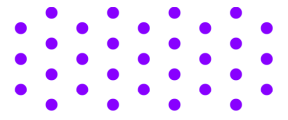


Autism

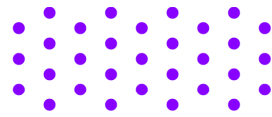


Community Web Platform Concept

Pacific Autism Family Network

September 2017
— May 2018

Health
Design
Lab.



Web-platform Concept
PAFN
Sept. 2017–May 2018

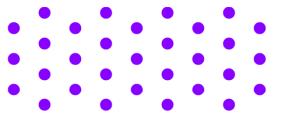


Table of Contents

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This project was funded by

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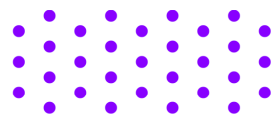
Michael Smith Foundation for Health Research,

Emily Carr University of Art and Design

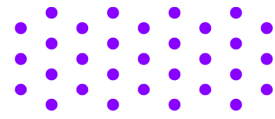
Publication Date

May 2018

01	Intro	page 2
02	Design Process.....	page 4
03	Co-design	page 8
04	Vision.....	page 20
05	Implementation.....	page 38



01 Intro



Web-platform Concept
PAFN
Sept. 2017–May 2018

Summary

In 2017/2018, the Health Design Lab (HDL) at Emily Carr University of Art + Design collaborated with the Pacific Autism Family Network (PAFN) to design a web-platform with the goal of facilitating the uptake of credible, evidence-based research by families and individuals with Autism. This work began with a focus on creating a research platform and evolved, through engagement of families in our design process, into a more substantial platform for guiding families towards local services and community events. We learned that the information and research of most value to families is actionable, linking research, services and events within a single site.

The mandate of PAFN is to be a knowledge centre and “one-stop shop” for bringing together state of the art resources, research, information, learning, assessment,

treatment and support, in addition to building capacity to address the lifespan needs of individuals with ASDs and their families, across BC.

The journey which follows an Autism spectrum disorder (ASDs) diagnosis has ups and downs, unique to each family and individual on the spectrum. Through this project, we aimed to ensure that the diverse range of lived experiences was reflected in a sensitive and responsive web-platform concept that creates clear linkages between research, services and community events.

This report summarizes our design process and provides recommendations for the development of an autism community web-platform that will create a digital ‘one-stop-shop’ for families in BC.

Background

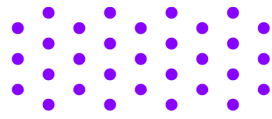
Since 2015, HDL has been collaborating with PAFN to gain a better understanding of the communication challenges and needs of families and researchers in the ASD community. This collaboration has undergone three distinct phases, each of which has illustrated different ways in which designers can support and facilitate social innovation.

- Phase 1: In 2015/16, exploratory research was conducted to better understand the research needs of families. Through co-design workshops with families, we learned that access to reliable and credible research for families is a significant challenge.

- Phase 2: In 2016/17, we led a series of co-creation workshops with researchers and families to better understand the current state of communication and knowledge exchange between these groups. Researchers and families identified the need for a curated web-platform with credible research content to improve knowledge exchange through more accessible communication modes.
- Phase 3: In 2017/18, we lead a series of co-design workshops to conceptualize a web-platform design with families. During these sessions, families identified major categories of interest and features that would be of benefit to them. The involvement of families in this process was critical to the development of a family centred web-platform.

2





Web-platform Concept
PAFN
Sept. 2017-May 2018

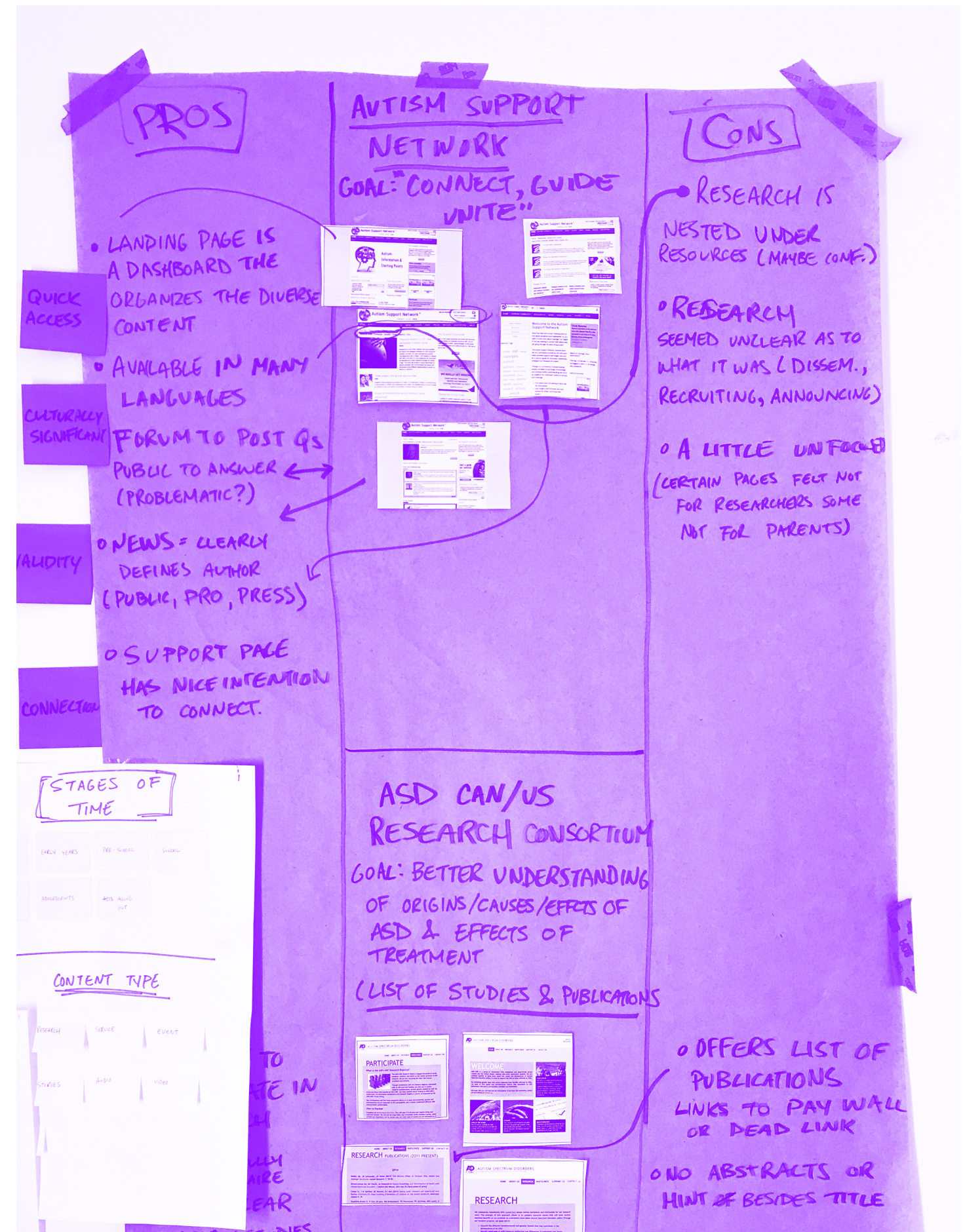
02 Design Process

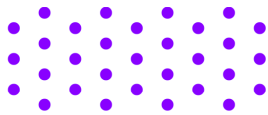
Intro

Based on the insights gathered through our work in 2016/2017, the PAFN and HDL had a basic concept established for the web-platform in September of 2017. To further develop this concept, HDL used a range of human-centred design and user experience design methods including precedent research, job stories, information architecture and co-design workshops.

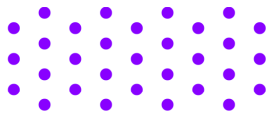
The design process and strategies utilized for this project often happened in conjunction with one another, through an iterative process. As new stakeholder needs and precedents were discovered, the objectives of the project pivoted in order to accommodate these changes. From inception to design, the platform sought to reflect the needs of families, utilizing co-design workshops to inform and validate design decisions.

4





Web-platform Concept
PAFN
Sept. 2017–May 2018



Precedent Research

In September 2017, we kicked off the year with a broad evaluation of websites related to the ASDs community. The sites often went beyond Autism research dissemination and included news sites, community blogs, government way-finding material, and service maps. We assessed their features and functions and gained an understanding of what is currently being offered. A kano analysis was completed to synthesize the expected functionality, excitable qualities, and anti-features of these sites. Some of the critical precedents we reviewed include: ‘Autism Speaks’, ‘Find Support BC’, ‘Spectrum News’, ‘Smart Path Automated Health Care’ and the ‘Autism Support Network’.

HDL observed that many of the sites were not user-friendly for a variety of reasons. Some were poorly organized with un-intuitive menu systems and

complicated language. Some left the user with no way of discerning the integrity of the information presented. Unfortunately, many were poorly maintained and contained dead links to websites and articles that no longer existed. Alternatively, a few precedents had delightful features that allowed those living with disabilities to assess and plan for the future, digest research through summation and layman’s terms more easily, and navigate asset maps responsive to location and needs.

Info Architecture

One of the first tasks in designing a web-platform is to start by mapping the information architecture. Information architecture is the underlying structure of a website, it demonstrates how sections of the website and its content connect to one another. The development of this structure allows designers and developers to check for redundancies within the design, discern gaps in navigation and aid in the creation of a site map. The information architecture for the project was developed through the knowledge gained by precedent research and tested by the job stories (explained on the following page). As the organizational structure of the website was being designed we also began iterating on

the material design looking for ways to make the user experience more delightful and intuitive. This design tool allowed us to start articulating and comprehending what would be needed and desired for the final design and implementation.

6

Job Stories

Job stories are a design tool which allows us to consider the motivation of a user, better. These stories take design problems, re-frame them into a simple sentence to highlight the event/situation, the user’s motivation, and the desired outcome. Job stories are crucial for understanding the gaps between behaviours, desires and outcomes. Families and individuals with ASDs have unique motivations and way-finding tactics to tackle their specific challenges. The creation of job stories helped us to understand the, “why” and “how” rather than the “what”, ensuring we stayed focused on the user rather than our design.

“When I read a research article,

Situation

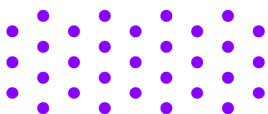
I want to be connected to the original source,

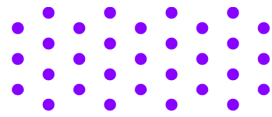
Motivation

so I can further investigate and learn more”

Expected Outcome

7





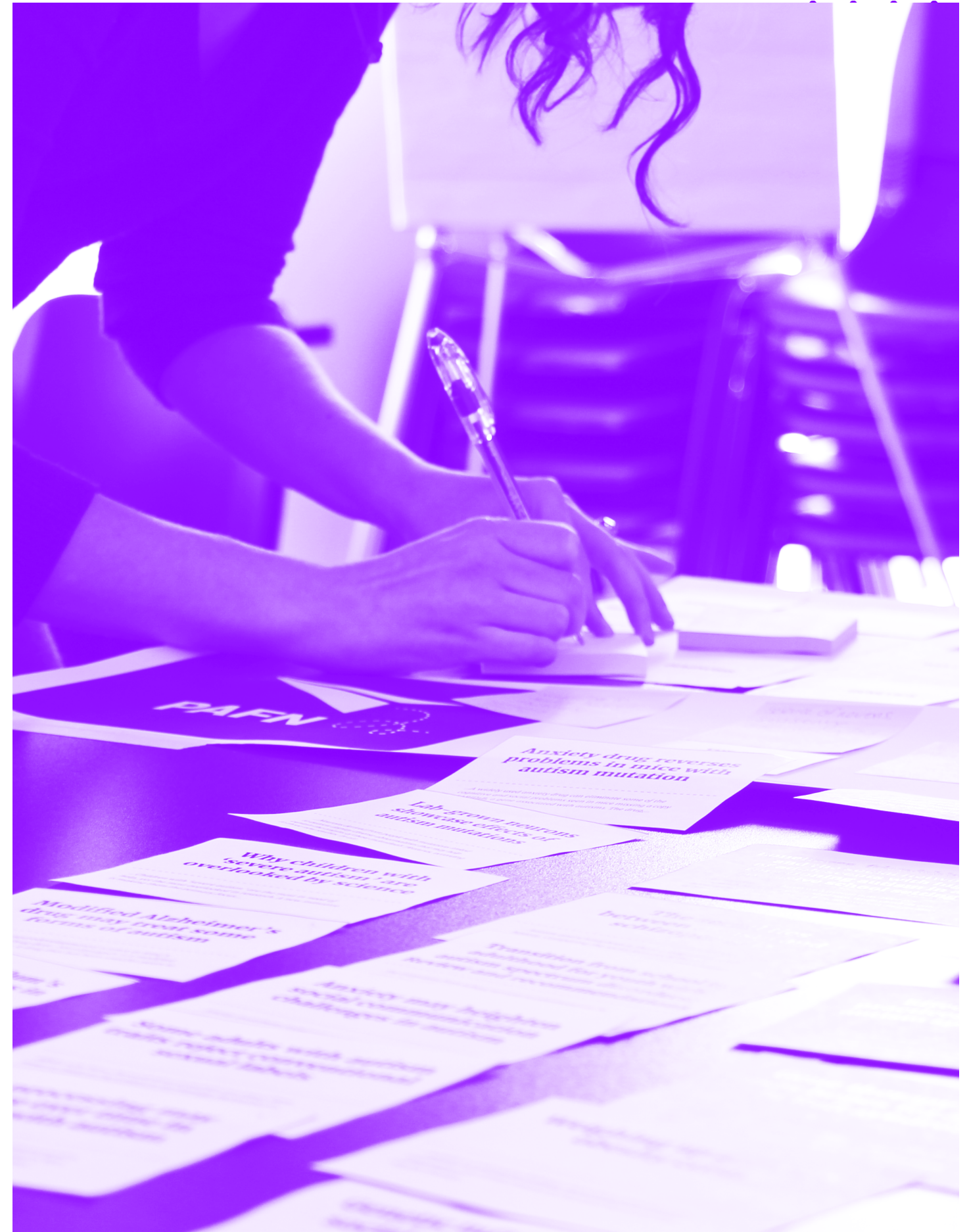
Web-platform Concept
PAFN
Sept. 2017–May 2018

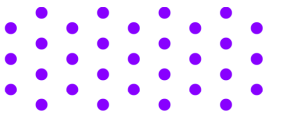
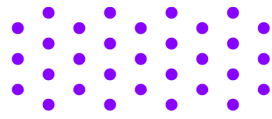
03 Co-design

Methodology

In February 2018, HDL hosted a total of six workshops in Prince George and Richmond, British Columbia, with 2–7 participants per workshop. The initial four workshops were organized in an effort to actively engage with those in the ASDs community, to co-design and to gain feedback on our initial concept for the web-platform. The activities were developed to facilitate dialogue between participants and aid in the understanding of individual research and resource acquisition journeys. In this spirit, HDL sought to better understand how families and individuals would use the site, what language (both visual and textual) would be preferred and what features and functions were appropriate.

8





3.1 Workshops – Round 1

Summary

The first round of workshops consisted of three activities. The activities were designed as a series, each priming participants for what was upcoming. Ultimately, our goal was to test our design assumptions and gain feedback critical to future iterations and the final design. In each workshop we gained valuable insights from family members and caregivers with a range of perspectives and experiences.

Activity 1

What would you search for today?

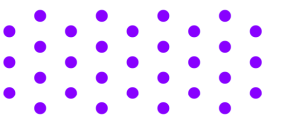
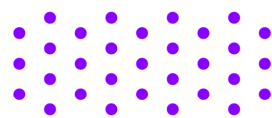
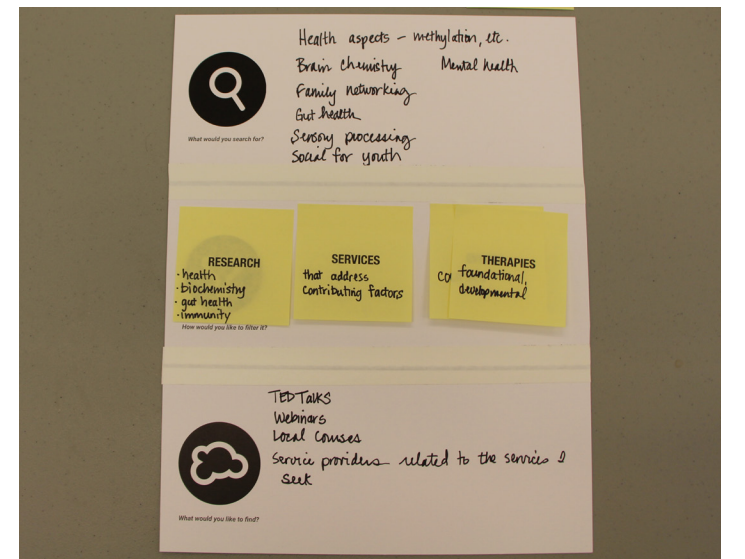
An important design feature of the web-platform is a search and filter function. In order to focus participants on this function, they were asked to speak about their experiences with autism, by coming up with possible web searches relevant to their day-to-day lives. This activity highlighted how families may search for content, before focusing on how this would be visually designed (activity 3).

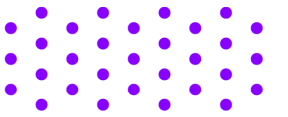
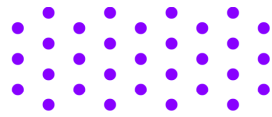
The activity was framed, as follows:

- We asked participants to write down a query they were likely to type into a search engine regarding ASDs. They were allowed to write down as few or as many as they liked.
- Next, using sticky notes with pre-written filter categories, we asked how they would filter their search.
- Lastly, they were asked to write what kinds of content they would expect to find in a search results (e.g. a TED talk, research journal, blog post, etc.).



Activity 1 - What would you search for today?





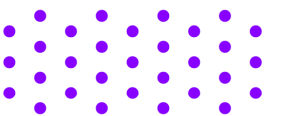
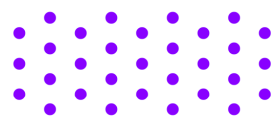
Activity 2

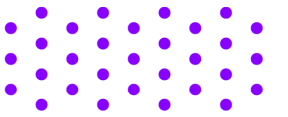
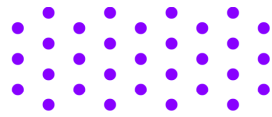
Open Card Sort

Organizing a web-platform is a complicated task because ASDs are highly diverse and complex. Each family and individual has their specific shorthand and a mental model for navigating digital spaces. To gain a more nuanced perspective on how individuals categorize and organize content, we developed an open card sort activity. We wanted to find out from families how they would group and organize various research articles into themes. Throughout this activity, participants described their sorting process to us and their interpretations of various headings such as: sensory, communication, the brain, the body, neurology, families etc. Participants were given the paper equivalent of a menu/tool-bar with six blank spaces, approximately 35 research article headlines and 14 category headings. It was then up to the participants to begin negotiating how best to group and organize headlines within categories.



Activity 2 - Open Card sort





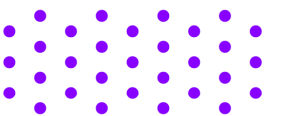
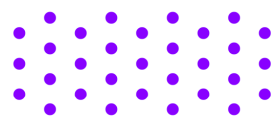
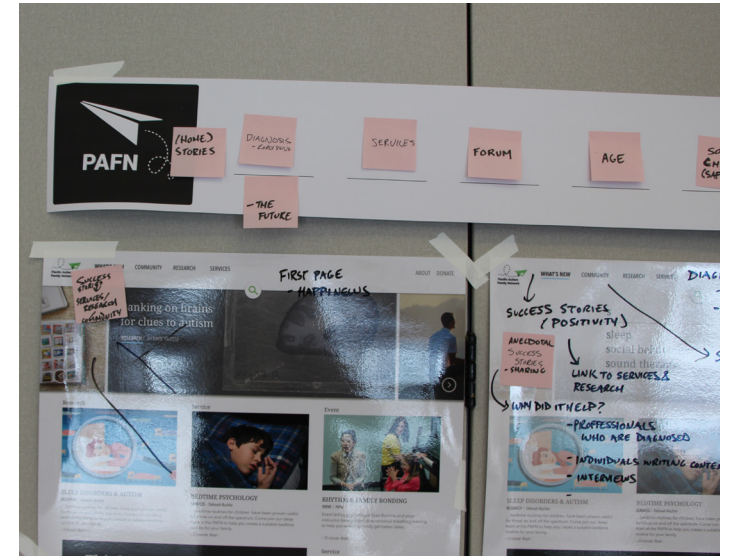
Activity 3

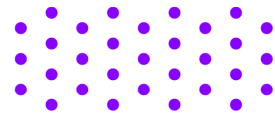
Screen Mock-Ups

After a brief break, we showed the participants our design concept including its features and functions. We printed off several ‘screen shots’ on laminated paper from the proposed site and walked participants through a use-case scenario to elicit further feedback. As the participants gave input, we sketched on the ‘screens’ affectively re-designing pages based on feedback and discussion. At this juncture we avoided showing a high fidelity prototype to ensure participants felt that the site was truly ‘editable’ and not fixed. The group discussions that resulted were extremely valuable to the next steps in the project and highlighted our errors and confirmed many assumptions.



Activity 3 - Screen mock-ups



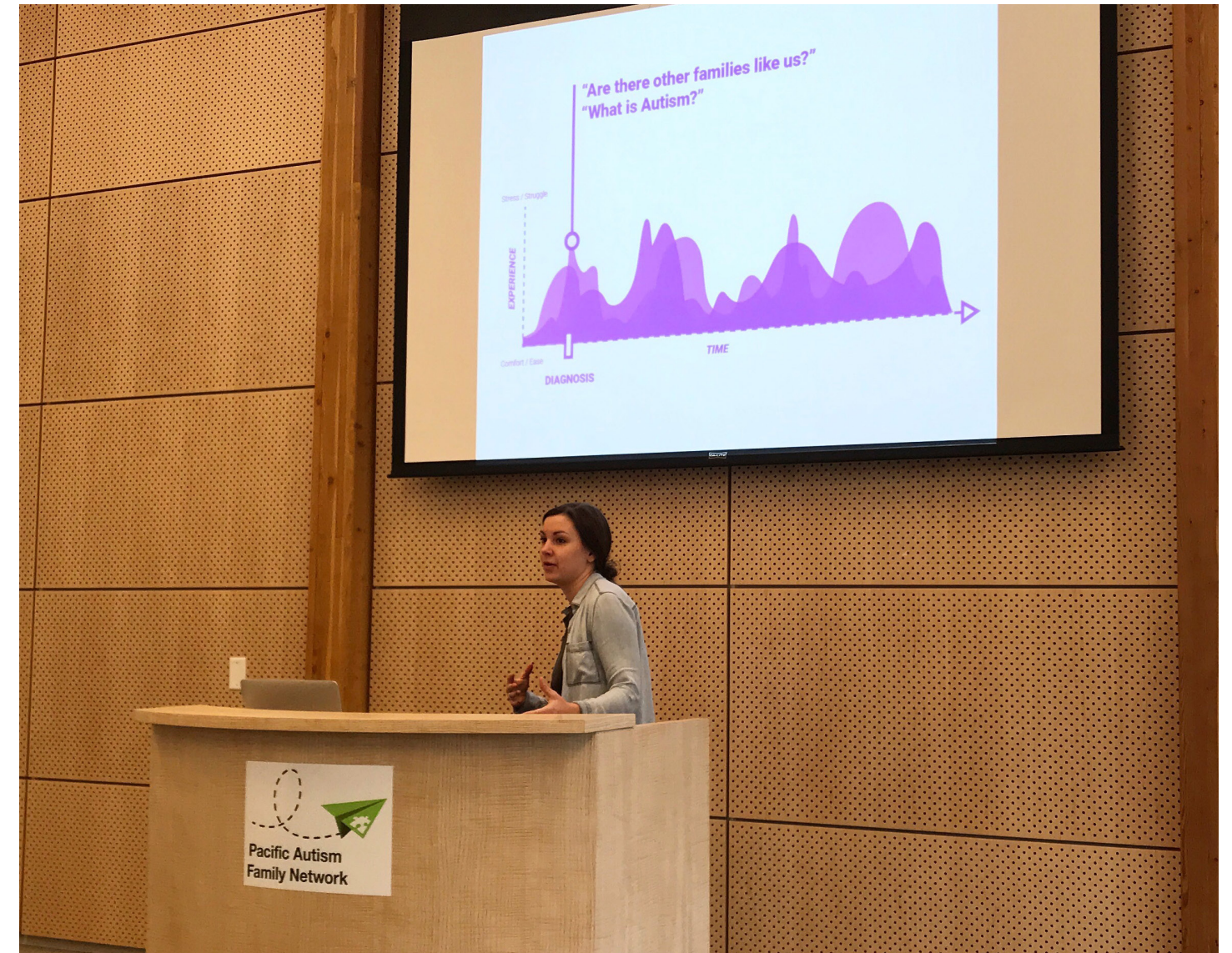


Web-platform Concept
PAFN
Sept. 2017–May 2018

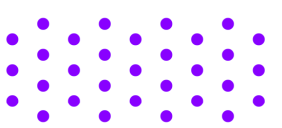
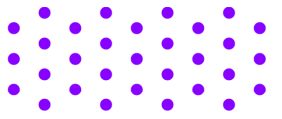
3.2 Workshops – Round Two

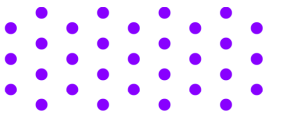
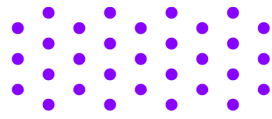
Summary

The second workshop was held with participants in a presentation and discussion format a month following the initial co-design workshops. This allowed us to show families how their contributions in the previous workshop had impacted the design of the site. Following the presentation, we encouraged more feedback and idea sharing. Our overall goals were to explain the work that had been done by the Health Design Lab on the web-platform and the future requirements for development.



Caption*****





3.3 Community Insights

Summary

Through our workshops with families, we were able to test, validate and shift our initial design concept to better address family needs through a more in-depth understanding of how they would like to use the web-platform. Themes and insights which emerged through these conversations profoundly influenced the final web-platform design concept. Our interactions were overwhelmingly positive. Participants reinforced how essential these conversations and activities are for

fostering empathy and understanding. One parent stated, “you’ve done a good job of looking at it from very many perspectives and seeing that there is value from whoever is in the room”. We tried to provide a creative and inclusive environment which supported opinions and ideas.

The following is an overview of key insights which emerged from our conversations with the community.

Diagnosis

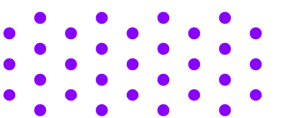
It became clear during the workshops that many individuals seek different types of information and resources during diagnosis compared to those further along in their Autism journey. Parents of those newly diagnosed are under immense stress; they face foreign medicalized language and jargon, lofty government institutions, newly felt and perceived stigmas, all while trying to provide the best care for their child. One parents stated that, “in the first year, I spent the whole time surviving,” describing her diagnosis journey as an experience that left her feeling isolated. Because diagnosis was described

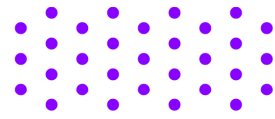
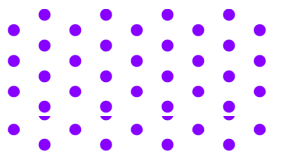
as a critical moment and pain point for many, we felt it necessary that our design incorporate it as one of the leading categories. We learned that families have very different needs for research and resources during this phase, and require more instructional, service-based information at this time which should be conveniently contained within its own section.

Varying Stages & Information Needs

As families and individuals navigate life with ASDs, they will encounter unique stressors and obstacles to which different types of information and resources will be necessary. One parent aptly stated, “So many people are looking for something different because their children are so different”. However, based on our workshops, we discovered that there seems to be a general trend for the type of information families need at various phases. Initially, families require basic information about autism and the diagnosis process. Rather than seeking research or services at this point, many families start by asking, “What is autism? How do I get a diagnosis?”. After finding basic diagnosis information, it seems that many families look for community & support. They wonder, “Are there any other families/people like us?” “Who can I talk to?”. There is a clear need at this phase of the journey to connect with others and to feel supported. Next, many families start to look for local services; they ask, “where can I get help”? Finally, once families start to access support and services, it appears that they are more prepared to dig a little deeper into research, they may ask “where can I find reliable information and research to learn more?”. As families continue their autism journey, they start moving back and forth between looking for relevant research, services and community events.

Although the above questions would not be entirely experienced in linear fashion, it echoes the journey of many of the participants. We therefore felt that the web-platform must do its best to account for these stages in the Autism experience.





Web-platform Concept
PAFN
Sept. 2017–May 2018

“A lot of websites have big drop-down menus, and it gets confusing. I like big text and simplifying things rather than having a million categories and menus. The website should be for people who do and do not have autism.”
— Participant on the spectrum

Search & Filter Tool

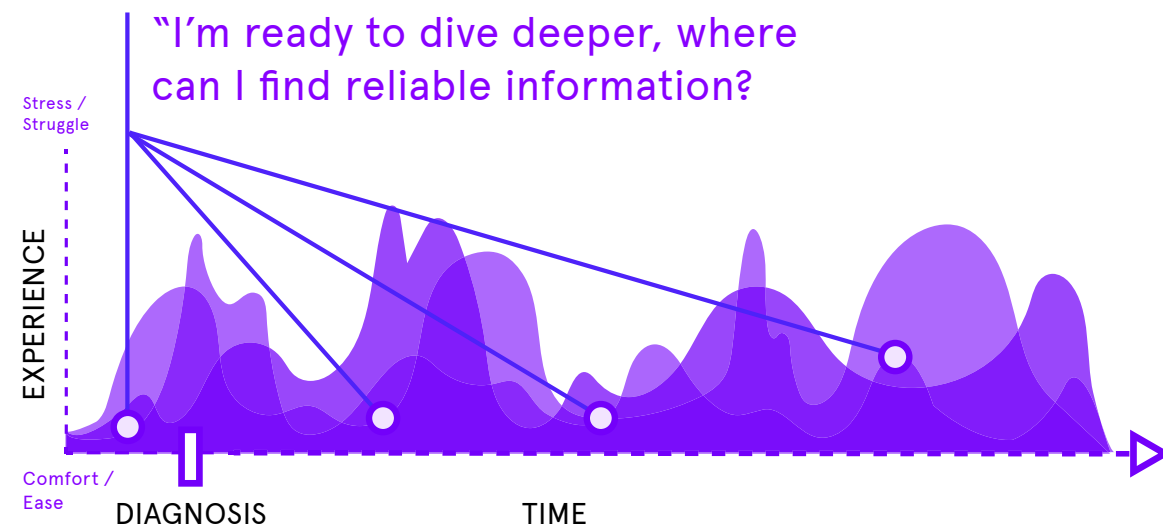
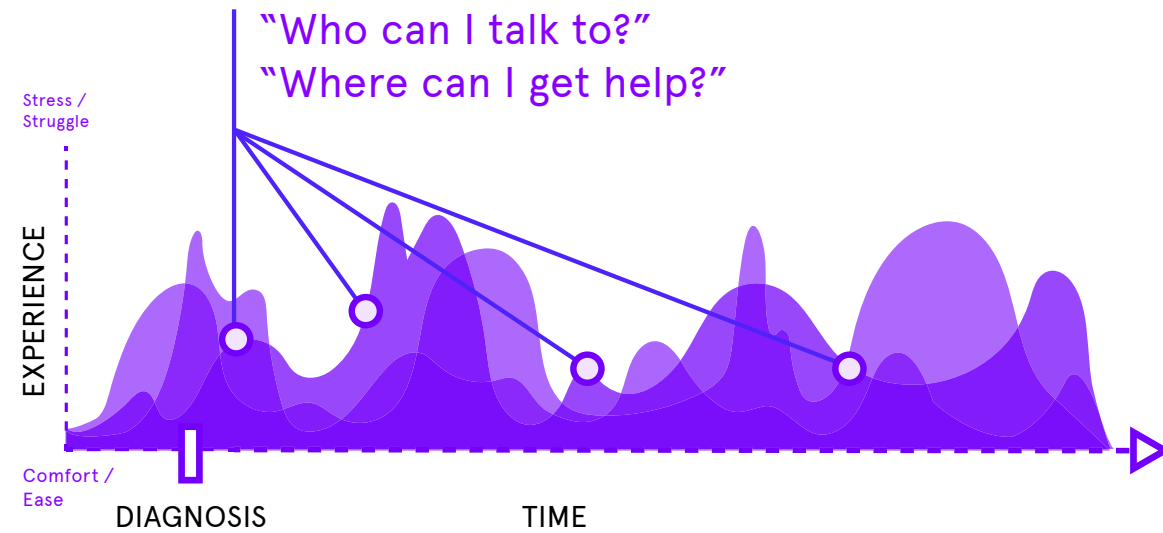
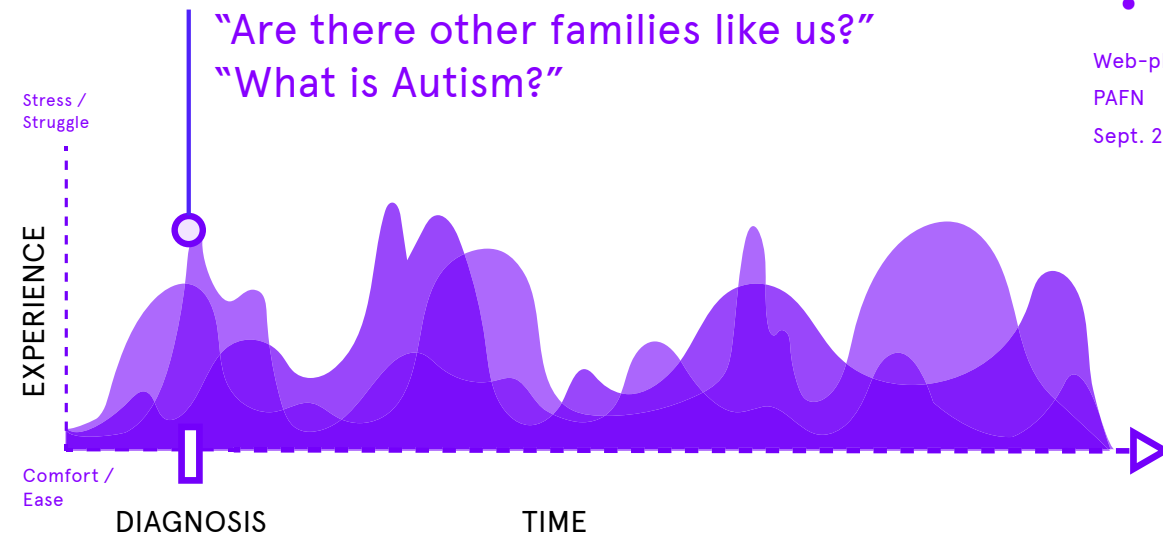
A key feature in our proposed design is a prominent search bar, to be discussed further in detail in the ‘Vision’ section. One of the primary functions of the workshop was to test how the participants reacted to it, and if it was perceived as a valuable way-finding function. Participants in all workshops responded positively to the search bar concept. Different search methods and directives surfaced as the workshops progressed. Many participants described wanting to dig further into one subject, while others expressed a desire to skim laterally in hopes of finding something new and unexpected. In our second workshop activity when we asked families to sort articles into core themes, difficulties arose as participants struggled to create taxonomies and organizational structures that conflicted with

others rather than overlapped. As users deliberated, we discovered that this task was difficult due to the lived experiences which gave way multiple ways of sorting the same information. The search and filter feature helps to address this challenge by allowing the user to search by selecting various categories.

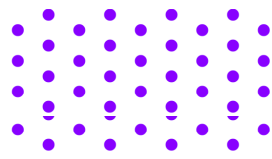
Stories

Participants often discussed wanting to hear stories and anecdotes with positive tones to help them feel a sense of support and community. It was suggested that these stories, could alleviate isolation and remind individuals and families that there are good days ahead. A service provider and participant stated, “Autism is a gift, not something that should be viewed as doors shutting”. He continued to express that he often observes a perceptual shift a few years following diagnosis in which the perceived burden of a ASDs is transformed into an opportunity. Families felt as if success stories and narratives may help mitigate the stress of managing autism.

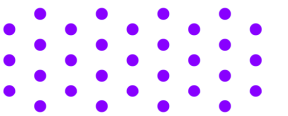
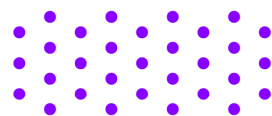
The desire for ‘success stories’ was requested in every workshop and championed by most of the participants. Even in one of the co-design sessions where families were focused on the need for evidence-based research, they identified the value and power of personal stories. It became apparent to us that the site should contain family stories in conjunction with evidence-based research, however, to avoid confusion, these two types of content should be differentiated in the design, so there is a clear distinction between what is anecdotal and what is evidence-led.



Graphs depicting the ups and downs of families in various stages in their ASDs experience. No two are alike, therefore needs will vary greatly



“The main thing is connecting people to actions, steps they can take themselves to connect with services, people and practitioners that can help.”



Content Delivery

Integrity of Information

It was expressed by both families and researchers throughout our years of research that it was important that information be credible and vetted by reputable publications and institutions. These sentiments were expressed in all of our workshops; participants wanted assurance that the information they were accessing was evidence-based, current and reliable. Moving beyond the research category, participants expressed concern over how stories and experiences would be curated and displayed; integrity as it relates to anecdotes relies heavily on the vetting system in place which ensures stories are not harmful or offensive.

Impact of Titles

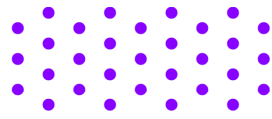
it was noted during the workshops that there were polarizing reactions garnered by some of the headlines in the card sorting activity. None of the articles were available to be read during the exercise; participants only had a short description to supplement the title. Some participants designated headlines as “garbage” while other took them as fact. Therefore we noted that titling will play a pivotal role in how individuals approach and reacted to content in the web-platform.

Local Services

It was expressed that it would be desirable for services and resources to be filtered based on the locality of the user. Participants from more remote areas wanted to be able to see what was local and available first, rather than being inundated with services that at first glance are appealing but inaccessible upon further inspection because they are located in the lower mainland. The website should connect users to proximate services then allow an exploration of services in other locales if the desired resource are not near by.

Videos are Favourable

In regards to content delivery, many families specifically mentioned a desire for video content. A participant described a video put together by a teacher (who is on the spectrum) for students, as helpful to her granddaughter because it was relatable and accessible. This example reflects the sentiment shared by many of the participants in both workshops. Many felt that videos were insightful, easy to digest and quick to scan through. Many recounted that watching streams of conferences, TED talks, informational or personal stories were the most desirable way to access content.



04 Vision

When I enter the site, want to have access to what is currently going on in the autism community, so I can quickly keep up to date and be inspired to explore new events, resources and research.

Web Platform

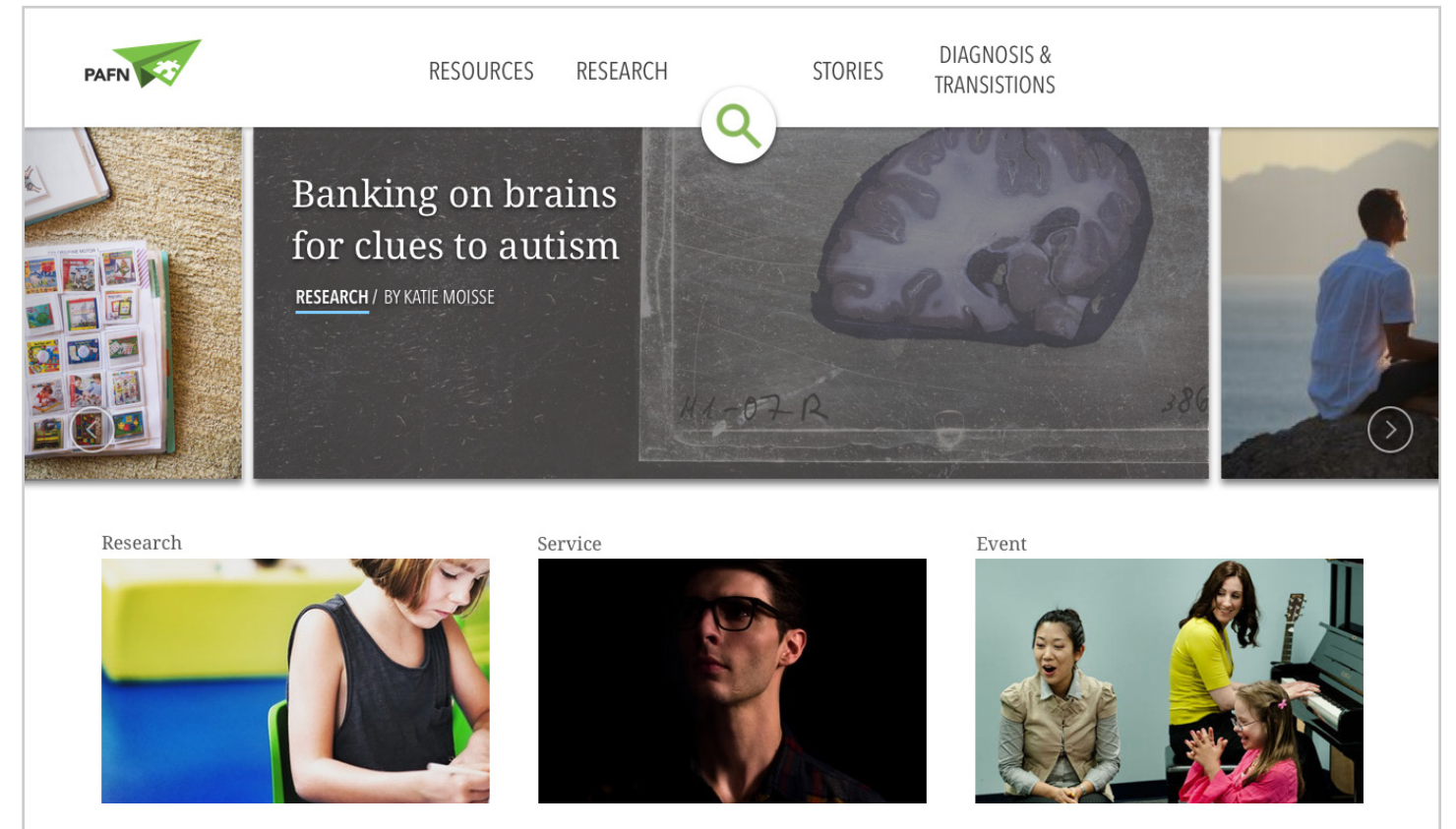
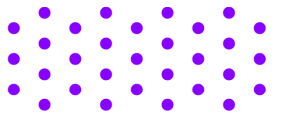
This section describes our co-design vision for a family centred web-platform. The following are recommended categories and subcategories for the main web-platform menu based on the previously described insights. These main categories for the menu include:

- Diagnosis & Transitions
- Stories
- Research
- Resources
- Search & Filter Tool

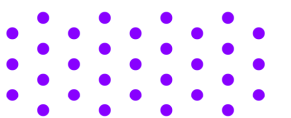
The following pages contains sample screen shots for what a web-platform could look like based on the vision and needs articulated by families. Specifics in design, vernacular and language used in the interface samples

are all subject to alteration and change in the spirit of future iteration and collaboration. It may not be feasible to develop all of these sections and content at once, however the intent is that this serves as a conceptual and visual ‘lighthouse’ towards the ideal final web-platform.

The home screen should contain a general overview of what is new in the autism community, with calls to participate, learn more and connect. It would house current events and activities, new research, stories and available resources. It is would be optimal for the home page to be location responsive as users in remote areas expressed that seeing resources, events and services that were unavailable to them was a significant pain-point.

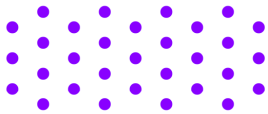
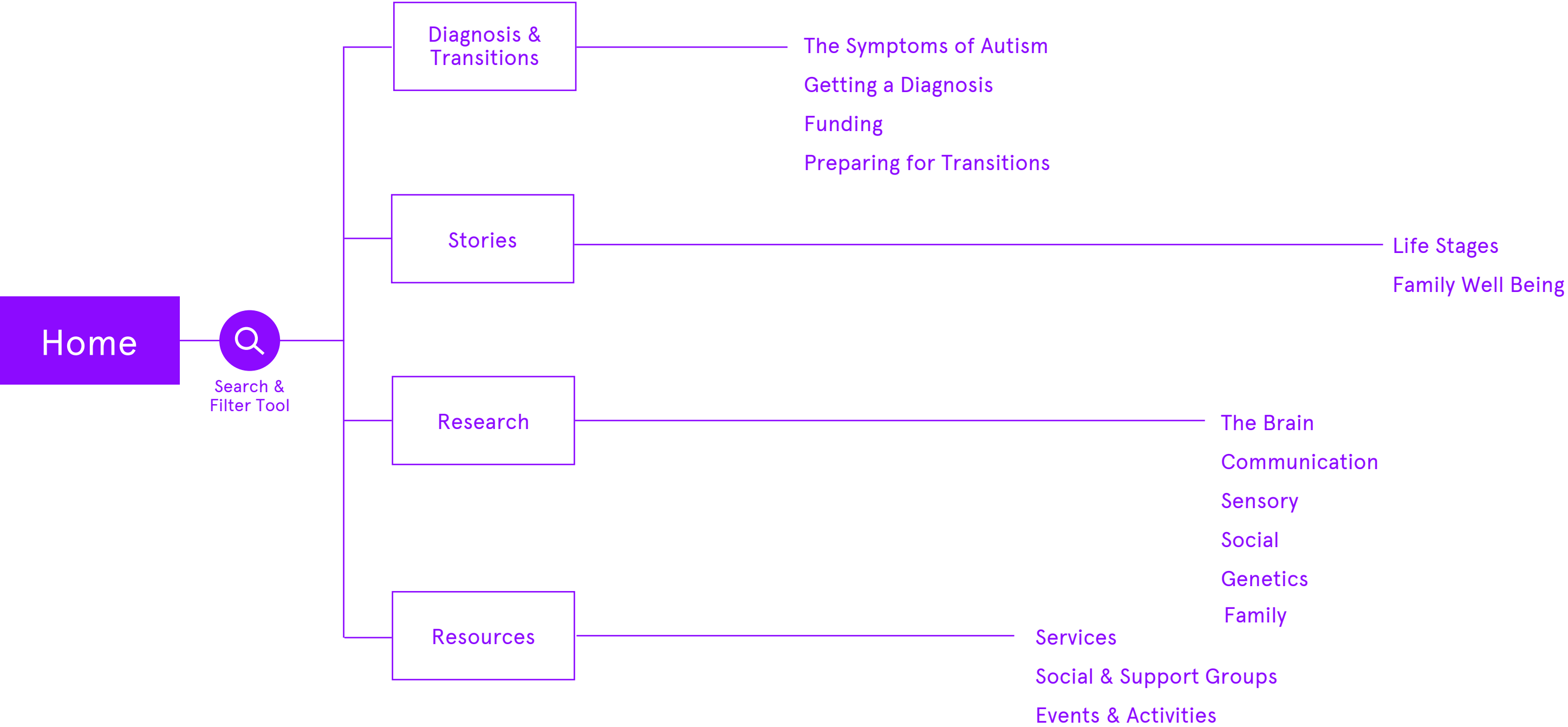
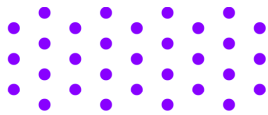


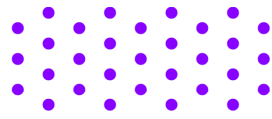
Home page example, showing main categories at the top including Resources, Research, Stories, Diagnosis & Transitions, as well as Search tool.



Site Architecture

This site architecture is a simplified map based on the recommended categories and sub-categories described earlier in the text.





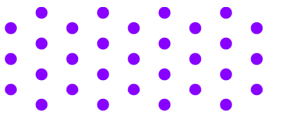
When I am overwhelmed with information before and after diagnosis, I want to be able to navigate easily and organize all the disparate pieces of information and services, so I can reduce my cognitive load and stress.

Diagnosis & Transitions

We identified that ‘Diagnosis and Transitions’ should become one of the main categories because there are key touch points in the Autism journey that require specific information which should be easily accessible. Under ‘Diagnosis and Transitions’ users should find information regarding symptoms correlated with autism under titles such as “What to look for” and resources mapping out how to approach the assessment journey and how to seek out a diagnosis. The purpose of creating a unique space for ‘Diagnosis and Transitions’ is to ensure that users are provided with pertinent information at the right time and to aim to reduce friction and confusion during stressful moment in time.

This category could include:

- The Symptoms of Autism
- Getting a Diagnosis
- Funding
- Preparing for Transitions



The Symptoms of Autism

Before parents begin to seek out a diagnosis or perhaps speak to their family physician, they may set out to discover if their child displays some of the symptoms of autism. As a preface to the next subcategory (Getting a Diagnosis), this category aims to educate those who are unfamiliar with autism and prepare them, if necessary, for the following steps.

Getting a diagnosis

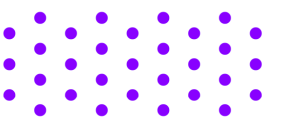
Many parents expressed that getting a diagnosis was complicated and confusing. Many roads can be taken with no one right path. Parents may opt for private health care services, to speed up the process, hoping that the money spent will be covered after a diagnosis is obtained. This approach runs the risk of wasting money on an expensive diagnostic process with no guarantee of coverage; it is also cost prohibitive. Going through the public healthcare system may not cost money, but takes considerably more time. Time is a critical asset for families as early intervention is crucial for the development of appropriate treatment and therapy strategies. This subcategory aims to help parents and individuals way-find and reduce the stress that comes before and during the diagnosis process. It should contain straight forward information about how to get a diagnosis.

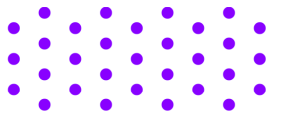
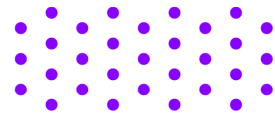
Funding

Once a diagnosis has been given, parents must begin educating themselves about the funding structures and schedules that will impact the services and resources available to them and their children. This category could inform parents on how new government policies, both federal and provincial affect them, upcoming dates when funding shifts, when tax credits are available to them, etc.

Preparing for Transitions

During the second workshop a service provider expressed to us that when it comes to “Some of the families [they] work with, [they] don’t even know how they make it through the day to day, nevermind plan for the future” He succinctly pointed out the difficulties of navigating the unique milestones, government deadline, funding structures, all the while looking towards the future. This section could aid families and individuals on the spectrum with planning, by providing checklists of key activities and things to consider at various life stages including: when to open a bank account, prepare for the workforce, etc.





When my child receives their diagnosis, I want to know it will be okay and hear what other have gone through, so I can be assured there are better days ahead.

stories

A key section of the web-platform should be stories. The stories section could be broken down into personal anecdotes, the sharing of milestones and narratives written by those in autism community, primarily families and individuals. Vetted by the PAFN, stories could take the form of interviews, videos and written media which explore the personal experiences and triumphs of the those in the community. As mentioned this component was reported by many in our workshops has crucial, as it serves as a boon to those overwhelmed and feeling hopeless. It is worth mentioning that although knowledge gained through the stories section is valuable, its design and titling must explicitly distinguish it as different from research.

This category could include:

- Family Well-Being
- Life Stages

Family Well-Being

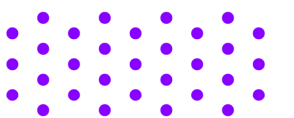
During the workshops, it was expressed that ASDs significantly impacts family dynamic and well-being. One parent expressed the imperative but straightforward

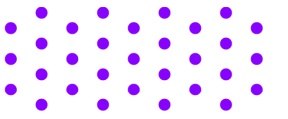
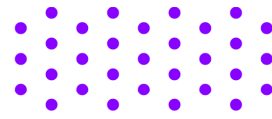
need to help others in her family communicate with her son in a meaningful way; she desired tools to “figure out a way to have people understand and teach them to engage (with my child)”. Children with ASDs require individual time and attention which can be hard on family relationships if feelings of neglect and guilt develop. This subcategory would aim to inspire new strategies and dialogues between family and friends to foster communication.

Life Stages

Milestones and events such as puberty, school transitions, divorce, sexual activity and adulthood can be challenging for most anyone regardless of an ASDs diagnosis. Participants suggested that these moments in time can exacerbate existing symptoms and create further complexity. It was also mentioned that these milestones tend to happen at moments in time that differ from what would be considered normative of the population. Life-stages would offer insights to parents and individuals on how best to tackle and cope with significant life events, based on personal stories and experiences of families

“Many of us have success stories, or stories that aren’t successful, and those are just as valuable. Each of our kids is a person who are actually in this. They are not piece of data on a sheet, they are an actual person.”





When I have the time, I want to access credible research that is in a easily digestible form, so I can apply the knowledge gained to our day to day lives and our search for local services.

Research

The research section of the site should allow people to access curated credible and accessible research articles and summaries. Research articles should be organized into-subcategories to make navigation easier. Based on conversations with families the following sub-categories are recommended:

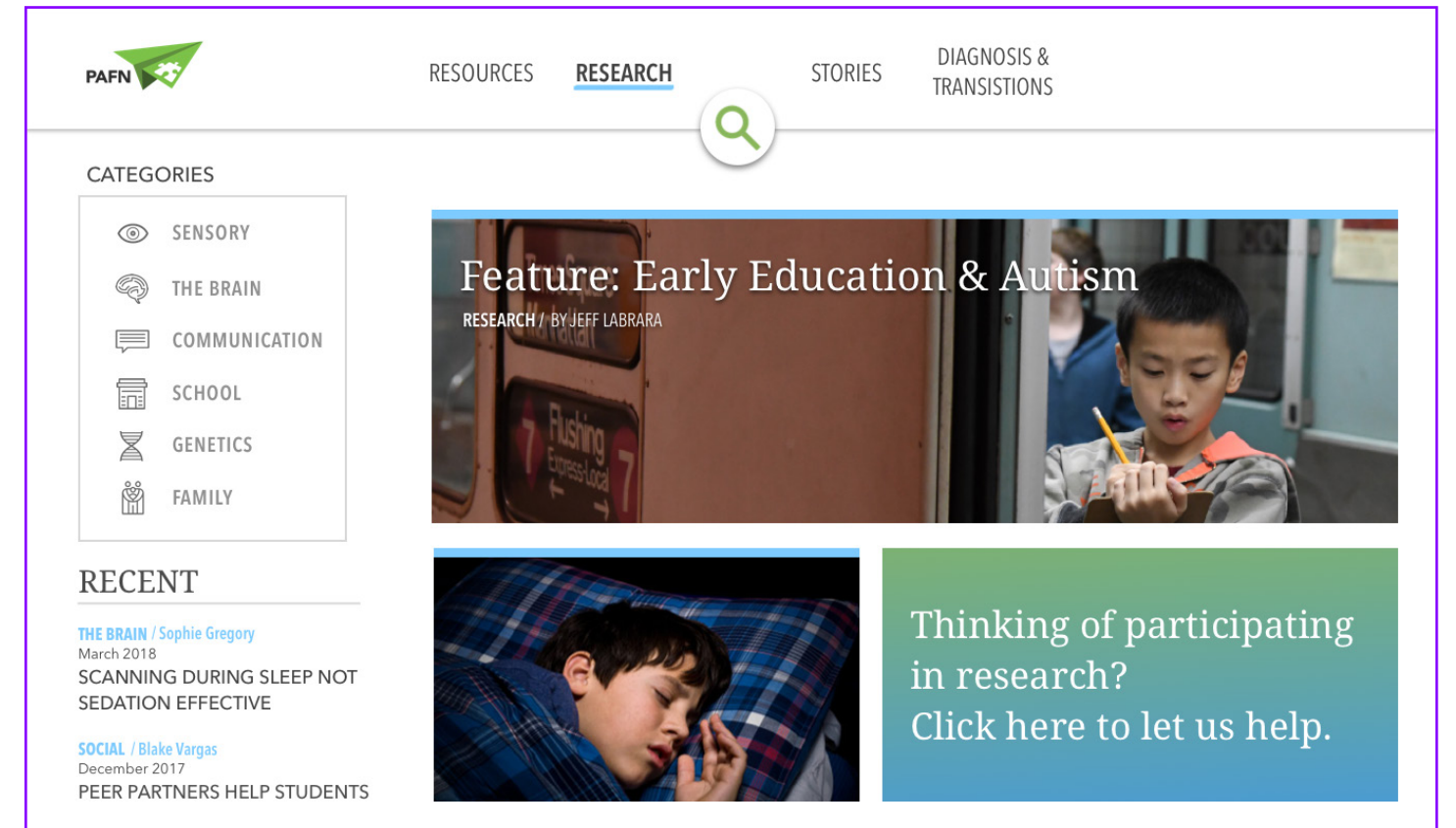
- The Brain
- Communication
- Sensory
- Social
- Genetics
- Family

Research articles in this section should include a list of research articles including the date it was published, a quick overview of what the research is about and the length of time it will take to engage with. After accessing a specific article users should encounter a brief summary, with an overview of the content and conclusion ideally followed by a link to the original source. Following every article should be links to related resources and stories.

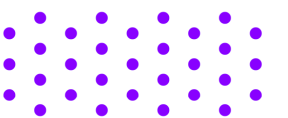
This supports parent's desire to have research connect to their day to day lives and reflects our goal to reinforce and strengthen the relationship between research and resources. The following page contains an example of how a user might interact with this page.

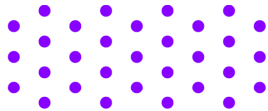
The Brain, Communication, Sensory, Social, Genetics, Family

The card sorting activity brought to our attention the overlapping approaches of classifying and grouping information. As such we aimed to select categories that made sense to the user and reflected their needs and wants. These subcategories in 'Research' were decided upon because we felt they broadly communicated what was discussed and often mentioned in the workshops. Further user-testing of this navigation would be recommended as the web-platform progresses.



Research page example, showing main sub-categories including Sensory, The Brain, Communication, School, Genetics and Family. It also includes a call to participant in research, a list of recent articles and a featured article.







RESOURCESRESEARCHSTORIESDIAGNOSIS & TRANSITIONS







SCANNING DURING SLEEP NOT SEDATION EFFECTIVE

RESEARCH | Heather McCormack Nov. 13 2013

WHAT RESEARCH WAS ABOUT

Scanning children's brains while they sleep is a viable alternative to sedation for infants and toddlers across the

A user has just opened a research article on sleep. They are provided with options to share, print or download the article.



SCANNING DURING SLEEP NOT SEDATION EFFECTIVE

RESEARCH | Heather McCormack Nov. 13 2013

WHAT RESEARCH WAS ABOUT

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Temporibus autem quibusdam et aut officiis debitis aut rerum necessitatibus saepe eveniet ut et voluptates repudiandae sint et molestiae non recusandae. Itaque earum rerum hic tenetur a sapiente delectus, ut aut reiciendis voluptatibus maiores alias consequatur aut perferendis doloribus asperiores

Following the pertinent information about the author and the publishing date there should be a general over view of what the research is about.



RESOURCESRESEARCHSTORIESDIAGNOSIS & TRANSITIONS



...bedtime routines for children have been proven useful for those on and off the spectrum. Come join our sleep team at the PAFN to help you create a suitable bedtime routine for your family.



RELATED

Resource



SLEEP SPECIALIST
SERVICE | Deborah Ruchler

...bedtime routines for children have been proven useful for those on and off the spectrum. Come join our sleep team at the PAFN to help you create a suitable bedtime routine for your family.

Support Group



COPING WITH SLEEP LOSS
SUPPORT | Jon Sandoval

...bedtime routines for children have been proven useful for those on and off the spectrum. Come join our sleep team at the PAFN to help you create a suitable bedtime routine for your family.

Activity



BEDTIME PSYCHOLOGIST
SERVICE | Marie Lyons

...bedtime routines for children have been proven useful for those on and off the spectrum. Come join our sleep team at the PAFN to help you create a suitable bedtime routine for your family.

Stories

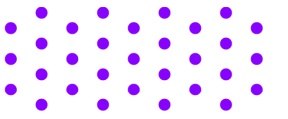
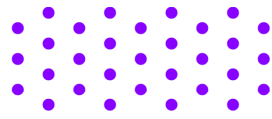


CREATION OF ROUTINE
EVENT | Bertha Jackson

...bedtime routines for children have been proven useful for those on and off the spectrum. Come join our sleep team at the PAFN to help you create a suitable bedtime routine for your family.

After the conclusion of the article related resources and stories should appear in the 'Related' section. This aims to connect the research to services, events and stories.

35



When I think of day to day life in regards to ASD,
I want to be able to find services and events
relevant to my child, so we can lead active lives.

Resources

Another key section of the web-platform, would be ‘Resources’. This section is intended to connect families to local services, social & support groups, and events & activities. The ‘Resources’ section should open to a map with several filter buttons situated directly underneath similar in design to those of the search and filter tool. Users should be able to toggle on and off services and resource themes while a map updates and displays availability in their area. Alongside the map would be a list of upcoming events and activities and perhaps calls for parents and individuals to start their own clubs and groups.

It is recommended that this category should include:

- Services
- Social & Support Groups
- Events & Activities

Services

Decisions on how to vet and promote services, will be an important consideration for the PAFN in the future development of this site. It is important that services included here are credible. It is our (and many participants) suggestion that there be no advertising on the site. Services listed should include: whether or not they

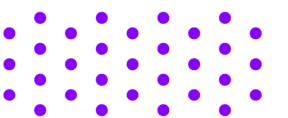
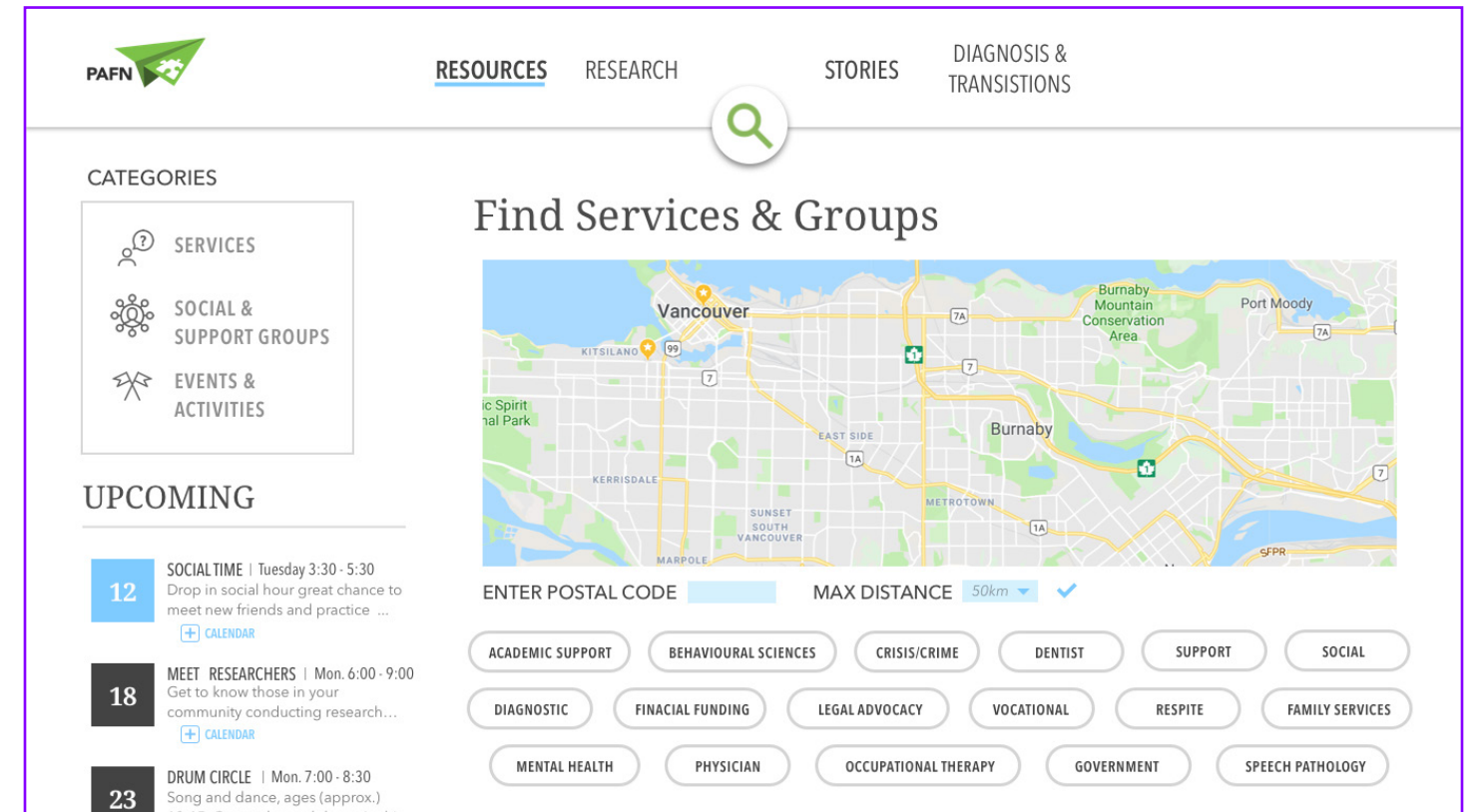
are included on the RASP (Registered Autism Service Providers) list, pertinent contact information and an external link to their website.

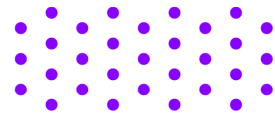
Social & Support Groups

Social and support groups are essential for both families and individuals on the spectrum. These groups reinforce and strengthen communities potentially creating vital support networks that move beyond digital spaces. Users should be able to find local or online social and support groups on the platform. It should be noted that we have differentiated ‘social’ and ‘support’ for the former suggests a more casual atmosphere, in which individuals and families socialize, and the latter acts to sustain more serious conversations about the challenges surrounding ASDs

Events & Activities

Events and activities should be promoted and organized both separately and within a community calendar. Events can be formal gatherings including talks from professionals and conferences, while activities are participatory events for individuals and families. We suggest if there is an opportunity to host an event live on the web, the PAFN should do so as many participants from remote areas expressed the desire for inclusion.





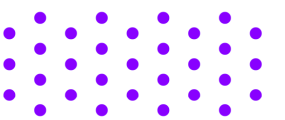
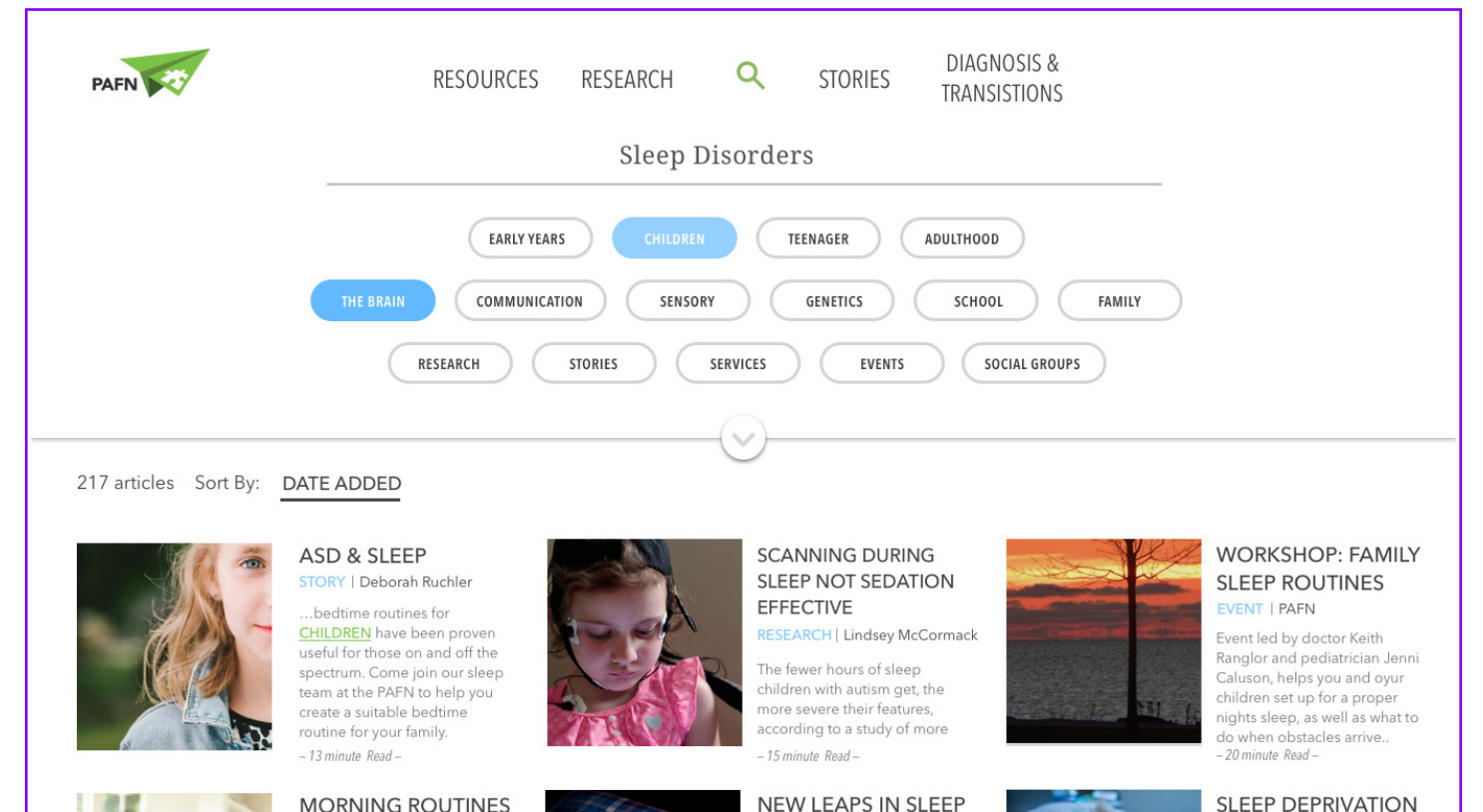
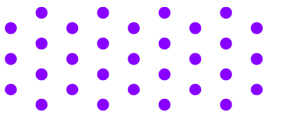
Web-platform Concept
PAFN
Sept. 2017–May 2018

When I open the web platform I may not always know what I am looking for. I want inspiration and guidance, so I can discover more about the ASDs community

Search & Filter Tool

The complexity of the individual journey is difficult to address; each individual that enters the site will have needs that are specific to their context. Users will have different methods of searching, some are looking for specific information and others prefer to laterally skim, traversing categories and topics. To address this complexity we created a series of filters that can be accessed under the search field. The filters exist as a prompt and to assist searching. The specific categories are organized into three sections greatly informed by our workshops: life stages (early year, childhood, teen, adult), research sub-categories (the brain, communication, sensory, social and genetics and content type (research, stories services, events and social groups).

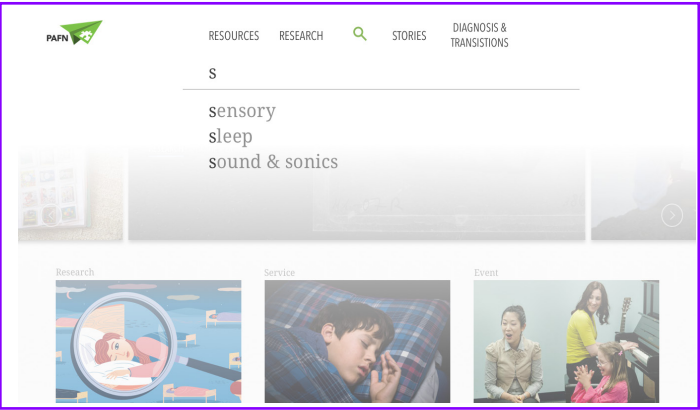
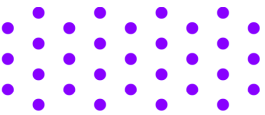
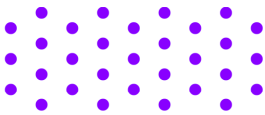
The following pages contain an example of how this feature could be used.



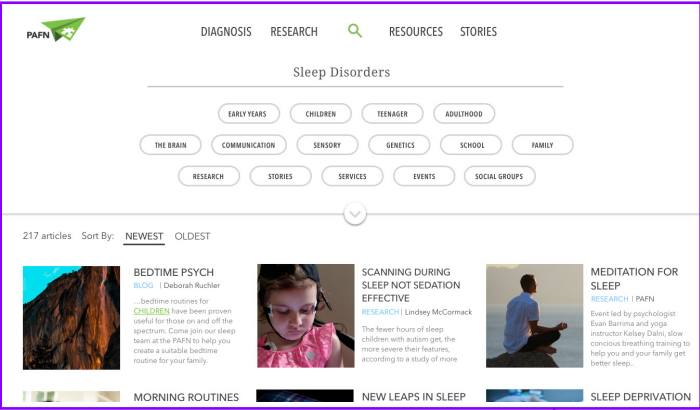
Persona: Jacob

Jacob is 34 with three children. The youngest Brianna, who is 4, has ASD. Brianna’s sleep cycle is becoming slightly irregular. Jacob is worried that her lack of sleep is interfering with her therapies and causing out of character behaviours. ASDs is relatively new for Jacob, and sometimes he does not know the right jargon that will help him find the things he is looking for.

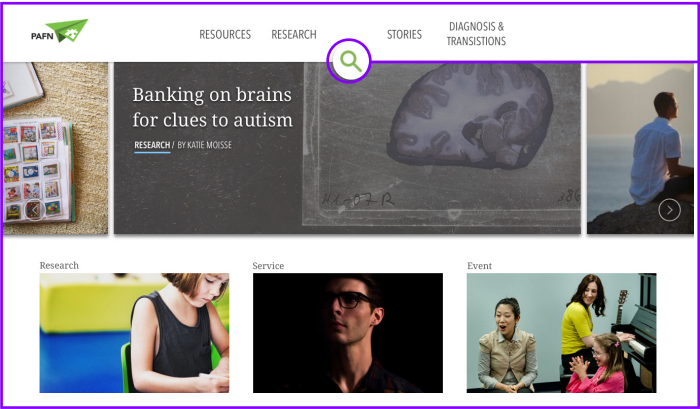
Web-platform Concept
PAFN
Sept. 2017–May 2018



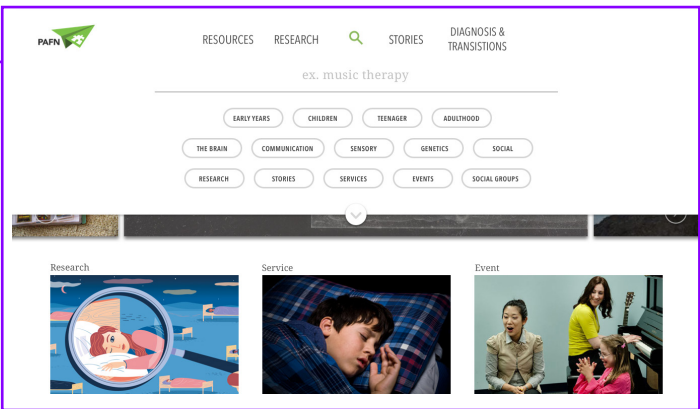
Jacob begins searching for 'sleep disorders' with predictive text assisting his query.



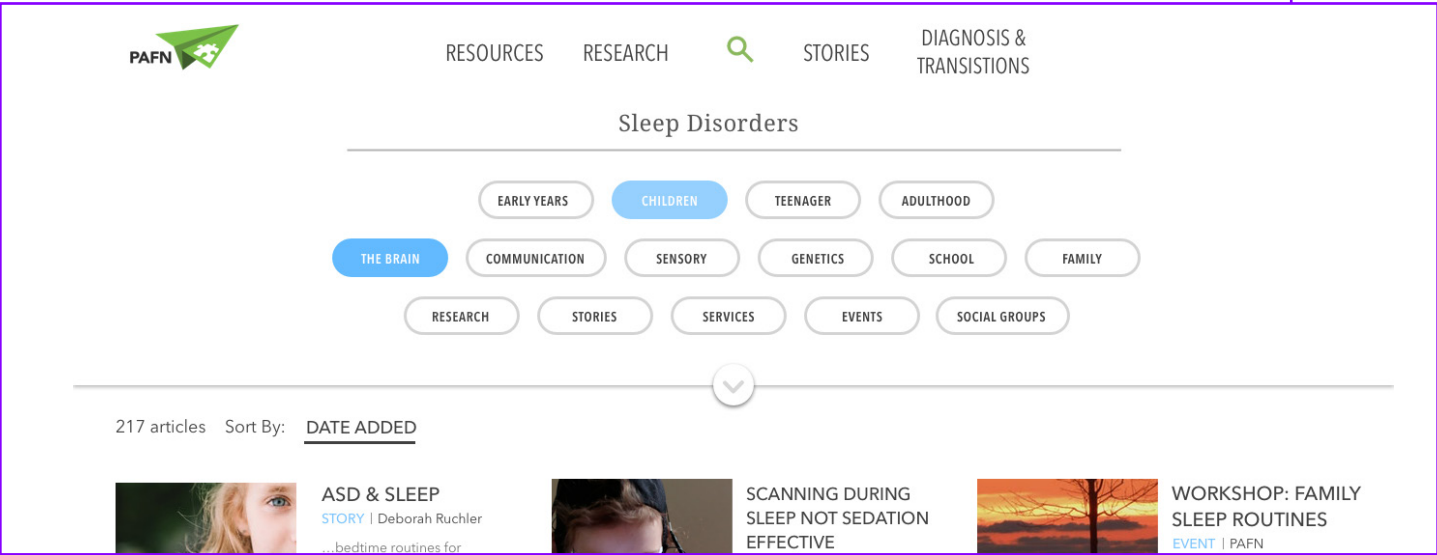
He completes his search and looks at the filter buttons which are grouped by time, theme, and content type.



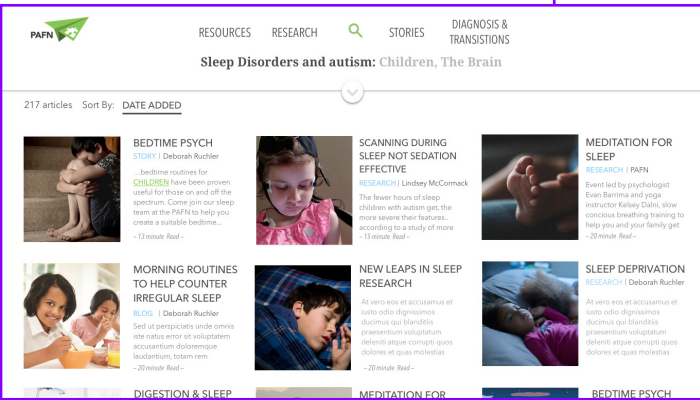
Jacob enters the site not knowing exactly what he is looking for but is very curious about sleep disorders.



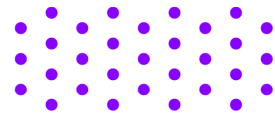
After clicking the search icon, the filter menu pops down



He is interested in discovering more about sleep disorders and how they relate to Brianna's age and brain.



He begins to explore his search and has the ability to toggle on and off options within the filter menu, to narrow or change the search results.



05 Implementation

Needed Features

There are many features that could be included in this web platform, but there are a few which are important to fully meet the needs of parents and families. It is also worth mentioning that the user interface design (typefaces, layout and language) should be as accessible as possible for individuals on the spectrum.

The main needed features are:

- Summarized & curated research
- Stories
- Resources

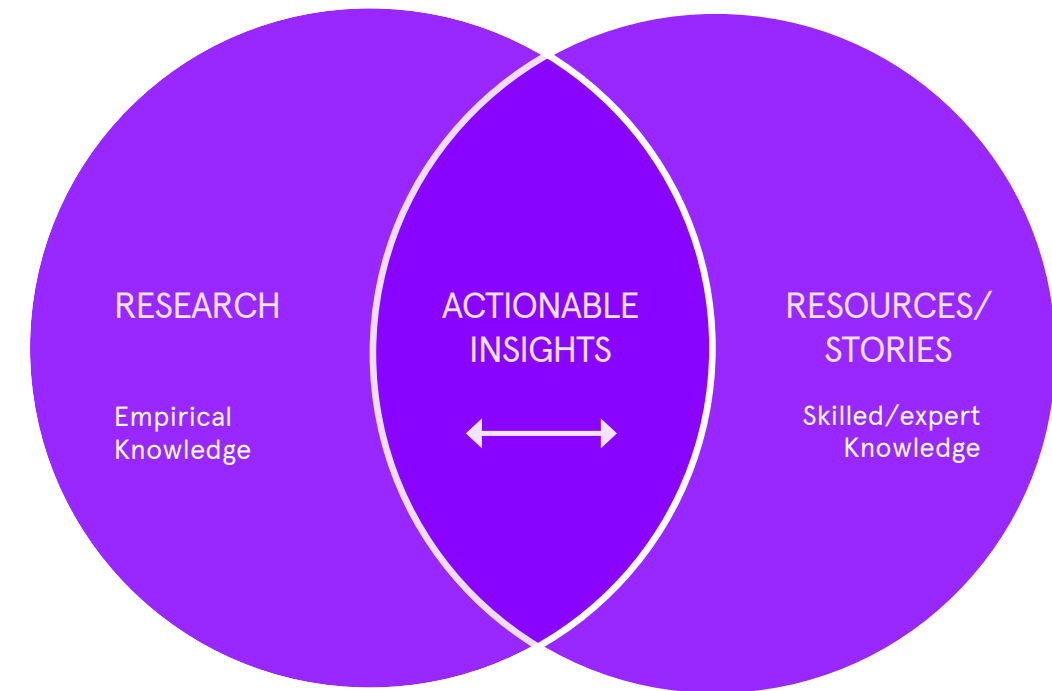
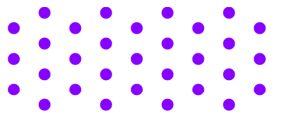
Creating connections between Research, Resources & Stories

If research could be synthesized into digestible chunks and segue into related resources and stories parents and individuals may be able to make actionable connections between research and their lives. Creating avenues for connections on the web-platform addresses the unique contexts from which the users are situated within, hopefully allowing them to access the most pertinent information at the right time.

Facilitating opportunities for face-to-face engagement

Parents often spoke about how isolating ASDs can be, and that workshops like the ones hosted by HDL give way to understanding and connection. This web-platform should aim to activate users by providing as many opportunities as possible to meet face-to-face. This could be achieved not only through providing options for parents to join/start their own support or social groups by also involving parents in the curatorial process.

Creating Connections



Desired Features

We acknowledge the complexity of this web-platform and the intricacies that certain elements could create in the future for designers, content curators and developers. With that in mind the following listed functions are secondary to the needed attributes previously listed.

Videos

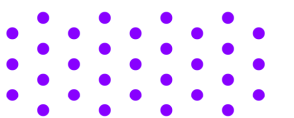
The desire to access information in the form of videos was mentioned countless times throughout our workshops. Although creating video content is time consuming and costly they could provide opportunities for employment and community engagement. An individual on the spectrum who attended our workshops expressed an interest in video editing for the PAFN and stated that videos are “good for people like me.” He suggested videos allow for more visual learning and increases the accessibility of information.

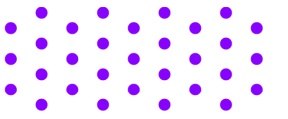
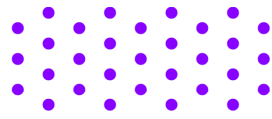
Location Responsiveness

This piece would be beneficial for users, especially those in remote areas to ensure that relevant resources for their child would be presented to them first instead of having to sift through events and resources located in metropolitan areas leading to disappointment.

Search & Filter Function

The filter function allows for both lateral and direct searching aiding in the articulation of queries for parents who may not be used to jargon and ASDs terminologies as well as exploration. Although not needed, this desired function would hopefully make the web-platform more approachable to a wider audience.





Inclusion of Families

The success of the web-platform is inextricably linked to the value individuals and parents derive from it. The participants throughout all three years of co-design work have shared their stories with us and their struggles and successes have created the foundation of this vision. For future implementation and platform development it is necessary to include these users not only through validity testing but in the design and curation team to ensure the web-platform is truly of worth to families. A parent in one of our final sessions stated their concern that money spent on the website may be more suited for services and resources directly related to their children. This was repeated by many participants, and it became clear that it will be relatively easy to create a poorly designed web-platform if the complexity of what needs

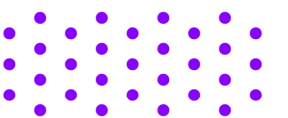
to be done is oversimplified or underestimated. As one parent stated, “With the best of intentions it could go totally off track.” The community will be a beneficial asset to the creation and sustainment of the web-platform, and should not be underestimated.

Content Curation

Creating, organizing and managing a curation team will be an integral component of the development of the web-platform. Curation guidelines will have to be developed in order to review and vet research, stories and resources. For example in the ‘Stories’ category, the content curation team must seek out, or create the necessary avenues for individuals within the community to submit stories and opinions. As for ‘Research’, the team would need to source relevant articles from research journals, or appropriate web sources, clarify the information and supply the web-platform with an easy to read summary. The curation team should serve as a patch-cord between academics, service providers and the

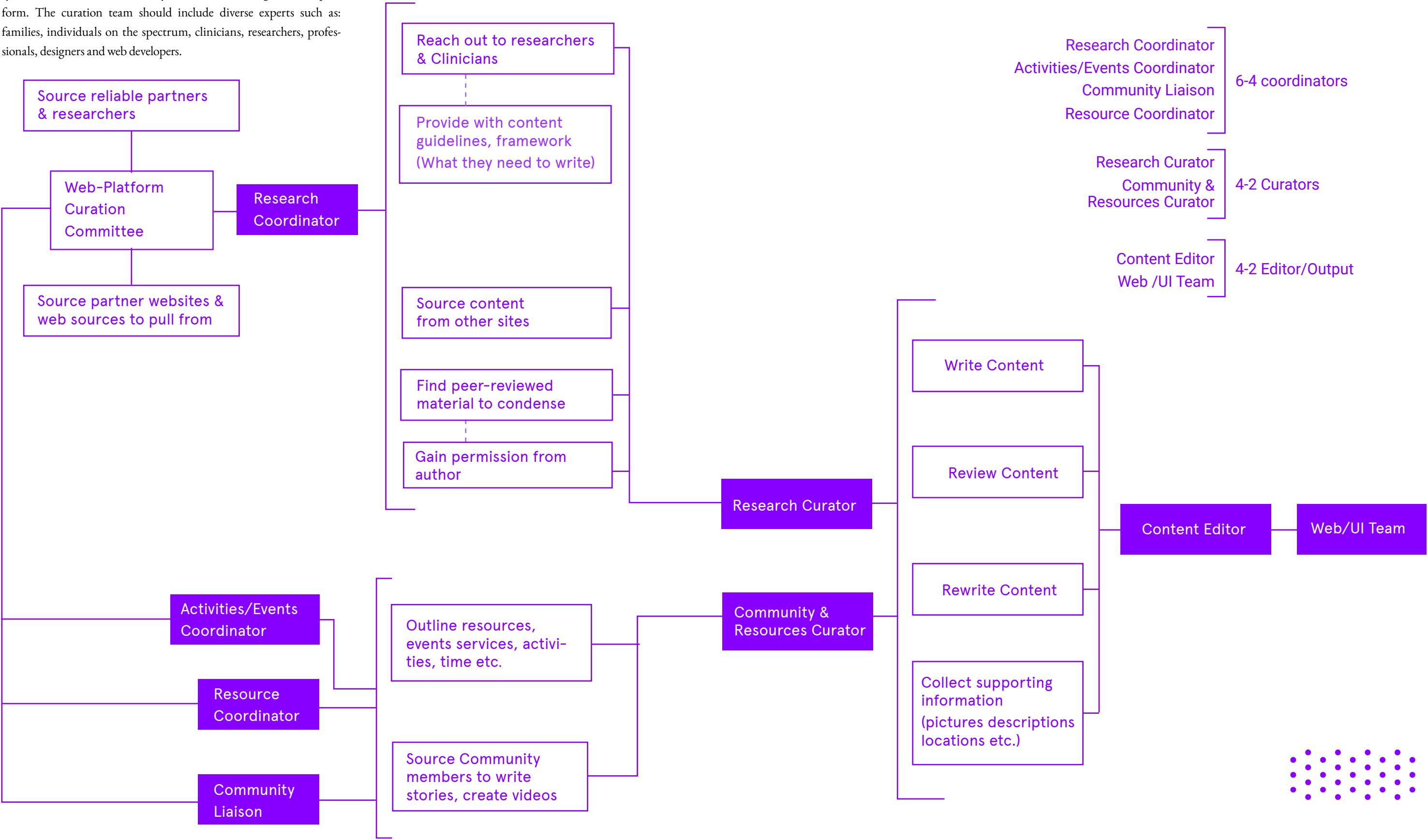
broader community. All information research, stories, services and otherwise should be thoroughly examined and reflect the needs of families and individuals.

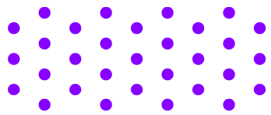
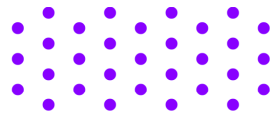
“The spectrum is so broad, it is hard to say what is needed at what time, but to have the resources and being able to access it from any area, is what is really needed.”



Sample Curation Map

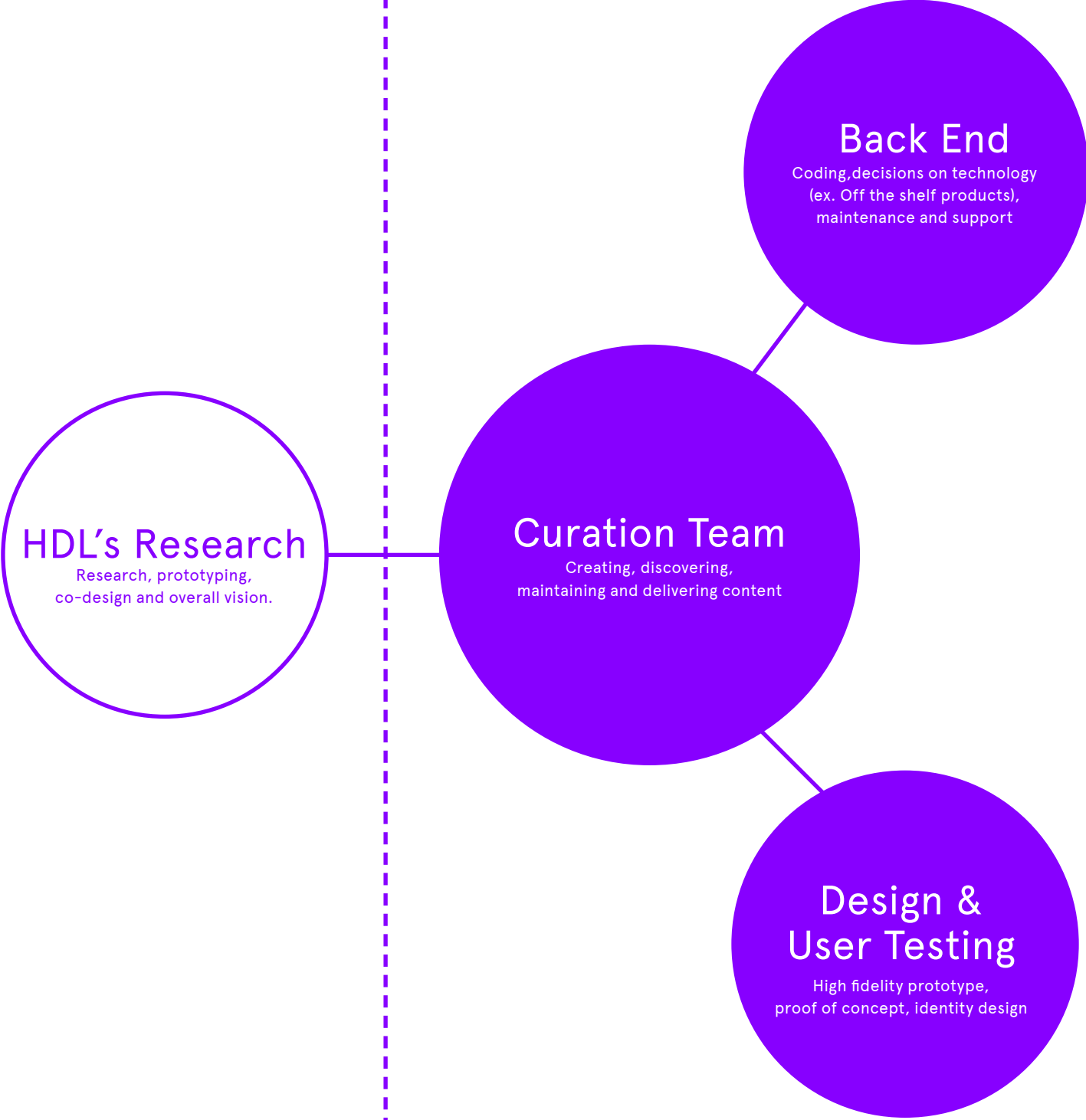
This sample demonstrates the types of professionals and community members that will be necessary to create and manage the web-platform. The curation team should include diverse experts such as: families, individuals on the spectrum, clinicians, researchers, professionals, designers and web developers.





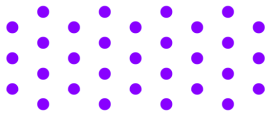
Work Completed

Future tasks & Work



Next Steps

The information presented in this report is an outline of a user-centred ASDs web-platform. The next step is to pursue further development of the front-end design, the back-end software development and the formation and sustainment of a curation team to support the proposed design. We suggest that the web-platform be viewed as a reflection of the social and physical manifestation of the PAFN in Richmond; a one-stop shop where families and individuals can seek knowledge, support, connection and improved health outcomes. The entirety of the web-platform is greater than the sum of its parts if each component is thoughtfully connected to one another. Developing components piece-meal could potentially exacerbate the existing communication challenges in the community by creating a disjointed and manifold web presence. A holistic design and development approach would acknowledge the diverse and variegated experiences families and individuals face and hopefully would act as a unifier by highlighting avenues of communication and access.



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