



Michael Smith Foundation for
Health Research

Building through Collaboration:
An Inventory and Analysis of Implications
for Building Autism Research Capacity in
Canada's Northwest Region



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Glossary of Frequently-Used Abbreviations and Acronyms

Acronym	Definition	Relating to Organization/ Region/ Country
AHFMR	Alberta Heritage Foundation for Medical Research	Alberta
ASD	Autism Spectrum Disorders	
ASD-CARC	Autism Spectrum Disorders - Canadian American Research Consortium	
BCAAN	BC Autism Assessment Network	BC
CAIRN	Canadian Autism Intervention Research Network	
CIHR	Canadian Institutes of Health Research	
CPEA	Collaborative Programs of Excellence in Autism	NICHHD
CRC	Canada Research Chair	
DSM	Diagnostic and Statistical Manual of Mental Disorders	American Psychiatric Association
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision	American Psychiatric Association
HELP	Human Early Learning Partnership	UBC
IHRT	Interdisciplinary Health Research Team	CIHR
IMFAR	International Meeting for Autism Research	NAAR
MCFD	Ministry of Children and Family Development	Government of BC
MOE	Ministry of Education	Government of BC
MOH	Ministry of Health	Government of BC
MOHP	Ministry of Health Planning	Government of BC
MSFHR	Michael Smith Foundation for Health Research	
NAAR	National Alliance for Autism Research	US
NICHHD	National Institute of Child Health and Human Development	National Institutes of Health (US)
NIH	National Institutes of Health	US
PDD	Pervasive Developmental Disorder	
PDD-NOS	Pervasive Developmental Disorder-Not Otherwise Specified	
PHSA	Provincial Health Services Authority	British Columbia
PI	Principal Investigator	
SSHRC	Social Sciences and Humanities Research Council	
YTD	Year to date	

Disclaimer

Note to the Reader:

This inventory has been produced by The Michael Smith Foundation for Health Research as a tool for policy-makers, researchers, service providers, and organizations funding health research who are interested in understanding more about western Canada's capacity for undertaking collaborative regional efforts to enhance research into autism spectrum disorders.

The report includes a detailed methodology section that outlines assumptions, data limitations, and analytical processes. An understanding of the methodology is critical for accurate interpretation: readers are urged to review the methodology before reading the findings of the report.

The report has been produced using publicly accessible information from reliable sources. Every attempt has been made to provide a document as accurate and complete as possible within the resources available for this project at the time research was undertaken. However, the analysis is bounded by data and research resource limitations. We thank the external reviewers of this paper for their generous input and perspectives, keeping in mind that any errors or omissions remain the authors' sole responsibility.

Readers are encouraged to inform the Michael Smith Foundation for Health Research of any concerns regarding the content and accuracy of this report so that these may be addressed in subsequent updates.

To assist us in improving this and subsequent reports, please take the time to complete and return to us a brief survey that can be found on our website at:
<http://survey.msfhr.org/ASDreport/ASDsurvey.htm>.

Thank you.

1. Executive Summary

This preliminary review analyzes autism-related research funding and activity in Canada. The funding and activity analyzed encompasses research across the country supported by major national and international granting agencies, as well as activity in Canada's west and north that is supported by various funding agencies and/or governments. The review is presented to help identify the current and possible future role of the provinces in the Northwest Region¹ in building their jurisdictions' capacity for excellence in Autism Spectrum Disorders (ASD) research.

With the exception of some direct government-supported research, the majority of funding analyzed has been awarded on a peer-reviewed, competitive basis. Thus the identification of jurisdictions that are relatively under-funded (e.g. compared to per capita population, for example) reflects a proportional lack of research capacity – fewer qualified individuals applying for, and receiving, fewer funding awards.

This analysis confirms the findings of an earlier (MSFHR 2003) inventory of autism research funding in Canada: the majority of funded activity identified continues to focus on understanding the biological and genetic causes of autism. This updated analysis also reconfirmed that most ASD research in Canada occurs outside the Northwest. In terms of the funding received by researchers headquartered in the Northwest Region from the various sources analyzed in this report, the region as a whole plays a fairly limited role. At the present time, only one of the four provincial funding agencies supporting health research in the region funds work in the area of ASD: the Alberta Heritage Foundation for Medical Research reports a single ASD-related research award made in 2001. During the period analyzed, no ASD-related research awards were made by the Michael Smith Foundation for Health Research (BC), the Manitoba Health Research Council or the Saskatchewan Health Research Foundation.

This inventory suggests that the autism research effort in Canada is fragmented and unevenly developed, without a consistent or high degree of coordination. There are clusters of researchers at various universities, particularly in Ontario, and emerging national networks connect researchers around some aspects of autism research. These networks include researchers from western provinces to a limited extent. While these networks attempt to increase the connectivity between autism researchers in Canada (for example, by establishing regional teams or engaging in attempts to set a common research agenda) overall coordination and strategic network planning are limited.

While some important ASD-related work is done in the Northwest, overall researchers working in this region are more likely to play a supportive or participatory rather than leadership role in Canadian autism research. There is a range of research activity in each of the western provinces (in the form of individual researchers and autism databases, for example), and researchers in the Northwest appear to seek national connections with the existing networks headquartered in eastern Canada. For example, about 35% of all researchers in Canada's two emerging autism research networks are from BC, Alberta, Saskatchewan or Manitoba. Apart from this network involvement, no substantial formalized links have been established between researchers working on similar questions across the region. The opportunity exists to build on existing connects to develop stronger and more productive networks, regionally and nationally.

¹ Defined by MSFHR for the purposes of this report as British Columbia, Alberta, Saskatchewan, Manitoba, the Yukon, and Northwest Territories.

2. Introduction

2.1 *Background and Scope of Report*

2.1.1 Initial Autism Research Inventory

Early in 2003, the British Columbia Ministry of Health asked the Michael Smith Foundation for Health Research (MSFHR) for information on health research activity in the province related to Autism Spectrum Disorders (ASD). In the absence of any existing collated data, MSFHR undertook a preliminary inventory of health research activity in Canada related to ASD, with a special focus on activity involving British Columbia.

The preliminary MSFHR report was based on extracts of funding data from the Canadian Institutes of Health Research (CIHR) and the Social Sciences and Humanities Research Council (SSHRC) to year end 2002. This analysis identified and analyzed awards indicating a scientific connection with ASD research, in order to give an overview of ASD research activity and related funding distribution across Canada. The inventory also identified investigators associated with two significant national collaborative autism research projects (emerging networks): the Autism Spectrum Disorders - Canadian American Research Consortium (ASD-CARC), and the Canadian Autism Intervention Research Network (CAIRN).

Relevant research activity funded directly by government, by service-provider agencies, or otherwise undertaken outside the major peer-reviewed agency processes, was not included in the preliminary survey. Consequently, further effort was applied to develop a more complete picture of ASD-related research in Canada, specifically in the western provinces and territories, to more fully understand the gaps and opportunities that currently exist nationally and regionally.

2.1.2 Phase Two Autism Research Inventory

In May 2003 the British Columbia Ministry of Health hosted a teleconference with government officials from BC, Alberta and Manitoba², and representatives of MSFHR, to discuss issues of common interest on health research activity relating to ASD. During that meeting, it was agreed to attempt to supplement the existing inventory by gathering information on government-funded research projects. To that end, a survey was circulated requesting additional information from key respondents in BC, Alberta, Saskatchewan, Manitoba, the Yukon, and the Northwest Territories on ASD research in their jurisdictions ("Survey #1").

It was further agreed that future collaborative research efforts across the western and northern Canadian jurisdictions could be greatly enhanced by access to high quality, comprehensive, longitudinal, shared databases. A second survey was therefore circulated, seeking to identify existing databases (research, clinical or administrative) in participating jurisdictions, as the basis for future discussions regarding enhancing this key platform resource ("Survey #2").

In anticipation of the receipt of data from the two survey tools, MSFHR agreed to undertake a revision/update to the preliminary inventory to include information on awards made to the end of fiscal year 2002/03, and for the CIHR, to fiscal year 2003/04 year-to-date. The latest CIHR data available to the MSFHR allows for forward projections of grant fiscal year payments, providing a more comprehensive picture of longer-term resources for Canadian ASD research.

² Saskatchewan, the Yukon and the Northwest Territories were also invited to participate and have been included in subsequent partnership discussions.

This document incorporates the survey results with an updated and expanded inventory of autism activity in Canada. This Phase Two inventory will be shared with respondents in participating jurisdictions as part of an ongoing consultation process to further regional collaboration (e.g. networking or shared funding) on research questions of common interest relating to ASD. The purpose of this work is to help identify the current and possible future role of the Northwest Region in ASD research, particularly in respect of the possibility of strengthening links between creators of knowledge and those who would seek to use it to improve policy and practice.

2.2 Report Structure

Extracts of funding data from CIHR, SSHRC and the US National Alliance for Autism Research (NAAR) form the basis of this report. All awards which indicate a scientific connection with autism research were identified, then analyzed, to create an overview of autism funding distribution across Canada (**Section 3**, with details by project in Appendix A).

Also analyzed were data from the National Institutes of Health (NIH) and the Canada Research Chairs program (CRCs). Autism-related CRCs are included in this report and are listed in Appendix B; however, due to the fact that CRCs are not projects and hence often have a broader research focus, funding amounts were not included in any funding data calculations. NIH data did not appear to contain any autism-related awards to researchers at Canadian institutions. Research into funding for autism-related projects remains to be done for other agencies, including Health Canada, for which only a preliminary search was done (producing no evidence of direct Health Canada funding for autism research).

The time-frame for data analyzed varies by funding source, in general spanning the period 1998 to 2003. Specific details as to the reporting timeframe for each agency are provided in Section 2.3 Process and Methodology, below. Readers are urged to carefully review that section in order to accurately interpret the balance of the report,

Section 4 of the report analyzes Canadian ASD-related health research and funding by research area (topic and focus), summarized by location of the activity and funding allocated.

Section 5 summarizes information on two significant emerging autism research networks in Canada: the Autism Spectrum Disorders - Canadian American Research Consortium (ASD-CARC); and CAIRN, the Canadian Autism Intervention Research Network, including a table that links Canadian autism researchers to these networks.

Section 6 provides an initial attempt to identify primary locations of autism research in Canada and initiatives of cooperation between researchers.

Section 7 reports on the results of a survey among western provinces and territories (BC, Alberta, Saskatchewan, Manitoba, Yukon, and the Northwest Territories) regarding the existence of autism-related databases in each jurisdiction.

Attached to this report are the following **Appendices**, each providing detailed data on which the summaries in this report are based:

- ◆ Appendix A - Researchers Currently funded by CIHR, SSHRC and NAAR, by Province
- ◆ Appendix B - Canada Research Chair Holders
- ◆ Appendix C - MSFHR Survey Results - Autism Researchers
- ◆ Appendix D - MSFHR Survey: Database Information
- ◆ Appendix E - CAIRN Member List
- ◆ Appendix F - ASD-CARC Member List (Canada)

2.3 *Process and Methodology*

The 2003 MSFHR Autism Research Inventory report was based on extracts of funding data from the Canadian Institutes of Health Research (CIHR) and the Social Sciences and Humanities Research Council (SSHRC) to year end 2002. This analysis identified and analyzed awards indicating a scientific connection with ASD research, in order to give an overview of ASD research activity and related funding distribution across Canada. In addition to the original data, and the information from the two surveys described in Section 2.1.2 above, this updated report includes revised funding information as follows:

1. CIHR data: now to include records of all funding 1999/00 to 2003/04 YTD (September 17, 2003) over the lifetime of the awards, and projected payments for future fiscal years to 2008/9.
2. SSHRC data: for funding from fiscal year 1998/99 to end of fiscal year 2002/03. Only amounts paid out during the aforementioned fiscal years were available in the data from the SSHRC online database and could be analyzed. Amounts representing “total value of award” (including projected award payments) were not available in SSHRC data accessible to MSFHR, thus forward projections are not included in this analysis. Also searched were SSHRC awards for competition year 2003 posted on the SSHRC website to September 25, 2003. Fiscal year 2003/04 payments for those awards are included in the analysis; projections for future year payments for those most recent SSHRC awards are excluded.
3. Review of funding data from two major US funding sources whose data is readily publicly available, the National Institutes of Health (NIH) and National Alliance for Autism Research (NAAR):
 - A. Review of results shows no NIH funded projects in Canada for the period fiscal year 1992/93 to fiscal year 2003 YTD.
 - B. Several NAAR-funded Canadian projects were identified and are included in the inventory. Unless otherwise indicated, NAAR amounts are presented in Canadian dollars.³ Projects funded based on competition years 1997 to 2003 including the total value of award over the lifetime of the award (generally one- or two-year awards). For purposes of this analysis, in the case of multiple-year awards, equal amounts were allocated to each fiscal year (based on information from NAAR that payments are usually made in this fashion). NAAR funding for a competition is announced at the end of the NAAR fiscal year in June (June 30) and paid out during the following fiscal year; e.g. funding for projects based on competition year 2003 is announced at the end of the NAAR fiscal year 2002/03 in June and paid out during fiscal year 2003/04. We captured NAAR awards released until the end of the NAAR fiscal year 2002/03 (with payments for these awards extending into future fiscal years).
4. Addition of a summary of Canada Research Chairs involved in autism research from the beginning of the CRC program in December 2000 to the latest announcement of chairs in October 2003.

³ Converted with an average exchange rate of 1.48 Canadian dollars to US\$1 for the years 1997 to 2003.

The **total dollar value** of autism research funding is the sum of the total value of all awards over their lifetime and based on the fiscal years analyzed; i.e., CIHR and NAAR data capture all awards that were released up until data download (see above) and including projected payments over the coming fiscal years. SSHRC data does not include those projected payments, but only shows funding released during a given fiscal year (up until the completed fiscal year 2002/03). (Due to the fact that Canada Research Chair awards are not projects and hence often have a broader research focus, CRC funding amounts were not included in any funding data calculations.)

With the exception of data received in the Surveys (2.1.2 above), information on organizations, research groups, funding agencies, etc. was largely obtained (and at times directly taken from) publicly accessible sources, such as websites and printed materials.

2.4 Definitions and Search Keywords

Defining the research to include in this inventory was a challenge, since research areas related to autism include a wide range of pervasive developmental disorders and scientific terms. As part of the recent increase in autism spectrum disorders research in North America, the definition of these disorders is shifting.

For the purpose of this report, funded projects were included if they referenced terms consistent with the American Psychiatric Association's "Diagnostic and Statistical Manual of Mental Disorders" (DSM), which provides the standard classification of mental disorders used by mental health professionals in the United States and in Canada.

The fourth (1994) edition of the DSM lists "Autistic Disorder", "Pervasive Developmental Disorder, Not Otherwise Specified", "Asperger Syndrome", "Rett Syndrome" and "Childhood Disintegrative Disorder" under the DSM-IV category "Pervasive Developmental Disorder". Of those pervasive developmental disorders, we excluded from our search the terms "Rett Syndrome" and "Childhood Disintegrative Disorder". This choice is based on scientific advice that their link to autism (as opposed to their link to autistic behaviours) is not yet firmly established. For the same reason, also not included in the report are projects focusing exclusively on Fragile-X Syndrome.

Based on the above definitions, the following search terms (and/or iterations thereof) were applied to the CIHR, SSHRC, NIH and NAAR datasets. Due to the relatively small size of NIH and NAAR datasets, all awards were checked individually for their relevance to ASD:

- ◆ Autism, Autisme, autistic
- ◆ Autism Spectrum Disorder, ASD
- ◆ Asperger Syndrome
- ◆ Pervasive Developmental Disorder, PDD-Not Otherwise Specified, PDD-NOS

Included in the dataset that forms the basis for this report are all awards with one of the above search terms occurring in any data field. Except as noted above, no awards were excluded, and no judgement regarding topic relevance was applied.

2.4.1 Definition of "Northwest Region"

For the purposes of this report, British Columbia, Alberta, Saskatchewan, Manitoba, the Yukon, and the Northwest Territories are referred to collectively as the "Northwest Region".

2.5 Notes on the Awards Data

2.5.1 Research Area

In this analysis, data populating the field “Research Area” is taken from the following data field sources:

Awarding Body	Data field
CIHR	Primary Research Area
SSHRC	Discipline
NAAR	no data field for this; “Research Area” is taken to be “Not Classified”.

Because a given individual may be involved in more than one area of research, some investigators’ names appear more than once in the tables referring to research area. (In CIHR data “Primary Research Area” is a field which is self-reported by the principal investigator.) For tables that show multiple research area involvement for a single investigator, this may occur because records for CIHR awards sometimes reflect a change in research areas over the life of the award, or because a researcher is involved in more than one research project during the time period covered in this report, each project having a different research area.

2.5.2 Province

The data may sometimes show a researcher as carrying out their research in a province that does not represent their current location. This is because data analyzed is presented here as originally provided by the funding agency. Discrepancies may reflect the fact that an award may have been made at a time when the investigator was at a different location, and has subsequently moved. In other cases, the investigator noted is affiliated with the award as a Co-PI/Co-Investigator, and the award location identified for the award record reflects the location of the award’s Principal Investigator.

2.6 Please Note

The information in this report has been produced from reliable sources using publicly accessible information. Every attempt has been made to provide a document as accurate and complete as possible within the resources available for this project. Interpretation of data is undertaken according to our best knowledge and objectivity of perspective as of the date of the report. Readers are encouraged to inform the Michael Smith Foundation for Health Research as to any errors, omissions or concerns so these may be addressed in subsequent updates.

3. Major National Funding for Autism Research in Canada

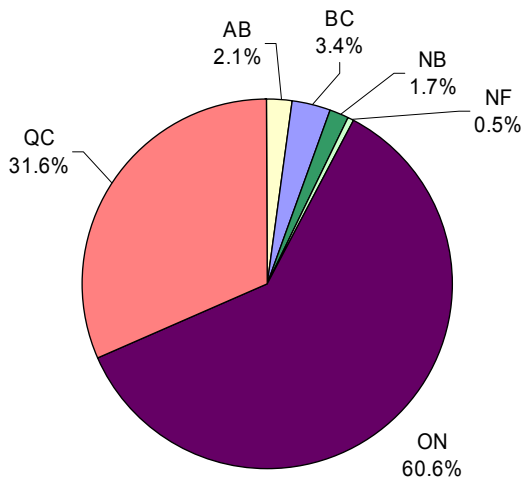
With the exception of some direct government-supported research (see Section 3.7), the majority of funding analyzed in this inventory has been awarded on a peer-reviewed, competitive basis. This analysis indicates that some jurisdictions are relatively under-funded (compared to per capita population, for example), reflecting a proportional lack of research capacity in the relatively under-funded regions where fewer qualified individuals apply for, and receive, fewer funding awards per capita, compared to other parts of Canada. Section 4 of this report discusses the research in terms of its distribution across topic areas; this section focuses on financial and geographic distribution of ASD-related research in Canada.

For the granting periods (defined in Section 2.3 above), a total of \$19,503,306 has been identified as awards in support of ASD-related research in Canada from three major funding bodies: the two largest Canadian health research funding agencies, Canadian Institutes for Health Research (CIHR) and Social Sciences and Humanities Research Council (SSHRC), and by the US-based National Alliance for Autism Research (NAAR). More than 90% of funding for autism research in Canada during the period analyzed by this report was provided by the CIHR.

Funding for Autism-Related Research in Canada (Three largest autism research funding sources)		
CIHR	NAAR	SSHRC
\$18,046,422	\$765,773 ⁴	\$691,111
92.5%	3.9%	3.5%

More than 92 percent of all autism-related research funding goes to principal investigators in Ontario and Quebec. The remaining 7.8 percent is distributed among four other Canadian provinces, with no awards made to researchers in the remaining four provinces and three territories.

Funding Amounts by Province, as % of Total



⁴ US funds converted to Canadian dollars by applying annual average exchange rates, prorated by NAAR fiscal year, for the granting years 1997 to 2003.

Between 1999 and 2003, the CIHR committed 5.74 Canadian cents per capita⁵ to ASD research (including payments committed for future fiscal years). The SSHRC ratio is 2.2 cents per capita (not including payments committed for future fiscal years). Also noteworthy is the fact that, between 1997 and 2003 NAAR spent 1.7 US cents (or 2.5 Canadian cents) per Canadian capita on ASD research in Canada. During the same time period, the US per capita funding⁶ of researchers at US institutions was US 4.4 cents (or 6.5 Canadian cents) per US citizen⁷.

Funding Amounts by Awarding Body and Province								
	CIHR		NAAR		SSHRC⁸		Total Funding	Total Provincial Share
Prov.	Funding	Provincial Share	Funding	Provincial Share	Funding	Provincial Share		
ON	\$11,029,574	61.1%	\$628,212	82.0%	\$166,738	24.1%	\$11,824,524	60.6%
QC	\$5,745,548	31.8%	\$69,561	9.1%	\$352,133	51.0%	\$6,167,242	31.6%
BC	\$567,120	3.1%	\$68,000	8.9%	\$35,200	5.1%	\$670,320	3.4%
AB	\$274,500	1.5%	—	0.0%	\$137,040	19.8%	\$411,540	2.1%
NB	\$340,324	1.9%	—	0.0%	—	0.0%	\$340,324	1.7%
NF	\$89,356	0.5%	—	0.0%	—	0.0%	\$89,356	0.5%
Total	\$18,046,422	100.0%	\$765,773	100.0%	\$691,111	100.0%	\$19,503,306	100.0%

3.1 Funding to the Northwest Region

The Northwest Region is home to a limited number of principal investigators involved in CIHR-, SSHRC- and NAAR-funded autism research. Overall, researchers in this region received \$1,081,860, or 5.5% of the total autism-related funding from CIHR, SSHRC and NAAR during the period analyzed for this report.

British Columbia received 3.4% or \$670,320. The remaining 2.1% of total regional funding went to Alberta. No funding was received by investigators in Saskatchewan, Manitoba or the Territories during the time frames analyzed.

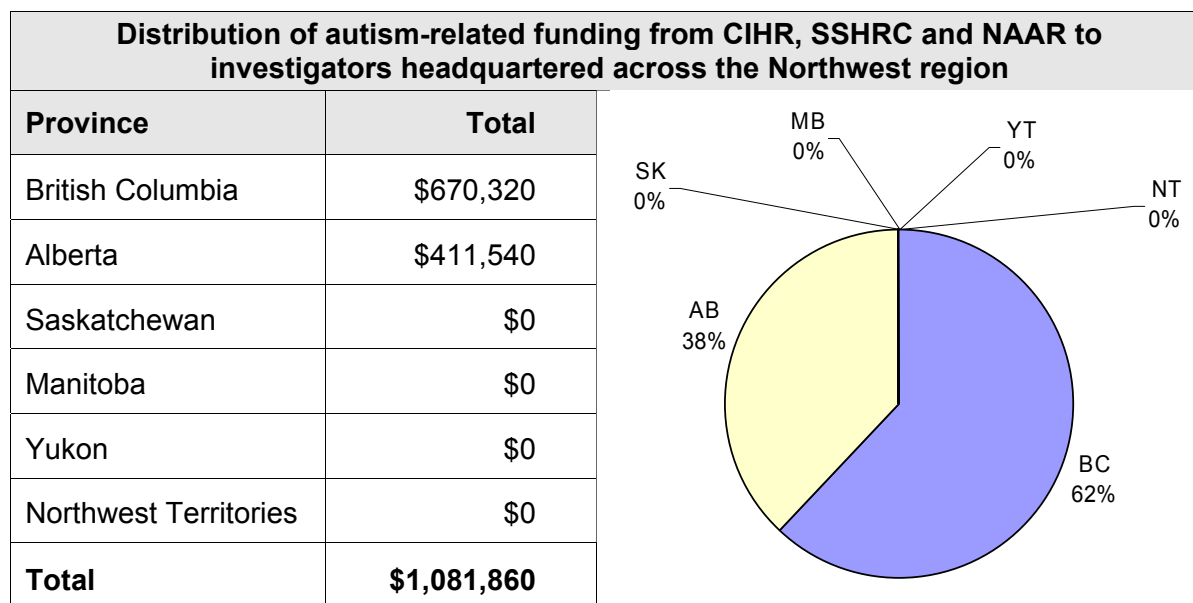
The table and chart on the next page illustrate funding received from CIHR, SSHRC and NAAR, as well as the distribution of autism-related funding to investigators headquartered across the Northwest Region.

⁵ Based on 2002 Statistics Canada population data.

⁶ Based on 2002 US Census Bureau data.

⁷ Converted with an average exchange rate of \$1.48 Canadian to \$1 US for the years 1997 to 2003.

⁸ Does not include projected award payments.



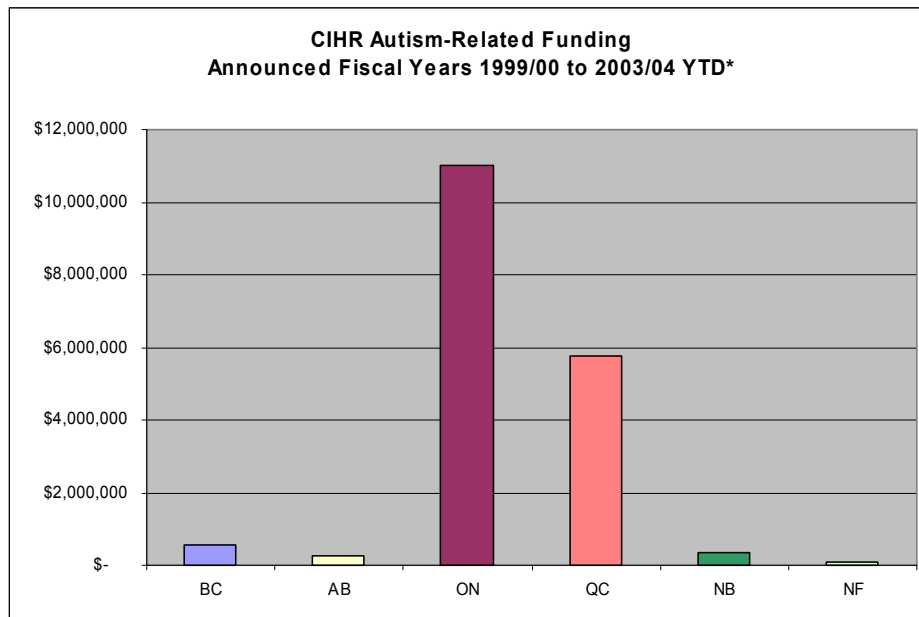
3.2 CIHR Funding

A preliminary analysis of CIHR awards data for the period fiscal year 1999/00 to 2003/04 YTD identified 37 funded projects in the field of autism research. A total of \$18,046,422 in CIHR funding went to autism-related research during this time period, including payments for future years based on awards released up to September 17, 2003. CIHR autism-related awards range from one to six years (with awards of the longest duration going to support research Training Centres).

CIHR Award Amounts by Jurisdiction⁹		
Province	Funding	Provincial Share
Ontario	\$11,029,574	61.1%
Quebec	\$5,745,548	31.8%
British Columbia	\$567,120	3.1%
New Brunswick	\$340,324	1.9%
Alberta	\$274,500	1.5%
Newfoundland	\$89,356	0.5%
National Total	\$18,046,422	100.0%

No autism funding was received by principal investigators located in Saskatchewan, Manitoba, Nova Scotia, Prince Edward Island, the Yukon, the Northwest Territories, or Nunavut. Of the funded projects, the majority were made to investigators in Ontario and Quebec. The balance went to researchers in British Columbia, New Brunswick, Alberta and Newfoundland. A detailed list of CIHR-funded projects and related information is included in Appendix A.

⁹ For those provinces/territories where researchers received awards for projects relating to ASD.



**Based on amounts paid during fiscal years 1999/00 to end September 17, 2003 (fiscal year 2003/04 YTD) including projections for future fiscal years, the total projected value of awards is reflected in the data.*

3.2.1 CIHR Autism Projects

In this section, a number of the major Canadian initiatives in ASD research are summarized. Please refer to Appendix A for a complete list of CIHR-funded autism projects.

The CIHR funds several projects or project areas with amounts exceeding \$1M.

- ◆ Jeanette Holden at Queen's University has been funded with two awards for her autism project, "Unravelling the mystery of autism: From genotyping and phenotyping to prospective identification and prevention". These awards total \$4.38M.
- ◆ Another genetic research project is led by Michel Maziade at Laval in Quebec. He received more than \$2.3M for his project, "The genetics of complex psychiatric disorders: an integrated approach to the study of bipolar disorder, schizophrenia, alcoholism and autism".
- ◆ Stephen Sherer's "Human chromosome 7 genome project" and "Genome discovery for genetic disease research" at the University of Toronto (funded with total \$1.87M) both look at genetic links to autism.
- ◆ Sabine Cordes at the University of Toronto works on hindbrain patterning/segmentation and its relation to autism. She has been funded with two projects totalling \$1.37M.
- ◆ Peter Szatmari at McMaster University has been funded for four projects with a combined value totalling more than \$1M. These include two projects on "The genetic epidemiology of autism; family and molecular studies" as well as "Developing a research agenda on early intervention in autism and other pervasive developmental disorders", and, most recently, "Understanding developmental trajectories in autism".

A number of other substantial awards exceed the half million dollar funding level. Among these are three major awards focusing on the genetics of autism:

- ◆ Guy Rouleau at McGill University in Quebec was awarded a total of \$734,931 for his project, “Searching for genes predisposing to autism”.
- ◆ Douglas Munoz at Queen’s University received a \$686,800 award for his project, “Using eye movements to probe brain function and dysfunction in humans”.
- ◆ Laurent Mottron at the University of Montreal holds funding for two related projects, “Characterizing cognitive deficit in pervasive developmental disorders” and “Characterizing cognitive deficits in high-functioning autism and Asperger syndrome”, together worth \$657,152.
- ◆ Suzanne Lewis at the University of British Columbia received funding for two consecutive projects totalling \$567,120, “New approaches toward understanding the genetic bases of form function and phenotype in Autism Spectrum Disorder” and “Autism spectrum disorders: Identification of culprit genes using genomic micro-arrays and molecular assessments of duplicon-mediated micro-deletions and duplications”.

Training Centres

The CIHR supports training centres that focus on increasing future Canadian ASD research capacity. Two such projects have been announced to date, each funded for more than \$600,000 in total. Jeanette Holden (Queen’s University) is the PI for the five-year, “Transdisciplinary inter-institute training program in autism spectrum disorders”. Eric Fombonne, Canada Research Chair in Child and Adolescent Psychiatry at McGill University in Montreal, leads the six-year “Training Program in Autism Research”. This latter project is co-sponsored by NAAR.

Other projects, most of which are smaller in financial scope, address less biomedically-focused aspects of ASD research, such as Connie Varnhagen’s “Strategies for critically appraising children’s health web resources”.

3.3 SSHRC Funding

A preliminary analysis of SSHRC awards data from fiscal year 1998/99 to 2003/04 shows 17 projects funded in autism research for a total of \$801,242. SSHRC autism-related awards range from one to four years in duration.¹⁰ Details are provided in Appendix A. Of 17 identified projects, five are located in the Northwest, and three of those are Doctoral Fellowships.

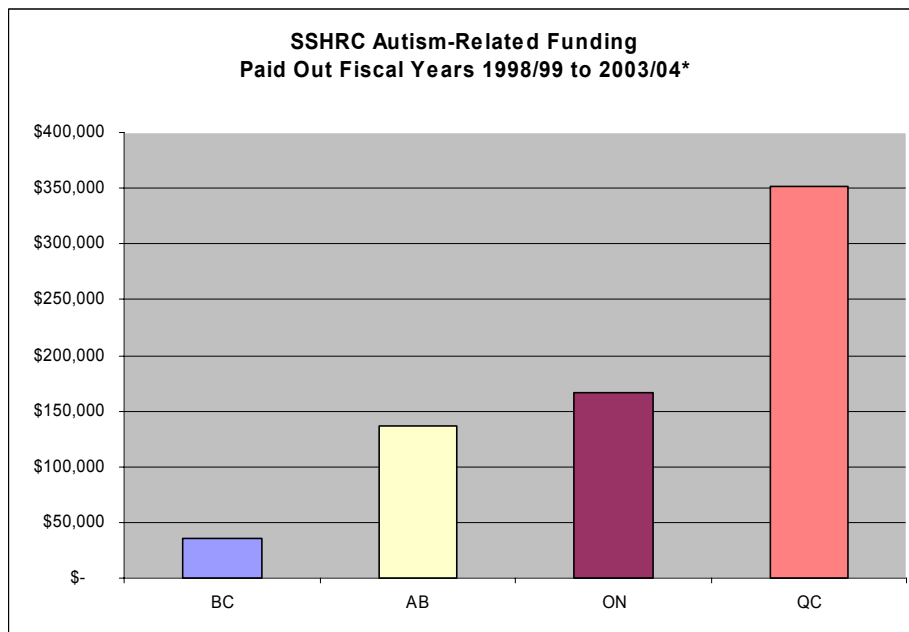
- ◆ In 2002 a two-year Doctoral Fellowship totalling \$35,400 went to Veronica Smith at the University of British Columbia to study “Social competence for children with autism following early intervention”.
- ◆ In 2000 Alissa Pencer at the University of Calgary was funded for her doctoral project “The role of pragmatic cues in typically developing and autistic children’s word learning” (total award amount over three years is \$53,100).

¹⁰ SSHRC funding analyzed in this report does not include projected payments for awards released up until the end of fiscal year 2002/03.

- ◆ In 1998 Deborah Brown-Godsave at the University of Alberta was awarded a three-year, \$50,940, Doctoral Fellowship to study “Child characteristics and the adjustment of families of young children with a pervasive developmental disability”.
- ◆ In the 2002 competition, Joanne Volden, professor at the University of Alberta, received an award for her project “Variation of language register in autism”, in its first year funded with \$33,000.
- ◆ In the 2003 competition, Tamara Kulusic of Simon Fraser University was awarded a \$17,500 Canada Graduate Scholarships Program award for her project, “Understanding autism and accessing help: parent’s perspectives of the family experience.”

Twelve other awards during this time period went to researchers from Quebec (seven awards) and Ontario (five awards).

SSHRC Award Amounts by Jurisdiction Fiscal Year 1998/99 to end of Fiscal Year 2003/04¹¹		
Province	Funding	Provincial Share
Quebec	\$352,133	51.0%
Ontario	\$166,738	24.1%
Alberta	\$137,040	19.8%
British Columbia	\$35,200	5.1%
New Brunswick	—	0.0%
Newfoundland	—	0.0%
Total	\$691,111	100.0%



**This chart illustrates amounts awarded during fiscal years 1998/99 to end of fiscal year 2003/04. The total value of award (including projected award payments) is not available in the SSHRC data currently accessible to MSFHR.*

¹¹ For those provinces/territories where researchers received awards for projects relating to ASD.

3.4 NAAR

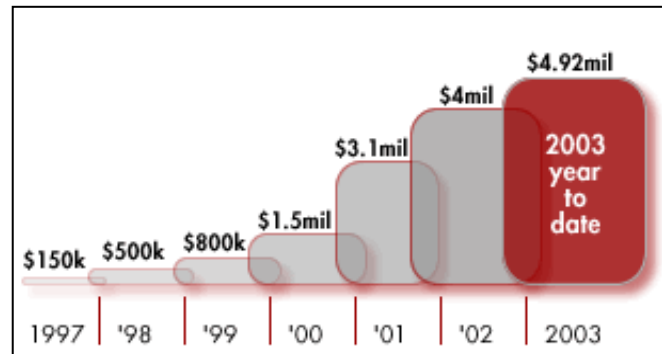
The US National Alliance for Autism Research (NAAR) is dedicated to funding and accelerating biomedical research that focuses on autism spectrum disorders. NAAR was established in 1994 by parents of children with autism concerned about the limited amount of funding available for autism research. Projects funded by NAAR have made an impact on the autism research landscape in the United States, Canada and Europe and, according to NAAR, have been leveraged to attract more than US\$37M in autism research awards by the National Institutes of Health (NIH) and other sources.

The mission of NAAR is to fund, promote and accelerate biomedical research and science-based approaches that seek to determine the causes, prevention, effective treatments of, and ultimately, a cure for autism spectrum disorders. This mission includes providing grants to researchers for innovative, new pilot studies; mentoring fellowships to recruit new researchers to focus on autism; and larger, collaborative research programs that have the potential to yield major scientific advances in autism research. NAAR funds autism studies that cover a wide range of research areas, including:

- ◆ Genetics
- ◆ Language & Communication
- ◆ Molecular & Cellular Biology
- ◆ Immunology
- ◆ Neuroanatomy & Neuroimaging
- ◆ Epidemiology Studies
- ◆ Behavioural Studies.

Since 1997, NAAR reports commitments of US\$14.9M to 169 biomedical autism research projects and fellowships¹² worldwide – more than any other non-governmental organization. Analysis of NAAR funding data shows that a total of US\$1,597,169 or 10.6 percent of NAAR's total research commitments to date went to researchers at institutions in countries other than the US and Canada.

NAAR Support for Autism Research



¹² NAAR Program types: *Pilot studies* are critical to attracting larger, multi-year grants from the NIH and other traditional medical research funding organizations. NAAR reports that to date, NAAR-funded pilot studies have been leveraged to attract more than \$23 million in large grants from the NIH and other sources. NAAR pilot study grants are typically one- and two-year awards.

NAAR's *Mentor-Based Fellowship Program* is designed to attract the best and brightest young investigators to the field of autism research. NAAR believes its investment in autism research training will grow exponentially as many of its fellows later assume teaching roles and join departments around the country and the world, which currently have no representation in autism research.

Collaborative programs and scientific consortiums unite researchers working towards a common goal, whether its is based in genetics, behavioural sciences or another field of research. NAAR states that many experts agree that a collaborative approach to autism research is the only way science will solve the mysteries of this disorder.

In recent years, NAAR has expanded the scope of its funding activities to encompass: mentoring fellowships; larger collaborative studies; and scientific consortia. Some recent and major initiatives are summarized here.

- ◆ In 2002, NAAR committed approximately \$4M to fund 22 pilot studies in autism in the US, England, Italy and Germany, and three larger, collaborative programs in the US, Canada and England. In the same year, NAAR played a key role in funding and presenting the first Canadian Autism Research Workshop, designed to enhance and increase autism research efforts in Canada.
- ◆ In 2001, NAAR committed approximately \$3.1M to fund 28 pilot studies, fellowships and programs, including its largest investment to date in a single project: The Baby Sibs Study – a collaborative, multi-site research program taking place in Canada and the US (see Section 3.4.1 below).
- ◆ Also in 2001, NAAR played a key role in funding and establishing the first annual International Meeting for Autism Research (IMFAR), the first international, interdisciplinary conference focusing on autism research. Additionally, NAAR was instrumental in funding and establishing the Autism Tissue Program in 1998, a brain tissue donation program dedicated to autism research.

3.4.1 NAAR Funding to Canadian Researchers

In recent fiscal years NAAR's support for Canadian researchers has increased, although the total number of projects funded is still fairly low, i.e., six funded projects in Canada out of the 169 projects NAAR has funded since its inception. (For details of specific Canadian projects funded by NAAR, please see Appendix A.) As a share of all amounts committed in NAAR competition years 1997 to 2003, 3.6 percent of the organization's US\$14.7M research budget to date has been awarded to researchers at Canadian institutions.

NAAR Award Amounts by Jurisdiction ¹³		
Province	Funding Amount In \$CDN ¹⁴	Funding Amount % of Total
Ontario	\$628,212	82.0%
British Columbia	\$69,561	9.1%
Quebec	\$68,000	8.9%
Total	\$765,773	100.0%

The two largest NAAR awards to Canada to date were made to researchers based in Ontario for research carried out at McMaster University. Lonnie Zwaigenbaum and Susan Bryson¹⁵ (Principal Investigators) along with Wendy Roberts and Peter Szatmari were awarded

¹³ For those provinces/territories where researchers received NAAR awards.

¹⁴ Converted with an average exchange rate of 1.48 Canadian dollars to US\$1 for the years 1997 to 2003.

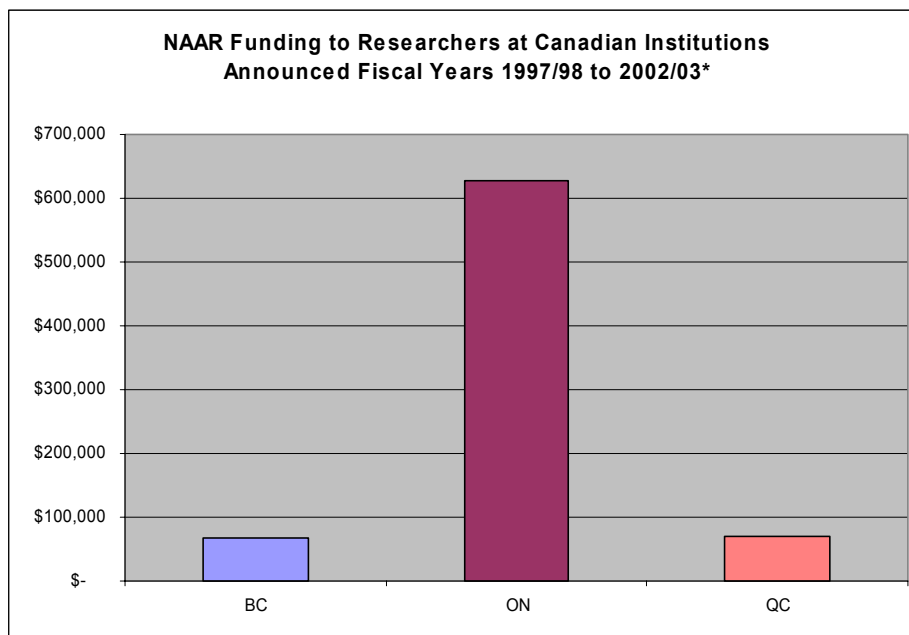
¹⁵ Susan Bryson is currently at Dalhousie University in Halifax. NAAR data shows the project as being carried out at McMaster University, the location of the main principal investigator, Lonnie Zwaigenbaum.

US\$99,993 for their study “Identifying Early Markers of Autism: A Longitudinal Study of Infant Siblings” (Baby Sibs Study).

Since 1997, NAAR has committed US\$700,000 in the US and Canada to the Baby Sibs Project – one of NAAR’s largest awards to a single project. The collective result of this work has helped form the basis for a larger scale study that addresses important clinical and theoretical questions about the causes, core symptoms, and course of autism, with key implications for early intervention.

The Baby Sibs study, which has received continuous funding since 1997, is a multi-site project led by Lonnie Zwaigenbaum. The study is conducted at three sites: McMaster Children's Hospital in Hamilton, The Hospital for Sick Children in Toronto, and the IWK Health Centre in Halifax. Plans call for expansion of the project to include additional sites in the US. Dr. Zwaigenbaum and his team leveraged the NAAR-funded pilot study into a larger grant by the CIHR, from where they received CDN\$340,709 for the Baby Sibs project.

Dr. Zwaigenbaum was also awarded with the maximum funding that NAAR offers – US\$120,000 over two years – for his collaborative project, “Investigating the Emergence of Familial Traits in Autism”.



**Based on competition years 1997 to 2003 including the total value of award over the lifetime of the award (generally one- or two-year awards). This graph includes NAAR pilot study grants (including collaborative programs) and fellowship grants.*

NAAR’s Mentor-based Fellowships

NAAR’s mentor-based fellowships provide financial support and professional guidance for young investigators interested in focusing on autism as a career. Fellowships typically provide a salary and professional support for two years. The program was established in 1998.

In 2003, NAAR budgeted US\$1M to fund pre- and post-doctoral mentor-based fellowships to attract the best and brightest young minds and to focus their talents on autism research. NAAR has recently committed nearly US\$1M to fund 13 pre- and post-doctoral mentor-based fellowships on autism research and two collaborative training programs in Canada.

NAAR's 2003 mentor-based fellowship awards include seven post-doctoral fellows and six pre-doctoral fellows. One pre-doctoral fellowship went to the Centre for Molecular Medicine & Therapeutics, a UBC-affiliated research group located at Children's & Women's Health Centre of British Columbia in Vancouver. The mentor and recipient of the funding is Canada Research Chair Elizabeth Simpson. The supported fellow is K.Y. Bibiana Wong, for her project "Mouse Models of Autism: Behaviour and Genetics."

As part of its 2003 fellowship portfolio, NAAR is collaborating with the Canadian Institute of Neurosciences, Mental Health and Addiction to co-sponsor a pair of six-year, interdisciplinary autism training programs for young Canadian investigators, known as the "Training Programs in Autism Research." NAAR will invest approximately \$200,000 annually for six years as a co-sponsor of this unique program – the first of its kind in Canada to focus on autism. NAAR's total commitment to fellowships and training programs in 2003 is US\$991,000. The program appears to have attracted the attention of an increasing number of prominent researchers interested in serving as mentors. In 2003, NAAR received 47 funding requests for fellowships, nearly twice as many requests as last year.

3.5 Canada Research Chairs

The Canada Research Chairs Program stands at the centre of a national strategy to make Canada one of the world's top five countries for research and development. In 2000, the Government of Canada allocated \$900 million to establish 2,000 research professorships (Canada Research Chairs) in universities across the country. Chairholders advance the frontiers of knowledge in their fields, not only through their own work, but also by teaching and supervising students and coordinating the work of other researchers.

Seven Canada Research Chairs have been awarded to investigators whose work is, to varying degrees, related to autism. Of particular note among these seven is Dr. Eric Fombonne, Professor of Psychiatry at McGill, who holds a Canada Research Chair in Child and Adolescent Psychiatry. Dr. Fombonne has an international recognition for his expertise in epidemiological child psychiatry, particularly in the field of autism. His research spans the interface of psychiatry, social and developmental sciences, and human genetics. It relies on epidemiological approaches to investigate childhood psychopathology in general, with a strong focus on autism and pervasive developmental disorders, and emotional disorders (in particular, childhood and adolescent onset depression).

As noted in Section 2 above, Canada Research Chairs salary award amounts are not included in funding data analyzed for this report, because of the varying degrees to which the work of these Chairs may be related to autism. (However, if a Canada Research Chair holder receives funding from one of the other sources analyzed in this report, that funding is included in the report data.)

The table on the next page summarizes CRC research foci and their relevance to autism research; further details can be found in Appendix B.

CRC-holders announced to October 2003			
Chairholder research foci relating to autism research			
Chairholder	Research Area and Location	Research Involves	Research Relevance
Jorge L. Armony	Affective Neuroscience, McGill University	Clinical research to measure how the brain detects, analyzes and responds to environmental events, especially those that signal danger.	Improved treatment of disorders such as phobias, anxiety and post-traumatic stress disorder.
Eric Fombonne	Child and Adolescent Psychiatry, McGill University	The study of psychopathology in children and adolescents using a developmental perspective.	Research will lead to a better understanding of autism and childhood/adolescent depression, and promote research into other disorders.
Michel Maziade	Genetics of Neuropsychiatric Disorders, Université Laval	Analysis of genetic material to detect linkages in susceptibility to schizophrenia and bipolar disorder.	Will aid in determining the genetic causes of severe neuropsychiatric disorders and in developing curative treatment.
François Michaud	Robotics and Mobile Intelligent Systems, Université de Sherbrooke	Mobile robotics, multi-agent and artificial intelligence with applications in health care.	Remote-controlled robots or robotic toys can help children with autism open up to their surroundings.
Douglas Munoz	Neuroscience, Queen's University, Kingston	The neural processes controlling rapid eye movements, called saccades.	Helping to diagnose and treat neurological and psychiatric disorders including Parkinson's disease, Alzheimer's disease, autism, Tourette syndrome, and Attention Deficit Hyperactivity Disorder.
Elizabeth M. Simpson	Genetics and Behaviour, University of British Columbia	Exploring the links between genetics, brain development and behaviour.	Development of new diagnostic techniques and drug therapies for specific brain disorders.
Philip D. Zelazo	Developmental Neuroscience, University of Toronto	Study of children aged two to five years to understand development of affective decision-making at behavioural, cognitive, and neurological levels of analysis.	Will lead to developing a profile that can be used to recognize children at risk of frontal lobe dysfunction, as well as possible intervention methods.

3.6 NIH (US National Institutes of Health)¹⁶

For this report, NIH databases were searched for autism-related funding to researchers at Canadian research institutions. The search showed no results for autism-related projects in Canada, based on the search parameters for this report (see Section 2.3 - Process and Methodology). However, NIH-funded PI's in the United States can sub-contract with researchers at Canadian institutions on a given project. Hence, there is a possibility of autism-related NIH

¹⁶ The NIH is an Agency under the US Department of Health and Human Services.

funding having indirectly (through the PI's institution) gone to researchers at Canadian institutions – information that is not reflected in the NIH data accessible to the MSFHR.

In recent years the NIH, whose mission it is to be “the steward of medical and behavioural research for the Nation”, has put a strong emphasis on autism research primarily through two major initiatives. While neither has an existing Canadian component, they are described below to illustrate the extent to which they reflect the increasing focus on research networking.

3.6.1 STAART Program

In May 2003, the NIH has awarded grants to support six new research centres of a major network focusing on the biomedical and behavioural aspects of autism. These centres will join two that were funded with US\$19M in 2002. The overall initiative, called STAART (Studies to Advance Autism Research and Treatment) Centers Program, responds to a need expressed in the Children's Health Act of 2000. NIH expects to spend a total of US\$65M over five years for the eight centres.

3.6.2 NICHD Collaborative Programs of Excellence in Autism (CPEA)

In 1997, the NICHD (National Institute of Child Health and Human Development; one of the 20 NIH institutes) started a five-year, US\$42M, international network of ten Collaborative Programs of Excellence in Autism (CPEA) to study autism. The network came about as a result of a congressionally mandated conference on the State of the Science in Autism, which took place in April 1995 to identify gaps in the knowledge of autism and directions for future research.

3.7 Survey Results: Research Activity in the Northwest Region

As described in Section 2.1, early in 2003 the British Columbia Ministry of Health asked the Michael Smith Foundation for Health Research for information on the scope of health research activity in the province related to Autism Spectrum Disorders. A preliminary MSFHR report was created based on extracts of funding data from CIHR and SSHRC to year end 2002. This analysis identified and analyzed awards indicating a scientific connection with ASD research, to give an overview of ASD research activity and related funding distribution across Canada.

To gain a fuller understanding of autism research in Canada, an attempt was made to gather information about relevant research activity not included in the preliminary inventory report. This includes updated CIHR and SSHRC data, and US funding data from NAAR and NIH. Also sought for this expanded inventory was data on research funded directly by government, by service-provider agencies, or otherwise undertaken outside the major peer-reviewed agency processes.

Survey #1 was circulated June 20, 2003 to six contact persons, one each in Alberta, BC, Saskatchewan, Manitoba, the Yukon and the Northwest Territories, requesting information on researchers in autism.¹⁷ A detailed summary of the information received was collated by the BC Ministry of Health and is attached (Appendix C).

¹⁷ A second survey (Survey #2) was circulated at the same time to the same six contact individuals, requesting information on autism-related databases. For details of the resulting data collection please see Section 7.

Overall, a total of six additional research projects were identified (four in BC and two in Alberta) that had not previously been included in the inventory – these have now been incorporated into this updated document (Section 3.7.1, below). Responses are summarized as follows:

MSFHR Research Survey Responses	
Responses - Research Survey #1	Jurisdiction
Funded researchers reported	British Columbia, Alberta
No additional autism research reported	Saskatchewan, Manitoba, Yukon, Northwest Territories

3.7.1 Research Project Data (Survey #1)

Initially, the survey identified a total of twelve research projects that had not been identified in the previous ASD research inventory. At the time of the survey, three of these 12 were at application stage only and not approved for funding. A further three of the funded projects had already been identified in MSFHR's expanded search of CIHR, NAAR and SSHRC funding data.

Because the survey was sent to key respondents in the Northwest region only, the net six additional projects identified are mentioned in this report but have not been incorporated into the report's analysis of funding data.

Summary of Other Projects Identified, Northwest Region	BC	AB	Total
Total funded projects	4	2	6

- ◆ **Helena Ho** of the Sunny Hill Health Centre for Children (in BC) was awarded \$39,000 in 2002 by the Woodward Foundation for her double-blind drug study, "Effects of Secretin on Children with Autism".
- ◆ **Linda C. Eaves**, also of the Sunny Hill Health Centre for Children, was awarded \$50,000 over six years for her project, "The very early identification of autism: Follow-up to age five of children identified at two years", which assessed children over several years. This project was funded by the BC Medical Services Foundation.
- ◆ **Dr. Maureen Hoskyn** of Simon Fraser University (BC) received a SSHRC two-year New Investigators Grant¹⁸ for her project, "Social development of children with Fragile-X syndrome". This project examines factors that influence social development of children with Fragile-X syndrome, as well as ways in which children with Fragile-X syndrome differ from children with autism.
- ◆ **Grace Iarocci** received a three-year pilot grant from the Human Early Learning Partnership (University of British Columbia) for a project which investigates early sensory and attentional disturbances and their relationship to social-cognitive skill deficits in young children with autism.

¹⁸ Indirect grant, administered through SFU and hence not captured in the SSHRC database of funded projects/researchers.

- ◆ **Sherry Thompson**, Director, Research Liaison, Community Strategies, Alberta Children's Services, received funding from the Alberta Children's Services Ministry for a three-stage research and evaluation program to look at Intensive Behavioural Intervention programs for children with autism.
- ◆ **W.B. Gibbard** of the Alberta Children's Hospital Foundation received a \$1,500 award for the project, "Complementary and Alternative Approaches to Diagnosis and Treatment for children with ASD: Patterns of Use."

4. Autism Research Areas

Section 3 of this report focuses on the financial and geographic distribution of ASD-related research in Canada, without detailed analysis of the distribution of research according to its topic focus. As noted in Section 2.4 above, developing definitions of terms relating to ASD research presents a challenge for analysis by topic. A further, related question lies in categorizing this research into areas with common or related themes and foci. This section discusses recent Canadian ASD-related research in terms of its distribution across topic areas.

Topics of ASD-related research projects funded in Canada span the four broad health research themes defined by the CIHR (biomedical; clinical; population health; and health services). Using the categories provided by some funding agencies, projects can be further allocated to common research areas as noted in the tables below.¹⁹ However, the functionality of this summary is limited: different funding agencies employ different definitions, reflecting the varied scope of their award support.

The data field “Research Area/Area of Research” exists both within the CIHR data and the SSHRC data. NAAR data does not contain this field. As a result, NAAR awards are included in the “not classified” category. For the autism-related projects in this report, our analysis identified a combined total of 15 research areas (plus the category “research area not specified”) in the CIHR and SSHRC data sets.²⁰

CIHR Research Areas Related to ASD
Cell Biology
Genetics
Genomics, Proteomics and Bioinformatics
Imaging
Mental Health
Molecular Biology
Nervous System
Psychosocial/ Health Behavioural Research
Vision
<i>Not Classified</i>

SSHRC Research Areas Related to ASD
Anthropology
Applied Linguistics
Behavioural Psychology
Child And Adolescent Psychology
Education; Educational Psychology
Exceptional, Special Education
Psychology

Occasionally, over the lifetime of a research project, more than one research area is involved. This is increasingly the case as ASD research follows the broader trend towards multi-disciplinary teams and networks. This most recent analysis none the less re-confirms the findings of MSFHR’s initial (2003) inventory of autism funding in Canada. The majority of

¹⁹ For details on autism research activity and funding distribution by research area, see the remainder of this section as well as Appendix A: Researchers Currently Funded by CIHR, SSHRC and NAAR by Research Area; Summary Table Principal Investigators by Research Area; and Summary Table Project Titles by Research Area.

²⁰ For example: when applying for funding from the CIHR, the applicant can choose from – but is not bound by – 36 research areas (listed in an “Areas of Research Code Table”) to assign to his/her research project. All research areas represented here are listed in that Code Table; no research areas have been created by any of the PIs funded for autism research identified in this report.

research identified to date continues to be in the biomedical area with a focus on understanding the causes of autism.

4.1 Analysis by Research Area and Jurisdiction

The following table summarizes the numbers of researchers (Principal Investigators) currently funded by CIHR, NAAR and SSHRC by location and research area. Full details are provided in Appendix A.

Canadian Principal Investigators currently funded by CIHR, NAAR and SSHRC							
Research Area	BC	AB	ON	QC	NB	NF	Total
Anthropology	1	-	-	-	-	-	1
Applied Linguistics	-	-	1	-	-	-	1
Behavioural Psychology	-	-	1	-	-	-	1
Cell Biology	-	-	-	2	-	-	2
Child And Adolescent Psychology	-	2	1	-	-	-	3
Education; Educational Psychology	-	-	-	3	-	-	3
Exceptional, Special Education	1	1	-	1	-	-	3
Genetics	1	-	3	1	1	-	6
Genomics, Proteomics, and Bioinformatics	-	-	1	-	-	-	1
Imaging	-	-	1	-	-	-	1
Mental Health	-	-	2	1	-	-	3
Molecular Biology	-	-	1	-	-	-	1
Nervous System	-	-	4	10	-	1	15
<i>Not Classified</i>	1	1	7	1	-	-	10
Psychology	-	-	2	2	-	-	4
Psychosocial/ Health Behavioural Research	-	-	3	1	-	-	4
Vision	-	-	-	1	-	-	1
Total	4	4	27	23	1	1	60

Note: As one researcher may be involved in more than one research area²¹, some researchers are double counted. This is reflected in the fact that we have a total number of 60 occurrences of researchers, in this table, out of a total number of 45 researchers in our data.

The analysis demonstrates that there is no significant clustering of researchers in any given research area in most provinces, except in Ontario and Quebec. With the small number of projects funded in all other provinces, the ability to identify areas of strength based on the data set used in this report is limited. Ontario and Quebec have a stronger representation in all research areas with some clustering of researchers working in the areas of “Nervous System” and “Genetics”, which predominantly represent biomedical research.

²¹ CIHR awards data sometimes changes over the life of the award in designated research areas, which are self-reported by the PI, or if a researcher is involved in more than one research project, each with a different research area.

4.2 Funding Amount by Research Area (CIHR, NAAR, SSHRC)

Funded autism research in Canada can be categorized according to the following research areas, listed here in descending order of amount of funding received.

Summary of funding by research areas for principal investigators currently funded by CIHR, NAAR or SSHRC		
Research Area	Funding Amount	Funding Amount: % of Total
Nervous System	\$9,839,892	50.5%
Genetics	\$3,815,400	19.6%
Psychosocial/ Health Behavioural Research	\$1,999,127	10.3%
<i>Not Classified (see note below)</i>	\$1,303,334	6.7%
Mental Health	\$1,211,359	6.2%
Molecular Biology	\$321,159	1.6%
Exceptional, Special Education	\$198,700	1.0%
Psychology	\$123,500	0.6%
Education; Educational Psychology	\$115,633	0.6%
Child And Adolescent Psychology	\$114,040	0.6%
Cell Biology	\$114,000	0.6%
Imaging	\$102,000	0.5%
Applied Linguistics	\$75,056	0.4%
Vision	\$60,449	0.3%
Behavioural Psychology	\$46,682	0.2%
Genomics, Proteomics, and Bioinformatics	\$45,475	0.2%
Anthropology	\$17,500	0.1%
Total	\$19,503,306	100.0%

Note: The “Not Classified” category includes all NAAR awards, totalling \$765,773, and six CIHR awards, totalling \$537,561. Among the latter are Peter Szatmari’s “The genetic epidemiology of autism” (McMaster University) and Connie Varnhagen’s “Strategies for critically appraising children’s health web resources” (University of Alberta), which together account for over 70% of the “Not Classified” dollars. The “Nervous System” category includes two Training Programs in autism research: Jeanette Holden’s (Queen’s University) “Transdisciplinary inter-institute training program in autism spectrum disorders”, and Eric Fombonne’s (McGill) “Training Program in Autism Research”; each funded with \$613,400 for a total of \$1,236,800.

4.2.1 CIHR

As a national health research funding agency, the CIHR classifies research in four themes:

1. Biomedical;
2. Clinical;
3. Social/Cultural/Environmental/Population Health; and
4. Health Systems/Services.

The CIHR requests that investigators applying for funding assign themes to their research projects. It is important to note that, as a result of the multi- and interdisciplinary nature of certain research projects, some researchers opt not to classify their research into the four theme categories.

The majority of CIHR-funded autism research identified in CIHR data with a specified theme is assigned to the biomedical theme, with the second largest number of projects involving clinical research. Population Health related research is funded to a lesser degree and the data shows no funding for Health Services projects with an autism focus during the analysis period.

Tables below illustrate the distribution of CIHR funding across the CIHR-defined four themes as well as its distribution by research area. Projects in the areas of the nervous system, genetics, psychosocial/health behavioural research and mental health received most funding:

CIHR Award Amounts Summarized by Research Area		
Research Area	Funding Amount	Funding Amount: % of Total
Nervous System	\$9,839,892	54.5%
Genetics	\$3,815,400	21.1%
Psychosocial/ Health Behavioural Research	\$1,999,127	11.1%
Mental Health	\$1,211,359	6.7%
<i>Not Classified</i>	\$537,561	3.0%
Molecular Biology	\$321,159	1.8%
Cell Biology	\$114,000	0.6%
Imaging	\$102,000	0.6%
Vision	\$60,449	0.3%
Genomics, Proteomics, and Bioinformatics	\$45,475	0.3%
Total	\$18,046,422	100.0%

CIHR autism-related funding by Primary Theme and Research Area			
Primary Theme	Research Area	Funding Amount	Percent of Total
Social/ Cultural/ Environmental/ Population Health	Psychosocial/ Health Behavioural Research	\$411,402	
	<i>Not Classified</i>	\$274,500	
Social/ Cultural/ Environmental/ Population Health Total		\$685,902	3.8%

CIHR autism-related funding by Primary Theme and Research Area			
Primary Theme	Research Area	Funding Amount	Percent of Total
Biomedical	Genetics	\$3,286,050	
	Nervous System	\$2,162,523	
	Psychosocial/ Health Behavioural Research	\$1,500,000	
	Mental Health	\$731,655	
	Molecular Biology	\$321,159	
	Cell Biology	\$114,000	
	Genomics, Proteomics, and Bioinformatics	\$45,475	
	<i>Not Classified</i>	\$15,000	
Biomedical Total		\$8,175,862	45.3%
Clinical	Nervous System	\$5,076,089	
	Mental Health	\$402,209	
	Imaging	\$102,000	
	Psychosocial/ Health Behavioural Research	\$87,725	
Clinical Total		\$5,668,023	31.4%
Not Specified	Nervous System	\$2,601,280	
	Genetics	\$529,350	
	<i>Not Classified</i>	\$248,061	
	Mental Health	\$77,495	
	Vision	\$60,449	
Not Specified Total		\$3,516,635	19.5%
Total		\$18,046,422	100.0%

4.2.2 SSHRC

Because of the relatively narrower scope of projects funded by SSHRC, the table below illustrates a less broad-ranging variety of research areas for which awards were made during the analysis period. Based on the total dollar value of awards, more than half of SSHRC funding during this period involved a psychology-related research area.

SSHRC Award Amounts by Research Area		
Research Area	Funding Amount	Funding Amount: % of Total
Exceptional, Special Education	\$198,700	28.8%
Psychology	\$123,500	17.9%
Education; Educational Psychology	\$115,633	16.7%
Child And Adolescent Psychology	\$114,040	16.5%
Applied Linguistics	\$75,056	10.9%
Behavioural Psychology	\$46,682	6.8%
Anthropology	\$17,500	2.5%
Total	\$691,111	100.0%

4.2.3 NAAR

As noted above, NAAR awards are not categorized by theme or research area. Our analysis indicates that, if such categorization was applied, the majority of NAAR-funded autism research would be assigned to the biomedical or clinical themes. The following table lists the NAAR awards and their funding amounts.

NAAR Awards to Canadian Principal Investigators: Award Amounts by Project Title		
Project Title	Funding Amount	Funding Amount: % of Total
Investigating the Emergence of Familial Traits in Autism	\$171,384	22.4%
MEG Correlates of Linguistic Processing at and Below the Word Level in Autism	\$171,267	22.4%
Identifying Early Markers of Autism: A Longitudinal Study of Infant Siblings	\$150,792	19.7%
Investigating Serotonin Receptor Function and Brain Structure as Potential Endophenotypes of Autism.	\$134,769	17.6%
Cerebellar and Cerebral Local Field Potential Oscillations; Relation with Attention and Movement	\$69,561	9.1%
Mouse Models of Autism: Behaviour and Genetics	\$68,000	8.9%
Total	\$765,773	100.0%

5. Collaboration and Networking in Canadian Autism Research

Until recently, most academic research tended to be conducted in what have been referred to as silos – organizationally distinct buildings, institutes or centres – with teams of people managed in traditional hierarchical teams. Research encompassed a wide array of activity, but was grounded in the concept of people sharing a building, a physical space, or an employment/faculty affiliation, in order to share and nurture exploration and new ideas. This way of organizing and conducting research has frequently resulted in duplication of effort, variations in practice and outcomes, insufficient critical mass to conduct meaningful, evidence-based research and sometimes, results that cannot be generalized. Furthermore, the location of these centres within hospitals and universities tended to isolate researchers from contact with policy makers and, sometimes, service providers and other stakeholders.

Due to the advent of new technologies and changes in how research funding is allocated over the last decade, there has been a shift in how research is conducted, with a greater focus on interdisciplinarity and networking. A network is a combination or system of lines or channels, a group of nodes (or stations) connected in such a way that they are linked, becoming a joint entity. Whatever their location or technological structure, this report defines networks as “interconnected people sharing a common professional focus and working together to pursue common goals”. As with other research areas, ASD-related health research is beginning to benefit from a networking approach.

Arguably the most important autism research underway today, both in Canada and abroad, is being undertaken by groups of investigators working in multi-disciplinary teams that span jurisdictions and institutions. By linking leading researchers across provinces and research institutes, these consortia have achieved the critical mass necessary to undertake studies of significant scope and capacity. At the same time, their activity contributes to reduced duplication of effort, enhanced use of resources and more effective knowledge translation across traditional stakeholder silos.

As one leading researcher pointed out to MSFHR staff in a recent conversation: “An added benefit is that more meaningful data is generated from looking at larger populations of ASD individuals and families using the same strategies in a standardized and consistent fashion. This is critical in reducing the vast heterogeneity and complexity of autism spectrum disorders and facilitates an approach where phenotypic sub-group analysis can be performed for phenotype-genotype correlation, thus allowing us to follow the analogy of finding the needles in several smaller haystacks, rather than one overwhelming one.”

Two such networks are of particular note with respect to the Canadian ASD research effort: the Autism Spectrum Disorders - Canadian American Research Consortium (ASD-CARC), and the Canadian Autism Intervention Research Network (CAIRN).

5.1 ASD-CARC

The ASD-CARC team is a group of more than 60 researchers, clinicians, and parents across Canada and the US who have come together to form a multidisciplinary consortium headed by Jeanette Holden of Queen's University. According to the ASD-CARC website, using their complementary expertise, members of the research team hope to:

- ◆ gain a better understanding of the biological basis of autism spectrum disorders;
- ◆ determine the very earliest of signs of ASD during infancy;
- ◆ identify genes important in determining risk for ASD; and
- ◆ develop methods for identifying individuals at risk for ASD during infancy so that treatments can be introduced even earlier, optimizing outcomes for children with ASD.

ASD-CARC participants are located across Canada and into the US, with regional teams in British Columbia, Alberta, Manitoba, Ontario, Nova Scotia, Prince Edward Island, New York, Massachusetts and Kansas. ASD-CARC also has several cross-regional teams, including one each in biochemical phenotyping, dysmorphology, genetics, and epidemiology, all of which have representation by a number of participants from BC.

ASD-CARC has an executive committee, with members from BC, Manitoba, and Ontario; a finance committee, with members from BC, Manitoba, and Ontario; and a management committee, with members from each of the regional teams and special projects. There is an annual meeting of ASD-CARC members, where progress is described and directions for research in the coming year are decided. In addition, ASD-CARC has a Newsletter which is disseminated to research participants and at various conferences and meetings on autism.

ASD-CARC was established on the premise that interdisciplinary research is essential for understanding the complexity of ASDs and that team members are “partners” sharing the data and working together to undertake research that will result in a better understanding of the causes and pathogenesis of ASD, as well as the effects of treatment of persons with ASD. ASD-CARC also engages in research across the ages – not only of children with ASD, but of adolescents and adults. In addition, projects are developing that address the needs and concerns of caregivers throughout the lifespan. To foster the development of young investigators in the field of autism research, members have obtained a CIHR Strategic Training Grant.²² Trainees from different parts of Canada are required to have mentors in at least two disciplines and to carry out two methodologically distinct research projects. Cross-institutional training is encouraged and supported, with one student going to Vancouver from Queen’s University to learn specific laboratory methods.

5.1.1 ASD-CARC Funding

ASD-CARC receives major funding from CIHR, through the Interdisciplinary Health Research Team (IHRT) program. IHRTs are interdisciplinary, multi-centre collaborations between at least two of the four themes of health research, with an emphasis on research translation between the sectors, and a focus on an important health problem.

Based on our funding analysis, the \$4.4M IHRT grant to ASD-CARC is the single largest current research study in autism currently underway in Canada. The project is titled “Unravelling the mystery of autism: From genotyping and phenotyping to prospective identification and prevention”. The grant is under the supervision of Jeanette Holden²³ (Professor, Department of Psychiatry, Faculty of Health Sciences and Department of Physiology, Queen’s University, and

²² Suzanne Lewis (see Section 3.2.1, CIHR Autism Projects)

²³ Jeanette Holden is previously mentioned in Section 3.2.1.

Director, Cytogenetics and DNA Research Laboratory, Ongwanada, Kingston, ON). Dr. Holden's current research is in the areas of Genetics of Autism Spectrum Disorders; Genetics of Developmental Disabilities (Fragile X syndrome, X-linked mental retardation syndromes); and Genetics of Psychiatric and Behavioural Disorders (Bipolar disorder, Depression, Schizophrenia, and ADHD).

Other funding for the consortium comes from the Ontario Mental Health Foundation. Team leader Dr. Holden received \$65,000 in 2002/03 for the project, "Identification and Characterization of Genes Involved in the Etiology of Autism Spectrum Disorders."

5.1.2 ASD-CARC Projects and Teams

ASD-CARC's research work is undertaken in six major projects: (1) research registry; (2) clinical and behavioural phenotyping; (3) genetics, including four sub-projects; (4) a prospective team; (5) a parent team; and (6) a team focused on epidemiology of Autism Spectrum Disorders in Canada.

Following is a brief description of these teams, as well as an overview of the teams for the western provinces. Complete descriptions including team members can be found in Appendix F.

Project Teams

1. Research Registry

By joining the Research Registry, families with a single or multiple cases of ASD can participate in various research projects carried out by members of the ASD-CARC. Some of these research projects are on-line (internet-based), whereas others involve a variety of laboratory procedures.

Project Leaders: Jeanette J.A. Holden, PhD and Nathalie Garcin, PhD

2. Clinical & Behavioural Phenotyping

To discover the subtle behavioural and clinical differences among individuals with ASD – and their family members – several different research projects have been and are being designed to assess different characteristics of the ASD "phenotype". This team of behavioural, developmental, and clinical psychologists, paediatricians, neuroscientists, neurophysiologists, and biochemists have come together to develop questionnaires and laboratory procedures to assess different aspects of ASD, with the objective of defining "ASD subgroups" that share specific characteristics. Such sub-grouping will ultimately lead to the development of specific diagnostic tests and hopefully specific treatments for individual subgroups of ASD.

Project Leaders: Jeanette J.A. Holden, PhD, Ira Cohen, PhD, and Nathalie Garcin, PhD

3. Genetics

In order to identify genes important in the etiology of ASDs, the team is combining direct studies of genes with the study of chromosome abnormalities and morphological features to identify "ASD subgroups". Identifying the genes involved in susceptibility to ASD may lead to novel treatments. This area includes four genetics projects: Molecular Genetics, Cytogenetics, Dymorphology and Statistical Genetics.

Project Leader: Jeanette J.A. Holden, PhD and Suzanne Lewis, MD

3a) Molecular Genetics

This laboratory characterizes a variety of genes to identify those involved in susceptibility to ASD, using modern molecular genetic methods.

Project Leader: Jeanette J.A. Holden, PhD

3b) Cytogenetics

A variety of chromosome abnormalities have been associated with ASD. Families with two or more affected children, as well as families where there appear to be subtle clinical abnormalities, are being assessed to determine whether there are very small chromosome abnormalities. Such findings can pinpoint the location of genes that may be involved in ASD.

Project Leaders: Ikuko Teshima, PhD and Evica Rajcan-Separovic, PhD

3c) Dysmorphology

Project Leader: Cynthia Forster-Gibson, MD, PhD

3d) Statistical Genetics

Project Leaders: Fabio Macciardi, MD, PhD, and Xudong Liu, PhD

4. Prospective Study of ASD

There is growing evidence that early intervention is effective in reducing or, in some cases, completely eliminating symptoms associated with ASD. The team's goal is to identify autistic precursors during infancy and intervene to prevent the full expression and diagnosis of ASD. The team will monitor very early development of autistic symptoms in 400 at-risk infants who have a sibling with ASD.

Project Leaders: Maurice Feldman, PhD; Jeanette J.A. Holden, PhD

5. Parent Advisory Group

The Parent Advisory Group currently has 15 parent members as well as one individual with an ASD. They meet every three to four months in Ottawa and have a private online forum for more frequent communications. They review questionnaires and new projects on a regular basis, and have developed a questionnaire for families that is part of the Phenotyping Study.

Team Leader: Anita Acheson, BSc

6. Epidemiology of ASDs in Canada

The National Epidemiologic Database for the Study of Autism in Canada (NEDSAC) is collecting anonymous information on Canadian children who have been diagnosed with or who are suspected of having an autism spectrum disorder (ASD). These data will be used to estimate the prevalence and incidence of ASDs among children in Canada, and to examine geographic variations and changes over time. Current regions being studied are: BC, Yukon, Southern Alberta (around Calgary), Manitoba, southeastern Ontario, PEI, and Newfoundland and Labrador. NEDSAC is hoping to engage all regions of Canada in this study.

Project Director/Regional Team Leader (Ontario): H el ene Ouellette-Kuntz, MSc, RN

Regional Teams

Listed below are the teams in the Northwest Region; for additional regional teams please refer to Appendix F, ASD-CARC Member List (Canada).

British Columbia (Vancouver) Regional Team:

The BC Interdisciplinary Health Research Team (IHRT) Autism Research Team (ASD-RT) is well-positioned to contribute broadly to the spectrum of projects and discoveries related to discerning the genetics of Autism Spectrum Disorder, and in this process, better understanding its incidence, diagnosis, management and prevention. The clinical members of the team actively contribute to a broad spectrum of clinical and academic programs funded by the BC Provincial Health Authority, and, in the course of that, provide highly specialized, tertiary care for the Children and Families across British Columbia. (For more detailed information on the BC Team members, see Appendix F.) Suzanne Lewis, who leads the regional team, has recently received significant autism-related funding in the form of a CIHR Clinical Investigatorship award (see Section 3.2.1).

Regional Leader: Suzanne Lewis, MD, FRCPC, FCCMG (Clinical Phenotyping, Genetics, Epidemiology, Prospective Study)

BC Member on the Biochemical Phenotyping cross-regional team: Hilary Vallance, MD

BC Member on the Dysmorphology cross-regional team: Suzanne Lewis, MD

BC Member on NEDSAC cross-regional team: Suzanne Lewis, MD

Alberta (Calgary) Regional Team

Regional Team Co-Leaders: Francois Bernier, MD, FRCPC, FCCMG (Epidemiology; Dysmorphology; Genetics); Deborah Dewey, PhD (Epidemiology; Clinical & Behavioural Phenotyping)

Manitoba (Winnipeg) Regional Team

The Manitoba regional team consists of researchers from St. Amant Centre, Children's Hospital of Winnipeg, and University of Manitoba. The team also benefits from the active participation of community partners such as Autism Society Manitoba; Manitoba Families for Effective Autism Treatment; Child Development Clinic; Health Sciences Centre; Child and Adolescent Psychiatry; and Children's Special Services.

Regional Team Co-Leaders: Dickie C.T. Yu, PhD, CPsych (Epidemiology; Clinical and Behavioural Phenotyping; Prospective Study); Albert E. Chudley, MD, FRCP(C), FCCMG (Genetics; Dysmorphology)

5.2 CAIRN (Canadian Autism Intervention Research Network)

CAIRN is a national network of stakeholders interested in early intervention in autism. CAIRN brings together scientists, parents, clinicians, and policy makers dedicated to the provision of high quality, evidenced-based, early intervention services for children with autism. The members of CAIRN come from across Canada and include parents of children with ASD, policy makers, researchers and clinical professionals from several different disciplines (psychiatry, paediatrics, psychology, education, health policy, speech and language pathology, and early childhood education). CAIRN's mission is:

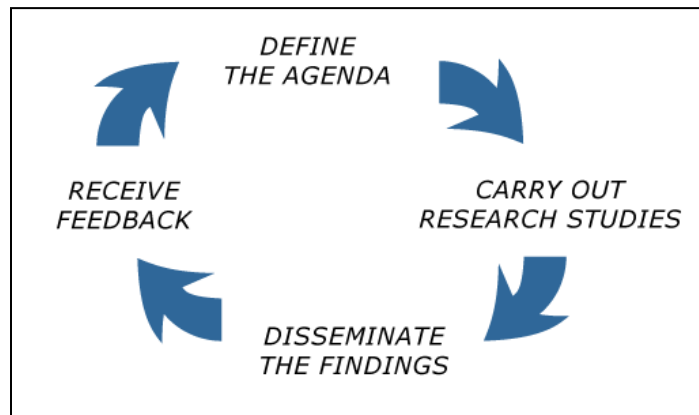
- ◆ to develop a national research agenda in intervention and early identification in autism spectrum disorders;
- ◆ to promote research into intervention, early identification, and diagnosis;
- ◆ to advocate for better intervention services across Canada for children with autism spectrum disorders that incorporate practices from the best available evidence;
- ◆ to press for better training for physicians and front-line clinicians, and for education of the general public about autism spectrum disorders;
- ◆ to research the best intervention trial designs, promote education about randomized controlled trials, and encourage the use of meaningful and rigorously measured outcomes in interventions research;
- ◆ to investigate and adopt the best methods for the dissemination of CAIRN's findings; and
- ◆ to provide an evidence-based website for use by researchers, professionals, parents, policy makers, and laypersons.

5.2.1 CAIRN Activity and Focus

According to its website, CAIRN carries out its mission by:

- ◆ sustaining the collaboration CAIRN has forged by continual free exchange of information and sharing of expertise, motivated by the best interests of affected children;
- ◆ generating and disseminating evidence-based information on autism spectrum disorders by using a sensitive search strategy to identify pertinent research studies and posting the results on the CAIRN Web site for use by all CAIRN members and the general public;
- ◆ eliciting feedback from the community as a means of generating new questions to be addressed in a scientific manner; and
- ◆ developing research proposals for submission to granting agencies, thereby reinforcing the "Research Iterative Loop" that provides structure for CAIRN's endeavours. CAIRN defines this "Research Iterative Loop" as a repeating cycle of defining the research agenda; carrying out the research; disseminating the findings; receiving feedback; and refining (defining) the research agenda.

The “Research Iterative Loop”, from the CAIRN website



A 2000 CAIRN workshop had the objective of broadening the network’s base to attract other researchers and stakeholders from across Canada, to assist in further developing a national ASD research agenda. Three major outcomes of that workshop have become the basis of CAIRN’s strategic direction:

1. A consortium of researchers has been established that will submit proposals to the Canadian Institutes of Health Research on early intervention in autism;
2. A partnership of researchers, parents, policy makers and front-line clinicians from across Canada has evolved that is dedicated to the provision of high quality early intervention services for children with autism; and
3. Priorities for immediate action have been selected, including:
 - A. advocating for more research into early intervention, specifically measurement, early identification, the design of intervention trials and best methods of dissemination;
 - B. promoting better education and training for physicians, front-line clinicians and the general public about autism/PDD (Pervasive Developmental Disorders); and
 - C. demanding better early intervention services across Canada for children with autism/PDD that incorporate practices based on the best available evidence.

CAIRN is led by a national steering committee with the following members (October 2003):

- | | |
|--|--|
| ◆ Dr. Susan Bryson, Dalhousie University | ◆ Dr. Isabel Smith, Dalhousie University |
| ◆ Dr. Elizabeth Starr, University of Windsor | ◆ Dr. Joanne Volden, University of Alberta |
| ◆ Dr. Eric Fombonne, McGill University | ◆ Dr. Pat Mirenda, University of British Columbia |
| ◆ Dr. Peter Szatmari, McMaster University | ◆ Dr. Lonnie Zwaigenbaum, McMaster University |
| ◆ Dr. Paul McDonnell, University of New Brunswick | ◆ Dr. Sheila Laredo, Sunnybrook & Women’s College Health Sciences Centre |
| ◆ Ms. Sherry Thompson, Alberta Children’s Services | |

5.2.2 Project GEARR

CAIRN's "Project GEARR" (Generating Early Autism Research and Resources) is primarily funded by the Lawson Foundation.²⁴ The total commitment for the project is \$1.2M. So far, two instalments have been made: \$392,000 in 2002; and \$420,000 in 2003. The funding went to the organization that formally leads Project GEARR: the Canadian Centre for Studies of Children at Risk, now the Offord Centre for Child Studies²⁵ at McMaster University. Over three years the grant will support the development of a research model within the context of autism in order to:

- ◆ develop a research agenda;
- ◆ carry out projects to evaluate the effectiveness of early identification and intervention; and
- ◆ share the evidence with the community.

Project GEARR is a unique comprehensive national initiative to improve the long-term outcomes for young children with autism. Through CAIRN, the project brings together scientists, parents, clinicians, and policy makers dedicated to the provision of high quality, evidenced-based, early intervention services for children with autism.

The grant supports the development of a research model within the context of autism to develop a research agenda, carry out projects to evaluate the effectiveness of early identification and intervention, and share the evidence with the community (the "Research Iterative Loop"). On the basis of the community's feedback, modifications to the research agenda in early intervention can take place so that the research loop comes full circle.

1. Agenda

The first component of the Research Iterative Loop within Project GEARR is the development of a national research agenda on early identification and treatment in autism based on input from all of the major autism stakeholder groups, using CAIRN as the means of communication. The research agenda states the important questions in the field and how research based on those questions is to be carried out. CAIRN members, parents and practitioners from a variety of disciplines, decided that the focus would be on early intervention; that is, both improved

²⁴ The Lawson Foundation is a Canadian philanthropic organization established as an extension of The Honourable Ray Lawson's personal philanthropy. Based in London, Ontario, it was incorporated in 1956 to serve the people of Ontario, especially the communities of London and Oakville. The mission of the Foundation is to enrich the quality of life in Canada through grants to registered charitable organizations. The Foundation's vision is to become a respected source of support for sustainable community-based programs that positively influence the quality of life for Canadian families. Since the Foundation's inception in 1956, it has donated over \$43M to charities across Canada.

²⁵ The Offord Centre for Child Studies is affiliated with the Hamilton Health Sciences Corporation and the Faculty of Health Sciences at McMaster University, and is governed by a volunteer board of directors. The vision of the Offord Centre (formerly the Canadian Centre for Studies of Children at Risk) is to improve quality of life and opportunities of children by optimizing the emotional and behavioural well-being of children. The Centre describes its mission as to lead the search for solutions that enhance the emotional, social and cognitive development of children. This is accomplished by leading academic and scientific research that influences programs, policies, and solutions to improve children's life opportunities; and by forging partnerships with key stakeholders and policy-makers.

diagnostic methods and effective treatments. Agenda development work is furthered annually by a national meeting of network members.

2. Research

The second component of the loop is actually carrying out the research. Project GEARR's research includes the pilot study, "Early Identification Pilot for 12- to 24-Month-Old Infants." This study looks at whether it is possible to identify infants and toddlers who are showing signs that they may go on to develop autism, and to see if intervention can alter their development. There are also two early intervention pilot projects that focus on identification and treatment of children with autism.

3. Dissemination

An important part of Project GEARR is the dissemination strategy, the next component of the loop, of which the CAIRN website (<http://www.cairn-site.com>) is a part. CAIRN's conference calls and annual research meetings also serve to spread the word about what research results are being reported and what they mean to the everyday lives of children with autism spectrum disorders and their families.

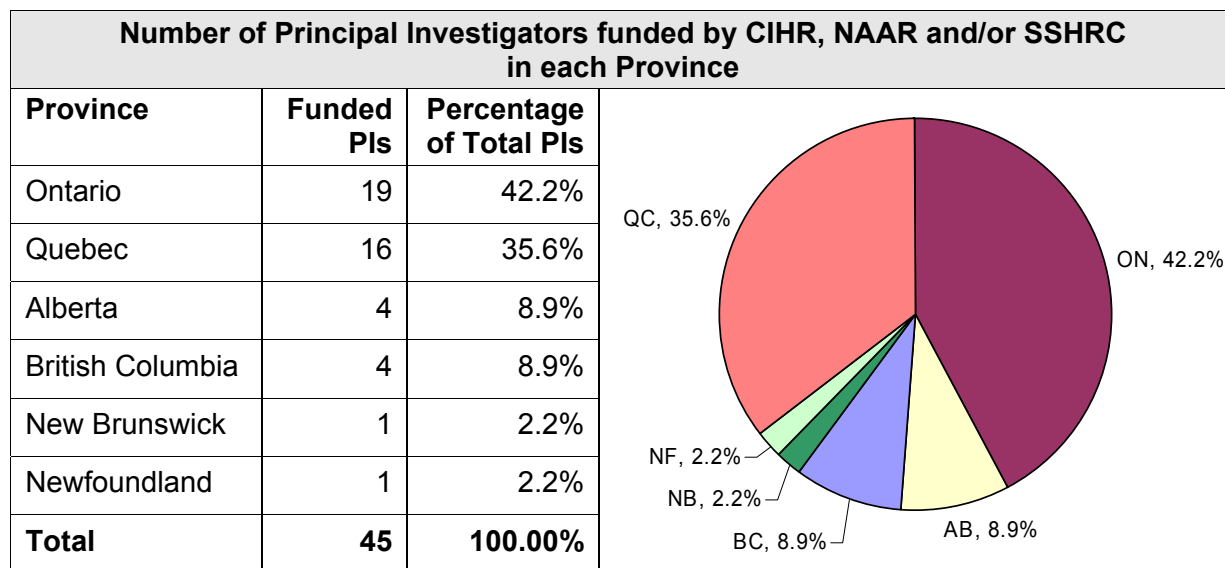
4. Feedback

CAIRN researchers seek feedback in order to find out if the studies they have conducted answered questions that they posed about early intervention. The feedback received during CAIRN annual research meetings is important to the process of re-looking at the research agenda and determining if the questions posed and the methods used have had the desired results: improved identification and treatment of children with autism spectrum disorders.

6. Locations for Autism Research

One of the underlying concerns expressed by Northwestern policy makers with respect to many health research-related issues is the question of critical mass: in a nation whose priorities often seem to be dominated by the most highly populated provinces, how can our regions achieve the critical mass necessary to undertake studies of significant scope and capacity?

The table below illustrates the extent to which, at the present time, health research activity for ASD in Canada is undertaken primarily in projects led by investigators working in the two most populous provinces, Ontario and Quebec:



This revised survey of CIHR, SSHRC, and NAAR-funded projects indicates that 45 PI's, 13 Co-PI's and seven Canada Research Chairs²⁶ have a primary research interest in autism and related pervasive developmental disorders.²⁷ Analysis indicates the following characteristics of this group:

- ◆ Because the basis for this inventory is an analysis of CIHR, SSHRC, and NAAR funding data (as well as a listing of membership/participant lists of important autism groups), the majority of the researchers mentioned in this report are researchers beyond the trainee level. Individuals planning or just beginning a career in this field, or working in the research programs of more senior investigators, are likely under-represented in our estimate.
- ◆ The majority of autism researchers identified are working in Ontario and Quebec. British Columbia has one autism researcher directly supported by the CIHR; two supported by SSHRC; and one by NAAR. In comparison, Ontario is home to 19 researchers in total, while Quebec has 16.

²⁶ Of the seven Canada Research Chairs, three of these are also receive CIHR, SSHRC, or NAAR funding and hence are also represented in our funding data.

²⁷ As described in Section 3.7 above, six additional Western Canadian-based research projects have also been identified (four in BC and two in Alberta); these are relatively modestly funded projects and due to lack of comparative data from other jurisdictions, are not included in this section's analysis.

- ◆ Three of the four BC autism researchers identified in the CIHR, SSHRC and NAAR data are affiliated with the University of British Columbia. Their respective departments and faculties within UBC include the Department of Medical Genetics (Faculty of Medicine) and the Department of Educational and Counselling Psychology and Special Education (Faculty of Education). Other affiliations include the Children's & Women's Health Centre of British Columbia; the Human Early Learning Partnership (within the Faculty of Graduate Studies), the BC Research Institute for Children's & Women's Health and its affiliated genetics research unit, the Centre for Molecular Medicine and Therapeutics. One researcher (Tamara Kulusic) is affiliated with Simon Fraser University.
- ◆ In Alberta, all researchers are at the University of Alberta. For more information on autism research in western Canada, see Section 6.1.

The following table summarizes funded autism researchers according to the largest award amounts each holds as a principal investigator. It is important to note that *the amount of funding held is not presented as a measure of research significance*. Depending on the research area and theme, projects tend to be funded with varying dollar amounts. For example, biomedical research that involves laboratories and technology often receives larger awards than research in other areas, and networks/training centres generally receive larger awards than individual operating grants.

Of note is the distribution of funding across provinces. All of the researchers whose total national grant funding exceeds \$1M are from Ontario and Quebec. In the \$250,000 to \$999,999 range, only one is in BC and one in Alberta.

Three of the CIHR, SSHRC and NAAR funded researchers are also Canada Research Chairs. Other Canada Research Chairs who have autism research relevance but did not obtain recent funding from the CIHR, SSHRC or NAAR are: Jorge Armony, François Michaud, Elizabeth Simpson, and Philip D. Zelazo. (See Section 3.5 - Canada Research Chairs, and Appendix B).

Principal Investigators by Province and Funding Amount ²⁸			
Province	Over \$1M	\$250,000 to \$999,999	Up to \$249,999
British Columbia	(none)	Lewis, M.E. Suzanne	Kulusic, Tamara Smith, Veronica Wong, K.Y. Bibiana
Alberta	(none)	Varnhagen, Connie K	Brown-Godsave, Deborah Pencer, Alissa Volden, Joanne C.
Saskatchewan	(none)	(none)	(none)
Manitoba	(none)	(none)	(none)
New Brunswick	(none)	Clark, Denise V	(none)
Newfoundland	(none)	(none)	Mclean, John H
Nova Scotia	(none)	(none)	(none)
PEI	(none)	(none)	(none)
<i>Please see next page for balance of table (Ontario and Quebec data)</i>			

²⁸ Based on figures from the available CIHR, SSHRC and NAAR funding data.

Principal Investigators by Province and Funding Amount²⁸			
Province	Over \$1M	\$250,000 to \$999,999	Up to \$249,999
Ontario	Cordes, Sabine P Holden, Jeanette J Szatmari, Peter Scherer, Stephen W	Munoz, Douglas P* O'Neill, Daniela K Zwaigenbaum, Lonnie	Astington, Janet Bryson, Susan E De Villiers, Jessica Feldman, Maurice A Goldberg, Jeremy King, Gillian A Konstantareas, Mary Oram, Janis E Penn, Helen Roberts, Timothy Spadafora, Alison
Quebec	Maziade, Michel*	Barker, Philip A Carmant, Lionel Fombonne, Eric* Mottron, Laurent Rouleau, Guy A	Godbout, Roger Bertone, Armando Bolduc, Christianne Burack, Jacob Fecteau, Shirley Flanagan, Tara Grivas, Tara Joseph, Shari Lamarre, Yves Limoges, Elyse
<i>Please see previous page for balance of table (Western and Atlantic provinces data)</i>			

* also a Canada Research Chair.

The table below illustrates the distribution of the country's population. It suggests that a lack of Northwestern ASD investigator capacity may in part be addressed by taking a regional view (i.e., as opposed to investing in efforts to achieve critical mass within a given single province or territory). As a collaborative region, the Northwest represents more than 30 percent of the current national population, a critical mass offering the same benefits and opportunities as the research funding leaders in Quebec (23.7% of the population) and Ontario (38.7% of the population). (Data source: Statistics Canada, CANSIM, table 051-0001.)

Population Data for Canada and Provinces	Population July 1, 2003	Share
Canada	31,629,700	100.00%
Subtotal, Atlantic Canada	2,344,000	7.41%
Manitoba	1,162,800	3.68%
Saskatchewan	994,800	3.15%
Alberta	3,153,700	9.97%
British Columbia	4,146,600	13.11%
Yukon	31,100	0.10%
Northwest Territories	41,900	0.13%
Nunavut	29,400	0.09%
Subtotal, Northwest Region	9,560,300	30.23%
Quebec	7,487,200	23.67%
Ontario	12,238,300	38.69%

6.1 Collaboration in Canadian Autism Research

6.1.1 International Collaboration

The need to collaborate and pool resources in autism research appears to become recognized as networks emerge and collaboration between researchers increases. For example, both NAAR and the CIHR have engaged in a joint project that involves researchers across North America. The two cross-national projects underway are the jointly CIHR- and NAAR-funded “Training Program in Autism Research” (PI: Eric Fombonne), and the aforementioned Baby Sibs Study, which was originally funded by NAAR and has since also received funding from the CIHR.

6.1.2 Research Collaboration through Networks

The two existing Canadian ASD research networks provide a significant opportunity for collaboration and information-sharing amongst leading investigators. Eight researchers (13 percent) of all researchers identified in our analysis of CIHR, SSHRC and NAAR funding data (including Co-PI’s) are members of CAIRN. Fifteen researchers (25 percent) are affiliated with ASD-CARC. In total therefore, 38 percent are linked to either CAIRN or ASD-CARC. However, the majority of researchers has no affiliation with either group and there are no researchers in our data who are involved with both groups. This comparison suggests that, even in cases where researchers do come together to form network-like organizations, there appears to be a lack of integration between researchers primarily involved in biomedical research (ASD-CARC) and researchers focusing predominantly on intervention aspects (CAIRN) of autism research.

Network association of CIHR-, SSHRC- and NAAR-funded researchers		
	CAIRN	ASD-CARC
Principal Investigators	Bryson, Susan E	Feldman, Maurice A
	Burack, Jacob	Holden, Jeanette J
	Fombonne, Eric	Lewis, M.E. Suzanne
	Roberts, Wendy	Munoz, Douglas P
	Szatmari, Peter	Simpson, Elizabeth
	Volden, Joanne C.	Wong, K.Y. Bibiana
	Zwaigenbaum, Lonnie	
Co-PIs	Perry, Adrienne M	Bebko, James M
		Chudley, Albert E
		Forster-Gibson, Cynthia J
		Macciardi, Fabio M
		Minnes, Patricia M
		Munhall, Kevin G
		Rajcan-Separovic, Evica
		Vallance, Hilary D
		Yu, Dickie C

For details see Appendices E and F.

6.1.3 Autism Research at Canadian Universities

In Canada, a few universities have emerged as important centres for autism research, based on the funding identified in this analysis. Queen's University and McMaster University, both in Ontario, have the greatest number of highly funded autism researchers at a single institution. The table on page 42 illustrates the Canadian research institutions at which the CIHR-, SSHRC- and NAAR-funded investigators in our analysis are located.

6.1.3.1 Queen's University

At Queen's University in Kingston, Ontario, Jeanette Holden, currently the most heavily funded autism researcher in Canada and head of ASD-CARC, focuses her research on the Genetics of Autism Spectrum Disorders. For details of ASD-CARC research see Section 5.1.2).

6.1.3.2 McMaster University

There is a strong group of autism researchers at McMaster University in Hamilton, Ontario, under the direction of Peter Szatmari, Professor in the Division of Child Psychiatry, Department of Psychiatry and Behavioural Neurosciences, Faculty of Health Sciences, and an associate member of the Department of Clinical Epidemiology and Biostatistics.

Dr. Szatmari's investigative interests fall broadly into areas of psychiatric and genetic epidemiology, specifically: (1) preschool children with autism and other forms of pervasive developmental disorders (development of these children and factors associated with good outcome); and (2) genetic etiology of autism (studying families with two autistic children and doing a linkage study to map susceptibility genes).

Peter Szatmari maintains a website called "Dr. Szatmari's Autism/PDD Research Page" at <http://www-fhs.mcmaster.ca/cscr/autism/>. He is also on the Steering Committee of CAIRN (along with other prominent autism researchers Lonnie Zwaigenbaum, Susan Bryson and Eric Fombonne).

Dr. Szatmari's group is presently conducting four separate studies of autism/PDD. The first two of those studies are under his direct supervision:

- ◆ The first, the "Genetic Study" (Co-Investigators: Susan Bryson, Michael Boyle), is an investigation of the genetic factors that may cause autism/PDD. The team is presently seeking volunteer families with two or more children with autism/PDD to participate in this study.
- ◆ The second study is a long-term "Follow-up Study" of high-functioning PDD children. The objectives of this study are to describe the outcome of PDD children over time and to identify variables that predict good outcome. They are also interested in seeing whether subtypes of PDD such as Asperger Syndrome might have a different outcome than those with autism.
- ◆ The third (under the supervision of Lonnie Zwaigenbaum and Susan Bryson) is the aforementioned Baby Sibs Study (see Section 3.4.1).
- ◆ The fourth study at McMaster is the PET and MRI Study (PI: Jeremy Goldberg; Co-Investigators: Claude Nahmias; Peter Szatmari; Lonnie Zwaigenbaum). Examined are a number of brain structures that were imaged with MRI and serotonin blood samples that

were collected at the time of performing the PET scans. Dr. Goldberg is funded by NAAR for his US\$89,368 project, "Investigating Serotonin Receptor Function and Brain Structure as Potential Endophenotypes of Autism". Based on provisional findings that link serotonin levels to autism, the group has been awarded a second and more substantial grant from NAAR to perform a more comprehensive study on parents and high functioning adults with PDD.

To provide an overview of autism researchers working at Canadian universities (based on the funding analysis in this report), the following table lists those researchers by their university affiliation.

Researchers by University Affiliation		
Province	University Affiliation	Affiliated Principal Investigators funded by CIHR, SSHRC or NAAR
British Columbia	Simon Fraser University	Kulusic, Tamara
	University of British Columbia	Lewis, M.E. Suzanne
		Simpson, Elizabeth*
		Smith, Veronica
		Wong, K.Y. Bibiana
Alberta	University of Alberta	Varnhagen, Connie K
		Volden, Joanne C.
	University of Calgary	Brown-Godsave, Deborah
		Pencer, Alissa
Ontario	McMaster University	Bryson, Susan E
		De Villiers, Jessica
		Goldberg, Jeremy
		King, Gillian A
		Roberts, Wendy
		Szatmari, Peter
		Zwaigenbaum, Lonnie
	Queen's University	Feldman, Maurice A
		Holden, Jeanette J
		Munoz, Douglas P*
	University of Guelph	Konstantareas, Mary
	University of Toronto	Astington, Janet
		Bryson, Susan E
		Cordes, Sabine P
		Oram, Janis E
		Roberts, Timothy
		Scherer, Stephen W
		Zelazo, Philip D.*

Researchers by University Affiliation		
Province	University Affiliation	Affiliated Principal Investigators funded by CIHR, SSHRC or NAAR
Ontario (continued)	University of Waterloo	O'Neill, Daniela K
	University of Windsor	Spadafora, Alison
	York University	Penn, Helen
Quebec	McGill University	Armony, Jorge*
		Barker, Philip A
		Burack, Jacob
		Flanagan, Tara
		Fombonne, Eric*
		Grivas, Anna
		Joseph, Shari
		Rouleau, Guy A
	Université de Montréal	Bertone, Armando
		Bolduc, Christianne
		Carmant, Lionel
		Fecteau, Shirley
		Godbout, Roger
		Lamarre, Yves
		Limoges, Elyse
Université de Sherbrooke	Michaud, François*	
	Université Laval	Maziade, Michel*
New Brunswick	University of New Brunswick	Clark, Denise V
Newfoundland	Memorial University	Mclean, John H

**also a Canada Research Chair.*

Note: Investigators may appear under a province that does not represent their current location (see Section 2.3, Process and Methodology) as the researcher may have moved location since receiving the award. In source data, university affiliation is based on the location of the main Principal Investigator of the award; therefore in this report, Co-PI's may appear under the university affiliation of the main PI.

6.1.4 Autism Research in the Western Provinces

In the west, the University of British Columbia, the University of Alberta, and the University of Calgary host autism researchers identified in this report. No researchers with funding from CIHR, SSHRC or NAAR were identified at institutions in Saskatchewan, Manitoba, the Yukon or the Northwest Territories.

At the University of British Columbia, **Suzanne Lewis** is the Clinical Associate Professor, Department of Medical Genetics, in the Faculty of Medicine. She also holds the appointment of Clinical Geneticist and Paediatrician at the Children's and Women's Health Centre (this is a

UBC teaching hospital, and this appointment is part of the UBC Provincial Program in Medical Genetics). She currently holds two CIHR awards, and, additionally, is the ASD-CARC Regional Team Leader for British Columbia and the Yukon.

Dr. Elizabeth Simpson, who is Associate Professor, Department of Medical Genetics at UBC, holds a Canada Research Chair in Genetics & Behaviour. In addition, Dr. Simpson is the mentor to NAAR award recipient **Bibiana Wong**, for a 2003 Mentor-Based Fellowship.

Veronica Smith, also at UBC, holds a SSHRC doctoral fellowship for her autism research in the area of Exceptional/Special Education.

Tamara Kulusic of Simon Fraser University holds a SSHRC Canada Graduate Scholarships Program award for her project: "Understanding autism and accessing help: parent's perspectives of the family experience."

At the University of Alberta, **Joanne Volden** holds one SSHRC award and has also been awarded the only autism award from western provincial granting agencies. The Alberta Heritage Foundation for Medical Research has funded Joanne Volden for her project, "Adjusting language style in autism", a study that will test autistic young people to determine if they spontaneously adjust language levels in social situations or if they could do so with direction. Joanne Volden is also a member of the CAIRN steering committee.

Also at the University of Alberta, **Connie Varnhagen** has recently received CIHR funding for "Strategies for critically appraising children's health web resources".

At the University of Alberta, **Deborah Brown-Godsave** and **Alissa Pencer** were each awarded a SSHRC grant for their autism work in the area of Child and Adolescent Psychology.

6.2 Autism Research Chair

Dr. Susan Bryson is the first holder of Dalhousie University's Joan and Jack Craig Chair in Autism, the first Chair of its kind in Canada. Susan Bryson is recognized internationally as a leading expert on autism and related disorders of development. Most recently, she worked at York University and the Toronto Hospital for Sick Children where she founded the Autism Research Unit. Her new duties as Chair mark Dr. Bryson's return to Dalhousie. In the 1980s, she was a Professor in Dalhousie's Department of Psychology. During her tenure there, she conducted a landmark epidemiological study of autism, the first conducted in North America. Dr. Bryson is a member of Dalhousie's Faculty of Medicine in the Department of Paediatrics.

Note: Dr. Bryson has been at Dalhousie in Nova Scotia since September 2001 but her CIHR award shows McMaster University as the "Research Institution". She also is a Co-PI on a NAAR award, which is listed in the NAAR data as residing with a researcher (Lonnie Zwiegenbaum) at McMaster University.

7. MSFHR Database Survey

High quality, longitudinal, comprehensive, shared databases are widely recognized as a fundamental platform technology with the capacity to underpin effective research and to inform policy and practice in any area of health and social services.

Survey #2 was circulated by MSFHR on June 20, 2003 to the same six contact individuals in the western provinces/territories as Survey #1 (Section 3.7.1 above). Survey #2 requested information on autism-related databases currently extant within the respondents' respective jurisdictions. A subsequent request was sent in August 2003, clarifying to participants the need to include information relating to any existing administrative databases for autism clinical services (such databases have proven an invaluable resource for health services evaluation and other types of research).

By September 15, 2003, responses were received from BC, Saskatchewan and Manitoba. As of the date of this report, no database information has yet been received from Alberta or the Territories. Responses also revealed that, while BC is in the forefront of having autism-related databases, no Northwest jurisdiction is currently maintaining a comprehensive provincial longitudinal database accessible for research purposes. This lack of shared platforms can be viewed as an opportunity for collaboration on a fundamentally important, shared research infrastructure across the region.

Details of the information received were collated by the BC Ministry of Health and are attached (Appendix D). Responses are summarized as follows:

Responses to Survey #2 (Databases)	
Province	Number of Current Autism-Related Databases Reported
British Columbia ²⁹	9
Alberta	0
Saskatchewan	1
Manitoba	3
Yukon	0
Northwest Territories	0

Note: ASD-CARC (see Section 5.1) also has a database which includes data from BC, Yukon, Manitoba, and southern Alberta.

In British Columbia, the province with the most autism-related databases, these resources are, for the most part, not yet provincially centralized and exist in various forms and locations (see table below). A detailed evaluation of existing databases regarding their purpose, potential synergies, and intended use remains to be undertaken. The purpose of the identified databases, as described by the providers of the information, is summarized in the table on the next page; further details can be found in Appendix D.

²⁹ Plus two databases under development; see Appendix D.

Summary Table of Autism-Related Databases ³⁰		
Prov.	Organization Administering Database	Purposes for which data is collected and used
BC	Provincial Autism Resource Centre	Health Care Services, Administrative, Longitudinal tracking, Research, Outcome and Evaluation
BC	Vancouver Island Health Authority	Health Care Services, Administrative, Longitudinal tracking, Outcome and Evaluation
BC	Northern Health Authority	Health Care Services, Administrative, Longitudinal tracking, Outcome and Evaluation
BC	Interior Health Authority, Mental Health Support Team	Health Care Services, Administrative
BC	Child Development Centres/Infant Development Programs	Health Care Services, Administrative, Longitudinal tracking
BC	BC Ministries of Government and Affiliates	Health Care Services, Education Services, Administrative, Social Services, Longitudinal tracking, Outcome and evaluation
BC	Edudata Canada	Education Services, Administrative, Longitudinal tracking, Research, Can also link to other Health and Economic data sets
BC	Intervention Service Providers	Longitudinal tracking, Outcome and Evaluation
BC	UBC, funded by BC Ministry of Children and Family Development.	Early Intensive Behavioural Intervention and Interim Early Intensive Intervention Outcome Data
SK		no details of database
MB	St. Amant Centre	Education Services, Longitudinal tracking
MB	St. Amant Centre	Education Services, Longitudinal tracking
MB	St. Amant Centre	Education Services, Administrative, Longitudinal tracking
BC, AB, MB, YT	Autism Spectrum Disorders Canadian American Research Consortium	Research

Some of the existing autism databases in the western provinces have the potential to become an important platform technology for autism research in the west and a tool to link existing research and researchers in British Columbia, Alberta, Saskatchewan, Manitoba, the Yukon, and the Northwest Territories. One database project in particular, the BC Autism Assessment Network (BCAAN), could serve as a model platform for autism research databases across the Northwest, because of its data quality and comprehensiveness. The following section describes this platform and discusses its potential value to the Region.

7.1 The BC Autism Assessment Network

In British Columbia, the Provincial Health Services Authority (PHSA) is one of six³¹ provincial Health Authorities responsible for delivering and evaluating health services. The PHSA's

³⁰ For those jurisdictions responding to the survey, as described above.

³¹ PHSA provides specialty services to the entire province; BC's other five Health Authorities serve specific geographic regions of the province.

primary role is to ensure that all BC residents have access to a coordinated network of high-quality, specialized, health care services. PHSA operates provincial agencies that include Children's & Women's Health Centre of British Columbia. By planning, coordinating and evaluating specialized health services, PHSA is working with the other health authorities across BC to provide high quality, equitable and cost-effective health care.

The BC Autism Assessment Network³² was formed by the PHSA in the fall of 2002. Its mandate is to support the development of a network of Regional Service Teams across the province to provide children and youth under 19 years of age with timely access to ASD diagnostic and assessment services. These services are provided within the Health Authorities where the child and family live. BCAAN works collaboratively with several branches of the provincial government such as the Ministries of Health/Health Planning (MOH/MOHP), Children and Family Development (MCFD), and Education (MOE).

The following information describes the ongoing creation and implementation of the British Columbia Autism Assessment Network's (BCAAN) provincial database. It is presented here to demonstrate the potential of such a database as both a clinical and research resource, one that could be adapted in scope for use with other child development populations and/or in other jurisdictions to facilitate networked research initiatives.

7.1.1 Key features of the BCAAN database

Key features of the BCAAN assessment process and database include:

Data Quality

- ◆ Uniform case definitions of autism spectrum disorders are facilitated through the use of validated clinical diagnostic instruments that have good sensitivity and specificity for ASD. These have been summarized in the Ministry of Health Planning's "Standards and Guidelines for the Assessment and Diagnosis of Young Children with Autism Spectrum Disorder in British Columbia".³³
- ◆ BCAAN has an ongoing mandate to train selected qualified specialists across the province in the use of these instruments, as well as to support a program for maintenance of competency. This assists in building and maintaining assessment/diagnostic capacity and standards across the province.
- ◆ The application of the above standards is facilitated through both government policy (e.g. intervention funding applications via the MCFD) and service agreements (e.g. between PHSA and the other BC Health Authorities).

Comprehensiveness

- ◆ Mandatory reporting is facilitated through both legislation (e.g. reporting requirements of BC Vital Statistics) and service agreements (e.g. between PHSA and the other BC Health Authorities). This helps to create comprehensive data acquisition and coverage of the entire province of BC.

³² Reference: <http://www.phsa.ca/ProgramsServices/Services/Autism.htm>

³³ Reference: http://www.healthplanning.gov.bc.ca/cpa/publications/asd_standards_0318.pdf

- ◆ All children and youth less than 19 years of age are eligible for assessment services.
- ◆ A web-based interface is available to allow easily accessible/secure data entry and centralized storage of data.

Flexibility

- ◆ Individual DSM-IV-TR³⁴ domains are recorded (as well as an overall “diagnosis”). This allows flexibility and retrospective searches of the database if the definition criteria for ASDs change over time, as well as potentially monitoring and evaluating the longitudinal outcomes of “borderline” cases.
- ◆ Both positive *and* negative cases of ASD are recorded, as well as co-morbid conditions. This is important for a number of reasons, including development and testing of ASD screening programs (ability to track false positive/false negative rates) and policy development (quality evaluation; tracking and monitoring referral burden).
- ◆ The BCAAN assessment process and database provides the potential to monitor health (e.g. behavioural intervention) and policy (e.g. economic) outcomes.
- ◆ Contingent upon parent/guardian consents, the database has the potential to address a number of tasks which include: program evaluation and quality assurance; communication/integration of data flow between different branches of government (e.g. MOH, MOHP, MCFD, MOE); and research (epidemiology, health and economic policy, intervention outcome analysis).

Expandability

- ◆ It is envisioned that the British Columbia Autism Assessment Network and its affiliated Regional Service Teams will serve as a template and foundation for regional assessment/diagnostic services for a variety of other developmental conditions across the province (e.g. Fetal Alcohol Syndrome).
- ◆ Because of the modular nature of the evolving BCAAN database, it is ideally suited to accommodate expansion to include these other developmental conditions.
- ◆ With suitable support and uniform application of standards/definitions, an inter-provincial and/or national network can be envisioned.

Research Implications

- ◆ *General considerations*
The BCAAN clinical model and its affiliated database have the potential to expand to monitor a variety of other developmental disabilities (e.g. Fetal Alcohol Syndrome) at a provincial, inter-provincial, and/or national level. It is envisioned that research access to the BCAAN database will be controlled by an ethics-approval system that considers hypothesis-driven research questions. Examples of potential research categories are listed below:

³⁴ Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision; *American Psychiatric Association*

- ◆ *Epidemiology*
The quality of epidemiological studies is generally dependent upon consistent application of a reproducible “case definition”, as well as the comprehensiveness of “case reporting”. Historically in British Columbia, there has been no mechanism to control the quality of a case definition of ASD, and reporting strategies have relied on ad hoc and/or voluntary systems that, by definition, are subject to bias. As detailed above, the BCAAN helps address both limitations. Additional flexibility is afforded by the recording of the individual DSM-IV-TR domains.
- ◆ *Health outcome research*
A large population base is required to generate the statistical power needed to compare the efficacy/effectiveness of different interventions. In this regard, the BCAAN database may be sufficient for studies designed to generate hypotheses, but not necessarily for those studies designed to test hypotheses. For the latter, an inter-provincial or national database would be required, and the BCAAN model could be amenable for such expansion.
- ◆ *ASD screening/diagnostic instruments*
Because the BCAAN database captures both positive and negative cases of ASD, it is ideally positioned to help test and/or develop ASD screening/diagnostic instruments.
- ◆ *Policy/economic research*
Within British Columbia, court decisions regarding the provision of intervention funding for families of children with autism have indirectly led to the formation of the BC Autism Assessment Network and its affiliated database. There is currently very little research addressing the impact of these court decisions on health policy and health economics (e.g. cost savings/expenditures; revenue generation), although the BCAAN database has the potential to provide some information in this regard. It is hoped that the principles of the BCAAN model will ultimately provide an economy of scale for the assessment and monitoring of children/youth with developmental disabilities, both within BC, and collaboratively with neighbouring provinces.

Appendices

The following appendices provide background and additional information to the body of the report. The information in the tables is based on the most recent data available to the MSFHR (see 2.3. Process and Methodology).

- Appendix A - Researchers Currently funded by CIHR, SSHRC and NAAR, by Province
- Appendix B - Canada Research Chair Holders
- Appendix C - MSFHR Survey Results - Autism Researchers
- Appendix D - MSFHR Survey: Database Information
- Appendix E - CAIRN Member List
- Appendix F - ASD-CARC Member List (Canada)

Appendix A Researchers Currently funded by CIHR, SSHRC and NAAR, by Province

Prov	Research Area	PI	Co-P.I.	Awarding Body	Research Location	Fiscal Year	Amount	Project Title	Primary CIHR institute	Primary Theme	
BC	Anthropology	Kulusic, Tamara		SSHRC	Simon Fraser University	2003-2004	\$17,500	Understanding autism and accessing help: parent's perspectives of the family experience			
	Exceptional, Special Education	Smith, Veronica		SSHRC	University of British Columbia	2002-2003	\$17,700	Social competence for children with autism following early intervention		Exceptional, Special Education	
	Genetics	Lewis, M.E. Suzanne			CIHR	University of British Columbia	2002-2003	\$60,000	New approaches toward understanding the genetic bases of form function and phenotype in Autism Spectrum Disorder		
							2003-2004	\$120,000	New approaches toward understanding the genetic bases of form function and phenotype in Autism Spectrum Disorder		
							2004-2005	\$60,000	New approaches toward understanding the genetic bases of form function and phenotype in Autism Spectrum Disorder		
							2003-2004	\$52,200	Autism spectrum disorders: Identification of culprit genes using genomic microarrays and molecular assessments of duplicon-mediated micro-deletions and duplications	Genetics	Biomedical
							2004-2005	\$104,400	Autism spectrum disorders: Identification of culprit genes using genomic microarrays and molecular assessments of duplicon-mediated micro-deletions and duplications	Genetics	Biomedical
							2005-2006	\$111,360	Autism spectrum disorders: Identification of culprit genes using genomic microarrays and molecular assessments of duplicon-mediated micro-deletions and duplications	Genetics	Biomedical
							2006-2007	\$59,160	Autism spectrum disorders: Identification of culprit genes using genomic microarrays and molecular assessments of duplicon-mediated micro-deletions and duplications	Genetics	Biomedical
							2006-2007	\$59,160	Autism spectrum disorders: Identification of culprit genes using genomic microarrays and molecular assessments of duplicon-mediated micro-deletions and duplications	Genetics	Biomedical

Prov	Research Area	PI	Co-P.I.	Awarding Body	Research Location	Fiscal Year	Amount	Project Title	Primary CIHR institute	Primary Theme	
BC	<i>Not Classified</i>	Wong, K.Y. Bibiana		NAAR	Centre for Molecular Medicine & Therapeutics, British Columbia	2003-2004	\$34,000	Mouse Models of Autism: Behavior and Genetics			
						2004-2005	\$34,000	Mouse Models of Autism: Behavior and Genetics			
AB	Child And Adolescent Psychology	Brown-Godsave, Deborah		SSHRC	University of Calgary	1998-1999	\$16,620	Child characteristics and the adjustment of families of young children with a pervasive developmental disability		Child and Adolescent Psychology	
						1999-2000	\$16,620	Child characteristics and the adjustment of families of young children with a pervasive developmental disability		Child and Adolescent Psychology	
						2000-2001	\$17,700	Child characteristics and the adjustment of families of young children with a pervasive developmental disability		Child and Adolescent Psychology	
		Pencer, Alissa		SSHRC	University of Calgary	2000-2001	\$17,700	The role of pragmatic cues in typically developing and autistic children's word learning		Child and Adolescent Psychology	
						2001-2002	\$17,700	The role of pragmatic cues in typically developing and autistic children's word learning		Child and Adolescent Psychology	
						2002-2003	\$17,700	The role of pragmatic cues in typically developing and autistic children's word learning		Child and Adolescent Psychology	
	Exceptional, Special Education	Volden, Joanne C.		SSHRC	University of Alberta	2002-2003	\$33,000	Variation of language register in autism		Exceptional, Special Education	
	<i>Not Classified</i>	Varnhagen, Connie K			CIHR	University of Alberta	2002-2003	\$26,667	Strategies for critically appraising children's health web resources	Human Development, Child and Youth Health	Social/ Cultural/ Environmental/ Population Health
							2003-2004	\$83,416	Strategies for critically appraising children's health web resources	Human Development, Child and Youth Health	Social/ Cultural/ Environmental/ Population Health
2004-2005							\$90,250	Strategies for critically appraising children's health web resources	Human Development, Child and Youth Health	Social/ Cultural/ Environmental/ Population Health	

Prov	Research Area	PI	Co-P.I.	Awarding Body	Research Location	Fiscal Year	Amount	Project Title	Primary CIHR institute	Primary Theme
AB	<i>Not Classified</i>	Varnhagen, Connie K				2005-2006	\$74,167	Strategies for critically appraising children's health web resources	Human Development, Child and Youth Health	Social/ Cultural/ Environmental/ Population Health
ON	Applied Linguistics	De Villiers, Jessica		SSHRC	McMaster University	2000-2001	\$40,028	Using discourse techniques to identify the linguistic characteristics of asperger syndrome		Applied Linguistics
						2001-2002	\$35,028	Using discourse techniques to identify the linguistic characteristics of asperger syndrome		Applied Linguistics
	Behavioural Psychology	Konstantareas, Mary		SSHRC	University of Guelph	2001-2002	\$24,241	Dimensions of temperament in children with pervasive developmental disorder: do they predict parental adaptation?		Behavioural Psychology
						2002-2003	\$22,441	Dimensions of temperament in children with pervasive developmental disorder: do they predict parental adaptation?		Behavioural Psychology
	Child And Adolescent Psychology	Astington, Janet		SSHRC	University of Toronto	2001-2002	\$10,000	Why Language Matters for Theory of Mind		Child and Adolescent Psychology
	Genetics	Cordes, Sabine P		CIHR	Samuel Lunenfeld Research Institute (Toronto)	2003-2004	\$77,091	Molecular interactions governing embryonic hindbrain patterning	Human Development, Child and Youth Health	Biomedical
						2004-2005	\$154,182	Molecular interactions governing embryonic hindbrain patterning	Human Development, Child and Youth Health	Biomedical
						2005-2006	\$154,182	Molecular interactions governing embryonic hindbrain patterning	Human Development, Child and Youth Health	Biomedical
						2006-2007	\$154,182	Molecular interactions governing embryonic hindbrain patterning	Human Development, Child and Youth Health	Biomedical
						2007-2008	\$154,182	Molecular interactions governing embryonic hindbrain patterning	Human Development, Child and Youth Health	Biomedical

Prov	Research Area	PI	Co-P.I.	Awarding Body	Research Location	Fiscal Year	Amount	Project Title	Primary CIHR institute	Primary Theme
ON	Genetics	Cordes, Sabine P				2008-2009	\$77,091	Molecular interactions governing embryonic hindbrain patterning	Human Development, Child and Youth Health	Biomedical
		Scherer, Stephen W		CIHR	Hospital for Sick Children (Toronto)	1999-2000	\$360,274	Human chromosome 7 genome project	Genetics	Biomedical
	2000-2001					\$360,274	Human chromosome 7 genome project	Genetics	Biomedical	
	2001-2002					\$360,274	Human chromosome 7 genome project	Genetics	Biomedical	
	2002-2003					\$360,274	Human chromosome 7 genome project	Genetics	Biomedical	
	2003-2004					\$57,750	Genome discovery for genetic disease research	Genetics	Biomedical	
	2004-2005					\$77,000	Genome discovery for genetic disease research	Genetics	Biomedical	
	2005-2006					\$77,000	Genome discovery for genetic disease research	Genetics	Biomedical	
	2006-2007					\$77,000	Genome discovery for genetic disease research	Genetics	Biomedical	
	2007-2008					\$77,000	Genome discovery for genetic disease research	Genetics	Biomedical	
	2008-2009					\$19,250	Genome discovery for genetic disease research	Genetics	Biomedical	
	Szatmari, Peter		CIHR	McMaster University	2002-2003	\$21,600	Genetic epidemiology of autism	Neurosciences, Mental Health and Addiction	Biomedical	
	Genomics, Proteomics, and Bioinformatics	Scherer, Stephen W		CIHR	Hospital for Sick Children (Toronto)	2003-2004	\$45,475	Human chromosome 7 project: Annotation, structure and function	Genetics	Biomedical
Imaging	Oram, Janis E			CIHR	University of Toronto	2003-2004	\$47,042	Neural correlates of auditory processing in autism and language disorders	Human Development, Child and Youth Health	Clinical
						2004-2005	\$51,000	Neural correlates of auditory processing in autism and language disorders	Human Development, Child and Youth Health	Clinical

Prov	Research Area	PI	Co-P.I.	Awarding Body	Research Location	Fiscal Year	Amount	Project Title	Primary CIHR institute	Primary Theme				
ON	Imaging	Oram, Janis E				2005-2006	\$3,958	Neural correlates of auditory processing in autism and language disorders	Human Development, Child and Youth Health	Clinical				
	Mental Health	Szatmari, Peter		CIHR	McMaster University	2002-2003	\$31,551	The genetic epidemiology of autism; family and molecular studies	Neurosciences, Mental Health and Addiction	Biomedical				
							\$38,995	Understanding developmental trajectories in autism						
						2003-2004	\$38,500	Understanding developmental trajectories in autism						
							\$116,684	The genetic epidemiology of autism; family and molecular studies	Neurosciences, Mental Health and Addiction	Biomedical				
						2004-2005	\$145,855	The genetic epidemiology of autism; family and molecular studies	Neurosciences, Mental Health and Addiction	Biomedical				
						2005-2006	\$145,855	The genetic epidemiology of autism; family and molecular studies	Neurosciences, Mental Health and Addiction	Biomedical				
						2006-2007	\$145,855	The genetic epidemiology of autism; family and molecular studies	Neurosciences, Mental Health and Addiction	Biomedical				
						2007-2008	\$145,855	The genetic epidemiology of autism; family and molecular studies	Neurosciences, Mental Health and Addiction	Biomedical				
						Zwaigenbaum, Lonnie	Bryson, Susan E	CIHR	McMaster University	2003-2004	\$105,193	Identifying early markers of autism: A prospective study of infant siblings	Neurosciences, Mental Health and Addiction	Clinical
										2004-2005	\$117,758	Identifying early markers of autism: A prospective study of infant siblings	Neurosciences, Mental Health and Addiction	Clinical
	2005-2006	\$117,758	Identifying early markers of autism: A prospective study of infant siblings	Neurosciences, Mental Health and Addiction	Clinical									
	Molecular Biology	Cordes, Sabine P			CIHR	Samuel Lunenfeld Research Institute (Toronto)	2000-2001	\$52,005	Molecular interactions governing hindbrain patterning		Biomedical			

Prov	Research Area	PI	Co-P.I.	Awarding Body	Research Location	Fiscal Year	Amount	Project Title	Primary CIHR institute	Primary Theme		
ON	Molecular Biology	Cordes, Sabine P				2001-2002	\$9,129	Regulation of hindbrain patterning	Human Development, Child and Youth Health	Biomedical		
							\$104,010	Molecular interactions governing hindbrain patterning		Biomedical		
						2002-2003	\$104,010	Molecular interactions governing hindbrain patterning		Biomedical		
						2003-2004	\$52,005	Molecular interactions governing hindbrain patterning		Biomedical		
	Nervous System	Bryson, Susan E			CIHR	Hospital for Sick Children (Toronto)	1999-2000	\$54,745	Autism and moebius syndrome: a neuropsychological study of visual-spatial attention and facial emotion			
							2000-2001	\$49,208	Autism and moebius syndrome: a neuropsychological study of visual-spatial attention and facial emotion			
		Cordes, Sabine P			CIHR	Undetermined	1999-2000	\$73,033	Regulation of early hindbrain patterning			
								\$87,130	Roles of proteins associated with and genes regulated by the Kreisler transcription factor in hindbrain segmentation			
								2000-2001	\$43,565	Roles of proteins associated with and genes regulated by the Kreisler transcription factor in hindbrain segmentation		
								\$73,033	Regulation of early hindbrain patterning			
		Holden, Jeanette J				CIHR	Queen's University	2000-2001	\$320,657	Unravelling the mystery of autism: From genotyping and phenotyping to prospective identification and prevention	Neurosciences, Mental Health and Addiction	Clinical
								2001-2002	\$882,626	Unravelling the mystery of autism: From genotyping and phenotyping to prospective identification and prevention	Neurosciences, Mental Health and Addiction	Clinical
								2002-2003	\$5,000	Transdisciplinary inter-institute training program in autism spectrum disorders		
									\$882,626	Unravelling the mystery of autism: From genotyping and phenotyping to prospective identification and prevention	Neurosciences, Mental Health and Addiction	Clinical

Prov	Research Area	PI	Co-P.I.	Awarding Body	Research Location	Fiscal Year	Amount	Project Title	Primary CIHR institute	Primary Theme		
ON	Nervous System	Holden, Jeanette J				2003-2004	\$834,082	Unravelling the mystery of autism: From genotyping and phenotyping to prospective identification and prevention	Neurosciences, Mental Health and Addiction	Clinical		
						2004-2005	\$834,082	Unravelling the mystery of autism: From genotyping and phenotyping to prospective identification and prevention	Neurosciences, Mental Health and Addiction	Clinical		
						2005-2006	\$625,561	Unravelling the mystery of autism: From genotyping and phenotyping to prospective identification and prevention	Neurosciences, Mental Health and Addiction	Clinical		
				Bebko, James M; Chudley, Albert E; Feldman, Maurice A; Lewis, M.E. Suzanne; Minnes, Patricia M; Munhall, Kevin G; Perry, Adrienne M; Woodhouse, Rosamund; Yu, Dickie C	CIHR	Queen's University	2003-2004	\$101,400	Transdisciplinary inter-institute training program in autism spectrum disorders			
		2004-2005	\$101,400				Transdisciplinary inter-institute training program in autism spectrum disorders					
		2005-2006	\$101,400				Transdisciplinary inter-institute training program in autism spectrum disorders					
		2006-2007	\$101,400				Transdisciplinary inter-institute training program in autism spectrum disorders					
		2007-2008	\$101,400				Transdisciplinary inter-institute training program in autism spectrum disorders					
		2008-2009	\$101,400				Transdisciplinary inter-institute training program in autism spectrum disorders					
				Munoz, Douglas P*		CIHR	Queen's University	2003-2004	\$72,923	Using eye movements to probe brain function and dysfunction in humans	Neurosciences, Mental Health and Addiction	Biomedical
		2004-2005	\$140,541					Using eye movements to probe brain function and dysfunction in humans	Neurosciences, Mental Health and Addiction	Biomedical		
		2005-2006	\$135,239					Using eye movements to probe brain function and dysfunction in humans	Neurosciences, Mental Health and Addiction	Biomedical		

Prov	Research Area	PI	Co-P.I.	Awarding Body	Research Location	Fiscal Year	Amount	Project Title	Primary CIHR institute	Primary Theme	
ON	Nervous System	Munoz, Douglas P*				2006-2007	\$135,239	Using eye movements to probe brain function and dysfunction in humans	Neurosciences, Mental Health and Addiction	Biomedical	
						2007-2008	\$135,239	Using eye movements to probe brain function and dysfunction in humans	Neurosciences, Mental Health and Addiction	Biomedical	
						2008-2009	\$67,619	Using eye movements to probe brain function and dysfunction in humans	Neurosciences, Mental Health and Addiction	Biomedical	
	Not Classified	Bryson, Susan E			NAAR	McMaster University	2002-2003	See footnote 15.	Identifying Early Markers of Autism: A Longitudinal Study of Infant Siblings		
							2001-2002		Identifying Early Markers of Autism: A Longitudinal Study of Infant Siblings		
		Goldberg, Jeremy			NAAR	McMaster University	2001-2002	\$67,777	Investigating Serotonin Receptor Function and Brain Structure as Potential Endophenotypes of Autism.		
							2002-2003	\$66,992	Investigating Serotonin Receptor Function and Brain Structure as Potential Endophenotypes of Autism.		
		Holden, Jeanette J			CIHR	Queen's University	2000-2001	\$15,000	Unravelling the mystery of autism spectrum disorders - Genotyping and phenotyping of ASD: identification of early markers and implications for intervention and prevention		Biomedical
		Roberts, Timothy			NAAR	University of Toronto	2003-2004	\$85,633	MEG Correlates of Linguistic Processing at and Below the Word Level in Autism		
							2004-2005	\$85,633	MEG Correlates of Linguistic Processing at and Below the Word Level in Autism		
		Roberts, Wendy			NAAR	McMaster University	2001-2002	See footnote 15.	Identifying Early Markers of Autism: A Longitudinal Study of Infant Siblings		
2002-2003							Identifying Early Markers of Autism: A Longitudinal Study of Infant Siblings				
		Szatmari, Peter		CIHR	McMaster University	1999-2000	\$45,000	Developing a research agenda on early intervention in autism and other pervasive developmental disorders (PDD)			
						2000-2001	\$57,600	The genetic epidemiology of autism			
ON	Not Classified	Szatmari, Peter				2001-2002	\$115,200	The genetic epidemiology of autism			

Prov	Research Area	PI	Co-P.I.	Awarding Body	Research Location	Fiscal Year	Amount	Project Title	Primary CIHR institute	Primary Theme
				NAAR	McMaster University	2001-2002	See footnote 15.	Identifying Early Markers of Autism: A Longitudinal Study of Infant Siblings		
						2002-2003		Identifying Early Markers of Autism: A Longitudinal Study of Infant Siblings		
		Zwaigenbaum, Lonnie		NAAR	McMaster University	2001-2002	\$75,835	Identifying Early Markers of Autism: A Longitudinal Study of Infant Siblings		
						2002-2003	\$74,957	Identifying Early Markers of Autism: A Longitudinal Study of Infant Siblings		
						2003-2004	\$85,692	Investigating the Emergence of Familial Traits in Autism		
						2004-2005	\$85,692	Investigating the Emergence of Familial Traits in Autism		
	Psychology	Penn, Helen		SSHRC	York University	2003-2004	\$17,500	Evaluating progress when treating children with autism		
		Spadafora, Alison		SSHRC	University of Windsor	2003-2004	\$17,500	Skill acquisition in preschool children with autism spectrum disorders in an intensive behavioural intervention program		
	Psychosocial/ Health Behavioural Research	Feldman, Maurice A		CIHR	Queen's University	2001-2002	\$60,444	Early detection, intervention and prevention of developmental and behavioural disorders in young children	Human Development, Child and Youth Health	Clinical
						2002-2003	\$20,383	Early detection, intervention and prevention of developmental and behavioural disorders in young children	Human Development, Child and Youth Health	Clinical
		King, Gillian A		CIHR	McMaster University	2002-2003	\$12,822	Understanding the values, priorities, and world views of families raising children with chronic developmental conditions	Human Development, Child and Youth Health	Social/ Cultural/ Environmental/ Population Health
						2003-2004	\$23,552	Understanding the values, priorities, and world views of families raising children with chronic developmental conditions	Human Development, Child and Youth Health	Social/ Cultural/ Environmental/ Population Health
						2004-2005	\$32,877	Understanding the values, priorities, and world views of families raising children with chronic developmental conditions	Human Development, Child and Youth Health	Social/ Cultural/ Environmental/ Population Health

Prov	Research Area	PI	Co-P.I.	Awarding Body	Research Location	Fiscal Year	Amount	Project Title	Primary CIHR institute	Primary Theme
ON	Psychosocial/ Health Behavioural Research	O'Neill, Daniela K		CIHR	University of Waterloo	2005-2006	\$16,393	Understanding the values, priorities, and world views of families raising children with chronic developmental conditions	Human Development, Child and Youth Health	Social/ Cultural/ Environmental/ Population Health
						2000-2001	\$32,392	Validation studies of a parent-report measure to assess early linguistic pragmatic competence	Human Development, Child and Youth Health	Social/ Cultural/ Environmental/ Population Health
						2001-2002	\$55,186	Validation studies of a parent-report measure to assess early linguistic pragmatic competence	Human Development, Child and Youth Health	Social/ Cultural/ Environmental/ Population Health
						2002-2003	\$25,365	Validation studies of a parent-report measure to assess early linguistic pragmatic competence	Human Development, Child and Youth Health	Social/ Cultural/ Environmental/ Population Health
						2003-2004	\$6,898	Standardization of the language use inventory: A parent-report measure to assess linguistic pragmatic development in children 18 to 47 months of age	Human Development, Child and Youth Health	Clinical
							\$45,436	Standardization of the language use inventory: A parent-report measure to assess pragmatic development in children 18 to 47 months of age	Human Development, Child and Youth Health	Social/ Cultural/ Environmental/ Population Health
						2004-2005	\$90,871	Standardization of the language use inventory: A parent-report measure to assess pragmatic development in children 18 to 47 months of age	Human Development, Child and Youth Health	Social/ Cultural/ Environmental/ Population Health
						2005-2006	\$60,972	Standardization of the language use inventory: A parent-report measure to assess pragmatic development in children 18 to 47 months of age	Human Development, Child and Youth Health	Social/ Cultural/ Environmental/ Population Health
QC	Cell Biology	Barker, Philip A		CIHR	McGill University	2003-2004	\$57,000	MAGE Genes and Autism	Genetics	Biomedical
						2004-2005	\$57,000	MAGE Genes and Autism	Genetics	Biomedical

Prov	Research Area	PI	Co-P.I.	Awarding Body	Research Location	Fiscal Year	Amount	Project Title	Primary CIHR institute	Primary Theme	
QC	Education; Educational Psychology	Burack, Jacob		SSHRC	McGill University	2003-2004	\$62,313	Attention and global-local processing among persons with autism			
		Joseph, Shari		SSHRC	McGill University	1999-2000	\$24,930	Executive function profiles in children with autism		Educational Psychology	
			2000-2001			\$9,390	Executive function profiles in children with autism		Educational Psychology		
		Flanagan, Tara		SSHRC	McGill University	2003-2004	\$19,000	Evaluating progress when treating children with autism			
	Exceptional, Special Education	Burack, Jacob			SSHRC	McGill University	1998-1999	\$35,000	Visual attention and processing in persons with autism		Exceptional, Special Education
							1999-2000	\$45,000	The development of attentional processes of persons with autism and down syndrome		Exceptional, Special Education
							2000-2001	\$34,000	The development of attentional processes of persons with autism and down syndrome		Exceptional, Special Education
							2001-2002	\$34,000	The development of attentional processes of persons with autism and down syndrome		Exceptional, Special Education
	Genetics	Rouleau, Guy A			CIHR	Montreal General Hospital	2000-2001	\$96,450	Searching for genes predisposing to autism		
							2001-2002	\$96,450	Searching for genes predisposing to autism		
							2002-2003	\$96,450	Searching for genes predisposing to autism		
	Mental Health	Bolduc, Christianne			CIHR	Hôpital Rivière-des-Prairies (Montréal)	2002-2003	\$20,500	Étude de l'EEG quantifié au cours de la veille et du sommeil chez des autistes de haut niveau	Neurosciences, Mental Health and Addiction	Clinical
							2003-2004	\$20,500	Étude de l'EEG quantifié au cours de la veille et du sommeil chez des autistes de haut niveau	Neurosciences, Mental Health and Addiction	Clinical
						2004-2005	\$20,500	Étude de l'EEG quantifié au cours de la veille et du sommeil chez des autistes de haut niveau	Neurosciences, Mental Health and Addiction	Clinical	

Prov	Research Area	PI	Co-P.I.	Awarding Body	Research Location	Fiscal Year	Amount	Project Title	Primary CIHR institute	Primary Theme		
QC	Nervous System	Barker, Philip A		CIHR	McGill University	2003-2004	\$57,750	Signaling mechanisms of the p75 neurotrophin receptor	Neurosciences, Mental Health and Addiction	Biomedical		
						2004-2005	\$77,000	Signaling mechanisms of the p75 neurotrophin receptor	Neurosciences, Mental Health and Addiction	Biomedical		
						2005-2006	\$77,000	Signaling mechanisms of the p75 neurotrophin receptor	Neurosciences, Mental Health and Addiction	Biomedical		
						2006-2007	\$77,000	Signaling mechanisms of the p75 neurotrophin receptor	Neurosciences, Mental Health and Addiction	Biomedical		
						2007-2008	\$77,000	Signaling mechanisms of the p75 neurotrophin receptor	Neurosciences, Mental Health and Addiction	Biomedical		
						2008-2009	\$19,250	Signaling mechanisms of the p75 neurotrophin receptor	Neurosciences, Mental Health and Addiction	Biomedical		
		Carmant, Lionel		CIHR	Hôpital Sainte-Justine (Montréal)	2002-2003	\$119,120	A randomised double blind trial of add-on flunarizine to prevent the cognitive deterioration associated with infantile spasms	Human Development, Child and Youth Health	Clinical		
						2003-2004	\$119,120	A randomised double blind trial of add-on flunarizine to prevent the cognitive deterioration associated with infantile spasms	Human Development, Child and Youth Health	Clinical		
						2004-2005	\$90,920	A randomised double blind trial of add-on flunarizine to prevent the cognitive deterioration associated with infantile spasms	Human Development, Child and Youth Health	Clinical		
						2005-2006	\$90,920	A randomised double blind trial of add-on flunarizine to prevent the cognitive deterioration associated with infantile spasms	Human Development, Child and Youth Health	Clinical		
				Fecteau, Shirley		CIHR	Université de Montréal	2000-2001	\$19,430	Transformation développementale des signes du désordre autistique		
								2001-2002	\$19,430	Transformation développementale des signes du désordre autistique		
2002-2003	\$8,333							Transformation développementale des signes du désordre autistique				

Prov	Research Area	PI	Co-P.I.	Awarding Body	Research Location	Fiscal Year	Amount	Project Title	Primary CIHR institute	Primary Theme		
QC	Nervous System	Fecteau, Shirley		CIHR	Université de Montréal	1999-2000	\$19,430	Transformation développementale des signes du désordre autistique				
		Godbout, Roger		CIHR	Université de Montréal	2001-2002	\$45,613	Studies of sleep, EEG and cognitive performance in pervasive developmental disorders	Neurosciences, Mental Health and Addiction	Clinical		
						2002-2003	\$68,216	Studies of sleep, EEG and cognitive performance in pervasive developmental disorders	Neurosciences, Mental Health and Addiction	Clinical		
						2003-2004	\$68,011	Studies of sleep, EEG and cognitive performance in pervasive developmental disorders	Neurosciences, Mental Health and Addiction	Clinical		
						2004-2005	\$34,005	Studies of sleep, EEG and cognitive performance in pervasive developmental disorders	Neurosciences, Mental Health and Addiction	Clinical		
		Limoges, Elyse		CIHR	Université de Montréal	2001-2002	\$19,530	Le sommeil, l'EEG et la performance cognitive dans l'autisme	Neurosciences, Mental Health and Addiction	Clinical		
						2002-2003	\$20,500	Le sommeil, l'EEG et la performance cognitive dans l'autisme	Neurosciences, Mental Health and Addiction	Clinical		
						2003-2004	\$20,500	Le sommeil, l'EEG et la performance cognitive dans l'autisme	Neurosciences, Mental Health and Addiction	Clinical		
		Mottron, Laurent		CIHR	Hôpital Rivière-des-Prairies (Montréal)	2001-2002	\$58,326	Characterizing cognitive deficit in pervasive developmental disorders	Neurosciences, Mental Health and Addiction	Biomedical		
						2002-2003	\$77,569	Characterizing cognitive deficit in pervasive developmental disorders	Neurosciences, Mental Health and Addiction	Biomedical		
						2003-2004	\$102,104	Characterizing cognitive deficit in pervasive developmental disorders	Neurosciences, Mental Health and Addiction	Biomedical		
								2004-2005	\$126,070	Characterizing cognitive deficit in pervasive developmental disorders	Neurosciences, Mental Health and Addiction	Biomedical
								2005-2006	\$127,233	Characterizing cognitive deficit in pervasive developmental disorders	Neurosciences, Mental Health and Addiction	Biomedical

Prov	Research Area	PI	Co-P.I.	Awarding Body	Research Location	Fiscal Year	Amount	Project Title	Primary CIHR institute	Primary Theme	
QC	Nervous System					2006-2007	\$64,484	Characterizing cognitive deficit in pervasive developmental disorders	Neurosciences, Mental Health and Addiction	Biomedical	
						Undetermined	1999-2000	\$67,577	Characterizing cognitive deficits in high-functioning autism and asperger syndrome		
						2000-2001	\$33,789	Characterizing cognitive deficits in high-functioning autism and asperger syndrome			
			Rouleau, Guy A		CIHR	Montreal General Hospital	2003-2004	\$12,056	Searching for genes predisposing to autism	Neurosciences, Mental Health and Addiction	Biomedical
			Joober, Ridha		CIHR	Research Institute of McGill University Health Ctr	2003-2004	\$90,873	Searching for genes predisposing to autism	Genetics	Biomedical
							2004-2005	\$137,061	Searching for genes predisposing to autism	Genetics	Biomedical
							2005-2006	\$137,061	Searching for genes predisposing to autism	Genetics	Biomedical
							2006-2007	\$68,530	Searching for genes predisposing to autism	Genetics	Biomedical
			Fombonne, Eric*		CIHR	McGill University	2003-2004	\$101,400	Training Program in Autism Research		
							2004-2005	\$101,400	Training Program in Autism Research		
							2005-2006	\$101,400	Training Program in Autism Research		
							2006-2007	\$101,400	Training Program in Autism Research		
							2007-2008	\$101,400	Training Program in Autism Research		
							2008-2009	\$101,400	Training Program in Autism Research		
		Szatmari, Peter		CIHR	McGill University	2002-2003	\$5,000	Training programme in autism research			
		Maziade, Michel*		CIHR	Université Laval	1999-2000	\$559,732	The genetics of complex psychiatric disorders: an integrated approach to the study of bipolar disorder, schizophrenia, alcoholism and autism			

Prov	Research Area	PI	Co-P.I.	Awarding Body	Research Location	Fiscal Year	Amount	Project Title	Primary CIHR institute	Primary Theme
QC	Nervous System	Maziade, Michel*				2000-2001	\$266,045	The genetics of complex psychiatric disorders: an integrated approach to the study of bipolar disorder, schizophrenia, alcoholism and autism		
	<i>Not Classified</i>	Lamarre, Yves		CIHR	Université de Montréal	2001-2002	\$30,261	Neurophysiologie du cerveau		
				NAAR	Center for Research in the Neurological Sciences, University of Montreal	1998-1999	\$69,561	Cerebellar and Cerebral Local Field Potential Oscillations. Relation with Attention and Movement		
	Psychology	Mottron, Laurent	Belleville, Sylvie	SSHRC	Université de Montréal	2001-2002	\$35,000	Étude de l'acquisition de nouvelles informations en mémoire dans l'autisme		Psychology
						2002-2003	\$36,000	Étude de l'acquisition de nouvelles informations en mémoire dans l'autisme		Psychology
		Grivas, Anna		SSHRC	McGill University	2003-2004	\$17,500	A developmental study of visual attention in persons with autism: issues of filtering efficiency and focus		
	Psychosocial/ Health Behavioural Research	Maziade, Michel*		CIHR	Université Laval	2000-2001	\$150,000	The genetics of complex psychiatric disorders: an integrated approach to the study of bipolar disorder, schizophrenia, alcoholism and autism	Neurosciences, Mental Health and Addiction	Biomedical
						2001-2002	\$300,000	The genetics of complex psychiatric disorders: an integrated approach to the study of bipolar disorder, schizophrenia, alcoholism and autism	Neurosciences, Mental Health and Addiction	Biomedical
						2002-2003	\$300,000	The genetics of complex psychiatric disorders: an integrated approach to the study of bipolar disorder, schizophrenia, alcoholism and autism	Neurosciences, Mental Health and Addiction	Biomedical
						2003-2004	\$300,000	The genetics of complex psychiatric disorders: an integrated approach to the study of bipolar disorder, schizophrenia, alcoholism and autism	Neurosciences, Mental Health and Addiction	Biomedical
							2004-2005	\$300,000	The genetics of complex psychiatric disorders: an integrated approach to the study of bipolar disorder, schizophrenia, alcoholism and autism	Neurosciences, Mental Health and Addiction

Prov	Research Area	PI	Co-P.I.	Awarding Body	Research Location	Fiscal Year	Amount	Project Title	Primary CIHR institute	Primary Theme
QC	Psychosocial/Health Behavioural Research	Maziade, Michel*				2005-2006	\$150,000	The genetics of complex psychiatric disorders: an integrated approach to the study of bipolar disorder, schizophrenia, alcoholism and autism	Neurosciences, Mental Health and Addiction	Biomedical
	Vision	Bertone, Armando		CIHR	Université de Montréal	2000-2001	\$2,086	An assessment of motion perception among high-functioning persons with autism		
						2001-2002	\$19,530	An assessment of motion perception among high-functioning persons with autism		
						2002-2003	\$20,500	An assessment of motion perception among high-functioning persons with autism		
						2003-2004	\$18,333	An assessment of motion perception among high-functioning persons with autism		
NB	Genetics	Clark, Denise V		CIHR	Undetermined	1999-2000	\$74,702	Genetics of purine nucleotide biosynthesis in Drosophila	Genetics	Biomedical
						2000-2001	\$74,702	Genetics of purine nucleotide biosynthesis in Drosophila	Genetics	Biomedical
						2001-2002	\$37,350	Genetics of purine nucleotide biosynthesis in Drosophila	Genetics	Biomedical
					University of New Brunswick	2001-2002	\$9,902	Genetics of purine nucleotide biosynthesis in Drosophila	Genetics	Biomedical
						2002-2003	\$53,584	Genetics of purine nucleotide biosynthesis in Drosophila	Genetics	Biomedical
						2003-2004	\$45,042	Genetics of purine nucleotide biosynthesis in Drosophila	Genetics	Biomedical
						2004-2005	\$45,042	Genetics of purine nucleotide biosynthesis in Drosophila	Genetics	Biomedical
NF	Nervous System	Mclean, John H		CIHR	Memorial University of Newfoundland	2001-2002	\$17,998	Making memories: Cellular correlates and circuit analysis in early olfactory learning	Neurosciences, Mental Health and Addiction	Biomedical
						2002-2003	\$29,463	Making memories: Cellular correlates and circuit analysis in early olfactory learning	Neurosciences, Mental Health and Addiction	Biomedical
						2003-2004	\$27,930	Making memories: Cellular correlates and circuit analysis in early olfactory learning	Neurosciences, Mental Health and Addiction	Biomedical

Prov	Research Area	PI	Co-P.I.	Awarding Body	Research Location	Fiscal Year	Amount	Project Title	Primary CIHR institute	Primary Theme
NF	Nervous System	Mclean, John H				2004-2005	\$13,965	Making memories: Cellular correlates and circuit analysis in early olfactory learning	Neurosciences, Mental Health and Addiction	Biomedical

* indicates the P.I. is also a Canada Research Chair

Note: As a researcher may be involved in more than one research area, some researchers will appear more than once in the above table. There are two possible reasons for multiple research area involvement: (1) CIHR awards sometimes change research areas, which are self-reported by the PI, over the life of the award; or (2) a researcher is involved in more than one research project, each with a different research area.

Summary Table – Researchers by Province

Prov	Self-Reported Research Area	PI	Awarding Body
AB	Child And Adolescent Psychology	Brown-Godsavé, Deborah	SSHRC
		Pencer, Alissa	SSHRC
	Exceptional, Special Education	Volden, Joanne C.	SSHRC
	<i>Not Classified</i>	Varnhagen, Connie K	CIHR
BC	Anthropology	Kulusic, Tamara	SSHRC
	Exceptional, Special Education	Smith, Veronica	SSHRC
	Genetics	Lewis, M.E. Suzanne	CIHR
	<i>Not Classified</i>	Wong, K.Y. Bibiana	NAAR
ON	Applied Linguistics	De Villiers, Jessica	SSHRC
	Behavioural Psychology	Konstantareas, Mary	SSHRC
	Child And Adolescent Psychology	Astington, Janet	SSHRC
	Genetics	Cordes, Sabine P	CIHR
		Scherer, Stephen W	CIHR
		Szatmari, Peter	CIHR
	Genomics, Proteomics, and Bioinformatics	Scherer, Stephen W	CIHR
	Imaging	Oram, Janis E	CIHR
	Mental Health	Szatmari, Peter	CIHR
		Zwaigenbaum, Lonnie	CIHR
	Molecular Biology	Cordes, Sabine P	CIHR
	Nervous System	Bryson, Susan E	CIHR
		Cordes, Sabine P	CIHR
		Holden, Jeanette J	CIHR
		Munoz, Douglas P*	CIHR
		Zwaigenbaum, Lonnie	NAAR
	<i>Not Classified</i>	Bryson, Susan E	NAAR
		Goldberg, Jeremy	NAAR
		Holden, Jeanette J	CIHR
		Roberts, Timothy	NAAR
		Roberts, Wendy	NAAR
		Szatmari, Peter	CIHR
		Zwaigenbaum, Lonnie	NAAR
	Psychology	Penn, Helen	SSHRC
		Spadafora, Alison	SSHRC
	Psychosocial/ Health Behavioural Research	Feldman, Maurice A	CIHR
		King, Gillian A	CIHR
O'Neill, Daniela K		CIHR	
QC	Cell Biology	Barker, Philip A	CIHR
	Education; Educational Psychology	Burack, Jacob	SSHRC
		Joseph, Shari	SSHRC
		Flanagan, Tara	SSHRC
	Exceptional, Special Education	Burack, Jacob	SSHRC
	Genetics	Rouleau, Guy A	CIHR
	Mental Health	Bolduc, Christianne	CIHR
	Nervous System	Barker, Philip A	CIHR
Carmant, Lionel		CIHR	

Prov	Self-Reported Research Area	PI	Awarding Body
QC	Nervous System	Fecteau, Shirley	CIHR
		Godbout, Roger	CIHR
		Limoges, Elyse	CIHR
		Mottron, Laurent	CIHR
		Rouleau, Guy A	CIHR
		Fombonne, Eric*	CIHR
		Maziade, Michel*	CIHR
	<i>Not Classified</i>	Lamarre, Yves	CIHR NAAR
	Psychology	Mottron, Laurent	SSHRC
		Grivas, Anna	SSHRC
Psychosocial/ Health Behavioural Research	Maziade, Michel*	CIHR	
Vision	Bertone, Armando	CIHR	
NB	Genetics	Clark, Denise V	CIHR
NF	Nervous System	Mclean, John H	CIHR

* indicates the P.I. is also a Canada Research Chair

Note: As a researcher may be involved in more than one research area, some researchers will appear more than once in the above table. There are two possible reasons for multiple research area involvement: (1) CIHR awards sometimes change research areas, which are self-reported by the PI, over the life of the award; or (2) a researcher is involved in more than one research project, each with a different research area.

Appendix B Canada Research Chair Holders

Name of Chairholder	Research Area	Research Location	Research Involves	Research Relevance	Summary
Jorge L. Armony	Affective Neuroscience	McGill University	Clinical research to measure how the brain detects, analyzes and responds to environmental events, especially those that signal danger.	Improved treatment of disorders such as phobias, anxiety and post traumatic stress disorder	<p>Fear Factors</p> <p>About 12 percent of Canadians are affected by anxiety disorders, according to the Canadian Mental Health Association. In the United States, the number may be even higher. Most of these disorders involve the fear system of the brain, and many other psychiatric disorders – including schizophrenia, depression, eating disorders and autism – also have a significant emotional component. While our ability to react appropriately in emotional situations is an essential part of what makes us human – allowing us to laugh, grieve, feel embarrassed and fall in love – our emotions can also interrupt our normal cognitive processes. Emotion has not traditionally been included in the study of either cognitive science or neuroscience.</p> <p>That situation has changed in recent years, and one of the researchers who has been examining the neural basis of emotional processing is Dr. Jorge Armony. Among his previous work is the use of functional magnetic resonance imaging (fMRI) to measure brain activity during psychological tasks.</p> <p>Dr. Armony's research as Canada Research Chair in Affective Neuroscience will explore how emotional processes interact with cognitive mechanisms, particularly attention and memory. He expects his findings to shed light on the important issue of how the brain deals with multiple, sometimes opposing, demands. The research will build on previous work that indicated that prolonged anxiety does not force the brain to re-learn how to react, but rather creates competition among learned patterns and triggers an emotional response.</p> <p>Among his approaches will be a variety of experimental tools, including measures of autonomic activity – such as electrodermal responses, heart rate and blood pressure – and event-related fMRI. His research findings will enable him to address the critical question of what happens when some components of the cognitive-emotional interaction in the brain become maladaptive, leading to psychiatric conditions like phobias, panic attacks and post traumatic stress disorder. This knowledge holds the potential to fuel the development of clinical methods to treat these disorders.</p>

Name of Chairholder	Research Area	Research Location	Research Involves	Research Relevance	Summary
Eric Fombonne	Child and Adolescent Psychiatry	McGill University	The study of psychopathology in children and adolescents using a developmental perspective.	Research will lead to a better understanding of autism and childhood/adolescent depression, and promote research into other disorders.	<p>Understanding Autism and Depression in the Young</p> <p>Developmental psychopathology is concerned with the relationship between normal and atypical development, and the identification of risk mechanisms that lead to the onset, persistence and offset of disorders over the developmental course. This science relies on a set of different research strategies which are characterized by an attempt to integrate measurement approaches across domains (i.e. genetic, biological, physiological, behavioural, social) and by the use of epidemiological (related to the incidence and distribution of disease) and longitudinal approaches to study various child psychiatric disorders.</p> <p>Dr. Eric Fombonne's research sits at the interface of psychiatry, social and developmental sciences, and human genetics. It relies on epidemiological approaches to investigate childhood psychopathology in general, with a strong focus on two groups of disorders: autism and pervasive developmental disorders, and emotional disorders (in particular, childhood and adolescent onset depression). As Canada Research Chair in Child and Adolescent Psychiatry, Dr. Fombonne has three main objectives for his studies: to improve our understanding of the etiology and outcome of autism, and to promote high quality assessment services, interventions, support and social integration over the lifetime; to increase our understanding of the mechanisms leading to child/adolescent affective disorders, and to research the efficacy of their treatment and prevention; and to promote research on other child psychiatric disorders and child mental health.</p> <p>Recognized internationally for his expertise in epidemiological child psychiatry, particularly in the field of autism, Dr. Fombonne will attract highly-qualified students and visiting scientists, and will foster collaborations with institutes such as the Genomic Centre, the Douglas Research Institute and the Montreal Neurological Institute. He sees as one of his major roles to provide advice on research methods and to facilitate the development of younger investigators' research.</p>

Name of Chairholder	Research Area	Research Location	Research Involves	Research Relevance	Summary
Michel Maziade	Genetics of Neuropsychiatric Disorders	Université Laval	Analysis of genetic material to detect linkages in susceptibility to schizophrenia and bipolar disorder.	Will aid in determining the genetic causes of severe neuropsychiatric disorders and in developing curative treatment.	<p>Untangling Genetic Knots</p> <p>Collectively, schizophrenia, bipolar disorder, alcoholism and autism affect more than 15 percent of Canadians, whose treatment costs more than 13 percent of the health care budget. The cost in terms of human suffering, family disruption and lost income is immeasurable.</p> <p>As Canada Research Chair in the Genetics of Neuropsychiatric Disorders, Dr. Michel Maziade's goal is to identify the susceptibility genes for these disorders, which will lead to more efficient diagnostic methods and allow for novel, individualized treatment. His particular interest is in finding the susceptibility genes that cause these illnesses.</p> <p>Dr. Maziade's research team has already completed significant work in the areas of isolating endophenotypes in autism, developing high-output genotyping for scanning the genome for schizophrenia and bipolar disorder, investigating common genetic mechanisms, and developing new analytical approaches to deal with genetic heterogeneity and direct linkage under complex transmission.</p> <p>Despite these achievements, funding issues have prevented the team (which is supported by a CIHR group grant) from exploiting the full potential of its samples, technologies and interdisciplinary collaborative links. The Canada Research Chair will increase the resources the team can bring toward making meaningful discoveries in the genetic underpinning of the four disorders. Dr. Maziade has identified seven specific areas of research concentration: work with its extensive sample of genetic material from families in eastern Quebec; screening the genome to identify susceptibility loci; defining dimensional phenotypes for molecular studies; identifying homogeneous subtypes of schizophrenia; developing novel analytic techniques for gene interactions; applying genomics and bioinformatics to psychiatric genetics; and developing a interdisciplinary environment for training (interlacing three universities and two languages).</p>

Name of Chairholder	Research Area	Research Location	Research Involves	Research Relevance	Summary
François Michaud	Robotics and Mobile Intelligent Systems	Université de Sherbrooke	Mobile robotics, multi-agent and artificial intelligence	Providing robots with the ability to move around in, and understand, unpredictable environments will expand their usefulness.	<p>A Declaration of Robotic Independence</p> <p>Today's robots are generally used for the repetitive and specific tasks in a known and constrained operating system. The next step in robotics will be mobile robots; ones that will work in hostile environments or help people with everyday activities.</p> <p>At the Université de Sherbrooke, Dr. François Michaud is taking that step. Some of today's robots can already move on wheels, tracks and even legs. What they lack are sensors to help them figure out new environments, and the artificial intelligence to decide how to move around in the unpredictable real world.</p> <p>As Chair of Mobile Robotics and Autonomous Intelligent Systems, Dr. Michaud has divided this problem into its four components: modularity (in which interchangeable hardware and software can be used for different jobs); interaction (in which robots work together on complex jobs); learning (so that the robot can adapt to new environments or user preferences); and holistic design approaches (which means looking at systems as a whole rather than as a collection of components).</p> <p>His team's current projects include analyzing how robot groups react when they have to trade off accomplishing a task with survival of all the group's members; designing a remote-controlled robot that can do some tasks on its own; "teaching" teams of robots to work together; working on sensors that can track objects in 3-D space; and developing robots that can play with children.</p> <p>These experiments will have broad applications in health care (where remote-controlled robots can stretch overtaxed health care systems or robotic toys can help children with autism open up to their surroundings), automobiles (where robots can help drivers), and building architecture (where wireless technology can augment automation).</p>

Name of Chairholder	Research Area	Research Location	Research Involves	Research Relevance	Summary
Douglas Munoz	Neuroscience	Queen's University at Kingston	The neural processes controlling rapid eye movements—called saccades	Helping to diagnose and treat neurological and psychiatric disorders including Parkinson's disease, Alzheimer's disease, autism, Tourette syndrome, and Attention Deficit Hyperactivity Disorder	<p>Rapid Eye Movements: Diagnosis of Disease</p> <p>The movement of our eyes is key to how our brain interprets and analyzes what we see. In his laboratory at Queen's University, Doug Munoz has invented an apparatus and a system for diagnosing neurological disorders—by detecting his subject's eye movement.</p> <p>One of the central nervous system's most important functions is its ability to generate movement in response to the stimulation of the senses. Rapid eye movements, called saccadic movements, have helped scientists understand motor control and the brain's ability to process sensory input. That's because between rapid eye movements, the eyes have to remain fixed in place so the visual system can analyze the image it has just captured.</p> <p>People with particular neurological disorders are often unable to suppress unwanted eye movements. Using that information, Munoz has been measuring eye movements to try to develop a test that will help diagnose these disorders. The award of this Canada Research Chair will allow him to build on his previous discoveries and unravel the connections between neurons and how they are connected into circuits in the brain that control cognitive processes, including attention, working memory, and decision-making.</p> <p>Munoz has already begun testing his hypothesis: that there is an objective measurement of Attention Deficit Hyperactivity Disorder—an increasingly commonplace diagnosis among children. Right now, ADHD can only be diagnosed through a subjective analysis of behaviour, provided by parents, teachers, and doctors. But Munoz's initial trials have demonstrated that children with ADHD have difficulty suppressing unwanted saccades (rapid eye movements). And that may be the key to an objective and definitive measurement.</p> <p>As a leading international researcher in this area, this award will only enhance the reputation of both Queen's University and Canada as being at the forefront of neurological science. Munoz's research will have practical applications and insights for both the diagnosis and treatment of these disorders.</p>

Name of Chairholder	Research Area	Research Location	Research Involves	Research Relevance	Summary
Elizabeth M. Simpson	Genetics and Behaviour	University of British Columbia	Exploring the links between genetics, brain development and behaviour	Development of new diagnostic techniques and drug therapies for specific brain disorders	<p>The Genetics of Behaviour</p> <p>Is violent behaviour just another symptom of mental disease? Are some people doomed to become violent because of a flaw in their genes? How much can animal studies reveal about the genetic and developmental mechanisms behind human brain disorders?</p> <p>Answering these questions may one day lead to innovative new treatments for anti-social behaviour.</p> <p>And where will the answers come from? Mice. They're being enlisted and put to good use in all kinds of scientific explorations. Even if they lack the higher brain functions of humans, mice are helping advance this critical area of research.</p> <p>Dr. Elizabeth Simpson and her colleagues at UBC's Centre for Molecular Medicine and Therapeutics have made significant advances in designing mouse models for human brain disorders. Their work builds on the fact that when it comes down to basic chemistry and genes, human and mouse are close matches. In fact, mice get many of the same diseases people do—diabetes, cancer and cardiovascular problems—and they develop these conditions for the same reasons that people do.</p> <p>For studies of human behaviour it is also critical that mice, like humans, are social animals, which naturally live in extended families. Both parents are important for the successful raising of young. Studying family interaction among mice may reveal important new information about the ways humans form family and social bonds.</p> <p>Do mice also suffer from brain disorders like schizophrenia, autism and pathological violence? Would we know a depressed mouse if we saw one? If Simpson's studies prove that genetic mutations can lead to such brain abnormalities in mice, future studies may lead to similar findings in humans.</p> <p>The Canada Research Chair strengthens Simpson's leadership in this groundbreaking area of research. Once a link between genetics and behaviour is scientifically established, it could lead to new therapies for mental disorders, including (1) a test for determining whether an individual has a genetic predisposition toward certain pathological behaviours and (2) a drug which reverses the effect of the mutant gene and restores normal behaviour.</p>

Name of Chairholder	Research Area	Research Location	Research Involves	Research Relevance	Summary
Philip D. Zelazo	Developmental Neuroscience	University of Toronto	Study of children aged two to five years to understand development of affective decision-making at behavioural, cognitive, and neurological levels of analysis.	Will lead to developing a profile that can be used to recognize children at risk of frontal lobe dysfunction, as well as possible intervention methods.	<p>Tracking the Age of Reason</p> <p>The ability of human beings to think rationally is our most unique attribute, but when does rational decision-making begin and how does it develop during childhood? These questions form the basis of the research Dr. Philip Zelazo has pursued for more than a decade. Much of his work has revolved around the development of executive function (EF) - the psychological processes involved in the conscious control of thought and action.</p> <p>In his previous work, Dr. Zelazo has attracted notice for his theory that children come to follow increasingly complex sets of rules by creating hierarchies of rules and choosing between them to regulate their behaviour. His work has been seen as a significant step beyond existing theories of cognitive development, and plays an important role in recognizing symptoms of autism and other developmental disorders associated with EF.</p> <p>As the Canada Research Chair in Developmental Neuroscience at the University of Toronto, Dr. Zelazo will expand his research to focus on the process of making decisions with uncertain personal consequences, or affective decision-making. Dr. Zelazo will study children aged two to five to try to ascertain when and how this aspect of EF develops. The research will involve measuring the cognitive and neurological processes of children using skin conductance and event-related potentials (ERP), which provides important information about neural mechanisms associated with specific behavioural and cognitive processes.</p> <p>It is known that affective decision-making is linked to systems involving the ventromedial prefrontal (VMF) cortex of the brain; for example, adults with damage to their VMF frequently perform poorly on affective decision-making tests. Dr. Zelazo's work promises to provide insight into EF and its development - at the behavioural, cognitive and neurological levels. This understanding will help Dr. Zelazo, his students and collaborators to characterize children at risk for disorders related to EF and create effective programs for therapeutic intervention and cognitive neurorehabilitation.</p>

Appendix C MSFHR Survey Results - Autism Researchers³⁵

Research Area	Pr	Principal Investigator	Funding Agency Program Family and Name	Parent Institution; Research Institution	Dates and Terms of Project	Award Amount	Research Project Title	Data Set/Patient Population Size	Other information
Multidisciplinary	BC	Helena Ho	Woodward Foundation	Sunny Hill/Children's Hospital of Eastern Ontario	2000	\$39,000	Effects of Secretin on Children with Autism	100 children under 6 with ASD	Collaborative double blind cross over drug study
Multidisciplinary	BC	Linda C. Eaves	BC Medical Services Foundation	Sunny Hill Health Centre for Children	1997-2003	\$50,000	The very early identification of Autism: follow-up to age 5 of children identified at 2 years	49 children first seen at 2, followed to age 5	This study used data from multidisciplinary team assessments including medical, psychological and language.
Psychology/ Psychosocial health behavioural/ Education	BC	Dr. Maureen Hoskyn	SSHRC- New Investigators Grant	Simon Fraser University	Sept. 2002- Sept. 2004	\$10,000	Social development of Children with Fragile X syndrome	Multiple case study/toddler, preschool and early school-aged girls with Fragile-X syndrome or permutation and girls with Autism	The project examines 1) factors that influence social development for children with Fragile-X syndrome and 2) ways that children with Fragile X syndrome differ from children with Autism.
Psychosocial health behavioural	BC	Grace Iarocci	Human Early Learning Partnership-MCFD-UBC	UBC	July 2002-July 2005	\$50,000 pilot grant	Multisensory Processing and Integration in children with autism	Children with ASD 20 in each of three groups— children under 6, older than 6, and adolescents	Investigates early sensory and attentional disturbances and their relationship to social-cognitive skill deficits in young children with autism.
Genetics	BC	M.E. Suzanne Lewis	CIHR—New Operating Grant	Children and Women's Health Centre of BC and BC Research Institute for Children and Women's Health	Oct 2003 to September 2006	\$327,120	Autism Spectrum Disorders: Identification of culprit genes using genomic microarrays and molecular assessments of duplicon-mediated micro-deletions and duplications	100 multiple incidence (multiplex) families with ASD from BC and across Canada and the USA	Subjects recruited via regional teams and centers affiliated with ASD-CARC
Education/ Genetics/ Mental Health/ Molecular Biology/ Nervous System/ Linguistics/ Psychology	BC	M.E. Suzanne Lewis	CIHR- in collaboration with Institute of Genetics	Department of Medical Genetics-UBC	Oct 2002-Sept. 2004	\$240,000	New approaches toward understanding the genetic bases of form, function and phenotype in ASD	400 multiple incidence families across Canada recruited with ASD-CARC; 50 infants at risk for ASD based on interdisciplinary prospective studies of genotype-phenotype correlations	

³⁵ Research projects still at the application stage have been omitted from this table.

Research Area	Pr	Principal Investigator	Funding Agency Program Family and Name	Parent Institution; Research Institution	Dates and Terms of Project	Award Amount	Research Project Title	Data Set/Patient Population Size	Other information
Genetics	BC	Dr. Elizabeth M. Simpson (Supervisor) and Bibiana K.Y. Wong (PhD Candidate)	National Alliance for Autism Research	UBC	July 2003-August 2005	Salary grant only-amount unspecified	Mouse models of Autism: Behaviour and Genetics Aim 1—establish behaviour tests to accurately characterize autistic like behaviours in mice Aim 2—study mice with different combinations of autism candidate genes, test the hypothesis that genes in mother and developing foetus can interact to cause autism Aim 3- perform a quantitative trait loci analysis to identify genes involved in autistic like behaviour	No human subjects	
Psychosocial health behavioural	AB	Sherry Thompson	Alberta Children's Services	Alberta Children's Services	Stage one report: January 2001, Stage Two report: August 2002	\$70,111 for Stage Two Research	Three stage research and evaluation strategy: One: a review of the literature and research on IBI programs for children with Autism Two: comparative evaluation of the IBI pilot project delivered by Family Linkages Foundation of Alberta Three: service inventory	Stage Two: Comprised 15 children with average age of seven years	
	AB	W.B. Gibbard	Alberta Children's Hospital foundation/ ReMax Southern Alberta fellowship	Centre for Advancement of Health	2001-2004	\$1500	Complementary and Alternative Approaches to Diagnosis and Treatment for children with ASD: Patterns of Use	Population size estimated at 400-500 Multiple sites: schools, intervention providers, interest groups.	Data set includes information of complementary and alternative therapies and diagnostic test utilization, perceived effectiveness, physician-parent/patient communication, conventional treatments used, ASD diagnostic information, other medical variables and sociodemographic information.
	SK	No reported autism research in Saskatchewan							

Research Area	Pr	Principal Investigator	Funding Agency Program Family and Name	Parent Institution; Research Institution	Dates and Terms of Project	Award Amount	Research Project Title	Data Set/Patient Population Size	Other information
	MB	No reported research							
	YT	No reported autism research in Yukon							
	NT	No reported autism research in NWT.							

Appendix D MSFHR Survey: Database Information

Province	Organization Administering Database	Database Administrator	Purposes for which data is collected And used	Year Database established	Continuously Maintained?	Privacy status	Notes
BC	Provincial Autism Resource Centre Clinic	Stephen Wellington c/o Sunny Hill Health Centre for Children	Health Care Services, Administrative, Longitudinal tracking, Research, Outcome and Evaluation	2002	Yes	Confidential. Cannot be used outside the PARC clinic without research/ethics approval from the Children and Women's Hospital and UBC.	Data pertain to clinical ASD assessment and diagnostic services for children and youth from 0 to 19 years. Current intake accepts referrals from all of BC – approx. 50 to 80 new referrals a month. Data to be provided by Regional Service teams under the five other Health Authorities as capacity develops. After April, 2003, ASD assessment and diagnostic services for children and youth over six are documented by completion of forms required by MCFD to release funding. An effective way of getting these forms to PHSA is being developed. Anelectronic provincial database system is scheduled for release in Spring 2004 (see also Section 7.1.
BC	Vancouver Island Health Authority	Phyllis Straathof Manager, Child and Family Rehabilitation Services, Queen Alexandra Centre for Children's Health	Health Care Services, Administrative, Longitudinal tracking, Outcome and Evaluation	Not yet available	N/A	N/A	Under the terms of the PHSA's proposal with the Ministry of Health Planning/Services, the Health Authorities are accountable for maintaining a regional database. These data pertain to clinical ASD assessment and diagnostic services for children under six years. Utilization of the provincial electronic database for ages 0-19 years is anticipated as of Spring 2004.
BC	Northern Health Authority	Carol Oosthuizen Director CDC Kathy MacDonald Regional Director Preventive Health	Health Care Services, Administrative, Longitudinal tracking, Outcome and Evaluation	Not yet available	N/A	N/A	See Vancouver Island Health Authority above.
BC	Interior Health Authority, Mental Health Support Team	Randy James	Health Care Services, Administrative	Fall 2003	Not yet implemented	TBA	See Vancouver Island Health Authority above.
BC	Child Development Centres/Infant Development Programs	Various	Health Care Services, Administrative, Longitudinal tracking	Not available yet	N/A		The BC Association for Child Development and Rehabilitation is a provincial association of agencies which provide child development and therapy services to children with special needs (age 3-6 years.) Many of the secondary clinical assessments for ASD could be performed in the Health Authorities using infrastructure provided by the Child Development Centres and Infant Development Programs; they have been listed here as potential sources of clinical/administrative data.

Province	Organization Administering Database	Database Administrator	Purposes for which data is collected And used	Year Database established	Continuously Maintained?	Privacy status	Notes
BC	BC Ministries of Government and Affiliates	various	Health Care Services, Education Services, Administrative, Social Services, Longitudinal tracking, Outcome and evaluation	N/A	N/A	N/A	The Ministry of Child and Family Development; Ministry of Health and Ministry of Education have extensive administrative data sets about children/youth with ASD. These datasets represent a vital link in the creation of an integrated research platform.
BC	Edudata Canada	Victor Glickman Faculty of Education, UBC	Education Services, Administrative, Longitudinal tracking, Research. Can also link to other Health and Economic data sets	unknown	Yes	Subject to privacy and confidentiality guidelines	Edudata Canada develops research databases of educational data from BC and elsewhere. Focuses on the k-12 sector.
BC	Intervention Service Providers	various	Longitudinal tracking, Outcome and Evaluation	N/A	N/A	unknown	There are few ASD outcome studies that are ongoing in BC; difficulties are the plethora of intervention services offered and difficulty in controlling for comparative purposes. Quality and completeness for these intervention providers is unknown.
BC	UBC, funded by BC Ministry of Children and Family Development.	Pat Mirenda, PhD	Early Intensive Behavioural Intervention (EIBI) and Interim Early Intensive Intervention (IEII) Outcome Data	2001	Yes.	All information in the database is confidential and cannot be used outside of the autism evaluation project without permission from the parents who consented to participate.	Current database has approximately 3,000 variable fields and is expanding monthly. 39 children who receive EIBI services and 38 who receive IEII services are represented.
AB	No Databases reported by Alberta						
SK	Saskatchewan sent list of data elements but did not describe database						
MB	St. Amant Centre	Jill Franchuk	Education Services, Longitudinal tracking	2003	Yes	All information collected in the database is protected under the Personal Health Information Act and subject to requirements of the Psychological Association of Manitoba.	Database is linked to the provision of Applied Behaviour Analysis programming to preschool children with autism. Tracks individual child program progress and allows clinical consultants to query specific responses.

Province	Organization Administering Database	Database Administrator	Purposes for which data is collected And used	Year Database established	Continuously Maintained?	Privacy status	Notes
MB	St. Amant Centre	Jill Franchuk	Education Services, Longitudinal tracking	2003	Yes	All information collected in the database is protected under the Personal Health Information Act and subject to requirements of the Psychological Association of Manitoba.	Database is linked to the provision of ABA programming to preschool children with autism. Tracks each child's/guardian's responding on standardized assessment at baseline and over time (follows program assessment protocol for retesting at indicated intervals).
MB	St. Amant Centre	Jill Franchuk	Education Services, Administrative, Longitudinal tracking	2002	Yes	All information collected in the database is protected under the Personal Health Information Act and subject to requirements of the Psychological Association of Manitoba.	Database is linked to the provision of ABA programming to preschool children with Autism. Tracks each applicant to the program, notes intake activities, identifies team members and service dates/activities.
BC, Southern AB, MB, YT	Autism Spectrum Disorders Canadian American Research Consortium	Helene Ouellette-Kuntz, Epidemiology Project Director, ASD-CARC	Research	2001	Yes	To protect privacy, the information in the database is anonymized and the database itself is secure. Access is restricted to designated research staff as per research ethics approvals.	ASD-CARC's database added western regions as follows: 2002: BC, Yukon, Manitoba 2003: southern Alberta

Databases Under Development

Province	Organization Administering Database	Database Administrator	Purposes for which data is collected And used	Year Database established	Continuously Maintained?	Privacy status	Notes
BC	Vancouver Coastal Health Authority	Jan Weaver Director Richmond Health Services	Health Care Services; Administrative; Longitudinal tracking; Outcome and Evaluation	Not yet available	N/A	N/A	The business plan for under 6's assessments and diagnosis identifies two locations for assessment/diagnosis to occur – Sunny Hill and North Shore. VCHA will work in partnership with PARC/BCAAN and VCH Information Management/Information Systems to achieve a mechanism. The VCHA is currently implementing PARIS (Primary Access Regional Information System) in Vancouver Community and Richmond Health Services. At this point, VCHA is implementing registration and referral functionality; however, the vision is for PARIS to become the community health electronic record that would link with the hospitals e-record.

Databases Under Development							
Province	Organization Administering Database	Database Administrator	Purposes for which data is collected And used	Year Database established	Continuously Maintained?	Privacy status	Notes
BC	Fraser Health Authority	Loretta Solomon	Health Care Services; Administrative; Longitudinal tracking; Outcome and Evaluation	Not yet available	N/A	N/A	

Appendix E CAIRN Member List

CAIRN Members as at October 2003

Mehran Alaei	Paul McDonnell
Valerie Barsky	Pat Mirenda
Marlene Breitenbach	Andrea Noonan
Susan Bryson*	Elizabeth Oliver
Jake Burack	Adrienne Perry
Eleanor Chornoboy	Jo-Ann Reitzel
Patricia Colton	Wendy Roberts*
Penny Corkum	Isabel Smith
Barbara D'Entremont	Margaret Spoelstra
Linda Eaves	Liz Starr
Kathryn Everest	Christina Strawbridge
Eric Fombonne*	Jane Summers
Erica Gatten	Peter Szatmari*
Robert Gauthier	Nancy Taylor
Keith Goulden	Sherry Thompson
Vicki Harvey	Lee Tidmarsh
Joy Hauck	Joanne Volden*
Jane Heintz-Grove	Kim Ward
Helena Ho	Steven Wellington
Marianne Knox	Margaret Whelan
Sheila Laredo	Heather Wingert
Michael Lewis	Lonnie Zwaigenbaum*
Mary MacDonald	

*These researchers are receiving CIHR, SSHRC, and NAAR awards, as analyzed in this report.

Appendix F ASD-CARC Member List (Canada)

Project Teams

1. Research Registry

By joining the Research Registry, families with a single or multiple cases of ASD can join in various research projects carried out by members of the ASD-CARC. Some of these research projects are "on-line", whereas others involve a variety of laboratory procedures. New studies are added to the On-Line Research Projects every few months, or more frequently, for example, the Fragile X Syndrome Research Registry, which will help better characterize subgroups of Fragile X Syndrome, including those with and without ASD symptoms, Prader-Willi-like symptoms, etc.).

Project Leaders: Jeanette J.A. Holden, PhD and Nathalie Garcin, PhD

Project Members: Melissa Hudson, BSc; Hugh Finnigan, BA

2. Clinical & Behavioural Phenotyping

To discover the subtle behavioural and clinical differences among individuals with ASD – and their family members – several different research projects have been and are being designed to assess different characteristics of the ASD "phenotype". This Team of behavioural, developmental, and clinical psychologists, paediatricians, neuroscientists, neurophysiologists, and biochemists have come together to develop questionnaires and laboratory procedures to assess different aspects of ASD, with the objective of defining "ASD subgroups" that share specific characteristics. Such sub-grouping will ultimately lead to the development of specific diagnostic tests and hopefully specific treatments for individual subgroups of ASD.

Project Leaders: Jeanette J.A. Holden, PhD, Ira Cohen, PhD, and Nathalie Garcin, PhD

Project Members: Rebecca Ward, PhD (Coordinator); Jim Bebko, PhD; Ira Cohen, PhD; John Connolly, PhD; Gregory Davies, MD; Deborah Dewey, PhD; Alison Fleming, PhD; Nathalie Garcin, PhD; Suzanne Hala, PhD; Helena Ho, MD; Liza Kasmara, BA; Mandy Kay-Raining Bird, PhD; Kang Lee, PhD; Suzanne Lewis, MD; Bruce McCreary, MD; Elizabeth Mickelson, MD; Patricia Minnes, PhD; Darwin Muir, PhD; Emanuela Mundo, PhD; Kevin Munhall, PhD; Doug Munoz, PhD; Marie-Helene Prud'homme, PhD; Mark Sabbagh, PhD; Garth Smith, MD; Graeme Smith, MD, PhD; Mike Storr, MD; Phillip Welch, MD; Janet Werker, PhD; Dickie Yu, PhD

3. Genetics

ASDs are highly genetic. In order to identify genes important in the etiology of ASDs, the team is combining direct studies of genes with the study of chromosome abnormalities and morphological features to identify "ASD subgroups". Identifying the genes involved in susceptibility to ASD may lead to novel treatments. This area includes four genetics projects: Molecular Genetics, Cytogenetics, Dysmorphology and Statistical Genetics.

Project Leader: Jeanette J.A. Holden, PhD and Suzanne Lewis, MD

3a) Molecular Genetics

Laboratory characterizing a variety of genes to identify those involved in susceptibility to ASD, using modern molecular genetic methods.

Project Leader: Jeanette J.A. Holden, PhD

Team Members: Xudong Liu, PhD - Research Associate and Laboratory Manager; Melissa Hudson, BSc - Research Assistant; Cuiling Zhang - Research Assistant; Huiping Zhang, PhD Candidate; Sonia Robitaille, MSc Candidate; Joe Hettinger, MSc Candidate; Patrick Malenfant, PhD Candidate.

3b) Cytogenetics

A variety of chromosome abnormalities have been associated with ASD. Families with two or more affected children, as well as families where there appear to be subtle clinical abnormalities, are being assessed to determine whether there are very small chromosome abnormalities. Such findings can pinpoint the location of genes that may be involved in ASD.

Project Leaders: Ikuko Teshima, PhD and Evica Rajcan-Separovic, PhD

3c) Dysmorphology

Project Leader: Cynthia Forster-Gibson, MD, PhD

Team Members: Judith Allanson, MD; Suzanne Lewis, MD; Francois Bernier, MD; Albert Chudley, MD; Sandra Farrell, MD; Rick Ward, PhD

3d) Statistical Genetics

Project Leaders: Fabio Macciardi, MD, PhD, and Xudong Liu, PhD

4. Prospective Study of ASD

There is growing evidence that early intervention is effective in reducing or, in some cases, completely eliminating symptoms associated with ASD. The team's goal is to identify autistic precursors during infancy and intervene to prevent the full expression and diagnosis of ASD. The team will monitor very early development of autistic symptoms in 400 at-risk infants who have a sibling with ASD.

Project Leaders: Maurice Feldman, PhD; Rebecca Ward, PhD; Jeanette Holden, PhD

Team Members: Margaret Bauman, MD; Jim Bebko, PhD; Francois Bernier, MD; Ira Cohen, MD; Sandra Farrell, MD; Allison Fleming, PhD; Jennifer Hill-Karrer, PhD; Suzanne Lewis, MD; Kevin Munhall, PhD; Darwin Muir, PhD; Allison Nicholls; Peter Vietze, PhD; Janet Werker, PhD; Dickie Yu, PhD

5. Parent Advisory Group

The Parent Advisory Group currently has 15 parent members as well as one individual with an ASD. They meet every three to four months in Ottawa and have a private online forum for more frequent communications. They review questionnaires and new projects on a regular basis, and have developed a questionnaire for families that is part of the Phenotyping Study.

Team Leader: Anita Acheson, BSc

6. Epidemiology of ASDs in Canada

The National Epidemiologic Database for the Study of Autism in Canada (NEDSAC) is collecting anonymous information on Canadian children who have been diagnosed with or who are suspected of having an autism spectrum disorder (ASD). These data will be used to estimate the prevalence and incidence of ASDs among children in Canada, and to examine geographic variations and changes over time.

Project Director/Regional Team Leader (Ontario): H  l  ne Ouellette-Kuntz, MSc, RN

Team Members: Helen Coo, MSc, Epidemiology Project Coordinator and Regional Project Coordinator (Ontario); Noor Ramji, Research Assistant (Ontario); Paula Hennessey, Regional Team Co-Leader (Newfoundland & Labrador); Robert Gauthier, Regional Team Co-Leader (Newfoundland & Labrador); Linda Longerich, Regional Project Coordinator (Newfoundland & Labrador); Andrea Noonan, MA, Regional Team Leader (Prince Edward Island); Dickie Yu, PhD, Regional Team Leader (Manitoba); Talia Prosick, BSc, Regional Project Coordinator (Manitoba); Fran  ois Bernier, MD, Regional Team Co-Leader (Alberta); Deborah Dewey, PhD, Regional Team Co-Leader (Alberta); Debra Busic, Regional Project Coordinator (Alberta); Suzanne Lewis, MD, Regional Team Leader (British Columbia); Susan Creighton, MS, Regional Project Coordinator (British Columbia); Linda Eaves, PhD, Consultant (British Columbia); Liza Kasmara, BA, Research Assistant (British Columbia)

Regional Teams

British Columbia (Vancouver) Regional Team:

The BC Interdisciplinary Health Research Team (IHRT) Autism Research Team (ASD-RT) is well-positioned to contribute broadly to the spectrum of projects and discoveries related to discerning the genetics of Autism Spectrum Disorder, and in this process, better understanding its incidence, diagnosis, management and prevention. The clinical members of the team actively contribute to a broad spectrum of clinical and academic programs funded by the BC Provincial Health Authority, and, in the course of that, provide highly specialized, tertiary care for the Children and Families across British Columbia. Suzanne Lewis, who leads the regional team, has recently received significant autism-related funding, in the form of a CIHR Clinical Investigatorship award (see Section 3.2.1).

Regional Leader: Suzanne Lewis, MD, FRCPC, FCCMG (Clinical Phenotyping, Genetics, Epidemiology, Prospective Study)

Team Members: Elizabeth Mickelson, MD, FRCPC (Clinical Phenotyping); Bruce Bjornson, MD, FRCPC (Imaging); Helena Ho, MD, FRCPC (Behavioural Phenotyping); Dagmar Kalousek, MD, FRCPC (Cytogenetics); Janet Werker, PhD (Behavioural Phenotyping, Prospective Study); Susan Creighton, MS (Project Coordinator, Genetic Counsellor); Linda Eaves, PhD (Epidemiology); Liza Kasmara, BA (Behavioural Phenotyping); Pratribha Reebye, MB, BS, DPM (Leeds). MRCPsych (UK), FRCPC (Child Psychiatrist); Evica Separovic, PhD, FCCMG; Hilary Vallance, MD, FRCPC, FCCMG (Biochemical Genetics); Vikram Dua, MD, FRCPC; Steve Wellington, MD, PhD, FRCPC

Collaborators: Elizabeth Simpson, PhD (Mouse Models); Tom Grigliatti, PhD (Cellular Model System); Bibiana Wong, B.Sc. (PhD Student); Representative, BC Autism Society; Representative, FEAT (Families of Early Autism Treatment)

BC Member on the Biochemical Phenotyping cross-regional team: Hilary Vallance

BC Member on the Dysmorphology cross-regional team: Suzanne Lewis, MD

BC Member on NEDSAC cross-regional team: Suzanne Lewis, MD

Alberta (Calgary) Regional Team

Regional Team Co-Leaders: Francois Bernier, MD, FRCPC, FCCMG (Epidemiology; Dysmorphology; Genetics)
Deborah Dewey, PhD (Epidemiology; Clinical & Behavioural Phenotyping)

Team Members: Debra Busic (Alberta Project Coordinator)
Andy Greenshaw, PhD (Biochemical Genetics)
Suzanne Hala, PhD (Behavioural Phenotyping)

Manitoba (Winnipeg) Regional Team

The Manitoba regional team consists of researchers from St. Amant Centre, Children's Hospital of Winnipeg, and University of Manitoba. The team also benefits from the active participation of community partners such as Autism Society Manitoba, Manitoba Families for Effective Autism Treatment, Child Development Clinic, Health Sciences Centre, Child and Adolescent Psychiatry, and Children's Special Services.

Regional Team Co-Leaders: Dickie C.T. Yu, PhD, CPsych (Epidemiology; Clinical and Behavioural Phenotyping; Prospective Study); Albert E. Chudley, MD, FRCP(C), FCCMG (Genetics; Dysmorphology)

Team Members: Talia Prosick, BSc Honours (Manitoba Project Coordinator);
Alison Elliott, Genetic Councillor

Community Partners: Jane Bow, MD - Psychologist, Autism Outreach; Eleanor Chornoboy - Director, Children's Special Services, Gov't of MB; Lorna Jakobson, PhD - Psychologist, U of M; Sally Longstaffe, MD - Director & Developmental Pediatrician, Child Dev. Clinic; Maureen Penko - Speech-Language Pathologist, Health Sciences Centre; Stephen Sutherland - President, MFEAT; Mary-Ann Updike - Representative, Autism Society of Manitoba; Helen Williams - Coordinator, St. Amant EIBI project

ASD-CARC stretches across Canada and extends into the US, with other regional teams in Ontario, Nova Scotia, Prince Edward Island, New York, California, Massachusetts, and Kansas.

Eastern Ontario (Kingston & Ottawa) Regional Team

Regional Team Leader: Jeanette J.A. Holden, PhD (Molecular Genetics; Clinical & Behavioural Phenotyping; Prospective Study; Research Registry)

Regional Team Co-Leader: Maurice Feldman, PhD (Genetics; Clinical & Behavioural Phenotyping; Prospective Study)

Team Members: H  l  ne Ouellette-Kuntz, MSc, RN (Epidemiology); Rebecca Ward, PhD (Clinical Co-ordinator; Prospective Study; Research Registry); Cynthia Forster-Gibson, MD, PhD (Dysmorphology, Genetics); Anne-Marie Pap (Administrative Assistant); Melissa Hudson, BSc (ASD-CARC Website & Research Registry); Heidi Penning (Research Assistant); Judith Allanson, MD (Dysmorphology); Hymie Anisman, PhD (Neurochemistry); Julio Arboleda-Florez, MD, PhD; Gregory Davies, MD (Clinical Phenotyping); Kang Lee, PhD (Behavioural Phenotyping; Deception); Bruce McCreary, MD (Clinical Phenotyping); Jennifer McKenzie, MD (Dysmorphology; Genetics); Patricia Minnes, PhD (Behavioural Phenotyping); Darwin Muir, PhD (Behavioural Phenotyping; Early Childhood Development); Kevin Munhall, PhD (Behavioural Phenotyping; Multi-Modal Communication); Doug Munoz, PhD (Behavioural Phenotyping; Eye-Tracking); Kevin Parker, PhD (Statistics); Mark Sabbagh, PhD (Behavioural Phenotyping; ERPs; Theory of Mind); Garth Smith, MD (Clinical Phenotyping); Graeme Smith, MD, PhD (Clinical Phenotyping); Mike Storr, MD (Clinical Phenotyping); Sandra Taylor, PhD (Bioethics)

Central-Western Ontario Regional Team

Regional Team Leader: Sandra Farrell, MD (Dysmorphology, Genetics)

Team Members: Jim Bebko, PhD (Clinical and Behavioural Phenotyping); Alison Fleming, PhD (Clinical and Behavioural Phenotyping; maternal-infant interactions); Fabio Macciardi, PhD (Statistical Genetics); Emanuela Mundo, PhD (Statistical Genetics; Clinical and Behavioural Phenotyping); Margaret Spoelstra (Executive Director of the Autism Society of Ontario); Ikuko Teshima, PhD (Cytogenetics); Lynn Trafford, RN, as local co-ordinator

PEI Regional Team

Regional Team Leader: Andrea Noonan is responsible for the epidemiology project in PEI and also recruits families for other studies (Research Registry and Genetics and Prospective Study).



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