ELIZABETH GOODWIN

"I DON'T SEE ANYONE ELSE LIKE ME"
CREATING AN ONLINE COMMUNITY WITH PARENTS OF DISABLED CHILDREN DURING COVID-19

"I DON'T SEE ANYONE ELSE LIKE ME"

CO-DESIGNING AN ONLINE COMMUNITY WITH PARENTS OF DISABLED CHILDREN

A thesis presented in partial fulfilment of the requirements for a Master of Design at Massey University, Wellington, New Zealand

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TABLE OF CONTENTS

ABSTRACT

This project seeks to implement and reflect on the findings of co-design projects I have done with parents of disabled children over the past three years which identified isolation and lack of informal support as barriers to wellbeing. It explores the process of developing a parent-led online community to address these issues and identifies the challenges that could impact on the future success of the project.

The aim of the online community, *Awhi Ngā Mātua*, is to empower parents of disabled children to lead positive change. This is a complex challenge that has used co-design to focus on clear intent, develop a technological solution, and guide visual design and content to create a community where parents find agency and belonging.

Parents of disabled children are more likely to feel isolated and alone as they navigate their way through a complex health and education system, adjust to having a disabled child and manage the additional demands of parenting. There are many channels for parents to receive information and connect, but these lack intent, are driven by provider or contractural needs or are on platforms that make navigation difficult. Parents have unique needs based on their circumstance and the needs of their child. They need support and information that is relevant and timely.

This research explores the potential for an online community to go beyond information provision and conversation threads towards developing parent confidence and ability to cope and the creation of a community that can advocate for social change. It recognises that technology has the power to contribute through tools that allow parents to interact and be part of building their community.

The process of exploring the community approach was unexpectedly influenced by COVID-19 when a Facebook page (*Awhi at Home*) was quickly launched to support parents during lockdown. This became a prototype for *Awhi Ngā Mātua*, a place where I could experiment and develop a network of parents who were able to test ideas and approaches. I describe how this, combined with a review of literature and learnings from other online communities led to the development of a cohesive and value-based strategy for *Awhi Ngā Mātua*.

ACKNOWLEDGEMENTS

MY BACKGROUND AND ROLE

My daughter Jessica has cerebral palsy and is dependent on others for all of her care. Jessie was born in 1984, a time of great change in the disability community. It was common for parents to meet and organise and as a result of this many became activists, calling for inclusion of people with disabilities in schools and communities. I was part of this movement and became a volunteer for IHC, largely in governance roles at a community and national level. The major changes during this time included the closure of institutions such as Templeton Psychopedic Hospital in Christchurch and new legislation, in 1989, that gave all children the right to go to their local school. For parents this was a major change which led them into a wider community. Conversely it also began to erode the parent community which had built around segregated settings such as special schools.

I made a conscious decision to leave the disability sector in order to separate my role as a mother from my career. I continued to work in areas of social change including the prevention of child abuse and neglect, and family violence. I increasingly saw the benefits of including the people most affected by these issues as being part of developing solutions and began to experiment with user-centred design as a way of creating real, sustainable change. I saw my role increasingly not as subject-matter expert, but as a facilitator and implementer.

I left my role in the public service to set up Connect+Co, a small company that focused on using co-design to create social change. In 2018 I was contracted to the *A Good Start in Life* project, a collaborative cross-government action research project sitting under the Disability Strategy and the Office for Disability Issues. This involved interviews with over 70 parents from around the country to explore their lives as mothers and fathers of disabled children. As a result of this work I wanted to find out more about the impacts on parent wellbeing and explore community-based solutions, and sought philanthropic funding to do this. IHC Foundation then funded a series of interviews and workshops in Manawatū and Horowhenua that led to the development of a range of ideas with parents that could address the challenges they face. This project is based on one of the ideas from that group of parents who identified the power of technology as a way to connect parents with each other.

After my years away from the disability sector, I have returned with new skills and experiences. My daughter continues to be a major motivator as I support her care team and provide regular care myself. I am conscious that I am now an older parent and that my parenting experience is very different to

that of younger parents today — I didn't have internet and I had meetings in living rooms. I work hard to withhold judgement — that's what the co-design approach has taught me. The many interviews I have done across Aotearoa to understand the current parent world have added layers of complexity and insight that were missing as I advocated for myself and my daughter, and other people like me, in my earlier activist days.

I feel I have a responsibility, having heard those stories, to create change through the exploration and implementation of the ideas they had. I feel I have permission to do this as I share the challenges of parenting a child who is so often seen as other and as her parent also feel the stigma attached to our world.

These experiences have informed my roles, initially in leading research and co-design projects with parents nationally and in Manawatū and Horowhenua, and then in leading the development of *Awhi at Home*, a Facebook page set up to support parents during the COVID-19 Level Four lockdown. This work has led me to the development of the online community described in this research. My leadership role includes — overseeing the design process, ensuring the voices of parents are to the forefront in all decision-making, overseeing visual communication, user experience and content creation. I also manage the project which includes managing relationships across sectors to build support for the project, managing contracted support, and working with potential funders.

BUILDING UNDERSTANDING

ISOLATION

"I don't see anyone else like me"

Parents-to-be assume they will parent a normal child and plan for that, gathering the equipment they need, organising time off work, organising their finances and sharing their news with family and friends. Findings from my research over the past three years (Connect+Co, 2018) indicate that the diagnosis is often made prior to or around the birth of a child, a time when they are already adjusting to being parents and when they may have an aspirational picture of what their life will be. Suddenly they are faced with a number of unknowns about the extent of their child's disability and how they will cope.

They also have to manage their relationship with their family and social circles, telling them about the diagnosis and attempting to answer questions about the future. They are suddenly perceived not just as the parent of 'Johnny', but the parent of 'Johnny who has Down syndrome'. As clinical psychologist Andrew Solomon in his book *Far From the Tree* describes it "if you have a child with a disability, you are forever the parent of a disabled child; it is one of the primary facts about you, fundamental to the way other people perceive and decipher you" (Solomon, 2012).

Woodgate and Ateah (Woodgate, 2008) use the term "living in a world of our own" to describe the parent experience. They describe parents of disabled children as having a sense of isolation that is linked to four main sources:

- **society's lack of understanding,** where parents "felt their suffering was not recognised by others around them…"

- **missing a way of life,** where parents feel "isolated from a normal way of life"

- **feeling disconnected from family** where parents feel "isolated from those extended family members who seemed to lack an essential understanding of what they were going through and/or failed to be present to provide support and assistance"

- **an unsupportive system** where "the sense of isolation left parents with a diminished sense of hope."

Parent insights

In 2017 I interviewed 19 parents of young disabled children in Manawatū and Horowhenua and found similar issues, with parents expanding on feelings of isolation because of perceived community judgement. This was often particularly difficult if the child had unusual behaviour or physical differences. Physical environments were also a barrier, for example parks with no fencing and noisy shopping centres that upset children who are prone to over stimulation.

Comments from parents included:

> *"For ages I never took her anywhere. I didn't want to be judged"*

> *"I feel I don't belong because I don't see anyone like me"*

> *"I don't have a social life. I haven't been out for years. I've lost all social contact"*

Reading through the interviews, I realised that the key to parent's ability to meet the many challenges they faced was their own wellbeing which was strongly impacted by the quality of informal supportive relationships they had in their lives, not by the quantity of services they received.

Quantity vs quality

Loneliness is increasingly recognised by policy makers who are acknowledging the impact of a lack of informal networks and support on wellbeing. In the paper *Alone Together* published in 2020 by the Helen Clark Foundation loneliness is described as presenting a "significant public policy challenge in Aotearoa New Zealand". The paper describes the mental and physiological health risks of loneliness and the impact on general health and life expectancy (Walker, 2020).

Many parents describe a large number of people in their lives as they navigate a complex health and support system. These relationships with a range of professionals such as specialists, therapists, assessors, coordinators and educators typically focus on the child. They require significant time and energy (physical and emotional) from the parent to manage appointments that often involve organising transport and care of other children. Appointments are in institutional buildings away from parents' communities, they offer little emotional support, personnel frequently change, and the relationships are based on one person being paid to be an expert. Parents enter into this demanding world, which leaves them with little time for informal relationships and increasingly less in common with the people around them.

Quality relationships become difficult to maintain, creating feelings of isolation and disconnection. A paper published by the Ministry of Social Development (MSD) in 2018 explores the difference between a structural definition of social connectedness, which is usually measured by the number of friends and frequency of contact, and the quality of social relationships (Frieling, 2018). The paper refers to MSD's definition of social connectedness as "the relationships people have with others and the benefits these relationships can bring to the individual as well as society." The paper also describes three common components of social connectedness. These are **socialising** —

interactions with others; **social support** — support from people with a social network, including emotional support, practical
support and informational support — and **a sense of belonging.**

An increasingly isolated world

An additional challenge is that parents of disabled children are living in a world where isolation and loneliness is becoming more widespread generally. Explanations for this include the move from collective rural communities to anonymous urbanised ones — the "way we live in the modern, industrial West" (Alberti, 2019). Writer and community activist Peter Block writes that the absence of belonging "is so widespread that we might say we are living in an age of isolation" (Block, 2009). He goes on to say that the "key to creating or transforming community, then, is to see the power in the small but important elements of being with others."

In summary, based on local research and reviewing the literature it is clear that the challenge for this project was to design a way to support parents to develop meaningful informal relationships with the people who share their experience. Through these a community will develop around the components of social connectedness — emotional, practical and informational support and a sense of belonging.

THE OPPORTUNITY

The need for parents of disabled children to have meaningful relationships with people who share their experiences and challenges is clear. The opportunity therefore was to do this in a way that had the most potential to create relationships, build practical support and create a sense of belonging. The idea of a community based on these elements became a clear way forward.

BUILDING COMMUNITY

Block describes community as the context for connection and addressing isolation. "Communities are human systems given form by conversations that build relatedness. The conversations that build relatedness most often occur through associational life, where citizens show up by choice and rarely in the context of system life, where citizens show up out of obligation," (Block, 2009).

Horizontal identity

Who the members of a community are is an important focus. The disability community is made up of disabled people, their parents, their family, their whānau, providers and policy makers. Taking the concept of conversation to build relatedness as described by Block, people need to want to join a conversation and when they do they want to feel they belong. Solomon explores this, saying there is a need for people who have a condition or experience that is "foreign" to "acquire identity from a peer group." He labels this *horizontal identity* (Solomon, 2009). My research, and my own experience, tells me that parents of disabled children have feelings of otherness and a horizontal identity connects them with other parents who share the same experiences and challenges. This is where there is potential for belonging.

The potential to influence

There is an additional power to community that reaches beyond connection — there is the opportunity to build confidence and collective power that can influence change. In reviewing the quality of family life and social connections Edwards, Parameter and O'Brien (Edwards *et al.*, 2018) suggest there is potential for parents to connect and influence the formal support they receive: "…connections that have the potential to be built among families may open up pathways towards positive change, ultimately allowing families to design the supports best suited to their needs and strengths…. Great potential still exists for families to be well-supported, highly effective agents of social change."

Barriers to community building

Although government is increasingly engaging with the impact of isolation on wellbeing, as shown in a Ministry of Social Development paper exploring the value of quality social relationships (Frieling, 2018). However, support for struggling parents in New Zealand is often expert or professionally-driven and funded by the government through contracts where success is measured against short term outcomes. An example is *Incredible Years*, a programme developed in the United States and imported into New Zealand, which requires busy parents to attend for up to 14 weeks. This is easily contracted as it follows a set curriculum and can be measured according to numbers of attendees and reported change between sessions.

While these programmes will be effective for some parents, it is questionable whether they address the fundamental issue of building quality relationships that not only address wellbeing but create communities that can influence policy for the better.

THE POWER OF TECHNOLOGY

Technology presents a number of powerful ways to build community because it enables people to connect based on common interests regardless of where they live. Social media, for example, has given rise to millions of online communities from groups of people with similar health issues and interests through to political organising and community pages. Wellman, Boase and Chen noted 18 years ago that the internet is capable of transforming community as it becomes integrated into daily life. They write that through the internet, connections are made to people not place. A shift which "facilitates the essentials of community separately to each individual: support, sociability, information, social identities and a sense of belonging" (Wellman, 2002). For the disabled community this is particularly powerful as they can move beyond geographical location to connecting through common interests and challenges.

IDENTIFYING THE GAP

There are a plethora of websites and Facebook pages that have been established to support parents of disabled children. These tend to fall into two categories: information-rich sites that push out information and parent-led sites that tend to be Facebook pages organised around a single diagnosis or challenge.

An example of an information-rich approach is the Ministry of Health website (Fig 1) which has information based on current policy. This is at a high level and difficult to navigate by users who have specific needs based on their child's disability, family circumstance and location.

Parent-run Facebook pages are often private and have rich conversation. However, the information shared by parents can promote treatments or views that are controversial and, if not well monitored, do lead to online conflict.

There are very few links to information that is authentic and useful because of the emphasis on conversation and support for the parent-administrators.

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In exploring these pages, I saw the potential to bring the two approaches together to build community through connection and conversation, and to present information in a way that is useful, relevant and timely.

This concept was developed further by in article by Ammari and Schoenebeck (Ammari, 2015) who write about the role of the internet for parents of disabled children seeking information and accessing social support. They note that parents feel less judged online than they do "offline among family and members of their community". They present a concept of networked empowerment which goes further than information provision and conversation. They see the potential of online communities to develop self-confidence and new cognitive models that support complex parenting demands, and the potential to create communities that are able to advocate for social change. The paper creates a powerful link between the findings of Edwards (Edwards *et al.,* 2018) where family connections have the potential to create social change and the place of technology in building community to achieve the same end.

MOVING TOWARDS IMPLEMENTATION

I took the idea of co-designing an online platform, where parents could connect and share ideas, to IHC Programmes. I went to IHC because it has a solid infrastructure and resources that could provide sustainability to the project over time and I was aware that the IHC library was wanting to develop online information and support for parents. IHC made an application for funding from the SKIP initiative in Oranga Tamariki and this was successful. SKIP funds community-driven projects that support parents to bring up their children in positive ways and has a history of funding innovative approaches to this. The project was described in the service description for the funding as 'interactive technology that includes stories, evidence-based information and online peer-to-peer support'.

As fund holder IHC has responsibility for reporting to funders, managing ethical considerations such as ensuring content is evidence-based and consented and overseeing privacy and confidentiality issues with any audience research.

Figure 2
The Design Council double diamond framework which was updated in 2020.
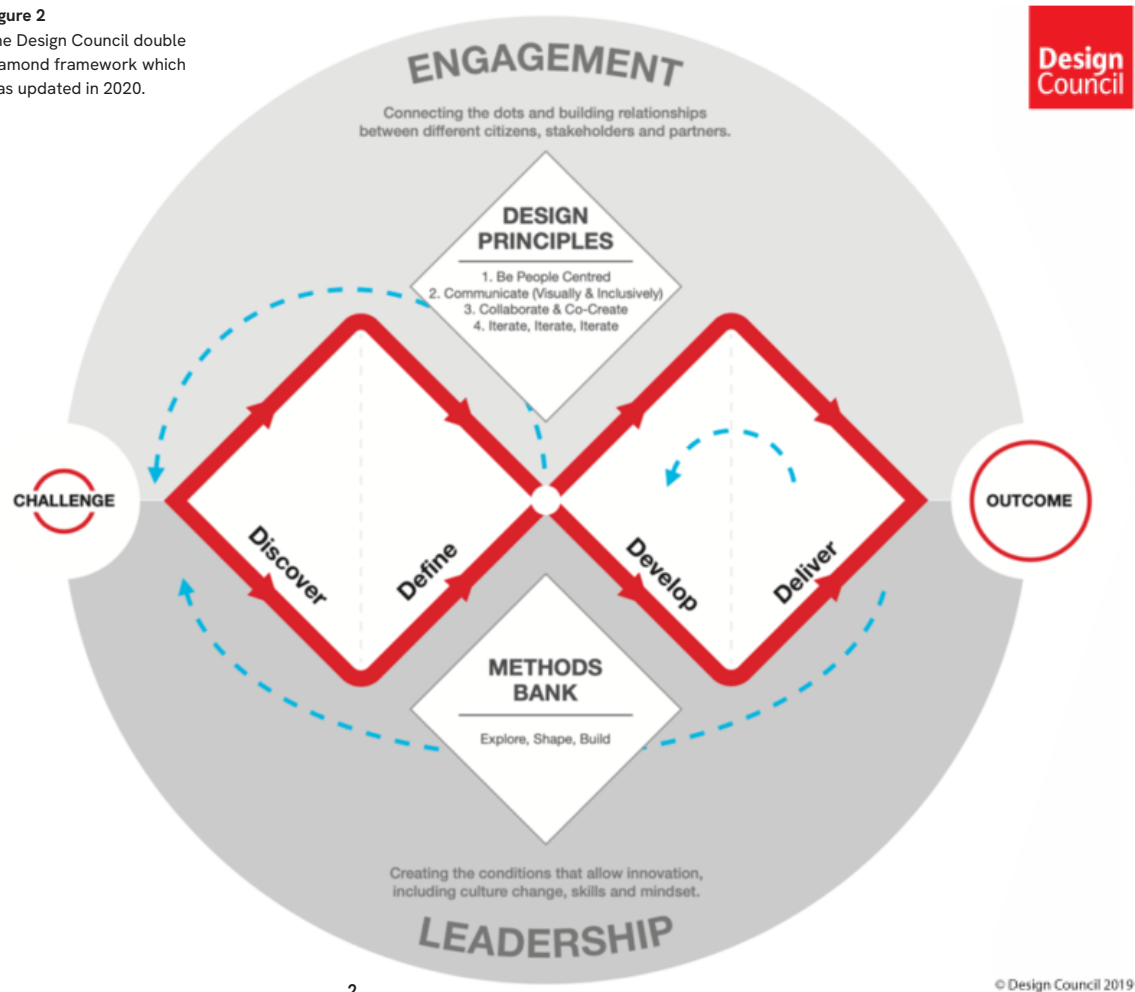
COMMITMENT TO THE TREATY OF WAITANGI

I recognise and respect the significance of Te Tiriti o Waitangi / the Treaty of Waitangi. In this project I have worked to ensure Māori whānau voices are heard and central to the community design approach.

The values of *Awhi Ngā Mātua* include: inclusion - we honour diverse cultures, backgrounds and experiences that parents bring; manaakitanga – generosity and open hearts guide how we respond to best support parents and their whānau; and tino rangatiratanga – we're here to lift parents up and build their agency so they can drive collective change.

CO-DESIGNING —
'WITH' NOT 'FOR'

In this section I explain the use of co-design to guide the development of *Awhi Ngā Mātua*. This begins with my previous research and co-design workshops, the opportunity of COVID-19 to rapidly prototype and the ongoing involvement of parents as the platform is developed.

Co-design is at the heart of this project. The review of other online supports showed little understanding of the complex and busy lives of parents of disabled children and the opportunity to form communities that influence change. My experience in addressing a range of issues has shown me that delivering a product or service to a specific audience benefits from being designed with that audience. Social designer Kelly Ann McKercher describes co-design as "an approach to designing with, not for, people. It involves sharing power, prioritising relationships, using participatory means and building capability. (McKercher, 2020)"

VALUING EXPERIENCE

In her book *Beyond Sticky Notes*, McKercher writes about "elevating the voices and contributions of people with lived experience" to create "transformational design" to produce outputs and social outcomes. An example of this is the themes and insights I gathered from the parents I interviewed in both the *Good Start* project and the Manawatū and Horowhenua projects. These workshops will be discussed in more detail in the following section. These laid bare the experiences of isolation and lack of connection and created the idea of developing community, rather than simply delivering a service or centrally driven information, which is more likely to be based on organisational rather than parent needs.

In describing co-design it is useful to reach for the ubiquitous double diamond (Fig 2), a framework first developed by the UK Design Council in 2004 (Design Council, 2020) that has guided practitioners through a co-design process of discover, define, develop and deliver since that time. This was reviewed and refined in 2019 to capture more of the complexity described above — the blue dotted arrows, design principles and methods bank are all new additions that reflect the non-linear process now recognised in the co-design approach.

Conventionally this approach to co-design happens with people physically — people are interviewed in a discovery process to inform focus, participate in design workshops, and in testing prototypes and ideas. This physical interaction was limited by the impact of COVID-19 when parents were challenged with just getting through the complications of the day and physical gatherings were not possible.

PRELIMINARY WORKSHOPS

The design of Awhi Ngā Matua was motivated and informed by the two workshops described below. These not only informed the project, but highlighted the importance of co-design in developing new approaches and products.

The design process began with parents of disabled children under eight years of age in Horowhenua and Manawatū. After a series of interviews with parents I developed a tool (Fig 3) which organised insights around the child, the parents, whānau, friends, services and community in both areas. This was a visual way of describing the experience of parents in each place and prompting discussion and ideation based on 'yes this is us'.

I asked the parents to form pairs and then chose an insight from the tool that resonated with them. They then went through a process of brainstorming, refining and developing a rough prototype (Figs 4 and 5).

At the Manawatū workshop one of the prototypes was an online platform which was designed as a way to provide information on different services and how the system as a whole worked, connect parents with each other and promote local events. The parents developing this idea noted that information and connection in one place with input from parents would provide a way they could connect meaningfully at a time that suited their complicated lives.

In Horowhenua parents also focused on ideas that would build connection and support, particularly around ways they could manage their children. They saw sharing ideas and experiences as useful and noted that this wasn't happening in their community.

I was beginning to work on developing the idea of an online platform for parents when the COVID-19 lockdowns were announced. I saw that the issues of isolation and the need for information was going to become urgent because of the lockdown and decided to develop a temporary solution. The idea of a comprehensive platform pivoted to a Facebook page, called *Awhi at Home*, that could be set up quickly, accessed easily and managed remotely. It was important to keep to the co-design principles that accompany the double diamond: people centred, communication, collaboration and co-creation and iterate, iterate, iterate.

AWHI AT HOME: USING CO-DESIGN PRINCIPLES

People centred, collaboration, communication

To manage *Awhi at Home*, the Facebook page created during the first COVID-19 lock down, I created a small team that worked remotely. This comprised three parents, who were able to discuss experiences and insights that created a curiosity about how other parents were managing during the lockdown. Contacts were shared, introductions made and a network began to build around the Facebook page we created. This was invaluable not only in developing content but also in increasing survey reach and testing early ideas. At times there was some tension when the experiences or feelings of parents on the team influenced decisions, but these were quickly responded to if an idea didn't engage the audience.

Figure 3
The tool I developed for a
design workshop with parents
in Horowhenua and Manawatū.

COMMUNITY

"Public facilities aren't idea, they don't cater for kids with disabilities"

"School is our respite care"

"We go to church in Palmerston North because no one understands us here"

"If you grew up here you are a bit more connected"

"I try to work but have lots of issues with after school care. My job has to fit into school hours"
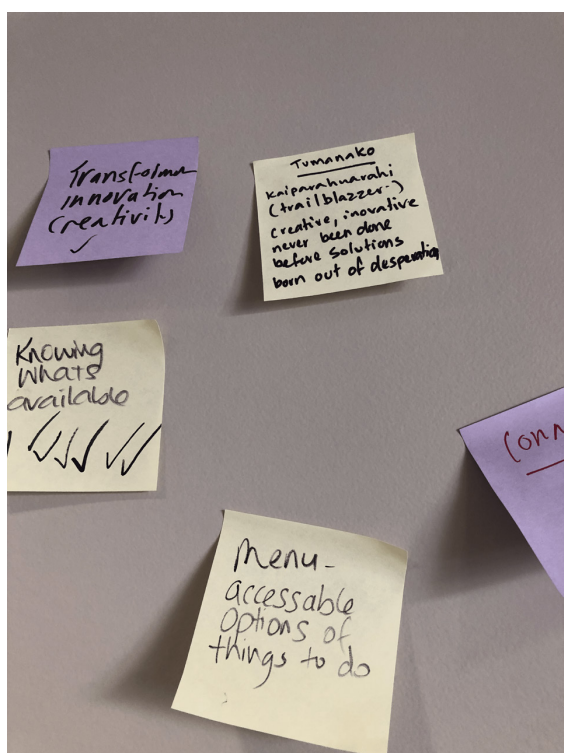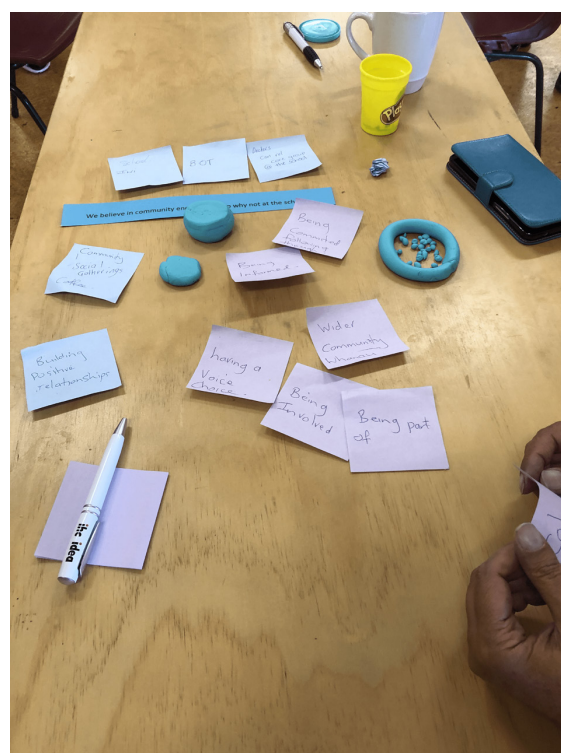
"I feel like I don't belong because I don't see anyone like me"

SERVICES

"You almost feel bad asking for help. You feel almost guilty about it."

"Counselling is an enormous need."

"I don't think parents support each other on a person level outside the school."

"Samoans view disability as a curse, there's denial."

"The support I got was for my son, not for me."

"I ask family and friends but its hard to ask agencies."

"I didn't know the things I could get help with."

"I can't go to the marae because its not my iwi."

"You can't just find someone to look after your kid because there are trust issues"

FRIENDS

"My friends thought I'd gone overseas because of my reclusiveness."

"I have friends and family that help."

"All my friends have kids, they ask me for advice."

"Most of my friends have kids with disabilities."

"Friends were around but not really understanding."

"For ages I never took her anywhere I didn't want to be judged."

"When you talk to someone you form a relationship. Just seeing each other and smiling can make a difference."

WHĀNAU

"It was hard for his sister cos she missed out on a lot of normal childhood stuff"

"I thought I'd get support from my family who work in disability, when I didn't it hurt."

"I don't have a social life, I haven't been out for years, I've lost all social contact."

"Not having family around makes it really challenging"

"I don't turn to family for support I like to cope on my own"

PARENT

"Lack of time together put a big strain on your relationship"

"When my mum got sick I felt very isolated"

"With six kids and 50 things to do in one day, I burnt myself dry"

"As time goes on you get better, you just can't break down"

"My mum has been my strength"

"My husband and I support each other"

CHILD

"I'm so tired but I just keep going"

"I sacrifice a lot to ensure my children get what they need, it brings me joy"

"I live for my kids and everything I do is for my kids"

3

Facebook analytics are a very stark way of seeing if an audience will engage or not. I found my role as leader was to ensure voices were heard, give space for experimentation and ensure the choices made by our audience of parents were acknowledged and followed.

With COVID-19 and the rapid deployment of the *Awhi at Home* Facebook page the principles of the double diamond; discovery, definition, development and delivery, all happened simultaneously. The team learnt from the page (through analytics, private messages and comments), gathered insights from other parent-run pages which were very active during the weeks of the lockdown, monitored other pages and websites to understand information gaps and had one-on-one conversations with parents. Although the actions described in the double diamond model happened, in reality the shapes fell away and instead we were managing a number of threads simultaneously — perhaps best represented by a more organic visual metaphor (Fig 6).

4

5

 The intent to support the wellbeing of parents (the path) remained strong and had forward motion, but it meandered as it collected ideas, tested, went back and tried again, often without a clear line of sight to the next step. The path does eventually open out, providing a clear view of where it goes next.

Although the path looked to be going to unexplored places, it still moved forward and used the necessary elements of co-design and guided reflection. There was an intentional focus on discovery through various interactions with parents, and continual focus on engagement. The design principles outlined in the double diamond were there — but they didn't happen in an organised or linear way.

It was valuable to understand during this time that co-design is often, and should be, messy and chaotic as it reaches into people's lives and gathers messages about experience. McKercher refers to this as "sitting in the fog" as the future reveals itself slowly, gaining clarity over time as ideas are formed and discarded and protoypes tested and iterated.

Iterate, iterate

Small experiments began with the initial focus of gathering activities for parents to do with their children. Lack of engagement with activity suggestions on *Awhi at Home* and others as well as personal contact quickly showed that this was further stressing parents and they struggled to cope with an overwhelming amount of information in this area, and the guilt of not being active with their children for periods of time. This brought the focus to parent wellbeing, an area where there was little information available. It was then envisaged that videoed interviews with experts in areas such as managing behaviour in children and stress in adults would be at the centre of the page.

Many contacts were made with organisations willing to support this, but it quickly became obvious that they were also overwhelmed and it was difficult to find time to support *Awhi at Home*.

This led to experiments with interviewing parents about their experiences, a move that quickly gained a following, and fitted with the original prototypes developed by parents in Palmerston North and Levin. Zoom interviews with parents were recorded and edited — these covered how people were coping with the lockdown, tips and strategies and personal stories.

I describe more about the response to COVID-19 in the following section.

Figure 6
The organic process which had clear intent but was organic as new insights emerged.


6

THE IMPACT
OF COVID-19 —
A CHALLENGE AND
AN OPPORTUNITY

COVID-19 presented me with an unexpected opportunity to build a prototype that accelerated the development of *Awhi Ngā Mātua.*

The World Health Organisation (WHO) describes COVID-19 as an infectious disease caused by the coronavirus, SARS-CoV-2, which is a respiratory pathogen (WHO, 2020). Symptoms are usually mild and most people (about 80 percent) recover without needing hospital treatment. However, people with underlying medical issues including heart and lung problems are at higher risk, and people of any age or condition can die of the virus. Many children with disabilities have the underlying conditions that make them particularly vulnerable.

The first case of COVID-19 was reported in New Zealand on 28 February. As media attention increased and overseas statistics of rapid spread and deaths were reported, uncertainty grew, bringing with it increasing levels of anxiety. Cases in New Zealand began to rise (Fig 7) and the Government began escalating its response. On 25 March Alert Level Four restrictions required people to stay at home and schools were closed. It is important to remember the fear and confusion around this time - it wasn't known whether

Figure 7
A visual representation of the rapid increase of COVID-19 cases.

918 cases
APRIL 11, 2020

NUMBER OF CASES

MARCH · APRIL · MAY · JUNE

TIME SINCE FIRST CASE
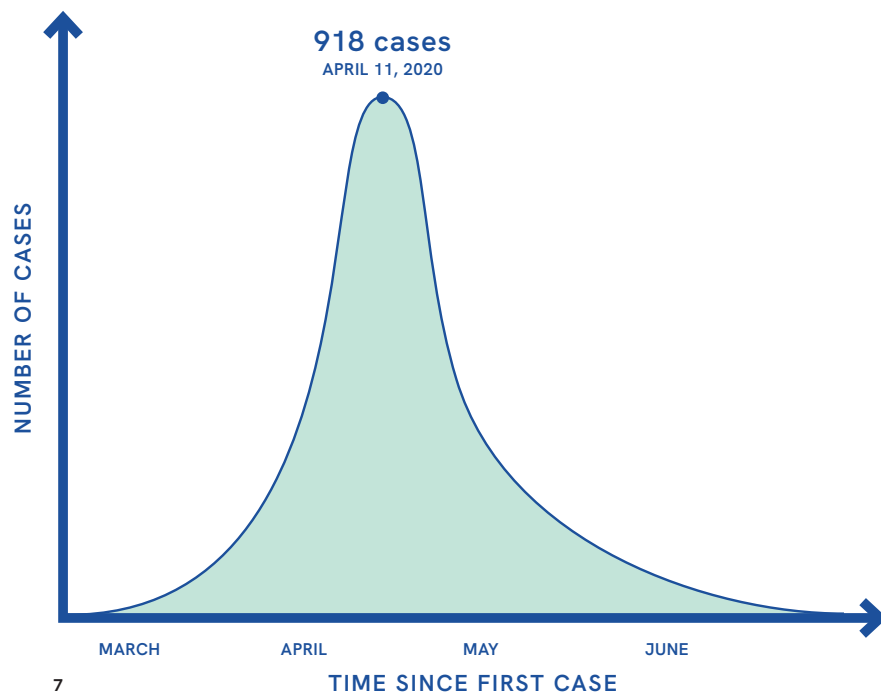
the virus would continue to spread and especially people with disabilities and parents were anxious about the impact of this on their family. Level Four was moved to Level Three on 27 April, and schools remained shut until 18 May, five days after the country moved to Level Two.

During the almost two months of the lockdown parents of disabled children faced a number of challenges. Children experienced sudden change and were not able to understand why — this increased anxiety and impacted on behaviour. Many parents were balancing working from home and caring for their children, but there were no respite or home support services during levels three and four and parents were expected to home school their children. In addition many parents experienced job losses or financial hardship due to decreased working hours.

A survey by Carers New Zealand (Carers New Zealand, 2020) carried out during the lockdown found:

> *"My carers were not keen to help during Levels 4 or 3. I was also not keen for them to come as my child with special needs is vulnerable to COVID-19."*

> *"I am providing more care because my son's difficulties have increased along with his anxieties and OCD routines."*

When the level three and four restrictions were announced I recognised that parents would be struggling to cope with the sudden change in routines and with caring for children with complex needs 24-hours-a-day. I approached IHC Programmes who agreed to change the immediate focus of the online platform to a tool that could be launched quickly to support parents during the lockdown. Oranga Tamariki agreed that the funding provided for the online platform could be used for this. This led to the establishment of the Facebook Page *Awhi at Home*.

THE PROTOTYPE —
AWHI AT HOME
FACEBOOK PAGE

The *Awhi at Home* Facebook page became a prototype, a place where ideas could be tested and iterated. It was also recognised that the page sat alongside a range of other Facebook pages and websites that are relevant to parents of disabled children which could also inform development. These largely fall into one of two groups:

1. Providers of services to parents and disabled children administered by professional staff

2. Support groups led by parents who don't always have access to original material.

Monitoring these gave a range of insights that were relevant to *Awhi at Home* approach, these included::

• Many sites were slow to acknowledge or include information about COVID-19. On 13 April I scanned a range of provider websites of providers and found some organisational messaging about COVID-19 (for example office closures) or no mention of it at all. There was little to reassure or acknowledge parents, instead any information tended to be pushed out and repetitive, rather than responding to the challenges parents were facing.

• The parent-run pages were busy. Most of these were discussion-based and had very little information from official sources such as the Ministry of Health, the Ministry of Education and other providers. Many of these pages support closed groups, but because I am a parent of a disabled child I was given access to the *Parents and Caregivers of Children with Autism* page, with an explanation about my role with *Awhi at Home*. This page has around 6,000 members and was invaluable in signalling challenges parents were facing. Through this page posts about managing behaviour, useful contacts, and parenting tips were developed for *Awhi at Home*, these were often shared back on the parent page.

• This circular process — seeing a post or discussion on the page, developing and posting a response on *Awhi at Home* and sharing it with parent pages became a powerful way of reaching a large number of parents. An example was a discussion on the autism page about severe tantrums. I contacted a provider with expertise in this area and developed a post on *Awhi at Home* with information about an 0800 number where parents could get professional advice and support. The provider didn't have the reach of *Awhi at Home* to publicise this and saw the potential of a partnership, the parent running the autism page didn't

have the contacts to find the relevant information, so *Awhi at Home* played a connecting role.

- This lack of original or parent-led content signalled a gap for *Awhi at Home* to fill. This led to *Awhi at Home* video posts being shared across multiple pages and contributed to the number of post views. These video posts became a powerful tool for communicating the ideas and experiences of parents on the page. I identified people who could contribute, and the film maker then recorded interviews on Zoom. These were then edited for Facebook. I posted these regularly (Figs 8 and 9) and ensured they covered issues such as managing behaviour, dealing with isolation during COVID-19 and family dynamics. There were also interviews with experts about specific issues such as fussy eating and teeth care.

Figure 8
The *Awhi at Home* parent filmmaker introduces a video with a parent talking about goal setting.
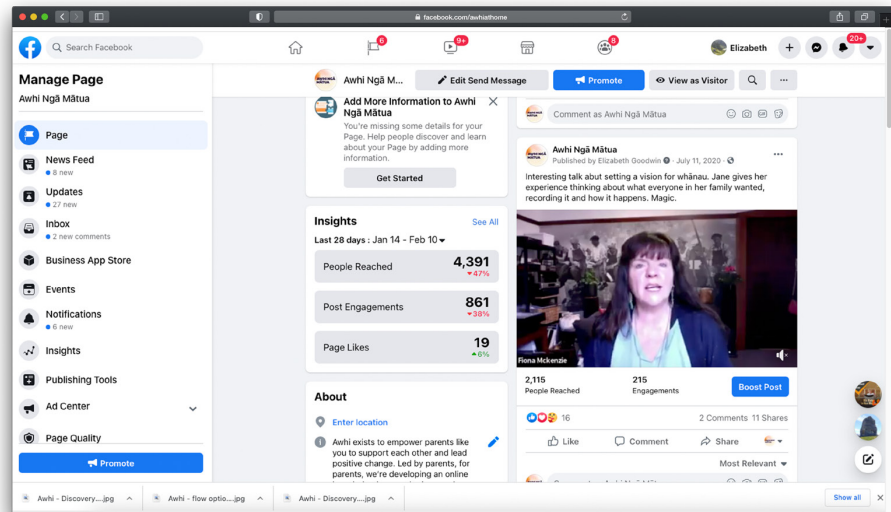
8

Figure 9
A video with the father of a young girl with Williams Syndrome discussing the diagnosis process.
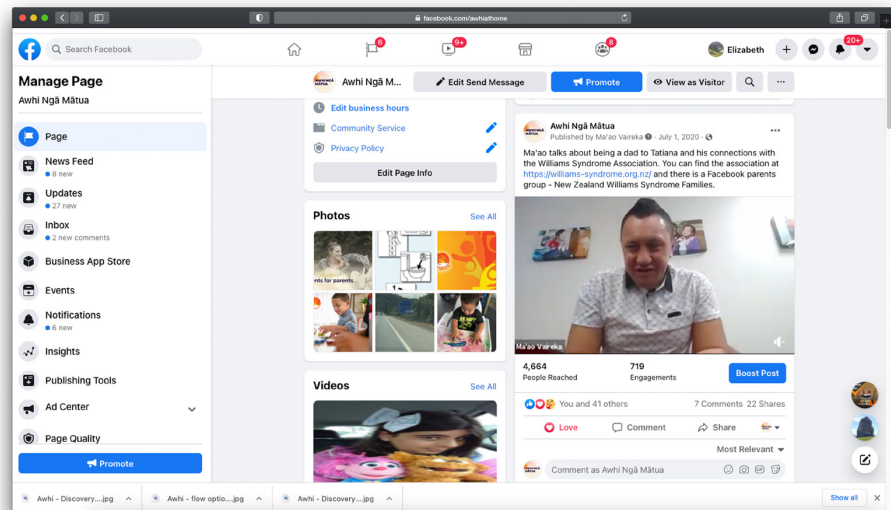
9

- Once providers became organised many concentrated on posting activities on their websites and Facebook pages that parents could do with their children. I noticed in parent comments online that this placed more pressure on parents who were managing their own anxiety and the needs of their children to adjust to change. As parents were expected to lead at home learning this at-home pressure increased as they struggled with their own work commitments, and children who were struggling with confinement, change and little support. *Awhi at Home* decided to focus on parent wellbeing and decided not to create this kind of content.

Figure 10
The Awhi at Home Facebook page launched three days after COVID-19 lockdown was announced.

10

Although *Awhi at Home* received over 200,000 views it became evident that Facebook had limitations. These were further explored with parents after the lockdown through an online survey that tested whether the assumptions made by the team were valid.

MOVING FROM *AWHI AT HOME* TO *AWHI NGĀ MĀTUA*

Once the COVID-19 lock down ended, the team reviewed *Awhi at Home*. This included our own personal reflections, reviewing analytics, discussions about Facebook as a platform and developing priorities for the next step.

Team reflections included:

- Posts disappear overtime — a useful post is only seen as it is posted or if a user scrolls down the page.

- It's difficult to build deeper content — posts have to be short and snappy and we didn't have a way of linking to our own deeper information.

- We wanted to build our audience so decided to remain public rather than create a private page.

- It was difficult to keep discussions going because users are reluctant to share information on a public site. We received private messages that confirmed this.

- It isn't possible to group people or information and people couldn't search for people with similar interests or groups of posts about a particular subject.

- Facebook algorithms decide who sees what.

An online survey with parents that was posted on *Awhi at Home* and the parents of children with autism page collected a number of responses about Facebook. These included:

- Trolls: if administrators don't oversee pages inappropriate posts appear.

- Facebook keeps data on users.

- There is a lack of anonymity, even if a parent posts on a private site other users can find their personal details.

- Concerns about ethics and Facebook. Parents made comments about their personal data being collected and had a general mistrust of Facebook as an organisation.

- The number of people complaining, there are some parent sites that are issue-specific and attract negative posts.

- There is too much judgement.

- You don't know if members are real people.

We found that feedback on the benefits of Facebook were equally useful as we reached the product design stage of the project. For example, parents found Facebook easy to use on a range of devices, accessible at any time, they knew how it worked and could connect with other people like them particularly when it was difficult to connect with people locally.

As part of our review process I developed two journey maps (Figs 11 and 12) based on my earlier research with parents and online conversations with parents following *Awhi At Home*.

NEVILLE AND REBECCA

Rebecca and Neville live in Timaru with their four-year-old daughter Maggie who has been diagnosed with Rhett Syndrome.

"It felt like one day we had this bright little girl and the next we were in a doctors surgery talking about total care and an early death. I'm scared."

WHAT'S HAPPENING	EMOTIONS	NEEDS
Rebecca has a normal pregnancy and birth	😁 Joy	
Visit to GP Maggie starts losing her balance and cries for long periods	😬 Concern	Trusting relationship with doctor
At first GP reassures, but after more visits refers to paediatrician, multiple tests	😟 Frustration Fear	Friends and family to talk to *How might we support Rebecca and Neville as early as possible*
Diagnosis made	😩 Shock Guilt Despair	Information about condition, and what is going to happen
Maggie continues to regress — wakes at night, loses ability to walk and sit	😞 Anger Exhaustion Frustration	Other people's stories without having to tell their own until they're ready
Parents find Rhett Syndrome online but don't join	😔 Isolation Fear of finding out the future	Connections with people like them — more watching than contributing
Rebecca goes to work and Maggie continues at day care	😅 Relief Guilt	Invitation to talk with other people like them in safe private space *How might we encourage Rebecca and Neville to join the community*
Planning for school starts	😟 Overwhelmed Scared	A place to go where they can learn about the system

11

MERI AND MOSES

Meri is a single mum with four children. Her second child, Moses, has autism and an intellectual disability. He is 12.

"I don't trust anyone else to look after Moses, but I really need a break. There's no one I can ask for help and I'm too exhausted."

WHAT'S HAPPENING	EMOTIONS	NEEDS
Moses was diagnosed when he was four	😧 Bewildered	Emotional support at diagnosis
Meri was referred to the local NASC. Moses had an assessment and offered respite hours	😟 Relief Alone	Practical help *How might Meri trust practical support*
Meri's partner left when her youngest child was 2	😌 Guilt Pride	Friends and family to talk to
The children help out where they can but Moses is getting big and its hard	😩 Exhaustion Fear of future	Offers of support *How might Meri find connections that understand her world and offer help*
Moses goes to school, where he has a teacher aide, but his behaviour is getting challenging as he enters puberty	😬 Resignation	Other people who understand *How might Meri find a community nearby*
Meri has had some support from Explore about Moses' behaviour. It was helpful but his needs are changing	😟 Worry Tired	An easy way to connect
Moses will go to intermediate next year. Change is hard	😫 Overwhelmed Helpless Alone	A place where she can talk about her fears *How might Meri find support within her own cultural world*
Meri has to move house as her landlord wants to sell her house		Someone who is alongside

Figure 11 and 12
(page 30 and 31)
The journey maps which
helped to keep the
experiences of parents alive
during travel restrictions.

These journey maps were based on common insights and show the strong emotions parents deal with as they navigate their way through difficult times. Issues of trust and connection are surfaced, as are practical ways the parents could be supported through connection and community.

At a time when it wasn't possible to include parents in the review process because of travel restrictions, these journey maps kept the experience and voices of parents at the centre of the design workshop, which was attended by the three parents involved in the page.

The outputs from this review process included a rough welcome page and a draft mission statement (Fig 13), for what would become *Awhi Ngā Mātua.*

Figure 13
Early ideas for developing
a way to tailor information
to need.

13

Figure 13 shows the idea of users going through a filtering process when they arrive on the site. This would allow for them to register for the community and fill out some basic information that would inform what they see on their screen once they enter the community.

The mission statement encapsulates the idea that the community is parent-led and is supported to become a driver of social change. The idea of the community forming a collective of parents, who then lead and develop the community grew out a reflection on the role of parents developing the Facebook page. We recognised that the experiences of parents are unique and a community has to be built by those who understand the power of horizontal connection. Over time, as the collective forms Awhi Ngā Matua, there is potential for co-design to develop in new ways through the deep connection of the community.

MOVING INTO DEVELOPMENT

After this review process I researched possible partners who shared our co-design, social change approach. Through the Being Sober site, which I reviewed as part of this project, I contacted Bamboo Creative, a team of developers and digital architects.

The challenge for this process was for a group of practitioners to build an understanding of parenting and disability — both areas where people can have preconceived constructs. My role has been to lead the design approach; communicate the world of parents of disabled children; to ensure they remain engaged in the development process,and to have their experiences and voices heard at each stage of development. An important part of this was not rushing the process, allowing time for parents to be involved, for discussions to take place and for each person involved to have time to understand more about the world they'd stepped into.

Part of this process was to spend time working through the complexity a parent has to manage around the diagnosis of their child. A brainstorming session led to the development of Fig 14 which shows the issues parents are dealing with (in purple), possible milestones (green) and their emotions (blue and orange). This illustrates the breadth of support and information an online community has to manage.

Figure 14
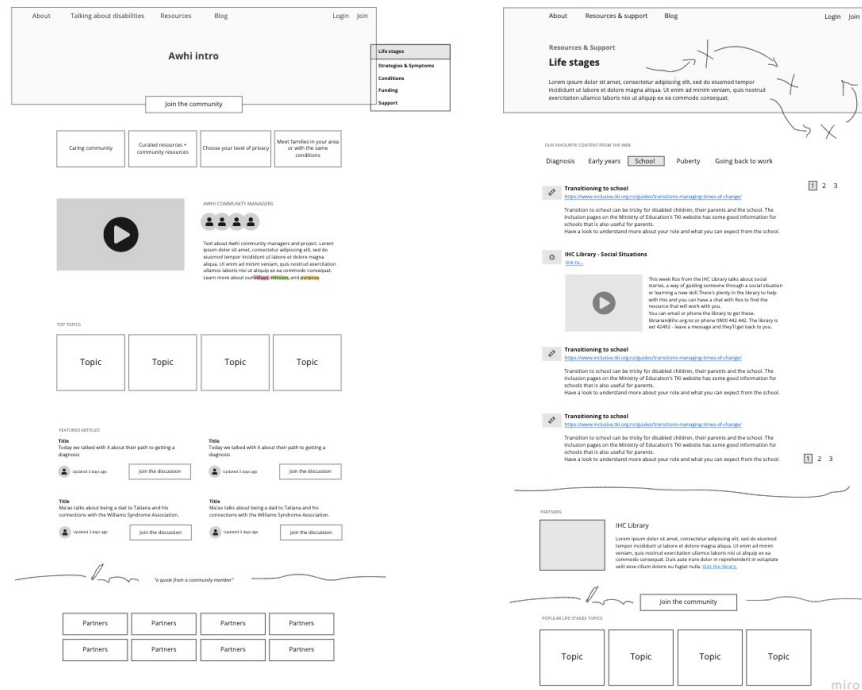An iteration of the journey maps showing the complexity of information needs.
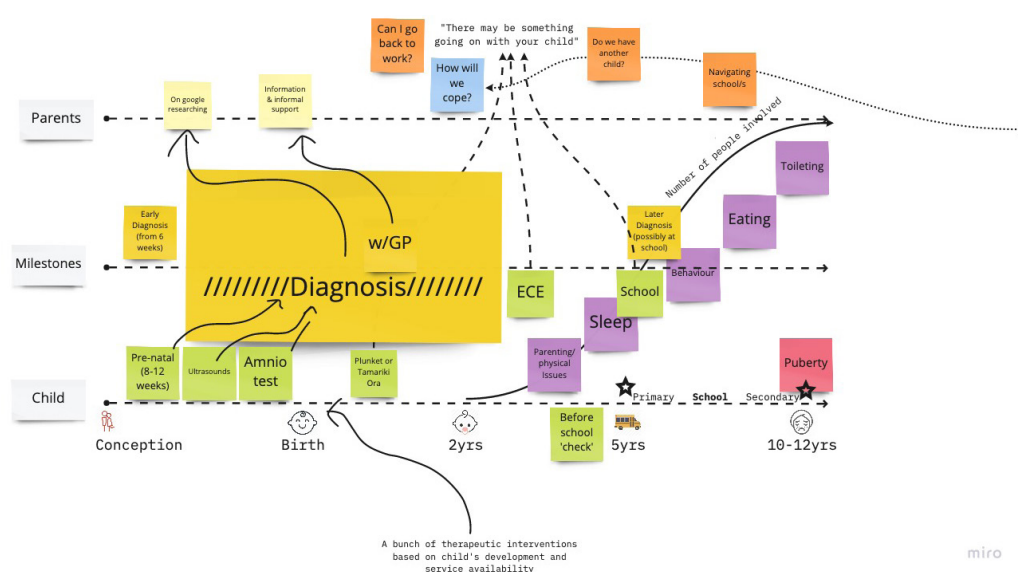
Journey maps continued to be developed as the focus moved from the experience of parents to the particular issues they were facing. The combination of practical information and connection through community continued to emerge.

Early wire frames (Fig 15) were developed to reflect this. These show a combination of media, the ability of parents to choose the information they want to see and ways discussions can evolve around topics.

Figure 15
Early workflows looking
at how to give parents
the information they need.

15

Online testing with parents who had been involved in videos on *Awhi at Home* was carried by Bamboo, the web developer, using Figma (Fig 16), a browser-based application that is used to test user experience based on basic prototypes. Testing was done through Zoom and parents were asked to navigate their way through a number of screens. The key finding of this was the need to keep everything as simple and easy to use as possible.

Figure 16
Mockup used to test
usability with parents.
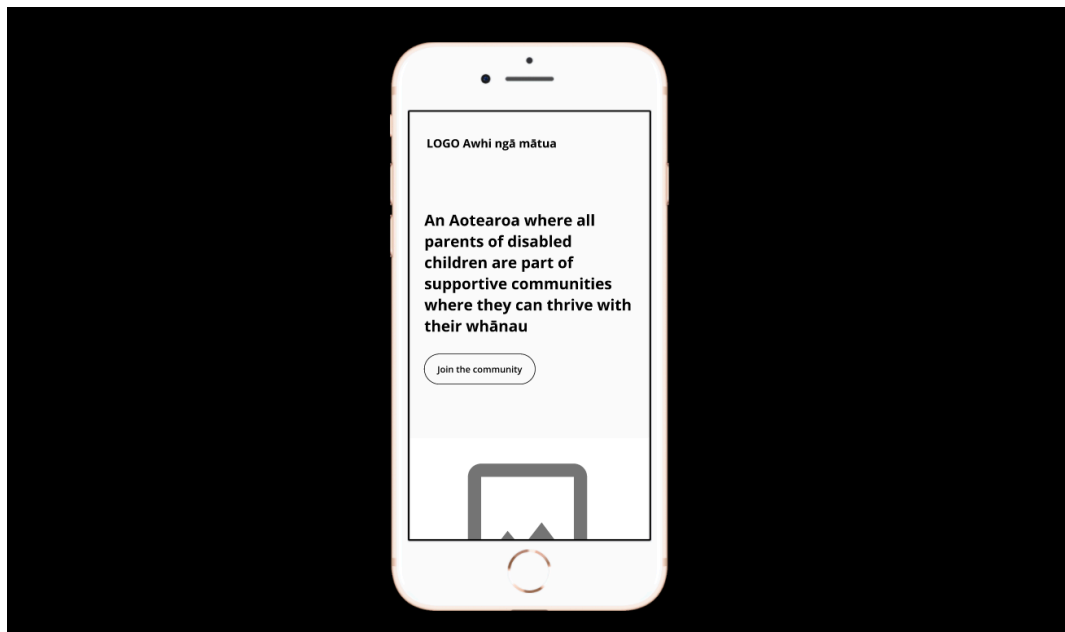
16

EXEMPLARS —
LEARNING FROM
OTHERS

Exploring online possibilities was an important part of the process. Each person in the team bought a different perspective, but the range of technology solutions can be very narrow due to limited joint experience, or very broad once the myriad of online tools is explored. I found the use of exemplars to be important to the design process. They helped us to look at different models and tools and to understand more about how an audience might respond. The knowledge that parents can feel judged and alone, that some want more privacy than others and that finding information that is right for them at the right time provided a lens for exploring other online communities.

I reviewed a number of websites and social media pages, thinking about the communities based on horizontal connection with users who might be in a position where they felt isolation caused by otherness, shame and guilt or lack of social support. I identified three which provided the most useful contextual guidance:

- *Fetlife*, a community site for people with an interest in fetishism and/or eroticism

- *Autism New Zealand (Parents and Caregivers)*, a Facebook page for parents and caregivers of children with autism

- *Living Sober*, a website that supports people to stop drinking.

These three were viewed because there was an element of users possibly feeling judgement or shame and placing a high value on privacy, comfort and safety. All three were private and required registration. The lessons from each of these are shared below.

FETLIFE: Safety, anonymity, understanding

Fetlife (Fig 17) is a free social networking site that connects people interested in being part of a global fetish/erotic sexual community. There are over three million members and the site continues to grow. It is described as a caring and community-led space where all users can "feel comfortable with who they are sexually." This site was identified as useful to this project because users want to be somewhere private and safe with other people who share and understand the choices they make.

Joining this community involves signing and giving information about age, interests and location. This information is then used to create a personal landing page where the user is welcomed and given information based on the

Figure 17
The *Fetlife* community
landing page

information they have given, for example to groups discussing relevant topics, events and meetings in their area, and links to people with similar interests. This gives a feeling of being in a safe place where people care about each other and won't judge, an issue commonly identified by parents of disabled children.
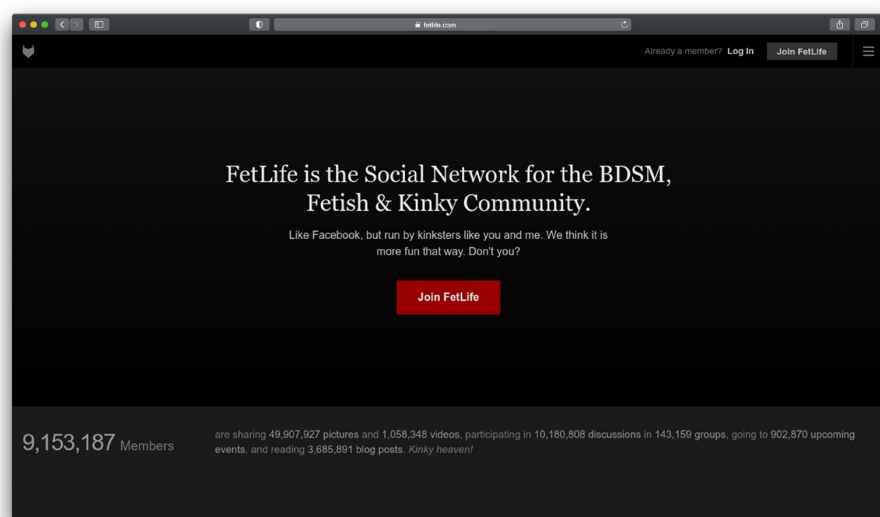
17

Anonymity is a key feature of this group. Members use an alias and can spend time looking around the community building confidence before they take part in any community conversation. There are clear rules about how to use the site, treat other people and provide content. Members can also set up their own groups and there is clear information about how to do this.

FACEBOOK PAGE FOR PARENTS AND CAREGIVERS OF CHILDREN WITH AUTISM: Connection, parent-led, active conversations

This page (Fig 18) was established in 2008 by a parent of a child with autism. It is a private page and users are required to fill in a form that is approved for entry. Users are required to be based in New Zealand. The page now has 6,200 users and focuses on discussing issues and seeking advice. People frequently post photos of their children and do share very private information. There are four parent admins running the page.

It has taken over 10 years to build this community. Although there are a large number of followers many are not active, many people watch and read posts but do not post themselves. A survey on the page found that concerns about Facebook privacy is one reason for this, another is parents' wish to be anonymous. Posting on the page does mean users are able to click on names to find more about a person, particularly if they haven't maintained security functions.

One of the challenges for the page is the large number of people who are working with children with autism, but are not parents. While users such as
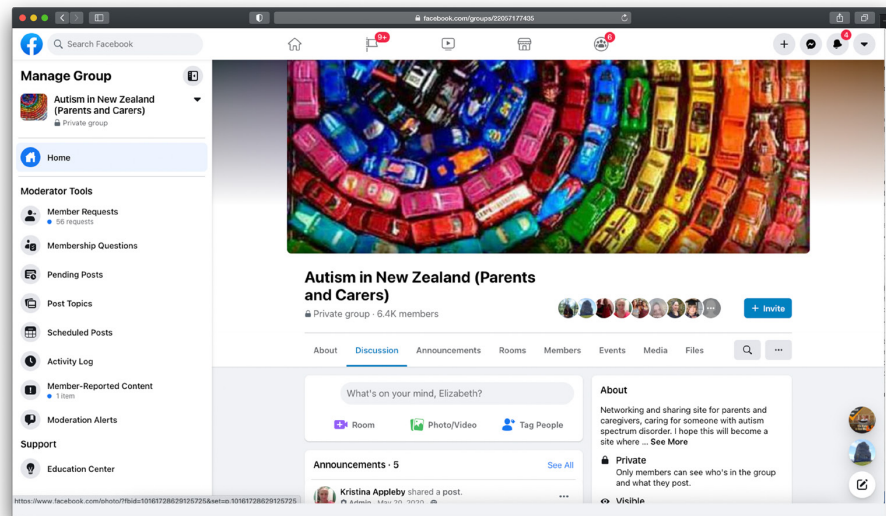
teachers and therapists can learn much from the discussions, it does mean they are privy to conversations that could compromise parents. For example, discussions are often about experiences with a particular school or service — if a teacher or practitioner reads this post it could lead to difficulties for the parent.

The administrators approve users and contribute to discussions, but there is very little linking to verified information. This has the risk of mixed messages around a specific issue as parents offer their different opinions or experiences. If there is a useful discussion this is lost as the feed moves on — no tags are used and the page isn't searchable.

The page does show that there is an appetite for connection and discussion.

LIVING SOBER: Welcoming, open with information, private community

Living Sober (Fig 19) was developed by Lotta Dann after she began anonymously blogging about becoming sober in 2011. The website was launched in 2014 when Ms Dann realised the "incredible power of online support for people quitting drinking" (Dann, 2020). The site has two sections — one open to all users and another an online community that requires sign up. The community is a welcoming and warm place, where new members are welcomed and encouraged. Users include people who are just starting their journey and others who have been sober for many years and share their tips and stories to encourage others. The community is not searchable and is based on only one group — users can't choose to join a group around a specific experience or challenge. This works well for this audience, who seek reassurance and support, but for an audience with a multitude of specific needs this is too broad. The site is curated by Ms Dann and community champions.

Figure 19
Living Sober landing page
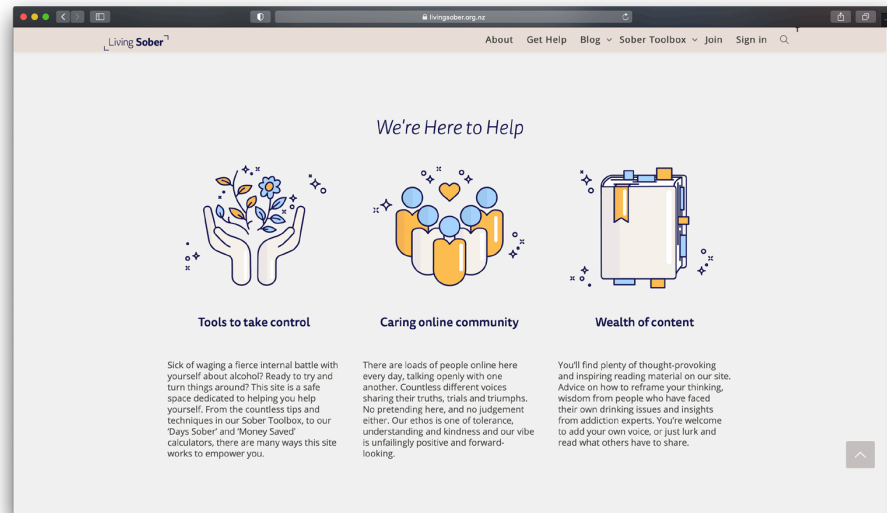
19

KEY INSIGHTS

The three exemplars provided useful guidance for me to feed into the development of *Awhi Ngā Mātua*. I was able to share them with the team and talk through the different strengths. Having visual examples was effective at prompting engagement and discussion.

Key insights were:

- **A sign-on process** asks people to verify that they are the target audience and can give them the opportunity to signal the areas they are interested in. This helps to tailor information for each user and prevent the information overload so many parents experience online.

- **Warm and welcoming branding** and messaging gives a feeling of safety and confidence.

- It is possible to meet the needs of a general audience through an **open website**, combined with a **private community** that is only available to particular users.

- **It takes time** to build a community.

- **Users create content and connection**.

- **Holding the community lightly**, while keeping it safe and prompting curiosity and discussion is key to building confidence and engagement.

AWHI NGĀ MĀTUA

THE NAME

The name *Awhi at Home* was chosen for the Facebook page because of the power of the word *awhi* to describe what we set out to do — to support parents in a positive and warm way, to hug them. Awhi set the tone for the whole project and when thinking about the name for the online community and knowledge base we wanted to keep this. We reached out to Māori parents and leaders in the disability community and developed *Awhi Ngā Mātua* — embracing parents. This reflects the continuance of warmth and support and our focus on parents.

THE FOUNDATION

Through my research I identified four core themes that form the foundation for the approach for the development of *Awhi Ngā Mātua*:

- The experiences of parents. The interviews I did for the Good Start in Life and co-design projects in Manawatū and Horowhenua found that **parents experienced isolation and talked of a lack of a connection with "other people like me." The solutions created by parents included online connection and learning.**

- A review of literature reinforced the experiences of parents, and the role that technology could play in creating connection. The paper by Ammari, based on work with parents stretched these ideas, giving **the concept of networked empowerment and the important three pillars of: interactional, intrapersonal and behavioural components that develop self-confidence, new cognitive models and self-advocacy** (Ammari, 2015).

- Learning from online communities, the *Awhi at Home* Facebook page and a parent survey found **privacy, safety and a welcoming and warm tone** were key to engagement with audiences who experienced feelings of otherness.

- **Information that is relevant, timely and easy to find.** The ability to search, to choose issues and groups to be involved in and to have practical information that is relevant and accessible is key.

Isolation and lack of connection with people like me

Awhi Ngā Matua is focussing on nurturing wellbeing through social connection (there are people like me who can help, they are interested in me),

practical information (I know how to do this) and community (together we can create change). This is being achieved through the development of two distinct parts to *Awhi Ngā Mātua* — a knowledge base which is publicly accessible, and a private community only accessible to parents of children with disabilities.

Parents are continuing to lead and implement this project, with support from people with specific skills. There is an ongoing cycle of testing ideas and online tools and flows with parents. As the community develops parents will be able to contribute in a range of ways (curation, contribution, governance, ongoing feedback) and over time create a social movement that gives the community its own unique voice.

Awhi Ngā Mātua is being built over time. This is allowing for ongoing review of what is working and continual iteration. Different tools will be phased in, beginning with a launch, or sign up page. The community won't be publicly launched until it is thoroughly tested with parents.

The timeline for the phased approach:

ONLINE PROMOTION THROUGH SOCIAL MEDIA, ONLINE WANANGA, WORKING WITH PARTNERS

January 2021
Launch sign-up page
and Facebook rebrand

February — March 2021
Build public facing knowledge
base (articles, links, videos)

April 2021
Launch online community

Networked empowerment: Self-confidence and self-advocacy

Awhi Ngā Mātua is designed to welcome the most struggling parents, offering privacy, groups based on culture or language and the ability to develop online relationships with others with similar challenges.

Parents will be able to join groups according to the disability of their child, their age and stage, particular challenges, where they live or life events. The community will also have a tagging system which will enable parents to search particular key words. This will lead them to group discussions, information, blogs videos etc that are relevant to their needs.

Privacy, safety and a warm welcoming tone

The community will be secure and private and communicate this clearly to users. This includes giving users the option to be anonymous or develop a user name. Issues of privacy will be included in guidelines for use. The community can only be accessed by parents who will register to gain ongoing entry.

Key content will be written by parents who are open about their own experiences and able to write in an inclusive way. This approach means parents from diverse backgrounds will have a leading voice.

The process of developing a visual identity for *Awhi Ngā Mātua* was important. This was based on key brand values that included welcoming, inclusive, nurturing, knowledgeable, positive and curious. Safety was added to this after the parent survey feedback.
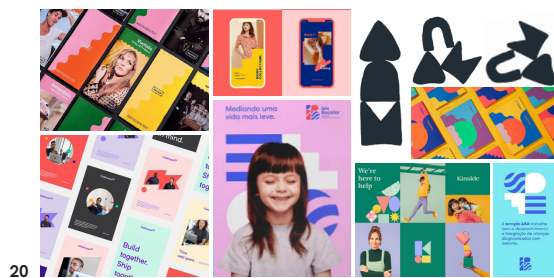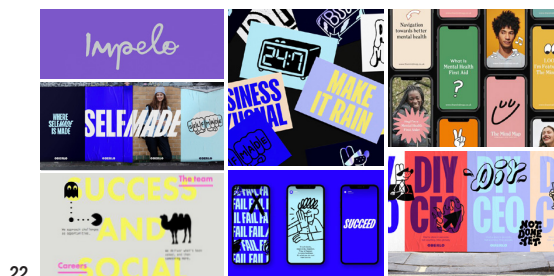
20

Welcoming	■■■■■■■□□	Upbeat	■■■■■■■■□
Inclusive	■■■■■□□□□	Curious	■■■■■■■□□
Nurturing	■■■□□□□□□	Safe	■■■□□□□□□
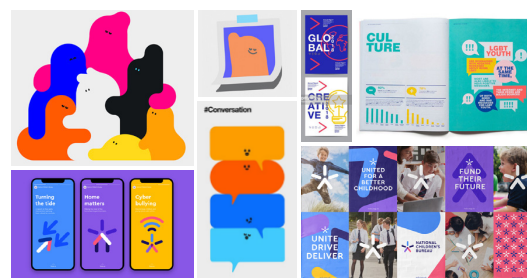
21

Welcoming	■■■■■■■■□	Upbeat	■■■■■■■□□
Inclusive	■■■■■■□□□	Curious	■■■■■■■□□
Nurturing	■■■■■□□□□	Safe	■■□□□□□□□

22

Welcoming	■■□□□□□□□	Upbeat	■■□□□□□□□
Inclusive	■■□□□□□□□	Curious	■■□□□□□□□
Nurturing	■■□□□□□□□	Safe	■■■□□□□□□
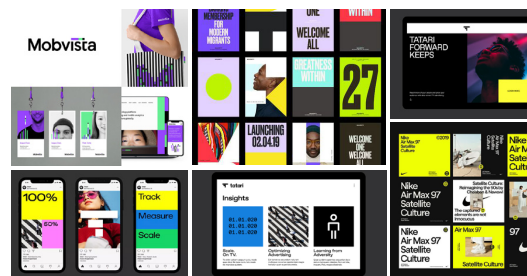
23

Welcoming	■■□□□□□□□	Upbeat	■■■■□□□□□
Inclusive	■■□□□□□□□	Curious	■■■■□□□□□
Nurturing	■■■□□□□□□	Safe	■■■■■□□□□

24

Welcoming	■■■■■■■■□	Upbeat	■■■■■■□□□
Inclusive	■■■■■■□□□	Curious	■■■■■■□□□
Nurturing	■■■■■■■□□	Safe	■■■■■■■■■
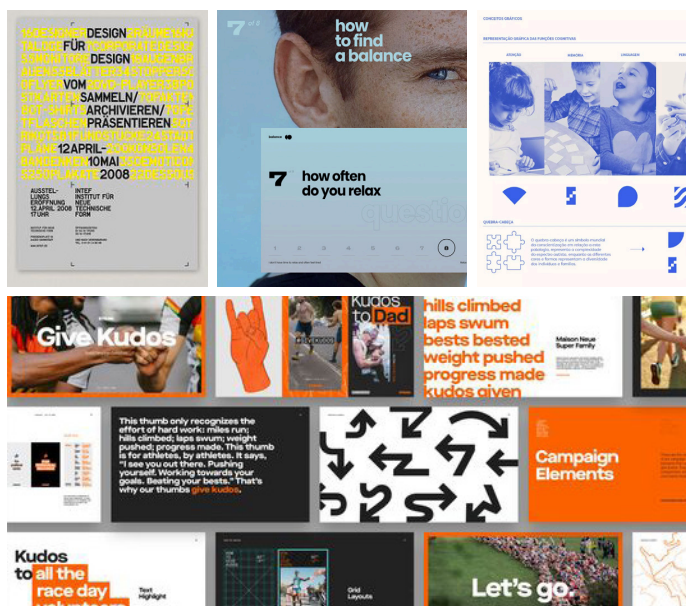
A series of mood boards (Figs 20-24) we developed and critiqued:

The mood board (Fig 24) most closely aligned with the values was then worked on, with emphasis on the warm colours and inclusive content.

Fig 25 shows the application of branding to the sign-up page. This was later iterated to include more active shapes.

Information that is easy to find

Parents will be able to find and learn about the community through social media but the community will be on a standalone platform comprising a number of tools that provide information in a variety of media (video, links, blogs, group wānanga/conversations), support an active private community, and send tailored information and notifications on topics selection by users.

The online community is initially working to engage with parents of children under 12. The initial research that has informed the project was with parents of children in this age group and made clear that the time from diagnosis, major developmental milestones and transitions to early childhood education, school and puberty were particularly challenging. The earlier a parent can have support the more impactful it is likely to be as they develop the skills and confidence to parent.

Parents will be able to join groups according to the disability of their child, their age and stage, particular challenges, where they live or life events. The community will also have a tagging system which will enable parents to search particular key words. This will lead them to group discussions, information, blogs videos etc that are relevant to their needs.

The structure of the knowledge base and the community is currently under development.

25

Figure 25
The first application of visual
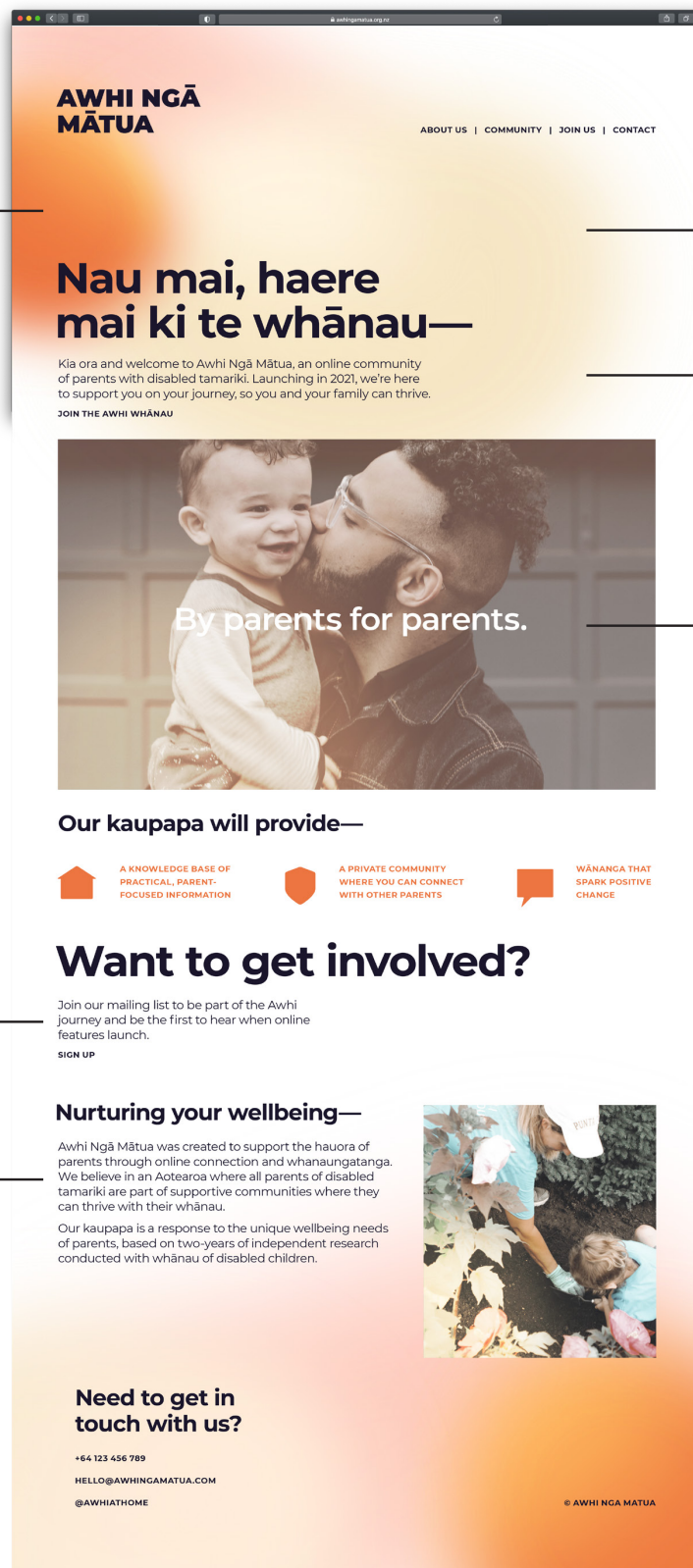identity to the sign-up page

Upbeat

Safe

Welcoming

Inclusive

Curious

Nurturing

THE TECHNOLOGY —
A STACK OF TOOLS

A model of the stack of tools is shown below in figure 26. This shows the complexity of creating a platform that has: private areas; is searchable, responsive and engaging; as well as a public area/knowledge base.

Along the top row are the tools that will engage with the audience. This includes the Discourse community tool, a blogging tool which will provide a way to write articles and provide video and links to information. The website platform which will house the landing page and knowledge base which will be available to the public. There is also a group mail function that will send out updates and notifications to community members, letting them know when there is new information that might interest them. Social media will be used to promote the community and its content.

Internally used tools cover project and information management. A database will manage content, social media content management and design tools. Reporting and security under pin everything.

Figure 26
A model of the stack of online tools being used to build the community and knowledge base


26
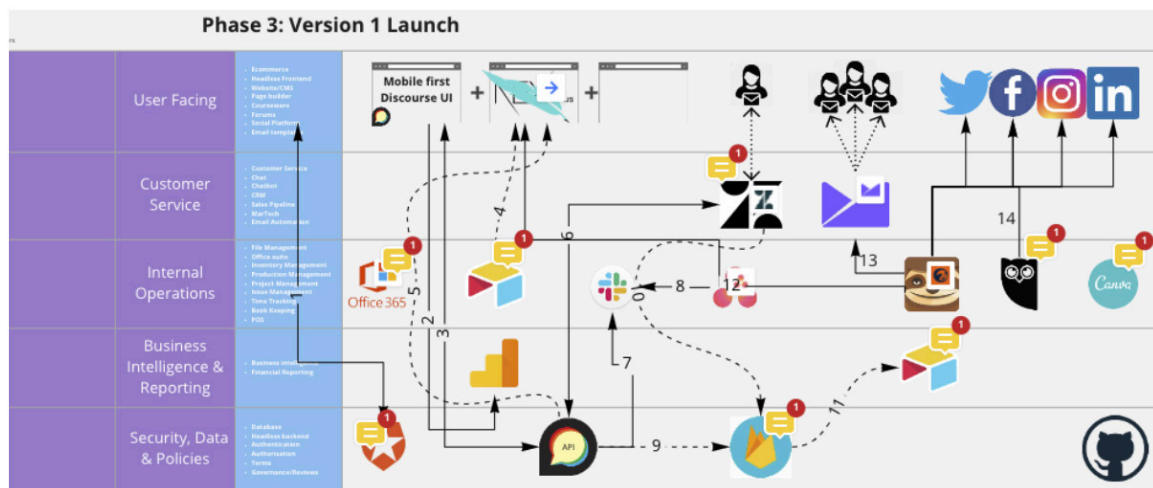
PROGRESS

As described above, the technical tools required for the project have been identified and we are currently in the process of ensuring these all work together.

A website page introducing *Awhi Ngā Mātua* and inviting parents to become part of the community and get involved has been launched. The *Awhi at Home* Facebook page has also been rebranded (Fig 28).

27
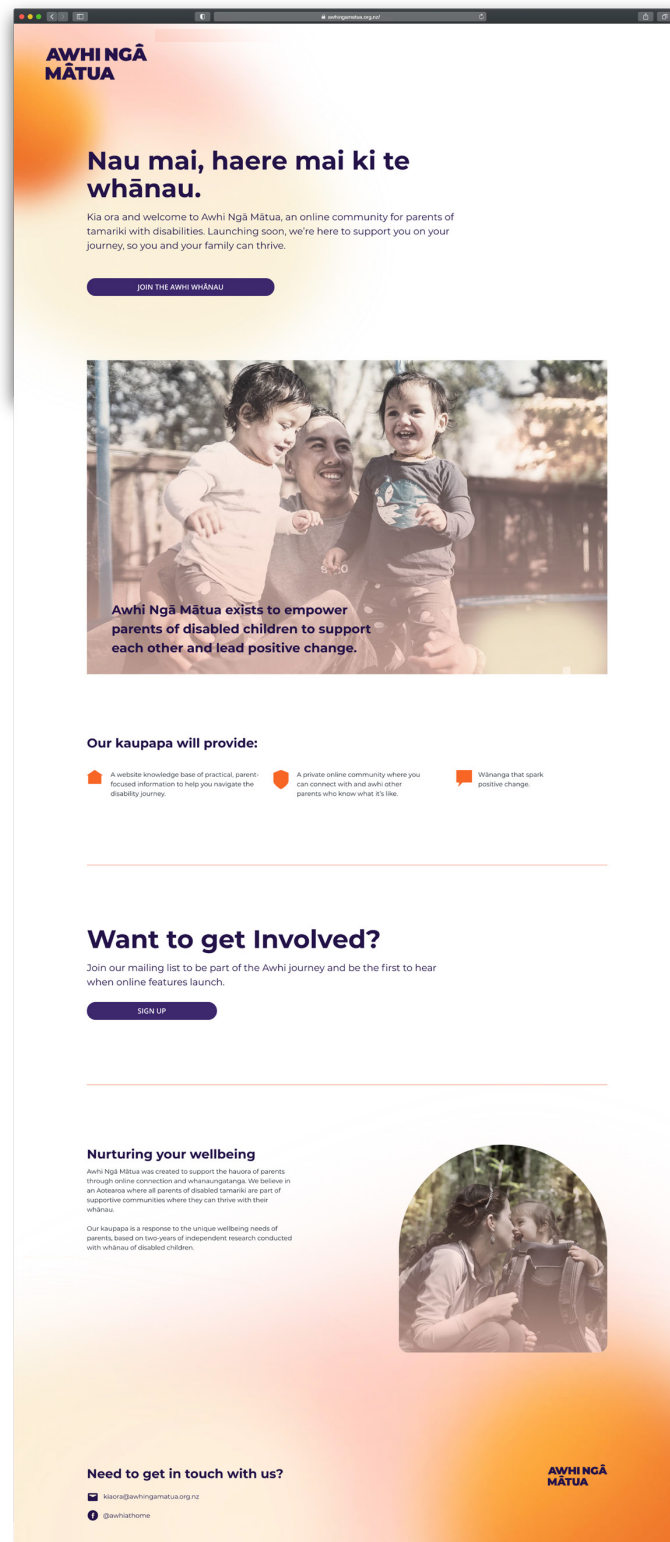
Figure 28
The rebranded Facebook page
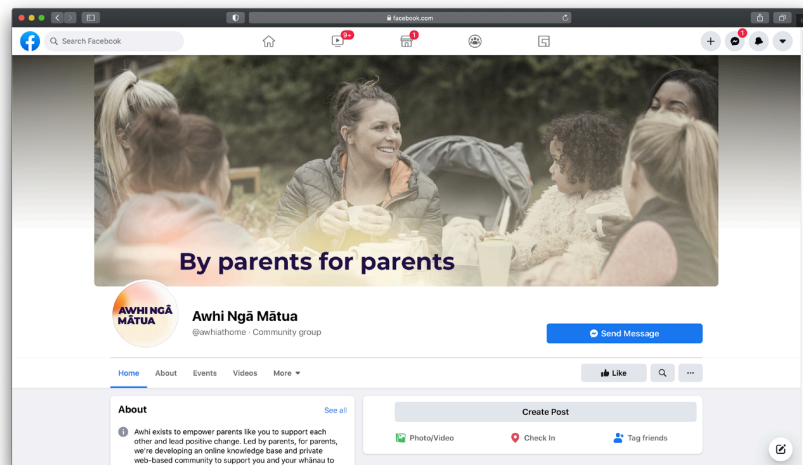
28

The next step is to develop the knowledge base, which will be accessed through the landing page. This will be open to the public and contain general information and links on disability. It will promote the community and its content and invite parents of young children to sign in.

The online community will be launched in late March 2021. This is the most complicated area of the project as it works to ensure parents can select the information areas they are interested in and receive updates and notification as new content is developed. Content will initially be developed as blog posts by the Awhi team and parents invited to comment and discuss. Over time it is anticipated that parent champions will become identifiable and invited to be regular contributors. This will be an organic process, with the community leading decision making — much like the process used to develop the *Awhi at Home* Facebook page.

FUTURE CHALLENGES
AND RISKS

There are a number of challenges that could affect the impact of *Awhi Ngā Mātua* that are being addressed. These include: engaging the audience, collaboration and sustainability over the long term.

ENGAGING THE AUDIENCE

Although considerable research and testing with parents has gone into the development of the knowledge base and community, there are unknowns that could impact on engagement with the audience. Parents are very active on Facebook and *Awhi Ngā Mātua* is asking them to move to a platform that they are not familiar with and to register before they are able to engage. Parents might have issues with Facebook privacy and security, as identified in the survey, but it is questionable whether they are willing to move from such an easily accessed tool to a new one.

One way to mitigate this is to avoid the trap of setting user number goals too high and to build the community over time. The user experience and value of the content to the audience will be crucial and will be closely monitored. A communication plan has been developed and includes marketing and promotional activities such as online wananga for parents about key life events.

The three exemplars described in this paper also contributed much to the approach taken to attract and engage parents. Understanding that it is possible to create a welcoming, safe and private place for people to join and contribute was important to the development of the technical approach and to the branding and communications. Paying attention to how people feel when they arrive at the welcome page or into the community is vital to this audience. They don't just want information — they already have that — they want to belong.

COLLABORATION

The disability sector is a complex place. There are many providers who are contracted by the government to provide services, they compete for these contracts and that environment of competition does make collaboration difficult. *Awhi Ngā Mātua* is not owned by a provider and is not funded through the conventional disability contracting process. It is hoped that overtime the many organisations involved in supporting parents will see that they are able to contribute to the network of support that will be part of the Awhi community. This could be a simple link to the website of a group supporting parents of a child with a rare condition, it could be publicising local parent groups and it could be promoting a new product or service. It is

hoped that as the sector sees the potential of the knowledge base and community they will join in supporting the wellbeing of parents.

My ongoing role will be to work with partners to see the benefit of collaboration to achieving this.

SUSTAINABILITY OVER THE LONG TERM

This project began with funding from Oranga Tamariki through the SKIP initiative which aims to support parents to raise their children to be happy, resilient and confident adults. No ongoing funding is assured, but as the project has progressed it has been able to attract further resources from the IHC Foundation. IHC Programmes also has a fundraising campaign which includes applying for ongoing philanthropic funding, and is providing ongoing support through the library. The financial cost of the community over time is difficult to quantify as it is not known how much content users will generate and how much curation and content will have to be provided by staff.

IHC Programmes is the fundhold for the Oranga Tamaki SKIP initiative grant, but is prepared to limit its involvement. It sees its role as supporting me lead a small team of parents who are working on developing the Awhi community, and it is prepared to provide ongoing support. This is a unique position to be in. So many projects are funded by the government to tight timelines and specifications that don't give time for discovery and development. This project has been able to set its own agenda, pivoting during the Covid-19 lockdown and pulling all the learning together to develop the approach to *Awhi Ngā Mātua*.

The stewardship of IHC Programmes will be key to ongoing sustainability. The benefit of this is that IHC is a large, well-staffed organisation that understands the value of this project. The risk is that the disability sector is going through substantial change due to a recent government review, and that priorities, funding and leadership change. The ongoing development of parent leadership and control will be important to maintaining the kaupapa of the community, and ongoing sustainability. The shape of this is yet to be developed and will depend on the evolution of *Awhi Ngā Mātua*.

CONCLUSION

Parenting a disabled child, while often challenging, is not a wholly negative experience. Parents I talked to love their children very much and had similar experiences to other parents, including delight as they developed and grew. However, the challenges they do face, including isolation and lack of belonging, impacts on their wellbeing. Services are focused on their children and often add to stress as they are poorly coordinated and time consuming to navigate. Parents talk about the value of informal support from people who understand their lives, and the co-design process I used in Horowhenua and Manawatū identified the potential of technology to build connection and community.

There are many opportunities for parents to connect and receive information online, but many of these lack intent, are driven by provider or contractual needs, or are on platforms that make navigation difficult. Parents lead complicated and busy lives and need to be able to find what they want when they want it with people they trust.

The opportunity to experiment with different information and media during the COVID-19 Level 4 lockdown was invaluable. This presented an opportunity to use Facebook analytics to understand what parents were reading, watching and responding to, to spend time on other pages such as the parents of children with autism, noticing the issues they were facing and responding quickly, and to experiment with different approaches. The *Awhi at Home* Facebook page became a prototype for the development of the online community platform the parent group suggested many months before.

The online world is a busy and complex place. There are new tools being developed constantly and it is a challenge to identify what to use and how to implement it. The literature review was invaluable in identifying the potential of an online community to not just connect parents, but to build their skills and confidence.

In the longer term an online space can create a community that can coalesce and create social change. This goal is important to the project — it creates an aspiration that will over time give permission for *Awhi Ngā Mātua* to experiment and iterate — to keep asking "are we there yet".

This design research project describes the process of designing *Awhi Ngā Mātua* to a point in time. This is the beginning of a process that is still very much like the path described in this exegesis. There is a strong intent, there is a path and there is an aspirational end. It is not a project based on set timelines and milestones. There is no gantt chart. Instead there is an increasing amount

of knowledge from doing the project and engaging and designing with the people who are at the centre of it all — parents of disabled children.

Co-design has the potential to be particularly powerful in the disability sector, where services have evolved over time through centralised policy development which drives procurement processes. Parents, whānau and children lead complex lives which are difficult to respond to in a generalised way. The current system makes lives more complicated through a contracting system that has multiple providers in one place to do the same task, or part of that task. Co-design presents an opportunity to be more responsive and innovative through hearing experiences and designing solutions together, building trust and relationships that address loneliness and contribute to wellbeing.

The research project has given me the opportunity to slow down and think beyond what I see right in front of me. The literature review challenged my initial ideas about what a community could do, taking me beyond connection into thinking about building the confidence of parents, to provide them opportunities to learn and grow and to become a collective that could drive social change.

The influence this will have on my future work will be of interest to me. I hope that I can organise my schedule to include more time to explore beyond the obvious and create different ways to investigate how I can use the design principles to contribute to the community of parents of disabled children.

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