

HEALTH PATHWAYS SUMMARY REPORT



LOGAN
together

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INTRODUCTION

While some parts of the Logan community are faring well, others experience deep and persistent disadvantage, with correspondingly high levels of developmental vulnerability for many children. The 2018 Australian Early Development Census, revealed 31% of five-year-olds in Logan (some 1,511 children), are developmentally vulnerable on one or more domain when they start school, which is higher than state and national averages. Anecdotally, identification and support for developmental vulnerabilities occurs late for some Logan children, for a range of reasons.

When this happens, the critical window to intervene early, when interventions are most impactful, is lost. Logan Together has been working with partner organisations including the Department of Education, Brisbane South PHN and the Centre for Children's Health and Wellbeing, to better understand the service needs and experiences of children with developmental vulnerabilities, and the key touch points for early intervention.

In 2018, the Department of Education collated data for a cohort of children commencing Prep, to retrospectively review support for children with developmental concerns prior to starting school. Several of the families from this cohort, subsequently met with staff from the Centre for Children's Health and Wellbeing in April 2019, to share their child's health journey through the personal accounts of parents.

In mid to late 2019, Logan Together commissioned interviews with a further 30 parents across Logan, to build on this earlier work and explore the issues in greater detail. This report provides a summary of the findings from these interviews and recommendations to guide planning and improvements efforts.



BACKGROUND

The early years of a child's life have a profound impact on their future health, development and wellbeing (McKenzie and DaCosta, 2015). There is strong evidence from Australia and overseas, that programs aimed at supporting healthy development and alleviating disadvantage during the early years of life, are effective in improving outcomes for children, and, yield higher returns on investment than remedial interventions later in life (Heckman, 2008).

Effective interventions have been found to have the greatest benefit during the first three years of life (Richter et. al, 2017). Early intervention and prevention programs particularly in the areas of maternal, child and family health, early childhood education and care, and family support programs, have been found to be especially beneficial for children and families from disadvantaged background (COAG, 2009a).

Listening activities undertaken by Logan Together with parents in 2016, highlighted delays in identifying developmental concerns and accessing services and support for children. Common barriers included cost, lack of available services, and the complexities of the service system. Parental beliefs were found to be another barrier, with some parents of the view that if their child had developmental issues, these would be resolved when their child entered the formal education system at Prep.

Consultations undertaken by Logan Together with Early Childhood Education and Care services the same year, also found that most staff have limited knowledge about healthy child development, and many centres are not equipped to identify and respond appropriately to children with vulnerabilities or delays. This is a critical gap given the potential of Early Childhood Education and Care settings to contribute substantially to a comprehensive system of early detection and support (ARACY, 2015).

PURPOSE AND SCOPE

Interviews were undertaken with parents and caregivers of children living in Logan to:

- better understand the health and early learning pathways children take before commencing formal schooling, and the key touch points where developmental concerns can be identified and responded to early.
- explore children's experiences accessing services and support through the eyes of parents.

Insights from the interviews will be used to inform future planning and improvement efforts across the health and early education sectors.

METHODOLOGY

Face to face interviews were conducted with parents of children in Prep, Grade 1 or Grade 2 using a semi-structured questionnaire. In a small number of cases parents also selected to self administer the questionnaire.

Consent was obtained from parents to participate and to digitally voice record interviews, and no personal (identifying) information was collected. Questionnaire responses and transcripts were then analysed to identify themes and patterns.

QUESTIONNAIRE PARTICIPANTS

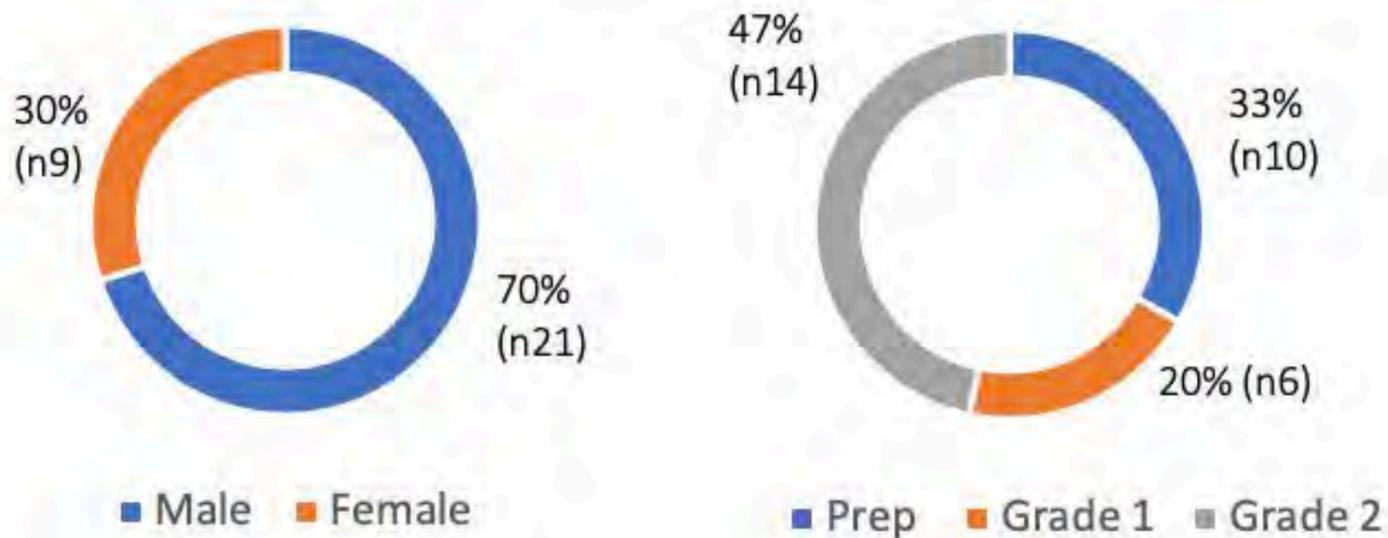
A total of 30 parents completed the questionnaire. These parents were sourced through local schools, community organisations, sporting groups and the Logan Mums n Bubs Facebook group. They were predominantly mothers whose first language was English.



QUESTIONNAIRE SUBJECTS

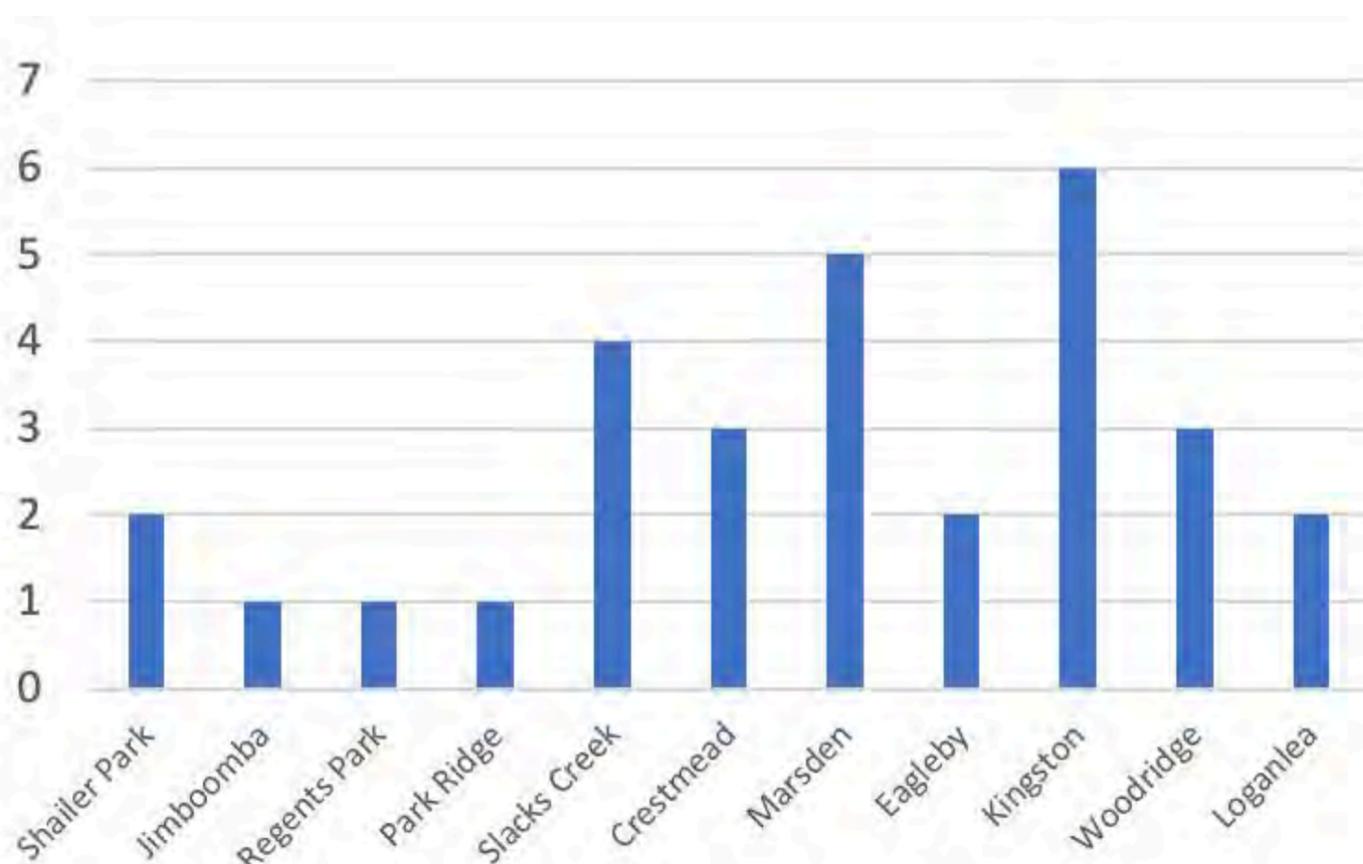
The children who were subject of the interviews were predominantly male and most children were in Grade 2.

Figure 1.0 Children by Gender & Year Level



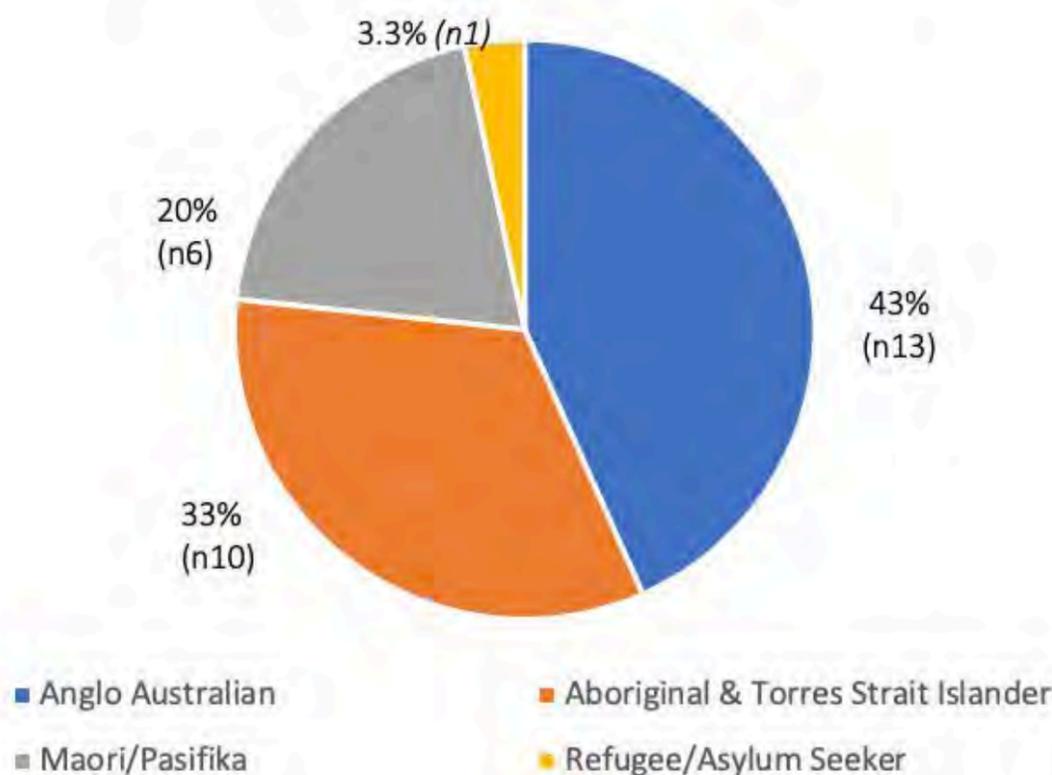
At the time, the majority of children were residing in Kingston, followed by Marsden and then Slacks Creek. Figure 2.0 outlines the distribution breakdown by suburb.

Figure 2.0 Children by Suburb of Residence



43% of the children were Anglo Australians, 33% were Aboriginal and Torres Strait Islander background and 20% were from Maori/Pasifika background.

Figure 3.0 Children by Cultural Background



Developmental delays were the most commonly reported issues experienced by the children represented (50%).

FINDINGS

1. General Practitioners and Early Education and Care Services are critical touch points for early identification and support for children with developmental issues and their families.
2. More than half of the parents interviewed were dissatisfied with the care provided by their child's general practitioner and felt they should have identified their child's developmental issue/s earlier (53%).
3. Other key concerns and experiences reported by parents include: lengthy waiting times through the public health system; difficulty obtaining a diagnosis for their child's behaviour concerns; cost of services; lack of coordination in health care services; not meeting criteria for funding; not feeling heard by their health professional; and lack of referrals/timely referrals by general practitioners.
4. Parents who visited an integrated service with their child found it easier to access services and support and had higher levels of satisfaction with the services they received (30%).
5. While all children had attended some form of Early Education and Care, there were few parental reports of Early Education and Care Services identifying children's developmental issues (n4, 13%).

6. A high proportion of parents (67%) did not know how to access services and support for their child, and 40% reported that they did not understand the type of services available to their child.
7. Parental beliefs and behaviours around when and where to seek support for their child, also acted as barriers to early identification and support for developmental issues.
8. No significant patterns emerged regarding children/parent's cultural backgrounds and their experiences.

RECOMMENDATIONS

1. The professional development needs of general practitioners regarding early identification and support for children with development issues, are explored in more depth and responded to as appropriate.
2. Efforts to advocate for and grow integrated services in Logan continue, in order to improve access, continuity and coordination of care for children with developmental and other issues.
3. There is a co-designed and coordinated response to ensure that Early Education and Care Services in Logan have the knowledge, resources and capability to identify and respond to developmental concerns early, and to provide appropriate support to families.
4. The Family Day Care and Playgroup sectors are also engaged around early identification & support for children in their care with developmental issues, and are part of the co-designed response moving forward.
5. The findings in relation to Early Education and Care Services are provided to the Integrated Tertiary Pathways for Early Childhood Education and Care in Logan, Project Team at Griffith University.
6. A communications response is co-designed to support parents to understand and navigate services for their children, and to address parental beliefs and misconceptions about early identification and support for developmental issues.



CHILD HEALTH AND DEVELOPMENT ISSUES

Developmental vulnerabilities and delays were the most commonly reported issue experienced by children (50%). These included Global Developmental Delay, cognitive and speech delays, Dyspraxia, Auditory Processing Disorder, Dyslexia and Dysgraphia. This was followed by Autism, Attention Deficit Hyperactivity Disorder and hearing difficulties. Some children experienced more than one issue.

Figure 4.0 Child Health & Development Issues

Issue by Category	(n)	%
Developmental vulnerabilities and delays	15	50
Autism*	4	16
ADHD*	4	16
Suspected developmental delay	4	16
Hearing impairment/difficulties	4	16
Vision impairment	3	12
Behavioural disorder/difficulties	2	8
Other	1	4

*Diagnosed and suspected

KEY TOUCH POINTS

The most common touch points for children and families within the health system were general practitioners (77%) and medical specialists (47%). All children and families had accessed some form of early education and care, with Long Day Care and Kindergarten being the most frequently reported touch points.

A significant number of families also accessed Integrated Services (30%) and these included the Aboriginal and Torres Strait Islander Community Health Service, the AEIOU Foundation, Early Childhood Development Programs and the Browns Plains Early Years Centre. Other touch points are outlined in Figure 5.0.

Figure 5.0 Touch Points for Children & Families

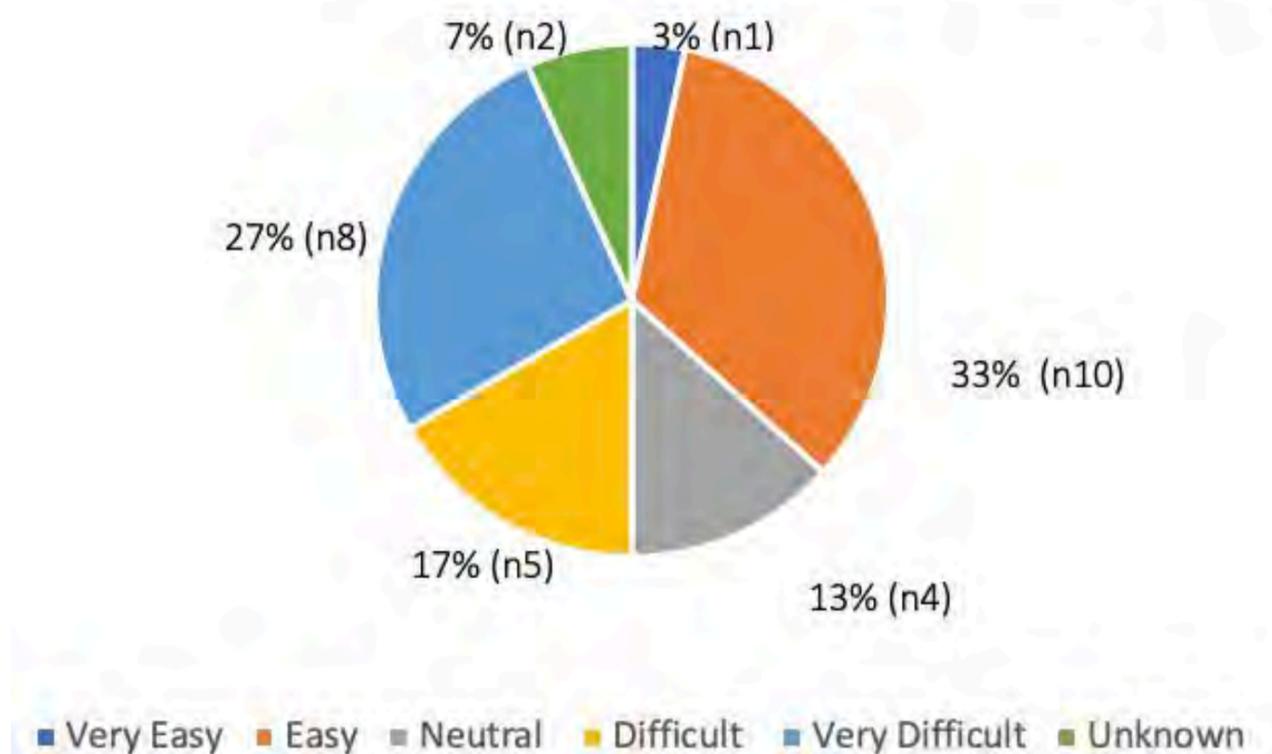
Health	(n)	%
Visited the same GP	23	77
Medical specialist	14	47
Child Health Nurse	11	37
Unknown	5	17
Early Education & Care	(n)	%
Long Day Care	16	53
Kindergarten	15	50
Family Day Care	6	20
Other	(n)	%
Integrated services	9	30
Playgroup	8	27
Online support groups	2	7

ACCESS TO SERVICES AND SUPPORT

Parents were asked to rate the degree of difficulty in accessing services and support for their children on a 5-point Likert Scale from "Very Easy" to "Very Difficult". A combined total of 44% of parents rated access "Very Difficult" or "Difficult".

33% of parents rated access to services and support "Easy". Of significance is these parents had accessed an integrated service and had high levels of satisfaction with these services. Conversely, parents who did not use integrated services had high levels of dissatisfaction with services and difficulty accessing these services.

Figure 6.0 Degree of Difficulty Accessing Services



PARENTAL VIEWS ON CHILDREN'S CARE

The top concern or experience reported by parents was they felt their child's developmental delay should have been identified by their general practitioner earlier (53%). This was followed by excessive waiting times through the public health system, difficulties obtaining a diagnosis for behavioural concerns, cost as a barrier to accessing services, lack of co-ordination in health care services, not meeting criteria for funding, not feeling heard by their health professional and lack of referral/timely referral by their general practitioner.

While all children had attended some form of Early Education and Care, there were only 4 reports of these services identifying children's developmental issues.

Figure 7.0 Parental Views on Children's Care

Theme	N	%
Parent felt their child's developmental vulnerability or delay should have been identified by a health professional* earlier.	16	53
Parent reported excessive waiting times through the public health system	14	47
Parent reported frustration and/or stress with trying to obtain a diagnosis for their child's behavioural concerns.	13	43
Parent report that the cost of services was a barrier to access	10	33
Parent reported a lack of coordination in health care services for their child	9	30
Parent reported frustration and/or stress that their child did not meet criteria for funding or support despite being in need of assistance (ADHD).	9	30
Parent said they did not feel heard by their health professional*	9	30
Parent reported that a health professional did not provide a referral when they raised concerns about their child*	8	27
Parent reported a lack of services available for their child (<i>Paediatricians, early interventions services for children with special needs</i>)	5	17
Parent believed ECEC staff were not trained to identify developmental delays and disabilities.	4	13
Parent reported a lack of continuous care/support for their child by the same professional (<i>GPs and Support Workers</i>)	4	13
Parent reported a lack of outreach/mobile services for their child aside from speech pathology and occupational therapy.	3	10
Parent felt there was inadequate emotional support for parents.	3	10
Parent reported lack of information sharing/co-ordination within health setting.	3	10
Parent reported a lack of outreach/mobile services for their child aside from speech pathology and occupational therapy.	3	10
Parent felt there was inadequate emotional support for parents.	3	10
Parent reported lack of information sharing/co-ordination within health setting.	3	10

*mostly General Practitioners and several Child Health Nurses

PARENTAL KNOWLEDGE AND BELIEFS

67% of parents said they did not know how to access services and support for their child, and 40% had difficulty understanding the type of services available. 60% did not seek assistance from their Early Childhood Education and Care Service for developmental concerns.

Parental beliefs and behaviours, including but not limited to when and where to seek support for their child, also acted as barriers to early identification and support for developmental issues. 23% of parents said they did not pursue their child's developmental issues or delayed pursuing these. Reasons for this included: fear of intervention by child safety; mistrust of services; being a young parent/lack of awareness; parental mental health; and difficulty accessing services.

Figure 8.0 Parental Knowledge and Beliefs

Theme	N	%
Parent said they did not know how to access services and support for their child.	20	67
Parent said they did not seek assistance from their child's ECEC for developmental concerns (<i>no reasons offered</i>)	18	60
Parent reported difficulty with understanding the type of services available to their child.	12	40
Parent said they did not pursue developmental concerns over their child or delayed pursuing concerns.	7	23
Parent said they were not aware they could engage with health services in relation to their child's developmental or behavioural concerns.	7	23
Parent reported feelings of grief and/or denial over their child's condition	3	10
Parent said they had difficult understanding funding eligibility	2	7
Parent said their own mental health prevented them from accessing services and support for their child	1	3
Parent believed their child's issues would be sorted out when they got to school	1	3
Parent believed their love for their child was all that was needed	1	3



CASE STUDY 5

Priscilla is the mother of Ruby who is of Aboriginal decent and currently in Prep. Ruby has a vision impairment and behavioural difficulties.

**Names in this case study have been changed to protect the identity of interview participants and subjects*

Ruby has bad vision. Her vision issue has affected her learning because she is having trouble reading. She won't keep her glasses on, and she can't see without her glasses.

It was discovered at her 4-year check at the Aboriginal Community Health Hub [Aboriginal and Torres Strait Islander Community Health Service]. I have found the service good. We have a Social Worker that works there as well. We just went and seen the Paediatrician at the same location. They are all in the one place which is so easy. The fact that you have to travel to the Children's Hospital makes it so hard.

Ruby has been suffering with enlarged tonsils now for three years. She just keeps getting told "Oh, you're on the waiting list". Anything to do with the hospitals is incredibly frustrating and I can't afford to go private. That's why I found the hub is great. Their waiting lists are a few months but at least it's local, and, you don't have to travel to the city just be told "Oh, we can't see you right now anyway".

They need more Community Health Hubs where you can see the one service – like the paediatrician and the podiatrist and all that sort of stuff in the one area – and not just for Aboriginal families.



CASE STUDY 7

Daisy is the mother of Cameron who is of Aboriginal decent. Cameron is currently in Grade 1 and has Autism.

**Names in this case study have been changed to protect the identity of interview participants and subjects*

I found out about the AEIOU through the GP at Logan Mums and Bubs [Aboriginal and Torres Strait Islander Community Health Service]. Cameron was two and a half, because it took us almost a year to get in to AEIOU. One major flaw, is not having enough of these Early Intervention Centres, and the waiting time and what to do in between. You're in limbo from getting the diagnosis, to accessing the service. You might be able to access Speech and OT but not as much. That was the main thing of getting him in to AEIOU. The doctor was very supportive.

With AEIOU it's a whole team of Speech, OTs, Behavioural Therapists, Behavioural Analysts, and then a Learning Facilitator. It's like a one stop shop for early intervention. You do parent information nights, where you go for two hours, and you learn about different techniques you got to use with the children.

There's a lot more pros. Just even the way that it operated. The service was operated like how a day care would – like the hours. You could drop them off between 7:00 and 9:00. The program starts at 9:00 to 2:30, and in between those hours, that's when they do the early intervention and work with the therapist one-on-one.

For Cameron, he had to have a lot of behavioural management plans put in place because of his behaviour. They were really able to accommodate him. There were a few times that his behaviour got really bad. He was head banging seventy times a day, and they called in other experts in the field - people that were more trained in that behavioural management side.

Before we went to AEIOU, it was like "Oh, you've got to go to speech therapy". The Speech Therapist would say, "Oh, you've got to go to OT because the OT is going to help with dealing with those frustrations, with getting dressed and tolerating sensory issues". Everyone has to be approaching it the same way, where one isn't more important than the other.

With his speech he was able to learn a few different things. He was able to count and his skills in that level went up like a lot.

At the AEIOU you drop your child there, and you could stay at the back and talk with the other parents, while you're watching your child. You could spend about twenty minutes just talking to other parents. You're just so open about things that you're not so open about - like faecal smearing, like the meltdowns. It was the first time since him being diagnosed where I was able to talk about it, but also laugh about it. I met some really beautiful people and beautiful families.

CASE STUDY 7 (CONTINUED)

I was the only single mum so that was tough. I always thought maybe Cameroun could get more from the service if we had a little bit more help at home to implement the strategies. With the AEIOU they come out to your house...they're just all ears. There's no judgment, and they always put a positive spin on things. I really learnt a lot from them. I was upset when Cameron left and we go past it every day.

I attended all the training. From the start the goal is [to] feel you're equipped - where you feel you're able to do what they're doing. They say "We're not here to change your child. We want you to be able to walk away from here feeling confident". I definitely am when I'm out in public now with him. He does have those meltdowns, but when I'm with him now I'm not, crying, you know.

I think for children who are not diagnosed yet, they just look like bad kids. But educators that are really trained, they just know. I think there just needs to be different ways that people can communicate to parents. Rather than bringing these bad things to parents' attention and trying to change them, and not really looking at what these children can do.

I found a lot of times that I did come up against "Well we can't really have Cameron because he's not toilet trained or he's not able to tolerate routine". What he looks like on paper looks too much and people aren't willing to give him a go. That's something that he still has to this day. I would just like for people to give the kids a chance, and get to know them and determine what they need from there.

Before they're into these services [AEIOU], it would just be nice if there were more inclusion practices in mainstream services. I think society in general wants to be like that - but they're not practicing it from the grassroots. The more included these children are in mainstream services, there probably wouldn't be such a clog in special-needs services, because they are able to integrate better in mainstream options.

I'd like to see something like the AEIOU for older kids. I think his regression in speech now that he is in primary school, is because he's not getting that one-on-one speech therapy, he's only getting about two hours a week at home. That's through NDIS. One thing I used to say to AEIOU, although they have workshops with the parents, it would be great to have a service where you're working with the children, and you're demonstrating how to play together. That's why I like speech at home. Having a therapist there in your home is pretty valuable. I just would like more of it.

CASE STUDY 8

Francene is the mother of Rory who is currently in Grade 2. Rory has Attention Deficit Disorder, Low Tone and Hearing and Speech difficulties.

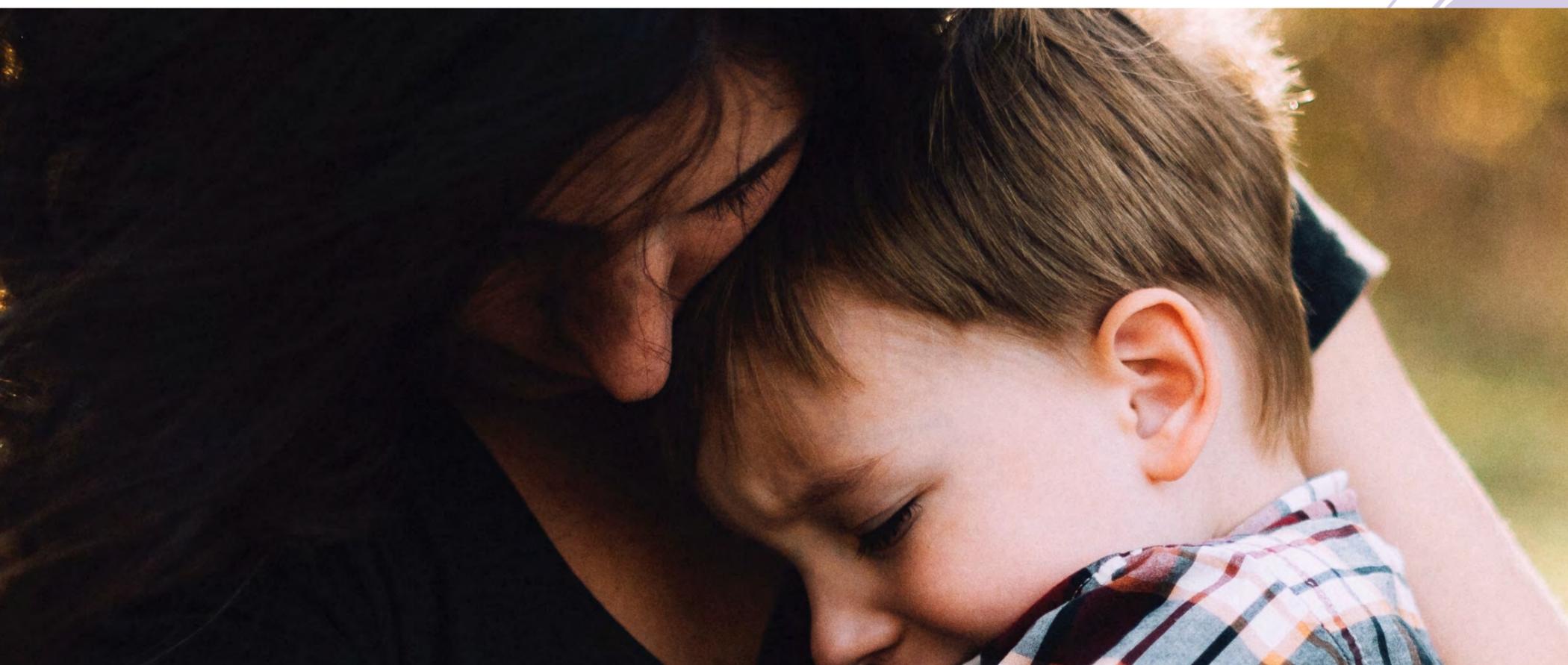
**Names in this case study have been changed to protect the identity of interview participants and subjects*

Nobody referred me anywhere until we sort of hit Year [Grade] one. I was conversing with the teacher a lot about his struggles. He struggled to learn his sight words, he struggled with maths, he struggles with writing and all this sort of stuff. I think it was term three of Year one, he was just crying and hiding under tables.

I went to the doctor and I said "No, I need a referral to the Paediatrician" because he hadn't referred me. He kept saying "He'll grow out of it, he'll grow out of it". When we finally went to the Paediatrician, as soon as we walked in the Paediatrician said, and this is the private system by the way, he said "Clearly he's got Low Tone." It's like, "Oh, my God", he knew straight away. He made him lay down and he couldn't sit up. From sitting down, he couldn't stand up. Basically, he's like a floppy kid, but that doesn't qualify him for any support at school at all. So, we have to come up with different ways of supporting him.

No one had picked up on it. I also think there's not enough knowledge in the early years. I know it's about health, but none of the girls [Early Childhood Educators] picked up on it either. I didn't even pick up on it. I knew there was something, but I didn't know what. It's all about paperwork, and this and that. But what about training on how to recognise disabilities? – and not just ADD and ADHD because that's so prominent.

Getting the diagnosis before school would have helped. We could have started to do things earlier.



CASE STUDY 11

Taylor is the mother of Paul who is currently in Grade Two. Paul has ADHD, severe dyslexia and dysgraphia.

**Names in this case study have been changed to protect the identity of interview participants and subjects*

I had a suspicion that he probably did have ADHD. I wasn't aware of the Dyslexia and the Dysgraphia probably until he started school. Certainly in Kindy, I was pushing the teacher to write a letter to the Paediatrician. I did something called PEDS [Parents' Evaluation of Developmental Status] through the Kindy. It was meant to be an early intervention sort of thing. Basically they said, "Oh yes, he's sort of lacking this, this and this".

I went to another childcare centre. I thought it was possibly an avenue to get more help and support with him. The Kindy teachers noticed he was different. It was just like "Oh yes, for these areas we would recommend this" - and then it was like see you later. There were no recommendations on where I could really go, what I could do. Which has been my whole sort of thing. I go from one professional to the next, to the next. They go "Ah, you should probably see a Speech Pathologist - I know this one but I don't know if they are in your area."

I didn't think to raise certain things with the GP for development and things like that. I don't know, that could be partly my fault as well. My GP did connect me with a Psychologist ...but your options are limited around the place as well. It's not like there's a plethora of psychologists around, or OTs or Speechies. It would be good to have a helpline to go "Where do I go to?", "I want to chat this out, these are my issues", "Who do I need to see about this - is this an OT issue? Is this a psychology issue?"

Sometimes with professionals, and I know I run into this in my job, you can get a bit stuck in our sort of jargon. We haven't broken it down enough for people to understand what to do. So, you can kind of feel like you have asked the question, and they've answered it in their way, but that hasn't given you a clear enough picture of what should I be doing, where should I be going, how often should I be seeing you? Even just having that "Can I touch base with you with an email or call you, or something like that to just check in about this or that" would be really great.

It's like me working in ... it's like having continuity of care. Like, you kind of need that ongoing relationship where you feel comfortable going "Look, this behaviour keeps happening", "I tried this, this and this and I'm out of ideas", "I need help. What do I do?". Sometimes you just don't know where to go ... you don't know what to do.

CASE STUDY 12

Alina is the mother of Katie who is 5 years of age and from a Refugee background. Katie is non-verbal and has undiagnosed developmental difficulties.

**Names in this case study have been changed to protect the identity of interview participants and subjects*

Katie doesn't talk to people. She is unable to express herself. She can sing and count, but will not respond to people. It's not shyness. She only uses three words – mum, dad and her sister's name. Out of the house, she wears nappies and won't communicate when she needs to go to the toilet.

I noticed she was different at two and a half years. We have informed the GP and hospital, but so far nothing has happened, and she is now 5. She was boisterous, aggressive and not talking to people. The GP did the referral to the hospital.

She should have gone to Prep this year, but she repeated Kindy. Next year, when she turns 6, she must attend school. We don't know whether she will be going to normal school or special school. We need to apply for schools, and we have only two more weeks to be able to apply - we are a bit worried about it. Before that, we want to meet the doctor, and get a report from the doctor about her condition. We are waiting for something to happen, but nothing has happened yet.

The Kindy teacher advised us to apply for the special school. There is one to one care for her at the Kindy and she has improved a lot in the last year. Three people are involved in helping us apply for school - the community people, the Kindy teacher and Access. They requested us to apply for NDIS. We have applied and we are waiting for the appointment. The Kindy teacher and ACCESS have given a report and we've also given the hospital appointment letters.

At the Kindy, a school teacher from the normal school and some other people have come in and observed her, but they haven't recommended or suggested for a particular person or anything.

We don't know if anything else could have helped because we have no knowledge about this type of problem. If we can find out from the OT or some other people what we can do to improve her, then that would be good - but we don't know.

CASE STUDY 15

Kathryn is the mother of William who is of Aboriginal and Maori decent. William is currently in Prep and has a speech impediment.

**Names in this case study have been changed to protect the identity of interview participants and subjects*

Before he started school, I was mainly concerned about his speech. I didn't talk to anyone about it until this year [Prep]. His older siblings said "Mom, mom he's slow". I knew it, but I was just "Oh yeah okay". He did have a 715 Health Check, which is a complete Indigenous health check, and they also picked it up too. They called it a speech impediment, so they referred us to the Speech Therapist at the Health Clinic [ATSICHS].

So every nine months, Indigenous people have a 715 Health Check. They'll let you know when it's your turn. They do everything from optical, speech, physio, dental. They do this whole test and we're like, "Oh, my god" - and they get free Deadly Choices glasses. Next month William's ready for his dental. They'll clean his whole teeth out, wash his whole mouth. She [the Speech Therapist] visits the clinic. They promote health and anti-smoking ... and they have free drop-offs and pickups for clients in the van. It's very community and I love it. I know everyone in there.

They do all the services. They've got a physio for William, podiatry, optometry, dental, you name it. They even have paediatrics. They've got my daughter booked in for paediatrics too. Because she has special needs, the doctor said, "Look, we'll book her in," because I was taking her to the city, and it cost like \$200 an appointment.

They've got all these allied professional health people, and they book them, and they come on a certain day. Everyone goes and sees them ... and counselling services, because I lost my son last year.

It's really easy getting help. I had to understand their system though. My husband wanted me to find an Indigenous Clinic. We either googled it or we knew friends and they were like, "Oh yeah, go to Woodridge." I went down there and bang. I just asked them questions, grabbed their pamphlets, and went online on their website.

Everything I need is there.

CASE STUDY 16

Cassie is the mother of Jack who is currently in Grade 2 and has suspected Autism.

**Names in this case study have been changed to protect the identity of interview participants and subjects*

We've been waiting for Jack to turn seven and a half so the school can diagnose him. They're going to do their testing probably next week or the week after. I was a drug addict in recovery, so Jack was with my mum for the first 3 years of his life. When I got him, I was always saying to my mom "Mum he's slow, he's behind, he should be talking now". He always had his speech problem. He didn't really talk until he was about three and a half. Mum said "He's just a boy, he's just a boy" and snubbed it off. The doctor was saying the same thing. I ended up changing doctors, but the new doctor wasn't really that helpful. So, I just thought, when he gets to school, they'll sort him out. When he started school, by that stage, I was begging the doctor to do something.

He was struggling, he was way behind everybody else. He didn't want to learn. The Speech Pathologist seen him for the first year and a half – prep, and half of year one, which definitely changed him. He's speaking better and he improved so much.

I'm sure he's sensory. He always has to have his socks inside out, he can't have them touching him. His tags have to be cut off. He can't look you in the eye when he's talking to you. He repeats everything you say to him, and walks around making some weird noise. He's full-on all the time. We had to wait for him to turn seven for the school to be able to do a sort of diagnosis. So they can see if he can go to special needs for some days and the normal classes for the rest of day.

I had to go to the doctors and get a mental health report done for him. We're finally seeing someone on [date removed] through the health department. It's taken a year on a waiting list to get an appointment. One year on a waiting list to get something done about this. I'm also waiting to see a Paediatrician. We've been referred to all these things. I'm like, "Why is it taking so long for anyone to see him?" Is it because I don't have the money to pay for these, to pay for the appointment right away? I have to wait on the public health system. Is it because he's not smashing tables or throwing?

No one listened to me because I was just in the early days of recovery. I can sort of understand that now, but back then, I was really angry and very defensive about it. He's not talking, he's not walking, all these things he should be doing. It's been going since he was about two - he's seven now. This is years I've been pointing it out, but no one was listening.

I've been telling her [the GP] for years, and she would just say it's because he's a boy and because of the traumatic childhood he had. Most people say "Oh, boys are slower."

I know he's definitely on the spectrum. I've Googled and I follow a lot of news feeds on Mums and Bubs and I see other people what they say about their kids. I've sort of self-diagnosed him and I reckon he's got Sensory Processing Disorder, I'm sure of it. He's probably got Defiant Disorder, maybe ADHD. I don't know, we'll find out.

CASE STUDY 16 (CONTINUED)

I didn't go anywhere before school, I just listened to everyone else. I just presumed like everyone else that it was because of my drug problem. Or maybe it's me. I took it all on.

I've spoken to the Kindy since then because he went to kindy for a few months. I've spoken to them and I said, "Did you think there was any sensory issues or anything?" And they said, "Well his speaking was a bit behind" – so they did notice but they never really said anything.

What could have helped is support, people listening. I think awareness around the situation, you know. My doctor didn't really understand it. She just labelled it as childhood. He's a boy blah blah. Same as my family.

I think people need awareness around it, they need to understand - parents, GPs, schools, hospitals. Everyone should be educated around this. They should be sat down and trained. There should be more funding or something to help. No one is listening ... I mean, us single mums, we're going crazy. We just want some sort of help for our kids so that they don't end up on in jails and institutions.



CASE STUDY 17

Kelly is the mother of Sam who is currently in Grade 1 and has learning difficulties and gastrointestinal issues.

**Names in this case study have been changed to protect the identity of interview participants and subjects*

I guess before going to school we knew there were issues then, but we kind of hadn't really addressed it. I guess the reason was, I'd heard services were really hard to get into. We knew she was a bit behind, but I guess we never really quite knew how far behind she was. We were just sort of going, she's a bit behind but she's a kid, she'll catch up.

I have mentioned to friends that I might start back up and go back to play group. Unfortunately, our Health Nurse has passed away that we had up there, which was really terribly sad. She was just such a lovely lady, full of so much knowledge. I probably would've been there more if my Health Nurse was still there.

You just feel like you're in this category where there's nothing you know. I guess the persona [sic] is to try to get anything through the public system, but the wait times are - just give up now. Why would you even bother going on a wait list, where they've said it'll be two or three years for you to see an OT? Your child can't wait two or three years to deal with that. Or for speech therapy, a three year wait.

Where are they going to be in three years, if they're not getting those services provided to them? A lot of people say that early intervention is key. Where's that early intervention, if you got a wait list a couple years long? Which is why a lot of people have to go privately, and then pay an absolutely bomb to try to get those diagnoses.

The hospital did an overall review of Sam's health. It came to that, because I was kicking up a stink about them not getting to a diagnosis on her gastro issues. That was from two ... When we got referred to them initially, they tried to send us through Gastro. Gastro rejected her referral, and said she needs to see general Paeds first. So we had to wait for an appointment through general Paeds ...which took months.

Once we got into general Paeds we went to a couple of appointments. Then they turned around and said she needs to see Gastro. Then it's like, we've got to wait for an appointment to get back into gastro, where we should've gone in the first place. So she probably didn't even end up getting in until I'd say she would've been closer to three.

It was probably a good year and a half of seeing them. They trialled things, we tried different diets, she'd done stool samples, she'd done blood tests, and they just couldn't come to an answer. She was still doubled over in pain daily, crying about stomach issues. And then pregnant hormonal me got to that point one day where I just said - "I've had enough ... I'm not happy, you guys need to do something". That's when they said let's do a whole new review on her case, where they had a whole set of new fresh eyes look over her.

CASE STUDY 17 (CONTINUED)

There was OTs, Psychologists, Speech - it was a lot of health. They spoke to me, they spoke to Sam, everyone sort of just went over her case. That's how they came up with a diagnosis of this pain processing disorder. Then they said, "We've picked up on some delays - we don't think she's developmentally where she needs to be, let's investigate further". So, then we went down that path within OT, into Speech, for them to assess her. It then branched off from that day.

After they did that testing, it basically was, you just go find all these services yourself, and pay for it privately. Which as I've said, I'm a single mum. That was just so far out the window. Once I was looking around to find out how much it was going to be, and I found out the cheapest OT was \$90 an hour - and that was a cheap one. I was like, I can't afford \$90 an hour every week. That's more than a food budget that I'm paying for myself and my children. That's when it kind of just stalled, and we went through Prep without her having any extra sort of support, just because I couldn't afford it.

When she went to kindy, we actually mentioned pretty much straight up, we think she's a little bit behind. At the end of that first year, I sat down and had a meeting with them, and said "How do you think she's traveling?" They said, "We think she's maybe not quite there, but we think she would be able to go throughn school and be okay". "She knows her basics" which is like they only had a very limited checklist of what they would look at as a Kindy teacher. Can they hold their pencil? Do they know some colours and shapes? Socially, would she be okay?

Once we did that second year at Kindy, it was funny because her Kindy teacher said to me " You definitely did the right thing. We can see how much further she's come within that next year of being with us. We think she'll go on and definitely do better now as opposed to if we had sent her". Her Kindy teacher said to me, "Sometimes mom's intuition is best".

At the four-year-old developmental check, they said she was fine. I'm sure it was her GP. Yeah, because it literally takes two minutes. It's not like a developmental check is an hour sitting down working with someone one-on-one. It's literally is she talking okay, let's string a sentence together. It's two minutes - the GPs, they run on a time limit.

What would have helped before school I think is proper developmental checks. Where this would pick up these things and then link you directly into services. Not send you on your way and say go sort this out yourself. Because, you'd send a mum on her way, and say well you've got to go back to a GP and get a referral... you go to a Paediatrician who is then going to say to you, well you now need to get a referral to go to this person.

CASE STUDY 17 (CONTINUED)

Why can't there just be an internal system where they can go, you know what, we've identified that your child needs speech therapy, we've identified your child is going to benefit from some OT sessions. Why not have that where it can just be straight it, it's there.

Those Health Nurses or whatever should be able to ... link you straight in ... if it's all in house, they all work together. Surely one health professional, if they can identify issues, should be able to then say to you "Let's get you on a wait list now, let's not delay this".

For autistic children, that worry is now taken away once they're on NDIS. Our children just fall into that category that it's not available. I think it just really comes down to wait times, funding, costs, maybe even GP knowledge. Is there a central database that a GP could access and say, well current wait times in the Logan area for a Speech Pathologist are two months, two years. If a GP had that knowledge straight up, they would then be able to openly tell a parent - this referral is going to be pointless. Having that knowledge, that would be really helpful for a GP.

