

Navigating care for rare disease developmental delay

A guide for parents and carers through diagnosis and accessing health and allied health services

Smith-Magenis Syndrome Australia

rare voices AUSTRALIA

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Note: This resource is accurate at the time of publishing (October 2026). The information provided does not necessarily represent the views of Rare Voices Australia (RVA). RVA and SMS Australia are not liable for any loss, damage, or consequences arising from the use or misuse of this resource.

Introduction

As parents of children with a rare disease that is also considered a developmental disability, our Smith Magenis Syndrome (SMS) board felt that development delay combined with rare or undiagnosed disease can be misunderstood.

About 2 million Australians live with a rare disease that impacts their daily life over a long time. The Australian Government defines a disability as a limitation, restriction, or impairment that has lasted -or is likely to last-for at least six months and restricts everyday activities[1]. Individuals who experience rare disease disability will often require life-long support and ongoing assistance, including for daily activities[2].

As parents, we had experienced challenges navigating services and systems when trying to get help for our children. It seems we are not the only ones who felt this way.

For this project, we spoke to 20[3] parents whose children with a rare or undiagnosed disease also experience developmental delays. We also had a project steering group made up of 9 parents of children with rare or undiagnosed disease developmental delay. We consulted with the project steering group at various stages of the project- when developing the interview guide, regarding initial analysis of the interview data and when developing content for this guide.

This guide was difficult to write, as a lot of the challenges we identified through the interviews are related to problems in practice and systems. In many cases, parents were doing the right things and asking the right questions. There are faults in health and allied health practice that need to be addressed. The National Disability Insurance Scheme (NDIS) and systems such as the public health and school systems need to be improved. Parents also need supports and guidance on navigating services and systems for rare or undiagnosed disease development delay.

Understanding developmental delay

Childhood developmental delay[4] occurs when a child does not reach expected physical, cognitive, communication, social or emotional milestones within the usual age range. The first 5 years are critical for identifying developmental concerns, as rapid brain development during this period provides the greatest opportunity for early intervention to improve long-term health, learning and wellbeing. Developmental delay[5] may be temporary or associated with a permanent disability. Some children experience ***transient*** delays related to illness, adverse life events or disruptions in caregiving. Early intervention can support them to catch up to expected developmental milestones. Others may have ***permanent*** developmental disabilities resulting from genetic, chromosomal or other medical conditions. ***Global developmental delay*** describes significant delays across 2 or more developmental domains in young children. It is often used as an interim diagnosis to facilitate assessment and access to support while longer-term developmental outcomes become clearer.

Children with a rare disease often present with developmental delays that are **subtle, fluctuating, or atypical**. Many children with rare disease disability will receive a global developmental delay or idiopathic autism diagnosis to explain their symptoms and functional impacts while they await further assessment, testing and interventions. In rare disease disability, developmental delay varies greatly but can include features such as speech and language impairment, muscle tone abnormalities, skeletal anomalies and distinct facial differences. It is important to acknowledge the significant and often lifelong functional impacts that may arise, affecting the daily lives of children living with rare disease disability and their families.

In Australia, developmental monitoring is undertaken through maternal and child health services, general practitioners (GP) and early childhood settings, with referral pathways to allied health, paediatric assessment, Medicare-funded services and the NDIS, where eligible.

Australian policy has increasingly prioritised the early identification and support of children with developmental delay and disability. This has been reflected through initiatives such as the NDIS Early Childhood Early Intervention[6] approach and more recent reforms, including the Thriving Kids[7] initiative, which aim to improve access to early supports and developmental outcomes for children and their families.

About this guide

The interviews we conducted as part of our study[8] provide valuable insights into the lived experiences of parents of children with rare or undiagnosed disease, who have or are currently navigating services and systems for childhood developmental delay. Through an analysis of the interviews and with the help of a project steering group, we drew together commonalities in experiences and suggestions for navigating services and systems. We also identified some things that work well! **The aim[9] of the following sections is to support parents and carers of children with rare or undiagnosed disease in seeking support to access health services and systems for their child.**

The guide is separated into 3 sections:

Section 1: Diagnosis – Getting a Diagnosis and Receiving a Diagnosis

Section 2: Supporting Yourself and Your Family

Section 3: Navigating Health and Allied Health Services

A summary guide is also available. Use the guide with the **Practical Tips for Parents and Carers companion resource**, which includes:

- Helpful tips and suggestions
- Suggested questions you might like to ask
- Useful services and links



Section 1

Diagnosis

Getting a diagnosis and receiving a diagnosis

Early diagnosis helps

Diagnostic tools such as genetic testing are increasingly becoming more available. In our project, people diagnosed earlier generally reported better experiences accessing supports (although there were still challenges, which we go on to discuss).

Getting a diagnosis

All but one of the participants from our study had children with disabilities caused by genetic abnormalities such as chromosomal deletions, or mutations/changes to a gene. One had a syndrome characterised by a range of physical disabilities/defects. Intellectual disability, behavioural challenges, and developmental delays such as speech and motor delays were common. Physical health problems were also common, such as feeding issues, hearing loss, delayed growth, breathing issues, and/or problems with the heart.

Parents' experience with diagnosis and healthcare really came down to who they were seeing at the time. Overall, participants indicated that a good paediatrician or GP came down to luck. Some participants reported that they had a wonderful paediatrician who picked up on developmental delays early and monitored their child closely. Our project also found that experiences of getting a diagnosis and accessing health services were easier when children had physical health problems. Those who had physical conditions or symptoms at birth, for example, were generally tested and diagnosed early.

Delayed diagnosis when there were developmental delays present ***was a significant issue discussed across our study***. Clinicians generally follow the 'Red Flag' Early Identification Guide to determine when to refer for further services for developmental delays. However, many participants in our study said their concerns about developmental delays were often dismissed. The 'anxious mum' was a common theme.

> "At six weeks old, I picked it. I remember saying to my GP [has she] got a syndrome? And he laughed at me, and then she got formally diagnosed with a blood test-ahh [at] about 2 [years old], I think. And that was because she wasn't talking at all... there was a speech therapist who said to me at the children's hospital because they were assessing her for a cleft ... I think you should probably go and get some genetic testing. "
>
> "... And then we went to the paediatrician, and he said she doesn't have a genetic problem, but I'll do the test anyway. And then it came back and she had [syndrome, deletion] ... "

In our study, developmental delays on their own did not generally appear to be a significant risk factor or red flag for health professionals that led to diagnosis in the early years[10]. Parents in our study said that the doctors and paediatricians they were seeing did not consider or explain developmental delays, such as being late to sit on their own or walking. Saying the child 'would get there in their own time' was common.

Two participants who were migrants ended up getting a diagnosis overseas, after raising multiple concerns with doctors in Australia.

> "Yeah, we were seeing [our] GP regularly ... But I feel like if the GP had referred us earlier, then we could have diagnosed it earlier ... what happened is, one day, our regular GP was not there, so we went to another GP and she said I feel something [is a] red flag. So, I will refer it to the children's hospital. And then we got the paediatrician appointment after 1 1 /2 years of her birth. So, definitely that could be done earlier.
>
> "We told [concerns about development delays] to [our] GP, but she said 'she will take time' ... "

Sometimes children were diagnosed with global developmental delay prior to diagnosis, but this was not explained in terms of what this meant, what services should be accessed, or if there was a plan to continue monitoring progress or undertake investigations for further diagnosis.

> "I'm still yet to have a medical professional tell me about the syndrome [at 2 years of age, diagnosed at birth] or what is a global delay? What is a developmental delay? What does this mean? Where to go from here? Everything that we are doing is because of self-research ...
>
> "I actually remember the last paediatrician appointment ... we went in and they did the weight and the measurements and all of those sorts of things. I said to them, look, she's been steady weight now for the last ... 6 months or whatever it is. She's not moving anywhere. And they said, oh yeah, but she's at a healthy weight, so that's fine ... and then they said to me, oh, but what do you want from us now? What do you need from us?
>
> "And I was like, well, I don't actually know. I feel like they should have been saying, alright, well, she's 1 1/2, so we should be doing this and she's not reaching these markers. So, this is where you need to go from here. Here's some resources or, you know, these are the therapies that you should talk to NDIS about including in a plan next. But there's nothing like that."

Health professionals come from different backgrounds, training and expertise - their concerns or ways of going about things might not match your expectations or needs concerning support. Additionally, lack of communication or misunderstandings might not necessarily be malicious. Doctors are not counsellors, for example, and are looking at treating medical symptoms. Feeling dismissed might also be a result of time constraints, or a lack of knowledge on the part of the health professional.

Medical Gaslighting[11] is a common phenomenon, and disproportionately affects women, mothers, Indigenous peoples, people from culturally diverse backgrounds, and people with poorly understood conditions, such as people with rare disease disability.

Receiving a diagnosis

Receiving a rare disease diagnosis is not easy - it can be life changing, devastating and scary. Not only are you finding out your child won't have the life you thought they would, but you don't know what the future will hold, or how to help them.

Unfortunately, during this time there can be very little support for parents. Most of the parents we spoke to described their **experience of receiving a diagnosis** as being told about xyz diagnosis (or, in the case of undiagnosed conditions, the deletion or abnormality), being given a pamphlet or some kind of printed information about the condition and **told not to Google** it for fear of getting the 'worst case scenario'.

In most cases, there was limited follow-up, explanation of the condition or development delay, and allied health services were not explained or referred to.

Parents were told to join the NDIS, although this also was left to the parent to navigate on their own, and specific supports were not often identified.

Referrals and supports after a diagnosis were generally only done where there were physical health problems.

> " ... because no one knew about [rare disease]. There was no such thing like, we weren't eligible for anything ... And I remember when she was little, the only reason why I guess we got supports was because she was hearing impaired. And I remember being at some hearing tests, being like [child] please fail, please fail, because that was the only way we were going to get into any type of early intervention program."

Not explaining how developmental delays relate to diagnosis, or what a child's condition or progression might look like in the future, was common. However, this was complex: Many participants in our project reported that doctors said they did not necessarily know how developmental delay would play out over a child's lifetime, advising that every child living with rare disease disability is different, and that they did not necessarily know how the rare or undiagnosed disease would affect them over their life.

> "[Doctor] was quite honest with us and said, 'I have no idea basically how this might affect her'. At that point, there were only 40 registered cases of her deletion worldwide. So, it was very rare. There is a little bit of a more common syndrome ... So, some of the readings and guidance around what might cause [it] or what might happen ... we've since, I guess, been made aware that that is a much more severe syndrome than what [child] has. So, we are thankful that it's not quite as severe as that. But basically, he just said, 'we'll just keep an eye on her, get early intervention and just tackle things as they come up'."

When asked, some participants said looking back, they didn't necessarily want to know how developmental delays would play out over their child's lifetime or would prefer to wait and see as per the doctor's advice. Sometimes this was described in terms of self-preservation, as these were the things they could not control.

Although, others said looking back, they would have liked to ask more questions about what was to come, to be able to prepare.

> " ... like, how does this play out sort of later? Because I feel like that kind of gives parents like, almost like the initial stuff. Like she did tell us a lot of this you won't see until she's about two. So, we enjoyed, like, the bliss. And I think that was helpful.
>
> "I wish I'd asked more questions about, like, how does this look long term for them in their life? Or to adults? Because I think that would have given me personally a better understanding ... like definitely [about] the behaviours. I wish I'd known a little bit more.
>
> "Not that it would have changed anything, but I think I had a very different view of what that was going to look like ... "

Others said they had asked all the questions they could think of. They added they wouldn't necessarily go back and ask questions if they could because they couldn't identify anything that might have changed as a result of this.

It's important to acknowledge that adapting to life with rare disease disability can be challenging and takes time. It can be helpful to consider the broader picture beyond diagnosis and developmental milestones. For example, how a child participates in daily activities, what they can and cannot do independently, supports needed, and how rare disease disability affects learning, communication, behaviour, safety, emotional wellbeing, and family life more broadly.

Section 2

Supporting yourself and your family

Grief

After receiving a diagnosis for your child, you will likely experience grief. It is OK to grieve – many participants in our study expressed guilt over grieving after receiving a diagnosis.



> " ... when [child] was first admitted into hospital, I was like, I just don't know why I'm struggling with it all. And [counsellor] was like, you're grieving. And I was like, what do you mean? Like, [child's] not dead. She's still alive. And she's like, no, no, you've just had a baby and you're coming up to Christmas, and you had in your head this picture of what life was going to be like. And it's been totally turned upside down.
>
> "She's like, you can grieve the picture in your head of what life would be like. And that really stuck with me because ever since then I've been like, you do have doubts of like, oh, this is what I imagined would happen. Even if you think you've, you know, with developments like, OK, we're going to reach this milestone, you might then regress and so then you grieve like it is. There's so much grieving that's not to do with death, but it's the same process."

Grieving after a diagnosis doesn't make you a bad parent or mean that you see your child as a 'burden'. But the reality is, caring for a child with rare disease disability changes your life in many ways. It is OK to recognise the life changing nature of diagnosis: to grieve the life you thought your child would have, the family you imagined, and to feel fear over what is going to come next, including 'not knowing' how life is going to look for your child, for you, or your family.

There are some well documented stages of grief[12] you might go through:

1 Denial

Initial shock or refusal to accept the diagnosis acts as a temporary buffer to help process overwhelming information.

2 Guilt

Thinking there were things with the pregnancy or the birth that were your fault, guilt over how this will affect your other children.

3 Anger

Feelings of frustration, helplessness, or resentment, might be directed at oneself, others, or the situation.

4 Bargaining

Attempts to negotiate or make sense of the diagnosis, often involves 'what if' or 'if only' thoughts.

5 Depression

Deep sadness, withdrawal, or emotional heaviness, can come in waves and vary in intensity.

6 Acceptance

Acknowledgment of the reality of the loss, does not mean being 'OK' with it, but learning to live with it.

None of these experiences or stages of grief are linear - they do not happen in order. People experience them in different ways, and at different times. Some participants in our project described the grief going 'in waves', meaning that they would go through phases of acceptance and then grief might come again as children missed certain milestones. For example, going to Special School instead of mainstream school. Other people close to you, for example, grandparents and partners, might also go through these things, and at different times to you.

Navigating changes to life and how other people reacted or dealt with their child's rare condition became another part of grief for parents we spoke to. Some participants talked about how they were the first in their family or immediate circle to have a child with rare disease disability, which made it harder to understand and navigate. Sometimes friends and acquaintances could misunderstand the diagnosis or developmental delays, saying things like 'they will get there', or pointing out that they also struggle with tantrums and so forth with their own children. Sometimes these words might be well-meaning with the intent of comfort. But it was also draining for some to talk with parents of children without rare disease disability about milestones, achievements, or being 'pitied' for having a child with rare disease disability. Some people said they withdrew or closed off from some parts of their life, or people in it, at times.

> "I realised that I was becoming a little bit bitter about other people. [They] just don't understand. And you find this disconnect. People start to isolate. Either you talk to them and you're open and then suddenly they can't relate, and so they feel bad and they stop talking to you about normal stuff. They think they can't complain. Or you start to become a bit resentful of other people who just have no idea. And there becomes this disconnect."

But parents in our study also spoke about working through grief and finding a 'new normal' parenting a child with rare disease disability. The same participant said:

> "But I didn't want to spend my life focused on disability. In just the negative and the weight of disability ... It is the weight and the worry I will always have for that child is there. She's in this world, it's here. But sometimes to diffuse that and have your focus on other things. It's like going to work when you've had bad news ... You want, you need a breather.
>
> "... But there's times where it can be such a hard day and the funny things that come out of her mouth or the things she does and you're just, there's not a day I don't laugh. And I'm like that is really important. And it also keeps you connected with the rest of the world ... It's great, I love connecting with people in disability, but it's also nice to still feel like you can connect with the greater world and that you're not like, it's us and them, I don't even understand that, and you don't get me."

A project steering group member talked about an analogy they had come across which offered comfort for them – 'Welcome to Holland' by Emily Perl Kingsley. This analogy describes planning for a trip to Italy, but you end up in Holland, likening this to the experience of raising a child with rare disease disability. When planning a trip to Italy, you might buy guidebooks, make plans specific to Italy, and anticipate wonderful experiences you have heard from others. But instead, the plane lands in Holland. Holland is a different place to Italy, and not what you had prepared for so there will be challenges. But Holland also still offers unique and beautiful experiences which you can come to learn and enjoy.

Just know that grieving is normal - it is OK and you are not the only one, even though it can feel very lonely at this time.

Looking after each other

It is important to look after yourself and your family. As well as grief, you can be pulled in many different directions regarding appointments and navigating services and systems. Most of the burden for caring and implementing early intervention is placed on parents and carers (particularly mothers). Remember that for systems and services, this is a job. For you, this is your life. And caring for a child with rare disease disability is lifelong.

Carer Burnout[13] is real and you need to look after yourself. Recognise that you don't need to have all the answers, and you don't need to do it all by yourself (although it can certainly seem that way!). For example, some parents in our study found that they had to change work arrangements to manage the needs of their child. Many participants had other children and talked about the impact on the family as a whole, including siblings.

For you

Counselling is an option for ***yourself individually***, as a couple, or ***as a family***. Ask your GP about a referral and a mental health care plan.

For siblings

Little Dreamers is an organisation dedicated to supporting ***young carers ranging from 4-25 years old***, providing counselling and group work, holiday programs, tutoring programs and so forth. Be sure to check eligibility for where you live as eligibility and programs differ by state/region.

In our study, family and friends were generally discussed as supportive. But some people didn't have family, or their family lived overseas or far away. Some parents in our study also discussed that their families (grandparents, for example) were grieving too. In addition to extended family being unable to offer support, they also relied on the parents of the child for information and support, which was draining. The following parent talked to some of these struggles, and suggested a model she found called the Ring Theory[14] for parent support.

> "I didn't realise why I was struggling with other people telling me how they felt about our situation… if you're at the centre of it, you can't be taking on board how everyone else feels about your situation. It's too much emotion. You vent outwards and then it's not that your mother or your sister can't feel sorry for you, but they can't put that on you. They have to go further out, and they have to vent to friends and family.
>
> "Because otherwise, living in a world where your child is at the centre of this as a parent, it's really heavy to constantly have people telling you how they feel about your child's condition. So, you've sort of got to teach people that it's OK to feel that way. Just don't tell me about it. Go and tell other people and other friends. Let me vent to you. And that also was helpful for me in sort of navigating all these things as that model of coping."

It is important to centre yourself and your immediate family and 'grieve out'. Identify what support you need from those close to you. Sometimes people like friends and extended family don't know what you are going through, or what they can offer.

Support groups for parents of children with disabilities will likely be your best friend.

> " ... talk to other parents [of children with disabilities]. So, through parents of kids in the ECDP [Early Childhood Development Program], at the special schools, you get more information from parents than you get from most other people, because even though all our kids have got something different, there is usually somebody [that's] tackled what you've needed to tackle.
>
> "There's a ... social group for parents that you can go, they have guest speakers ... and you just have coffee and you just chat and you can just offload there or, you know, I found that's how I started and found a massive group of very supportive women."



Section 3

Navigating health and allied health services

The choice between private and public health comes down to finances and personal choice. It emerged through our project that private health wasn't always the answer. Unsurprisingly, private healthcare did have benefits regarding paediatricians and more timely access to specialist services.

As discussed earlier, co-morbid physical conditions alongside developmental delays appeared to be a more straightforward path through the health system.

For developmental delays, such as delayed speech, walking, motor skills and so forth, **allied health services** like speech therapists and occupational therapists (OT) **generally provide the best interventions.**

In most cases, participants reported that allied health services were not explained to them by health professionals in terms of who to access, and what they could help with regarding development delays and rare disease disability. Referrals were only usually made in cases where there were physical co-morbidities. It was up to parents to source allied health supports.

> "It was only through like other people, and I guess a bit of Googling, it has probably [been] a lot of Googling, and trial and error with different therapists and staff as well to find. But I think, yeah, that would have been helpful to, you know, having doctors or even the paediatrician or people that we were coming in contact with saying, you know, like, here ... this is like the priority area. Here is a good OT or you know."

Parents often expressed they came to find that **waitlists were incredibly long** (sometimes 1-2 years for speech therapy). Waitlists and a lack of access to services generally diminished choice of providers and added to worries about their child as they could not access services perceived as needed to help with developmental delays and their rare disease disability. Not every provider offers the services needed. Many discussed good providers they had found, only to have that provider leave the service or relocate. In these cases, there was never a handover or referral. The parent had to source a new provider themselves. Some parents in our project said that after being on a waitlist, they came to find that a service or practitioner did not have the required skills to work with their child's identified needs.

> "I asked before ... that we are using [a] AAC [Augmentative and Alternative Communication] device. How familiar are you with the AAC device? And [therapist said] oh, no, not a big deal. Yeah, I can do it. Now I came to know [therapist] is using [a] AAC device [for the] first time ... because I can't find anyone now onwards, right? And it will be another wait time."

Participants in our project often discussed that developmental delays were viewed by services in terms of 'goals'. For example, aligning with goals in a NDIS plan. Goals were often described as generic and unrealistic in that they might be set or compared against a 'normal' child or person and not tailored for a child with rare disease disability. This kind of goal setting could be frustrating or distressing for parents as they were aware their child might not achieve the goal. Some parents expressed that generic and unrealistic goals were deficit based. They did not recognise the strengths of their child, and that being different and having rare disease disability is OK. Asking parents what their goals were for their child was also described as unhelpful as parents want realistic goals and expert opinions.

> "Well, I think it has to be a really collaborative approach, right? Like you as a parent can only do so much, but the therapist has to like put the hard work in to actually try and reach that goal, right? Like I think if you're not on the same page, or if you don't agree with the goals ... like I do think it's really important for the therapist to come up with the goals to the parents because I think sometimes in that specific specialty, they are half an expert with your child, right? And it's hard for parents like, oh my god, how much more do you want us to like make a decision on?"

Participants got the impression from services that developmental delays were not lifelong and could be caught up on (i.e. transient and not permanent). But this generally wasn't the case where there was a diagnosed rare disease disability. Or children might catch up with some developmental delays, but others remain and become more pronounced over time. For example, a child might catch up on their speech delay, or gross motor skills, but intellectual disability is lifelong. In many cases across our study, children would progress in skills but then lose other skills and/or regress.

> " ... There are some times where you think, oh my gosh, it's so slow and you, like, you feel like you've mastered one skill, or [child's] mastered the skill, and then you move on to the next skill and then she seems to forget the previous skill.
>
> "But also, I've never felt so ignored and powerless as to ... every year going, we've made progress, but ... you're almost scared to tell the NDIS any progress that's been made with development delay because are they going to then cut funding? And then the next year [they're] going to go backwards and they're going to regress."

Finally, given that our study was on rare disease developmental delay, most parents talked about the frustrations of providers not knowing about their child's condition. Parents expressed it was tiring having to go through the same assessments and repeat information about pregnancy, birth, and milestones. They then eventually came to find that the allied health provider does not know about the rare disease, and/or having information they provided dismissed with generic 'one-size-fits-all' interventions applied. Participants in our study discussed that generic services for everyone such as OT, speech and physio all at once can result in too many appointments. In the end, parents often found that long awaited services did not help in the way they had imagined.

> "I feel like it was very overwhelming in terms of like, these are all the things that [child] she could struggle with later down the track, and these are the things she is struggling with. So, we'll just cover all bases and just, and we probably overloaded her and ourselves in terms of getting every single therapy.
>
> "It's like your trial and error. It's like, OK, well, now I've wasted 12 months of all this money in therapy, but I figured out ... no, that's not the good one to go to. Like, oh, this person needs to specialise in this, or this is what we're looking for. But it's purely the parent is educating themselves on all these rare things."

Looking for more practical tips? Download the Practical Tips for Parents and Carers companion resource.

Notes and references

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3. 20 x interviews were conducted online, via Microsoft Teams, in 2026. Participants came from Queensland, New South Wales, Victoria, and South Australia - 3 x regional. Participants were parents of children with a diagnosed or undiagnosed rare disease/disability, of which development delay played a part. 9 of the children had Smith Magen is Syndrome, caused by a genetic deletion or mutation, 9 x children had other syndromes caused by genetic deletions and/or duplications/mutations, 1 x child had a syndrome characterised by multiple physical disabilities, and 1 x did not have a diagnosis. They had a genetic abnormality (one-of-a-kind in the world). Ages of children of the participants were: 4 x 5 years and under, 10 x 6-10 years, 4 x 11-16 years, 2 were adult children - 23 years (diagnosed in 2024 at age 21), and 34 years (diagnosed in 2020 at age 8).
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8. The findings captured in this resource are a snapshot relevant to building the capacity of parents to navigate services systems. The study resulted in other findings relevant to health and allied professionals and systems which we hope to build on in future projects.
9. NB It is not the aim of this guide to provide health advice on development delay, rare disease or disability. If you have concerns about your child's development and/or health, please see a relevant health provider.

Notes and references

10. We acknowledge that this is a small sample, and that the intent of this project was not to conduct health and/or clinical research. However, this finding is considered significant across 20 interviews, and we would suggest warrants further investigation via research and advocacy.
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