

# Connecting Family Needs to ASD Research in BC

## SUMMARY REPORT 2015/2016

A COLLABORATION BETWEEN THE HEALTH DESIGN LAB AT EMILY CARR UNIVERSITY AND THE PACIFIC AUTISM FAMILY CENTRE FOUNDATION WITH ADDITIONAL FUNDING FROM THE MICHAEL SMITH FOUNDATION FOR HEALTH RESEARCH.

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## FOREWORD

Welcome to our Connecting Family Needs to ASD Research in BC: Summary Report. This report represents the first of many family consultations Inform Every Autism is committed to holding for research in autism spectrum disorders (ASDs). This report, specifically designed to be qualitative, represents the voices of 20 families in British Columbia living with ASDs.

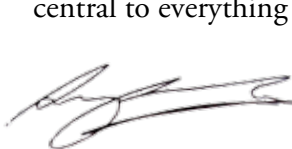
As the innovation and research arm of the Pacific Autism Family Centre, Inform Every Autism will create linkages between the needs of individuals with ASDs and their families and the research and innovation communities. Understanding and communicating those needs through an inclusive dialogue across our province and beyond is fundamental to everything we do.

Throughout this consultation, families expressed a need for research in 12 key areas. The scope is broad and covers the lifespan, ranging from earlier diagnosis to evidence based treatments and therapy options, to the health of their children through to transitioning to adulthood. In addition, there emerged a greater need for research on the effects of ASDs on the wider family support unit. This need highlights the overwhelming effect of ASDs not just on the individual but on a much wider group of people around them.

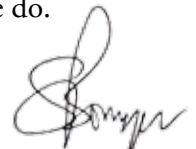
We also heard two key messages from families, 1) positive feedback about including families in this dialogue and of the co-creation process itself and 2) more research is needed but in a context that could directly connect to their needs.

In British Columbia there are 68,000 individuals diagnosed with ASDs, a prevalence rate of 1 in 68. This preliminary report does not aim to be representative of this community but as a parent/caregiver reading this you may very well connect to some of the stories, concerns and needs families expressed. To this end, over the next 12 months we plan to hold more face to face consultations that bring together families and researchers and to also expand the number of family participants through online and social media channels.

This report has provided great insights and created a pathway for opportunities to connect families to researchers and for researchers to understand how their work may connect directly to parents' needs. Clearly there is much to do and the Pacific Autism Family Centre and Inform Every Autism are committed to fostering greater collaboration and ensure families remain central to everything we do.



Sergio Cocchia, OBC  
Board Chair/President,  
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## RESEARCH IN COMOX

Four participants engaging in Activity One of the co-creation kit during the Comox/Courtenay session



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## HDL

The Health Design Lab (HDL) at Emily Carr is a research centre that specializes in applying human-centred design research practices to complex problems in health and healthcare. Human-centred design puts people at the core of the research process. It ensures that the experts, the actual stakeholders in a problem, have a voice. This involvement results in more innovative outcomes, a better “fit”, and higher acceptance rates of proposed solutions than with traditional design methodologies. As part of this process, we often hold co-creation workshops with our stakeholders. These workshops consist of a series of exercises that engage these participants by asking, listening, learning, and creating solutions collaboratively. In all cases, Emily Carr students are at the core of our projects; led by faculty, they develop research strategies, engage users, design final outcomes, analyze the results, and make recommendations for change. This approach to design and design research teaches critical thinking to our students and better prepares them to take leadership roles in society.

## PAFC

The Pacific Autism Family Centre (PAFC) is a new centre of excellence and network of supports for individuals with Autism Spectrum Disorder and their families across British Columbia and beyond. The PAFC’s core purpose is to be a knowledge centre: bringing together state of the art resources for research, information, learning, assessment, treatment and support; and building capacity to address the lifespan needs of individuals with ASD, and their families, across BC. The goal is to ensure that the Centre builds upon existing lifespan services while at the same time addressing the need for support and services across the province.

Serving British Columbians and ultimately all Canadians is a priority of the PAFC. The Centre of knowledge and innovation will involve the development of physical “hub and spoke/satellite” centres located in communities across the province, in collaboration with local community partners and staffed by Regional Navigators. The spoke centres will have full access to the expertise and information services offered in the hub location.

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## EXECUTIVE SUMMARY

The Pacific Autism Family Centre Foundation has a vision to create an environment where autism researchers and clinicians can come together to bring current, evidence-led best practices to families and adults living with ASD. They engaged the Health Design Lab (HDL) at Emily Carr University of Art + Design to further develop a deep understanding of family needs as well as probe for a family-centric perspective on research. The HDL uses a human-centred approach to design research which builds knowledge and understanding through bringing stakeholders into the design process. For this project they led a series of co-creation workshops in Vancouver, Prince George and Courtenay/Comox with parents of children on the ASD spectrum as well as adults on the spectrum. This report summarizes the research and design process, offering insights towards families' needs for research.

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## INTRODUCTION

The unique premise of PAFC is its focus on families with a guiding principle to "actively foster, and benefit from, the synergy of bringing together families, practitioners, researchers and policy makers" (PAFC Strategic Plan). While there are numerous initiatives at many research centres across BC, they mostly operate independently. The resulting silos make accessing information difficult and inter-institutional collaborations challenging. PAFC's mission for the coordination of autism services presents an opportunity to build a collaborative approach that may enable more connected and family-centred research.

A clear place to start is with what is held in common by parents and researchers—a commitment to improving the lives of those on the spectrum, and by extension, their families. This aligns well with the BC Ministry of Health's first priority (Setting Priorities for the BC Health System.

Ministry of Health, 2014): "provide patient-centred care; shift the culture of healthcare from being disease-centred and provider-focused to being patient centred." Additionally, this fits well with the BC Minister of Child and Family Development's Mandate Letter from 2015, with its emphasis on making recommendations on the effectiveness and coordination of Autism services in BC. If we extend this initiative to encompass research, we may be able to bring families into the research process by providing a means for them to connect their own needs to research in autism. By understanding how parents relate research to their own specific needs, we might be able to present a different perspective on that research. If a structure can be created from this unique perspective that provides natural links between researchers and orients them towards a common vision, new opportunities for collaborative research may emerge.



## PROJECT OBJECTIVES

To gain a family-centred perspective we need to answer 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 new areas of research might parents propose?**

This project sought to address these questions by giving families an opportunity to explore and represent their own needs, and identify how their needs may connect to existing and new areas of research. This was done through a series of facilitated co-creation workshops led by Emily Carr's Health Design Lab.

## WHAT IS CO-CREATION?

Co-creation is a human-centred design research method, where design researchers engage participants in the creative act of making, telling and enacting, in order to gain insights into the needs of those participants. In a co-creation session designers prompt participants to interpret and answer ambiguous questions; discuss problems; describe future experiences, concerns or opportunities; make “things;” and create prototypes. Co-creating allows us to quickly understand complex social problems, explore possible solutions, detect mistakes in design ideas, and create solutions tailored to people's needs. Ultimately, co-creation taps into the latent and tacit knowledge of the co-creators (participants) and provides insights into the needs, hopes, and desires that may not be captured in traditional research methods such as interviews and surveys. The design researcher will typically use a series of co-creation activities to facilitate this process during a one to two hour session with the participants.



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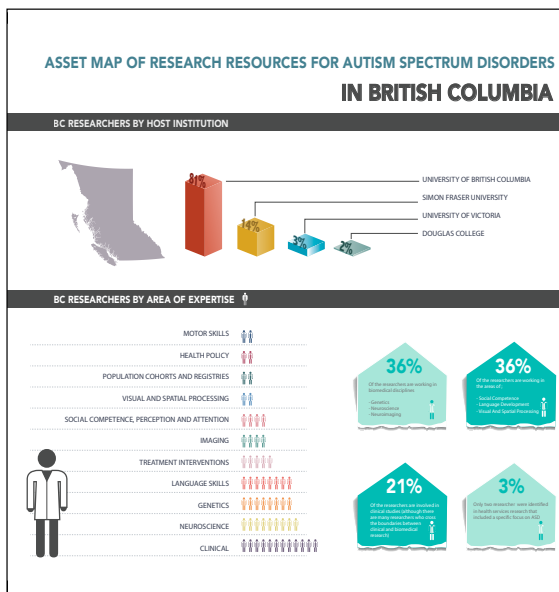
## CO-CREATION ACTIVITIES

For this project, the Health Design Lab developed kits to support a 2-hour activity-based session with parents of children on the spectrum in Prince George, Courtenay/Comox, and Vancouver. Each group ranged in size from 1 - 5 people, with 20 participants in total. They represented children from the ages of 5 - young adults. It is important to understand that this small sample is not necessarily intended to be representative of a wider population. The purpose of co-creation is not to provide statistical validity for findings. Instead, the primary purpose is to gain tacit knowledge from a specific group to help design researchers gain empathy for the people they are designing for. In this case, essentially we are giving designers with the Health Design Lab (and by publicizing this report, the public) a window into the lives of families

with a child on the autism spectrum. This is tremendously important as it connects us to these families emotionally and viscerally in a way that quantitative data never really can. All of us who have worked on the project have been affected by the parents we've met. We are now in a much more educated space to design outcomes that fit the participant group. In the future, we can apply this knowledge to designing outcomes for families with a child on the spectrum with a much improved sense of context. This knowledge is invaluable for a designer. Additionally, the work of co-creation builds bridges between researchers and participants. In this case, parents were keenly interested in (and critical of) research, but most of them were also highly engaged and enthusiastic in contributing to this dialogue with researchers. They expressed interest in seeing the results of these sessions and want to continue to be involved.

# “...TO ACTIVELY FOSTER, AND BENEFIT FROM THE SYNERGY OF BRINGING TOGETHER FAMILIES, PRACTITIONERS, RESEARCHERS AND POLICY MAKERS”

*PAFC Strategic Plan*



## ICEBREAKER ACTIVITY

A visualization of current autism research in BC.

## ICEBREAKER

At the beginning of each session, we introduced ourselves and this project, and we showed participants a visualization of current autism research in BC to give them a sense of the work currently being done. This acted as an icebreaker, allowing participants an opportunity to voice opinions and easily establish common ground with other participants.

## ACTIVITY ONE: ROAD MAP

For our first activity, we laid out an abstracted ‘roadmap’, and supplied the participants with markers and stickers, in order for them to ‘map out’ their experiences from diagnosis through education, to adolescence and transitioning to adulthood. Combining this with stop signs, yield signs, and comments, the participants were then able to give us a visualization of their experience, and an understanding of where they felt frustration and/or confusion. The duration of this activity was about 15-30 minutes, or until the participants felt they were finished. This activity was designed to get the parents talking to each other, sharing and comparing experiences and getting

oriented towards communicating their overall needs. Insights were captured in two ways: note-taking of the conversations, and notes made by participants on the maps.

### ACTIVITY TWO: BLOCKS

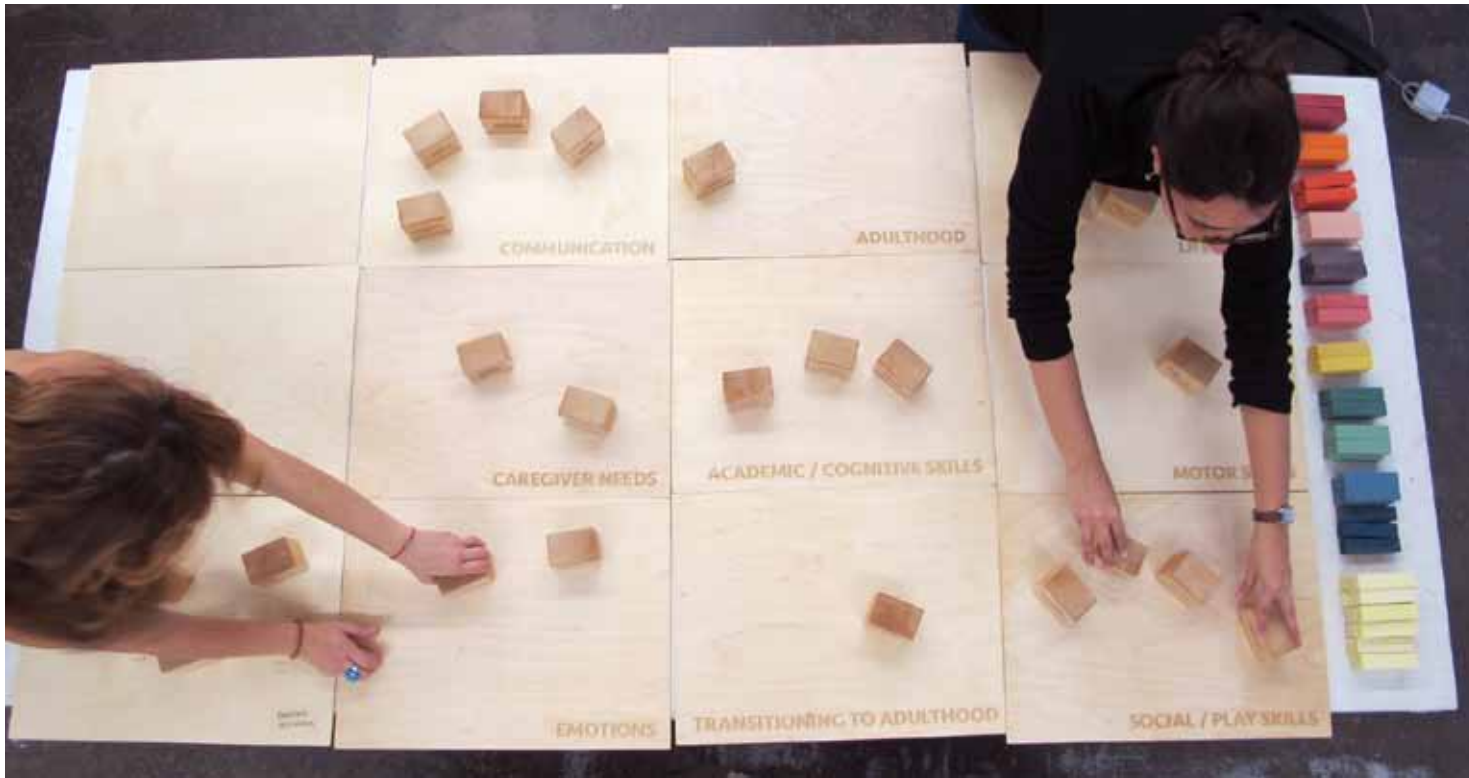
In the second activity, participants were given two sets of wooden blocks. The first set of blocks represented their own needs and the second set represented areas of research. Parents were asked to title the blocks from a set of pre-made labels, or to create their own from a set of blank labels. They were then asked to arrange the blocks and use string to

illustrate connections between their needs and areas of research. The intent behind the exercise was to gain a rich understanding of parents'/caregivers' needs, their current awareness and emphasis on research, and where they would make connections. Our intention was to extrapolate a theoretical structure or framework from the participants' physical representation, in order to show the relationship between needs and research. This activity provided a richly complex understanding of the relationship of research areas to needs, from a parent's/caregiver's perspective.

### ACTIVITY ONE

Participants create a road map of their experience.





**ACTIVITY TWO**

Participants use blocks to express their areas of need and connect them to research areas.



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## THE SESSIONS

During a two month period (December 2015-January 2016) our team hosted eight sessions with a total of 20 participants. Three sessions were held in Prince George with six participants; three in Comox with eight participants; and two in Vancouver with six participants. Each session was 1.5-2 hours long (depending on participant engagement,) and held in a comfortable environment for the participants. Facilitators captured data in note form, photo documentation, and collected thoughts written by the participants.

Parents were highly engaged in the sessions. They seemed grateful for the opportunity to be able to talk about their struggles and frustrations with others; and they appreciated having the opportunity to contribute their voice to research. All were curious about how they could access the project results to see how their contribution would be making a difference. Though not asked specifically about the PAFC, they were enthusiastic about the idea of their community being able to access resources from a central hub.

To analyze the results, we used a process called affinity diagramming to focus findings through a process of categorization. First, each “bit” of information from the sessions was re-entered on a post-it note. For example, every area of need or research identified by a parent/caregiver was entered on a separate post-it note. These notes were then clustered based on their affinity, naturally grouping into needs and research-based themes. The team then began the process of interpreting notes and considering the underlying significance of each. Notes that shared a similar intent, problem, or issue were clustered together. Out of this work, a story emerged about people, their daily routines, and the nature of their problems or concerns. This process was repeated for each location. The generalized results are summarized here.

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## **SUMMARY**

After analyzing the sessions and identifying the major areas of needs expressed by parents, the next step was to generalize the research findings. To do this we clustered individual areas of need according to overarching themes. The resulting 12 areas of need are briefly summarized below—the full chart is on pages 24-27.

## **DIAGNOSIS**

Parents/caregivers were almost unanimous in their expressed frustration around the diagnostic process. This is reflected in the chart, where diagnosis appears to have few entries, when in fact there was simply much agreement on those items. Wait times were certainly an issue, but as well, many expected their Family Physicians to have been the first to recommend diagnosis, but this was not often the case. Additionally, parents/caregivers expected emotional and educational support along with the diagnosis, but this was not usually provided. They had to learn about options on their own and often felt frustrated by a complex system.

## **TOOLS TO SUPPORT ASD**

Generally, parents/caregivers were interested in any tools or materials that they could use to help with their children. While no specific areas of research were connected to this need, it was generally felt that knowledge from research is only useful to them when applied to tools to help them with their children. These included ideas such as apps that might support learning about emotions, but ranged to include any educational materials that might be used to help their children learn, particularly social skills.

## **HEALTH AND WELLNESS**

This area of need was expressed in many ways. Parents/caregivers were unanimous in their concern for the health of their children, but differed widely in how they expressed it. Some needed help with teaching hygiene and self care. Others were more concerned with diet and nutrition and its effects on ASD. Still others were much more aware of the need to support their children in learning to regulate emotions. Parents/caregivers saw that much research is being done in this area already, and had no specific recommendations for more research.



# WHAT IS HUMAN CENTRED DESIGN?

## TREATMENTS AND THERAPIES

Here again, parents/caregivers converged on a few specific needs. All of them had experience with applied behavior analysis as the primary treatment available. Some found it quite useful, others were highly critical. But most wanted some research into other modes of treatment. They felt there was a general lack of evidence-led research into alternatives. Some expressed a need for more focus on the needs of high-functioning children while others wanted more research into the effects of food and diet on behavior, hoping it might lead to nutrition/diet focused treatments.

## FAMILY SUPPORT

Families overwhelmingly agreed on the need for more family-focused support. Many participants told heart-wrenching stories of the effect of a child with ASD on their families. Marriages dissolved, some families split apart to find care for their child, and others indicated a huge effect on siblings. All showed a need for respite care occasionally when things became unmanageable. Here too, many ideas around other areas of research were indicated that might contribute to their needs. Could non-competitive physical activities provide for better health outcomes than competitive ones? Would diet changes contribute to fewer issues at home? Could siblings be encouraged to take on supportive roles, without negatively impacting their own development?

IDEO, one of the world's leaders in human-centred design, posts the following definition on its web site: embracing human-centred design means believing that all problems, even the seemingly intractable ones like poverty, gender equality, and clean water, are solvable. Moreover, it means believing that the people who face those problems every day are the ones who hold the key to their answer. Human-centred design offers problem solvers of any stripe a chance to design with communities, to deeply understand the people they're looking to serve, to dream up scores of ideas, and to create innovative new solutions rooted in people's actual needs. (IDEO, 2015)

In the human-centred design process, designers are focused on looking for ways to ensure that the thing being designed (e.g. the system, object, communication, space, interface, service, etc.) meets the needs of the people who will be using it (users). As design researchers we collect primary data through the generative design process of co-creation and use secondary sources to learn about the needs of the user.

## VANCOUVER - ACTIVITY TWO

Participants working towards connecting their needs to areas of research.



### EDUCATION

Insights in this area fell into two broad categories: general needs around education, and problems with schools. Parents/caregivers represented varying needs. Some home-schooled their children as they felt schools were unable to provide for their needs. Others saw the schools trying, but with limited resources were not able to give their children appropriate levels of support. Still others had specific concerns with a general lack of awareness and understanding of ASD among professionals, such as teachers, who they feel should be better educated. Generally, all had some level of frustration with a school system that tried to accommodate for children with ASD, but was largely unprepared. Parents/caregivers identified many existing areas of research that they connected to their needs, but did not identify any other ones specifically.

### LANGUAGE DEVELOPMENT

Parents/caregivers identified clear needs around language development and its importance in helping their children socialize. They identified many existing areas of research that connected to this need. Overall they seemed satisfied that research was being done to address this area, and did not indicate other suggestions.

### TRANSITIONING TO ADULTHOOD

The topic of transitioning to adulthood was of particular importance to parents/caregivers of children entering adolescence. Difficult conversations were happening with their children around sex, social relationships, bullying, etc. They wanted to give their children basic life skills and many were concerned for their children after they were no longer able to support them. Areas of research that they connected to this need included studies into coping and anxiety, stress, sleep disorders and decision-making.

## ADULTHOOD

We were not able to engage many participants who had ASD themselves. The issues identified were a combination of one adult's input, a participant whose spouse is on the spectrum, and a parent with an adult child. Concerns were raised about the need for specific skill-based learning to facilitate independence. Parents/caregivers generally thought their children were going to need much more help with this transition than seems to be available. They indicated several other areas of research that were important: navigating social situations at work; employment; dating and sexuality; making and keeping friends. While some of this research is being done, they feel it is mostly directed at children, rather than young adults.

## COMMUNITY AWARENESS

Unsurprisingly, parents/caregivers felt deeply hurt by a largely unaware community. All expressed issues around bullying, intolerance, and exclusion, not just by schools, but by society in general. The long list of needs in the chart reveals the many stories parents shared. They wanted better public awareness and education, so that they didn't always have to take on the role of advocate in a system that is not well suited to their children. They asked for research that might contribute to a more supportive community as well as tools and procedures to help their children cope.

## SYSTEM NAVIGATION

Parents/caregivers showed a need for support in navigating the sometimes confusing networks of resources, support and services for people living with ASD. They felt completely unprepared after diagnosis, and quickly had to become experts in finding and accessing support. Many expressed disillusionment with some private services

that are expensive and not useful. Others had problems accessing services locally, and in at least one instance, moved to find such services. Many had to give up employment to work full time on their child's behalf. No other areas of research were suggested and not much existing research was seen as pertaining to this need. It would be fair to assume that this need is more structural than research-oriented.

## UNDERSTANDABLE ACCESS TO RESEARCH

The final area of need established by parents/caregivers was one of access to research. There was a general sense of disconnection from research, and where available, it was difficult to comprehend by a non-professional. This disconnect has led, in some instances, to parents/caregivers seeking private treatments that may not be evidence-based. They certainly did not want to give up their freedom of choice in treatments, as their children all had such different needs. But many mentioned so much evidence and support for ABA, for example, that other treatment options were seldom considered and had had no research into their effectiveness at all. This sometimes created an opportunity for what some parents/caregivers referred to as "dubious" practices. Here, many connections were made between needs and research and several other areas of importance were suggested. These included research into holistic alternatives and focusing research more towards treatment than cause. Overall parents wanted a clear map of the research with specific ways they could access current, evidence-led best practices for treatment. They wanted this information laid out clearly and in plain language.

## MAKING CONNECTIONS

Connecting areas of research to needs during the Prince George co-creation session.



## TOWARDS A NEW FRAMEWORK

The chart on fs 24-27 reflects a first step toward creating a family-centric framework for ASD research in BC by organizing research projects around how parents see them connecting to their needs. Although some groupings may seem oddly disconnected at first glance, to the best of our ability, we tried to represent these connections exactly as parents presented them. While this structure may make little sense from a researcher's point of view, it does represent parents'/caregivers' perspectives, and may offer researchers a different way to look at their work.

For example, parents connected widely varying areas of research to the "Family Support" area of need. From sleep disorders, stress, and health, to genetic research — parents saw this research as connecting to their needs as a family unit. This speaks to the overwhelming effect of ASD, not just on the individual, but on a much wider group of people around them. Here, we learn from parents that we cannot easily isolate any single aspect of ASD without considering the whole. And while by definition research often must isolate variables, it may be instructive for researchers to connect their findings back to the overall picture and consider wider implications.

On another level, simply bringing parents into a discussion on research changes the

picture — it allows parents to express their needs in a way that can inform research and it creates a greater awareness of existing research for parents. The whole notion of co-creation is based on the idea that stakeholders are the experts. In this case, co-creation acknowledges that parents are the experts on their children. Bringing them into the conversations around research benefits us in two ways: first, parents feel included rather than excluded, and second, researchers gain empathy and a greater understanding of how their work may connect directly to parents and parents'/caregivers' needs.

**“LIFE SKILLS OFTEN TAKE THE BACK BURNER, WHILE OTHER MORE IMPORTANT ISSUES ARE DEALT WITH. LEARNING LIFE SKILLS LIKE TOILETING AND EATING IN A RESTAURANT BECOME LUXURIES.”**

*Anonymous Parent (Co-creation session)*

# “IT IS PROBLEMATIC NOT KNOWING HOW TO GET THE SKILLS FOR DATING/EMPLOYMENT/MAKING AND KEEPING FRIENDS.”

*Anonymous Parent (Co-creation session)*

## LOOKING FORWARD

For most of the Health Design Lab team, this was our first encounter with parents of children on the spectrum and we were all struck by the radical life changes that families have made to accommodate their children's needs. They become, by necessity, advocates for their children, and often mentioned feeling alone and isolated. They understand the general need for research, but it sometimes feels removed to them, not connected to their needs or their children specifically. Parents want research. But they want it applied to tools, treatments, materials, and support mechanisms that can directly benefit their children. They are highly supportive of any such initiative that might connect research more directly to their needs.

This project has shown that parents are passionate about their children. This passion was indicated by an enormous enthusiasm for the co-creation exercises, and a willingness to re-engage with the project in the future. Parents certainly see the value in better access to research and they were highly appreciative of the outreach

effort made by the PAFC and the HDL to engage them. This interest creates a huge opportunity to continue this dialogue with parents in a coordinated manner. A natural next step would be to bring researchers and parents together in mixed co-creation events to build research questions together. Parents would benefit from engaging directly with researchers by understanding more about the perspectives and constraints around research in academic institutions. Researchers may benefit from connecting directly with parents by learning perspectives on their work, potentially building actionable research questions. Researchers may also benefit by meeting and connecting personally with other researchers, perhaps allowing for new collaborative opportunities. PAFC, Inform Every Autism, and the HDL could continue their role in mediating this dialogue between parents and researchers, providing a much needed link.

The sessions also revealed an unexpected sense of community. Parents, particularly in Prince George and Courtenay/Comox, have self-organized into very casual but

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meaningful support communities. Most parents seemed to either know, or know of, each other, and many used the sessions to trade information, update each other on treatments, techniques, and practitioners. They happily shared their experiences with each other and this created an “ad hoc” body of knowledge that was critical for them in navigating their child's journey. There is further opportunity here for PAFC to be an active part of these communities. PAFC is already planning to support these communities with access to resources (the hub to spoke model) but it may also be interesting for PAFC to play a lead role in making research available to the community in a meaningful, organized, digital structure that would allow for two-way communication between parents and researchers. This could take many forms, but likely at the core of it would be a curated body of plain language research, or evidence-led critiques of existing treatments, helping parents make informed choices. Going further, the structure could provide a way for smaller local groups to connect with other groups, and with researchers, expanding their informal local communities into larger communities. The groups might then, with various ethics processes in place, provide researchers with access to enthusiastic participants for their own projects.

The work that is currently being done and planned by the PAFC and Inform Every Autism is highly important in fostering connections: parents to resources, research to practice, and parents to researchers. Parents are excited by this opportunity and are poised to be active and engaged participants. Emily Carr's Health Design Lab was proud to have been part of this project.

## **“EVERYONE’S JOURNEY IS SO DIFFERENT.”**

*Anonymous Parent (Co-creation session)*







# RESULTS MATRIX

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>Diagnosis</b>	<ul style="list-style-type: none"> <li>- Easier and more transparent access to diagnostic services</li> <li>- Accurate early diagnosis</li> <li>- Emotional support</li> <li>- Support and diagnosis for high functioning kids</li> </ul>	<ul style="list-style-type: none"> <li>- Early detection</li> <li>- Coping and anxiety</li> <li>- Counselling</li> <li>- Research for high functioning ASD</li> </ul>	<ul style="list-style-type: none"> <li>- Find source, dispel with cause/ cure</li> </ul>
<b>Tools to Support ASD</b>	<ul style="list-style-type: none"> <li>- Support tools and equipment</li> <li>- Product design for ASD &amp; sensory issues</li> <li>- Tools to control, manage and express emotions</li> <li>- Visual communication support</li> </ul>		
<b>Health &amp; Wellness (Mental/Physical)</b>	<ul style="list-style-type: none"> <li>- Hygiene &amp; self care</li> <li>- Diet and health maintenance</li> <li>- Health as a mind/body system</li> <li>- Co-morbidities</li> <li>- Play/social skills</li> <li>- Emotional support</li> <li>- Emotional understanding and support</li> <li>- Managing emotional well - being</li> <li>- Tools to control, manage and express emotions</li> <li>- Recognizing situations and boundaries</li> <li>- Responses and recognition of environment</li> <li>- Autonomy in problem solving</li> <li>- Autonomy in decision making</li> <li>- Moderating dangerous situations</li> <li>- Motor skills function and activities and play to support development</li> </ul>	<ul style="list-style-type: none"> <li>- Goals &amp; aspirations</li> <li>- Self regulation</li> <li>- Sleep disorders</li> <li>- Health &amp; well-being</li> <li>- Positive behaviour support</li> <li>- Behaviour in everyday life</li> <li>- Child &amp; youth mental health</li> <li>- Social determinants of child development</li> <li>- Social processing</li> <li>- Social competence</li> <li>- Coping and anxiety</li> <li>- Expressing emotions</li> <li>- Recognizing emotions</li> <li>- Decision making &amp; problem solving</li> <li>- Brain's ability to adapt</li> <li>- Treatment of repetitive behaviour</li> <li>- How brain interprets vision</li> <li>- Effective school based interventions</li> <li>- Counselling</li> <li>- Early detection</li> <li>- Development of origins of stress &amp; self-regulation</li> <li>- Social attention</li> <li>- Use of functional imaging to improve treatment</li> <li>- Applied behavioural analysis</li> <li>- Nervous system impact on autism</li> <li>- Management of epilepsy</li> <li>- Motor skills impact on autism</li> <li>- Physical activity</li> <li>- Motor skills learning</li> <li>- Effect of exercise on brain cells</li> </ul>	

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>Family Support/Respite Care</b>	<ul style="list-style-type: none"> <li>- Respite</li> <li>- Study groups</li> <li>- Approaches to counselling and emotional support</li> <li>- Parent/family education and training</li> <li>- Learn to self advocate</li> <li>- Visual communication support</li> <li>- Support family communication</li> <li>- Perspective change on quality of life</li> </ul>	<ul style="list-style-type: none"> <li>- Sleep disorder</li> <li>- Parenting stress</li> <li>- Counselling</li> <li>- Motor skills learning</li> <li>- Brain's ability to adapt</li> <li>- Health &amp; well-being</li> <li>- Diagnosis</li> <li>- Coping with anxiety</li> <li>- Expressing emotions</li> <li>- Parenting stress</li> <li>- Social competence</li> <li>- Early detection</li> <li>- How the brain interprets vision</li> <li>- Health and well being</li> <li>- DNA profile</li> <li>- Genetic links to autism</li> <li>- Determinants of health and children's rights</li> <li>- Speech development</li> </ul>	<ul style="list-style-type: none"> <li>- Navigator/advocate</li> <li>- Non-competitive activities that provide physical activity</li> <li>- Vitamins and supplement support</li> <li>- Auto-immune disorder</li> <li>- Food sensitivities</li> <li>- Biomedical help and info.</li> <li>- Gut related bacteria</li> <li>- Diet intervention</li> <li>- Gut health vs brain health</li> <li>- Siblings as supporters</li> </ul>
<b>Education</b>	<ul style="list-style-type: none"> <li>- Affordable and accessible education</li> <li>- Effective and appropriate education</li> <li>- Appropriately trained educators/tutors</li> <li>- Student support in school</li> <li>- School support</li> <li>- Alternative to public school</li> <li>- Education and ability to learn throughout life</li> <li>- Adult education</li> <li>- Public school support therapists lacking</li> <li>- Effective school based interventions</li> <li>- Home school</li> </ul>	<ul style="list-style-type: none"> <li>- Effective school-based interventions</li> <li>- Speech development</li> <li>- Development of origins of stress &amp; self-regulation</li> <li>- Nervous system impact on autism</li> <li>- Sleep disorder</li> <li>- Applied behavioural analysis</li> <li>- Motor skills learning</li> <li>- The brain's ability to adapt</li> <li>- Improving intervention outcome</li> <li>- Social processing</li> <li>- Attending &amp; responding to social information</li> <li>- Expressing emotions</li> <li>- Recognizing emotions</li> <li>- Counselling</li> <li>- How brain interprets vision</li> <li>- Communication (listening, watching, interpretation)</li> <li>- Social competence</li> <li>- Behaviour in everyday life</li> <li>- Writing</li> <li>- Positive behaviour support</li> <li>- Individual education plans</li> <li>- Ability to learn</li> </ul>	

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>Language Development</b>	<ul style="list-style-type: none"> <li>- Social communication</li> <li>- Language skills</li> <li>- Development of speaking, reading and writing</li> </ul>	<ul style="list-style-type: none"> <li>- Reading</li> <li>- Writing</li> <li>- Speech development</li> <li>- Language comprehension</li> <li>- Ability to learn</li> <li>- Individual education plans</li> <li>- Nervous system impact on ASD</li> <li>- Use of functional imaging to improve treatment</li> <li>- Decision making &amp; problem solving</li> </ul>	
<b>Transitioning to Adulthood</b>	<ul style="list-style-type: none"> <li>- Life skills</li> <li>- Transition to adulthood support</li> </ul>	<ul style="list-style-type: none"> <li>- Coping and anxiety</li> <li>- Genetic links of autism</li> <li>- Parenting stress</li> <li>- Sleep disorders</li> <li>- Decision making &amp; problem solving</li> <li>- Development of origins of stress self-regulation</li> <li>- Child and youth mental health</li> </ul>	
<b>Adulthood (Independent Living)</b>	<ul style="list-style-type: none"> <li>- Independence skills, opportunities and responsibilities throughout lifetime</li> <li>- Adult support in transitioning</li> <li>- Self-advocating</li> <li>- Reaching academic / job potential</li> </ul>	<ul style="list-style-type: none"> <li>- Nervous system impact on autism</li> <li>- Counselling</li> <li>- Ethics related to disability</li> <li>- Social attention</li> <li>- Behaviour in everyday life</li> <li>- Social Competence</li> </ul>	<ul style="list-style-type: none"> <li>- How to navigate social skills at work</li> <li>- Employment for ASD adults</li> <li>- Dating skills</li> <li>- Sexuality</li> <li>- Making &amp; keeping new friends</li> </ul>
<b>Understandable Access to Research</b>	<ul style="list-style-type: none"> <li>- Up to date understanding of healthcare best practices</li> <li>- Impact of treating medical co-morbidities on quality of life and outcomes</li> <li>- Effectiveness of alternatives to ABA</li> <li>- More efficient knowledge translation</li> <li>- Access to information</li> <li>- Present research in layman's terms</li> <li>- Faster turnaround for diagnosis</li> <li>- Sourcing and accessing information</li> <li>- Mapping out the research terrain</li> <li>- Understanding information</li> </ul>	<ul style="list-style-type: none"> <li>- The brain's ability to adapt</li> <li>- Research in layman's terms on how it is informing practice &amp; clinical services</li> <li>- Determinants of health &amp; children's rights</li> <li>- Connecting research professionals/clinicians/educators to improve lives of those with ASD</li> <li>- Improving intervention outcome</li> <li>- Health &amp; well-being</li> <li>- Management of epilepsy</li> </ul>	<ul style="list-style-type: none"> <li>- Maternal medication use &amp; ASD</li> <li>- Pediatrician training - ASD related</li> <li>- Holistic care - nutrition/allergies /sleep</li> <li>- Medical Doctor Training</li> <li>- Epi-genetic determinants of autism</li> <li>- Research to focus on treatment not cause</li> </ul>

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>- Accountability 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 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 behavior</li> <li>- Community inclusion</li> <li>- Moderating repetitive 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>- Feelings 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>- Interpreting 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</li> <li>- Coping &amp; anxiety</li> <li>- Speech development</li> <li>- Ability to learn</li> <li>- Early intervention</li> <li>- Treatment of repetitive behaviour</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>- Suitable educational environment &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 dispel with cause/cure</li> <li>- Branch out the focus of treatment interventions (other than ABA)</li> </ul>

## REFERENCES

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**Discussing Results**  
Team members considering the  
co-creation results.

