Gatlinburg Conference
on Research and Theory in Intellectual and Developmental Disabilities

Proceedings of the 45th Annual Gatlinburg Conference
March 7-9, 2012 • Loews Annapolis Hotel • Annapolis • Maryland

Rare and Neglected IDD Disorders:
A Case Study in 15q
THANK YOU!

The Gatlinburg Conference especially thanks the following institutions for their financial contributions and generous support of the 2012 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
  - Kennedy Krieger Institute
- 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: *The Parrots* by Bernadette Resha
45th Annual
Gatlinburg Conference
On Research and Theory in Intellectual and Developmental Disabilities

Loews Annapolis Hotel • Annapolis • Maryland
March 7-9, 2012

This volume contains abstracts for invited talks, symposium papers, and poster presentations at the 45th Annual Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities. Permission to quote or reprint any of these materials must be obtained from the author(s).

EXECUTIVE COMMITTEE

Leonard Abbeduto
University of California–Davis

Don Bailey
RTI International

Shannon S. C. Bert
University of Oklahoma

James Bodfish
University of North Carolina

John Borkowski
University of Notre Dame

Brian Boyd
University of North Carolina-Chapel Hill

Frances Conners
University of Alabama

Elisabeth Dykens, Conference Chair
Vanderbilt University

Deborah Fidler
Colorado State University

Frank Floyd
University of Hawaii

Susan Hepburn
University of Colorado-Denver

Marygrace Yale Kaiser
Eureka College

Connie Kasari
University of California-Los Angeles

William MacLean
University of Wyoming

Marsha Mailick Seltzer
University of Wisconsin–Madison

Richard Serna
University of Massachusetts–Lowell

Wayne Silverman
Johns Hopkins University School of Medicine

Steven Warren
University of Kansas

THEME COMMITTEE

Elisabeth Dykens
Vanderbilt University

Deborah Fidler
Colorado State University

Susan Hepburn-Chair
University of Colorado-Denver

Steven Warren
University of Kansas

CONFERENCE COORDINATION

Laura McLeod – Conference Manager
Vanderbilt University

Ellen Margulies – Conference Co-Manager
Vanderbilt University

CONFERENCE SUPPORT

This conference is supported by grant number R13 HD38335 from the Eunice Kennedy Shriver National Institute of Child Health and Human Development.

Additional support provided through generous donations from:
The American Psychological Association-Division 33 • Kennedy Krieger Institute • The University of Kansas
The University of Massachusetts Medical School • The University of Wisconsin-Madison • Vanderbilt University
Brookes Publishing • Noldus Information Technology
# Table of Contents

**Program at a Glance** ............................................................................................................................................... 3  
**Award Recipients** ............................................................................................................................................... 4  
**Exhibitors** ........................................................................................................................................................... 7  
**Plenary Speakers and NIH Sessions** .................................................................................................................. 8  
**Detailed Conference Program** .......................................................................................................................... 10  

## Wednesday Presentations

### Afternoon
Symposium 2: Mindfulness-Based Stress Reduction: Introducing the World of Zen to I/DD ........................................... 29  
Symposium 3: Basic and Applied Research in Reading of Children with Intellectual and Developmental Disabilities (I/DD) .................................................................................................................................................. 35  
Symposium 4: Premutation Carriers of FMRI Gene Expansions: Prevalence, Language Profiles, and Health ................. 41  
Symposium 5: Co-Morbid Features in PWS, ASD, and 15q Disorders ............................................................................. 47  
Symposium 6: Social Anxiety and Stress in Neurodevelopmental Disorders ................................................................. 53  

### Evening
Poster Session 1 ............................................................................................................................................................... 59  

## Thursday Presentations

### Morning
Symposium 7: Multi-Modal and Multi-Method Approaches to Assessment and Intervention for SIB ................................. 89  
Symposium 8: Biobehavioral Investigations of Temperament in Fragile X, Williams, and 7q11.23 Duplication Syndromes ................................................................................................................................................. 97  
Symposium 9: Mining Public Health Data for IDD Research ............................................................................................. 103  
Symposium 10: Adult Aging with Down Syndrome ......................................................................................................... 109  
Symposium 11: Evaluating Reading Interventions for Children with Down Syndrome .................................................. 117  
Symposium 12: Translational Analysis and Treatment of Chronic Aberrant Behavior—Transition States, Behavioral Economics, and Idiosyncratic Functions ........................................................................ 123  

### Evening
Poster Session 2 ............................................................................................................................................................... 129  

## Friday Presentations

### Morning
Symposium 14: Uses of Eye Tracking/Pupillometry to Enrich Understanding of Information and Sensory Processing in Individuals with ID .................................................................................................... 165  

**Index** .................................................................................................................................................................................. 171
<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Wednesday, March 7, 2012</strong></td>
<td></td>
</tr>
<tr>
<td>8:00-8:45 am</td>
<td>Registration</td>
</tr>
<tr>
<td>8:45 -9:00 am</td>
<td>Opening Remarks: Elisabeth Dykens</td>
</tr>
<tr>
<td>9:00 am-10:30 am</td>
<td><strong>Plenary Session 1:</strong> Brenda Finucane, From Single Syndromes to Shared Pathways: The Evolution of Behavioral Genetics Research in Developmental Disabilities</td>
</tr>
<tr>
<td>10:45–11:05 am</td>
<td>NIH Workshop: What's New in Intellectual and Developmental Disabilities at NICHD and NIH</td>
</tr>
<tr>
<td>11:05-11:35 am</td>
<td>Training Opportunities at NICHD and NIH</td>
</tr>
<tr>
<td>11:35 am-12:05 pm</td>
<td>Where Does My Application Get Reviewed—SR or DSR?: Review Issues at NICHD and NIH</td>
</tr>
<tr>
<td>12:05-12:15 pm</td>
<td>General Questions and Answers</td>
</tr>
<tr>
<td>2:00-3:30 pm</td>
<td><strong>Symposium 1</strong> (Regatta A) Latino Families with Children with Disabilities and Risk: Understanding Culture, Needs, and Innovative Support Processes (Cohen)</td>
</tr>
<tr>
<td>3:45 – 5:15 pm</td>
<td><strong>Symposium 4</strong> (Regatta A) Premutation Carriers of FMR1 Gene Expansions: Prevalence, Language Profiles, and Health (Seltzer)</td>
</tr>
<tr>
<td>5:30 – 7:30 pm</td>
<td><strong>Poster Session 1 Reception</strong></td>
</tr>
<tr>
<td><strong>Thursday, March 8, 2012</strong></td>
<td></td>
</tr>
<tr>
<td>8:45 -10:15 am</td>
<td><strong>Symposium 7</strong> (Regatta A) Multi-Modal and Multi-Method Approaches to Assessment and Intervention for SIB (Schroeder)</td>
</tr>
<tr>
<td>10:30 am-12:00 pm</td>
<td><strong>Symposium 10</strong> (Regatta A) Adult Aging with Down Syndrome (Silverman)</td>
</tr>
<tr>
<td>1:30-3:00 pm</td>
<td><strong>Plenary Session 2:</strong> Ben Philpot, A New Angle on Angelman Syndrome</td>
</tr>
<tr>
<td>3:15 – 4:45 pm</td>
<td><strong>Plenary Session 3:</strong> Stormy J. Chamberlain, Human Induced Pluripotent Stem Cell (iPSC) Models of Chromosome 15q Imprinting Disorders</td>
</tr>
<tr>
<td>5:00-7:00 pm</td>
<td><strong>Poster Session 2 Reception</strong></td>
</tr>
<tr>
<td><strong>Friday, March 9, 2012</strong></td>
<td></td>
</tr>
<tr>
<td>8:45 – 10:15 am</td>
<td><strong>Symposium 13</strong> (Regatta A) More Positive than Negative...The Study of Families in Context. A Special Presentation Honoring Laraine Glidden at Gatlinburg Conference 2012 (Kasari)</td>
</tr>
<tr>
<td>10:45 am-12:15 pm</td>
<td><strong>Plenary Session 4:</strong> Jennifer Miller, Lessons About Chromosome 15q from Prader-Willi Syndrome</td>
</tr>
<tr>
<td>12:15 pm</td>
<td>Closing Remarks: Elisabeth Dykens, PhD</td>
</tr>
</tbody>
</table>
Award Recipients

David Zeaman Student Award

Nathan Dankner
Vanderbilt University

Miriam Lense
Vanderbilt University

Jennifer Frey
Vanderbilt University

Allyson Phillips
University of Alabama

Theodore Tjossem Postdoctoral Fellow Award

Karla Ausderau
University of North Carolina-Chapel Hill

Reyna Gordon
Vanderbilt University

Shana Cohen
University of California-Riverside

Amy Weitlauf
Vanderbilt University

American Psychological Association Division 33 Graduate Student Travel Award

Ashley Woodman
Boston College

Diversity Travel Awards

Bianca Brooks
Georgia State University

Ani Whitfield
Georgia State University
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.
SAVE THE DATE!

Please save the date for the 46th annual Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities.

The 2013 conference will be held at the Hotel Contessa in San Antonio, Texas, March 6-8.
Thank You to Our 2012 Exhibitors

The Gatlinburg Conference thanks Noldus Information Technology for its generous sponsorship of the Wednesday morning coffee break.

Noldus Information Technology, Inc.
1503 Edwards Ferry Road, Suite 201
Leesburg, VA 20176
Phone: 1-800-355-9541
Fax: 703-771-0441
Email: info@noldus.com • www.noldus.com

The Gatlinburg Conference thanks Brookes Publishing Co. for its generous sponsorship of the Thursday morning coffee break.

Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285
Phone: 1-800-638-3775
Fax: 410-337-8539
www.brookespublishing.com
Invited Speakers

Brenda Finucane, MS, CGC  
“From Single Syndromes to Shared Pathways: The Evolution of Behavioral Genetics Research in Developmental Disabilities”
An important outcome of the Human Genome Project has been the identification of numerous genetic loci associated with developmental disabilities. In some cases, advances in gene discovery have revealed specific physiological mechanisms that underlie cognitive and behavioral symptoms. By far, the most promising work in this area has been achieved for fragile X syndrome, a common cause of autism and intellectual disabilities. The strong association of autism with genetic copy number differences on chromosome 15q has also attracted research interest. Specifically, duplications involving the 15q11.2-q13 chromosomal region have long been implicated in autism spectrum disorders. Gene deletions in the same region are known to cause Prader-Willi and Angelman syndromes, two distinct genetic conditions with characteristic behavioral profiles and psychiatric co-morbidities. The biochemical pathways affected by genes involved in 15q duplications, fragile X, and several other genetic syndromes are intertwined at a molecular level. This may explain how multiple different etiological disorders can all result in similar behavioral outcomes, including autism. This presentation will describe the evolution of biobehavioral research in chromosome 15q disorders, illustrating how genetic bench science and behavioral investigation combine to offer powerful insights into human behavioral pathology. By focusing on shared etiological pathways rather than behaviorally-based symptom constellations, a combined research approach has the potential to revolutionize the future study of developmental disorders.

Ms. Finucane is a certified genetic counselor and Executive Director of Genetic Services at Elwyn.

Ben Philpot, Ph.D.  
“A New Angle on Angelman Syndrome”
Both autism and the autism spectrum disorder Angelman syndrome are characterized by the emergence of cognitive and behavioral deficits in the first two years of life. For example, autism is associated with moderate to severe communication deficits, whereas Angelman syndrome is typically characterized by a complete lack of speech. The etiology of Angelman syndrome and some forms of autism can be traced to abnormalities within a similar sequence of genetic code on chromosome 15 (15q11-q13). This genetic sequence encodes several proteins, one of which is termed UBE3A. Angelman syndrome is caused by having too little UBE3A in the brain, while some autism disorders may be caused by having too much.

My lab has been performing studies to examine how changes in UBE3A levels affect brain development, and in particular, how synapses and synaptic plasticity are affected. We have also been performing high-throughput screens to identify approaches for restoring appropriate UBE3A levels and normalizing brain functions in autism spectrum disorder. This presentation will provide an overview of several recent discoveries that have been made in mouse models. First, we have found that the loss of UBE3A prevents the normal expression of synaptic plasticity in vitro. Second, normal levels of UBE3A are required for the brain to properly express in vivo plasticity driven by our experiences. Third, the loss of UBE3A leads to cell type-specific deficits, rather than generalized synaptic defects. Finally, we have identified compounds that can adjust the expression levels of UBE3A, and these compounds thus have therapeutic potential.

Dr. Philpot is an Associate Professor of Cell and Molecular Physiology at the University of North Carolina-Chapel Hill.

Stormy Chamberlain, Ph.D.  
“Human Induced Pluripotent Stem Cell (iPSC) Models of Chromosome 15q Imprinting Disorders”
Induced pluripotent stem cells (iPSCs) are functionally equivalent to human embryonic stem cells. Whereas embryonic stem cells are generated from discarded human embryos, iPSCs are produced by converting skin cells into stem cells. With this technology, researchers can take a skin punch biopsy from an individual with a genetic disorder and produce indefinitely self-renewing stem cells that can be differentiated into other cell types, such as neurons, that have the same genetic problem. Using these cells, live human neurons from individuals with genetic problems can be created and studied.

We have generated iPSCs and iPSC-derived neurons from individuals with Angelman (AS), Prader-Willi (PWS), and 15q duplication (idic(15)) syndromes for the purpose of studying these disorders. The AS and PWS iPSCs were generated from individuals with large deletions of the chromosome 15q11-q13 region. These iPSC models enable us to investigate the
Jennifer Miller, M.D.

“Lessons About Chromosome 15q from Prader-Willi Syndrome”

Prader-Willi syndrome (PWS) is a complex neurobehavioral disorder which is due to the absence of normally active paternally expressed genes from the chromosome 15q11-q13 region. Clinical features of PWS include hypotonia; poor feeding in infancy, often associated with failure to thrive; obesity and hyperphagia; speech, developmental, and cognitive delay; behavioral problems; restrictive and repetitive behaviors; and neuroendocrine abnormalities. Many of these features also occur in other genetic aberrations affecting chromosome 15q, making PWS an excellent model to investigate which genes in this region are associated with which clinical features.

Studies of individuals with Prader-Willi like features have identified specific genes in the chromosome 15q region that are likely associated with autism spectrum disorders, psychiatric illness, speech and language impairment, cognitive impairment, attention deficit disorder, hyperphagia, and obesity. Investigations of the phenotypic findings in individuals with genotypic abnormalities of chromosome 15q will continue to provide information about the role of these genes, and may provide insight into therapies and treatments for the various clinical features associated with PWS and other conditions affecting chromosome 15q.

Dr. Miller is an Associate Professor of Pediatric Endocrinology at the University of Florida-Gainesville.

Invited Speakers

Jennifer Miller, M.D.
Friday, March 9, 2012 • 10:45 a.m.-12:15 p.m. • Regatta Ballroom

“Lessons About Chromosome 15q from Prader-Willi Syndrome”

Prader-Willi syndrome (PWS) is a complex neurobehavioral disorder which is due to the absence of normally active paternally expressed genes from the chromosome 15q11-q13 region. Clinical features of PWS include hypotonia; poor feeding in infancy, often associated with failure to thrive; obesity and hyperphagia; speech, developmental, and cognitive delay; behavioral problems; restrictive and repetitive behaviors; and neuroendocrine abnormalities. Many of these features also occur in other genetic aberrations affecting chromosome 15q, making PWS an excellent model to investigate which genes in this region are associated with which clinical features.

Studies of individuals with Prader-Willi like features have identified specific genes in the chromosome 15q region that are likely associated with autism spectrum disorders, psychiatric illness, speech and language impairment, cognitive impairment, attention deficit disorder, hyperphagia, and obesity. Investigations of the phenotypic findings in individuals with genotypic abnormalities of chromosome 15q will continue to provide information about the role of these genes, and may provide insight into therapies and treatments for the various clinical features associated with PWS and other conditions affecting chromosome 15q.

Dr. Miller is an Associate Professor of Pediatric Endocrinology at the University of Florida-Gainesville.

NIH Workshop

Wednesday, March 7, 2012

10:45-11:05 a.m.
What’s New in Intellectual and Developmental Disabilities at NICHD and NIH
Alice Kau, Program Officer, Intellectual and Developmental Disabilities Branch, NICHD

11:05-11:35 a.m.
Training Opportunities at NICHD and NIH
Dennis Twombly, Extramural Training Officer and Deputy Director, Office of Extramural Policy, NICHD

11:35 a.m.-12:05 p.m.
Where Does My Application Get Reviewed—SR or DSR?: Review Issues at NICHD and NIH
Cathy Wedeen, Scientific Review Officer, Division of Scientific Review, NICHD

12:05-12:15 p.m.
General Questions and Answers
Speakers and IDD Branch staff
2012 Gatlinburg Conference

WEDNESDAY
March 7, 2012

8:45-9 A.M.
OPENING REMARKS
REGATTA BALLROOM
Elisabeth Dykens, Ph.D.
Gatlinburg Conference Chair
Vanderbilt Kennedy Center, Vanderbilt University

9-10:30 A.M.
PLENARY SESSION 1
REGATTA BALLROOM
From Single Syndromes to Shared Pathways: The Evolution of Behavioral Genetics Research in Developmental Disabilities
Brenda Finucane, MS, CGC
Ms. Finucane is a certified genetic counselor and Executive Director of Genetic Services at Elwyn.

NIH WORKSHOP
REGATTA BALLROOM
10:45-11:05 A.M.
What’s New in Intellectual and Developmental Disabilities at NICHD and NIH

11:05-11:35 A.M.
Training Opportunities at NICHD and NIH

11:35 A.M.-12:05 P.M.
Where Does My Application Get Reviewed—SR or DSR?: Review Issues at NICHD and NIH

12:05-12:15 P.M.
General Questions and Answers

2-3:30 P.M.
SYMPOSIUM 1—REGATTA A
Chair: Shana Cohen, University of California-Riverside

Discussant: Keith Crnic, Arizona State University
Maternal Depression and Infant Development in Latino Families: Cultural Influences on Risk
Shayna Coburn
Keith Crnic
Nancy Gonzales
Arizona State University
Familismo: How Do Cultural Beliefs about Family Frame Latina Mothers’ Perceptions of Support in Caring for their Child with Developmental Disabilities?
Shana Cohen
Susan Holloway
Irenka Domínguez-Pareto
1University of California-Riverside
2University of California-Berkeley
Empowering Latino Families of Children with ASD: A Psycho-Educational Intervention
Sandy Magaña
Rebecca Paradiso
Elizabeth Miranda
Waisman Center, University of Wisconsin-Madison

SYMPOSIUM 2—REGATTA B
Mindfulness-Based Stress Reduction: Introducing the World of Zen to I/DD
Chair: Elisabeth Dykens, Vanderbilt Kennedy Center, Vanderbilt University

Discussant: TBA
Mindfulness-Based Stress Reduction: Overall Findings from the Parent-Stress Intervention Project (PSIP)
Elisabeth Dykens
Vanderbilt Kennedy Center, Vanderbilt University
Mindfulness-Based Stress Reduction: Mental Health Outcomes for Parents of Children with Autism Spectrum Disorders and Other I/DD Conditions
Nancy Miodrag
Elisabeth Dykens
Vanderbilt Kennedy Center, Vanderbilt University
Mindfulness-Based Stress Reduction: Mental Health Outcomes for Mothers Attending with their Spouse and Mothers Attending Alone
Marisa Fisher
Elisabeth Dykens
Vanderbilt Kennedy Center, Vanderbilt University
A Pilot Study of Mindfulness-Based Stress Reduction in Williams Syndrome: Physiology, Psychological State, and Behavioral Traits
Miriam Lense
Nancy Miodrag
Elisabeth Dykens
Vanderbilt Kennedy Center, Vanderbilt University

SYMPOSIUM 3—REGATTA C
Basic and Applied Research in Reading of Children with I/DD
Chair: William McIlvane, Eunice Kennedy Shriver Center, University of Massachusetts Medical School
Discussant: Janet Twyman, Eunice Kennedy Shriver Center, University of Massachusetts Medical School

Orthographic Processing in Youth with Intellectual Disability
Susan Loveall
Frances Conners
Marie Moore
University of Alabama-Tuscaloosa

A Model of Phonological Processing for Students with Mild Intellectual Disability: The Relationship between Phonological Processing Abilities, Language, and Reading
R. Michael Barker
Rose Sevcik
Robin Morris
Mary Ann Romski
University of Kansas
Georgia State University

Validity of an Assessment of Phonological Awareness Using a Non-Speech Response Mode: A Pilot Study
Kathryn Saunders
R. Michael Barker
Mindy Sittner Bridges
University of Kansas

Generalized Syllable Recombination in Reading of Portuguese Words by Brazilian Children With and Without Intellectual and Developmental Disabilities
Deisy de Souza
Julio de Rose
Elenice Hanna
William McIlvane

SYMPOSIUM 4—REGATTA A
Premutation Carriers of FMR1 Gene Expansions: Prevalence, Language Profiles, and Health
Chair: Marsha Maillick Seltzer, Waisman Center, University of Wisconsin-Madison
Discussant: Steven Warren, University of Kansas

Prevalence of CGG Expansions of the FMR1 Gene in a U.S. Population-Based Sample
Marsha Maillick Seltzer
Mei Wang Baker
Jinkuk Hong
Matthew Maenner
Jan Greenberg
Daniel Mandel
Waisman Center, University of Wisconsin-Madison
Wisconsin State Laboratory of Hygiene
Centers for Disease Control and Prevention

Language Dysfluencies as a Measure of Executive Function in Female Premutation Carriers of FXS
Audra Sterling
Marsha Maillick Seltzer
Jan Greenberg
Waisman Center, University of Wisconsin-Madison

Daily Health Symptoms of Mothers of Adolescents and Adults with Fragile X Syndrome
Leann Smith
Marsha Maillick Seltzer
Jan Greenberg
Waisman Center, University of Wisconsin-Madison

SYMPOSIUM 5—REGATTA B
Co-Morbid Features in PWS, ASD, and 15q Disorders
Chair: Elizabeth Roof, Vanderbilt Kennedy Center, Vanderbilt University
Discussant: James Bodfish, University of North Carolina-Chapel Hill
March 7, 2012

Psychiatric Symptoms in Prader-Willi Syndrome
Elizabeth Roof
Carolyn Shivers
Lauren Deisenroth
Elisabeth Dykens
Vanderbilt Kennedy Center, Vanderbilt University

Social Functioning and Face Discrimination in Prader-Willi Syndrome
Anastasia Dimitropoulos
Benjamin Feldman
Cheryl Klaiman
1Case Western Reserve University
2Marcus Autism Center, Children’s Healthcare of Atlanta and Emory University School of Medicine

Restricted and Repetitive Behavior in Children and Adolescents with Prader-Willi Syndrome and Autism Spectrum Disorder
Evon Batey Lee
Carolyn Shivers
Vanderbilt Kennedy Center, Vanderbilt University

Autism Spectrum Profiles in MECP2 Duplication Syndrome Compared to Idiopathic Autism
Sarika Peters
Rachel Hundley
Amy Wilson
Alison Vehorn
Zachary Warren
Claudia Fonseca
Melissa Ramocki
1Vanderbilt University
2Baylor College of Medicine

SYMPOSIUM 6—REGATTA C
Social Anxiety and Stress in Neurodevelopmental Disorders
Chair: Blythe Corbett, Vanderbilt Kennedy Center, Vanderbilt University

Biobehavioral Stress in Response to Different Social Interactions in Autism
Blythe Corbett
Clayton Schupp
Kimberly Lanni
Vanderbilt University

Neural Mechanisms of Developmental Risk for Social Anxiety
Jennifer Urbano Blackford

Amil Allen
Suzanne Avery
Ron Cowan
Vanderbilt University

Atypical Early Social Experience Programs the Serotonergic Raphe and Anxiety-Like Behavior
Elizabeth Hammock
Vanderbilt University

5:30-7:30 P.M.
POSTER SESSION 1—ANNAPOLIS ATRIUM

1. Sensory Experiences Questionnaire (3.0)
Psychometric Properties: Characterizing Sensory Features in Children with Autism Spectrum Disorder
Karla Ausderau
John Sideris
Lauren Little
Grace Baranek
University of North Carolina-Chapel Hill

2. A Longitudinal Case Study of a Young Girl with Angelman Syndrome: Language and Parent Outcomes Following Participation In an Early AAC Language Intervention
Andrea Barton-Hulsey
Ashlyn Smith
Ani Whitfield
Georgia State University

3. Correlates of Wayfinding Performance of Persons with Down Syndrome
Megan Benson
Susan Loveall
Edward Merrill
University of Alabama-Tuscaloosa

4. Predictors of Peer Network Size and Dimensions of Group Play Among Children with ASD
Paul Benson
University of Massachusetts-Boston

5. Context-Specific Social Behaviors that Predict Social Successes for Children with Disabilities
Bianca Brooks
Frank Floyd
1Georgia State University
2University of Hawaii
6. Research to Practice Divide in Services for Children with Autism: A Tale of Two Regions
Mallory Brown
Kenya Talton
Laura Lee McIntyre
University of Oregon

7. A Longitudinal Study of the Emergence of Autistic Profiles in Young Children with Down Syndrome—What is the Picture Over 3 Years?
Sue Buckley¹,²
Stephanie Bennett¹,²
¹Down Syndrome Education International (UK)
²University of Portsmouth (UK)

8. Pain and Sensory Function in Neuronal Ceroid Lipofuscinosis (NCL)
Chantel Burkitt¹,²
John Hoch¹
Breanne Byers¹
Adele Dimian¹
Frank Symons¹
¹University of Minnesota
²Gillette Children’s Specialty Healthcare

9. The Relationship of Maternal Criticism toExternalizing Behaviors of Children with FXS
Abbey Campbell
Nancy Brady
Michaela Beals
Juliana Keller
Steven Warren
The Schiefelbusch Institute for Life Span Studies, University of Kansas

10. Pessimism and Expectations for the Future and Sibling Relationship Affective Tone in Siblings of Adolescents with Developmental Disabilities
Amanda Cannarella
Penny Hauser-Cram
Boston College

11. Receptive Language Ability in Mandarin-Speaking Children with Autism Spectrum Disorders
Hsu-Min Chiang³
Yueh-Hsien Lin³
³Teacher’s College, Columbia University
¹National Taiwan Normal University

12. SENSE Theatre—Improving Social Interaction and Reducing Stress in Autism
Blythe Corbett
Catherine Coke
Cassandra Newsom
Emelyn Bingham
Tori Stromp
Deanna Swain
Courtney Taylor
Lily Wang
Yanna Song
Vanderbilt University

13. Autism Spectrum Symptoms in Prader-Willi Syndrome: Comparison Across Genetic Subtypes
Nathan Dankner
Evon Batey Lee
Elisabeth Dykens
Vanderbilt Kennedy Center, Vanderbilt University

14. Prodromal Symptoms in Prader-Willi Syndrome
Lauren Deisenroth
Elizabeth Roof
Elisabeth Dykens
Vanderbilt Kennedy Center, Vanderbilt University

Jennifer Frey
Kelly Windsor
Ann Kaiser
Megan Roberts
Vanderbilt University

Dina Ghoneim
Blythe Corbett
Vanderbilt University

17. The Early-Onset + Regression ASD Phenotype in the Simons Simplex Collection
Robin Goin-Kochel
Anna Laakman
Stephen Kanne
Baylor College of Medicine

18. Alterations of MECP2 Expression and Brain Indices of Autism-Related Social Engagement
Reyna Gordon
Rachel Hundley
Amy Wilson
Alexandra Key
March 7, 2012

Sarika Peters
Vanderbilt Kennedy Center, Vanderbilt University

19. What Past Tells of Present: Predicting Parental Outcome Variables across 20 Years
Katherine Grein
Jesse Ludwig
Laraine Glidden
St. Mary's College of Maryland

20. Visual Fixation Patterns During Emotional Face-Voice Matching
Ruth Grossman¹²
Anna Schmid²
Erin Steinhardt²
Teresa Mitchell²
¹Emerson College
²Eunice Kennedy Shriver Center, University of Massachusetts Medical School

21. Adaptive Behavior in Young Children with Williams Syndrome
Laura Hahn¹
Deborah Fidler¹
Susan Hepburn²
¹Colorado State University
²University of Colorado–Denver Health Sciences Center

22. Predicting Ratings of Adolescent Motivation from Early Childhood Indicators: A Study of Children with Developmental Disabilities
Miriam Heyman
Ashley Woodman
Miriam Tillinger
Amanda Cannarella
Penny Hauser-Cram
Boston College

Linda Hickson¹
Ishita Khemka¹
Harriet Golden²
Aikaterini Chatzistyli²
¹Teacher's College, Columbia University
²AHRC New York City

Robert Hodapp
Meghan Burke
Nancy Miodrag
Emily Tanner-Smith
Vanderbilt University

25. Longitudinal Studies of Gycoproteinoses—Cognitive and Adaptive Functioning
Lucia Horowitz
Richard Simensen
Sara Cathey
Greenwood Genetic Center

Dwight Irvin
Brian Boyd
Sam Odom
Frank Porter Graham Child Development Institute, University of North Carolina-Chapel Hill

27. Face Perception in Adolescents and Adults with Prader-Willi Syndrome
Dorita Jones
Alexandra Key
Amber Vinson
Elisabeth Dykens
Vanderbilt University

Marygrace Yale Kaiser¹
Lynne Katz²
Laura Dinehart³
Mary Anne Ullery²
¹Eureka College
²University of Miami
³Florida International University

29. Mental State Verb Use in Children with Fragile X Syndrome
Juliana Keller
Nancy Brady
Steven Warren
University of Kansas
8:45-10:15 A.M.

SYMPOSIUM 7—REGATTA A
Multi-Modal and Multi-Method Approaches to Assessment and Intervention for SIB
Chair: Stephen Schroeder, University of Kansas
Discussant: William MacLean, University of Wyoming

Treating Severe Self-Injury in the Natural Environment Using a Multi-Component Approach
Andrea Courtemanche
Stephen Schroeder
Jan Sheldon
James Sherman
University of Kansas

Predictors of Self-Injurious Behavior Exhibited by 617 Individuals with Autism
David Richman
Lucy Barnard-Brak
Amanda Bosch
Samuel Thompson
Laura Grubb
Layla Abby
Texas Tech University

The Effects of Developmental Quotient and Diagnostic Criteria on Challenging Behavior in Toddlers with Developmental Disabilities
Kristen Medeiros
Alison Kozlowski
Jennifer Beighley
Johannes Rojahn
Johnny Matson
1George Mason University
2University of Kansas
3Centro Ann Sullivan del Peru

Peripheral Innervation of Children at Risk for SIB
Frank Symons
Raymond Tervo
Chantel Burkitt
John Damerow
Erica Suski
Brian McAdams
Shawn Foster
Gwen Wendelschafer-Crabb
William Kennedy
1University of Minnesota-Minneapolis
2Gillette Children's Specialty Healthcare

SYMPOSIUM 8—REGATTA B
Biobehavioral Investigations of Temperament in Fragile X, Williams, and 7q11.23 Duplication Syndromes
Co-Chairs: Jane Roberts, University of South Carolina
Carolyn Mervis, University of Louisville
Discussant: Elisabeth Dykens, Vanderbilt Kennedy Center, Vanderbilt University

Behavioral and Physiological Correlates of Negative Affect in Young Children with Fragile X Syndrome
Bridgette Tonnsen
Sam McQuillin
Deborah Hatton
Jane Roberts
1University of South Carolina
2Vanderbilt University

Temperament in Williams Syndrome: Factor Analysis of the Children's Behavior Questionnaire
Ovsanna Leyfer
Angela John
Janet Woodruff-Borden
Carolyn Mervis
1Center for Anxiety and Related Disorders, Boston University
2MIND Institute, University of California-Davis
3University of Louisville

Genetic Factors in Temperament: A Comparison of Children with 7q11.23 Deletions (Williams Syndrome) and Duplications (7q11.23 Duplication Syndrome)
Danielle Henderson
Nicole Crawford-Zelli
March 8, 2012

Janet Woodruff-Borden
Carolyn Mervis
University of Louisville

**SYMPOSIUM 9—REGATTA C**
*Mining Public Health Data for IDD Research*
Co-Chairs: Richard Urbano, Vanderbilt Kennedy Center, University
Robert Hodapp, Vanderbilt Kennedy Center, Vanderbilt University

**How to Link Birth, Death, Marriage, Divorce, and Hospital Discharge Records**
Richard Urbano
Vanderbilt Kennedy Center, Vanderbilt University

**Examining Health Issues Among Persons with Down Syndrome**
Nancy Miodrag
Vanderbilt Kennedy Center, Vanderbilt University

**Studying Families of Children with Down Syndrome**
Robert Hodapp
Vanderbilt Kennedy Center, Vanderbilt University

**Lead Exposure and Developmental Disabilities**
Marygrace Yale Kaiser
Eureka College

10:30 A.M.-12 P.M.

**SYMPOSIUM 10—REGATTA A**
*Adult Aging with Down Syndrome*
Chair: Wayne Silverman, Kennedy Krieger Institute and Johns Hopkins University School of Medicine

**Impact of the Family Environment on Aging in Down Syndrome**
Anna Ebensen¹
Marsha Mallick Seltzer²
¹Cincinnati Children's Hospital Medical Center
²Waismann Center, University of Wisconsin-Madison

**Preclinical Stage of Alzheimer's Disease: The Neuropsychological Profile of Asymptomatic Adults with Down Syndrome Evidencing Amyloid Deposition**
Sigan Hartley¹
Benjamin Handen²
Bradley Christian¹
Patty Jo Murray²
Julie Price²

Sterling Johnson¹
William Klunk²
Darlyrne Devenny³
¹University of Wisconsin-Madison
²University of Pittsburgh
³New York State Institute for Basic Research

**Altered DNA Methylation of TMEM131 and TCF7 in Leukocytes is Associated with Increased Risk of Dementia and Death in Adults with Down Syndrome**
Nicole Schupf¹
Kristi Kerkel¹
Deborah Pang²
Alexis Temkin¹
Warren Zigman²
Wayne Silverman¹
Benjamin Tycko¹
¹Columbia University Medical Center
²University of Pittsburgh
³New York State Institute for Basic Research in Developmental Disabilities

**Sensory Disorders in Older Adults with Down Syndrome**
Sharon Krinsky-McHale¹
Wayne Zigman¹
Wayne Silverman²
¹New York State Institute for Basic Research in Developmental Disabilities
²Kennedy Krieger Institute and Johns Hopkins University School of Medicine

**APOE Genotype and Trajectory of Change in Adults with Down Syndrome Developing Dementia**
Warren Zigman¹
Sharon Krinsky-McHale¹
Nicole Schupf¹²
Wayne Silverman³
¹New York State Institute for Basic Research in Developmental Disabilities
²Columbia University Medical Center
³Kennedy Krieger Institute and Johns Hopkins University School of Medicine
SYMPOSIUM 11—REGATTA B
Evaluating Reading Interventions for Children with Down Syndrome
Chair: Sue Buckley, Down Syndrome Education International (UK), University of Portsmouth (UK)

Teaching Early Reading Skills to Young Children with Down Syndrome
Sue Buckley\textsuperscript{1,2}
Rebecca Baxter\textsuperscript{1}
Stephanie Bennett\textsuperscript{1,2}
Gillian Bird\textsuperscript{1}
Julie Hughes\textsuperscript{1}
\textsuperscript{1}Down Syndrome Education International (UK)
\textsuperscript{2}University of Portsmouth (UK)

Outcomes from a RCT of Reading and Language Intervention for Children with Down Syndrome
Kelly Burgoyne\textsuperscript{1,2}
Fiona Duff\textsuperscript{3}
Paula Clarke\textsuperscript{4}
Sue Buckley\textsuperscript{1,2}
Margaret Snowling\textsuperscript{1}
Charles Hulme\textsuperscript{3}
\textsuperscript{1}Down Syndrome Education International (UK)
\textsuperscript{2}University of Portsmouth (UK)
\textsuperscript{3}University of York (UK)
\textsuperscript{4}University of Leeds (UK)

Evaluation of a Blending Programme for Children with Down Syndrome: Outcomes from a Feasibility Study
Kelly Burgoyne\textsuperscript{1,2}
Fiona Duff\textsuperscript{3}
Paula Clarke\textsuperscript{4}
Sue Buckley\textsuperscript{1,2}
Margaret Snowling\textsuperscript{1}
Charles Hulme\textsuperscript{3}
\textsuperscript{1}Down Syndrome Education International (UK)
\textsuperscript{2}University of Portsmouth (UK)
\textsuperscript{3}University of York (UK)
\textsuperscript{4}University of Leeds (UK)

SYMPOSIUM 12—REGATTA C
Translational Analysis and Treatment of Chronic Aberrant Behavior—Transition States, Behavioral Economics, and Idiosyncratic Functions
Co-Chairs: Michael Cataldo, Kennedy Krieger Institute and Johns Hopkins University School of Medicine
William McIlvane, Eunice Kennedy Shriver Center, University of Massachusetts Medical School
Discussant: Travis Thompson, University of Minnesota

Translational Research: Understanding and Treatment of Behavior Problems During Transitions in Persons with IDD
Dean Williams
University of Kansas

Behavioral Economic Analyses to Gauge the Utility of Reinforcers for Behavior Intervention
Iser DeLeon\textsuperscript{1,2}
Michelle Frank-Crawford\textsuperscript{1}
Abbey Carreau-Webster\textsuperscript{1}
Griffin Rooker\textsuperscript{1,2}
Jessica Becraft\textsuperscript{1}
Mariana Castillo\textsuperscript{1}
James Chastain\textsuperscript{1}
Erin Schaller\textsuperscript{1}
Christopher Bullock\textsuperscript{1,2}
Lisa Toole\textsuperscript{1}
\textsuperscript{1}Kennedy Krieger Institute
\textsuperscript{2}Johns Hopkins University School of Medicine

Functional Analysis of Problem Behavior: A Systematic Approach to the Identification of Idiosyncratic Variables
William Dube\textsuperscript{1}
Kevin Schlichenmeyer\textsuperscript{1}
Eileen Grant\textsuperscript{1}
Eileen Roscoe\textsuperscript{2}
\textsuperscript{1}University of Massachusetts Medical School
\textsuperscript{2}New England Center for Children
THURSDAY
March 8, 2012

1:30-3 P.M.
PLENARY SESSION 2
REGATTA BALLROOM
A New Angle on Angelman Syndrome
Ben Philpot, Ph.D.
Dr. Philpot is an Associate Professor of Cell and Molecular Physiology at the University of North Carolina-Chapel Hill.

3:15-4:45 P.M.
PLENARY SESSION 3
REGATTA BALLROOM
Human Induced Pluripotent Stem Cell (iPSC) Models of Chromosome 15q
Stormy Chamberlain, Ph.D.
Dr. Chamberlain is the Raymond and Beverly Sackler Assistant Professor of Genetics and Developmental Biology at the University of Connecticut Health Center.

5-7 P.M.
POSTER SESSION 2—ANNAPOLIS ATRIUM
1. Correlates of Sensory Processing with Adaptive and Problem Behaviors
Lisa Daunhauer¹
Deborah Fidler¹
Susan Hepburn²
¹Colorado State University
²University of Colorado-Denver

2. Neuropsychological Functioning in Children with Prader-Willi Syndrome: A Comparison of Genetic Subtypes
Megan Kovac
Stephen Hooper
Anne Wheeler
Carolina Institute for Developmental Disabilities, University of North Carolina-Chapel Hill

3. Examining Mental State Attribution in Autism Spectrum Disorders: An fMRI Study
Lauren Libero¹
Floris de Lange²

4. A Closer Look at Contingency Space Analysis: How Does It Compare with Yule's Q?
Blair Lloyd
Craig Kennedy
Paul Yoder
Vanderbilt University

5. The Down Syndrome Advantage in the Transition to Adulthood
Jesse Ludwig
Katherine Grein
Laraine Glidden
St. Mary's College of Maryland

Matthew Maenner
Leann Smith
Jinkuk Hong
Renee Makuch
Jan Greenberg
Marsha Mailick Seltzer
Waisman Center, University of Wisconsin-Madison

Helena Mawdsley
Johns Hopkins University

8. Psychometric Evaluation of Depression Measures among Adults with Intellectual Disability
Inga Mileviciute¹
William MacLean¹
Sigan Hartley²
¹University of Wyoming
²University of Wisconsin-Madison

9. Partner Stress as a Contributor to Family Cohesion in Parents of Adolescents with Disabilities
Darcy Mitchell
Penny Hauser-Cram
Colby-Sawyer College

Rajesh Kana³
¹University of Alabama-Birmingham
²Donders Institute for Brain, Cognition, and Behavior, Radboud University (Netherlands)
10. Development and Predictors of Effortful Control in Young Males with Fragile X Syndrome
Marissa Mounts¹
Deborah Hatton²
Jane Roberts¹
¹University of South Carolina
²Vanderbilt University

11. Adherence and Psychological Evaluation Recommendations for Young Children with ASD
Evon Batey
Cassandra Newsom
Alison Vehorn
Julie Lounds Taylor
Elizabeth Dohrmann
Zachary Warren
Vanderbilt University

12. An Overview of the BAPQ in a Large Sample of Simplex Families
Caroline Oates
Carolyn Shivers
Elisabeth Dykens
Vanderbilt Kennedy Center, Vanderbilt University

13. Receipt of Mammography Among Women with Intellectual Disabilities: Medical Record
Susan Parish¹
Jamie Swaine²
Esther Son¹
Karen Luken³
¹Lurie Institute for Disability Policy, Brandeis University
²University of North Carolina-Chapel Hill
³Frank Porter Graham Child Development Institute, University of North Carolina-Chapel Hill

Allyson Phillips
Frances Conners
Edward Merrill
University of Alabama-Tuscaloosa

15. The Influence of Cortisol and Child Factors on Maternal Responsivity in Mothers of Boys with Fragile X Syndrome
Ashley Robinson¹
Jane Roberts¹
Nancy Brady²
Marjorie Grefer¹
Steven Warren²
¹University of South Carolina
²University of Kansas

16. Relationship Between Engagement of Preschool Children with ASD and Adult Participation
Ann Sam
Sam Odom
Brian Boyd
University of North Carolina-Chapel Hill

Emily Schaidle
Sigan Hartley
University of Wisconsin-Madison

Richard Serna¹
Mark Preston²
Teresa Mitchell²
¹University of Massachusetts-Lowell
²Eunice Kennedy Shriver Center, University of Massachusetts Medical School

19. Patterns and Predictors of Anxiety among Siblings of Children with Autism Spectrum Disorders
Carolyn Shivers
Lauren Deisenroth
Julie Lounds Taylor
Vanderbilt Kennedy Center, Vanderbilt University

20. Sibling Relationship Quality and Interaction for Sibling Pairs With and Without a Disability: Examining the Unique Role of Communication
Ashlyn Smith
Mary Ann Romski
Rose Sevcik
Georgia State University

Brittany Travers¹,²
Patrick Powell¹
Laura Klinger¹,³
Mark Klinger¹,³
¹University of Alabama
²Waismann Center, University of Wisconsin-Madison
³TEACCH, University of North Carolina-Chapel Hill
March 8, 2012

22. Mining Public Health Datasets with ‘Coupler’
Richard Urbano
Jeremy Stephens
Cole Beck
Vanderbilt University

23. A Case Study of Co-Occurring 15q13.3 Deletion and Williams Syndrome
Faye van der Fluit
Bonita Klein-Tasman
University of Wisconsin-Milwaukee

24. Maternal Intelligence and Parenting Knowledge Predict Executive Functions
Keri Weed
John Borkowski
Tom Whitman
University of South Carolina-Aiken
University of Notre Dame

25. Relation of Child Problem Behaviors, Dyadic Adjustment, and Parenting Stress to Maternal Depression Following ASD Diagnosis
Amy Weitlauf
Alison Vehorn
Julie Lounds Taylor
Zachary Warren
Vanderbilt Kennedy Center, Vanderbilt University

26. Parenting Stress and Efficacy in Mothers of Children with Prader-Willi Syndrome
Anne Wheeler
Stephen Hooper
Carolina Institute for Developmental Disabilities, University of North Carolina-Chapel Hill

27. Parental Distress in Pursuit of ASD Diagnostic Consultation
Stormi White
Julie Davidson
Amy Nicholson
Alison Vehorn
Hylan Noble
Amy Weitlauf
Zachary Warren
Vanderbilt Kennedy Center, Vanderbilt University

28. Describing the Motor Skills of Young Children with Developmental Delays Before and After Participating in a Non-Augmented or Augmented Language Intervention
Ani Whitfield

29. Visual Attention to In-Vivo vs. Video Models in Preschoolers with Autism
Kaitlyn Wilson
University of North Carolina-Chapel Hill

30. Outcome Predictors of a Community Center-Based Early Intervention Program for Toddlers with Autism Spectrum Disorder
Connie Wong
Mark Akstinas
Frank Porter Graham Child Development Institute, University of North Carolina-Chapel Hill
Orange County Department of Education

31. Group-Based Trajectories of Parenting Stress among Mothers and Fathers of Children with Developmental Disabilities: From Infancy through Young Adulthood
Ashley Woodman
Penny Hauser-Cram
Boston College

32. Implicit Contextual Cueing of Persons with Intellectual Disability
Yingying Yang
Edward Merrill
University of Alabama
8:45-10:15 A.M.

SYMPOSIUM 13—REGATTA A
Chair: Connie Kasari, University of California-Los Angeles
Leonard Abbeduto\textsuperscript{1}
Elisabeth Dykens\textsuperscript{2}
Deborah Fidler\textsuperscript{3}
Frank Floyd\textsuperscript{4}
Robert Hodapp\textsuperscript{2}
Ann Kaiser\textsuperscript{2}
Marsha Mailick Seltzer\textsuperscript{5}
\textsuperscript{1}University of California-Davis
\textsuperscript{2}Vanderbilt University
\textsuperscript{3}Colorado State University
\textsuperscript{4}University of Hawaii
\textsuperscript{5}Waisman Center, University of Wisconsin-Madison

SYMPOSIUM 14—REGATTA B
Uses of Eye Tracking/Pupillometry to Enrich Understanding of Information and Sensory Processing in Individuals with ID
Chair: Krista Wilkinson, The Pennsylvania State University and Eunice Kennedy Shriver Center, University of Massachusetts Medical School
Discussant: William Dube, Eunice Kennedy Shriver Center, University of Massachusetts Medical School

Eye Tracking Helps Reveal Mechanisms Underlying Facilitation of Responses to Visual Communication Displays by Individuals with and without Intellectual Disabilities
Krista Wilkinson\textsuperscript{1,2}
Tara O’Neill\textsuperscript{1}
Jennifer Nauss\textsuperscript{1}
Jennifer Thistle\textsuperscript{1}
William McIlvane\textsuperscript{2}
\textsuperscript{1}The Pennsylvania State University
\textsuperscript{2}Eunice Kennedy Shriver Center, University of Massachusetts Medical School

10:45 A.M.-12:15 P.M.

PLENARY SESSION 4
REGATTA BALLROOM

Lessons About Chromosome 15q from Prader-Willi Syndrome
Jennifer Miller, M.D.
Dr. Miller is an Associate Professor of Pediatric Endocrinology at the University of Florida-Gainesville.

12:15 P.M.

CLOSING REMARKS
REGATTA BALLROOM

Elisabeth Dykens, Ph.D.
Gatlinburg Conference Chair
Vanderbilt Kennedy Center, Vanderbilt University
SYMPOSIUM 1

LATINO FAMILIES WITH CHILDREN WITH DISABILITIES AND RISK: UNDERSTANDING CULTURE, NEEDS, AND INNOVATIVE SUPPORT PROCESSES

Chairs: Shana Cohen, University of California-Riverside

Discussant: Keith Crnic, Arizona State University
SYMPOSIUM 1

Maternal Depression and Infant Development in Latino Families: Cultural Influences on Risk

Chairs: Shana Cohen, University of California-Riverside
Discussant: Keith Crnic, Arizona State University

Maternal Depression and Infant Development in Latino Families: Cultural Influences on Risk
Shayna Coburn
Keith Crnic
Nancy Gonzales
Arizona State University

Familismo: How do Cultural Beliefs about Family Frame Latina Mothers’ Perceptions of Support in Caring for their Child with Intellectual Disabilities?
Shana Cohen¹
Susan Holloway²
Irenka Domínguez-Pareto²
¹University of California-Riverside
²University of California-Berkeley

Empowering Latino Families of Children with ASD: A Psycho-Educational Intervention
Sandy Magaña
Rebecca Paradiso
Elizabeth Miranda
Waismann Center, University of Wisconsin-Madison
Maternal Depression and Infant Development in Latino Families: Cultural Influences on Risk

Shayna Coburn, Keith Crnic, Nancy Gonzales
Arizona State University
Department of Psychology, Arizona State University, Tempe, AZ 85287
(sskelley@asu.edu)

Introduction: Culture, and its influence on parenting and children's development, is only beginning to have a more prominent place in developmental science, and understanding the role of culture on developmental processes in Latino families represents a critical area for study in both normative and risk contexts. Births to Hispanic women have increased in the past decade (National Vital Statistics Report, 2006), and studies suggest a significantly greater risk of postpartum depression (PPD) for Hispanic women. However, these studies rarely investigate the unique experiences of Hispanic mothers that affect developmental trajectories for infants. With the putative risks of maternal depression for children's social and cognitive functioning (Goodman, 2006), and the apparent health disparity for PPD in Latina mothers, studies that explore how cultural-ecological forces affect mother-infant coregulation and children's later social and cognitive development are critical. The current study involves a longitudinal investigation of Mexican American mothers and their infants recruited from low-income health clinics in Arizona. A multi-method examination of risk and protective factors assessing PPD and infant development addresses questions of relations among culture, risk, maternal depression, the mother-infant relationship, and children's developmental functioning at age 12 months.

Method: Data are drawn from interviews conducted prenatally (wave 1) and 6 weeks after delivery (wave 3). Bilingual interviewers assess prenatal acculturation, cultural values, parenting expectations, and perceived stress. Depressive symptoms are assessed using the Edinburgh Postpartum Depression Scale (EPDS; Cox et al 1987) at each time point. Mother-infant coregulatory observations are conducted four times across the first six months, and infant cognitive functioning is assessed with the Bayley Scales at 12 months.

Preliminary Results: Preliminary analyses indicate that sample families have substantial economic and social risk. Mothers have low levels of education (mean=9.93, sd=3.52), are mostly unemployed (76.6%), have household incomes between $5,000-15,000/year, and typically have four people dependent on the income (mean=3.90, sd=2.20). Most mothers were born in Mexico (81%) and spoke Spanish as their primary language (81%), but time in the U.S. ranged widely from 0 to 32 years (mean=10.56, S=.6.73). EPDS scores were generally below the clinical cutoff of 12/13, but ranged from 0 to 18 (mean=4.98, sd=4.71). Correlations for wave 1 indicated that measures of life hassles and perceived stress were positively correlated with EPDS (p<.01), while prenatal expectations were negatively correlated with EPDS (p<.01). Cultural factors neither predict nor moderate early maternal depression in this population. Subsequent analyses will address the role of cultural factors as mediators or potential moderators of the relation between maternal depression and behavior on infant cognitive status at 12 months.

Discussion: Acculturation may not relate to early depressive symptoms but cultural values may serve a critical role in more sophisticated conceptual approaches to understanding the connections among risk and protection for Latina families and their young infants. Findings from SEM and path analyses will shed particular light on the nature of the associations between culture, health disparity, risk, and developmental outcomes for Latino children. Better understanding of the mechanisms that underlie such connections will inform more culturally sensitive and culturally competent approaches to intervention.
Introduction: Latina mothers who care for a child with an intellectual disability experience more depression than non-Latina mothers who care for a child with an intellectual disability (Blacher, Shapiro, Lopez, Diaz, & Fusco, 1997; Magaña, Seltzer, & Kraus, 2004). Family support has been shown to reduce stress and depression particularly for Latina mothers who care for a child with a disability (Keefe, Padilla, & Carlos, 1979). The structural risk factors present in some Latino families do not fully explain why Latina mothers experience more depression than non-Latina mothers who care for a child with a disability (Blacher et al., 1997). Some Latino families hold certain culturally situated beliefs pertaining to family cohesiveness and individual family obligations that may be useful for understanding how family support functions within this population (Correa, Bonilla, & Reyes-MacPherson, 2010; Magaña, 1999). Attitudinal familism, a value considered distinctly Latino, is the belief in the commitment of family members to their family relationships. It emphasizes the importance of family closeness, family obligation to assisting its members, and family member responsibility for the well being of the entire family (Cauce & Domenech-Rodriguez, 2002). The aim of this study is to understand how familism moderates the relation between family support and well being for Latina and non-Latina mothers who care for a child with a disability.

Method: This study used an OLS regression analysis to understand how familism moderated the relation between perceived support and family and caregiver well being among 146 partnered mothers (84 Latina mothers, and 62 non-Latina mothers), with children with intellectual disabilities. First we examined whether there were differences between Latina and non-Latina mothers in their endorsement of familism using the Attitudinal Familism Scale (Steidel & Contreras, 2003). Second, we examined whether a mother’s endorsement of familism is related to family well being using the Family Quality of Life Measure (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006). Third, we examined whether familism moderated the relation between traditional forms of familial support and family well being.

Results: Latina mothers have a significantly greater sense of familism than non-Latina mothers (t = 4.19, p < 0.001). Also, familism significantly predicted family quality of life (b = 0.52, p < 0.01). The interaction between familism and partner emotional support showed that a strong belief in familism is more important for mothers with no partner emotional support than for mothers with some or a lot of partner emotional support (b= -0.50, p < 0.01). When mothers exhibited a high sense of familism and a high sense of partner emotional support they had a higher family quality of life than mothers who had a low sense of familism but high partner emotional support.

Discussion: A belief in familism may contribute to mothers’ expectations of support. Mothers who hold a strong belief in familism may expect more familial support than mothers who do not hold such a strong belief. Mothers who believe in familism have a higher family quality of life perhaps due, in part to the perceptions of family support and unity that familism embodies.

References:

Empowering Latino Families of Children with ASD: A Psycho-Educational Intervention

Sandy Magaña, Rebecca Paradiso, Elizabeth Miranda
Waisman Center, University of Wisconsin-Madison
Waisman Center and School of Social Work, University of Wisconsin-Madison, 1500 Highland Avenue, Madison, WI 53705
(magana@waisman.wisc.edu)

Introduction: Recent research has found disparities in health care and specialty services for Latino children with ASD compared to White children, particularly among those whose parents are Spanish speaking. Contributing to these disparities are language barriers, lower socioeconomic status, and limited access to information about disabilities and autism. Furthermore, Latinos are rarely included in autism intervention studies. An empowerment approach to addressing educational and informational needs of Latino parents is essential in order to better support their children with ASD. The purpose of our pilot study was to develop and assess a psycho-educational intervention which aims to help Latino parents learn about child development, autism and its symptoms, advocating for services, how to share information with family members, and how reduce stress and depression among parental caregivers.

Methods: This pilot intervention used Promotoras de Salud, which are lay community members who are bilingual, bicultural and from the same community as the participants and are trained in specific interventions. Furthermore, our promotoras were also mothers of children with an ASD. A curriculum was developed with the content listed in the introduction, and a one group pre and post-test design was used. Working with a community based organization, Wisconsin FACETS, 20 Spanish speaking mothers of children with an ASD between the ages of 2 and 8 years old were enrolled in the study. Promotoras carried out 8 home visits with each participant using the developed curriculum. Promotoras also administered the pre and post-tests, which included the following measures: Family Outcome Survey (Bailey et al., 2008); Caregiver Burden, Satisfaction and Efficacy (Heller, Miller, & Hseih, 1999), and the Center for Epidemiology Studies Depression Scale (CESD). Focus groups were held with participants after completing the program.

Results: Using paired t-tests, pre and post-test data showed significant improvements in all five of the Family Outcome subscales: Understanding Child's Strengths and Needs, Knowing your Rights and Advocating for Child, Helping your Child Develop and Learn, Having Support Systems, and Accessing the Community. We also found significant improvement in caregiver efficacy, but not in caregiver burden or satisfaction. Qualitative data shows that mothers were very satisfied with the program and valued having another parent of a child with ASD deliver the content material.

Conclusions: Interventions are needed for Latino families of children with ASD to address the disparities in services received by their children. This pilot study used an empowerment approach to improve knowledge and skills about how to better help their children. Results suggest that this may be a promising psycho-educational intervention for Spanish speaking Latino families. A second module is currently being developed to increase parental skills in using evidenced based applied behavior analytic strategies with their child with ASD. Plans are underway to conduct a randomized trial for the first module.

References:
MINDFULNESS-BASED STRESS REDUCTION:
INTRODUCING THE WORLD OF ZEN TO I/DD

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

Mindfulness-Based Stress Reduction: Introducing the World of Zen to I/DD

Chair: Elisabeth Dykens, Vanderbilt Kennedy Center, Vanderbilt University

Mindfulness-Based Stress Reduction: Overall Findings from the Parent-Stress Intervention Project (PSIP)
Elisabeth Dykens  
Vanderbilt Kennedy Center, Vanderbilt University

Mindfulness-Based Stress Reduction: Mental Health Outcomes for Parents of Children with Autism Spectrum Disorders and Other I/DD Conditions
Nancy Miodrag  
Elisabeth Dykens  
Vanderbilt Kennedy Center, Vanderbilt University

Mindfulness-Based Stress Reduction: Mental Health Outcomes for Mothers Attending with their Spouse and Mothers Attending Alone
Marisa Fisher  
Elisabeth Dykens  
Vanderbilt Kennedy Center, Vanderbilt University

A Pilot Study of Mindfulness-Based Stress Reduction in Williams Syndrome: Physiology, Psychological State, and Behavioral Traits
Miriam Lense  
Nancy Miodrag  
Elisabeth Dykens  
Vanderbilt Kennedy Center, Vanderbilt University
A full 1 in 5 children in the US has a developmental disability, and prevalence estimates are particularly high for autism spectrum disorders, seen in 1 in 150 children. Parents of these children experience more stress than parents of typically-developing children, as well as more depression, anxiety, and health and mental health problems (Hodapp & Ly, 2005). Negative health and mental health outcomes are complicated by the fact that offspring with disabilities are now living longer and co-residing with their aging parents, and by the increased economic hardships faced by families of children with disabilities (Parish et al., 2008). Parents of children with autism spectrum disorders (ASD) are especially prone to negative psychological and economic outcomes (Kogan et al., 2008), although stress levels are also significantly elevated in mothers of children with Down syndrome and other etiologies.

Conventional parent group interventions provide information, support, and advocacy, and are often used in the disability field. These groups are of benefit to parents, but are inconsistently available, do not directly treat maternal stress or depressive symptoms, and do not take into account the accumulated health burden of parents who are rearing challenging children over time. We recently found that mindfulness, or being aware of and focused on the present moment in a nonjudgmental way, was the best mediator between maternal stress and outcome in 140 mothers of children with ASD or other disabilities. Mindfulness predicted reduced depression and anxiety, as well as increased happiness, meaning in life, improved health, and more normal patterns of diurnal cortisol (Dykens et al., 2009). These findings suggest that mindfulness-based interventions may be more effective than conventional groups for parents of children with disabilities.

This project compared the effectiveness of a conventional Parent Group intervention to Mindfulness-Based Stress Reduction (MBSR) in parents of children with ASD or other disabilities. MBSR is a well-proven, efficacious treatment for people with elevated stress related to pain, everyday living, and medical or psychiatric disorders. We randomly assigned 287 parents of children with disabilities to 6 weeks of a Parent Group versus MBSR group intervention. Parents were followed for 6 months post-treatment. Mothers and fathers of children with disabilities were hired as research assistants and trained to conduct either the Parent Group or MBSR group interventions. Peer-mentors are effective providers of advocacy and support.

The overall trends and patterns found from this study will be discussed in terms of understanding the health and mental health outcomes of parents raising children with ASD and various intellectual and developmental disability conditions.
Mindfulness-Based Stress Reduction: Mental Health Outcomes for Parents of Children with Autism Spectrum Disorders and Other I/DD Conditions

Nancy Miodrag, Elisabeth Dykens
Vanderbilt Kennedy Center, PMB 40, 230 Appleton Place, Nashville, TN 37203 (nancy.miodrag@vanderbilt.edu)

Introduction: Decades worth of research suggests increased rates of stress and other health problems in parent raising children with various intellectual and developmental disability (I/DD) conditions. Yet, no public large-scale interventions are in place to treat their distress or prevent their burdens over time. Mindfulness-Based Stress Reduction (MBSR) is an empirically-based integrative health intervention that has successfully treating a number of clinical populations including individuals with cancer, chronic pain, and depression (Kabat-Zinn, 1990). The MBSR program has yet to be evaluated in treating high-stressed groups of parents including those raising children with I/DD conditions. The purpose of this study was to compare mental health outcomes in parents of children with Autism Spectrum Disorders (ASD) or other I/DD conditions who participated in either MBSR or a conventional Positive Parenting group (PP).

Methods: 287 parents of children with I/DD (e.g., Down syndrome, cerebral palsy) were randomly assigned to a 6-week MBSR (n = 146) or PP (n = 141) intervention. We compared parents of children with ASD (n = 176) to parents of children with all other I/DD conditions (n = 111). Parents completed self-report measures of depressed mood, anxiety, parental stress, and satisfaction with life at the beginning of treatment (T1), 6 weeks later at the end of treatment (T6), and 1 month after treatment (T10). Parents and children with ASD were younger (parent mean = 40.30 years, child mean = 9.62 years) than parents and children with other I/DD (parent mean = 43.23 years, child mean = 14.0 years, p < .05). Thus, age was used as a covariate.

Results: Between-group. Separate two-way ANOVAs were conducted to examine the effect of treatment and child diagnosis on depression, anxiety, stress, and life satisfaction. The PP group scored significantly higher on depressive symptoms than the MBSR group (F(1,186) = 7.91, p = .005), as did parents of children with ASD compared to parents of children with other I/DD conditions (n = 111). There were no significant interaction effects between treatment and child diagnosis. The PP group scored significantly higher on anxiety than the MBSR group (F(1,188) = 5.35, p = .02), and parents of children with ASD reported greater levels of anxiety than parents of children with other I/DD, F(1,188) = 5.55, p = .02). There were no significant interaction effects. We found no significant effects for parental stress and satisfaction with life.

Within-group. For MBSR, repeated measures ANOVAs with a Greenhouse-Geisser correction determined that mean depression decreased significantly from T1 to T10 (F(3, 156) = 3.23, p = .024) for ASD and I/DD. Anxiety also decreased significantly from baseline to treatment completion (F(3, 83) = 5.14, p = .026), but not to follow-up, p = 0.68. There was a trend towards significance for increased satisfaction with life from T1 to T6, F(1, 81) = 3.62, p = .061, but no differences to follow-up, p = .54. Levels of stress did not change. For the PP group for both ASD and I/DD, there were no significant changes from T1 to T6 on any measures.

Discussion: This is the first study to evaluate mindfulness training in parents of children with ASD and other I/DD conditions. The findings suggest fewer mental health symptoms for parents in the MBSR program (compared to conventional support) and for parents rearing children with I/DD conditions (compared to ASD). Depressed mood and anxiety decreased across a brief, 6-week MBSR program, but not for conventional support. Mindfulness practice is a powerful psychological tool that can quickly improve the psychological well-being of families parenting children with ASD and other disabilities.
Mindfulness-Based Stress Reduction: Mental Health Outcomes for Mothers Attending with a Spouse Versus Mothers Attending Alone

Marisa Fisher, Elisabeth Dykens
Vanderbilt Kennedy Center, PMB 40, 230 Appleton Place, Nashville, TN 37203
(marisa.fisher@vanderbilt.edu)

Introduction: As many as 20% of US families are raising children with intellectual and developmental disabilities (I/DD), and these parents experience more stress than parents of typically-developing children, as well as more depression, anxiety, and health and mental health problems. Mindfulness-Based Stress Reduction (MBSR) is an empirically-based integrative health intervention that has successfully treated a number of clinical populations including individuals with cancer, chronic pain, and depression (Kabat-Zinn, 1990); yet, the MBSR program has yet to be evaluated in treating high-stressed groups of parents raising children with I/DD conditions. Mental health outcomes of parents participating in MBSR were compared to those attending a conventional parent support group (Positive Parenting [PP]). This presentation compared mental health outcomes in mothers who participated in either MBSR or PP with their spouse and mothers who participated in the sessions alone.

Methods: 287 parents of children with various I/DD (e.g., Autism Spectrum Disorders, Genetic Syndromes, Mood Disorders) were randomly assigned to a 6-week MBSR (n = 146) or a 6-week PP (n = 141) intervention. Data were drawn from this larger sample to compare mothers who attended with their spouse (MBSR n = 29, PP n = 26) to mothers who attended alone (MBSR n = 46, PP n = 49). Mothers completed self-report measures of depressed mood, anxiety, parental stress, and satisfaction with life at the beginning of treatment (T1), 6 weeks later at the end of treatment (T6), and 1 month after treatment (T10). Mother’s age (M = 41.18), child’s age (M = 11.08), number of child’s diagnoses (M = 1.57), and the number of children in the family (M = 2.57) did not differ across groups.

Results: Between-group: Separate two-way ANOVAs were conducted to examine the effect of mother’s type of attendance on depression, anxiety, stress, and life satisfaction. Post-intervention, mothers who attended treatment alone scored significantly lower on the measure of depression (10.76 (1.34)) compared to mothers who attended with their spouse (15.39 (1.71), F (1, 90) = 4.52, p < .05). There were no other differences and there were no interaction effects between type of treatment and type of attendance.

Within group: For both depression and anxiety, there was main effect for time: both mothers who attended with a spouse and who attended alone displayed decreased mean scores from T1 to T10 (F (2, 134) = 40.54, p < .01 and F (2, 134) = 28.47, p < .01, respectively). A similar main effect was found for parent stress in that both groups of mothers displayed decreased mean stress scores from T1 to T6, F (1, 90) = 9.97, p < .01. There were no interaction effects for depression, anxiety, or stress and whether the mother attended with a spouse or attended sessions alone. There was also a main effect for time on scores of satisfaction with life in that both groups increased their mean scores from T1 to T10 (F (2, 132) = 11.10, p < .01). Furthermore, there was an interaction effect; specifically, compared to mothers who attended alone, mothers who attended with a spouse had significantly higher mean scores from T1 to T10 (F (2, 132) = 3.09, p < .05).

Discussion: Results indicate that mothers benefit from both MBSR and PP, whether they attend sessions alone or with a spouse. Mothers who attended with a spouse displayed higher feelings of satisfaction with life. Data collection up to 6 months post-treatment is currently being completed and higher-level analyses will be presented.
**SYMPOSIUM 2**

**A Pilot Study of Mindfulness-Based Stress Reduction in Williams Syndrome: Physiology, Psychological State, and Behavioral Traits**

Miriam Lense, Nancy Miodrag, Elisabeth Dykens
Vanderbilt Kennedy Center, PMB 40, 230 Appleton Place, Nashville, TN 37203 (miriam.lense@vanderbilt.edu)

**Introduction:** Mindfulness is defined as “paying attention in a particular way; on purpose, in the present moment, and nonjudgmentally” (Kabat-Zinn, 1994). In recent years, mindfulness based stress reduction (MBSR) has been successfully used with medical, psychiatric, and healthy persons to reduce stress and anxiety and improve quality of life (e.g., Chiesa & Serretti, 2009; Carlson et al., 2003; Miller, Fletcher, & Kabat-Zinn, 1995). However, to our knowledge, MBSR has not yet been used in populations with intellectual and developmental disabilities (IDDs). Williams syndrome (WS) is a genetic neurodevelopmental disorder associated with high rates of anxiety and attention problems (e.g., Martens et al., 2008). Thus, people with WS may benefit from MBSR.

**Methods:** Twenty-four adults (54% male) with WS participated in 20-minutes of MBSR activities daily for five days while attending a weeklong residential camp. Individuals completed MBSR activities of seated meditation, deep breathing, Qigong yoga, body scans, and lessons on incorporating mindfulness into everyday life. Prior to and after each session (except session 3), participants rated their anxiety levels on a mood thermometer and provided saliva samples for cortisol (neuroendocrine stress hormone) and alpha-amylase (sAA; protein related to sympathetic nervous system activity). Their parents completed the Child Behavior Checklist to assess emotional and behavioral difficulties. We were specifically interested in the Somatic symptoms subscale because it appears to capture anxiety in WS (Lense, Tomarken, & Dykens, under review) and the Attention Problems subscale because paying attention is critical to mindfulness (Kabat-Zinn, 1994). Hierarchical linear models were used to assess patterns of the two biomarkers during MBSR and their relationship to emotional/behavioral characteristics.

**Results:** Cortisol levels significantly declined each day in response to the MBSR ($F_{1,128.482} = 15.271, p < .001$, Cohen’s $d = 0.47$). Self-related anxiety was also significantly related to cortisol ($F_{1,119.080} = 6.356, p = .013$), as was CBCL Somatic subscale ($F_{1,15.453} = 5.926, p = .027$). In contrast, for sAA levels, there was a significant effect of session ($F_{3,117.332} = 31.363, p < .001$), and session*sample interaction ($F_{4,117.033} = 3.385, p = .012$). sAA levels were significantly higher during sessions 1 and 2 versus sessions 4 and 5 ($p < .001$). sAA levels were stable during sessions 1 and 2, but declined during session 4 ($p = .017$) and increased during session 5 ($p = .01$). Finally, CBCL attention scores significantly predicted sAA levels ($F_{1,17.897} = 5.811, p = .027$).

**Discussion:** This is the first study to examine MBSR in WS, specifically, and in an IDD population in general, and used a combination of biomarkers, self-report, and parent behavior ratings. We found unique patterns for each biomarker with the MBSR activity, suggesting differential relationships for these two physiological systems in response to MBSR in WS. Findings have important implications for the ability of people with WS to successfully engage in MBSR and the use of MBSR to improve common emotional and behavioral problems in WS.
SYMPOSIUM 3

BASIC AND APPLIED RESEARCH IN READING OF CHILDREN WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (I/DD)

Chair: William McIlvane, Eunice Kennedy Shriver Center, University of Massachusetts Medical School

Discussant: Janet Twyman, Eunice Kennedy Shriver Center, University of Massachusetts Medical School
SYMPOSIUM 3

Basic and Applied Research in Reading of Children with Intellectual and Developmental Disabilities (IDD)

Chair: William McIlvane, Eunice Kennedy Shriver Center, University of Massachusetts Medical School

Discussant: Janet Twyman, Eunice Kennedy Shriver Center, University of Massachusetts Medical School

Orthographic Processing in Youth with Intellectual Disability
Susan Loveall
Frances Conners
Marie Moore
University of Alabama-Tuscaloosa

A Model of Phonological Processing for Students with Mild Intellectual Disability: The Relationship Between Phonological Processing Abilities, Language, and Reading
R. Michael Barker
Rose Sevcik
Robin Morris
Mary Ann Romski
University of Kansas, Georgia State University

Validity of an Assessment of Phonological Awareness Using a Non-Speech Response Mode: A Pilot Study
Kathryn Saunders
R. Michael Barker
Mindy Sittner Bridges
University of Kansas

Generalized Syllable Recombination in Reading of Portuguese Words by Brazilian Children with and without Intellectual and Developmental Disabilities
Deisy de Souza
Julio de Rose
Elenice Hanna
William McIlvane

1Instituto Nacional de Ciência e Tecnologia sobre Estudos de Comportamento, Cognição, e Ensino (Brazil)
2Universidade Federal de São Carlos (Brazil)
3Universidade Federal de Brasilia (Brazil)
4Eunice Kennedy Shriver Center, University of Massachusetts Medical School
Orthographic Processing in Youth with Intellectual Disability

Susan Loveall, Frances Conners, Marie Moore
University of Alabama-Tuscaloosa
University of Alabama, Department of Psychology, Tuscaloosa, Alabama 35487
(sjloveall@crimson.ua.edu)

Introduction: Orthographic processing involves acquisition and manipulation of orthographic representations during reading (Stanovich & West, 1989). It requires recognition of specific spelling patterns in real words as well as common letter patterns (Barker, et al., 1992; Perfetti, 1984). Little research has examined orthographic processing in youth with intellectual disability (ID). Even in the typically developing (TD) literature, research has yet to consider different aspects of orthographic processing. We studied cumulative orthographic knowledge (Study 1) and current orthographic learning (Study 2) in two ID groups. Study 1 also examined two types of cumulative orthographic knowledge: general and word-specific.

Study 1: Cumulative Orthographic Knowledge

Method: The sample consisted of 15 participants with ID (age $M = 15.53; SD = 1.49$) and 38 TD participants (age $M = 8.86; SD = .90$). Because the groups differed in verbal mental age (ID group $M = 7.55; SD = 1.88$; TD group $M = 8.86; SD = .90$), statistical analyses controlled for verbal ability. Participants completed a 3-session test battery assessing a wide range of skills related to reading. Those included in the present analyses were: (1) Homophone Choice, which measures word-specific orthographic processing; (2) Orthographic Awareness, which measures general orthographic knowledge, and (3) the Kaufman Brief Intelligence Test, 2nd Edition.

Results: One-way between-group ANCOVAs were used to compare across groups for each orthographic measure. There was no significant different between groups for either general orthographic knowledge, $F(1, 49) = .45, p = .51$, partial eta squared $=.01$ or for word-specific orthographic knowledge, $F(1, 50) = .25, p = .62$, partial eta squared $=.01$.

Study 2: Current Orthographic Learning

Method: The sample had 18 children with ID (age $M = 19.97; SD = 4.99$) and 19 TD children (age $M = 8.87; SD = 1.30$) matched on verbal mental age (ID group $M = 8.87; SD = 1.30$; TD $M = 8.72; SD = 1.72$). Participants phonologically recoded nonwords at Time 1 and were then tested on orthographic learning of those nonwords about 3-5 days later at Time 2. Orthographic learning was assessed using an Orthographic Multiple Choice Task and a Spelling Test.

Results: A one-way MANOVA compared the groups on two measures (orthographic choice and spelling). There was a significant between-group difference on the combined dependent variables, $F(2, 34) = 9.52, p = .001$; Wilks’ Lambda $=.64$, partial eta squared $=.36$. Follow-up univariate tests showed marginally significant differences for each measure. For orthographic choice, the trend favored the ID group; for spelling, the trend favored the TD group.

Discussion: Youth with ID showed cumulative orthographic knowledge consistent with their verbal level (both specific and general knowledge of letter patterns that occur in real words). They also showed current orthographic learning at or above their verbal level, at least as measured by orthographic recognition. Thus, for both cumulative knowledge and current learning, orthographic recognition seems to keep pace with verbal level in youth with ID. Future research should examine reading interventions that could capitalize on relatively good orthographic recognition skills while aiming also to improve relatively poorer reading skills.

References:


SYMPOSIUM 3

A Model of Phonological Processing for Students with Mild Intellectual Disability: The Relationship Between Phonological Processing Abilities, Language, and Reading

R. Michael Barker¹, Rose Sevcik², Robin Morris², Mary Ann Romski²
¹University of Kansas, ²Georgia State University
1000 Sunnyside Avenue, Room 3017, Lawrence, KS 66045
(rmbarker@ku.edu)

Introduction: Models of phonological processing in children with typical development indicate that phonological awareness and naming speed are core components that contribute to reading success (Anthony et al., 2006, 2007). Emerging evidence shows that these same components are related to reading success in individuals with intellectual disability (ID). To date, however, no model of phonological processing exists for students with ID. Our purpose was to determine the components of phonological processing for students with mild intellectual disability (MID), and determine the relationship between its components, language, and reading skill.

Method: Baseline data were analyzed for 294 school-aged students with MID who participated in a reading intervention. Participants were administered elision, sound matching, blending words, blending nonwords, segmenting words, segmenting nonwords, rapid color naming and rapid letter naming from the Comprehensive Test of Phonological Processing. In addition, the Clinical Evaluation of Language Fundamentals – 4 (CELF-4) Expressive Language Index (three subscales) and the EVT were administered as measures of expressive language. The CELF-4 Receptive Language Index (three subscales) and the PPVT-III were administered as measures of receptive language. Finally, the word identification and word attack subscales of the Woodcock Reading Mastery Test – Revised were administered as measures of reading skill.

Results: The structure of phonological processing was determined by testing nested models in a confirmatory factor analysis. The results indicated that a model of phonological processing with three latent factors fit the data best: phonological awareness, analysis, and naming speed. Elision, sound matching, blending words, and blending nonwords were indicators of phonological awareness. Segmenting words and segmenting nonwords were indicators of analysis. Rapid color naming and rapid letter naming were indicators of naming speed. Controlling for age, phonological awareness and analysis were highly correlated, $r = .87$, naming speed was moderately correlated with phonological awareness and analysis, $rs = -.48$ and -.38, respectively. In addition, phonological awareness had strong correlations with expressive and receptive language latent variables, word identification, and word attack. Analysis demonstrated similar, but slightly smaller correlations with those variables. Naming speed demonstrated still smaller negative correlations.

Discussion: Results were consistent with studies of children with typical development; Phonological awareness and naming speed were indicated by similar variables. The analysis latent variable likely was an indicator of participants’ awareness of speech on the phoneme level, instead of the word or syllable level, as all items on segmenting words and nonwords required segmenting phonemes. The relationships between phonological processing, language, and reading were in predicted directions and of a similar magnitude compared to studies of children with typical development. The results indicate that phonological processing functions in similar ways in children with MID and that phonics approaches to reading instruction should be strongly considered for children with MID.

References:


Validity of an Assessment of Phonological Awareness Using a Non-Speech Response Mode: A Pilot Study

Kathryn Saunders, R. Michael Barker, Mindy Sittner Bridges
University of Kansas
2601 Gabriel Avenue, Parsons, KS 67357
(ksaunders@ku.edu)

Introduction: Most assessments of phonological awareness (PA) rely on speech responses (e.g., Comprehensive Test of Phonological Processing [CTOPP]; Wagner, Torgesen and Rashotte, 1999). Many individuals with intellectual disability (ID), however, have impaired speech. In addition, assessments have difficult-to-understand instructions. We developed a PA assessment that did not have complex instructions or require speech responses and thus may be more suitable for individuals with ID. The goal of this study was to establish the validity of our Computerized Phonological Awareness Assessment (CPAA) by determining the relationship between scores on it and conventional measures of phonological awareness in participants with ID who could speak.

Method: Sixteen adults with mild to moderate ID participated. They were administered the elision, blending words, sound matching, and rapid letter naming from the CTOPP, a test of letter-sound knowledge, and the word identification and word attack subscales of the Woodcock Reading Mastery Test. They also received the CPAA. The CPAA had 4 subscales (i.e., onset, rime, coda, and vowel) and was administered over the course of 1 to 4 visits. Each subscale assessed discrimination of the corresponding segment of the spoken word. For example, for onset, the computer presented a spoken nonword (e.g., “mib”), along with a pair of printed words, one that corresponded to the spoken word (i.e., mib), and one that differed by the onset (i.e., sib). Participants were instructed to touch the printed word that they heard. Each word in a pair was presented 3 times for a total of 6 presentations for the pair. Criterion was set at 5 of 6 correct. If criterion was met, the computer presented the next pair of words with the same two onsets (e.g., mob/sob). If not, the next six trials supplemented the spoken word with the correct printed word presented as a prompt. If the participant met criterion s/he was returned to the nonprompted set of trials. For each pair of words, participants received a score of 3 if they met criterion on the first non-prompted presentation, 2 if they did so on the non-prompted presentation after receiving prompts, 1 if they did so on the prompted presentation, and 0 if they did not meet criterion.

Results: Pearson’s correlations between the subscales of the CPAA were high, rs = .77 to .92, ps < .01. There also was high internal consistency between each subscale, α = .96, and within each subscale αs = .89 to .96. There was a ceiling effect on the total CPAA score. Of the 6 participants who scored >5 items correct on Woodcock word attack, 5 scored 100% on the CPAA. Of the 10 who scored 5 or less, 1 scored 100%. Removing these 6 participants, the CPAA correlated highly with letter-sound knowledge, sound matching, blending words, and word identification, rs = .70, .66, .73, and .64, ps < .05, respectively.

Discussion: Preliminary results indicate that the CPAA assessment is a reliable and valid measure of phonological awareness in adults with intellectual disability. Moreover, the CPAA may be a sensitive measure of phonological awareness. Participants with word attack scores higher than grade 1.2 consistently scored at the ceiling on the CPAA; participants below this mark had scores that were highly correlated with other measures of phonological awareness. Consequently, the CPAA assessment may be an ideal measure for assessing phonological awareness in individuals with significant speech impairments.
Introduction: We report results of a series of multi-site studies that sought to teach generative receptive and expressive reading skills to Brazilian children who had histories of failure in school. The population had a broad mix of children with intellectual disability, other learning disabilities, and/or insufficient educational opportunities at home and school. The methodology took advantage of characteristics of the Portuguese language. Many words are comprised of two-letter syllabic units (e.g., BO+LA = ball, CA+BO = handle, LA+TA = can) that can be recombined to form new words (e.g., BOCA = mouth, BOTA = boot), thus establishing a route to generative reading via recombinative generalization. Such syllabic units were incorporated within curricular framework that used matching-to-sample methods derived from NICHD-supported behavioral research (e.g., learning by exclusion, component matching, etc.) to teach matching relations involving pictures, printed and spoken words, and printed and spoken syllables.

Method: Initial studies were conducted within an UFS-Car-based learning center that maintained aspects of laboratory conditions. Follow-up studies, conducted in public school programs in four Brazilian cities, applied the same basic methodology. As shown in Table 1, the time period (TP) spanned some 13 years. The population was very large for studies of this type, each child had 2-3 teaching sessions per week (SPW), thus resulting in a very large number of sessions contributing data (SCD) and a mean participation of about 10 weeks per child.

<table>
<thead>
<tr>
<th>Site</th>
<th>TP</th>
<th>Ss</th>
<th>SPW</th>
<th>SCD</th>
</tr>
</thead>
<tbody>
<tr>
<td>UFSCar</td>
<td>1998-2011</td>
<td>840</td>
<td>3</td>
<td>25,200</td>
</tr>
<tr>
<td>Boa Esper.</td>
<td>2006-2011</td>
<td>2,256</td>
<td>3</td>
<td>67,680</td>
</tr>
<tr>
<td>Limeira</td>
<td>2006-2011</td>
<td>801</td>
<td>2</td>
<td>16,020</td>
</tr>
<tr>
<td>Muzambinho</td>
<td>2006-2008</td>
<td>432</td>
<td>2</td>
<td>8,640</td>
</tr>
<tr>
<td>Ibaté</td>
<td>2009-2010</td>
<td>339</td>
<td>3</td>
<td>10,170</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>4,668</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Implementation in the latter settings used a variety of evaluation designs including intervention control group comparison, naturalistic multiple baselines that were analogous to wait-list control procedures, pretest-posttest, and single-subject experimental control procedures.

Results: Teaching matching relations between dictated and printed syllables with recombinative generalization opportunities established generalized receptive reading skills in the vast majority of children, many of whom had shown protracted school failure. Even children who showed less complete learning outcomes made significant gains over baseline/pretest performance. In the intervention-control group comparison study, for example, learning outcomes of the former group were 3-5 times greater than for the latter group. Expressive reading and writing to dictation also showed improvement, but improvement was somewhat more variable, relating apparently to size of the established reading vocabulary.

Discussion: These studies will show that NICHD behavioral research has had a clear impact on instructional science in Brazil. It has led to procedures that can be translated from the lab to the community via delivery systems that can be implemented within regular school settings. Potential opportunities for and barriers to broader scale implementation will be discussed.

Financial Support: MCT/CNPq-FAPESP and NICHD (HD25995)
PREMUTATION CARRIERS OF \textit{FMR1} GENE EXPANSIONS: PREVALENCE, LANGUAGE PROFILES, AND HEALTH

Chairs: Marsha Mailick Seltzer, Waisman Center, University of Wisconsin-Madison

Discussant: Steven Warren, University of Kansas
SYMPOSIUM 4

Premutation Carriers of FMRI Gene Expansions: Prevalence, Language Profiles, and Health

Chair: Marsha Mailick Seltzer, Waisman Center, University of Wisconsin-Madison

Discussant: Steven Warren, University of Kansas

Prevalence of CGG Expansions of the FMRI Gene in a U.S. Population-Based Sample
Marsha Mailick Seltzer¹
Mei Wang Baker²
Jinkuk Hong¹
Matthew Maenner¹
Jan Greenberg¹
Daniel Mandel³
¹Waisman Center, University of Wisconsin-Madison
²Wisconsin State Laboratory of Hygiene
³Centers for Disease Control and Prevention

Language Dysfluencies as a Measure of Executive Function in Female Premutation Carriers of FXS
Audra Sterling
Marsha Mailick Seltzer
Jan Greenberg
Waisman Center, University of Wisconsin-Madison

Daily Health Symptoms of Mothers of Adolescents and Adults with Fragile X Syndrome
Leann Smith
Marsha Mailick Seltzer
Jan Greenberg
Waisman Center, University of Wisconsin-Madison
Prevalence of CGG Expansions of the FMR1 Gene in a U.S. Population-Based Sample

Marsha Mailick Seltzer\textsuperscript{1}, Mei Wang Baker\textsuperscript{2}, Jinkuk Hong\textsuperscript{1}, Matthew Maenner\textsuperscript{1}, Jan Greenberg\textsuperscript{1}, Daniel Mandel\textsuperscript{3}

\textsuperscript{1}Waisman Center, University of Wisconsin-Madison, \textsuperscript{2}Wisconsin State Laboratory of Hygiene, \textsuperscript{3}Centers for Disease Control and Prevention

Waisman Center, University of Wisconsin-Madison, 1500 Highland Avenue, Madison, WI 53705
(msletzer@waisman.wisc.edu)

Introduction: The prevalence of the premutation of FMR1 is of considerable public health significance because carriers are at greatly increased risk of having a child with the full mutation of FXS. In addition, the premutation itself is associated with a range of emotional and physical problems that become increasingly evident in midlife and old age (Hagerman & Hagerman, 2002), including clinically significant emotional problems, primary ovarian insufficiency (FXPOI), and late-onset Parkinson-like neurological problems (Fragile X Tremor Ataxia Syndrome, or FXTAS). The prevalence of the premutation of the FMR1 gene in the US has not yet been established using epidemiological methods.

Methods: We calculated the prevalence of the premutation of the FMR1 gene and of the “gray zone” using a population-based sample of older adults in Wisconsin (the Wisconsin Longitudinal Study, WLS). Using a high-throughput assay for exact sizing of the number of CGG repeats, we screened DNA from 6747 older adults (48.5% male). We also used WLS data to examine whether identified premutation carriers had elevated rates of symptoms associated with FXTAS or FXPOI, and children with disabilities.

Results: The prevalence of the premutation of the FMR1 gene was relatively high (1 in 167 females and 1 in 521 males for the premutation and 1 in 12 females and 1 in 21 males for the gray zone). Individuals with the premutation (n = 30, 7 males and 23 females) had a significantly higher rate of divorce than controls, as well as higher rates of symptoms that might be indicative of FXTAS (numbness, dizziness/faintness). Women were more likely to report going through or having gone through menopause than controls. Although not statistically significant (p = .07), premutation carriers were twice as likely as controls to have a child with a disability.

Discussion: To the best of our knowledge, this is the first population-level US study of the prevalence of premutation and gray zone expansions, and the second-largest study in the world literature of the prevalence of FMR1 expansions to include both males and females.

References:

Language Dysfluencies as a Measure of Executive Function in Premutation Carriers of Fragile X Syndrome

Audra Sterling, Marsha Mailick Seltzer, Jan Greenberg
Waisman Center, University of Wisconsin-Madison
Waisman Center, University of Wisconsin-Madison, 1500 Highland Avenue, Madison, WI 53705
(asterling@waisman.wisc.edu)

Introduction: There is a growing body of evidence indicating a continuum of clinical impairment associated with the FMR1 gene, including age-related vulnerabilities in executive function and cognitive decline in premutation carriers (e.g., fragile X tremor/ataxia syndrome; FXTAS). Kogan and Cornish (2011) recently reported cognitive decline in respect to executive function (EF) and working memory in premutation males asymptomatic for FXTAS; however, there has been a lack of research on EF in female carriers. Language dysfluencies are a measure of executive function and have been noted in individuals with Parkinson's in the general population. The purpose of the current paper is to examine the language characteristics indicative of executive function in female premutation carriers of FXS.

Methods: Participants included 192 premutation female carriers of FXS ages 25 to 79 years ($M = 46$ years). They completed a five-minute language sample. Mothers of children with autism ($n = 50$), matched on maternal age and child residential status served as the control group. Interviews were transcribed using standard language transcription procedures, and analyzed for standard language measures including dysfluencies (e.g., repetitive speech, “I went I went to the store”), and the overall structure of language.

Results: After controlling for the amount of talk, we found that maternal age was significantly related to all of the measures of dysfluency (e.g., dysfluencies per utterance, $r = .27^{**}$). The measures of dysfluences as well as several other key language variables were related to biological variables associated with FXS (e.g., protein activation ratio and CGG repeat length). Maternal education was not related to any of the language variables. We completed a secondary analysis with the control group and a subset of the permutation carriers. The mothers with the premutation had a significantly more dysfluent pattern of language ($F(1, 99) = 5.60, p<.05$). Maternal age was not significantly related to language dysfluencies in the mothers of children with autism, indicating a unique age effect in FXS.

Discussion: The most striking finding was the relationship between language dysfluencies and maternal age as well as biological variables associated with FXS (i.e., CGG repeat length and protein activation ratio). Given the relationship with maternal age, the language dysfluencies observed in this sample could be an indicator of decline in executive function abilities.

References:

Introduction: Mothers of children with FXS frequently are carriers of the premutation of the FMR1 gene. Premutation carriers were originally considered to be unaffected, but in recent years consensus has been growing that at least some premutation carriers display signs of impairment. FXS is now considered to be part of a multigenerational collection of clinical conditions including the Fragile X Tremor Ataxia Syndrome (FXTAS) and Premature Ovarian Insufficiency (POI). Less is known, however, regarding the extent to which premutation carriers are at risk for other types of health problems. The present study addressed this gap by investigating the frequency of daily health symptoms in premutation-carrier mothers of adolescents and adults with FXS in comparison to a nationally-representative sample of mothers whose children do not have disabilities and also to a group of mothers of individuals with autism spectrum disorders (ASD).

Methods: Participants were mothers of adolescents and adults with fragile X syndrome (FXS; n=112), mothers of similarly-aged children without disabilities (n=230), and mothers of adolescents and adults with ASD (n=96). Mothers were interviewed by telephone each evening for 8 consecutive days and reported health symptoms in the previous 24 hours, using an adapted version of the Larsen and Kasimatis (1991) symptom checklist.

Results: We used analysis of covariance (ANCOVA) to describe the daily health symptoms of premutation-carrier mothers of adolescents and adults with FXS in comparison to (a) mothers of individuals with ASD and (b) mothers of individuals without disabilities. Bonferroni post hoc multiple comparisons were used to determine the specific differences between the groups. Both mothers of a son or daughter with FXS and mothers of a son or daughter with ASD had a higher proportion of days with headaches, backaches, muscle soreness, fatigue, and hot flashes than mothers of children without disabilities. Both groups of caregiving mothers reported at least one health symptom on approximately three-fourths of days in the 8-day diary study, compared with about 50% of days for the mothers of children without disabilities ($F(1, 433) = 31.25, p < .001$).

Discussion: The present study documented elevated levels of daily health symptoms in premutation-carrier mothers of adolescents and adults with FXS and mothers of similarly-aged children with ASD, indicating a need for services that support the health and well-being of parents of children with disabilities across the life course.

References:
CO-MORBID FEATURES IN PWS, ASD, AND 15Q DISORDERS

Chair: Elizabeth Roof, Vanderbilt Kennedy Center, Vanderbilt University

Discussant: James Bodfish, University of North Carolina-Chapel Hill
SYMPOSIUM 5

Co-Morbid Features in PWS, ASD, and 15q Disorders

Chair: Elizabeth Roof, Vanderbilt Kennedy Center, Vanderbilt University

Discussant: James Bodfish, University of North Carolina-Chapel Hill

Psychiatric Symptoms in Prader-Willi Syndrome
Elizabeth Roof
Carolyn Shivers
Lauren Deisenroth
Elisabeth Dykens
Vanderbilt Kennedy Center, Vanderbilt University

Social Functioning and Face Discrimination in Prader-Willi Syndrome
Anastasia Dimitropoulos¹
Benjamin Feldman¹
Cheryl Klaiman²
¹Case Western Reserve University
²Marcus Autism Center, Children’s Healthcare of Atlanta, and Emory School of Medicine

Restricted and Repetitive Behavior in Children and Adolescents with Prader-Willi Syndrome and Autism Spectrum Disorder
Evon Batey Lee
Carolyn Shivers
Vanderbilt Kennedy Center, Vanderbilt University

Autism Spectrum Profiles in MECP2 Duplication Syndrome Compared to Idiopathic Autism
Sarika Peters¹
Rachel Hundley¹
Amy Wilson¹
Alison Vehorn¹
Zachary Warren¹
Claudia Fonseca²
Melissa Ramocki²
¹Vanderbilt University
²Baylor College of Medicine
Symposium 5

Psychiatric Symptoms in Prader-Willi Syndrome

Elizabeth Roof, Carolyn Shivers, Lauren Deisenroth, Elisabeth Dykens
Vanderbilt Kennedy Center, Vanderbilt University
Vanderbilt Kennedy Center, PMB 40, 230 Appleton Place, Nashville, TN 37203
(elizabeth.roof@vanderbilt.edu)

Introduction: Although many persons with PWS have problems in thinking, mood and social interactions, most do
not meet formal criteria for ASD, psychosis, or other psychiatric disorders. Even so, studies to date on psychopathology
in PWS rely primarily on psychiatric diagnoses, and these labels differ considerably across countries, clinical per-
spectives, labs, and nosologies (i.e., ICD-10, DSM-IV, adapted systems). Making reliable psychiatric diagnoses is also
challenging in people with intellectual disabilities in general (Dykens, 2000), which further clouds diagnoses in PWS.
Among adolescents and adults with PWS, data are needed on the emergence of specific symptoms of psychosis and af-
fective illness. Those with mUPD are at particularly high risk for these disorders, and some assert that all mUPD cases
will develop severe illness, with initial episodes seen in late adolescence or young adulthood (Boer et al., 2002; Vogels
et al., 2003; Whittington & Holland, 2004). If so, then PWS due to mUPD may provide an extremely useful window
into psychosis in the general population. We hope to identify specific symptoms in PWS and how these emerge and
change over the course of time.

Methods: This study includes a sample of 94 individuals (48 males) with PWS aged 4 to 50 years, with a mean age
of 14.94 years. Participants were recruited with assistance from the PWSA, and through our ongoing research pro-
gram on PWS conducted at Vanderbilt Kennedy Center. Parents or caregivers completed an in-depth interview with a
trained clinician of past and current psychiatric symptoms (K-SADS-PL) and Scale of Prodromal Symptoms (SOPS)
that might indicate increased risk of psychotic symptoms or its precursor. Their offspring with PWS were also ob-
served throughout the day in formal and informal settings to assess these behaviors by the same clinician to determine
diagnosis and severity of impairment. Parents also completed a family psychiatric history questionnaire for issues like
anxiety, depression and substance abuse to determine family risk factors.

Results: Those with the mUPD subtype versus Deletion subtype of PWS showed a significant increase of psychotic
symptoms (t = -2.00, p<.05) on the K-SADS-PL with delusions, magical thinking and other perceptual disturbances be-
ing the most commonly endorsed features. In addition, age is positively correlated with brief reactive psychosis (r=.29,
p<.05) and negatively correlated with ADHD. Those with Imprinting Defect subtype of PWS are also scoring signifi-
cantly higher on the psychotic subtype, suggesting they may share some common psychiatric features with those who
have the UPD subtype.

Discussion: Findings will be discussed further in terms of further refined genetic subtypes (Type I and Type II), gen-
der and age differences, and relation to hyperphagia. Focus will be given to potential family risk factors that may be
superimposed on top of the PWS genetic phenotypic predisposition for psychiatric symptoms and how these emerge
and change over time.
Introduction: Prader-Willi syndrome (PWS) is caused by either the structural loss of material or the absence of gene expression from the paternally inherited copy of chromosome 15 (q11-q13). In addition to a well-described behavioral phenotype that includes hyperphagia, obsessive-compulsive symptoms, disruptive behavior and cognitive delays, research also suggests that some persons with PWS have repetitive behavior and social deficits reminiscent of autism spectrum disorders (ASD). In addition, individuals with the maternal uniparental disomy (m-UPD) subtype of PWS are at greater genetic risk for autistic symptomatology than those with paternal deletions (DEL) of 15q11-q13 because maternal duplications of the same chromosomal interval have been shown in 1-3% of idiopathic autism. Furthermore, since the ability to discriminate faces is central to social skills, facial processing skills have been investigated in various developmental disabilities. Much of this research has found facial processing deficits are well characterized in ASD. The purpose of this research was to examine social functioning and face discrimination ability in individuals with PWS, as well as to test the hypothesis that m-UPD is a specific risk factor for autistic symptomatology.

Method: Forty-two individuals with PWS (23 DEL, 19 m-UPD) and 19 individuals with an ASD (7-36 years old) and their caregivers comprised the total sample. Participants underwent intelligence testing (WISC-IV, WAIS-III, or WASI) and a battery of social and cognitive assessments as part of a larger project including the Autism Diagnostic Observation Schedule (ADOS) and the Benton Facial Recognition Test (BFRT); caregivers were interviewed on the Autism Diagnostic Inventory-R (ADI-R) and completed the Social Competence Inventory (SCI; Rydell, 1997) and Social Responsiveness Scale (SRS; Constantino & Gruber, 2005).

Results and Discussion: All groups performed in the impaired range on the BFRT (ASD mean=35.06, overall PWS mean =36.63). PWS and ASD groups did not significantly differ on BFRT but did differ significantly on the Lighting subdomain (F=8.14, p=.006) with PWS scoring higher than ASD. Participants with m-UPD performed more similarly to those with ASD than DEL on measures of social responsiveness. They were also more likely to meet cutoff criteria for an autism spectrum disorder than individuals with DEL. With regard to face discrimination, while it was predicted that the PWS group as a whole would outperform ASD on all measures of face processing, both groups showed significant impairments and genetic subtype differences were not marked. Results will be discussed in relation to ADOS and ADI-R diagnostic criteria. These findings give further insight into the social functioning of persons with PWS and indicate need for intervention in this population, particularly those with the m-UPD subtype of Prader-Willi syndrome.
Introduction: Restricted and repetitive behavior (RRB) is one of the three core diagnostic domains of autism spectrum disorder (ASD), but is also commonly found in other neurodevelopmental and psychiatric disorders, including Prader-Willi Syndrome (PWS). RRB consists of a wide array of maladaptive behaviors, such as stereotyped movements, self-injurious behavior, restricted interests, compulsive behavior, and insistence on sameness. Flores, et al. (2011) recently found higher RRB in ASD samples as compared to a PWS sample. They stated that this was the first study to use the Repetitive Behavior Scale – Revised (RBS-R) to investigate RRB in both populations. However, the study was limited by a small PWS sample size, wide age range, and lack of controls for a number of potential covariates. To address these concerns, we investigated RRB in well-characterized samples of children and adolescents with PWS and ASD that were comparable in terms of age, gender, cognitive, and social adaptive skills.

Methods: Data were obtained from a longitudinal study of individuals with PWS and from the Simons Foundation Autism Research Initiative (SFARI). In order to control for potential covariates, we used propensity scores to create samples of 58 individuals with PWS and 58 with ASD who were matched on age, gender, IQ, and the Vineland II Adaptive Behavior Composite. These matched samples were compared on the Repetitive Behavior Scale – Revised (RBS-R) and Autism Diagnostic Observation Schedule (ADOS). Higher scores on both measures indicate greater symptom severity.

Results: On the RBS-R, average scores for the PWS sample were significantly higher than the ASD sample for 3 of the 6 subscales: Self-Injurious (t=-2.32, p<.05), Compulsive (t=-3.05, p<.01), and Ritualistic Behavior (t=-4.32, p<.001). In contrast, the ASD sample had higher scores on the Restricted Behavior subscale (t=2.25, p<.01). The ASD and PWS samples did not differ on the Stereotyped or the Sameness subscales of the RBS-R. ADOS algorithm scores were significantly higher for the ASD compared to the PWS sample for the Communication (t=2.64, p<.01), Social Interaction (t=8.15, p <.001), and Stereotyped Behaviors and Restricted Interests (t=4.25, p<.001) Totals.

Discussion: Restricted and repetitive behavior is a common feature of both ASD and PWS, but there is great heterogeneity within RRB. We used the RBS-R to measure different types of RRB, and found that the PWS sample showed significantly more self-injurious (e.g., skin-picking), compulsive (e.g., hoarding), and ritualistic behaviors (e.g., repeating topics), while the ASD sample showed more restricted behaviors (e.g., preoccupation with parts of objects) when controlling for age, gender, IQ, and adaptive behavior skills. The overall pattern of results differed from Flores, et al. (2011), suggesting that covariates may disguise differences in RRB between ASD and PWS samples. Better understanding restricted and repetitive behavior in PWS and ASD may foster the development of useful intervention strategies and facilitate future genetic investigations.
SYMPOSIUM 5

Autism Spectrum Profiles in MECP2 Duplication Syndrome Compared to Idiopathic Autism

Sarika Peters1, Rachel Hundley1, Amy Wilson1, Alison Vehorn1, Zachary Warren1, Claudia Fonseca2, Melissa Ramocki2
1Vanderbilt University, 2Baylor College of Medicine
Vanderbilt Kennedy Center, Vanderbilt University, PMB 40, 230 Appleton Place, Nashville, TN 37203
(sarika.u.peters@vanderbilt.edu)

Background: Epigenetic modifications affect the expression of several genes without altering the underlying sequence of DNA and occur in response to genetic and environmental factors. There is mounting evidence that epigenetic mechanisms play a role in autism spectrum disorders (ASD) as evidenced by the overlap in ASD with Prader-Willi Syndrome, Angelman syndrome, as well as mutations in an X-linked gene encoding the methyl-CpG-binding protein 2 (MECP2). MECP2 is a gene with known epigenetic function in genetic regulation, and mutations in MECP2 have been linked to idiopathic autism (ASD), and alterations in MECP2 expression in the absence of MECP2 mutations are linked to ASD. MECP2 duplication syndrome primarily affects males and these patients share many of the core social impairments (albeit to a slightly lesser degree) associated with ASD (48% had ASD as a first diagnosis).

Methods: Our prior studies of boys with MECP2 duplication syndrome reveal that many boys had an existing diagnosis of ASD, and most exhibited poor eye gaze on direct evaluation. In this study, we detail the ASD-related social profiles of an additional 9 boys (not part of our original cohort group) with MECP2 duplication syndrome and have compared them to a chronological and mental age-matched sample of 11 nonverbal individuals with idiopathic ASD (no known genetic cause) from our clinical research database. Participants were between the ages of 3-10. All participants were mobile and had the full use of their hands. Our data indicate that 48% of this new cohort of 9 boys with MECP2 duplication syndrome had an initial diagnosis of ASD. All participants were evaluated using the Autism Diagnostic Observation Schedule (ADOS) Module 1 (No Words). Nonverbal mental age was assessed using the Mullen Scales of Early Learning, and the Vineland Adaptive Behavior Scales was utilized to compare profiles of adaptive behavior.

Results: Upon direct evaluation, six of 9 boys (67%) exceeded total cutoff scores for ASD on the ADOS. Although the majority of boys with MECP2 duplications exceed threshold cutoff scores, they do not have as many impairments in social affect as compared to individuals with ASD [F(1, 18)=17.81; p<.001]. Features of ASD that were common in the phenotype of MECP2 duplications include reduced eye gaze, and impaired quality of social overtures. No differences in restricted/repetitive behaviors (RRB) were noted between the groups (F=.905, p=ns). Complex mannerisms, stereotyped play, insistence on sameness, and sensory sensitivities were common amongst boys with MECP2 duplications.

Discussion: Comparisons of epigenetic single gene disorders such as MECP2 duplication syndrome to idiopathic ASD provides an important perspective by reducing heterogeneity, identifying phenotypic signatures, and further highlighting common biological pathways that are linked to ASD features. A majority of boys with MECP2 duplication syndrome have impairments in social affect, albeit to a lesser degree than a matched sample of kids with idiopathic ASD. In addition, we found no differences in RRB between the two groups. Finally, the findings could have broad impact for the assessment of ASD related social impairment in populations of individuals who are non-verbal/low-functioning, a group that is often excluded from research studies.
SOCIAL ANXIETY AND STRESS IN NEURODEVELOPMENTAL DISORDERS

Chair: Blythe Corbett, Vanderbilt Kennedy Center, Vanderbilt University
SYMPOSIUM 6

Social Anxiety and Stress in Neurodevelopmental Disorders

Chair: Blythe Corbett, Vanderbilt Kennedy Center, Vanderbilt University

Biobehavioral Stress in Response to Different Social Interactions in Autism
Blythe Corbett
Clayton Schupp
Kimberly Lanni
Vanderbilt University

Neural Mechanisms of Developmental Risk for Social Anxiety
Jennifer Urbano Blackford
Amil Allen
Suzanne Avery
Ron Cowan
Vanderbilt University

Atypical Early Social Experience Programs the Serotonergic Raphe and Anxiety-Like Behavior
Elizabeth Hammock
Vanderbilt University

Overview: Social anxiety and stress contribute to the onset, maintenance and developmental trajectory of many neurodevelopmental and psychiatric disorders. The proposed symposium will present research investigating anxiety and stress utilizing behavioral, biological, neuroimaging and animal models to inform both typical and atypical development.
**Introduction:** Autism is defined by impairment in social interaction, reciprocal communication and flexible adaptation to the changing environment. Moreover, elevated and variable arousal and stress responsivity may be an important moderator in symptom profile (Corbett et al., 2008, 2009). Previously we have shown differential stress responses as measured by salivary cortisol to social situations in children with autism compared to neurotypical peers. In the current study we compared stress responsivity in children with autism exposed to two social stress protocols to determine whether stress responsivity is differentiated by: between group (autism vs. typical development), within group (individual) or moderating (age) factors.

**Methods:** The study included two social paradigms: 1) a standardized psychosocial performance task of social evaluative threat (Lanni, Schupp, Simon & Corbett, in press) and 2) a validated peer interaction paradigm of social play with peers (Corbett et al., 2010). The comparison study included 22 children between 8 to 12 years of age (14 with autism and 8 with typical development). Biological stress was measured by salivary cortisol taken at arrival as well as 20 and 40 minutes post stressor to reflect response to initial and continuing exposure, respectively. Biobehavioral measures were analyzed using Pearson product correlations as well as repeated measures using a linear mixed model.

**Results:** Correlational analyses revealed that cortisol baseline levels between the groups were moderately correlated across experiments \( (p=0.02, r = 0.47, df = 20) \) ostensibly driven by anticipatory stress in children with ASD \( (p = 0.018, \quad r = 0.62, \quad df = 12) \) compared to typical peers \( (p = 0.55, \quad r = 0.25, \quad df = 6) \). The 20 min post value in each experiment was strongly correlated \( (p = 0.009, \quad r = 0.56) \) during the early exposure to stressors; thus, reflecting heightened response to novelty in the children with ASD \( (p =0.05, \quad r = 0.55, \quad df = 12) \) versus typical peers \( (p = 0.13, \quad r = 0.59, \quad df = 6) \). However, the 40 min post value was not correlated across conditions between the groups \( (p = 0.66, \quad r = 0.10, \quad df = 20) \) or within the groups \( (p>0.05) \). For the peer interaction \( (N=53) \), age was strongly correlated for both the 20 min \( (p = 0.004, \quad r = 0.39, \quad df = 51) \) and 40 min post cortisol \( (p = 0.003, \quad r = 0.40, \quad df = 51) \) values suggesting that age is a modifying variable for peer interactions such that older children with autism demonstrate higher levels of stress when engaging with peers.

**Discussion:** The results support the idea that stress responsivity in autism is associated with heightened reactivity to novelty across different social and nonsocial paradigms. Children who exhibit higher responsivity during anticipation and initial exposure in one situation will similarly show enhanced responsivity to another novel situation. Importantly, factors, such as age, appear to have moderating effects for enduring stress responses to specific social situations.

**References:**

Neural Mechanisms of Developmental Risk for Social Anxiety

Jennifer Urbano Blackford, Amil Allen, Suzanne Avery, Ron Cowan
Vanderbilt University
Vanderbilt University, 1601 23rd Avenue South, Nashville, TN, 37212
(Jennifer.Blackford@vanderbilt.edu)

Introduction: Social anxiety is a neurodevelopmental disorder with average onset in the early teenage years. One of the most clearly established developmental risk factors for social anxiety disorder is inhibited temperament—the chronic tendency to avoid new people, places, or objects. Previous studies have identified the amygdala as an important neural substrate of inhibited temperament (Schwartz et al, 2003). We recently discovered that individuals with an inhibited temperament continue to show an amygdala response to newly familiar faces, in contrast to the reduced amygdala response seen in individuals with an uninhibited temperament (Blackford et al, 2011). It remains unknown whether a failure in a more rapid amygdala habituation process underlies the sustained amygdala response in inhibited individuals.

Methods: Functional magnetic resonance imaging (fMRI) was used to measure rapid amygdala habituation to novel faces in young adults with an inhibited (n = 19) or uninhibited temperament (n = 20). Participants were selected based on having extreme inhibited or uninhibited temperament both as children and as adults. Participants viewed 6 novel, neutral faces randomly presented twice within each of four 18-s blocks. Habituation was defined as a decrease in amygdala activation between the first and last blocks. Using SPM5, we tested for a significant difference between the two temperament groups on amygdala habituation. A cluster-based threshold of p < .05 and cluster size > 11 provided a family-wise error corrected p < .05 for the amygdala. Percent signal change values were extracted and all effects were confirmed using ANOVA.

Results: Across all subjects, both the left and right amygdala showed significant habituation. A cluster in the right amygdala (15 voxels, 405mL) showed a significant difference in habituation between the two groups (p < .05, corrected). In the uninhibited individuals, the right amygdala habituated over time, as expected. However, in individuals with an inhibited temperament, the right amygdala failed to habituate. An ANOVA confirmed the effect of temperament, F(1,37) = 10.98, p = .003, habituation in the uninhibited temperament group (p < .0001), and failure to habituate in the inhibited temperament group (p = .37).

Discussion: In inhibited temperament, a failure of the amygdala to habituate to faces provide a novel neural mechanism for the behavioral avoidance of people and increased risk for developing social anxiety.

References:

Introduction: The mammalian brain requires properly timed input from the environment to optimally execute its genetic potential (Fox, Levitt et al. 2010). Developmental neglect is a potent risk factor for maladaptive outcomes in adulthood. We have adopted an early weaning model in mice to study the mechanisms of environmental programming of mood and emotion regulation. Because serotonin is a major neurotransmitter regulating mood and emotion, and because weaning is coincident with a developmental sensitive period for serotonin maturation (Ansorge, Zhou et al. 2004), we investigated the effects of early weaning on anxiety-like behavior and serotonergic raphe programming in mice. We specifically tested the hypothesis that early weaning may down-regulate Pet-1, which is known to positively regulate the expression level of serotonin-related genes (Liu, Maejima et al. 2010).

Methods: Twelve synchronized breeder pairs of C57BL/6J mice yielded up to 6 litters each. Offspring from odd litters were weaned at post-natal day 16 or at the typical age of post-natal day 21. Animals (n = 121) were tested as adults on a variety of behavioral tests to measure anxiety-like behavior, depression-like behavior and social behavior. At the end of testing, animals were killed and brains were harvested for analysis. The median and dorsal raphe were microdissected with a 1mm micropunch from 60 micron sections in a cryostat. RNA, isolated from the micropunches, was converted to cDNA and relative abundance of specific transcripts was determined by qPCR. Males and females were both tested and analyzed.

Results: As adults, early-weaned animals showed significantly higher scores for anxiety-like behavior in the elevated plus maze (p=0.0075), the open field (p=0.0006) and the light/dark box (p=0.0003). Early weaning did not significantly impact depression-like behavior in the forced-swim test (p=0.58) nor did it affect rates of winning ($\chi^2$ = n.s.) or latency to win (p=0.38) in the tube test for social dominance. Finally, early weaning resulted in lower expression of serotonin-relevant transcripts in the dorsal and median raphe. In particular, early weaning significantly down-regulated the transcription factor, Pet-1 (p<0.05).

Discussion: The early weaning insult in mice was a potent inducer of persistent anxiety-like effects. Down-regulation of the transcription factor Pet-1 suggests that it may be possible to environmentally program the raphe through a single master-regulator gene. These findings highlight the role of early atypical social experiences in later persistence of anxiety, which may be especially relevant in neurodevelopmental disorders with early social challenges.

References:


POSTER SESSION 1

WEDNESDAY, MARCH 7, 2012
5:30-7:30 P.M.
1. Sensory Experiences Questionnaire (3.0) Psychometric Properties: Characterizing Sensory Features in Children with Autism Spectrum Disorder

Karla Ausderau, John Sideris, Lauren Little, Grace Baranek
University of North Carolina-Chapel Hill
200 N. Greensboro Street, Suite D-12 Carrboro, NC 27510
(ausderau@med.unc.edu)

Introduction: Sensory processing problems are highly prevalent in children with ASD and interfere with daily activities of children and families. Limited assessment tools have been developed specifically to characterize sensory processing in this population. The Sensory Experience Questionnaire 3.0 (SEQ), a recently expanded caregiver-report assessment specific to children with ASD, measures behavioral responses to sensory experiences.

Methods: SEQ data were collected as part of a national online survey from 1307 participants with an ASD diagnosis, ages 2-12 years. Sample consisted of 1068 boys (CA 93 (34) mos.) and 239 girls (CA 96 (35) mos.). ASD symptom severity was assessed using the Social Responsiveness Scale. A confirmatory factor analytic model with 4 substantive factors of hypothesized sensory response patterns (i.e., hyporesponsiveness, hyperresponsiveness, sensory seeking, and enhanced perception) and method factors of sensory modalities and social context were tested. Method factors provide a parsimonious technique for modeling shared error variance. Correlations between the substantive factors were freed, but fixed to zero between the method factors, as well as between the method factors and the substantive factors. Mixed models, allowing for nesting of observation within family, were used to explore the association of autism severity to the sensory response patterns.

Results: The structure was tested as a confirmatory factor analysis. Model fit was assessed using standard fit measures: chi-square = 16,153.86 (3630)**, RMSEA =.051 and CFI=.698. Factor loadings for the items on the latent variables were generally strong and provided support for each of the hypothesized sensory content factors. Between-factor correlations ranged from .19 to .77, which implies that these factors (sensory response patterns) are distinct and they covary significantly. In the mixed models analysis while controlling for mental age, interaction of specific sensory patterns made significant contributions to autism severity.

Discussion: The large sample allowed a complex hypothesized model to be confirmed for a specified factor structure, including sensory response patterns in ASD. The complexity of the contribution of sensory patterns to autism severity was revealed. Greater knowledge of the sensory processing patterns of children with ASD may lead to improved diagnostic practices, precise assessment tools, and intervention strategies.

References:


Funding: NICHD/NIH A10-0589 (3-R01-HD042168-06S1)
2. A Longitudinal Case Study of a Young Girl with Angelman Syndrome: Language and Parent Outcomes Following Participation in an Early AAC Language Intervention

Andrea Barton-Hulsey, Ashlyn Smith, Ani Whitfield
Georgia State University
One Park Place, Suite 928, Atlanta, GA 30303
(abarton@gsu.edu)

Introduction: Recent research in molecular genetics continues to provide us with a better understanding that chromosome 15q can be responsible for a number of genetic syndromes, including Angelman syndrome (AS). Due to the genetic mechanism causing AS and the effect it has on motor systems, prognosis for speech development as a primary means of communication is limited. Most people with AS are able to produce less than 10 verbal words. Therefore, interventions that focus on the use of Augmented and Alternative Communication (AAC) may be a valuable tool for children with AS. Additionally, levels of parent stress and how parents perceive their child’s language development for this population is unknown. The purpose of this poster is to examine longitudinal data that includes participation in an augmented language intervention for a young child with AS from toddlerhood to elementary school.

Method: A 29-month-old Caucasian girl with a diagnosis of AS and her mother participated in a 24-session parent-coached language intervention comparing traditional speech intervention to components of two different augmented language interventions. She and her mother were randomly assigned to the Augmented Communication-Output (AC-O) condition. The AC-O intervention consisted of an integrated set of components that included: an individualized set of target vocabulary appropriate to three activities (play, book, and snack), a speech-generating communication device (SGD), and verbal and/or hand over hand prompts provided by the interventionist and parent so that the child produced communication using the SGD. The child completed assessments of receptive and expressive language, number of vocabulary spoken and understood. The mother completed measures of parent stress, and parent perceptions of language development. These measures were obtained at four time points: pre-intervention, post-intervention, 12-months following completion of the intervention when the child was in preschool, and again when she was in elementary school.

Results: Assessment results indicated that at pre-intervention, post-intervention, preschool, and elementary school, the child exhibited receptive and expressive language age equivalents of 16 and 4 months, 24 and 4 months, 28 and 4 months, and 28 and 12 months, respectively. For number of vocabulary words spoken, results indicated that the child used no spoken vocabulary words at pre-intervention, post-intervention, or preschool, but used five spoken words at elementary school. For number of vocabulary words understood, results indicated that at pre-intervention, post-intervention, preschool, and elementary school, the child understood 78, 133, 251, and 231 words, respectively. Intervention findings indicated that after 24 sessions of experience with a SGD, the child reliably used 10 out of 14 of her total target vocabulary words on the SGD. She continued her use of a SGD through preschool and elementary school as her primary mode of communication with family and teachers. For parent stress, results indicated that the child’s mother began the intervention exhibiting clinically significant levels of parent stress and maintained this level through the elementary school time point. Finally, both the mother’s perceptions of success in impacting her child’s communication development and severity of her child’s language skills remained high and stable over time.

Discussion: Findings of this case study indicate that the child’s receptive and expressive language skills from toddlerhood to elementary school are consistent with what is known about language abilities of children with AS. Additionally, the use of AAC is a viable early intervention approach for children with AS by giving them a modality to communicate. Finally, implications of the mother’s perceptions of language development and clinically significant levels of parent stress will be discussed.
Wayfinding is a common spatial skill that refers to a general ability in which individuals navigate from one location to another unseen location via some mostly unmarked route. It is also an important skill for independent functioning. A relatively simple method of wayfinding can involve learning to travel along a specific path and making a specific sequence of movements along that path to reach the goal location. A more sophisticated method of wayfinding can rely on the use of survey knowledge, a more configural understanding of the interrelations among several routes in the environmental space, and can allow for the use of novel pathways to reach a goal location. Previous research in our lab has indicated that persons with intellectual disability (ID) resulting from Down syndrome (DS) exhibit significantly poorer performance on measures of wayfinding than persons with ID without DS of approximately equal nonverbal MA (Benson et al., 2010). The goal of the research reported here was to replicate our earlier finding of differences between these groups in wayfinding and to evaluate whether there were also differences between groups in the cognitive abilities that predict their wayfinding performance.

Participants were 18 persons with DS and 17 persons with ID without DS. The participants completed several different measures, including the Leiter-R Brief form to assess nonverbal ability, a list learning task to assess explicit verbal learning, a stop signal task to assess inhibition, a wayfinding procedure through a virtual environment, the BRIEF to assess executive function, and a recall measure of landmark objects from the wayfinding task. The wayfinding task required participants to reproduce an 8-turn path through a series of hallways after having been guided along the path one time. The number of wrong turns was the dependent measure. Because the participants with ID without DS achieved slightly higher scores on the Leiter-R (472 vs. 464 on total growth scores), this measure was used as a covariate in the analysis of mean performance. The analyses revealed that participants with DS performed more poorly than the participants without DS in WAYFINDING ERRORS, LIST LEARNING, and LANDMARK LEARNING. However, there was no difference between groups in INHIBITION and EXECUTIVE FUNCTION. These data are consistent with Pennington et al. (2003) in suggesting that persons with DS exhibit special difficulties in tasks that rely on hippocampal functions and not on tasks that rely on prefrontal functions. Correlations among the measures indicated two striking differences between groups. The correlation between LIST LEARNING and WAYFINDING ERRORS was -.56 for the participants without DS and +.19 for the participants with DS. The correlation between INHIBITION and WAYFINDING ERRORS was +.62 for the participants without DS and -.46 for the participants with DS.

Taken together, our results suggest two conclusions. Persons with DS have a specific difficulty with wayfinding relative to persons with ID not resulting from DS. This result essentially replicates our earlier research. In addition, it appears that our participants with and without DS used different cognitive abilities in support of wayfinding. The participants without DS appear to have relied heavily on explicit learning processes. The participants with DS may have relied more on “feelings of knowing” and habit formation, as indexed by the observation that inhibition of pre-potent responses was negatively correlated with their wayfinding performance.
POSTER SESSION 1

4. Predictors of Peer Network Size and Dimensions of Group Play Among Children with ASD

Paul Benson
Center for Social Development and Education, University of Massachusetts-Boston
100 Morrissey Blvd., Boston MA 02125
(paul.benson@umb.edu)

Introduction: While much attention has been devoted to delineating the social deficits of children with autism spectrum disorder (ASD), relatively little research has examined the characteristics of the peer networks of these children or the factors associated with peer network size. Similarly, while studies have examined various individual level factors affecting the social relationships of children with ASD, little research has examined the impact of environmental factors on these outcomes (for an exception, however, see Orsmond, Krauss, and Seltzer, 2004). In the present study, we investigate children's peer network characteristics and individual and environmental factors associated with peer network size and whether or not children participate in unstructured group play. In addition we examine factors predicting three key dimensions of child group play: play interaction, play disconnection, and play disruption.

Methods: Data on child peer networks and group play were gathered by parent report, with the study sample consisting of 118 parents (113 mothers and 5 fathers) of children aged 7-11, participating in a longitudinal investigation of children with ASD and their families in Massachusetts. Data on child peer networks were gathered using a modified version of the Antonucci Social Convey Interview, while data on child play interaction, disconnection, and disruption were gathered using the Penn Interactive Peer Play Scale (Fantuzzo, et al. 1998). In addition, data was gathered on child demographics, child autism symptomatology, child problem behavior severity, parent and family characteristics, stressful life events, and family coherence.

Results: Descriptively, parents reported a mean of 5 children (including family members) in children's peer networks, with the parents of children identified with autism reporting significantly fewer peers than did parents of children diagnosed with other ASDs. In regard to factors predicting peer network size and child involvement in group play, both outcomes were found to be significantly predicted by decreased child autism symptomatology, inclusion in an integrated school program, and increased family coherence. In regard to children reported as participating in unstructured group play (n=79), play interaction and disconnection were significantly predicted by increased autism symptomatology, while play disruption was found to be predicted by increased autism symptomatology and by increased severity of child problem behaviors.

Discussion: While study results clearly emphasize the major role played by individual child factors (particularly autism symptom severity) in predicting the extent and form of peer play engaged in by children with ASD, findings also point to the important role played by family and school environment as well. These results are consistent with the those of Orsmond et al. (2004) and suggest that environmental factors, including the maintenance of equilibrium within the family system, can have important consequences for the social lives of children with ASD.

References:


5. Context-Specific Social Behaviors that Predict Social Successes for Children with Disabilities

Bianca Brooks¹, Frank Floyd²
¹Georgia State University, ²University of Hawaii
(bbrooks11@student.gsu.edu, ffloyd@hawaii.edu)

Young school-age children with intellectual disability (ID) are at risk for social isolation from peers even when provided with opportunities to interact with other children (e.g., Guralnick et al., 2009). Social isolation has been linked to deficits in social skills and social cognitive abilities for these children (Gresham & MacMillan, 1997; Leffert, Siperstein, & Widaman, 2010). This link suggests that interventions to improve social functioning with peers might focus on teaching children with ID a variety of social skills; however, the modest success of these interventions at improving peer relationships, suggests that there is a need to better understand the associations between social skills and social success for children with ID. The purpose of the present investigation is to assess whether greater use of skillful as opposed to unskillful social behaviors is associated with greater social success. Notably, we evaluated specific behavioral responses in the context of specific social situations that children commonly encounter, and we compared associations with social success for children with and without ID.

The children participated in a larger study of family relationships and children’s social adjustment for 7-13 year-old children. They were recruited from public schools. Children with mild or moderate ID (n = 42) were compared with age-matched children with no disabilities (n = 32), and a second comparison group of children with learning disabilities (n = 53). Their mothers completed the “Peer Social Tasks Rating Scale,” which described seven common social tasks for children, including joining groups, responding to approaches from other children, managing disagreements, giving help, playing games, having conversations, and coping with teasing. For each task, the mother rated how often the child responded with each of 3-5 social behaviors (1 = rarely, 5 = almost always), which included both skillful behaviors and unskillful behaviors (e.g., “compromise” and “insist on getting own way” when managing disagreements). The mothers also rated the frequency of the children’s success at each task (1 = rarely, 5 = very often).

The predictions of social success ratings from skillful and unskillful behaviors were examined for the entire sample and for the separate groups. Initial correlations indicated that, for the entire sample and across tasks, as expected, most of the skillful behaviors (10 of 12) were significantly associated with greater task success, r’s = .27 to .79, and the majority of the unskillful behaviors (11 of 16) were significantly associated with less task success, r’s = -.21 to -.60. In some of the task situations (i.e., giving help and having conversations), the behavior-success associations were generally similar for children with and without ID. However, in other situations the associations were relatively greater for the children with ID. Notably, children with ID were most successful at managing disagreements when they compromised (r = .61, p < .01) or gave in (r = .38, p < .05), and did not insist on getting their own way (r = -.43, p < .05). These associations were not significant for the children without disabilities (r’s = -.12 to .09, ns). Similarly, both children with ID and those with learning disabilities had greater success at playing games when they followed rules and took turns (r’s = .61 to .71, p <.01), but these skills were not as highly related to success for children without disabilities (r = .30 and .28, ns), possibly due to limited variance because most children in the group had mastered the skills. Interestingly, the task of coping with teasing was the only situation in which skillful behaviors (i.e., stand up for self, ask adult for help) were not associated with success for any of the groups (r’s = .06 and .17, ns), suggesting that all children are vulnerable.

The findings support the potential usefulness of efforts to foster the acquisition of social skills for children with disabilities, and they specify skillful behaviors that are relevant for specific social circumstances.
**POSTER SESSION 1**

**6. Research to Practice Divide in Services for Children with Autism: A Tale of Two Regions**

Mallory Brown, Kenya Talton, Laura Lee McIntyre

University of Oregon

Department of Special Education and Clinical Sciences, 5208 University of Oregon, Eugene, OR 97403

(malloryb@uoregon.edu)

**Introduction:** An increase in the prevalence of autism spectrum disorders (ASDs) has resulted in a high demand for specialized programs. Although there is no prescribed treatment protocol, there is general consensus that early intervention is integral in serving children with ASDs (National Research Council, 2001). When parents seek services for their child with ASD, they are often confronted with a plethora of competing and complementary treatment options, many of which are not evidence-based (e.g., McIntyre & Barton, 2011). Although there is a growing evidence-base for practices to support positive outcomes for children with ASD, there remains a large gap between research and practice.

**Methods:** The aims of this study were to investigate predictors of service utilization (early education and related services) in two community samples of young children with ASDs and compare services to best practice standards as reported in the National Research Council’s *Educating Children with Autism*. Data were collected from 108 families ($N = 78$ in Northeast; $N = 30$ in Northwest, with data collection ongoing) with children 2 – 7 years ($m$ age = 56.45 months) through the use of extensive, in-home interviews. Data for the current investigation included family and child demographic variables, child characteristics (CARS; Schopler et al., 1993; Vineland – II; Sparrow et al., 2005; TABS; Neisworth et al., 1999), and children’s current service utilization.

**Results:** All children had special education eligibility, with the majority (63.9%) enrolled in part-time school programs. Children from the Northeast received significantly more therapeutic services ($m = 4.91$ different services) than children in the Northwest ($m = 1.73$ services) ($t (1, 106) = 11.22, p < .001$). Children from the Northeast received significantly more service hours per week ($m = 18.38$ hours) than children from the Northwest ($m = 14.27$) ($t (1, 105) = 2.79, p < .05$). Across samples, most commonly utilized services were speech therapy (84.3%), occupational therapy (79.7%), and physical therapy (48.1%). One quarter of the sample (24.1%) was reported to use complementary and alternative medical approaches, with only 20.4% receiving services based on the principles of applied behavior analysis (ABA). Additional analyses will focus on child and community predictors of service utilization across the two regions.

**Discussion:** Results suggest that children with ASDs in two separate community samples received significantly fewer service hours than recommended by the American Academy of Pediatrics and the National Research Council. Furthermore, only 20% of children were reportedly receiving services based on the principles of applied behavior analysis (ABA), a treatment approach with a growing body of evidence (e.g., Reichow & Wolery, 2009). Results will be discussed within an evidence-based practice framework.

**Reference:**


**Funding:** Supported by NICHD grant HD047711, an Innovation Grant from the Burton Blatt Institute, and Fairway Funds awarded to the third author.
**POSTER SESSION 1**

7. A Longitudinal Study of the Emergence of Autistic Profiles in Young Children with Down Syndrome—What is the Picture Over 3 Years?

Sue Buckley\(^1\), Stephanie Bennett\(^1\)

\(^1\)Down Syndrome Education International (UK), \(^2\)University of Portsmouth (UK)

DSEI, Belmont Street, Southsea UK PO5 1NA
(sue.buckley@dseinternational.org)

**Introduction:** An increasing number of children with Down syndrome (DS) are being given an additional diagnosis of autistic spectrum disorder (ASD) with some studies suggesting as many as quarter of the children could have this additional diagnosis\(^1\). However, diagnosing autism in populations with a range of impairments from another condition is not straightforward and recently authors have questioned whether those receiving the diagnosis actually have typical ASD.\(^1\)\(^2\) Because there is no purely objective diagnostic test for autism there is room for error and the possibility that some symptoms seen in children with ASD may be seen in children with DS but do not indicate the core social impairment indicative of autism. This study was planned to investigate the way that behaviours which could be symptomatic of ASD develop and change over time in young children with Down syndrome.

**Method:** We have collected data on a widely used autism screening tool, the M Chat, for 36 children with Down syndrome at 3 time points. Their age range at Time 1 was 24-46 (M 32.8) months, at Time 2 36-58 (M 44.8) months and at Time 3 60-84 (M 69.03) months. We also have standardised measure of cognition, language, temperament and motor development (Bayley Infant Scales III, Carey Toddler Temperament Scale, CDI) and data on health, family and services at the first 2 time points.

**Results:** At Time 1, 15 children (41.67%) scored in the ‘at risk’ range, at Time 2, 6 (16.67%) and at Time 3, 4 (11.11%). An item by item analysis showed the pattern of ‘failed’ items varied and at T1 a number of children were not using pointing and showing behaviours. At T2 very few children ‘failed’ on social items though the 3 children still ‘at risk’ at T3 did show some core social impairments at each time point. At T3, 21 (58.33%) of children were reported as oversensitive to noise. If questions ‘does your child walk’, ‘have you ever though your child was deaf’ and oversensitivity to noise are not included in ‘failed’ count at T1, 12 (33.33%), T2, 5 (13.89%) and T3, 3 (8.33%) still ‘fail’. At each point, few other children in the group failed the same items – so, although this may not be typical autism, these children were ‘different’ from the rest of the group. Associations with cognitive, language, health and motor factors at each time point are still being explored.

**Discussion:** The 3 children considered ‘at risk’ at T3 had been in the ‘at risk’ group at each time point. However, other children would have been ‘misidentified’ at earlier points. This suggests that a diagnosis of ASD should not be considered before 5-6 years in children with Down syndrome. There is a need to develop a more specific screening tool than the MChat as at least 3 of the questions may not be indicative of ASD in this group and a child only has to ‘fail’ on 3 of 23 items to be ‘at risk’.

**References:**


8. Pain and Sensory Function in Neuronal Ceroid Lipofuscinosis (NCL)

Chantel Burkitt1,2, John Hoch1, Breanne Byiers1, Adele Dimian1, Frank Symons1
1University of Minnesota, 2Gillette Children’s Specialty Healthcare
(burki005@umn.edu)

Introduction: Neuronal Ceroid Lipofuscinosis (NCL; Batten disease) is a rare neurodegenerative and fatal inherited disorder with multiple variants, the most common of which is characterized by childhood onset. Vision loss, seizures, hallucinations, cognitive and motor impairment emerge after seemingly typical development. Given a rapid decline and the health conditions associated with the disease, it is reasonable to suspect the possibility of pain and suffering. Breau et al. (2011) provided an initial report on the pain experience of 35 children with NCL with almost half the sample experiencing recurrent pain. The primary goal of this preliminary study was to more fully characterize the pain experience among a convenience sample of individuals with NCL including pain type, frequency, interference, and its relation to sensory reactivity.

Methods: Following informed consent, 8 participants with NCL (M age=14.8 years, range=8-22) were characterized in terms of (a) the type, location, and frequency of pain experience, and (b) the degree to which pain interfered with activities of daily living (Brief Pain Inventory [BPI]). Sensory testing was conducted with each participant specifically testing predetermined body locations (non painful and body sites that were reported as painful). The sensory test consisted of 1) light touch (cotton ball), 2) discrimination between blunt (flat end of cotton swab) and sharp (tooth-pick) stimuli, and 3) application of a 60g von Frey monofilament applied repeatedly (1Hz for 30 seconds – a partial test of central sensitization). Pain expression during sensory testing was coded using the Batten’s Observational Pain Scale (BOPS; Breau et al., 2011). BOPS pain expression scores were calculated for each segment of the sensory test (light touch, blunt/sharp, central sensitization). Thermal imaging was used as a novel approach to quantify changes in skin surface temperature and indirectly characterize changes in autonomic function during sensory testing.

Results: Individuals with NCL had numerous pain sources including musculoskeletal pain (n=5), gastrointestinal pain (n=5), headaches (n=4), and everyday pain (n=4). Locations of pain included head, knees, feet, stomach, and arms. All participants experienced pain at least weekly and two experienced pain daily. Pain most negatively impacted enjoyment of life, mood, sleep, and social interactions. BOPS pain scores were marginally increased (p < 0.08) during repeated von Frey application (M = 7.3, SD = 2.4) compared to light touch (M = 4.5, SD = 4.4). Infrared thermograms of the face and eyes showed increased surface temperature for all participants from the light touch to the repeated von Frey applications.

Discussion: In this sample of children and adolescent with NCL pain was frequent with multiple sources that interfered with a range of daily activities. BOPS scores were elevated prior to sensory testing suggesting that individuals with NCL are living with ongoing pain. The increased pain expression during the repeated application of the von Frey filament, a partial test of central sensitization, further suggests that the pathophysiology of the ongoing pain individuals with NCL are living with is likely centrally not peripherally mediated.

Reference:


Supported, in part, by NIH Grant No. 47201.
9. The Relationship of Maternal Criticism to Externalizing Behaviors of Children with FXS

Abbey Campbell, Nancy Brady, Michaela Beals, Juliana Keller, Steven Warren
The Schiefelbusch Institute for Life Span Studies, University of Kansas
University of Kansas, 1000 Sunnyside Avenue, 1052 Dole, Lawrence KS 66045
(abbey86@ku.edu)

Introduction: A mother’s attitude and behavior toward her child play an important role in the development of the mother-child relationship and the emotional climate of the home. A link between maternal parenting behaviors and attitudes and child problem behavior has been well documented within samples of children with autism and IDD, as well as for typically developing children. Recently, this relationship has been documented within samples of individuals with fragile X syndrome (FXS)\(^1\). The purpose of this study is to further explore differences in problem behaviors of children with FXS parented by mothers who express varying levels criticism.

Method: This study is an extension of an ongoing longitudinal study on maternal responsivity and language development in children with FXS\(^3\). 51 mothers of children with FXS completed the Child Behavior Checklist (CBCL) and provided a Five Minute Speech Sample (FMSS)\(^2\) about their child that was then coded for the expressed emotion variable of maternal criticism. An experienced, independent coder rated each FMSS and categorized mothers in one of three groups (high, borderline, or low) of criticism based on frequency of the following: mother’s use of negative opening remarks, negative descriptions of the parent-child relationship and criticisms of the child. Raw scores from the externalizing and internalizing scales of the CBCL were used to measure child problem behaviors. All data were collected from mothers when their children were between 75 and 104 months of age.

Results: A one-way analysis of variance showed significant differences between mean levels of child externalizing behaviors based on degree of maternal criticism \([F(2,47)=4.51, p <.05]\). The number of mothers classified in each level of EE criticism was approximately equal. LSD post hoc analyses indicated that the children's CBCL mean was significantly lower among low criticism mothers \((M=5.94, SD=4.68)\) than either borderline \((M=11.53, SD=6.32, p<.01)\) or high criticism mothers \((M=11.13, SD=6.67, p<.05)\). There was no significant difference between borderline and high criticism mothers. No significant relationship was found between maternal criticism and CBCL internalizing behaviors.

Discussion: As expected, child externalizing behaviors were greater for children of borderline and high criticism mothers as compared to children of low criticism mothers. The lack of significant differences found in child externalizing behaviors between borderline and high criticism mothers may reflect a potential limitation of the FMSS measure as more than a general indicator of maternal criticism. Alternatively, the results also suggest that maternal criticism reaches a tipping point as child behavior problems increase. Findings complement past research demonstrating the association between maternal expressed emotion and child behavior problems\(^1\), and suggest new directions for research.

References:


Supported by NICHD 02538 and NICHD 03110.
POSTER SESSION 1

10. Pessimism and Expectations for the Future and Sibling Relationship Affective Tone in Siblings of Adolescents with Developmental Disabilities

Amanda Cannarella, Penny Hauser-Cram
Boston College, Lynch School of Education, Campion Hall, Chestnut Hill, MA, 02467
(cannarel@bc.edu)

Introduction: For brothers or sisters of children with disabilities, the sibling relationship may take on additional importance. Although many individuals with developmental disabilities (DD) mature into independent adults, many others require supervision and care throughout their lifetime. By the adolescent with a disability’s 18th birthday, many families have begun the guardianship process in some way. Consequently, around this time, siblings have been shown to exhibit concern and stress regarding their role in this process (Harris & Glasberg, 2003). However, little is known how the siblings’ thoughts about their brother or sister with a disability’s future impacts the sibling relationship. The current study will examine siblings’ feelings of pessimism and their expectations regarding their brother or sister’s future and its association with a change in sibling relationship closeness over adolescence.

Methods: The current study utilizes data from the Early Intervention Collaborative Study (EICS), a longitudinal investigation of children with DD and their families (Hauser-Cram et al., 2001). The sample for this analysis consisted of 45 adolescents with DD and their siblings when the adolescent with DD was both 15 and 18 years of age. Type of disability is coded throughout the study as motor impairment, developmental delay or Down syndrome. The current study utilizes the data from the siblings’ Questionnaire on Resources and Stress Short Form – Pessimism (QRS-SF; Friedrich et al., 1983), an EICS-created measure assessing sibling expectations for their brother or sister’s future, and the Positive Affect Index (PAI; Bengtson & Black, 1973) also completed by the sibling. The QRS-SF Pessimism and the expectations measure were completed with the teen with DD was 15 years old while he PAI was completed when the teen with DD was both 15 and 18 years old. Functional skills of the teen with DD were measured with a composite of the Vineland Adaptive Behavior Scales (Sparrow et al., 1984) and the Stanford-Binet Intelligence Scales (Roid, 2003). Family SES was measured using a composite of maternal years of education and approximate annual family income.

Results: Preliminary analyses indicated that there were no differences on the PAI by diagnostic category or sibling or teen gender. Lagged regression analyses were conducted to determine the effects of sibling pessimism above and beyond any effects of levels of relationship closeness at age 15, family SES, and teen functional skills. Results indicated that net of levels of relationship closeness at age 15, higher levels of pessimism were associated with lower levels of relationship closeness when the teen with DD was 18 (β=-2.135, p<.05, ΔR²=.062). Sibling expectations for the teen with DD’s future were not statistically significant in this model (β=-.122, p=.91).

Discussion: The results suggest that for siblings of adolescents with DD, higher levels of pessimism when their brother or sister with DD is 15 are associated with a decrease in relationship closeness over adolescence. Pessimism may represent an interesting contrast with the expectations siblings have for the teen with DDs future as the items on the QRS-SF address more affective aspects of the impact of the teen’s disability, as opposed to the more tangible future goals addressed with the expectation items. Further study is needed to determine which types of the sibling’s thinking about the teen with DD’s future matter most for the sibling relationship. Additionally, this may indicate an important area of intervention. Discussion around the teen’s needs and future may help reduce negative thinking in the siblings, which may help to improve the sibling relationship in adolescence.

References:
11. Receptive Language Ability in Mandarin-Speaking Children with Autism Spectrum Disorders

Hsu-Min Chiang¹, Yueh-Hsien Lin²
¹Teacher’s College, Columbia University, ²National Taiwan Normal University
Department of Health and Behavior Studies, TR 529H; Teachers College, Columbia University; Special Education Program, Box 223; 525 West 120th Street; New York, NY 10027
(hchiang@exchange.tc.columbia.edu)

Introduction: Receptive language ability seems to lag behind expressive language ability in many individuals with autism spectrum disorders (ASDs) (Tager-Flusberg & Caronna, 2007). Although receptive language ability in individuals with ASDs have been reported in previous studies (e.g., Luyster, et al., 2007; Saalasti, et al., 2010), there is a lack of research investigating receptive language ability of Mandarin speaking children with ASDs. Receptive language ability in individuals with autistic disorder may be different from that in individuals with Asperger syndrome. IQ and chronological age may be the factors associated with receptive language ability in individuals with ASDs. However, more research needs to be conducted to confirm these assumptions. Thus, the purpose of this study was to investigate receptive language ability of Mandarin speaking children with ASDs (e.g., autistic disorder, Asperger syndrome). Specific research questions that were addressed in this study included: (a) Is there a significant difference between children with ASDs and children with typical development (TD) in receptive language ability? (b) Do children with Asperger syndrome differ from children with autistic disorder in receptive language ability? (c) What is the relationship between IQ and receptive language ability in children with Asperger syndrome and children with autistic disorder? (d) What is the relationship between chronological age and receptive language ability in children with Asperger syndrome and children with autistic disorder?

Methods: A total of 100 children with TD (mean age 9.34 years, range 7.0 -12.5 years), 50 children with Asperger syndrome (mean age 9.58, range 7.0 -12.6 years), and 50 children with autistic disorder (mean age 9.58, range 7-12.6 years) were included in this study. These participants were selected from the participants for the study aiming to establish the validity of the Mandarin Token Test (Lin, et al., 2011) and to expand its norm population in Taiwan. None of the participants had hearing impairment or intellectual disability. Participants’ receptive language ability was assessed by using the Mandarin Token Test and their intelligence was assessed by using the Wechsler Intelligence Scale for Children (WISC)-III or WISC-IV.

Results: Children with TD showed better receptive language ability than did children with ASDs (t (198) = 5.25, p < .001). However, there was no significant difference between children with autistic disorder and children with Asperger syndrome in receptive language ability (t (98) = -.78). Receptive language ability of children with autistic disorder was associated with IQ (r (48) = .59, p < .01). Receptive language ability of children with Asperger syndrome was also associated with IQ (r (48) = .50, p < .01). However, chronological age was not associated with receptive language ability of children with autistic disorder or receptive language of children with Asperger syndrome.

Discussion: The finding of this study indicated receptive language ability of Mandarin speaking children with ASDs was lower than receptive language ability of Mandarin speaking children with TD. This finding is consistent with the receptive language ability observed in Finnish speaking children with ASDs (e.g., Saalasti, et al., 2008) and English speaking children with ASDs (e.g., Luyster, et al., 2007). Although there is early language delay in autistic disorder but not in Asperger syndrome (DSM-IV-TR), this study found children with Asperger syndrome did not show better receptive language ability than did children with autistic disorder.

References:
Background: Deficits in social skills prevent children with autism spectrum disorders (ASD) from achieving age-appropriate developmental milestones and as a consequence, they struggle to establish interpersonal relationships, especially with peers. Furthermore, many children with ASD exhibit notable stress in response to engaging with others.

Objective: The purpose of the study was to evaluate social interaction skills and stress responsivity in children with ASD before and after a novel intervention, SENSE Theatre, using behavioral and theatrical approaches. A previous SENSE Theatre study occurred over a 3 month span, utilizing a distributed model of the program, whereas the current study used a massed practice model implemented in a two-week intervention summer camp concluding with two public performances of an original play.

Method: The intervention combined established behavioral strategies (e.g., peer-mediation, video modeling) alongside theatrical techniques (e.g., improvisation, role-play) to target social interaction and stress responsivity. Participants included 11 youth with ASD 7 to 18 years (7 males, 4 females), including nine Caucasian and two African-American children. Neuropsychological and observational measures of social perception and interaction as well as biological (cortisol) and parent report measures of behavioral stress were assessed using a within-group pre-test, post-test design with Wilcoxon signed-rank test for the pairwise comparisons.

Results: Significant changes occurred in social interaction behaviors conducted by two independent raters for mutual planning (p=0.001, r = 0.75), eye contact (p=0.002, r = 0.37), negotiation (p = 0.001, r = 0.74), and sharing (p=0.002, r = 0.79). There were no changes on neuropsychological measures of social perception over the two week camp (all p>0.05). However, significant reductions in stress responsivity (cortisol) were observed on the first day compared to home sampling (p=0.04, r=0.48). Additionally, there was a significant decrease in behavioral stress (SSS) reported for positive (p=0.03, r = 0.27) and sensory (p=0.004, r = 0.54) stimuli.

Conclusions: The findings revealed within-treatment-context change in social interaction skills with peers, a lack of physiological stress and reductions in behavioral stress ostensibly stemming from participation in the two-week intervention. The findings support the incorporation of trained peers in a community service model utilizing theatrical techniques for improving social interaction in youth with ASD.

Funding provided by Vanderbilt University Hobbs Positive Psychology Grant (Corbett), Autism Speaks Baker Summer Camp Scholarship Grant, (SENSE Theatre) and R01 MH085717 (Corbett).
**Introduction:** Recent research indicates that there is some phenotypic overlap between Prader-Willi Syndrome (PWS) and Autism Spectrum Disorders (ASD). Much of the research investigating the common features of the two disorders has focused on restrictive/ repetitive and stereotyped behaviors. However, empirical studies and clinical reports suggest that social behavior is impaired in PWS as well. Little research has examined these characteristics as a factor of genetic subtype of PWS, but this work shows that individuals whose PWS is caused by maternal uniparental disomy (UPD) are at greater risk for expression of ASD symptoms versus those whose PWS is caused by deletions (DEL) on chromosome 15. The current study sought to examine ASD symptoms in a sample of individuals with PWS as a factor of genetic subtype, predicting that the UPD group would show more ASD symptomatology as compared to the DEL group.

**Methods:** Data from 46 individuals with DEL and 34 subjects with UPD were drawn from a larger longitudinal study. Individuals ranged in age from 4-52 years of age and ranged in full scale IQ from 40-130. Autism symptoms were measured using the ADOS, and parents/caretakers of the individuals completed a battery of questionnaires assessing child behaviors. ADOS algorithm scores were calculated utilizing the new standards set forth in Gotham et al., including the use of a score which rates overall severity of ASD symptoms.

**Results:** Verbal IQ was the only demographic variable that was significantly different between groups, with the UPD group having higher scores. After controlling for these effects, the subtype groups differed significantly on the Social Affect score of the ADOS, the Restricted Repetitive Behavior score, and the Severity Score such that individuals with UPD displayed more ASD symptoms relative to their counterparts in the DEL group, consistent with our hypotheses. Caretakers of individuals in the UPD group also endorsed more social problems on the Child Behavior Checklist (CBCL).

**Discussion:** This study supports a small but growing body of literature indicating that individuals with the UPD subtype of PWS are at greater risk for ASD symptoms in comparison to those whose with the DEL subtype. These symptoms include social deficits, which to this point have been understudied relative to restrictive/repetitive behaviors. Increased copies of the maternal chromosome in this genomic interval are the most common genetic abnormality found to be associated with idiopathic autism. Taken together with these genetic findings, the behavioral evidence of phenotypic overlap between ASD and PWS supported by this study indicate that this overlap may arise from shared genetic mechanisms. This has implications not only within ASD and PWS, but also for research investigating social cognition and obsessive-compulsive tendencies in psychopathology and typical development as well.
**Poster Session 1**

14. Prodromal Symptoms in Prader-Willi Syndrome

Lauren Deisenroth, Elizabeth Roof, Elisabeth Dykens
Vanderbilt Kennedy Center, Vanderbilt University
Vanderbilt Kennedy Center, PMB 40, 230 Appleton Place, Nashville, TN 37203
(lauren.k.deisenroth@vanderbilt.edu)

**Background:** Anecdotally, many parents report significant concern about social functioning in their child with Prader-Willi syndrome. Many of these social impairments resemble negative prodromal symptoms, such as flat emotionality, lack of close friends, and absence of spontaneity in conversation. Those individuals with mUPD subtype of Prader-Willi syndrome (PWS) are more likely to be diagnosed with an autism spectrum disorder (i.e., a significant social impairment) as well as a diagnosis of psychotic disorder. This suggests that individuals with mUPD subtype might present with a greater number of both negative and positive prodromal symptoms than people with the deletion subtype. As the symptoms of psychosis in PWS are yet to be well characterized (Dykens, Lee, & Roof, 2011), this study fills a void that could lead to further research on the link between PWS and ASD. This study has two aims: First, to identify whether negative or positive prodromal symptoms are more prevalent in people with PWS as a whole. Second, compare rates of negative and positive prodromal symptoms by genetic subtypes (i.e., deletion and mUPD).

**Methods:** We used data from a longitudinal study of phenotypic trajectories to examine prodromal symptoms in 100 individuals with a confirmed genetic diagnosis of Prader-Willi syndrome. Participants ranged in age from 4 to 62 years old ($M = 15.7$ years, $SD = 10.5$). The sample was 45% male and 55% female. Moreover, 53.0% of people had a deletion subtype and 47.0% had a mUPD subtype. Data was collected through parent interviews performed by an experienced psychological examiner. Prodromal symptoms were measured using both the Positive Symptoms and Negative Symptoms subscales of the Scale of Prodromal Symptoms (SOPS). Rates of positive and negative prodromal symptoms were compared within the entire group of individuals with PWS. Symptoms were also evaluated by genetic subtype.

**Results:** When examined as an entire PWS group, individuals with PWS expressed a greater number of negative prodromal symptoms than positive, $t(99) = 4.771, p<.001$. Not surprisingly, those individuals with mUPD showed significantly more positive prodromal symptoms than those individuals with deletions, $t(98) = -2.22, p<.05$. However, the prevalence of negative prodromal symptoms did not significantly vary by genetic subtype. When the means are further examined, they show a non-significant trend towards individuals with mUPD expressing more negative symptoms than individuals with deletion ($M = 5.98$ and 4.43, respectively).

**Discussion:** We found that individuals with PWS demonstrate more negative prodromal symptoms than positive ones. This result makes sense in light of our clinical observations that the majority of participants, regardless of subtype, seem to have some level of social deficit. In terms of the prevalence of positive prodromal symptoms, we found that individuals with mUPD subtype express more of these outwardly psychotic symptoms than individuals with deletions. Surprisingly though, negative prodromal symptoms were not more common in people with mUPD than in those with deletions. It is interesting to note that the results trended to towards significance, so future research should focus on increasing the sample size to further flesh out this area.
**POSTER SESSION 1**


Jennifer Frey, Kelly Windsor, Ann Kaiser, Megan Roberts
Vanderbilt University
Vanderbilt University, Department of Special Education, PMB 228, 230 Appleton Place, Nashville, TN 37203
(jennifer.frey@vanderbilt.edu)

**Introduction:** Children with Down syndrome (DS) have delays in their language and communication development. Differences in rate of verbal communication, complexity of verbal utterances, pragmatic skills, and speech accuracy are observed between children with DS and children with typical language development (Roberts, Price, & Malkin, 2007). Early language intervention is essential for children with DS. Enhanced Milieu Teaching (EMT; Kaiser, 1993) is an evidence-based, naturalistic early language intervention for increasing language use and linguistic complexity. The purpose of this study was to examine changes in expressive communication skills of children with DS following implementation of EMT intervention by (a) a parent, (b) a therapist, and (c) a parent and a therapist.

**Method:** Data for 21 children with DS were selected for this report. These children were part of a larger, randomized group design study investigating the effects of EMT for children with intellectual disabilities. Children were between 32 and 60 months old at the start of the study. Children were randomly assigned to one of three experimental conditions: parent only, therapist only, or parent + therapist. All children received intervention twice per week for 10 min per session for a total of 36 intervention sessions. Six intervention sessions were conducted within the child’s home, and 30 sessions were completed in clinic. Children were assessed in clinic and observed at home at four time points: before intervention, immediately following intervention, 6 months following intervention, and 12 months following intervention. To examine pre to post changes in expressive language, pre-post effect sizes were calculated for each interventionist condition across a set of standardized and non-standardized measures. In addition, changes in number of different words (NDW) used in clinic language samples and during home play probes were examined across all four time points for each condition.

**Results:** The greatest pre- to post changes were observed on parent report of children’s spoken words on the MCDI (d = 0.90 for parent only and parent + therapist conditions; d = 1.28 for therapist only condition). On play probes and language samples, children receiving EMT in the parent + therapist condition had the largest increases in NDW (effect sizes ranged from d = 0.60 to d = 1.01). Exploratory analyses indicated increases in NDW from post-treatment to 6-mo follow-up and from 6-mo follow-up to 12-mo follow-up generally were greatest for the parent only condition.

**Discussion:** Overall, children with DS receiving EMT implemented by parents and jointly by parents and therapists made greater gains in their use of spoken words compared to children with DS in the therapist only condition. Because of the small sample size, findings should be interpreted cautiously. Although training parents of children with DS may promote generalized effects of the intervention, the overall effects of intervention are still modest. Strategies for improving communication outcomes for children with DS are discussed.

**References:**


**POSTER SESSION 1**


Dina Ghoneim, Blythe Corbett  
Vanderbilt University  
1500 21st Avenue South, Suite 2200, The Village at Vanderbilt, Vanderbilt University, Nashville, TN 37212  
(dina.h.ghoneim@vanderbilt.edu)

**Introduction:** Autism is defined by impairment in social interaction, reciprocal communication and flexible adaptation to the changing environment. Elevated and variable arousal and stress responsivity may be an important moderator in symptom profile. This study involved looking at the correlation between scores on the Social Responsiveness Scale (a quantitative measure of autism symptoms) and stress response as measured by cortisol levels during an MRI scan protocol, a novel nonsocial stressor.

**Methods:** Subjects were 40 children, ages 8-12 years (16 with high-functioning autism and 24 with typical development). The Social Responsiveness Scale (SRS) was used to quantitatively measure autism symptomatology. SRS scores were measured both as a total score and across five treatment subscales. Biological stress was measured via salivary cortisol throughout the MRI protocol: at arrival as well as at 20 and 40 minutes post-stressor to reflect response to initial and continuing exposure, respectively. Biobehavioral measures were analyzed using Pearson product correlations.

**Results:** Correlational analyses revealed that cortisol levels at 20 and 40 minutes during the MRI protocol were moderately correlated with SRS score (p = 0.05, r = 0.31 and p = 0.04, r = 0.31 respectively). Mean SRS total score was 21.25 (SD = 16.76) in typically developing children vs. 96.69 (SD = 27.06) in children with autism. Among the SRS subscales, cortisol levels at 20 and 40 minutes were correlated with elevated scores on social communication (p = 0.03, r = 0.33 and p = 0.02, r = 0.36) and social motivation (p = 0.02, r = 0.35 and p = 0.06, r = 0.30).

**Discussion:** The results support the idea that stress responsivity in children with autism is heightened in response to a 20 minute MRI protocol, a novel stimulus. Subscore analysis reveals correlations between SRS score and stress response in this paradigm were driven by elevated scores on social communication and social motivation. One could speculate that stress responsivity to a novel stressor is moderated by difficulties with expressive communication and social engagement. The results support the implication of HPA axis dysregulation in autism. Additionally, the results continue our exploration of variable stress responsivities in subtypes of autism, an area where there is much opportunity for further research.

**References:**


17. The Early-Onset + Regression ASD Phenotype in the Simons Simplex Collection

Robin Goin-Kochel, Anna Laakman, Stephen Kanne
Baylor College of Medicine
(kochel@bcm.edu)

Introduction: Parents have long since reported that some children with autism spectrum disorder (ASD) experienced regression, or a loss of skills after a period of seemingly typical development. Videotape studies have confirmed the phenomenon of regression but also noted that many children exhibited delays/aberrant development prior to the regression. Recent work noted that >35% of parents of children with ASD who experienced skill losses also reported developmental concerns prior to the regression; however, it is unknown whether similar results are observed when using the Autism Diagnostic Interview—Revised (ADI-R)—perhaps the most widely accepted, interview-based tool used to operationalize skill losses. Understanding the prevalence of this early-onset plus regression phenotype is important because different onset trajectories for ASD may suggest different etiological mechanisms and/or different long-term outcomes. The objectives of this study were to utilize a large, well-characterized sample of children with ASD to (a) understand how frequently parental concerns are noted prior to regression and at what ages each is reported, per the ADI-R, and (b) examine clinician perception of ASD onset and congruence with parents’ first concerns.

Methods: Data were analyzed for children with ASD (probands; N = 2105; 86.5% male; M age = 8.9 years, SD = 3.5 years, range = 4—18 years) who participated in the Simons Simplex Collection (SSC). All had regression data as measured with the ADI-R. Analyses focused on losses occurring at or before 36 months of age. Frequencies of skill losses were calculated by type of loss. Average ages at first parental concern (FPC) and (a) onset of regression and (b) clinician judgment of age at onset (CJ) were compared using paired t-tests. The proportion of children who reportedly showed developmental abnormalities prior to the loss will be calculated.

Results: A total of 559 children (26.6%) experienced regression at ≤ age 3, with 16.1% experiencing a language loss and 21.3%, some other-skill loss; most often, other-skill losses were social regressions (91.0%). Average age at FPC for those with any skill loss was 19.6 months (SD = 8.9); 85.7% reported concerns in hindsight at ≤ 2 years. Average ages at language loss or some other skill loss were 20.2 months and 20.7 months, respectively; only other-skill losses were noted at significantly later ages than FPC, t(444) = -3.187, p = .002. Mean age for CJ was 16.6 months, which was significantly earlier than FPC, t(554) = 10.604, p < .001. Findings concerning the proportion of children who had first concerns noted prior to regression are forthcoming.

Discussion: Ages at FPC were only slightly earlier than ages for skill-loss onset, with language losses noted earlier than other-skill losses—perhaps because they are easier to recognize. Information conveyed during the ADI-R prompted clinicians to judge abnormalities as occurring earlier than parents recognized. Implications, limitations, and new findings will be discussed.

References:


POSTER SESSION 1

18. Alterations of MECP2 Expression and Brain Indices of Autism-Related Social Engagement

Reyna Gordon, Rachel Hundley, Amy Wilson, Alexandra Key, Sarika Peters
Vanderbilt Kennedy Center, Vanderbilt University
Vanderbilt Kennedy Center, PMB 74, 230 Appleton Place, Nashville, TN 37203
(Reyna.Gordon@vanderbilt.edu)

Introduction: Differences in the dosage of a single gene can confer an increased risk for autism spectrum disorders (ASD). ASD is characterized by deficits in social interaction accompanied by restricted, repetitive/stereotyped behaviors. Studies indicate that both over and underexpression of the methyl CpG binding protein 2 (MeCP2) are related to ASD. In this study, we examine brain and behavioral indices of social engagement in boys with MECP2 duplication syndrome, which involves over expression of MeCP2. Based on our previous research demonstrating a high co-morbidity of ASD in MECP2 duplication syndrome, we anticipated that boys with MECP2 duplication syndrome would show impairments in social affect on both brain and behavioral measures. We also predicted that level of impairment on behavioral measures would correspond to the level of impairment on brain indices.

Methods: In this study, brain responses to familiar and unfamiliar voices were compared in children with MECP2 duplication syndrome (n=12) between the ages of 3-10 years. Social affect was assessed in boys who had appropriate mobility using the Autism Diagnostic Observation Schedule (ADOS), Module 1. EEG was recorded in an equi-probable paradigm while participants listened passively to the word “Hi” spoken by their mother and two female strangers. Wavelet-based time-frequency representations were computed on single EEG trials and then averaged together for each participant. Cluster-based randomization analyses were carried out to identify significant differences in scalp topography of time-frequency representations derived from the EEG data.

Results: Preliminary results in the MECP2 duplication group for familiar vs. unfamiliar voices show early alpha band left vs. right hemisphere asymmetry (p = 0.024, see figure, left column), which was negatively correlated with social affect scores on ADOS (r = -0.786, in n=8 participants for whom EEG and ADOS scores were available). Furthermore, we observed a marginally significant late peak in gamma band power for familiar vs. unfamiliar voices (p =0.083, right column in figure), which was also negatively correlated with ADOS social affect scores (r = -0.514).

Discussion: The EEG results show that in boys with MECP2 duplications, brain oscillations involved in selective attention and processing meaningful stimuli (alpha and gamma, respectively) are engaged during voice discrimination. These processes are also essential during social engagement, and impairment is related to ASD. Moreover, a combination of brain and behavioral measures indicate that individuals with better social affect were also better at discriminating their mothers’ voices from strangers’ voices. These preliminary results help to establish the phenotypic portrait of behavioral and brain indices of social impairment in overexpression of MECP2 and suggest similarities to idiopathic ASD.
19. What Past Tells of Present: Predicting Parental Outcomes across 20 Years

Katherine Grein, Jesse Ludwig, Laraine Glidden
St. Mary’s College of Maryland
18952 E. Fisher Road, St. Mary’s City, MD 20686
(lmglidden@smcm.edu)

Introduction: Analyses of data from a 23-year longitudinal study have shown generally positive scores on a series of outcome variables in a sample of parents with children with intellectual and developmental disabilities (IDD; Glidden & Jobe, 2009). In the current study, we use data from the second (T2) and fifth (T5) times of measurement to examine what early parent, family, and child characteristics predict variance in these parental outcome variables 20 years after their original measurement. The T5 outcome variables consisted of 5 self-reported measures of adjustment: Subjective Well-Being (SWB) Global, SWB Current, SWB Child, DEP5 (a 5-item measure of depression taken from a larger scale), and TDRWQ6 (a 6-item measure of transition period worries and rewards taken from a larger inventory). In our analyses, we asked two main questions: 1) Are variables measured at T2 capable of predicting outcomes of well-being measured 20 years later, at T5? 2) If so, what variables account for the most variance, or predict the most outcomes?

Method: Using linear regression analyses, we tested the predictive power of T2 variables on outcomes at T5 in a sample of 83 mothers (T2 M age= 38; T5 M age= 58) and 47 fathers (T2 M age= 40; T5 M age= 60) of children with IDD. We selected T2 variables for these analyses based on the strength of their correlations with T5 variables of interest, then constructed, tested, and reduced predictive models. These models contained a mixture of family, parent, and child characteristics measured at T2.

Results: All final models for the selected T5 outcome variables were significant (p<.05) and accounted for between 20% and 30% of variance in the outcome variables. These models consisted of a mix of T2 family, parent, and child characteristics, and differed between outcome measures and, to some extent, between mothers and fathers. Models for each of the three measures of SWB (Global, Current, and Child) were more similar to one another than to the models for DEP5 and TDRWQ6. Several T2 variables appeared as significant predictors in multiple models (e.g. measures of family strength and expectations of the long-term dependency of the child). In general, more positive scores on predictor variables predicted more positive scores on outcome variables. The addition of the personality variable Neuroticism, measured at T3 but presumed to be stable from T2, increased the amount of variance accounted for by the SWB Global and DEP5 mother models to 40%, but had little effect on other models.

Conclusions: Overall, the findings of these regression analyses suggest that characteristics of a family soon after the introduction of a child with IDD are capable of predicting self-reported outcomes for those parents even 20 years later. Different outcome variables yielded different predictive models, highlighting the importance of multiple measurements of self-reported outcomes. These results have implications for refining prognoses for parents.

Reference:
**POSTER SESSION 1**

**20. Visual Fixation Patterns During Emotional Face-Voice Matching**

Ruth Grossman¹,², Anna Schmid¹, Erin Steinhart², Teresa Mitchell²
¹Emerson College, ²Eunice Kennedy Shriver Center, University of Massachusetts Medical School
(ruth.grossman@umassmed.edu)

**Introduction:** Individuals with autism spectrum disorders (ASD) have significant social communication deficits, particularly in the realm of non-verbal communication, such as maintaining eye contact, or the decoding of emotion from facial expressions (Pelphrey et al. 2007) and tone of voice, or prosody (Shriberg et al. 2001). The purpose of our study was to use eyetracking to analyze the looking patterns of adolescents with ASD and their typically developing (TD) peers in an emotional face voice matching task. Our hypothesis was that adolescents with ASD would focus their visual attention to the lower face/mouth region of the face, while TD controls would look to the upper face/eye region.

**Methods:** We used eight semantically neutral sentences recorded in happy, surprised, sad, and angry emotions with high and low emotional intensity (Grossman et al. 2009). The 64 prosodic stimuli were presented to 29 adolescents with ASD and 27 TD controls. After each sentence, participants saw two static facial expressions side-by-side on a computer screen. Their task was to determine which of the two faces was more likely to have spoken the preceding sentence. One facial expression in each pair matched the emotion and intensity level of the sentence. The other also matched on intensity level, but represented either an emotion with opposite valence (e.g. angry sentence with happy and angry facial expressions) or the same valence (e.g. angry sentence with sad and angry facial expressions).

**Results:** We recorded the percent of looking time to regions of interest (ROIs) on the correct and the incorrect face (upper face, lower face, eye region, mouth region, and non-face) and calculated a 2 (group) x 2(side: accurate vs. inaccurate) x 3 (ROI: upper face, lower face, and non-face) repeated measures ANOVA. Results show a main effect for side and ROI, but not for group. Both groups fixated significantly more on the upper face than the other ROIs. We also conducted a 2 (group) x 2(side) x 2 (ROI: eyes vs. mouth) repeated measures ANOVA and found a main effect for side and ROI, but not for group. Both groups spent significantly more time looking at the eyes than the mouth. There were no significant differences in looking times between the two groups for any of the ROIs.

**Conclusion:** Our data indicate that adolescents with ASD allocate looking time similarly to their TD peers when processing the emotional content of static facial expressions during a face-voice matching task. Most striking are the data showing that adolescents with ASD look at the eye regions of the faces as much as their TD peers, despite frequent reports in the literature that individuals with ASD avoid looking at eyes.

**References:**


The present study aims to describe the emerging adaptive behavior profile of young children with Williams syndrome (WS). Previous studies on adaptive behavior in WS have suggested that during childhood, both Socialization and Communication are areas of relative strength (Greer et al., 1997; Mervis et al., 2001). Daily Living skills are somewhat weaker and there is suggestive evidence of a relative weakness of Motor Skills (Gosch & Pankau, 1994; Greer et al., 1997; Mervis et al., 2001). The profile of adaptive behavior in children with WS has not been explored in children younger than 4 years, which may provide insight into how the patterns of strengths and weaknesses described in other studies emerge in early childhood.

Participants were 19 children with a confirmed diagnosis of Williams syndrome and 19 chronological- and nonverbal mental age-matched children with developmental disabilities (DD). Children with WS had a mean age of 49 months and a mean non-verbal mental age of 24.63 months. Children with DD had a mean age of 43.11 months and a mean non-verbal mental age of 25.7 months. Adaptive behavior was assessed using Vineland Adaptive Behavior Scales – Interview Edition, Survey Form (Sparrow et al., 1984). The two groups were compared on four domains of the Vineland. For this study age equivalence scores were used for a more substantively meaningful discussion of performance between the two groups.

Results indicated significant differences between the children with WS and children with DD on the Communication domain (Pillai’s Trace = .28, $F(4,33) = 3.24, p = .02, \eta^2 = .28$), such that children with WS had a higher age equivalence on the Communication domain ($M = 29.47$ months) than children with DD ($M = 20.21$ months). However, there were no significant differences between the two groups on the other domains of the Vineland. Further analyses were conducted to examine within-individual performance on the Vineland in children with WS. Results suggested that children with WS had distinct areas of strengths and weakness (Wilks’s $\Lambda = .60, F(3,16), p = .04, \eta^2 = .40$). Follow-up pairwise comparisons indicated that children with WS had a higher Communication age equivalence when compared to their age equivalence in Daily Living Skills ($p = .006$). Also, children with WS had a higher age equivalence in Motor Skills than they did in the Daily Living Skills ($p = .008$).

These findings add to the research on adaptive behavior in WS, and suggest that even in early childhood, adaptive Communication is a relative strength. In other areas, it appears that children with WS have demonstrated adaptive behavior performances similar to children with DD at similar nonverbal mental ages. Despite early strengths in social relatedness in children with WS, Socialization was not identified as an area of adaptive strength. This contradicts previous findings on adaptive behavior in this population and suggests that these early social behavioral strengths do not place children with WS at an adaptive functioning advantage relative to other children with DD. Further, past research on adaptive behavior in WS has suggested a relative weakness in Motor Skills, but in the present investigation children with WS had a higher age equivalence in this domain when compared to their age equivalence in Daily Living, and did not significantly differ from the comparison group.

References:


22. Predicting Ratings of Adolescent Motivation from Early Childhood Indicators: A Study of Children with Developmental Disabilities

Miriam Heyman, Ashley Woodman, Miriam Tillinger, Amanda Cannarella, Penny Hauser-Cram
Boston College
Boston College, Lynch School of Education, Campion Hall, Chestnut Hill, MA 02467
(miriam.grill-abramowitz@bc.edu)

Introduction: Individuals with developmental disabilities (DD) score lower on measures of motivation than individuals without DD (Zigler, Bennett-Gates, Hodapp, & Henrich, 2002). This lower level of motivation is thought to contribute to the fact that many individuals with DD achieve at a level that is beneath their intellectual capabilities (Zigler et al., 2002). The current study investigates the stability of motivation in individuals with DD between early childhood and adolescence. Because motivation scores impact achievement, if an early lack of motivation predicts low motivation scores later in life, it will be important for practitioners to identify children with low levels of motivation during the early childhood years and intervene accordingly.

Methods: The current study utilizes data from the Early Intervention Collaborative Study, a longitudinal investigation of children with DD and their families (Hauser-Cram, Warfield, Shonkoff, & Kraus, 2001). The sample for this analysis consisted of 99 children with Down Syndrome, Motor Impairment, or other developmental disabilities. When the children were 3 years old, researchers assessed children’s cognitive performance through administration of either the McCarthy Scales of Children’s Abilities (McCarthy, 1972) or, for children whose cognitive functioning precluded their use of this measure, the Bayley Scales of Infant Development (Bayley, 1969). Also at age 3, mothers completed the Dimensions of Mastery Questionnaire (DMQ) (Morgan, Harmon, Maslin-Cole, & Busch-Rossnagel, 1992). The DMQ measures mastery motivation, or “an individual’s drive to solve problems and master new skills” (Igoe et al., 2011, p. 280). When the children were 18 years old, mothers completed the EZ Personality Questionnaire (Zigler et al., 2002). This measure yields scores on effectance motivation (EM) (alpha=0.84), or the “pleasure derived from tackling and solving difficult problems” (Zigler et al., 2002, p. 182). It also measures expectancy of success (ES) (alpha=0.82), or the degree to which one expects success with these problems (Zigler et al., 2002).

Results: Preliminary analyses revealed that there were no differences between diagnostic groups, gender, or SES on scores of EM or ES in adolescence. Regression analyses were conducted to determine whether or not mastery motivation at age 3 predicts EM or ES at age 18. After removing the variance predicted by cognitive performance scores, mastery motivation at age 3 is positively related to and is a significant predictor of both EM (p=0.046) and ES (p<0.005) fifteen years later. Mastery motivation reported at age 3 accounts for an additional 3.6% of the variance in EM scores, and an additional 7.7% of the variance in ES scores at age 18. Overall models, including age 3 cognitive performance and DMQ scores as predictors, accounted for 16.6% of variance in age 18 EM scores, and 11.2% of the variance in age 18 ES scores.

Discussion: These results suggest that for individuals with DD, mastery motivation at age 3 predicts levels of EM and ES fifteen years later. Given the theoretical and empirical relation between motivation and achievement, it is important to identify predictors of motivational outcomes. Ideally, practitioners will be able to identify young children with low motivation, and implement targeted interventions.

References:


POSTER SESSION 1


Linda Hickson1, Ishita Khemka1, Harriet Golden2, Aikaterini Chatzistyli2
1Teacher’s College, Columbia University. 2AHRC New York City

Teachers College, Columbia University, 525 West 120th Street, New York, NY 10027
(hickson@tc.columbia.edu)

Introduction: Social policies of inclusion and self-determination have provided individuals with intellectual disabilities (ID) with expanded opportunities for social interaction. However, research has indicated that individuals with ID are at heightened risk for abuse and that they often have difficulty making effective decisions in situations where they may be at risk. To address this issue, we conducted a series of studies on decision making in situations of abuse (e.g., Hickson, Golden, Khemka, Urv, & Yamusah, 1998; Khemka, 2000). Building upon this work, the ESCAPE curriculum was developed and evaluated with women with ID (Khemka, Hickson, & Reynolds, 2005). The current study consists of an evaluation of ESCAPE-DD, an adapted version of ESCAPE aimed at teaching both male and female adults with developmental disabilities to make effective, self-protective decisions in situations of abuse.

Method: Subjects included 29 male and 29 female adults with mild and moderate ID. The 58 subjects were randomly assigned to either an intervention group, which received 12 instructional sessions with ESCAPE-DD, or a control group, which was given delayed access to ESCAPE-DD upon completion of the study. The intervention group (M age = 39.42, SD = 14.36; M IQ = 56.83; SD = 8.62) did not differ from the control group (M age = 38.16, SD = 13.52; M IQ = 56.71, SD = 9.58) on age or IQ. Subjects received pretests and posttests consisting of six vignettes depicting abuse situations. After each vignette was read to them, subjects were asked to respond to one comprehension question and one decision-making question.

Results: Mean number of comprehension responses that captured the gist of the abusive situation did not differ for the intervention group (M = 3.63, SD = 1.79) and the control group (M = 3.14, SD = 2.19) on the pretest. On the posttest, there was a nonsignificant trend for subjects in the intervention group (M = 4.17, SD = 2.00) to produce more correct gist responses than subjects in the control group (M = 3.29, SD = 2.16) (t (56 df) = 1.61, p < .11). Mean number of decision-making responses that reflected attempts to avoid or escape from the abuse did not differ for the intervention group (M = 3.70, SD = 2.02) and the control group (M = 3.32, SD = 2.13) on the pretest. On the posttest, subjects in the intervention group produced significantly more responses reflecting attempts to avoid or escape from the abuse (M = 5.07, SD = 1.46) than did subjects in the control group (M = 3.79, SD = 2.39) (t (56 df) = 2.48, p < .02).

Discussion: Results are discussed in terms of specific response patterns and their implications for increasing effective, self-protective decision making and, ultimately, the personal safety of individuals with ID.

References:


**POSTER SESSION 1**


Robert Hodapp, Meghan Burke, Nancy Miodrag, Emily Tanner-Smith
Vanderbilt University
Vanderbilt Kennedy Center, PMB 40, 230 Appleton Place, Nashville, 37212
(Meghan.m.burke@vanderbilt.edu)

**Introduction:** We conducted a meta-analysis to compare physical health problems among parents of children with disabilities versus parents of children without disabilities.

**Methods:** Eligible studies were those that used the long form of the Parenting Stress Index (PSI; Abidin, 1990), and reported results from the 5-item PSI Health domain separately for parents of children with and without disabilities. We conducted a systematic literature search to identify all published studies and dissertations. Group comparison effect sizes from studies were synthesized in a meta-analysis to examine overall differences in physical health problems. We also examined the moderating effect of study characteristics such as child and parent demographics, publication year, and study quality.

**Results:** The literature search yielded 17 eligible studies examining health problems among parents of children with a range of disability types, ages, and parent characteristics. Compared to parents of children without disabilities, parents of children with disabilities reported higher levels of perceived health problems, with a weighted mean effect size of 0.36 (95% = 0.20 - 0.51; $r^2 = .06; F = 59.8%$). Child and parent demographics did not explain any of the heterogeneity in the effect sizes. However, results indicated larger differences in perceived health problems among studies of higher quality, whereas more recent studies showed somewhat smaller differences.

**Discussion:** Beyond increased levels of stress, parents of children with disabilities also report increased health problems. Although more studies are needed, practitioners and policymakers should be alerted to the need to prevent and provide early treatment for the physical health problems of parents of children with disabilities.

**References:**

25. Longitudinal Studies of Glycoproteinoses—Cognitive and Adaptive Functioning

Lucia Horowitz, Richard Simensen, Sara Cathey
Greenwood Genetic Center
Greenwood Genetic Center, 106 Gregor Mendel Circle, Greenwood, SC 29646
lhorowitz@ggc.org

Introduction: The glycoproteinoses are the subset of lysosomal diseases that includes alpha-mannosidosis, beta-mannosidosis, aspartylglucosaminuria, galactosialidosis, sialidosis, fucosidosis, mucolipidosis II (MLII), mucolipidosis III (ML III), and Schindler disease. The underrepresentation of these rare diseases in medical literature contemporary research prompted our Longitudinal Studies of the Glycoproteinoses. This report focuses on results of cognitive and adaptive behavior studies in individuals with ML II, ML III, and alpha-mannosidosis. At the start of this natural history study, there were no reports in the literature of formal cognitive assessments in patients with ML, and the few reports on alpha-mannosidosis focused primarily on children. The largest reported cohort of ML II and ML III patients has been established through this project. A minority of patients with ML are best characterized as intermediate ML, with clinical and molecular features more severe than typical ML III and less severe than ML II. Multiple affected individuals were evaluated during dedicated Glycoproteinoses Clinics held at the Greenwood Genetic Center in 2006 and 2009 and in Australia and New Zealand in 2009.

Methods: Longitudinal studies attempt to assess developmental data comparisons between groups and over time in order to gain a body of information about specific disorders. Cognitive assessment was accomplished in all clinics through the use of the K-BIT-2 for the majority of the participants. In the US clinics, adaptive behavior was assessed using the VABS-II. The SIB-R was used in the Australia/New Zealand clinics because of time constraints and the greater skill differentiation provided. In the US clinics 17 ML patients (11 ML III, 3 ML II and 3 intermediate ML) were evaluated. Most patients participated in 2 assessments separated by several years. In Australia/New Zealand clinics, 4 ML III patients and 3 intermediate ML patients participated. ML patients ranged in age from 3-43 years at time of assessment. The age range of the 5 alpha-mannosidosis patients was 8-59 years. At least one parent of every patient was also interviewed.

Results: Consistent with the spectrum of severity noted in other features of the diseases cognitive assessment scores were compatible with moderate intellectual disability (ID) in ML II patients, mild to borderline ID in intermediate ML, and low average cognitive functioning in individuals with ML III. Adaptive behavior ratings for ML III and intermediate ML patients fell generally in the Borderline ID range. Several distinctive patterns were noted within the adaptive behavior ratings. Alpha-mannosidosis patients who had not undergone bone marrow transplant (4/5) scored in the moderate to severe ID range with some regression noted with age. The adaptive behavior ratings were also significantly low for the non-transplanted cohort.

Conclusion: Formal psychometric assessments of individuals with ML II and III and alpha-mannosidosis revealed trends in both cognitive and adaptive functioning. These studies allow focus on the specific strengths and areas of concern for developmental outcome and academic performance. Additional assessments for all groups will enhance this beginning body of data for these very rare disorders.

References:


This project was supported in part by Award Number U54NS065768 from the National Institute of Neurological Disorders and Stroke, Bethesda, Maryland.
Children with Autism Spectrum Disorder.

Introduction: Difficulties with social competence is a core deficit of autism spectrum disorder. Research on typically developing children suggests that the amount of adult talk they experience can positively affect their development of social competence. With growth in the number of children with ASD enrolled in schools, there is a need to understand how adult talk in this context influences their development of social competence. This study aims to determine: (1) the types and amounts of adult talk children with ASD receive in the preschool classroom; (2) how child characteristics (i.e., autism severity, language, cognitive ability and behavior) relate to adult talk; and (3) the association between adult talk and immediate displays of socially competent behavior by children with ASD?

Methods: The data for this study are drawn from a larger study comparing the efficacy of comprehensive treatment models serving preschool-aged children with ASD. For this study, data will be analyzed for a subset of children (ages 3-5) with ASD who were enrolled in business-as-usual (BAU) (n= 20) or LEAP (n= 60) inclusive preschool classrooms. Children in these classrooms were videotaped for roughly 30 minutes during normal center time activities. Videotapes were then coded post-hoc by observers naïve to the purposes of the study using Kontos's (1999) teacher talk categories.

Results: Behavioral coding and data analysis are ongoing. Preliminary results (n= 35) indicate low proportions of adult talk related to supporting peer relations (5%) and behavioral management (2%), whereas talk related to positive social contacts (10%), supporting object play (13%) and personal/practical assistance (14%) took place more often. For nearly half the time, adults were not talking to children with ASD (49%). Children's socially competent behavior was directed at adults (11%) more often than peers (1%) following some form of adult talk, but was largely absent (82%). Prior to the conference, additional analyses will use linear mixed models to examine associations between child characteristics and adult talk.

Discussion: Preliminary findings indicate the adult talk children with ASD experience resembles previous research on typically developing children. Specifically, adults provide more verbalizations related to supporting object play and practical/personal assistance than supporting peer relations. This is concerning since children with ASD often having difficulty forming relationships with peers. Further, the small proportions of children's socially competent behavior directed at peers may be related to the minimal talk focused on supporting peer relations children received.

References:

Introduction: Prader-Willi syndrome (PWS) is a genetic disorder associated with a deletion from the paternal chromosome (DEL) or duplication (UPD) of the maternal chromosome 15. The phenotype includes intellectual disabilities, compulsivity, hyperphagia, and increased risks of life-threatening obesity. Recently, the PWS phenotype has been expanded to include an increased risk of autism-spectrum disorders (ASD), especially in persons with the UPD subtype. Atypical social functioning, including altered face perception, is extensively documented in people with ASD, but research has yet to focus on the phenotypic variability in social perception associated with the two major genetic subtypes of PWS. The current study examined differences in brain activity associated with processing of faces and nonsocial stimuli varying in emotional valence in persons with PWS as measured by event-related potentials (ERPs).

Methods: Visual ERPs were recorded from 24 individuals with PWS (M age = 22.04 +/- 5.60 years), 13 with the DEL and 11 with the UPD subtype, using 128-electrode nets. Stimuli included color photographs of upright and inverted faces as well as nonsocial objects with positive (e.g., smiling faces, friendly puppy) and negative (e.g., sad face, mean dog) emotional valence. Stimuli from these categories were presented equally often and in random order. Participants were asked to view the pictures and note when a smiling face (upright or inverted) was presented (48 of 144 trials, 33.33%).

Results: PWS subtype-related differences were observed within 96-196 ms after stimulus onset and were associated with early perceptual processes. Participants with the DEL subtype evidenced modulation of the face-specific posterior N170 response where face stimuli elicited the largest response, nonsocial objects had the smallest N170, and inverted faces had an intermediate response. There were no significant stimulus-related differences in the N170 response in the UPD group, and their overall amplitude of face-elicited ERPs was smaller than that of the DEL group.

Brain responses to emotional content did not vary by subtype as all participants elicited a larger LPP response (342-592 ms) to upright and inverted negative faces than negative pictures or inverted happy faces. Furthermore, detection of the target smiling faces was evident in the amplitude of the frontal and central P3 responses but only for inverted smiling faces, which were associated with larger amplitudes than upright smiling faces or positive pictures, while amplitudes to upright smiling faces did not differ from other stimuli.

Discussion: Our results extend prior behavioral findings noting genetic subtype differences in social functioning among adolescents and adults with PWS. This is the first study to demonstrate brain-related differences in social perception (face vs. object), with more ASD-like (i.e., less face-specialized) brain response in persons with the UPD than DEL subtype. Additionally, all participants with PWS demonstrated potentially altered attention to and/or recognition of facial expressions, as more processing resources were devoted to inverted than upright smiling faces and greater affective response was observed to all negative faces compared to objects and positive faces. Future studies will need to investigate whether similar affective responses and subtype differences in face perception are already present in children with PWS or if such differences emerge over time.

Marygrace Yale Kaiser, Lynne Katz, Laura Dinehart, Mary Anne Ullery

1Eureka College, 2University of Miami, 3Florida International University

300 E. College Avenue, Eureka, IL 61530

(mgkaiser@eureka.edu)

Introduction: Children experiencing maltreatment, neglect, and exposure to violence are also likely to experience poverty, ongoing changes in custody and regular changes in residence. As a result, children in child welfare are more likely to demonstrate developmental and academic delays, experience mental health issues, and receive special education services (Spieker, Nelson, Petras, Jolley, & Bernard, 2003). The purpose of the current study was to provide information about the development of children in the child welfare system and to discuss implications of how quality care impacts developmental outcomes.

Methods: Participants included toddlers enrolled in a childcare or learning center in a large metropolitan city in the southeastern US. At baseline, one group of participants was selected based on their status as a child in the welfare system (CW group; n = 49). The other group of participants (NCW group; n = 72) attended the same classrooms. Both groups of children were predominantly of minority ethnicity. Predictor, outcome, and potentially moderating variables were assessed every six months for two years. Quality of child-care as measured by the ITERS-R was the predictor in the current study. Outcome variables included cognition, language, motor skills, and social behavior as measured by the Battelle Developmental Inventory-2nd edition. Potential moderating variables included family environment and type, # of custody changes, type of custody/placement (i.e. foster, natural parent, relative), SES, and child ethnicity.

Results: As a whole, children in the child welfare system were demographically similar to children not in the system. In general, children in the child welfare group had significantly lower scores on measures of developmental outcome compared to children not in the child welfare system. Analyses indicated that quality, as measured by the ITERS-R, was a significant predictor of cognitive subscale of the BDI across all four time points for both children in the child welfare system and children outside the child welfare system ($F(1, 236) = 9.937$, $p < .01$) in that higher quality classroom environments resulted in higher cognitive skills for both groups of children. A closer examination within time point indicated that the ITERS-R was a significant predictor of the change score between the BDI communication score at baseline and the BDI communication score at 6-month follow-up for the child welfare group only ($F(1, 33) = 5.71$, $p < .03$). For the CW group, the number of books in the home at baseline predicted BDI communication, cognition and total scores one year later. Additionally, the number of placement changes that children in the child welfare system experienced was a significant and negative predictor of the BDI Total and communication scores at subsequent time points.

Discussion: These data illustrate that there continues to be a high risk of poor outcomes for very young children entering the child welfare system. While high quality early learning environments had a positive impact for all children, children in child welfare were more adversely affected by poor quality centers than children not in the child welfare system in terms of their communication skills. These data also provide further evidence that the number of placement changes negatively impacts developmental outcomes for children in the child welfare system.

Reference:

POSTER SESSION 1

29. Mental State Verb Use in Children with Fragile X Syndrome

Juliana Keller, Nancy Brady, Steven Warren
University of Kansas, 1000 Sunnyside Avenue, 1052 Dole, Lawrence KS 66045
(jpkeller@ku.edu)

Introduction: Several studies have examined the language profile of children with fragile X syndrome (FXS), as well as the expressive language abilities of individuals with FXS. Very few studies have examined specific lexical categories such as mental state verbs (MSVs; e.g., know, think). Using MSVs is an important skill for successful social interactions, which are known to be problematic for children with FXS and autism. The purpose of the current study was to examine the use of MSVs in the spontaneous speech of children with FXS.

Method: As a part of an ongoing longitudinal study on maternal responsivity and language development in children with FXS, 52 children with FXS and their mothers participated in videotaped structured and unstructured interactions with their mothers. All child communicative utterances in the videos were transcribed, and the transcripts were examined for uses of 25 mental state verbs (MSVs). Children were also given the PPVT-4, EVT-2, and Leiter-R. Mothers completed the Vineland Adaptive Behavior Scales (VABS) for their children, and two researchers completed the CARS for each child. Correlations were conducted to examine the relationship between the seven variables and the use of MSVs. Regression models were built to examine these variables as predictors of the use of MSVs.

Results: Children with FXS used a mean of 15.1 MSVs and a mean of 4.2 different MSVs in their spontaneous speech with their mothers. Four language measures were significantly positively correlated with the number of different MSVs used by the children. Raw scores on the EVT-2 significantly predicted the number of different MSVs the children used. Chronological age was not related to MSV use, but both nonverbal IQ and the Adaptive Behavior Composite (ABC) from the VABS were significantly positively correlated with MSV use. Autistic behaviors, as measured by the CARS, were significantly negatively correlated with the use of MSVs. However, scores on the CARS did not predict the number of different MSVs used by the children after controlling for language ability.

Discussion: The present study provides evidence that children with fragile X syndrome do use a variety of mental state verbs in conversations with their mothers, and that the use of these verbs is related to the children’s language and developmental abilities, but not to their autistic behaviors. These findings suggest that specific pragmatic impairments in FXS influence the use of mental state verbs regardless of the presence of autistic behaviors.

References:


Supported by NICHD 02538 and NICHD 03110.
MULTI-MODAL AND MULTI-METHOD APPROACHES TO ASSESSMENT AND INTERVENTION FOR SIB

Chair: Stephen Schroeder, University of Kansas

Discussant: William MacLean, University of Wyoming
SYMPOSIUM 7

Multi-Modal and Multi-Method Approaches to Assessment and Intervention for SIB

Chair: Stephen Schroeder, University of Kansas
Discussant: William MacLean, University of Wyoming

Treating Severe Self-Injury in the Natural Environment Using a Multi-Component Approach
Andrea Courtemanche
Stephen Schroeder
Jan Sheldon
James Sherman
University of Kansas

Predictors of Self-Injurious Behavior Exhibited in 617 Individuals with Autism
David Richman
Lucy Barnard-Brak
Amanda Bosch
Samuel Thompson
Laura Grubb
Layla Abby
Texas Tech University

The Effects of Developmental Quotient and Diagnostic Criteria on Challenging Behavior in Toddlers with Developmental Disabilities
Kristen Medeiros¹
Alison Kozlowski²
Jennifer Beighley²
Johannes Rojahn¹
Johnny Matson²
¹George Mason University
²Louisiana State University

Multi-Method Assessment of Challenging Behavior in Young Children with Neurodevelopmental Disorders: The Aberrant Behavior Checklist, the Behavior Problems Inventory-01, and the Repetitive Behavior Scale-Revised
Johannes Rojahn¹
Stephen Schroeder²
Liliana Mayo-Ortega³
Rosa Oyama-Ganiko³
Judith LeBlanc²
Janet Marquis²
Elisabeth Berke¹
¹George Mason University
²University of Kansas
³Centro Ann Sullivan del Peru
Peripheral Innervation in Children at Risk for SIB

Frank Symons
Raymond Tervo
Chantel Burkitt
John Damerow
Erica Suski
Brian McAdams
Shawn Foster
Gwen Wendelschafer-Crabb
William Kennedy

1University of Minnesota-Minneapolis
2Gillette Children's Specialty Healthcare

SIB is a multiply caused and multiply affected serious behavioral problem that begins in early childhood and can persist throughout life if untreated. The papers in this symposium examine assessment instruments and methods which can be helpful in predicting its early emergence and later treatment.
Treating Severe Self-Injury in the Natural Environment Using a Multi-Component Approach

Andrea Courtemanche, Stephen Schroeder, Jan Sheldon, James Sherman
University of Kansas
Department of Applied Behavior Sciences, University of Kansas
(acourtem@ku.edu)

Introduction: Self-injurious behavior among individuals with intellectual and developmental disabilities is a devastating chronic condition for which there is no known cure. Past research has demonstrated that a variety of medical/pharmacological and behavioral strategies may be effective at reducing self-injury. Unfortunately, the effectiveness of these interventions is rarely evaluated in the natural environment, and staff who are responsible for the care of these individuals are often not adequately trained in the use of these procedures. The purpose of the present study is to evaluate treatments for self-injury that combine both behavioral and medical components in the natural environment with a staff-training component.

Methods: Three participants (ages 28-50) diagnosed with a profound intellectual and developmental disability who engage in severe self-injury are participating. Functional assessments indicate that all of the participants’ self-injury is multiply controlled by a number of environmental consequences and may also be affected by some medical and biological factors. A multi-component treatment package was developed for all participants including 1) reinforcing the absence of self-injury with attention and tangibles, 2) communication training, 3) blocking self-injury with redirection to appropriate activities, 4) environmental enrichment, and 5) an individualized intervention to address medical and biological factors (e.g., PRN for prescription pain medication). After the effectiveness of these interventions is demonstrated with the investigator, a staff-training package will be implemented which includes role-playing, feedback, and reinforcement for successful implementation of the intervention. Video cameras in the homes are used to monitor staff behavior in the absences of the investigator.

Results: The multi-component package was effective at reducing self-injury to near zero levels for all participants when implemented by the investigators. The staff-training program is currently in progress.

Discussion: The results of the current study support the development and implementation of interventions that address both environmental and biological influences on self-injury. Identifying all environmental, biological, and mental and physical health concerns during functional assessments may increase the likelihood that an effective treatment will be developed. Additionally, these results support that multifaceted interventions can be effectively used in the natural environment. Interventions should be developed in a way that allow staff to effectively implement these procedures so that reductions in self-injury can be maintained in the absence of the investigator.

References:


Introduction: Previous research has shown that high levels of impulsivity and overactivity combined with chronic repetitive behaviors are correlated with increased likelihood of individuals with intellectual disabilities exhibiting self-injurious behavior (SIB; Arron et al., 2011). A recent study by Chris Oliver and colleagues (currently unpublished) suggests motor inhibition control and low mood (negative affect) are two within-organism variables that are associated with increased SIB exhibited by individuals with autism. The purpose of the current study is to replicate and extend previous research on within-organism variables that predict SIB in a relatively large and diverse sample of individuals with autism.

Method: A heterogeneous sample of 617 individuals (average age was 11.21 years old; SD = 6.78) with autism was derived from the National Database of Autism Research (NDAR; http://ndar.nih.gov/). Data used in the preparation of this study were obtained and analyzed from the controlled access datasets distributed from the NIH-supported NDAR. NDAR is a collaborative biomedical informatics system created by the National Institutes of Health to provide a national resource to support and accelerate research in autism. The study included the following collection IDs (along with submitters): NDARCOL0000011 (Jeff Munson); NDARCOL0001854 (Dan Hall); and NDARCOL0000001 (Stephen Guter). This abstract reflects the views of the authors and may not reflect the opinions or views of the NIH or of the investigators that submitted original data to NDAR. Structural equation modeling techniques were employed in testing our model of predictors of SIB. Latent constructs for potential predictors were estimated from data derived from items of the community version of the Aberrant Behavioral Checklist. After model fit was established, path values of interest were evaluated.

Results: We statistically controlled for IQ and severity of symptoms of autism as measured by ADOS scores. IQ was significantly negatively associated with SIB with a standardized path coefficient value of -.39*. ADOS scores were not significantly associated with SIB, but ADOS and IQ scores were significantly associated with a standardized path value of .26*. It should be noted that ADOS scores did not predict IQ scores nor did IQ scores predict ADOS scores when testing competing models. We also initially statistically controlled for age given the range of ages in the sample, which was not significantly associated with SIB in the current study. In evaluating predictors of SIB, two were identified as significant: impulsivity (.46**) and stereotypy (.23**). Among the predictors that were modeled, impulsivity, followed by stereotypy, appeared to be the most salient variables associated with SIB among individuals with autism. Hyperactivity and Low Mood did not predict SIB in the current study.

Discussion: Implications for identifying relevant treatment options that combine assessment of organism and environmental variables will be discussed.

Reference:
The Effects of Developmental Quotient and Diagnostic Criteria on Challenging Behaviors in Toddlers with Developmental Disabilities

Kristen Medeiros¹, Alison Kozlowski², Jennifer Beighley², Johannes Rojahn¹, Johnny Matson²
George Mason University¹, Louisiana State University²
(kmedeiro@masonlive.gmu.edu)

Challenging behaviors, including aggression, self-injury, and stereotypy, are remarkably prevalent among individuals with developmental disabilities. While it is generally accepted that a decrease in intellectual functioning is associated with an overall increase in challenging behavior, the details regarding which specific types of challenging behaviors are affected by intellectual functioning are somewhat less clear. We examined 1,509 infants and toddlers with developmental delays in three diagnostic categories: [1] atypically developing with no specific diagnosis (71.8%), [2] Autistic Disorder (14.7%), and [3] PDD-NOS (13.5%). The toddlers ranged in age from 17 to 36 months ($M = 25.7$, $SD = 4.7$). There were 1,070 males (70.9%), 434 females (28.8%). For each participant the Modified Checklist for Autism in Toddlers (M-CHAT) (Robins et al., 2001), the Baby and Infant Screen for Children with Autism Traits (BISCUIT)–Part 3 (Matson et al., 2007) and the Battelle Developmental Inventory, 2nd Edition (BDI-2) (Newborg, 2005) were completed.

A hierarchical multiple regression showed that diagnostic category was a significant moderator in the effect of total DQ on aggressive/destructive behavior ($R^2$ change $= .024$, $p < .001$), stereotypic behavior ($R^2$ change $= .007$, $p < .001$), and self-injurious behavior ($R^2$ change $= .006$, $p < .01$). Specifically, higher total DQ was associated with more challenging behaviors in toddlers diagnosed with Autistic Disorder, whereas the opposite was found in toddlers with atypical development and no specific diagnosis. A series of multiple regressions for each diagnostic group, using the five DQ domains as predictors and the three challenging behaviors as outcomes, determined the areas of development that were more highly associated with particular challenging behaviors for toddlers with distinct diagnoses. For the Autistic Disorder and PDD-NOS groups, communication and motor development were significantly positively correlated with most of the three challenging behaviors. For atypically developing toddlers without diagnosis, personal-social and cognitive development were significantly correlated with all three challenging behaviors; adaptive behavior and communication were significantly negatively correlated with some of the challenging behaviors.

The results demonstrated that the relationship between total DQ and challenging behaviors in young children at risk for developmental problems depended on the diagnosis. Toddlers with Autistic Disorder and PDD-NOS exhibited more challenging behaviors with higher total DQ, while atypically developing toddlers with no specific diagnosis exhibited less challenging behaviors with higher total DQ. However, different developmental domains impacted particular challenging behaviors in different ways for toddlers with varying diagnoses at a young age. The differential effects of the developmental domains suggest intervention strategies for individuals of particular diagnostic categories exhibiting unique challenging behaviors.

References:


Multi-Method Assessment of Challenging Behavior in Young Children with Neurodevelopmental Disorders: The Aberrant Behavior Checklist, the Behavior Problems Inventory-01, and the Repetitive Behavior Scale-Revised

Johannes Rojahn¹, Stephen Schroeder², Liliana Mayo-Ortega³, Rosa Oyama-Ganiko³, Judith LeBlanc², Janet Marquis², Elisabeth Berke¹
George Mason University¹, University of Kansas², Centro Ann Sullivan del Peru³ (jrojahn@gmu.edu)

Individuals with neurodevelopmental disorders (ND) are at a heightened risk of developing aberrant behaviors during the course of their lives. Reliable and valid assessment of such behaviors is an important element in empirically verifying successful prevention and intervention. However, only a few instruments exist which were developed for behaviors in children of a very young age. The purpose was to examine the performance of three behavior rating instruments for individuals with developmental disabilities that have been proven useful and psychometrically sound in older populations.

Parents of 106 Infants and toddlers with ND, between 12 and 52 months of age, who were at risk for aberrant behaviors completed the Aberrant Behavior Checklist (ABC; Aman & Singh, 1994), the Behavior Problems Inventory (BPI-01 Rojahn, et al., 2001), and the Repetitive Behavior Scale-Revised (RBS-R; Bodfish, et al., 1999). The ABC consists of 58 items that are divided into five subscales: (Irritability, Lethargy, Stereotypic Behavior, Hyperactivity, and Inappropriate Speech. The BPI-01 is a 49-item behavior-rating instrument with self-injurious, stereotypic, and aggressive/destructive behavior items. The RBS-R has 43 items were assigned to six behavior subscales (Stereotyped, Self-injurious, Compulsive, Ritualistic, Sameness, and Restricted).

Data analysis is in progress. We will report confirmatory and discriminant validity (Campbell & Fiske, 1959) using a multitrait-multimethod matrix for the constructs self-injurious behavior (SIB), stereotyped behavior, and aggressive/destructive behavior. Furthermore, we will compute internal consistency of the subscales of all three instruments and establish sensitivity and specificity parameters of the BPI-01 compared to the RBS-R in detecting the presence of SIB and stereotyped behavior.

References:

Supported by Fogarty International Research grant HD060500
Peripheral Innervation in Children at Risk for SIB

Frank Symons1, Raymond Tervo1,2, Chantel Burkitt1,2, John Damerow1, Erica Suski2, Brian McAdams1, Shawn Foster1, Gwen Wendelschafer-Crabb1, William Kennedy1
1University of Minnesota-Minneapolis, 2Gillette Children’s Specialty Healthcare

(symon007@umn.edu)

Introduction: In prior work, we investigated whether there may be a self-injurious behavior (SIB) subtype or subgroup associated with a specific pattern of peripheral biomarkers characterized by alteration in the structure of small-diameter unmyelinated sensory nerve fibers and concentrations of substance P (SP), a neuropeptide relevant to nociceptive signaling. In our preliminary adult samples with intellectual disability and chronic SIB, we observed altered intra-epidermal nerve density differences and subsequently replicated this finding with a larger sample of SIB cases relative to matched controls as well as observing increased SP-positive fiber counts in some but not all samples and extensive mast cell degranulation (consistent with immune mediated inflammatory response). We also found that, compared with matched controls without SIB, individuals with SIB and altered peripheral markers were more (not less) responsive during a modified quantitative sensory testing protocol. In our current work, we are extending a ‘peripheral biomarker’ approach to a pediatric sample at high risk for intellectual disability. The purpose of this presentation is to describe our preliminary findings specific to the morphology and neuropeptide density of epidermal nerve fibers quantified through skin biopsy samples from an emerging early identified pediatric risk sample being evaluated for intellectual delay/disability and related co-morbidities.

Methods: Following informed parental consent, skin biopsies were obtained from two sites (forearm and calf or distal leg) that had no pre-existing skin damage and no history of SIB. The biopsy was made with a 3 mm punch tool (Acupunch; Acuderm; Fort Lauderdale, FL). Biopsies were fixed in Zamboni's solution, cryoprotected, and sectioned with a freezing sliding microtome (Leica, Nussloch, Germany). After immunohistological localization of nerve (PGP 9.5 and substance P) and tissue antigens (type IV collagen and tryptase), sections were adhered to coverslips with agar, dehydrated via an alcohol series, cleared with methyl salicylate, and mounted in DPX (Fluka BioChemika, Ronkonkoma, NY). The primary outcomes measured for this preliminary analysis were ENF density, frequency of substance P (SP) positive fibers, and mast cell granulation state.

Results: To date, skin samples from 6 children with global and specific developmental delays (33% male; mean age = 2.8; 1.5-4.9) have been assayed. Initial quantitative analyses (nerve fiber counts) have been completed for 3/6 participants for the calf biopsy sites. Visual microscopic examination and qualitative analyses of the microscopy images suggest there are innervation abnormalities characterized by extremely high epidermal nerve fiber innervation densities (ENFd) (all three cases exceeding 95% cut off values from a normative [non disability archived skin biopsy comparison group]). Specifically, comparing the calf biopsy sections to those from twenty normal healthy control children (studied previously), the median calf ENFd for the control group was 608 with maximum of 2015 ENFs/mm². The median calf ENFd from our at-risk for IDD/SIB sample from calf was approximately 2,594 ENFs/mm². SP+ fiber counts appear to be elevated as well relative to the non disability comparisons (mean = 13 vs 3.5, respectively). Mast cells appear to be intact (i.e., not degranulated). The same 3 participants had clinically elevated CBCL ‘externalizing’ and ‘internalizing’ scores as well as elevated ‘mood & affect’ and ‘emotional liability’ scores from the Conner’s. All 3 children had parentreported problems related to repetitive behavior in the form of SIB (1), tics (1), and motor stereotypy (1).

Discussion: In our emerging cohort, we found preliminary evidence for the possibility of already altered peripheral innervation (i.e., increased ENF densities) and neurochemistry (i.e., elevated SP fiber density). The results from this novel immunohistological analysis of skin in very young children with developmental delays at risk for intellectual disability and SIB do not definitively confirm or refute a subtype model, but do suggest that there may be significant differences in peripheral innervation prior to the emergence of severe SIB. There are myriad neurodevelopmental questions concerning the increased ENFd related to trophic factors for fiber growth and guidance and the clinical significance of these observations as possible markers for SIB risk.

References:


Supported, in part, by NICHD Grant No. 44763, 47201
SYMPOSIUM

8

BIOBEHAVIORAL INVESTIGATIONS OF TEMPERAMENT IN FRAGILE X, WILLIAMS, AND 7Q11.23 DUPLICATION SYNDROMES

Chairs: Jane Roberts, University of South Carolina-Columbia
Carolyn Mervis, University of Louisville

Discussant: Elisabeth Dykens, Vanderbilt Kennedy Center,
Vanderbilt University
SYMPOSIUM 8

Biobehavioral Investigations of Temperament in Fragile X, Williams, and 7q11.23 Duplication Syndromes

Co-Chairs: Jane Roberts, University of South Carolina-Columbia
Carolyn Mervis, University of Louisville

Discussant: Elisabeth Dykens, Vanderbilt Kennedy Center, Vanderbilt University

Behavioral and Physiological Correlates of Negative Affect in Young Children with Fragile X Syndrome
Bridgette Tonnsen¹
Sam McQuillin¹
Deborah Hatton²
Jane Roberts¹
¹University of South Carolina-Columbia
²University of Louisville

Temperament in Williams Syndrome: Factor Analysis of the Children's Behavior Questionnaire
Ovsanna Leyfer¹
Angela John²
Janet Woodruff-Borden³
Carolyn Mervis³
¹Center for Anxiety and Related Disorders, Boston University
²MIND Institute, University of California-Davis
³University of Louisville

Genetic Factors in Temperament: A Comparison of Children with 7q11.23 Deletions (Williams Syndrome) and Duplications (7q11.23 Duplication Syndrome)
Danielle Henderson
Nicole Crawford-Zelli
Janet Woodruff-Borden
Carolyn Mervis
University of Louisville

Summary: Consistent with the 2012 conference theme of increasing knowledge on genetic syndromes associated with intellectual and developmental disabilities, this symposium presents investigations of the biobehavioral predictors and expression of temperament in children with fragile X, Williams, and 7q11.23 duplication syndromes. We discuss physiological, genetic, and behavioral factors associated with temperament in these three genetic disorders and examine the factor structure and individual differences that contribute to temperament and associated psychopathology including anxiety, autism, and attention deficit hyperactivity disorder.
Behavioral and Physiological Correlates of Negative Affect in Young Boys with Fragile X Syndrome

Bridgette Tonnsen1, Sam McQuillin1, Deborah Hatton2, Jane Roberts1
1University of South Carolina, 2Vanderbilt University
(kellehbl@email.sc.edu)

Introduction: Children with fragile X syndrome (FXS) face high risks for comorbid problem behaviors that substantially limit daily functioning. Understanding the biobehavioral underpinnings of problem behaviors in FXS is essential to informing earlier detection and effective intervention. Considerable research has documented robust associations between negative affect (NA) and problem behaviors in clinical and non-clinical pediatric samples, including emerging work in FXS. The present study examines the behavioral and physiological correlates of NA in young children with FXS using both parent-report and experimental methods. We also examine the relationship between biobehavioral indicators of NA and problem behaviors; including anxiety, autism, oppositional behaviors and withdrawal.

Methods: Participants included 44 young boys with FXS and 20 TD controls (ages 18-76 months). Using the Child Behavior Questionnaire, we calculated NA using two algorithms: the original Rothbart NA factor (Gagne et al., 2011) and a NA factor derived through factor analysis of a FXS sample. Problem behaviors were measured using the Childhood Autism Rating Scale (CARS) and Child Behavior Checklist. Behavioral indicators of NA were coded during the Stranger Approach paradigm of the Laboratory Temperament Assessment Battery (phases: Baseline, Approach, Kneel, Recovery). We also collected physiological data on a subset of our sample (12 FXS, 12 TD) during this paradigm.

Results: We compared mean levels of parent-reported negative affect in FXS and TD groups using both Rothbart and FXS algorithms. All models included chronological and mental age as covariates. Although groups did not differ in NA using Rothbart’s algorithm ($p=.12$, partial $\eta^2=.10$), the FXS group displayed lower NA using the FXS algorithm ($p=.02$, partial $\eta^2=.17$). In light of this difference, we will compare both algorithms in subsequent analyses.

Next, we used partial Pearson correlations to examine the relationship between NA and behavioral and physiological stranger responses. Within the FXS sample, higher NA corresponded to more delayed expression of distress vocalizations. In both FXS and TD groups, parent-reported NA correlated with differences in heart activity (inter-beat-interval, IBI; vagal tone, VT) during Approach and Kneel phases, relative to Baseline. Higher NA corresponded to greater changes in heart activity across phases. Parent-reported NA also correlated with Baseline IBI and VT in the TD group, with higher NA correlating with lower VT and shorter IBI.

In light of these associations between NA and biobehavioral variables, we examined the relationship between NA and problem behaviors in our FXS sample. Higher parent-reported NA correlated with higher anxiety and oppositional behaviors. Increased intensity of escape behaviors correlated with more severe autistic behavior. Greater change in IBI during Approach corresponded with higher anxiety and withdrawal. Less change in VT between Approach and Kneel phases corresponded with greater attention problems. Although autism outcomes did not significantly correlate with physiological variables, we identified and will present correlational trends suggesting higher CARS scores may relate to IBI and VT.

Discussion: The present study examined the relationship between parent-reported NA and both behavioral and physiological indicators of NA during a stranger approach paradigm. Across FXS and TD groups, higher NA corresponded to less modulation of arousal. Consistent with previous research, indices of NA also related to problem behaviors including anxiety, autism, oppositional behaviors and withdrawal in the FXS sample. These findings will be discussed in the context of theoretical models for self-regulation and problem behaviors in FXS.

Funded by NICHD (P30-HD003110-35S1) and U.S. Department of Education (H324C990042).
Temperament in Williams Syndrome: Factor Analysis of the Children’s Behavior Questionnaire

Ovsanna Leyfer¹, Angela John², Janet Woodruff-Borden³, Carolyn Mervis³
¹Center for Anxiety and Related Disorders, Boston University, ²MIND Institute, University of California-Davis, ³University of Louisville (oleyfer@bu.edu)

Introduction and Method: This study examined the factor structure of the Children’s Behavior Questionnaire (CBQ) in children with Williams syndrome (WS), a neurodevelopmental disorder caused by deletion of 26 genes on chromosome 7q11.23. Parents of 192 5 – 10-year-olds with WS completed the CBQ; parents of 109 of the children also completed the Anxiety Disorders Interview Schedule, Parent version (ADIS-P), a semistructured interview designed to diagnose anxiety and related disorders in children.

Results: Exploratory factor analysis using maximum likelihood with oblimin rotation was conducted, yielding four factors with eigenvalues greater than 1. The goodness of fit test indicated a satisfactory fit for the model \( \chi^2 (24) = 26.30, p = .34 \). Factor 1 was closely related to Effortful Control. Factor 2 included items related to Negative Affectivity/Behavioral Inhibition. Factor 3 included items related to Surgency/Positive Affectivity. Factor 4 was related to reactivity and excitability.

To examine the relation between temperament and psychopathology, the factor scores were compared between the children with and without anxiety disorders as well as between the children with and without Attention Deficit Hyperactivity Disorder (ADHD). Of the 109 children, 76 (69.7%) were diagnosed with at least one anxiety disorder. There was a significant difference between the No-Anxiety Disorder group and the Anxiety Disorder group on Factor 1, with the Anxiety Disorder group having a significantly lower mean score \( M = -.17, SD = .88 \) than did the No-Anxiety Disorder group \( M = .57, SD = .96 \) \( t(107) = 3.96, p < .001 \). There were no significant between-group differences in the factor scores for the remaining factors. Because recent studies of models of emotional disorders have excluded specific phobia (e.g., Brown, 2007), we re-ran the analyses comparing the scores for each factor, excluding the children whose only anxiety disorder diagnosis was specific phobia. Consistent with the findings for the original Anxiety Disorder group, the mean score for Factor 1 was significantly lower for the Anxiety Disorder Other Than Specific Phobia group \( n = 18, M = -.21, SD = .77 \) than for the No-Anxiety group \( n = 33, M = .57, SD = .96 \) \( t(49) = 2.97, p = .005; Cohen's d = .85 \). There also were significant between-group differences on Factors 2 and 4 but not on Factor 3. The mean for Factor 2 was significantly higher for children in the Anxiety Disorder Other Than Specific Phobia Group, \( M = .41, SD = .93 \) than for the No-Anxiety Group \( M = -.41, SD = .76 \) \( t(49) = -3.40, p = .005; Cohen's d = -.97 \). The mean score for Factor 4 also was significantly higher for the Anxiety Disorder Other Than Specific Phobia group \( M = .44, SD = .69 \) than for the No-Anxiety group \( M = -.13, SD = .80 \) \( t(49) = -2.54, p = .01; Cohen's d = -.73 \).

Of the 109 children, 69 (63%) were diagnosed with ADHD. The mean score for Factor 1 was significantly lower for the ADHD group \( M = -.26, SD = .86 \) than for the No-ADHD group \( M = .56, SD = .91 \) \( t(107) = 4.73, p < .001; Cohen's d = .91 \). The mean score for Factor 4 was significantly higher for the ADHD group \( M = .18, SD = .82 \) than for the No-ADHD group \( M = -.26, SD = .80 \) \( t(107) = -2.78, p = .006; Cohen's d = -.54 \).

Discussion: The factor structure of the CBQ for children with WS bears considerable similarity to the factor structure found by Rothbart et al. (2001) for children in the general population. Longitudinal studies of children with WS will help to further delineate pathways to childhood psychopathology both in children who have other developmental disorders and in typically developing children.

Funded by NICHD grant #R37 HD29957 and NINDS grant #R01 NS35102.
Introduction: Genetic factors are generally considered to play an important role in individual differences in temperament. One strategy to address the influence of small sets of genes on temperament is to compare the temperaments of children who have a deletion of a specific set of genes to those of children who have an extra copy of the same genes. In the present study, we have used this approach to compare the temperaments of children with deletions of 7q11.23 (Williams syndrome; “WS”) to the temperaments of children with duplications of 7q11.23 (7q11.23 duplication syndrome; “Dup7”). In addition, the WS sample size was large enough to permit comparisons of the temperaments of children who did or did not have DSM-IV anxiety or ADHD diagnoses. Temperament was measured by parental responses to the Children’s Behavior Questionnaire (CBQ; Rothbart et al., 2001). Rothbart et al.’s (2001) factor analysis of the responses of parents of typically developing children yielded three factors for the CBQ: Extraversion/Surgency (positive emotional reactivity), Negative Affectivity (negative emotional reactivity), and Effortful Control (self-regulatory aspects of attention). The Surgency factor includes the Impulsivity, High Intensity Pleasure, Activity Level, Shyness (reversed), Positive Anticipation, and Smiling/Laughter scales; Negative Affectivity includes the Discomfort, Sadness, Fear, Anger/Frustration, and Soothability (reversed) scales; and Effortful Control includes the Low Intensity Pleasure, Smiling/Laughter, Inhibitory Control, Perceptual Sensitivity, and Attentional Control scales.

Methods: Participants were 116 4 – 10-year-olds with WS (M = 7.12 years, SD = 2.06) and 20 same-aged children with Dup7 (M = 7.22 years, SD = 2.18). Parents completed the CBQ and the Anxiety Disorders Interview Schedule for DSM-IV: Parent Version (ADIS-IV: P).

Results: Due to large differences in group size, statistical comparisons were conducted with nonparametric Mann-Whitney U tests. An alpha level of .01 was used. The distribution on the CBQ Extraversion/Surgency factor was higher for the WS group than for the Dup7 (p < .0001) as were the distributions for the three scales included in this factor: Impulsivity (p < .0001), Shyness-reversed (p < .0001), and Positive Anticipation (p = .001). The distributions for the Negative Affectivity and Effortful Control factors did not differ significantly between groups. However, the distribution for the WS group was significantly higher than for the Dup7 group for the Discomfort (p = .01) and Low Intensity Pleasure (p < .0001) scales and significantly lower than for theDup7 group for the Attentional Control scale (p = .008).

Within the WS group, the distribution for the Negative Affectivity factor was significantly higher for the Anxiety Diagnosis group (n = 83) than for the No Diagnosis group (n = 33) (p = .003) as were the distributions for the Fear (p < .0001) and Positive Anticipation (p = .01) scales. The distribution for the Effortful Control factor was significantly higher for the No ADHD Diagnosis group (n = 44) than for the ADHD diagnosis group (n = 72) (p = .001) as were the distributions for the Impulsivity (p < .0001), Inhibitory Control (p < .0001), Attentional Focusing (p < .0001), and Positive Anticipation (p = .01) scales.

Discussion: Results suggest a dosage effect of one or more genes in the 7q11.23 region on individual differences in Extraversion/Surgency, particularly in gregariousness (Shyness-reversed), one of the most striking characteristics of the WS phenotype. In addition, within the WS group, there were clear temperamental differences related to presence or absence of an anxiety or ADHD diagnosis. Theoretical implications will be discussed.

Funded by NICHD grant #R37 HD29957 and NINDS grant #R01 NS35102.
MINING PUBLIC HEALTH DATA FOR IDD RESEARCH

Chairs: Richard Urbano, Vanderbilt University
       Robert Hodapp, Vanderbilt University
Public health authorities collect vast amounts of detailed data on the US population. These data represent an untapped resource for investigating intellectual and developmental disabilities. To provide the denominators for estimates of incidence, prevalence, and risk calculations, for example, state and local public health authorities systematically compile vital statistics datasets, including information about all of a state or region's births, deaths, marriages, and divorces. Embedded within these datasets are variables describing conditions related to intellectual and developmental disabilities.

Simply using each individual vital statistics dataset, we can learn much about the birth and death characteristics for specific conditions. Beyond these single dataset-analyses, we can create richer datasets by linking records within and between datasets. For example, we can use maternally-linked birth records to study characteristics of those families who do (versus who do not) have a child with intellectual and developmental disabilities. Similarly, for any individual child, we can create health profiles by linking the child's birth to hospital discharge data. We can even perform both within- and across-dataset linkages, creating (for example) health profiles on each member in the family.

In this symposium we first describe methods for creating multi-decade analysis dataset from linked and unlinked state-level vital statistic and hospital discharge datasets. We then present three studies of intellectual and developmental disabilities using these datasets.
SYMPOSIUM 9

How to Link Birth, Death, Marriage, Divorce and Hospital Discharge Records

Richard Urbano
Vanderbilt Kennedy Center and Department of Pediatrics, Vanderbilt University
Vanderbilt Kennedy Center, PMB 40, 230 Appleton Place, Nashville, TN 37203
(richard.urbano@vanderbilt.edu)

Introduction: Public Heath population-based data on vital events—births, deaths, marriage, divorce, hospitalizations and reportable conditions provide a wealth of information relevant to IDD research. In particular, IDDs identified at birth or with specific ICD 9/10 codes are recorded in the birth, death and hospital discharge datasets allow the identification and profiling of individuals with IDDs. It is possible to use these datasets individually (So et al., 2007) or in combination (Urbano et al., 2007) to study IDDs.

Objective: The purpose of this presentation is to describe the content of these datasets relevant to IDD research and how analysis datasets were created for use in the research presented in other topics in this symposium.

Datasets: Variables in the birth, death and hospital discharge datasets for identifying individuals with IDDs and profiling their conditions will be presented.

Creating Analysis Datasets: The procedures used to identify individuals with IDDs and then link the identified individuals within and between birth, death and hospital discharge datasets will be presented.

Discussion: This presentation will provide the audience with detailed description of the analysis datasets used by researchers presenting in this symposium.

References:


Examining Health Issues Among Persons with Down Syndrome

Nancy Miodrag
Vanderbilt Kennedy Center, Vanderbilt University
Vanderbilt Kennedy Center, PMB 40, 230 Appleton Place, Nashville, TN 37203
(nancy.miodrag@vanderbilt.edu)

Introduction: Using linked birth, hospitalization, and death records over the 1990-2008 span, we examined health problems and death in both infants and young persons with Down syndrome. Using linked hospitalization records, we examined the amounts, lengths, timing, and causes of hospitalizations for young children with Down syndrome, as well as the amount, correlates, and timing of death for both infants and for young persons (1-29 years) with the syndrome.

Objective: This presentation illustrates how vital statistics datasets can answer a variety of unanswered health questions among infants, children, and young adults with Down syndrome.

Methods: We first identified over 1,300 children with Down syndrome over the 1990-2008 period. Children were identified via notation of Down syndrome within their official birth records (with some extra children noted via in-patient hospitalization records). Links were then performed between the person's birth records to all subsequent hospitalization and/or death records.

Results: Infants with Down syndrome experience high levels of hospitalization, with approximately half of these infants showing (non-birth-related) hospitalizations over the first three years (most during the first year). Causes of hospitalization were most often respiratory conditions such as pneumonia and bronchitis, with children with congenital heart defects most prone to respiratory conditions. Infant mortality was extremely high—approximately 7.4% of all DS births. Causes differed by time of death, with most early deaths (i.e., on the 1st day) involving prematurity and low birthweight, most later births (28-364 days) related to respiratory-cardiac problems. Mortality was low for the first two decades of life, but rose during the 20-29 year period. During this time-period, females and African-Americans were more likely to die, and, compared to the hospitalized group that survived, the group that died showed longer hospitalizations.

Discussion: This presentation provides the audience with detailed description of how large-scale datasets can shed light on unexplored health issues among populations with IDD.
Studying Families of Children with Down Syndrome

Robert Hodapp
Vanderbilt Kennedy Center and Department of Special Education, Vanderbilt University
Vanderbilt Kennedy Center, PMB 40, 230 Appleton Place, Nashville TN 37203
(robert.hodapp@vanderbilt.edu)

Introduction: Using the same Tennessee administrative databases described in the first two presentations, we examined a series of issues related to the families of children with Down syndrome. Specifically, we examined the amount, timing, and correlates of divorce and families’ reproductive choices following the birth of a child with Down syndrome (versus with spina bifida or in the general population).

Objective: Throughout these and several ongoing studies, our objective was to use multi-year, linked, vital statistics databases to examine major questions of family functioning in families of children with Down syndrome (and, more recently, with spina bifida as well). Despite their importance for practitioners and policymakers, these issues have generally not been examined for most disability populations.

Methods: Having identified over 1,300 children with Down syndrome and over 350 with spina bifida over the 1990-2008 period, these studies examined divorce and the birth of subsequent children following the birth of the target child. For the divorce study, links were made between the child’s birth records (which note marriage status) and divorce; for the reproductive patterns study, links were made across birth records, such that we searched for—and linked—subsequent children’s births to the same mother.

Results: Although divorce seems no more likely in Down syndrome versus population families (it may even occur slightly less often), various parent-family characteristics predispose couples to divorce. These include lower age and/or education and living in a rural area. These correlates will also be examined within families of children with spina bifida, with the aim of distinguishing whether findings pertaining solely to families of children with Down syndrome or to families of children with disabilities more generally. Families of children with Down syndrome and with spina bifida were both more likely to have additional children, and this finding held across maternal education levels, race, and birth order (i.e., mothers of, say, second-borns with either Down syndrome or with spina bifida were more likely than mothers of other second-borns to have a subsequent child).

Discussion: Although they cannot answer all family questions, linked administrative datasets can answer important, heretofore unanswered questions concerning the family status of children with IDD.
Lead Exposure and Developmental Disabilities

Marygrace Yale Kaiser
Eureka College
Department of Psychology, Eureka College
(mgkaiser@eureka.edu)

Introduction: Elevated levels of lead detected in the blood are associated with harmful effects on children's learning and behavior (Bellinger, Leviton, Allred & Rabinowitz, 1994; Bellinger, Stiles, & Needleman, 2001). The current study utilized administrative databases to examine the relationship between selected developmental disabilities and elevated childhood blood lead levels (BLLs) in a population-based sample.

Methods: Lead exposure data obtained from the Florida Childhood Lead Poisoning Prevention Program were linked using a probabilistic computer algorithm to school records from the Florida Department of Education. A final linked sample of 171,365 children who were screened for lead exposure from 1993 to 2004 and attended public school during the 2003-2004 school year were compared to a sample of 846,352 children who were attending the same schools but were not screened for lead exposure. This project was undertaken for purposes of educational planning to evaluate the need for special services for children who were screened for lead poisoning once they reach elementary school. Special education status served as a proxy for developmental disability.

Results: The prevalence of behavioral problems (OR = 1.61, 95% CI 1.56-1.66), intellectual disabilities (OR = 1.44, 95% CI 1.40-1.49), learning disabilities (OR = 1.11, 95% CI 1.09-1.13) and speech-language impairments (OR = 1.29, 95% CI 1.26-1.32) was significantly higher in the sample of children who were screened for lead exposure compared to children who attended the same schools but were not screened for lead exposure.

Discussion: These data complement results from previous studies and demonstrate that administrative datasets can be used to examine this relationship. This project was uniquely possible partly because of university partnerships with state departments of health and of education. The findings are limited and preliminary in that they do not specify a specific BLL which increased risk for developmental disability nor can they identify other sociodemographic or health factors which may confound the results. Despite these limitations, these results highlight the usefulness of extant administrative datasets in tracking exposures to environmental hazards and the outcomes associated with those exposures.

References:


ADULT AGING WITH DOWN SYNDROME

Chair: Wayne Silverman, Kennedy Krieger Institute and Johns Hopkins School of Medicine
SYMPOSIUM 10

Adult Aging with Down Syndrome

Chair: Wayne Silverman, Kennedy Krieger Institute and Johns Hopkins University School of Medicine

Impact of the Family Environment on Aging in Down Syndrome
Anna Ebsensen\textsuperscript{1}
Marsha Malick Seltzer\textsuperscript{2}
\textsuperscript{1}Cincinnati Children's Hospital Medical Center
\textsuperscript{2}Waismann Center, University of Wisconsin-Madison

Preclinical Stage of Alzheimer's Disease: The Neuropsychological Profile of Asymptomatic Adults with Down Syndrome Evidencing Amyloid Deposition
Sigan Hartley\textsuperscript{1}
Benjamin Handen\textsuperscript{2}
Bradley Christian\textsuperscript{1}
Patty Jo Murray\textsuperscript{3}
Julie Price\textsuperscript{2}
Sterling Johnson\textsuperscript{1}
William Klunk\textsuperscript{2}
Darlynne Devenny\textsuperscript{3}
\textsuperscript{1}University of Wisconsin-Madison
\textsuperscript{2}University of Pittsburgh
\textsuperscript{3}New York State Institute for Basic Research

Altered DNA Methylation of \textit{TMEM131} and \textit{TCF7} in Leukocytes is Associated with Increased Risk of Dementia and Death in Adults with Down Syndrome
Nicole Schupf\textsuperscript{1}
Kristi Kerkel\textsuperscript{1}
Deborah Pang\textsuperscript{2}
Alexis Temkin\textsuperscript{1}
Warren Zigman\textsuperscript{2}
Wayne Silverman\textsuperscript{3}
Benjamin Tycko\textsuperscript{1}
\textsuperscript{1}Columbia University Medical Center
\textsuperscript{2}New York State Institute for Basic Research in Developmental Disabilities
\textsuperscript{3}Kennedy Krieger Institute and Johns Hopkins University School of Medicine

Sensory Disorders in Older Adults with Down Syndrome
Sharon Krinsky-McHale\textsuperscript{1}
Warren Zigman\textsuperscript{1}
Wayne Silverman\textsuperscript{2}
\textsuperscript{1}New York State Institute for Basic Research in Developmental Disabilities
\textsuperscript{2}Kennedy Krieger Institute and Johns Hopkins University School of Medicine

APOE Genotype and Trajectory of Change in Adults with Down Syndrome Developing Dementia
Warren Zigman\textsuperscript{1}
Sharon Krinsky-McHale\textsuperscript{1}
Nicole Schupf\textsuperscript{1,2}
Wayne Silverman\textsuperscript{3}
\textsuperscript{1}New York State Institute for Basic Research in Developmental Disabilities
\textsuperscript{2}Columbia University Medical Center
\textsuperscript{3}Kennedy Krieger Institute and Johns Hopkins University School of Medicine

110
Introduction: Adults with Down syndrome (DS) are at increased risk of dementia and declines with aging. However, there is a great deal of within-group heterogeneity in the aging of adults with DS. We investigated the long-term contribution of the prior family environment on later life outcomes of adults with DS.

Method: Interviews were conducted with 75 family members of adults with DS (mean age of adults with DS = 51.1, SD = 6.0) regarding current (2010) behavior problems, functional abilities, health, and dementia symptoms. These data were linked to prior data (1988-2000) from a larger longitudinal study of mothers age 55 and older with a co-residing adult son or daughter with intellectual disability (ID) (Krauss & Seltzer, 1999). Hierarchical multiple regression was used to predict current behavior problems, functional abilities, health, and dementia status from measures of the prior family environment. The initial status and slope scores of the dependent variable were controlled for in the first step (this step did not apply to predicting dementia status). Demographic covariates (age of adult with DS, level of ID) were entered in the second step. Initial status and slope scores of one measure of maternal well-being were entered in the third step. Three separate regression models were run with the quality of the relationship, maternal psychological well-being and maternal depression being used individually in the third step. In a fourth regression model, dementia status was predicted using the same variables except for initial status and slope.

Results: In the final regression models, decline in maternal depression over 1988-2000 was predictive of fewer current behavior problems (β = .29, p < .05), improved functional abilities (β = -.20, p < .05), and better current health (β = -.20, p = .07) in the adult with DS. Lower maternal depression in 1988 was predictive of improved functional abilities (β = -.21, p < .05), better current health (β = -.27, p < .05), and lower likelihood of having a current diagnosis of dementia (β = .26, p < .05) in the adult with DS. Improvement in maternal psychological well-being over 1988-2000 was predictive of better current health (β = .27, p < .05) in the adult with DS. The quality of the mother-child relationship did not predict any current outcomes.

Discussion: Of the measures of the family environment, maternal mental health has a substantial and long-lasting impact on aging of adults with DS decades later, and improvements in maternal mental health over time also impact adult outcomes. These findings highlight the need to consider the family environment as a target for intervening in better aging outcomes for adults with DS.

References:


This research was supported by R03 HD059848 (Esbensen, PI), R01 AG08768 (Seltzer, PI), and P30 HD03352 (Seltzer, PI)
Preclinical Stage of Alzheimer’s Disease: The Neuropsychological Profile of Asymptomatic Adults with Down Syndrome Evidencing Amyloid Deposition

Sigan Hartley¹, Benjamin Handen², Bradley Christian¹, Patty Jo Murray², Julie Price², Sterling Johnson¹, William Klunk², Darlynne Devenny³

¹University of Wisconsin-Madison, ²University of Pittsburgh, ³New York State Institute for Basic Research Waisman Center, University of Wisconsin, 1500 Highland Avenue, Madison, WI 53705 (hartley@waisman.wisc.edu)

Introduction: Adults with Down syndrome are at high risk for developing Alzheimer’s disease (AD); more than one-third of adults with Down syndrome in their 50s and half of adults with Down syndrome in their 60s and beyond exhibit symptoms of AD (Holland et al., 2000). The high prevalence of AD in adults with Down syndrome is due to the presence of an extra copy of chromosome 21, which codes for the amyloid-beta (Aβ) precursor protein (APP) gene. Deposition of amyloid plaques is purported to play a central role in the neuropathology of AD. Amyloid deposition can be detected using the PET tracer Pittsburgh Compound-B (PiB). Preliminary findings from an ongoing study (supported by the National Institute on Aging; NIA AG031110, B. Handen) aimed at documenting the course of amyloid deposition in asymptomatic adults with Down syndrome will be discussed. Data on the neuropsychological profile of 15 subjects evidencing amyloid deposition (PiB+) as compared to 25 subjects without amyloid deposition (PiB-) will be presented. Hypothesizes regarding patterns of cognitive decline over a 5 year period will be discussed.

Method: Analyzes are based on 40 adults (M = 39 years, SD = 7) with Down syndrome (22 male, 18 female). Subjects completed a battery of neuropsychological measures and completed MRI and PET scans at the University of Wisconsin or University of Pittsburgh. Neuropsychological measures were selected to assess verbal learning and memory (Cued Recall Test and WMS-IV Logical Memory), visual memory (Rivermead Face Recognition and Picture Recognition), attention/processing speed (Corsi Span forward, WISC-IV Digit Span Forward, NEPSY Visual Attention), executive/working memory (Corsi Span Backward, WISC-IV Digit Span Backward, and Stroop Cat and Dog), visuoconstruction (WISC Block Design, Extended Block Design, VMI, and Purdue Pegboard), and language (NEPSY Verbal Fluency, PPVT-IV, and Expressive One-Word Vocabulary Test). Tissue ratios were calculated for cortical regions-of-interest (ROI) and normalized to cerebellum (SUVR). Subjects were identified as PiB+ if they were above the cutoff (>1.5) in 5 cortical areas using the iterative outlier approach.

Results: Separate ANCOVAs were conducted to compare age- and IQ-adjusted means on each neuropsychological measure for the PiB+ versus PiB- subjects. The PiB+ subjects evidenced a lower mean score on several neuropsychological measures, with differences approaching statistical significance on measures of executive/working memory, delayed recall, and attention/processing speed. These mild differences are hypothesized to become more pronounced at follow-up time points.

Discussion: This study provides an unique opportunity to study the preclinical manifestations of AD. Findings may not only provide information that could affect early detection, prevention, and treatment of AD for individuals with DS, but also may offer information that will prove useful in the detection, prevention, and treatment of AD in the general population.

Reference:

Altered DNA Methylation of *TMEM131* and *TCF7* in Leukocytes Is Associated with Increased Risk of Dementia and Death in Adults with Down Syndrome

Nicole Schupf¹, Kristi Kerkel¹, Deborah Pang², Alexis Temkin¹, Warren Zigman², Wayne Silverman³, Benjamin Tycko¹

¹Columbia University Medical Center, ²New York State Institute for Basic Research in Developmental Disabilities, ³Kennedy Krieger Institute and Johns Hopkins University School of Medicine (ns24@columbia.edu)

**Introduction:** How chromosomal gain in trisomy 21 produces the complex Down syndrome (DS) phenotype is not well understood. Studies profiling mRNA expression in cells and tissues with trisomy 21 have shown that while many genes on chromosome 21 are over-expressed, subsets of genes on other chromosomes also show consistently altered expression due to gene-gene interactions. Previously, we profiled DNA methylation in total peripheral blood leukocytes (PB) and T-lymphocytes and found gene-specific abnormalities of CpG methylation in DS, with several of the differentially methylated genes having known or predicted roles in lymphocyte development and function, including *TMEM131* and *TCF7* (1,2). We suggested that hypo-methylation in *TMEM131* and *TCF7*, both important in T-lymphocyte development, might contribute to the increased risk of infections associated with the DS phenotype, and we now examined associations with mortality risk and dementia risk within this population.

**Method:** 193 adults with DS, 31 to 78 years of age at baseline (mean = 50.6) were followed at 14- to 20-month intervals for an average period of 6.1 (±.6) years. Information from cognitive assessments, caregiver interviews, medical record reviews and neurological examinations was used to classify dementia onset. Information from caregivers and the National Death Index was used to ascertain age at death. Methylation was assessed by quantitative methylation-sensitive bisulfite Pyrosequencing. We used Cox proportional hazards modeling to evaluate the association between degree of methylation and risk of dementia and death, adjusting for age, sex and level of intellectual disability.

**Results:** Over the course of the study 42 participants (22%) developed dementia and 46 participants (24%) died. Participants with lower levels of methylation in *TMEM131* were 1.5 times as likely to develop dementia (HR=1.6, 95% CI 0.7-3.5) and nearly eight times as likely to die (HR= 7.8, 95% CI, 2.5-24.1) as participants with higher levels of methylation in *TMEM131*. Participants with lower levels of methylation in *TCF7* were twice as likely to develop dementia (HR= 1.97, 95% CI: 1.01-3.8) and nearly four times as likely to die (HR=3.6, 95% CI, 1.7-7.7) as participants with higher levels of methylation in *TCF7*.

**Discussion:** Hypomethylation in *TMEM131* and *TCF7* was associated with increased risk of both dementia and death for adults with DS. These findings are consistent with the hypothesis that DNA methylation regulates the immune system in adults with DS and thereby influences overall survival and, to a lesser extent, development of dementia. While additional studies are needed to test these hypotheses and clarify the underlying mechanism(s), the present findings suggest that impaired immune system functioning throughout the lifespan has important cumulative effects.

**Reference:**


This research was supported by NIH grants R01AG014673 (Schupf) and P01HD035897 (Silverman) and by NYS through its OPWDD.
Introduction: The life expectancy of adults with Down syndrome has increased substantially over the last several decades [1, 2] and as a consequence, they are prone to experience health problems associated with advancing age, including sensory impairments. We evaluated the characteristics and prevalence of vision and hearing disorders in older adults with Down syndrome (DS group) and compared them to their peers with intellectual disability from other unspecified etiologies (ID Group).

Participants: The DS Group included 455 adults ($M_{age}=50.9$, range 30 to 83 years) and the ID Group included 153 ($M_{age}=72.7$, range 47 to 90 years). All participants were enrolled in a multidisciplinary study focused on aging and dementia in adults with intellectual disabilities [3].

Method: The primary data for this report came from the medical records of participants examined upon their entry into the study. Data from these records were recorded in a standard format organized by body system, and findings regarding the presence of specific vision and hearing disorders were examined.

Results: For both Groups, risk for vision and hearing disorders increased with advancing age. The medical records of 78% of adults within the DS Group and 68% within the ID Group indicated that they had at least one vision disorder. In addition, 69% of DS Group and 56% of the ID Group had at least one hearing disorder. Prevalence for both vision and hearing disorders was slightly higher among the DS Group. Further, they were considerably younger when they were first diagnosed with either vision or hearing abnormalities and risk increased with age more rapidly for them compared to the ID Group. Of particular concern, 57% of the DS Group and 41% of the ID Group were found to have both vision and hearing abnormalities. As expected, older adults with DS were more likely to have concerns with both vision and hearing, and for adults with Down syndrome, 78% of individuals over 60 years of age and over had dual sensory impairment.

Discussion: The high prevalence of vision and hearing disorders highlights the need for regular evaluations of all adults with intellectual disability to identify age-related changes and other pathological eye and ear conditions. Moreover, as this population ages, supports will need to be provided to an increasing number of adults having a combination of impairments. It is critical to assure that sensory impairment and its ramifications are understood. Additionally, the possibility of impaired vision and/or hearing needs to be investigated whenever declines in functional abilities suggestive of dementia occur in an older adult with Down syndrome or another developmental disability to ensure an accurate differential diagnosis.

References:


This work was supported by funds from the New York State Office for People with Developmental Disabilities and NIH grant P01 HD35897.
Introduction: The prevalence of Alzheimer’s disease pathology in adults with Down syndrome (DS) has been well documented, and the fact that some proportion but clearly less than 100% develops frank dementia has been shown repeatedly (e.g., Krinksy-McHale et al., 2010). APOE genotype exerts a clear influence on prevalence of dementia and age at onset, with APOE-4 associated with increased risk (Schupf et al., 1996). Within the typically dementing population, APOE E4 has also been shown to be a strong predictor of rate of decline in both cognitive and neuropsychological status, but similar findings have not been reported for adults with DS. The duration of our longitudinal study has enabled us to follow a subsample of adults with DS from the preclinical state of Alzheimer’s disease through the development of frank dementia. Here we examined the effects of APOE genotype on trajectories of change for these select individuals.

Participants and Method: The sample consisted of all adults with DS who had APOE genotype determined and who transitioned from “not demented” to “definite dementia” by the end of six cycles of data collection (≈ 7.5 years). This subgroup included 40 adults with a mean age at the beginning of the study of 52.7 (SD = 4.5) and mean Stanford-Binet IQ of 33.9 (SD = 9.5). Of these adults, 28 had an APOE-4 allele present and 12 had another APOE genotype. All participants received comprehensive evaluations at approximately 18-month intervals, which included assessments of health, functional abilities, cognition and neuropsychiatric concerns. Dementia status of all participants was determined at Case Consensus Conferences where all data were evaluated, including profiles of change over time. As various participants developed frank dementia at different cycles of assessment and there was mortality within the group, analyses ranged from simple descriptive statistics to generalized estimating equations.

Results and Discussion: Analysis of overall scores on the Adaptive Behavior Scale indicated that functional declines were steeper for adults with an APOE-4 genotype compared to their peers over the 18-month period prior to dementia onset, suggesting a more rapid deterioration in abilities and underlying progression of Alzheimer’s neuropathology. Additional analyses are planned to describe changes in abilities occurring before and after dementia onset. If these results parallel our findings for overall adaptive behavior, it would suggest that determination of APOE genotype for older adults with DS might help to anticipate rate of disease progression once dementia is diagnosed and aid in the planning for necessary services and supports.

References:


This work was supported by funds from the New York State Office for People with Developmental Disabilities and NIH grant P01 HD35897 to W. Silverman.
EVALUATING READING INTERVENTIONS FOR CHILDREN WITH DOWN SYNDROME

Chair: Sue Buckley, Down Syndrome Education International (UK), University of Portsmouth (UK)
SYMPOSIUM 11

Evaluating Reading Interventions for Children with Down Syndrome

Chair: Sue Buckley, Down Syndrome Education International (UK), University of Portsmouth (UK)

Teaching Early Reading Skills to Young Children with Down Syndrome
Sue Buckley¹,²
Rebecca Baxter¹
Stephanie Bennett¹,²
Gillian Bird¹
Julie Hughes¹
¹Down Syndrome Education International (UK)
²University of Portsmouth (UK)

Outcomes from a RCT of Reading and Language Intervention for Children with Down Syndrome
Kelly Burgoyne¹,²
Fiona Duff³
Paula Clarke⁴
Sue Buckley¹,²
Margaret Snowling³
Charles Hulme³
¹Down Syndrome Education International (UK)
²University of Portsmouth (UK)
³University of York (UK)
⁴University of Leeds (UK)

Evaluation of a Blending Programme for Children with Down Syndrome: Outcomes from a Feasibility Study
Kelly Burgoyne¹,²
Fiona Duff³
Paula Clarke⁴
Sue Buckley¹,²
Margaret Snowling³
Charles Hulme³
¹Down Syndrome Education International (UK)
²University of Portsmouth (UK)
³University of York (UK)
⁴University of Leeds (UK)
Teaching Early Reading Skills to Young Children with Down Syndrome

Sue Buckley\textsuperscript{1,2}, Rebecca Baxter\textsuperscript{1}, Stephanie Bennett\textsuperscript{1,2}, Gillian Bird\textsuperscript{1}, Julie Hughes\textsuperscript{1}

\textsuperscript{1}Down Syndrome Education International (UK), \textsuperscript{2}University of Portsmouth (UK)

Down Syndrome Education International, Belmont Street, Southsea UK PO5 1NA

(sue.buckley@dseinternational.org)

Introduction: A number of case reports and small sample studies have reported reading skills in preschool children with Down syndrome. However, these studies do not provide information on the range of achievements in a representative sample of children—the case examples may describe unusually able children. In addition, evaluations of effective teaching methods are limited. This study was designed to evaluate two aspects of early reading skills, sight word learning and phonics, in a sample of 40 children with Down syndrome age range 2;3 to 4;2 at the start of the study. Data was collected on their cognitive, receptive and expressive language skills at the beginning and end of the 18 month study in order to see if a. these were related to the children’s progress and b. if progress in reading was related to progress in language.

Method: Families were recruited from those receiving a monthly early intervention service. The children were assessed pre and post intervention on standardised measures: the Visual Reception, Receptive Language (RL) and Expressive Language (EL) scales of the Mullen Scales of Early Learning, the Word Reading and Letter Knowledge scales of the York Assessment of Reading Comprehension and bespoke measures of sight word reading, initial letter identification, blending and segmenting. The reading intervention used steps 2 and 4 in the See and Learn Language and Reading programme designed to teach sight words in meaningful contexts—see http://www.seeandlearn.org/en/gb/language-reading/ The phonics intervention was designed for the study using sets of cvc rhyming words chosen to be understood by children of this age. The child worked through each programme at their own pace. Early intervention staff demonstrated activities with the child on the monthly visits and parents were asked to continue the teaching activities at home. Progress was monitored and new targets set each month. Six months into the study, 15 children started school in mainstream schools. Their teachers were encouraged to continue with the programmes alongside class literacy instruction.

Results: Data is analysed for the school group SG (N=15) separately from the preschool group PG (N=15). 10 children were lost from the younger group: 3 left the EI service and 7 were unwilling to attend for the post intervention assessments. These 10 children are not significantly different on any baseline measures from those who continued. Post intervention both groups of children have mean YARC letter sound and word reading age scores (months) that are at their CA level (SG letters 65;2, words 63;9, CA 63;0, PG letters 58;8, words 59;75, CA 50;5) despite language ages at this time which are significantly below CA (SG RL 41;3, EL 37;7, PG RL 34;0 EL 32;1). Progress on both reading measures is significantly correlated with language skills at T1. There is no relationship between rates of language and reading progress during the intervention period. Progress on initial letter identification, blending and segmenting will also be reported – these show considerable individual differences.


Reference:

Outcomes from a RCT of Reading and Language Intervention for Children with Down Syndrome

Kelly Burgoyne1,2, Fiona Duff3, Paula Clarke4, Sue Buckley1,2, Margaret Snowling1, Charles Hulme3
1Down Syndrome Education International (UK), 2University of Portsmouth (UK), 3University of York (UK), 4University of Leeds (UK)
Down Syndrome Education International, The Sarah Duffen Centre, Belmont Street, Portsmouth, UK PO5 1NA (Kelly.Burgoyne@dseinternational.org)

Introduction: Most individuals with Down syndrome can learn to read though there is wide variation in attainment levels. There remains limited evidence about how best to intervene to improve these children’s skills. A small number of studies suggest that phonics-based reading instruction can support the reading development of this group. Language impairments are common in Down syndrome and may affect response to intervention; work with typically-developing children suggests that incorporating phonics-based reading instruction with vocabulary teaching may be particularly effective. This paper reports the first randomized controlled trial of a reading and language intervention for children with Down syndrome.

Method: A waiting list control design was employed, in which half the sample received intervention immediately, while the remaining children received the intervention after a 20 week delay. Fifty-seven children with Down syndrome aged 5-10 years, in mainstream primary schools in the North (York) and South (Hampshire) UK, were randomly allocated to intervention (40-weeks intervention) and waiting control (20-weeks intervention) groups. Trained teaching assistants delivered intervention to individual children in daily 40-minute sessions. The intervention incorporated book reading, work on letters, sounds and phonology, sight word reading, learning new vocabulary and developing expressive language skills. Children were assessed on a range of standardised and bespoke measures before intervention, after 20-weeks of intervention and after 40-weeks of intervention.

Results: After 20 weeks of intervention the intervention group made more progress on measures of word reading, letter-sound knowledge, phoneme blending and taught expressive vocabulary (effect sizes 0.23 – 0.54). Effects did not transfer to wider measures of literacy and language (nonword reading, spelling, standardised expressive and receptive vocabulary, expressive information and grammar). Though the intervention group remained numerically ahead of the control group on most outcome measures after 40-weeks of intervention, differences were not significant at this time point. Children who were younger, had better receptive language skills at the start of the study, and received more intervention sessions made more progress.

Discussion: A targeted intervention delivered by trained teaching assistants in school produced gains in reading and language for children with Down syndrome when compared with routine classroom practice. Gains were seen in skills directly taught with little evidence of generalization at this time. Ways in which this programme could be adapted to other school systems will also be discussed.

References:


Introduction: Children with Down syndrome typically demonstrate better word reading than decoding skills and may have difficulties utilising a phonological route to reading. Particular problems in mastering blending skills have been observed: though children can sound out individual letters in words, many have difficulties combining those sounds to pronounce the word. The extent to which this is due to a lack of focused instruction is unclear. Some children with Down syndrome are clearly able to develop phonological reading skills; targeted teaching may enable more children with Down syndrome to develop these skills. This paper presents the results of a teaching programme targeting blending skills in children with Down syndrome.

Method: A 6-week intervention programme designed to support phoneme blending skills was developed. The programme followed a structured, sequential progression introducing new letter-sounds every two days and training blending of words with 2-4-phonemes. Six games were used as teaching activities; these included listening games and games supported with letters, games which utilised visual supports and those which required oral responses, and non-word and sentence reading games. A training DVD and scripted teaching sessions were provided to teaching assistants who delivered intervention to individual children in daily 10-15 minute sessions. Ten children with Down syndrome aged 7-10 years, in mainstream primary schools in the North (York) and South (Hampshire) UK, received 30 sessions of intervention. Children were assessed on reading and phonological measures at two time points over 3 months before training (baseline) and immediately after the 6-week training programme.

Results: Baseline data has been collected; this will be compared to post-intervention data (data collection November 2011) to explore gains on standardised and bespoke measures of word reading, decoding (non-word reading), phoneme blending (with and without picture support), letter sound knowledge, phonological awareness (sound isolation) and spelling. Data from individual children will also be used to examine individual differences in progress made over the course of the intervention.

Discussion: The efficacy of the programme in supporting the development of blending and reading skills in children with Down syndrome will be discussed. The results will also be discussed in relation to the literature on reading development and literacy instruction for children with Down syndrome.

References:


TRANSLATIONAL ANALYSIS AND TREATMENT OF CHRONIC ABERRANT BEHAVIOR—TRANSITION STATES, BEHAVIORAL ECONOMICS, AND IDIOSYNCRATIC FUNCTIONS

Chairs: Michael Cataldo, Kennedy Krieger Institute and Johns Hopkins University School of Medicine
William McIlvane, Eunice Kennedy Shriver Center, University of Massachusetts Medical School

Discussant: Travis Thompson, University of Minnesota
SYMPOSIUM 12

Translational Analysis and Treatment of Chronic Aberrant Behavior—Transition States, Behavioral Economics, and Idiosyncratic Functions

Chairs: Michael Cataldo, Kennedy Krieger Institute and Johns Hopkins University Medical School
William McIlvane, Eunice Kennedy Shriver Center, University of Massachusetts Medical School

Discussant: Travis Thompson, University of Minnesota

Translational Research: Understanding and Treatment of Behavior Problems During Transitions in Persons with IDD
Dean Williams
Schiefelbusch Institute for Life Span Studies, University of Kansas

Behavioral Economic Analyses to Gauge the Utility of Reinforcers for Behavior Intervention
Iser DeLeon1,2
Michelle Frank-Crawford1
Abbey Carreau-Webster1
Griffin Rooker1,2
Jessica Becraft1
Mariana Castillo1
Jessica Chastain1
James Chastain1
Erin Schaller1
Christopher Bullock1,2
Lisa Toole1
1Kennedy Krieger Institute
2Johns Hopkins University School of Medicine

Functional Analysis of Problem Behavior: A Systematic Approach to the Identification of Idiosyncratic Variables
William Dube1
Kevin Schlichenmeyer1
Eileen Grant1
Eileen Roscoe2
1University of Massachusetts Medical School
2New England Center for Children
Chronic, severe, disruptive and destructive behaviors such as self-injury, physical aggression, property destruction, and severe tantrums are extremely common in persons with IDD. These “challenging” behaviors present barriers to habilitation and independent living, and they are a long-standing treatment challenge. Because of these behaviors, the use of psychotropic medications has remained at high levels in this population. Behavior problems during transitions from one activity to another are prevalent. Research in this area is sparse and little is known about the behavioral and neural processes that underlie and/or precede problematic transitions. This paper will present a translational research program conducted in laboratory, naturalistic and clinical settings, showing that transitions to normally benign activities can trigger challenging behaviors.

Our initial studies drew upon basic behavioral literature showing that hungry animals responding for food reinforcement will stop responding for long periods and emit escape behaviors that delay the next reinforcer. This counterintuitive result occurs when the animal transitions from conditions of relatively rich to relatively lean reward. The lean conditions do not produce response disruption or escape if they were not preceded by the relatively rich conditions. We adapted these procedures for use with persons with IDD, and showed reliable response disruption analogous to the animal preparation. When people with IDD and histories of self-injurious behaviors (SIB) were exposed to these procedures, SIB occurred predominately in the transitions from relatively rich to relatively lean reinforcement, suggesting that the same process may engender response disruption and SIB. Our next study arranged for naturalistic tasks (sorting utensils) and highly preferred vs low preference rewards. Again, persons with IDD and histories of SIB showed little SIB in the lean-reward task unless it was preceded by the high-reward task. To extend this process to clinical settings, we recruited individuals with histories of SIB and aggression, and assessed preference for engaging in a variety of activities typically encountered in their environments. We then arranged analogue conditions in which they would engage in either the most preferred or least preferred activity. We alternated activities such that four transition types were obtained; transition from high to high preference (rich to rich), low-to-low preference (lean to lean), low to high preference (lean to rich), and high to low preference (rich to lean). No extrinsic rewards were given for engaging in the activities. Thus, the processes that engender challenging behaviors are limited the controlled laboratory procedures. We are expanding this research to the daily activities encountered in a specialpurpose classroom for individuals with IDD and challenging behaviors to extend the predictive validity of the laboratory model, as well as experimenting with procedures that will prevent the problem and disruptive behaviors in the laboratory and clinical settings. One tested procedure is to impose a “time out” between activities such that when the high preference activity ends, the low preference activity does not start for 30 seconds. This has reduced disruptive behaviors in the laboratory, and challenging behavior in the naturalistic setting. Taken as a whole, this translational research program implicates basic behavioral processes (negative incentive contrast) in the generation of challenging behaviors, a laboratory and animal model for study of these processes, and potentially informs treatment.

Research supported by NICHD grant P01 HD055456 01 A2
Behavioral Economic Analyses to Gauge the Utility of Reinforcers for Behavior Intervention

Iser DeLeon1,2, Michelle Frank-Crawford1, Abbey Carreau-Webster1, Griffin Rooker1,2, Jessica Becraft1, Mariana Castillo1, James Chastain1, Erin Schaller1, Christopher Bullock1,2, Lisa Toole1
1Kennedy Krieger Institute, 2Johns Hopkins University School of Medicine
707 N. Broadway, Baltimore, MD 21205
deleon@kennedykreiger.org

Introduction: Behavioral interventions for chronic aberrant behavior (CAB) have proven remarkably effective under temporally circumscribed and well-controlled conditions, but their effectiveness may wane when implemented under circumstances that mimic what is practicable in the natural environment (i.e., when schedules of reinforcement are thinned or extinction is implemented with less than perfect integrity). The efficacy of these interventions can sometimes be enhanced through the use of potent reinforcers to support alternative, replacement behaviors. However, the literature on the use and selection of such reinforcers has generally failed to consider that reinforcers that seem equally effective when the amount of behavior required to produce them is low may have very different effects when that behavioral “cost” is increased. The current series of experiments describe a method, based on behavioral economic demand curve analysis, for gauging the efficacy of different reinforcers across increasing cost manipulations.

Method: Brief demand elasticity analyses were conducted for participants whose CAB was found to be maintained by access to caregiver attention or escape from instructional demands. Each session in the elasticity analyses consisted of 25 trials. Within each session, either the delay to reinforcement (attention) or the number of responses required to access a preferred food (escape) were increased across trials. In the attention elasticity analysis, communication for attention resulted in the provision of attention following some delay (0s, 5s, 10s, 20s, or 40s). During the delay, a preferred toy was delivered and CAB was reinforced. During each trial of the escape elasticity analysis, a concurrent chain schedule was arranged such that the participant was given a choice between two options. Responses on one option resulted in the presentation of a demand and an edible was delivered following task completion. The schedule of reinforcement began at FR1 and was systematically thinned within session (FR2, FR5, FR10, FR20). Responses on the second option resulted in no work requirements (i.e., a 30-s break). Both analyses were conducted with four highly preferred toys (attention) or foods (escape) and were repeated up to five times with each stimulus to gauge the reliability of the assessment.

Results: Results of both types of elasticity analyses suggested that most of the stimuli competed with CAB or were selected over a break at low delays or costs, but fewer were found to do so at higher delays or costs. For participants for whom the analysis was completed five times with each stimulus, results appeared to become more stable during the last three repetitions of the analysis.

Discussion: The results provide further support for the notion that demand profiles for reinforcers may differ as delay to reinforcement or schedule requirements associated with earning the reinforcer increase. The elasticity analysis may have some utility in enhancing interventions for CAB. That is, when behavioral interventions for CAB cannot be implemented faithfully in the natural environment, treatment effects may deteriorate. Under such circumstance, the elasticity analysis may prove to be a useful tool in identifying which reinforcers would maintain their effectiveness as reinforcement schedules are thinned and extinction is implemented with less than perfect integrity.

This research was supported by NICHD grant #P01HD055456-01 A2
Introduction: The diagnostic technique of functional analyses (FA) is widely used in clinical settings to identify consequences that maintain problem behavior. Standard FA procedures (e.g., Iwata et al., 1982/1994) often produce clear outcomes, but sometimes the results are ambiguous and cannot be interpreted. When this occurs, clinicians may need to modify the FA conditions to include idiosyncratic antecedent and/or consequent variables. Idiosyncratic variables refer to stimuli that are (a) functionally related to the target behavior but (b) not presented or unmeasured during typical FA procedures. To date, a systematic strategy for identifying idiosyncratic variables to include in FA conditions has not been reported. In this study, we evaluated a systematic protocol for identifying such variables that included indirect assessment and descriptive analysis.

Method: Participants were five residential students referred to our project by their clinical teams because of significant problem behavior of aggression or self-injurious behavior. Initial FA results using standard procedures were ambiguous in three cases because of low rates of problem behavior within the assessment sessions, and in the fourth case variable and inconsistent response patterns. The protocol for identifying idiosyncratic variables consisted of: (1) An indirect assessment consisting of a 72-item checklist in which clinicians rated the likelihood of problem behavior in relation to a range of potential idiosyncratic variables identified by a literature review of applied behavior analysis studies. (2) An open-ended indirect assessment in which clinicians were asked to identify general characteristics of situations in which the problem behavior occurs. Two clinicians familiar with the participant independently completed the indirect assessments. (3) A descriptive analysis of video recordings of problem behavior in the typical environment. The descriptive analysis results were expressed as conditional vs. non-conditional probabilities (e.g., Vollmer et al., 2001) of problem behavior in relation to events that were consistently (across clinicians) highest-rated in the indirect assessments. The FA procedures were then modified to incorporate events that were both (a) highly and consistently rated in the indirect assessment, and (b) related to the problem behavior by a positive contingency in the descriptive analysis.

Results: For all participants, modified FA procedures produced differentiated outcomes after testing one, two, or three candidate variables. These modifications included events such as: walking in the hallways, ritualistic arranging of school supplies, watching specific parts of videos, and introducing a specific form of task demand (putting on shoes).

Discussion: The results indicate that a systematic approach incorporating indirect assessment and descriptive analysis can guide the identification of idiosyncratic variables relevant to problem behavior. Further, when those variables were incorporated into modified FA procedures, the results of the modified FA revealed clear behavioral functions.

References:


Research supported by NICHD grant P01 HD055456 01 A2
POSTER SESSION 2

THURSDAY, MARCH 8, 2012
5-7 P.M.
POSTER SESSION 2

1. Correlates of Sensory Processing with Adaptive and Problem Behaviors in Children with Down Syndrome

Lisa Daunhauer¹, Deborah Fidler¹, Susan Hepburn²
¹Colorado State University
²University of Colorado-Denver

Department of Human Development and Family Studies, Colorado State University, Fort Collins, CO 80523
(lisa.daunhauer@colostate.edu)

Introduction: Children with Down syndrome (DS) often present with a profile of relative challenges in motor skills, problem-solving, goal-directedness, expressive language, and adaptive behavior (see Fidler & Daunhauer, 2011) as well as problem behaviors (Dykens, 2007). Additionally, recent research has described a specific profile of sensory processing challenges in children with DS (Bruni et al. 2010). However, researchers have not methodically examined how sensory processing relates to either problem or adaptive behaviors in this population. This study examined the relationship between sensory processing and both problem and adaptive behaviors in children with DS to better understand targets for intervention.

Methods: Participants were 53 children ranging in age from 3 to 10 years (M MA = 33.24, SD = 11.41, n = 33 males) diagnosed with DS, without co-morbid autism spectrum disorder (ASD), who were part of a larger study on the comorbidity of Down syndrome and ASD. Parents completed the Short Sensory Profile (SSP), the Developmental Behavior Checklist (DBC), and the Vineland Adaptive Behavior Scales-II (VABS-II).

Results: For the SSP total score, over a third of the group (39.5%) was reported to have clinical -level sensory difficulties, defined as greater than 2 SDs below the performance of the standardization population. The SSP domains with the greatest clinical-level sensory difficulties included: low energy/weak (65.1%), underresponsive/seeks sensation (34.9%), and auditory filtering (34.7%). There was a strong significant relationship between total SSP score and problem behaviors as measured on the total DBC score \((r = -.59, p < .001)\) indicating that more difficulties reported in sensory processing was associated with more problem behaviors. Of the SSP domains with the greatest sensory difficulties, low energy/weak, did not correlate with the total DBC score, however, both the domains of underresponsive/seeks sensation and auditory filtering did \((r = -.56, p < .001\) and \(r = -.62, p < .001\) respectively). For adaptive behavior, the SSP total score correlated with the VABS-II Coping subdomain \((r = .34, p = .03)\).

Discussion: This project adds to the current body of literature by highlighting the relationship between sensory processing with both problem-behaviors, and coping. Therefore, targeting sensory processing difficulties with auditory filtering and underresponsive/seeks sensation could potentially decrease problem behaviors. While the majority of the parents reported their child to have clinical-level difficulties in the ’low energy/weak’ domain of the SSP, this is not surprising given that DS is associated with hypotonia (Fidler & Daunhauer, 2011). No meaningful relationship was found between this difficulty and behaviors examined in this study. Finally, the pattern of sensory domains with the greatest relative challenges reported in this study converge with the findings of Bruni et al. (2010), though the frequencies of several other domains did not. Differences in sampling methods and inclusion criteria will be discussed.

References:


2. Neuropsychological Functioning in Children with Prader-Willi Syndrome: A Comparison of Genetic Subtypes

Megan Kovac, Stephen Hooper, Anne Wheeler
Carolina Institute for Developmental Disabilities
University of North Carolina School of Medicine
CIDD, CB# 7255, UNC School of Medicine, Chapel Hill, NC 27599
(Megan.Kovac@cidd.unc.edu)

Introduction: Prader-Willi Syndrome (PWS) is a genetic disorder created by a deletion on the paternal leg of chromosome 15 (15q11-q13) and is characterized by specific genetic subtypes. The Paternal Deletion (PD) subtype is classified as Type I or Type II based on the size of the deletion, while the Maternal Uniparental Disomy (UPD) subtype is a duplication of the maternal chromosome with no copies from the father. There is some evidence to suggest that these genetic subtypes manifest different neuropsychological profiles (Gross-Tsur, 2001; Walley, 2005; Whittington, 2004), although these findings have been mixed. The primary purpose of this study is to examine neuropsychological functioning as it relates to two genetic subtypes of PWS. Using a comprehensive neuropsychological battery, it is hypothesized that the PD Subtype will perform more poorly than the UPD Subtype across all domains.

Methods: Participants included 41 children with genetically confirmed PWS, ranging in age from 3.1 to 12.7 years. The PD Subtype included 29 children with an average age of 7.0. This subtype was 89.6% Caucasian, 55.2% male, with maternal education levels of high school or more. The UPD Subtype included 12 children with an average age of 7.5 years. This subtype was 100% Caucasian, 58.3% males, with maternal education levels of high school or more. Neuropsychological measures represented Fine-Motor, Language Visual-Spatial, Memory, and Executive Functions.

Results: The groups did not differ in terms of chronological age, race, gender, or maternal education; consequently, these variables were not covaried in the group comparisons. Serial MANOVAs did not show significant differences between the groups on Language (p < .59), Visual-Spatial (p < .18), or Executive Functions (p < .45); but, significant groups differences were present for Fine-Motor, F (2, 30) = 3.42, p < .05, and Memory, F (4, 17) = 3.50, p < .03. Specifically, the PD Subtype performed significantly higher than the UPD Subtype on Imitative Hand Positions and Object Memory Recall, with moderate to large effect sizes being noted.

Discussion: This study was conducted to address the relative dearth of work examining the neuropsychological differences between deletion (PD) and non-deletion (UPD) PWS subtypes. In contrast to our hypothesis, findings reflected group differences only on the Fine-Motor and Memory domains, with the PD subtype performing at a higher level than the UPD subtype. Considering that our study indicated more similarities than differences between these two genetic subtypes of PWS, further research should continue to focus on specific behavioral and cognitive manifestations of this disorder, both as a function of genetic subtype and as they describe the functioning of individuals with 15 (15q11-q13) deletions as a whole.

References:


Human beings are often engaged in interpreting the means (*how*) and intent (*why*) of others’ actions. It has been proposed that understanding the intention of others’ actions is accomplished by means of an automatic motoric simulation (Gallese and Goldman, 1998), possibly mediated by mirror neuron system (MNS) activity in the ventral premotor cortex and inferior parietal lobule (Rizzolatti et al., 1998; Gallese et al., 2004). In contrast to this, others argue that mentalizing recruits regions outside the motor system, such as the temporoparietal junction (TPJ), superior temporal sulcus (STS), and medial prefrontal cortex (MPFC) (Saxe, 2006; Frith & Frith, 2003). Recently, it has been found that these two systems may be complementary in understanding actions (de Lange et al., 2008). While impairments in both systems have been reported separately in people with autism spectrum disorders (ASD), to our knowledge, they have not been investigated in conjunction. The present study addresses the validity of mirroring and mentalizing hypotheses in autism in understanding the means and intent of actions.

fMRI data was acquired from 5 high-functioning adults with ASD and 5 typically developing controls (data collection in progress) while they made action and intention judgments about a series of static images of a model using household objects (adapted from de Lange et al., 2008). The participants’ task was to view the model’s action and determine whether the means (how the action was carried out) or intent (the model’s goal) of the action was ordinary or unusual. The stimuli were presented in blocked design and the data were acquired on a Siemens 3T scanner and analyzed using SPM8.

The results are as follows: 1) ASD participants showed significantly reduced response in bilateral TPJ and left inferior frontal gyrus (IFG), relative to controls, while inferring the model’s intent; 2) While detecting unusual means the ASD group activated significantly lesser, relative to controls, in bilateral IFG and left angular gyrus; but showed greater response in right supramarginal, bilateral supplementary motor, and right superior MPFC; and 3) Paired samples t-tests on the behavioral data determined no significant differences between the groups for accuracy and reaction time for all experimental conditions.

Our finding of TPJ and IFG activation in controls for inferring the model’s goal underscores the complementary roles of the mirror neuron and mentalizing networks for inferring intentions. That the means condition also activates the IFG in controls is suggestive of the role of the IFG for the simulation of actions and intentions, whereas the TPJ is likely additionally recruited for interpretation of the intentions. Despite finding no behavioral differences between autism participants and controls, our participants with autism showed reduced response in these regions while processing the intent of actions, indicating a possible use of an alternate cortical route in individuals with autism when interpreting others’ actions.
Contingency space analysis (CSA) is a method of identifying operant contingencies by comparing probabilities of a consequent stimulus following and not following a target response. Yule's Q, a linear transformation of the Odds Ratio, is the current recommended method for statistically quantifying the sequential association between two events. Each method may be used to quantify response-consequence relations from descriptive assessment data and identify potential functions of problem behavior. CSA and Yule's Q previously have been defined using different terms, making it difficult to compare these methods and evaluate the extent to which they correspond. The purpose of the current poster is to (a) define CSA in the same terms as Yule's Q, (b) identify two potential measures of contingency strength from CSA to assess correspondence with Yule's Q, and (c) use simulated data to identify areas of contingency space that may produce discrepancies in contingency strength among the CSA indices and Yule's Q. Demonstrations suggest Yule's Q and each of two effect size measures for CSA (i.e., difference in transitional probabilities vs. ratio of transitional probabilities) correspond to varying degrees depending on the location of points in contingency space. The extent to which each measure of contingency is affected by base rates of the consequent stimulus highlights a potential disconnect between statistical and operant paradigms.

References:


**POSTER SESSION 2**

5. **The Down Syndrome Advantage in the Transition to Adulthood**

Jesse Ludwig, Katherine Grein, Laraine Glidden
St. Mary’s College of Maryland, 18952 E. Fisher Road, St. Mary’s City, MD 20686
(lmglidden@smcm.edu)

**Introduction:** Children with Down syndrome (DS) are sometimes perceived as being easier to rear than are children with other intellectual/developmental disabilities (IDD), with reports of fewer behavior problems and greater adaptive behavior. Previous research has identified these behavioral characteristics as explaining the “Down syndrome advantage”, but still other research has found that confounding variables such as maternal age and child age may also contribute. Corrice and Glidden (2009) corroborated the importance of maternal age and child age as well as adaptive behavior in understanding the reason for the Down syndrome advantage, as reported by mothers when children were, on average, 18 years old. The aim of the current study was to determine if the Corrice and Glidden results persisted 8 years later, now that the children had entered into early adulthood. Using a somewhat different set of parental functioning variables, differences in the effects of DS and other IDD were analyzed for both mothers and fathers.

**Method:** As part of an ongoing longitudinal study, 80 mothers and 46 fathers of children with IDD completed surveys including a Global Evaluation of the Impact, Subjective Well Being – Child (SWB-C), and a subset of the Transition Daily Rewards and Worries Questionnaire (TDRWQ6). ANOVAs compared parents of children with DS to parents of children with other IDD. There were differences between the two groups on the Personal Self-Sufficiency score of the Adaptive Behavior Scale, Parent Age, and Child Age, and, therefore, the analyses were re-run with these as covariates (ANCOVA).

**Results:** Based on initial ANOVAs, mothers of children with DS had significantly better scores on the TDRWQ6 and the Global Evaluation of the Impact than did mothers of children with other IDD. This difference disappeared after the addition of the covariates, with a significant effect of the child’s Personal Self-Sufficiency score, but not Maternal or Child Age. Fathers of children with DS had better scores on the SWB-C than did fathers of children with other IDD ($p = .057$), though this finding was no longer significant when Child Age was added as a covariate.

**Discussion:** Mothers of children with DS reported that it was easier to raise a child with DS and that they experienced greater rewards and fewer worries than did mothers of children with other IDD. Although these mothers were older and their children younger than in families of children with other IDD, these variables no longer accounted for any of the Down syndrome advantage. Instead, it appeared to be almost completely explained by the greater levels of personal self-sufficiency in children with DS. This result replicated the findings of Corrice and Glidden (2009) that much of the Down syndrome advantage was explained by child-specific variables. This advantage has continued beyond childhood and into early adulthood.

**Reference:**


Matthew Maenner, Leann Smith, Jinkuk Hong, Renee Makuch, Jan Greenberg, Marsha Mailick Seltzer
Waisman Center, University of Wisconsin-Madison
1500 Highland Avenue Room 529A, Madison, WI 53705
(mjmaenner@wisc.edu)

Introduction: Adults with developmental disabilities experience a wide range of difficulties in performing daily activities; some might encounter severe limitations in self-care and basic tasks necessary for independent living, while others have few limitations in these areas. Activities of Daily Living (ADLs) are considered durable indicators of “activity limitations”—consistent with the World Health Organization’s dimensional framework for disability (WHO). ADL instruments have been used extensively in clinical applications and research. However, there is a paucity of freely-available and high quality tools for measuring activity limitations among adults with developmental disabilities. The purpose of this analysis is to describe the development of the Waisman Activities of Daily Living (W-ADL) Scale, and to thoroughly evaluate its measurement properties for adults with developmental disabilities.

Methods: This analysis utilized four well-characterized and longitudinally-studied groups of adults with developmental disabilities: 406 adults with autism; 147 adolescents and adults with fragile-X syndrome; 169 adults with Down syndrome, and 292 adults with intellectual disability. The 17 W-ADL items pertain to the target adult’s current performance in daily activities such as grooming, bathing, running errands, and preparing meals. The performance of each activity is rated on a 3-point scale (0=”does not do at all”, 1=”with help”, 2=”independent”), and summed to produce an overall score. W-ADL items were administered at the beginning of each study, and re-administered at several additional time points for adults with autism, Down syndrome, or intellectual disability. We evaluated the W-ADL according to an established set of quality criteria for the measurement properties of health status questionnaires (Terwee et al).

Results: Cronbach’s alphas for the W-ADL ranged from 0.88 to 0.94 in the four disability groups, and a single-factor structure was most parsimonious. We observed high reliability between consecutive time points with weighted kappas ranging from 0.92 to 0.93. Construct validity was supported through substantial associations between the W-ADL and the level of employment or degree-seeking education, maternally-reported need for respite services, maternal caregiving burden, and target adult IQ. Criterion validity was demonstrated with a correlation of 0.78 between the W-ADL and Vineland Screener among adults with autism. The W-ADL demonstrated no floor or ceiling effects in any of the four groups. Among adults with Down syndrome and intellectual disability, there were significant group differences in W-ADL scores by subjective maternal ratings of “mild”, “moderate”, “severe”, and “profound” intellectual disability. We estimate that a 1-point change in W-ADL scores is detectable in samples of at least 35 people.

Discussion: The W-ADL exceeded the recommended threshold for each quality criterion we evaluated, and appears to have desirable measurement properties as a research instrument. Additional work is needed to evaluate its utility and applicability in different cultures and contexts. This freely-available tool has practical applications as an efficient measure of activities of daily living for research concerning adults with developmental disabilities.

References:


POSTER SESSION 2


Helena Mawdsley
Johns Hopkins University
Johns Hopkins University, School of Education, 6740 Alexander Bell Drive Suite 302, Columbia, MD, 21046
(hmawdsley@jhu.edu)

Introduction: According to the model delineated by Dunst and Trivette (1990), the helpfulness of social support (SS) provided to parents directly and indirectly affects parent, family, and child functioning. Family stress models (Crnic, et al., 1983) applicable to families of children with developmental disabilities (DD), assert that SS is an ecological variable that may assist families in coping with the stresses of having a child with a disability. Examining families of children with DD, Plant and Sanders (2007) found positive impacts of SS on parent stress at the preschool level such that SS provided by professionals served to buffer the impact of high levels of child problem behavior on maternal stress. Less is known about the buffering impact of the helpfulness of SS during the middle childhood years for families of children with DD. This study hypothesizes that the helpfulness of SS will moderate the relation between child problem behavior and parenting stress such that high levels of the helpfulness of SS may protect later parenting stress from the potential negative impacts of high levels of child problem behavior.

Methods: The current study analyzes data from the Early Intervention Collaborative Study (EICS), a longitudinal investigation of children with DD and their families (Hauser-Cram Warfield, Shonkoff, & Krauss, 2001). As infants, the children were diagnosed with Down Syndrome, Motor Impairment, or Developmental delay. The sample for the current analysis consisted of 107 mother-child dyads and 65 father-child dyads. Mothers completed the Child Behavior Checklist (CBCL) (Achenbach & Edelbrock, 1983) when the child was age 5 years. Both parents completed the Family Support Scale (FSS) (Dunst, Trivette, & Jenkins, 1984) at age 5 and the Parent Stress Index (PSI) (Abidin, 1995) when the child was age 10 years.

Results: Separate hierarchical regression models were conducted for each parent to determine the moderating impact of each parent’s SS. Following Baron and Kenny (1986) predictor variables were centered at zero and an interaction term was created between child behavior and SS. Parenting stress at age 10 was regressed on the following variables in the following steps: Step 1 - child problem behavior at age 5; Step 2 - parent rating of SS at age 5; Step 3 - interaction term of child behavior at age 5 and SS at age 5. For the mother sample, the interaction term was a significant predictor of later maternal stress (age 10) ($\beta = -.236$, $p = .004$) and added 5.3% of variance to the outcome ($F$ change = 8.73, $p = .004$). Thus, the helpfulness of SS at age 5 moderated the relation between child problem behavior at age 5 and maternal stress at age 10 such that mothers who had children with high levels of problem behavior but who also received high levels of helpfulness from their social supports, reported lower levels of parenting stress by age 10. For the father sample, the interaction term was not significant but SS served as a main effect ($\beta = -.267$, $p = .016$) where higher levels of the helpfulness of SS at age 5 predicted lower levels of paternal stress at age 10. The helpfulness of SS contributed 31% of the variance to paternal stress at age 10 ($F$ change = 6.96, $p = .010$).

Discussion: The current investigation suggests that the helpfulness of SS provided to mothers of children with DD may buffer the impact of high levels of child behavior on parent stress. Fathers who reported higher levels of helpfulness from SS at age 5 reported lower levels of parenting stress five years later. The findings have implications for families of school age children with DD who may be experiencing significant stress and are navigating educational and medical treatment systems. Both medical and school systems should employ a more family centered approach which may allow the family to feel more supported as they try to acquire the best services and care for their child with DD. Additionally, the continuity of support services and trans-disciplinary partnership among settings are also indentified by parents as qualities of social support (Trivette & Dunst, 2007). In this way, parents may perceive their supports as even more helpful which may provide a protective factor for their well-being.

Reference:
Introduction: Depression is a common diagnosis among people with intellectual disability (ID; Richards et al., 2011). Diagnosing depression relies heavily on self-report of affective, cognitive, and somatic symptoms (McBrien, 2003). However, it is often beneficial to use corroborative reports from caretakers when deciding upon a diagnosis (Lunsky, 2003). Several depression measures have been developed to distinguish depressed versus non-depressed individuals with ID. In this study, we examine the reliability and validity of a caregiver scale and two self-report depression measures among a sample of individuals with ID. We also investigate whether the depressed group differs on their symptom subtypes (i.e. cognitive, affective, and somatic) from the non-depressed group and whether all symptom types are recognized by the participants’ caregivers.

Methods: 97 adults with ID (IQ 40 -78 and concomitant impairments in adaptive behavior) were recruited from eight disability service providers in the Rocky Mountain region of the United States. Of the 97 adults, 79 completed the Self-Report Depression Questionnaire (SRDQ; Reynolds & Baker, 1988), the Glasgow Depression Scale – ID (Cuthill, Espie, & Cooper, 2003). The informant version of the GDS-ID was also collected from the participants’ caretakers. The items on the SRDQ, GDS-ID and the Informant GDS-ID were categorized into subscales of affective, cognitive or somatic symptomatology. Of the 79 participants, 40 were male and 39 were female. The age range of participants was 20 to 87 (M = 39.8, SD = 14.31) and mean IQ was 62.71 (SD = 9.18). 26 of these participants had the diagnosis of depression that was determined by their provider and verified using the DC-ID criteria.

Results: The calculation of Cronbach’s α for the SRDQ revealed a highly satisfactory internal consistency (Cronbach’s α = .89). It was significantly correlated with the GDS-ID (r = .66, p < .001). The internal consistency of GDS-ID was also satisfactory (Cronbach’s α = .84) and correlated with the caretaker supplement of the scale (r = .45, p < .001). The informant GDS-ID was also reliable instrument (Cronbach’s α = .85). All three scales significantly differentiated the depression diagnosis and non-depression groups. When the scales were divided into subscales according to symptom type, the SRDQ was strongly correlated with the GDS-ID on the affective (r = .74, p < .001), cognitive (r = .75, p < .001), and somatic (r = .59, p < .001) symptom types. The symptom types on the SRDQ or the GDS-ID were not significantly correlated to the symptom types on the informant GDS-ID. All of these subscales were also successful in differentiating between the depressed and non-depressed groups. Converting the scores into standard scores revealed some differences among the participant and their informant’s ratings of depressive symptoms. For example, the somatic symptom type correlated negatively on the GDS-ID when compared to the informant GDS-ID, but only for those in the depressed group (r = - .50, p = .01).

Discussion: The SRDQ, GDS-ID and the informant GDS-ID all appear to be good instruments in detecting depression among individuals with mild ID. Depression is most often assessed through self-report measures. The extent to which adults with ID are able to report on their internal experiences (affect and cognitive) remains unclear, and thus informant measures are often used to assess depressive symptoms in this group. Although both self-report and informant versions are able to differentiate the depressed versus non-depressed groups, the items used to arrive at this diagnosis may depend on whether the symptoms are self-reported or rated by the individual’s caretaker.
9. Partner Stress as a Contributor to Family Cohesion in Parents of Adolescents with Disabilities

Darcy Mitchell, Penny Hauser-Cram
Colby-Sawyer College, New London, NH 03257
(Darcy.B.Mitchell@colby-sawyer.edu)

Introduction: Cohesive family relationships have been found to relate to a number of important factors in the families of children with developmental disabilities (DD), such as fewer child behavior problems (Minuchin, 2002) and less maternal stress (Warfield et al., 1999). Additionally, parenting stress in these families tends to be greater than in families of children without DD (Deater-Deckard, 2005). These relations, however, have rarely been studied in families of adolescents with disabilities and even less with fathers in these families. As fathers have been shown to respond differently from mothers to support by others (Kersh et al., 2006), this investigation independently examined the contributions of maternal stress on fathers’ reports of family cohesion and of paternal stress on the cohesiveness reported by mothers.

Methods: Participants included 83 parents and their children (age 15) who participated in the Early Intervention Collaborative Study (Hauser-Cram et al., 2001), a longitudinal study of children with disabilities and their families. Children in the study were originally diagnosed with Down syndrome (n=28), motor impairment (n=32), or developmental delay (n=23). Parents individually completed the FACES II scale (Olsen, Portner, & Bell, 1982) and the Parent Domain subscale of the Parent Stress Index (PSI) (Abidin, 1995). Mothers completed the Child Behavior Checklist (CBC) (Achenbach & Edelbrock, 1983).

Results: Preliminary analyses revealed there were no differences between diagnostic groups or gender on the outcome variable, family cohesion. Parents experienced similar levels of stress, but mothers reported higher levels of cohesion in their families than did fathers (t(82)=2.73, p=.008). Two separate hierarchical linear analyses were conducted using mother and father data. Child functioning and behavior and family socioeconomic status were included as control variables. The level of parent stress (PSI) reported by the partner parent was added last to determine if it added significant unique variance in predicting feelings of family cohesion. Moreover, parenting stress is a psychological construct that is amenable to intervention. For mothers, teen behavior was a significant predictor of feelings of cohesion in the family (β=-.36, p=.002), but father’s stress was not. Fathers reported greater cohesion when both behavior problems were fewer (β=-.23, p=.041) and when mothers reported experiencing less stress (β=-.33, p=.017).

Discussion: These findings suggest that service providers should consider the needs of families well beyond the early childhood years as important to the continuing effectiveness of family processes. Reducing teen behavior problems is likely to have wide ranging effect in the lives of families, and reducing stress in parents is important to children’s development. Interestingly, the stress experienced by mothers in caring for adolescent children may carry over into overall family functioning and deserves particular programmatic emphasis.

References:


**POSTER SESSION 2**

**10. Development and Predictors of Effortful Control in Young Males with Fragile X Syndrome**

Marissa Mounts¹, Deborah Hatton², Jane Roberts¹  
¹University of South Carolina, ²Vanderbilt University  
(mounts@email.sc.edu)

**Introduction:** Effortful control or the ability to inhibit, suppress, and regulate emotional responses develops during the first years of life in typically developing children and is related to positive social-emotional outcomes (Derryberry & Rothbart, 2007). High levels of effortful control indicate the ability to inhibit and regulate behaviors. Several temperament dimensions compose effortful control including inhibitory control, low-intensity pleasure, smiling/laughter, activity level, and attention focusing. Deficits in effortful control are related to internalizing and externalizing problems. Fragile X syndrome (FXS) has been characterized as a deficit in inhibitory control or the ability to modulate arousal and control attention. Research supports lower levels of self-regulation and inhibitory control for children with FXS compared to typically developing controls (Cornish, Sudhalter, & Turk, 2004). The primary behavioral deficits displayed by children with FXS are inattention, hyperactivity, and impulsivity leading to increased attention deficit hyperactivity diagnoses in children with FXS. Between 25% and 60% of individuals with FXS also meet criteria for autism spectrum disorders (Hatton et al., 2006). Studies have shown that children with autism have impairments in effortful control leading to self-regulation difficulties and problem behavior (Christ et al., 2007; Adamek et al., 2011). While impairments in effortful control in children with FXS have been investigated, the developmental trajectory—change and continuity—of effortful control in children with FXS is not fully understood. Therefore, the current study examines the differences in effortful control between children with FXS and typical controls across age. To explain individual differences in effortful control, potential predictors will be examined including mental age, autistic symptom severity, and ADHD ratings.

**Methods:** Participants will include 92 males with fragile X syndrome and 23 typically developing controls between the ages of 34 and 118 months from a series of longitudinal studies evaluating early development in children with FXS. Parent report measures were used to assess effortful control using the Child Behavior Questionnaire and ADHD symptoms using the DSM-ADHD scale of the Child Behavior Checklist. Mental age was measured using the parent interview of the Vineland Adaptive Behaviors Scale and autism symptom severity through the Childhood Autism Rating Scale. Longitudinal analyses will be conducted on a subset of our sample observed between 2 and 3 times which includes 57 males with FXS (135 total observations) and 7 typically developing controls (14 total observations).

**Preliminary Results:** ANOVA analyses on the cross-sectional data were conducted to examine group differences. Compared to typical controls, children with FXS were found to have significantly lower ratings of effortful control ($F=28.30, p<.05, \eta^2=.34$), higher levels of autistic symptoms ($F=56.93, p<.001, \eta^2=.50$), and increased ADHD symptoms ($F=10.63, p<.001, \eta^2=.22$) when controlling for chronological age. Autistic symptoms ($r=-.45$), mental age ($r=-.41$), chronological age ($r=-.40$), and ADHD symptoms ($r=-.64$) significantly correlated with measures of effortful control ($p's <.001$). Final analyses will be conducted using multi-level modeling of longitudinal data to better explain the developmental trajectory of effortful control across ages.

**Discussion:** Our results are consistent with previous studies that males with FXS display lower levels of effortful control than typical controls. Preliminary results suggest that chronological age, mental age, and ADHD symptoms relate to differences in effortful control between children with FXS and typical controls. Through a better understanding of the developmental trajectories of effortful control, these findings may inform intervention to promote self-regulation and social competence in children with neurodevelopment disabilities.

Funded by National Institute of Child Health and Human Development (P30-HD003110-35S1) and the Office of Special Education Programs, U.S. Department of Education (H324C990042).
11. Adherence and Psychological Evaluation Recommendations for Young Children with ASD
Evon Batey Lee, Cassandra Newsom, Alison Vehorn, Julie Lounds Taylor, Elizabeth Dohrmann, Zachary Warren
Vanderbilt University
Vanderbilt Kennedy Center, PMB 40, 230 Appleton Place, Nashville, TN 37203
(Cassandra.r.newsom@vanderbilt.edu)

Background: American Academy of Pediatrics [AAP] guidelines endorse universal screening for Autism Spectrum Disorders (ASD) at 18- and 24-months of age, and at any point the caregiver expresses concerns (Johnson & Myers, 2007). These screenings are intended to enable parents and clinicians to act on developmental concerns as soon as they arise (Warren & Stone, 2011). Recently Al-Qabandi, Gorrier & Rosenbaum (2011) reviewed the early ASD detection literature and concluded that there was not a sufficient evidence base to support routine population-based screening programs for young children with ASD, such as the one proposed by AAP. They noted the dearth of published studies addressing families’ adherence with recommended interventions as well as cost and time barriers to accessing effective therapies within communities.

Objective: The current study represents a brief empirical evaluation of the ability of a clinical sample to implement recommendations following an ASD diagnosis. We examined not only the specific types of interventions implemented but also the association of implementation with parenting distress.

Methods: Seventy-five mothers of young children diagnosed with ASD through a university-based preschool autism clinic completed surveys, representing a response rate of 41%. Caregivers were presented with a list of common clinic interventions and asked to indicate the specific recommendations they had implemented. Blinded research assistants extracted recommendations from the original evaluation reports. An overall non-weighted percentage of recommendations implemented variable was calculated. Mothers were asked to complete the Center for Epidemiological Studies – Depression Scale (Radloff, 1977) the Beck Anxiety Inventory (Beck et al., 1988), and the Parenting Stress Index–Short Form (PSI: Abidin, 1995) as an index of psychological and parenting distress. Non-parametric correlations were conducted to determine bivariate relations between percentage of services implemented and measures of parental anxiety, depression, and parenting stress.

Results: The majority of mother’s (72%) were able to successfully implement most interventions (i.e., >75% of offered recommendations). Mothers reported considerable success in terms of implementing educational and/or early intervention services (Individualized Education Program, 85.7%; Individualized Family Service Plan, 95.5% and conducting specific readings, 94.5%). Mothers’ reported more moderate success regarding implementation of autism clinic follow-up visits (74%), speech/language intervention (74.2%), and occupational therapy (67.7%), and medication consultation (66.7%). A minority of families reported the ability to implement ABA based intensive intervention (42.1%), sleep evaluations (30.8%), and genetic testing (29.6%). Challenges implementing recommendations within this sample were not significantly associated with differences in terms of maternal depression, anxiety, or parenting stress.

Conclusions: Results suggest that despite numerous and significant barriers toward accessing some recommended services following diagnosis of ASD, many families will be successful in implementing many core services. While some categories of service appear very challenging to access and implement (e.g., intensive levels of ABA-based intervention), failure to implement services may not always be powerfully related to caregiver distress.
12. An Overview of the BAPQ in a Large Sample of Simplex Families

Caroline Oates, Carolyn Shivers, Elisabeth Dykens
Vanderbilt Kennedy Center, Vanderbilt University
Vanderbilt Kennedy Center, PMB 40, 230 Appleton Place, Nashville, TN 37203
(caroline.oates@vanderbilt.edu)

Background: The Broader Autism Phenotype (BAP) is a topic of growing popularity in autism research. Measures designed to identify ASD, and more recently measures specific to the BAP, have been used to examine BAP characteristics in parents of children with autism. The Broader Autism Phenotype Questionnaire (BAPQ; Hurley et al., 2007) has strengths for identifying the BAP in parents in that it is tailored to adults, has high validity, and is a short questionnaire which does not require a clinician or reliable coders. As a relatively new scale, there are few studies, however, which have examined the BAPQ, most with relatively small samples. The goal of this study is to give an overview of the BAPQ in a large sample of simplex families, as it relates to demographic and child characteristics.

Methods: We used data from the SFARI Simplex Collection database to explore BAP characteristics of 5459 parents (2758 families) of a single child with autism. The sample included “true” simplex (multiple children; only 1 with autism) and “trio” families (no other children, half-siblings, or siblings <4 yrs). Parent BAP characteristics were assessed using the Broader Autism Phenotype Questionnaire, which consists of three subscales (aloof personality, pragmatic language deficits, and rigid personality) designed to parallel the three core deficits in ASD (social, communication, and stereotyped-repetitive behaviors). We assessed BAPQ scores in relation to parent and child demographics, and child characteristics related to autism. Child and parent demographic information was collected via parent-report questionnaire. Child characteristics related to autism were assessed with commonly used measures in autism research including the Autism Diagnostic Observation Schedule and Child Behavior Checklist.

Results: Paternal BAPQ average scores were significantly higher than maternal total score and each subscale (Total: t(5457)=-18.19, p<.01; Pragmatic Language: t(5457)=-14.77, p<.01; Aloof t(5457)=-19.51, p<.01; Rigid: t(5457)=-9.33, p<.01). There were significant but minute correlations between parent BAPQ scores and child characteristics (eg. paternal pragmatic language and proband ADOS communication scores: r(2416)=.055, p<.01). Mothers of “trio” families had significantly higher BAPQ average scores than mothers from true simplex families (t(2416)=2.67, p<.01); fathers did not.

Conclusions: Results contrast previous inter-sex comparisons of the BAPQ in parents of autism (Seidman et al. 2011) and typical adults (Ingersoll et al. 2011). Findings suggest fathers in simplex families show more BAP characteristics than mothers, but BAPQ scores in this simplex sample were not higher than previously found scores in typical adults (Ingersoll et al., 2011). Correlations indicate autism-like personality traits of parents may not be good predictors of autism characteristics of children in simplex families.
13. Receipt of Mammography Among Women with Intellectual Disabilities: Medical Record

Susan Parish¹, Jamie Swaine², Esther Son¹, Karen Luken³
¹Lurie Institute for Disability Policy, Brandeis University, ²University of North Carolina-Chapel Hill, ³Frank Porter Graham Child Development Institute, University of North Carolina-Chapel Hill
Lurie Institute for Disability Policy, Heller School for Social Policy and Management, Brandeis University, 415 South Street - MS 035, Waltham, MA 02454
(slp@brandeis.edu)

Objective: We compared rates of mammography receipt among African American and White women with intellectual disabilities living in community settings (n=90) in one Southeastern state in the United States.

Method: Data were collected from women's medical records or abstraction forms obtained from medical practices. Multivariate logistic regressions were modeled for receipt of mammography in one year, one of two years, or both study years (2008-2009). Covariates included the women's age, living arrangement, severity of impairment and urban/rural residence location.

Results: In 2009, 28% of African American women and 59% of White women in the sample received mammograms. Similar disparities were found for receipt of mammography in either 2008 or 2009 and both 2008 and 2009. These disparities persisted after inclusion of model covariates. Adjusted for model covariates, White women with intellectual disabilities received mammograms at rates that were nearly six times higher than African American women.

Conclusion: African American women with intellectual disabilities receive mammography at significantly lower rates than White women with intellectual disabilities. Assertive measures to improve the screening rates for African American women with intellectual disabilities are urgently needed.

B. Allyson Phillips, Frances Conners, Edward Merrill
University of Alabama
Department of Psychology, University of Alabama, Box 870348, Tuscaloosa, AL 35487
(bashelton1@crimson.ua.edu)

Introduction: Explicit learning is active, conscious, controlled, and intentional; it is a deliberate attempt to acquire new knowledge or skill from repeated tries with feedback. Explicit learning improves with age throughout childhood and is closely related to intelligence. Because of its relation to intelligence, we expect individuals with ID to perform below the level expected for their chronological age. However, several studies have shown that individuals with Down syndrome (DS) perform below the level expected for their mental age as well (e.g., Lanfranchi et al., 2010). The current study focuses on the estimated rate of growth in explicit learning in youth with DS relative to TD and ID controls. Although quite a bit is known about the cognitive profile of DS, very little work has been conducted to examine the growth patterns related to cognitive abilities. This will be the first study to examine explicit learning in DS using the cross-sectional developmental trajectory approach (Thomas et al., 2009).

Methods: The sample was comprised of 90 participants. Of the 40 participants with DS, the age range was 10.25 – 21.92 years ($M = 15.37$, $SD = 3.21$), and the nonverbal mental age range was 4.00 – 8.42 years ($M = 5.41$, $SD = 1.08$). Of the 23 participants with ID, the age range was 10.25 – 20.67 years ($M = 15.68$, $SD = 2.57$), and the nonverbal mental age range was 4.42 – 7.63 years ($M = 6.32$, $SD = 1.04$). Of the 27 TD individuals, the age range was 4.25 – 18.42 years ($M = 8.65$, $SD = 4.32$), and the nonverbal mental age range was 4.50 – 9.75 years ($M = 6.88$, $SD = 1.83$). As part of a larger study, all participants completed a measure of nonverbal ability, the Leiter International Performance Test- Revised brief form (Leiter-R), and two measures of explicit learning, the Concept Formation subtest of the Woodcock-Johnson III (WJ-III) and the Category Task. The growth score value (GSV) was used from the Leiter-R for computing cross-sectional developmental trajectories.

Results and Discussion: Two developmental trajectories for explicit learning against GSV were created and compared using ANCOVA, one for the WJ-III and one for the Category Task. For the WJ-III, the ANCOVA revealed a significant interaction between Group and GSV, $F(2, 84) = 5.13, p = .008$, indicating a difference in growth between groups (see Figure). For the Category Task, the ANCOVA did not reveal a significant interaction, indicating no difference in growth between groups. Neither ANCOVA found a significant main effect of Group, suggesting that the level of explicit learning between the groups did not begin at different starting points. These results suggest that for some explicit learning tasks youth with DS may show slower development than would be expected based on their nonverbal ability, whereas for other explicit learning tasks, they may show the expected rate of growth. Analysis of the task differences will provide further insight.

References:


Funded by E. K. Shriver NICHD Grant HD055345
15. The Influence of Cortisol and Child Factors on Maternal Responsivity in Mothers of Boys with Fragile X Syndrome

Ashley Robinson¹, Jane Roberts¹, Nancy Brady², Marjorie Grefer¹, Steven Warren²
University of South Carolina¹, University of Kansas²
1512 Pendleton Street, Columbia, SC 29208
(Robin384@email.sc.edu)

Introduction: Maternal responsivity, comprised of warm, nurturing, and stable parenting behaviors, has been found to be associated with increased cognitive, social, emotional, and language development in typically developing children and children with disabilities. A previous study by the authors examined the relationship between maternal responsivity (MR) and physiological arousal in mothers of young boys with fragile X syndrome (FXS). Results of this study suggested an interaction between child age and maternal baseline cortisol that predicted MR scores. Further examination of this interaction revealed a shift in the relationship between cortisol and responsivity over time such that cortisol was positively correlated with MR when children were younger and became negatively correlated as children aged.

Although this study discovered a critical relationship between parenting behaviors and HPA functioning in mothers of boys with FXS, it failed to address additional variables including child behavior and developmental level that may also predict responsivity levels. The current study expands upon the previous research in an attempt to further explain the shift in the relationship between MR and physiological arousal in mothers of boys with FXS across child's age.

Methods: The present analyses included data for 37 mother-child dyads from an ongoing longitudinal study on families of children with FXS. Participating families had at least one boy with FXS and were assessed over three different time points at 18-month intervals. Mean ages of children assessed at each time point include 31.08 months at Time 1, 46.72 months at Time 2, and 62.15 months at Time 3. Thirty-six mothers had the FMR1 premutation and one mother had the full mutation. Maternal responsivity data were collected from video files of ten-minute naturalistic observations in the home. Physiological data included baseline salivary cortisol that was collected at each assessment. Child behavioral data were derived from the Child Behavior Checklist (CBCL), which assesses mothers' perceptions of children's emotional and behavior features. Additionally, child developmental level was determined by scores on the Mullen Scales of Early Learning and included an overall early learning composite score and an overall age equivalent.

Results: Based on results of the previous study, the data were divided into four age quartiles to better understand the interaction between child age and baseline cortisol levels that predicted MR. Hierarchical multiple regression models were conducted at each age quartile where baseline cortisol was entered into the model first, followed by either behavioral or developmental data predicting MR. At the first age quartile (11-35 months), boys' scores on the Mullen early learning composite and their overall Mullen age equivalent scores significantly predicted MR scores over and above baseline cortisol. At the second age quartile (36-48 months), baseline cortisol did not significantly predict MR; however, scores on the early learning composite approached significance. Both overall child problem behavior and internalizing behavior predicted MR at the third age quartile (49-58 months) and only baseline cortisol, not child behavior or developmental level was related to MR at the fourth age quartile (59-76 months).

Discussion: The findings of this study suggest that the shift in the relationship between MR and baseline cortisol can be explained, in part, by changes in children's behavioral and developmental characteristics over time. More specifically, higher child developmental level is predictive of increased MR scores in younger boys with FXS. As these children age, however, there is a shift to lower rates of problem behavior being stronger predictors of increased responsivity up until 59 months of age.

Supported by NICHD 02538 and NICHD 03110
**POSTER SESSION 2**

**16. Relationship between Engagement of Preschool Children with ASD and Adult Participation**
Ann Sam, Sam Odom, Brian Boyd
University of North Carolina-Chapel Hill
(annwil@email.unc.edu)

**Introduction:** A child's ability to maintain engagement in the classroom is linked to better academic outcomes (Ponitz et al., 2009). While characteristics of children potentially affect a child's ability to engage in classroom activities (Mc-William & Bailey, 1995), support and guidance from adults can facilitate children's classroom engagement (Chien et al., 2010). There is limited information concerning the interactions between adult participation and the engagement of preschool children with ASD. With recommendations from the National Research Council (NRC, 2001) for young children with ASD to receive intensive services for 25-hours per week, information is needed concerning how engaged preschool children with ASD are in classroom activities and how adults in these classrooms support their engagement. The purpose of this study is to address this research gap by examining (1) the pattern(s) of adult participation in classrooms that serve children with ASD, (2) the associations between child engagement and adult participation and (3) how this relationship is moderated by characteristics of ASD (i.e. autism severity, language ability, and problematic behaviors).

**Methods:** Participants included 190 preschool children with ASD in 73 classrooms. Trained research staff collected a 30-minute, videotaped observational sample during center time. Research assistants were trained to use CASPER-III (Tsao, et al., 2001), an ecobehavioral assessment, and to code videos using momentary time sampling. Three CASPER variables (group arrangement, child behavior, and adult support) were used to create the two variables of interest: child engagement and adult participation. Child engagement was coded as either active engagement or no active engagement. Adult participation was defined as active participation (adult actively involved with focal child), passive participation (adult present but not interacting directly with child), and no adult participation (adult not interacting with child or present). The CARS, CBCL, and PLS measures were used to examine variables that may moderate the relationship between adult participation and child engagement.

**Results:** Data analysis is ongoing. However, preliminary results indicate that adults spend the largest amount of time passively participating with children (36%) followed by active participation (34%) and no adult participation (29%). Children were actively engaged for 72% of the time and not engaged for 28% of the time. When adults were actively participating, the focal child was actively engaged for 70% of the time and not engaged for 30%. When the adult was passively participating, the child was actively engaged 72% of the time and not engaged 29% of the time. For no active adult participation, the child was engaged 75% of the time and not engaged for 25% of the time. Multilevel logistic regression models will be used to explore how these relationships are moderated by the child characteristics described above.

**Discussion:** This study provides needed information examining the relationship between adult participation and child engagement in preschool classrooms that serve young children with ASD. Better understanding of the variables influencing adult participation can lead to intervention development and teacher training with the focus on adult behaviors.

**References:**


Emily Schaidle, Sigan Hartley
University of Wisconsin-Madison
Waisman Center, University of Wisconsin, 1500 Highland Avenue, Madison, WI 53705
(schaidle@wisc.edu)

Introduction: Parents of children with autism spectrum disorders (ASDs) report higher levels of stress as compared to parents of typically developing children as well as parents of children with other types of developmental disabilities. Child behavior problems have been shown to be a major source of stress for parents of children with ASDs. In line with Lazarus and Folkman's (1984) Model of Stress and Coping, the level of stress experienced by parents should, in part, depend on their attributions for their child's behavior problems, as well as the types of coping strategies used. Although substantial research has been conducted on mothers of children with ASDs, little is known about fathers' attributions for child behavior problems or how they cope with child-related stress. In this study, we examined fathers' attributions about the cause of their child's behavior problems as well as the extent to which their coping efforts moderate the negative impact of child behavior problems on their psychological well-being.

Method: Forty fathers of children with an ASD ($M = 12.5, SD = 4.28$) living in Wisconsin participated in this study. Fathers completed self reported measures of attributions for their child's positive and negative behaviors (Parental Attribution Questionnaire; Whittingham et al., 2008), coping strategies (Brief COPE; Carver, 1997) parenting stress (Parenting Burden Interview; Zarit et al., 1980), and symptoms of depression (CES-D; Radloff, 1977) and anxiety (BAI; Beck, 1993).

Results: Multiple linear regression analyses were conducted and indicated that fathers' attributions for their child's behavior problems varied by child age, severity of behavior problems, and functioning level. Fathers who attributed child behavior problems as internal, controllable, and more likely to go away in the future reported less parenting stress than fathers who held external, uncontrollable, and unstable attributions. Coping moderated the relationship between child behavior problems and psychological well-being; fathers who used higher rates of problem-focused coping strategies experienced more positive psychological well-being in the face of child behavior problems.

Discussion: The results of the current study reveal that attributions for child behavior problems predict level of parenting stress in fathers. This study served to identify coping strategies that may help fathers adapt to stressors of raising a child with ASD.

References:


Richard Serna¹, Mark Preston², Teresa Mitchell²
¹University of Massachusetts–Lowell, ²Eunice Kennedy Shriver Center, University of Massachusetts Medical School Department of Psychology, University of Massachusetts, Mahoney Hall, 870 Broadway Street, Lowell, MA 01854 (Richard_Serna@uml.edu)

Introduction: Many children with developmental disabilities, particularly those with Autism Spectrum Disorders (ASDs), show limited and impaired auditory learning skills. These problems impose limitations on a wide range of learning opportunities. Converging evidence from language and speech-perception research suggests that individuals with ASDs may be particularly prone to deficits in verbal performance (compared to visual) and speech perception (compared to non-speech sound), respectively. One reason may be that spoken words contain many auditory features that distinguish them, including pitch, duration, rise and fall, rhythm, etc. Children with ASDs may show selective attention to only a single auditory feature of a word, the results of which could interfere with spoken-word learning. Though some research exists in this area, most of it has been conducted with “high functioning,” verbal children with ASDs. Almost no research in this area exists with children with ASDs who have more pronounced intellectual disabilities. The purpose of this poster is to present initial data on pitch discrimination from an ongoing research project aimed at better understanding the auditory discrimination capabilities of children with both ASDs and intellectual disabilities.

Method: Thus far, 38 participants have served, representing five groups: High-Functioning ASD (n=7) and Matched Typically Developing (n=14), ASD + Intellectual Disability (n=8) and Intellectual Disability Only (n= 2) and Matched Typically Developing (n=7). Each participant completed a non-verbal assessment protocol (Serna et. al., in press) to determine the just-noticeable-difference threshold between a 3,000Hz pure tone and a tone of lesser frequency.

Results: Initial data show similar results between the High-Functioning ASD (mean threshold = 18Hz) and Matched Typically Developing (mean threshold = 18.77Hz) groups. However, mean difference thresholds differ greatly between the High-Functioning ASD (18Hz) and the ASD + Intellectual Disability (38.89Hz) groups. Threshold differences were also found between the ASD + Intellectual Disability (38.89Hz) and Intellectual Disability Only (66Hz) and Matched Typically Developing (51.26Hz) groups.

Discussion: Preliminary results suggest a key finding could emerge: Children with ASDs who have intellectual disabilities tend to be better able to discriminate pitch than their counterparts who have intellectual disabilities, but no ASDs, as well as their typically developing counterparts. Additional data collection is ongoing and is needed before statistical conclusions can be drawn, but the findings have the potential to contribute to the paucity of auditory research with children who have ASDs and more pronounced intellectual disabilities.

Reference:


Grant support: NICHD P01 HD25995.
Background: The extant research on siblings of individuals with autism spectrum disorder (ASD) has yielded mixed results regarding whether siblings are at risk for negative outcomes, including anxiety. As anxiety disorders are related to numerous concurrent and future problems, it is important to identify which individuals may be at risk for elevated anxiety symptoms. Typically, females show higher levels of anxiety symptoms than males, while parental history of anxiety and proband behavior problems have been shown to be related to negative sibling outcomes, including increased anxiety. The purpose of this study was to examine patterns of anxiety among 5-18 year old siblings of individuals with ASD, as well as to determine the parental characteristics and proband behaviors that predict anxiety.

Methods: We used data from the Simons Simplex Collection to examine anxiety among 1755 siblings of children with ASD. Siblings ranged in age from 3 to 18 years (M = 9 years). Data was collected via psychological assessment and parental report. Anxiety among siblings was measured using the Anxiety Problems subscale of the Child Behavior Checklist (CBCL). Patterns of sibling anxiety were compared by sibling age category (2-5, 6-11, and 12-18) and sibling gender. Anxiety was also predicted from indicators of parental and proband functioning, including: parental history of anxiety disorder, parental scores from the Broader Autism Phenotype Questionnaire (BAPQ), proband internalizing and externalizing behaviors as measured by the CBCL, and proband autism severity. Household income, sibling birth order (0=sibling is younger than proband, 1=sibling is older than proband), and proband IQ were statistically controlled.

Results: Male siblings, as well as siblings between the ages of 6 and 11, were at increased risk for borderline and clinical-level anxiety problems, with 9.5% of males and 10.6% of siblings ages 6-11 falling above the borderline cutoff (X² = 4.83 and 22.09, respectively, ps < .05.). Paternal history of anxiety disorders (B=.36, p<.01), maternal history of anxiety disorders (B=.49, p<.001), maternal pragmatic language (B=.37, p<.001), and proband behavior problems (B>.01, p<.001) predicted sibling anxiety. Similar patterns of prediction were found for male and female siblings separately, though paternal history of anxiety disorders did not predict anxiety for female siblings. Paternal broader autism phenotype characteristics and proband autism severity did not predict sibling anxiety.

Conclusions: While siblings as a whole did not show elevated clinical anxiety symptoms, higher rates of sub-clinical anxiety problems among males and siblings aged 6-11 years are cause for concern. In terms of predictors of anxiety, our findings support previous research showing that parental history of anxiety and proband behavior problems are related to negative outcomes for siblings. The relationship between maternal pragmatic language and sibling anxiety was less expected, and may be representative of problems in parent-child communication, which has been previously linked to childhood anxiety. Future research should examine the factors that may place male siblings at greater risk for anxiety problems, as well as the role of maternal pragmatic language in the development of sibling anxiety.
**Introduction:** Sibling relationships in families of children with disabilities are generally positive despite difficulties that may result from the child’s disability. Many developmental disabilities have associated communication impairments that could affect how siblings interact with each other and the closeness between them. Research has rarely addressed the role of communication skills and how potential deficits in communication may impact the sibling relationship. The purpose of this study is to examine the characteristics of sibling communication interaction patterns when one sibling has a developmental disability and the unique role that communication skills play in the quality of the sibling relationship.

**Method:** Thirty mixed and same-sex sibling dyads and their parents participated in this study. The dyads included one typically developing sibling and their brother or sister with an identified developmental disability including Down syndrome, Williams syndrome, Angelman syndrome, and Autism. Families were visited in their homes during which time siblings engaged in a ten-minute videotaped interaction, the child with a disability participated in a brief language assessment, and both parents and the typically developing sibling completed several questionnaires. Using parent report, children with disabilities were placed into three communication status groups according to their communication skills: emerging communicators (children needed help from a parent or familiar partner to be understood by others and communicated primarily through gestures, simple words, and phrases), context-dependent communicators (children sometimes needed help from a parent or familiar partner to be understood by others and primarily communicated by phrases and sentences) and independent communicators (children did not need help from a parent or familiar partner to be understood by others and used sentences as their primary mode of communication).

**Results:** Results indicated that when children with disabilities were independent communicators, they exhibited interactions with their siblings that were similar in terms of lexical complexity while those who were context-dependent and emerging communicators exhibited significantly less sophisticated morphological and syntactic skills than their typical siblings. However, regardless of communication status, typically developing siblings dominated the interaction by using more consecutive utterances than their sibling with a disability. For sibling relationship quality, typically developing siblings reported high levels of warmth and closeness regardless of communication status. Differences emerged however, in the symmetry within the sibling relationship as siblings of independent communicators reported the highest levels of asymmetry within the sibling relationship.

**Discussion:** As a whole, these results represent a first step in understanding the unique role of communication skills in the sibling relationship for families of children with disabilities. It established that when children are grouped together according to their communication abilities, findings regarding interaction are consistent with and extend what we know about sibling interactions by showing that when children with disabilities were independent communicators they were comparable in terms of lexical complexity, but not in terms of being equal communicative partners in the interaction. The findings regarding symmetry in the sibling relationship are different than what would be expected based on the literature and should be explored further. Finally, although typical siblings acknowledged that their relationship would be different if their sibling with a disability had different communication skills, it did not lessen the importance of that sibling in their life or how well they were able to communicate.

Brittany Travers¹,², Patrick Powell¹, Laura Klinger¹,³ Mark Klinger¹,³

¹University of Alabama, ²Waisman Center, University of Wisconsin-Madison, ³TEACCH, University of North Carolina-Chapel Hill

Waisman Center, University of Wisconsin-Madison, 1500 Highland Avenue, Madison, WI 53705 (btravers@wisc.edu)

Introduction: Postural stability and postural symmetry are fundamental aspects of motor ability that allow individuals to successfully navigate a spatial environment. Using force-plate technology, decreased postural stability has been previously reported in persons with Autism Spectrum Disorder (ASD) (Minshew et al., 2004; Molloy et al., 2000). However, force plates can be expensive and may often not be readily accessible to researchers or their participants. Past research has demonstrated excellent reliability and validity in using the Wii balance board for research purposes (Clark et al., 2010), but this method has not yet been used to study postural stability in persons with ASD. Therefore, the present study aimed to examine postural stability (i.e., balance time and degree of waiver) and postural symmetry (i.e., center of balance) during standing postures on a Wii balance board in individuals with ASD.

Method: Twenty-six individuals with ASD with average-IQ and 26 age-and-IQ-matched individuals with typical development stood on one leg or two legs with eyes opened or closed on the balance board (age range 16-30 years). Participants were timed for how long they could hold each posture. Additionally, postural stability and left-right center of balance were recorded by a Wii balance board connected via Bluetooth to a laptop computer. Balance board data were recorded every 16.7 milliseconds.

Results: The present results found significant group differences during one-legged standing in postural stability (balance time, $p = .01$, and postural drift, $p = .02$), but there were no significant group differences during two-legged standing. Degree of waiver during two-legged standing in the group with ASD was significantly related to current repetitive behaviors (RBS-R), $r = +.48$, social symptoms (SRS), $r = +.54$, and empathy (EQ), $r = -.49$ (i.e., decreased postural stability was associated with more severe symptoms and less empathy). Additionally, current repetitive behavior symptoms were significantly related to postural symmetry during two-legged standing, $r = +.46$ (i.e., decreased postural symmetry was associated with more severe symptoms).

Discussion: The present results suggest that the Wii balance board may be a useful and sensitive tool for examining postural stability in individuals with ASD. The current findings suggest that diagnostic group differences may emerge during more difficult standing postures in individuals with ASD. Moreover, postural stability was significantly related to ASD symptom severity measures, suggesting that postural stability may be intimately intertwined with ASD symptoms. Understanding how postural stability may contribute to the behavioral profile of persons with ASD (as well as the behavioral profile of persons with other developmental disabilities) may be an important avenue for future research and intervention development.

References:


**POSTER SESSION 2**

**22. Mining Public Health Datasets with ‘Coupler’**

Richard Urbano, Jeremy Stephens, Cole Beck  
Vanderbilt University  
Vanderbilt Kennedy Center, PMB 40, 230 Appleton Place, Nashville, TN 37203  
(richard.urbano@vanderbilt.edu)

**Introduction:** State Public Health agencies and the Centers for Disease Control and Prevention collect and maintain population based data on vital events—births, deaths, marriage, divorce—and hospitalizations. A wealth of ancillary information, in addition to a comprehensive description of the basics of the events, is recorded. In particular, developmental disabilities identified at birth or with specific ICD9/10 codes are recorded in the birth, death and hospital discharge dataset. Thus, it is possible to use these datasets individually (So, et al, 2007) or in combination (Urbano et al, 2007) to study developmental disabilities.

**Objective:** The purpose of this poster is to describe the application of the software package, Coupler (2011) to the creation of 2 between and 1 within dataset linkages.

**LINKAGES**

**Between Dataset 1:** Individuals with Down syndrome can be identified in the birth, death and hospital discharge datasets. Approximately half of the expected number of births with Down syndrome are identified in the birth record. Additional individuals with Down syndrome are identified in the death and hospital discharge records. Birth and hospital discharge and then birth and death were linked to identify 1,636 individuals with Down syndrome born between 1990 and 2009.

**Between Dataset 2:** Birth records identify children who died within the first year of life. All deaths are on in the death dataset. By linking birth and death records, individuals who died after 1 year of age can be identified. Of the 1,636 individuals with Down syndrome born between 1990 and 2009 119 died before 1 year and an additional died post one year.

**Within Dataset:** This multi-step linkage created wide records with birth information on all children within families where one of the children had Down syndrome. First, a dataset with the identifiers of mothers of children with Down syndrome was created. There was one record per mother. Next the mother dataset was linked back to birth collect the information on all children to the specific mother. In the 1990 to 2009 births, 4,485 families with at least one child with Down syndrome were identified.

**References:**


23. A Case Study of Co-occurring 15q13.3 Deletion and Williams Syndrome

Faye van der Fluit, Bonita Klein-Tasman
University of Wisconsin–Milwaukee
Department of Psychology, University of Wisconsin, P.O. Box 413, Milwaukee, WI 53211
(vanderf2@uwm.edu)

Introduction: Recent studies have reported various behavioral commonalities among individuals with a deletion at chromosome 15q13.3 (Sharp et al, 2008; Ben-Shachar et al, 2009; Pagnamenta et al, 2009). Mild to moderate intellectual disability is among the most frequently reported phenotypic expressions of the deletion, as are facial dysmorphologies. Behavioral symptoms overlapping with the autism spectrum have also been reported and are of particular interest considering previous studies linking other genetic disorders with similarities with the autism spectrum, such as Prader-Willi and Angelman syndromes, with deletions in this region (Kwasnicka-Crawford, Roberts, & Scherer, 2007; Hogart, Wu, LaSalle, & Schanen, 2010). We present a case study of a young child with confirmed 15q13.3 deletion, as well as Williams syndrome (WS), a genetic disorder involving the deletion of approximately 22 genes on chromosome 7q11.23, associated with some degree of impairment in intellectual functioning, typical medical and facial features (see Mervis & Klein-Tasman, 2000 for a review), and a behavioral phenotype characterized by overfriendliness and anxiety. Recent studies have also suggested that a proportion of individuals with WS demonstrate socio-communicative difficulties that overlap with the autism spectrum (Klein-Tasman, Phillips, Lord, Mervis, & Gallo, 2009).

Method: J was a 3 year 11 month male with WS and 15q13.3 deletion, with various behaviors that overlapped with the autism spectrum, leading his parents and interventionists to consider a possible additional diagnosis of an autism spectrum disorder (ASD). A second assessment was conducted one year later to monitor J's progress and the stability of the initial assessment results. At the first assessment, a comprehensive autism diagnostic assessment using “gold standard” measures, the Autism Diagnostic Interview-Revised (ADI-R; Rutter, LeCouteur, & Lord, 2003) and the Autism Diagnostic Observation Schedule (ADOS; Lord et al, 2000), was completed. The follow-up visit included developmental testing and parent and teacher questionnaires.

Results: Results of the first assessment revealed moderate delays in cognitive abilities across all areas measured using the Mullen Scales of Early Learning (Mullen, 1995), as well as delays in adaptive functioning (Vineland Scales of Adaptive Behavior; Sparrow, Cicchetti, & Balla, 2005). Parent report of social communicative behaviors (Social Communication Questionnaire; Rutter, Bailey, & Lord, 2003) indicated the need for additional screening for an ASD. J's parents reported significant symptoms in the communication and repetitive behaviors domains of the ADI-R, but not in the reciprocal social interaction domain. J's observed behaviors during the ADOS exceeded the communication and reciprocal social interaction cutoffs for an “autism spectrum” classification, at or slightly above the cutoffs. However, the behaviors observed were not above and beyond those commonly seen in WS, and an ASD was therefore not diagnosed. Recommendations included full-day educational services, including applied behavior analysis approaches and speech and occupational therapy. At follow-up one year later, results of developmental testing continued to reveal moderate delays; however, J made impressive gains in all areas. Adaptive behavior continued to be delayed, although some gains were reported. Based on parent and teacher report, as well as informal observation, socio-communicative behavior was significantly improved from the previous assessment.

Discussion: A comprehensive ASD assessment was conducted on J, a young boy with a 15q13.3 deletion and WS. While some sociocommunicative difficulties and considerable repetitive behavior were reported, a diagnosis of ASD was not made. A subsequent assessment further demonstrated the stability of the non-spectrum diagnosis and the benefits of educational supports that were put in place following initial evaluation. Implications for understanding co-existing genetic disorders in children and the diagnosis of ASD in genetic syndromes will also be discussed.
**Introduction:** Executive functions refer to a variety of higher order cognitive skills which all involve control, including selective attention, planning, self-regulation, divided attention, response inhibition, set shifting, and the manipulation of information in problem solving tasks. Executive functions develop slowly during childhood, not reaching adult status until late adolescence (Casey, Getz, & Galvan, 2008; Paus, 2005; Steinberg, 2005). Children with intellectual and cognitive deficits tend to show deficits in executive functions that persist into adulthood. It is important to note that the parents and teachers have many opportunities to shape and reinforce executive skills. However, few projects have investigated the development of executive functions in at-risk children raised by teen mothers with low intelligence living in poverty. This project assessed whether prenatal maternal intelligence and readiness to parent were related to their children’s executive functioning during late adolescence.

**Methods:** The current study relies on longitudinal data collected from the Notre Dame Adolescent Parenting Project (NDAPP; Whitman, Borkowski, Keogh, & Weed, 2001) to investigate the impact of maternal intelligence and cognitive readiness on executive functions. The study included 269 pregnant adolescents first seen during the last trimester of their pregnancy. Cognitive readiness for parenting was assessed prior to the child’s birth negating the possibility of child effects on parenting style and knowledge. Latent predictor and outcome variables were generated using M-Plus software. Maternal intelligence (M = 87, SD = 12.3) was estimated using the block design and vocabulary subtests of the WISC-R or the WAIS-R, depending on age. Two latent variables were constructed to reflect cognitive readiness for parenting. The first, Parenting Style, was generated from the Empathetic Awareness, Physical Punishment, Abuse, and Role Reversal subscales of the AAPI (Bavolek, 1984). The second, Parenting Knowledge, was based on items generated for the NDAPP (Whitman et al., 2001). When children were between the ages of 17 and 21, executive functions were assessed using the Trails and Tower subscales of the Delis-Kaplin Executive Function System (D-KEFS; Delis, Kaplan, & Kramer, 2001) and the Dual Task Counting task from the Tests of Everyday Attention (TEA; Sterr, 2004).

**Results:** Regression analyses using M-Plus were used to model relationships among the latent variables representing Parenting Style, Parenting Knowledge, Maternal IQ, and interactions between Style and IQ, and Knowledge and IQ on children’s Executive Function. Maximum Likelihood Estimation allowed for all 269 participants to be included in the analyses since the covariance matrix was used in all calculations. Executive functioning was significantly predicted by IQ (b = .74, p = .02) and by the interaction of IQ and Parenting Knowledge (b = -.96, p = .05), but not by Parenting Style. Follow up analyses using the Johnson-Neyman technique to identify the region of significance for interactions suggested that intelligence was more strongly related to Executive Function for mothers with lower Parenting Knowledge.

**Discussion:** Low maternal intelligence was a strong predictor of children’s executive function skills at a time when children were poised to make the transition from adolescence to adulthood—a time when executive functions are vital. However, the impact of low maternal IQ was less for pregnant adolescents who had reasonable knowledge of child development and more appropriate expectations for their infants’ achievement of developmental milestones.

**Reference:**

**Introduction:** Mothers of children with autism report more stress and depression than mothers of typically developing children and children with other developmental disabilities (Griffith et al., 2010). Previous studies have found that child behavior problems contribute to these high maternal depression rates (Ingersoll et al., 2011). Further investigation of the factors that contribute to maternal depression may provide more clearly defined targets for intervention than those in the extant literature. Our primary aim was to explore the relation between parent-rated child problem behaviors and current depression levels, independent of (and in addition to) parenting stress and dyadic adjustment. We hypothesized that dyadic adjustment and parenting stress would relate to maternal depression beyond the contributions of challenging behavior.

**Methods:** Participants included 75 mothers of children who received autism diagnoses an average of 1.4 years earlier as part of a research project at Vanderbilt University. Mothers provided self-report information at one time point on depression (Center for Epidemiological Studies – Depression scale; CES-D), dyadic adjustment (Dyadic Adjustment Scale; DAS), child behavior problems (Child Behavior Checklist; CBCL), and parenting stress (Parent Stress Inventory; PSI).

**Results:** We used multiple regression analyses to examine the relations of the PSI and DAS to maternal depression, above and beyond CBCL scores (externalizing, internalizing, and total). Several main effects and one interaction emerged. A main effect of externalizing behaviors disappeared after dyadic adjustment ($\beta = -.284, p = .001$) and parenting stress ($\beta = .54, p < .001$) were included in the model. Conversely, the main effect of internalizing behaviors remained significant ($\beta = .19, p < .05$) after including dyadic adjustment ($\beta = -.28, p = .001$) and parenting stress ($\beta = .537, p < .001$). When total problem behaviors were examined, a significant main effect emerged for parenting stress ($\beta = .53, p < .001$) in addition to an interaction between stress and dyadic adjustment ($\beta = -.30, p < .05$).

**Discussion:** Results suggest that the relation between child problem behaviors and maternal depression should be considered in conjunction with other measures of interpersonal and environmental stress. Parent ratings of child internalizing (but not externalizing) behavior seem uniquely related to current maternal depression beyond dyadic adjustment and parenting stress. When considering overall child problem behaviors, an interaction between parenting stress and dyadic adjustment emerged. Mothers with poor dyadic adjustment and high parenting stress reported more depression than those with poor dyadic adjustment and low parenting stress. These findings indicate that in addition to endorsing multiple internalizing and externalizing problem behaviors in their children, depressed mothers report stress related to their parenting capabilities and marital relationships. Dyadic adjustment and perceived parenting efficacy may therefore provide important intervention targets for families of young children with ASD.

**References:**


This initiative was funded by a grant from the Vanderbilt Kennedy Center / Marino Autism Research Institute. This includes core support from NCRR/NIH (UL1 RR024975-01) and NICHD (P30HD15052).
**POSTER SESSION 2**

**26. Parenting Stress and Efficacy in Mothers of Children with Prader-Willi Syndrome**

Anne Wheeler, Stephen Hooper
Carolina Institute for Developmental Disabilities, University of North Carolina School of Medicine
CIDD, CB# 7255, UNC School of Medicine, Chapel Hill, NC. 27599
(Anne.wheeler@cidd.unc.edu)

**Introduction:** Parents of children with PWS often report high levels of stress in the parenting role (Hodapp, et al, 1997; Wulffaety et al., 2010). Challenging behaviors are frequently described in the literature as being strongly related to parenting stress more so than the child's cognitive, academic, social, or medical needs. However, a parent's perception of how competent they are in the parenting role may also strongly impact the amount of stress they experience (Wells-Parker et al., 1990). Given the complex behavioral, health, and daily living demands that often come with raising a child with PWS, parenting efficacy is likely to be challenged. This study explored differences in parenting stress and efficacy among PWS subtype, as well as the relationship between parenting stress, parental efficacy, child problem behaviors, and the family environment.

**Methods:** Seventy-nine mothers of children with PWS between the ages of 3 and 17 participated in this study. Parents completed the Parenting Stress Index, the Self-Efficacy for Parenting Tasks Index, the Global Assessment of Individual Behavior—PWS, and the Family Environment Scale. Scores were compared to normative standards to determine the level of parenting stress and efficacy, and across genetic subtypes using t-tests or ANOVAs with the presence of a covariate. Pearson correlations and linear regressions were run in order to describe the relations between the parenting stress, efficacy, family environment, and child problem behavior variables.

**Results:** High levels of parenting stress and relatively low levels of parenting efficacy were reported. Efficacy in the provision of discipline was the highest, while health-related parenting efficacy was rated lowest overall. Mothers of boys reported less health-related parenting efficacy than did parents of girls, t = 2.07, p < 0.43. No significant differences were between mothers of children with UPD vs. the deletion subtypes. Linear regression models suggested that high child problem behaviors and low parenting efficacy predicted high parenting stress when controlling for child age, genetic subtype, cognitive abilities, and family support.

**Discussion:** Parents of children with PWS experience high levels of stress in the parenting role. Stress levels are most strongly related to high problem behaviors and lower self-efficacy rather than the child's age, genetic subtype, or cognitive abilities. While reporting relatively low levels of overall efficacy in the parenting role, mothers in this sample reported lowest perceived competency with regards to their child's health than any other area of parenting.

**References:**


27. Parental Distress in Pursuit of ASD Diagnostic Consultation

Stormi White, Julie Davidson, Amy Nicholson, Alison Vehorn, Hylan Noble, Amy Weitlauf, Zachary Warren
Vanderbilt Kennedy Center, Vanderbilt University
Vanderbilt Kennedy Center, PMB 74, 230 Appleton Place, Nashville, TN 37203
(stormi.p.white@vanderbilt.edu)

Introduction: Given the numerous challenges involved in raising a child with an autism spectrum disorder (ASD), it is not surprising that parents of children with ASD report higher levels of parenting stress and psychiatric difficulties than do parents of both typically developing children and children with other developmental disabilities. Recent research indicates that parents of young children receiving a diagnosis of ASD report potent symptoms of acute distress following diagnosis (Davis & Carter, 2008; Taylor & Warren, 2011); however, not much is known about parent functioning and distress prior to the child receiving a diagnosis. This poster represents preliminary data from a larger longitudinal study investigating the well-being of parents with concerns related to their child's development, including ASD. The focus is on family functioning while developing concerns, pursuing consultation, and in the immediate aftermath of a diagnosis. Ultimately links to functioning over a more extended timeframe will be explored in order to elucidate factors associated with deleterious distress and resilience in caregivers of young children with ASD.

Methods: Participants were caregivers of families of children between 18 and 39 months of age who endorsed developmental concerns, often including ASD specific concerns, and wanted to participate in a specific psychological evaluation to clarify their child's functioning and diagnostic profile. Parents completed measures of depressive symptoms (Center of Epidemiological Studies-Depression Scale; CES-D) and provided data regarding child functioning (i.e., Achenbach Child Behavior Checklist; CBCL, Modified Checklist for Autism in Toddlers; MCHAT). Children subsequently participated in a direct assessment (Autism Diagnostic Observation Schedule; ADOS, Mullen Scales of Early Learning; MSEL) and families were provided with explicit feedback about their child's profile and performance.

Results: Data was collected on a total 24 parents (18 mothers). When looking at a measure of depression (i.e., CES-D), 50% of mothers (n=9) and 50% of fathers (n=3) endorsed clinically significant levels of depression prior to their child being evaluated. Results indicate that symptoms of depression were not related to the child's level of cognitive functioning (i.e., MSEL) or symptom severity (i.e., ADOS). A significant correlation was found between mothers' scores on CES-D and number of items failed on the MCHAT (r =.759, p≤ .001). This relationship was not significant for fathers.

Discussion: Ideal models of screening, identification, and diagnosis must take into account family functioning prior to and following ASD diagnosis in order to optimally join and engage caregivers in pursuit of the most appropriate services possible for children. Enhanced awareness of pointed distress and the factors associated with such distress prior to diagnosis may provide information to adapt clinical diagnostic best practices for families of children with ASD.

References:


Introduction: Several studies have provided support for the language-motor relationship in children with language delays (Hill, 1998; Iverson & Braddock, 2011; Owen & McKinlay, 1997; Webster et al., 2005). However, typical language interventions do not examine language outcomes in relation to the possible gains made in a child’s motor abilities. Augmented and alternative communication (AAC) language interventions may affect a child’s motor skills through the repetitive use and direct selection of a speech-generating device (SGD) symbol. The purpose of this study is to describe the effect of language interventions on the upper-body, gross and fine motor skills of toddlers at the onset and conclusion of the intervention. The data presented is from a larger longitudinal study by Romski, Sevcik, Adamson, Cheslock, Smith, Barker, & Bakeman (2010) that compared the effects of a non-augmented (Spoken Communication, SC) and two augmented language interventions (Augmented Communication-Input, AC-I or Augmented Communication-Output, AC-O) on the communication development of toddlers with difficulty acquiring speech.

Methods: Sixty-two children who participated in the original Romski et al. (2010) study also participated in this study. Romski et al. (2010) recruited participants (mean CA= 29.50) from local sources throughout metropolitan Atlanta and randomly assigned them to one of the three language interventions; two participants were excluded from a portion of the analyses due to damaged videotapes used for coding. The MacArthur-Bates Child Development Inventory (CDI; Fenson et al., 2007), Mullen Scales of Early Learning (MSEL; Mullen, 1995), and Vineland Adaptive Behavior Scales (VABS; Sparrow et al., 1984) were given at pre-intervention. The CDI was given again at post-intervention. Five observational measures that used event-coding schemes, including one used in the Romski et al. (2010) study, measured the participants’ motor skills used to activate the SGD, language abilities and outcomes collected by Romski et al. (2010).

Results: Participants had significantly delayed motor skills. The MSEL Fine Motor subscale raw scores were correlated with the frequency of the finger pointing observed during the 1st intervention session, $r=0.35$, $p=0.03$. Toddlers in the AC-O intervention decreased their need for physical prompting, $F(1,19)=4.48$, $p<0.05$, partial $\eta^2=0.19$, while toddlers in both augmented interventions increased their frequency of error-free SGD symbol activations, $F(1,38)=8.13$, $p<0.01$, partial $\eta^2=0.17$. Furthermore, toddlers in the AC-O language intervention increased their use of developmentally appropriate gross motor, $F(1,38)=9.08$, $p<0.01$, partial $\eta^2=0.19$, and fine motor skills to access the SGD from pre- to post-intervention, $F(1,38)=7.21$, $p<0.01$, partial $\eta^2=0.16$. The change in pre-post intervention developmentally appropriate gross and fine motor use and CDI raw scores predicted post-intervention symbol use, $R^2=0.21$, $F(3,36)=3.25$, $p<0.05$, $B=0.06$, $SD=0.02$, $\beta=0.42$, $t(3,36)=2.71$, 95% CI=0.01-0.10.

Discussion: Despite the children’s overall motor delays, there was an effect of intervention type on the decrease in physical prompting, increase in error-free symbol activations, and increase in developmentally appropriate gross and fine motor use. The effect may be the result of the repetitive use of the SGD as a communicative output for the AC-O language intervention. Overall, these results suggests that an AAC language intervention that utilizes a SGD may facilitate development within both domains simultaneously through the combination of the communicative goal of AAC and the increased motor learning opportunities when accessing the device.

Reference:
29. Visual Attention to In-Vivo vs. Video Models in Preschoolers with Autism

Kaitlyn Wilson
University of North Carolina-Chapel Hill
113 Kingsbury Drive, Chapel Hill, NC 27514
(kwilson@med.unc.edu)

Introduction: More than two decades of research has established video modeling as an evidence-based, cost-effective, and time-efficient intervention tool for children with autism. Despite its clear promise, however, video modeling is not widely used in classrooms serving students with autism, and has never been compared to other intervention approaches in the school setting. As one step in exploring the relative potential of video modeling as a treatment option for young students with autism, this study compared participants’ visual attention to two model types, video and in-vivo, when used as classroom-based interventions.

Methods: As part of an alternating-treatment single-subject design, visual attention data were collected for four preschoolers with ASD diagnoses (DSM-IV). Additional inclusion criteria were: absence of a co-occurring neurological or genetic disorder; vision and hearing acuity within normal or corrected normal ranges; ability to visually attend to a video for three minutes; and basic imitation skills. In addition, participants’ visual reception, language, social, and fine motor skills were assessed prior to collection of visual attention data. Participants were each provided with individualized in-vivo and video modeling interventions targeting a personal social-communication goal (e.g., reaching to request), three times per week for four weeks. The modeling was performed in the classroom by the teacher and teaching assistant, with the teacher acting as the model and the assistant as the facilitator. For each participant, the video and in-vivo models were matched for goal, length, number of models, and preference for materials. Interventions were provided one hour apart, with the order randomized daily. During each three minute modeling session, a research assistant used momentary time sampling to record the child’s presence or absence of visual attention to the model based on the child’s attention state every five seconds (i.e., 36 times). Participants’ visual attention to the video and in-vivo models was recorded as a series of percentages reflecting the proportion of intervals during which each participant attended to the particular model type on each day of treatment.

Results: Results are interpreted both descriptively and through statistical analysis, using paired-samples t-tests to identify significant differences in visual attention to the two model types. Results show overall greater attention to the video model than to the in-vivo model, with statistically significant differences suggesting the same pattern. In addition, examination of individual participants’ graphs shows a lack of habituation to either model type over the course of the treatment study. Means, ranges, and p-values will be reported, and initial skill profiles and social-communication outcomes will inform discussion of individual participants’ results.

Discussion: Results of this study augment the growing body of literature illustrating video modeling’s promise as an intervention for children with autism. These results provide insight into the learning processes and visual preferences of the participants, and have implications for interventionists, parents, and educators choosing interventions for students with autism.

References:

Introduction: As more children with autism spectrum disorders (ASD) are being identified and diagnosed earlier (before age 3), it is extremely important to research intervention programs for toddlers with ASD. While research is just emerging in this area, many of the models of intervention evaluated are home- and/or parent-based. Little is known about the effects of center-based interventions in the community for toddlers with ASD. Therefore, the purpose of the research is to examine outcomes and predictors of outcomes of a center-based model of intervention for toddlers with ASD located in the community.

Methods: School records were examined from the Interagency Assessment Center (IAC), a 20 hours/week comprehensive center-based assessment and intensive early intervention program for toddlers who have a diagnosis of, or are suspected of an ASD. The IAC provides early intervention services delivered within a classroom environment as well as support services for families. The classroom is staffed by an educational specialist (teacher) and four paraeducators who provide a 5:7 adult to child ratio and is supported by a school psychologist, nurse, speech and language pathologist, occupational therapist, and a program administrator. The program integrates multiple instructional strategies including but not limited to structured teaching, visual supports, naturalistic teaching, and positive behavioral strategies that address the unique learning style of children with ASD. Children were assessed at entry into the program and again just prior to transitioning to their school district at three years of age. Standard scores from the Bayley Scales of Infant Development II, Preschool Language Scale-4th Edition, and Scales of Independent Behavior-Revised were examined to investigate developmental outcomes.

Results: Data were collected on 139 toddlers with ASD and have been analyzed for 74 toddlers with ASD (mean age=27.6 months; range=21.0 months to 32.8 months). Children (51 male, 23 female) attended IAC for a period of 3.2 to 15 months with an average of 8.4 months. Repeated measures (entry and exit) ANCOVAs were conducted on dependent variables of cognition, language, and adaptive skills with length of stay at IAC (time) as a covariate. Results show significant positive differences between entry and exit assessment scores on measures of cognition, language, and adaptive skills. Interaction effects demonstrated that the longer a child attended IAC, the greater the increase in scores. However, the length of time attending IAC was directly related to the child’s chronological age. A child entering IAC at a younger age is able to attend the program longer before transitioning to preschool services.

Discussion: Preliminary findings of this study indicate that children attending a community-based early intervention program can make significant developmental gains in cognition, language, and social behavior. Results suggest that toddlers attending the public program for longer periods made greater developmental gains; however, one needs to consider the age at which the child entered the program.

References:

31. Group-Based Trajectories of Parenting Stress among Mothers and Fathers of Children with Developmental Disabilities: From Infancy through Young Adulthood

Ashley Woodman, Penny Hauser-Cram
Boston College
Boston College, Lynch School of Education, Campion Hall 309, Chestnut Hill, MA 02467
(ashleywo@bc.edu)

Introduction: Parents of children with developmental disabilities (DD) face greater caregiving challenges than other parents, which may place them at risk for experiencing elevated levels of stress (Dyson, 1991). Problematic behavior is often found to contribute to parents’ experience of stress (Baker et al., 2002), although additional research is needed to identify the unique contributions of internalizing and externalizing symptoms. Children's socialization skills appear to be influential on parent well-being (Beck et al., 2004), but few studies have examined how children's perceptions of loneliness contribute to their parents' stress levels. Despite caregiving challenges, many parents successfully adapt to raising a child with DD. Use of problem-focused coping strategies has been identified as one such resiliency factor (e.g., Smith et al., 2008). The present study examines the role of child behavior problems and loneliness as well as parent use of problem-focused coping in predicting membership in distinct trajectories of parenting stress among mothers and fathers of children with DD. Little is known about how parenting stress changes over time for parents, especially fathers, of children with DD.

Methods: Data for this study were drawn from 186 mothers and 182 fathers who participated in the Early Intervention Collaborative Study (Hauser-Cram et al., 2001), a longitudinal study of children with early-onset disabilities and their families. Parents completed the Parenting Stress Index (PSI; Abidin, 1995) when their child with DD was ages 1, 2, 3, 5, 10, and 15 and the Stress Index for Parents of Adolescents (SIPA; Sheras et al., 1998) at ages 18 and 23. To compare scores across measures, raw scores were converted to percentile scores following the PSI and SIPA manuals. Mothers completed the Child Behavior Checklist (CBCL/2-3; Achenbach et al., 1987) at child age 3 as a measure of internalizing and externalizing symptoms. Children completed the Loneliness and Social Dissatisfaction Questionnaire (Williams & Asher, 1992) at age 10. Parents’ use of problem-focused coping was based on the COPE (Carver et al., 1989), administered at child age 15. A semi-parametric group-method (Jones et al., 2001) was used to identify distinct trajectories of parent-domain and child-domain stress among parents, from their child's infancy (<age 1) through young adulthood (age 23). First, an unconditional model was fit to identify the number and shape of trajectory groups. Next, a conditional model was fit to examine the association between the predictors and trajectory group membership, with the number of negative life events entered as a time-varying covariate.

Results: For mothers, four parent-domain stress trajectories were identified: Stable Low (30%), Moderate Declining (10%), Peak in Middle Childhood (35%) and Stable High (24%). A similar pattern was found for fathers’ parent-domain stress, with 30% in Group 1, 33% in Group 2, 10% in Group 3, and 27% in Group 4. Compared to the Stable Low group, mothers were more likely to fall into the Peak in Middle Childhood or Stable High trajectory groups if they used less problem-focused coping and their child had higher internalizing symptoms and loneliness. Fathers were more likely to fall into the Peak in Middle Childhood group if their child had higher internalizing symptoms. Three child-domain stress trajectories were identified for mothers: Stable Low (22%), Peak in Middle Childhood (37%) and High Declining (40%). Mothers were more likely to fall into the High Declining group than the Stable Low group if their child had higher externalizing symptoms. Four child-domain stress trajectories were found for fathers: Stable Low (19%), Peak in Adolescence (25%), Peak in Middle Childhood (24%) and Stable High (32%). Compared to the Stable Low group, fathers were more likely to fall into the Peak in Adolescence or Middle Childhood groups if their child had higher externalizing symptoms.

Discussion: To our knowledge, this is the first study to examine trajectories of stress among parents of children with DD over this length of time (23 years). Distinct trajectories of parent-domain and child-domain stress were found for mothers and fathers. The findings point to key child and parent characteristics, in particular child problematic behavior and parental coping, that increase the likelihood of falling into trajectories of higher stress.
Contextual Cueing effects involve an attentional guidance mechanism that makes use of previously experienced visuo-spatial regularities in the environment to facilitate search for a target object. In a typical contextual cueing study, participants are presented displays of multiple stimuli and are required to search for a particular target. The location of the target in some displays can be predicted by the positions of the other stimuli in the display, which remain the same over repeated trials. After many repetitions, learning in this task is evidenced by faster response times on displays where the target can be predicted from the other stimuli relative to displays in which the target cannot be predicted (Chun & Jiang, 1998). This learning is generally considered implicit for young adults (Chun, 2003). The value of such a learning mechanism is that it allows persons to make use of regularities in the environment to locate important objects and signals without having to explicitly learn them all. The goal of the research presented here was to evaluate contextual cueing effects in persons with intellectual disability (ID) to determine if the mechanisms that support this form of learning are intact for persons with ID.

Participants were 12 persons with ID, 15 children without ID (matched with the participants with ID on the Matrices subtest of the KBIT-2), and 15 young adults without ID. The participants completed a contextual cueing task patterned after Chun and Jiang (1998). The basic task was to search visual displays presented via computer for a rotated letter “T” that was surrounded by 15 distractor letters (rotated letter “L”). The tail of the T could point to the right or the left. The participants had to locate the T and identify which direction it was pointing by pressing the appropriate key on the computer keyboard. Response times were recorded to the nearest ms. During an acquisition phase, each of four different contexts accurately predicted the quadrant in which the target appeared (but not the direction the letter pointed). These PREDICTIVE displays were repeated 60 times each. The acquisition phase was followed by a test phase in which the PREDICTIVE displays were presented 6 times each (24 total) and intermixed with new UNPREDICTIVE displays. The UNPREDICTIVE displays were 24 displays in which the distracters were presented in random locations and did not predict the target location. The contextual cueing effect was calculated by subtracting median RTs of the PREDICTIVE displays from that of the UNPREDICTIVE displays for each participant. The analysis of the contextual cueing effects revealed that the participants with ID and the children without ID exhibited significant and equal contextual cueing effects (620 vs 636 ms, respectively; both p’s<.01). The contextual cueing effect was also significant for the young adults (222 ms). However, the magnitude of the effect was significantly greater for the children and the participants with ID than it was for the young adults (p <.01).

Our results are the first to show significant contextual cueing in persons with ID. They indicate that the learning mechanisms that support contextual cueing are fundamentally intact for persons with ID and that, at least under the conditions tested in our study, they result in effects that are equivalent in magnitude to children approximately matched on nonverbal MA. The finding that young adults actually exhibit a smaller contextual cueing effect may be due to the fact that these individuals have more effective search strategies for finding targets in the UNPREDICTIVE displays. Hence, the difference score may reveal less facilitation when comparing PREDICTIVE and UNPREDICTIVE displays for this group.
MORE POSITIVE THAN NEGATIVE…
THE STUDY OF FAMILIES IN CONTEXT

A SPECIAL PRESENTATION HONORING LARAINIE GLIDDEN
AT GATLINBURG CONFERENCE 2012

Organizer: Connie Kasari, University of California-Los Angeles

Presenters:
Leonard Abbeduto, University of California-Davis
Elisabeth Dykens, Vanderbilt Kennedy Center, Vanderbilt University
Deborah Fidler, Colorado State University
Frank Floyd, University of Hawaii
Robert Hodapp, Vanderbilt University
Ann Kaiser, Vanderbilt University
Marsha Mailick Seltzer, Waisman Center, University of Wisconsin-Madison
SYMPOSIUM 13

More Positive than Negative…..The Study of Families in Context
A Special Presentation Honoring Laraine Glidden
at Gatlinburg Conference 2012

Organizer: Connie Kasari, University of California-Los Angeles

Presenters: Leonard Abbeduto, University of California-Davis
Elisabeth Dykens, Vanderbilt Kennedy Center, Vanderbilt University
Deborah Fidler, Colorado State University
Frank Floyd, University of Hawaii
Robert Hodapp, Vanderbilt University
Ann Kaiser, Vanderbilt University
Marsha Mailick Seltzer, Waisman Center, University of Wisconsin-Madison

This Special Presentation is submitted to honor the contributions of Laraine Masters Glidden to the field of developmental disabilities generally and the Gatlinburg Conference specifically. (Laraine is retiring from St. Mary's College this year.)

Laraine Masters Glidden has spent the last 30 years studying family adaptation to children with disabilities in the family. She began studying family adaptation at a time when most believed that the demands of caring for a child with a disability resulted in stress and crisis for the family. Over her long career, Laraine's research has countered this view in several different ways.

One contribution is her recognition that research on family stress and adjustment to children with intellectual disability was hindered by confusion about the definition and measurement of these constructs, which generally confounded external stressors, burden, distress, and general well-being. She presented a framework for distinguishing these constructs and colleagues will discuss how she and they were able to separate disability-specific stress from general distress in commonly-used measures of family stress. This important clarification led to greater clarity and sophistication in subsequent work on family adaptation.

In another contribution, Laraine compelled researchers to consider a more integrated understanding of parenting children with disabilities. In particular, her dedication to studying family outcomes not just at one point in time, but over long periods and across many transitions has had a strong influence on the field. Taking this longitudinal view has helped researchers view family functioning as a dynamic process that changes in various ways as a child develops. Such work has led to a more nuanced understanding of the real lives of families and children.

Finally, in a unique data set of families who knowingly adopted and families who gave birth to a child with a disability, she found that over time families were similarly resilient. Results indicate that the rewards and satisfaction of rearing a child with a disability often outweigh the worries and troubles.

Laraine's focus on positive psychology has greatly influenced her many students and colleagues. In this symposium we describe her important contributions, the ways in which she influenced the work of others, and tell a few stories along the way.
USES OF EYE TRACKING/PUPILLOMETRY TO ENRICH UNDERSTANDING OF INFORMATION AND SENSORY PROCESSING IN INDIVIDUALS WITH ID

Chair: Krista Wilkinson, The Pennsylvania State University; Eunice Kennedy Shriver Center, University of Massachusetts Medical School

Discussant: William Dube, Eunice Kennedy Shriver Center, University of Massachusetts Medical School
SYMPOSIUM 14

Uses of Eye Tracking/Pupillometry to Enrich Understanding of Information and Sensory Processing in Individuals with Intellectual Disabilities

Chair: Krista Wilkinson, The Pennsylvania State University; Eunice Kennedy Shriver Center, University of Massachusetts Medical School

Discussant: William Dube, Eunice Kennedy Shriver Center, University of Massachusetts Medical School

Eye Tracking Helps Reveal Mechanisms Underlying Facilitation of Responses to Visual Communication Displays by Individuals with and without Intellectual Disabilities

Krista Wilkinson1,2
Tara O’Neill1
Jennifer Nauss1
Jennifer Thistle1
William McIlvane2
1The Pennsylvania State University
2Eunice Kennedy Shriver Center, University of Massachusetts Medical School

Eye Tracking and Pupillometry Measures of Receptive Vocabulary in Children with Autism

Nancy Brady
Christa Anderson
The Schiefelbusch Institute for Life Span Studies, University of Kansas

Eye Gaze Behaviors during Face Processing in Down Syndrome

Teresa Mitchell1
Steven Meyer1
Kevin Monk2
William McIlvane1
1Eunice Kennedy Shriver Center, University of Massachusetts Medical School
2Brandeis University
Eye Tracking Helps Reveal Mechanisms Underlying Facilitation of Responses to Visual Communication Displays by Individuals with and without Intellectual Disabilities

Krista Wilkinson¹, Tara O’Neill¹, Jennifer Nauss¹, Jennifer Thistle¹, William McIlvane²

¹The Pennsylvania State University, ²Eunice Kennedy Shriver Center, University of Massachusetts Medical School
The Pennsylvania State University, 308 Ford Building, University Park, PA 16802
(kmw22@psu.edu)

One body of clinical practice demonstrated to effectively support communication involves aided augmentative and alternative communication (aided AAC), which consists of low-technology books or high-technology devices that contain picture symbols or text to supplement spoken language (Beukelman & Mirenda, 2005). Most aided AAC systems rely on a visual modality. If a communicator cannot process the information that is presented visually, however, it is unlikely that the aided AAC system will be used effectively (cf. Wilkinson & Jagaroo, 2004). Maximizing the effectiveness of aided AAC must involve an optimal match between the display design and the visual-cognitive processing of their users. This paper will illustrate how eyetracking analysis can reveal why certain visual features of aided AAC displays influence speed and efficiency of visual search of a simulated AAC communication display in children with Down syndrome, IDD of unknown origin, and nondisabled peers.

Nine nondisabled children and four children with IDD participated in a 0-delay matching-to-sample task with two different 16-symbol displays. One of the experimental conditions presented an “optimal” display design, while the other presented what is often the standard-of-care design. At the level of reaction time, all participants demonstrated more rapid responding with the optimally-designed displays, consistent with data presented previously at Gatlinburg conferences (e.g., Wilkinson et al., 2010, 2011).

What features of this “optimal” display design helped facilitate this behavioral responding? Examining the eye gaze patterns of participants as they underwent the task revealed that the individuals with Down syndrome or ID of unknown origin showed less efficient eye gaze patterns overall than nondisabled children. Moreover, individuals with Down syndrome were more vulnerable to distraction of their visual attention by irrelevant stimuli with the “non-optimal” symbol array than the others. This finding underscores the critical importance of display design for guiding visual attention to relevant features, particularly among individuals who would be most likely to use those displays.

Supported by P01 HD25995
Eye Tracking and Pupillometry Measures of Receptive Vocabulary in Children with Autism

Nancy Brady, Christa Anderson
The Schiefelbusch Institute for Life Span Studies, University of Kansas
University of Kansas, 1000 Sunnyside Drive, Lawrence, KS 66045
(nbrady@ku.edu)

Verbal comprehension is an important measure for all children, including children with autism. It is the ability to understand what is said so that one can function as a listener in a communication exchange (Sevcik and Romski, 2002). Verbal comprehension may be a predictor of language outcomes for nonverbal children and it has also been viewed as a proxy for cognitive development because it correlates so highly with overall cognitive measures. Obtaining comprehension measures through behavioral means may be very difficult for some children with autism, however (Luyster et al., 2007). Standardized tests often require a child to show joint attention between pictures (or objects) and the tester, a difficult skill for many children with autism. A variation on a method used in infancy studies may hold promise for children with autism. This method is the intermodal preferential looking paradigm (IPLP; Golinkoff, Hirsh-Pasek, Cauley, & Gordon, 1987). Infants are simultaneously presented with two images (usually video) and one auditory stimulus. Infants tend to look longer at the image that matches the auditory stimulus. Eye tracking technology can greatly facilitate the determination of looking behaviors. The current study employed the Gaze Tracker system to determine the amount of time children looked at named stimuli from an array of four images. Concurrently, measures of children’s pupil size were obtained. Data obtained to date from 25 typically developing and 13 verbal children with autism indicates that eye gaze patterns match behavioral measures, validating the procedure. Data from ten nonverbal children with autism indicate that most did have at least some verbal understanding even though they were not able to pass training items on the PPVT. In addition, pupillometry measures show covariation between pupil size while observing target stimuli compared to nontarget stimuli. These outcomes suggest that eye tracking and pupillometry may be useful biomarkers for verbal understanding.

References:


Face processing is a foundation of social interaction and communication. Individuals with Down Syndrome (DS) are known to have difficulties identifying emotional facial expressions (e.g., Williams, Wishart, Pitcairn, Willis, & Dykens, 2005), displaying difficulties discriminating between expressions with the same hedonic tone as well as those with different hedonics. To date, there are no studies of eye gaze in this population to determine whether their difficulties in identifying emotional facial expressions may stem from anomalies in their fixation patterns.

In this paper, we use eye tracking to examine gaze patterns during face perception in individuals with Down Syndrome (DS) and mental age-matched typically developing (TD) controls. Individuals with DS ranged in age from 8 to 18 years, with IQs ranging from 45 to 75. Participants completed a simple task requiring same/different judgments of two sequentially-presented faces. The first face was presented for a full two seconds, during which eye gaze behaviors were recorded, followed by a 1.5 second delay, then the presentation of the test face, which remained on the stimulus display until the subjects button response. In one condition they were asked to judge the identity of the pair of faces, while in the other they were asked to judge the facial expression.

TD controls varied their gaze patterns with task demands, making nearly all fixations to the eye area when judging identity and making occasional excursions to the mouth area when judging emotions. By contrast, fixation patterns in individuals with DS did not vary with task demands. They made comparatively more fixations to the mouth area than TD controls and did so across both conditions. Further, individuals with DS were less accurate than TD controls, suggesting that their atypical gaze patterns result in poorer encoding of faces. These data illustrate how eye tracking data provide additional insight into visual information processing unavailable in overt behavioral responses.

Supported by P01 HD25995
INDEX

A
Abbeduto, Leonard 1, 21, 163, 164
Abby, Layla 15, 90, 93
Akstinas, Mark 20, 159
Allen, Amil 12, 54, 56
Anderson, Christa 21, 166, 168
Ausderau, Karla 4, 12, 60
Avery, Suzanne 12, 54, 56

B
Bailey, Don 1
Baker, Mei Wang 11, 42, 43
Baranek, Grace 12, 60
Barker, R. Michael 11, 36, 38, 39
Barnard-Brak, Lucy 15, 90, 93
Barton-Hulsey, Andrea 12, 61
Baxter, Rebecca 17, 118, 119
Beals, Michaela 13, 68
Beck, Cole 20, 151
Becraft, Jessica 17, 124, 126
Beighley, Jennifer 15, 90, 94
Bennett, Stephanie 13, 17, 66, 118, 119
Benson, Megan 12, 62
Benson, Paul 12, 63
Berke, Elisabeth 15, 90, 95
Bert, Shannon S. C. 1
Bingham, Emelyn 13, 71
Bird, Gillian 17, 118, 119
Blackford, Jennifer Urbano 12, 54, 56
Bodfish, James 1, 11, 47, 48
Borkowski, John 1, 20, 153
Bosch, Amanda 15, 90, 93
Boyd, Brian 1, 14, 19, 85, 145
Brady, Nancy 13, 14, 19, 21, 68, 88, 144, 166, 168
Bridges, Mindy Sittner 11, 36, 39
Brooks, Bianca 4, 12, 64
Brown, Mallory 13, 65
Buckley, Sue 13, 17, 66, 117, 118, 119, 120, 121
Bullock, Christopher 17, 124, 126
Burgoyne, Kelly 17, 118, 120, 121
Burke, Meghan 14, 83
Burkitt, Chantel 13, 15, 67, 91, 96
Byers, Breanne 13, 67

C
Campbell, Abbey 13, 68
Cannarella, Amanda 13, 14, 69, 81
Carreau-Webster, Abbey 17, 124, 126
Castillo, Mariana 17, 124, 126
Cataldo, Michael 17, 123, 124
Cathey, Sara 14, 84
Chamberlain, Stormy 8, 18
Chastain, James 17, 124, 126
Chatzistyli, Aikaterini 14, 82
Chiang, Hsu-Min 13, 70
Christian, Bradley 16, 110, 112
Clarke, Paula 17, 118, 120, 121
Coburn, Shayna 10, 24, 25
Cohen, Shana 4, 10, 23, 24, 26
Coke, Catherine 13, 71
Connors, Frances 1, 11, 19, 36, 37, 143
Corbett, Blythe 13, 53, 54, 55, 71, 75
Courtemanche, Andrea 15, 90, 92
Cowan, Ron 12, 54, 56
Crawford-Zelli, Nicole 15, 98, 101
Crnic, Keith 10, 23, 24, 25

d
Damerow, John 15, 91, 96
Dankner, Nathan 4, 13, 72
Daunhauer, Lisa 18, 130
Davidson, Julie 20, 156
Deisenroth, Lauren 12, 13, 19, 48, 49, 73, 148
DeLeon, Iser 17, 124, 126
Devenny, Darlynne 16, 110, 112
Dimian, Adele 13, 67
Dimitropoulos, Anastasia 12, 48, 50
Dinehart, Laura 14, 87
Dohrmann, Elizabeth 19, 140
Domínguez-Pareto, Irenka 10, 24, 26
Dube, William 17, 21, 124, 127, 165, 166
Duff, Fiona 17, 118, 120, 121
Dykens, Elisabeth 1, 10, 11, 12, 13, 14, 15, 19, 21, 29, 30, 31, 32, 33, 34, 48, 49, 72, 73, 86, 97, 98, 141, 163, 164

E
Esbensen, Anna 16, 110, 111

F
Feldman, Benjamin 12, 48, 50
Fidler, Deborah 1, 14, 18, 21, 80, 130, 163, 164
Finucane, Brenda 8, 10
Fisher, Marisa 10, 30, 33
Floyd, Frank 1, 12, 21, 64, 163, 164
Fonseca, Claudia 12, 48, 52
Foster, Sharon 15, 91, 96
Frank-Crawford, Michelle 17, 124, 126
Frey, Jennifer 4, 13, 74

G
Ghoneim, Dina 13, 75
Glidden, Laraine 2, 14, 18, 21, 78, 134, 163, 164
Goin-Kochel, Robin 13, 76
Golden, Harriet 14, 82
Gonzales, Nancy 10, 24, 25
Gordon, Reyna 4, 13, 77
INDEX

Grant, Eileen 17, 124, 127
Greenberg, Jan 11, 18, 42, 43, 44, 45, 135
Greer, Marjorie 19, 144
Grein, Katherine 14, 18, 78, 134
Grossman, Ruth 79
Grubb, Laura 15, 90, 93

H

Hahn, Laura 14, 80
Hammock, Elizabeth 12, 54, 57
Handen, Benjamin 16, 110, 112
Hanna, Miriam 14, 81
Hickson, Lina 14, 82
Hoch, John 13, 67
Hodapp, Robert 14, 16, 21, 83, 103, 104, 107, 163, 164
Holloway, Susan 10, 24, 26
Hong, Jinkuk 11, 18, 42, 43, 135
Hooper, Stephen 18, 20, 131, 155
Horowitz, Lucia 14, 84
Hughes, Julie 17, 118, 119
Hulme, Charles 17, 118, 120, 121
Hundley, Rachel 12, 13, 48, 52, 77

I

Irvin, Dwight 14, 85

J

John, Angela 15, 98, 100
Johnson, Sterling 16, 110, 112
Jones, Dorita 14, 86

K

Kaiser, Ann 13, 74, 163, 164
Kaiser, Marygrace Yale 1, 14, 16, 87, 104, 107
Kana, Rajesh 18, 132
Kanne, Stephen 13, 76
Kasari, Connie 1, 21, 163, 164
Katz, Lynne 14, 87
Kau, Alice 9
Keller, Juliana 13, 14, 68, 88
Kennedy, Craig 18, 133
Kenedy, William 15, 91, 96
Kerkel, Kristi 16, 110, 113
Key, Alexandra 13, 14, 77, 86
Khemka, Ishita 14, 82
Klaiman, Cheryl 12, 48, 50
Klein-Tasman, Bonita 20, 152
Klinger, Laura 19, 150
Klinger, Mark 19, 150
Kluck, William 16, 110, 112
Kovac, Megan 18, 131
Kozlowski, Alison 15, 90, 94
Krinsky-McHale, Sharon 16, 110, 114, 115

L

Laakman, Anna 13, 76
Lange, Floris de 18, 132
Lanni, Kimberly 12, 54, 55
LeBlanc, Judith 15, 90, 95
Lee, Evon Batye 12, 13, 19, 48, 51, 72, 140
Lense, Miriam 4, 11, 30, 34
Leyfer, Ovsanna 15, 98, 100
Libero, Lauren 18, 132
Lin, Yueh-Hsien 13, 70
Little, Lauren 12, 60
Lloyd, Blair 18, 133
Loveall, Susan 11, 12, 36, 37, 62
Ludwig, Jesse 14, 18, 78, 134
Luken, Karen 19, 142

M

MacLean, William 1, 15, 18, 89, 90, 137
Maenner, Matthew 11, 18, 42, 43, 135
Magaña, Sandy 10, 24, 27
Makuch, Renee 18, 135
Mandel, Daniel 11, 42, 43
Margulies, Ellen 1
Marquis, Janet 15, 90, 95
Matson, Johnny 15, 90, 94
Mawdsley, Helena 18, 136
Mayo-Ortega, Liliana 15, 90, 95
McAdams, Brian 15, 91, 96
McIvane, William 11, 17, 21, 35, 36, 40, 123, 124, 166, 167, 169
McIntyre, Laura Lee 13, 65
McLeod, Laura 1
McQuillen, Sam 15, 98, 99
Medeiros, Kristen 15, 90, 94
Merrill, Edward 12, 19, 20, 62, 143, 161
Mervis, Carolyn 15, 16, 97, 98, 100, 101
Meyer, Steven 21, 166, 169
Mileviciute, Inga 18, 137
Miller, Jennifer 9, 21
Miodrag, Nancy 10, 11, 14, 16, 30, 32, 34, 83, 104, 106
Miranda, Elizabeth 10, 24, 27
Mitchell, Darcy 18, 138
Mitchell, Teresa 14, 19, 21, 79, 147, 166, 168
Moi, Kevin 21, 166, 169
Moore, Marie 11, 36, 37
Morris, Robin 11, 36, 38
Mounts, Marissa 19, 139
Murray, Patty Jo 16, 110, 112

N

Nauss, Jennifer 21, 166, 167
Newsom, Cassandra 13, 19, 71, 140
Nicholson, Amy 20, 156
Noble, Hylan 20, 156

O

Oates, Caroline 19, 141
Odom, Sam 14, 19, 85, 145
O’Neill, Tara 21, 166, 167
Oyama-Ganiko, Rosa 15, 90, 95

P

Pang, Deborah 16, 110, 113
Paradiso, Rebecca 10, 24, 27
Parish, Susan 19, 142
Peters, Sarika 12, 14, 48, 52, 77
Phillips, Allyson 4, 19, 143
Philpot, Ben 8, 18
Powell, Patrick 19, 150
Preston, Mark 19, 147
Price, Julie 16, 110, 112

R

Ramocki, Melissa 12, 48, 52
Richman, David 15, 90, 93
Roberts, Jane 15, 19, 97, 98, 99, 138, 144
Roberts, Megan 13, 74
Robinson, Ashley 19, 144
Rojahn, Johannes 15, 90, 94, 95
Romski, Mary Ann 11, 19, 36, 38, 149, 157
Roof, Elizabeth 11, 12, 13, 47, 48, 49, 73
Rooker, Griffin 17, 124, 126
Roscoe, Eileen 17, 124, 127
Rose, Julio de 11, 36, 40

S

Sam, Ann 19, 145
Saunders, Kathryn 11, 36, 39
Schaidle, Emily 19, 146
Schaller, Erin 17, 124, 126
Schlichenmeyer, Kevin 17, 124, 127
Schmid, Anna 14, 79
Schroeder, Stephen 15, 89, 90, 92, 95
Schupf, Nicole 16, 110, 113, 115
Schupp, Clayton 12, 54, 55
Seltzer, Marsha Mailick 1, 11, 16, 18, 21, 41, 42, 43, 44, 45, 110, 111, 135, 163, 164
Serna, Richard 1, 19, 147
Sevcik, Rose 11, 19, 36, 38, 149
Sheldon, Jan 15, 90, 92
Sherman, James 15, 90, 92
Shivers, Carolyn 12, 19, 48, 49, 51, 141, 148
Sideris, John 12, 60
Silverman, Wayne 1, 16, 109, 110, 112, 114, 115
Simensen, Richard 14, 84
Smith, Ashlyn 12, 19, 61, 149
Smith, Leann 11, 18, 42, 45, 135
Snowling, Margaret 17, 118, 120, 121
Son, Esther 19, 142
Song, Yanna 13, 71
Souza, Deisy de 11, 36, 40
Stehnhart, Erin 14, 79
Stephens, Jeremy 20, 151
Sterling, Audra 11, 42, 44
Stromp, Tori 13, 71
Suski, Erica 15, 91, 96
Swain, Deanna 13, 71
Swaine, Jamie 19, 142
Symons, Frank 13, 15, 67, 91, 96

T

Talton, Kenya 13, 65
Tanner-Smith, Emily 14, 83
Taylor, Courtney 13, 71
Taylor, Julie Lounds 19, 20, 140, 148, 154
Temkin, Alexis 16, 110, 113
Tervo, Raymond 15, 96
Thistle, Jennifer 21, 166, 167
Thompson, Samuel 15, 90, 93
Thompson, Travis 17, 123, 124
Tillinger, Miriam 14, 81
Tonnsen, Bridgette 15, 98, 99
Toole, Lisa 17, 124, 126
Travers, Brittany 19, 150
Twombly, Dennis 9
Twyman, Janet 11, 35, 36
Tycko, Benjamin 16, 110, 113

U

Ullery, Mary Anne 14, 87
Urbano, Richard 16, 20, 103, 104, 105, 151

V

van der Fluit, Faye 20, 152
Vehorn, Alison 12, 19, 20, 48, 52, 140, 154, 156

W

Wang, Lily 13, 71
Warren, Steven 1, 11, 13, 14, 19, 41, 42, 68, 88, 144
Warren, Zachary 12, 19, 20, 48, 52, 140, 154, 156
Wedeen, Cathy 9
Weed, Keri 20, 153
Weitlauf, Amy 4, 20, 154, 156
INDEX

Wendelschafer-Crabb, Gwen 15, 91, 96
Wheeler, Anne 18, 20, 131, 155
White, Stormi 20, 156
Whitfield, Ani 4, 12, 20, 61, 157
Whitman, Tom 20, 153
Wilkinson, Krista 21, 165, 166, 167
Williams, Dean 17, 124, 125
Wilson, Amy 12, 13, 48, 52, 77
Wilson, Kaitlyn 20, 158
Windsor, Kelly 13, 74
Wong, Connie 20, 159
Woodman, Ashley 4, 14, 20, 81, 160
Woodruff-Borden, Janet 15, 16, 98, 100, 101

Y

Yang, Yingying 20, 161
Yoder, Paul 18, 133

Z

Zigman, Warren 16, 110, 113, 114, 115
The Foundation for Angelman Syndrome Therapeutics (FAST) is a research organization narrowly focused on funding research that holds the greatest promise of treating Angelman Syndrome.

FAST-Trac Grants and Grants-in-Aid are reviewed on a rolling basis with no application deadline. To learn more about FAST’s mission and funding priorities, visit www.CureAngelman.org.
Foundation for Prader-Willi Research
Working Toward an Independent Future

DUP15q Alliance

www.dup15q.org
Visit the Brookes table for these and other essential resources:

- **The Handbook of High-Risk Challenging Behaviors in People with Intellectual and Developmental Disabilities**
  - James K. Luiselli
  - Foreword by Pete Barton

- **AAC Strategies for Individuals with Moderate to Severe Disabilities**
  - S. Johnstone
  - J. E. Knoch
  - K. M. Feeley
  - S. K. Jones

- **Neurogenetic Syndromes**
  - Bruce K. Shapiro, M.D.
  - Pasquale J. Accardo, M.D.

- **Genetics and Mental Retardation Syndromes**
  - Elisabeth M. Dykens
  - Robert M. Hodapp
  - Brenda M. Finucane

Visit us at 1-800-638-3775 | www.brookespublishing.com

---

**Observation made simple!**

- Collect rich and meaningful behavioral data
- Code behavior live or from video
- Calculate statistics & assess reliability
- Discover our state-of-the-art observation labs
- Join a worldwide community of users

**Innovative solutions for behavioral research**

- **The Observer® XT** – the professional software for the collection and presentation of observational data. Replace paper-and-pencil methods by this event logging software which is also at the core of our portable and stationary observation labs; ideal to make synchronous recordings of video, eye tracking, physiology, and behavior.
- **FaceReader** – unique software for the automatic analysis of the six universal facial expressions, and more.

Find out more at [www.noldus.com](http://www.noldus.com)
# 2012 Gatlinburg Conference

**Wednesday, March 7, 2012**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:00-8:45 am</td>
<td>Registration</td>
<td>Annapolis Atrium</td>
</tr>
<tr>
<td>8:45 -9:00 am</td>
<td>Opening Remarks: Elisabeth Dykens</td>
<td>Regatta Ballroom</td>
</tr>
<tr>
<td>9:00 am-10:30 am</td>
<td><strong>Plenary Session 1:</strong> Brenda Finucane, From Single Syndromes to Shared Pathways: The Evolution of Behavioral Genetics Research in Developmental Disabilities</td>
<td>Regatta Ballroom</td>
</tr>
<tr>
<td>10:45-11:05 am</td>
<td><strong>NIH Workshop:</strong> What’s New in Intellectual and Developmental Disabilities at NICHD and NIH</td>
<td>Regatta Ballroom</td>
</tr>
<tr>
<td>11:05-11:35 am</td>
<td>Training Opportunities at NICHD and NIH</td>
<td></td>
</tr>
<tr>
<td>11:35 am-12:05 pm</td>
<td>Where Does My Application Get Reviewed—SR or DSR?: Review Issues at NICHD and NIH</td>
<td></td>
</tr>
<tr>
<td>12:05-12:15 pm</td>
<td>General Questions and Answers</td>
<td></td>
</tr>
<tr>
<td>2:00-3:30 pm</td>
<td><strong>Symposium 1</strong> (Regatta A): Latino Families with Children with Disabilities and Risk: Understanding Culture, Needs, and Innovative Support Processes (Cohen)</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Symposium 2</strong> (Regatta B): Mindfulness-Based Stress Reduction: Introducing the World of Zen to I/DD (Dykens)</td>
<td></td>
</tr>
<tr>
<td>3:45 – 5:15 pm</td>
<td><strong>Symposium 4</strong> (Regatta A): Premutation Carriers of FMR1 Gene Expansions: Prevalence, Language Profiles, and Health (Seltzer)</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Symposium 5</strong> (Regatta B): Co-Morbid Features in PWS, ASD, and 15q Disorders (Roof)</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Symposium 6</strong> (Regatta C): Social Anxiety and Stress in Neurodevelopmental Disorders (Corbett)</td>
<td></td>
</tr>
<tr>
<td>5:30 – 7:30 pm</td>
<td><strong>Poster Session 1 Reception</strong></td>
<td>Annapolis Atrium</td>
</tr>
</tbody>
</table>

**Thursday, March 8, 2012**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:45 -10:15 am</td>
<td><strong>Symposium 7</strong> (Regatta A): Multi-Modal and Multi-Method Approaches to Assessment and Intervention for SIB (Schroeder)</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Symposium 8</strong> (Regatta B): Biobehavioral Investigations of Temperament in Fragile X, Williams, and 7q11.23 Duplication Syndromes</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Symposium 9</strong> (Regatta C): Mining Public Health Data for IDD Research (Urbano/Hodapp)</td>
<td></td>
</tr>
<tr>
<td>10:30 am-12:00 pm</td>
<td><strong>Symposium 10</strong> (Regatta A): Adult Aging with Down Syndrome (Silverman)</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Symposium 11</strong> (Regatta B): Evaluating Reading Interventions for Children with Down Syndrome (S. Buckley)</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Symposium 12</strong> (Regatta C): Translational Analysis and Treatment of Chronic Aberrant Behavior–Transition States, Behavioral Economics, and Idiosyncratic Functions (Cataldo/McIlvane)</td>
<td></td>
</tr>
<tr>
<td>1:30-3:00 pm</td>
<td><strong>Plenary Session 2:</strong> Ben Philpot, A New Angle on Angelman Syndrome</td>
<td>Regatta Ballroom</td>
</tr>
<tr>
<td>3:15 – 4:45 pm</td>
<td><strong>Plenary Session 3:</strong> Stormy J. Chamberlain, Human Induced Pluripotent Stem Cell (iPSC) Models of Chromosome 15q Imprinting Disorders</td>
<td>Regatta Ballroom</td>
</tr>
<tr>
<td>5:00-7:00 pm</td>
<td><strong>Poster Session 2 Reception</strong></td>
<td>Annapolis Atrium</td>
</tr>
</tbody>
</table>

**Friday, March 9, 2012**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:45 – 10:15 am</td>
<td><strong>Symposium 13</strong> (Regatta A): More Positive than Negative...The Study of Families in Context. A Special Presentation Honoring Laraine Glidden at Gatlinburg Conference 2012 (Kasari)</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Symposium 14</strong> (Regatta B): Uses of Eye Tracking/Pupillometry to Enrich Understanding of Information and Sensory Processing in Individuals with ID (Wilkinson)</td>
<td></td>
</tr>
<tr>
<td>10:45 am-12:15 pm</td>
<td><strong>Plenary Session 4:</strong> Jennifer Miller, Lessons About Chromosome 15q from Prader-Willi Syndrome</td>
<td>Regatta Ballroom</td>
</tr>
<tr>
<td>12:15 pm</td>
<td>Closing Remarks: Elisabeth Dykens, PhD</td>
<td>Regatta Ballroom</td>
</tr>
</tbody>
</table>