THANK YOU!

The Gatlinburg Conference especially thanks the following institutions for their financial contributions and generous support of the 2014 Conference:

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  - The Eunice Kennedy Shriver Center, University of Massachusetts Medical School
  - The Waisman Center, University of Wisconsin-Madison
  - The University of North Carolina at Chapel Hill
  - The Schiefelbusch Institute for Life Span Studies, University of Kansas
- Center on Human Development and Disability, The University of Washington
  - The American Psychological Association–Division 33

Cover Art: Puddy Cat Paradise by Leigh Ward
47th Annual
Gatlinburg Conference
on Research and Theory in Intellectual and Developmental Disabilities

Hotel Allegro • Chicago, Illinois
March 5-7, 2014

This volume contains abstracts for plenary sessions at the 47th Annual Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities. Abstracts of symposia and poster presentations may be found at http://kc.vanderbilt.edu/gatlinburg/program.html. Permission to quote or reprint any of these materials must be obtained from the author(s).

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Award Recipients

Laraine Masters Glidden Undergraduate Award

Olena Zyga
Case Western Reserve University

David Zeaman Graduate Award

Nasreen Akhtar
Jamia Millia University

Gayle Graham Faught
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Dissertation Award

Sin Lo
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John G. Borkowski Diversity Travel Award

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University of North Carolina at Chapel Hill

Yangmu Xu
Loma Linda University

American Psychological Association Division 33 Graduate Student Travel Award

Andrea Lewallen
Loma Linda University
A Word on the Naming of Our Travel Awards

John G. Borkowski

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

Laraine Masters Glidden

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

Theodore Tjossem

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.

David Zeaman

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

Luc Lecavalier, Ph.D.
Professor of Psychology and Psychiatry, The Ohio State University
Wednesday, March 5, 2014 • 8:30-9:45 a.m. • Historic Walnut Ballroom

The past decade has witnessed a surge in writings on psychopathology in young people with autism spectrum disorder (ASD). Evidence suggests that children and adolescents with ASD have high rates of behavioral and emotional problems, especially so-called disruptive behaviors and anxiety. The exact reasons why this is the case remain elusive. In fact, the very conceptualization, measurement, and classification of these problems remain onerous and contentious issues. The overlap with intellectual and language delays, and the reliance on caregiver reports, are examples of why the measurement of psychopathology in ASD is complex. In spite of all of these challenges, a significant quantity of treatment research on the topic has recently been published. Some of this treatment literature will be reviewed, focusing on psychopharmacology and psychological interventions such as parent training, cognitive behavior therapy, or social skills training. The discussion will focus on efficacy/effectiveness and outcome measurement, but also on trends in the field, methodological progress and obstacles, and general observations and reflections based on the studies in which Dr. Lecavalier has been involved.

Susan Hepburn, Ph.D.
Director of Research, JFK Partner, and Associate Professor of Psychiatry and Pediatrics, University of Colorado Denver - Anschutz Medical Campus
“Extending Evidence-Based Practices to Improve Access to Services for Youth with Autism Spectrum Disorder and Anxiety”
Thursday, March 6, 2014 • 8:30-9:45 a.m. • Historic Walnut Ballroom

There is increasing evidence for the efficacy of manualized psychosocial interventions focused on improving mental health in youth with ASD; however, these highly specialized interventions are not readily available to many families of psychiatrically complex youth with ASD. Families who live far from specialty medical centers or who have children whose anxiety precludes consistent participation in clinic-based services require a different form of service delivery. In this presentation, Dr. Hepburn will describe the efforts of the research group at JFK Partners of the University of Colorado to develop, evaluate, and extend a manualized, family-focused, cognitive-behavioral group treatment targeting anxiety reduction in youth with ASD (i.e., Facing Your Fears [FYF]; Reaven et al, 2011). In an effort to improve access to mental health services for those families unable to participate in groups in their center, Dr. Hepburn’s team developed the TeleCopes Project, which is a modified version of FYF, designed to be delivered through commercially available videoconferencing software that allows for home-to-clinic real-time interactions. Feasibility and preliminary efficacy data will be shared and implementation challenges will be discussed, in the hopes of providing practical strategies for other researchers and clinicians considering telehealth delivery of evidence-based practices.

Special Presentations

Wednesday, March 5 • 12:15-1:15 p.m.: Cinema Room
NADD Round Table Discussion
Led by Robert J. Fletcher, DSW, ACSW, CEO of NADD
We welcome you to attend this informal discussion during the Wednesday, Mar. 5, lunch break. Grab a quick bite beforehand or bring in a lunch and participate in conversation with colleagues and the CEO of NADD.
Invited Speakers

Sheila Eyberg, Ph.D., ABPP
Professor Emerita, Department of Clinical and Health Psychology, University of Florida; Diplomate in Clinical Psychology, ABPP; Fellow, Division of Clinical Psychology, Division on Child, Youth, and Family Services, APA
“Treatment of Young Children with Co-Occurring Disruptive Behavior Disorders and IDD”
Thursday, March 6, 2014 • 1:15-2:30 p.m. • Historic Walnut Ballroom

Sheila Eyberg is a Professor Emerita of the University of Florida. Dr. Eyberg earned her Ph.D. from the University of Oregon. Her interests include clinical child psychology, behavioral assessment, parent-child interaction therapy, and treatment research methodology. In addition to her professorship at UF, Dr. Eyberg also serves as a Diplomate in Clinical Psychology, ABPP, and a Fellow within the Division of Clinical Psychology, Division on Child, Youth, and Family Services, American Psychological Association (APA). She serves as an Editorial Board Member for the Journal of Pediatric Psychology, Journal of Clinical Child Psychology, Clinical Psychology: Science and Practice, Clinical Child Psychology and Psychiatry, Clinical Child and Family Review, and Child & Family Behavior Therapy. She is a past president of the Society of Pediatric Psychology (Division 54, APA); Society of Clinical Child and Adolescent Psychology (Division 53, APA); Southeastern Psychological Association; and Division of Child, Youth, and Family Services (Division 37, APA).

Bryan H. King, M.D.
Director, Psychiatry and Behavioral Medicine; Program Director, Seattle Children’s Autism Center
“Sex, Drugs, and Diagnostic Rigamaroles”
Friday, March 7, 2014 • 9:30-10:45 a.m. • Historic Walnut Ballroom

One of the recurring themes revealed in the history of medicine is that as underlying causes for disorders are identified, not only are more effective treatments developed, but also the boundaries around the disorders themselves are invariably redrawn. Illustrating the protean manifestations associated with a disorder with known cause, Osler coined the term “the great imitator” for neurosyphilis. He observed that to know this disorder would be “to have all things clinical opened up to you.” In the years following the introduction of the DSM-3 and DSM-4 criteria for neuropsychiatric disorders, advances in genetics coupled with a significant increase in the prevalence of PDDs laid the foundation for the changes that were incorporated in DSM-5. But even as the ink was drying on the DSM-5, there were calls to revisit the entire system in favor of an approach that is organized around dimensions of neurobiology and observable behavior. This talk will highlight genetic and other studies that have begun to challenge the demarcation of the boundaries between phenotypically quite distinct, diagnostic entities such as autism and schizophrenia. We are at the threshold of being able to chart these disorders from the inside out. In so doing, the door is opened to the consideration of new therapeutics that are developed based upon molecular, synaptic, and systems targets common to both.

Special Presentations

Wednesday, March 5 • 3:15-4:45 p.m.: Historic Walnut Ballroom
NIH/NICHD Workshop: Open Doors and Closed Doors: NIH from the Program and Review Perspectives
Led by Melissa Parisi, M.D., Ph.D., Chief, Intellectual and Developmental Disabilities Branch, Eunice Kennedy Shriver National Institute of Child Health & Human Development, and NIH/NICHD colleagues
2014 Gatlinburg Conference

WEDNESDAY

March 5, 2014

8:15-8:30 A.M.
OPENING REMARKS
HISTORIC WALNUT BALLROOM
Elisabeth Dykens, Ph.D.
Gatlinburg Conference Chair
Vanderbilt Kennedy Center, Vanderbilt University

8:30-9:45 A.M.
PLENARY SESSION 1
HISTORIC WALNUT BALLROOM
The Nature and Treatment of Behavior and Emotional Problems in Young People with Autism Spectrum Disorders
Luc Lecavalier, Ph.D.
The Ohio State University

10:00 A.M.-11:30 A.M.
SYMPOSIUM 1—HISTORIC WALNUT BALLROOM
Beyond the Behavior: The Impact of Challenging Behaviors on Parents, Siblings, and Teachers
Chair/Discussant: Julie Lounds Taylor, Vanderbilt Kennedy Center, Vanderbilt University

Characteristics of Comorbid Disorders in Young Children with Autism Spectrum Disorders
Gazi Azad1
Jan Blacher2
Abbey Eisenhower1
1University of Pennsylvania
2University of California-Riverside

Associations Between Behavioral and Emotional Problems in Children with Autism Spectrum Disorder and Their Siblings’ Self-Reported Behavior Problems and Sibling Relationship Quality
Richard Hastings1
Michael Petalas2
1Centre for Educational Development Appraisal and Research, University of Warwick, UK
2Mental Healthcare UK, Wales, UK

Factors Affecting Maternal Stress and Mental Health in 574 Mothers of Children with 11 Rare Genetic Intellectual Disability Syndromes and 65 Mothers of Children with Autism
Dawn Adams1 Tjossem Award Winner
Richard Hastings2
Jo Moss2
Chris Oliver1
1Cerebra Centre for Neurodevelopmental Disorders, University of Birmingham, UK
2Centre for Educational Development Appraisal and Research, University of Warwick, UK

Factors Contributing to Parent-Teacher and Student-Teacher Relationships Over Time for Young Students with Autism Spectrum Disorders
Hilary H. Bush1
Abbey Eisenhower1
Jan Blacher2
1University of Massachusetts-Boston
2University of California-Riverside

SYMPOSIUM 2—PRESS ROOM
Self-Injurious Behavior: The Importance of Person Characteristics
Chair: Chris Oliver, University of Birmingham, UK

A Prospective Study of Self-Injury and Aggression in Children with Severe Intellectual Disability
Chris Oliver
Louise Davies
University of Birmingham, UK

Early Self-Injury in a Clinical Cohort of Young Children with Global Developmental Delay
Adele Dimian1
Raymond Tervo2
Frank Symons3
1University of Minnesota
2Gillette Children’s Specialty Healthcare

A Gene-Brain-Environment Investigation of Skin-Picking Behavior in Prader-Willi Syndrome
Scott Hall
Kristen Husty1
Jennifer Hammond
Stanford University
Immune-Related Inflammatory Salivary Biomarkers and Self-Injury
Frank Symons¹
Raymond Tervo²
Angela Panoskaltsis-Mortari¹
Michael Ehrhardt¹
John Damerow¹
Chantel Barney¹
George Wilcox¹
¹University of Minnesota
²Gillette Children's Specialty Healthcare

SYMPOSIUM 3—SCREENING ROOM I
Understanding Autism Symptomatology in Fragile X Syndrome
Chair: Leonard Abbeduto, University of California-Davis MIND Institute
Discussant: Jim Bodfish, Vanderbilt Kennedy Center, Vanderbilt University

Symptoms of Autism in Fragile X Syndrome: A Between Disorder Comparison
Andrea McDuffie
Angela John Thurman
Randi J. Hagerman
Leonard Abbeduto
University of California-Davis MIND Institute

Angela John Thurman¹
Andrea McDuffie¹
Sara T. Kover²
Randi J. Hagerman¹
Leonard Abbeduto¹
¹University of California-Davis MIND Institute
²University of Wisconsin-Madison Waisman Center

Characterizing Repetitive Behaviors in Young Males with Fragile X Syndrome
Ashley Oakes
Angela John Thurman
Andrea McDuffie
Lauren Bullard
Randi J. Hagerman
Leonard Abbeduto
University of California-Davis MIND Institute

■ 12:15-1:15 P.M.
NADD ROUNDTABLE—CINEMA ROOM
Moderator: Rob Fletcher, CEO of NADD

■ 1:30-3:00 P.M.
SYMPOSIUM 4—HISTORIC WALNUT BALLROOM
Deletion and Duplication of the Williams Syndrome Region: Relations with Anxiety Disorders, Externalizing Disorders, and Autism
Chairs: Carolyn B. Mervis, University of Louisville
Bonita P. Klein-Tasman, University of Wisconsin-Milwaukee
Discussant: Elisabeth Dykens, Vanderbilt Kennedy Center, Vanderbilt University

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

Socio-Communicative Functioning of Verbal Children with Williams Syndrome: Performance on the Autism Diagnostic Observation Schedule Modules 2 and 3
Faye van der Fluit¹, Zeaman Award Winner
Carolyn B. Mervis¹
Catherine Lord³
Bonita P. Klein-Tasman¹
¹University of Wisconsin-Milwaukee
²University of Louisville
³Weill Cornell Medical Center

Children with 7q11.23 Duplication Syndrome: Findings from Gold-Standard Autism Spectrum Disorder Assessment Measures
Bonita P. Klein-Tasman¹
Danielle Walerus³
Carolyn P. Mervis³
¹University of Wisconsin-Milwaukee
²University of Louisville
March 5, 2014

SYMPOSIUM 5—PRESS ROOM

Dose Frequency Effects on Early Communication and Vocabulary
Chair: Paul Yoder, Vanderbilt Kennedy Center, Vanderbilt University
Discussant: Steve Warren, University of Kansas

Dose Frequency Effects on Vocabulary in Preschoolers with Intellectual Disabilities
Marc Fey¹
Paul Yoder²
Steve Warren¹
¹University of Kansas
²Vanderbilt University

Does Dose Frequency of an Early Communication Intervention Affect a Key Prelinguistic Communication Skill in Toddlers with Intellectual Disabilities?
Tiffany Woynaroski¹
Zeaman Award Winner
Paul Yoder¹
Mark Fey²
Steve Warren³
¹University of Kansas
²Vanderbilt University
³University of Kansas

Why Does Dose Frequency Affect Vocabulary in Preschoolers with Down Syndrome?
Paul Yoder¹
Tiffany Woynaroski¹
Zeaman Award Winner
Mark Fey²
Steve Warren³
¹University of Kansas
²Vanderbilt University
³University of Kansas

Discussion
Steve Warren
University of Kansas

SYMPOSIUM 6—SCREENING ROOM I

Psychological Interventions for Individuals with Developmental Disability and Co-Occurring Mental Health Problems: New Evidence and Delivery
Chair: Andrew Jahoda, University of Glasgow
Discussant: Richard Hastings, University of Warwick

Group Cognitive Behavioral Therapy for People with Asperger Syndrome Who Have Problems with Anxiety: The Initial Results of the PAsSA Pilot Treatment Trial
Peter Langdon¹
Glynis Murphy²
Edward Wilson¹
Lee Shepstone¹
David Fowler¹
¹University of East Anglia
²University of Kent
³Norfolk and Suffolk NHS Foundation Trust

BEAT-IT: A Pilot Behavioral Activation Intervention for People with Intellectual Disabilities and Depression
Andrew Jahoda¹
Craig Melville¹
Carol Pert¹
Anna Cooper¹
Helen Lynn²
Claire Davidson¹
¹University of Glasgow
²NHS Ayrshire and Arran

Equity of Access and Effectiveness of Mainstream Primary Care Mental Health Services for Adults with Intellectual Disabilities: The Case of IAPT Services in Cumbria, England
Chris Hatton¹
Dave Dagnan¹, ²
Richard Thwaites²
John Masson ²
Avy Cavagin²
¹University of Lancaster
²Cumbria Partnership NHS Foundation Trust

3:15-4:45 P.M.
NIH/NICHD WORKSHOP—HISTORIC WALNUT BALLROOM

Open Doors and Closed Doors: NIH from the Program and Review Perspectives
Melissa Parisi, M.D.,Ph.D.
Eunice Kennedy Shriver National Institute of Child Health and Human Development

5:00-7:00 P.M.
POSTER SESSION 1 RECEPTION
SCREENING ROOM II
Full abstracts for all posters presented at the 2014 Gatlinburg Conference are available at http://kc.vanderbilt.edu/gatlinburg/program.html
**Poster Session 1, 5:00-7:00 p.m., Screening Room II**

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Full abstracts for all posters presented at the 2014 Gatlinburg Conference are available at http://kc.vanderbilt.edu/gatlinburg/program.html
March 6, 2014

**PLENARY SESSION 2 — HISTORIC WALNUT BALLROOM**

**Extending Evidence-Based Practices to Improve Access to Services for Youth with Autism Spectrum Disorder and Anxiety**

Susan Hepburn, Ph.D.
University of Colorado Denver-Anschutz Medical Campus

**SYMPOSIUM 7 — HISTORIC WALNUT BALLROOM**

**The Co-Occurrence of Anxiety in Fragile X and Idiopathic Autism: A Behavioral and Biomarker Approach to Assessment and Treatment Across the Lifespan**

Chair: Jane E. Roberts, University of South Carolina

**Antenatal Anxiety in Mothers with the FMR1 Premutation Predicting Outcomes in Children with Fragile X Syndrome**

Ashley Robinson¹
Don Bailey²
Jane E. Roberts¹
¹University of South Carolina
²RTI International

**Anxiety as a Predictor of Pragmatic Language Difficulties in Women with the FMR1 Premutation**

Jessica Klusek
Jane E. Roberts
University of South Carolina

**Anxiety of Adolescents and Young Adults with Fragile X Syndrome Associated with Emotional Climate in the Family**

Joan R. Gunther¹
Andrea McDuffie¹
Beth Goodlin-Jones¹
Mary Beth Steinfield¹
Ingrid Leckliter¹
Angela John Thurman¹
Ashley Oakes¹
Robyn Tempero-Feigles¹
Jane E. Roberts²
Leonard Abbeduto¹
¹University of California-Davis
²University of South Carolina

**Assessment and Treatment of Anxiety and Problem Behavior in Children with Autism Spectrum Disorders and Intellectual Disability**

Lauren J. Moskowitz¹
Emilie Mulder²
Caitlin Walsh²
Darlene McLaughlin³
Jennifer Zarcone⁴
Greg Hajcak Proudfit²
Edward G. Carr²
¹St. John’s University
²Stony Brook University
³Positive Behavior Support Consulting
⁴Kennedy Krieger Institute, Johns Hopkins University School of Medicine

**Anxiety Vulnerability in Young Males with Fragile X: Maternal Predictors of Risk and Resilience**

Bridgette L. Tonnsen¹
Don Bailey²
Jane E. Roberts¹
¹University of South Carolina
²RTI International

**SYMPOSIUM 8 — PRESS ROOM**

**Characterization of Aging Individuals with Down Syndrome: Examination of Neuropsychological Measures, Neuropsychiatric Symptoms, and Genetic Biomarkers**

Chair: Sharon J. Krinsky-McHale, New York State Institute for Basic Research in Developmental Disabilities

**Psychiatric Disorders in Elderly Adults with Down Syndrome**

Sharon J. Krinsky-McHale¹
Warren B. Zigman¹
Wayne Silverman²
¹New York State Institute for Basic Research in Developmental Disabilities
²Kennedy Krieger Institute, Johns Hopkins University School of Medicine
Measures to Characterize Cognitive Change in Adults with Down Syndrome
Wayne Silverman¹
Sharon J. Krinsky-McHale²
Warren B. Zigman³
¹Kennedy Krieger Institute, Johns Hopkins University School of Medicine
²New York State Institute for Basic Research in Developmental Disabilities
³Kennedy Krieger Institute, Johns Hopkins University School of Medicine

Candidate Genes for Alzheimer’s Disease Associated with Individual Differences in Plasma Levels of Beta-Amyloid Peptides in Adults with Down Syndrome
Nicole Schupf¹
Annie Lee¹
Naeun Park¹
Deborah Pang²
Alexander Yale¹
Wayne Silverman³
Benjamin Tycko¹
Sergey Kisselev¹
Lorraine Clark¹
Joseph H. Lee¹
¹Columbia University Medical Center
²New York State Institute for Basic Research in Developmental Disabilities
³Kennedy Krieger Institute, Johns Hopkins University School of Medicine

Variable Risk for Alzheimer’s Disease Explained by Genes on Chromosome 21 and Other Chromosomes in Adults with Down Syndrome
Joseph H. Lee¹
Annie Lee¹
Naeun Park¹
Deborah Pang²
Edmund C. Jenkins²
Wayne Silverman³
Benjamin Tycko¹
Sergey Kisselev¹
Lorraine Clark¹
Nicole Schupf¹
¹Columbia University Medical Center
²New York State Institute for Basic Research in Developmental Disabilities
³Kennedy Krieger Institute, Johns Hopkins University School of Medicine

Aggression and Self-Injurious Behavior in Individuals with Intellectual or Developmental Disabilities
Chair: Anne C. Wheeler, RTI International
Discussant: Jim Bodfish, Vanderbilt Kennedy Center, Vanderbilt University

Aggressive and Self-Injurious Behaviors in the Behavioral Phenotypes of MeCP2-Related Syndromes
Breanne J. Byiers¹ Tjossem Award Winner
Sarika Peters²
Frank J. Symons¹
¹University of Minnesota
²Vanderbilt University

Aggression and Self-Injurious Behaviors in Individuals with Fragile X Syndrome
Anne Wheeler
Melissa Raspa
Don Bailey
Anne Edwards
RTI International

Aggression and Self-Injurious Behaviors in a Broad Clinical Population
Robert B. Christian¹
Anne Wheeler²
Kylene Miller¹
Adrienne Villagomez¹ Borkowski Award Winner
¹University of North Carolina at Chapel Hill
²RTI International

1:15-2:30 P.M.
PLENARY SESSION 3—
HISTORIC WALNUT BALLROOM
Treatment of Young Children with Co-Occurring Disruptive Behavior Disorders and IDD
Sheila Eyberg, Ph.D., ABPP
University of Florida
March 6, 2014

■ 3:00-4:30 P.M.

SYMPOSIUM 10—HISTORIC WALNUT BALLROOM
Decision Capacity in Fragile X Syndrome
Co-Chairs: Melissa Raspa, RTI International
          Don Bailey, RTI International
Discussant: Elizabeth Berry-Kravis, Rush University

Decisional Capacity for Informed Consent: Theory and Approach to Assessment
Paul Appelbaum
Columbia University College of Physicians & Surgeons

Parental Rating of Decision Making Ability in Fragile X Syndrome
Don Bailey
RTI International

Development and Psychometric Evaluation of a Modified MacCAT-CR to Assess Decisional Ability in Fragile X Syndrome
Melissa Raspa
RTI International

SYMPOSIUM 11—PRESS ROOM
The Down Syndrome Cognitive Phenotype Profile: An Examination of Underlying Components and Links to Functional Performance in the School-Age Years
Co-Chairs: Lisa A. Daunhauer, Colorado State University
           Deborah J. Fidler, Colorado State University
Discussant: Susan Hepburn, University of Colorado-Denver, Anschutz Medical Campus

Object-Related Generativity in Children with Down Syndrome
Deborah J. Fidler¹
Lisa A. Daunhauer¹
Elizabeth Will¹
Jeannie Visootsak²
¹Colorado State University
²Emory University

Are Inhibitory Control Deficits a Component of the Cognitive Phenotypic Profile in School-Aged Children with Down Syndrome?
Lisa A. Daunhauer
Deborah J. Fidler
Colorado State University

School Function in Students with Down Syndrome
Elizabeth Will
Lisa A. Daunhauer
Deborah J. Fidler
Colorado State University

SYMPOSIUM 12—SCREENING ROOM I
Expanding Research on Family Environment: How, Who, and When to Measure
Chair: Anna J. Esbensen, Cincinnati Children’s Hospital Medical Center
Discussant: Gael Orsmond, Boston University

I Second That Emotion: Concordance and Synchrony in Physiological Arousal Between Children with ASD and Their Parents
Jason K. Baker
Rachel M. Fenning
Mariann Howland
Christopher Murakami
California State University-Fullerton

Division of Labor in Married Couples of Children and Adolescents with ASD
Sigan Hartley
Emily J. Hickey
Paige M. Bussianich
Iulia Mihaila Zeaman Award Winner
University of Wisconsin-Madison

Impact of Implementing Future Caregiving Plans Among Adults with Down Syndrome
Anna J. Esbensen
Cincinnati Children’s Hospital Medical Center

■ 5:00-7:00 P.M.

POSTER SESSION 2 RECEPTION
SCREENING ROOM II
Full abstracts for all posters presented at the 2014 Gatlinburg Conference are available at http://kc.vanderbilt.edu/gatlinburg/program.html
## Poster Session 2, 5:00-7:00 p.m., Screening Room II

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FRIDAY
March 7, 2014

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

9:30-10:45 A.M.
PLENARY SESSION 4—
HISTORIC WALNUT BALLROOM
Sex, Drugs, and Diagnostic Rigamaroles
Bryan H. King, M.D.
Seattle Children’s Hospital

11:00 A.M.-12:30 P.M.
SYMPOSIUM 13—HISTORIC WALNUT
BALLROOM
Lessons in Parent Training and Education
Chair: John R. Lutzker, Georgia State University
Discussant: Laura Lee McIntyre, University of Oregon

A Qualitative Discussion of Technology Enhanced Service Delivery: Parent and Provider Considerations
Katelyn M. Guastaferro
Megan Graham
John R. Lutzker
Georgia State University

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John R. Lutzker
Georgia State University

Padres en Acción: A Parent Training Program for Latina Mothers of Children with Autism Spectrum Disorder (ASD)
Sanda Magana
Wendy Machalicek
1University of Illinois at Chicago
2University of Oregon

Mindfulness-Based Stress Reduction of Young Children with Developmental Delays: Follow-Up Results from the MAPS Project
Cameron L. Neece
Loma Linda University

Effectiveness of a Mindfulness-Based Stress Reduction Program for Parents of Adolescents and Adults with Intellectual/Developmental Disabilities
Yona Lunsky
Anna M. Palucka
Buddhi Hatharaliyadda
Ryan Howes
The Centre for Addiction and Mental Health

SYMPOSIUM 14—PRESS ROOM
Language, Reading, and School-Readiness in Down Syndrome
Chair: Susan J. Loveall, Life Span Institute, University of Kansas
Discussant: Sue Buckley, University of Portsmouth, Down Syndrome Education International

Reading Skills in Down Syndrome: An Examination of Orthographic Knowledge
Susan J. Loveall
Frances A. Conners
1Life Span Institute, University of Kansas
2University of Alabama

Developmental Trajectories of Pre-Academics and Self-Directedness in Preschoolers with Down Syndrome
Laura J. Hahn
Deborah Fidler
David Most
Lisa Daunhauer
1Life Span Institute, University of Kansas
2Colorado State University

How Speech-Language Pathologists Address Phonological Memory in Down Syndrome
Gayle Graham Faught
Frances A. Conners
Angela Barber
Sarah Steeley
Hannah Rapport
University of Alabama

The Use of Mental State Language by Children and Adolescents with Down Syndrome
Marie Moore Channell
Mandeep K. Chela
Leonard Abbeduto
University of California-Davis MIND Institute
Implicit Learning and Language in Down Syndrome
Frances A. Conners¹
Leonard Abbeduto²
Mark R. Klinger³
Edward C. Merrill
Laura Grofer Klinger³
Jamie DeCoster⁴
¹University of Alabama
²University of California-Davis MIND Institute
³TEACCH, University of North Carolina at Chapel Hill
⁴University of Virginia

SYMPOSIUM 15—SCREENING ROOM I
Fetal Alcohol Spectrum Disorder: Mental Health Issues Across the Lifespan and the Need for Education
Chair: Shelley Watson, Laurentian University

“The Knowledge Just Has to Get Out There”: Parents’ Reflections on Knowledge and Awareness of FASD in Ontario, Canada
Kelly D. Coons
Shelley L. Watson
Laurentian University

“When I See the Future for My Child, I See Jail”: Legal Issues in Individuals with FASD
Shelley L. Watson
Elisa Radford-Paz
Laurentian University

Treatment Needs and Interventions for Adolescents with an FASD
Jacqueline Pei
University of Alberta

The Professionals Without Parachutes Training Initiative: An Innovative Approach to Supporting Students with FASD in the Classroom
Stephanie A. Hayes
Jacqueline Pei
Cheryl Poth
Amanda Radil
University of Alberta
Full abstracts for all posters presented at the 2014 Gatlinburg Conference are available at http://kc.vanderbilt.edu/gatlinburg/program.html
Poster Breakfast, 8:00-9:30 a.m., Screening Room II

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### Poster Breakthrough, 8:00-9:30 a.m., Screening Room II

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Symposium 1 Title: Beyond the Behaviour: The Impact of Challenging Behaviour on Parents, Siblings and Teachers

Chair and Discussant: Julie Lounds Taylor, Vanderbilt Kennedy Center, Vanderbilt University

Paper 1: Characteristics of Comorbid Disorders in Young Children with Autism Spectrum Disorders

Gazi Azad, University of Pennsylvania; Jan Blacher, University of California Riverside; Abbey Eisenhower, University of Massachusetts Boston

Introduction: Children with autism spectrum disorders (ASD) frequently have comorbid symptoms along with the characteristic features that define their disability. Leyfer et al. (2006) reported that children and adolescents with ASD demonstrated high prevalence of specific phobia, OCD, and ADHD. However, there is very limited research on the early comorbid characteristics of young children with ASD. The aims of this presentation will be to: 1) Describe the rates of clinical-level comorbidities, 2) Identify classes of comorbidities, and 3) Identify variables that differentiate these classes.

Methods: Participants were 173 children and their parents. The children ranged in age from 4 to 7 years, with an average age of 5.17 years (SD=1.0). A majority of the children were boys (83.6%), who primarily spoke English (85%). The children attended the following types of schools: 60.6% public elementary, 3.2% private elementary school, 12.3% public preschool, 3.2% private preschool, 3.2% Head Start program, 12.9% special preschool, 6% child care center, 1.3% developmental pre-K, and 2.6% other; a majority (85.3%) received special education services. Children had an average WPPSI full scale IQ of 87.61 (SD= 20.16). On the ADOS, 73.4% met criteria for autism, 18.3% met criteria for autism spectrum, and 8.3% met criteria for non-spectrum. With regard to parents, 84.8% reported being the children's biological mother. The parents ranged in age from 24 to 54 years, with an average age of 37.76 years (SD= 5.96). A majority of parents reported being married (80.6%). Over half had a college degree or higher (64.7%), were employed (53.8%), and had an annual income of over $50,000 (67.9%). The racial background of the parents were as follows: 69% Caucasian, 7.7% African American, 6% Asian, 1.8% American Indian/Alaskan Native, and 15.5% Other. The Autism Diagnostic Observation Schedule (ADOS) was used to categorize children into their respective diagnostic classifications. The Child Behavior Checklist (CBCL) and the Social Responsiveness Scale (SRS) were used to identify and describe the comorbid classes. Variables used to differentiate classes included IQ (Wechsler Preschool and Primary Scale of Intelligence), social skills (Social Skills Improvement System) and language (Comprehensive Assessment of Spoken Language and the Children's Communication Checklist-2).

Results: Preliminary results suggested that almost half (43.2%) of the children presented with clinical levels of internalizing problems and about a third (32.2%) presented with clinical levels of externalizing problems on the CBCL. On the SRS, 63% of the children presented with clinical levels of autistic mannerisms. Slightly over half presented with clinical levels of deficits in social cognition (54.6%) and social communication (51.3%). Approximately a third presented with clinical levels of deficits in social awareness (36.1%) and social motivation (31.1%). Of particular importance is the percentage of children whose scores on social awareness and social motivation were in the borderline clinical range (both 47.1%). Latent class analysis will be used to identify comorbid classes and subsequently determine whether classes differed based on the variables of interest.

Discussion: Children with ASD presented with high rates of clinical-level comorbidities, particularly with regard to internalizing problems, social cognition, and social communication. Implications will be discussed.

Key References:

Introduction: There are few published research studies in which siblings of children with autism spectrum disorder (ASD) provide self-reports about their own behavioral and emotional problems and their sibling relationships. Reliance on parent reports may lead to incomplete conclusions about the experiences of siblings themselves.

Methods: Siblings 7-17 years and their mothers from 94 families of children with ASD were recruited. Mothers reported on family demographics, the behavioral and emotional problems of their child with ASD, and on their own symptoms of depression. Siblings reported on their relationship with their brother or sister with ASD, and siblings 11+ years of age also self-reported on their behavioral and emotional problems.

Results: Compared to normative British data, siblings reported very slightly elevated levels of behavioral and emotional problems. However, none of the mean differences were statistically significant and all group differences were associated with small or very small effect sizes - the largest being for peer problems (ES = .31). Regression analysis was used to explore family systems relationships, with sibling self-reports predicted by the behavior problems scores for the child with ASD and by maternal depression. Maternal depression did not emerge as a predictor of siblings' self-reported sibling relationships or their behavioral and emotional problems. Higher levels of behavior problems in the child with ASD predicted decreased warmth/closeness and increased conflict in the sibling relationship.

Discussion: These data support the general findings of recent research in that there was little indication of clinically meaningful elevations in behavioral and emotional problems in siblings of children with ASD. Although further research replication is required, there was some indication that sibling relationships may be at risk where the child with ASD has significant behavioral and emotional problems.
**Symposium 1: Beyond the Behaviour: The Impact of Challenging Behaviour on Parents, Siblings and Teachers**

**Paper 3: Factors Affecting Maternal Stress and Mental Health in 574 Mothers of Children with 11 Rare Genetic Intellectual Disability Syndromes and 65 Mothers of Children with Autism**

Dawn Adams, Cerebra Centre for Neurodevelopmental Disorders, University of Birmingham, UK; Richard Hastings, Centre for Educational Development Appraisal and Research, University of Warwick, UK; Jo Moss, Cerebra Centre for Neurodevelopmental Disorders, University of Birmingham, UK; Chris Oliver, Cerebra Centre for Neurodevelopmental Disorders, University of Birmingham, UK

**Introduction:** It is well established that parents of individuals with intellectual disabilities show increased levels of stress and mental health problems in comparison to parents of typically developing children. Specific factors, notably challenging behaviour and autism, have been identified as predictors of parental psychological problems. However, the literature focusing upon parental mental health in parents with rare genetic syndromes is sparse. Initial studies report elevated levels of stress and depression with parents of some syndromes, such as Angelman syndrome, reporting higher levels of anxiety than mothers of children with autism (e.g. Griffiths et al., 2011). Further research with larger samples is needed to extend the knowledge within this area.

**Objectives:** (1) To compare parental stress, mood and positive gains in mothers of children with 11 different genetic syndromes associated with an intellectual disability to mothers of children with autism. (2) To identify factors which may contribute towards increased stress both across and between genetic syndromes.

**Method:** A cross-sectional design was used to collect data from 574 mothers of children with 11 different rare genetic syndromes. A comparison group of 65 mothers of children with autism was also recruited, as this population are documented to have high levels of stress and mental health difficulties. Questionnaires were used to collect data on Pervasive Behavioural Characteristics (SCQ, Hyperactivity, Impulsivity), Challenging Behaviour (CBQ), self-help and mobility (Wessex scales). Mothers completed self-report measures of depression (HADS), positive emotions (Positive Affect Scale, Positive Gains Scale) and Stress (QRSF).

**Results:** ANOVAs identified significant differences in the level of stress (F(12, 613)=3.3, p<.001) and depression (F(12, 620) = 2.4, p=.004) reported between the syndromes. Mothers of children with autism reported significantly higher levels of both stress and depression than some, but not all of the syndromes. LSD post-hoc analyses revealed that stress levels in mothers of children with Angelman and Smith Magenis Syndromes are comparable to mothers of children with autism, suggesting these parents are at high-risk for elevated stress levels. The depression scores of mothers of children with Cornelia de Lange, Smith Magenis and 1p36 syndromes did not differ from the level report in mothers of children with autism. Self-reported levels of positive emotions and positive gains did not differ between the groups. Using regression analyses, syndrome group, challenging behaviour and pervasive behavioural characteristics were able to predict and explain some, but not all, of the variability between the syndrome groups.

**Discussion:** Positive mood and positive gains remain constant across the syndrome groups despite significant differences in low mood. Predictive factors for stress and low mood included genetic syndrome, highlighting the need for tailored and syndrome-specific parental interventions for these families.

**Key References:**

Symposium 1: Beyond the Behaviour: The Impact of Challenging Behaviour on Parents, Siblings and Teachers

Paper 4: Factors Contributing to Parent-Teacher and Student-Teacher Relationships Over Time for Young Students with Autism Spectrum Disorders

Hilary H. Bush, University of Massachusetts Boston; Abbey Eisenhower, University of Massachusetts Boston; Jan Blacher, University of California

Introduction: Children with autism spectrum disorders (ASD) are at heightened risk for poor school adjustment (e.g., Chamberlain, Kasari, & Rotheram-Fuller, 2007). Existing research with typically developing yet behaviorally at-risk children has shown that protective factors, including positive student-teacher relationships (STRs) and parent-teacher relationships (PTRs), may help children transition to the school environment (e.g., Rimm-Kaufman & Pianta, 2005). Behavior problems and other child factors have been shown to be associated with the quality of STRs and PTRs (Henricsson & Rydell, 2004), although these relations remain poorly understood for students with ASD. The proposed study will explore the factors that may impact STRs and PTRs for young children with ASD, and will address the research question: do internalizing and externalizing problems moderate the relations between STRs and PTRs over time for young children with ASD?

Methods: Analyses will include two waves of quantitative data from a longitudinal, multi-site study on the school experiences of 4-7 year-old children with ASD (parent and child dyads N = 130, teacher N = 95). Data were collected from parents and teachers during the fall and the winter/spring of the same school year. PTR quality was measured with the parent- and teacher-report Parent-Teacher Involvement Scale (NICHD, 2005) and STR quality was measured with the teacher-report Student-Teacher Relationship Scale (Pianta, 2001). Internalizing and externalizing problems were measured using the parent-report Child Behavior Checklist and the teacher-report Caregiver Teacher Report Form (Achenbach and Rescorla, 2000).

Results: Preliminary cross-lagged panel analyses revealed an association between PTR and STR quality within, but not across time points; high consistency in parent-reported PTR quality, and teacher-reported PTR and STR quality across the school year was observed [Model Fit: χ²(13, n=107) = 13.848; RMSEA = .025; CFI = .999, TLI = .998, SRMR = .022]. While parents' and teachers' ratings of externalizing problems [r(88) = .17, p = .12] and internalizing problems [r(88) = .12, p = .25] were not significantly correlated at the first time point, children's teacher-reported externalizing problems were negatively correlated with teacher-reported STR quality [r(90) = -.69, p < .001] and PTR quality [r(88) = -.29, p = .005]. No such relations were found for teacher-reported internalizing problems, or for parent-reported externalizing or internalizing problems. It is important to note that these correlations were for baseline levels of PTRs, STRs, and behavior problems only, and that subsequent analyses will examine how these factors may influence change in one another over the school year. Also, analyses will test and incorporate sociodemographic covariates, and will test the potential moderating effects of internalizing and externalizing problems on the relation between STRs and PTRs over the school year.

Discussion: Our findings will show how PTR and STR quality interact over time for young students with ASD, and how these relations may differ for children with different levels of internalizing and externalizing problems. These may inform school readiness intervention programs for children with ASD, their parents, and their teachers.

Key References:


Symposium 2 Title: Self-Injurious Behavior: The Importance of Person Characteristics

Chair: Chris Oliver, University of Birmingham, UK

The aim of this symposium is to explore the relevance of person characteristics to generic models of the causes of self-injury. Data are presented on characteristics such as genetic and biological disorder and psychological difference.

Paper 1: A Prospective Study of Self-Injury and Aggression in Children with Severe Intellectual Disability

Chris Oliver, Louise Davies, University of Birmingham

Introduction: Self-injurious and aggressive behaviours in children and adults with intellectual disability have a demonstrably negative impact on the person showing the behaviour, their families and carers. There is emerging evidence that: 1) prevalence rises between childhood and early adulthood, 2) the behaviours are persistent over many years, 3) the behaviours are associated with risk markers such as specific genetic disorders, autism spectrum conditions and degree of intellectual disability and 4) risk markers may be different for self-injury and aggression. Risk markers are important as they afford the opportunity of targeting high risk children within an early intervention strategy and they may inform theoretical models of the development of these behaviours. To date, broad person characteristics have been the focus of risk marker research in cross sectional or group comparison designs only. In this study we extend the analysis of risk markers by focussing on behavioural markers in a high risk group within a prospective design.

Methods: Data were collected on 417 children with severe intellectual disability aged between 2 and 12 years old (Mage 7.33 years) at baseline (T1) and 15 months later (T2). Measures were taken of degree of intellectual disability, repetitive and restricted behaviours and interests (RRBI), overactive and impulsive behaviour (O\I) and self-injury, aggression and destruction.

Results: As expected within a high risk group characterised by severe intellectual disability, degree of intellectual disability did not confer further risk. Age and gender showed a similar pattern. Self-injury was persistent in 58% of children with an incidence rate of 4.7%, corresponding proportions for aggression were 69% and 8.25%. In line with previous research binary logistic regression showed O\I but not RRBI predicted the presence of aggression whilst both behavioural markers were associated with self-injury. Interestingly, the onset of self-injury within the 15 month period was predicted by the presence of RRBI (relative risk 2.66; CI 1.84-6.02) but not O\I, whilst the onset of aggression was predicted by the presence of O\I at T1 (relative risk 2.42; CI 1.36 - 3.13) but not RRBI.

Discussion: The data on persistence show self-injury and aggression are likely to continue in this young group over a 15 month period. The results further demonstrate the differing association between behavioural risk markers and self-injury and aggression, alluding to important underlying child characteristics. Of most importance is the demonstration that the future onset of self-injury and aggression can be predicted in an already high risk group from the presence of behavioural risk markers and that these differ for self-injury and aggression. The immediate implication for services is that it is possible to identify children who are at the highest risk for the onset of these behaviours and that these behaviours are persistent if not treated effectively.
Symposium 2 Title: Self-Injurious Behavior: The Importance of Person Characteristics

Paper 2: Early Self-Injury in a Clinical Cohort of Young Children with Global Developmental Delay

Adele Dimian, University of Minnesota; Raymond Tervo, Gillette Children's Specialty Healthcare, Mayo Clinic; Frank Symons, University of Minnesota

Introduction: The early development of self-injurious behavior (SIB) in intellectual and developmental disabilities (I/DD) is not well understood. When conventional developmental factors (e.g., severity of intellectual impairment, communicative impairments) reported to be associated with SIB in adults with I/DD are tested in young at-risk children there are inconsistencies such that it is less than clear whether and how those same factors function in relation to risk for SIB.1,2,3 There are still a relatively limited number of empirical studies focused on the risk factors for the emergence of SIB in children with intellectual disability. The purpose of the current exploratory study was to compare young children with global developmental delay (and at risk for I/DD) with and without parent-reported SIB on a number of variables relevant to psychosocial development.

Methods: A prospective cohort study with children with global developmental delay (n=22, age range= 19-64 mo) was conducted with a clinical sample of consecutive cases from a neurodevelopmental pediatric clinic at a children's specialty hospital. Behavioral measures including the Child Development Inventory (CDI), the Inventory for Client and Agency Planning (ICAP), the Child Behavior Checklist (CBCL), the Conners Parent Rating Scale Revised (CPRS-R), and the Repetitive Behavior Scale Revised (RBS-R) were distributed to parents. Two groups were formed: a no self-injury group (NOSIB) consisting of children with no SIB items endorsed on the RBS-R SIB subscale (n=11; mean age= 40.18 mo; 100% male) and a self-injury group (SIB) including children with any SIB endorsed on the RBS-R SIB subscale (n=11; mean age= 47.64 mo; 45% male). Groups were matched on developmental level based on CDI scores (NOSIB mean = 28.82; SIB mean = 37.09; ns).

Results: Given the exploratory nature of the investigation, significance levels were set at 0.10. Differences were observed between the SIB and NOSIB group on externalizing problems (CBCL NOSIB M= 15.89, sd= 10.37; SIB M= 24.36, sd= 10.28; p=.084; Cohens' d = 0.82) and emotional lability (CPRS-R NOSIB M= 65.36, sd= 18.73; SIB M= 77.18, sd= 11.55; p=.09; Cohen's d = 0.76). Trends (i.e., higher mean values all going in the same direction) were also evident for aggression, mood/affect, internalizing problems, and sleep problems (SIB > NOSIB group).

Discussion: Small sample size and power issues notwithstanding, the preliminary results suggest that in a clinical sample of young children with global developmental delay, a subgroup of children were already reported to SIB and that this same group has significant problems with more general externalizing problems and emotional lability. Data such as these are consistent with a developmental psychopathology model of SIB. In such a model, risk for SIB may be considered in relation a broader set of emotion- and behavior-regulation parameters. If a consistent pattern of aberrant responding is apparent early, risk factors specific to the development and emergence of SIB in young children at risk for I/DD could be more precisely identified and used for early intervention purposes.

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References:


Introduction: Individuals diagnosed with genetic syndromes are often at increased risk for showing particular forms of self-injurious behavior. For example, skin-picking behavior is a highly significant and intransigent behavioral issue for individuals with PWS. Yet, very little is known about the potential biological and environmental determinants of this behavior.

Methods: Twelve individuals with PWS (6 with deletion subtype, 6 with UPD subtype) received functional magnetic resonance imaging (fMRI) scans while they were allowed to engage in skin-picking behavior on a free-operant basis. Episodes of skin-picking behavior were observed on a video-camera placed unobtrusively in the bore of the scanner. Subjects were also exposed to a series of experimental conditions similar to those devised by Iwata et al., (1994) over 2 days. The conditions were: alone, ignore, attention, play and demand. Each condition was repeated 4 to 6 times. Heart rate levels were recorded in each condition.

Results: Skin picking was observed at sufficiently high rates in the scanner for approximately 50% of the participants. Results from the experimental functional analyses showed that for 8 participants (4 DEL, 4 UPD), high rates of skin-picking behavior occurred predominantly in the alone and ignore conditions. For the remaining subjects, skin picking occurred at high rates across all conditions. There were no differences between those with DEL or UPD subtypes in terms of frequency, severity or function.

Discussion: The functional analysis indicated that skin picking in PWS was sensitive to environmental manipulations, and in the majority of cases, appeared to be maintained by automatic reinforcement. Treatments designed to address the sensory consequences of skin-picking behavior in PWS (e.g., sensory extinction) should therefore be attempted before pharmacological interventions. It may be possible to use fMRI methodology to augment our understanding of problem behavior maintained by automatic reinforcement. Investigators undertaking fMRI evaluations of problem behavior must be aware, however, that movement and physiological artifacts, as well as sampling issues, are important factors that need to be considered.
**Symposium 2 Title:** Self-Injurious Behavior: The Importance of Person Characteristics

**Paper 4:** Immune-Related Inflammatory Salivary Biomarkers and Self-Injury

Frank Symons, University of Minnesota; Raymond Tervo, Mayo Clinic, Gillette Children's Specialty Healthcare; Angela Panoskalsis-Mortari, University of Minnesota; Michael Ehrhardt, University of Minnesota; John Damerow, University of Minnesota; Chantel Barney, University of Minnesota; George Wilcox, University of Minnesota

**Introduction:** Biological risk factors for self-injury among children with intellectual disabilities are poorly understood. Prior work investigating peripheral innervation found that mast cells were degranulated in the skin of individuals with self-injury. Mast cells release myriad inflammatory-relevant molecules (cytokines/chemokines) that function, in part, to sensitize primary sensory afferents and, in principle, enhance nociceptive signaling. Enhanced nociceptive signaling may be part of a pathophysiological pathway relevant for the development of SIB. The purpose of this preliminary study was to investigate whether inflammatory molecules were detectable in saliva and related to the presence or absence of SIB in a high-risk pediatric clinical sample.

**Methods:** Following informed consent, children being evaluated for global developmental delay were consecutively recruited from a tertiary children's rehabilitation specialty care hospital. Two groups (SIB [N=7], NoSIB [N=8]) were created based on the Repetitive Behavior Scale-Revised (RBS-R; any SIB item endorsement = SIB). Saliva was collected passively in the early AM when the children were arriving at the hospital for an initial evaluation (participants received no food or liquid, nor did they display self-injury within the hour prior to collection). Saliva was collected by swabbing the individual child's mouth using Toothettes. Toothettes were cut and placed into Salivette tubes and centrifuged at 3,000 rpm for 5 minutes, aliquoted into labeled microtubes, and stored at -80 C until used. On the day of the assay, samples were thawed and vortexed. Freeze-thaw cycles were minimized. Simultaneous profiling of multiple cytokines were performed in the Cytokine Reference Laboratory located in the University of Minnesota's Department of Pediatrics using a commercially available 22-plex Human Cytokine Array Panel (LUH000, R&D Systems, Minneapolis, MN). Pro-inflammatory mediators included monocyte chemotactic protein-1 (MCP-1), tumor necrosis factor alpha (TNF-a) and interleukin-6 (IL-6); anti-inflammatory mediators included interleukin-10 (IL-10).

**Results:** There was a significant mean difference for MCP1 between SIB (M = 345.5 [sd = 205] and NOSIB (M= 193.9 [sd = 86]) groups (p = 0.053). Subsequent within group (SIB,NOSIB) correlations were performed between MCP1 and IL10 (r= -0.58 NOSIB, 0.52 SIB), TNFα (r= -0.48 NOSIB, 0.60 SIB), and IL6 (r = -0.44 NOSIB, 0.75 SIB).

**Discussion:** This was a small sample exploratory investigation of immune-system relevant inflammatory molecules in children with global developmental delay. In each of the comparisons, the direction of the relation between the inflammatory mediators consistently differed between the SIB and NoSIB samples. Although the immediate clinical relevance of this preliminary set of observations is not clear, there are two important issues the findings raise. First, inflammatory relevant markers can be readily detected in human saliva and may be a useful non-invasive approach to investigate biomarkers. Second, the relation between immune function in relation to inflammatory processes in young children with global developmental delay and significant behavioral issues should be further investigated.

Supported, in part, by NIH/NICHD Grant No. 44763

**References:**

**Symposium 3 Title:** Understanding Autism Symptomatology in Fragile X Syndrome

**Chair:** Leonard Abbeduto

The three papers in this symposium use different measures and research designs to characterize autism symptoms in young children with fragile X syndrome (FXS). All three papers suggest that symptoms are manifested differently and may reflect different underlying mechanisms in FXS and nonsyndromic autism. These differences may require different approaches to treatment.

**Paper 1:** Symptoms of Autism in Fragile X Syndrome: A Between Disorder Comparison

Andrea McDuffie, University of California - Davis MIND Institute; Angela John Thurman, University of California - Davis MIND Institute; Randi J. Hagerman, University of California - Davis MIND Institute; Leonard Abbeduto, University of California - Davis MIND Institute

**Background and Purpose:** Symptoms of autism are frequent in males with fragile X syndrome (FXS) and are often numerous and severe enough to warrant a diagnosis of an autism spectrum disorder (ASD). Researchers do not agree, however, as to whether symptoms of ASD are qualitatively the same in individuals with FXS relative to individuals with nonsyndromic ASD (i.e., ASD that is not associated with a known genetic etiology) or whether these symptoms reflect the same or different underlying neural substrates or psychological mechanisms.

The refinement of gold standard diagnostic instruments has enabled increased precision in characterizing the symptoms of ASD in FXS and provides an opportunity to examine symptom profiles between these two neurodevelopmental disorders. Previous studies using the Autism Diagnostic Observation Schedule (ADOS) (Clifford et al., 2009; Hall et al., 2010; Wolff et al., 2012) suggest that boys with FXS are more impaired in Communication and less impaired in Social Reciprocity than are boys with nonsyndromic ASD. The question of how and why symptoms of ASD are expressed in FXS is particularly important because pharmacological interventions that are efficacious for one of these conditions are assumed to hold promise for the other condition. Thus, the current study examined similarities and differences in individual items scores from the ADOS for a group of young boys with a confirmed diagnosis of FXS relative to an age-matched group of boys with nonsyndromic ASD.

**Method:** Two samples of participants were created. Eighty-eight boys (n=49 FXS, n=39 nonsyndromic ASD) matched on chronological age (p = .66) ranging in age from 6 to 10 years comprised the CA-Match Group. A subsample of these same boys (n=40 FXS, n=39 ASD), who met criteria for a categorical diagnosis of ASD on both the ADI-R and ADOS, comprised the DX-Match Group. Each boy completed at least 2 subtests of the Brief IQ Screener of the Leiter International Performance Scales - Revised (Roid & Miller, 1997) and was administered an ADOS by a research-reliable examiner. Each boy’s biological mother completed the ADI-R.

Nonparametric Mann-Whitney U Tests were used to compare current ADOS scores for individual items that were common across modules 1, 2, and 3, resulting in the analysis of five items from the Social Affective domain (Eye Contact, Conventional Gestures, Facial Expression, Shared Enjoyment, Quality of Social Overtures) and four items from the Repetitive Behaviors domain (Stereotyped Language, Unusual Sensory Behaviors, Hand/Finger Mannerisms, and Repetitive Interests).

**Results:** For the CA-Match group comparison (after controlling for family-wise error) significant between-group differences emerged for all ADOS items with the exception of Gestures and Mannerisms. The results were the same for the DX-Match group comparison (after controlling for family-wise error), with the exception of no group difference on Eye Contact or Unusual Sensory Behaviors.

**Discussion:** On average, boys with FXS display less severe symptoms of autism than boys with ASD who are matched on chronological age. Differences continue to be observed when only boys with a comorbid diagnosis of FXS and ASD are included in the analyses. These results suggest important differences exist between the two disorders and these differences may have implications for understanding mechanisms and for treatment efficacy. Larger samples would allow future studies to compare ADOS item scores for each module separately. Additionally, future studies should conduct between-group comparisons using instruments that measure other important aspects of the FXS behavioral phenotype. Finally, neuroimaging studies will be necessary to determine whether differences observed at the behavioral level actually represent between-syndrome differences in brain organization and function.
**Symposium 3: Understanding Autism Symptomatology in Fragile X Syndrome**

**Paper 2:** Cross-Sectional Developmental Trajectories of Autism Symptomatology in Fragile X Syndrome: A Comparison with Nonsyndromic Autism Spectrum Disorder

Angela John Thurman, University of California - Davis MIND Institute; Andrea McDuffie, University of California - Davis MIND Institute; Sara T. Kover, University of Wisconsin - Madison Waisman Center; Randi J. Hagerman, University of California - Davis MIND Institute; Leonard Abbeduto, University of California - Davis MIND Institute

**Background and Purpose:** Although the majority of males with fragile X syndrome (FXS) are frequently described as demonstrating autism symptomatology, there is much debate regarding whether the behavioral symptoms representing the core domains of autism are the result of the same or different underlying neurological/psychological mechanisms. Given recent neuroimaging findings suggesting potentially important structural and functional differences between the brains of individuals with FXS and those with nonsyndromic ASD, research focused on elucidating the similarities and differences between the two disorders at multiple levels of analysis is of particular importance. The present study used a cross-sectional developmental trajectories approach (Thomas et al., 2009) to compare the profiles of autism symptomatology relative to chronological age (CA), nonverbal IQ, and expressive vocabulary ability between individuals with FXS and individuals with nonsyndromic ASD.

**Method:** Participants were 53 boys with FXS (M(age) = 7.51; M(IQ) = 57.77) and 42 boys with nonsyndromic ASD (M(age) = 7.31; M(IQ) = 63.79) who ranged from 4 to 10 years of age and had nonverbal IQs less than 85, a cut-off inclusive of essentially all males with FXS (Hessl et al., 2009). Each participant was administered measures of autism symptomatology (Autism Diagnostic Observation Scale; ADOS), nonverbal ability (Leiter International Performance Scales-Revised; Leiter), and expressive vocabulary ability (Expressive Vocabulary Test; EVT). Calibrated Severity Scores proposed by Hus et al. (in press) were used to assess autism symptomatology in the Social Affect (SA-CSS) and Restricted and Repetitive Behavior (RRB-CSS) domains. Between-group comparisons of the cross-sectional trajectories for SA-CSS and RRB-CSS were examined as a function of CA, Leiter nonverbal IQ, and EVT standard score.

**Results:** Results indicated that, when comparing intercept values, SA-CSS were significantly lower for boys with FXS than for boys with nonsyndromic ASD (p = .005). In addition, a trend (p = .06) for a difference in the rates at which SA-CSS changed as a function of CA was observed. More specifically, SA-CSS increased as chronological age increased for boys with FXS; for boys with nonsyndromic ASD, SA-CSS did not change as a function of age. When SA-CSS was examined as a function of nonverbal ability, a significant difference in the rates at which SA-CSS changed as a function of IQ was observed between the two groups (p = .03). For boys with FXS, SA-CSS decreased as nonverbal IQ increased; for boys with nonsyndromic ASD, the SA-CSS did not change as a function of nonverbal IQ. No differences were observed in terms of either the intercept values of the two trajectories or the rates of change when SA-CSS was examined as function of EVT standard score.

The between-group comparisons of the trajectories for RRB-CSS as a function of age and nonverbal IQ revealed no between-group differences in either the intercept values of the trajectories or in the rates at which RRB-CSS changed. The rates at which RRB-CSS changed as a function of EVT standard score; however, differed between the two groups. More specifically, RRB-CSS decreased as EVT standard scores increased in FXS; in nonsyndromic ASD, however, RRB-CSS did not change as a function of EVT standard score.

**Discussion:** Although autism symptomatology is frequently observed in males with FXS, the onset of these symptoms and their trajectories as a function of CA, nonverbal ability, and expressive vocabulary ability differ in important ways when compared to males with nonsyndromic ASD. Because developmental outcomes reflect interactions across domains of functioning, these differences may be key in understanding whether similar behavioral features have different developmental origins in FXS and nonsyndromic ASD.
**Symposium 3: Understanding Autism Symptomatology in Fragile X Syndrome**

**Paper 3: Characterizing Repetitive Behaviors in Young Males with Fragile X Syndrome**

Ashley Oakes, University of California - Davis MIND Institute; Angela John Thurman, University of California - Davis MIND Institute; Andrea McDuffie, University of California - Davis MIND Institute; Lauren Bullard, University of California - Davis MIND Institute; Randi J. Hagerman, University of California - Davis MIND Institute; Leonard Abbeduto, University of California - Davis MIND Institute

**Background and Purpose:** Repetitive behaviors are commonly mentioned as a part of the fragile X syndrome (FXS) phenotype. Past research has documented heightened degrees of verbal perseveration; sensory motor behaviors, such as hand stereotypes; difficulties with changes in routine; and self-injurious behaviors, such as hand biting, in males with FXS. Several studies have suggested that repetitive behaviors in individuals with FXS are simply a reflection of the comorbidity of FXS and ASD; however, there is growing evidence suggesting that the same behavioral symptoms in FXS and ASD may emerge from different underlying mechanisms. Furthermore, there is limited research directly focused on characterizing the profile of repetitive behaviors in FXS and on exploring the mechanisms that underlie their development. Insight into repetitive behaviors in FXS can help characterize the behavioral phenotype, clarify the comorbidity with ASD, and guide the formulation of appropriate targets of intervention. In the current project, we examined the profile of repetitive behaviors and their predictive correlates, specifically anxiety, nonverbal IQ, and ASD social affective symptomatology.

**Method:** Participants were 39 boys with FXS (M(age) = 7.41; M(IQ) = 59.26). Testing occurred at two time points, approximately 18 months apart. At T1, participants were administered measures of nonverbal cognitive ability (i.e., Leiter-R) maladaptive behaviors (i.e., Anxiety, Depression, and Mood Scale), and autism symptomatology (i.e., ADOS and ADI-R). At T2, parent informants completed the Repetitive Behavior Scale - Revised (RBS-R; Bodfish, Symons, & Lewis, 1999), a questionnaire designed to assess the presence of repetitive behaviors. We also used the Restricted Sensory Motor (RSM) and Insistence on Sameness (IS) subscale scores from the restricted and repetitive behavior domain of the ADI-R (Bishop et al., 2012) and the newly standardized calibrated severity scores (CSS) for the Social Affect (SA) domain and Restricted and Repetitive Behavior (RRB) domain from the ADOS (Hus, Gotham, & Lord., in press) and examined the associations among the different measures of repetitive behaviors.

**Results:** The magnitude of scores on the RBS-R varied as a function of subscale. Ritualistic/Sameness behavior yielded the highest mean rating score (M = 6.36) and was significantly higher than all other subscales except Sensory Motor behavior. Self-injurious behaviors had the lowest mean rating score (M = 2.39) and was significantly lower than all other subscales except Restricted Interests. RSM behavior from the ADI-R was related to Sensory-Motor behavior (r = .40), Self-injurious (r = .30) behavior, and Restricted Interests (r = .28) on the RBS-R. IS behavior from the ADI-R was related to Restricted Interests (r = .37) and Ritualistic/Sameness (r = .36) behaviors on the RBS-R. Anxiety was significantly related to the two RBS-R scales that were found to correlate with ADI-R IS behaviors (i.e., Restricted Interests (r = -.39) and Ritualistic/Sameness (r = -.45) behavior). In addition, nonverbal IQ and ADOS social affective symptoms were significantly related to Restricted Interests on the RBS-R (r = .30 and r = .31 respectively).

**Discussion:** This study provides preliminary evidence for an empirically derived model of repetitive behaviors and characteristics relating to repetitive behaviors in young males with FXS. We found that some forms of repetitive behavior are more problematic than others in boys with FXS. In addition, results indicate that "higher order" repetitive behaviors, or repetitive behaviors associated with a distinct cognitive component, are more closely related to anxiety and nonverbal IQ than autism symptomatology. Clinical implications will be discussed.
Symposium 4 Title: Deletion and Duplication of the Williams Syndrome Region: Relations with Anxiety Disorders, Externalizing Disorders, and Autism

Chair: Carolyn B. Mervis, University of Louisville

Discussant: Elisabeth Dykens, Vanderbilt Kennedy Center, Vanderbilt University

According to the NICHD Vision Statement, major goals for this Institute over the next 10 years are to identify 5000 genetic variants that influence specific behavioral or cognitive characteristics, to identify the causes of autism spectrum disorder, and to identify key biological markers for five behavioral or cognitive disorders. The study of rare syndromes associated with deletion or duplication of a relatively small set of genes offers an important opportunity to address these goals. This opportunity is further enhanced when a group of children with a deletion of a specific set of genes is compared to a group of children with an extra copy (duplication) of the same genes, allowing researchers to consider the possibility of contrasting effects of different types of dosage effects (too little of a gene product vs. too much of that product) of the same genes. The presentations in the proposed symposium will compare psychopathology in children who have Williams syndrome (WS), which is caused by a deletion of ~25 genes on chromosome 7q11.23, and 7q11.23 duplication syndrome (Dup7), which is caused by a duplication (extra copy) of the same set of genes. In the first presentation, Henderson et al. report that the prevalence of several DSM-IV diagnoses is considerably higher than in the general population for children with WS and/or children with Dup7, at the same time as providing evidence of significant differences between WS and Dup7 in the proportion of children who evidence these disorders. The second and third presentations focus on autism spectrum disorder characteristics. In the second presentation, van der Fluit et al. use ADOS classifications to estimate the proportion of children with WS who produce phrase speech (Module 2) or have fluent language (Module 3) who meet the ADOS criteria for autism spectrum disorder (ASD) and compare these proportions to those for a group of children with intellectual disability of mixed etiology and a group of children with clinical diagnoses of PDD-NOS who have no known syndrome. In the third presentation, Klein-Tasman et al. report ADOS and ADI-R results, as well as clinical diagnoses, for children with Dup7. The rates of ADOS classifications of ASD were found to be considerably higher for both WS (which often is argued to be ‘the opposite of autism’) and for Dup7 (which recently was identified as a risk factor for autism based on an analysis of a large sample of children in the Simons Simplex Collection; Levy et al., 2011; Sanders et al., 2011) than for children in the general population. Clinical diagnoses were available for the Dup7 study but not for the WS study. The clinical diagnosis findings for Dup7 confirm that the rate of ASD is considerably higher than for the general population. In summary, the findings presented in this proposed Symposium strongly suggest that one or more genes on chromosome 7q11.23 are involved in the development of specific anxiety disorders, ADHD, oppositional or disruptive disorders, and ASD. Future studies will address specific symptoms associated with each disorder, as the genetic liability is most likely for a specific symptom(s) rather than for a disorder as a whole.
**Symposium 4: Deletion and Duplication of the Williams Syndrome Region: Relations with Anxiety Disorders, Externalizing Disorders, and Autism**

**Paper 1: Genetic Factors in Psychiatric Diagnoses: A Comparison of Children with 7q11.23 Deletions (Williams Syndrome) and Duplications (7q11.23 Duplication Syndrome)**

Danielle R. Henderson, Nicole A. Crawford-Zelli, Janet Woodruff-Borden, Carolyn B. Mervis, University of Louisville

**Introduction:** Genetic factors are generally considered to play an important role in individual differences in psychiatric vulnerabilities. One strategy to address the influence of genes on these vulnerabilities is to compare the psychiatric diagnoses 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 psychiatric diagnoses of children with deletions of 7q11.23 (Williams syndrome; "WS") to the psychiatric diagnoses of children with duplications of 7q11.23 (7q11.23 duplication syndrome; "Dup7").

**Methods:** Participants were 204 4 - 17-year-olds with WS (M = 9.49 years, SD = 4.10) and 52 same-aged children with Dup7 (M = 8.70 years, SD = 3.61). Psychiatric disorders were diagnosed based on parental responses to the Anxiety Diagnostic Interview Schedule for DSM-IV: Parent Version (ADIS; Silverman & Albano, 1996), a semi-structured interview designed to diagnose current internalizing and externalizing disorders. Parents of 74 6 - 17-year-olds with WS (M = 9.98 years, SD = 3.42) and 17 same-aged children with Dup7 (M = 10.52 years, SD = 3.48) also completed the Conners CBRS - Parent (Conners CBRS; Conners, 2008), a parental questionnaire that provides a comprehensive assessment of characteristics associated with childhood disorders. The Conners CBRS includes DSM-IV symptom scales for both internalizing and externalizing disorders.

**Results:** Statistical comparisons of the proportion of each group diagnosed with particular DSM-IV disorders were conducted with Chi-Square tests. Specific Phobia diagnoses were very common for both groups but were significantly more likely (p = .03) for the WS group (67.2%) than for the Dup7 group (50%). Social phobia, selective mutism, and separation anxiety were common among children with Dup7 and occurred significantly more often than for children with WS (all ps < .0001). 50% of the Dup7 group but only 2% of the WS group met criteria for Social Phobia. For Selective Mutism, 23.1% of the Dup7 group but no one in the WS group met criteria, and for Separation Anxiety, 15.4% of the Dup7 group but only 1.5% of the WS group met criteria. Generalized Anxiety Disorder diagnoses occurred at about the same rate in both groups (7.7% for the Dup7 group, 6.4% for the WS group). Two children in each group met criteria for Obsessive-Compulsive Disorder. None of the children met criteria for Post-traumatic Stress Disorder or for Panic Disorder with or without Agoraphobia. One child in each group had a depression type diagnosis. ADHD diagnoses were common for both groups but were significantly more likely (p = .002) for the WS group (66.7%) than for the Dup7 group (42.3%). An ODD or Disruptive Behavior - NOS diagnosis was common for the Dup7 group (28.8%) and occurred significantly more often (p < .0001) than for the WS group (6.9%). None of the children met criteria for Conduct Disorder. Statistical comparisons of the distributions for each group on the Conners CBRS scales corresponding to these ADIS diagnoses were conducted with Mann-Whitney U tests. The pattern of between-syndrome differences was consistent with the pattern for the ADIS diagnoses. In particular, the distribution of T-scores on the ADHD - Predominantly Inattentive Type Scale was significantly higher for the WS group than for the Dup7 group (p = .01), and the distributions on the Separation Anxiety Disorder scale and Social Phobia scale were significantly higher for the Dup7 group than for the WS group (ps < .0001).

**Discussion:** Internalizing and externalizing psychiatric diagnoses were common in both the WS and Dup7 groups, although the pattern of diagnoses differed across groups. Results suggest a dosage effect of one or more genes in the 7q11.23 region on individual differences in these diagnoses. Theoretical implications will be discussed.

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**Symposium 4: Deletion and Duplication of the Williams Syndrome Region: Relations with Anxiety Disorders, Externalizing Disorders, and Autism**

**Paper 2: Socio-Communicative Functioning of Verbal Children with Williams Syndrome: Performance on the Autism Diagnostic Observation Schedule Modules 2 and 3**

Faye van der Fluit, University of Wisconsin - Milwaukee; Carolyn B. Mervis, University of Louisville; Catherine Lord, Weill Cornell Medical Center; Bonita P. Klein-Tasman, University of Wisconsin - Milwaukee

**Introduction:** Children with Williams syndrome (WS), a genetic disorder resulting from a deletion of ~25 genes on chromosome 7q11.23, show a unique pattern of cognitive abilities and a distinctive personality profile. They are often described as friendly, outgoing, and highly sociable (Gosch & Pankau, 1997; Klein-Tasman & Mervis, 2003; Tomc et al., 1990), which has historically led some to contrast WS with autism spectrum disorders (ASDs). However, recent research has revealed weaknesses in the same areas as are affected in ASDs (i.e., verbal communication, social interactions, and restricted patterns of behavior; Laing et al., 2002; Stojanovik et al., 2001; Udwin & Yule, 1999; Klein-Tasman et al., 2010). Research using the Autism Diagnostic Observation Schedule (ADOS) Module 1 with young children with WS who either were nonverbal or communicated primarily in single-word utterances has revealed that almost 50% had more sociocommunicative difficulties than expected based on developmental delay alone. Difficulties with joint attention, eye contact, integration of gaze with other behaviors, and the use of gestures were especially common (Klein-Tasman et al., 2007, 2009). The present study aims to extend these findings by describing the sociocommunicative functioning of children with WS who had more advanced language skills.

**Methods:** Children were administered a measure of cognitive ability (Differential Ability Scales, DAS) and the ADOS. 34 children with WS (M age = 5.39 years, SD = 1.11; mean GCA = 59.93, SD = 13.02) were administered Module 2 (M2) of the ADOS and 50 children with WS (mean age = 10.05 years, SD = 2.55; mean GCA = 65.20, SD = 12.13) were administered Module 3 (M3). Two contrast groups, one composed of children with developmental disabilities of mixed etiology (ME) and one composed of children with PDD-NOS diagnoses who did not have known genetic syndromes, were also included.

**Results:** 26% of the children with WS who completed ADOS M2 and 30% who completed ADOS M3 exceeded the ADOS ASD cutoff. Speech abnormalities, conversational difficulties, paucity of directed facial expressions and gestures, and repetitive behaviors were common for children with WS regardless of their ultimate ADOS classification. Children with WS also struggled to express understanding of the nature of social relationships. Relative to the children with WS who did not have ASD classifications (WS-NS group), the children with WS who had ASD classifications (WS-ASD group) demonstrated less enjoyment in interaction [M2: t(33) = -3.02, p < .01; M3: t(49) = 5.08, p < .001], had overall poorer quality social overtures [M2: t(33) = -5.10, p < .001; M3: t(49) = -4.74, p < .001] and responses [M2: t(33) = -4.97, p < .001; M3: t(49) = -7.35, p < .001], and poorer rapport with the examiner [M2: t(33) = -4.80, p < .001; M3: t(49) = -6.72, p < .001]. The WS group as a whole demonstrated difficulties at a level similar to the ME group but evidenced less difficulty than did the PDD-NOS group [M2: t(66) = -5.28, p < .001; M3: t(88) = -6.04, p < .001]. However, the children in the WS-ASD group had difficulties at a level similar to the PDD-NOS group [M2: t(41) = 0.31, p = .76; M3: t(56) = -0.84, p = .41].

**Discussion:** The majority of the children with WS did not demonstrate sociocommunicative difficulties commensurate with those seen in children with ASDs. However, the proportion of children with WS with significant sociocommunicative impairments (ASD classifications on the ADOS) was considerably higher than in the general population, and when these impairments were present, they were similar to those for children with PDD-NOS. Implications for clinical management of children with WS and future genotype-phenotype investigations will be discussed.

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**Symposium 4: Deletion and Duplication of the Williams Syndrome Region: Relations with Anxiety Disorders, Externalizing Disorders, and Autism**

**Paper 3: Children with 7q11.23 Duplication Syndrome: Findings from Gold-Standard Autism Spectrum Disorder Assessment Measures**

Bonita P. Klein-Tasman, University of Wisconsin - Milwaukee; Danielle M. Walerius, University of Louisville; Carolyn B. Mervis, University of Louisville

**Introduction:** Recent findings from studies of de novo copy number variants (CNVs) in a large sample of children in the Simons Simplex Collection identified a strong association between duplication of the Williams syndrome region (Dup7q11.23) and autism (Levy et al., 2011; Sanders et al., 2011). In the current study, gold-standard diagnostic assessments of ASD symptomatology were conducted for a group of children with Dup7q11.23 who participated in a specialty research clinic for individuals with this syndrome.

**Methods:** Participants were 29 children with genetically confirmed Dup7q11.23 (10 girls, 19 boys), ranging in age between 4 and 17 years (M age = 7.84 years, SD = 3.43). A comprehensive battery assessing cognitive, language, and psychosocial functioning was administered by a multidisciplinary team, including autism spectrum diagnosis by a Licensed Psychologist with specialized training in the diagnosis of ASD. Within this battery, parents were interviewed about ASD-related symptomatology with the Autism Diagnostic Interview - Revised (ADI-R) and children were administered a measure of cognitive functioning (Differential Ability Scales-II; DAS-II) as well as the appropriate module of the Autism Diagnostic Observation Schedule - 2 (ADOS-2; Mod 1 n = 4, Mod 2 n = 11, Mod 3 n = 14).

**Results:** Mean cognitive functioning was in the low average range (DAS-II GCA M = 81.55, SD = 16.49). Based on the ADOS-2 algorithm, 24 children (83%) were classified as Nonspectrum (NS) and 5 (17%) were classified "autism spectrum (AS)" (3 "AS", 2 "autism"). Of the children classified "NS," 13 had severity scores of 1 (minimal to no evidence), four had severity scores of 2, and seven had severity scores of 3. Based on the ADI-R diagnostic algorithm, which heavily weights retrospective accounts of functioning, 11 participants (38%) were classified "autism." Accounts of current functioning and retrospective accounts of functioning were sometimes discrepant. All of the participants classified "AS" or "autism" by the ADOS-2 also exceeded the ADI-R cutoffs. Based on a combination of ADOS-2, ADI-R, and clinical judgment, four of the five participants classified "autism spectrum" or "autism" by both the ADOS-2 and the ADI-R were diagnosed with an autism spectrum disorder clinically (14% of the sample). The remaining participant showed significant communication difficulties and repetitive behaviors but current social affective reciprocity was largely appropriate, and diagnosis was therefore not made. Discussion: Careful characterization of the triad of impairments using both gold-standard ASD assessment measures combined with clinical judgment indicated that about 14% of children with Dup7q11.23 showed symptomatology consistent with an ASD clinical diagnosis. This rate indicates an elevated risk in comparison to the general population but also suggests that the presence of Dup7q11.23 by itself is not strongly indicative of the presence of an ASD. Reliance on parental report alone results in a higher rate (38%) of identified ASD-related symptomatology. It is likely that the children's history of language impairments coupled with extreme social anxiety and/or considerable shyness characteristic of the syndrome contributes heavily to parental observations of sociocommunicative challenges, based on retrospective report in particular. The implications of these findings for clinical management of children with Dup7q11.23 and for genotype-phenotype investigations will be addressed.

Supported by a grant from the Simons Foundation (SFARI award #238896).
These three papers describe the results of an RCT on the effects of daily vs weekly Milieu Communication Teaching on the communication and language of preschoolers with intellectual disabilities. This well-conducted experiment provides a rich source of information regarding the complexity of answer to question of whether more is better. The first provides a description of the overall study and indicates that dose frequency effects on vocabulary, the primary dependent variable, are limited to children with Down syndrome and those with high object interest. The second provides a description of the test of the main effects of dose frequency on speech-like vocal communication early in the treatment phase. The final presentation indicates that dose frequency effects on vocabulary in children with Down syndrome occurred because of earlier effects on receptive vocabulary growth and speech-like vocal communication.
**Symposium 5: Dose Frequency Effects on Early Communication and Vocabulary**

**Paper 1: Dose Frequency Effects on Vocabulary in Preschoolers with Intellectual Disabilities**

Marc Fey, University of Kansas; Paul Yoder, Vanderbilt; Steve Warren, University of Kansas

**Introduction:** The basic goal of Prelinguistic Milieu Teaching is to facilitate nonverbal children's communication skills by combining eye contact, physical gestures, and vocalizations in children into a solid foundation of nonverbal skills that can serve as the basis for early spoken language. Once children in PMT begin reliably using words in their communication acts, they are provided with the theoretically consistent milieu teaching (MT), which targets production of early words and word combinations. When provided together, in sequence, we refer to these interventions as milieu communication teaching (MCT). Over several group experimental studies, effects of MCT have generally been positive but medium in magnitude, and conditional, influencing only children with characteristics such as responsive parents, etiology other than down syndrome (DS), or limited vocalizations. One speculated reason for the absence of broader and stronger effects is that MCT has been studied exclusively as a low intensity intervention, with 3 or 4 weekly sessions, 20 min in length. In the present study, we compared the outcomes of MCT when delivered in one weekly one-hour session (weekly) and when delivered in five one-hour sessions per week (daily) over a 9-month period. Specifically, we asked whether daily one-hour doses of MCT would lead to significantly more words reported on the McArthur-Bates Communicative Development Inventories than weekly doses. We asked further whether the effects of MCT dose frequency were moderated by the children's level of object play, parental responsivity, presence or absence of DS, rate of child intentional communication at study onset, and level of parental stress.

**Method:** Analyses were performed on 64 children, 33 of whom were randomly assigned to receive daily doses of MCT, and 31 of whom received weekly doses. 35 children had DS and 29 had other etiologies for their ID. Participants averaged 22 months in chronological age and 12 months in developmental age. At study onset, they produced an average of three words or signs and averaged 60 words understood, based on parental report. There were no statistically significant differences between groups on 34 preexperimental measures on which they were compared. All analyses were based on data collected at five points: immediately before treatment, three months, six months, nine months (the end of treatment), and 15 months after treatment onset. Communication was evaluated observationally and by parent report at each time point. All testing and coding was carried out by individuals who were blind to group assignments of the children. Linear and nonlinear growth curve analyses were performed to address the experiment questions.

**Results:** Considering both DS and non-DS groups collectively, the model that best fit the data included a random quadratic term. Spoken word inventories at nine-months (the end of MCT) were significantly smaller for children with DS than for children without DS. When growth curves were modeled within the DS and non--DS subgroups and with the children's developmental quotients controlled, dose frequency was shown to have a significant, positive effect on the spoken vocabulary outcomes of children with DS. Children with DS were reported to use more words after nine months of treatment if they got daily rather than weekly MCT. No effects of dose frequency were observed for the non--DS subgroup. Only one of the suspected mediators or moderators of MCT was shown to have a significant effect on outcomes. Taken collectively or as separate DS and non-DS subgroups, children who demonstrated high interest in functional play with objects at study onset made greater vocabulary gains if they received daily rather than weekly MCT. Thus, object interest moderated the relationship between MCT and word usage for children with language learning problems, regardless of the etiology for their ID.

**Discussion:** This study adds to an increasing body of evidence indicating that children with DS have vocabulary learning problems that by the age of three or before limit the number of words they speak even by comparison with a group of children with ID and similar developmental ages. The study also indicates that more MCT may be significantly better than less for children with DS. Children with a strong interest in object play may also benefit from more frequent MCT sessions, whether or not they have DS.
Symposium 5: Dose Frequency Effects on Early Communication and Vocabulary

Paper 2: Does Dose Frequency of an Early Communication Intervention Affect a Key Prelinguistic Communication Skill in Toddlers with Intellectual Disabilities?

Tiffany Woynaroski, Vanderbilt University; Paul Yoder, Vanderbilt University; Marc Fey, University of Kansas; Steve Warren, University of Kansas

Introduction: Many children with intellectual disabilities (ID) struggle to develop spoken language. Previous studies have demonstrated that spoken language in children with ID is predicted, in part, by a prelinguistic skill called canonical syllabic communication (Yoder & Warren, 2004; Yoder, Warren, & McCathren, 1998). Canonical syllabic communication acts are intentional acts that serve a communication function and contain at least one canonical syllable (i.e., consonant and vowel sequence produced with adult-like speech timing; Oller, Wieman, Doyle, & Ross, 1976). This particular prelinguistic skill may signal that a child with ID is poised to develop spoken words. In this study, we evaluated whether increasing the dose frequency of a popular communication and language treatment produces an effect on canonical syllabic communication as measured after only 3 months of treatment (Yoder & Warren, 2004; Yoder et al., 1998).

Methods: The present study draws on extant data from our previous RCT (Fey, Yoder, Warren, & Bredin-Oja, 2013; Yoder, Woynaroski, Fey, & Warren, in press) in which 63 prelinguistic toddlers with ID were randomly assigned to receive Milieu Communication Teaching (MCT; Fey et al., 2006) at either high dose frequency (five, 1 hour sessions per week) or low dose frequency (one, 1 hour session per week) over a period of nine months (Fey et al., 2013; Yoder et al., in press). Daily and weekly treatment groups were non-significantly different on several important variables, including canonical syllabic communication, at entry to the study. Additionally, attrition was low, and attendance to non-project treatment was equally distributed between dose frequency groups. Finally, fidelity of treatment coding confirmed that children in the high dose frequency treatment group experienced about 4 times more cumulative teaching episodes than the low dose frequency treatment group over the course of treatment. Children’s canonical syllabic communication after three months of treatment was measured in three sampling contexts that varied in the level of structure provided and in the familiarity of the examiner: a) the Communication and Symbolic Behavior Scales sample Communicative Temptations and Book Sharing procedures (Wetherby & Prizant, 1993); b) an examiner-child semi-structured free play, and c) a parent-child free play. Communication samples were coded for intentional child communication acts and the production of canonical syllables. The metric employed in analyses was the proportion of child communication acts in which canonical syllables were used across the three communication samples (i.e., number of child communication acts including a canonical syllable/ total number of child communication acts). The ICC estimate of the reliability of inter-observer agreement, based on a randomly selected sample of the sessions, was .97.

Results: An independent samples t-test confirmed that participants produced a higher proportion of communication acts including canonical syllables after three months of treatment if they had received five, 1 hour MCT sessions per week (M = .37 , SD = .27) than if they received only one, 1 hour MCT session per week (M = .23 , SD = .20), t(61) = 2.34, p = .02 (g = .58).

Discussion: The present result extends our previous findings by demonstrating that the four-fold increase in MCT dose frequency that we achieved yielded an unconditional, medium-sized effect on children’s canonical syllabic communication after only three months of treatment.

Key References:


Symposium 5: Dose Frequency Effects on Early Communication and Vocabulary

Paper 3: Why Does Dose Frequency Effect Vocabulary in Preschoolers with Down Syndrome?

Paul Yoder, Vanderbilt University; Tiffany Woynaroski, Vanderbilt University; Marc Fey, University of Kansas; Steve Warren, University of Kansas

Problem: Children with Down syndrome (DS) have particular difficulty acquiring spoken vocabulary. Fortunately, a recent randomized clinical trial with strong internal validity showed that daily communication and language therapy resulted in more favorable spoken vocabulary outcomes relative to weekly therapy (i.e., a dose frequency effect) for a sample of 35 initially, nonverbal preschoolers with Down syndrome (DS). Knowledge of at least one of the mechanisms of this dose frequency effect would enhance the clinical and policy value of this finding. Empirical and theoretical bases exist for hypothesizing that the extent to which children use speech-like but nonsymbolic vocal communication (canonical syllabic communication) mediates the dose frequency effect on spoken vocabulary in children with intellectual disabilities, some of whom have DS.

Research Questions: Is there a greater effect of daily MCT versus weekly MCT for canonical syllabic communication and receptive vocabulary in children with DS that is detectable early in the treatment phase? Is the previously observed dose frequency effect on spoken vocabulary outcomes of children with DS explained by earlier dose frequency effects on canonical syllabic communication?

Design and Participants: A randomized control trial with strong internal validity on 35 initially-nonverbal preschoolers with DS. The two groups were different only whether they received Daily (five 1-hour session per week) vs. Weekly (one 1-hour session per week) Milieu Communication Teaching (MCT) in their homes for 9 months. Non-project treatment attendance during the treatment phase was similar (about 2.5 hours per month in each group) and nonsignificantly different (p = .56) between dose frequency groups. Attrition was low (5%).

Measures: These included (a) monthly fidelity of treatment coding to documents the extent to which the attempt to manipulate dose frequency experimentally was successful, (b) proportion of communication of acts with canonical syllables three months into the treatment phase, (c) number of words parents said child used at the post-treatment period.

Results: Mean cumulative exposure to correct teaching episodes was more than four times greater for daily (M = 9718, SD = 3417) versus weekly (M = 2242, SD = 519) MCT groups, t(33) = 8.6, p < .001, d = 2.7. The following results are from analyses that control for IQ. The total effect of dose frequency on spoken vocabulary was significant and positive, .38, 95% CI [.03, .73]. Contemporary mediational analysis showed: (a) The indirect effect of dose frequency on spoken vocabulary through canonical syllabic communication was significant, AB = .18, 95% CI [.03, .50] and (b) The direct effect of dose frequency on spoken vocabulary, controlling for canonical syllabic communication, was not significant, .20, 95% CI [-.15, .57].

Discussion: It has been proposed that children with DS may struggle with spoken language acquisition due to difficulty with planning or executing motor programs used to produce the speech sounds that, when combined, comprise words (Miller & Leddy, 1999). The mediation model results are compatible with the concept that, although producing words is difficult for children with DS, more MCT therapy may aid practice and feedback in a way that enables sufficient vocal control and accuracy to enhance spoken vocabulary despite possible motor dysfunction.
Symposium 5: Dose Frequency Effects on Early Communication and Vocabulary

Paper 4: Discussion

Steve Warren, University of Kansas

This discussion will summarize the importance of the findings to the field in light of the broader context of studies on dose of early intervention or language interventions.
The evidence would suggest that people with intellectual and developmental disabilities are more vulnerable to mental health problems. Yet they remain doubly disadvantaged due to an absence of evidence about effective psycho-social interventions.

This symposium presents work on the development of novel interventions targeted to the needs and circumstances of people with intellectual and developmental disabilities; behavioural activation for people with intellectual disabilities and depression and a CBT intervention for people with Aspergers and anxiety. The former work has led to a multi-centre randomised trial being funded and the latter study has used a randomised design. This leads into the final presentation concerning early data from a very large initiative in England to offer increased access to psychological therapies for all people with mental health problems, including those with intellectual and developmental disabilities. It is hoped that reflecting on the delivery of psychological therapies to clients with intellectual and developmental disabilities through generic services, will stimulate debate about the need for the kind of specialist therapies that have been described in the first two presentations versus the right to better access to mental health professionals who should serve all.
**Symposium 6: Psychological Interventions for Individuals with Developmental Disability and Co-Occurring Mental Health Problems: New Evidence and Delivery**

**Paper 1: Group Cognitive Behavioural Therapy for People with Asperger Syndrome Who Have Problems with Anxiety: The Initial Results of the Passa Pilot Treatment Trial**

Peter Langdon, University of East Anglia; Glynis Murphy, University of Kent; Edward Wilson, University of East Anglia; Lee Shepstone, University of East Anglia; David Fowler, Norfolk and Suffolk NHS Foundation Trust

**Introduction:** A number of studies have established that children, adolescents and adults with Asperger Syndrome (AS) and high functioning autism (HFA) have significant problems with anxiety. Cognitive behavioural therapy (CBT) is an effective treatment for anxiety in a variety of clinical populations, and there is a growing interest in exploring the effectiveness of CBT for people with AS who have mental health problems. The current study aims to examine whether modified group CBT for clinically significant anxiety in an AS population is likely to be efficacious.

**Methods:** This study is a randomised single-blind cross-over trial. Fifty-four participants were randomised into a treatment arm or a waiting-list control arm. During treatment, individuals received 3 sessions of individual CBT, followed by 21 sessions of group CBT. Primary outcome measures focused on anxiety. Secondary outcome measures focused on everyday social and psychiatric functioning, additional measures of anxiety and fear, depression, health-related quality of life and treatment cost.

**Results:** The initial findings from this pilot trial suggest that group CBT may be helpful for people with AS, and a further definitive trial is warranted. The effects on anxiety, depression and social functioning will be presented, along with acceptability and feasibility data.

**Reference:**

Introduction: Important work has been carried out adapting Cognitive Behavioural Therapy for people with intellectual disabilities. Unfortunately CBT can make excessive cognitive and communicative demands for many people. Behavioural Activation (BA) for depression is less reliant on verbal communication and focuses on increasing purposeful activity and reducing avoidance. This pilot study examined the feasibility of an adapted manualised version of BA for people with intellectual disabilities. The intervention consisted of 9-11 sessions and a key adaptation was that the therapist worked with the clients alongside a significant other in their life, either a paid carer or family member. Tasks included goal setting, activity scheduling and skills training.

Methods: Twenty-three adults with intellectual disabilities with symptoms of depression were recruited from specialist health services in two Scottish Health Boards. Baseline, post intervention and 3 month follow-up data were gathered by a researcher independently from the therapist. Primary outcome data were gathered, where possible, concerning self and informant report of depressive symptoms. However, 4 participants did not have sufficient understanding or communicative skills to complete the self-report measure. Data was also gathered about the participants' levels of activity and their general well-being.

Results: In terms of feasibility the therapy was well received and only two individuals dropped out of the therapy, with a further two lost to follow-up. Pre to post intervention data showed a significant reduction in self-report of depressive symptoms with a strong effect size (r =.78), that was maintained at follow-up (r=.86). Positive change was also obtained for informant reports of depressive symptoms from pre to post intervention, with a strong effect size (r=.7). Once again, the effect was maintained at follow-up (r=.72). There was little evidence of increase in the participants' level of activity, although the informants reported a significant increase in the participants' overall sense of well-being.

Discussion: The study suggested that BEAT-IT may be a feasible and worthwhile approach to tackling depression in people with intellectual disabilities. However, a randomised controlled trial would be required to establish its effectiveness, with more sensitive measurement of change in activity. A randomised controlled trial comparing a behavioural activation treatment for depression in adults with learning disabilities with an attention control has now been funded and is underway.

**Symposium 6: Psychological Interventions for Individuals with Developmental Disability and Co-Occurring Mental Health Problems: New Evidence and Delivery**

**Paper 3: Equity of Access and Effectiveness of Mainstream Primary Care Mental Health Services for Adults with Intellectual Disabilities: The Case of IAPT Services in Cumbria, England**

Chris Hatton, University of Lancaster; Dave Dagnan, University of Lancaster, Cumbria Partnership NHS Foundation Trust; Richard Thwaites, Cumbria Partnership NHS Foundation Trust; John Masson, Cumbria Partnership NHS Foundation Trust; Amy Cavagin, Cumbria Partnership NHS Foundation Trust

**Introduction:** In England ambitious goals for universally accessible psychological interventions for adults with mental health problems, based in primary care, have been rolled out (called Improving Access to Psychological Therapies, or IAPT). Despite the stated intention of IAPT services to cater for all adults with mental health problems, the uptake and effectiveness of these services for people with intellectual disabilities is unknown.

**Methods:** Data for all referrals to IAPT services in the first two years of its operation in one English county, Cumbria, were cross-referred to health and social service databases to ascertain which adults known to specialist intellectual disability services had accessed the IAPT service.

**Results:** Of the 27,064 adults in contact with the IAPT service, 72 (0.27%) were identified by specialist health services as people with intellectual disabilities. Around 90% of referrals across both groups were made by general medical practitioners, with similar proportions across both groups diagnosed with anxiety and/or depressive disorders. Once contact had been made with the IAPT service, people with intellectual disabilities were more likely than the general population to be referred or signposted elsewhere and were less likely to be discharged as a result of completed treatment. However, if people with intellectual disabilities did complete IAPT treatment positive outcomes were reported for a majority of cases.

**Discussion:** There are barriers to accessing effective IAPT services for adults with intellectual disabilities, but IAPT services can be effective for adults with intellectual disabilities and mental health problems.
Symposium 7 Title: The Co-Occurrence of Anxiety in Fragile X and Idiopathic Autism: A Behavioral and Biomarker Approach to Assessment and Treatment Across the Lifespan

Chair: Jane E. Roberts, University of South Carolina

Autism spectrum disorder (ASD) and fragile X syndrome (FXS) are neurodevelopmental disorders with a high co-occurrence of behavioral and psychiatric conditions. Anxiety is one most common co-morbid conditions affecting nearly 70% of males with FXS and up to 80% of males with ASD. Despite the high association of anxiety in ASD and FXS, little work has been done to examine the developmental pathway and underlying mechanisms in either of these conditions. This symposium represents behavioral data and biomarkers focused on developmental trajectories, outcomes, treatment and underlying mechanisms of anxiety in children with ASD and FXS and in women with the FMR1 premutation. A central tenet of these presentations is the importance of recognizing multiple etiological mechanisms for anxiety including genetic, physiological, social and environmental factors that vary and interact across and within persons in a transactional manner over time.
Introduction: The prenatal period is a critical time of development with heightened vulnerability to a number of endogenous and exogenous factors. A relationship between maternal anxiety during pregnancy, known as antenatal anxiety, and negative child outcomes has been consistently found in the literature in non-clinical samples. Children with mothers who experienced antenatal anxiety are associated with higher rates of inattention, anxiety and poor executive functioning. To date, research on antenatal anxiety and child outcomes is almost exclusively limited to non-clinical populations. Therefore, little is known about the relationship between maternal anxiety during pregnancy and suboptimal cognitive and behavioral development in children with disabilities. Families with FXS are a unique population with which to examine these relationships, as children with the full mutation have higher rates of problem behavior and cognitive deficits compared to typical children and mothers with the pre- and full-mutation are at an increased risk for developing mood and anxiety disorders themselves. The current study examines the relationship between maternal antenatal anxiety and child outcomes, specifically attention, internalizing and anxiety/depression symptoms and HPA axis functioning in children with the full mutation. We hypothesized that elevated maternal antenatal and current anxiety would be associated with poor attention, increased anxiety/depression and internalizing behaviors and elevated cortisol in the children.

Methods: Data on 93 mothers with the FMR1 premutation (M age=36.40) and their children with the full mutation were included (79 boys, M age= 6.1 years; 14 girls, M age = 4.8 years). Maternal current and antenatal anxiety were determined using the Structured Clinical Interview for DSM Disorders. Antenatal anxiety was defined as meeting diagnostic criteria for any anxiety disorder at any time during pregnancy using onset and offset dates for each episode. Nineteen (20%) of mothers met criteria for antenatal anxiety. Thirty (32%) mothers met criteria for current anxiety disorder and two of these mothers also met for current mood disorder. Child problem behavior was assessed using the Child Behavior Checklist domains of internalizing, attention, and anxiety/depression symptoms. Salivary cortisol at baseline, reactivity, and change was included to examine the influence of maternal antenatal stress on child HPA functioning.

Results: Multiple regression models were used to test the hypotheses. Antenatal anxiety predicted child anxiety/depression F (2, 79) = 9.771, p = <.001, R^2=.20 controlling for current maternal anxiety. In contrast, current maternal anxiety predicted child internalizing scores F (3, 77) = 19.440, p = .000, R^2=.269 and child attention F (3, 86) = 3.958, p = .011, R^2=.13 controlling for antenatal anxiety. Neither antenatal nor current maternal anxiety predicted child salivary cortisol.

Discussion: The results of this study provide support for a relationship between antenatal anxiety in mothers with the FMR1 premutation and anxious/depressive behaviors in their children with the full mutation. These findings align with previous evidence that antenatal anxiety leads to suboptimal child outcomes, specifically increased rates of anxiety and depression. The ability to identify early indicators of anxiety/depression in children with the full mutation is critical, as anxiety is present at such high rates in FXS. The current finding on the relationship between maternal antenatal anxiety and increased rates of anxiety/depression in children with the full mutation provides support for prevention treatment efforts aimed at reducing maternal anxiety with assumed benefits to the child, mother and family system.
**Symposium 7:** The Co-Occurrence of Anxiety in Fragile X and Idiopathic Autism: A Behavioral and Biomarker Approach to Assessment and Treatment Across the Lifespan

**Paper 2:** Anxiety as a Predictor of Pragmatic Language Difficulties in Women with the FMR1 Premutation

Jessica Klusek, University of South Carolina; Jane E. Roberts, University of South Carolina, University of South Carolina

**Introduction:** New population-based screening indicates that 1 in 151 women have premutation alleles on the Fragile X Mental Retardation-1 (FMR1) gene (Seltzer, Baker, et al., 2012), which highlights research on the clinical phenotype of the FMR1 premutation as a significant public health priority. Emerging evidence suggests that individuals with the FMR1 premutation show difficulties with pragmatic language, or the social use of language (Aziz et al., 2003; Losh, Klusek, et al., 2012). Pragmatic language skills are critical for effective communication, and deficits in this area may lead to ineffective social interchange and difficulty managing social relationships (Bates, 1976). Given that anxiety disorders are common in the FMR1 premutation (Bailey et al., 2008; Roberts et al., 2009), and anxiety has been shown to negatively impact pragmatic abilities in the study of other populations (e.g., Solomon et al., 2008), this study examined the interplay between anxiety and pragmatic difficulties in the FMR1 premutation.

**Methods:** Participants included 13 adult women with the FMR1 premutation who were mothers of an adolescent son with fragile X syndrome (aged 15-21 years). Data represent preliminary analyses from a larger ongoing study; it is projected that data from an additional 12 participants will be collected and available for analysis at the time of presentation, as well as data from a comparison sample of mothers of sons with autism spectrum disorder. Pragmatic language features of the women were characterized with the pragmatic language subscale of the Broad Autism Phenotype Questionnaire (BAP-Q; Hurley et al., 2007). General anxiety was measured with the Beck Anxiety Inventory (BAI; Beck & Steer, 1990), and anxiety specific to social situations was indexed with the Liebowitz Social Anxiety Scale (LSAS; Liebowitz, 1987).

**Results:** Linear regression showed that symptoms of general anxiety on the BAI accounted for 49% of the variance in pragmatic language scores on the BAP-Q \( R^2 = .49, F (1, 12) = 10.35, p = .008 \). Social anxiety as indexed with the LSAS did not account for significant variance in pragmatic language abilities \( R^2 = .15, F (1, 12) = 1.99, p = .186 \).

**Discussion:** Results suggest that symptoms of general anxiety (such as nervousness, difficulty breathing, and lightheadedness) are linked with pragmatic language difficulties that are seen as part of the FMR1 premutation phenotype. Social anxiety, on the other hand, did not predict pragmatic language abilities. These findings suggest that pragmatic language difficulties in the FMR1 premutation are not rooted in social fear or avoidance, but rather may stem from anxiety more broadly. The results of this study may have implications for potential prevention and treatment efforts, and may inform underpinnings of language phenotypes associated with the FMR1 premutation and dysfunction of the FMR1 gene more generally.
Introduction: The mother-child relationship has been implicated as a potential source of child anxiety (1). Additionally, literature supports that familial anxiety may have a bidirectional impact on parent and child (2). Biological mothers of children with fragile X syndrome are premutation or full mutation carriers with an altered form of the FMR1 gene and at increased risk for anxiety and mood disorders (3). Additionally, anxiety is considered a core symptom of fragile X syndrome (4). Thus, the mother-child dyad of families affected by fragile X syndrome is likely to be strongly shaped by anxiety.

Expressed emotion (EE) is a quantitative measure of attitudes along dimensions such as criticism and emotional over-involvement expressed by one individual toward another. The Five Minute Speech Sample (FMSS) is a measure of EE that is often used to gauge the emotional climate between family members. A number of studies have demonstrated that high EE, (reflective of high criticism and/or over-involvement) on the part of the parents is predictive of symptom exacerbation in sons/daughters across a variety of conditions including schizophrenia, anxiety, obsessive compulsive disorder, depression, autism & intellectual disability (5,6, 7). Therefore, the current study examined association between maternal EE and anxiety in their adolescent or adult sons with fragile X syndrome.

Methods: Twenty biological mothers of adolescent and young adult males ranging in age from 15 - 22 with fragile X syndrome (FXS) were interviewed using the Five Minute Speech Sample (FMSS) to assess EE. Each mother was asked to speak for five minutes about her son stating her thoughts and feelings about him and describing her relationship with him. Each speech sample was then independently coded with respect to verbal content and tone by two trained coders to assure reliability. Overall EE was calculated from measuring dimensions of criticism and emotional over-involvement. Additionally, each mother filled out the Anxiety, Depression, and Mood Scale (ADAMS)(8) regarding their son’s symptoms. A two-tailed T-Test was used to compare the anxiety levels of sons of mothers with low EE ratings with sons of mothers with high EE ratings. Data collection for this study is ongoing, with the intention of further defining the factors that contribute to high EE ratings in fragile X families and to delineate aspects of low EE ratings that contribute to effective family dynamics. Additionally, data is currently being collected for mothers of same-age males with autism spectrum disorder to allow for cross-syndrome comparisons.

Results: Significant group differences (p = .03) on participants enrolled thus far emerged between the sons of mothers with low EE ratings (M 3.78, SD 2.4) and those of mothers with high EE ratings (M 6.64, SD 2.9). Therefore, the sons of mothers with low EE (n = 9) were significantly less anxious than the sons of mothers with high EE ratings (n =11).

Discussion: These results are consistent with the claim that high EE exacerbates core symptoms of an existing disorder, although our ongoing longitudinal analyses will help to clarify the direction of causation. Thus, it would follow that low EE would contribute to decreasing symptoms. This suggests that psychoeducational intervention may lead to more effective family dynamics by providing guidance and support to those members measuring high in EE. Modifying parenting style may be an important component of a treatment plan for the child who suffers from anxiety. Furthermore, due to the bidirectional effect of anxiety, intervention may also provide respite to the mother. This is of particular importance in families of fragile X as carriers often suffer symptoms of anxiety.

References/Citations:
(1)Raudino et al., 2013; (2)Schrock & Borden, 2010; (3)Bourgeois et al., 2011; (4)Cordeiro et al, 2011; (5)Magaña et al., 1985; (6)Przeworski et al., 2011; (7)Hooley, et al., 2007; (8)Esbensen, 2003)
Symposium 7: The Co-Occurrence of Anxiety in Fragile X and Idiopathic Autism: A Behavioral and Biomarker Approach to Assessment and Treatment Across the Lifespan

Paper 4: Assessment and Treatment of Anxiety and Problem Behavior in Children with Autism Spectrum Disorders and Intellectual Disability

Lauren J. Moskowitz, St. John’s University; Emile Mulder, Stony Brook University; Caitlin Walsh, Stony Brook University; Darlene McLaughlin, Positive Behavior Support Consulting; Jennifer Zarcone, Johns Hopkins School of Medicine, Kennedy Krieger Institute; Greg Hajcak Proudfit, Stony Brook University; Edward G. Carr, Stony Brook University

Introduction: Despite the increased risk for anxiety disorders in children with autism spectrum disorders (ASD; White, Oswald, Ollendick, & Scahill, 2009), there is a lack of research on the assessment and treatment of anxiety in this population, particularly for those with an intellectual disability (ID). Further, the relationship between anxiety and problem behavior has not been systematically investigated in children with ASD. Thus, the present studies evaluated a multimethod strategy for the assessment and treatment of anxiety and problem behavior in three children with comorbid ASD and ID.

Method (Study 1 - Assessment): In Study 1, the construct of “anxiety” was operationally defined using: (1) behavioral data from anxious behaviors, (2) affective/contextual data from parent-report and observer ratings of overall anxiety, and (3) physiological data (heart rate [HR] and respiratory sinus arrhythmia [RSA]). A functional assessment of problem behavior during High-Anxiety and Low-Anxiety conditions was conducted.

Results (Study 1): Results indicated a relationship between anxiety and problem behavior in that, for all three participants, substantially higher levels of problem behavior occurred in the High-Anxiety than in the Low-Anxiety contexts. Further, two of the three participants (Jon and Ben) exhibited a significantly higher HR in the High-Anxiety than in the Low-Anxiety conditions, and two of the three participants (Ben and Sam) exhibited significantly lower RSA in the High-Anxiety than in the Low-Anxiety conditions (Moskowitz et al., in press).

Introduction (Study 2 - Intervention): Although there are numerous studies demonstrating the successful treatment of anxiety in neurotypical populations, there is little research on the treatment of anxiety in children with ASD and ID.

Method (Study 2): In Study 2, a multiple baseline design was used to evaluate the effectiveness of a multicomponent behavioral intervention package to treat anxiety and associated problem behavior. The intervention package incorporated strategies from the Cognitive Behavioral Therapy (CBT) literature for neurotypical children with strategies from Applied Behavior Analysis (ABA) and Positive Behavior Support (PBS) for children with developmental disabilities.

Results (Study 2): Following intervention, all three participants showed substantial decreases in anxiety and associated problem behavior in the situations that had previously been identified as anxiety-provoking (Moskowitz et al., in preparation).

Discussion: Results of Studies 1 and 2 provide evidence that anxiety, and problem behavior related to anxiety, can be reliably assessed and treated using a multimethod approach in children with ASD and ID. Results support the hypothesis that anxiety may be causally or functionally related to problem behavior in some children with ASD and ID, in that they may engage in problem behavior to reduce their anxiety. Conceptualizing problem behavior as due to fear or anxiety rather than due to noncompliance, disobedience, anger, or irritability may lead to different interpretations and attributions by parents, teachers, and therapists, as well as different intervention strategies to reduce or prevent the problem behavior.

References:


**Symposium 7: The Co-Occurrence of Anxiety in Fragile X and Idiopathic Autism: A Behavioral and Biomarker Approach to Assessment and Treatment Across the Lifespan**

**Paper 5: Anxiety Vulnerability in Young Males with Fragile X: Maternal Predictors of Risk and Resilience**

Bridgette L. Tonnsen, University of South Carolina; Don B. Bailey, RTI International; Jane E. Roberts, University of South Carolina

**Introduction:** Children with fragile X syndrome (FXS) demonstrate high rates of anxiety disorders, with 65-83% of children meeting diagnostic criteria. The severity of anxiety symptoms in FXS is predicted by elevated negative affect across infancy and toddlerhood (Tonnsen, et al., 2013), suggesting biologically-driven vulnerability emerges early in development. However, anxiety emergence is likely moderated by multifaceted genetic, biological and environmental risk and protective factors. Mothers with the FMR1 premutation have exhibited elevated parenting stress and internalizing symptoms, which have each been associated with child behavior problems (Bailey, et al., 2008). Despite these associations, it is unclear whether maternal factors directly relate to anxiety vulnerability in high-risk children with FXS. Thus, the present study examines how maternal protective and risk factors relate to (1) child anxiety symptoms, (2) child trajectories of negative affect, and (3) the association between child anxiety and negative affect. Primary predictors include maternal indicators of risk (anxiety and depressive symptoms, parenting stress) and resilience (hope, optimism). We also examine genetic correlates in mothers (activation ratio [AR], mRNA, CGG repeats) and children (FMRP).

**Methods:** Fifty-five mother-child dyads were included from a longitudinal study of families affected by FXS. Mothers completed the Rothbart Temperament questionnaires when children were between 8 and 107 months old (average number of assessments = 3.5, range 2-7). Mothers also completed the Child Behavior Checklist, Parenting Stress Index, Beck Depression Inventory II, State Anxiety Scale, Hope Scale, and Life-Orientation Test-Revised.

**Preliminary Results:** Analyses were conducted using multilevel modeling and multiple regression, each controlling for maternal and child cognitive abilities as appropriate. Child anxiety was associated with elevated total parenting stress. Higher mean levels of negative affect were predicted by lower optimism and elevated parenting stress, particularly in the difficult child domain. Neither maternal nor child factors moderated the association between negative affect and anxiety, although higher parenting stress was associated with lower maternal AR.

**Discussion:** Our results suggest that maternal protective and risk factors are associated with both negative affect and anxiety symptoms in young males with FXS. Genetic vulnerability may also contribute to parenting stress in women with the FMR1 premutation. These data highlight the importance of contextualizing child risk factors within a broader family system. We will discuss potential implications for anxiety etiology and treatment in FXS.

**References:**


Symposium 8 Title: Characterization of Aging Individuals with Down Syndrome: Examination of Neuropsychological Measures, Neuropsychiatric Symptoms and Genetic Biomarkers

Chair: Sharon J. Krinsky-McHale, New York State Institute for Basic Research in Developmental Disabilities

Adults with Down syndrome have benefited from advances in medical care, nutritional practices, and public health policy which has resulted in a dramatic extension of their life expectancy. As a consequence, they are prone to experience health problems associated with advancing age such as Alzheimer’s disease and psychiatric disorders. This symposium will discuss the measures that characterize cognitive change, the prevalence of neuropsychiatric symptoms and genetic biomarkers that may influence risk for dementia.
**Introduction:** As adults with Down syndrome age, they are at increased risk of experiencing certain common mental health disorders like depression and anxiety [1]. However, studies examining psychiatric conditions in later adulthood are sparse and gaps exist in our knowledge about prevalence rates of specific disorders.

**Participants:** Older adults with Down syndrome (N=66; 32 males, 34 females) were examined in this study (Mage =56.4, range 50 to 73 years; MIQ =38.6, range 20 to 68). None of the participants showed the signs or symptoms of either dementia or mild cognitive impairment. All individuals were enrolled in a multidisciplinary study focused on aging and dementia [3].

**Procedure:** We administered the Neuropsychiatric Inventory (NPI; [2]) which is a structured, informant-based interview that rates symptoms in 12 domains; delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, elation/euphoria, apathy/indifference, disinhibition, irritability/lability, aberrant motor behavior, sleep, and appetite/eating disorders. We examined the presence, frequency and severity of these symptoms.

**Results:** It was exceedingly common for adults with Down syndrome who were over 50 years of age and free from dementia or mild cognitive impairment to have at least one psychiatric disorder, 74.2% (49 of 66 individuals). They were often described as exhibiting aggressive or agitated behaviors (48.5%), irritability (31.8%) anxiety (19.7%), and depression (18.2%). Disinhibition and sleep problems were each reported in 15.2% of individuals. Symptoms such as hallucinations (3.0%), delusions (9.1%), and euphoria (4.6%) were less commonly reported.

**Discussion:** This study provided information on the prevalence and nature of psychiatric disorders in older adults with Down syndrome. Longevity has dramatically increased for individuals with Down syndrome, many individuals are now living into their late 50s, 60s and even into their 70s. It is crucial to learn about the medical conditions that may be commonly encountered in later adulthood in individuals with Down syndrome. Adults with Down syndrome, along with their caregivers, need accurate information about what to anticipate as a part of growing older to help with the planning of services and foremost to ensure successful aging.

(Supported by funds from the New York State Office for People with Developmental Disabilities and NIH grant P01 HD35897 (Silverman).

**References:**


**Symposium 8: Characterization of Aging Individuals with Down Syndrome: Examination of Neuropsychological Measures, Neuropsychiatric Symptoms and Genetic Biomarkers**

**Paper 2: Measures to Characterize Cognitive Change in Adults with Down Syndrome**

Wayne Silverman, Kennedy Krieger Institute Johns Hopkins University School of Medicine; Sharon J. Krinsky-McHale, New York State Institute for Basic Research in Developmental Disabilities; Warren B. Zigman, New York State Institute for Basic Research in Developmental Disabilities, Johns Hopkins University School of Medicine

**Introduction:** The recent emphasis accelerating the process of translating advances in basic research into practice has highlighted the need for valid and objective indicators of responses to treatment and intervention. In fact, NIH is currently soliciting applications to develop and evaluate such outcome measures for use with individuals having intellectual disability (PAR-13-213). We have been following a large sample of adults with Down syndrome for many years, documenting functional, cognitive and health status. These longitudinal studies employ a battery of assessments, some developed explicitly for evaluations of individuals with intellectual disability, and we now have a rich body of data documenting the characteristics of these measures. This presentation will describe some of these characteristics and discuss the potential of these measures, as well as their limitations, as tools to quantify responses to treatment in clinical trials.

**Methods:** The cognitive assessment section of the battery examined: (a) mental status (modified MMSE, Test for Severe Impairment, longer mental status evaluation), (b) verbal fluency, (c) block design (from the WISC-R + easier items), (d) visual-motor integration, and (e) episodic memory (modified Selective Reminding Test). Testing of all participants with Down syndrome (n = 400+) has been attempted at 14-22 month intervals, taking place in a quiet room located at participants' day programs. The full battery is completed in two sessions, each lasting no longer than one hour with breaks available between instruments. However, not all individuals are able to complete all tests, and in these cases testing sessions are abbreviated. Given the length and diversity of the battery, multiple options for scoring are available. The present analyses considered only overall summary scores for each instrument.

**Results:** Analyses focused on determining: (a) "testability" and test-retest reliability when individuals were not demented (N = 287), and (b) sensitivity to changes in performance associated with development of mild cognitive impairment (MCI). As expected, testability was strongly related to severity of intellectual impairment. Testability was a major concern for people with IQs <30, but over 70% of individuals with Stanford-Binet IQs of 35-39 were able to complete most instruments (over 93% with IQs of 45+). Test-retest reliability, assessed conservatively by correlating Cycle 1 and Cycle 2 scores, ranged from 0.64 < r < 0.91. Analyses examining the ability of these instruments to detect onset of MCI focused on sensitivity and specificity. Taking a decline of 1.5 standard errors of measurement (SEM) as suggestive of MCI, specificity was good to excellent in all cases, ranging from 0.81 to 0.94, but sensitivity was only acceptable for one instrument, a modified MMSE (0.66). For other measures, sensitivity ranged from a low of 0.30 to a high of 0.51.

**Conclusions:** Findings indicated that choice of methods for assessing change within populations with ID must be sensitive to multiple factors, including severity of intellectual impairment and the anticipated impact of treatment/intervention on specific domains of functioning and cognition. In this instance, no single instrument seemed well-suited as an outcome measure in clinical trials, and combinations of instruments may prove to be needed. In addition to good psychometric properties, measures must also have high documented sensitivity and specificity to be informative.

(Supported by NIH grants PO1 HD035897, RO1AG014673 and P30HD024061 and by the New York State OPWDD.)
Introduction: Beta amyloid peptides, Aβ40 and Aβ42, are the 2 major species generated by cleavage of the amyloid precursor protein (APP), located on chromosome 21. Adults with Down syndrome (DS) have three copies of chromosome 21 and overexpress APP and other genes on chromosome 21. Overexpression of APP is associated with early onset of AD neuropathology and high risk for dementia. In previous work, we have shown that high initial levels of plasma Aβ42 in non-demented adults with DS, decreasing levels of Aβ42, a decline in the Aβ42/Aβ40 ratio and increasing levels of Aβ40 can be sensitive indicators of the development of AD. However, there are large individual differences in Aβ peptide levels, a wide range of age at onset of dementia and not all adults with DS develop dementia, suggesting the importance of additional risk factors. Factors that contribute to individual differences in initial level and rate of change in Aβ peptides are not well understood. This study examined the contribution of candidate genes for AD that may influence individual differences in Aβ peptide levels in a cohort of adults with DS.

Methods: Participants were ascertained through the developmental disability service systems of New York and neighboring states and included 254 adults with Down syndrome, 30-78 years of age, who were not demented at baseline data collection. Analyses focused on variants in candidate genes on chromosome 21 (APP, SOD1, DSCR1, RUNX1, BACE2, UMODL1 and S100β) and on variants in 51 candidate genes on other chromosomes that had been implicated in AD pathogenesis. We examined 266 single nucleotide polymorphisms (SNPs) on chromosome 21 and 1110 SNPs on other chromosomes. Genomic DNA was genotyped using an Illumina GoldenGate custom array. Clustering and genotype calling of Chromosome 21 SNPs/variants was performed using GenomeStudio genotyping module v1.8 which supports polyploidy loci. We coded the minor allele as the risk allele, and used linear regression to examine differences in levels of Aβ at baseline associated with the number of risk alleles, controlling for age, sex, level of intellectual disability and the presence of the apolipoprotein E ε4 allele.

Results: Mean age of the participants was 49.6 + 6.7 years and 194 participants (74.6%) were female. Aβ40 levels increased with age (r= .162), while Aβ42 and the ratio of Aβ42/Aβ40 levels decreased with age (r= -.0138 and r= -.0153, respectively). We found significant associations with Aβ peptides for variants from 6 of the 7 genes examined on chromosome 21 (APP, DSCR1, SOD1, BACE2, RUNX1 and UMODL1). Variants in these genes may influence β amyloid production and processing (APP, BACE2,) response to oxidative stress (SOD1, DSCR1), or structural aberrations, and neurodevelopmental DS phenotypes (RUNX1, UMODL1). We found significant associations with Aβ peptides for 19 of the 51 genes examined on other chromosomes (MTHFR, CR1, BIN1, NEDD9, MTHFD1L, RELN, MSRA, DAPK1, IDE, ALDH18A1, CALHM1, SORCS1, MS4A6A, GAB2, PICALM, SORL1, ACAN, ACE, and LDLR). The strongest associations with Aβ peptides for variants in genes on other chromosomes were in SORCS1 and IDE. Variants in these genes may influence APP trafficking (SORCS1) and β-amyloid catabolism (IDE).

Conclusion: Our findings show interrelated effects on Aβ peptides between APP and other variants associated with AD. These findings may help to understand pathways active in the pathogenesis of AD in adults with DS and guide the development of biomarkers for early identification of AD risk.

Acknowledgments: This research was supported by grants P01HD035897 (Silverman) and R01AG014673 (Schupf) from NICHD and NIA and by NYS through its Office for People with Developmental Disabilities.
**Introduction**: Linkage and association studies have provided ample evidence for significant genetic influences on risk for Alzheimer disease (AD), but the role for most of these genetic factors has not yet been investigated in adults with Down syndrome (DS). Moreover, adults with DS overexpress many genes on chromosome 21, including the gene for β amyloid precursor protein (APP). Overexpression of APP is associated with early onset of AD neuropathology and high risk for dementia. However, phenotypic expressions vary widely among individuals with DS. To better understand the importance of additional determinants of risk, this study examined the contribution of candidate genes on chromosome 21 and other chromosomes that may influence risk for dementia, age at onset of dementia, and differences in beta amyloid (Aβ) levels in a large cohort of adults with DS.

**Methods**: Participants included 357 adults with DS, 30-78 years of age at study entry. Participants were ascertained through the developmental disability service systems of New York and neighboring states and were followed at 14-18 month intervals for an average period of 4.7 (±1.9) years. Information from cognitive assessments, caregiver interviews, medical record reviews and neurological examinations was used to classify dementia onset. Using the findings from earlier genetic studies of AD, we selected and analyzed variants in candidate genes that were located on chromosome 21 as well as other chromosomes. For Chromosome 21, we examined variants on APP, SOD1, DSCR1, RUNX1, BACE2, UMODL1 and S100β. In addition, we examined 51 genes on other chromosomes. Genomic DNA was genotyped using an Illumina GoldenGate custom array. Clustering and genotype calling of Chromosome 21 SNPS/variants was performed using GenomeStudio genotyping module v1.8, which supports polyploidy loci. We coded the minor allele as the risk allele, and computed risk associated with the number of risk alleles to identify polymorphisms that confer the strongest influence on risk for AD, controlling for age, sex, level of intellectual disability and apolipoprotein E (APOE) genotype.

**Results**: Participants who developed dementia were older at study entry than those who remained non-demented (55.4 vs. 47.7 years), but did not differ in the distribution of sex or level of intellectual disability. We found significant associations with variants from 5 of the 7 genes on chromosome 21 (APP, DSCR1, RUNX1, BACE2, and UMODL1). Variants in these genes may influence Aβ production and processing (APP, BACE2, and DSCR1), response to oxidative stress (DSCR1), structural aberrations, and neurodevelopmental DS phenotypes (RUNX1 and UMODL1). Compared with those without the risk allele, relative risks for dementia ranged from 0.8-1.8. The strongest associations were with two SNPS on APP (rs2830031 and rs3991: OR=1.7 and 1.8, respectively). For genes that are not on chromosome 21, RELN, MARK4, and CST3 were significant contributors toward risk for AD. These genes are involved in neuronal development (RELN), regulation of microtubules (MARK4), and amyloid fibril formation (CST3).

**Conclusion**: These findings demonstrate that multiple genes on chromosome 21 and other chromosomes are likely to influence the wide range observed in age at onset, risk for AD through different pathways. Our findings allow better assessment of AD risk and age at onset in individuals with DS, which may lead to development of early prevention and treatment measures.

(Supported by grants R01AG014673 (Schupf) and P01HD35897 (Silverman) from NIA and NICHD and by NYS through its Office for People with Developmental Disabilities.)
Symposium 9 Title: Aggression and Self-Injurious Behavior in Individuals with Intellectual or Developmental Disabilities

Chair: Anne Wheeler, RTI International

Discussant: Jim Bodfish, Vanderbilt Kennedy Center, Vanderbilt University

Aggression and Self-Injurious Behaviors (SIB) are two of the most challenging behaviors exhibited by individuals with intellectual and developmental disabilities (IDD). This symposium will provide an overview of the nature and prevalence of aggression and SIB with a particular focus on the co-morbidity and functions of the two behaviors in different IDD groups. Specifically, data on aggression and SIB in diagnostic groups with different genetic and general phenotypic presentations (fragile X syndrome, Rett syndrome, and MECP2 duplication syndrome) will be presented. In addition, the prevalence of these specific behaviors in a clinically referred heterogeneous sample of individuals with IDD will be described with a particular focus on the evaluation of treatment options for individuals who present clinically with one or both of these behaviors.
Symposium 9: Aggression and Self-Injurious Behavior in Individuals with Intellectual or Developmental Disabilities

Paper 1: Aggressive and Self-Injurious Behaviors in the Behavioral Phenotypes of MECP2-Related Syndromes

Breanne J Byiers, Department of Educational Psychology, University of Minnesota; Sarika U Peters, Department of Pediatrics, Vanderbilt University; Frank J Symons, Department of Educational Psychology, University of Minnesota

Introduction: Loss- and gain-of-function mutations of the X-linked methyl-CpG-binding protein 2 gene (MECP2) cause Rett syndrome (RTT) and MECP2 duplication syndrome (Dup), respectively. The two syndromes share several important clinical features, including repetitive midline hand movements, communication and motor impairments, and epilepsy.1,2 To date no studies have compared the behavioral features associated with the two conditions, although self-injurious and aggressive behaviors have been reported in both syndromes.1,3 The purpose of the current study was to examine the frequency of caregiver-reported SIB and aggression among individuals with RTT and Dup.

Methods: The caregivers of 33 females with RTT (mean age = 9.8 years, range = 2-21), and 11 males with Dup (mean age = 10.2 years, range = 2-22) were recruited through syndrome-specific parent conferences. Information on SIB, aggression, other behaviors, and health problems were collected via paper surveys. Descriptive statistics and chi-square analyses were used to compare the rates of reported topographies across diagnostic groups.

Results: The majority of caregivers in both groups reported the occurrence of SIB (RTT = 86%, Dup = 55%), although it was more common in RTT (x² = 4.31, p = .038). In RTT, the most frequent topographies were rubbing/scratching (50%), and biting hands/arms (46%). In Dup, the most frequent topographies were biting hands/arms (27%), and poking eyes/ears (27%). Rates of aggressive behavior were somewhat lower, and did not differ across groups (RTT = 36%, Dup = 45%). Pinching/scratching was the most common form of aggression in RTT (24%), whereas pulling hair/skin was most common (45%) in Dup. Relationships between aggression/SIB and other behaviors will also be reported.

Discussion: This study extends previous reports of the occurrence of SIB and aggression in RTT and Dup by comparing the rates and topographies across the syndromes. These results suggest that SIB and aggression are frequent problems in both syndromes, although the specific topographies varied between the groups. Additional research is needed to identify specific risk factors, and effective intervention strategies for challenging behaviors among individuals with MECP2-related syndromes.

Key References:


**Symposium 9: Aggression and Self-Injurious Behavior in Individuals with Intellectual or Developmental Disabilities**

**Paper 2: Aggression and Self-Injurious Behaviors in Individuals with Fragile X Syndrome**

Anne Wheeler, RTI International; Melissa Raspa, RTI International; Don Bailey, RTI International; Anne Edwards, RTI International

**Introduction:** Problem behavior is one of the most challenging and debilitating aspects of fragile X syndrome (FXS) for both the individual and their caregivers [Bailey et al., 2008; Hall et al., 2007; McCarthy et al., 2006; Wheeler et al., 2008]. Although multiple types of behavior problems have been reported, including tactile defensiveness, hand flapping, poor eye contact, hyperactivity, tantrums, perseveration, hyperarousal to sensory stimuli, impulsivity, none is more disturbing or more limiting than physical aggression, behavior that results in physical harm to self or others. Aggression towards others as well as self-injurious behaviors (SIB) have both been reported in the literature, although there have been few reports of the overlap between these two within the FXS population. In order to understand and treat both of these challenging behaviors and understanding of the nature and prevalence of the overlap between aggression and SIB in the FXS population is needed.

**Methods:** As part of a large national survey, 774 caregivers of at least one child with FXS answered questions about the nature, frequency, and consequences of aggressive behavior in their child with FXS. Respondents also reported on the occurrence of SIB in these same children. Respondents chose to complete a web-based survey or a phone interview and were directed to modules based on age and genetic status.

**Results:** A large majority (>90%) of both males and females were reported to have engaged in some aggression over the previous 12 months, with a third of males and slightly fewer than 20% of females being described as engaging in moderate to severe aggression or being diagnosed or treated for aggression. Further, aggressive behaviors in males were serious enough that 30% had caused injuries to caregivers and 22% had caused injuries to peers or friends. Several of these injuries were severe enough to require a hospital or clinic visit. Of males who exhibited any aggressive behavior in the previous year, 44.16% were reported to have SIB. SIB was strongly correlated with the frequency of aggressive acts (p<.001), the reported severity of aggression (p <.001), and reported injuries to caregivers (p = .009). Additional analysis examining predictors (e.g. sensory hypersensitivity, autism co-morbidity, age) of aggression, SIB, and the co-occurrence will be reported.

**Discussion:** The results of this study suggest that the frequency and severity of aggression in a subset of individuals with FXS is considerable and deserves focused attention by researchers and service providers who work with individuals with FXS and their families. Further, there is significant overlap with regards to aggressive behavior and SIB. These results highlight an important, but not yet well studied, subset of behavioral phenotypes in fragile X syndrome.

**Key References:**


Symposium 9: Aggression and Self-Injurious Behavior in Individuals with Intellectual or Developmental Disabilities

Paper 3: Aggression and Self-Injurious Behaviors in a Broad Clinical Population

Robert B Christian, Carolina Institute for Developmental Disabilities; University of North Carolina at Chapel Hill; Anne Wheeler, RTI International; Kylee Miller, Carolina Institute for Developmental Disabilities; University of North Carolina at Chapel Hill; Adrienne Villagomez, Carolina Institute for Developmental Disabilities; University of North Carolina at Chapel Hill

Introduction: Self-injurious behavior (SIB) and external physical aggression are common presenting behavioral problems in the developmental disabilities population, with overall prevalence ranges of 10-15% for both behaviors.(Davies & Oliver, 2013). Self-injury and external aggression are often considered by clinicians and researchers as distinct in nature and definition. However, less is known regarding the extent to which these challenges co-present in the developmental disabilities population. Even less is known regarding treatment response patterns for the problem behavior groups when they do co-occur.

Methods: Using a clinically referred sample from the Behavioral Medicine Clinic at the CIDD at UNC Chapel Hill, data was reviewed from initial visits from 2009-2013. The Aberrant Behavior Checklist (ABC) was examined for 81 initial evaluations (Aman, Singh, Stewart, & Field, 1985). The 3 ABC SIB items, the external aggression item, the irritability subscale total score, and the withdrawal/lethargy subscale were reviewed. Further, presence/absence of formal diagnosis of an Autism Spectrum Disorder was noted along with intellectual disability. Descriptive statistics and multiple regressions were conducted for key variables to determine the best linear combination of gender, age, level of ID, and presence of ASD symptoms for predicting external aggression or SIB.

Results: The mean age of the group was 14.3 years and consisted of 74.1% males. The mean ABC irritability subscale score was 21.3. The overall prevalence of external aggression was 80.3% (mean aggression item score=1.53) and the overall prevalence of SIB was 58% (with a mean SIB item score of 1.53). External aggression and SIB co-occurred in 49.4% of cases and SIB occurred in isolation in a minority (8.6%) of cases. Neither age, gender, ASD status, ABC Withdrawal subscale score, nor ID severity were predictive of aggression or SIB. Additional analysis will further examine the interaction of these variables in the prediction model of the co-occurrence of aggression and SIB.

Discussion: The results of this exploratory study suggest that in this outpatient group referred for severe behavior challenges, the overall prevalence of external aggression is high and the prevalence of co-occurring SIB is high. Key variables do not seem predictive of overall aggression or overall SIB. A pending analysis will evaluate their relationship to the co-occurrence of these two behavior areas. In addition, further analysis will evaluate treatment response patterns in this group. The symposium presentation will contain a summary of what has been reported in the literature regarding the treatment response of SIB and aggression when there is co-occurrence. Findings serve as a reminder for clinicians not to overlook the possibility of SIB, even when it is not the primary concern. Future intervention studies should attend to both areas independently and together as specific outcomes of interest.

Key References:


Symposium 10 Title: Decision Capacity in Fragile X Syndrome

Chairs: Melissa Raspa and Don Bailey, RTI International

Discussant: Elizabeth Berry-Kravis, Rush University

With the advent of clinical trials to test new medications in fragile X syndrome (FXS) and the broad range of the phenotype, it is essential to examine whether and how much individuals with FXS are able to make meaningful, informed decision about their health care. This symposium will provide an introduction to decisional capacity and present preliminary data on ratings of decisional capacity in FXS.
Symposium 10: Decision Capacity in Fragile X Syndrome

Paper 1: Decisional Capacity for Informed Consent: Theory and Approach to Assessment

Paul Appelbaum, Columbia University College of Physicians & Surgeons

Introduction: Informed consent to treatment and research is predicated on patients and subjects having sufficient capacity to make meaningful choices. Since the 1970s, consensus has evolved regarding the essential components of decisional capacity, including the abilities to understand relevant information, appreciate the implications for one’s own condition, reason about the options, and evidence a choice. However, the poor reliability of clinical assessments of decisional capacity has underscored the importance of developing reliable and valid structured approaches to assessment.

Method: Beginning with the core abilities required for decisional capacity, we developed an approach to structured assessment embodied in the MacArthur Competence Assessment Tools for Treatment (MacCAT-T)1 and for Clinical Research (MacCAT-CR).2 With good reliability and validity, the tools have been applied to a wide variety of clinical populations to identify groups at particular risk for decisional incapacity and to stimulate efforts to compensate for impairments.

Results: Most populations of patients or research subjects show considerable heterogeneity on measures of capacity. Based on group means, general medical patients, even with serious conditions, show few indications of decisional impairment so long as neither the condition nor treatment directly affects mentation.3 However, up to 25% of inpatients with major depression, and up to half of inpatients with schizophrenia and bipolar disorder manifest impairments sufficient to call their competence into question.3,4 The highest rates of impairment are found among patients with Alzheimer’s and other dementias, with reduced capacity seen even in mild cognitive impairment.5 Few studies have examined decisional capacity among persons with intellectual disabilities; using an instrument modified from the MacCAT, persons with mild intellectual disabilities were shown to have highly variable capacities, many overlapping with a normal comparison group.6

Discussion: Advances in the conceptualization of decisional capacity have enabled the development of assessment instruments and the growth of empirical studies. Most diagnostic groups show considerable heterogeneity of performance, emphasizing the need for individualized assessment. For persons with intellectual disabilities, assessment approaches may need to be modified to take into account their limitations.

References:


**Symposium 10: Decision Capacity in Fragile X Syndrome**

Paper 2: Parental Rating of Decision Making Ability in Fragile X Syndrome

Don Bailey, RTI International

**Introduction:** With the advances in genetic discovery and the increased opportunity to participate in clinical trials, there is a need to examine the ability of individuals with intellectual disabilities to make health-related decisions and determine their capacity to provide informed consent. This paper will examine parental rating of decision making ability in individuals with fragile X syndrome (FXS), the most commonly known inherited form of intellectual disability.

**Method:** As part of a large national survey, 422 families who have a child with FXS 12 years of older answered questions about their son/daughters ability to understand and participate in the informed consent process for a hypothetical clinical trial. Respondents chose to complete a web-based survey (96%) or a phone interview (4%). Ninety three percent of families were Caucasian, 2% were African American, 2% were Hispanic, and 3% were from another racial or ethnic background. A quarter (25%) of the families had incomes below $50,000, 36% had incomes between $50,000 and $100,000, and 39% had incomes over $100,000. The majority of respondents were mothers (90%), married (81%), employed (61%), and had a 4 year college degree or more education (62%). Families had a total of 505 children with FXS. Age ranges of the children in the study were 12 to 17 years (31%), 18 to 22 years (22%), 23 to 29 years (22%), and 30 or older (25%). Most children were males (89%).

**Results:** Parental rating of their son/daughters' ability to understand various components of the consent process, including: (a) that he/she is being asked to participate in a study to find out if a medication works for people with FXS, (b) that the study medication is different from regular treatment, (c) that he/she might get the medication or a sugar pill, (d) that there are both potential benefits and risks of participating, and (e) that he/she can choose to participate and to withdraw at any time. Respondents also rated their son or daughter's ability to make a decision about study participation. A high percentage of males were rated as not at all capable (ranging between 34% and 63% across items), whereas females were more likely to be rated as fully capable (able (ranging between 29% and 48% across items). Mean ratings indicated that the most difficult item for males was the ability to understand and weigh the potential benefits and risks of participating. A summary score was calculated across the 6 items and regression models indicated that willingness to participate in clinical trials and older children were significant predictors of higher decisional ability.

**Discussion:** We conclude that many individuals with FXS appear to be able to participate at some level in the consent process, but will likely need individualized support to maximize effective participation. These results support other findings suggesting that individuals with intellectual disability be provided support decision-making with regards to health care and treatment choices.

**References:**


**Symposium 10: Decision Capacity in Fragile X Syndrome**

Paper 3: Development and Psychometric Evaluation of a Modified MacCAT-CR to Assess Decisional Ability in Fragile X Syndrome

Melissa Raspa, RTI International

**Introduction:** The MacArthur Competence Assessment Tools for Clinical Research (MacCAT-CR) 1 was developed to assess decisional capacity in individuals with different forms of cognitive impairment, such as schizophrenia or dementia.2,3 There has been a paucity of research to date that has examined the application of the MacCAT-CR to individuals with an intellectual disability.4 This paper will focus on the development and psychometric evaluation of a modified version of the MacCAT-CR for use with individuals with fragile X syndrome (FXS).

**Method:** As part of a study that was designed to assess the multiple components of decisional capacity in FXS, we created two modified versions of the MacCAT-CR: a direct assessment measure and a parent-completed tool. Both versions maintain the four core subscales of the MacCAT-CR: (a) the ability to understand information about a hypothetical clinical trial, (b) the ability to appreciate the implications of participating on one's own care, (c) the ability to reason about the options, and (d) evidence a choice. The modified version was simplified in a number of ways, including using short, basic sentences and plain language (Flesch-Kincaid Reading Level: 4.0). For the direct assessment version, we included pictures to accompany the text.

**Results:** Preliminary descriptive and psychometric data will be presented. Descriptive statistics include frequency distributions, means, standard deviations, as well as skewness and kurtosis for the each item. Psychometric properties of the items, subscales, and overall scale will be discussed, including (a) Cronbach's alpha to examine inter-item correlation within each subscale, (b) confirmatory factor analysis to check whether the modified items align with the original MacCAT-CR subscales, and (c) item response theory to study the relationship between the latent trait the item is intended to measure (e.g., understanding) and the item's properties. Fit statistic, including (a) a nonsignificant chi-square (p > .05), (b) a root mean square error of approximation (RMSEA) of .04 or below, and (c) a value of .90 or greater on the Tucker-Lewis index (TLI) and comparative fit index (CFI), will be examined to determine item utility.

**Discussion:** A modified version of the MacCAT-CR for individuals with FXS will be an essential tool to assist researchers and clinicians in assessing decisional capacity. Although not all individuals with FXS will be able to fully participate in the informed consent process, this tool will support clinicians and family members of individuals with FXS to become more engaged in making informed health care decisions.

**References:**


Children with Down syndrome (DS) show challenges in some aspects of goal-directed behavior when compared to developmentally matched children (Daunhauer et al., in press; Fidler et al., 2005; Lee et al., 2011). In particular, deficits in the development of goal-directed action on objects has been observed in preschoolers (Fidler et al., 2005a, b) and infants with DS (de Campos et al., 2013; MacTurk et al., 1985). While the importance of goal-directed behavior on objects has been established in the literature on typical development (See Bornstein et al., 2013), new evidence indicates that deficits in goal-directed actions on objects in DS negatively impact outcomes in critical ways. Fey et al (2013) recently reported that less engagement with objects moderated intervention effects for preschoolers with DS in a rigorous language-based early intervention program. Thus, the dimension of object-related generativity, or the flexible planning of a variety of behaviors and strategies on objects, may be of critical importance for understanding the atypical presentation of goal-directed behavior on objects in childhood in DS.

In this study, we examined object-related generativity in school-aged children with DS (n = 53), a developmentally matched group of children with intellectual disability, but not Down syndrome (DD; n = 22), and a group of chronologically younger but developmentally matched typically developing children (TD; n = 45). We administered the Leiter-R, the OWLS, and an the Object-Related Generativity Task, which involved 2 minutes of unstructured play with a variety of objects that have divergent usages (foam squares with holes on the perimeter, pipe cleaners, toy coins, sensory items). Naïve coders coded each administration, and coders overlapped on 30% to establish a mean kappa of .75. Groups were matched on Leiter-R Brief IQ age equivalence.

Children with DS held fewer objects overall, F (2; 120) = 4.04, p = .02), and generated significantly fewer instances of initiating actions on new objects (objects that they had not yet manipulated; F (2; 120) = 8.02, p = .001). Children with DS were also less likely to reproduce a familiar functional action on a new object, F (2; 120) = 3.02, p = .05), and they showed fewer instances of functional object engagement (new or familiar acts) with new objects overall (F (2, 120) = 3.20, = .04). The DS group did show equivalent levels of sensory acts on objects when compared with the other two groups overall. Frequency of acts on new objects in DS was strongly associated with overall Leiter-R Brief IQ age equivalence (r (44) = .44, p = .003); Figure Ground Raw Scores (r (46) = .35, p = .02); Form Completion Raw Scores (r (46) = .49, p = .001); and OWLS Listening Comprehension Raw Scores (r (46) = .31, p = .04).

These findings suggest that children with Down syndrome produce fewer overall actions on new objects during exploratory play than other developmentally matched children. And more specifically, children with DS showed fewer instances of applying familiar functional actions (actions they had already produced on a previous object) onto new objects. The associations between these generativity behaviors and cognitive-linguistic outcomes echo findings reported in Fey et al (2013), though the direction of effects in this relationship should be further examined. These findings tie into growing evidence for a specific deficit in the area of goal-directed behavior and self-regulatory skills in individuals with Down syndrome. Implications for education and intervention will be discussed.
Symposium: 11: The Down Syndrome Cognitive Phenotypic Profile: An Examination of Underlying Components and Links to Functional Performance in the School-Age Years

Paper 2: Are Inhibitory Control Deficits a Component of the Cognitive Phenotypic Profile in School-Aged Children with Down Syndrome?

Lisa A. Daunhauer, Colorado State University; Deborah J. Fidler, Colorado State University; Elizabeth Will, Colorado State University; Jeannie Visootsak, Emory University; Susan Hepburn, University of Colorado- Denver Health Sciences Center

Introduction: Individuals with Down syndrome (DS) are predisposed to a specific cognitive phenotypic profile. The existing literature on individuals with Down syndrome (DS) provides mixed evidence regarding whether deficits in inhibitory control are part of the DS cognitive phenotypic profile. One study examining preschoolers with DS showed significantly shorter latency to touch a prohibited target toy than MA-matched children (Kopp et al., 1983) and another (Kogan et al.; 2009) found that a group of young adults (M age 16 years) with DS had significantly more difficulty performing tasks requiring inhibition compared to a matched Fragile X syndrome group. Recently, Daunhauer et al. (in press) found that 32% of parents reported clinical-level problems with inhibitory control in school-aged children with DS using a caregiver reported inventory of executive function. Given the relationship between inhibitory control and both academic achievement (Blair & Razz, 2007) and adaptive behavior in the school context (Zingerevich & LaVesser, 2008), further characterizing the inhibitory control abilities of individuals with DS will be important in developing targeted intervention and instruction.

Method: We examined inhibitory control in school-aged children with DS (n = 45), a developmentally-matched group of children with intellectual disability, but not DS (DD; n = 18), and a group of typically developing children matched for MA, but not CA (TD; n = 40). We administered the Leiter-R, a parent-reported measure of executive function (the Behavior Rating Inventory of Executive Function, BRIEF-P), a teacher-reported assessment of school function (the School Function Assessment, SFA), and a snack delay task. In this task, we queried the children’s caregivers to ensure we offered a snack known to be tempting to the child. We then instructed children to wait until the bell is rung to retrieve the snack from under a clear cup. We administered four trials for each participant with 5-, 10-, 15-, and 20-s delays respectively. Behaviors coded included: (a) total disinhibited behaviors (total frequency of the following behaviors-reaching for cup, reaching for bell, tapping cup, and fidgeting) and (b) actual premature snack retrieval. Naive coders established a mean kappa of .75 with 30% overlap on administrations. Groups were matched on Leiter-R Brief IQ age equivalence.

Results: We conducted a MANOVA to assess between group differences on the linear combination of the disinhibited behaviors and premature snack retrieval. A significant difference was found F (2; 99) = 94.26, p < .001. η² = .66. Post hoc analyses indicated that the DS group, but not the DD group, had higher rate of disinhibited behaviors compared to the TD groups (t= 2.01 (1, 72.92), p =.048. Furthermore, moderate agreement was found between observation of premature snack retrieval on the snack delay task and caregiver reports of deficits in inhibitory control on the BRIEF (r = .44, p=.019). Finally, frequency of premature snack retrieval was associated with the amount of assistance and adaptations required for cognitive-behavioral tasks during school (r = .34 and .36 respectively).

Discussion: Results support and extend earlier findings of children with DS experiencing challenges with inhibitory control deficits. Future investigation is needed to elucidate methodological considerations regarding measurement of executive function in early development, particularly in regards to lab tasks in contrast to reports of function in important contexts such as home and school.
Symposium: 11: The Down Syndrome Cognitive Phenotypic Profile: An Examination of Underlying Components and Links to Functional Performance in the School-Age Years

Paper 3: School Function in Students with Down Syndrome

Elizabeth Will, Lisa A. Daunhauer, Deborah J. Fidler, Colorado State University

Individuals with Down syndrome (DS) are predisposed to specific areas of relative developmental strength and challenge, but it is unclear whether and how this profile impacts participation in school and community settings. Identifying and understanding patterns of school function in DS is critical because effective engagement in functional school tasks serves as a foundation for further academic instruction. School function involves "a student's ability to perform important functional activities that support or enable participation in the academic and related social aspects of an educational program" (Coster et al., 1998, p 2). Without these foundational skills, students are unable to engage in academic activities without the need for assistance or accommodations. While much work has been conducted on the developmental and behavioral components of the DS phenotypic profile (see Daunhauer & Fidler, 2011 for a review) it is not yet clear how these patterns of strength and challenge manifest in the school setting.

In this study we evaluated the profile of school-based function in the context of participation, use of task support, and activity performance in a sample of school-aged children with DS (N= 26; M age = 7.86 years; SD = 1.75). We also characterized the degree to which task supports are utilized in physical activity and cognitive/behavioral domains for student with DS in the school setting. Additionally, we examined the predictors of variability in school function by evaluating the relationship between IQ, language functioning, executive functioning and overall school functions. Participants were administered the Leiter-R (Roid & Miller, 1997) to obtain a brief IQ composite, and the OWLS (Carrow-Woolfolk, 2008) to obtain a measure of language functioning. Participants' teachers completed the Behavior Rating Inventory of Executive Function- Preschool version (BRIEF-P; Gioia, Espy, & Isquith, 2003) as a measure of executive function, and the School Function Assessment (SFA; Coster et al., 1998) questionnaire.

Results indicated that students demonstrated a pronounced pattern of assistance and adaptation-related needs across various domains of school function, specifically requiring more assistance rather than adaptations on both Physical Tasks (t(23) = 3.92, p = .001) and Cognitive/Behavioral Tasks (t(24) = 2.97, p = .007). Students with DS demonstrated areas of greatest challenge in the following school function domains: Recreational Movement, Computer and Equipment Use, Following Social Conventions, Functional Communication, Compliance with Adult Directives and School Rules, Personal Care Awareness, Task Behavior/Completion, Positive Interaction, Safety and Written Work. In addition, the strongest predictor of overall school function was found to be student executive function skills, as reported by teachers (adjusted R2 = 47, p=.003).

Findings from this study suggest a profile of strengths and challenges for students with DS, rather than a global difficulty in functioning. Overall, students with DS were reported to need less assistance and adaptations for Physical Tasks than Cognitive-Behavioral tasks. Safety was a domain of particular challenge for students with DS, as well as Behavior Regulation and Following Social Conventions. School function was most strongly predicted by measures of teacher reported executive function. Collectively these findings have implications for the role of executive function in outcomes of school function, as well as implications for future targeted intervention and school-related planning for elementary school students with DS.
Symposium 12 Title: Expanding Research on Family Environment: How, Who, and When to Measure

Chair: Anna J Esbensen, Cincinatti Children’s Hospital Medical Center

Discussant: Gael Orsmond, Boston University

Paper 1: I Second that Emotion: Concordance and Synchrony in Physiological Arousal between Children with ASD and their Parents

Jason K Baker, California State University, Fullerton; Rachel M Fenning, California State University, Fullerton; Mariann Howland, California State University, Fullerton; Christopher Murakami, California State University, Fullerton

Introduction: Young children with developmental difficulties experience challenges with emotion regulation, and these problems may mediate certain effects of early risk (Baker et al., 2007). Emotion dysregulation is common in Autism Spectrum Disorder (ASD), and recent calls to integrate emotion regulation frameworks into autism research have been made (Mazefsky et al., 2012). Affective synchrony in parent-child interaction appears to serve a co-regulatory function in non-ASD dyads (Feldman, 2012) and it predicts empathy in children at risk for ASD (McDonald et al., 2013). Such synchrony can be considered not only in terms of behavior, but also in the match or mismatch of certain physiologic responses—the integration of these two processes has been coined bio-behavioral synchrony (Feldman, 2012). One aspect of autonomic nervous system arousal, electrodermal activity (EDA), is a physiologic index of emotional state, response, and regulation, and plays an important role in child outcomes (Erath et al., 2011). Despite the historical consideration of EDA in ASD populations (primarily focused on explaining status-group differences in sensory behavior; Rogers & Ozonoff, 2005), research has yet to consider the role of EDA in understanding individual differences in emotion regulation, social-emotional development, and/or parent-child interaction in this population.

Method: A culturally and economically diverse sample of 15 children aged 4 to 9 years (12 male; MAge = 6.97; MIQ = 83.73; SDIQ = 28.97) and diagnosed with an ASD participated with their primary caregivers (one father) in a laboratory visit. The visit included direct child assessments (SB5 and the ADOS) and several parent-child emotion regulation tasks. Wireless, unobtrusive wrist sensors were worn by parents and children during dyadic free play, clean-up, a wait task, and a problem-solving task (see Baker et al., 2007). The sensors logged EDA scores in microsiemens each 8 hz. Free play was coded (blind and reliable) for behavioral Affective Synchrony using the scales developed by the NICHD ECCRN (e.g., 1999), which were previously adapted for use with families of children with ASD (McDonald et al., 2013).

Results: Substantial individual differences in both tonic (mean) and phasic (variability) child EDA were found, with moderate support for proposed hypoactivation in some children with ASD (see Messinger et al., in press). Concordance was found between children and their parents in average EDA variability across the shared tasks, p = .53, p < .05 and for mean EDA at a trend level, p = .50, p = .06, which is consistent with genetic and interactive evidence (Guastello et al., 2006; Tuvblad et al., 2010). In-time, within-dyad data for the free play task revealed tremendous heterogeneity in EDA synchrony, with eight dyads demonstrating positive synchrony (Mr =.61), five negative (-.54), and two less than a weak association (.01). Convergence between EDA synchrony and observed behavioral synchrony was high, p = .74, p < .01, supporting the notion of bio-behavioral synchrony. Child IQ and ADOS Social Affect scores were not significantly related to synchrony; however Restrictive and Repetitive Behavior ADOS scores were negatively associated with EDA synchrony, p = -.57, p<.05 (-.33,ns for behavioral synchrony). Lagged (5-sec) regression analyses suggested clear individual differences across dyads in the extent to which child EDA appeared to be influencing parent EDA and vice versa, with behavioral synchrony related to higher child-to-parent physiological effects, p = .54, p<.05.

Discussion: Our study suggests significant concordance in EDA profiles between children with ASD and their primary caregivers, and clear individual differences in the degree to which dyads exhibited in-time bio-behavioral synchrony. Synchrony was not dependent upon child IQ, but some evidence for a disruption in physiological synchrony was observed as a function of children’s restrictive and repetitive behaviors. In-time data revealed higher child-to-parent EDA effects in more behaviorally synchronous dyads. We will continue to examine the implications of these laboratory data for broader child and family functioning.
**Symposium 12: Expanding Research on Family Environment: How, Who, and When to Measure**

**Paper 2: Division of Labor in Married Couples of Children and Adolescents with ASD**

Sigan Hartley, University of Wisconsin-Madison; Emily J Hickey, University of Wisconsin-Madison; Paige M Bussanich, University of Wisconsin-Madison; Iulia Mihaila, University of Wisconsin-Madison

**Introduction:** Couples who have a child or adolescent with autism spectrum disorder (ASD) are faced with a high level of childcare responsibilities. Couples must tackle the difficult decision of how to divide childcare responsibilities and paid employment. Little is known about the division of labor within families of children and adolescents with ASD or its implication for parents’ psychological well-being or marital relationship. The purpose of the present study was to examine the childcare and employment activities of married couples who have a child or adolescent with ASD through a 10-day daily diary and to explore the association between the division of labor and level of parenting stress and marital adjustment. Additional goals were to identify factors associated with the division of labor and to understand the impact of spousal differences in childcare experiences on parenting stress and marital adjustment.

**Method:** To date, 115 married couples who had a child or adolescent with ASD have participated in the study. Fathers had a mean age of 42.47 years (SD = 8.43) and mothers had a mean age of 44.32 years (SD = 8.11). The average household income was $90 to $100K (SD = $30K). The child or adolescent with ASD had an average age of 9.81 (SD = 3.53) and most were male (75.8%). Mothers and fathers independently completed a 10-day online daily diary in which they reported on their time spent in childcare and paid employment activities in the previous 24 hrs and their level of satisfaction with the time that their partner spent in childcare for 10 consecutive days. Parents also completed the Scales of Independent Behavior-Revised (Bruininks et al., 1996) each day of the diary and reported their household income, educational level and child/adolescent age, gender, intellectual disability status, and autism symptoms.

**Results:** Paired sample t-tests were used to compare the within-couple time usage of mothers and fathers within a 24 hour period. Fathers spent significantly more time in paid employment than mothers (t (114) = 6.18, p < .001) and mothers spent significantly more time in childcare than fathers (t (114) = 5.99, p < .001). Hierarchical multiple linear regressions were conducted to identify child/adolescent and parent variables related to time usage within couples. Role specialization (i.e., greater within-couple difference in childcare and employment of spouses) was negatively related to child age (b = -.42, t (109) = 5.34, p < .01) and positively related frequency of autism symptoms (b = .31, t (109) = 4.53, p < .01). Multilevel modeling using hierarchical linear modeling was conducted to examine the association between time usage and parenting stress and marital adjustment while controlling for within-couple interdependency of data and between-couple differences in child/adolescent with ASD and parent variables. Satisfaction with the time that one’s spouse spent in childcare was associated with parenting stress and marital adjustment. Time spent in paid employment was positively associated with parenting stress in fathers but not in mothers. Functions in child behavior problems were related to fluctuations in parenting stress in both mothers and fathers. Mother-father difference in daily ratings of child behavior problems was negatively associated with marital adjustment.

**Discussion:** Services and interventions should not focus exclusively on the needs of mothers, as has often been the case in the past, but attend to the needs of both mothers and fathers as both are involved in childcare and affected by child behaviors. Role specialization was common and is not necessarily related to higher levels of parenting stress in mothers or fathers of children and adolescents with ASD; but becomes problematic if one spouse is dissatisfied with the division of labor. High levels of paid employment appear to put fathers at risk for experiencing high levels of parenting stress, perhaps because of spillover of work stress to the home life. Greater spousal difference in childcare experiences is related to marital strain.

**References:**

**Symposium 12: Expanding Research on Family Environment: How, Who, and When to Measure**

**Paper 3: Impact of Implementing Future Caregiving Plans among Adults with Down Syndrome**

Anna J Esbensen, Cincinnati Children's Hospital Medical Center

**Introduction:** Given that adults with Down syndrome (DS) are more commonly outliving their parents than before (Bittles & Glasson, 2004) and their families are more likely to have made future caregiving plans than their peers without DS (Essex et al., 1997), it is important to examine what factors contribute to the implementation of future caregiving plans. We are in a unique position to have prospective longitudinal data to explore outcomes of implementing future caregiving plans. We investigated the extent to which future caregiving plans were implemented in cases of parental death or incapacitation and how implementing or not implementing these future plans was related to previous and subsequent family relationships, and subsequent behavior problems and functional abilities in adults with DS.

**Method:** Participants with DS were selected from a larger longitudinal study of adults with intellectual disability (ID) who were co-residing with their families, and interviews were conducted with 58 families of adults with DS who had experienced maternal death or incapacity between 1988 and 2011 (Kraus & Seltzer, 1999). Prior to the transition of care, information had been collected regarding the existence of long-term care plans. After the transition of care, successor caregivers were asked to what extent the plans were implemented and families categorized as those who implemented or did not implement (including those with no plan) the caregiving plan. ANCOVAs were used to assess group differences in the family environment prior to (family cohesion, relationship quality, SES, number of siblings) and after the caregiving transition (frequency of contact, relationship quality), and on the adult with DS (behavior problems, functional abilities, social activities).

**Results:** Successor caregivers were primarily sisters (53.4%) and also included brothers (27.6%), fathers (15.5%) and other family members (3.4%). After the transition of care, 37.9% of adults with Down syndrome were living with the successor caregiver. At the transition of care, adults with Down syndrome ranged in age from 19 to 58 (M = 41.5, SD = 8.0). Half of families did not implement the caregiving plan, which included 12% who did not implement a future caregiving plan and 38% who did not develop a plan. Residential placement after the transition of care was controlled for in all group comparisons. Prior to the transition of care, families who later implemented a future caregiving plan had lower prior levels of independence [F(1,54) = 4.25, p = .04], and tended to have higher levels of control among non-coresiders and lower levels of control among co-coresiders [F(1,54) = 3.47, p = .07] than families who did not implement a future caregiving plan. After the transition of care, families who implemented a future caregiving plan had better relationship quality (among non-coresiders) [F(1,43) = 4.28, p = .04] than families who did not implement a future caregiving plan. No group differences were observed for change in behavior problems, functional abilities or social activities after the transition of care.

**Discussion:** The implementation of future caregiving plans was impacted by the prior family environment and had some impact on relationship quality among family members; however, it had little impact on behaviors and functional abilities of adult with DS as measured in the current study. Implications of transitions and prior planning for transitions will be reviewed regarding their impact on the individual and measurement of this impact. These findings have implications for how future caregiving plans and managing transitions of care are communicated to families.

**Key References:**

Symposium 13 Title: Lessons in Parent Training and Education

Chair: John R. Lutzker, Georgia State University

Discussant: Laura Lee McIntyre, University of Oregon

This symposium will discuss parent training and education strategies for parents with intellectual disabilities and parents of children with intellectual/developmental disabilities. The first paper, 'A Qualitative Discussion of Technology Enhanced Service Delivery: Parent and Provider Considerations', will discuss the use and opinion of technology in parents with intellectual disabilities in everyday life and in interactions with social service caseworkers. In the second paper, 'Padres en Acción: A parent training program for Latina mothers of children with Autism Spectrum Disorders (ASD)', a parent education intervention targeted to Latina mothers of children two- to eight-years-old will be discussed. The third and fourth papers discuss the delivery of Mindfulness Based Stress Reductions to parents of children ages two-and-a-half through age five with developmental disabilities ('Mindfulness-Based Stress Reduction for Parents of Young Children with Developmental Delays: Follow-Up Results from the MAPS Project') and parents of adolescent or adult children with intellectual/developmental disabilities ('Effectiveness of a Mindfulness Based Stress Reduction Program for Parents of Adolescents and Adults with Intellectual/Developmental Disabilities'). The presented results and lessons gleaned form parent training and education efforts in this symposium are significant for future research and service delivery. The discussant Laura Lee McIntyre is a well-regarded expert in parent training. She will provide synthesis and commentary.
**Introduction:** Parents with intellectual disabilities (ID) are not only at high-risk for child maltreatment, but are overrepresented in child welfare caseloads. Home visiting parenting programs, such as SafeCare®, have been shown to be effective in the reduction of risk factors and in improving child outcomes in these specific families, but also in other high-risk families. In effort to respond to different learning strategies and overburdened caseloads, technologically enhanced interventions are options to improve service delivery. Gaskin and colleagues (2012) used a digital frame to enhance the delivery of the Parent-Infant Interaction (PII) module of SafeCare with a mother with ID. This mother's rate of skill acquisition was faster than previously seen with typically developing mothers (Lutzker, Lutzker, Braunling-McMorrow, & Eddleman, 1987). The present research sought examine how parents with ID utilize technology in their everyday life and in service delivery? Implications for future research and implementation practice are discussed.

**Method:** Qualitative data are drawn from three collection methods: 1) individual in-depth interviews with six mothers with ID receiving social support from an Atlanta metro based agency, 2) four individual phone interviews with caseworkers implementing SafeCare® in North Dakota, and 3) a focus group of six caseworkers from an agency serving the Atlanta metro area. At the end of each interview, the interviewer discussed, and demonstrated when possible, the application of the digital frame enhancement of PII. All interviews were audio transcribed verbatim and subsequently analyzed using a phenomenological approach with NVIVO® analysis software.

**Results:** Overwhelmingly, the mothers with ID displayed skill affinity for technology, specifically the use of texting and downloading music or ringtones to their cell phones. Caseworkers described their professional use of technology, but unfamiliarity and lack of knowledge were overriding themes in their statements. Regarding the proposed technological enhancement of the digital frame to the PII module, the general consensus was positive. Parents spoke highly about the prospect of having pictures of their children in their home. Caseworkers expressed potential, but brought up concerns about privacy.

**Discussion:** This research indicates that technology is a viable option for enhancing service delivery and that parents receiving social services are skilled and comfortable with it. Not only could technological enhancements improve rates of skill acquisition, but could also potentially reduce face-to-face time and improve participant engagement. Revealed in this research is the generational gap between providers and clients, which must be considered in the implementation of technologically enhanced services.
Introduction: Latinos represent the fastest growing population in the US, and Latino children are one of the fastest growing ASD populations. Yet they are one of the most underserved groups with respect to diagnostic services, health care, and specialty autism services. Barriers for receiving diagnosis and services in a timely way among Latino children include lack of insurance, low income status, language, lack of information and knowledge about autism and disabilities, and limited bilingual and culturally competent providers. A culturally-based 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 test the feasibility and acceptability of a parent education intervention which aims to empower Latino parents to better advocate for and help their children develop and grow.

Methods: This pilot intervention used Promotoras de Salud, community health workers 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 and a one-group pre and post-test design was used. Twenty Spanish speaking mothers of children with an ASD between the ages of 2 and 8 years old were enrolled in the study. Promotoras delivered 2 modules that included 16 home visits with each enrolled mother. We previously reported on the first module which focused on family empowerment outcomes. In this presentation we will report on results from Module II which focused on teaching mothers evidenced-based (EB) strategies for improving communication, play, social skills and reducing problem behaviors among their children. Promotoras administered pre and post-tests, which included the Autism Behavior Checklist (ABC; Krug, Arick, & Almond, 1993) and two measures developed by the authors: confidence in using EB strategies with their children and the self reported use of EB strategies. Focus groups were held with participants after they completed the intervention.

Results: Using paired sample t-tests, pre and post-test data showed significant improvements in Confidence in use of Strategies. While we did not find significant differences for the other outcomes, we found moderate effect sizes for changes in use of strategies, and in the ABC subscales of language and social/self-help skills. Effect size statistics may be more meaningful given the small sample size. In the focus groups, mothers described the use of specific EB strategies and how they valued the relationship and positive influence of the promotoras.

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 a culturally relevant approach to improve knowledge and skills among Latina mothers of children with ASD about how to better help their children. Results suggest that this may be a promising parent education intervention for Spanish speaking Latino families. A randomized trial of the intervention is currently underway.

Reference:
**Symposium 13: Lessons in Parent Training and Education**

**Paper 3: Mindfulness-Based Stress Reduction for Parents of Young Children with Developmental Delays: Follow-Up Results from the MAPS Project**

Cameron L. Neece, Loma Linda University

**Introduction:** Parents of children with developmental delays (DD) typically report more parenting stress than parents of typically developing children (Baker et al., 2003; Emerson, 2003; Hauser-Cram, Warfield, Shonkoff, & Kraus, 2001). Additionally, there is consistent evidence that children with delays are more likely to have significant behavior problems and to develop psychopathology (Baker, Blacher, Crnic, & Edelbrock, 2002; Emerson & Einfeld, 2010; Merrell & Holland, 1997). Given the increased levels of both child behavior problems and parent stress among families affected by DD, it is likely that these variables have a reciprocal relationship over time whereby elevated levels of child behavior problems predict increased parenting stress which, in turn, results in even higher levels of behavior problems. However, despite evidence showing that parenting stress is an important predictor of child outcomes, it is rarely directly addressed in interventions targeting child problems. Last year the PI of the Mindful Awareness for Parenting Stress (MAPS) Project presented preliminary data from a randomized controlled trial pilot study examining the efficacy of Mindfulness-Based Stress Reduction (MBSR), an evidence-based stress reduction intervention, for parents of children with DD. Findings indicated that parents who participated in MBSR reported significantly less stress and depression as well as greater life satisfaction compared to waitlist-control parents. Regarding child outcomes, children whose parents participated in MBSR were reported to have fewer behavior problems following the intervention, specifically in the areas of attention problems and ADHD symptomatology (Neece, 2013). The current study expands on these findings by examining teacher-reports of child outcomes as well as 6-month follow-up outcomes.

**Method:** The current study involves data from the MAPS Project, which included 51 parents of children, ages 2.5 to 5 years old, with DD. These parents participated in a randomized controlled trial examining the efficacy of Mindfulness-Based Stress Reduction (MBSR) in reducing parental stress and subsequent child behavior problems. Parents were assigned to an immediate treatment or a waitlist control group. Both parent and teacher data were collected at pre-treatment, post-treatment, and at 6-month follow-up assessments. Parenting stress was measured using the Parenting Stress Index (PSI, Abidin, 1990); parent-reports of child behavior problems were assessed with the Child Behavior Checklist (CBCL, Achenbach & Rescorla, 2000); and teacher-reports of child behavior problems were assessed using the Caregiver-Teacher Report Form (TRF, Achenbach & Rescorla, 2000).

**Results:** Preliminary results investigating teacher reports of child behavior problems indicated that there were no differences between the immediate and waitlist-control groups on any of the TRF subscales at intake. However, after the first round of the intervention, children of parents in the treatment group were reported to have significantly fewer externalizing behavior problems (t=1.82, p<.05, d=0.91), specifically ODD (t=1.88, p<.05, d=0.94) and ADHD symptoms (t=1.90, p<.05, d=0.95). Findings examining follow-up data suggested that the initial positive outcomes of MBSR (Neece, 2013) were maintained over time. At the 6-month follow up assessment, the majority of parents (73.9%) reported continued practice of mindfulness a few days a week to nearly every day. Their PSI scores decreased significantly from pre-treatment (mean=36.23) to post-treatment (mean=30.77, t=3.01, p<.01, d=1.12) and remained lower at 6-months follow-up (mean=28.83, t=.36, p=ns, d=.15). Follow-up results examining child behavior outcomes indicated a significant decrease in child behavior problems from pre-treatment (mean=68.49) to post-treatment (mean=61.17, t=2.31, p<.05, d=.79) and a continued decrease from post-treatment to 6-months follow-up (mean=53.41, t=2.36, p<.05, d=.84) suggesting a continued benefit of this intervention for the children with DD.

**Discussion:** In addition to hopefully helping families cope with their children’s behavior more effectively, this study is critical because it is a rigorous, experimental test of the effectiveness of MBSR training on parenting stress and how that subsequently affects child behavior. We experimentally manipulated parenting stress and saw subsequent changes in child behavior problems both by parent and teacher report, which were maintained an even increased over time. These findings provide stronger evidence that parenting stress has an effect on the development of children's behavior problems. Other clinical implications and directions for future research will be discussed.
**Symposium 13: Lessons in Parent Training and Education**

**Paper 4: Effectiveness of a Mindfulness Based Stress Reduction Program for Parents of Adolescents and Adults with Intellectual/Developmental Disabilities**

Yona Lunsky, The Centre for Addiction and Mental Health; Anna M. Palucka, The Centre for Addiction and Mental Health; Buddhi Hatharaliyadda, The Centre for Addiction and Mental Health; Ryan Howes, The Centre for Addiction and Mental Health

**Introduction:** Being a parent to a child with an intellectual or developmental disability (IDD) is associated with increased stress and poorer psychological well-being. Emerging evidence suggests that mindfulness and acceptance based interventions can be of some benefit to parents of young children (Singh et al., 2010; Blackledge & Hayes, 2006). Most recently, Ferraioli et al. (2013) demonstrated that the parents of children participating in Mindfulness Based Parent Training showed greater improvements than parents participating in a behaviourally based Parent Training program. Mindfulness based interventions may be even more relevant to parents of adults with IDD than parents of children, because of the service gaps and stresses these aging parents face. In contrast to other types of interventions focused on fixing the situation, a mindfulness based approach can be helpful even when a situation cannot be easily resolved. The current study was aimed at evaluating the effectiveness of a group based mindfulness program to reduce parent distress.

**Methods:** Four groups of 8-12 parents (mean age = 55.4 ± 8.6 years; female = 85%), participated in a mindfulness program which consisted of 4 (spring 2012) and 6 (fall 2012, spring 2013 and summer 2013) sessions, respectively. The weekly 2 hour sessions offered experiential mindfulness training tailored to parents, which involved practices such as sitting meditation, walking meditation and gentle yoga as outlined in the Mindfulness Based Cognitive Therapy program (MBCT) (Segal et al., 2002). Parents completed a measure of distress (DASS-7), the Mindfulness Attention and Awareness Scale (MAAS) as well as the Bangor Mindful Parenting Scale (BPMS), prior to and at the end of intervention.

**Results:** Of the 40 parents who participated in the groups, 27 completed pre and post measures. (These individuals did not differ demographically from those who did not complete the measures at both time points.) Parent distress levels decreased significantly on the DASS-7, t (26)= 5.78, p <0.001. However, there were no significant changes reported with regard to overall mindfulness (MAAS) t (25)= -1.48, p=0.152, or mindful parenting (BPMS), t(26)= -0.47, p=0.643. The lack of change in objective mindfulness measures was in contrast to subjective changes that parents reported in their approach to life, and their interactions with their children.

**Discussion:** Our preliminary results indicate that a mindfulness based intervention shows promise for parents of adolescents and adults with IDD as a way to reduce distress. It is unclear, however, whether these parents became more mindful in the process. Parents enjoyed being in the group and participating in formal mindfulness practices with other parents, but they struggled with being able to practice outside of session. Further research is needed to understand the mechanisms that lead to parent change, and the role that mindfulness may play. Such research would inform how mindfulness programs could best be tailored to meet the unique needs and stresses faced by these families.

**References:**


Symposium 14 Title: Language, Reading and School-Readiness in Down Syndrome

Chair: Susan J. Loveall, Life Span Institute, University of Kansas

Discussant: Sue Buckley, University of Portsmouth, Down Syndrome Education International

Paper 1: Reading Skills in Down Syndrome: An Examination of Orthographic Knowledge

Susan J. Loveall, Life Span Institute, University of Kansas, University of Alabama; Frances A. Conners, University of Alabama

Introduction: Down syndrome (DS) is the leading genetic cause of intellectual disability. It is associated with a fairly specific cognitive profile including known patterns of impairment in verbal domains but comparatively stronger performances in visuospatial domains (Conners, Moore, Loveall, & Merrill, 2011). This cognitive profile could be indicative of the slightly altered reading pattern seen in DS. Word identification has two main subskills: phonological recoding and orthographic knowledge, both verbal and visual aspects, respectively. Research on reading in DS shows evidence of strong word identification skills relative to mental age, despite poorer phonological recoding abilities (Kay-Raining Bird, Cleave, & McConnell, 2000). If phonological recoding is impaired in DS, it is possible that orthographic knowledge is relatively strong. However, research on orthographic knowledge in DS is limited to a few studies using only exception word measures. While these do tap orthographic knowledge, they require a verbal production by participants, which could be disproportionately difficult for individuals with DS due to speech difficulties. The goal of the present study was to examine orthographic knowledge in DS in comparison to typically developing (TD) children matched on word identification by including both recognition and production measures of orthographic knowledge in the protocol.

Method: The study consisted of 20 participants with DS (age M = 16.16; SD = 3.33) and 20 with TD (age M = 7.33; SD = .97) matched on word identification level, (DS group M = 7.64; SD = 1.01; TD group M = 7.60; SD = 1.18), p = .72. Participants completed three measures of orthographic knowledge (one production: Exception Word Reading; two recognition: Orthographic Choice and Orthographic Awareness), one measure of phonological recoding (Word Attack), an IQ test (KBIT-2) and one measure of receptive vocabulary (PPVT-4).

Results: A one-way MANOVA revealed a significant difference between groups on the three orthographic tasks, F(3, 36) = 6.35, p = .001; partial eta squared = .35. When the results for the dependent variables were considered separately, the only difference to reach significance was Orthographic Awareness, F(1, 38) = 5.01, p = .03, partial eta squared = .12, with the TD group performing better than the group with DS. A mixed ANOVA revealed a significant interaction between group and orthographic measure, F(2, 37) = 9.58, p < .001, partial eta squared = .34. Follow-up t-tests revealed that the TD group performed significantly better than the group with DS on Orthographic Awareness, t(38) = -2.24, p = .03, while the group with DS performed slightly, though not significantly, better than the TD group on Exception Word Reading and Orthographic Choice. A Mann-Whitney U test revealed a significant difference between groups on phonological recoding, U = 98.50, z = -2.76, p = .006, r = .44, again with the TD group scoring significantly higher than the group with DS.

Discussion: This pattern of results further confirms difficulty in phonological recoding for individuals with DS. In contrast, orthographic knowledge appears mostly on par with word identification, as the group with DS performed similarly to the TD group on two measures of orthographic knowledge. Interestingly, the group with DS performed worse on the third measure. While this was not a recognition vs. production distinction, another pattern did emerge. The first two orthographic tasks both included real words as stimuli, while Orthographic Awareness used letter patterns. These results suggest that individuals with DS may have a strength in word-specific orthographic knowledge but difficulty with letter patterns.

References:


**Symposium 14: Language, Reading and School-Readiness in Down Syndrome**

**Paper 2: Developmental Trajectories of Pre-Academics and Self-Directedness in Preschoolers with Down Syndrome**

Laura J. Hahn, Life Span Institute, University of Kansas; Deborah Fidler, Colorado State University; David Most, Colorado State University; Lisa Daunhauer, Colorado State University

**Introduction:** The present study examined the developmental trajectories of pre-academic skills and self-directedness in a longitudinal sample of preschoolers with Down syndrome (DS) in comparison to preschoolers with other intellectual and developmental disabilities (IDD). There is a paucity of research on early academic abilities in children with DS, despite research on typically developing children indicating that academic outcomes are highly stable after the first three years of school. These early academic outcomes also have implications for later learning. Later in development, there maybe a slowing or plateau in academic achievement in DS (Turner & Alborz, 2003, Turner et al., 2008). It is possible that this trend is related to early academic abilities. Early academic experiences of children with DS may be influenced by the behavioral phenotypic associated with DS, especially weakness in skills related to self-directedness (e.g., task persistence, inhibition, etc.). Difficulties with self-directedness may lead children with DS to abandon tasks sooner and to use strategies that divert their attention away from tasks, which in turn may lead to missing valuable opportunities to challenge themselves and gain new skills (Fidler, 2005; Fidler & Nadel, 2007; Wishart, 1996).

**Methods:** Participants for this study were identified from The Pre-Elementary Education Longitudinal Study (PEELS) database. This is a nationally representative sample of more than 3,000 children enrolled in Part B preschool services. At the start of the study, children were between the ages of 3 and 5. Data were collected at four different time points (i.e. four waves) until the children were between the ages of 8 and 10 (see http://www.peels.org for details). We identified 57 young children with DS and a developmentally matched group of 107 children with IDD. At Time 1 groups were matched on mean chronological age, t(162) = .38, p = .70, and pre-functional academic standard scores, t(162) = .05, p = .96. No significant differences were observed between the two groups. Pre-functional academic and self-directedness were measured using the Adaptive Behavior Assessment System (ABAS; Harrison & Oakland, 2008).

**Results and Discussion:** Human growth models were estimated to explore the individual trajectories of pre-academics and self-directedness in preschoolers with DS and IDD. Preschoolers with DS experienced greater deficits in both pre-functional academics and self-directedness over time than did the preschoolers with IDD, despite being similar on both of these skills at Time 1. It is important to note that the rate of decline in self-directedness for preschoolers with DS was greater than pre-academics. In addition it appears that for both groups, preschoolers who had lower scores on self-directedness also had lower scores on pre-functional academics over time. However, this pattern appeared more pronounced for preschoolers with DS. The findings of this study, in combination with past research into the academic development of children with DS, indicate that there is a need to develop interventions to improve educational outcomes in this population. Specifically, interventions that target skills related to self-directedness may be essential for improving educational outcomes for individuals with DS. Finally, the information gained in this study and future studies examining the relation between academic outcomes and the patterns of strength and weakness associated with DS may be particularly relevant to provide for educators.

**References:**


**Symposium 14: Language, Reading and School-Readiness in Down Syndrome**

**Paper 3: How Speech-Language Pathologists Address Phonological Memory in Down Syndrome**

Gayle Graham Faught, Frances A. Conners, Angela Barber, Sarah Steeley, Hannah Rapport, University of Alabama

**Introduction:** Phonological memory (PM) is immediate memory for speech information (e.g., remembering a phone number) and can be measured using digit span or nonword repetition tasks. PM plays a significant role in language development and language disorders. In our study "Cognitive Predictors of Language Impairment," PM significantly predicts both receptive and productive language impairment in Down syndrome (DS), even more so than other constructs like implicit learning. The current study sought to find out if and how Speech-Language Pathologists (SLPs) address PM in their therapy with clients who have DS. This client group was compared to clients with specific language impairment (SLI) and clients with autism spectrum disorders (ASD). PM is a well established impairment in both DS and SLI, though not in ASD.

**Method:** Participants included 292 SLPs who provide language therapy to clients with DS (n=265), SLI (n=257), and/or ASD (n=281) and who completed an online survey sent to them either by their state SLP organization or directly from our lab based on their listing on the American Speech-Hearing-Language Association website. Nearly all participants held a master's degree (91%), had earned their Clinical Certificate of Competence (94%), and were currently practicing (96%). The number of years practicing ranged from 0-49 (M=19.6). Although the participants served clients from age 0-80+, most worked primarily with children ages 3-12 in school settings. Participants were from 29 different states.

This 15-minute survey asked SLPs whether and how they address PM in their therapy with clients who have DS, SLI, or ASD. For instance, SLPs were asked to mark if they (1) use exercises to expand PM directly, (2) use techniques to compensate for PM limitations, and/or (3) teach strategies to the client, teacher, or caregiver to address PM limitations. SLPs were then asked their opinions about the importance, practicality, and difficulty of addressing PM in these three groups using 5-point Likert scales.

**Results:** Results indicated that, for clients with DS, only 10% of SLPs address PM regularly and 32% address PM occasionally in their therapy, leaving 47% who do not address PM in DS and 11% unsure. The pattern was similar for clients who have ASD, with 18% of SLPs addressing PM regularly, 34% addressing PM occasionally, 40% not addressing PM, and 7% unsure. On the other hand, for clients with SLI, a large majority of SLPs either address PM regularly (34%) or occasionally (41%), leaving only 21% who do not address PM in SLI and 4% unsure. Of those SLPs who do address PM, approximately 72% use exercises to expand PM directly, 79% use techniques to compensate for PM limitations, and 72% teach strategies to the client, teacher, or caregiver to address PM limitations. This pattern was similar across the three client groups. In regard to SLPs' opinions, results indicated that SLPs consider addressing PM for clients with DS and ASD to be somewhat important (each M=3.3 on a 5-point scale), somewhat practical (each M=3.1), and moderately difficult (Ms=3.7 and 3.6, respectively), with no significant differences between these client types (all ps>.35). However, results also indicated that SLPs consider addressing PM for clients with SLI to be important (M=4.1), practical (M=4.1), and only somewhat difficult (M=3.0), with each of these judgments being significantly different from those for clients with DS and ASD (all ps<.001).

**Discussion:** SLPs were less likely to address PM in their language therapy with clients who have DS or ASD than for clients who have SLI. This is surprising for clients with DS because of this population's profound impairment in PM. SLPs may be less likely to address PM with clients who have DS because they view it as less important, less practical, and more difficult in this group when compared to clients who have SLI. If PM concerns are to be addressed more regularly in language therapy with clients who have DS, SLPs will need more support and more resources to do so.
**Symposium 14: Language, Reading and School-Readiness in Down Syndrome**

**Paper 4: The Use of Mental State Language by Children and Adolescents with Down Syndrome**

Marie Moore Channell, Mandeep K. Chela, Leonard Abbeduto, MIND Institute, University of California, Davis

**Introduction:** Narrative storytelling is an important component of communicative competence. Narrative skill shapes and is shaped by the acquisition of literacy and becomes increasingly important to successful social interaction, especially during adolescence. Although individuals with Down syndrome (DS) show deficits in expressive language at the syntactic level, little is known about their broader ability to narrate a story. The communication of the thoughts, desires, and feelings held by story protagonists is an important component of narratives. This requires the ability to infer others' mental states, recognize their relevance to the story, and express them linguistically. The present study was designed to analyze mental state language use by children and adolescents with DS in a narrative context, thereby providing insight into the foundation of narrative skill.

**Method:** Participants who were enrolled in a larger study were included in the present analyses if their nonverbal mental age equivalent (Leiter-R) was in the 3-6 year range and they completed the narrative task. A total of 23 youth with DS (10-15 years old, M= 12.80, SD= 1.59) and 25 TD children (3-6 years old, M= 4.50, SD= 0.83) met these criteria and were well matched groupwise on nonverbal cognitive ability level (p=.64). In the narrative task, participants viewed a wordless picture book and were instructed to narrate the story to an examiner. Audio recordings of participant narratives were transcribed by trained personnel using Systematic Analysis of Language Transcripts (SALT; Miller & Chapman, 2000) software and segmented into communication units (C-units; defined as an independent clause and its modifiers). Only complete and intelligible C-units were used in analyses. We used SALT to search all C-units for a list of common mental state terms (LaBounty et al., 2008) across three categories - thought, desire, and emotion, and then included only instances in which the terms were used in reference to a mental state. Density scores were calculated as the proportion of C-units that included a mental state term, and diversity scores were calculated as the number of different mental state terms used.

**Results:** Mental state terms were used in 9 percent of C-units by participants with DS and in 15 percent by TD participants. Independent samples t-tests were conducted to examine between-group differences in density scores for thought, desire, and emotion terms. The group with DS achieved significantly lower density scores for desire terms (M= .003, SD= .009) than the TD group (M= .02, SD= .03), t(46)= 2.62, p= .012. There was no significant difference between groups for thought (p=.35) or emotion (p=.33) density scores. A similar pattern emerged for diversity scores. The group with DS achieved lower diversity scores for desire terms (M= .17, SD= .49) than the TD group (M= .52, SD= .65), t(46)= 2.06, p= .045, with no significant difference between groups for thought (p=.55) or emotion (p=.11) diversity scores. Emotion terms were used most frequently by all participants, so we further explored participant use of emotion language. Both groups provided a causal framework for a similar amount of emotion terms (DS= 12.09, TD= 12.92 percent) and showed a similar pattern for use of emotion verbs (DS= 36.74, TD= 35.17 percent) vs. adjectives (DS= 63.26, TD= 64.83 percent).

**Discussion:** The youth with DS used less mental state language, particularly for terms indicative of desire, than nonverbal ability-matched TD children while story-telling from a picture book. These deficits in mental state language are likely to constrain the acquisition of a range of narrative skills, with adverse impacts on social interaction and literacy. Additional analyses will be conducted to explore predictors of mental state language to identify potential mechanisms to target in interventions aimed at enhancing social and communicative abilities in youth with DS.
Symposium 14: Language, Reading and School-Readiness in Down Syndrome

Paper 5: Implicit Learning and Language in Down Syndrome

Frances A. Conners, University of Alabama; Leonard Abbeduto, MIND Institute, University of California, Davis; Mark R. Klinger, TEACCH, University of North Carolina at Chapel Hill; Edward C. Merrill, University of Alabama; Laura Grofer Klinger, TEACCH, University of North Carolina at Chapel Hill; Jamie DeCoster, University of Virginia

Introduction: Young children learn many aspects of language implicitly, without specific intention, in spite of the complexity of language features. We investigated the possibility that poor implicit learning is a problem underlying language impairment in Down syndrome (DS). If it is, then we would expect youth with DS to perform more poorly than their typically developing peers of similar age and possibly also those of similar nonverbal cognitive ability. In addition, we would expect implicit learning to statistically predict language skills (e.g., receptive grammar) among youth with DS. Following is a preliminary look at our data relevant to these hypotheses.

Method: Participants were 48 youth with Down syndrome (DS) age 10-21 (IQ M = 45.2, SD = 8.6), 36 typically developing children age 4-9 matched on Leiter nonverbal cognitive ability (TDNA), and 61 typically developing youth matched on chronological age (TDCA). The two TD groups were different in chronological age but were matched on Leiter IQ (M = 102.4, SD = 10.9 and M = 100.9, SD = 10.9, respectively). Participants were screened for vision, hearing, and autism, and met certain performance eligibility criteria. Group match comparisons were all adequate, with p > .49.

Participants completed a set of laboratory implicit learning tasks, a set of language measures, and a set of phonological memory measures. The implicit learning tasks were modeled after standard cognitive psychology tasks. Each task included a learning phase that exposed participants to covarying information, and a test phase that assessed implicit learning. The Contextual Cuing task measured learning of visual context to guide search. Implicit contextual learning was observed if search speed increased with consistent cues, but then decreased when consistent cues were replaced by random cues. The Prototype Learning task measured implicit category learning of novel animals. Implicit learning was observed if participants consistently selected a novel animal composed of the average of all previously seen animals (i.e., the prototype) the prototype over a novel exemplar. The Artificial Grammar Learning task measured learning of a complex set of sequential contingencies or rules (i.e., grammar). Implicit artificial grammar learning was observed if, after exposure to grammatical sequences, participants discriminated between new grammatical sequences and similar new sequences that violated the grammar. The Serial Reaction Time task measured learning of a complex motor sequence embedded within a simple task (touch the car). Implicit learning was apparent if response speed increased with exposure to the sequence, but then decreased when switched to a random sequence.

Results: The four implicit learning tasks produced different patterns across groups. Significant contextual cuing occurred in the TDCA and DS groups, with group comparisons showing DS > TDNA and no other significant contrasts. Significant prototype learning occurred in all groups, with group comparisons showing TDCA> DS, TDNA. Significant artificial grammar learning occurred only in the TDCA group, with group comparisons showing TDCA>DS, TDNA. Significant motor sequence learning learning occurred in the TDCA and DS groups, with group comparisons showing TDCA>TDNA (all ps < .05).

Within each group, implicit learning tasks were generally uncorrelated. However, together they predicted significant variance in scores on theTROG-2, a measure of receptive grammar, in the group with DS, R2 = .32, p = .01, and in the TDCA group, R2 = .28, p = .001. After entering phonological memory in the first step, the contribution of implicit learning to receptive grammar remained marginally significant in the group with DS, R2Δ = .18, p = .06, and significant in the TDCA group; R2Δ = .23, p = .002.

Discussion: The data showing different implicit learning task patterns across groups suggests that implicit learning is not unitary. Participants with DS performed poorly for their age on two of 4 implicit learning tasks, but they performed at or above their nonverbal cognitive ability level on all of the tasks. Thus, the present data do not clearly support a general impairment in implicit learning in DS. Nevertheless, implicit learning may be an important contributor to grammar learning in this population.

Supported by NICHD Grant HD055345.
**Symposium 15 Title:** Fetal Alcohol Spectrum Disorder: Mental Health Issues Across the Lifespan and the Need for Education

**Chair:** Shelley Watson, Laurentian University

**Paper 1:** "The Knowledge Just Has To Get Out There": Parents' Reflections on Knowledge and Awareness of FASD in Ontario, Canada

Kelly D. Coons, Laurentian University; Shelley L. Watson, Laurentian University

**Introduction:** Despite the wealth of literature on families of children with developmental disabilities, limited research has been conducted on families raising children with Fetal Alcohol Spectrum Disorder (FASD; Watson, Coons, & Hayes, 2013). Current research with families raising children with FASD reveals that parents and caregivers often do not feel supported by those from whom they expect help, such as doctors, mental health practitioners, teachers, and legal professionals (Watson, Hayes, Coons, & Radford-Paz, 2013). Despite the Public Health Agency of Canada's framework for action, in which they identify increasing public and professional awareness and understanding of FASD as their number one broad goal (Public Health Agency of Canada, 2005), awareness of FASD still remains low in the general population (Walker et al., 2005). Because of this lack of knowledge and awareness, parents and caregivers of children with FASD frequently express barriers in getting help from support networks, medical and mental health professionals, schools, government agencies, and community organizations.

**Methods:** Following the recommendations for mixed methods designs outlined by Teddlie and Tashakkori (2009), this study integrated qualitative research (collected in in-depth, semi-structured interviews) and quantitative research (as measured by a number of psychometric questionnaires). Employing a basic interpretive approach (Merriam, 2002), informed by the Family Adjustment and Adaptation Response (FAAR) model (Patterson & Garwick, 1994), this study was conducted with 84 adoptive, foster, and biological caregivers of children with FASD from 59 families in Ontario, Canada. Qualitative findings are presented here.

**Results:** Interpretative phenomenological analysis of the interviews (IPA; Lyons & Coyle, 2010) revealed three main themes regarding parents' experiences in dealing with professionals and the general community in relation to the level of knowledge and awareness of FASD. Parents discussed not feeling supported by those from whom they expect assistance, such as medical professionals, diagnostic teams, mental health practitioners, teachers, and police officers. More specifically, when discussing professionals and the greater community, family members discussed the lack of understanding regarding a FASD diagnosis as well as how FASD may affect their child's level of functioning. Parents and caregivers identified the need for more training of professionals and highlighted the importance of increasing awareness of both FASD and addiction issues. Furthermore, parents discussed the lack of perceived support in Ontario and conveyed their feelings that awareness and management of FASD was "better out West", referring to the Western provinces in Canada such as Alberta and British Columbia.

**Discussion:** It is imperative that professionals increase their knowledge and understanding of FASD including the physical, neurological, and behavioural features of FASD, as well as the collective family experience. Findings from this study highlight that stressors for families raising children with FASD do not always originate internally within the family system, but rather are often the result of limited support in the greater community.

**Key References:**


Introduction: The teratogenic effects of alcohol cause lifelong physical, cognitive, and behavioural impairments that are collectively called FASD. As many as 60% of individuals with FASD will experience trouble with the law (Streissguth, Barr, Kogan, & Bookstein, 1997) and systematic studies have established that individuals with FASD are 19 times more likely to be incarcerated than members of the general population (Popova, Lange, Bekmuradov, Mihic, & Rehm, 2011). Although current models of delinquency in FASD emphasize the poor fit between an individual’s capabilities (e.g., neurocognitive impairments) and the environmental demands (e.g., multiple transitions, lack of structure; Brown, Connor, & Adler, 2012; Malbin, Boulding, & Brooks, 2010), few studies have examined the specific risk and protective factors associated with the family system and the psychosocial milieu of the individual. The purpose of this qualitative study was to explore the family experience of adults with prenatal alcohol exposure (PAE) to better understand the factors that increase or decrease criminality.

Methods: A qualitative study consisting of semistructured interviews was undertaken to explore the factors associated with delinquency in adults with PAE. Data collection is ongoing, but in order to participate in the study, caregivers had to have at least one child with an FASD.

Results: Employing Interpretive Phenomenological Analysis (IPA; Lyons & Coyle, 2010), interviews were analyzed for primary and secondary themes. Preliminary analysis reveals that families identified four risk factors that contributed to their adult child’s trouble with the law, including difficulty with self-regulation, negative influences from the peer group, substance use, and multiple transitions. Protective factors that were reported to help mitigate the effects of the legal issues were structure and supervision, educational and occupational success, access to clinical and financial support, and having a strong network of positive influences.

Conclusion: The overarching theme discussed by families was the need for structure and support for individuals with PAE, regardless of their age. According to the parents in this study, individuals with PAE face vulnerabilities that increase the likelihood of criminality. Difficulties with behavioural and emotional self-regulation, combined with environmental factors such as negative peer influences, substance use, and multiple transitions can create situations in which the demands placed on the individuals outweigh the capabilities to cope with the exigencies. The findings from this study emphasize the need for more family-centred interventions to improve the outcome for adults with PAE.

Key References:


Symposium 15: Fetal Alcohol Spectrum Disorder: Mental Health Issues Across the Lifespan and the Need for Education

Paper 3: Treatment Needs and Interventions for Adolescents with an FASD

Jacquie Pei, University of Alberta

Introduction: Fetal Alcohol Spectrum Disorders present unique challenges in the provision of intervention services. Researchers have underscored the importance of early identification and intervention to optimally meet the needs of this group and prevent the development of secondary disabilities (Streissguth et al., 1996; 2004). However, some children do not receive these early services, and even those who do will continue to require supports throughout their lifetimes. Yet this group faces significant challenges as environmental and developmental expectations grow; because of their prenatal alcohol exposure they experience increasing difficulties performing to these expectations (Rasmussen et al., 2009). This increasing gap between adolescents with an FASD and their peers may reflect the executive function (EF) deficits reported for this population (Pei et al., 2011), which may not be evident in their cognitive function as measured by intelligence testing (Jirikowic et al., 2008). This in turn contributes to the high rate of secondary disabilities reported for this population (Streissguth et al., 1996), which can include trouble with the law (Fast et al., 1999), mental health issues (Pei et al., 2011), increased drug and alcohol abuse (Baer et al., 2003), and increased risk of suicide (Huggins et al., 2008). Also contributing to these secondary disabilities are the frequent environmental contributors, such as victimization and unstable family environments (Streissguth et al., 2004). Consequently, adolescence is a period of convergence of high risk factors, including increased expectations for independence, increased demand on executive function systems, and heightened likelihood of environmental stressors, all of which come together to produce high risk behaviour that has a large impact on society (as noted in Paley et al., 2011). Given these treatment needs, the importance of effective interventions for this group is clear, yet the evidence lags.

Methods: This presentation will discuss a range of interventions. Current areas of interventions being explored include coordinated efforts to increase the capacity of both the youth and the support system.

Results: Preliminary findings are positive, and key themes identified include the need for reasonable expectations, involvement of both the youth and caregivers.service providers, supports to facilitate communication between service providers, increased coordination between organizations involved, stability in the home environment, and targeting high risk behaviours (Duquette et al., 2006; Swaffield, 2011).

Discussion: Early evidence indicates that intervention supports with adolescents with an FASD can have a positive impact but increased investigation into the best approaches is necessary.

Key References:


Introduction: Despite gains in research knowledge about many complex disabilities such as Fetal Alcohol Spectrum Disorder (FASD), there continues to be a lack of available resources translating research into accessible information for educators (Job et al., 2013). Furthermore, educators often receive information by way of professional learning opportunities that are commonly delivered in short-term didactic "expert" led transmissions that are not consistently linked to increases in knowledge or changes in practice (McLeskey, 2011). Thus, there is a pressing need for alternative ways to deliver professional learning opportunities that can translate new disability relevant, evidence-based findings, knowledge, or teaching techniques from research into classroom practice. One way to bridge the research to practice gap, is through the creation of collaborative networks, also known as professional learning communities (PLCs; Blanton & Perez, 2011), where the aim is to work together to support and improve educational practices for students with disabilities like FASD. This presentation will describe the development and implementation of the Professionals without Parachutes training initiative, a PLC designed to target the needs of students with FASD. As University-based researchers, we sought to pilot a collaborative approach by partnering with "success coaches" who provide direct support to students with FASD in schools, to engage other members of the broader educational community (e.g., teachers, and school counselors) to work together, forward their thinking and generate school-based tools to support both the needs of educators and students with FASD.

Methods: The Professionals without Parachutes initiative was implemented across three different contexts; an urban high school, a rural school district, and a rural setting that included participants from both a public and separate school district. Following a multiple case study design (Stake, 2013), data was collected across settings and included session audio-recordings, project documentation, and a focus group conducted with the success coaches. The focus group transcript was analyzed using a basic interpretive approach (Merriam, 2002). For this presentation, results will focus on the experience of the success coaches across the different contexts and will draw on the findings of the focus group.

Results and Discussion: Findings from the focus group emphasized the positive impact of the Professionals without Parachutes initiative on both the experience of the success coach and on the broader educational community. Three themes emerged highlighting that PLC members gained; an increase in knowledge about FASD, reframed their understanding of the impact FASD has on students and fellow educators, and that this experience fostered advocacy in the educational community to support the complex needs of students with FASD.

Key References:


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SAVE THE DATE

48th Annual Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities
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