kiind. Kids Informal Navigation | Innovation Unit

"Caught between systems"

The journey of families raising children living with disability and/or chronic conditions

This journey map aims to represent the struggles and strengths of families caring for children living with disability, developmental delay, autism, genetic, rare, undiagnosed and/or chronic conditions who have to navigate complex service systems to access supports for their children. These diverse stories are illustrated here in the story of Max and his family.

Max's family

Max's family are 'personas', semi-fictional characters based on the stories that we heard. Their journey is typical of the journeys that families share within a system, but neither the hardest or the easiest one. While it doesn't represent all families' experiences, the journey displayed here highlights some common challenges encountered by families as they seek support for their children, and the impact of those challenges on their lives and wellbeing.

Reading the Journey map:

This journey map has been built in several layers: as you read about this family's story, you're also encouraged to discover the insights gathered through this project about systems challenges and impact for families, and get inspired by the opportunities for change associated with different moments in the journey.

The icons below help to pinpoint the role of specific systems and key impacts for families:

Health | NDIS | Education | Impact for families

Anna's mental load

Knowing my child is different

I knew something was going on

Max's birth was tough. The pregnancy had gone relatively well overall but he was premature and I was in labour for a long time. It was a relief to finally welcome him into the world. But as time went on, I noticed I could see that he was different. He was a beautiful boy, but some of his features seemed really unusual. He really struggled to feed as well which was so different from my other kids. I was trouble with it at all I couldn't put my finger on it, but I knew something was going on.

Insights on systems challenges & impact for families

The parents we spoke to often felt that professionals' assessments often underestimated the impact on the parent "there's no one really being the whole picture". Parents reported that each new professional would seem to make decisions based on their initial assessment, with a focus, rather than working with parents to understand the broader context and history of what their child has been and is experiencing.

Opportunities for change

How much hardship (and resources) could be saved if these systems by minimising the time from when carers first seek support, to when they receive it?

Is there a need for a single source of truth, accessible to multiple professionals and controlled by the family, with tools like Max's whole story?

Researching

I went down the Google rabbit hole

A few weeks after we got Max home, things still felt off, and he was really hard to settle. When the Child Health Nurse came around, I tried to explain some of the things I was seeing, behaviours I was seeing, but she couldn't see them for herself, and said that nothing seemed too unusual from what she observed. She told me that I shouldn't worry, that I'd never had an appointment with a paediatrician.

Whether it's about symptoms, diagnoses, or services and supports, the parents we spoke to described feeling that the world is full of research* to find information that could have been provided by the services and professionals they were engaging with.

We hear many stories of parents spending sleepless nights looking up conditions that could explain their child's symptoms, and then spending days and weeks trying to meet their child's needs, but only does this take time, but it also takes a significant physical and emotional toll on parents.

How might we provide parents with timely, accessible, and trustworthy information to help them understand what's going on for their children and where they could find help?

Seeking assessment

No one also could see the whole picture

No one else seemed to think there was an issue, but I knew something was wrong with Max. I started to look into it myself. I went down the Google rabbit hole and was researching at all hours at night. I found the name of a particular condition, and the more I read about it, the more convinced I was that this is what Max had.

I tried to share my research with Nico, but he wouldn't have a bar of it. He kept saying I should just treat the doctors, that Max being different to Olivia didn't mean that anything was wrong.

Nobody would listen

I took Max to the GP to try to get a referral or at least a professional opinion, but he ended up making the conversation about me, not Max. He talked about the stress of parenthood and about some of the mental health conditions mothers can develop, and it felt like he was suggesting I was just being paranoid.

I took Max to two other doctors, but they just had a quick look and didn't want to hear my concerns. By this point I was getting really frustrated that nobody would listen.

Parents experience a "lot of wrong doors" on their journey to accessing supports for their children, as well as long wait lists (up to several years) to see health specialists to get their children assessed. While parents are waiting for appointments with specialists, they are left to navigate intervention windows for their children, which comes at a cost for their children's wellbeing, but also for the systems that will need to deliver more support for those children in the future.

Researching, gathering evidence, and advocating to get support is exhausting for carers. Parents told us about their frustration of feeling "ignored" by the system, and their disappointment about their disappointment of finding providers only to discover that they didn't have availability.

How might we streamline pathways to supports, to enable early intervention which lead to better results for children and reduced pressure on systems?

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How might we ensure that parents are supported to be the best advocates they can be for their children, without placing an further burden on parents' specialised knowledge and expertise?

Chance encounters

My friend knew just the right person to go to

Just when I was feeling so stuck, I happened to bump into an old friend who knew just the right person to go to. What were the odds! Lauren and I used to regularly catch up at the park with our kids, but I hadn't seen her in ages. With all the stress, I pretty much wasn't going out anymore. We got talking, and she told me about an amazing private paediatrician, Dr Smith, who was a friend of hers and had helped her with her daughter. She said she could put me in contact, and I jumped at the chance.

Dr Smith squeezed us in for an appointment

Dr Smith squeezed us in for an appointment towards the end of her day the following week. It was a relief that someone was finally willing to listen to me, and we talked about Max's whole story up to that point. I didn't know if I wasn't crazy, the advice we got was worth it. She told me about the kind of testing we needed to get done for Max, and referred us to the specialist hospital team.

In an increasingly disconnected service environment, crucial connections that families need to make happen happened by pure chance. Multiple parents told us stories of an unlikely chance encounter that changed everything for them. Often these casual conversations with people who were in similar situations happened to run into, who told them about another child with similar symptoms or characteristics to theirs, or offhandedly suggested looking into a particular diagnosis or service. It seems to be crucially important.

How could 'positive deviance' in these systems deep-dive into the rule which lead to better results?

Inquire how and better approaches for all families?

Getting a diagnosis

The letter from the hospital came in the mail; we had no choice

Having to wait for another appointment brought on a fresh round of anxiety. We still didn't have answers and we didn't know when we would get them, and Max's behaviour was getting harder and harder for me to manage. We had been to hospital came in the mail. Max would be seen in 2 months, on the 3rd of August at 10am. No choice given. We would just have to make that appointment work, as it was too important for Max.

The specialist gave us the diagnosis in such a blunt way

After having to wait another 6 months for the test results, we finally had an appointment with the specialist to discuss Max' diagnosis. I had all these questions I wanted to ask him, but he was overwhelmed, so quick, he told us the name of the condition (confirming what I already thought), and talked about what it would mean for Max in such a blunt way. I can still remember him listing all the things he wouldn't be able to do. I was devastated. This was our baby we were talking about, not statistics.

The way professionals in these systems talk to parents about their children is important, especially at crucial times like at the point of diagnosis. After a long and frustrating journey, parents told us that the way in which their child's diagnosis was delivered and the lack of information, support, or referrals provided. Moments like these can have a lasting impact on the whole families, and the way they're handled is crucial for enabling families to process life-changing news, and for setting them up with the knowledge and supports they

What would it mean for carers to be cared for in their journeys through these systems?

What interventions could address the unseen pressures on carers, navigation, and support men to take a stronger role in this work?

Looking for supports

We had no idea what kind of supports were out there

When we got out of the office, I realised I didn't even know what was supposed to happen from here. We finally knew what Max had now, but we had no idea what kind of supports were out there for him. I didn't know where to start, so I did what I do best. I started researching. I found a forum, I would have done almost anything, I found a few Facebook groups for parents in similar situations. It was good to see I wasn't alone: people in these seemed supportive, and there were some good tips and advice.

The NDIS application was overwhelming

One of the parents I connected with suggested I should apply for the NDIS to get more support with Max.

I started the application but I didn't really know what I was doing. It was overwhelming: there was so much information, and it felt like one click since Nico was so busy with work, I felt a bit guilty not spending more time with the kids, but they didn't mind playing with the cat or sitting in their screens, and it gave me some time to focus on the NDIS application. I felt like I was finding myself every single step of the way were getting exhausting.

Accessing NDIS funding is often a crucial step for families, but we heard that this step is much harder than it should be. Parents told us that diagnosis that doesn't fit neatly into the NDIS system's boxes' Some conditions are not recognised or underway by the NDIS (e.g. rare and genetic conditions), while some conditions are excluded from the NDIS, such as ADHD.

In most cases, mothers were the ones to take on the caring responsibilities for their child and carry the mental load of navigating the system, while fathers were often described as the "breadwinners". Women talked about feeling alone throughout the journey and having to carry the mental load on their own.

Having to constantly justify myself was exhausting

A while after I'd lodged the application, I got a call from someone from the NDIS out of the blue. They told me the evidence I'd provided wasn't enough to make a decision, and they needed more information. It was right after one of Max's outbursts and I was already exhausted, and now I felt put on the spot and interrogated, like they didn't really believe Max was disabled. I felt like I had to prove myself every single step of the way were getting exhausting.

Many parents reported that their experience trying to access NDIS supports was difficult and impersonal. We heard about long wait times, a lack of human-to-human communication and unchecked assumptions from NDIS staff, bureaucratic delays, and supports being changed or revoked without sufficient explanation. Parents also described systemic issues, making relationship building extremely difficult: one parent reported having spoken to 16 different planners over 15 meetings in their 3.5 years accessing the NDIS.

Dr Smith knew the right words

Thankfully, I went back to Dr Smith and she helped me provide the evidence required for the NDIS which helped us get the funding. She knew the right words to use in her reports. We hadn't asked her to, but she was also kind enough to write a letter to our occupational therapists she knew were good, which was so helpful. Trying to find supports had been incredibly difficult, and it was so hard to know who would be a good fit for Max.

Parents told us the NDIS applications and reviews demand a lot of onerous preparation work from them, and that you need to know and use the specific language the system expects and prefers ("all those words that I'd never heard before"). Parents also worried that they were more successful in getting their plan and funding requests approved when they were coached by a professional or friend who could speak the system's language and knew how to advocate for themselves in their own words.

How might we ensure all families have the same opportunities to access crucial systems like the NDIS?

I had a full time job, and that was Max

Before long, our calendar was completely full with appointments. Between meetings with specialists at the hospital and weekly appointments with the GP and everyone else, I was constantly on the go. Nico was working full time, and I was constantly juggling the different plates he knew were good, which was so helpful. Trying to find supports had been incredibly difficult, and it was so hard to know who would be a good fit for Max.

Because of the complexity of their children's needs and the lack of supports in place, many families are often accessing a large number of supports at once; one family, for example, described having 14 different professionals, 3 different therapists, and attending regular appointments across three different hospitals. Parents told us that their days are ride to 24 hours a day, 7 days a week, with some parents reporting spending at least 80 hours a week caring for their child.

At but one of the mothers we spoke to had to leave their job, let go of career opportunities, or reduce work hours during their journey, due to the significant care and navigation load demanded of them. The constant stress and the lack of supports in place also forced many parents to stay apart, with many of them feeling "burnt out" and having to take a break from work to be able to manage the rest of their responsibilities.

How might we create spaces for women to maintain work and resume their careers, while caring for their children? Are there ways we could better recognise, value, and reward the immense care work women undertake?

The appointments were all over the place

To make things worse, all the appointments were in different places and on different days. It was so hard to keep track and try to coordinate it all. Some OTs said they could come to the house but I didn't know if I could trust them. The principal explained that the teacher was following their standard procedures, even though I'd told them that Max's behavioural approaches didn't work for Max because of his condition.

While many parents opt for appointments to take place at home to save time, many parents and up driving to appointments, sometimes with the goal of minimising travel time, but this can mean that they spend more time around the amount of funding going towards direct support time for their child.

Parents told us that the time spent on appointments comes at the expense of time spent with family or caring for their own needs. The travel is even worse for families who live in regional or remote areas, with some spending half a day to a day per week to manage it. This is a significant stress on parents' limited time, and it also adds to their emotional load, with many parents describing themselves as "overcharged" by service providers, or feeling stressed about being audited by the NDIS.

What supports, platforms, tools, or processes could enable more multiple services and professionals to deliver coordinated care with children and family as the carer?

No one was taking responsibility to cover specific supports

On top of that, I was spending a lot of time on the phone to agencies to get funding for specific supports. Max needed extra support to help with his reading at school, but no one was willing to cover it. The education would take responsibility to cover it. I think every time I got in touch I spoke to a different person, and it felt like I was going around in circles.

Children with disabilities and chronic conditions often require support from multiple systems at different times to meet their different needs, but we heard many stories of these systems appearing to be in a "tug of war" with each other, and of fulfilling aspects of a child's care.

Managing NDIS funding was noted as a particular pain point, with many parents dreading for carers, with some spending half a day to a day per week to manage it. This is a significant stress on parents' limited time, and it also adds to their emotional load, with many parents describing themselves as "overcharged" by service providers, or feeling stressed about being audited by the NDIS.

How might we provide supports for carers, and resolve funding disagreements and delays?

I arranged a meeting with the school principal

I arranged a meeting with the principal to review Max' support at school. I'd picked up a part-time job just for one day a week, but I kept getting calls to tell me Max was in trouble or needed to close again, and I felt his needs weren't being met. The principal explained that the teacher was following their standard procedures, even though I'd told them that Max's behavioural approaches didn't work for Max because of his condition.

Many parents find themselves having to spend a lot of time and energy advocating for their child's needs to be met at school, which can fracture relationships with teachers and school staff. Parents described having to request regular meetings with teachers and school leaders, or even write their child's Individual Education Plan themselves. Parents described repeatedly that 'mainstream' public schools are often unwilling to be flexible in supporting children with disabilities, or under-resourced to be flexible when they are willing.

What would an education offering look like that could achieve both wellbeing and academic results?

Max missed out on learning opportunities and school trips

In the meantime, Max was missing out on learning opportunities and school trips. He very much needed that 1:1 support to fully engage in school, and he struggled with time away from his routine, the trip to the zoo and I just lost it with the teacher. It wasn't entirely her fault but I was just at my wits' end. I could see some of the other mums watching and judging me, so I pulled myself together and just took Max home.

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We heard many stories about a lack of flexibility from the NDIS, schools, and other, that limits access to important learning and recreational opportunities. When systems don't provide children with the adjustments and/or additional funds they need to enable their full participation in mainstream activities, they are left missing out on opportunities that are crucial for their healthy development and general wellbeing.

Many carers described how they felt judged about their parenting and how they'd had their friendships, been excluded from events, or had to restrict their social circle because of their child's complex behaviours.

Is there room for interventions that decrease the social isolation and judgement that families experience?

What if we were able to reduce inequities in access to supports between people with different resources or who live in different places?

Breakdown

We had to look for another school; it was expensive

After so many meetings trying to advocate for better support at school for Max and not getting anywhere, I knew we had to look for another school. A friend recommended a special school that was good for kids with additional needs, but it was expensive and on the other side of the river.

Carers reported difficulties accessing consistent and high quality services for their children across various systems. Many have to travel a long way to access quality services, which is time-consuming and in some cases families even escape their entire lives to access better supports.

Families with low resources are the most affected by this inconsistency. Whether in the health, mental health, or education system, parents who had more financial resources had more choices of supports, and shorter wait times and better coping for private services.

What interventions could address the unseen gendered impacts of care and navigation, and support men to take a stronger role in this work?

Nico had had enough of me fighting for everything

Nico was always worried that I spent too much time and energy on Max, and this time he thought I was taking things too far. He didn't agree with changing schools, and he felt that I should just hold tight and stop all the fighting for everything. I wanted to continue on that path, it would have to be without him. These disagreements weren't anything new, but this was the straw that broke the camel's back. We'd already drifted apart so much... there was no coming back.

The demands of carer and systems navigation, and the uneven gendered impacts of the workload they create, can fracture relationships and relationships. This can lead to relationship breakdowns, which was the case for almost half of the families we spoke with. Women talked about the compounding impact of feeling alone in their journeys, and how it can be difficult to maintain partner regarding their child's condition or parenting approaches. The stress of navigating systems, especially financial stress, was seen as adding significant pressure on relationships.

What interventions could address the unseen gendered impacts of care and navigation, and support men to take a stronger role in this work?

Advocating for my child at school

Coordinating care

Being a single mum is tough

Nico left, and we ended up moving to be closer to the new school. Changing schools hasn't been easy for Olivia but it's made a massive difference for Max. The school is much better equipped to deal with Max and TJ support he needs. Being a single mum is tough, and it's taken a financial toll on our lives, but my friends keep me going.

One of the biggest chronic impacts described by carers is the social isolation they experience. Their care responsibilities make it difficult to maintain friendships with family or friends, date or engage in hobbies. In addition, parents feel that the reality of their lives is not well understood by others, including friends and family members, and they find it difficult to maintain relationships with people who don't understand their support network, including family and friends who can offer both practical and emotional support, was noted as an important factor in families' journeys to help alleviate the significant load carried by carers.

How might we build inclusive, accessible opportunities for social support and community for parents?

We've found our footing now

Our lives are busy and we still have to juggle all these appointments, but we've found our footing now. We've got a big camping trip coming up with other families the Kids and I organised through our local support group. It takes a lot of planning and coming together as a family, but our favourite time, I would do anything to see Max have fun just like any other kid!

Despite the struggles experienced by families as they navigated systems to get support, the stories we heard consistently highlighted the resilience and strength of carers and children as they became advocates for their children's needs. Many support groups are set up by parents who want to connect with and support others who can't relate to their day-to-day lives. Making friendships through these connections, which help them and their children.

How might we build inclusive, accessible opportunities for social support and community for parents?

How might we ensure that stories of families for systemic advocacy?