Autism Research Centre

The Autism Research Centre, co-directed by Dr. Lonnie Zwaigenbaum and Dr. Joanne Volden, is pleased to share an update on current studies and collaborations

Pathways in Autism Spectrum Disorders

Pathways is a national study that examines how newly diagnosed preschool children with autism grow and develop. We hope to identify factors associated with the best possible outcome in order to help individuals and families affected by ASD. Our team collaborates with the Autism Follow-Up Clinic to recruit families into the study.

Currently, we have 48 families enrolled at the Edmonton site. Families have enjoyed receiving a regular update on their child's development. After each visit, parents receive a written report describing their child's progress; these reports can be shared with program staff to assist with treatment goals or used to help advocate for ongoing support. The Pathways study recently received a new grant that will allow the research group to follow participating children all the way through to grade 5. The hope is to eventually follow the entire group through transition to adulthood. Pathways has become the largest longitudinal study of children with ASD ever conducted, and promises to generate new insights for families, clinicians and health and policy makers about how to help children and youth with ASD reach their full potential. The first scientific paper from the Pathways study group has just been published in the Journal of Autism and Developmental Disorders; it focuses on the assessment of repetitive interests and behaviors in preschool children with ASD. Other papers currently being prepared address other interesting and important topics, including age of referral and diagnosis, early language development, emotional and behavioral symptoms, and parent stress. An update on study findings will be presented at an upcoming Autism Research Rounds.

We continue to recruit families with a child who is between the ages of 2 years and 4 years, 11 months with a recent diagnosis of ASD (within 4 months). Please contact Megan Alexander, Research Coordinator, at (780) 735-6106 if you would like more information about this study.

pathways
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Infant Sibling Study

Siblings of children with ASD are at an increased risk of developing ASD, as well as other difficulties such as language delay. The Infant Sibling study follows high-risk infant siblings and low-risk infants with no family history of ASD in order to better understand early development in ASD. Our goal is to develop better strategies for early detection and diagnosis as well as early intervention, to give children with ASD the best possible chance at reaching their full potential. This national study includes over 500 families, including 62 families participating in Edmonton. Families have found the extra attention paid to their child's early development very valuable and our team has enjoyed getting to know each child and family throughout the course of the study. In instances where concerns do arise, our team assists the family in accessing appropriate clinical services. We conclude each assessment appointment by discussing our observations with the family to ensure that our picture of the child fits with the parent's perspective. The feedback from families participating in the Infant Sibling study has been very positive.

New funding is now allowing our team to follow these younger siblings from infancy through to 8 years of age, which will provide a unique opportunity to learn about how individual differences expressed during infancy might help predict later emotional and behavioral issues, and to develop better early identification strategies for children with ASD across the spectrum. Typically children with milder ASD symptoms and/or more advanced language and intellectual development are diagnosed later, but this could change with more knowledge about how these children present early in life.

We are currently recruiting families with infants 6 to 12 months old to be part of either the high-risk or low-risk group. If you are interested in learning more about the Infant Sibling study, please contact Jana Roberto, Research Coordinator, at (780) 735-6106.

Autism Research Centre

Genetics Study

The Autism Research Centre is part of a Canadian Autism Research Genetics team (CAN-A-GEN) aiming to discover genes that cause or contribute to the risk of ASD. Identifying genes linked to autism may have important implications for diagnosis and intervention. The families involved in the Genetics study have enjoyed the opportunity to be part of such a large scale research effort to learn more about the genetics underlying ASD, and have also appreciated the assessment reports that they receive from the study team.

There has been exciting progress by CAN-A-GEN as well as our international collaborators over the past year. Several genes have been identified as having a role in vulnerability to ASD, based on 'copy number variants' in DNA sequence. These genes play an important role in brain development and synaptic plasticity. Findings from this research have been published in top scientific journals, and have received considerable media attention (e.g. recent stories in the Globe and Mail, and on CTV's Canada AM).

Our genetics study will begin to focus more on families participating in the Pathways and Infant Sibling studies, as part of an exciting new national research initiative focused on neurodevelopmental disabilities, NeuroDevNet (see www.neurodevnet.ca), but we continue to recruit other families as well. For the Genetics study, we are currently recruiting extended families with at least 3 individuals diagnosed with ASD across generations and also families that include a girl diagnosed with ASD. If you would like more information about the Genetics study or NeuroDevNet study, please contact Jordana Eliason, Research Coordinator, at (780) 735-6114.

Connecting the Dots Study

Dr. Sandra Hodgetts, in collaboration with Dr. David Nicholas and Dr. Lonnie Zwaigenbaum, is examining the processes and experiences of families and service providers negotiating care for young persons with autism in Alberta. This project aims to identify the demands experienced by families of young persons with autism, determine how parents and young persons with autism navigate the health, education and social service systems, and how families manage change in service systems over time. Through this study, Dr. Hodgetts hopes to determine means to improve family experience and enhance systems of care in Alberta. If you are a parent or service provider interested in participating in an interview to discuss your experiences, know someone who might be interested in participating, or would like more information, please contact Dr. Sandra Hodgetts at (780) 492-7219.

Examining the Experiences of Mothers and Fathers of a Young Person with Autism

Dr. David Nicholas and Dr. Lonnie Zwaigenbaum are examining the shifting experiences of parents of a child with autism (up to age 25 years) and their families over the journey of ongoing care provision, development of the young person with autism, and changing resource needs. The study also examines how parents–both individually and together as a couple or co-parents – navigate care for their child. Currently, we have interviewed approximately 60 parents, and are hoping to recruit another 20 more families. If interested in more information, contact the principal investigator, Dr. David Nicholas at nicholas@ucalgary.ca or 780-492-8094.

Mathematical Development in Children with Autism Spectrum Disorder

Carley Piatt, along with Dr. Jeffrey Bisanz and Dr. Joanne Volden of the University of Alberta, is studying how children with ASD learn math skills such as counting and arithmetic. Currently, we know very little about how children with ASD learn math. By learning more about the development of math skills in children with ASD, we may be able to find ways to help them learn better. If you would like more information on this study, please contact Carley Piatt at (780) 492-5262.

Understanding "Figures of Speech" in Children with Communication Disorders

Dr. Joanne Volden is examining communication skills in children with ASD. We need children with ASD who are 6-, 9- or 12-years old. Children with autism frequently have difficulty understanding figurative language, like "skating on thin ice", but we don't know exactly why. This study examines how understanding figurative language develops in children with ASD. We also want to know what factors make it easier to understand.

Children with ASD, with specific language impairment (SLI) and typically developing children will participate. Tests will be given to evaluate language and problem solving skills. Games will evaluate how well children understand "figures of speech". This will take approximately 4 hours, spread over 3 visits. Testing can take place either at Corbett Hall at the University of Alberta or in the home. Parental consent is required and we can offer a report of your child's language skills. When the testing is finished, we will provide you with a short summary of the results. Also, we will send you a summary of the whole research project when the study is complete.

If you are interested, please contact Dr. Joanne Volden at 780-492-0651.