

Bridging researchers and families in the ASDs Community

EMILY CARR UNIVERSITY HEALTH DESIGN LAB
2016/2017

A collaboration between the Health Design
Lab at Emily Carr University and the Pacific
Autism Family Network



Health Design Lab



HEALTH DESIGN LAB

PROJECT LEAD

Caylee Raber - *Director*

PROJECT SUPPORT

Deborah Shackleton - *Dean, Faculty of Design and Dynamic Media*

PROJECT COORDINATION

Jacqueline Kler - *Operations Coordinator*

RESEARCH ASSISTANTS

Ateret Buchman

Natalia Franca

Stacie Schatz

Zora Trocme

PROJECT SPONSORS:

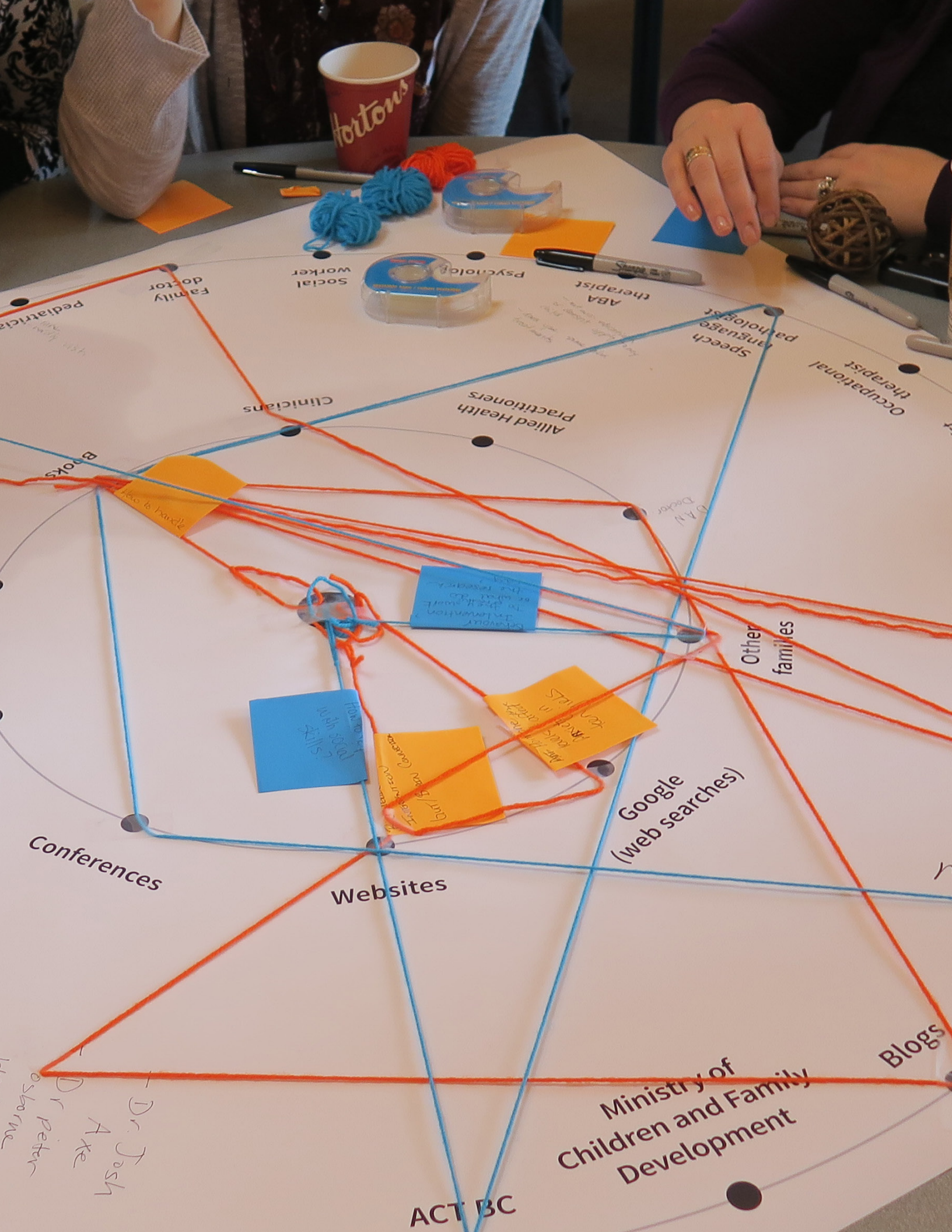


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INTRODUCTION

1.1 BACKGROUND

The Health Design Lab (HDL) at Emily Carr University of Art + Design has been collaborating with the Pacific Autism Family Network (PAFN) and Inform Every Autism 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. This collaboration began in 2015 with a focus on creating a family-centered framework for ASDs research.

In 2015/2016 the HDL held eight co-creation workshops with a total of 20 participants in Prince George, Courtenay/Comox, and Vancouver. Participants included parents of children on the spectrum as well as adults with ASDs. The goal of these workshops was to better understand the needs of families and how they envisioned existing and new areas of research might connect to those needs. The research was in accordance with the PAFN's mission to "actively foster, and benefit from, the synergy of bringing together families, practitioners, researchers and policy makers" (PAFN Strategic Plan).

After concluding the co-creation workshops with caregivers/parents in 2015/2016, the Health Design Lab team discovered that many families had a difficult time navigating through vast amounts of information and research concerning ASDs. The internet affords caregivers the opportunity to access large quantities of information about ASDs. This can be a great way for caregivers to share information, access research and seek new therapies. Conversely the sheer amount of information available can become overwhelming especially as misinformation and peer-reviewed research are presented side by side within search engine results. It was noted in one of our meetings with members of the the PAFN Steering Committee that researchers have a handle on the state of the science, while caregivers have a handle on the state of the family, but we need to get a better handle on the state of communication and information.

Through our collaboration in 2015/2016 we saw a keen interest from families and researchers to connect with one another through participatory workshops. At the

BC Autism Research Blue Sky Meeting held in January 2016, there was a clear interest in fostering communication between researchers and families. One of the priorities identified at the meeting was to “build two-way communication between researchers and parents of individuals with ASDs so parents can express their interests in research and researchers can explain their research initiatives” and to “listen to families and individuals with ASDs to discover their research priorities” (Report from the BC Autism Research Blue Sky Meeting, 2016).

The goal for our 2016/2017 collaboration with PAFN was therefore to gain a better understanding of how researchers and families currently communicate, and to foster ideas for improving future communication. This document summarizes the research and design process we engaged in over the last year with researchers and families, it offers insights into the benefits and challenges of current research sources, and it highlights new ideas for fostering improved communication and access to research in the future.



PAFN

The Pacific Autism Family Network (PAFN) 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 PAFN'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 PAFN.

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.

HDL

The Health Design Lab is a research and design centre at Emily Carr University of Art + Design. Within the lab, faculty and students work collaboratively on projects with industry and community partners to address complex challenges in health and healthcare through a human-centred design approach that places an emphasis on participatory design research and the involvement of users throughout the design process.

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. 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.

caregiver / parent

Other families

Don't have a lot of experience of working with families who have children with autism

I have never heard back from them.

social worker

DOESNT DO a lot of research... we tell them what to do as a kid

KNOWS MY CHILD WELL

CARE GIVER

Pros: can sympathize with my experiences cons: with similar work

HARD TO TELL IF TRUE

NEWS LESS BAKED

NO TIME TO ATTEND.

OVERWHELMING / OVER STIMULATED

1.2 PROJECT OBJECTIVES

The HDL worked with PAFN in 2016/2017 to gain a better understanding of the communication challenges and needs of researches and families, through co-creation activities. The objective of the 2016/2017 project was to discover ways to bridge the communication gap between researchers and families, and to collect insights that may inform new communication strategies and approaches to foster increased communication and collaboration.

With these objectives in mind, students and faculty at the Health Design Lab expanded upon the work from 2015/2016, creating an interactive installation at the PAFN opening, and facilitating co-creation workshops with families of individuals with ASDs and researchers to answer the following questions:

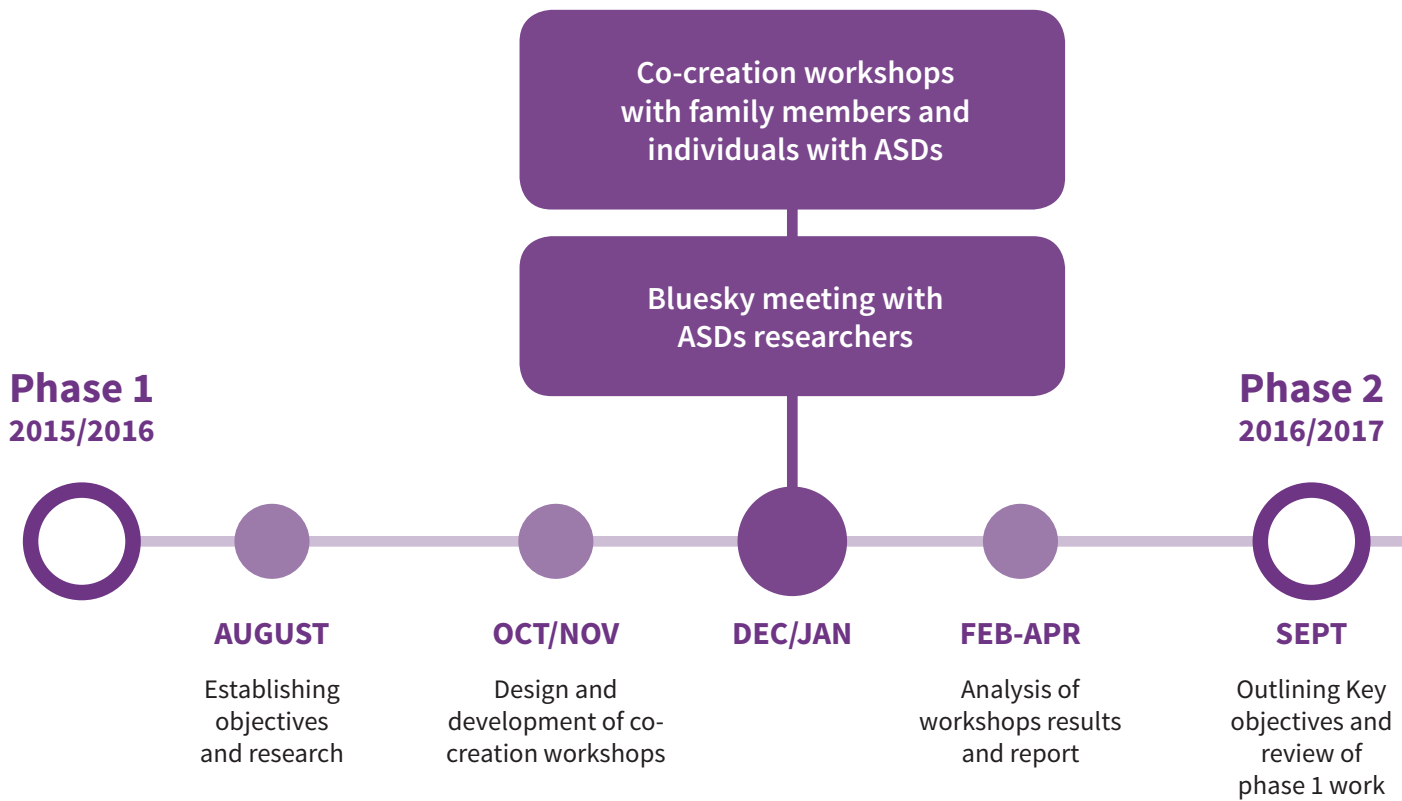
This project addressed these questions by providing an avenue for families and researchers to connect and listen to one another, bringing insights into each other's perspectives, knowledge and experiences. It was an opportunity for families to express how they currently navigate and access ASD information and for researchers to express how they disseminate information. Together they envisioned ideas for the future state of communication between researchers and family members of individuals with ASD.

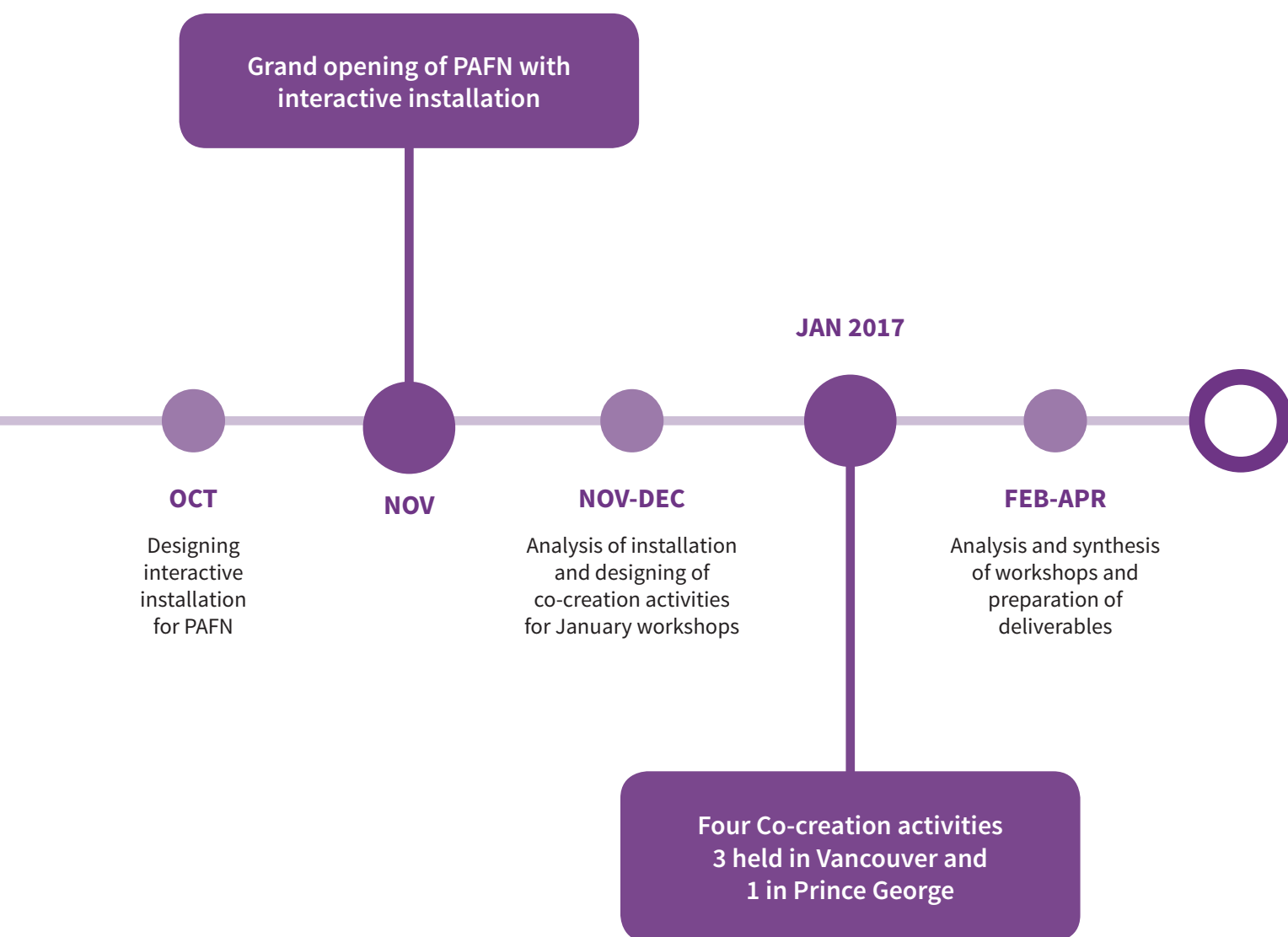
How are families currently accessing and navigating information and research? And what are their challenges?

How are researchers currently disseminating information and research? And what are their challenges?

How do families and researchers envision the future state of communication?

1.3 PROJECT TIMELINE





1.4 METHODOLOGY

The HDL's primary focus is human-centred design research practices. Research methodologies used in a human-centred design process aim 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). Involving users into the design process is crucial for understanding the different perspectives of the people whose needs are being addressed, and it ensures that the experts, the actual stakeholders in the case, have a voice.

This project utilized design methodologies, which enabled a multidisciplinary approach for creating and developing knowledge and empathy between the designers, researchers and families engaged in this project. Design research mainly uses qualitative research methods for gathering and analyzing data. In the Health Design Lab we use generative methods, including co-creation to enable participants to express their thoughts, feelings and needs, through verbal and visual means. We design objects or artifacts that act as triggers for conversation to help foster dialogue and draw out latent and tacit knowledge from participants. "The creation of an artifact around which a participant may talk will act as a trigger for engaged

and comfortable conversation" (Hanington, 2007). In this project these methods were used to foster dialogue between researchers and families and to enable us to capture their perspectives on the state of communication between knowledge holders in the ASDs community.

Co-creation has been used in other healthcare and social projects as a way to create a common understanding and improve communication between stakeholders. Co-creation's main concern is to find ways to help in the communication of experiential knowledge and establish meaningful dialogue between people coming from different backgrounds. According to Sanders and Stappers (2012) this type of generative design research "gives people a language with which they can imagine and express their ideas and dreams for future experiences".

One challenge in bringing people together is to create an environment that allows everyone to meaningfully contribute to the discussion. Scientific knowledge is often given more value than the experiential knowledge of the general public. Co-creation workshops however, give special attention to methods of engagement that create a level playing field and enable all the participants to express

themselves in meaningful ways. Therefore we felt that co-creation activities would be a useful tool for fostering conversations between researchers and families, with the goal of breaking down hierarchical barriers and acknowledging both groups as knowledge

holders. This project included two key co-creation components. First, we engaged with the public through an interactive installation at the PAFN Grand Opening and secondly, we ran a series of four co-creation workshops with researchers and families.



2. PAFN INTERACTIVE INSTALLATION

2. PAFN INTERACTIVE INSTALLATION

The HDL conceptualized and designed a public interactive installation for the official launch of the new PAFN facility in November 2016. This temporary installation was set-up on a wall within the new facility and sought to engage a variety of visitors, including families and researchers, to ‘drop-in’ and respond to two key questions:

1. What is your vision for ASDs in British Columbia?
2. Where do you access ASDs research?

The purpose of the installation was to create a highly visual display to showcase the interest of PAFN in connecting families to research, and to promote and recruit participants for the co-creation workshops which were held in January 2017. The installation also acted as a priming activity for workshop participants and the Health Design Lab team. Participants who were recruited through the installation had an opportunity to meet the HDL team and learn about the project. The installation also gave the HDL team the opportunity to personally engage with the ASDs community and to gain information which was used to inform the design of the workshop activities.



What is your vision for ASDs in British Columbia?



Where do you access
ASDs Research?

Add to our live bar graph



Parents &
Caregivers

Help us discover more
about how you want
to connect with ASDs
research!

Share
your vision
with us!

The Health Design Lab at Emily
Carr University and the Pacific
Autism Family Network want to
hear your thoughts, needs and
ideas for bridging communication
between researchers and families



Health Design Lab



Project Sponsors:



2.1 VISION WALL

The first activity as part of the installation was a vision wall which asked visitors at PAFN to respond to the question “What is your vision for ASDs in British Columbia”. Participants were encouraged to write down their vision on a paper hexagon and add it to a wall display. Yellow hexagons began with the prompt, “I hope..”, while green hexagons began with the prompt, “I need...”. The goal of this activity was to learn more about the priorities, needs and dreams of people within the ASDs community.

Over the course of 4 days, hundreds of visitors touring the new PAFN Centre participated in sharing their vision. Through an analysis and synthesis of all of the contributions, nine themes emerged:

OBSERVATIONS

PUBLIC PERCEPTION & INCLUSION

Inclusivity and public education was one of the most referenced themes. Acceptance by the broad public and proper training for police (transit and otherwise), teachers, hospitality workers was an important part of peoples’ vision. It was often written that it was hoped the public and community would understand ASDs for its complexity and nuances rather than merely as a disorder.

“I hope... that people will see autism as something more than an illness”

“I need... to meet others who will accept me and like me for me”

PEER/SOCIAL SUPPORT

Friendship and networking beyond clinical appointments and treatments were mentioned frequently. Through this analysis it became apparent that for many individuals a less structured means of connecting to others would be of great value.

“I hope... our province continues to lead to the way and also acknowledges the work still needing to be done.”

“I need... more social groups for young teens”

TRANSITIONING TO ADULTHOOD

An apprehension and fear about the transitions into adulthood was expressed on many of the hexagons. To define these feelings more aptly, the process of aging did not seem to be an issue, rather the funding, vocational services, and life skills training were expressed as hard to access.

“I hope... that I can assist my son as he moves into his future years. Adulthood scares us - it’s the unknown”

“More help to live independently as an adult on the spectrum”

COHESIVE PROGRAMMING/SERVICES

This is a broad category in which many expressed specific needs or suggestions for PAFN. For example, difficulties way-finding through information and funding opportunities was mentioned often. Connections between agencies and programs especially as an individual with ASDs begins to age out of programs was also expressed regularly. The overall tone was an excitement for PAFN as a “one-stop shop.”

“I hope... That families will find all the necessary support in one place rather than not knowing where to go as”

“I need... a one stop shop for ASD resources, next steps after diagnosis, etc. It’s very overwhelming for a family with a new diagnosis. For example a consultant to help us throughout the process of setting up services, instead of a one-time meeting with MCFD”

VOCATIONAL

Although this could be related to transitioning into adulthood, many participants mentioned specific concerns about gainful employment and public acceptance. This theme could also be related to public perception and inclusion as it corresponds to the readiness of employers to hire an individual with ASDs.

“I hope... hospitality industry employers to be aware of what a great asset a young adult would be to their organization with ASDs”

“I more opportunities for jobs for and social integration”

EDUCATION

Much like vocational skills this could be a subset of other themes such as public inclusion and cohesive programs/services, but it was mentioned specifically too often to ignore. Many participants spoke of wanting more specially trained teachers, teachers-assistants and access to therapists in the classroom. By extension it was also mentioned that individual attention and transitions to post-secondary programs and services would be extremely helpful.

“I need... to have more after school care for youth and young adults with ASDs”

“I hope... for more schools for children on the spectrum, not just therapy facilities”

FUNDING

Access to funds throughout an individual's life emerged to be of great importance to these participants. It was also highlighted that communication between funding sources could be of benefit to families.

“I hope.. Better funding and resources for my daughter to have a full productive life”

“I need... More funding for therapy and funding for more awareness in the community”

RESEARCH

When research was mentioned it was often in conjunction with time. It was mentioned that individuals hoped or needed quicker results and a “cure”. Specific desires were written often, such as a more in-depth understanding of the neural structures implicated in ASDs.

“I hope... for more research and development in regard to the different interventions used for people with autism”

“I need... to expand research beyond ABA”

FAMILY SUPPORT AND QUALITY OF LIFE

The desire for family therapy and sibling training was often referenced. Family support and quality of life were generally written about in conjunction. It could be assumed that many participants feel there is a direct correlation between their family’s health/happiness and the supports that are offered through programming. Many spoke of a holistic approach in which family members and individuals with ASDs each lead fulfilling lives in all spheres.

“I need... counselling for families that have kids with ASDs”

“I hope... that there is more training and support for families. More services that are based on individuals”

The nine themes that were derived from the hexagon activity echoed the themes that emerged from the 2015/2016 workshops. This activity helped reaffirm what was discovered and also aided in the construction of the January 2017 workshops by highlighting the desires and needs of the community. There was not a

significant difference between comments written on the “I need” hexagons in comparison to the “I hope” hexagons, but it is worth mentioning that “I hope” was more popular. Perhaps this language was preferred as a way to publicly declare ideas and desires.



2.2 LIVE BAR GRAPH

The second activity in the installation encouraged visitors to contribute to a live bar graph located on a wall adjacent to the hexagon installation. Participants were asked to take a rectangular piece of paper and place it above the category that they felt best answered the question, “Where do you access ASDs research?”. The categories provided were as follows: web search, MCFD, other families, clinicians, service providers, research journals and other. Participants were encouraged to write specific resources onto the bars if they felt the inclination.

OBSERVATION

As predicted through last year’s research, *web search* was overwhelmingly the most popular category, followed by *other families* and *service providers*. Chart 1 outlines specific resources that were recorded on bars within the categories. The live bar graph revealed the prevalence of search engines as a tool to gain information as well as the dependence on digital portals

to access social spaces. Google, and Facebook were mentioned many times, not only within *web search* but in the *other families* and *other categories*. It is worth mentioning that although *web search* was the most popular category, we could not establish whether or not participants used search engines to directly access services and programs or for a broad search. *MCFD*, *clinicians* and *service providers* were the lowest ranking categories.

This installation suggested that the community relies on search engines to access research rather than on clinicians and research journals. These results, in addition to the Blue-sky meeting held in January 2016, highlighted the opportunity to strengthen communication lines between families and researchers. This activity helped us to gain a better understanding of how members of the ASDs community way-find and access services, programs and research. During the co-creation workshops that followed, we built upon this question to gain further insight into how parents access and source new research and information.

Where do you access ASDs Research?

Add to our live bar graph



3. CO-CREATION WORKSHOPS

3.1 DESCRIPTION

Looking at the information gathered through the interactive installation and past workshops, the HDL team developed tools and activities for facilitating co-creation workshops with families and researchers. The intent of these workshops was two-fold. The workshops were set-up to allow researchers and families to connect directly and engage in dialogue with one another as a learning opportunity for both groups. Additionally, the workshops were used as a research strategy to gather qualitative information about the current state of communication between researchers and families, and to gather ideas for new communication strategies and approaches.

The HDL team facilitated 4 workshops, each two hours in length. Three of the workshops were held at the Vancouver PAFN facility, and one was held in Prince George. In total 45 people participated in these workshops, with approximately 10-15 participants in each session. Within this participant group 26 were caregivers/family members of individuals on the spectrum, and 20 were researchers/service providers.

Some of the participants held dual-roles as researcher and practitioner, or caregiver and researcher. We also had a few individuals with ASDs participating in the workshops.

Families came from a variety of different backgrounds and different stages of parenthood. They were recruited through the PAFN network, the HDL interactive installation and through participants in previous workshops. Researchers from a wide array of autism research fields came to the workshops and were identified based on the *Asset Map of Research Resources for Autism Spectrum Disorders in British Columbia*, published on the Inform Every Autism site. Researchers were also recruited through local universities such as UBC, SFU, BCIT, UVic and UNBC.

Each workshop included four activities: introduction/warm up, string mapping, interviews and final group discussion. The workshop activities were facilitated by the HDL team and detailed notes and photographs were captured throughout the workshops upon receiving participant consent.

OBSERVATIONS

WORKSHOPS OBJECTIVES

In general participants had a clear understanding of the purpose of the workshops. Parents came to talk about issues that they have been struggling with, to support each other and to contribute their personal knowledge. Researchers came to inform and be informed and showed great willingness to participate and contribute. Clinicians came to support families and learn more about the day to day struggle without having to worry about providing a specific service. Not everyone realized they were participating in a research; some came because they simply wanted to communicate with each other. The activities were well structured to allow the HDL to gather the data needed while still allowing for open conversations between parents and researchers. Many participants appeared to leave the workshops with new connections and useful information.

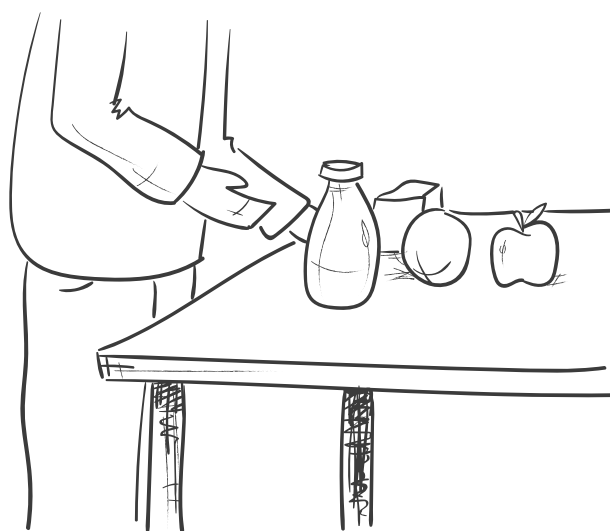
INTERACTION BETWEEN PARTICIPANTS

Overall the interaction between workshop participants was very positive. Like in last year's workshops, family members offered each other advice and support and enjoyed the opportunity to connect. Participants seemed relatively comfortable interacting with each other and sharing information. Researchers were very open to listen and excited to talk about their work, and parents were eager to hear about research and share their experiences.

Whenever disagreements arose, participants acknowledged the fact that their experience were different and tried to express their unique points of view. In some discussions it seemed that there were tensions between researchers and parents especially around the different perspectives in regard to information credibility. This provided a valuable glimpse into the state of communication between both sides. To some of the parents it was important to be seen as a valid source of knowledge and expertise, they were not willing to have their knowledge dismissed for being anecdotal.

INTRODUCTION / WARM UP

To begin the workshops, a collection of objects was placed on a table and as the participants walked into the room they were asked to pick an object that stood out to them, or represented aspects of their personality. While standing in a group circle each participant introduced themselves by saying their name, what brought them to the workshop and why they chose that particular object. This activity was quite effective in creating a fun and casual environment for participants to get to know each other before moving on to the next stages of the workshop.



OBSERVATIONS

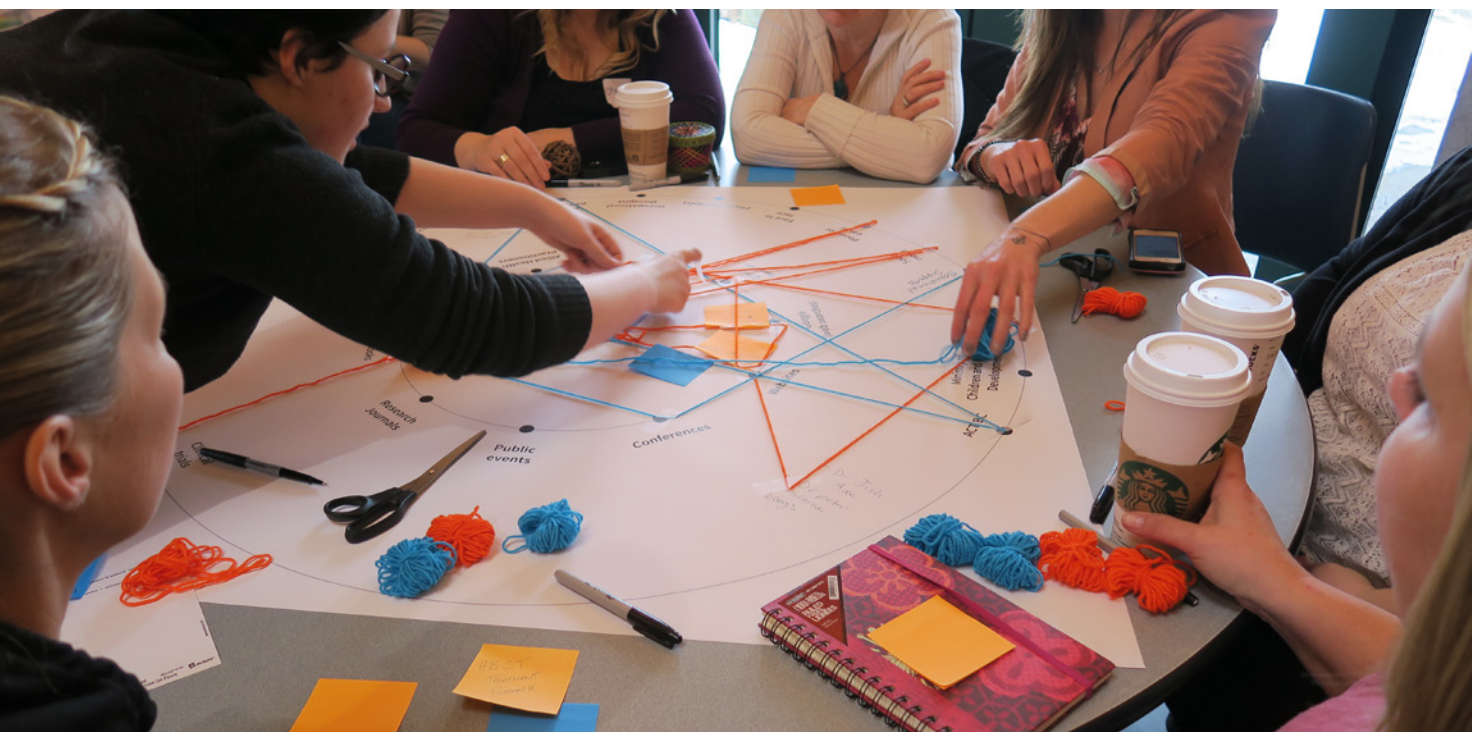
INTRODUCTION / WARM UP

The warm up activity was quite effective in creating a casual and friendly environment. Generally people were able to quickly select an object and we found the level of difficulty and abstraction was appropriate for this activity. This format encouraged people to tell a little bit more about themselves, helping us to get to know one another at the start of the workshop. Participant's stories and rationale gave insights into their personality and life stories. As facilitators it was very effective in helping us understanding what 'roles' people were representing.

STRING MAPPING

The first half of the workshop focused on understanding the current state of communication between researchers and family members and probed for how families access research and how researchers disseminate it. This conversation was facilitated by a string mapping activity. To begin, participants were separated into two smaller groups in order to create a non-intimidating discussion environment. Each group had its own table with a peg board and an HDL facilitator. We ensured that each table group had a combination of family representatives and researchers present.

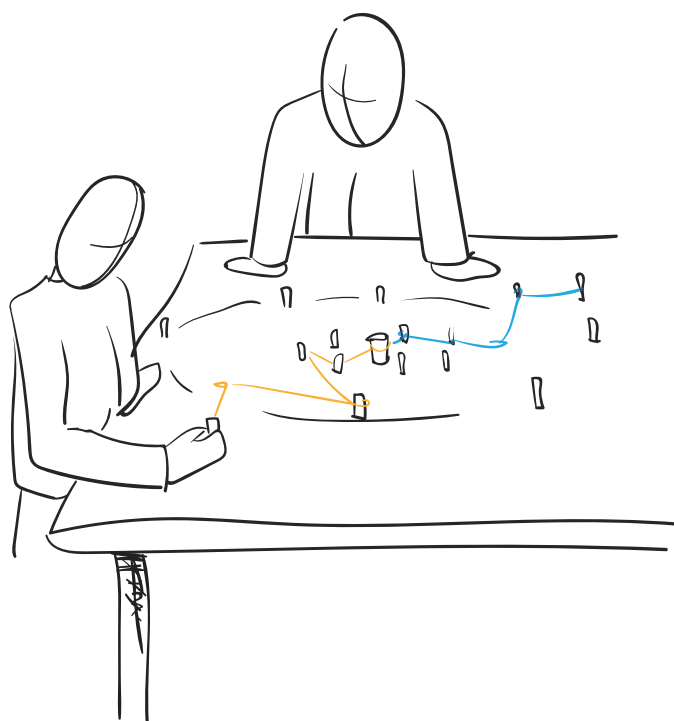
To begin, family members were asked to write down some of the questions that they are currently trying to find answers to on orange post-it notes. For example, “I am looking for research on the effectiveness of music therapy”. At the same time researchers were asked to write down the areas of research that they are currently engaged with, on blue post-it notes. Those notes acted as starting points for participants to then articulate and visualize their journey of accessing/ disseminating information.



Taking turns around the table, each family member was asked to articulate where they might look for information to answer their question. Using an orange string on the peg board, families members marked their journey, wrapping the string around the various places/people they might go to in order to find the information they are looking for. The boards had 24 suggested sources (places and people) to choose from, but participants were also encouraged to add new points in case they didn't find the ones they needed. While each family member visualized their journey using string, the other participants listened and discussion about these sources of information occurred.

Researchers also participated in the string mapping activity. Using blue string, they mapped the sources where they typically disseminate their research and explained their process and rationale for dissemination.

After all participants finished mapping their personal routes, they were asked to engage in a group discussion about the pros and cons of the different points of access. This activity helped the HDL team and the participants to see where their paths overlapped and where they didn't. It established an understanding of the present state of communication and the various benefits and challenges afforded by different sources.



Here are some examples of the research topics that family members said they were trying to find information on. During the string activity they mapped the paths they take in search of information and research on these topics.

- » Anger management for individuals with ASD
- » Adult ASD individuals preferred therapy experiences
- » Brain activity in individuals with ASD who begin typing
- » Building the executive function on spectrum kids
- » Hormone levels effects on teen girls
- » Neuroplasticity and autism
- » Neurotherapy research on ASD kids
- » Stem cell research in the field of autism
- » The environmental influences on child development in complex environments
- » Value of music therapy in helping non-verbal autistic children express themselves

OBSERVATIONS

STRING MAPPING

With support from facilitators participants engaged really well with this activity; it gave them an opportunity to share their experience and generated many discussions. The string created a useful visual and kinesthetic task which triggered rich conversations. The board provided prompts for conversations about different avenues for accessing/disseminating research, but was not limiting as new avenues could be added.

Breaking into smaller groups made sharing personal information at the table less intimidating and gave everyone an opportunity to speak. Participants were able to express their vulnerabilities and challenges, which encouraged empathy between them. Having a similar number

of researchers and parents at each table was important for balancing the dynamics.

During this activity many parents ended up describing their journey between different service providers instead of the journey searching for research information. This may indicate that it is really through those services that they access research. In general it seems that researchers were more confident verbalizing their thoughts on many topics, while parents mostly felt confident expressing their personal knowledge and experiences.

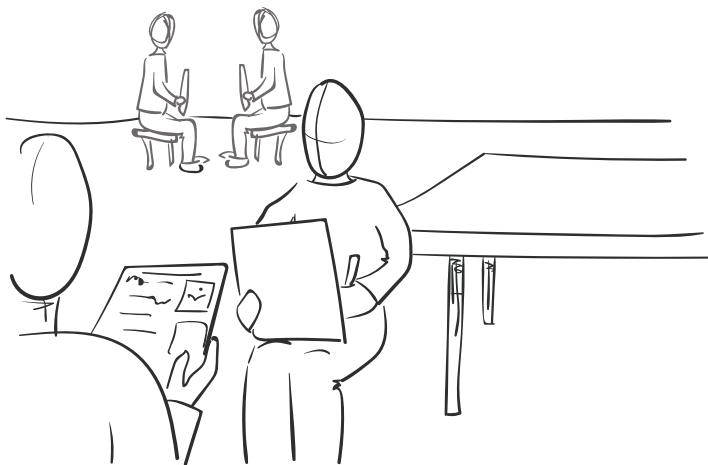
At the end of this activity came a break, yet groups generally stayed seated and continued talking, as they didn't want to pause their conversations.

INTERVIEW

Following the string mapping activity the participants were given a short break. During this time we observed researchers and families chose to continue their conversations and many began seeking help from one another, even exchanging contact information.

After the break we began the next activity which focused on gathering ideas for ways to improve communication between researchers and family members in the future. Participants were asked to pair up (ideally one researcher to one family member) and interview each other. Each participant was given a set of interview questions depending upon whether they identified as a researcher or family member.

We asked them to record their partners answers during the interview as they listened. Researcher answers were recorded on blue post-it notes and family answers were recorded on orange post-it notes. This activity was intended to help researchers and family members to connect and give them an opportunity to have an intimate conversation about what they would like to see in the future.



Interview Question Guide

INTERVIEWING A RESEARCHER:

- » Who is the audience of your research and do you feel you are reaching them?
- » What might help you disseminate your research to a broader community?
- » What questions do you have for your interviewee?

INTERVIEWING A FAMILY MEMBER OR AN INDIVIDUAL WITH ASD:

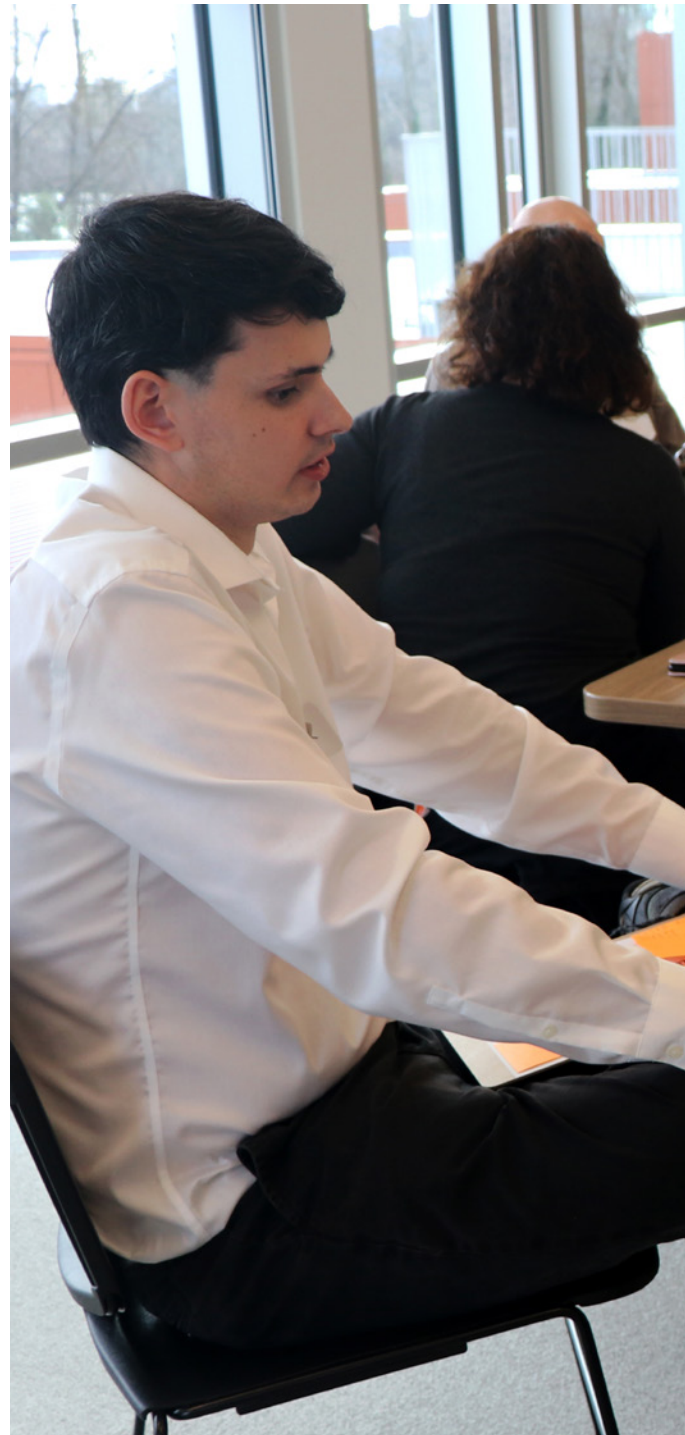
- » How do you use the information/research that you find?
- » What might help you to access the research you need?
- » What questions do you have for your interviewee?

OBSERVATIONS

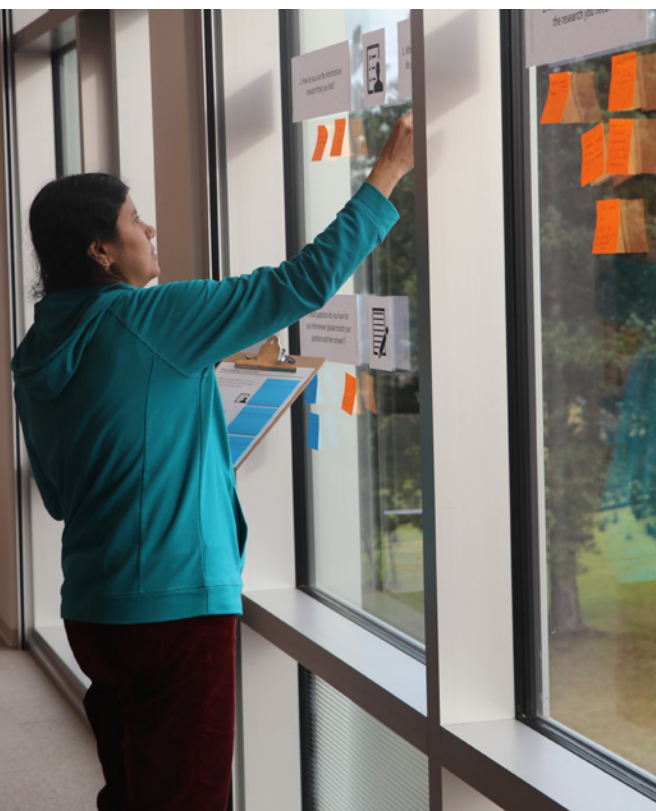
INTERVIEW ACTIVITY

All of the participants, including the most introverted ones, seemed highly engaged in the interview activity. Having a one-on-one moment took the pressure off of speaking up and created a safer environment for them to connect. It was helpful that by the time participants began the interviews, they already knew each other and could ask more specific questions, tying back to what had already been discussed in the string activity.

The clipboard questions were a useful way to gather information, but most importantly, it providing a base structure for participants to engage with each other. Allowing participants to take notes on post-its and add them to the wall, was helpful to make the transition between the interviews and the large group discussion that followed.

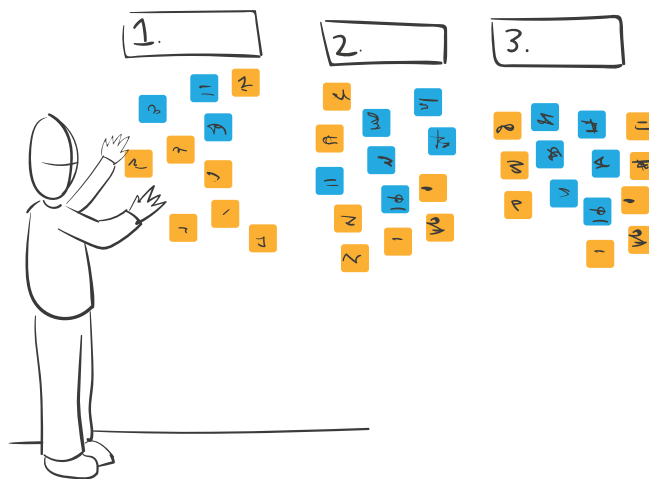






GROUP DISCUSSION

Following the interview activity, participants were asked to add their notes to a vision wall and discuss the main ideas and insights they had generated with the larger group. This was an opportunity to listen and share each other's ideas and brainstorm together. This activity was also effective as a wrap up for the workshop.



OBSERVATIONS

GROUP DISCUSSION

The open discussion at the end of the workshop was successful in connecting fragmented insights from previous activities into a rich brainstorming session. It was exciting to see the amount of ideas generated by a small group of participants in a very short time. The discussion was relatively short in comparison to the previous activities. After it officially ended many participants stayed and continued their conversations. Overall the workshops could have been longer to accommodate even further discussion.

Overall the variation of group sizes throughout the workshop was found to be quite effective. The format transitioned from a full group intro, to a small group string activity, to one-on-one interviews, and back to a full group discussion at the end. This provided opportunities for intimate conversations and encouraged everyone to contribute, while also providing opportunities for full group sharing.

FEEDBACK FROM PARTICIPANTS

One key objective of the workshops was to create a mechanism for researchers and families to connect face to face. In order to assess the value of the workshops as a tool for generating conversations, we gathered feedback through an online survey from the workshop participants. In total 18 out of 45 participants responded to the survey (40%), representing 38.5% of parents, 18% of researchers and 75% of service providers who attended. Below is a summary of the feedback received.

CONNECTION TO PARENTS AND/OR INDIVIDUALS WITH AUTISM

DID YOU FIND IT VALUABLE TO CONNECT WITH PARENTS AND/OR INDIVIDUALS WITH AUTISM? IN WHAT WAY?

Based on the survey responses, it seems that all groups felt the workshops allowed them to connect with parents and/or individuals with autism. Through this opportunity parents felt they gained valuable information and had a chance to learn about other parent's experiences and generate ideas together. It made some of them feel like they are a part of a larger ASD community. Researchers felt they were exposed to a range of individual insights and perspectives as well as to some common themes that had emerged. They also saw this as an opportunity to look at knowledge dissemination from a different perspective. Service providers felt like this opportunity for discussion had clearly marked some gaps in knowledge on both sides. They also stated that it allowed them to increase awareness in regard to the services they provide and how to better fit them to the needs of parents.

"I found it useful to connect with parents of children with autism because there are huge gaps in the knowledge/experience that they have versus what I know..."

"Connecting with them allowed me to increase awareness of my services, but at the same time, learn about how I can improve services to parents and individuals with autism."

CONNECTION TO RESEARCHERS

DID YOU FIND IT VALUABLE TO CONNECT WITH RESEARCHERS? IN WHAT WAY?

Parents expressed they gained valuable information on the chain of research and how it occurs, while also learning about specific research that is currently being done locally. To some, this confirmed that current research is very far from being implemented into mainstream clinical practice.

Researchers felt they had a chance to learn about other researchers work and expressed a need to foster a collaboration with other researchers outside their own institution. Service providers learned about research that is ongoing, and the communication challenges that researchers face.

“Very valuable--helped me to understand the chain of research, and how it occurs. Really learned that parents/people on the spectrum need a connection to the researchers.”

“It confirmed that what they do is years away from being brought into the mainstream of everyday life.”

“It was great to learn as a service provider what research is happening, and understand the challenges they face communicating this to families.”

WORKSHOP ACTIVITIES AS TOOLS FOR FOSTERING CONVERSATION

WHAT DID YOU THINK OF THE FORMAT OF THE WORKSHOP? WAS THERE ANYTHING YOU FOUND PARTICULARLY EFFECTIVE? DO YOU HAVE ANY SUGGESTIONS FOR NEXT TIME?

Most participants found the workshop activities very helpful in fostering conversation. Parents stated they liked the format and found the activities hands-on and thought-provoking. Several of them wished they had more time to talk to researchers. Researchers appreciated the non-intimidating environment the workshops provided, and wished for even more time for discussion amongst group members.

Service providers found the format highly useful in that it allowed participants to talk freely and brainstorm, creating a visual representation of their different experiences navigating the system. Some also gained insights into how to improve their information delivery methods. Overall, many participants commented that the workshops could be longer in the future. This was a positive response which demonstrated that the participants felt the workshops were of value and a good use of their time.

“The activities were helpful in fostering conversations -- almost too helpful as we could not stop talking (...). There was a lot of interaction, the activity was hands-on and thought-provoking. I could have stayed many more hours... I think the only downside was that the parents want so desperately to engage on a wide range of topics, that it is tough to get us to narrow down.”

“I found the format of the workshop was incredibly useful. It allowed for the participants to talk freely as well create a visual representation of how people have different experiences navigating the system.”

“I would like to see PAFN used for these types of things on a routine and ongoing manner... We have the space now. Let's use it to come together and have frank and meaningful conversations. Let's use it to have autistic adults and NT adults working (& playing!) together.”

3.2 ANALYSIS

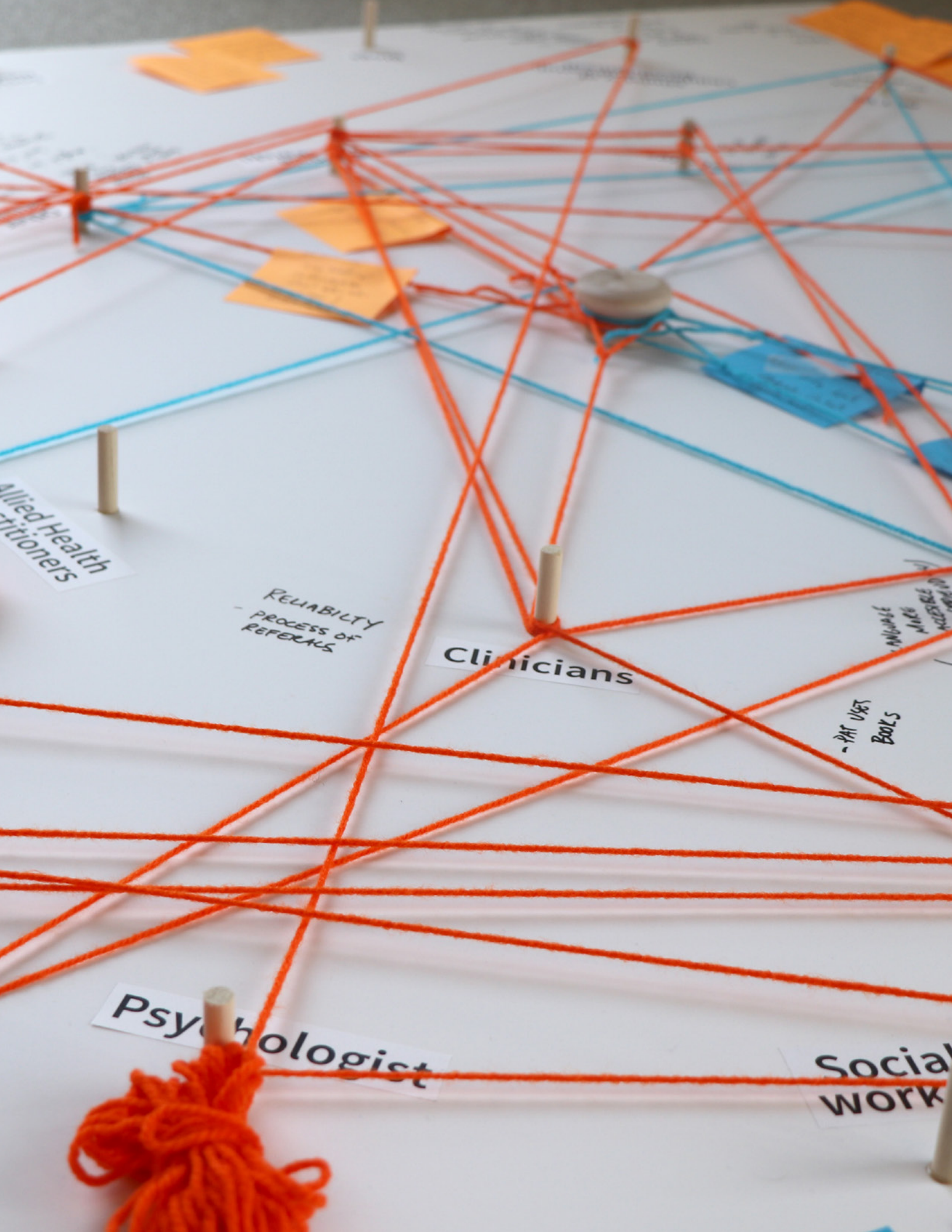
After facilitating the four workshops the HDL team took the materials back to the studio and began to analyse the data collected. Half of the team focused on the data surrounding the current state of communication, while the other half of the team focused on synthesizing the ideas proposed for future communication strategies.

The *Current State* data came mainly from the string mapping activity. The notes taken during the workshops were combined with the information on the boards and merged into a single document. Much of this information pertained to the pros and cons of the various sources of information. We used a process of affinity diagramming, common in design research, to externalize and meaningfully cluster observations and insights from the research (Martin & Hanington, 2012). This method uses a process of categorization to focus findings. To begin this process, each “bit” of information from the sessions was captured and then clustered based on their affinity. Notes that shared a similar intent, problem, or issue were grouped together. The team then began the process of interpreting

notes and considering the underlying significance of each. Out of this work, key themes emerged about the types of sources that are most accessible to families and current barriers that exist to accessing and disseminating research.

The *Future State* vision was synthesized by reviewing our detailed workshop notes, including the interview post-it notes, and flagging any comments that spoke to how participants wished their reality to be. Future state ideas were expressed by participants in all three of the workshop activities. These comments were then tagged with larger themes and synthesized through an affinity mapping technique. The ideas captured from participants were grouped according to end-user and type of solution. The ideas fell into seven different core categories: web, community, navigation, research, expert, caseworker, and resource. The synthesis of the ideas captured can be found on page X. The ideas summarized here provide an overview of all of the ideas that arose through the workshops. Some of these ideas were endorsed and discussed by many, while some ideas were suggested by individuals.





3.3 INSIGHTS

A. CURRENT STATE

Many researchers in our workshops identified individuals with ASDs and their families as true experts in ASDs community. Likewise, individuals with ASDs and their families acknowledge the expertise of the research community and look to researchers for valuable information that informs their decision making. Through an analysis of the data gathered in our workshops, it was found that although researchers and families currently have some opportunities to connect, there are several barriers that prevent meaningful exchanges and valuable learning opportunities are often lost. Accessing and disseminating information requires clear lines of communication, allowing for cohesion and understanding. Access to credible information is imperative for parents as they

journey through the ASDs community. Both families and researchers indicated that that it can be very difficult to find relevant information that is both credible and accessible. As we unpacked the conversations captured through the co-creation workshops we identified key areas that heavily impact accessibility and credibility, including: language, money, time, location, trust and systemic constraints. These themes intersect to create a complex landscape that often creates barriers in knowledge exchange between researchers and families.

Outlined below are the key barriers for families in accessing research, as well as key barriers for researchers in disseminating research to the broader ASDs community.

LANGUAGE

The the language used in academic writing and research journals can pose a challenge to families. When participants spoke about books, social media, blogs and information accessed through other families, they often stated that those sources were easier to glean information from and offered a more accessible entry point. The aforementioned sources are often anecdotal but deliver information and research in digestible and approachable chunks. In regards to research journals it was suggested that the language was often inaccessible and took too long to read through. Although many who attended, felt they could grasp the information and language there were barriers when it came to critically evaluating findings and validity of research.

Some family members explained that in order to gain information from sources such as blogs, social media, books and other families, they don't necessarily need to have a specific research question in mind first. This suggests that although parents have many questions, some may be difficult to articulate or they may not know exactly what they are looking for in advance. In these cases a dialogic transferring of information may be more appropriate to help family members discover research.

“Things that are common, you know who to call, but things more on the fringe it can become more difficult to determine who is credible.”

Researchers expressed concerns over the misuse of language and the creation of “predatory journals,” namely pseudo-research that used common academic vernacular. Articles like this were felt to proliferate misinformation, placing the family and individuals with ASDs at risk. There were also concerns surrounding books, blogs, social media and face to face conversation as anecdotal information can also be a source of misinformation.

“It can be dangerous if you try something just because someone else has done it.”

MONEY

Money is inextricably linked to the funding and dissemination of research and information. Pay-walls and closed source information create financial barriers, which many participants expressed they were not likely to overcome. One family member explained, “Research Journals are inaccessible and families would not know how to access them, it can cost \$90”. Unlike researchers who typically access journals through their academic institution, families do not have the same sort of entry point and downloading journal articles often comes with a fee. For families, this is particularly prohibitive especially if they aren’t sure if the article will be of benefit to them. This highlights one major issue surrounding public access to peer-reviewed information. Informal information is cheaper (books, social media, blogs etc.) and therefore more accessible to the general ASDs community.

Another major challenge is that in general the academic research cycle is not set-up to fund or reward researchers for dissemination to the broader public. According to many of the discussions held within in the workshops, researchers seek out citations

and publishing because that is the best way to secure future funding. This is problematic because the audience for current research becomes solely academic. Some funding agencies have begun to support researchers with knowledge translation and dissemination activities. This is a useful step in creating more accessible research paths for families.

Money was also a barrier for both researchers and families in regards to conferences and public events. They tend to be expensive to coordinate for researchers and expensive to attend without proper child care for families.

Credible, evidence based research tends to be costly, while anecdotal and speculative information is often free. This poses a major problem for the ASDs community. It is imperative that valid information and research reaches families in order to empower their journey through their ASDs experience. Inexpensive access to credible information is a key component in strengthening the current state of communication.

TIME

Family members in the workshops often spoke about the importance, and lack of, time. One parent suggested ironically that she needs respite care in order to have enough time to find information/research about the effectiveness of respite care. Family members expressed that although they want to do what is best by spending time accessing the right information, they often did not have the time. Whether it is a search for new information or attending a workshop, it was often said that it took away from daily tasks. Finding, distilling and activating information takes time and it became clear in many of our workshops that there simply wasn't time for this activity.

Another challenge is that the timelines in which families and researchers operate are often in tension with one another. Research studies often requires large sample sizes, time, money and a significant host of resources. This lengthy process ensures credibility by producing statistically valid results that stimulate further research and inform our institutions and systems. Alternatively families expressed the need for quick access to research in order to make timely decisions about their child's care. In some cases, the pace in which families desire information exceeds the speed in which it can be produced. Due to the need for researchers to follow strict research guidelines this gap will



always exist to some extent. The co-creation workshops that we hosted helped to bridge this gap. Through conversation and activity the stakeholders began to understand the challenges facing each other, and as a result developed empathy for one another. We saw this happen as one of the researchers spoke about a current ASDs research project that has been on going for over 5 years. Although the family members listening expressed the urgency of their own situations they came to understand the importance of the researcher's work and why it would take over half a decade to complete. This empathy is crucial in establishing two-way communication.

“You sometimes have to go with the anecdotal, not everything will be scientifically proven. I’m educated enough to appreciate the scientific proof, but it can’t keep up”

-- researcher



LOCATION

Location as a barrier, was mentioned often in the workshops, especially in Prince George. It was expressed that those far away from major hubs felt isolated from research and services. For example accessing a blog or Facebook group rather than attending workshops in Lower-Mainland Vancouver is easier for those living in Greater Vancouver, the interior or northern BC. Moreover web resources have the benefit of being accessible from home, on-demand and without the need for child care.

Locally, the first place many family members and individuals sought out information was their general practitioner, who then often refers families to specialists and Allied Health Professionals. These specialists and professionals are the bridge between researchers and families and tend to aggregate in larger centers. This creates a challenge for those in rural areas, as they can become segregated from the larger community and face great difficulty in accessing current and emerging research.

On a global scale some parents suggested that Canadian research on ASDs has not matured yet and appropriate resources were often found in the United States. A few family members mentioned they often travel to the United States to attend conferences and feel as if Canada is behind in ASDs research.

TRUST

“They’ve paved the way for me and I trust their research”

-- family member regarding information coming from other families.

Emotion

Navigating through the ASDs community can be an extremely emotional experience. Emotions often operate in tandem with vulnerability in which discerning who and what to trust can become convoluted. A family participant stated, “It didn’t seem dangerous and I wanted to feel like I was trying everything.” The willingness to try anything is rooted in the desire to improve the life of the individual with ASD. Gathering information from other families (face to face, phone and email) was touted as a means of gaining connection and insight; other families are trusted to provide a strong connection because of similar lived experiences. This openness to anecdotal information and support has its benefits and its drawbacks. Researchers worried that families were willing to try anything anecdotal, letting their trust for others overrun criticality as it relates to research.

Services

Community programming and organizations such as Canucks Autism Network, Autism Richmond Family Group and ACT were described as extremely valuable and trustworthy sources of information and services. Families found these programs useful not only because of the information they can offer but because they provide opportunities for informal sharing and learning with other families during scheduled activities, such as hockey games. Many expressed the need for more resources such as this and spoke optimistically about the opportunities the Pacific Family Autism Network would offer to families and researchers alike.

varied greatly due to individual experiences. Since the workshops did not specifically target conversations about practitioners, further discussions on this topic are needed. However, a clear desire to strengthen communication and research dissemination through professionals and practitioners was expressed by many stakeholders.

“I know that the best way to get stuff to families is through the people that they hire for intervention”

-- Researcher

Allied Health Practitioners and Clinicians

Researchers described professionals and clinicians as trusted and reliable. They are often the first line of communication for families and therefore they are a link between the research and families. One researcher suggested “Researchers should funnel work through the family physician so there is more connection”. Although families trusted their clinicians and professionals some felt their knowledge base was not up to date with current research and had their own agendas which do not serve the needs of family members and individuals with ASDs. Opinions on allied health practitioners



SYSTEMIC CONSTRAINTS

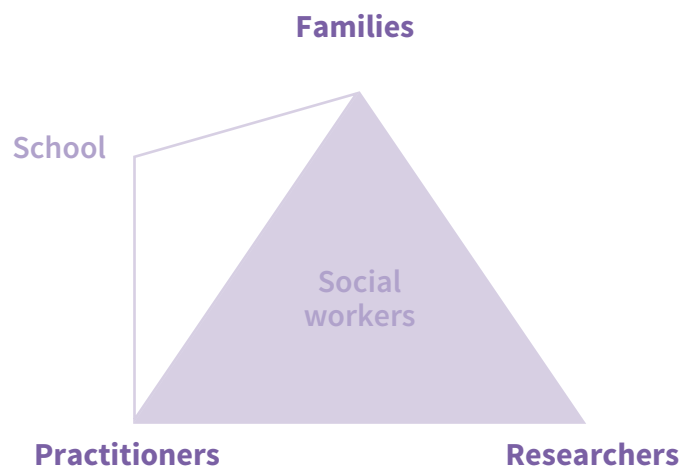
There are many key institutions and stakeholders beyond families and researchers that direct the course of communication. School divisions and social services play an integral part in connecting families to research. Many parents expressed the lack of reliability in the work of the school and the social worker. Some parents said that they had to become full-time advocates for their children in order to get things done. If the basic needs of parents are not being met by the institutions that make up the ASDs community, communication will cease before it even begins. All of the aforementioned barriers are exacerbated if families spend the majority of their time trying to understand the system rather than addressing the wellbeing of their families.

“My Social worker sent me to self advocate”

“I only met with my social worker once to go through some websites”

“I didn’t know I had a social worker for years”

-- parents



SUMMARY

The state of communication in the ASDs community is constantly in flux. One family member stated, “You never fully engage in one resource. You are constantly checking and rechecking”. Communication in a growing and changing community requires stable and clear pathways to ensure all stakeholders can access the most up-to-date information. Currently communication has proven to be strong amongst families and between researchers and the academic community. Although communication with like individuals is beneficial there is a need to increase knowledge sharing between relative adjacent groups. Moving forward it will be

important to include practitioners in future conversation as it was identified that they can play a vital role in bridging communication between researchers and families. Language, time, money, trust and location are complex hurdles to overcome, yet the ASDs community is rich with experts that come in many forms. The barriers outlined here can serve as valuable guidelines in the design of better two-way communication systems. Although several barriers and challenges were articulated, many suggestions for how to improve communication were also suggested. These have been summarized in the following section.

B. ENVISIONING THE FUTURE STATE

During the workshops, once participants had thoroughly mapped and discussed the way information is currently disseminated and accessed we began to look toward the future. We asked family members and researchers to imagine any solutions that might improve how they as an individual and a community could access and share information and research. The following is a summary of the core ideas and mechanisms that participants voiced during our workshops.

“I even have trouble going through some of the literature. It’s distilling the information and trying to make sense of it. Wouldn’t it be nice to have a resource that does that for you?”

KNOWLEDGE BROKERS

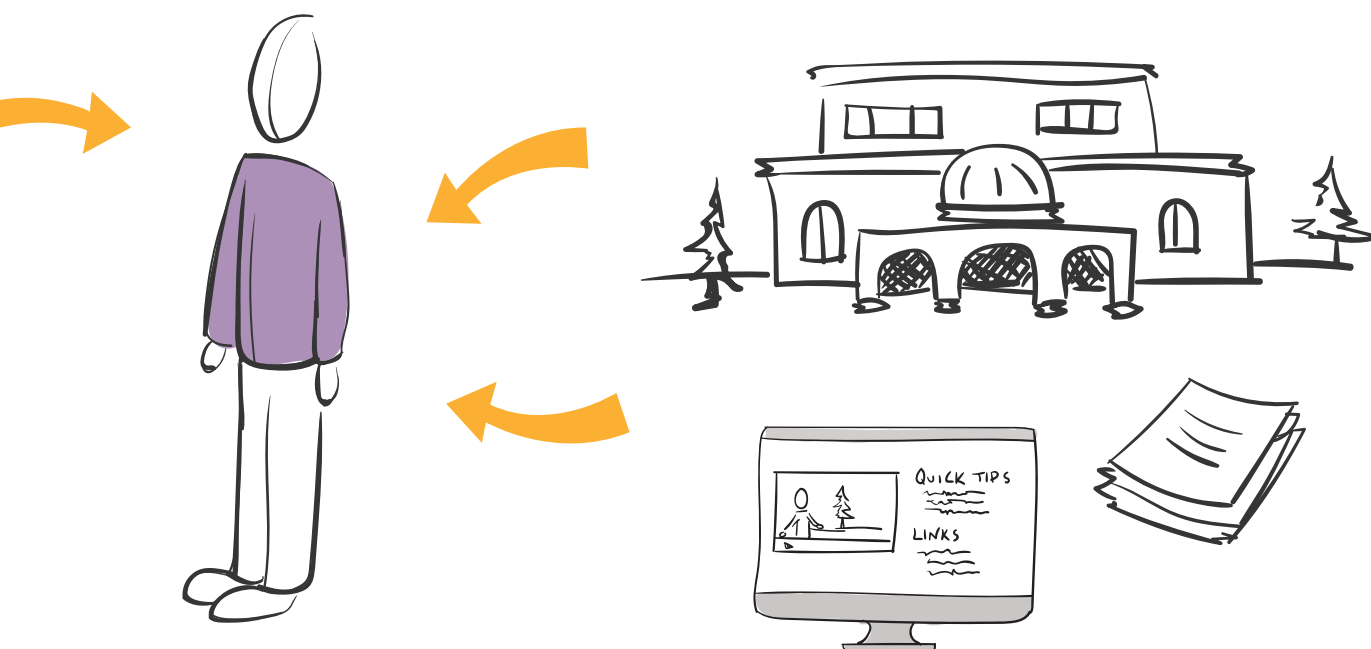
The idea of a knowledge broker was a consistent topic through every workshop we held. Researchers pictured this person as a colleague who would be dedicated to publishing their work in a format digestible to those outside of academia, and someone who could support the coordination of



**Families and
Individuals**

events or workshops. Parents tended to see this person's role as a dedicated expert who had the time to sit with them and explain any questions they might have about the research, or give a verbal summary of the paper and its findings. This person might also help the family to devise ways to implement the research's findings, such as through a new treatment approach or

routine. A knowledge broker could play a role in directly engaging with families, or they could play a role in curating and disseminating information online from academic channels to family-oriented channels. There are many possibilities and avenues to consider for the integration of knowledge brokers moving forward.



**Knowledge Broker/
Translator**

**Research and
Academia**

PHYSICAL PLATFORM

Another very popular idea, which links well to the concept of knowledge brokers was a center or a 'one stop shop' that would hold workshops and events for the community on a regular basis. This would provide children and young adults with opportunities to socialize and foster strong friendships with other individuals with ASDs, and give parents a chance to socialize amongst themselves, creating opportunities for informal knowledge transfer. Additionally, workshops and events for researchers, practitioners and families could be held here. Researchers and families who attended the co-creation workshops responded positively to the opportunity to connect directly and many expressed an interest in participating in more similar workshops. A physical platform for connection would help both researchers and families to see themselves as part of the same community. It was clear that parents and researchers were hopeful that the PAFN would fulfil this role.

ONLINE PLATFORM

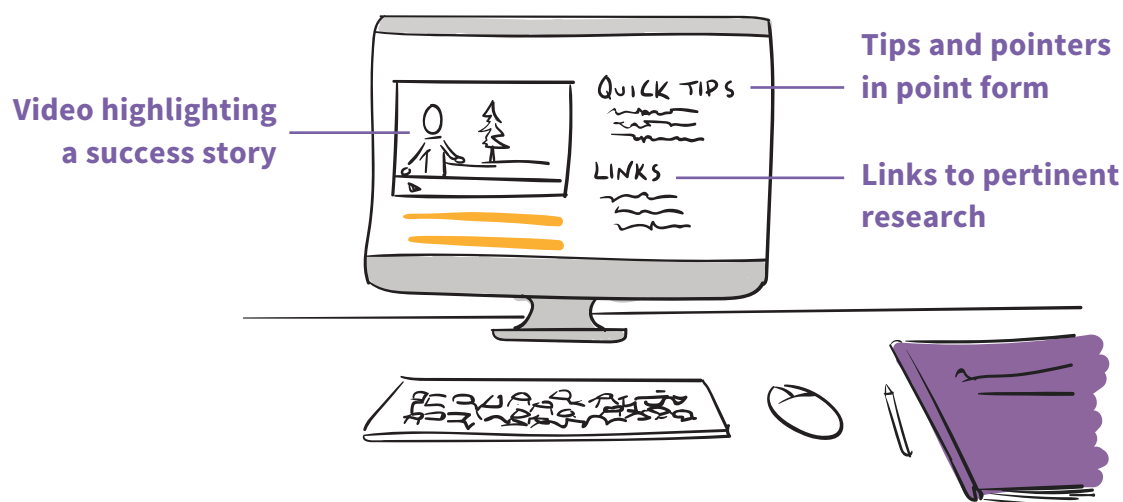
In addition to a physical platform, participants also envisioned an online platform or 'one-stop-shop' website. This site would be routinely updated to link to reputable research, services, clinicians and specialists in the autism field. This could function as an autism-specific search engine curating credible resources and translating verified research into plain language. Parents could also utilise the platform to connect with each families navigating similar challenges.

It was mentioned that PAFN would be an ideal organization to create and facilitate this particular platform. When researchers talked about how they could better share their research findings with the community they saw PAFN as an opportunity to disseminate their work and as a support mechanism for translating their findings into a format that was approachable and relevant to parents, tying back into the idea of a knowledge broker.

SUCCESS STORIES

Based on these suggestions from participants the HDL team envisioned an online platform that acted as a wayfinding system for families. This platform would not only connect individuals and families to research, it would also aid in the navigation of the highly complex ASDs system. For example, this platform could also be used to filter research and other information, so that everything is relevant to the child or individual's diagnosis, behaviors, abilities and mental health. Filters could also be used to create channels of conversations between individuals, families, researchers and clinicians on and offline.

One idea that came up a few times at different workshops, was to better highlight the success of flourishing individuals on the spectrum. When highlighting these individuals, their story would ideally include what types of barriers they faced, and what types of treatments, therapies and approaches led them to where they are today. Parents felt that by understanding another individual's full journey to success they might be able replicate relevant aspects of the journey for their own child. It was also suggested that these types of stories could then link to relevant research articles about treatments and therapies featured in the story. In this way a personal story or case study would provide an accessible and engaging entry point into more academic research content.



VIDEO CONFERENCING

An idea that many participants brought forward, was to create a video conferencing portal to connect families to practitioners, researchers, clinicians and even other families. Video conferencing would allow families to eliminate travel time, and save time spent acclimatizing their child to new environments. This would also give families in more remote areas, such as Prince George, the opportunity to access specialized practitioners, researchers and experts. There was also excitement regarding the ability to connect to families who have children with similar diagnoses and symptoms thousands of miles away. A few parents, alongside researchers, talked about creating a global autism community. While they did not point to a specific way to create this global community, these wishes were brought up in the same discussion as video calling.



MENTORSHIP

Some parents wanted their child to be connected to successful individuals through a mentorship program. In this way they hoped to foster success in their child's life by creating a meaningful connection with another family. Quite a large number of parents also expressed the desire to be connected to a mentor or other family who was further ahead in their own child's journey. This way a 'newer' family could learn from how an 'older' family had navigated the system.

"I get very frustrated when people say, well it's on the website, read it" because we are all different kinds of learners." "So when we are disseminating information we need to be cognitive of the fact that (some) people are used to somebody explaining it..."

DIVERSIFYING INFORMATION DELIVERY MEDIUMS

Multiple parents expressed the need for more diverse delivery of content through a variety of formats. For some parents, this meant they wanted an expert dedicated to walking them through the latest research in person, while others envisioned video or audio components as alternatives for text. One parent explained that when research and information on autism is available through an audio format it gives her the ability to multitask, allowing her to spend more time reviewing research. A podcast series or text to speech services for research articles could be helpful for parents as well as individuals with ASDs. Some parents expressed that they needed video or audio components, because they learn differently and find these alternative formats more effective for learning. Additionally, videos allow people to view behaviours of the subject, how they react to therapies and the way in which the therapy is delivered, providing information that cannot be expressed through text alone.

TIMELY DELIVERY OF INFORMATION

Delivering information and relevant research to parents just before timely transition points in their child's life, was a concept that was suggested by parents at many of the workshops. At different points in an individual's life span, different types of research and information become more or less relevant and this can be hard for a parent to track or remember. Furthermore, families explained that often upon diagnosis they receive an abundance of information, to the extent that it can be very overwhelming, but later on in their journey they receive very little information and can become extremely isolated.

A few parents suggested that they would like to receive information through an online newsletter or email at relevant points in time (i.e. developmental and school based transitions) based on their child's age. This would make it much easier for them to keep track of relevant therapies, resources and funding. Workshops or community engagement events could also be organized based on age-groups or developmental stages.

“We need a mailing list for transition points to remind us, like when we get to kindergarten, ok this is how we can improve our child's life...because all the information is at the beginning and then you move on with life.”

4. CONCLUSION

4.1 RECOMMENDATIONS & NEXT STEPS

In the digital era it is becoming increasingly difficult to navigate and access credible research and resources as vast amounts of information are now traveling inconsistently across various platforms. This is a key challenge for families and individuals with ASDs who require credible and relevant research to inform their decision making.

In collaboration with the PAFN, Emily Carr University's Health Design Lab aims to facilitate a better exchange of knowledge between researchers and families, using a human-centered design approach. The ability to foster meaningful conversations between

individuals, all with different points of view, was one of our goals in this year's project. We believe this will provide a strong foundation for the co-creation of better communication tools/systems in the near future. Through the workshops we gained insights into the way families and researchers currently navigate and share information; we gained an understanding of the barriers to information exchange within the ASDs community; and we gathered ideas to improve future access to ASDs resources and research. Building upon this year's findings we can begin to design better communication systems for the members of this community.

IMPLEMENTING SUGGESTED IDEAS

At the workshops, regardless of the form of the solution, all participants wanted to see knowledge translation and communication improve. Diversifying the ways in which content is delivered and creating unified platforms for delivery will aid tremendously in allowing family members and practitioners to understand research more effectively.

While every solution participants came up with during the workshops would certainly improve the ways in which knowledge is shared in the ASDs community, each solution has its own set of implementation challenges and benefits that should be considered. Some of the ideas proposed are already under development, such as offering workshops for families through the PAFN. Other ideas can be implemented relatively easily, such as a research newsletter targeted to specific age groups and developmental stages. While other ideas, such as the creation of a robust online platform, will require significant time, investment and collaboration in order to implement successfully. It will be important for the ASDs community to identify which

solutions will have the most impact and to establish an implementation and development strategy for moving ahead with some of the suggestions presented here.

The conversations and insights gathered from families and researchers were extremely rich, and begin to define key strategies for improvement. Moving forward, it will be important to also engage clinicians and practitioners in the design process, as we identified in our workshops that this group can play a key role in facilitating the exchange of knowledge between families and researchers. At this time it is necessary to prioritize a few of the suggested ideas for further design and development. This process should include additional focused co-creation workshops to engage the ASDs community in the design of the new communication strategy and/or tools. The continued engagement of families, researchers and practitioners is critical to ensure the final solution remains true to the needs of the family unit and the ASDs community at large.

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