Asset Map of Resources for Autism Spectrum Disorders (ASD) Research in Canada
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Executive Summary

CANADIAN AUTISM SPECTRUM DISORDERS ALLIANCE (CASDA)

This Asset Map was commissioned by CASDA as part of the development of the plan for a Canadian Autism Partnership (CAP) and to inform the development of a National Autism Spectrum Disorders (ASD) Strategy. Canada is a leader in the international autism research community and Canada’s contributions to the understanding the causes and biology of ASD, and the development of improved treatment and support mechanisms across the lifespan is a valuable asset. Research and research partners will be vital elements in the effective execution of CAP.

The core document and extensive appendices provide a snapshot of the current strengths in the Canadian ASD research environment, and highlight areas where further investment would advance the field and accelerate progress towards improving the outcomes for those living with ASD and their families.

AUTISM SPECTRUM DISORDERS

With an estimated incidence of 1:68 births (1:43 boys; 1:189 girls), ASD represent the most common childhood developmental disability, with symptom severity ranging from individuals mildly affected by the symptoms of ASD to those who remain non-verbal, at risk for self-injury, and requiring 24-hour care. The causes of ASD are unknown but evidence points towards complex interactions between genetic background and multiple environmental factors. There is currently no cure for ASD. Treatment options consist of behavioural interventions, such as Applied Behavioural Analysis (ABA), or medications directed towards ASD-related symptoms, that show mixed results in treating the underlying symptoms of ASD and can have significant adverse side effects. Families of children diagnosed with an ASD face a series of life-long challenges, including accessing reliable, consistent information; finding affordable treatment and intervention options; and providing for adolescent and adult children. ASD can reduce the quality of life across many of the social determinates of health including income and social status, social support networks, education, employment/working conditions, social environments, healthy child development, personal health practices and coping skills. ASD have become a global crisis.

NATIONAL ASD RESEARCH ASSET MAP

This Asset Map captures the current funding landscape in ASD research, the researchers receiving this funding, and the distribution of resources and capacity across the country. Key ASD research centres and national and international networks are also highlighted. The data points to a healthy, vibrant and collaborative Canadian ASD research community that is highly competitive on the international ASD stage. ASD research in Canada spans the health, engineering, education and social sciences domains and encompasses both fundamental and applied research. Canada has particular strength in research on the causes of, and risk factors for, ASD as well as the underlying biology of the condition. The country’s strong investment into the molecular biology, especially genome sequencing, has built a world-class research community that is ideally placed to probe the genetic and environmental factors that lead to the development of ASD. Canada also has a strong clinical research community which drives multidisciplinary collaborations on the etiology of ASD, as well as early interventions and mechanisms for supporting individuals with ASD through a series of life transitions towards and throughout adulthood. The ASD researchers consulted all expressed strong endorsement for the mandate and goals of the Canadian Autism Partnership Project and many are already engaged in providing support and advice towards accelerating the uptake of research results into improved practice and policy to improve the lives of those living with ASD and their families.
SECTION 1.0: INTRODUCTION

1.1 AUTISM SPECTRUM DISORDERS (ASD)

The Etiology and Characteristics of ASD:

Autism was first described as a syndrome in the 1940’s, when psychiatrists Leo Kanner (US), and Hans Asperger (Austria), documented similar behavioural characteristics in a group of children that included crippling anxiety, an inability to connect with others, and a tendency to withdraw from the world. Autism is now recognized as a spectrum of highly complex neurological disturbances defined by difficulty communicating, social impairments and restricted and repetitive behaviours (1). ASD are the most commonly diagnosed neurological disorder in Canada and the most common childhood developmental disability. The symptoms and characteristics of ASD vary so widely that there really is no standard type or typical person with an ASD. Symptom severity and occurrence ranges from individuals who go on to earn a Ph.D. or who have gifted/savant abilities, to those who remain non-verbal, at risk for self-injury, and requiring 24-hour care (2). A definitive cause for ASDs has yet to be identified but evidence points towards complex interactions of a person’s genetic background with multiple environmental factors (3,4).

The Rising Incidence of ASD:

The incidence of ASDs appears to have risen dramatically over the last 35 years, with a 600% increase in just the last two decades (1975-2015) (5). However, it is not clear whether this is a true increase or if most, if not all, of the reported rise in incidence is due to more sensitive screening tools and changes in diagnostic criteria, such as the recategorization of children with a number of distinct intellectual disabilities as autistic (6,7).

ASD Treatments:

There is currently no cure for ASD. Treatment options are comprised of behavioural interventions designed to remedy specific symptoms, such as Applied Behavioural Analysis (ABA), or medications directed towards ASD-related symptoms, such as anxiety, depression or obsessive-compulsive disorder, that don’t treat the underlying pathology of the disorder and often have significant adverse side effects (8). Most experts agree that the signs of ASD are evident in the first year of life in nearly 50% of affected children, when impaired social interaction becomes apparent (9). However, although the development of new tools and better training of diagnosticians is making early diagnosis feasible, access to these services remains a barrier in many cases. This delay in diagnosis means that a major window of opportunity for effective intervention is frequently missed (10-13).

The Socio-economic Impact of ASD:

It is estimated that more than 515,000 Canadians are now living with ASD, including about 87,000 school-age children. With a current incidence of 1:68 births (roughly four times as many boys as girls), it is predicted that five years from now as many as 1:54 children will be born with ASD, a forecast with serious long-term socio-economic implications for Canada. The lifetime costs of raising children with ASD can be enormous, and completely unaffordable for many families. Although early interventions have been shown to lower the total costs of care and increase dependency-free years, effective intervention programs can cost as much as $60,000 - $75,000 per year, far in excess of the available public funding and considerably more than many families can afford (14-16). Few teachers, social workers and medical practitioners have sufficient specialized training in autism, and the wait to see specialists can be years long, leading to many families seeking private services at considerable expense. The search for treatments and care often takes a huge toll on the emotional wellbeing of the entire family. A lack of reliable information, inconsistent and potentially inappropriate service delivery, and inadequate resources leaves families vulnerable to unproven interventions and “quick fixes” that, not only don’t work, but may financially and emotionally bankrupt the family.

Disorders classified as ASD:
- Autism
- Asperger’s Syndrome
- Rhett’s Syndrome
- Childhood Disintegrative Disorder
- Pervasive Developmental Disorder
- Not Otherwise Specified
Managing Life Transitions:

Once children graduate from secondary school there is virtually no available organized support to help with post-secondary education, vocational training or entry into the workforce. This translates into a significant cost to the Canadian economy in terms of lost opportunities for employment. Adolescents and young adults with ASD can become vulnerable targets and, without access to intervention and support are at high risk of becoming homeless or entering the penal system. As children with ASD transition to adolescence and adulthood, they experience an increasing need for training in social and life skills; access to employment opportunities or adult day programs; more housing/residential options; and often more mental health support. These claims were confirmed in the recent CASDA national needs assessment survey.

1.2 ASD RESEARCH: CANADIAN STRENGTHS

ASD research in Canada is a growing field, particularly in the areas of developmental neurobiology and molecular genetics. A 2016 bibliometric analysis of ASD research across the world (16), shows that from 2005-2014 the number of published articles on ASD rose from 909 to 2,992, with Canada ranking third out of the 10 countries studied, after the US (1st) and the UK (2nd). When calculated according to the number of publications per one million inhabitants, Canada ranked a close 4th, after Sweden (1st), Australia (2nd) the Netherlands (3rd) and the UK (4th) with 30.3 papers per one million inhabitants. Canada also ranked well, at 3rd place, after the US and UK, in terms of the number of citations. Interestingly when it comes to collaborations, Canada ranks fourth for the number of multiple country publications, with almost 48% of Canadian articles representing collaborations with other countries as compared to 19% of US publications and 39% of UK publications. This speaks to the collaborative nature of Canadian research in general and confirms the perception of the Canadian ASD research community.

1.3 THE PURPOSE OF THE ASSET MAP

This Asset Map was commissioned by the Canadian Autism Spectrum Disorders Alliance (CASDA) as part of their activities related to the development of a Canadian Autism Partnership model and to inform their work in advancing a National ASD Strategy for Canada (17). Formed in 2007, as a coalition of organizations and individuals tasked with advocating to the federal government for the development of a comprehensive National ASD Framework, CASDA has a mandate to ensure that all Canadians living with ASD have equal access to the resources they require to achieve their full potential. CASDA has developed its role as a united voice for autism on the national landscape. Since its launch, CASDA has conducted a comprehensive Needs Assessment Survey (2014) of close to 6,000 ASD stakeholders drawn from across Canada, and developed a position paper detailing the current status of ASD services and support infrastructures across Canada.

In 2015, the Government of Canada accepted CASDA’s proposal for the development of a Canadian Autism Partnership and announced a $2 million investment to engage with Canadians across the country to develop a comprehensive business plan for the model.

CASDA launched the Canadian Autism Partnership project (CAP) as a means to engage with Canadians to shape the development of the CAP model and to identify the priority issues to be addressed in such a mechanism. The CAP model provides the platform to accelerate innovation and action to address the challenges faced by those living with ASD and their families and create a model for partnership. During the last year CAP has conducted wide-ranging national consultations with ASD stakeholders, including leaders in the ASD research community and funders who will play a critical role in CAP.
This Asset Map provides a snapshot of the Canadian ASD research landscape, that will contribute to an evidence-based assessment of ASD research activities and resources, and provide context for the analysis of Canada's strengths and assets relative to those in other countries. The report highlights existing Canadian strengths in the ASD field, as well as potential gaps and collaborative opportunities. The objective is to use the information in this Asset Map to guide future planning exercises aimed at establishing Canada as a world leader on best practices in ASD research and clinical care, with the ultimate goal of improving the long-term outcomes for those with ASD and their families.

1.4 METHODOLOGY

The methodology used in the preparation of this asset map is fully described in Appendix 1. In addition to the web and database searches and analyses outlined, a number of interviews were conducted with leading researchers drawn from across the broad ASD research community (Appendix 2). The input from these interviews provided valuable insights into the Canadian ASD research field that are reflected throughout the document.
SECTION 2.0: ASD RESEARCH FUNDING

2.1 GOVERNMENT FUNDING FOR ASD RESEARCH

Federal government funding for ASD research can be obtained from a number of sources, including but not limited to:

- Canada Research Chairs Program (CRCP)
- Canadian Foundation for Innovation (CFI)
- Canadian Institutes of Health Research (CIHR)
- Genome Canada
- Natural Sciences and Engineering Research Council of Canada (NSERC)
- Networks of Centres of Excellence Program (NCE)
- Social Sciences and Humanities Research Council (SSHRC).

Tri-Council Funding for ASD Research:

The majority of ASD research in Canada is supported by funding from the three government funding bodies that comprise the Tri-Council agencies: CIHR, NSERC and SSHRC. Although some overlap exists among the mandates of the three agencies, for the most part CIHR is responsible for health research funding across the four domains of basic, clinical, health services and population health; NSERC focuses on science, technology and innovation in the natural sciences and engineering fields; and SSHRC supports research and training in the humanities and social sciences.

All three agencies award funding through a peer reviewed competitive process comprised primarily of regular open grants competitions, supplemented by strategic initiatives. All three agencies therefore have a role to play in the support of ASD research. Figure 1 shows the total amount of Tri-Council ASD funding over time. A dramatic difference in the comparative levels of funding, is immediately apparent, with CIHR providing several orders of magnitude more funding than NSERC and SSHRC. This reflects the difference in the average grant size, which in turn corresponds to the relatively high cost of basic and clinical health research, especially in the areas of genome sequencing and neurobiology, two key areas of ASD research supported primarily by CIHR. Fig. 1 shows a doubling in CIHR funding from 2008 to 2010 followed by a more gradual increase that appears to plateau except for a dramatic increase in 2014. This peak in funding is due primarily to the award of five CIHR Foundation Grants in the ASD field (Craig, Lerch, Scherer, Szatmari, Zwaigenbaum), in 2014, representing an investment of more than $15 million over seven years.

Figure 2 more clearly shows SSHRC and NSERC funding over time. The gradual fall in SSHRC ASD funding since 2008, can be accounted for, in part, by changes in SSHRC’s mandate and a corresponding move away from health research funding. NSERC funding for ASD research shows a gradual rise from 2007 and a sudden spike in funding in 2015. This funding spike is due to an increase in the number and size of the research grants awarded.
Appendix 3 shows more detailed funding data for each Tri-Council Agency, including funding by province for the last five years (2010/11-2015/16). The data includes all funding: research grants, trainee awards, special programs, etc. available from the respective funding databases. Although there is some variation in the distribution of funding among the three agencies, the majority in all cases goes to Ontario, followed by Quebec for CIHR and SSHRC, and BC for NSERC.

**Genome Canada:**

Genome Canada supports large-scale science, leading edge-technologies, and knowledge translation through strategic funding competitions that span the field of science, including health research. Genome Canada has supported ASD research through the Ontario Genomics Institute, originally to support the Autism Genome Project, and currently to support the Autism Spectrum Disorders: Genome to Outcomes Project, both led by Stephen Scherer at the Hospital for Sick Children.

Collectively, the Tri-council Agencies and Genome Canada have invested more than $96 million over the last five years in research relevant to ASD. Appendix 4 lists the researchers and trainees who have received these funds and the Universities with which they are affiliated. The Principal Investigators holding research grants are highlighted in yellow (for further discussion of Appendix 4, see section 4.0: ASD Researchers).

Figure 3 shows the distribution across Canada of the Tri-Council and Genome Canada funds awarded only to the Principal Investigators holding research grants and awards. A total of $81.5 million was invested from 2010/11-2015/16. Half of this funding was divided among several Ontario institutions, with the majority of the remaining funds going to Quebec (21%) followed by BC (14%). The funded research covers the broad scope of the ASD field, as shown in Appendix 4.

**CRCP Funding for ASD Research:**

The Canada Research Chairs Program (CRCP) is a Tri-Council initiative intended to attract and retain new talent to Canada as Research Chairs in engineering and the natural sciences, health sciences, humanities, and social sciences. Chairs are awarded directly to host academic institutions rather than individual researchers and tend to encompass broad fields of research. Tier 1 chairs, are awarded for a seven-year, renewable, term and for each Tier 1 chair, the institution receives $200,000 annually. Tier 2 chairs, are awarded for a five year term and are renewable once. For each Tier 2 chair, the host institution receives $100,000 annually for five years. Appendix 5 lists the eight ASD researchers currently holding a CRC to support their work in an area of research that is either solely or partially related to ASD, as well as a summary of their research interests. In total CRCP has provided a total of $3.3 million to the host Institutions of these Chair-holders over the last five years.

**CFI Funding for ASD Research:**

CFI Funding is awarded to institutions rather than individual researchers to support infrastructure such as state-of-the-art equipment, laboratories, databases, specimens, scientific collections, computer hardware and software, communications linkages and buildings necessary to conduct leading-edge research. Funding is provided to Canada’s universities, colleges, research hospitals and non-profit research institutions. Many of Canada’s ASD researcher groups and centres have benefited from CFI investments, especially in the areas of brain imaging and genome sequencing. CFI also provides
support to the ASD Studies Centre at Queen’s University, the Canadian Centre for Lifespan Development Research at Brock University, and the Centre for Cognitive and Neurological Development Disorders at the University of Calgary, to name just a few funding recipients. Generally speaking CFI funding supports multi-user, multi-purpose infrastructure making it challenging to determine the level of funding specifically supporting ASD research.

**NCE Funding for ASD Research:**

The NCE program supports large-scale academically-led research networks that harness the creativity and inventiveness of Canadian health, natural, and social scientists and engineers and mobilize multidisciplinary research capacity across the country. NCE competitions are launched periodically, as funds become available. NeuroDevNet is a national network, based in Vancouver BC and led by Daniel Goldowitz. The Network has received a commitment of $39.1 million for 2009-19 to support research on treating and preventing childhood brain disorders, including autism. NeuroDevNet researchers have identified new autism risk genes, and are investigating a number of risk factors for ASD.

**Provincial Government Funding for ASD Research:**

ASD research funding, often on the form of trainee support, is also available on an ad-hoc basis from many of Canada’s provincial funding agencies, including the members of the National Alliance of Provincial Health Research Agencies (NAPHRO):

- Alberta Innovates – Health Solutions
- Fonds de recherche du Québec – Santé
- Manitoba Health Research Council
- Michael Smith Foundation for Health Research – BC
- New Brunswick Health Research Foundation
- Newfoundland and Labrador Centre for Applied Health Research
- Nova Scotia Health Research Foundation
- Ontario Ministry of Health and Long-Term Care
- Ontario Ministry of Research and Innovation
- Saskatchewan Health Research Foundation

Of special note is the Ontario Brain Institute (OBI), a provincially funded, not-for-profit research centre focusing on brain research, commercialization and care. OBI’s “Integrated Discovery Research Programs”, include a program on neurodevelopmental disorders. The “integrated discovery” concept was developed by OBI to bring together researchers, clinicians, industry and patient advocates to maximize new insights and promote their translation into improved care. This kind of multidisciplinary format is particularly well-suited to the ASD field. OBI has contributed $18,750 over 5 years (2013-2018), to the Province of Ontario Neurodevelopmental Disorders (POND) network, of which approximately $12,500 comes from OBI. The remaining funds are provided by a required 'matched partner contribution'. The Ontario Research Fund has also contributed funding to support ASD research particularly in the genomics field, including almost $10 million for the Autism Spectrum Disorders: Genomes to Outcomes project led by Stephen Scherer.

### 2.2 NON-GOVERNMENTAL FUNDING FOR ASD RESEARCH

Appendix 6 lists examples of research grants awarded to Canadian researchers by key non-governmental organizations (NGOs) in the ASD field. The largest NGO funding ASD research is Autism Speaks which, through its grant program, has provided almost $7 million in funding over the last five years to 15 leading Canadian ASD researchers from coast to coast. Other NGOs supporting Canadian ASD research include the Simons Foundation and the Azrieli Foundation, through the Azrieli Neurodevelopmental Research Program, a partnership between the Azrieli Foundation, and the federal government’s “Brain Canada”. In addition, many other NGOs in the ASD field support modest research programs such as, but not limited to, the Miriam Foundation’s Gold Centre in Montreal and the St. Amant Research Centre in Winnipeg. There are also a number of philanthropic enterprises across the country, led by family and community members, that provide small research grants primarily to locally-based researchers.
SECTION 3.0: ASD RESEARCH ASSETS AND RESOURCES

3.1 ASD RESEARCH CENTRES OF EXCELLENCE

One impact of Canadian geography and demographics is that critical mass can be hard to achieve in any but the major cities. As a result, there tend to be less centres focused on specific research areas, such as ASD, than you might find in the US and the UK. For example, the US has the Autism Centres of Excellence (ACE) program - a trans-NIH initiative that links three ACE Research Centres at Boston University, Emory University, and the University of California with eight ACE Networks across the US. The UK is home to a number of ASD Research Centres at academic institutions such as the University of Cambridge, University of Oxford, University of Birmingham, University of Kent, University College (London), King's College (London), University of Sunderland and a national centre for Wales, based at Cardiff University.

Canada does have a number of, perhaps more modest, research centres with a sole or partial focus on ASD. Appendix 7 lists 15 of these centres located in six Canadian provinces, with Ontario being home to the largest number of ASD focused laboratories and centres. The centres vary considerably in size and focus and collectively cover the broad field of autism research from the biology of the condition, to early diagnosis and through to treatment and interventions, including a centre studying a relatively new and potentially groundbreaking area of research – the role of the gut microbiome and its products in the etiology of ASD.

3.2 ASD RESEARCH NETWORKS

Canada excels in networking and collaboration, which has become a trademark of Canadian research across many sectors, including health. ASD research is no exception. Table 1 gives examples of some of the regional and provincial ASD networks across the country, in alphabetical order. Some of these networks bring people together within a particular university or research/medical centre, whereas others link researchers from many different disciplines across a city or even a province.
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<th><strong>Name</strong></th>
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<tr>
<td>Applied Behavioural Analysis (ABA) Group</td>
<td>University of Manitoba Leads: Garry Martin, Toby Martin, Joseph Pear, CT. Yu</td>
<td>The ABA group focuses on behavioural assessment, training strategies and knowledge translation in developmental disabilities, including autism. The group provides supervised training to students in the practice of ABA and works closely with the St Amant Centre, a service provider for people with disabilities.</td>
</tr>
<tr>
<td>Autism Spectrum Education, Research and Training (ASERT) Group</td>
<td>University of Calgary Lead: Adam McCrimmon</td>
<td>ASERT research focuses on resiliency in individuals with ASD; bullying in children with ASD; the effectiveness of interventions to develop social skills; and strategies for communicating with children about their ASD diagnosis. ASERT also provides clinical assessment to families and individuals, as well as training to professionals.</td>
</tr>
<tr>
<td>Centre for Interdisciplinary Research and Collaboration in Autism (CIRCA)</td>
<td>University of British Columbia Lead: Pat Mirenda</td>
<td>CIRCA is a network of faculty, students, provincial service providers, policy makers, and both basic and applied researchers from BC post-secondary institutions together that addresses issues of common concern that are relevant to improving the lives of individuals with ASD and their families.</td>
</tr>
<tr>
<td>McMaster Autism Research Team (MacART)</td>
<td>McMaster University Leads: Stelios Georgiades and Terry Bennet</td>
<td>A Network that brings together ASD researchers (faculty and students), clinicians and clinician scientists from 10 different departments and 5 research centres at McMaster with the goal of linking ASD research to clinical practice.</td>
</tr>
<tr>
<td>Montreal Autism Cognitive Neuroscience Research Group</td>
<td>McGill University; University of Montreal</td>
<td>The group brings together researchers with expertise in brain imaging and cognition, perception, social aspects and special abilities in people with ASD, and the functional relationship between primary and social perception.</td>
</tr>
<tr>
<td>Province of Ontario Neurodevelopmental Disorders (POND)</td>
<td>Holland Bloorview Kids Rehabilitation Hospital Lead: Evdokia Anagnostou</td>
<td>The POND Network is a coordinated effort of Ontario scientists, clinicians, engineers and community stakeholders who share the goal of improving the long-term outcomes for children with ASD and related neurodevelopment disorders. POND has created a clinical trials network that is the first of its kind in Canada.</td>
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Table 2 gives some examples of ASD Networks that are all national in scope but serve very different purposes. For example, the Autism Research Training Program (ART) based out of McGill University and the University of Alberta and funded by CIHR, with additional support from the Sinneave Family Foundation, has been in existence since 2005. One of the most innovative aspects of the ART Program is the mentorship program. Trainees are mentored by three ART Faculty, chosen by the trainee, in consultation with the Program Advisory Committee (PAC). The 39 ART Faculty members represent a “Who’s Who” of the ASD multidisciplinary research community.

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<tr>
<td>Autism Research Training Program (ART)</td>
<td>University of Alberta Lead: Lonnie Zwaigenbaum URL: <a href="http://www.traininautism.com/">http://www.traininautism.com/</a></td>
<td>An ASD training program that coordinates activities among 16 Canadian universities. The goal of ART is to recruit and train outstanding researchers in the field of autism, in disciplines such as genetics, brain imaging, epidemiology, neurology, psychiatry, psychology and others.</td>
</tr>
<tr>
<td>Autism Spectrum Disorders: Pathways to Better Outcomes</td>
<td>Offord Centre for Child Studies, McMaster University Director: Peter Szatmari URL: <a href="http://www.asdpathways.ca">http://www.asdpathways.ca</a></td>
<td>A longitudinal cohort study to describe the developmental pathways in children with ASD and identify factors related to the social, communication, and behavioural outcomes. Project began in 2004 (Phase I) and was renewed in 2015 for another 7yrs.</td>
</tr>
<tr>
<td>Child Health Innovations Limiting Disability—Brain Research Improving Growth and Healthy Trajectories (CHILD-BRIGHT)</td>
<td>McGill University Health Centre Lead: Annette Majnemer URL: <a href="https://muhc.ca/newsroom/news/ri-muhc-leads-innovative-network-support-children-brain-based-developmental-disabilities-and-th">https://muhc.ca/newsroom/news/ri-muhc-leads-innovative-network-support-children-brain-based-developmental-disabilities-and-th</a></td>
<td>CHILD-BRIGHT is one of CIHR’s SPOR Networks, launched in March 2016 with $12.5 million in funding from CIHR and matching funds from partners. Similar to NeuroDevNet, this network will focus on life outcomes for children with brain-based developmental disabilities (including autism) and their families. The CHILD-BRIGHT network will be co-directed by the BC Children’s Hospital and The Hospital for Sick Children (SickKids) and will include a patient-oriented research program, a citizen engagement program, and knowledge translation and training initiatives.</td>
</tr>
<tr>
<td>NeuroDevNet</td>
<td>UBC Director: Dan Goldowitz URL: <a href="http://www.neurodevnet.ca">http://www.neurodevnet.ca</a></td>
<td>A Networks of Centres of Excellence (NCE) Program focused on improving the diagnosis, prevention and treatment of a number of children’s neurodevelopmental disabilities, including ASD.</td>
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ART has proven to be an exceptional program for the recruitment and training of researchers in transdisciplinary ASD research, having trained 50 students in their three-year program during the last five years alone, as well as a large number of summer students. Of the ART graduates, many are now working in the field as funded investigators and at least four of the ART graduates (Hyde, Bennet, Elsabbagh, Georgiadis) are represented in the “Key Researcher” table in Appendix 7.

The NCE NeuroDevNet, which is about to change its name to the “Kids Brain Health Network” is national network of investigators based out of UBC, lead by Scientific Director, Dan Goldowitz. The Network includes a focus on ASD as part of its broader mandate and Network members include many of Canada’s leading ASD researchers.

The Pathways to Better Developmental Health in Autism Spectrum Disorders initiative is the largest longitudinal study in the world to examine the psycho-social factors in children with ASD. Funded by CIHR, Autism Speaks, the Government of British Columbia, the Alberta Foundation for Medical Research, the Sinneave Family Foundation and John Mayberry, and based at the Offord Centre for Child Studies at McMaster University, Pathways is now in its third phase of operation, having been renewed in 2014 for a further 5-year term. The initiative is national in scope, collecting data from Halifax, Montreal, Hamilton, Edmonton and Vancouver in an effort to identify predictors of good outcomes in children with ASD that might form the basis for the development of effective intervention programs that will improve the long term outcomes for children with ASD.

Table 3 gives examples of international ASD networks that include Canadian nodes. Two of these networks, ASC and MSSNG focus on genome sequencing in ASD and the Canadian lead for both studies is Stephen Scherer at the Hospital for Sick Children and University of Toronto. Autism Speaks, a major funder of these initiatives, has been supporting research on the role of genetics in the etiology of ASD, for more than 20 years, beginning in 2004 with the launch of the Autism Genome Project; followed, in 2011, by the 10K Genome Project a partnership with the Beijing Genomics Institute with the goal of sequencing 10,000 genomes taken from families affected by autism and, in 2014, the launch of MSSNG. Collectively these studies aim to unravel the genetic factors involved in ASD leading to the identification of ASD subgroups and opening the door to more personalized and accurate diagnoses and treatments.
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<th>Name</th>
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<tr>
<td>ASD-Canadian-American Research Consortium (CARC)</td>
<td>Queens’ University and UBC. Leads: Xudong Liu (Ontario); Suzanne Lewis (BC)</td>
<td>ASD-CARC is a multi-disciplinary team of more than 70 ASD researchers and clinicians working with over 3000 families in Canada and internationally.</td>
</tr>
<tr>
<td>Autism Sequencing Consortium (ASC)</td>
<td>Hospital for Sick Children Lead: Stephen Scherer</td>
<td>ASC is a huge multi-site, international collaboration focused on understanding the genetic architecture of ASD. Canada’s contribution is the sequencing of the genomes from more than 700 well-characterized Canadian families.</td>
</tr>
<tr>
<td>Autism Treatment Network (ATN)</td>
<td>Bloorview Research Institute Leads: Alvin Loh, Evdokia Anagnostou, Wendy Roberts</td>
<td>ATN is a network of hospitals, physicians, researchers and families at 17 sites across the United States and Canada which began in 2008. The Toronto Site of the ATN is one of two sites in Canada (the second site is in Edmonton, Alberta-Glenrose Rehabilitation Hospital). ATN experts carry out innovative research to develop more effective treatment standards for ASD.</td>
</tr>
<tr>
<td>Baby Siblings Research Consortium (BSRC)</td>
<td>Universities of Calgary, Dalhousie and Edmonton Leads: Suzanne Curtin (Calgary), Susan Bryson (Halifax), Lonnie Zwaigenbaum (Edmonton)</td>
<td>BSRC, brings together research groups from around the world in a quest to discover the earliest predictors of ASD. The study focuses on the younger siblings of children with ASD. The goal is to identify autism at the earliest age possible so that intervention strategies can be developed that improve the developmental trajectory of infants who may be later diagnosed with autism.</td>
</tr>
<tr>
<td>European Autism Interventions (EU-AIMS)</td>
<td>Bloorview Research Institute Lead: Evdokia Aganostou</td>
<td>EU-AIMS is a multicentre study for developing new medications for autism. The study is a collaboration between Autism Speaks, academia and industry. EU-AIMS collaborates with POND.</td>
</tr>
<tr>
<td>&quot;MSSNG&quot;</td>
<td>Hospital for Sick Children Lead: Stephen Scherer</td>
<td>A collaboration between Autism Speaks, The Hospital for Sick Children, Google and BGI-Shenzhen (China), MSSNG is well over half way to sequencing the world’s largest database of 10,000 autism genomes to discover subtypes for individualized diagnosis and treatment.</td>
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SECTION 4: CANADIAN ASD RESEARCHERS

A search of the Tri-Council funding databases for the five-year period 2010/11 - 2015/16 produced a total of 341 researchers in the ASD field, of whom 141 were full investigators holding research grants and awards as a Principal Investigator (PI), and 200 were trainees (Masters, Doctoral, Post-Doctoral Fellow). Appendix 4 lists all these researchers by province and host institution and provides the title of their most recent grants, as well as the source of the funding. Many of the senior investigators in this group also have funding from additional sources such as NGOs, and provincial organizations. In addition some hold Canada Research Chairs or are recipients of CFI funding for infrastructure support. Of the 341 researchers, 128 (38%) were engaged in research that would be considered to be basic/fundamental science primarily in the fields of genetics and neurobiology. These researchers are studying the biology and etiology of ASD, in humans subjects, animal models and in vitro/cellular systems. The remaining 62% are engaged in studies focused on individuals already diagnosed with ASD in the realm of social interaction, perception, education and intervention. Fig 4 shows the distribution of PIs by province. The ASD investigators receiving Tri-Council funding as PIs, especially in the case of CIHR funding, are frequently the leaders of teams comprised of multiple Co-PIs and collaborators, who may or may not hold their own grants as a PI. The PIs listed in Appendix 4 should therefore be viewed more as a resource linking to the broader ASD research community than an absolute representation of active researchers in the field.

Fig 5 shows the distribution of trainees by province. Again, the students captured through the Tri-Council funding almost certainly represent only a sample of the trainees actually working in the field. Trainees are often supported through other funding sources, such as PI grants, provincial programs, host institutions, NGOs, and philanthropic donations.

However, the data shows that BC is home to a sizeable student population compared to some other provinces. Interestingly, Ontario also has more students than PIs, which can be accounted for almost entirely by the fact that all the Tri-Council ASD funding at Brock University is going towards the support of 13 Masters students. This confirms input received from a key informant (M.Feldman) regarding the challenges in obtaining Tri-Council PI funding for behavioural interventions. Despite the fact that Applied Behavioural Analysis (ABA) is currently one of the few effective treatments for ASD, especially if administered to children at a young age, there are few traditional sources of funding for academic behavioural analysts. Those based universities can access Tri-Council funding for students, as is the case at Brock, but this reality points to a potential disconnect between the basic and applied ASD research communities and a lack of recognition for the important contribution to the field made by behavioural analysts who are often conducting academic research programs within their own client base, with little or no external funding.
Appendix 8 Lists 60 of the "Key" the ASD researchers in Canada based on the criteria described in the Methodology Section, Appendix 1. These researchers are a great resource for the ASD community in Canada and abroad. Many of them are recognized leaders in the field and, in fact, Ontario-based researcher Peter Szatmari is principal author of one the top 10 cited articles in the ASD field, placing 6th for his paper entitled: Mapping autism risk loci using genetic linkage and chromosomal rearrangements, published in Nature Genetics in 2007.

SECTION 5: CONCLUSIONS

It is apparent from the data presented here that Canada is home to a strong ASD research community who are, for the most part, well connected across the country, sharing the leadership of many national networks and participating in extensive international collaborations. There are always inherent challenges in identifying the key researchers in any field of study. Therefore, the researchers highlighted in this report do not represent an exclusive list. There are many more, working alongside those mentioned here, who are making important contributions to the field as long-time pioneers and collaborators and Co-PIs of large research endeavors. The current snapshot does, however, provide a solid base, from which to link to the broader ASD research community.

Research funding for ASD research comes from multiple sources with the majority being from federal and provincial government agencies, followed by national and international non-governmental organizations and family trusts. Identified needs included additional targeted funding for clinician scientists, including tailored training programs, and funding for academic scientists/practitioners working in the ABA field. There was also a call for alternative funding mechanisms, based perhaps on the OBI model, to complement the traditional Tri-Council granting programs.

Recent bibliometric studies show that Canada “bats above its weight” in many of the criteria used to measure success, such as publications, citations, and collaborations. This confirms the opinions expressed by the key informant interviewees, who unanimously felt that Canadians are key players on the international stage, especially with respect to genomics, neurobiology, longitudinal studies and early developmental interventions. Many commented on the strong relationships across the country between basic researchers, and the clinical, patient and advocacy communities. One potential area for improvement, however, was identified as being the integration between pre-clinical (before diagnosis) and post diagnosis research, where the focus shifts to managing the condition across the lifespan.

With respect to the need for a Canadian ASD research forum, opinion among interviewees was divided. Some felt that the Canadian research community is already well-represented in the US-based International Society for Autism Research (INSAR) and many attend the annual International Meeting for Autism Research (IMFAR). Others considered that a national conference would encourage a focus on Canadian research and build linkages across the country. Such a forum could bring together people from all stakeholder groups, including researchers (basic and applied), students, policy makers, health care and education administrators, NGOs, and people living with ASD and their families.

One area highlighted for further attention was implementation science. ASD research is a highly applied, practice-based and patient-oriented field, that requires a strong knowledge translation/implementation strategy to ensure that the results produced by the research community are rapidly translated into changes in policy and practice to improve the outcomes for those living with ASD and their families across the whole lifespan. CASDA and CAP have an important roles contributing to the development of a national strategy that will coalesce Canada’s considerable talent towards achieving this goal and reducing the health, social and economic burden of ASD.


