Canadian Research Initiatives
Best Practices Literature

It is important to research the causes and prevalence of ASD and to better understand early identification and diagnostic techniques. However, while this kind of research is providing better medical understanding and hope for the future, thousands of Canadians with ASD, young and old and their families are presently requiring better quality services and treatment options to manage their conditions and improve the quality of their lives.

This page highlights current research initiatives relating to the development of better outcomes for children, youths and adults with ASDs. This includes research into the design of improved life-span health and social services, delivery models and best practices in treatment.

In general, more research is needed to:

- Further develop current treatment models and interventions and to investigate new approaches
- Determine which approach works for which individual and at which stage of their development
 - Deepen understanding of ASDs across the lifespan
 - Assess functioning and quality of life for children, youth and adults with ASD
 - Assess behavioural, psychological, psychosocial and psycho-educational treatments
- Determine the communication needs and differences for individuals with ASD and evaluate treatment outcomes with respect to speech, language and communication skills
 - Better understand the needs of families
- Investigate methods of cross-discipline cooperation and effective service delivery (e.g., guidelines, sharing of knowledge and training needs)
 - Understand the barriers to accessibility of treatments for ASD

Canadian Research into Treatment and Intervention

The Behavioural/Developmental Continuum of Interventions for Autism Spectrum Disorder: A Systematic Review

At the Alberta Centre for Child, Family and Community Research, a team of co-investigators, working collaboratively under the leadership of Drs. Brenda Clark and Veronica Smith, (Co-Principal Investigators of the study) is currently undertaking a systematic review of the research evidence supporting the effectiveness of various behavioural/developmental-based interventions for individuals with autism spectrum disorder. Along with other stakeholders, Autism Society Canada is acting in an advisory role on this project.

A wide range of behavioural/developmental interventions and treatments are currently being used to help people with ASDs function in three core areas: reciprocal social interaction, communication, and restricted, stereotyped, repetitive behaviour. A Canadian-based review of the best interventions, treatment approaches and services for people with ASDs is long overdue and should be very useful in decision-making about the provision of services to families of individuals with ASD. Health professionals, policy makers, families and caregivers are responsible for choosing or implementing interventions, but many do not feel they have sufficient evidence on which to base these decisions.

Hopefully the results of this research will provide much needed guidance in two key areas:

- how to match existing interventions with the needs of individual children, and,
- the appropriate balance and sequence of interventions over the lifespan of an individual with ASD.

Advocates of many early interventions report substantial improvement in certain outcomes, but there is little information about what component of the intervention causes the improvement and how or whether particular improvements will affect the person's functioning over time.

Canadian Autism Intervention Research Network (CAIRN) Studies

Pathways to Better Outcomes Study

The Canadian Autism Intervention Research Network (CAIRN) is conducting a cross-Canada study to identify the factors that promote healthy development in children with Autism Spectrum Disorders. More than 500 children from Nova Scotia, Quebec, Ontario, and B.C. are participating in the study. This will be the largest study of its kind ever carried out anywhere in the world and it is expected to provide a wealth of new information. The study aims to describe the developmental pathways of children with ASD and identify what services, what interventions, and what factors promote the healthiest development among these children. Instead of only focusing on the deficits of children with ASD, the researchers are also focusing on individual strengths that allow kids with ASD to be resilient in the face of challenges.

<u>Follow-up Study – Developmental Trajectories Among Children with Pervasive Developmental Disorders</u>

CAIRN study is looking at whether children with Asperger syndrome (AS) have a different outcome than children with high-functioning (HF) autism, and also investigating factors that enhance the life quality of these children and their families. It is the most comprehensive and longest-lasting follow-up study of children with HF autism in the world and the only study that has focused on Asperger syndrome.

Canadian Early Intervention Research Project

(<u>View study description</u>) McGill University is spearheading this project in partnership with the Yaldei Developmental Centre

(YDC). The project is being conducted through the Faculty of Education, in the Department of Educational and Counseling Psychology (ECP). The project goals are to determine the efficacy of Early Childhood Intervention (EI) programs that impact the health, wellness, and environment of families with children who have developmental delays; and to engage practitioners and policy makers in early childhood development to reassess and facilitate the change of current policies and practices in this area where necessary.

Research costs less than "band-aid" therapy and will save and improve lives. ASC estimates that **lifetime assistance costs can be cut by 50% with:**

- Early diagnosis
- Effective early treatment
- Adequate family supports

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Best Practices Literature

<u>Autism Program Quality Indicators:</u> A self-review and quality improvement guide for schools and programs serving students with Autism Spectrum Disorders. The University of the State of New York, New York State Education Department Office of Vocational and Educational Services for Individuals with Disabilities.

Albany, NY 12234. August, 2001.

<u>Behavioural Interventions for Preschool Children with Autism:</u> McGahan L. Ottawa: Canadian Coordinating Office for Health Technology Assessment (CCOHTA); 2001. Technology report no 18.

Best Practices for Designing and Delivering Effective Programs for Individuals with Autistic Spectrum Disorders - Recommendations of the Collaborative Work Group on Autistic Spectrum Disorders: Sponsored by the California Departments of Education and Developmental Services. (July 1997). Several intervention methods (such as discrete trial, environmental modifications, naturalistic teacher moments, or inclusion with typically developing peers) are considered. States that ABA is usually needed to assist a child to gain skills and reduce negative behaviors.

Clinical Practice Guideline (Report of the Guideline Recommendations) for Autism / Pervasive Developmental Disorders: Assessment and Intervention for Young Children (Age 0-3 Years): Report of the Guideline Recommendations Autism/Pervasive Developmental Disorders Assessment and Intervention for Young Children (Age 0-3 Years). Sponsored by New York State Department of Health Early Intervention Program. This guideline was developed by an independent panel of professionals and parents sponsored by the New York State Department of Health, Early Intervention Program (1999).

Considerations for Administrators in the Design of Service Options for Young Children with Autism and their Families: Strain, P., Wolery, M., & Izeman, S. (1998, Winter). *Young Exceptional Children*, 8-16.

<u>Discrete Trial Training in the Treatment of Autism:</u> Smith, T. (2001). Discrete trial training in the treatment of autism. *Focus on Autism and Other Developmental Disabilities, 16,* 86-92.

Early Intensive Intervention Best Practices.

<u>Educating Children with Autism:</u> Lord, Catherine and McGee, James P. Eds. (June 13, 2001). Committee on Educational Interventions for Children with Autism National Research Council,

National Academies (U.S.) Division of Behavioral and Social Sciences and Education Board on Behavioral, Cognitive, and Sensory Sciences and Education.

<u>Evidence-Based Practices for Children and Adolescents with Autism Spectrum Disorders:</u>

<u>Review of the Literature and Practice Guide:</u> Perry, Adrienne and Condillac, Rosemary. (2004). Children's Mental Health Ontario.

<u>Un geste porteur d'avenir - Des services aux personnes présentant un trouble envahissant du développement, à leurs familles et à leurs proches:</u> Ministère de la Santé et des Services sociaux Québec.

<u>Intensive Intervention Programs for Children with Autism:</u> Alberta Health Technology Assessment Unit.

<u>Position Paper PP2004-02: Early Intervention for Cildren with Autism:</u> Canadian Paediatric Society.

Practice Parameter: Sreening and Diagnosis of Autism: Report of the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society: Filipek PA, Accardo PJ, Ashwal S, Baranek GT, Cook EH Jr, Dawson G, Gordon B, Gravel JS, Johnson CP, Kallen RJ, Levy SE, Minshew NJ, Ozonoff S, Prizant BM, Rapin I, Rogers SJ, Stone WL, Teplin SW, Tuchman RF, Volkmar FR. Neurology 2000 Aug 22;55(4):468-79.

Reference Manual for Best Practices in Assessment of Autism Revised: Illinois School Psychologists Association

Report of the MADSEC Autism Task Force: Maine Administrators of Services for Children with Disabilities, February 2000.

A Review of the Research to Identify the Most Effective Models of Best Practice in the

<u>Management of Children with Autism Spectrum Disorders:</u> University of Sydney, Center for Developmental Disabilities Studies.

Service Guidelines for Individuals with Autistic Spectrum Disorder/Pervasive Developmental Disorder: Birth through Twenty-One:

Guidelines to help families, educators, medical professionals, care providers and other service providers make informed decisions about children and young adults with ASD/PDD. Ohio Developmental Disabilities Council.

<u>Service Guidelines: Children with Autistic Spectrum Disorders:</u> Guidelines support the mission of early intervention, promote consistency in service delivery across the state and most importantly, address the specific needs of children with autism spectrum disorders and their families. Susan Evans, George DiFerdinando, Department of Health and Senior Services, New Jersey Early Intervention System.

Standards and Guidelines for the Assessment and Diagnosis of Young Children with Autism Spectrum Disorder in British Columbia:

Vikram Dua, British Columbia Ministry of Health Planning. Priority was to establish a common definition of autism; common language, assessment practices; and eligibility for autism services. Another priority was to enhance regional capacities to complete multidisciplinary assessments and diagnoses.

<u>Teaching Students with Autism Spectrum Disorder:</u> Newfoundland and Labrador Department of Education.

<u>Teaching Students with Autism: A Resource Guide for Schools:</u> No single method for teaching students with autism is successful for all students. Needs change over time, making it necessary for teachers to try other approaches. British Columbia Ministry of Education.

Teaching Students with Learning or Behavioural Differences: A Resource Guide for Teachers:

The challenge for teachers is to provide each student in their classroom with learning activities that provide challenge and success promote growth, involve the student as an active learner, are age appropriate, and enhance self-concept.

British Columbia Ministry of Education

Treatment Research

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<u>The Pediatrician's Role in the Diagnosis and Management of Autistic Spectrum Disorder in Children:</u> American Academy of Pediatrics: Pediatrics 2001 May;107(5):1221-6.

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