

## Canada's Top Researchers are Beating a Path to Help Children with Autism Realize Their Full Potential

Parents of children with autism spectrum disorder (ASD) are desperate to know what the future holds for their child and what they can do to maximize the chances of a good outcome. Yet we can tell them very little about the mediators, moderators and mechanisms associated with good outcomes for children with ASD.

All that may soon change, thanks to a new study, the largest of its kind in the world, led by some of Canada's leading autism experts.

Autism Spectrum Disorders: Pathways to Better Outcomes made history when the Canadian Institutes of Health Research (CIHR), announced it would provide more than \$2.1 million over five years to fund the study. Not only was it the largest Canadian grant ever awarded for autism research, it's the largest longitudinal study in the world to examine psycho-social factors in children with ASD.

CIHR made the commitment in partnership with Autism Speaks, a U.S. non-profit organization dedicated to funding biomedical research in autism. The Government of British Columbia has provided an additional \$1.275 million over five years to fund the BC portion of the study.

### How does the study work?

The study will follow approximately 500 children in four locations across Canada

*"By gaining a better idea of what contributes to healthy outcomes for these children, we will be able to guide the development of new policies, programs and interventions that will optimize strengths and reduce the burden of suffering for children with ASD and their families."*

*Peter Szatmari*

during the critical transition between diagnosis and entry into elementary school. "This is a critical time period for children with ASD," says Dr. Peter Szatmari, Director of the Offord Centre for Child Studies at McMaster University and one of the lead investigators on the project. "Some children are able to cope with this transition extremely well, while others suffer a severe setback."

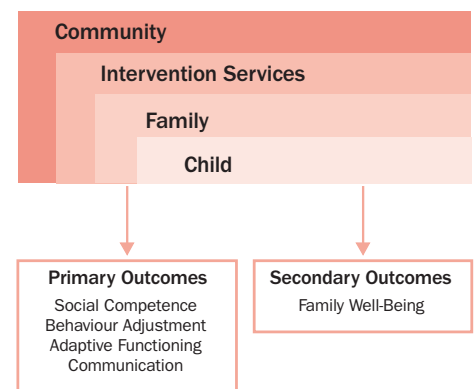
Each child will be seen an average of four times between the time they receive a diagnosis of ASD (2-4 years of age) and when they finish grade 1 (roughly 6 years of age).

During these visits, researchers will be looking at how the child develops in a number of key areas, including social competence, communication skills, behaviour, and ability to adapt and function independently.

They will be assessing many factors that influence these areas of development, including those related to the child, the family and the community as a whole.

The goal, says Dr. Szatmari, is to gain a better understanding of the critical variables associated with optimal outcomes for children with ASD.

"How do these variables interact with critical child skills such as joint attention, imitation, and language. Can identifying these potentially modifiable factors – parent child interactions, processes of care, etc. – have a major impact on how care is delivered? Will it shed light on the core mechanisms affecting the development of other vulnerable, high-risk children? Can we use this information to develop evidence-based, early intervention programs that will benefit all children? These are the questions we hope to answer."



### Where are these children and families located?

More than 271 children are currently enrolled in the study. The largest group is in Montreal, with 106 children participating. Another 69 children from across the province of British Columbia are participating, along with 54 in Hamilton, Ontario, and 42 in Halifax, Nova Scotia. A new site has just been added in Edmonton, Alberta, where the number of participants is still to be determined.

*(Read more about this project on page 4)*

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## Meet the Study Leaders

**Peter Szatmari**  
**Offord Centre for Child Studies**  
**McMaster University**



Dr. Szatmari is professor, vice-chair of research, and head of Child Psychiatry at McMaster University, where he holds the Chedoke Health Chair in Child Psychiatry. He is also Director of the Offord Centre for Child Studies, a leading centre of research on healthy child development. He was instrumental in developing the Pervasive Developmental Disorder Team at Chedoke Child and Family Centre, a regional diagnostic and treatment program for children with ASD. He has served on the Board of Autism Society Ontario, and as a consultant on research and treatment for children with ASD to government agencies in Canada, the U.S. and internationally.

**Susan Bryson**  
**IWK Health Centre**  
**Dalhousie University**



Dr. Bryson is founding director of the Autism Research Centre at the IWK Health Centre at Dalhousie University, where she holds the Joan and Jack Craig Chair in Autism Research, and of the newly developed Provincial (NS) Autism Centre for families and professionals. She is a leading authority on the early detection and treatment of autism, and on mechanisms of attention, emotion and learning in autism. She has served as a consultant to Health Canada, the U.S. Centers for Disease Control, and the Nova Scotia Departments of Health, Education and Community Services.

**Eric Fombonne**  
**Montreal Children's Hospital**  
**& McGill University**



A leading authority on the epidemiology of autism, Dr. Fombonne is Director of Psychiatry at the Montreal Children's Hospital and head of Child Psychiatry at McGill University, where he holds a Canada Research Chair. He has worked at INSERM in France and at the London Institute of Psychiatry, U.K., and has consulted to the National Academy of Sciences, the Center for Diseases Control, the American Academy of Pediatrics, the MRC (U.K.), and the MIND Institute (U.C. Davis). He is Associate Editor of the Journal of Autism and Developmental Disorders.

**Pat Miranda**  
**University of British Columbia**



Dr. Miranda is a professor and Board Certified Behavior Analyst in the Department of

Educational and Counseling Psychology and Special Education at the University of British Columbia, where she received the Killiam Faculty Teaching Prize in 2004. A Fellow of the American Speech-Language-Hearing Association, she lectures widely and teaches courses about inclusive education, developmental disabilities, autism, augmentative communication, and positive behaviour support. She is co-author of the book *Augmentative and alternative communication: Management of severe communication disorders in children and adults* (3rd edition, 2005).

**Wendy Roberts**  
**The Hospital for Sick Children**  
**& University of Toronto**



Dr. Roberts is a professor of Pediatrics at the University of Toronto, and Co-Director of the Autism Research Unit at The Hospital for Sick Children. She received her training at both institutions. Following 8 years of part-time academic and part-time community practice in general and developmental paediatrics, she returned to Sick Kids in a full-time academic position. Her research is focused on examining the impact of early identification of autism, as well as the genetic origins of autism and Attention Deficit/Hyperactivity Disorder (ADHD). In particular, she has been instrumental in bringing gold-standard autism assessment protocols to Canada.

**Isabel Smith**  
**IWK Health Centre**  
**Dalhousie University**



Dr. Smith is a clinical child psychologist and an associate professor in the Departments of Pediatrics and Psychology at Dalhousie University. Her research interests include the early diagnosis, developmental course, and outcomes of ASD, as well as the development of imitation and action control in ASD. She has promoted evidence-based practices and programs for children and youth with ASD throughout the Maritimes.

**Tracy Vaillancourt**  
**McMaster University**



Dr. Vaillancourt is an associate professor and associate chair of Psychology in the Department of Psychiatry and Behavioural Neurosciences at McMaster University. Her research examines the links between aggression and bio-psychosocial functioning, with particular focus on bully-victim relations. She is currently leading a Community-University Research Alliance on the prevention

and intervention of bullying. Her interest in autism relates to the longitudinal study of autistic symptoms and what predicts optimal outcomes for children and families. As well, the bulk of her clinical work has been in the area of autism.

**Joanne Volden**  
**University of Alberta**



Dr. Volden is an associate professor of Speech Pathology and Audiology at the University of Alberta, and co-director of the Autism Research Centre at Glenrose Rehabilitation Hospital. Her research interests are in language and communication development, particularly pragmatic language impairment in children, adolescents and adults with ASD. Her work has been funded by the Social Sciences and Humanities Research Council of Canada, the Alberta Heritage Foundation for Medical Research, and the Canadian Language and Literacy Research Network.

**Charlotte Waddell**  
**Simon Fraser University**



Dr. Waddell is a child psychiatrist with longstanding interests in health policy and public health. She studies the policy process and conducts research to inform policy-making: addressing the determinants of health; preventing problems in children at risk; promoting effective services; and monitoring our collective progress towards improving children's mental health. She is an associate professor and Director of the Children's Health Policy Centre in the Faculty of Health Sciences at Simon Fraser University. Dr. Waddell was recently appointed as the Canada Research Chair in Children's Health Policy.

**Lonnie Zwaigenbaum**  
**Glenrose Rehabilitation Hospital**  
**University of Alberta**



Dr. Zwaigenbaum is associate head of Developmental Pediatrics and associate professor of Pediatrics at the University of Alberta. He is co-director of the Autism Research Centre at Glenrose Rehabilitation Hospital. He received his training at Queen's University, The Hospital for Sick Children, and McMaster University, where he was on faculty for eight years. His research focuses on the early development of children with ASD. He is leading a study of younger siblings of children with ASD, and co-chairs an international consortium of research groups following similar high-risk cohorts.

## Researchers Seek Pathway to National Autism Strategy

**“Investments in children’s mental health are among the most important investments that any society can make.”**

*Charlotte Waddell*

Any discussion of policy and services for children with autism inevitably involves the Auton case in BC and the Wynberg case in Ontario.

Both the Auton and Wynberg families argued that insufficient funding for behavioral interventions for children with autism spectrum disorder (ASD) – whatever their age – is discriminatory. The Supreme Court of Canada eventually ruled against them, but their efforts have had an impact on the policy process. Both BC and Ontario have increased funding for ASD services. BC now helps parents pay for behavioral interventions, while Ontario provides publicly-funded behavioral interventions for young children.

Whether these new investments are sufficient is a matter of debate. There is also ongoing uncertainty about which interventions to use and how they should be delivered for the greatest benefit of children. The result is considerable variation from province to province in the availability and quality of ASD services. Consequently, many parents across Canada must shoulder significant burdens when their children are diagnosed with ASD.

Charlotte Waddell, an associate professor and director of the Children’s Health Policy Centre at Simon Fraser University, believes the issues raise important questions for all Canadians.

“How do we make collective decisions about public investments in children?” asks Dr. Waddell. “How do we make ethical decisions?”

These questions prompted Dr. Waddell to explore the relationship between researchers, policy-makers and parents of children with ASD. Her study, *Policy Pathways to Better Outcomes for Children with Autism*, is a qualitative study involving in-depth interviews with researchers, policy makers and parents across Canada. Part of the national Pathways in ASD study, its aim is to find ways in which these groups might work together more effectively.

“In order to make collective decisions on behalf of children,” Dr. Waddell suggests, “we need to understand the perspectives of everyone involved – parents, policy makers and researchers. Reconciling these different perspectives is a necessary step towards a national autism strategy.”

This year, Dr. Waddell’s research team will be speaking with people from BC, Alberta, Ontario, Quebec and Nova Scotia. Two years from now, they will reconnect with the participants to report on the progress made toward collective decision-making for children with ASD.

### The changing face of autism

Autism is a complex neurodevelopmental disorder characterized by impairments in reciprocal social interaction and in communications with others, and by a preference for repetitive, stereotyped behaviours.

Our understanding of autism has changed dramatically over the past decade. We now know that several closely related "disorders" exist that share the same essential features but differ on specific symptoms, age of onset, or natural history. These disorders, which include Asperger syndrome, Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), atypical autism and disintegrative disorder, are viewed as lying on a spectrum with autism, hence the popularity of the term "autism spectrum disorders."

Autism spectrum disorder (ASD) now affects as many as one in every 165 Canadian children and adolescents, a number that has risen dramatically in recent years. This increase is generally thought to be the result of new advances in knowledge that has changed how we define autism/ASD, as well as an increased awareness that has improved our ability to recognize the symptoms and diagnose affected children at an earlier age.

Clinical signs of ASD can now be observed as early as 12-18 months in some children, and by utilizing gold-standard diagnostic procedures it can most often be distinguished from other developmental and psychiatric disorders. Still, the average age of diagnosis is approximately 4 years, more than 2 years after most parents first note symptoms.

## Resources for Parents

### Web sites

#### Autism Society Canada

[www.autismsocietycanada.ca](http://www.autismsocietycanada.ca)

This web site includes general information about autism and treatment options, and helpful links to the provincial Autism Societies and to other information resources.

#### Canadian Autism Intervention Research Network (CAIRN)

[www.cairn-site.com](http://www.cairn-site.com)

This site publishes summaries of research from around the world on the latest, evidence-based treatments and early interventions for children with ASD.

#### www.autism-resources.com

This U.S. web site was developed by the father of a child with autism as a comprehensive listing of autism resources worldwide. It includes links to libraries, academic and research programs, online papers and other autism sites, and lists 700 books on autism for professionals and parents.

#### Autism Speaks

[www.autismspeaks.org](http://www.autismspeaks.org)

Autism Speaks is a U.S. non-profit organization dedicated to funding and accelerating biomedical research in autism. In 2005, it merged with the National Alliance for Autism Research (NAAR) and Cure Autism Now (CAN).

[www.nimh.nih.gov/publicat/autism.cfm](http://www.nimh.nih.gov/publicat/autism.cfm)

This is the Autism Page of the National

Institute of Mental Health (NIMH) in the U.S. It contains a wide range of information and resources for professionals and the public.

### Books

#### Visual Strategies for Improving Communication: Practical Supports for School and Home

By L.A. Hodgdon

Published by QuirkRoberts Publishing, Troy, MI (1995).

#### Solving Behavior Problems in Autism: Improving Communication with Visual Strategies

By L.A. Hodgdon

Published by QuirkRoberts Publishing, Troy, MI (1999)

#### Families and Positive Behavior Support: Addressing Problem Behaviors in Family Contexts

Edited by Joseph M. Lucyshyn, Ph.D., Glen Dunlap, Ph.D., & Richard W. Albin, Ph.D.

Published by Paul H. Brookes, Baltimore (2002)

#### Communication-Based Intervention for Problem Behavior: A User's Guide for Producing Positive Change

By Edward G. Carr, Ph.D., Len Levin, M.A., Gene McConnachie, Ph.D., Jane I. Carlson, M.A., Duane C. Kemp, Ph.D., & Christopher E. Smith, M.A.

Published by Paul H. Brookes, Baltimore (1994)

**on the path** was developed to inform families, researchers and public policy specialists about the Autism Spectrum Disorders: Pathways to Better Outcomes project. We would like to thank our funders, the Canadian Institutes of Health Research, Autism Speaks, the Government of British Columbia, and the Alberta Heritage Foundation for Medical Research.

Editor: Sherry Cecil

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Several sub-studies are also underway:

- In Halifax, Dr. Susan Bryson and Dr. Isabel Smith are looking at relationships among joint attention, executive control and social imitation.
- In Montreal, Dr. Eric Fombonne is evaluating the effectiveness of More Than Words, an intervention to promote

communication skills in young children with ASD.

- In Hamilton, Toronto, and Halifax, researchers are comparing the children's progress to that of a high-risk group of younger siblings of children with autism.
- In BC, Dr. Charlotte Waddell is comparing provincial policies to determine what

changes are needed to ensure availability and quality of ASD services nationwide.

- Also in BC, Dr. Vikram Dua, Dr. Stephen Wellington and Karen Kalyinchuk at the Provincial Autism Resource Centre are evaluating diagnostic accuracy and stability in young children with autism and other developmental disabilities.