

# Connecting Family Needs to Autism Spectrum Disorder Research in BC



## PACIFIC AUTISM FAMILY CENTRE FOUNDATION

With additional funding from Michael Smith Foundation for Health Research  
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GENERAL AREAS OF NEED INDICATED BY PARENTS	SPECIFIC NEEDS	AREAS OF RESEARCH THAT PARENTS CONNECTED TO THEIR NEEDS	OTHER AREAS OF RESEARCH INDICATED AS IMPORTANT BY PARENTS
<b>System Navigation/ Legal Rights</b>	<ul style="list-style-type: none"> <li>Evaluate, monitor and manage programs</li> <li>Accessibility and integrity of services</li> <li>Support services</li> <li>Geographical availability of services</li> <li>Adults with ASD services</li> <li>Medical overhead</li> <li>Support services</li> <li>Financial challenges</li> <li>Appropriate funding</li> <li>Lack of funding</li> <li>Financial lifestyle change (job loss and more expenses)</li> </ul>	<ul style="list-style-type: none"> <li>Improving intervention outcome</li> <li>Applied behavioural analysis</li> <li>Financial cost</li> </ul>	
<b>Community Awareness/ Inclusion/ Social Connections</b>	<ul style="list-style-type: none"> <li>Inclusion</li> <li>Friend to friend programs</li> <li>Creating a safe place for families to connect</li> <li>Ability to interact with more than one child at a time</li> <li>Ability to initiate play</li> <li>Understanding social conventions</li> <li>Appropriate public behaviour</li> <li>Community inclusion</li> <li>Marking negative behaviour</li> <li>Peer interaction</li> <li>Social processing</li> <li>Understanding personal boundaries</li> <li>Ability to express needs, goals and aspirations</li> <li>Social skills for daily life</li> <li>Public awareness</li> <li>Parents creating support programs</li> <li>Feedback around support from professionals</li> <li>Community outside of support personnel</li> <li>Organized physical activities for kids</li> </ul>	<ul style="list-style-type: none"> <li>Motor skills learning</li> <li>Effect of exercise on brain cells</li> <li>Determinants of health and children's rights</li> <li>Reading</li> <li>Interacting emotions</li> <li>Social processing</li> <li>Attending &amp; responding to social information</li> <li>Behaviour in everyday life</li> <li>Developmental delay</li> <li>Development of origins of stress &amp; self-regulation</li> <li>Social attention</li> <li>Social competence</li> <li>The brain's ability to adapt and separate</li> <li>Cooping &amp; anxiety</li> <li>Speech development</li> <li>Decision making &amp; problem solving</li> <li>Goals &amp; aspirations</li> <li>Behavioural analysis</li> </ul>	<ul style="list-style-type: none"> <li>Subtle educational environments &amp; approach</li> <li>Research to focus on developing high quality living skills for those with ASD</li> </ul>
<b>Treatments &amp; Therapies/ Integrity of Services</b>	<ul style="list-style-type: none"> <li>Mental health counselling and support</li> <li>Support and diagnosis for high-functioning kids</li> <li>Diversified therapies</li> <li>Holistic treatment</li> </ul>	<ul style="list-style-type: none"> <li>DNA profile</li> <li>Positive behaviour support</li> <li>Sleep disorder</li> <li>Research for high-functioning ASD</li> </ul>	<ul style="list-style-type: none"> <li>What supplements are best for ASD</li> <li>How food affects behaviours</li> <li>Find out if certain DNA is more susceptible to external triggers increasing symptoms</li> <li>Find source deposit with causal</li> <li>Branch out the focus of future interventions (other than ASD)</li> </ul>



## THE PROJECT

The Health Design Lab (HDL) at Emily Carr University of Art + Design has been collaborating with the Pacific Autism Family Centre (PAFC) and Michael Smith Foundation for Health Research (MSFHR) with the goal of deepening the understanding of family needs and connecting those needs to research opportunities. For the 2015/16 school year we collaborated on a two-phase project to engage with families directly. In the first phase, the HDL led a series of community based co-creation workshops with families of autistic children as well as adults with Autism Spectrum Disorder (ASD) in both the Greater Vancouver area and smaller communities within BC. For the second phase the HDL evaluated and summarized the results and proposed key areas for further ASD research based on family needs, creating a family-centred perspective towards ASD research.



Health Design Lab

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## THE OUTCOME

Based on the co-creation sessions the HDL produced a report which articulates needs expressed by families and areas of research families felt were unmet. This report seeks to give a voice to parents and foster a family-centred perspective towards ASD research. Families needs and opportunities for further research fell into 12 core themes:

Diagnosis	Family Support	Adulthood
Tools to Support ASD	Education	Community Awareness
Health and Wellness	Language Development	System Navigation
Treatments and Therapies	Transitioning to Adulthood	Understandable Access to Research

## THE PROCESS

The co-creation sessions focused on gathering responses to the following questions:

- What are the needs of individuals with ASD and their families?
- How do parents view research as connecting to these needs?
- What other areas of research might parents propose?

During the first phase of this project, the Health Design Lab developed kits to support 2-hour activity-based sessions in Prince George, Courtenay/Comox, and Vancouver. Participants included parents of children on the autism spectrum as well as adults with ASD. They were asked to express their own needs as well as how they envisioned that existing and new areas of research might connect to those needs.

In the second project phase the team analyzed the data generated, building their understanding of the relationship between family needs and research. Using such techniques as affinity diagramming we were able to generalize key themes and establish relationships between areas of need and research.



### ROADMAP ACTIVITY

This roadmap activity was used to help gain information about the experiences of parents of children with ASD.



### BLOCK ACTIVITY

Parents used blocks to express their areas of need and connect them to existing areas of ASD research.



### AFFINITY MAPPING

Data analysis and synthesis from co-creation sessions.