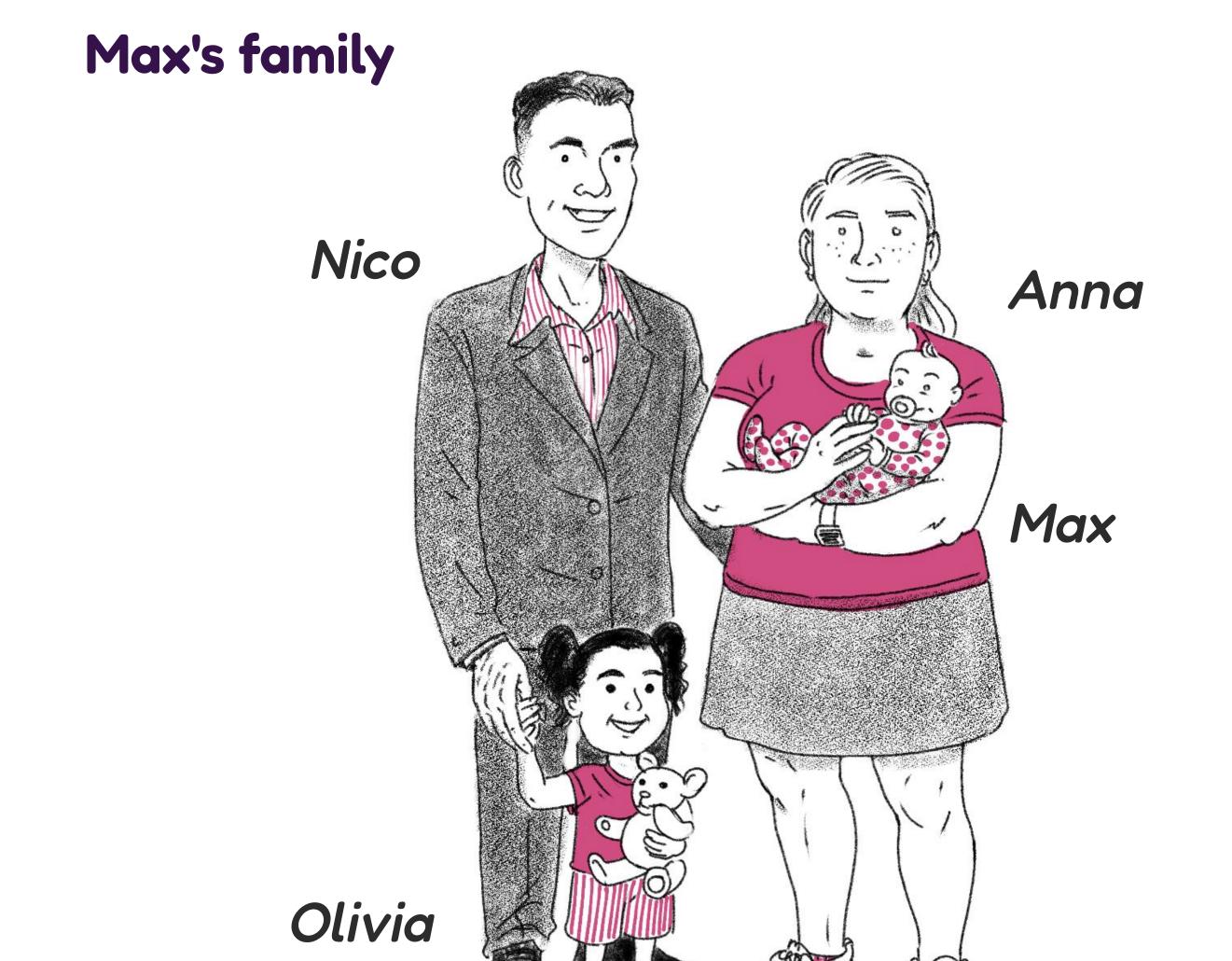
Formerly Kalparrin Innovation

"Caught between systems"

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



children, and the impact of those challenges on their lives and wellbeing.

Reading the journey map:









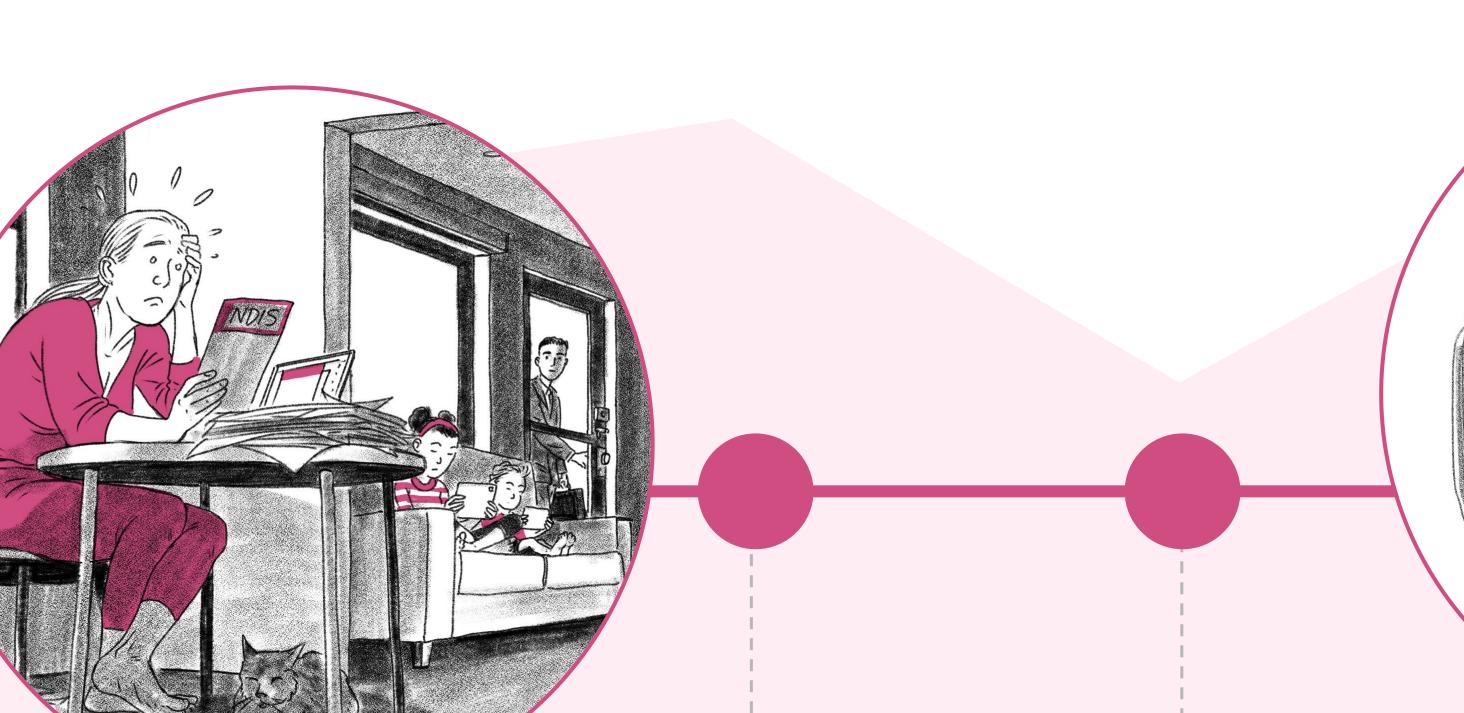


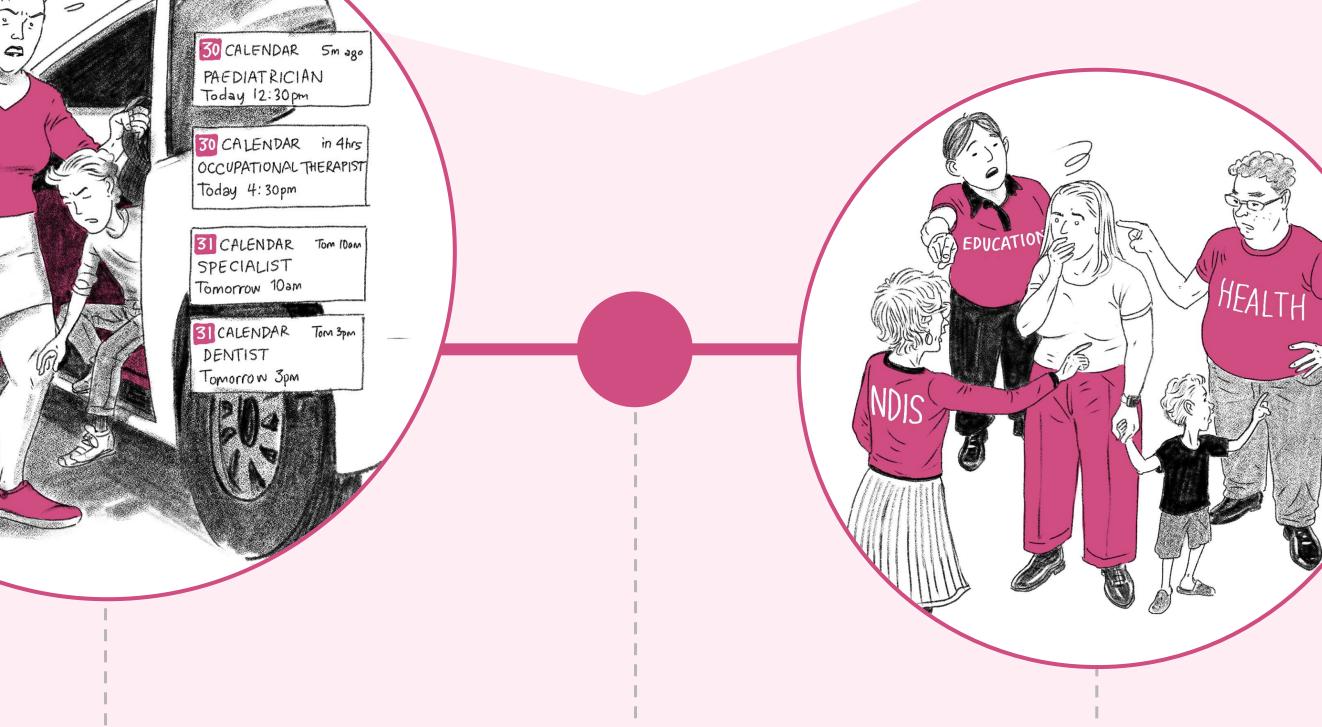


Knowing my child is different

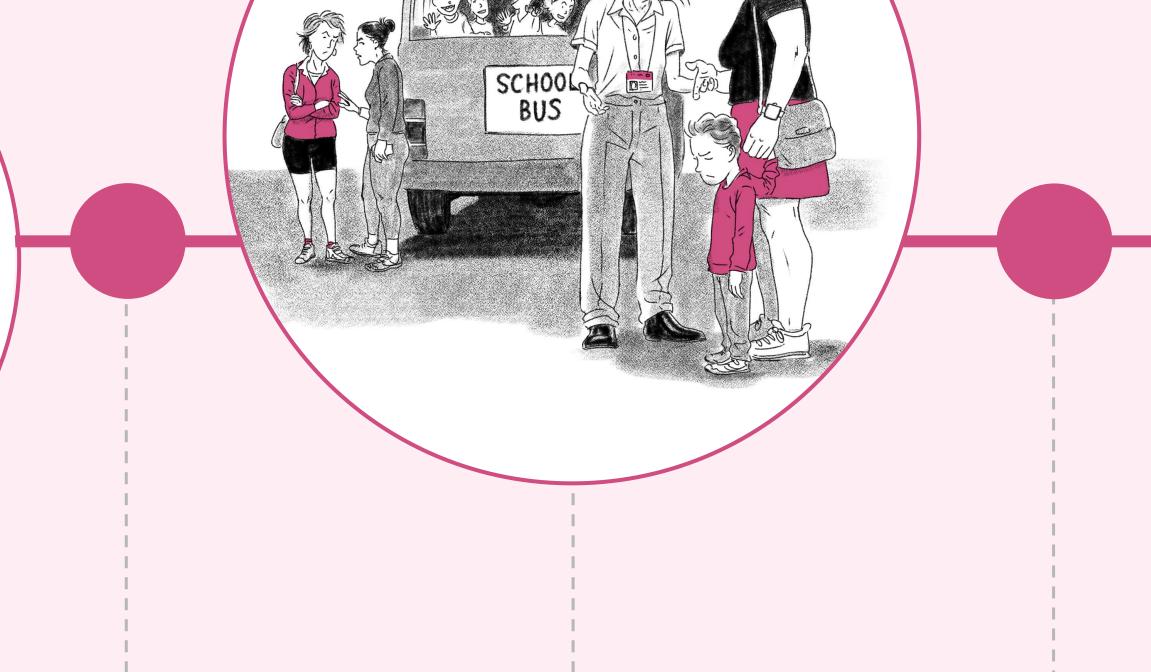
Getting a diagnosis

Looking for supports

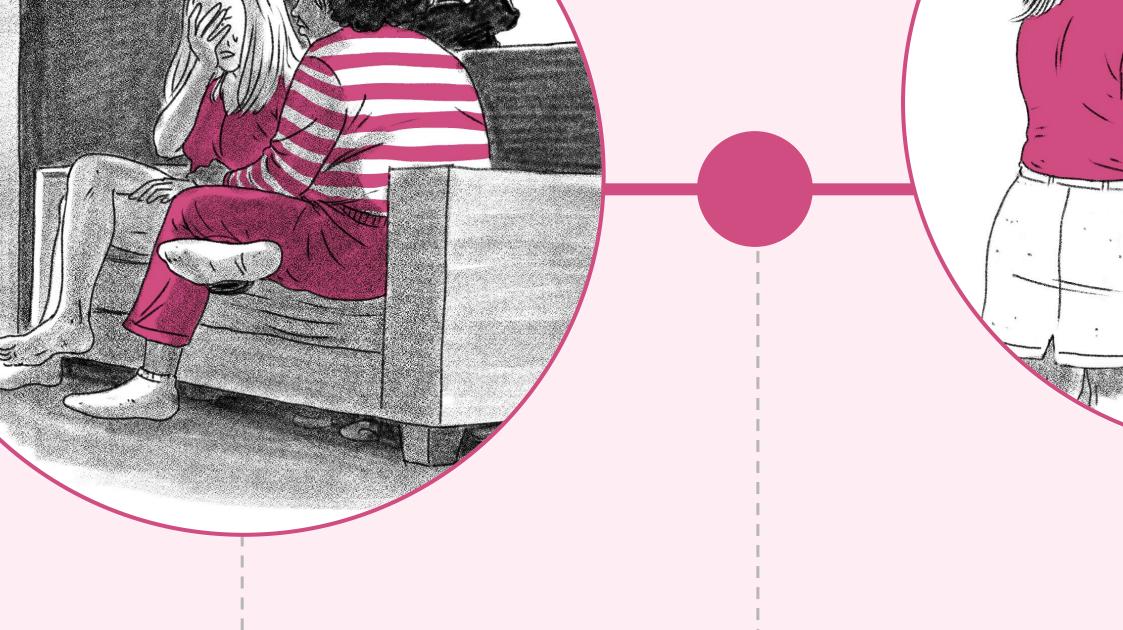


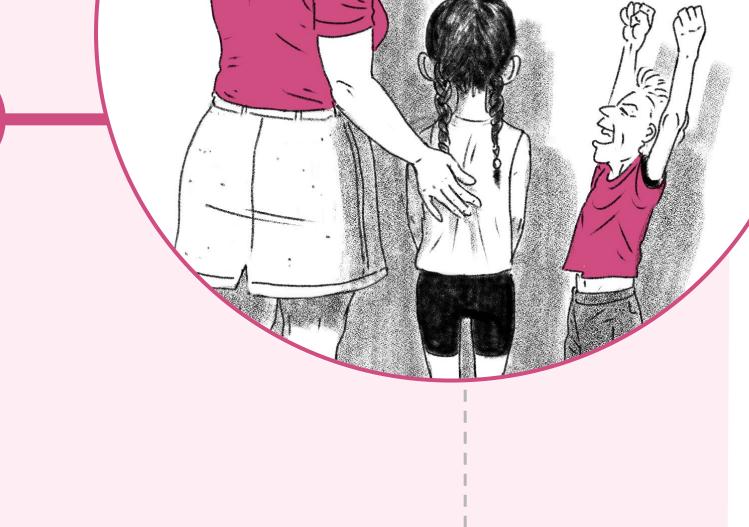


Coordinating care



Advocating for my child at school





Looking forward



for change

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
soon as I got to hold him, 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
to Olivia who'd had no
trouble with it at all. I

might need extra support from a parent "there's no one really [seeing]

their concerns dismissed by that each new professional would

difficult to access information brief assessments with a narrow

about the services and supports parents to understand the broader

that might be available. context and history of what their

others were diagnosed with Munchausen

that could have been provided by the dismissed, and were sometimes even

supports to meet their child's needs. Not children, who turned out to have very real

only does this take time, but it also takes a disabilities and chronic conditions.

what's going on for their children and parents' significant knowledge and

significant physical and emotional toll on

parents.

resource) could be saved in _____ of truth', accessible to multiple _____ timely, accessible, and trustworthy ____ practice of professionals, and support

about their disappointment of finding providers only to discover that they didn't have availability.

How might we streamline pathways to If 'chance encounters' often lead to

diagnosis, to enable early interventions which breakthroughs for families, how could we

lead to better results for children and reduced deliberately create the conditions for more

friends or medical professionals they parents to advocate on their

these systems (exceptions to the professionals to better understand

to design person-centred supports

quick. He told us the name of th

statistics.

through these systems?

'navigation' support to help them find and

be the role of other carers with lived experience

in providing this kind of support?

and the lack of information, support, or asked about the most helpful supports along the

crucial for enabling families to process the time or mental space to enjoy these

system's 'boxes'. Some conditions are not

alone throughout the journey and having to carry

navigation, and support men to take a

In most cases, mothers were the ones to take on explanation. Staff turnover amplifies these

What interventions could address the How could we provide families with

poor communication and unchecked

bureaucratic delays, and supports being

extremely difficult: one parent reported

over 15 meetings in their 3.5 years

they hold with the professionals and

work from them, and that you need to know

expects and prefers ("all those words tha

eported that they were more successful ir

advocated for themselves in their own word

How might we ensure all families have and return to their career aspirations even while caring processes could enable multiple

role is 24 hours a day, 7 days a week, with some parents they can maximise the amount of

recognise, value, and resource the extensive care work coordinated support with children

job, let go of career opportunities, or reduce work hours appointments comes at the expense a day to a day per week to manage it. This is schools are often unwilling to be

navigation load demanded of them. The constant stress their own needs. The travel is even and it also adds to their emotional load, with disabilities, or under-resourced to be

aspects of a child's care. parents. Parents described having to

being particularly time-consuming and Plan to provide to teachers. We heard

How might we create spaces to negotiate

teachers and school leaders, or even

What would an education offering

shorter waiting periods through opting for

What will it take to reduce inequities

Nico had had enough of me fighting for everything

already drifted apart so much... there

was no coming back.

the health, mental health, or education parenting approaches. The stress of navigating offer both practical and emotional support, was noted

What interventions could address the uneven

support men to take a stronger role in this work?

children across various systems. Many have The demands of care and systems navigation, and One of the biggest negative impacts described by highlighted the resilience and strength of and in some cases families even relocate relationships. This can lead to relationship up with family or friends, date, or engage in hobbies. In Many support groups are set up by parents the families we spoke to. Women talked about the well understood by others, including friends and family others, and parents told us they'd made

these systems.

enormous potential in mobilising and empowering families to lead change i
