

Canadian Autism Research Agenda and Canadian Autism Strategy

A White Paper



Prepared by
Autism Society Canada
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Canadian Autism Research Agenda and Canadian Autism Strategy: A White Paper

Prepared by



Autism Society Canada

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Executive Summary

On October 2-4, 2002, Autism Society Canada (ASC) hosted the Canadian Autism Research Workshop (CARW) in Toronto, Ontario to bring together Canada's leading autism researchers, government health officials, autism societies, and funding agencies to increase and enhance autism research in Canada. The workshop was held with the lead financial support of the Canadian Institutes of Health Research (CIHR) through 10 of their 13 Institutes and the (American) National Alliance for Autism Research (NAAR), as well as the American Autism Tissue Program and Maritime Life.

The objectives of the workshop were:

- To provide a forum to present the latest information on Autism Spectrum Disorders (ASD) to Canada's scientific, medical and government leaders
- To develop an internationally linked Canadian Autism Research Agenda that will foster increased funding as well as increase and enhance Canadian autism research
- To publish a White Paper summarizing the Canadian Autism Research Workshop that will serve as a strategic plan for guiding the implementation of the Canadian Autism Research Agenda.

The Canadian Autism Research Workshop had two components. The first part consisted of overview presentations on the state of science related to Autism Spectrum Disorders by internationally recognized experts in the fields of neuroanatomy, cognitive neuropsychology, genetics, epidemiology, psychosocial interventions, other medical issues, education and early intervention. In addition, there were overview presentations from parents, individuals with ASD, Health Canada, Canadian Institutes of Health Research, National Institute of Mental Health (U.S.A.), Autism Tissue Program (U.S.A), the Canadian Brain Tissue Bank, the Scottish Rite Charitable Foundation of Canada, and the National Alliance for Autism Research (see Appendix H).

In the second part of the workshop, mixed working groups (each comprised of autism research scientists, research funding agencies, autism societies, and government health officials) brought forward specific priorities for the development of:

1. *Canadian Autism Research Agenda* (see 3.2, 3.3, 3.4, 4.1, 4.2, 4.3, Conclusion and Appendix C, D & E)
2. *Canadian Autism Strategy* (see 5.1 and Conclusion)

From the closing summaries of the breakout groups who discussed overarching research priorities, there emerged **a clear research priority of improving outcomes for people with Autism Spectrum Disorders** (see 3.2 and Appendix E).

Currently, better outcomes are associated with intensive early intervention which requires research in order to improve early screening, diagnostics and assessments. Such research should include refining psycho-social markers and finding additional biomedical (genetic

and/or other) markers and their relationship to possible aetiologies (causes). However, this **research should be coupled with the development of best treatment practices** that make use of psycho-social and biomedical markers in designing treatment, including the development of improved life-span treatment models. Such integrated health services need to be designed to include individual and family support and take into account individual and family differences.

It is noteworthy that Canada has a unique opportunity to undertake such integrated research because of the recent establishment of province-wide autism intervention programs in several provinces. The current emphasis of these programs is on early diagnosis and intervention. These could represent a starting point. Representatives from provincial governments indicated that they would eagerly collaborate in such research.

There is a need for a Canadian Autism Research Agenda that **builds on our existing capacities** and ensures the **involvement of all key stakeholders**, including families and communities. Canada is a large country, but we have a small population; this provides us with the opportunity to build on existing networks and undertake integrated research. Research will assist in piecing together the puzzle of autism and, as a result, more successfully, efficiently and cost-effectively lead to best outcomes for people with ASD and their families.

During the Workshop, it became very clear that, in addition to the development of the Canadian Autism Research Agenda, there was a need for a Canadian Autism Strategy to develop and move forward the Canadian Autism Research Agenda, coordinate activities across Canada, and provide linkages/support for autism researchers, practitioners working with persons with autism and their families and persons with Autism Spectrum Disorders (see 5.1 and Conclusion).

The White Paper summarizes the proceedings of the CARW, the Canadian Autism Research Agenda and its associated Canadian Autism Strategy. It also outlines identified priority research and research funding issues. As well, it acts as an action plan: to promote a significant increase and enhancement of autism research conducted throughout Canada; to foster an improved dissemination system of autism research knowledge; and, to facilitate the provision of better evidence-based assistance to people with Autism Spectrum Disorders and their families.

1.0 Introduction

1.1 Autism Society Canada

Autism Society Canada¹ (ASC) was founded in 1976 by a group of parents in an effort to encourage the formation of autism societies in all provinces and territories and to address national autism issues. Today ASC is the only national autism charitable organization committed to advocacy, public education, information and referral, and autism society development in provinces and territories. Its Board of Directors includes representatives from all the provincial and territorial autism societies.

The goals of ASC, through collaboration with Canadian governments, are to reduce the impact of ASD on individuals and their families, maximize individual potential, and minimize cost of Autism Spectrum Disorders (ASD). ASC feels that this can be accomplished through universally available, reasonably accessible and timely expertise in the following areas:

- Screening, diagnosis and assessment services for Autism Spectrum Disorders
- Scientifically validated effective treatments and condition improvement actions for Autism Spectrum Disorders
- Proactive adequate family supports and assistance
- Increased funds for all areas of Autism Spectrum Disorders research

ASC works on a national basis to address issues and concerns common to its constituent members, the provincial and territorial autism societies, who provide support to individuals and families affected by Autism Spectrum Disorders. As a collective, ASC:

- Provides information and general referrals to the public regarding Autism Spectrum Disorders
- Promotes awareness of Autism Spectrum Disorders
- Encourages research in fields related or relevant to Autism Spectrum Disorders
- Communicates with governments, agencies, and other organizations on behalf of persons affected by Autism Spectrum Disorders
- Promotes actions to ensure people with Autism Spectrum Disorders live in an environment that supports their well-being and enables them to reach their full potential
- Promotes and encourages the convening of conferences and workshops focused on Autism Spectrum Disorders

For the past few years, Autism Society Canada has worked to significantly increase the profile of autism and related conditions among the general public, researchers, and the health care, social service and education systems. Awareness is growing; however, much still needs to be done to determine and apply appropriate screening, diagnosis, treatment and support

¹ Autism Society Canada Pamphlet, 2002.

mechanisms for autism and related conditions. Autism Society Canada is ready to promote the forward movement of the priorities outlined in this White Paper.

1.2 The Need for a Canadian Autism Research Agenda

Autism is on the Increase

Autism, once considered a ‘rare’ disorder, has increased dramatically from a prevalence of 4-5 in 10,000 (1 in 2,000 to 2,500) 15 years ago to at least 1 in 500 in 2001 (CDC).² Using data from three provincial Departments of Education, about one in 200 children in Canada has an ASD.³ In the past 6 years, there has been a 150% increase in the number of reported cases. Evidence from recent California studies indicates that improved knowledge of ASD does not account for the staggering rise in the number of reported cases in the past ten years; the number of people receiving a diagnosis of autism is on the increase.⁴ Although this research from California is important, it is critical that accurate epidemiological studies be carried out to determine the actual incidence and possible geographic “pockets” of ASD.

Currently, Autism Society Canada estimates there are more than 100,000 individuals with Autism Spectrum Disorder (ASD) in Canada, and about 3,000 new cases of autism conditions are identified each year in our country.⁵

The Cost of Identifying, Treating and Supporting Autism

Published and informal research indicates that a person not receiving effective ASD treatments and supports will accumulate a lifetime average cost of \$2 million.⁶ At that rate, Canada’s provinces/territories are cumulatively spending about \$4.6 billion each year on autism services (special education costs, group homes, institutionalization etc), much of which is not supported by evidence-based research. With what we do know from evidence-based research, the lifetime costs of assisting a person with autism can be cut by 50% if he/she receives an early diagnosis, effective treatments, and adequate family supports;⁷ clearly, this is in the financial interests of governments and taxpayers.

It is also clearly in the financial interests of all levels of government to pursue how much more can be done to improve the condition of autism and further reduce the associated lifetime costs and wasted potential for this community of people. This requires research of: autism causes; how autism manifests itself in a person; what kinds of treatments work most effectively and for which group of people with autism conditions specific treatments are best suited; and, what kind of supports are essential and most useful for individuals with ASD and their families.

² Center for Disease Control, USA, http://www.cdc.gov/od/nvpo/fs_tableVII_doc2.htm.

³ Autism Facts in Canada, 2003, Autism Society Canada (data from British Columbia Dept of Education, Saskatchewan Dept of Education and Quebec Dept of Education).

⁴ The Epidemiology of Autism in California, A comprehensive pilot study, October 2002, M.I.N.D. Institute, University of California, Davis.

⁵ Autism Facts in Canada, 2003, Autism Society Canada.

⁶ Cost-benefit Estimate for Early Intensive Behavioural Intervention for Young Children with Autism – General Model and Single State (Jacobson et al, 1998) and Jarbrink, K. & Knapp, M. (2000). ‘The economic burden of autism in Britain’.

⁷ Ibid.

It should be noted that although research indicates that the most productive timeframe for effective treatments is in the pre-school years, research also indicates that effective treatments can make critical differences to the lives of youth and adults with ASD (and their families), regardless of age, and regardless of prior treatment.⁸ Research has a cost, but it is not nearly as much as ignoring or applying “band-aid therapy” to the autism situation in Canada. Research can save both money and lives,⁹ in addition to improving the lives of persons with ASD and their families.

The Lack of Autism Research in Canada and Around the World

While there is currently increased research activity in some areas of autism, in many important areas there is little or no research being conducted. In particular, there is a dearth of information on the understanding of effective treatments for individuals affected by Autism Spectrum Disorders. Much more research is required to address the urgent needs of individuals and families living with these conditions.

Representatives of some provincial/territorial governments have indicated there is currently a struggle to provide health, education and social services related to autism. These governments are looking to a Canadian Autism Research Agenda and associated Canadian Autism Strategy to assist them in the consideration of policies and the future of autism related services.

Advancing Autism Research in Canada

Canada has a nucleus of experienced high quality researchers who are working specifically on autism issues. They form a strong foundation from which to build greater capacity through enhanced focused funding, training initiatives and a focused research agenda generated from CARW. Examples that already exist can be seen in the coalitions and networks that have developed in the autism research community in recent years. There is a dearth of professionals with training in autism related diagnosis, screening and assessment, and there are relatively few Canadian accredited professionals trained and experienced in providing research validated effective autism treatments. However, increasing the number of ASD researchers and research projects will almost certainly have a domino effect, producing more diagnosticians and a commensurate number of treatment providers. The implementation of a Canadian Autism Research Agenda with adequate funding supports for research and training will build capacity in the field of autism research and the requisite associated clinical expertise throughout Canada.

Autism is more common than multiple sclerosis or cystic fibrosis¹⁰ yet the amount of public research funding for autism is not commensurate with the prevalence of ASD when compared to the public research funding of some other medical conditions when consideration is paid to the prevalence of the condition (see Appendix I).

⁸ Treatments for People with Autism and Other Pervasive Developmental Disorders: Research Perspectives, National Institute of Mental Health (NIMH) Sponsored by: The NIH Autism Coordinating Committee and the Department of Education, Office of Special Education, Neuroscience Center, Rockville, MD 20852 November 8-9, 1999
<http://www.nimh.nih.gov/research/autismworkshop.cfm>

Clinical Practice Guideline (Report of the Guideline Recommendations) for Autism / Pervasive Developmental Disorders: Assessment and Intervention for Young Children (Age 0-3 Years), sponsored by the New York State Department of Health Early Intervention Program (1999)

⁹ J Autism Dev Disord 2001 Dec; 31(6):569-76 Causes of death in autism. Shavelle RM, Strauss DJ, Pickett J. Life Expectancy Project, San Francisco, California, USA.

¹⁰ Cure Autism Now, <http://www.cureautismnow.org/aboutcan/autismis.cfm>

2.0 Overview of Autism and Autism Research

2.1 Understanding Autism Spectrum Disorders

Autism Spectrum Disorders (ASDs) are lifelong neurological disorders that affect a person's development and how the brain processes information. They are characterized by challenges in communication, social interaction and learning, as well as by unusual behaviour, perceptions, interests and activities. Autism conditions are spectrum disorders, meaning that the symptoms can be present in a variety of combinations each of which can range from mild to severe.

Autism is one of the Pervasive Development Disorders (PDD), thus potentially affecting all areas of a person's development. Other Pervasive Development Disorders, all of which share features of Autistic Disorder, include Rett's Disorder, Asperger's Disorder, Childhood Disintegrative Disorder, and PDD Not Otherwise Specified (PDD-NOS). Autism Spectrum Disorders (ASD) and most statistics on autism/ASD refer to autism itself, or autism and the other four PDD disorders (autism/PDD).

ASD can co-exist with other medical conditions, including seizures and anomalies of the metabolic, motor control and immune systems. Other conditions that also share features of ASD (and which may respond to effective autism interventions) include William Syndrome, Tuberous Sclerosis, Prader-Willi Syndrome, Fragile X, and Tourette Syndrome. The value of autism related research is that it can benefit people with all disorders that have features of autism.

Without effective treatments, Autism Spectrum Disorders can continue as a severely incapacitating lifelong disability, leading to a life of isolation, dependency and institutional care. Autism usually appears during the first three years of life and affects most aspects of a person's development. Twenty years ago, the prevalence of autism was 4-5 out of every 10,000 births (1 in 2,000 to 2,500).¹¹ A few years ago, this rate was one in 1,000,¹² and now it appears to be more than one in every 200 births in Canada.¹³ Increasing and consistent evidence from recent surveys elsewhere shows that the prevalence rate for all Autism Spectrum Disorders is approximately 60 per 10,000 (1 in 167).¹⁴ It is four times more common in boys than girls and has been found throughout the world in families of all racial, ethnic and social backgrounds.¹⁵

¹¹ Center for Disease Control, USA, http://www.cdc.gov/od/nvpo/fs_tableVII_doc2.htm

¹² Croen LA, Grether JK, Hoogstrate J, Selvin S. The changing prevalence of autism in California. *J Autism Dev Disord* 2002 Jun;32(3):207-15

¹³ Autism Facts In Canada, 2003 (data from British Columbia Dept of Education, Saskatchewan Dept of Education and Quebec Dept of Education)

¹⁴ JAMA January 1, 2003-Vol 289 No 1 49 Editorial by Dr. Eric Fombonne, M.D.

¹⁵ JAMA. 2003 Jan 1;289(1):49-55. Prevalence of autism in a US metropolitan area. Yearnin-Allsopp M, Rice C, Karapurkar T, Doernberg N, Boyle C, Murphy C. National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (F-15), 4770 Buford Hwy NE, Atlanta, GA 30341, USA.

With increased awareness and knowledge, families are beginning to learn about and seek the services, treatments and supports that are critical for a person with an ASD to have the best chance of significant improvement, and enable the person to reach his/her highest potential. While this was deemed impossible two decades ago, research has confirmed that it is possible to help most people with Autism Spectrum Disorders experience significant improvements in their overall condition and ability to function within regular society. This significantly reduces the lifetime cost of support that taxpayers must ultimately pay (see section 1.2).

2.2 Current Autism Research Activity in Canada and Internationally

A decade ago the lower prevalence of ASD was matched with a limited number of dedicated autism scientists; however the dramatic increase in ASD prevalence has sparked greater interest and concern from families, governments, and the larger research community.

As the result of a late start, autism research knowledge has only begun to explore the complexities of autism conditions. Some areas that have been and are being explored internationally include:

1. brain structural and chemical differences;
2. causal involvement elements (genetics, infection and environment, etc);
3. dysfunction in body systems (e.g., neurology, sensory, metabolic, immune, digestion, endocrine, muscular);
4. effective treatment, especially early behavioural, biomedical and pharmacological interventions; and effectiveness of treatments for adolescents and adults;
5. learning and cognitive patterns;
6. family support; caregiver well-being;
7. standardized tools for screening, diagnosis and assessment;
8. application of current best practices knowledge on a national scale;
9. cost-effectiveness of treatments and supports;
10. biomedical aspects of screening and treatment;
11. epidemiology.

Within the areas listed above are many that require additional attention, including replication. There is a need for international collaboration to ensure that ASD research is linked to current research ongoing in other countries and that ASD research is initiated in areas not yet addressed. The goal is to have the most productive and meaningful body of research information that can be used on a global basis.

Cross-regional research communication is a challenge in our large country due in part to the autonomous nature of the provincial health and education systems. Thus, the Canadian Autism Research Agenda requires national facilitation. Through CARW, the Canadian Autism Research Agenda and the Canadian Autism Strategy, ASC will work to spearhead the facilitation and promotion of the priority elements identified at the CARW.

For information on current Canadian autism research initiatives, including which discipline areas are and are not the subject of Canadian research, see Appendix A.

3.0 Developing a Canadian Autism Research Agenda

3.1 Increasing and Enhancing Autism Research in Canada

On October 2-4, 2002, Autism Society Canada hosted the Canadian Autism Research Workshop (CARW) in Toronto, Ontario with financial support from the Canadian Institutes of Health Research (CIHR) through 10 of their 13 Institutes, with a lead role taken by the Institute of Neuroscience, Mental Health and Addiction, as well as the (American) National Alliance for Autism Research (NAAR). Other funding support was provided by the American Autism Tissue Program and Maritime Life.

The purpose of the forum was to bring together leading Canadian autism researchers, practitioners, government health officials, funding agencies and family representatives from provincial/territorial autism societies to increase and enhance autism research in Canada. Seventy-three Canadian and US key stakeholders participated in the workshop, with the majority coming from Canada and a smaller number coming from the U.S. (see Appendix B for a list of participants).

The objectives of the workshop were:

- To provide a forum to present the latest information on Autism Spectrum Disorders to Canada's scientific, medical and government leaders
- To develop an internationally linked Canadian autism research agenda that will foster increased funding as well as increase and enhance Canadian autism research
- To publish a White Paper summarizing the Canadian Autism Research Workshop that will serve as a strategic plan for guiding the implementation of the Canadian Autism Research Agenda

3.2 Overarching Autism Research Priorities

The CARW had two components:

- Overview presentations from leading North American scientists in a number of autism research disciplines (see Appendix H)
- Identification of pressing autism research issues (19 - see 3.3 and Appendix C & D), with a prioritization of several of those issues within each related research discipline area; and a discussion of overarching autism research priorities (see Appendix E)

From the closing summaries of the breakout groups discussing overarching autism research priorities, **there emerged a clear research priority around the development of better outcomes for people with Autism Spectrum Disorders (ASD)**. Currently, better outcomes are the result of intensive early intervention which, to be more successful, requires the development of more accurate methods of early screening, diagnosing, and assessment of the component aspects of the disorders and includes refining psycho-social markers and finding additional biomedical (genetic and/or other) markers and their relationship to possible

aetiologies (causes). **ASD research should focus on the development, regulation and dysfunction of body systems as well as the identification of risk factors for ASD. In addition, ASD research should be coupled with the design of improved life-span health service delivery models and treatment best practices** that take into account individual and family differences and include individual and family support.

3.3 Priority Autism Research Issues Within Each Research Area

The participants included representatives from the following groups: families, scientists, government officials, and research funding agencies (see Appendix B for a complete list). They identified the highest priority autism research issues within each research area. It should be noted that these issues are not ranked within each area of research, and they are not ranked across topics, as they were all considered to be critical autism research issues. It was noted that these issues included a number of aspects that crossed disciplines.

Autism research is complex and requires much cross-discipline expertise. From the cross-reference analysis, the research areas with the highest degree of cross-issue involvement were: Other Medical (17) and Autism Education (15). It is noteworthy that Epidemiology issues had cross-topic aspects in every research area (7). For a complete cross-reference analysis of the 19 critical autism research issues, see Appendix C.

Below are the top ranking 19 Autism Spectrum Disorder research priorities by area of research. A detailed list of all of the autism research pressing issues identified by the CARW participants can be found in Appendix D.

Neuroanatomy

- Infrastructure
 - Tissue availability
 - Control (Comparison tissues)
 - Standardized tissue processes
 - Distribution prioritization
 - Establish (imaging) bio-markers for autism

Epidemiology

- Studies aimed at developing and evaluating strategies for identifying developmental disorders (including autism) early in life
- Studies aimed at measurement of autism prevalence in the general population
 - Quality of life issues
 - Co-morbidity

Neuropsychology

- What is the developmental trajectory of cognitive strengths and weaknesses in relation to autism symptoms, brain functioning, and intellectual functioning in high and low functioning people with autism
- How does intervention at various ages effect the trajectory

Education and Early Intervention

- Research in Education and Early Intervention
 - Clinical trials (multiple interventions)
 - Identification of outcome measures
 - Mediators and moderators of outcomes
 - Treatment fidelity
 - Standardized external evaluation
 - Linkages with early interventions transition to school
 - Evaluation of evidence based models in schools
 - Connect with service providers
- Training
 - Centre for Excellence
 - Professional development
 - Standards/requirements

Psychosocial Interventions

- What are the best outcome measures for evaluating effectiveness including quality of life
- What are the best practices for establishing a continuum of care for life-span services and how health care systems can be best organized to provide services that minimize the impact on families (cost-effective services tied to quality of life)

Other Non-Medical

- Identification of the needs of adults with ASD and effective interventions to address those needs
- Identification of the needs of families and effective interventions (stress, supports...)
- Standardized accurate identification and assessment and continuing follow-up
- Health Services organizations

Genetics

- Well characterized families
 - Standardized phenotypic information including broader phenotype
 - Sample selection
 - Co-morbidity
 - International collaboration
- Gene-Environment Interactions
 - Environmental exposures (international collaboration)
 - Using epidemiologic methods (birth cohort studies, twin studies)

Other Medical

- Education
 - Training of physicians
 - Dissemination of information

- Medical
 - Etiology of medical issues related to autism
- Pharmacology

For the list of all identified autism pressing research issues from which the above list of high priority issues was derived, see Appendix D. Appendix E provides an overview of what came forward during the small group closing summaries.

3.4 Strengths and Capacities for Autism Research in Canada

There is a growing demand for quality autism research and a commensurate need for a Canadian Autism Research Agenda **that builds on our existing capacities and ensures the involvement of all key stakeholders**, including families and communities. Success is dependent on bringing all parties together at the very beginning to initiate the research agenda and foster commitment to its implementation.

Canada has a unique opportunity to undertake a more integrated research approach – recently, several provincial/territorial autism intervention programs have been established which could represent an excellent starting point. Representatives from provincial/territorial governments indicated that they would eagerly collaborate in such research.

Canada is a large country, but we have a small population, and as a result we are able to develop successful, action-oriented networks and agendas. We have strong senior researchers in some autism content areas, and there are some untapped Canada-wide data collection mechanisms, including the census, which could be utilized. Additionally, the population health approach adopted by the CIHR and Health Canada provides a great starting point for **developing inclusive, multi-sectoral autism research** that focuses on determinants of health, interventions and other related research. Another key strength is that we can **build on international research support and financial partnerships** to move autism research forward within Canada.

Below is information on the primary Canadian research partner and a key American partner, followed by a more comprehensive list of potential autism related research partners.

The Canadian Institutes of Health Research (CIHR)

The Canadian Institutes of Health Research (CIHR) is Canada's premier federal agency for health research. CIHR is comprised of thirteen different institutes. Autism issues fall within the mandates of at least 10 of these institutes (see Appendix F for CIHR Potential Institute Involvement), all of which supported the Canadian Autism Research Workshop held in October 2002, and encouraged the development of the White Paper as a means of advancing autism research in Canada.

The National Alliance for Autism Research (NAAR)

Established in 1994, the National Alliance for Autism Research (NAAR) was formed by parents of children with autism. To date, NAAR has committed approximately \$10 million to

fund 117 autism research projects worldwide, including Canada. NAAR was a lead sponsor of the Canadian Autism Research Workshop and plans to remain a strong partner.

3.5 Potential Autism Research Partners

Research Partners are groups, organizations or agencies that can fund, disseminate or conduct autism research. These groups are:

Canada

Research Funders

CIHR (Canadian Institutes of Health Research)
SSHRC (Social Sciences and Humanities Research Council)
NSERC (Natural Sciences and Engineering Research Council)
CHSRF (Canadian Health Services Research Foundation)
Foundations with mandates that include autism related research issues

Canadian Autism Research Foundations

Canadian National Autism Foundation
Autism Canada Foundation
Autism Research Fund of Canada (in development)

Research Networks

CAIRN (Canadian Autism Intervention Research Network)
ASD-CARC (Autism Spectrum Disorders – Canadian American Research Consortium)
3C-RND (Canadian Center for Cognitive Research on Neurodevelopmental Disorders)

Research Agencies

CCOHTA (Canadian Coordinating Office of Health Technology Assessment)
Provincial/territorial health research agencies

Data Collection/Information Dissemination

CIHI (Canadian Institute of Health Information)
Statistics Canada
Health Canada

Health Organizations

Professional Associations (medical practitioners and educators)
Autism service providers and regional autism organizations
Provincial and territorial autism societies
Autism Society Canada
National health and other related national organizations (NGO's)
Social Development Canada (SDC), Office for Disability Issues
Universities and Teaching Hospitals

Other Organizations

Provincial Departments of Health, Education, Social Services, Children and Families
Selected Corporations

United States

Research Funders

NAAR (National Alliance for Autism Research)
NIH (National Institutes of Health)
CAN (Cure Autism Now)
Autism Society of America Foundation (through Cycle USA)

Research Agencies/Networks/Institutes

ARI (Autism Research Institute)
UC Davis MIND Institute (Medical Investigation of Neurodevelopmental Disorders) at Davis University of California

Research Advocacy and Information Dissemination

DAN (Defeat Autism Now)
IMFAR (International Meeting for Autism Research)

3.6 Canadian Autism Research Agenda

The following points summarize the Canadian Autism Research Agenda:

Research Goal

1. Overarching priority of improved outcomes for individuals with ASD and their families.

Research Agenda

2. ASD research activities focused in the 19 priority areas determined at the CARW (3.3).
3. Work toward long-term ASD Canadian Autism Research Agenda in collaboration with Health Canada and the provincial and territorial health departments (4.3).
4. Build on existing capacities; develop multi-sectoral ASD research (3.4).
5. Involve all stakeholders; build on Canadian and international research support and financial partnerships (2.2 & 3.4).
6. Facilitate enhancement of the Canadian Brain Tissue Bank and the development of a Canadian autism tissue collection program, perhaps using the (American) Autism Tissue Program model (3.3).

Knowledge Transfer

7. Facilitate translation of research into clinical practice and service delivery (3.2).
8. Facilitate the development of a comprehensive national database to include items such as: screening, diagnosis and cognitive evaluations with the instruments used; evaluators, treatment types and providers; outcomes for the individual with ASD and his/her family; blood samples; neurological images; brain tissues, etc. (3.3).

Research Funding

9. Initial ASD RFA through CIHR; suggested partnership total of \$10 million (4.1).
10. Work toward multi-agency ASD RFA (4.2).

4.0 Next Steps

4.1 Working with the Canadian Institutes of Health Research (CIHR)

Participants were highly supportive of CIHR leading the development of an autism research Request For Applications (RFA) which would support the priorities identified in sections 3.2 and 3.3 of this White Paper. Autism Society Canada and the Canadian autism research community look forward to working with CIHR and other agencies toward this critical element to increase and enhance autism research in Canada.

During the CARW, Dr. Rémi Quirion, Scientific Director of the CIHR Institute of Neuroscience, Mental Health and Addiction, informed participants that autism and the advancement of autism research are important for CIHR, and expressed a keen interest in working with the autism research community to develop a strong research agenda for autism in Canada. Autism research is seen as a potential large strategic activity that crosses ten of the thirteen CIHR Institutes (Appendix F). As larger strategic areas are an emerging priority for CIHR, autism research is ideal as an initiative on which to build Requests For Applications (RFA) to support the priorities identified in this White Paper.

Autism Society Canada suggests that the initial autism RFA have a total value of at least \$10 million, including partnerships. This will foster interest on the part of additional scientists working in disciplines related to autism, and should foster a number of projects in various locations across Canada. Building autism research interest, training, activity and expertise in every province is a goal that can be ultimately realized through the initiative of an inaugural autism RFA.

4.2 Working with Other Research Partners

Building a productive RFA for autism research requires the involvement of other research funding partners. Toward this end, NAAR has already begun discussions with CIHR, which also builds in the international collaboration identified as critical to the success of a Canadian Autism Research Agenda.

Autism Society Canada continues to work with other agencies and organizations working toward the development of targeted autism research funds in Canada. Several projects initiated by various organizations are currently in progress or development, and promise to be very productive, including public awareness components to foster both public and private increase of targeted autism research funds.

The participants' identification of improving outcomes as a primary priority means that the environment of most treatments, which is currently within the educational system, is a factor that cannot be overlooked. In an analysis of the 19 specific priority areas identified earlier in this White Paper (see 3.1 Specific Research Priority Needs), the one identified as having the greatest degree of cross-disciplinary application is education. This points strongly to the requisite involvement of the Social Science and Humanities Research Council (SSHRC). Although SSHRC declined to support or participate in the CARW, their involvement in the

development of a productive and hopefully joint autism RFA is essential if the highest overarching priority (improving outcomes) is to be reasonably addressed. Autism Society Canada will continue to work toward bringing SSHRC to the autism research table as an autism RFA is developed.

4.3 Long-term Autism Research Development

While an initial autism research RFA is the immediate goal, there is a need for a long-term plan to foster continuing, increasing, and productive autism research. This will require ongoing discussions with all the potential autism research parties identified (see 2.4 Potential Autism Research Partners). It will also require the leadership of the Government of Canada and collaboration with provincial/territorial health departments to address autism as a serious health issue for Canadians. Autism Society Canada will work to lead these discussions.

4.4 Autism Research Knowledge Dissemination

Fostering an improved dissemination system of autism research knowledge and the facilitation of the provision of better evidence-based assistance to people with autism conditions and their families are critical for Canada. CIHR has begun an initiative to address knowledge translation issues, and Autism Society Canada will work with CIHR as well as federal and provincial/territorial governments and the research community to build an improved system of applying autism related research to practice so that it directly benefits Canadians and Canadian taxpayers.

5.0 Development of a Canadian Autism Strategy

5.1 Canadian Autism Strategy Priorities

During the Canadian Autism Research Workshop, it became very clear through the discussions of the participants that a Canadian Autism Strategy is needed to provide a framework for moving the Canadian Autism Research Agenda forward, coordinating activities across Canada and providing linkages/support for autism researchers, practitioners working with persons with ASD and their families and persons living with autism.

Autism Society Canada, along with the national autism research community, will collaborate on the Canadian Autism Strategy to move the issues as well as the Canadian Autism Research Agenda forward.

Below are the specific priority areas/next steps for the Canadian Autism Strategy that came forward during the Workshop.

1. Implement the Canadian Autism Research Agenda.
2. Facilitate on-going communication between Canadian autism researchers, practitioners, government health officials, funding agencies and representatives from provincial/territorial autism societies.
3. Create awareness among government departments of autism as a health priority, and encourage Health Canada to support a national strategy to address autism in Canada.
4. Advocate for secured/on-going federal/provincial/territorial funding for autism related intervention, health services and individual as well as family supports.
5. Facilitate translation of knowledge learned through autism research into best practices to enable parents, policy makers and service providers to make better-informed decisions.
6. Facilitate enhancement of the Canadian Brain Tissue Bank and the development of a Canadian autism tissue collection program, perhaps using the (American) Autism Tissue Program model.
7. Build international links, particularly with the United States, to jointly work toward addressing autism through research and practice, especially in collaboration with the (American) National Institutes of Health, autism research agencies such as NAAR (National Alliance for Autism Research), CAN (Cure Autism Now) as well as the National Academies (U.S.) National Research Council.
8. Advocate for secured/on-going federal/provincial/territorial funding for autism related intervention, services and supports for the individual and family.
9. Respond to emerging issues.

Conclusion

The Canadian autism research priority is better outcomes for people with Autism Spectrum Disorders (ASD). This requires the design and implementation of integrated health services that include better screening, diagnostic, assessment, and treatment procedures related to the development, regulation and dysfunction of involved body systems and the identification of risk factors associated with ASD. To meet these priorities, the CARW participants articulated the following elements of a Canadian Autism Strategy and a Canadian Autism Research Agenda as the next steps to increase and improve ASD research in Canada.

Canadian Autism Strategy

Summary:

- Advocate for and facilitate development of dedicated ASD research funds
- Advocate for funding to ensure effective ASD intervention, services and supports
- Encourage national ASD strategy development through Health Canada
- Facilitate communication and collaboration between all ASD stakeholders on an international basis
- Facilitate ASD research knowledge translation into clinical best practices and advocacy for the adoption of best practices
- Facilitate development of a national ASD research, intervention and supports data base
- Encourage support and development of tissue collection programs for ASD research
- Respond to emerging issues

Desired Outcomes:

- Increased communication and synergy between Canadian autism researchers, practitioners, government health officials, funding agencies and representatives from provincial/territorial autism societies
- Improved awareness of autism and autism research by Canadian scientific, medical, and government communities
- Increased number of people with autism expertise contributing to autism diagnosis, interventions and potential autism prevention
- Increased rate of transfer of knowledge from research to clinical practice
- Sufficient government funding to ensure universal effective ASD treatment, services and supports for the individual and family
- Improved individual outcomes of people with Autism Spectrum Disorders, minimizing the impact of autism on individuals and their families, and reducing the lifetime costs to their families and Canadian taxpayers

Canadian Autism Research Agenda

Summary:

- Overarching priority of improved outcomes for individuals with ASD and their families
- ASD research activities focused in the 19 priority areas determined at the CARW
- Build on existing capacities; develop multi-sectoral ASD research
- Involve all stakeholders; build on Canadian and international research support and financial partnerships
- Initial ASD RFA through CIHR; suggested partnership total of \$10 million
- Work toward multi-agency ASD RFA
- Work toward long-term ASD Canadian Autism Research Agenda in collaboration with Health Canada

Desired Outcomes:

- Increased Canadian targeted funding for autism research by federal and provincial/territorial governments; and by private supporters of research
- Increased autism research initiatives through Canadian universities, hospitals, national organizations, and communities
- Increased number of researchers and clinicians involved in autism related research;
- Increased capacity to respond to emerging issues and opportunities in a coordinated manner
- Improved individual outcomes of people with autism conditions, minimizing the impact of autism on individuals and their families, and reducing the lifetime costs to their families and Canadian taxpayers
- Research activities centered on Canadian autism research priorities determined at the Canadian Autism Research Workshop (see 3.2 and 3.3)

Appendix A: Canadian Autism Research 2000-2008

Canadian Autism Research Networks

Autism Spectrum Disorders-Canadian-American Research Consortium (ASD-CARC), headed by Dr. Jeanette Holden, Kingston, Ontario, on genetics (including phenotyping), epidemiology, and early identification.
<http://www.autismresearch.ca>

Canadian Autism Intervention Research Network_(CAIRN), headed by Dr. Peter Szatmari, Hamilton, Ontario, on early identification and early intervention.
<http://www.cairn-site.com/about.html>

Canadian Network for the Study of Cognitive Processing in Neurodevelopmental Disorders, headed by Dr. Laurent Mottron, Rivières des Prairies, Québec, specializing in the neurocognitive aspects of autism. Infrastructure previously founded by a \$315,000 CFI (federal and provincial) grant in 1999 – include this also as operating grant in the section below under Funded Autism Research in Canada.

Current Canadian Autism Research Projects

(Ranking by % of total number of current projects)
 (Sources: Canadian autism researchers Feb 2004; this information may not be entirely inclusive of all existing autism research in Canada, but rather represents all of what is currently known for the years presented)

81 (50 Canadian funded projects, 15 Doctoral/Investigator Awards, 16 internationally funded autism research projects)

# projects	% of total	discipline area
31	38%	condition manifestation (incl. cognitive neuropsychological)
22	27%	genetics
7	9%	screening
6	7%	education/early intervention (treatment)
5	6%	pharmacology (treatment)
4	5%	research training
3	4%	not specified
2	2%	imaging
1	1%	behaviour (treatment)
{12	14%	treatment (behaviour, education/early intervention, pharmacology)}

Discipline areas not being currently researched in Canada: neuroanatomy, epidemiology, psychosocial interventions, and other non-medical.

Discipline sub-areas not being currently researched in Canada: education and early intervention – training; genetics – environmental exposures; other medical – education (of medical personnel) and medical (etiology of medical issues related to autism)

Funded Autism Research in Canada

Behavioural inflexibility in autism: Implications for intervention

SMITH, Isabel, IWK Health Centre

Investigatorship Research on ASD. 2002-2003 \$54,300/2yrs

The Hospital for Sick Children Foundation grant

Early detection of autism and other disorders of development: Capacity building in regions throughout Nova Scotia

SMITH, Isabel; BRYSON, Susan, IWK Health Centre

(2002-03) \$20,000

Nova Scotia Health Research Foundation

Supporting children with autism in child care settings: Distance education strategies

SMITH, Isabel, IWK Health Centre; **LYON, Mary**, Mount Saint Vincent University

(2002-04) \$20,000

Human Resources Development Canada (HRDC)

School aged children with Autism Spectrum Disorders: A collaborative project between educators and health researchers

CORKUM, Penny, PI; BRYSON, S.E., CI; SMITH, Isabel, CI

(2003-04) \$354,450/3yrs

Nova Scotia Health Research Foundation

Brain Magnetic Resonance Imaging and Spectroscopy in Autism

NICOLSON, Rob, Children's Hospital of Western Ontario

(2002/03) \$55,894

Ontario Mental Health Foundation

A Double-Blind Placebo-Controlled Randomized Clinical Trial of Fluvoxamine and Sertraline in Childhood Autism

VOHRA, Sunita, The Hospital for Sick Children

2002/03 \$55,894

Ontario Mental Health Foundation

Mood Stabilizers and Neuroprotection

WANG, Jun-Feng, Center for Addiction and Mental Health

2002/03 grant \$64,604; 2003-04 \$64,784

Ontario Mental Health Association

Identification and Characterization of Genes Involved in Susceptibility to Autism Spectrum Disorders. (2002-2006) 2002/03 grant \$65,000

HOLDEN, Jeanette J.A. Queen's University

Ontario Mental Health Foundation

The Genetic Epidemiology of Autism; family and molecular studies

SZATMARI, Peter, McMaster University

Individual Group Project – Operating (1991-03) 2000-01 \$57,600; 2001-02 \$115,200; 2002-03 \$21,600

Canadian Institutes of Health Research

Genetic Epidemiology of Autism

SZATMARI, Peter, McMaster University (\$145,000/YEAR)

Operating Grants (2003-08) 2002-03 \$31,551; 2003-04 \$116,684

Canadian Institutes of Health Research

A randomized double blind trial of add-on flunarizine to prevent the cognitive deterioration associated with infantile spasms

CARMANT, Lionel, Hôpital Sainte-Justine (Montréal)

Randomized Control Trials (2002-2006) 2002-03 \$119,120; 2003-04 \$119,120

Canadian Institutes of Health Research

Studies of sleep, EEG and cognitive performance in pervasive developmental disorders

GODBOUT, Roger, Université de Montréal

Operating Grants (2001-2004) \$70,651 x 3 years and \$3,892 for purchase of equipment
2001-02 \$45,613; 2002-03 \$68,216; 2003-04 \$68,011

Canadian Institutes of Health Research

Unraveling the mystery of autism spectrum disorders – Genotyping and phenotyping of ASD: identification of early markers and implications for intervention and prevention

HOLDON, Jeanette J.A., Queen's University

Interdisciplinary Research Teams (2000-01) \$15,000

Canadian Institutes of Health Research

Training Program in Autism Research

FOMBONNE, Eric; SZATMARI, Peter; McGill University

Strategic Training Program Grants (2002-03) \$5,000

Canadian Institutes of Health Research

Unraveling the mystery of autism: From genotyping and phenotyping to prospective identification and prevention

HOLDEN, Jeanette J.A., Queen's University

Interdisciplinary Health Research Team Program (2001-05)

2000-01 \$320,657; 2001-02 \$882,626; 2002-03 882,626; 2003-04 \$834,082

Canadian Institutes of Health Research

The genetics of complex psychiatric disorders: an integrated approach to the study of bipolar disorder, schizophrenia, alcoholism and autism

MAZIADE, Michel, Université Laval

CIHR Group Program (1997-2005)

2000-01 \$416,045; 2001-02 \$300,000; 2002-03 \$300,000; 2003-04 \$300,000

Canadian Institutes of Health Research

Making memories: Cellular correlates and circuit analysis in early olfactory learning

MCLEAN, John H, Memorial University of Newfoundland
CIHR/Regional Partnership Program/Operating Grant
(2001-04) 2001-02 \$17,998; 2002-03 \$200,203; 2003-04 \$200,304
Canadian Institutes of Health Research

Role of BDNF and neurotransmitters in autism

FAHENSTOCK, M.; SZATMARI, P.
Grant – (2003-05) \$128,942/2 yrs
Ontario Mental Health Foundation

Characterizing cognitive deficit in pervasive developmental disorders

MOTTRON, Laurent J, Hôpital Rivière-des-Prairies (Montréal)
Operating Grant (2001-2006) \$107,657 x 5 years and \$17,500 for purchase of equipment
2001-02 \$58,326; 2002-03 \$77,569; 2003-04 \$102,104
Canadian Institutes of Health Research

Étude de l'acquisition de nouvelles informations en mémoire de l'autisme

MOTTRON, L.; BELLEVILLE, S.
(2001-2004) \$33,000/year/3years
Social Sciences and Humanities Research Council (SSHRC)

*Structure et interaction en mémoire de travail: étude de patients autistes avec
Capacité spéciales*

BELLEVILLE, S.; MOTTRON, L.
(2001-2004) \$26,000/year/3years
Conseil de la recherche en sciences naturelles et en génie du Canada (CRSNG-NSERC)

MAGE Genes and Autism

BARKER, Philip Amos, McGill University
New Discoveries – High Risk Grants
(2003-05) 2003-04 \$57,000
Canadian Institutes of Health Research

Searching for genes predisposing to autism

ROULEAU, Guy A., McGill University
The Research Institute of the McGill University Health Center
Operating grant - (2003-2006) \$137,061 x 3 years and \$22,342
Canadian Institutes of Health Research

Understanding autism and depression in the young.

FOMBONNE, Eric, McGill University
Canada Research Chair in Child and Adolescent Psychiatry (2001)

Multisensory Processing and Integration in Autism

IAROCCI, Grace, Simon Fraser University
(2002-04) \$50,000/2 yrs
Human Early Learning Partnership (HELP)

Attention and global-local processing among persons with autism

BURACK, Jake, McGill University

Social Sciences and Humanities Research Council (SSHRC) Grant 2003-2006
(SSHRC has funded continuously funded this line of research since April 1992)

Early Identification for Autism

EAVES, Linda; HO, Helena, Sunny Hill Centre for Children, UBC

Vancouver Foundation Grant

Adjusting Language Style in Speakers with ASD

VOLDEN, Joanne, University of Alberta

(2000-04) \$92,500

Alberta Heritage Foundation of Medical Research

Varying Language Register in Speakers with ASD

VOLDEN, Joanne, University of Alberta

(2002-05) \$99,000

Social Sciences and Humanities Research Council of Canada

Autism and moebius syndrome: a neuropsychological study of visual-spatial attention and facial emotion

BRYSON, S.E., Hospital for Sick Children

Operating Grant (1999-01) 2000-01 \$49,208

Canadian Institutes of Health Research

Video modeling interventions for young children with autism

MIRENDA, Pat; BOPP, Karen

(2002-04) \$25,000

Human Early Learning Partnership (HELP) Institute

*Interim Early Intensive Intervention for Children with Autism Spectrum Disorders
Evaluation Project*

MIRENDA, Pat

(2001-2004) \$1.1 million

BC Ministry for Children and Families

Identification of Candidate Genes for Autism

SCHERER, Stephen Wayne

(2000-05) \$50,000

Canadian Genetic Diseases Network, Networks of Centres of Excellence

Genetic Studies of Autism

SCHERER, Stephen Wayne

(2004) \$50,000/yr

Philanthropic Grant

Hospital for Sick Children Foundation

Inhibitory Impairment in children with autism
BRYAN, Jessica Ann, Hospital for Sick Children
Scottish Rite Charitable Foundation of Canada Grant

Adults with Autism Spectrum Disorders in Newfoundland and Labrador: "A Constant Struggle". April 2003.

A Report prepared by the Health Research Unit, Division of Community Health, Faculty of Medicine, Memorial University of Newfoundland.

MURRAY, Michael; CANNING, Patricia; CALLANAN, Ted; VARDY, Cathy; RYAN, Ann; KEOUGH, T. Monty. (2003-2003 for 16 months) \$20,000 Autism Society of Newfoundland and Labrador; \$20,000 Newfoundland and Labrador Center of Applied Health Research

MEG Correlates of Linguistic Processing At and Below The Word Level in Autism

ROBERTS, Tim; ROBERTS, Wendy; FLAGG, Elissa; ORAM, Janis

(2003-05)\$169,284

National Alliance of Autism Research

Role of BDNF and Neurotransmitters in Autism

FAHNESTOCK, Margaret

Operating Grant (2003-05) \$64,471 per year

Ontario Mental Health Foundation

Identifying Early Markers of Autism: A Prospective Study of Infant Siblings

ZWAIGENBAUM, Lonnie; BRYSON, S.E., McMaster University

Operating Grant

(2003-2006) \$110,000/year 2003-04 \$105,193

Canadian Institutes of Health Research

Fellowships

Understanding Developmental Trajectories in Autism and Related Pervasive Developmental Disorders

SZATMARI, Peter, McMaster University

Senior Research Fellowship

(2002-03) 2002-03 \$38,995; 2003-04 \$38,500

Canadian Institutes of Health Research

Behavioural and Biological Markers of Autism

ZWAIGENBAUM, Lonnie; BRYSON, S.E., McMaster University

Intermediate Investigator Fellowship (2002-2005) \$40,000/year

Ontario Mental Health Foundation

Brain Magnetic Resonance Imaging and Spectroscopy in Autism

NICOLSON, Rob, University of Western Ontario

New Investigator Fellowship

Ontario Mental Health Foundation

Characterizing cognitive deficit in autism and Asperger syndrome: neuropsychological and brain imaging study

MOTTRON, L.,

Senior research Fellowship (2002-2006) \$63,000/year

FRSQ (fonds de la recherche en santé du québec)

Training Program in Autism Research

FOMBOMME, Eric, McGill University

(2003-2009), \$240,000/year/6 yrs 2002-04 \$101,400

Canadian Institutes of Health Research, National Alliance of Autism Research, Fonds de la Recherche en Santé du Québec

FLANAGAN, Tara, McGill University

Doctoral Fellowship (May 2003 - April 2005)

Social Sciences and Humanities Research Council of Canada (SSHRC)

Neural correlates of auditory processing in autism and language disorders.

ROBERTS, S.W., ORAM, J., ROBERTS, T.

Postdoctoral fellowship for Janis Oram (2003-05) \$80,000 2003-04 \$47,042

Canadian Institute of Health Research,

Studentships

Awareness of Visual-Auditory Temporal Synchrony by Young Children with Autism or Language Delays

DEMARK, Jenny, York University

Ontario Mental Health Foundation

Identification and Characterization of Functional Variations in Genes Associated with Autism Spectrum Disorders (ASDs)

HETTINGER, Joseph, Queen's University

Ontario Mental Health Foundation

Les comportements d'exploration visuelle atypique dans l'autisme de bas niveau

SAUVÉ, L.M. (Summer, 2003)

Conseil de recherche en sciences naturelles et en génie du Canada (CRSNG)

Surfonctionnement par domaine - étude de patients autistes avec capacités spéciales

MENARD, M.C., (Summer 2003)

Conseil de recherche en sciences naturelles et en génie du Canada (CRSNG)

Doctoral Awards/Investigator Awards

An assessment of motion perception among high-functioning persons with autism

BERTONE, Armando, Université de Montréal

CIHR Doctoral Research Awards (2001-04)

2000-01 \$2,086; 2001-02 19,530; 2002-03 \$20,500; 2003-04 \$18,333

Canadian Institutes of Health Research

Early detection, intervention and prevention of developmental and behavioural disorders in young children

FELDMAN, Maurice A, Queen's University

CIHR Investigators (2001-02) 2001-02 \$60,444 2002-03 \$20,383

Canadian Institutes of Health Research

Reconnaissance des visages dans l'autisme de haut-niveau

LAHAIE, A. (doctoral research award end of studentship: Sept. 2003)

Fonds Qu Québecoise de la Recherche sur la Nature et les Technologies (FCAR)

Fonds de la Recherche en Santé du Québec (FRSQ)

Cognition spatiale dans l'autisme (doctoral research award end of studentship: Sept 2003)

CARON, M.J.

Fonds Québecoise de la Recherche sur la Nature et les Technologies (FCAR)

Fonds de la Recherche en Santé du Québec (FRSQ)

Catégorisation perceptive dans l'autisme de haut niveau

SOULIÈRE, I. (doctoral research award end of studentship: sept 2005)

Conseil de recherche en sciences naturelles et en génie du Canada (CRSNG)

Le sommeil, l'EEG et la performance cognitive dans l'autisme

LIMOGES, Elyse, Université de Montréal

CIHR Doctoral Research Awards (2001-04) 2001-02 \$19,530 ; 2002-03 \$20,500 ; 2003-04 \$20,500

Canadian Institutes of Health Research

Transformation développementale des signes du désordre autistique

FECTEAU, Shirley, Université de Montréal (doctoral research award end of studentship: sept 2003)

CIHR Studentship (1998-02) 2000-01 \$19,430; 2001-02 \$19,430; 2002-03 \$8,333

Canadian Institutes of Health Research

New Approaches Toward Understanding the Genetic Bases of Form, Function and Phenotype in Autism Spectrum Disorder

LEWIS, M.E. Suzanne, University of British Columbia

Institute of Genetics Clinical Investigator Award (2003-05) 2002-03 \$60,000 2003-04 \$120,000

Canadian Institutes of Health Research

Genome discovery for genetic disease research (30% on autism)

SCHERER, Stephen Wayne, Hospital for Sick Children

CIHR Investigators (2003-08) 2003-04 \$57,750

Canadian Institutes of Health Research

Autism Spectrum Disorders: Identification of Culprit Genes using Genomic Microarrays and Molecular Assessments of Duplicon-Mediated Micro-Deletions and Duplications

LEWIS, M.E. Suzanne, HOLDEN, Jeanette J.A.; RAJCAN-SEPAROVIC, Evica; VALLANCE, Hillary Debra; FORESTER-GIBSON, Cynthia Jane; MACCIARDI, Fabio M., University of British Columbia

Operating Grants (July 2003 - June 2006) 2003-04 \$52,200

Canadian Institutes of Health Research

Transdisciplinary Inter-Institute Training Program in Autism Spectrum Disorders

HOLDEN, Jeanette, J.A., Queen's University

Strategic Training Program Grants – (2002-02) 2002-03 \$5,000

Canadian Institutes of Health Research

Transdisciplinary Inter-Institute Training Program in Autism Spectrum Disorders

HOLDEN, Jeanette J.A.; FELDMAN, Maurice Abraham; MUNHALL, Kevin G.; WOODHOUSE, Rosamund, LEWIS, Suzanne M.E.; CHUDLEY, Albert; YU, Dickie C.T.; BEBKO, James; PERRY, Adrienne, M.D.; MINNES, Patricia Margaret Queen's University

Strategic Training Program Grants (2003-2009) 2002-03 \$5,000 2003-04 \$101,400

(Canadian Institutes of Health Research and National Alliance of Autism Research)

Étude de l'EEG quantifié au cours de la veille et du sommeil chez des autistes de haut niveau

BOLDUC, Christianne, Hôpital Rivière-des-Prairies (Montréal)

CIHR Doctoral Research Award (2002-05) 2002-03 \$20,500; 2003-04 \$20,500

Canadian Institutes of Health Research

CHOUFANI, Dr. Sanaa

Post-doctoral fellowship Research Training Centre- (2004) \$30,000/yr

The Hospital for Sick Children Foundation

FEUK, Dr. Lars

(2004) \$50,000/yr

The Swedish Foundation for International Cooperation in Research and Higher Education (STINT)

Internationally Funded Research in Canada

Investigating the Emergence of Familial Traits in Autism 2003-2005

ZWAIGENBAUM, Lonnie (2003-2005) \$60,000US/year

National Alliance for Autism Research (NAAR)

Early Markers of Autism: A Longitudinal Study of Infant Siblings

ZWAIGENBAUM, Lonnie (2001-2003) \$100,000 US

National Alliance for Autism Research

Supplement to Identifying Early markers of autism: a longitudinal study of infants siblings

ZWAIGENBAUM, L.; SZATMARI, P

(2002-2004) \$250,000 US

National Alliance for Autism Research

Investigating Serotonin Receptor Function and Brain Structure as Potential Endophenotypes of Autism

GOLDBERG, Dr. J.

(2001-2003) \$89,367 US

National Alliance for Autism Research

Characterization of Genes Involved in the Etiology of Autism Spectrum Disorders

HOLDEN, Jeanette J.A., Queen's University, 2001

Autism Tissue Program

Molecular genetic studies of autism

SCHERER, Stephen, University of Toronto

International Scholar Award (2002-07) \$70,000 US

Howard Hughes Medical Institute

BDNF and 5-HT₂ Receptor mRNA in Autistic and Control Brain Tissue

FAHNESTOCK, Margaret, McMaster University, Canada. 2002

Autism Tissue Program 2003-04 \$64,471

Ontario Mental Health Foundation

Using event-related potentials (ERP) to characterize auditory processing deficits in autism spectrum disorder and epilepsy

PANG, Elizabeth, The Hospital for Sick Children (Canada)

Cure Autism Now Foundation

Investigating shared liability to autism and language disorders and Language Impairments in Extended Families

ZWAIGENBAUM, Lonnie, SZATMARI, P., McMaster University

(2003-05) \$58,000 US/yr

Cure Autism Now Foundation

NIMH Centre for Collaborative Genetic Studies
TISCHFIELD, Jay, Rutgers University
(2003-2004) \$213,875 US
National Institute of Mental Health (NIMH)

Generating early autism research and resources
SZATMARI, P., McMaster University
(2002-05) \$1,230,000
Anonymous funding

Serotonin receptor function and brain structure in autism
GOLDBERG, J.; SZATMARI, P.
(2001-03) \$89,367 US
National Alliance for Autism Research

Phenotype and genotype of brain stem injury in autism
BRYSON, S.E. (PI of Behavioural Project and Canadian site; with **RODIER, P.** PI of Program
(1998-2003) (\$447, 050.)
National Institutes of Health, National Institute of Health Development Research

Phenotype and genotype of brain stem injury in autism
BRYSON, S.E. (PI of Behavioural Project and Canadian site; with **RODIER, P.** PI of Program grant)
(2003-2008) (\$225,000)
National Institutes of Health, National Institute of Health Development Research

Genetic Dissection of Autism Phenotype
FOLSTEIN, S.; SZATMARI, P.
(2002-07) \$62,000 US/yr
National Institute of Health

Pivotal skills acquisition through IBI for young children with autism
REITZEL, J.; SZATMARI, P.
Research Development Fund
(2003-05) \$9,393
HHS

Appendix B: Canadian Autism Research Workshop Participants

Last Name	First Name	Organization Name	Province
Alaee	Dr. Mehran	Autism Society Ontario	Ontario
Alvi	Dr. Mansour	McMaster University	Ontario
Aylward	Joyce	Nunavut Department of Health	Nunavut
Bebko	Dr. James	York University	Ontario
Berthelot	Jean-Marie	Statistics Canada - Health Division	Ontario
Bradley	Dr. Elspeth	University of Toronto and Surrey Place	Ontario
Brownlee	Dale	Manitoba Department of Health	Manitoba
Bryson	Dr. Susan	IWK Health Ctr/Dalhousie Univ., Dept of Pediatrics	Nova Scotia
Burack	Dr. Jake	McGill University, Dept. of Educational Psychology	Quebec
Button	Pamela	Lunch Speaker on Thursday	Ontario
Cohen	Dr. Karen	Canadian Psychology Association	Ontario
Connell	Krista	Nova Scotia Health Research Foundation	Nova Scotia
de Villiers	Dr. Jessica	University of British Columbia	B.C.
D'Entremont	Barbara	Univ. of New Brunswick, Psychology Department	New Brunswick
Dewey	Dr. Deborah	University of Calgary	Alberta
Eaves	Dr. Linda C.	Sunny Hill Health Ctr for Children	B.C.
Elkin	Lynn	Autism Society Canada	NWT
Fahnestock	Dr. Margaret	McMaster University	Ontario
Feldman	Dr. Maurice	Queens University	Ontario
Fenton	Jo-Lynn	Autism Society Canada	Nova Scotia
Foote, Ph.D.	Dr. Stephen L.	Dir., Div. of Neuroscience & Behavioural Sciences	USA
Forster-Gibson	Dr. Cynthia	Queen's University	Ontario
Goldberg	Dr. Jeremy	McMaster University	Ontario
Harding	Denise	Autism Society Canada	Ontario
Hennessey	Paula	Newfoundland Dept of Health	Newfoundland
Ho	Dr. Helena	University of British Columbia	B.C.
Holden	Dr. Jeanette	Queen's University	Ontario
Hyman	Dr. Susan	University of Rochester	USA
Iarocci	Dr. Grace	Simon Fraser University	B.C.
Kemper	Dr. Thomas	Boston Medical Center	USA
Keough	Montgomery	Memorial University	Newfoundland
Leith	Dr. Eric	Canadian Society for Allergy & Clinical Immunology	Ontario
Lewis	Dr. Suzanne	U. of BC & Children & Women's Health Ctr	B.C.
Lord	Dr. Catherine	Univ. of Michigan Autism & Comm. Disorders Ctr.	Michigan
MacQuarrie	Colleen	PEI Department Health & Soc. Serv.	PEI
Mirenda	Dr. Pat	University of British Columbia	B.C.
Monro	Dr. Frances	Canadian Assn. Speech and Language Pathologists & Audiologists	B.C.

Last Name	First Name	Organization Name	Province
Moosavi	Sayed	Canadian Brain Bank	Ontario
Mottron	Dr. Laurent	University of Montreal	Quebec
Noonan	Andrea	Department of Health and Social Services	PEI
O'Neill	Dr. Daniela	University of Waterloo	Ontario
Ofner-Agostini	Dr. Marianna	University of Toronto	Ontario
Ouellette-Kuntz	Dr. Helene	Queen's University; ASD-CARC	Ontario
Perry	Dr. Adrienne	York University & Thistletown Reg Ctr	Ontario
Persad	Dr. Rabin	Canadian Assn. of Gastroenterology	Ontario
Pickett, Ph.D.	Dr. Jane	Director, Autism Tissue Program	USA
Pugsley	Darlene	Autism Society Canada	New Brunswick
Quirion	Dr. Rémi	Institute of Neuroscience, Mental Health and Addiction, CIHR	Quebec
Raskin	Avery	Autism Society Canada	B.C.
Reitzel	Dr. Jo-Ann	Hamilton Health Sciences, Chedoke Child & Family	Ontario
Roberts	Dr. Wendy	Hospital for Sick Children	Ontario
Rutherford	M.D. (Mel)	McMaster University, Dept. of Psychology	Ontario
Ryan	Ann	Memorial University	Newfoundland
Scherer	Dr. Stephen W.	The Hospital for Sick Children	Ontario
Schnurr	Dr. Rosina G.	Children's Hospital of Eastern Ontario	Ontario
Shih	Dr. Andy	National Alliance for Autism Research	USA
Shore	David	McMaster University	Ontario
Simmermon	Lisa	Autism Society Canada	Saskatchewan
Smith	Dr. Isabel	Dalhousie University	Nova Scotia
Smith	Linda J.	Nova Scotia Dept of Health	Nova Scotia
Spoelstra	Margaret	Autism Society Ontario	Ontario
Starr	Dr. Elizabeth	Univ. of Windsor, Faculty of Education	Ontario
Stoddart	Dr. Kevin	Surrey Place Centre	Ontario
Summers	Dr. Jane	Chedoke Child & Family Ctr, Hamilton Health Science	Ontario
Szatmari	Dr. Peter	McMaster University	Ontario
Tidmarsh	Dr. Lee	Montreal Children's Hospital Autism Disorders Program	Quebec
Tringali	Glenn R.	National Alliance for Autism Research	USA
Turpin	Pamela	Health Canada, Child and Youth Division	Ontario
Turza	Laurie	Autism Society Canada	Ontario
Vardy	David	Autism Society Canada	Newfoundland
Volden	Dr. Joanne	U. of Alberta, Speech Pathology & Audiology	Alberta
Waleski	Gary	Lunch Speaker on Thursday	Ontario
Wellington	Dr. Steve	PHSA Public Health Services	B.C.
Werker	Dr. Janet	UBC Psychology	B.C.
Whelan	Margaret	Geneva Center	Ontario
Wherrett	John	Canadian Brain Bank	Ontario
Wyatt	Gail	Autism Society Canada	Alberta
Zwack	Peter, PhD	Autism Society Canada	Quebec
Zwaigenbaum	Dr. Lonnie	Hamilton Health Sciences Corp.	Ontario

Appendix C: Critical Autism Research Issues and Cross-Reference Table

Critical Research Issues (not ranked)

Neuroanatomy

Infrastructure

- Tissue availability
- Control (Comparison tissues)
- Standardized tissue processes
- Distribution prioritization

Establish (imaging) bio-markers for autism

Epidemiology

Studies aimed at developing and evaluation strategies for identifying developmental disorders (including autism) early in life

Studies aimed at measurement of autism prevalence in the general population

- Quality of life issues
- Co-morbidity

Neuropsychology

What is the developmental trajectory of cognitive strengths and weaknesses in relation to autism symptoms, brain functioning, and intellectual functioning in high and low functioning people with autism

How does intervention at various ages effect the trajectory

Education and Early Intervention

Research in Education and Early Intervention

- Clinical trials (multiple interventions)
- Identification of outcome measures
- Mediators and moderators of outcomes
- Treatment fidelity
- Standardized external evaluation
- Linkages with early interventions transition to school
- Evaluation of evidence based models in schools
- Connect with service providers

Training

- Centre for Excellence
- Professional development
- Standards/requirements

Psychosocial Interventions

What are the best outcome measures for evaluating effectiveness including quality of life

What are the best practices for establishing a continuum of care for life-span services and how health care systems can be best organized to provide services that minimize the burden on families (cost-effective services tied to quality of life)

Other Non-Medical

Identification of the needs of adults with ASD and effective interventions to address those needs

Identification of the needs of families and effective interventions (stress, supports...)

Standardized accurate identification and assessment and continuing follow-up

Health Services organizations

Genetics

Well characterized families

- Standardized phenotypic information including broader phenotype
- Sample selection
- Co morbidity
- International collaboration

Gene-Environment Interactions

- (Environmental exposures (international collaboration)
- Using epidemiologic methods birth cohort studies, twin studies)

Other Medical

Education

- Training of physicians
- Dissemination of information

Medical

- Etiology of medical issues related to autism

Pharmacology

Cross-Referencing of Issues and Disciplines

Neuro-anatomy (total 11)	Epi-demiology (total 11)	Neuro- psychology (total 12)	Education (total 15)	Psycho-social (total 13)	Other non- medical (total 12)	Genetics (total 11)	Other medical (total 17)
1. (+2)						*	*
2. (+4)	*	*				*	*
*	3. (+7)	*	*	*	*	*	*
*	4. (+7)	*	*	*	*	*	*
*		5. (+6)	*	*	*	*	*
	*	6. (+5)	*	*	*		*
	*	*	7. (+6)	*	*	*	*
			8. (+2)	*	*		
	*	*	*	9. (+5)	*		*
	*	*	*	10. (+5)	*		*
*		*	*	*	11. (+5)		*
*			*	*	12. (+4)		*
	*	*			13. (+2)		
			*	*	14. (+3)		*
*	*	*	*			15. (+5)	*
*	*					16. (+3)	*
			*			*	17. (+2)
*	*	*	*	*		*	18. (+6)
*			*	*		*	19. (+4)

Appendix D: Identification of All Pressing Autism Research Issues

All pressing autism research issues were determined by self-selected research discipline interest groups that included families, scientists, government officials, and some included funding agencies.

Unofficial ranking was determined by the participants through a “dotmocracy” exercise where each participant was provided with a limited but equal number of sticky dots colour coded to their community of involvement with autism, and which were applied next to the identified pressing autism research issues on flip charts. This provided an indication of ranking within each participant community, as well as an indication of ranking across all the participants. It should be noted that although some research issues did not receive ranking votes, this does not indicate that the issue is not pressing. It was agreed that all of the pressing autism research issues identified require prompt and in-depth research.

The “dotmocracy” voting is summarized with the following abbreviations:

gov -Provincial and Territorial government representatives

fam – Families, represented by provincial autism societies

fun – research funding agencies

sci – scientists and medical practitioners

For ease of reviewing this information, it has been presented in a descending total ranking order within each discipline area.

All issues

Total 465 gov: 48 fam:72 fun:52 sci:293

Neuroanatomy

Total 37 gov: 1 fam: 3 fun: 6 sci: 37

- Tissue availability, including controls (comparison tissue), standardized tissue process, and distribution prioritization
Total 13 gov: 0 fam: 1 fun: 5 sci: 7
- Establish imaging biomarker for autism
Total 6 gov: 0 fam: 1 fun: 0 sci: 5
- Establish imaging registry, including structural and functional
Total 4 gov: 0 fam: 0 fun: 1 sci: 3
- Tie in with early intervention and risk
Total 3 gov: 0 fam: 1 fun: 0 sci: 2
- Correlate functional imaging (M.E.G. (SPECT) and medication) and E.E.G’s with neuropsychology (visual)
Total 3 gov: 0 fam: 0 fun: 0 sci: 3

- Determine regionally specific gene expression
Total 3 gov: 1 fam: 0 fun: 0 sci: 2
- Interfacing with normative brain images
Total 2 gov: 0 fam: 0 fun: 0 sci: 2
- Standardized clinical information including developmental and intervention history
Total 2 gov: 0 fam: 0 fun: 0 sci: 2
- Identify researcher expert in neuroanatomy area in Canada
Total 1 gov: 0 fam: 0 fun: 0 sci: 1
- Brain RFA CIHR
Total 0 gov: 0 fam: 0 fun: 0 sci: 0
- Determine if there is a difference in the corpus collosum of people with ASD
Total 0 gov: 0 fam: 0 fun: 0 sci: 0

Epidemiology

Total 61 gov: 9 fam: 8 fun: 7 sci: 37

- Studies aimed at developing and evaluating strategies for identifying developmental disorders early in life (including autism) (CHSRF, CIHR)
Total 32 gov:7 fam: 4 fun: 4 sci: 17
- Studies aimed at measurement of prevalence of autism in the general population (population health)
Total 12 gov: 2 fam: 3 fun: 2 sci: 5
- Identification/research regarding the broader autism phenotype (e.g. Relatives of children diagnosed with ASD)
Total 7 gov: 0 fam: 0 fun: 1 sci: 6
- Creation and maintenance of an infra-structure for future development of a surveillance system (data management)
Total 4 gov: 0 fam: 0 fun: 0 sci: 4
- Population sampling by family to determine reoccurrence risk
Total 4 gov: 0 fam: 1 fun:0 sci: 3
- Studies aimed at evaluating strategies for identifying autism early in life
Total 2 gov: 0 fam: 0 fun: 0 sci: 2

Neuropsychology (Cognitive)

Total 66 gov: 5 fam: 6 fun:5 sci: 50

- What is the developmental course of cognitive strengths and weaknesses?
Total 21 gov: 2 fam: 1 fun: 3 sci: 15
- How to extend cognitive neuropsychology research to lower functioning and younger children
Total 12 gov: 0 fam: 2 fun: 1 sci: 9

- How does intervention affect developmental course of sensory differences and cognitive impairment?
Total 7 gov: 3 fam: 0 fun: 0 sci: 4
- What is mental retardation in autism?
Total 5 gov: 0 fam: 0 fun: 0 sci: 5
- Is integration across sensory modalities impaired?
Total 4 gov: 0 fam: 0 fun: 0 sci: 4
- How does cognitive neuropsychology map onto autism symptoms?
Total 3 gov: 0 fam: 1 fun: 0 sci: 2
- Relationship of language to underlying cognitive neuropsychology
Total 3 gov: 0 fam: 0 fun: 0 sci: 3
- How to incorporate methodologies and technology from various disciplines
Total 2 gov: 0 fam: 0 fun: 0 sci: 2
- Relate change in neuropsychology measures with stages of brain development
Total 2 gov: 0 fam: 0 fun: 1 sci: 1
- Research on at-risk individuals, including siblings, en early infancy (younger than 6 months)
Total 2 gov: 0 fam: 1 fun: 0 sci: 1
- Identify the developmental course and determine if basic learning processes are intact in autism
Total 1 gov: 0 fam: 0 fun: 0 sci: 1
- Relationship between sensory differences and cognitive impairment
Total 1 gov: 0 fam: 0 fun: 0 sci: 1
- Include more ecologically relevant measures
Total 1 gov: 0 fam: 0 fun: 0 sci: 1
- Explore perception-action links in autism (executive versus receptive)
Total 1 gov: 0 fam: 1 fun: 0 sci: 0
- Develop/suggest appropriate methods for characterization of cohorts for large genetic studies (work with genetics)
Total 1 gov: 0 fam: 0 fun: 0 sci: 1
- How to ensure cognitive neuropsychology research is clinically relevant
Total 0 gov: 0 fam: 0 fun: 0 sci: 0

Education and Early Intervention

Total 88 gov: 12 fam: 15 fun: 9 sci: 52

- Research into early intervention addressing mediators and moderators of outcome, comparing education/intervention models, and addressing treatment fidelity
Total 26 gov: 4 fam: 4 fun: 3 sci: 14

- Development (at all levels of graduate work) of post graduate fellowships at centres of research and practice in autism, perhaps rotating among the centres and disciplines
Total 14 gov: 0 fam: 2 fun: 3 sci: 9
- Professional development and training requirements, addressing training requirements, ongoing training and evaluation of training
Total 13 gov: 3 fam: 1 fun: 2 sci: 7
- Education - implementation and evaluation of evidence-based school-wide models
Total 11 gov: 1 fam: 5 fun: 0 sci: 5
- External evaluation of interventions and national standards to evaluate early intervention programs
Total 6 gov: 0 fam: 1 fun: 0 sci: 5
- Development and evaluation of intervention strategies for children at or younger than 2 years with ASD (link to early identification/screening, and link to supports for families)
Total 5 gov: 0 fam: 1 fun: 0 sci: 4
- Build bridge between education and interventions at the system level
Total 4 gov: 2 fam: 1 fun: 1 sci: 0
- Clinical trials (RCT) on efficacy and effectiveness of early intervention
Total 4 gov: 1 fam: 0 fun: 0 sci: 3
- Continuing education for professionals specific to evidence-based assessment and practice in autism
Total 3 gov: 1 fam: 0 fun: 0 sci: 2
- Rural education issues
Total 1 gov: 0 fam: 0 fun: 0 sci: 1
- Use of technology for intervention
Total 1 gov: 0 fam: 0 fun: 0 sci: 1
- Proximal and distal outcome measures for today and long-term
Total 0 gov: 0 fam: 0 fun: 0 sci: 0
- Continuity of services begun before school age to school age
Total: 0 gov: 0 fam: 0 fun: 0 sci: 0
- What is or could be impact of technology on service provision and intervention
Total 0 gov: 0 fam: 0 fun: 0 sci: 0

Psychosocial Interventions

Total 54 gov: 7 fam: 3 fun: 7 sci: 27

- What are the outcome measures needed to measure effectiveness (which includes quality of life)
Total 21 gov: 3 fam: 4 fun: 3 sci: 11
- What are best practices for continuing care/"life span services"?
Total 11 gov: 1 fam: 7 fun: 1 sci: 2

- How can health services systems be best organized to maximize impacts/supports?
(health systems research)
Total 4 gov: 1 fam: 0 fun: 2 sci: 1
- Psychotherapy/counselling for families and individuals with ASD
Total 4 gov: 0 fam: 1 fun: 0 sci: 3
- How to promote/facilitate social communicative competence
Total 4 gov: 0 fam: 0 fun: 0 sci: 4
- What are best practices in holistic approaches to services for adults
Total 3 gov: 0 fam: 1 fun: 0 sci: 2
- How can services be organized to minimize the burden of families?
Total 3 gov: 1 fam: 0 fun: 0 sci: 2
- Needs to prioritize with other medical research
Total 2 gov: 1 fam: 0 fun: 1 sci: 0
- Impact of technology: 1) what is the impact of technology on intervention, and 2) how
can technology be developed to facilitate the delivery of services?
Total 2 gov: 0 f am: 0 fun: 0 sci: 2
- How can we partner researchers and practitioners to ensure high quality, effective
research?
Total 0 gov: 0 fam: 0 fun: 0 sci: 0
- Family/group therapy
Total 0 gov: 0 fam: 0 fun: 0 s ci: 0

Other Non-Medical

Total 54 gov: 8 fam: 13 fun: 4 sci: 29

- Family coping strategies and advocacy: how to formulate/measure; how to intervene
effectively (i.e. support, training, etc.); impact on families including siblings (positive and
negative outcomes); impact on child with autism
Total 18 gov: 2 fam: 7 fun: 0 sci: 9
- Accurate early identification and late identification with the development of feasible
community based models
Total 13 gov: 3 fam: 1 fun: 0 sci: 9
- Identification of effective interventions for adults with ASD
Total 11 gov: 2 fam: 1 fun: 3 sci: 5
- Adapting successful models to “geographic realities” (remote and rural areas)
Total 4 gov: 1 fam: 2 fun: 1 sci: 0
- Follow-up services and supports for families
Total 2 gov: 0 fam: 0 fun: 0 sci: 2
- Pragmatics of conversation for children, adolescents and adults with ASD
Total 2 gov: 0 fam: 0 fun: 0 sci: 2

- Lifelong positive outcomes (how adults with ASD measure this themselves, and who decides on their behalf)
Total 2 gov: 0 fam: 2 fun: 0 sci: 0
- Psychosocial interventions for adults with ASD
Total 1 gov: 0 fam: 0 fun: 0 sci: 1
- Identify health and stress for parents/families (e.g. More than 30% of mothers of ASD individuals have depression), and links to genetics
Total 1 gov: 0 fam: 0 fun: 0 sci: 1
- Need for research funding to cover clinical infrastructures, parent support and ongoing care
Total 0 gov: 0 fam: 0 fun: 0 sci: 0
- Cost benefits of late diagnosis (adults with ASD)
Total 0 gov: 0 fam: 0 fun: 0 sci: 0
- Consideration of broader phenotype issues with family for provision of all services
Total 0 gov: 0 fam: 0 fun: 0 sci: 0
- Is autism research in Canada at a stage where we can obtain a network grant (NCE)?
Total 0 gov: 0 fam: 0 fun: 0 sci: 0
- Peer relationships in adolescence
Total 0 gov: 0 fam: 0 fun: 0 sci: 0
- Psychotherapy for children and adults with ASD
Total 0 gov: 0 fam: 0 fun: 0 sci: 0
- Characteristics and broader phenotype and pre-existing conditions in parents, and the implications for support, counselling and respite
Total 0 gov: 0 fam: 0 fun: 0 sci: 0
- Research into supports needed for parents and families (development of community based supports that are realistic and determine costs)(this should be in research funding and clinical infrastructure)
Total 0 gov: 0 fam: 0 fun: 0 sci: 0
- Vocational training and support
Total 0 gov: 0 fam: 0 fun: 0 sci: 0

Genetics

Total 51 gov: 4 fam: 9 fun: 10 sci: 28

- Standardized phenotypic information and genetic studies in well characterized families though sample collection and combined analysis of samples; also include broader phenotype, sex differences and gender phenotype
Total 17 gov: 1 fam: 3 fun: 4 sci: 9
- Systematic study of co-morbidities (syndromic, chromosomal, and other medical) in dissecting heterogeneous gene influences
Total 11 gov: 1 fam: 0 fun: 1 sci: 9

- Interaction with environmental factors (e.g. drug interactions affected by genes) using birth cohort and interact with epidemiology as a tool to develop ability to identify families
Total 10 gov: 2 fam: 3 fun: 2 sci: 3
- International collaboration; cross-hybridization through research registries
Total 4 gov: 0 fam: 0 fun: 2 sci: 2
- Training
Total 4 gov: 0 fam: 2 fun: 0 sci: 2
- Understanding sex differences
Total 3 gov: 0 fam: 0 fun: 1 sci: 2
- Contribute to birth cohort study
Total 1 gov: 0 fam: 0 fun: 0 sci: 1
- Family support to allow them to contribute
Total 1 gov: 0 fam: 1 fun: 0 sci: 0
- Genetic isolates through sample collection
Total 0 gov: 0 fam: 0 fun: 0 sci: 0
- Interaction with epidemiology
Total 0 gov: 0 fam: 0 fun: 0 sci: 0

Other Medical

Total 54 gov: 2 fam: 15 fun: 4 sci: 33

- Training of physicians
Total 15 gov: 2 fam: 4 fun: 0 sci: 9
- Co-morbid conditions
Total 10 gov: 0 fam: 0 fun: 3 sci: 7
- Dissemination of evidence-based information to parents and regional associations
Total 10 gov: 0 fam: 2 fun: 1 sci: 7
- Can sensory and motor processes be used for diagnosis and determining efficacy of treatment
Total 6 gov: 0 fam: 1 fun: 0 sci: 5
- Diet, nutrition/G.I./metabolism
Total 4 gov: 0 fam: 3 fun: 0 sci: 1
- Immunology
Total 3 gov: 0 fam: 4 fun: 0 sci: 0
- Pharmacology
Total 3 gov: 0 fam: 0 fun: 0 sci: 3
- Toxins (E.g. Metals)
Total 2 gov: 0 fam: 1 fun: 0 sci: 1
- Apraxia and motor skills and stereotypic behaviours
Total 0 gov: 0 fam: 0 fun: 0 sci: 0

- Prenatal and perinatal environment
Total 0 gov: 0 fam: 0 fun: 0 sci: 0

Informal Summaries

Discipline areas with the greatest total support:

1. Education and Early Intervention (88)
2. Neuropsychology (66)
3. Epidemiology (61)

Specific autism research issues with the greatest total support:

1. Epidemiology - Family coping strategies and advocacy: how to formulate/measure; how to intervene effectively (i.e. support, training, etc.); impact on families including siblings (positive and negative outcomes); impact on child with autism (32)
2. Education and Early Intervention - Research into early intervention addressing mediators and moderators of outcome, comparing education/intervention models, and addressing treatment fidelity (26)
3. Psychosocial Interventions - What are the outcome measures needed to measure effectiveness (which includes quality of life) (21)
4. Neuropsychology - What is the developmental course of cognitive strengths and weaknesses? (21)
5. Other Non-Medical - Family coping strategies and advocacy: how to formulate/measure; how to intervene effectively (i.e. support, training, etc.); impact on families including siblings (positive and negative outcomes); impact on child with autism (18)

Specific autism research issues with the greatest support from provincial and territorial government representatives:

1. Epidemiology - Family coping strategies and advocacy: how to formulate/measure; how to intervene effectively (i.e. support, training, etc.); impact on families including siblings (positive and negative outcomes); impact on child with autism (7 = 15%)
2. Education and Early Intervention - Research into early intervention addressing mediators and moderators of outcome, comparing education/intervention models, and addressing treatment fidelity (4)
3. (Issues with equal support)
 - a. Education and Early Intervention - Professional development and training requirements, addressing training requirements, ongoing training and evaluation of training (3)
 - b. Other Non-Medical - Accurate early identification and late identification with the development of feasible community based models (3)
 - c. Psychosocial Interventions - What are the outcome measures needed to measure effectiveness (which includes quality of life) (3)

- d. Neuropsychology - How does intervention affect developmental course of sensory differences and cognitive impairment? (3)

Specific autism research issues with the greatest support from family representatives:

1. (Issues with equal support)
 - a. Psychosocial Interventions - What are best practices for continuing care/"life span services"? (7=10%)
 - b. Other Non-Medical - Family coping strategies and advocacy: how to formulate/measure; how to intervene effectively (i.e. support, training, etc.); impact on families including siblings (positive and negative outcomes); impact on child with autism (7)
2. Education and Early Intervention - implementation and evaluation of evidence-based school-wide models (5)
3. (Issues with equal support)
 - a. Education and Early Intervention - Research into early intervention addressing mediators and moderators of outcome, comparing education/intervention models, and addressing treatment fidelity (4)
 - b. Psychosocial Interventions - What are the outcome measures needed to measure effectiveness (which includes quality of life) (4)
 - c. Other medical – Immunology (4)

Specific autism research issues with the greatest support from research funding agencies:

1. Neuroanatomy - Tissue availability, including controls (comparison tissue), standardized tissue process, and distribution prioritization (5=10%)
2. (Issues with equal support)
 - a. Epidemiology - Studies aimed at developing and evaluating strategies for identifying developmental disorders early in life (including autism) (CHSRF, CIHR) (4)
 - b. Genetics - Standardized phenotypic information and genetic studies in well characterized families through sample collection and combined analysis of samples; also include broader phenotype, sex differences and gender phenotype (4)
3. (Issues with equal support)
 - a. Other medical - Co-morbid conditions (3)
 - b. Psychosocial Interventions - What are the outcome measures needed to measure effectiveness (which includes quality of life) (3)
 - c. Other Non-Medical - Identification of effective interventions for adults with ASD (3)

Specific autism research issues with the greatest support from scientists and medical practitioners:

1. Epidemiology - Studies aimed at developing and evaluating strategies for identifying developmental disorders early in life (including autism) (CHSRF, CIHR) (17=6%)

2. Neuropsychology - What is the developmental course of cognitive strengths and weaknesses? (15)
3. Education and Early Intervention - Research into early intervention addressing mediators and moderators of outcome, comparing education/intervention models, and addressing treatment fidelity (14)

Appendix E: Break-Out Group Closing Summaries

Each group included families, scientists, and government officials who were asked to formulate a summary statement for prioritized autism research.

1. Research to guide early and accurate identification of persons with autism conditions, measures of development and change, and best practices across the lifespan that maximize outcomes for the individuals and their families.
2. Understanding autism towards health for all. - money for intervention, health services, others.
3. A national strategy for understanding and altering the cause and course of ASD for individuals and families across the lifespan in their communities.
4. Innovative research on ASDs: identifying biological and psychosocial markers, advancing early detection and care and treatment across the lifespan.
5. Unlocking the potential of people with autism screening, diagnosis, appropriate delivery, early intervention, treatment - psychosocial and biomedical.
6. Canadian research funding to underwrite the clinical services that will allow the research to get done in the following four areas: basic mechanisms and causes; early ID and population screening with education; intervention to improve quality of life; and, health services research.

Appendix F: Opportunities for CIHR Institutes Involvement in Autism Research

Principal institute related to autism research:

Institute of Human Development, Child and Youth Health: autism conditions causes, prevention, screening, diagnosis, treatment and support.

Nine other institutes with mandates applicable to autism research:

Institute of Aboriginal People's Health: autism conditions screening, diagnosis, treatment and family support in aboriginal families, especially those in more isolated communities.

Institute of Gender and Health: quadruple prevalence of autism in males; Rett's disorder almost exclusively in females.

Institute of Genetics: involvement of certain genes and chromosomes in some forms of autism conditions.

Institute of Health Services and Policy Research: application of research validated effective autism condition screening, diagnosis, treatment and support processes.

Institute of Infection and Immunity: infectious causal elements and anomalies in autism conditions; compromised immune function in autism conditions.

Institute of Musculoskeletal Health and Arthritis: autism condition dysfunction in motor imitation and movement/muscle control.

Institute of Neurosciences, Mental Health and Addition: neurology, sensory function, cognitive function, behaviour, perception, learning, and memory issues in autism conditions.

Institute of Nutrition, Metabolism and Diabetes: autism condition metabolism, peptide and protein anomalies; diet and nutrient treatments for autism conditions.

Institute of Population and Public Health: autism condition environmental influences, vaccine involvement, and caregiver well being.

CIHR Peer Review Disciplinary Grant Committees covering autism related research (29 of 33) (Examples of research covered by each committee that can be applicable to autism conditions research):

Behavioural Sciences – A (Basic studies including animal models of psychiatric disorders, Neuropsychology, sensory/motor functions, pain, motivation, reinforcement, learning, sleep)

Behavioural Sciences - B (clinical/applied studies in psychiatric populations, childhood and adolescent disorders, language, speech pathology)

Biochemistry & Molecular Biology - A (structural biology, membrane proteins, enzymology and enzyme mechanisms)

Biochemistry & Molecular Biology - B (protein and nucleic acid molecular biology; gene expression; developmental biology)

Biomedical Engineering (organ and tissue preservation; gait studies; imaging studies)

Cardiovascular System - B (neuro- and endocrine regulation)

Cell Physiology (secretion mechanisms; muscle contraction)

Clinical Investigation (dermatology; ophthalmology; pediatrics; obstetrics; orthopedics; otolaryngology; mineral metabolism)

Clinical Trials (clinical trial methodology; randomized controlled clinical trials)

Endocrinology (protein and polypeptide hormones; peptide and steroid hormones and their receptors, hormones; fetal endocrinology)

Experimental Medicine (gastroenterology, metabolism, including calcium; nutrition)

Genetics (clinical genetics; population genetics; linkage analysis; gene regulation)

Health Ethics, Law & Humanities (systematic analyses of values and ethical theory as applied in health care, health research, and new health technologies; individual rights related to health technologies and treatments; health law; research in the humanities relevant to health and health care, including historical insights to current health issues)

Health Services Evaluation and Interventions Research (effectiveness and efficiency of interventions and population levels; clinical epidemiology; economic evaluation; technology assessment and cost-benefit analysis; quality of life measurement; increasing and enabling independence; rehabilitation, chronic care, palliative care; care-provider challenges; evaluation of complementary and alternative treatments; program evaluation; primary-care evaluation; home-care evaluation)

Health Information & Promotion Research (health informatics; health statistics and biostatistics; disease surveillance, health status, measurement, and need assessments; education related to patients and/or professional practice of health-care providers. Information sciences; methods; dissemination and uptake of information)

Health Policy & Systems Management Research (health policy, health economics, financing of the health-care system; health systems analysis and management; human resources, structure and organization of the health professions; community-based service delivery, integrated health systems; health care management and organization)

Immunology & Transplantation (synthesis of antibodies; immunogenetics; autoimmunity; immunoglobulins and Ig genes)

Metabolism & Nutrition (carbohydrate metabolism and pancreatic hormones; human nutrition)

Microbiology & Infectious Diseases (immunology as related to microorganisms; epidemiology, diagnosis and therapy of infectious diseases; virulence factors)

Neurosciences – A (neural cell biology; neuroanatomy; neurochemistry; molecular neurobiology; autonomic nervous system; neuropathology; neuroimmunology;

developmental neurobiology; motor and sensory systems and associated disorders; integrated Neurosciences; ANS and CNS transmitters; regulatory Neurosciences including neuroendocrinology)

Neurosciences - B (see above)

Pathology & Morphology (developmental biology; embryology)

Pharmaceutical Sciences (drug delivery; drug design; medicinal chemistry; biopharmaceutics and drug analysis; pharmacognosy and pharmacokinetics)

Pharmacology & Toxicology (drug metabolism, toxicology; mechanisms of drug action; drug receptors; pharmacology and biological substances)

Psychosocial, Sociocultural & Behavioural Determinants of Health (language, narrative and analysis of the human experience of disease, disability, trauma and chronic illness, and the social and cultural features of patienthood, including studies of interactions with care providers; behavioural responses to illness and treatment in individuals and families; social, psychological, economic, and cultural determinants of health and disease, and of health-seeking behaviours in the individual and family; impact of coping skills, social support and life style on health)

Public, Community and Population Health (screening programs; health inequalities and gradients, health and health care of diverse and disadvantaged populations; health impact of food and product safety; environmental factors; etiology research)

Respiratory System (sleep-related disorders)

Virology & Viral Pathogenesis (virology; immunology as related to viruses; epidemiology, diagnosis and therapy of viral diseases)

Appendix G: National Institutes of Health (U.S.A.) Funded Research

The National Institutes of Health (NIH) announced grants totaling \$19 million to support the first two (of five) research centers of a major network of facilities to focus on the biomedical and behavioural aspects of autism. The overall initiative, called STAART (Studies to Advance Autism Research and Treatment) Centers Program was established in response to the Children's Health Act of 2000, which calls for five new autism research centers by the end of FY 2003. The STAART program will expand NIH's commitment to autism research, which last year totaled \$56 million. The NIH Autism Coordinating Committee (NIH/ACC) coordinates autism research conducted by its five member Institutes: The National Institute of Mental Health (NIMH), the National Institute of Child Health and Human Development (NICHD), the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and Other Communication Disorders (NIDCD), and the National Institute of Environmental Health Sciences (NIEHS). All will contribute funds to the STAART program.

In October 2001 - The National Institutes of Health (NIH) has awarded grants totaling \$3.9 million to support new autism research at 13 universities across the country. These grants are in addition to \$50 million a year that NIH currently provides to a wide range of autism research projects. The NIH Autism Coordinating Committee (NIH/ACC) makes funding recommendations for autism research activities conducted by five NIH components: the National Institute of Mental Health, the National Institute of Child Health and Human Development, the National Institute of Neurological Disorders and Stroke, the National Institute on Deafness and Other Communication Disorders, and the National Institute of Environmental Health Sciences.

These grants are focused on innovative treatments and on supporting an initiative to create a nationwide network of major autism research centers. The seven innovative treatment grants, which will run for three years each, were solicited by NIH through a Request for Applications mechanism. Each of the grants will focus on an aspect of autism spectrum disorder treatment:

- Comparing two methods for teaching speech to nonverbal children
- Refining a method to teach imitation skills
- Developing a method to teach joint attention skills using parents as therapists
- Refining the use of an anti-seizure medication to treat difficult behaviour
- Testing the usefulness of a cognition-enhancing medication to treat learning difficulties and mood disturbances
- Examining the biological effects of a commonly used mood-stabilizing medication in order to refine its use in treating autism
- Testing a new animal (mouse) model to increase understanding and treatment of self-injurious behaviour

These grants were awarded to the University of Pittsburgh; Mount Sinai School of Medicine, New York City; the University of California, Los Angeles; University of Colorado Health Sciences Center, Colorado Springs; Vanderbilt University, Nashville; Children's Hospital Medical Center, Cincinnati; and Rutgers State University, New Brunswick, N.J.

Appendix H: CARW Planning Committee Members, Presenters and Speakers

Planning Committee Members

- Lisa Simmermon, ASC President
- Dr. Peter Zwack, ASC Vice-President
- Laurie Turza, ASC Executive Director
- Dr. Jeanette Holden, Queen's University
- Dr. Peter Szatmari, McMaster University
- Dr. Susan Bryson, Dalhousie University
- Dr. Andy Shih, Director of Research and Programs, NAAR
- Glenn Tringali, Chief Operating Officer, NAAR
- Dr. Rémi Quirion, Scientific Director, INMHA, CIHR

CARW Presenters and Speakers

- Dr. Catherine Lord, University of Michigan. General Overview of Autism Science and Current Autism Education and Early Intervention Research (Keynote Address)
- Dr. Thomas Kemper, Boston Medical Centre. Neuroanatomy
- Dr. Laurent Mottron, Rivière des Prairies Hospital, Montreal. Cognitive Neuropsychology
- Dr. Jeanette Holden, Queen's University. Genetics
- Dr. Susan Bryson, Dalhousie University. Epidemiology
- Dr. Peter Szatmari, McMaster University. Psychosocial Interventions Across the Lifespan
- Dr. Susan Hyman, University of Rochester. Other Medical & Practice Issues
- Lisa Simmermon, President, Autism Society Canada; parent of child with autism
- Peter Boehm, Minister of Political & Public Affairs, Canadian Embassy to the United States of America; parent of child with autism
- Dr. Stephen Foote, Director of Neurosciences & Basic Behavioural Science, National Institute of Mental Health (USA)
- Anuradha Marisetti, Acting Director for Ontario and Nunavut, Health Canada
- Dr. Rémi Quirion, Scientific Director, Institute of Neuroscience, Mental Health and Addiction; CIHR
- Gary Waleski, individual with ASD
- Pamela Button, individual with ASD
- Dr. Jane Pickett, Autism Tissue Program
- Sayeda Moosavi, Canadian Brain Tissue Bank
- Glenn Tringali, CEO, National Alliance for Autism Research
- Donald Thornton, Scottish Rite Charitable Foundation of Canada

Appendix I: Canadian and U.S. Autism Research Funding Data

Canadian autism research funding from public and private sources by funding years:
(All amounts are in Canadian dollars; exchange rates used to produce Canadian equivalents for U.S. dollars are averages for that year)
(Sources: \$ - Canadian autism researchers; population - Statistics Canada)

	<u>Public Funding</u>			<u>Private Funds</u>		<u>Total</u>	% +
	Can.	% increase	\$/capita U.S.				
00/01	953,564		0.03	489,053		1,442,617	
01/02	1,578,761	+66%	0.05	96,002	201,400	1,876,163	+30%
02/03	1,805,240	+14%	0.06	97,362	716,220	2,618,822	+40%
03/04	2,677,684	+48%	0.08	148,555	829,435	3,655,674	+40%
00/04	7,015,249	+181%		341,919	2,236,108	9,593,276	+153%

American autism research funding from public sources by funding years:
(Sources: NIH <Kim Garr-Ferguson, March 17, 2003>; population - CIA World Factbook, US Census Bureau)
(Exchange rates are average for that year)
(2003 is estimate; 2000 – 2002 are actual)

	U.S. \$	% increase	\$(US)/capita	Can \$ equivalent	\$(Can.)/capita
2000	51,724,000		0.19	76,820,548	0.27
2001	55,775,000	+7.8%	0.20	86,363,184	0.31
2002	73,850,000	+32.4%	0.26	115,971,010	0.41
2003	81,271,000	+10.0%	0.28	113,898,198	0.39
00/04		+57%			

Canadian public research funding from the Canadian Institutes of Health Research for various medical conditions:
(Source: CIHR database February 2004; amounts are inclusive for 1999 – 2004; amounts are not necessarily directly targeted for the specific medical condition, but also include amounts for research having relevance to a particular medical condition)

Ranking is according to cumulative amount of public funding provided by CIHR

AIDS	98,804,124
Asthma	46,139,793
Epilepsy	36,519,637
Alzheimer's Disease	29,192,279
Schizophrenia	26,695,121
Multiple Sclerosis	22,711,708
Cystic Fibrosis	13,580,948
Autism	10,611,912 (including one grant of \$46,500 which went to the United States)
Huntington's Disease	7,875,410
Deafness	6,645,879
Cerebral Palsy	2,307,752
Childhood Cancer	406,235
Down's Syndrome	367,760

Financial ranking according to prevalence in Canada

(Sources: prevalence data obtained from national organization website of each medical condition and Health Canada; population data from Statistics Canada 2003 figure for Canada)

Condition	Prevalence	# of Cases (est.)	CIHR \$ per affected person (est).	Ranking Estimated CIHR \$ per affected person	
Asthma	1/5	2	6,325,940	7.29	13
ADHD	1/17	.06	1,897,782	.09	14
Schizophrenia	1/100	.01	316,297	84.40	7
Epilepsy	1/100	.01	316,297	115.46	5
Alzheimer	1/100	.01	316,297	92.29	6
Deafness	1/150	.006	189,778	35.02	9
Autism	1/200	.005	158,148	67.10 (25% of average)	8
Cerebral Palsy	1/500	.002	63,259	36.48	10
Multiple Sclerosis	1/500	.002	63,259	359.03	3
AIDS	1/500	.002	63,259	1,561.90	1
Down's	1/1000	.001	31,629	11.63	12
Huntington's	1/1100	.0009	28,467	276.65	4
Childhood Cancer	1/1400	.0007	22,141	18.35	11
Cystic fibrosis	1/2500	.0004	12,652	1,073.42	2
Estimated average CIHR research \$ per affected person (Estimated average for the above conditions)			267.08		