding our understanding about the neurodevelopmental mechanisms underlying FXS. The presence of early brain differences in young children with FXS points to aberrant early brain development in this condition. These findings will be discussed in relation to data on infants with FXS from an ongoing longitudinal study of infant brain development.

References:


Symposium 11

WHICH CAME FIRST? ANXIETY, REPETITIVE BEHAVIOR, AND HOARDING IN PWS, ASD, ID, AND OCD

Chair: Elizabeth Roof, Vanderbilt Kennedy Center, Vanderbilt University

Discussant: William MacLean, University of Wyoming
SYMPOSIUM 11

Which Came First? Anxiety, Repetitive Behavior, and Hoarding in PWS, ASD, ID, and OCD

Co-Chairs: Elizabeth Roof, Vanderbilt Kennedy Center, Vanderbilt University
Discussant: William MacLean, Jr., University of Wyoming

Anxiety and Other Psychiatric Features in Prader-Willi Syndrome
Elizabeth Roof
Carolyn Shivers
Lauren Deisenroth
Caroline Oates Zeaman Award Winner
1Vanderbilt Kennedy Center, Vanderbilt University
2University of Alabama-Birmingham

Hoarding in Prader-Willi Syndrome
Elisabeth Dykens
Elizabeth Roof
Lauren Deisenroth
Loren Tilson
Vanderbilt Kennedy Center, Vanderbilt University

Prader-Willi Syndrome: Does Repetitive Behavior Change With Age?
Evon Lee
Carolyn Shivers
Vanderbilt Kennedy Center, Vanderbilt University

Repetitive Behaviors, Interests, and Reward in Autism and Anxiety Disorders
Jim Bodfish
N. Sasson
L. Turner-Brown
Cara Damiano
J. Richey
A. Rittenburg
S. Miller
A. Sabatino
E. Hanna
M. Kovac
1Vanderbilt Bill Wilkerson Center
2University of Texas-Dallas
3Virginia Tech University
4University of North Carolina-Chapel Hill
Anxiety and Other Psychiatric Features in Prader-Willi Syndrome

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Introduction: Anxiety is the most common form of psychopathology in the general population, with a 12-month prevalence rate of 18.5% (Kessler et al., 2005). Yet, anxiety is often overlooked in persons with ID because it may manifest differently and is an internal state which makes it difficult for caregivers to accurately report. Anxiety is a common feature in Prader-Willi syndrome and other developmental disorders like ASD, but may be underreported by parents and caregivers. Anxiety in PWS is reported less commonly than externalizing problems like: food stealing, temper tantrums, stubbornness, and verbal outbursts, though it may create more day-to-day problems for caregivers. Anxiety in PWS may be often related to food situations and be characterized by a number of observable behaviors including irritability, insistence on sameness, repetitive behaviors and thinking, constant questions about scheduled activities, avoidance and shutting down. These behaviors are often reported by caregivers, teachers and other professionals as behavioral hallmarks of PWS, though not often seen as anxiety-driven behaviors.

Methods: This study includes a sample of 169 individuals (80 males) with PWS aged 4 to 62 years (mean age=15.29, SD=10.94). Participants were recruited through our ongoing research program on PWS conducted at the Vanderbilt Kennedy Center. All participants had genetic testing to determine genetic subtype. Parents or caregivers completed an in-depth interview with a trained clinician to assess levels of past and current psychiatric symptoms (i.e., anxiety, obsessive compulsive symptoms, hyperphagia and repetitive behavior) using the K-SADS-PL, the Yale-Brown Obsessive Compulsive Scale (YBOCS), a Hyperphagia Questionnaire and the Repetitive Behavior Scales-Revised (RBS-R). Their offspring with PWS were also observed throughout the day in formal and informal settings by the same clinician to assess these behaviors and to determine diagnosis and severity of impairment. Parents also completed a medical history questionnaire to determine co-morbid health risk factors and medication use.

Results: 42% (71) of the PWS sample met full criteria for Obsessive-Compulsive disorder on the K-SADS-PL and were more likely to be taking any psychotropic medication than those who did not meet criteria. (x²=5.72, p <.05). 22% (38) of the PWS sample met full criteria for Generalized Anxiety Disorder (GAD) on the K-SADS-PL and also had significantly lower IQ's than those without GAD (t=2.07, p <.05). In addition, those with PWS diagnosed with GAD obtained the diagnosis at a significantly younger age (t=2.55, p <.05) than those who did not meet criteria. Total scores on RBS-R were positively correlated with scores on K-SADS-PL showing high levels of Stereotyped, Self-Injury, Ritualistic and Sameness behavior in those with PWS. Surprisingly, there were no gender or subtype differences on any these measures. There was also no correlation with hyperphagia which contradicts clinical lore, that hyperphagia drives anxiety in those with PWS.

Discussion: Using a standardized semi-structured interview, like K-SADS-PL, may be a more effective way to diagnose underlying psychiatric diagnosis than parent report alone. It is important for an experienced interviewer to help parents tease out daily accommodations that they make in order to make these symptoms less disruptive for families. Those with PWS may have a pattern of repetitive and other observable behaviors that may hint at underlying anxiety disorders and help pinpoint effective treatments.

Support of this work comes from NICHD grants P30 HD15052 and R01HD35684.
Prader-Willi syndrome (PWS), a genetic disorder caused by an absence of paternally-derived information on chromosome 5q11-q13, has a complex behavioral phenotype. Individuals are prone to hyperphagia, obesity, restricted and repetitive behaviors, and intellectual disabilities. Repetitive behaviors in PWS are increasingly well-described, previously in relation to those with obsessive-compulsive disorder (OCD) or other intellectual disabilities, and currently in relation to autism spectrum disorders and other syndromes. Compared to these other groups, hoarding is consistently elevated in PWS. The emergence of Hoarding Disorder as a new, distinctive diagnosis in the DSM-V may offer new insights into hoarding in PWS.

Methods: We examined repetitive behaviors, hoarding, and psychiatric status in 192 individuals with PWS aged 4 to 62 years (M = 15.07) using the Repetitive and Restricted Behavior Questionnaire, K-SADS (Schedule for Affective Disorder and Schizophrenia) and SOPS (Scale of Prodromal Symptoms). These were individually administered to parents, and the interviewer completed clinician ratings on the SOPS. A content analysis was also performed of specific types of hoarded items.

Results: A full 80% of participants engaged in hoarding behaviors, although 32% of these appeared to have vast collections of specific items related to thematic content (e.g., trains, dolls, music stars, DVDs), and would not likely have a formal Hoarding Disorder. The most frequently occurring hoarded items were paper products (33%), office and craft supplies (20%), and food-related items (10%, e.g., wrappers, take out menus, coupons). Other items, seen in 4% to 9%, included personal grooming supplies, clothing, purses, backpacks, and such oddities as the tops of plastic syringes. The total number of hoarding categories was correlated with hoarding severity (r = .65, p < .001), age, and indices of delusional ideas, bizarre thinking, and perceptual abnormalities on the SOPS or K-SADS (r's from .15 to .34, p's < .01). No gender or genetic subtypes differences were found in hoarding behaviors or severity.

Discussion: Although further work is needed, many participants with PWS would likely meet criteria for the forthcoming new DSM-V Hoarding Disorder (i.e., persistent difficulty discarding or parting with possessions, regardless of their actual value; perceived need to save items and distress associated with discarding them; and the accumulation of possessions that congest or clutter living areas unless cleaned by an outside party). Hoarding is not typically found in autism spectrum disorders or other disability groups, who may instead have objects or collections based on their specialized interests. Future research on hoarding in PWS may help inform genetic or neural mechanisms associated with hoarding in the general population.

We are grateful for the support of this work from NICHD grants P30 HD15052 and R01HD35684.
Prader-Willi Syndrome: Does Repetitive Behavior Change With Age?

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Introduction: Restricted and repetitive behavior (RRB) is one of the core domains of autism spectrum disorders (ASD), but it is also found in a wide variety of other developmental, genetic and psychiatric conditions. Rather than being a unitary construct, RRB includes diverse behaviors, from atypical sensory responses and repetitive motor movements to compulsive behaviors and circumscribed interests. To better understand how RRB may change over the life course of individuals with ASD, Esbensen et al. (2009) studied over 700 people from 6 studies and found that the frequency and severity of both the global picture of RRB and individual subtypes decreased with age. Our focus is on Prader-Willi Syndrome (PWS) where RRB is also common and is manifested by behaviors such as self-injurious (e.g., skin-picking), compulsive (e.g., hoarding), and ritualistic behaviors (e.g., repeating topics). The current study will investigate potential developmental changes in patterns of RRB in a sample of children, adolescents, and adults with PWS and will evaluate whether the patterns differ by genetic subtype (UPD vs Deletion).

Methods: Data were obtained from a longitudinal study of PWS conducted at Vanderbilt University. The sample included a total of 174 individuals with PWS (N=94 4 - 13 yrs, N=42 14-21 yrs, and N=38 22-62 yrs) who were administered the Repetitive Behavior Scale-Revised (RBS-R), along with other cognitive and behavioral measures. Total and individual subscale scores on the RBS-R were analyzed to investigate relationships with age, as well as IQ, gender, and genetic subtype.

Results: Of the 6 RBS-R subscales, only the Stereotyped Behavior scores showed a significant relationship to age (r=-.208; p<.01), as scores were significantly lower in adults than young children. This decrease in stereotyped behavior was found for individuals with PWS both with and without intellectual disabilities (IQ < or > 70). However, this developmental pattern seems to be driven by males (r=-.247, p<.05) and individuals with UPD (r=-.247, p<.05). When age was not considered, individuals with UPD scored significantly higher than those with the Deletion subtype on the Total RBS-R score, as well as the Stereotyped, Ritualistic, Sameness and Restricted subscales, indicating more significant problems in these areas.

Discussion: This study investigated developmental patterns in RRB in a large sample of individuals with PWS who ranged from 4 to 62 years of age, utilizing a single measure with non-overlapping items to assess different types of repetitive behavior. Consistent with previous studies of ASD, we found that stereotyped behavior decreased with age - particularly for males and individuals with the UPD subtype (which has been previously linked to ASD symptomatology). However, it was also evident that other forms of RRB were common in our sample of individuals with PWS, and these remained fairly stable across the ages assessed. This has implications for the development of treatment strategies and suggests the need to take a life course perspective. Findings will be further discussed within the context of other variables, such as social communication, intellectual functioning, adaptive behavior, and medication use.

Key References:
Repetitive Behaviors, Interests, and Reward in Autism and Anxiety Disorders

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**Background:** Circumscribed interests (CI) were a key part of Kanner’s original description of autism and now are a central part of the diagnostic criteria proposed for DSM V. Anxiety is often assumed to be functionally related to both repetitive behaviors and social deficits in ASD as it is known to be in anxiety disorders like OCD (where RBs are prominent) and Social Anxiety Disorder (where social impairments are prominent). Comparisons of ASD to anxiety disorders may help uncover pathogenic factors important to the development of autism. CI appear to be relatively specific to ASD and, unlike common OCD-related RBs, CI seem to function motivationally as approach-mediated behaviors opposed to avoidance-mediated behaviors.

**Methods:** We are comparing high [HFA] and low [LFA] function subjects with ASD to subjects with anxiety disorders (Social Anxiety Disorder [SAD], Obsessive Compulsive Disorder [OCD]), subjects with Intellectual & Developmental Disability [IDD], and typically developing [TYP] control subjects in a multi-method protocol that probes varieties of repetitive behaviors (RBS-R, CYBOCS, ADI-R, Interests Scale [ALL GROUPS], visual salience (eye-tracking visual exploration paradigm [HFA, OCD, TYP], and fMRI responses during reward processing (incentive delay task [HFA, SAD, OCD, TYP]).

**Results:** PHENOTYPE: Analyses of both RBS-R and ADI-R data on RBs in two separate samples of ASD (RBS-R n = 712; ADI-R n = 316) indicate (a) that CIs emerge as a unique RB factor within ASD (along with a Stereotyped Movement, and an Insistence on Sameness factor), (b) that CIs occur in both LFA and HFA subgroups, (c) that within the overall ASD group the presence of co-occurring IDD contributes to a difference in the occurrence of Stereotyped Movements (LFA > LFA), but no such difference emerges for CI. Further, whereas both ASD and IDD (without ASD) differ from TYP in Stereotyped Movements (ASD = IDD > TYP), ASD differs from both IDD and TYP (ASD > IDD > TYP) in the occurrence of CIs. EYE-TRACKING: In a visual exploration eye-tracking task that compares fixation to complex arrays that contain social stimuli (e.g. pictures of people, faces) and nonsocial stimuli (e.g. pictures of objects), HFA subjects show reduced exploration of images overall characterized by excessive fixation to nonsocial images when they are present and compete for attention with social images. Further, fixation patterns are significantly correlated with autism severity within the ASD group. (RB, & eye-tracking data on anxiety disorder subjects is currently being collected and will be available to present at the meeting.) FUNCTIONAL NEUROIMAGING: fMRI was used to examine neural responses to social and nonsocial rewards for subjects from the ASD, SAD, and TYP groups. Analyses modeling all three groups revealed increased nucleus accumbens (NAc) activation in SAD relative to ASD during monetary reward anticipation, whereas both the SAD and ASD group demonstrated decreased bilateral NAc activation relative to the TYP group during social reward anticipation. Analyses modeling only responses of the ASD and SAD groups revealed greater bilateral amygdala activation to social rewards in SAD relative to ASD during both anticipation and outcome phases of the task, and the magnitude of amygdala hyperactivation in the SAD group during anticipation of social rewards was significantly correlated bilaterally with the severity of trait anxiety.

**Discussion:** Results to date suggest that CIs are relatively specific to ASD and appear to be associated with unique ways that persons with ASD attend to and process nonsocial versus social information. Further study of well-established gene-brain-behavior relationships in the context of reward processing may yield new opportunities for understanding and treating autism.

Supported by: R01 MH073402
FAMILIES OF CHILDREN WITH DISABILITIES: A FOCUS ON RESOURCES AND ADAPTATION

Chairs: Shelley Watson, Laurentian University
SYMPOSIUM 12
Families of Children With Disabilities: A Focus on Resources and Adaptation
Chair: Shelley Watson, Laurentian University

Life Satisfaction Over Time Among Mothers of Children With Prader-Willi Syndrome
Carolyn M. Shivers
Caroline Oates
Elisabeth Dykens
Vanderbilt Kennedy Center, Vanderbilt University

Facilitators of Social Inclusion and Participation For Children With an Intellectual or Developmental Disability: Access Ramps Are Not Enough!
Claude Normand¹
André C. Moreau¹
Julie Ruel²
Thierry Boyer²
¹Université du Québec en Outaouais
²Pavillon du Parc Rehabilitation Center

“It’s Like Being On a Bicycle, You Just Have to Keep Peddling and Do the Best You Can”: Adaptation In Families Raising Children With Fetal Alcohol Spectrum Disorder
Kelly D. Coons
Alexandra Clement
Elisa Radford-Paz
Shelley L. Watson
Laurentian University

“I’m Hoping, I’m Hoping...”: A Comparison of Resiliency and Hope In Families of Individuals With Fetal Alcohol Spectrum Disorder and Autism
Shelley L. Watson¹
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Life Satisfaction Over Time Among Mothers of Children With Prader-Willi Syndrome

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Introduction: Prader-Willi syndrome (PWS) is a genetic disorder with characteristics including hyperphagia (insatiable appetite), which often leads to weight problems and obesity, and intellectual disability. Parents of children with PWS face many difficulties due to these features. Many studies have shown that parents of children with disabilities experience more stress than those without. Some research suggests parents with a child with PWS experience more stress and family problems than parents of children with other intellectual disabilities (e.g., Lanfranchi & Vianello, 2012). While parents of children with PWS face many challenges, some families appear to be doing quite well. The goal of this study is to examine factors that both negatively and positively influence life satisfaction in parents of children with PWS, as well as changes in life satisfaction across the lifespan. By identifying child ages at which parents with children with PWS have lower life satisfaction, we can identify the most important times for intervention and support. Additionally, by identifying which parents are thriving despite their child's disability, we can promote positive outcomes in families, rather than just prevent negative ones.

Methods: We used data from a longitudinal of individuals with Prader-Willi Syndrome (PWS) and their families, conducted at the Vanderbilt University Kennedy Center. Of the 191 families that have at least one visit, 166 have life satisfaction data at Time 1, 57 at Time 2, and 41 at Time 3. Maternal life satisfaction was measured using the Satisfaction with Life Scale (Deiner et al., 1985), a five-item self-report measure using a 7-point Likert scale (minimum score = 7, maximum score = 35). Independent variables include maternal age, child BMI, child hyperphagia severity, child age, and genetic subtype. We used hierarchical linear modeling (HLM) to determine 1) what percentage of maternal life satisfaction can be attributed to individual differences and 2) what factors are related to maternal life satisfaction.

Results: Mean maternal life satisfaction was 21.19 at Time 1, 20.73 at Time 2, and 25.45 at Time 3. Analyses determined that 55% of the variance in life satisfaction was due to individual differences. When maternal age, child BMI, and child hyperphagia severity were included in the model, only mean hyperphagia predicted maternal life satisfaction (β = 2.86, p<.05). Child age results, as well as interactions, will be reported in the presentation.

Discussion: These analyses indicate that one of the most distinguishing features of Prader-Willi syndrome is also one of the most salient to maternal life satisfaction. While maternal age, child genetic subtype, and child BMI did not significantly predict maternal life satisfaction, more severe child hyperphagia predicted lower total life satisfaction among mothers. This finding suggests that interventions aimed at controlling hyperphagia may help not only the child's overall health, but also maternal well-being.

Key Reference:
Facilitators of Social Inclusion and Participation For Children With an Intellectual or Developmental Disability: Access Ramps Are Not Enough!

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Introduction: Although much has been done to facilitate the social participation of people with disabilities by modifying our environments (e.g., access ramps, automatic doors) it has often been said their inclusion in our communities is merely physical (i.e., they are present among us, but not full participants of community life; Office des Personnes Handicapées du Québec, 2007). This exclusion is especially true of people with an intellectual or developmental disability (Proulx, 2008). Statistics Canada’s Participation and Activity Limitation Survey (PALS) has highlighted some of the barriers children and adults with disabilities face at home, at school, at work, and in the community. Using the PALS data, a team of York University researchers has developed a Barriers and Accommodations Index (Zubrow, et al., 2009) for adults, which we have attempted to reproduce for children with an intellectual disability (ID) or autism spectrum disorder (ASD).

Methods: Fifty parents of children 0-14 years of age, receiving services from an intellectual and developmental disabilities rehabilitation center in Western Quebec took part in a telephone interview using our questionnaire. Their children were diagnosed with an intellectual disability (n = 24) or autism spectrum disorder (n = 26).

Instrument: While the PAL survey questions focused largely on limitations and barriers, for each item we added our own questions to target the corresponding accommodations or facilitators to children's participation in various social environments (e.g. daycare, school, after school care, municipal sports and leisure, family outings). Multiple choice answers were developed to aim at different categories of facilitators, such as structural modifications, financial aid, transportation, human support and services, technical aids, and community attitudes.

Results: Results demonstrated that while families do face many barriers, they have also developed or discovered several facilitators to their child's inclusion and participation. The most important and often cited accommodation, throughout social settings, was information, training and support of caretakers and service providers. Accompaniment of the child, by someone other than the parents, also allowed the child to partake in organized activities with or without family members.

Discussion: We conclude that work is needed in collaboration between various service sectors (education, health, and social services) to facilitate inclusion and ensure greater social participation of children with an intellectual or developmental disability, since it is shown that children who take part in their communities of children, become more active as adult citizens.

Key References:


Introduction: Despite the wealth of literature on families of children with disabilities, limited research has been conducted on the experience of families raising children with Fetal Alcohol Spectrum Disorder (FASD; Watson, Coons, & Hayes, in press). Current trends in family disability research have transitioned from negative, deficit-based models of coping to those that bring to light positive, strength-based aspects of family functioning (Summers, Behr, & Turnbull, 1989), such as adaptation. When viewed over time and in response to crisis situations, families employ adaptive resources to adapt to their situation (McCubbin & Patterson, 1983).

Methods: A mixed methods study was conducted with caregivers of children with FASD in Ontario, Canada. 66 parents or grandparents from adoptive, foster, and biological families have participated in the study to date. Employing a basic interpretive approach (Merriam, 2002) informed by the Family Adjustment and Adaptation Response (FAAR) model (Patterson & Garwick, 1994), qualitative interviews were conducted. Participants also completed a number of quantitative questionnaires, including the Family Crisis Oriented Personal Scales (F-COPES; McCubbin, Olson, & Larsen, 1981) and the Family Resource Scale (FRS; Dunst & Leet, 1987).

Results: Preliminary results show that many families utilize similar strategies and supports, but unique differences may exist depending on family type (e.g., parents compared to grandparents). Interpretive phenomenological analysis of the interviews (IPA; Lyons & Coyle, 2010) revealed two main superordinate themes, with several constituent sub-themes regarding what has helped families adapt to having a child diagnosed with FASD. For example, parents identified strategies they found helpful, including educating themselves about FASD, using routine, consistency, and repetition, taking things day to day, and picking their battles. Parents also discussed their use of both formal and informal supports, such as significant others, family members, and friends as important sources of informal support. Participants also identified support groups, respite services, and important professionals who were supportive in a formal capacity. Interestingly, initial data analysis reveals no significant correlations between the F-COPES and the FRS; however, responses to individual items on each measure will be considered and discussed in their relation to the qualitative findings.

Discussion: Understanding what families do in order to transform from a family in crisis to a family that is successfully adapting is important when implementing appropriate family supports. The lack of significant correlations between the F-COPES and FRS may suggest that a family’s ability to cope or adapt may not be limited by the resources available to them.

Key References:
Introduction: Regardless of disability diagnosis, researchers have been suggesting for decades that having a child with a disability is associated with the experience of parenting stress (see Watson, Hayes, & Rafford-Paz, 2011 for a historical review). Although parents of children with disabilities report high levels of stress, researchers have begun to focus on resiliency factors that may impact parents’ perceptions, such as hope. The authors of this presentation compared the experience of two family types, parents of children with Fetal Alcohol Spectrum Disorder (FASD) and parents of children with Autism Spectrum Disorder (autism) with regards to the future of their children and the role that hope may play in a family’s ability to overcome stressors and foster their belief in positive outcomes.

Methods: Following the recommendations for mixed methods designs outlined by Teddlie and Tashakori (2009), this study integrated qualitative research (collected in in-depth semi-structured interviews) and quantitative research (as measured by two psychometric measures listed below). As part of a larger study addressing family adaptation to disability, 28 parents of children with autism were compared with 57 parents of children with FASD on the Questionnaire on Resources and Stress (Friedrich’s version) and the Hope Scale (Snyder et al., 1991).

Results: Pessimism scale responses on the QRS-F revealed that both family types expressed significant worry about the future. For example, 98% of parents of children with FASD and 80% of parents of children with autism responded “true” to the question, “I worry about what will be done with _____ when he/she gets older”. There was no statistical difference between the groups for any QRS-F item. Although families had fears for the future, both family types had moderately high levels of agency, pathways thinking, and overall hope, as measured by the Hope Scale. No significant differences were found between family types on any aspect of hope. Although quantitative data did not reveal differences between the groups, interview data revealed that both family types demonstrated resiliency in dealing with significant stressors. Specifically, parents of children with FASD and autism faced unique challenges and reported distinctive qualitative experiences when speaking about their resources and future expectations. Families of children with autism believed that, despite the fact that life may be harder for them, their children could potentially live fully independently, hold meaningful employment, and have their own families in the future. In contrast, parents of children with FASD had less hope and shared greater concerns for their children’s future, often recognizing the potential impact of secondary disabilities (including incarceration, unplanned teen pregnancies, and vulnerability to victimization) to impede their ability to establish independent lives.

Discussion: In qualitative interviews, families of children with autism appeared to be more hopeful for their children’s futures when compared to families of children with FASD. Given the increasing prevalence of FASD, as professionals it therefore becomes imperative that we continue to investigate and make evidence-based interventions accessible to families of children with FASD. Such investigations and supports will permit families of children with FASD to no longer feel as though families of children with autism are the only ones with access to hopeful futures.

Key Reference:
INDEX

A
Abbeduto, Leonard 1, 11
Adeyemi, Elizabeth I. 10, 12
Anderson, Christa J. 15
Aquilar, Monica 9
Aschner, Judy L. 6
Ausderau, Karla 9

Bailey, Don 1, 5, 9, 13
Baker, Bruce 11
Baranek, Grace T. 9, 10
Barker, R. Michael 12
Barney, Chantel 7
Barton-Hulsev, Andrea 8
Beisang, Arthur 7
Belger, Aysenil 10
Belmonte, Colleen 12
Berke, Elizabeth 8
Berry-Kravis, Elizabeth 13
Bert, Shannon S.C. 1
Blacher, Jan 11
Bodfish, Jim 1, 9, 14
Bolourian, Yasamine 12
Boyd, Bryan 1
Boyer, Thierry 14
Brady, Nancy C. 15
Brosco, Jeff 5, 13
Bryant, Julie D. 12
Bullock, John 9
Burke, Meghan 8
Byers, Breanne 7

C
cascio, Carissa J. 10
Channell, Marie Moore 12
Chorna, Olena 6
Cleary, Katherine M. 10
Clement, Alexandra 14
Cohen, Shana R. 11
Connors, Frances 1
Coons, Kelly D. 14
Courtbois, Yannick 15
Crossman, Morgan K. 15
Cuellar, Matthew 2, 12

D
Damiano, Cara 14
Dankner, Nathan 8
Daunhauer, Lisa A. 10
Davis, Allyson 2, 11
De Sonia, Anna 13
Deal, Sara 13
Deisenroth, Lauren 13, 14
Derrington, Ta’letha M. 15
Dimian, Adele 7
Donkers, Franc C.L. 9
Dueñas, Ana 2, 12
Dykkens, Elisabeth 1, 5, 6, 14

E
Edwards, Sarah 2, 8
Ehrhardt, Michael J. 7
Eisenhower, Abbey 11
Ellingsen, Ruth 11
Erikson, La’Tosia 7
Esbensen, Anna J. 10
Feyma, Tim 7
Fidler, Deborah J. 1, 10
Fisher, Marisa H. 2, 6, 9
Floyd, Frank 1, 10
Foster, Matthew E. 2, 12
Frey, Jennifer 11
Fuller, Amy 11
Furlong, Melissa 9

G
Gerstein, Emily 8
Giedd, Jay N. 10
Goin-Kochel, Robin P. 15
Golya, Nandita 2, 8
Gotham, Katherine 12
Graham, Megan 9
Greenberg, Jan S. 10
Greenspan, Stephen 9
Grefer, Marjorie 12
Grein, Katherine A. 2, 8
Guastaferro, Katelyn 9
Gulsrud, Amanda 11

H
Haebig, Eileen 8
Hagerman, Randi 13
Hahn, Laura J. 2, 8, 10
Hampton, Lauren H. 12
Hanna, E. 14
Harris, Sandra L. 6
Hassenfeldt, Tyler A. 8
Hauser-Cram, Penny 10
Hayes, Stephanie A. 14
Hazlett, Heather Cody 13
Henderson, Danielle R. 2, 12
Henninger, Natalie A. 15
Hepburn, Susan L. 1, 10
Hickey, Emily J 12
Hickson, Linda 9
Hoch, John 7
Hodapp, Robert 10
Howell, Rod 4, 6
Huddleston, Lillie 8

I
Iadarola, Suzannah 6

J
John Thurman, Angela E. 12

K
Kaat, Aaron J. 8
Kaiser, Ann 11
Kaiser, Marygrace Yale 1
Kasari, Connie 1, 11
Key, Alexandra F. 6
Khemka, Ishita 9
Kirby, Anne V. 2, 9
Klusek, Jessica 8
Kovac, M. 14

L
Lacoste, Ameante 7
Lahav, Amir 6
Lambert, Warren E. 6
Lauderdale-Littin, Stacy 11
Lee, Nancy Raitano 10
Lee, Evon 14
Lightbody, Amy A. 13
Linn, Regan H. 11
Little, Lauren M. 2, 9
Lloyd, Blair P 8
Lorenzi, Jill 10, 12
Loveall, Susan J. 8
Lutzker, John R. 9
Luu, Susanna 2, 12

M
MacLean, William 1, 7, 13
Maillick, Marsha R. 1, 7, 10, 11
Maitre, Nathalie L. 6
Makhiawala, Kenya T. 8
Mallory, Sarah 9
McFadd, Emily 12
McIntyre, Laura Lee 11
McLeod, Laura 1
McMahon, Erin 6
Miller, S. 14
Miodrag, Nancy 6
INDEX

Mitchell, Teresa 15
Mitchell, Darcy B. 15
Morales, Yamile 9
Moreau, André C. 14

N
Neece, Cameron L. 6, 11
Normand, Claude 14

O
Oates, Caroline 2, 8, 13, 14
O’Brien, Katy H. 12
Olsen, Darren 2, 8

P
Panoskaltsis-Mortari, Angela 7
Parisi, Melissa 5, 7
Phillips, B. Allyson 12
Peters, Sarika 6
Pitts, C. Holley 15
Piven, Joseph 13
Prescott, Christina 13

Q
Quest, Kelsey 7

R
Radford-Paz, Elisa 14
Raspa, Melissa 15
Reiss, Allan L. 13
Richards, John E. 13
Richardson, Shana 12
Richey, J. 14
Richman, David 15
Rittenburg, A. 14
Rivera, Susan M. 13
Roberts, Jane E. 13
Romski, Mary Ann 11
Roof, Elizabeth 13, 14
Rose, Chad A. 9
Ruel, Julie 14

S
Sabatino, A. 14
Sanders, Eric 15
Sasson, N 14
Scherr, Jessica F. 12
Schipul, Sarah E. 2, 9
Schroeder, Stephen 15
Serna, Richard 1
Sevcik, Rose A. 11
Shivers, Carolyn M. 13, 14
Shogren, Karrie A. 15
Sideris, John 9
Silverman, Wayne 1
Simpson, Cynthia G. 9
Slaughter, James C. 6
Smith, Ashlyn 8
Smith, Leann E. 10
Solomon, Jessica E 2, 6
Spofford, Lisa 7, 8
Stone, Zolinda 15
Sudhalter, Vicki 15
Symons, Frank 6, 7

T
Tassone, Flora 13
Taylor, Cora 12, 15
Taylor, Julie L. 11
Tervo, Raymond T. 7
Tillem, Scott 2, 12
Tilson, Loren 14
Tonnsen, Bridgette 13
Travers, Brittany 8

Turner, Elizabeth 1
Turner-Brown, L. 14

U
Unruh, Kathryn E. 12
Urbano, Richard 10
Urv, Tiina 1, 5, 7, 10

V
Valdovinos, Maria 15
Visootsak, Jeannie 15

W
Walerius, Danielle M. 8
Wang, Paul P. 15
Wang, Lu 6
Warren, Steven 1
Wasserman, Melissa 12
Watson, Shelley L. 14
Wheeler, Anne 13, 15
Wilson, Amy 15
Windsor, Kelly 2, 8
Wolff, Jason 2, 8
Woodman, Ashley C. 8, 10
Wright, Courtney 12

Y
Yang, Yingying (Jennifer) 2, 8
Yoder, Paul J. 15
Yoshinaga-Itano, Christine 4, 7

Z
Zealand, Ruth 9
Zeedyk, Sasha 11
Zimmerman, Emily 6

---

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SECOND LEVEL
# Program at a Glance

## Wednesday, March 6, 2013

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:30 - 8:30 a.m.</td>
<td>Registration &amp; Breakfast</td>
</tr>
<tr>
<td>8:30 - 8:45 a.m.</td>
<td>Opening Remarks: Elisabeth Dykens, Conference Chair</td>
</tr>
<tr>
<td>8:45 - 10:00 a.m.</td>
<td>Plenary Session 1&lt;br&gt;The 50th Anniversary of Newborn Screening: PKU 50 Years Later (Howell)</td>
</tr>
</tbody>
</table>
| 10:30 a.m. - 12:00 p.m. | Symposium 1<br>Infant Sensory Processing and Neurodevelopmental Outcomes (Maitre)<br>Contessa A & B  
|                   | Symposium 2<br>Contessa A<br>Mindfulness-Based Stress Reduction in Intellectual and Developmental Disabilities (Dykens)<br>Contessa B  
|                   | Symposium 3<br>Health and Behavior in Rett Syndrome: How Well Do We Understand the Behavioral Phenotype? (Symons)<br>Contessa B |
| 1:30 - 2:45 p.m.  | Plenary Session 2<br>Evolution of Universal Newborn Hearing Screening: The Importance of Sensitive Periods of Development and High-Quality Early Intervention Services (Yoshinaga-Itano) |
| 2:45 - 3:15 p.m.  | Poster blitz                                                         |
| 3:30 - 4:10 p.m.  | NICHD: Reflections on Its 50th Anniversary and Update on Related NIH Activities (Paris/Urvo) |
| 4:10 - 4:30 p.m.  | Special video presentation: Breakthroughs in Developmental Disabilities Research: What Do Our Leaders Have To Say? (Dykens) |
| 5:00 - 7:00 p.m.  | Poster Session 1 Reception                                            |

## Thursday, March 7, 2013

<table>
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<tr>
<th>Time</th>
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<tr>
<td>8:00 - 8:45 a.m.</td>
<td>Registration &amp; Breakfast</td>
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<td>8:45 - 10:00 a.m.</td>
<td>Plenary Session 3&lt;br&gt;Newborn Screening for Fragile X: Reflections on a Multi-Year Pilot Investigation (Bailey)</td>
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| 10:30 a.m. - 12:00 p.m. | Symposium 4<br>Social Vulnerability of Individuals With Intellectual and Developmental Disabilities Across the Lifespan (Fisher)<br>Contessa A & B  
|                   | Symposium 5<br>Contessa A<br>Characterizing Sensory Features in Children With Autism Spectrum Disorders: Behavior and Physiology (Little)<br>Contessa B  
|                   | Symposium 6<br>Down Syndrome: Identifying Targets for Intervention Across the Lifespan (Daunhauer)<br>Contessa B |
| 1:45 - 2:45 p.m.  | Special Presentation<br>Newborn Screening: Who Does What and Where Do I Fit In? A Federal Perspective (Urvo) |
| 2:45 - 3:15 p.m.  | Poster blitz                                                         |
| 3:45 - 5:15 p.m.  | Symposium 7<br>Magnolia Life Course Trajectories of Adaptive Behavior and Vocational Achievement in Individuals With Autism and Other Developmental Disabilities (Mallick)<br>Contessa A & B  
|                   | Symposium 8<br>Contessa A<br>Powerful Predictors: An Update on the Role of Family and School Experiences in the Development of Children with IDD (Neece)<br>Contessa B  
|                   | Symposium 9<br>Contessa B<br>Early Identification of Children Most at Risk for Deficits in Spoken Language (Kaiser)<br>Contessa B |
| 5:15 - 7:15 p.m.  | Poster Session 2 Reception                                            |

## Friday, March 8, 2013

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tr>
<td>8:00 - 9:30 a.m.</td>
<td>Poster Breakfast</td>
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<td>9:30 - 10:45 a.m.</td>
<td>Plenary Session 4&lt;br&gt;Bedside Genome Sequencing: What History Tells Us About the Future of Newborn Screening (Brosco)</td>
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| 11:15 a.m. - 12:45 p.m. | Symposium 10<br>Magnolia Biobehavioral Examination of Development in Infants and Toddlers Across the Fragile X Spectrum of Involvement (Roberts/Hazlett/Rivera)<br>Contessa A & B  
|                   | Symposium 11<br>Contessa A<br>Which Came First? Anxiety, Repetitive Behavior, and Hoarding in PWS, ASD, ID and OCD (Roof)<br>Contessa B  
|                   | Symposium 12<br>Contessa B<br>Families of Children with Disabilities: A Focus on Resources and Adaptation (Watson)<br>Contessa B |
| 12:45 p.m.        | Closing Remarks: Elisabeth Dykens                                     |