

PACIFIC AUTISM FAMILY CENTRE

Report from the BC Autism Research Blue Sky Meeting January 29, 2016



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©Pacific Autism Family Centre Ad Hoc Autism Research Steering Committee

Executive Summary

Since 2015, an *ad hoc* Autism Research Steering Committee has been helping the Pacific Autism Family Centre (PAFC) to connect to the Autism Spectrum Disorders (ASD) research community. PAFC aims to become a centre of excellence for individuals with ASD and their families across BC and beyond. The goal, ultimately, is working towards PAFC's vision to be "informed by research and to inform research."

The Committee invited researchers with an interest in the ASD field to a "BC Autism Research Blue Sky Meeting" on January 29, 2016. The session's goals included developing PAFC's research vision, and inviting participants to learn more about the PAFC and its vision; developing a common understanding of current research on ASD in BC; and engaging in a discussion of the opportunity for ASD research connected to the PAFC. The following recommendations for the PAFC emerged from the meeting:

Opportunities for autism research presented by PAFC

Participants advised PAFC to capitalize on the connection between families and researchers at the centre to support recruitment for studies and develop data that informs ASD practice and research. They recommended that PAFC continue to act as a convenor, encouraging the consolidation of ASD research efforts to accelerate collaboration and synergy, and to build research capacity at various levels. They anticipate that such connections will also accelerate translation and sharing of evidence-based knowledge for parents, providers and policy-makers. They also identified PAFC as a unique opportunity to evaluate how congregating services in one centre as a hub affects outcomes for people affected by ASD.

Who to engage from BC's ASD research community

Workshop attendees agreed that a full range of stakeholders needs to be involved in shaping the PAFC research agenda, including all those whose decisions and actions impact the future well-being of individuals with ASD and their families:

- People affected by ASD, including individuals with ASD and their families
- Policymakers and funders
- Clinicians and professionals working directly with families and people with ASD
- Technical experts to provide specialized support
- Employers and people involved in jobs creation

Next steps for developing a research agenda and relationships

The session ended with an expressed desire to meet again, to assess and coordinate collaborative ASD research opportunities. Participants spoke to the need to develop systems and infrastructure to support ASD research; to develop a comprehensive communications strategy; and to create an Ethics Board for PAFC. Together, they believe these actions would combine to build a reputation for the PAFC as a trusted centre and repository for ASD research.

In addition to providing further details of these recommendations, this report provides a summary of information presented by researchers on their areas of ASD research in BC.

Table of Contents

Introduction..... 1

Pacific Autism Family Centre..... 2

Asset Map of ASD Research Resources in BC..... 3

Lightning Round Researcher Presentations 3

PAFC Autism Research 4

 Opportunities for autism research presented by PAFC 4

 Inclusive participation in the conversation..... 5

 Recommended next steps to develop PAFC’s research agenda and relationships 7

Appendix 1: Autism Research Lightning Round 9

Appendix 2: Acknowledgements..... 12

 Ad Hoc Autism Research Steering Committee..... 12

 Staff 12

Introduction

The Pacific Autism Family Centre (PAFC) is a forthcoming centre of excellence for individuals with Autism Spectrum Disorders (ASD) and their families across BC and beyond. A research arm called “Inform Every Autism” will advise how the PAFC can interact with the research community and supply information on research results to create outcomes that best serve individuals and families affected by ASD. The goal, ultimately, is working towards PAFC’s vision to be “informed by research and to inform research.”

In the interim, an ad hoc Autism Research Steering Committee, established in May 2015, is helping to connect the PAFC to the ASD research community, with representatives from:

- BC Institute of Technology (BCIT)
- Child & Family Research Institute (CFRI)
- Emily Carr University of Art + Design (ECUAD)
- Inform Every Autism
- Genome British Columbia (Genome BC)
- Michael Smith Foundation for Health Research (MSFHR)
- Ministry of Children and Family Development (MCFD)
- PAFC
- University of Victoria (UVIC)
- University of British Columbia (UBC)

The Committee invited researchers with an interest in the ASD field to a “BC Autism Research Blue Sky Meeting” on January 29, 2016. The meeting was designed to help PAFC develop its research vision. The goals for the session were for participants to:

- Learn more about the PAFC and its vision
- Develop a common understanding of current research on ASD in BC
- Engage participants in a discussion of the opportunity for ASD research connected to the PAFC

This report presents an overview of the proceedings, as well as recommendations for the PAFC on potential research opportunities, who to engage from the ASD research community, and next steps for developing a research agenda and relationships.

Pacific Autism Family Centre

Sergio Cocchia, O.B.C., Co-Founder, President and Chief Executive Officer, PAFC Foundation

Multiple ministries and agencies are responsible for funding and delivering ASD services under the current model in BC. Parents face challenges coordinating access to resources among agencies, as their children transition across providers and into adulthood. Because autism is a spectrum, the approach, care and requirements for support differ for individual families. Many families are not equipped to navigate the system. Some pay privately for support.

The new 60,000 square foot PAFC is slated to open in Richmond in fall 2016. PAFC aims to bring resources for research, learning, assessment, treatment and support together to address the lifespan needs of individuals with ASD and their families in BC.

PAFC leaders developed the mandate, vision and strategic plan for the centre through extensive consultation with the autism community, in meetings held throughout the province. (PAFC has already become an ASD social media leader, with the largest number of followers for ASD on Facebook as of January 2016.)

PAFC will, ultimately, be the “hub” to at least eight “spoke” satellite centres in communities across the province, with a linked client database; three will open in fall 2016. The hub is designed to be a centre of excellence and one-stop shop for families, offering a:

- **Treatment Centre:** best practice preschool and afterschool programs
- **Knowledge Centre:** library, videoconferencing, networking, counselling
- **Information Centre:** counsellors, navigators, knowledge translation
- **Leadership Space:** collaborative office space for partners
- **Clinic & Research:** medical, lab, assessment, state-of-the-art research facility
- **Lifespan Centre:** vocational, social and educational support for youth and adults

The satellite centres will offer video conferencing for assessments, treatment planning, training, distance learning, counselling, and more, building capacity and providing access to specialized services across BC.

From its inception, the PAFC has aimed to be research focused and is seeking guidance on how to integrate ASD research in the new facility to “inform research and be informed by research,” as a continuous evolution of improvement.

Asset Map of ASD Research Resources in BC

Gabe Kalmar, Vice President, Entrepreneurship and Commercialization, Genome BC

The ad hoc Autism Research Steering Committee engaged a consultant to produce an asset map of current ASD research resources in the province. The report will be completed and posted on the PAFC website later in 2016. Some high level findings reveal:

- BC has at least 58 established ASD researchers at all major BC academic and clinical institutions, working in multiple disciplines—from social sciences and population studies, to health policy, clinical work, genetics and treatment interventions
- BC also recruits students and trainees, providing potential for capacity building across the field
- Research interests may relate solely or partially to the broad ASD field; some research is identified as research into ASD and other disorders
- BC has eight internationally recognized Canada Research Chairs who work entirely or partly in the ASD field, in various disciplines and at different career stages
- Federal funding for ASD research in Canada¹ (2009-2014) totalled \$44.1 million, with BC receiving a fair share of \$5.8 million (13%)
- BC researchers are already leading several ASD networks and research groups, many of which are international in scope

In conclusion, BC has a critical mass of ASD researchers and networks in multiple disciplines at many academic and clinical institutions, which offers opportunities to leverage BC resources and research expertise across Canada and beyond.

Lightning Round Researcher Presentations

During the lightning round, 16 researchers gave short presentations on their work related to ASD—from genetics to assessing the effectiveness of therapies to population health studies. The intent of this session was to:

- Provide the group with a common understanding of the range of BC-based projects
- Open the door for future research collaborations

Appendix one, Autism Research Lightning Round, contains a list of the researchers and a brief synopsis of each presentation.

¹ Canadian Institutes of Health Research (CIHR), Canada Research Chairs Program (CRC), Networks of Centres of Excellence (NCE), Natural Sciences and Engineering Research Council (NSERC), Social Sciences and Humanities Research Council (SSHRC)

PAFC Autism Research

Meeting participants worked in breakout groups to provide their views on three questions:

- *What is the opportunity presented by PAFC for autism research?*
- *Who else needs to be part of this conversation?*
- *What is your advice to PAFC on next steps to develop its research agenda and relationships?*

Opportunities for autism research presented by PAFC

Participants noted that the PAFC offers an opportunity to create a unified voice for autism in BC. They proposed opportunities for ASD research in five priority areas; each area includes several components:

- 1) *Capitalize on the connection between families and researchers at the centre to support recruitment for studies and develop data that informs ASD practice and research:*
 - Collect data from families for longitudinal/clinical studies across the lifespan (e.g., specimens, brain imagery, demographics, family histories)
 - Listen to families and individuals with ASD to discover their research priorities
 - Connect families to relevant studies
 - Create a large ASD database
 - Mine patient databases to develop statistics and profiles across pillars, from genetics to diagnosis, in a move toward personalized medicine
- 2) *Consolidate ASD research efforts to accelerate collaboration and synergy:*
 - Bring interdisciplinary research groups together
 - Facilitate communication among researchers
 - Support research across the four pillars
 - Integrate community-based and institutional research
 - Build connections with researchers across Canada and internationally
- 3) *Evaluate how congregating services in one centre as a hub affects outcomes:*
 - Conduct patient and family focused research
 - Investigate the effectiveness of commonly used interventions
 - Identify any ineffective treatments that should not be put to parents
 - Investigate cohorts based on research needs (e.g., diagnosis, intellectual disability, Indigenous)
 - Investigate comorbidities and environmental factors
 - Track outcome data over time, through services provided at PAFC

4) *Build research capacity at various levels:*

- Explore novel approaches and novel research at PAFC
- Provide research training from the centre hub to the more isolated spokes of the system
- Include the spokes in ASD research
- Build two-way communication between researchers and parents of ASD individuals, so parents can share their interests in research and researchers can explain their research initiatives
- Provide vocational opportunities for people with ASD to work with the research team
- Bring parents together to coordinate funding opportunities to support research

5) *Translate and share evidence-based knowledge for parents, providers and policymakers:*

- Communicate research findings to families
- Develop networking/support for families to access best practices
- Develop a protocol for families to access and own their own data
- Use findings to change clinical practice in a continuous cycle to improve outcomes, so care informs and is informed by research
- Organize and disseminate research studies relevant to particular profiles, and stratify treatments based on research results
- Inform government ministries of findings as well, so families who access support through a ministry rather than the centre are also informed of advances

Inclusive participation in the conversation

In addition to consulting researchers, participants recommended the following individuals, groups and organizations be involved in the research conversation with the PAFC:

1) *Policymakers and funders:*

- Representatives of the various BC ministries involved with ASD—Health, Children and Family Development, Education, and Social Development and Social Innovation—and the federal government to engender cross ministry initiatives and both provincial and national scope
- Funding agencies, with cooperative opportunities to support more successful applications
- Policymakers who can connect with and be involved in research to raise research awareness within the system and develop data to inform policy changes in BC
- Ministry of Advanced Education representation to impact people studying to be teachers and providers
- Representatives from the justice system and first responders

- 2) *People affected by ASD*, including:
 - Individuals with ASD and their families
 - Caregivers
 - Groups that may be harder to reach: Indigenous, socioeconomic differences, English-as-a-second-language (ESL)
 - Spokespeople from isolated communities to find out what is needed in these locations
- 3) *Clinicians and professionals working directly with families and people with ASD*, who might not normally have access to research data, would benefit from a better understanding of research, and can assist with implementing the latest findings to improve care:
 - General practitioners/family doctors, who are usually the first point of contact for parents
 - Medical specialists
 - Nurses
 - Applied behavioural analysis therapists
 - Allied health professionals
 - Educators and students
 - Autism Community Training (ACT)
- 4) *Technical experts to provide specialized support*:
 - Database designers/managers, involved in simplifying access to high speed data
 - Engineering/technology specialists to help with applied research
 - Private sector representatives involved in research applications
- 5) *Employers and people involved in jobs creation* could benefit from learning about and being involved in the research process. Their participation could, ultimately, lead to greater work opportunities for people with ASD.

Recommended next steps to develop PAFC's research agenda and relationships

Participants also offered advice to the PAFC on the next steps needed to develop the centre's research agenda and relationships:

- 1) *Assess and coordinate collaborative ASD research opportunities:*
 - Use the asset map to identify research strengths and gaps in BC
 - Coordinate research speed dating opportunities where experts list skill sets, seek complementary skills with researchers in other areas, and create collaborative efforts
 - Have the PAFC Research Director track and coordinate ASD research in BC and beyond, with the PAFC as the central source (and lead liaison with research ethics boards)
 - Develop research themes for the PAFC to build upon in national and international partnerships
 - Contribute toward building a much needed national strategy for ASD research
 - Explore ways to connect basic research with the centre
 - Promote researcher/service provider/family collaborations
- 2) *Develop systems and infrastructure to support ASD research, such as:*
 - Create a flow chart and work plan documenting next steps:
 - Establish a Research and Engagement Advisory Council, with well recognized members in the ASD field who bring clinical, cultural and linguistic diversity
 - Develop a job description and hire a Research Director (e.g., with capacity to bridge these boundaries, facilitate with researchers, lead the creation of a database, set direction for ASD research in BC, and secure research funding)
 - Develop a PAFC research agenda
 - Develop a research funding strategy (e.g., small catalyst grants, seed funds to connect researchers, student training opportunities)
 - Create a database and a strategy for sharing data
 - Develop a consent process/consider universal consent to maximize researcher access to data
 - Build strong connections between research and service delivery
 - Identify metrics and test the excellence of research associated with PAFC

- 3) *Develop a comprehensive communications strategy*, including, for instance:
 - Communicate PAFC research priorities
 - Ensure two-way knowledge development and exchange with the community as well as academic centres
 - Hold an annual research conference to develop an integrated ASD research network in BC
 - Hold multidisciplinary meetings and smaller meetings for specific disciplines
 - Hold regular research talks
 - Use social media to promote awareness; take advantage of being the ASD site on Facebook with the most links to find out what's hot, what people are interested in, and share what's on the research agenda
 - Empower families and parents to be advocates and spokespeople in their communities so they can drive change
- 4) *Build a reputation for the PAFC as a trusted centre and repository for ASD research*:
 - Create an online repository for ASD research, so the PAFC website becomes the “go to” site for research people can trust
 - List funding opportunities online
 - Send PAFC representatives to ASD conferences to report research and outcomes
 - Create a Knowledge Translation Committee or Coordinator
 - Use data collected and research conducted to guide practice, so people can learn in real time about what works and what doesn't
- 5) *Create an Ethics Board for PAFC*:
 - Develop ethical standards and guidelines for providing access to data and conducting research at the centre

Appendix 1: Autism Research Lightning Round

At the BC Autism Research Meeting, the following researchers presented information on their areas of ASD research, and expressed interest in seeking collaborative opportunities with PAFC:

Emily Gardner, Child & Family Research Institute, NeuroDevNet Postdoctoral Fellow

This study is examining the Family Quality of Life scale (FQOL) among families and children/adolescents with ASD, looking into risk factors and family satisfaction with the model in BC. Daily living skills emerged as the biggest issue, but this area is not frequently targeted for intervention. Although parents appreciate provincial funding, they are concerned about a lack of guidance to choose among approaches, and wanted greater transparency about the options, availability and quality.

Bernard Crespi, Professor of Evolutionary Biology, Simon Fraser University

This research into evolutionary biology in genetics and psychology is looking at the evolutionary bases for autism risk and its relationship with schizophrenia, which is commonly misdiagnosed as autism. The study is collecting data on causes in all domains, ultimately designed to support personalized medicine.

Nancy Lanphear, Head, Division of Developmental Pediatrics, BC Children's Hospital and Sunny Hill Health Centre for Children (SHHC)

BC developed a standardized ASD diagnosis in 2004; now the database using this standard has information on function and outcomes for 14,000 children with ASD. The SHHC Autism Research Group is the only jurisdiction in North America using such a database to evaluate autism trends and collaborate with other researchers.

Gillian Hanley, Post Doctoral Fellow, School of Population and Public Health, UBC

The population-based database mentioned above links gold standard diagnostic data on ASD from BC with information from other data sources on the impact of various exposures on health for mothers and children. Data can be linked retrospectively and prospectively, and this resource is available for collaborative ASD research projects.

Tim Oberlander, Senior Clinician Scientist, CFRI; Developmental Pediatrician, BC Children's Hospital and BC Women's Hospital & Health Centre

Using the data sets described above, this study has noted that an increase in incidence of ASD seems to be linked to an increase in use of antidepressants (SSRIs – selective serotonin reuptake inhibitors) to treat depression during pregnancy. Researchers are investigating whether there is an increased risk for ASD with serotonin changes, why, and what role the antidepressants play.

Bruce Lanphear, Clinician Scientist, CFRI; Professor, Faculty of Health Sciences, Simon Fraser University

Also using the same data sets, this research examines the impact of three agents—air pollution, toxic chemicals like lead, and pesticides—on the developing brain. Researchers will do spatial mapping to look at the rise of autism, the first such study in world. This information could ultimately help prevent autism.

Daniel Goldowitz, Scientific Director, NeuroDevNet; Professor, Department of Medical Genetics, UBC

NeuroDevNet (NDN) leads autism research into early diagnosis, evidence-based interventions, and improved support for families. NDN and Brain Canada have spearheaded a national training program in developmental neurosciences. As well, NDN participates in provincial projects looking into comorbidities, and uses neuroimaging data for informatics analysis and ethical critiques.

Suzanne Lewis, Chair, Project Operations Board, iTarget Autism; Clinical Professor, Department of Medical Genetics, UBC, Children's and Women's Health Centre of BC

iTARGET Autism is studying the hypothesis that ASD can be stratified into clinically distinct subgroups, which could lead to earlier diagnostic tools, best fit therapies, and improved outcomes. The interdisciplinary team of 20 researchers across BC and Canada will sequence the genomes of features that consistently cluster together, and link this molecular data with longitudinal clinical data to obtain insights into brain development.

Sam Doesburg, Associate Professor, Biomedical Physiology and Kinesiology Department, Faculty of Science, Simon Fraser University

Researchers will use a newly installed translational imaging lab, the only one in western Canada, to objectively evaluate the impact of various ASD therapies. Brain scan results from before and after the treatments will be combined with behavioural measures to assess effectiveness. The findings will be shared with service providers to guide practice.

Sherri Ferguson, Director, Environmental Medicine and Physiology Unit, Simon Fraser University

This clinical trial is doing a randomized double blind study to determine the effectiveness of 100% oxygen for treating ASD, using the only hyperbaric unit in Canada. The procedure is currently approved for 14 conditions, but not ASD. Researchers will determine how the procedure works on the brain and, if proven effective, provide evidence for delivering access through the health system.

Judy Illes, Professor of Neurology and Canada Research Chair in Neuroethics, UBC

The National Core for Neuroethics is a 20-person centre for excellence looking into the ethical, legal, policy and social implications of neuroscience discovery across the lifespan. The centre provides consultation province-wide, and is the "go to" authoritative body on neuro-ethical issues. One study found almost a complete absence of research with Aboriginal children and ASD, indicating either they have a protective aspect, or there's a lack of needed support.

Stefka Marinova-Todd, Associate Professor, School of Audiology and Speech Sciences, and Director, Centre for Intercultural Language Studies, UBC

This research found no developmental differences between English speaking individuals with ASD and bilingual or multilingual individuals with ASD. Children with autism can be bilingual and function in both languages, so families should be encouraged to speak the language they are most comfortable using, and not stop with a diagnosis of autism.

Jean-Paul Collet, Clinical Professor, Department of Pediatrics, UBC; Director, Partnership Development, CFRI

NDN has funded a team of ten programs collaboratively examining the impact of therapeutic recreation programs for children and youth with neurodisabilities and their families, and the implications for public health, education and policy. Results show the programs increase social integration for parents and motor and executive functioning for children. Inclusion, motivation and quality of life also improved.

Paul Fijal, Lead Biomedical Engineer, Awake Labs

Awake Labs has developed Reveal—an ankle bracelet that measures anxiety using skin temperature, heart rate, etc.—and sends the information to parents. The device is intended to help parents, caregivers and teachers prevent or mitigate knock downs before they happen, and to help people with ASD self-moderate and, thereby, support workplace integration.

Georgina Robinson, Administrator, Provincial Outreach Program for Autism and Related Disorders (POPARD)

POPARD focuses on assisting staff in the BC school system with evidence-based support. While research is not POPARD's primary goal, the program has done a range of research projects, such as using group cognitive behavioural therapy to increase coping skills for anxiety among youth with ASD. POPARD is interested in research collaboration to help children with ASD and can offer access to the school system.

Pat Mirenda, Director, Centre for Interdisciplinary Research and Collaboration in Autism (CIRCA); Professor, Faculty of Education, UBC

This centre at UBC primarily focuses on research aimed at ASD intervention, everything from how to teach swimming instructors to teach children with ASD, to support groups for fathers of children with ASD, to assessing the effectiveness of iPads for children with ASD. Since 2004, the centre has been following 400 children and families from time of diagnosis to graduation from high school, which will, when done, be largest longitudinal study into community factors that affect best outcomes.

Appendix 2: Acknowledgements

The organizers would like to acknowledge the following individuals for their roles in supporting the BC Autism Research Meeting:

Ad Hoc Autism Research Steering Committee

Jonathan Aitken, Director, Health Design Lab, Emily Carr University of Art & Design

Karen Bopp, Senior Behaviour Consultant, Ministry of Children and Family Development

Stuart Bowyer, Chief Business Officer, Inform Every Autism

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