REPORT ON PROCEEDINGS BEFORE

LEGISLATIVE ASSEMBLY COMMITTEE ON COMMUNITY SERVICES

IMPROVING ACCESS TO EARLY CHILDHOOD HEALTH AND DEVELOPMENT CHECKS

At Jubilee Room, Parliament House, Sydney, on Monday 18 November 2024

The Committee met at 9:00.

PRESENT

Mr Clayton Barr (Chair)

Mrs Helen Dalton
Ms Donna Davis
Mrs Tanya Thompson
Ms Felicity Wilson

PRESENT VIA VIDEOCONFERENCE

Ms Liza Butler

The CHAIR: I acknowledge the Gadigal people, who are the traditional custodians of the land on which we are meeting. I pay my respects to Elders past and present of the Eora nation and extend that respect to other Aboriginal and Torres Strait Islander people who are present here or watching proceedings online. Welcome to the first hearing of the Committee on Community Services inquiry into improving access to early childhood health and development checks.

My name is Clayton Barr. I am the Committee Chair. I am joined here in the room by my colleagues Mrs Helen Dalton, who is the member for Murray, and Ms Donna Davis, who is the member for Parramatta. Ms Liza Butler is online. She is the member for the South Coast. At this stage of the day we have apologies from Mrs Tanya Thompson, the member for Myall Lakes, and Ms Felicity Wilson, the member for North Shore, who will be joining later today. We thank the witnesses who are appearing before us today and the stakeholders who have made written submissions. We appreciate their input to this inquiry.

Ms NICHOLE CALLAN, Member, NSW Nurses and Midwives' Association, before the Committee via videoconference, affirmed and examined

Ms EMMA HARDY, Professional Officer, NSW Nurses and Midwives' Association, affirmed and examined

Ms JENNIE CUSITER, Speech Pathology Manager, Health Services Union, sworn and examined

Ms TESSA BOLLARD, Senior Paediatric Dietitian, Health Services Union, affirmed and examined

Mr BLAKE ADAIR-ROBERTS, Divisional Secretary, Allied Health, Health Services Union, affirmed and examined

The CHAIR: Please note that the Committee staff will be taking photos and videos during the hearing. The photos and videos may be used for social media and public engagement purposes on the Legislative Assembly social media pages and websites. Please let the Committee staff know if you object to having photos and videos taken. Do any of you have any questions about the hearing process? If not, I offer the opportunity for both organisations to make a short, two-minute, opening statement. Going to the Health Services Union first, would you like to make an opening statement before we get into questions?

BLAKE ADAIR-ROBERTS: Just briefly. The HSU's submission is focused around, firstly, the Sydney Children's Network in terms of where the survey results have come from and where we've taken the data from. But our recommendations go much broader than that, to the entirety of NSW Health, in relation to the allied health workforce. Noting the recommendations relating to the Henry review that demand for allied health services far exceeds supply, the HSU's recommendations in the submission relate to five key areas. Firstly, mandatory reporting on paediatric health gaps, boosting staff and resourcing, improved wages to ensure attraction or retention of allied health staff, fostering a safe reporting culture for staff within the system and expanding access for vulnerable groups to paediatric allied health services.

The CHAIR: Would anybody from the Nurses and Midwives' Association like to make a two-minute opening statement?

EMMA HARDY: No, thank you.

NICHOLE CALLAN: No, thank you.

The CHAIR: I will kick off the questions and start with the Nurses and Midwives' Association. For the sake of the record, could you please introduce us to the concept of the blue book and developmental health checks? A woman becomes pregnant. At what point in time, and who would typically be starting the conversation with the pregnant person? "We're going to introduce you to this concept of having this blue book. It's got really important markers throughout the journey. It continues, obviously, after the birthing process and into the first couple of years of life." Who, where and when would that introduction be made, and who is most likely to be following it through?

EMMA HARDY: Care starts in the early antenatal period. However, the physical Blue book doesn't actually enter the women's and families' hands until postpartum. That is usually done a few hours after birth. But the entire process starts in pre-conception, all the way through to the first 2,000 days. Nicky will be able to tell you a little bit more about the Blue book as well and what it does for the women.

NICHOLE CALLAN: The blue book starts with our one-to-four-week check. That's when our child and family health nurse does our universal home visit and completes that one-to-four-week check and goes on for a six-week check, and so forth. The child community health nurse completes all those checks with the child and completes the immunisations as per the blue book as well. That's working in partnership with the mum.

The CHAIR: After birth—which on most occasions takes place in a medical facility somewhere but not always, or at least under medical guidance, potentially home birthing and sometimes we have births that take place elsewhere. Once the birth happens—and, in theory, we're engaging on this journey with the mother and newborn—who's responsible then for doing the follow-ups and trying to make sure that the mother and the baby have access to the necessary health checks along the way?

EMMA HARDY: Basically, from the hospital the midwives follow up for the first five days and then they're usually instructed to either see a GP or they can see a child and family health nurse. Child and family health nurse has a more comprehensive follow-up plan. They follow the children through for the first 2,000 days. And whose responsibility is it? Basically, when there's an issue that arises, usually a trained medical professional, such as a child and family health nurse, is able to identify and then they will refer on as required.

NICHOLE CALLAN: In my space, we try and work with the mum before she actually delivers. We meet her at the 36-week gestation mark, so that when I come into the universal home visit, she already is aware of me, she already engages with me and it's a much better connection and partnership so that I'm not a stranger. That is done at the 36-week mark with a belly cast, so a positive engagement process. The hospital where the baby is born—the service there then refers through our administration or our documentation process and the referral is sent straight to the child and family health nurse in that community. We then connect with mum and give her a phone call and see how she is going and then connect with her. We also work with the outreach midwives who work in partnership with us and let us know who has delivered as well. No mum is missed in our communities.

The CHAIR: That final statement there, Nichole, is that just for hospital births where "no mum is missed"?

NICHOLE CALLAN: We are still sent the mums that birth, we're still sent the referrals, but if a mum delivers in another community, and then moves to our community, it is the child and family health nurse from the other community to let us know that she's moved, which they do all the time. We connect with each other all across the State.

The CHAIR: Do you have any sense of how many births take place not in or around a medical environment?

NICHOLE CALLAN: In my space, there's not a massive amount of home births or births outside of the hospital space. Most of the births are completed. I don't have that data. Emma may know. We don't have that data but I am aware that it is only a small amount.

EMMA HARDY: I can take that on notice.

The CHAIR: My basic thinking is that this gets harder and harder and harder as you get more regional, rural and then remote?

NICHOLE CALLAN: I actually find in my space we work so well together because you don't have a lot of services, so you work in partnership to provide the services that are required for mums. Yes, you can travel long distances but these mums are very well cared for because we're all working together, because we know we're all they've got.

Mrs HELEN DALTON: Thank you for attending. I'm from around Griffith, so it is a rural-remote electorate. I have lots of questions about the services. If the maternity department of a local hospital is closed down and you say you're two hours from Wagga and you birth at Wagga, what services are available for that person who is two hours from Wagga? I know you have the initial visit by a qualified practitioner. What happens after that?

NICHOLE CALLAN: This is outside my area, but I believe it would still work the same way as in our area. The mum is still contacted. That universal home visit is completed. Depending on how mum is going, we still offer a second visit to see if mum is breastfeeding or how she's feeding and if there are any concerns. We also check on her in the second week. Depending on how that's going, we will continue to see her on and off if she needs us, or she'll give us a call. Our one-to-four-week check also advises a GP check, and a six-week check also advises a GP check. In my space, we work together with the GPs so that our mums are provided the services they require at the time.

Mrs HELEN DALTON: A big problem with us too, in many of our areas, is that GPs are leaving the area in droves. What happens when the last GP goes? You've got no backup. Say you're at Booligal and you're going into Hay and the last doctor in Hay goes. What happens then for that woman?

NICHOLE CALLAN: I'm afraid they have to travel, or they'll follow up at their local hospital with a telehealth appointment. That's how it is.

Mrs HELEN DALTON: That's how it is. When I was having my children, we had what they called a clinic sister. The clinic sister was based in every town. You could just walk in, whatever the problem. Often when you're having children, you've got more than one. I can remember the clinic sister spotting some problem in my two-year-old. What backup is there now for those people, particularly in rural and remote areas, when it's so difficult? Getting in the car and travelling two hours, if you've got four little kids, can be prohibitive. A lot of those women are not doing that.

NICHOLE CALLAN: No.

Mrs HELEN DALTON: What would be the answer? What's the current push for nurses and midwives? I think there's a real gap.

NICHOLE CALLAN: The child and family health nurse in my space works so well with our families. My positions were vacant for 12 and 18 months before I applied. These families were having to travel. Where I am now, they are covered and I have to travel quite long distances to make sure that these mums are okay. At the moment, I am the first port of call with the mum, the baby and the family when they arrive home. If need be, I connect them into a GP. If I can't get them into the two or three services that I'm aware of, we will then link them into another service and they may be able to do a video link or telehealth consult over the phone with a GP. Our child and family health nurse and our midwife work so hard to ensure that the health services for these families are covered. I have travelled many kilometres on dirt tracks and been in the middle of nowhere to ensure that this care is carried out. These mums are so grateful because before I started they had nobody.

Mrs HELEN DALTON: For sure. You're absolutely working incredibly hard. It's just that we need to return some of those services.

The CHAIR: Do you go from home to home, or do you go into some of these small towns and book a room, and then the mums can come to you? How does it work?

NICHOLE CALLAN: I work across two communities. I have my own office in each community at the local health service, so I work out of the health service. For the first universal visit, we offer a home visit, which is part of the first 2,000 days and the blue book assessments. If mum gives consent, I will travel to her home and check in with her and the baby and see that everything is okay. Then I follow up with that mum and bub as required. I'm travelling long distances from my home to where I work, but it's an amazing job to help these parents. I do think that there definitely needs to be some change, and we can talk about that later.

Mrs HELEN DALTON: Where are you based, Nichole?

NICHOLE CALLAN: I'm not allowed to say—just rural and remote New South Wales.

Ms DONNA DAVIS: Thank you to everyone for being here today and for your contributions. My first question is to Ms Callan. You said that the position had been vacant for a long time. How long have you now been in that position?

NICHOLE CALLAN: It'll be two years—December 2022, two years.

Ms DONNA DAVIS: Do you cover the whole of New South Wales? What is your geographical space?

NICHOLE CALLAN: I cover two communities in rural and remote New South Wales, so I actually work beside the Aboriginal Liaison Officer.

Ms DONNA DAVIS: Okay. How many of you would there be across the State?

NICHOLE CALLAN: Emma?

EMMA HARDY: It's hard to identify in terms of our data. You can either select to be a nurse or a midwife. We don't have many that actually specify whether they're in child and family health, whether they're just a midwife, anything like that. So that is something that we are trying to ascertain ourselves at the moment. I apologise.

Ms DONNA DAVIS: No. There is no need to apologise.

The CHAIR: That's a system problem.

NICHOLE CALLAN: I do know there are many gaps in our service, and the farther rural and remote you go, the worse it becomes.

Ms DONNA DAVIS: Yes. I think Ms Dalton can testify to that. Another question is about the physical clinics. I know the clinic that I took my boys to 20 years ago doesn't exist anymore. I know that councils are predominantly responsible for the buildings that the services have been traditionally delivered in, not only in regional and remote but also in suburban areas. Are you still generally visiting council buildings, or do you tend to be in other premises now?

EMMA HARDY: That varies across LHDs. You will find that sometimes they will be getting the families to come into a certain facility. Other times, as Nicole said previously, they are doing home visits. It really just depends on where they are located within a community and what the circumstances of that LHD are.

Ms DONNA DAVIS: The Chair was asking about mums who don't have a baby in a hospital, but my question is more about what percentage of mums don't engage with the process, or attend the first one, go "Oh, that's not for me", for whatever reason. Do you have that information on what the drop-off is?

EMMA HARDY: I can take that on notice. I think, though, having done some research for this submission, there are definite gaps where there are families falling through the gaps and you will often find that it's due to cultural safety—I think that was a huge thing. I know that Nichole's community has done amazing things, as she said previously, to try to engage that community early so that they form trust and a bond. I think that's very important. Nichole goes in alongside with an Aboriginal health worker. Together, they create plans for these women. They create trust, and they are able to follow these women and families through. So you'll often find that they're opportunistic in terms of doing assessments on the children and families and making sure that their wellbeing and needs are met. Nicky will talk a little bit more about that with her belly castings that she does with her community.

NICHOLE CALLAN: Yes. We actually have a belly casting program where the Aboriginal midwife and the Aboriginal health worker and myself all work together as a partner to engaging a woman early at 36 weeks. We complete a belly cast. It's a really magical experience for our mums. We first offered it to all Aboriginal and Torres Strait Islander mums in our community and it was so successful that we then offered it to all mums to include them as important as within the first 2,000 days. Our immunisation rate when we first started was quite low because, remember, the position was vacant for quite some time. Our immunisation rate over six months—we got up to 100 per cent of that time for our Aboriginal and Torres Strait Islander children. Also engagement in our data, from our documentation, was quite high. It was an amazing project and we have just partnered with another service allowing these women to paint their belly cast. It has been a very positive and rewarding and cultural experience for these families.

The CHAIR: I'm going to throw to Ms Butler for some questions.

Ms LIZA BUTLER: Chair, you and Mrs Dalton actually asked the questions that I was going to ask, so I'm good.

Ms DONNA DAVIS: I have another question.

The CHAIR: We'll come back around because we still have to get to the HSU representatives, who represent people like physiotherapists, dietitians et cetera. If we think our nurses are thin on the ground—

Mrs HELEN DALTON: I just want to ask, because I also come from a community that has about 80 different nationalities, whether there's a push, or what connection the services have with those people. We have a lot of illegal people in this country. Does that mean that, if they're having a baby, they're just slipping through the gap?

EMMA HARDY: Is that to myself?

Mrs HELEN DALTON: Anyone can answer that, if you like.

NICHOLE CALLAN: Can I answer that? In my space, we actually still follow those families up in child and family health. We still carry out the checks for these families.

Mrs HELEN DALTON: That's if you've got the services in your community.

NICHOLE CALLAN: We've actually worked very hard and we've actually worked together as a community to gain the services for our community, so our community has worked very hard since I started and we actually have services. They're not huge amounts, but they cover our communities. But that's only happened since I've commenced the role.

Mrs HELEN DALTON: One other question—a looming issue, and I know this is a little bit left field—and this is for any of you: A lot of these particularly Indigenous children that are born don't have birth certificates. They don't get birth certificates. They go along through life. Is there any concern? Have you noted that yourselves?

NICHOLE CALLAN: We currently work with a service called Barnardos and they actually help us to get the birth certificates for the children. There's another service, too, that also supplies the birth certificates at no cost for the children. We work together as a community to help these kids.

Mrs HELEN DALTON: They're still slipping through the net. That's all from me.

The CHAIR: I'm just going to turn attention to the HSU. That's not to let you off just yet, though; there's every chance we're coming back. I make the point that we've got tens of thousands of nurses and we are struggling to get the nurses to the families and the children. I appreciate your survey et cetera, but what are your thoughts on getting physiotherapists and dietitians? How do they access the more remote communities? It doesn't have to be remote. Rural is probably far enough to struggle and, in some instances, just being regional, it's hard to get to some of these professionals. What are your thoughts about that? As in how good are we doing right now—and I appreciate your survey—and how do we do it better?

BLAKE ADAIR-ROBERTS: I might quickly provide some framing comments on this. The Ministry of Health provided a submission to this inquiry. Within their own submission they acknowledge that there is a significant gap in allied health services—not just in rural areas, but obviously it's quite pronounced in those areas. The impact here is that a lot of children cannot access, or wait far longer than clinically advisable to access, allied health services like physiotherapy, like dietetics, like speech pathology—a range of different professions—and the ministry's submission at 5.5 noted the need for allied health award reform.

One of the big gaps that we do have in this State is that the awards that have been made for a group of 23 different professions have not been updated—have not been modernised—in over 20 years. They predate AHPRA, they predate a lot of the scope and work changes that have occurred in these professions, and that is an attraction and retention issue. When we talk about whether it's a metro area, whether it's a regional area, whether it's a rural or remote area, the fact of the matter is that the awards and the conditions that our members work under in allied health do not reflect modern practices. They do not attract new graduates into the system and they don't retain highly skilled workers. What we then see happening is a kind of compressing effect. You lose highly skilled, qualified clinicians, and that puts more pressure on those entering the profession.

To give you an example of how stark and challenging this is in terms of attraction and retention, the difference in earning for a Queensland physiotherapist versus a New South Wales physiotherapist over the first seven years of their career is $70,000. It causes a big challenge in terms of getting workers in. If we follow that career trajectory over the next four years as they move into a senior clinician role, the next four years of their career, a senior clinician in Queensland will earn $70,000 more to a total of $144,000 over the first 11 years. When we're talking about trying to attract and retain and fill these gaps, which are noted in the Henry review, noted by the ministry, it does boil down to what are the conditions and the pay that our members are working under in New South Wales.

The CHAIR: How are we going with getting your professionals in front of our young people in regional, rural and remote areas? How is that panning out?

TESSA BOLLARD: Not well, no. I think there are long, long, long waitlists at any centre you look at. It doesn't matter if it's rural, regional, metropolitan, at the tertiary centres, primary—they're all really long and to the point where you're waiting to see speech pathology for 18 months and that's getting worse. We're already in a terrible position, but if you look at the children who are surviving conditions that they previously wouldn't have, and you're looking at the complexity of those patients, we're just getting more and more and more patients that we're needing to see and it's taking us longer to see them.

Even if you kept the waitlist the same, we're getting into a worse position than previously. That is most marked in the rural and regional communities. I think a big part of that is that you often have a junior clinician working in those areas, perhaps a new graduate dietician who is working rurally, who simply doesn't have the experience or expertise to be dealing with these complex patients. They will have pushback from their managers saying, "You simply can't manage these patients", so they will decline referrals from the tertiary services and those complex patients then need to stay with the tertiary services, which increases the waitlist to see all of the patients.

Then there's no incentive to stay rural and to stay working in that job, so those clinicians will leave and then you get a new graduate come in, who can't deal with the workload, doesn't have the experience. There's no framework to educate or train them or support them. I think, when you're talking about development checks and looking at gaps in those and how do we screen more people and monitor more children and make sure that all of the families are getting access to those things, I think the bigger issue becomes where those children go when they are identified as being at risk. Because at the moment if they go down the path of trying to access rural services initially and then not being able to access them because there's either not the service or they don't have the experience to be able to manage them, they then get filtered down into the tertiary service and it's just the cycle that goes over and over and over again. So, not well, is my short answer.

JENNIE CUSITER: If I can just add that rural and remote is an important focus for us but it is not the only area that has significant wait times. There are many at-risk, low socio-economic communities that have very high identification rates of developmental issues. A hundred per cent, Tessa has identified that intervention is the thing that changes trajectories and that identification actually needs to occur across a range of different milestone components across the first 2,000 days. You can't pick up developmental issues necessarily before 18 months, and sometimes we are seeing referrals come through at 3½ to four years of age, and that's just too late for us to change things.

Intervention also is costly, I'm going to say. We need time in order to invest in these children's lives. They need specialist intervention, from speech pathology, from occupational therapy. We know that 20 per cent of four-year-olds have a communication issue. That increases to 40 per cent minimum when you're looking at children from low SES areas. The problem is big. Identification is an important part and then the follow-through is the critical changer of lives.

The CHAIR: In my mind, the focus of this inquiry is really around the assessment process. Once someone gets a diagnosis, they need access to ongoing interventions, but how do we get just the assessment done in the first place?

What methodologies are in place to get your professional services into these regional, rural and remote areas, just to do the assessments, first of all—just to see the child?

JENNIE CUSITER: There are some programs that are launching. Brighter Beginnings is a big initiative that's going into early childcare settings, reliant on people engaged in those settings. But, again, it's a little too late, because once you identify them at four years of age, you've only got maybe a year before they're going to school. I think there are some self-funded initiatives that plant themselves in local communities and go into early childcare settings earlier and see the children when they're two or engage with playgroups, but those are sporadic. They're not system-wide initiatives and they are usually self-funded. But there are models there to piggyback off, if we had the investment to do that.

Mrs HELEN DALTON: Often these children who do not have speech pathology or whose diagnosis is not done go into the school system. Then, eventually, they opt out because they can't cope. Are there any longitudinal studies or is there any sort of connection with those figures to understand how important it is?

JENNIE CUSITER: Yes, 100 per cent. Children with communication issues are seven times more likely to have literacy difficulties. We do have studies—I can take it on notice and get back to you—around increased risk of literacy or academic dropout and increased connection with juvenile justice services. There are many studies that show the long-term outlook of these children if they're not addressed in time.

Mrs HELEN DALTON: We should focus on that too.

Ms DONNA DAVIS: I've got two questions. I know that virtualKIDS exists at Westmead and Newcastle. Does that feed into the work that you do in terms of that initial assessment?

JENNIE CUSITER: Virtual care is certainly a great initiative. It has its challenges, as you could be aware from a personal perspective, around trying to engage a two-year-old or three-year-old online. Often, parent-reported assessments can be useful in that space. I know this is focused on the identification, but it's not a mechanism that's necessarily useful for intervention—not when you're talking about communication disorders.

TESSA BOLLARD: Virtual care is great, and it certainly has a place, but there's only so much you can pick up from parent reports and seeing a child online. You don't get a good sense of what's happening at home and the overall—"vibe" is probably not the right word to use in this forum, but you don't get an overall sense of how the family is coping. On a growth chart, they might be looking okay. But seeing them in person, they might look dishevelled and not washed. You can't pick up that sort of thing online. It has a place, but it doesn't provide equity between someone who's living next door to Sydney Children's Hospital and someone living in Wagga. You need eyes on people to create that equity.

Ms DONNA DAVIS: Going back to the shortage of trained staff and attracting people, I was speaking to someone recently who is studying radiography, and one of the challenges is they can't even get a placement in New South Wales. They have to go interstate to get a placement. They don't receive any support because they're just outside of being eligible for Youth Allowance or whatever they call that these days. Can you please talk to us about your knowledge of that and whether or not you have given any recommendations? It horrifies me that we have people willing to enter these careers and yet there are so many barriers. If they don't get a placement in New South Wales, how on earth do they afford to go interstate and survive during that placement?

BLAKE ADAIR-ROBERTS: Yes. It's a really good question. I think radiography is a really good example of that because, if we go back 20 years, there was a structure, a supervised practice year, where staff would be brought in—when provisional registration at the time was State boards—and work a year. They'd have that opportunity to work, supervised by more senior staff, and then have a career pathway into being a qualified radiographer, radiation therapist and so on. The university's gone from a three-year to a four-year degree. They've made clinical placements mandatory across not just radiography but across a range of different professions from 1,000 hours up to 2,000 hours for a sonographer. Really big amounts of time and commitment are required there. It's done unpaid, as you identified, and there aren't enough positions for those pathways to come in. I think that's a big gap for the public system.

A big drawcard is to provide a career pathway, to provide supervision, to provide support for early career graduates. When people are having to go elsewhere to get that placement, we know it's a lot harder to get someone into the New South Wales public system if they don't start in that. You often don't bring people from private or interstate back into the system as much as if they start within it. The HSU has, on the back of the university accord that came out earlier this year, made submissions to the Federal Government and to the Federal Education Minister around the need for paid placements, which are now in place for nursing, teaching and social work. The HSU welcomes all of those professions, but it does raise the question of why stop there.

Providing clinical paid placements for an occupational therapist, a psychologist, a radiographer—these are all really crucial endeavours, which will assist. As I said before—I don't want to labour the point—we are starting from behind the starting line, compared to other States in terms of commencing salary. We're behind them in terms of the commencing salary; we don't offer the same pathways; and it's unpaid placements. It's a really difficult environment to encourage workers to come into the system when you've got all of those things brought in together.

The CHAIR: Liza, I will throw to you again, given that our focus just over the last little bit has been on the HSU as opposed to the nurses. Did you have anything specific you wanted to ask at this stage?

Ms LIZA BUTLER: Let me just go to my notes. What else can we do to attract people to go out to our more remote areas? We've put things in place, but is there something that's glaringly obvious other than what you've just outlined about the hours for radiographers, sonographers et cetera, to get people into especially early intervention services?

JENNIE CUSITER: I can only speak from speech pathology, but I just wonder if partnership roles where you can rotate between rural and inner-city experiences would attract workers so that they can get support and tie in expertise underneath the guidance of supervisors, and then go out and spend six months and kind of rotate around. I think more cross-LHD partnerships would be helpful there. That's one thing from me.

TESSA BOLLARD: Yes, I agree. I think potentially having some sort of fly-in fly-out service or outreach where you provide incentives to those clinicians who are already experienced and would be happy to spend three months, six months, rurally, to either focus on training clinicians that are already working out there, or setting up services and that sort of thing out in those remote areas. But there's got to be incentive. No-one wants to move away from their family out to rural areas, as much as you might love your job and want to do it out of the goodness of your heart. There needs to be some sort of incentive and at the moment there just isn't.

Ms LIZA BUTLER: Do you think that the answer lies in ensuring, especially in remote Indigenous communities, training people up locally so they provide culturally appropriate services? How do we do that?

TESSA BOLLARD: Yes, absolutely. The people who work in those remote communities and are already a part of the community; those are the experts. We can come in with the expertise of clinical knowledge and we can learn from them about how to appropriately engage with those communities from the metropolitan areas as well. Then we can improve things from both ends.

Ms LIZA BUTLER: Going back a little bit, we know from your submission—this is to the nurses and midwives—that the percentage of children in remote Aboriginal communities is higher, and one of the reasons you outlined was intergenerational trauma. What other reasons are there? It's about the why. Why are we seeing higher rates? Do we need to do something else to at least try to reduce that?

NICHOLE CALLAN: Can I comment?

EMMA HARDY: Yes, you go first, Nicky. That's fine.

NICHOLE CALLAN: Currently, yes, we have reduced services, but we have nil access to a paediatrician for any behavioural, developmental or global delay for these children. There's nil access at all. I actually have an idea, a solution, where you build a rural and remote team, you go and engage with a community with invitation, you identify with this community the gaps in service and then you come back and build a team to complement the services that are already in the community. That team would be fully led by your Aboriginal health worker and engage with your Aboriginal health Elders in those communities, but only with invitation.

I think it would be amazing because people are not going to have to move to rural and remote, which we know they're not going to do, because they're not doing it now and they won't do it. They're not happy to come away from their own home. But if you had monthly clinics where your team could go in and provide the services to these children and families—and it's the services that the community actually identifies as a need—this is, I feel, a really possible solution. Again, with the pay incentives, I think that would be great for the speechies and OTs, because I work hand in hand with them every day, but for job satisfaction too. To be working in a rural and remote community, there's nothing better than that—the fly-in fly-out—but only providing the services that are required by the community, because I don't know if any community has been asked, "What do you actually need?"

Ms LIZA BUTLER: Is there any data showing the gap of children in remote Aboriginal communities, compared to the city, as they get older?

NICHOLE CALLAN: The AEDC data.

EMMA HARDY: Correct, yes. We did touch on that in our submission. It basically shows that the further you are rural and remote, the more likely you are to have multiple vulnerabilities and needing further supports.

Ms LIZA BUTLER: If there was a rural and remote team, you would see that it would close the gap?

EMMA HARDY: That's our aim, to try to work as a multidisciplinary team. We need more nurses and midwives to go out with Aboriginal health workers, speech therapists and occupational therapists, and together create complete plans for these kids.

JENNIE CUSITER: If I can just add that, from a broader perspective around Closing the Gap, it's around increasing educational and rich learning environments at home with those families—and that's not always just in health perspectives—so investing in their early childhood settings to make sure they're as high quality as possible, that there's integration between perhaps allied health and early childhood settings so that we can increase capacity of workers there. It's about a range of strategies to close the gap for those children.

BLAKE ADAIR-ROBERTS: Can I add quickly, when we talk about Aboriginal health workers, and bringing it back to some of the challenges we're facing system-wide, in New South Wales Aboriginal health workers work under a particular requirement, qualification requirement, and many of our members that are Aboriginal health workers are actually registered as Aboriginal health practitioners with a broader scope of practice. They're paid the same, even though they have a higher qualification requirement, and have to be registered with AHPRA. There is a real gap in terms of utilising the scope of practice that Aboriginal health practitioners have and are able to utilise compared to Aboriginal health workers, so there is a loss of that scope which could be utilised from Aboriginal health practitioners as well.

Mrs HELEN DALTON: I'm trying to work out how you define the gaps in different communities because different communities certainly have different problems. I know, travelling through my electorate, that is the case. Is there any scope for the idea of perhaps a survey amongst the community to rate your health district and work out what the gaps are? We tend to do it the other way around, where you'll have the health district, if you're going to be centralised to Wagga, they'll have a postcode—this person came from Hanwood to Wagga Wagga for service—but to actually have a survey from the community that rated the health district or maybe defined the key performance indicators and actually then can scrutinise what's being delivered and what's not being delivered. Have there been any discussions about that?

BLAKE ADAIR-ROBERTS: I can't speak to that, but I do note one of our major recommendations is the need to do mandatory reporting on paediatric health gaps and publicly report on that. Noting that suggestion—and I don't think it is one we have a position on, about a local survey—but one of the challenges we face is that there just isn't the publicly reported information. When we speak to local health districts, they tell us they don't have the data on allied health vacancies in particular services and point-blank say that they cannot get it. We've heard that now in the last month from several LHDs, including regional and rural and remote LHDs, where we're dealing with staffing reductions of allied health and we've said, "What is your allied health vacancy number?" They said, "We can't provide it." The HSU would put that the first step is to identify the vacancies, identify the gaps in the services being provided and then explore those options.

The CHAIR: How can they not know that there's an empty position?

BLAKE ADAIR-ROBERTS: That's a very good question, and one that we've put on several occasions, noting that we had put these questions on the back of four weeks of industrial action to some of these LHDs and they still communicated to us that they simply could not provide data on their vacancies within their local health districts.

Mrs HELEN DALTON: Or don't want to.

BLAKE ADAIR-ROBERTS: That's the other alternative, but I can only express what was communicated to me.

TESSA BOLLARD: Can I just add, Mrs Dalton, that is a really fantastic idea about doing a survey or having a conversation with these communities and figuring out what the actual gaps are rather than making assumptions and, "What do you need in your community?" I think that conversation would be fantastic, but we need to then respond to whatever the answer is. I think the problem is we keep having these conversations figuring out where the gaps are, noting years ago in the Henry review that allied health is wildly understaffed. We don't do anything about it. Who is going to gain any trust in us if we can't actually respond to the surveys or the conversations or whatever it is that we're having with these communities? I think doing something about it is what we need to focus on.

The CHAIR: Can I ask a question to reframe or rephrase many of the questions we have been asking over the last 15, 20, 30 minutes? What about city-based communities that are also missing out? I guess I'm talking about either migrant communities, culturally and linguistically diverse, or low socio-economic. Can you talk to the issues facing those communities and why they're not participating in this process of identifying these markers in these first 2,000 days for the young children? I'm throwing to both of you. I will ask the HSU to comment first and then the Nurses and Midwives' Association.

JENNIE CUSITER: I think there are a multitude of issues that will vary. For culturally and linguistically diverse—I mean, there is the obvious one around language access and having access to interpreters and feeling engaged in that process. There are different child rearing processes that we do in different cultures, so there's also those differences there that we need to be mindful of. In terms of low SES areas, I think it's about the capacity of a family. When the family is taxed, certain things have to fall off. When they're overwhelmed with housing, when they're overwhelmed with basic healthcare needs, it is these kinds of little things that become too much for the family unit in the moment. We do have to be aware that we've got to address some of those other kind of—I don't know if they're social determinants of health, but that's usually why they struggle to engage, because they've got a range of pressures on the family unit.

BLAKE ADAIR-ROBERTS: Not discounting anything that was just said—they're all valid points—what we started talking about was how demand is larger than supply. Yes, there might be reasons within the family unit that mean there is trouble with access. But when we talk about interpreters, there aren't enough interpreters in our system, and the interpreters within NSW Health get paid significantly less than those under the Crown employees award. We can talk about the pressures on the family unit but ultimately, like the Henry review said and like the Ministry of Health submission into this inquiry said, there is a demand there. People do want to access these services. It's the supply. We don't have any allied health staff to provide them. We can look at those components about how we get more people in the system but, as we've talked about, we're just adding more and more people to a waiting list. We're not addressing the core issue, which is how many staff are available to perform these assessments.

EMMA HARDY: Adding on to what was just said, the average age of nurses and midwives in child and family health is 51. There is going to be a mass exodus in the next 10 years. There are major waits and delays for these kids in the city as well, and every single nurse and midwife on the ground has ample paperwork, aside from the fact that they need to take care of the family in front of them. Something needs to be done within the system to try to address these gaps so that these children can be seen, in both the city and the country.

NICHOLE CALLAN: We have to change how we deliver health services and paediatric health services to children living in rural and remote New South Wales and the cities. I believe we can do this together by working in partnership with our communities. Every child should be able to have the service that they require. Also, children living in rural and remote New South Wales shall not and will not be forgotten.

TESSA BOLLARD: The gaps also get worse when everyone has the same sort of waiting periods. Everyone gets prioritised and we do prioritise those from vulnerable populations. But when you get told that your child can't be seen for 12 months, one family might have the means to say, "I'll go to a private dietician, private speech pathologist or private paediatrician", or whatever it might be. Another family might not have the means to do that and they're forced to wait that 12 months to see someone. Then the gap gets bigger. If you can go down an alternative route, that is great, but that just makes the gap bigger.

The CHAIR: Can I ask about fear of government intervention if a child is deemed to be not progressing the way they should be? Do you have any data or anecdotal response to the question of whether some families, in low socio-economic, culturally and linguistically diverse or Indigenous communities, are frightened about having an assessment? I might start with nurses and midwives.

EMMA HARDY: I think those families definitely exist, but that's where you start that relationship and try to engage as early as possible. You try to build that bond and show that we're not there to create fear. We're there to support them and help their child. As I said before, Nicky has done amazing things within her community to try to bridge that gap, but we need to do more of that. We need more staff on the ground to show that we're not there to create fear.

NICHOLE CALLAN: Going back to what Emma just said, because we have that positive engagement early, our mums do come back. Our mums are more accepting of our services and us coming into their homes and providing assessment.

The CHAIR: HSU delegates, on the question about fear, do you see or experience people who are afraid of the system?

TESSA BOLLARD: Yes—anecdotally, for sure. I couldn't give you data specifically on how many or anything like that. But, certainly, anecdotally there is that fear, particularly around faltering growth and obesity. That's obviously related to my particular profession. I don't know how we reduce that fear, other than being more available and more present in these families' lives. I don't know how we do that without more resourcing.

The CHAIR: Hopefully it starts by acknowledging it exists. Thank you for appearing before us today. You will be provided with a copy of the transcript of your evidence for corrections. Committee staff will also email to you any questions taken on notice. I think there were two. Instead of you having to worry about figuring out exactly what the question was, we will email to you specifically the question you've taken on notice. The Committee members may develop supplementary questions that we would like to send to you to get further information. If we do that, we ask that you respond to those in about a week. If that's not possible, please talk to us and we'll figure it out. I thank you all again for your valuable time this morning.

(The witnesses withdrew.)

Ms OLIVIA WRIGHT, Director, School Gateway Project, NSW Council of Social Service, affirmed and examined

Ms CARA VARIAN, Chief Executive Officer, NSW Council of Social Service, affirmed and examined

Ms JACQUI EMERY, Chief Executive Officer, Royal Far West, affirmed and examined

The CHAIR: I welcome our next witnesses. Thank you for appearing before the Committee today to give evidence. Please note that the Committee staff will be taking photos and videos during the hearing. The photos and videos may be used for social media and public engagement purposes on the Legislative Assembly's social media pages and websites. Please let Committee staff know if you object to these images being taken and/or used. Before we start, do you have any questions about the hearing process?

JACQUI EMERY: No.

CARA VARIAN: No.

OLIVIA WRIGHT: No.

The CHAIR: Would you like to make a two-minute opening statement before we begin questions? I make that offer to Royal Far West first and will then come back to NCOSS.

JACQUI EMERY: Thank you for the opportunity to appear before the inquiry Committee today. Early developmental checks for children in rural and remote New South Wales are now, more than ever, a significant necessity. Rural areas of New South Wales have been hit hard over recent years with COVID, droughts, bushfires, floods and increasing cost-of-living pressures. These have all combined to what is being reported to our clinicians on the ground as a significant increase in mental health issues reported at schools and particularly students starting school with less social interaction. Paediatricians in rural towns are also reporting this issue.

The workforce shortage of both paediatricians and allied health specialists for children in many country areas exacerbates the challenge faced by health services and schools in many areas of rural New South Wales. Many children are not being seen by a specialist until they arrive at school, presenting with significant speech or behavioural challenges. We all are aware of the research which shows early intervention for children is crucial, often before the age of five and definitely before the age of nine. Otherwise, we risk losing these children to a life of reduced possibilities.

NAPLAN results show us that regional children have worse learning outcomes because, when vulnerabilities do emerge, they are less likely to have access to services to address them. Our own Healthy Kids Bus Stop screening, stopped in 2022 when Brighter Beginnings screening was announced, referred 80 per cent of the 5,000 children screened to at least one other health service as a result of the screening. The initiative under Brighter Beginnings to include compulsory screening for four-year-olds is welcomed, but reports on the ground suggest what is happening is not a comprehensive screening, and we are worried that disadvantaged children with limited access to travel or early learning will again fall through the cracks. We need place-based early intervention assessment programs funded in both the early years and middle school years. We need to address current workforce shortages with a combination of outreach and telehealth until longer term recruitment strategies are effective. I welcome any questions on our submission.

The CHAIR: NCOSS?

CARA VARIAN: Good morning. I acknowledge the traditional custodians of the land on which we are meeting, the Gadigal, and pay my respects to their Elders past and present. My name is Cara Varian. I am the CEO at NCOSS. Olivia Wright is the director of our School Gateway Project. The hub that has been created through that project is called Mirrung, which is based at Ashcroft Public School in south-west Sydney. I'm going to quickly tell you a story about a boy called Daniel. He is seven and he goes to that school. He lives with his three-year-old brother and their dad in social housing and Daniel's dad has sole custody of his two boys.

His mum is incarcerated and has been in and out of prison since Daniel was born. They don't have a family GP. Daniel did not go to early childhood education. The boys have not had regular health checks. When they joined the school they were connected to the wellbeing and learning hub called Mirrung, which is philanthropically funded and co-developed with NCOSS and the school. It is an example and a model of how the education, the social service and the health sector work together. Daniel took part in a health and development screening program and he was assessed as missing key developmental milestones across all five domains.

Based on those results, Daniel was placed in an intensive speech group, referred to a paediatrician and his classroom teacher rolled out a series of in-class adjustments. There's still some way to go, but Daniel has made significant gains throughout the year and he's going to continue to receive some support. Even more importantly, because of the trust built between Mirrung and Daniel's family, his little brother had that assessment done when he was three. A full paediatric assessment discovered that his little brother also had developmental delays, but he has been referred to a speech therapist and now attends a guided playgroup, and with early intervention we're hopeful that at his four-year screening he will be meeting all his milestones.

Daniel's story is common in communities with concentrated socio-economic disadvantage. Seventy per cent of the children who were screened through Mirrung this year were flagged as requiring additional support to meet their developmental milestones. We have a model that shows how we can do better. We also know that the earlier it happens, the better it works for the communities and the individuals. And it shows that the interface between the social service sector, the education sector and the health sector is key to making this work well for communities. It also shows that checks alone are not enough. We need support provided to the families after those checks take place. I thank the inquiry for the opportunity to attend today and Olivia and I look forward to your questions.

The CHAIR: Can I ask about Daniel's story? You mentioned the socio-economic situation. Is it also a culturally and linguistically diverse family arrangement?

CARA VARIAN: I'll ask Olivia.

OLIVIA WRIGHT: It's not, actually, in this case. He identifies as Aboriginal. But at the school that we're working at, Ashcroft Public School, 70 per cent of the students come from a family that speaks English as a second language at home, so the multiple vulnerabilities, the deep socio-economic disadvantage, the cultural and linguistic, and I think 15 per cent of the school identify as Aboriginal—so it is definitely that intersecting of vulnerability that impacts Daniel and his cohort.

The CHAIR: Ms Varian, you said that Mirrung is philanthropic, so it is funded by generosity in donations. What about all of the assessments, in the first instance, and then referral to further assessment and support? Is all of that free of charge? At what point does money start to play a role?

CARA VARIAN: The way the philanthropic funding works is that it funds Olivia's position in the school. Olivia sits at the school and is—and I think this is part of the secret sauce—this independent person that doesn't sit in the education system or in the social service sector or in the health sector. That's where that philanthropic funding comes through. There is also a contribution to the hub through the school resources, so the learning and support teacher is part of the hub, but that's coming from departmental—and then Olivia pulls together a kind of amazing patchwork of both government-funded health services and other philanthropically funded donations and Foodbank stuff, as well as paediatricians. Olivia can talk to more detail.

OLIVIA WRIGHT: I would add that I guess the difference is that we're in a school that has both a pre-school and, in fact, a SACC—a school as community centre—which is, I think, the two- and three-year-olds. But it is a school-based approach, our model. Of course, there are different models that are as effective in other settings, but in our case a lot of the costs are picked up in the school. So, as Cara said, my role is philanthropically funded. We have a dedicated team in the school and there is another role that is partly funded by our philanthropic funding. But the other roles within the school are part of the school's funded positions—the learning and support teacher; the Aboriginal education officer; there's a community liaison officer who speaks Arabic; and there are other SLSOs who are engaged.

To meet the gaps in service provision, the school funds a speech pathologist to attend the school two days a week. We fund a psychologist to attend the school. We've just, this term, started funding a paediatrician who provides two clinics a term at the school. In addition, the school has funded a lot of professional learning for educators. The preschool educators, the SACC coordinators and kindergarten educators have all received professional learning in both speech and OT programs so that that extends the value of the programs that we can run out.

The CHAIR: And so the Department of Education, through the school, is funding access to speech pathologists, OTs and paediatricians?

OLIVIA WRIGHT: Yes, I guess.

The CHAIR: Or health is funding?

OLIVIA WRIGHT: No, they're education funded, but it is a mix of. We're trying to work mostly within the service system. We do work with the LHD-funded speech pathology unit. We work within the LHD-funded community paeds. But to meet the demand at a school in a community like Ashcroft, where, as Cara said, 70 per cent of the children who were screened were flagged as requiring extra support, we have had to add to what is available because of the wait times, because of the barriers to access that a community like Ashcroft, which is very culturally diverse and has deep socio-economic disadvantage and a large community of Aboriginal and Torres Strait Islander children as well.

The CHAIR: I know you were in the gallery during most of what the previous witnesses were talking about. The speech pathologist and dietitian were indicating that by the time a child gets to school, in many ways it's been left too late—that we need earlier assessments. A lot of these things are picked up when they finally get to school at the age of five or six, but the best time for intervention was when they were one or two or three or four. Is that your understanding of best practice for these young people?

OLIVIA WRIGHT: Certainly, as I understand it, that is best practice. I think though that any support that we can give children in the four- and five-year-old age group as well is going to improve their ability to meet curriculum at school. For us, the focus has been—although understanding that, yes, it's probably not best practice to be supporting these children at four, there are still assessments and then supports we can provide for. Although I don't have access at this point to any broader data than what is available from our own work, I know that we've reassessed our four- and five-year-old cohort six months from the first assessment that we conducted this year and the numbers of students who were flagged dropped by 40 per cent. Even with our own internal work, there was a fairly significant improvement in the way in which these children can now access the curriculum.

CARA VARIAN: Can I add to that, Chair?

The CHAIR: Yes, sure.

CARA VARIAN: We chose the school because—

The CHAIR: I am sure you did.

CARA VARIAN: —one of the issues is around building trust with the community. Every family knows they have to bring their child to school. But, as a society, there is varying expectations about what families should do before the school age. There are also varying levels of health, education and community support. Schools provide us an amazing universal platform to provide that connection with the community but, ideally, we would also be creating that connection through local neighbourhood centres and place-based services much earlier in their lives. We know having good support in the first 2,000 days is excellent, but it's not an inoculation for poverty or socio-economic disadvantage, and you need to continue that through primary school and high school. I agree we should also be doing it in community centres. But at the moment they are not funded by the Government, so here we are.

The CHAIR: Trust is a nice segue to the question I want to ask Ms Emery about the bus. Did you literally have a bus travelling around the State for eight years?

JACQUI EMERY: Yes.

The CHAIR: Surely that built trust? There is a frequent turning up of this wonderful facility and opportunity.

JACQUI EMERY: Yes, it did build trust. We operated it, as I said, for eight years. It was philanthropically funded throughout that period of time. It was supposed to be in collaboration with the local health districts. What we found was that our role in the beginning was to do the coordination and to take the bus, which was fitted out with audiology units, for example. We would also use place-based community centres, schools and early learning centres to conduct the screenings. We would often find children that weren't turning up in any system. We would also work with the local health district, initially, with their allied health staff. Together we would screen all of those children. I think there were close to 19,000 assessments done during that period of time.

We were really pleased when Brighter Beginnings came in. We were obviously involved in that consultation, given the data that we had. We shared all of that data. As I said, most of the children needed a referral to speech pathology or audiology. They were the two greatest referrals. Over time, however, as workforce shortages were really crunched, Royal Far West had to provide their own allied health staff to do those assessments. We also followed up the referral processes with families. I heard you ask earlier about fear of assessment. I think there is also something to consider around navigating the health system. For our most vulnerable families, we really needed to hold their hand in order to take up those referrals. In many cases, however, there weren't local services. We also ended up needing to philanthropically support ongoing therapy for some of those families in greatest need.

The CHAIR: I am going to pass to my colleagues. Ms Emery, so that you know, a number of the members of this Committee are also on the Select Committee on Remote, Rural and Regional Health. When you were giving evidence during that, you talked about the cessation of the healthy bus service, which, in very direct ways, prompted this inquiry. We appreciate your time and everything that you have done in the past. We don't want to lose that momentum.

Mrs HELEN DALTON: Thank you for attending. It's wonderful to have you here. I want to work out what's going on with providers of services. You've got Royal Far West, Marathon Health, Variety and probably a number of others that I don't know about. Is there any coordination of who's doing what? What do you think the answer is to mapping out where the gaps in services are across rural and remote New South Wales? Obviously, I'm from out there. I'm sure there are gaps in the city too. I just know about the gaps in my area. What's your idea about that, and how do we solve that? Who's doing what?

JACQUI EMERY: It's a great question, Helen. There has been progress. Since the other inquiry, we're seeing much greater coordination in the Murrumbidgee Local Health District and the Western NSW Local Health District. I have been a part of some paediatric forums in both of those locations. There is a recognition that there needs to be much more coordination and communication between NGOs, the LHDs and the primary health networks. To comment on an earlier discussion, the primary health networks actually do surveys around what community needs are. There is a lot of great information out there. There is information around, I think, allied health workforce shortages. The National Rural Health Alliance publishes workforce data in each State and Territory.

You do get a sense of the allied health availability—or lack thereof, of course—in rural and remote areas. However, Speech Pathology Australia do their own service, so they actually can't identify in that workforce tool speech pathologists. The other complication around determining allied health is how many areas are being supported by allied health that aren't on the ground via telehealth. For our part, we know that some of the local health districts haven't had full visibility about the allied health service provision that Royal Far West provides into many schools in rural and remote areas. Again, that is getting back to the point that it is really important that we all collaborate around where we're working, where our footprints overlap and really looking at those gaps.

Mrs HELEN DALTON: For us here, what would be the step forward to working out who is doing what?

JACQUI EMERY: I think that, again, I'd like to see that happening in other local health districts as well. Really, that probably needs to come from the local health districts once these discussions are being had around who is doing what. We're quite transparent about where our footprint is. We are talking to other services like Marathon Health and making sure that we are not duplicating. None of us wants to do that. I would have to say there are still huge gaps in service provision, even with all of the players that are working in the areas.

As we noted in our report, I think it is important to remember that it's very, very clear through the Australian Early Development Census, that there is much, much greater need in rural and remote areas, although I acknowledge that there are certainly pockets in metro areas where there are huge levels of disadvantage and vulnerability. But, as I said in my report, across this State one child in 10 is developmentally vulnerable on two or more domains. That will preclude them from learning and having better life outcomes; yet, across the State the highest developmental vulnerability on two or more domains are Bourke, 40 per cent; Cobar, 31 per cent; Coonamble, 31 per cent; and Griffith, 26.7 per cent. They are much higher averages than the State average. I would have to say that those are the areas with the least amount of resources.

Ms DONNA DAVIS: Thanks for attending today. The New South Wales Government describes the Brighter Beginnings health and development checks as a universal program. Is this service accessible for all children and families? I know that Royal Far West referred to Brighter Beginnings screening process as a tick-the-box exercise. How can Brighter Beginnings be improved?

JACQUI EMERY: Look, resources is number one. I think the local health districts are doing their best. They do have really limited allied health services in western, which is obviously a massive area. They have one nurse, one speech pathologist and an occupational therapist trying to cover 4,000 children, so it's a pretty difficult task and massive distances to travel. I think, as well, we have to acknowledge that finding children under five in rural and remote areas is sometimes tough because we know that there are huge areas that are childcare deserts. Children aren't turning up in early childhood centres. They're not necessarily visiting local health clinics.

It is difficult, sometimes, to find those children as well. I think that the local health districts, anecdotally from what I'm hearing on the ground, are doing their best to try to provide those services, but—again because of the resourcing—it's certainly not the multidisciplinary assessment that we were offering through Healthy Kids Bus Stop. To be honest, that's what was on the label when Brighter Beginnings was first announced, and it's not delivering on that.

OLIVIA WRIGHT: Adding to that, when we did our screening program at Ashcroft, we translated the screening tools into Arabic, Mandarin, Vietnamese and Spanish. There were parents who didn't have access to the internet to be able to respond. They don't have literacy themselves. They didn't have digital literacy. They don't have health literacy. When they came into the school, we supported a significant proportion of the parents to sit down and answer the questions. We had an Arabic-speaking SLSO with us to assist in that process.

Going back to your question of fear, I think that parents in our community genuinely fear—there was a portion who thought, well, their siblings were like this, so why are they not? So an understanding of developmental milestones but also a fear that "If I'm exposed as a bad parent, what are the implications of that down the road?" My sense is that with the Brighter Beginnings offering in our community—and I speak only with that experience—if they blow in, do an assessment and then leave, they haven't got the trust that the community centre or the school setting that we're working in has with the families. We are able to support the families and then to assure them that whatever findings will not have a bad outcome but will have an outcome where we're able to support the children to meet their milestones and access their education.

Ms DONNA DAVIS: Just touching on something you mentioned before—assumed knowledge—when I was a young mum or an expecting mum, I hadn't grown up in the New South Wales system and I had no concept of what the blue book was. We were told by the previous witnesses that it's handed to you a couple of days or within hours after giving birth. You're definitely going to absorb all of that at that time, aren't you! In addition to that, there is the assumption that people know that you can take your kids to playgroup, that you know where they are—just like people assume that all kids are going to go to swimming lessons. It is that same sort of thing. What can we do? I am the member for Parramatta, an incredibly diverse community, representing people of many languages. What can we do to better communicate to our expecting mums and parents what is available, what we can do to assist, and that all of these things are in place for you to be able to provide the best opportunities for your kids?

OLIVIA WRIGHT: I think your use of the word "assumption" is really good and important. We cannot assume that parents are going to meet the level of anything that we recommend to them. One of the principles of our model—and I know, for example, The Hive in Mount Druitt and other child and family health hub spaces and models—is a principle of soft entry. I would say that if we're trying to engage a family, it would be at a barbecue or at a morning tea—food often—or a painting class, or they come in for playgroup to do something else, and it's through that engagement and building trust that we're then able to make recommendations and suggestions, and engage families with the health system. I think partnerships is the other thing. Jacqui talked about it, but collaboration between the health service system, the social service system and the education system are so important. We have to work more closely together so that we can meet families at the point at which they are able to come into these services that are designed to support their children.

Ms DONNA DAVIS: In our CALD communities, particularly women who are isolated at home or not understanding what the processes are rely on other women to provide them with information. Do we have any models in place where we are engaging well, through our different CALD communities, with information to then disperse to others? I know that we have got places like the Community Migrant Resource Centre, they exist in different communities. Are we using those types of organisations to engage and provide advice right at that early, early age, not when they are three but when they are pregnant?

OLIVIA WRIGHT: I can't speak with any experience to that early stage. Certainly, from the school age and even the earlier stages, I know that migrant resource centres and neighbourhood centres are engaging groups of migrant mothers. But I can't speak with experience to the early, early stage.

CARA VARIAN: From my experience, I guess, in that coordination role across the State, the answer to your question is it's patchy. It really comes down to the person that's in that position at that time and whether they've thought about it or they've got enough headspace to create it. Typically it is being done on top of what they are actually getting paid to do. That's the struggle. We have got a loneliness inquiry going on at the same time. These issues are not separate.

Ms DONNA DAVIS: And our migrant communities in remote areas.

JACQUI EMERY: Absolutely. I think every inquiry seems to be raising this very important issue around a coordinator, navigator, family partner role. That is really critical in rural and remote areas as well, so that if you cannot have the services on the ground—and that just isn't possible in some cases—you have a point that can connect you into where you need to go. I think that that's currently not funded.

The CHAIR: Is that what NCOSS would refer to as a "linker"?

CARA VARIAN: Yes.

The CHAIR: In your submission, you have a section on "Invest in linker or navigator roles".

CARA VARIAN: Typically we've talked about linkers in the context of schools, because our experience at Ashcroft has shown us that teachers don't know who to talk to in the DCJ. One of the stories that has come out of Ashcroft is that the teachers have got kids, they need to do a mandatory report on them, they spend hours on the phone and nothing happens. Then they go back and they still have to deal with the kids. The Mirrung has been this connection between the services. But that linker role outside of the school system could very well work in a local community neighbourhood centre or a migrant resource centre as well.

Ms LIZA BUTLER: Ms Wright, you spoke about collaborating and having early intervention screenings at morning teas, playgroups, preschools et cetera. Do you think that early intervention screening has gone backwards since Ageing, Disability and Home Care became non-existent and services transitioned to NDIS?

OLIVIA WRIGHT: I can't answer that question in my own experience, I'm afraid. I would have to take that on notice.

JACQUI EMERY: I can make a comment around that, certainly in rural and remote areas. Basically, when families get on a plan, which is pretty difficult to do in a rural and remote area to begin with, requiring an assessment and diagnosis, often by a paediatrician—but then families are essentially exited out of community health or public health into NDIS. When you go on the NDIS website, that early partner navigator, where you're not required to have an assessment or diagnosis, it very clearly states there that there are no early childhood partners in rural areas in New South Wales. There is just no access for families and no navigation through that system.

Ms LIZA BUTLER: Ms Emery, have you worked at Royal Far West for a number of years?

JACQUI EMERY: Yes, for eight years.

Ms LIZA BUTLER: It would be before that. The State Government rolled out Early Start early intervention services. I used to work for Ageing, Disability and Home Care. Royal Far West had the money to do exactly what Ms Wright spoke about, dropping into preschools, playgroups or wherever mums were—it might be in a park. They just screened while they were sitting there watching, to help them refer into early intervention services. I seem to be hearing that that's a core piece that's missing.

JACQUI EMERY: Yes, absolutely. We still do that to a certain extent, but certainly not for the need. We have to acknowledge that the need has grown significantly in recent years because of the issues that I've raised. We're seeing an explosion in behavioural issues and developmental challenges in rural and remote areas.

OLIVIA WRIGHT: I would also add that, even in a metro setting, the early childhood NDIS coordinator does most of their work online. That precludes anyone who speaks a language other than English, anyone who doesn't have access to the internet and anyone who is unfamiliar with or lacks confidence in using the internet.

Ms LIZA BUTLER: Ms Emery, you spoke about having a coordinated rural and remote team. We heard earlier from one of the other people giving evidence today that that's something that's needed. Would you agree with that?

JACQUI EMERY: Absolutely. Families are very isolated in many situations. It's an incredibly fragmented system. I would have to say that what we are seeing is a huge health burden that has fallen on schools and early learning centres where they do exist. They are picking up the pieces. In some cases, families have really reduced capacity to support their children and a lack of understanding around developmental milestones. As we talked about before, it's a bit like, "They'll get sorted when they start school." A lot of that is down to cost-of-living pressures and mental health issues—70 per cent of the parents who attend our multidisciplinary assessment service have mental health issues themselves. We have to acknowledge that they really need that wraparound support for the whole family—not just the child—in order to get these positive outcomes.

I would like to comment too on an earlier point. We know that 90 per cent of a child's brain has developed by the time that they are aged five. It is really important that we get in as early as possible. However, I would agree—because a lot of the work we do is in the middle years—that it's not like you can't support a child in those years. In some cases, we have to recognise that we will not see many of those children until they start school, when they start being identified, because teachers are great identifiers of children with developmental challenges. We still need supports into those middle years, but after the age of nine, it becomes really difficult to address what are often then comorbidities around developmental changes and mental health.

The CHAIR: Continuing on, why is it difficult, or almost impossible, after the age of nine to access the services?

JACQUI EMERY: Children's developmental trajectories, their ability to learn and the plasticity of their brains start to slow down. You think about a child picking up a new language. Everyone knows that a child can pick up a new language when they are really young. Those things get harder the older that you get. We can just rewire those trajectories at those younger ages. We see children in this category all the time who have missed that early intervention. They may have started with a speech and language issue. They may have challenges in their family environment and their home environment—isolation, disadvantage, domestic violence, et cetera. By the time they're nine, 10, 11, they are not understood. No-one understands what's going on for that child. Often by that stage they're presenting with mood disorders, anxiety. Then you've got a much more complex set of circumstances to address in that child's development and trajectory. That is part of the reason why it becomes more difficult to treat them after that point in time.

The CHAIR: That brings me to a question I was going to ask of NCOSS. In your submissions, you normally have for every dollar spent, the benefit is X in a lot of work that you do and in publications. Unusually, we don't have that in your submission. Do you have any work that you've done around for every dollar spent in early childhood interventions that the State benefits by X amount of dollars?

CARA VARIAN: We don't have that, but you'll be delighted to hear that in about a week and a half we will be releasing some research on the economic cost of childhood poverty. It quantifies the cost of us not addressing childhood poverty. As you would imagine, there's a lot of what we're discussing today that is connected to that cost.

The CHAIR: So, you do have this information, Ms Varian. You're just not sharing it with us. It's Secret Squirrel, is it?

CARA VARIAN: I will release it in a week and a half.

The CHAIR: Do we need to invite you back for another session?

CARA VARIAN: I'd love that. I will share a copy of the research with the Committee as soon as it's released.

The CHAIR: Ms Emery, do you have any sense of for every dollar spent we get X amount of benefit out?

JACQUI EMERY: There's a well-established body of work around this, and it is called the Heckman Equation. That equation says that for every dollar spent, there's a $13 saving to government. That is kind of a global measure. We would love to have a bit more of an idea. But there are various measures that say it is anything between a $13 saving per dollar spent up to $25 per dollar spent. We see that play out anecdotally all the time. Again, as I say, the cost of supporting a child with a whole range of different developmental challenges that require a clinical psychologist and speech pathologist, an occupational therapist, and a psychiatrist is much more expensive than a child that we see at three or four that gets two terms of speech pathology via telehealth that can actually address and resolve their issue in many cases.

The CHAIR: You're not surprised I'm not familiar with the Heckman indicators. Is that an Australian based piece of work?

JACQUI EMERY: No. That's a global measure that's standardised and well accepted around the benefit of early intervention, the return on investment.

OLIVIA WRIGHT: There's also a recent piece of research released by Community Hubs Australia, which isn't pertaining to health and development checks, but it certainly speaks to the engagement of migrant communities in that soft approach that hubs at schools take. They, too, have done a social return on investment study to show that it's between $3 and $4 per dollar invested just to engage the family in a school setting where there is trust, and you can then add on and add on, as hubs do.

The CHAIR: In terms of migrant communities, I wanted to come back because I think you made a comment earlier that you translated a certain document into these different languages, but then you've got literacy challenges at home anyway. As a Government, we sometimes think that if we produce this brochure and put it in 48 different languages, then we're doing our work. But if the people at home can't read it, it doesn't matter. It's still useless.

OLIVIA WRIGHT: Yes, and I think that goes back to the idea of needing a linker role—somebody who will stand and walk beside a family to support them into both undertaking the screening assessment and then accessing the supports beyond that. I would say it requires more than just a translation of the brochures. Definitely, having a linker role and having access to the internet—because there is an increasing digital divide, and I'm sure rural and remote communities would appreciate that as well, as much as some of the lower socio-economic communities in our city centres.

The CHAIR: Even then, there is the complexity of our health arrangements and the challenges and long delays, sometimes being on hold for a long period of time or getting told that your appointment is not going to be for 12 months.

OLIVIA WRIGHT: Yes, I think delay and fragmentation—the fact that you have to access different specialists in different places, the delay in how you will access those and the need to repeat, to get an assessment and come back in 12 months time. As Jacqui said, people's lives are so complex already in these marginalised communities that adding those layers of navigation to a family who perhaps has insecure housing or violence in the home or is trying to feed a family in the cost-of-living crisis makes it very hard.

The CHAIR: I want to thank you for making the point in your submission that if someone has to drive an hour or an hour-and-a-half to get to an appointment, number one, you have to have transport, but then you've got to pay $50 in petrol. Even if the appointment at the specialist is free, the cost of getting to and from—

OLIVIA WRIGHT: And they're often in different places. We've had families who have to take their children out of school for the entire day to access the three different—because they've got to catch a bus and then a bus and then a third bus before they've even met their appointment. Again, in our setting, we've really focused on bringing both NDIS-funded allied health professionals but also these checks into the school setting, because children are coming to the school, families are coming to the school, and they're not missing school hours, face-to-face teaching hours, because they have to hop on buses to travel to their appointments.

JACQUI EMERY: I think that that's exacerbated even further in rural and remote areas where it can be many, many hours of travel for one appointment. I think the other comment around visiting multiple specialists is the lack of communication between those specialists. Having a holistic view of that child as well is often a real barrier—a poor client experience with families having to repeat their story multiple times to different clinicians. It's not an easy process for families, especially when you consider the impact of the cost-of-living crisis on these families. It's just out of reach to be going and searching for the services that their children really need to have a positive trajectory.

The CHAIR: While we in this room might all be aware of IPTAAS and access to it, some of these families probably won't be, and NCOSS makes the point about potentially changing the rules around public transport accessibility so that some of these families who are most in need could potentially access the $2.50 fare that our aged pensioners have access to. Is that right?

CARA VARIAN: Exactly. There has to be better access to both public transport and community transport. Also, if we look at it from a whole-of-government and whole-of-society perspective, if we gave these families free public transport it would still be better for the long-term trajectory of these families' futures and almost certainly be a really great return on investment, even if it was free, but at least $2.50 will make it accessible.

The CHAIR: You also made the point about free internet access and a free computer or gadget or something to allow that?

CARA VARIAN: Yes. Minister Dib has been out talking about digital inclusion.

The CHAIR: Yes, which isn't just black spots. Sometimes people think of digital inclusion as being in a black spot or you don't have access to the NBN. Digital inclusion also means the machinery.

CARA VARIAN: Yes, exactly. We have great examples at Mirrung where the school requires a printed piece of paper. That requires a printer as well as ink as well as paper as well as the internet connection that connects the phone to the printer. There are so many unintended consequences of the very fragmented system. One of the striking stories for me is when Olivia was telling me about a family that had managed to get a paediatric assessment of their child, but they were culturally and linguistically diverse and had to then translate this very technical medical information into an education form. If you are not a doctor, it is very hard to understand what paediatricians are writing. Then you have to do it in a second language, so they've got the digital inclusion and the language exclusion. It's incredibly challenging. There has been a decentralisation of services across New South Wales in the last ten years.

The CHAIR: Sorry? There has been a decentralisation?

CARA VARIAN: No, there has been a centralisation of services across New South Wales, which is making it so hard. We have members who are now using their funding to pay for petrol so they can drive to communities and bring them to a legal service or a health service, because they know there will be no other way for those people to get there unless they walk three hours.

The CHAIR: It sounds like we should have a bus that goes out to these communities!

Mrs HELEN DALTON: They did have a bus.

The CHAIR: Ms Emery, some of what has just been described there, access to a computer and a printer and things like that—I don't know. On the bus that you used to operate did you have some of that equipment so you could sit with people and walk them through and assist them with that?

JACQUI EMERY: Absolutely. We had a coordination role on the bus and at some point through, probably four years in, we digitised the bus. As I said earlier, we ended up having to use some of our own clinicians who would travel out with the bus. If for some reason they couldn't, they could beam in and do their assessment via telehealth with the support of the other clinicians that were on the ground and the coordination function. We have a family partner navigator role at Royal Far West. It is such a critical role in helping families get through. They want to but they are precluded because of all of these reasons that we discussed before.

But, again, we support families around their health literacy, their digital literacy. That is all part of what we do, because we recognise that there are, in the cohorts that we support, low literacy levels. We will basically translate that information and help them step by step. Again, it gets back to this kind of linker role that is really critical if we are going to think about really supporting our most vulnerable families. The only other thing I would say is that even most of our vulnerable families do have a mobile. So, actually thinking about mobile, taking a lot of our forms, for example, and digitising forms in a mobile version is helpful for some of these families as well that don't necessarily have a laptop.

Ms DONNA DAVIS: A lot of them have mobiles but don't necessarily have data on their phones.

JACQUI EMERY: Yes.

Ms DONNA DAVIS: There are better ways of being able to communicate, surely, by sending text messages to let people know. Has there been any work done or any research into taking the services to the people? I know you talk about your bus, but I mean literally taking services? We have Healthy Harold go to schools. Have we looked at having services go to a shopping centre and then attracting young mums and bubs into visiting while they are at the shopping centre, that type of approach, so that we actually have got the service where the people are, rather than trying to get the people to a service?

JACQUI EMERY: Absolutely. I think that comes down to resources and funding. There are certainly lots of organisations that would like to do that and have done that. In the case of our Healthy Kids Bus Stop, we weren't just in schools. We were in community centres, we were in all sorts of different places, and really going and literally shaking the trees to find the kids that needed the help. I agree with you. I think that there are huge benefits in doing that and that is what families want. I think realistically some of the services and some of these supports are specialist supports, so you are not necessarily always going to find them on the ground. But as long as there is some connection, even if it is coordination that can open those doors, and with a no-wrong-door policy or approach, then you can get these supports to families. We're doing it every day. There are ways to do it but, again, it comes back to this fragmentation and not working together as well as we could in order to identify where the greatest need is—we actually know where it is—and how we meet that need.

OLIVIA WRIGHT: I agree. I think there are great models. We've just run a free dental check from the dental bus through the school, and an optometrist at the same time. Whilst it was an operational nightmare, we got 200 kids free eye checks with professional optometrists and checks with dentists. There's a model there that works and demonstrates that you can take the health professionals to a setting. There is an initiative I know of, again in Mount Druitt, called CUBS, which is an acronym for check-up before school. They do exactly that. They take a child and family health nurse with a family coordinator role into preschools and cafes in the Mount Druitt community. I'm not sure how many sites they operate their check-ups in, but it is a model that is already in operation in places. We've just started talking to the LHD about having a one-day-a-week child and family health nurse coming into the school setting—again, because it's a trusted setting. We've got the infrastructure and the families are coming in.

Ms DONNA DAVIS: Do you know if CUBS is run by the Western Sydney Local Health District?

OLIVIA WRIGHT: It is, yes, in collaboration with the Hive and, I think, part of KEYS.

Ms DONNA DAVIS: What is KEYS?

OLIVIA WRIGHT: It is Kids Early Years services, and it is a LHD and PHN initiative of Western Sydney.

Mrs HELEN DALTON: That's not for every health district, though, is it? It almost seems overwhelming, when I take a helicopter view of my electorate. You're talking about $2 for a train ride; we've got no public transport. Then you've got women that are working. They're trying to make ends meet. They're migrants who might be working at Baiada in Griffith or somewhere like that. Trying to get those kids the services is almost too hard. But there must be a better way of doing things.

OLIVIA WRIGHT: My answer to that would always be that the solution has to be local.

Mrs HELEN DALTON: Exactly.

OLIVIA WRIGHT: We can't have a one-size-fits-all Brighter Beginnings. Taking nothing away from the value of Brighter Beginnings, we must have a local solution. It has to be nuanced to the context. There is a great example of the bus. I've met with an initiative called Project Sprouts. That's all local—I'm going to misrepresent them, but women over the age of 60 or 70 who are retired early educators volunteer their time. They've gone in and done exactly that. They've conducted assessments in four or five different settings to capture all of the four-year-olds and then patchwork together supports to intervene and assist those children to meet the developmental milestones. But I think it has to be place based, to use the language that is current parlance. It's got to be local.

JACQUI EMERY: We actually established Project Sprouts in Parkes. This was, again, off the back of the Healthy Kids Bus Stop, before Brighter Beginnings was announced, to develop a more sustainable, locally based model. We worked with the local council to identify volunteers and local people. We got philanthropic funding to fund a local coordinator. We got some local corporate funding to establish that. Since that time—and it must be at least five years now—the local community have taken that on and established pathways with local universities and students to conduct those assessments. So there are some wonderful models. Sometimes we find that in trying to get traction and elevate the good work that is being done in all sorts of different areas, one of the challenges we have is sharing knowledge and learnings, and picking up those good frameworks and applying them elsewhere. But, again, it's always about funding, getting support and seeing NGOs as a partner alongside government. We often can get the funding, be nimble and create innovative solutions for these sorts of things. That is now a sustainable locally based model that is intervening early with kids and making a big difference as well as building local workforce pipelines through students that are actually working in that space.

The CHAIR: Thank you all for appearing before us today. You will be provided with a copy of the transcript of your evidence for corrections. Committee staff will email you any questions that you've taken on notice today and any supplementary questions that the Committee may develop in the coming days that we'd like to send to you. If possible, we ask for you to return that within a week, but if that's not possible, please talk to us about that. The Committee will take a short break. We will return at 11.15 a.m. Thank you again for your time today and your wonderful submissions.

(The witnesses withdrew.)

(Short adjournment)

Dr TOM McCLEAN, Head of Research and Social Policy, Uniting NSW.ACT, affirmed and examined

Ms CLARE LAWRENCE, Principal Policy Officer, Uniting NSW.ACT, affirmed and examined

Ms JENNY HARGREAVES, Centre Manager, Western NSW – Children and Families, Barnardos Australia, before the Committee via videoconference, affirmed and examined

The CHAIR: I welcome our next witnesses. Thank you for appearing before the Committee today to give evidence. Please note that Committee staff will be taking photos and videos during the hearing. The photos and videos may be used for social media and public engagement purposes on the Legislative Assembly social media pages and websites. Please let the Committee staff know if you object to having photos and videos taken. Before we start, do you have any questions about the hearing process?

TOM McCLEAN: No.

CLARE LAWRENCE: No.

The CHAIR: Would any of you like to make an opening statement on behalf of your organisation?

TOM McCLEAN: Chair and members of the Committee, thank you for this opportunity to speak with you today. As I'm sure you know, Uniting is the social services advocacy and pastoral care arm of the Uniting Church in New South Wales and the ACT. In our submission we drew on two kinds of experience that we have as a provider, specifically. We provide quality early learning services across more than 50 centres, reaching over 4,200 children each year, and we also support families facing vulnerability through targeted intervention programs in regional and urban communities across the State—many of these operating in communities with substantial Aboriginal, culturally and linguistically diverse populations.

It is this experience which paints a clear picture for us. While our educators connect families to health checks, there remain systemic gaps that are hindering consistent and equitable access to early assessments. We believe that we, as a society, could do a lot better at identifying developmental challenges in time for meaningful intervention. We would welcome the Committee recognising and formalising the critical role of early learning staff and of early intervention staff in facilitating access to health checks. We believe there's a role for the New South Wales Government to support this through sustainable funding models and that this could take the form of targeted investments to expand local health district services, ensuring children awaiting or outside of the NDIS framework do not face undue delays in receiving necessary support. Additionally, a place-based approach in communities would better address localised barriers to access, particularly for Aboriginal and multicultural populations.

Our final appeal is that children and families directly impacted by these services and issues are given a voice in shaping what comes next. Their insights are invaluable for crafting solutions that are both effective and inclusive, and it often helps to identify issues that maybe aren't apparent from behind a desk in metropolitan Sydney. At Uniting, we're committed to collaborating with the Government, with communities and with those who use our services to develop a responsive, consistent and child-centred approach to early health and development checks across New South Wales. Thank you for your consideration of these priorities, and we are looking forward to supporting the Committee with this important work to secure a strong start for all children.

The CHAIR: Ms Hargreaves, did you want to make an opening statement on behalf of Barnardos?

JENNY HARGREAVES: No, I'm fine, thank you. I think ours is all in the documents, so I'm happy with that.

The CHAIR: I might start with the first question to you, Ms Hargreaves. I'm going to ask Uniting the same question. For the record, could you please provide us your footprint, or your existence and delivery of services, in areas that we might consider as more rural/remote?

JENNY HARGREAVES: Yes, of course. Barnardos works within New South Wales. At our western centre, which I'm the centre manager for, we cover from Orange out to Cobar through to the Warrumbungle shire, Cowra. There are eight local government areas that we cover within the western area and five of those would be classed as rural and remote.

The CHAIR: In those centres is it you with a team of people working?

JENNY HARGREAVES: Yes. We have centres within each location across the local government areas and we have staff who provide support to families and young people within each centre, and they do provide outreach to smaller villages within those local government areas.

The CHAIR: Perfect, thank you. Uniting, what about you and your footprint in remote and rural areas?

TOM McCLEAN: We have two different sorts of service footprint that are relevant to the Committee. Our early learning services are mostly in urban areas, mostly in metropolitan Sydney or in large urban areas in other parts of the State. Our early intervention services are a bit more widespread and are more relevant to your question. We have a large service presence in western New South Wales that is centred in Dubbo, and we also have a presence on the Mid North Coast and northern New South Wales, which has some services in the large urban centres but some out in the countryside as well.

The CHAIR: If you're based in a centre like Dubbo, do you then have work that goes out to some of those smaller communities?

TOM McCLEAN: Yes. For example, our Dubbo team provides a range of services in the child, youth and family space from early intervention all the way through to out-of-home care, and those services are provided from Dubbo right across western New South Wales as far out as Bourke, Brewarrina and the smaller centres around there. So, yes, it's not just in the Dubbo area.

The CHAIR: Excellent. I will start with Uniting on this broad, overarching question for the record. Can you talk to us about your role as NGOs linking in with essentially the health district and the staff that are employed as government public servants. How does that work for you? Are you just working into the gaps that aren't already being met, or are you working in partnerships et cetera?

TOM McCLEAN: My impression from the stories that we hear from our frontline staff is that it varies from program to program. The typical experience is that our staff, especially in early intervention but also in early learning, will notice an issue that has arisen for a family or a group of families. We tend to be among the earliest to see that there's something that's not quite right—that there's a service gap. There are some programs that we operate that are formal partnerships. For example, we're part of some research that's taking place in south-west Sydney at the moment to establish virtual hubs that involve collaboration with the local health district. But there are other occasions where we simply notice that there's a service gap and we work with the family to find the services that are appropriate for them to receive support. And there's a similar sort of practice that emerges in our early learning centres, where we notice a lack in services and we broker support on a one-on-one basis. So my impression is that it varies, and it's that variation which many of our frontline staff find challenging.

The CHAIR: What about for Barnardos?

JENNY HARGREAVES: I'll just speak specifically about the western area if that's okay. Within the western area we do provide family preservation and family support services, and youth services, within the locations. We do work closely with Health and Education. Particularly with Health, our caseworkers support families to attend medical appointments and with the early childhood nurse. There are barriers to that, which we can speak about later, but we do work very closely with our local health services.

The CHAIR: One of the questions that I posed to our witnesses earlier, because it had come through in some of the submissions, was around this sense of fear for some of the families to be judged by the State Government, by the government agencies—the fear of, number one, the judgement, and then, number two, the consequence of that, which might be children being torn and taken away. Is your experience in the communities that you work in that fear is present and that it's significant, or would you say that you really don't see and witness much of that?

JENNY HARGREAVES: Most certainly. For many of our families that we work with, their history with government agencies has gone a long way back. The trauma that they have suffered themselves when they were children, that's been exacerbated by living in small rural communities, and stigmatised, that certain families have had history with those local agencies. So it's very difficult for those families then to walk into a government agency and ask for help, because of the fear of what they went through themselves and they suffered personally. That's why it's important for agencies to support those families to build a positive relationship with those government agencies. We have seen lately those relationships improving significantly within the last two years, which is great for those families.

TOM McCLEAN: I would agree. Our child protection and out-of-home care services have similar relationships with the health services, just to go back to the previous answer, to what Jenny described. The experience of stigma and of fear in those services is very similar based on what our staff tell us. In early intervention the story is similar, but perhaps for different reasons. There is also in that space a fear among many families that, if they seek help for reasons which raise their risk profile for child protection services, they're at risk of that sort of intervention.

We also hear many stories in places like Fairfield, and even in places like Dubbo, that families are reluctant to acknowledge that their children, for example, might have a developmental delay that's related to disability. They don't want a diagnosis. There are many reasons for that. There's stigma within their own community, and there's stigma with services. We've also heard stories that I've not personally verified, but it's been reported to me regularly, that that sort of diagnosis can interfere with people's visa conditions for people who are on temporary protection visas. So this isn't just an issue where people are afraid of the intervention of State services; there's also a Commonwealth element.

CLARE LAWRENCE: It relates to the interpretative declaration that we have under the CRPD that a child's diagnosis of disability can then be a barrier towards their migration status and permanent residency status.

The CHAIR: Can you just clarify CRPD?

CLARE LAWRENCE: The Convention on the Rights of People with Disabilities. Under that interpretive declaration the Government can deny permanent residency based on a child's disability status.

TOM McCLEAN: I think that the point we are trying to make is that, regardless of whether that is true or not, we hear the fear reported to us regularly when we speak with our frontline services.

Mrs HELEN DALTON: There are many providers of services, such as Variety and Marathon and Uniting. How can we make sure the community's needs are met and that we don't slip through the net? You've talked about your footprint with Uniting. It's in the city and at Dubbo too. Is that right? I'm the member for Murray. We're in the south of the State, from Griffith all the way west to the South Australian border. I'm sure there's lots of services out there, but the coordination of what's going on, who's doing what—how can we make sure that communities aren't left behind?

TOM McCLEAN: I think that your question is partly a matter for the Government to decide about what level of service it funds and that sort of thing. That's not something that I feel comfortable answering directly. I think it's a question for the Government. But there is an issue that we experience that's related to that, which is that it's often quite difficult for us, and for our frontline staff, to identity services that we should be working with and how to build those networks at a local level so that we can support families. There's a level of opacity in the system which we struggle with as well. We would welcome the Committee investigating that a little further and seeing if the Government could maybe provide more information on what services are available where so we know who to work with. That is something that in our experience is a real issue. But the question of how to make sure the that right services are funded in the right areas and the level of funding is a matter for the Government, I think.

JENNY HARGREAVES: Within the local areas we work in, our staff, they have very good relationships with those providers—Health, et cetera—who do provide those services. Many of those services then provide outreach to these smaller communities, and it depends on staffing et cetera as to whether those services are regular. Also, it's about the cost to travel. For us to take clients to paediatricians, it's exorbitant. It's a six-hour round trip from Cobar to Dubbo to see a paediatrician; there's a two-year waiting list, and it costs $450, so we need to work smarter. Whether we can provide those services fly-in fly-out and build those relationships—the issue for people in these smaller communities is there's a huge staff turnover within health and the medical fraternity. Every time they go to the baby health nurse, or to see the OT or the doctor, they have to retell their story and they get sick of telling it. I don't know what the answer is, but it's exhausting.

Mrs HELEN DALTON: How would you describe the integration between government agencies and the community services—such as child and family hubs, and early childhood providers—to offer early years support for children? In my electorate we have, I think, 80 different nationalities. A lot would not be accessing too much because they're either illegal or they're worried about their visa status.

JENNY HARGREAVES: What we try to do within our family support—like in our supported playgroup and things like that, we invite the early childhood nurses and the health workers into the playgroups to meet the families and to build that relationship. That's something that's really important to develop because we don't want our workers for two years having to take our families to medical appointments. We want families to have the skills to go by themselves, and feel confident enough to go by themselves, so we do work really hard at building those relationships.

Something that Barnardos did a couple of years ago, we partnered with Marathon Health, who provide occupational therapy and speech and physio. We had some funds and we invited them to our centres. They assessed those children, and then did the programs, and then supported the parents and the workers to deliver those programs. That built a really good relationship and that worked really well. Unfortunately, we ran out of money and couldn't continue it. But something like that works really well and builds good, positive relationships within the local community.

TOM McCLEAN: From Uniting's perspective there's a lot of goodwill, but there are two major structural challenges in terms of the way services are currently working. One is—as in the experience of Barnardos—services are pretty thin on the ground in some areas. There are very long waiting lists. There are thin markets, especially for things like allied health professionals, so there's just an unmet need. The other, which is consistent with the experience in the playgroups that we just heard about, is that government systems are big and are complex to navigate for people who are experiencing vulnerability and disadvantage in other parts of their lives. People often find it quite hard to do what government services are effectively requiring of them, which is to stitch together support and needs from all of the different areas of their lives.

We operate a program called Links to Early Learning which has been running in south-west Sydney for several years, and which is now also running in Nambucca. It has quite a simple mission, which is to help families who are not connected to the early learning system to get access to quality early learning. We find that in order to do that we often need to help families with all of the other things that are happening for them, like how to access Centrelink benefits and how to negotiate support with an early learning centre so that the child's disability is properly catered to and not seen as an inconvenience or as a challenge to good service delivery. There are lots of ways that families struggle simply to find their way through systems in a way that maybe you wouldn't expect unless you've actually lived in that situation. So coordination and sufficiency of services are two big challenges that we see on the front line.

Ms FELICITY WILSON: You've just touched on early learning, and particularly children that are not in the early learning system. You spoke quite a bit in your submission about the role that early learning centres and early childhood educators play in identifying needs of children. What kind of information do you have—from Barnardos as well—about the proportion of kids that need support that are in these more accessible systems and those that are not? Is there a correlation that children who are not within early learning are more likely to need access to support services or interventions, or is that not a fact?

TOM McCLEAN: I don't think it's possible to draw rigorous conclusions of the kind that you're suggesting, because the system itself is sorting people into different outcomes. The statements in our submission that you're referring to come from the experience of our frontline staff in our early learning centres. They've told us that, because of the nature of the interaction they have with children, they will often identify that a child almost certainly has a developmental delay, or some sort of other issue, years before they're able to access services, simply because they're interacting with them every day in a play-based environment and they see the signs. So the statements in our submission were about identifying this as an ideal location to "triage" if you like—that's my word rather than one that our staff would use—or prioritise children for those sorts of checks so we can get them help.

The question of whether there are more or fewer children in early learning or not is difficult to say. We do know from our experience and links to early learning that the child having a disability or some sort of delay, a cognitive disability, is often a very significant barrier to families being able to navigate getting into an early learning environment. We've also heard that the proportion of children who are exhibiting behaviours that may place them in a category where some support is needed has gone up since COVID. There's definitely a secular effect here of the experience of when they've grown up, and that's having issues. There are lots of things at play. I don't think you can say there are necessarily more or fewer in one or the other. There are just different reasons why children end up being identified as needing support.

Ms FELICITY WILSON: I think about some of the research that was done a couple of years ago where they were referring to "oases" and "deserts" for access to early learning. In many ways that's geographic, which the member for Murray would know only too well. It seems that you have the same oases and deserts for services comparatively as well. So there's a bit of an overlap from my understanding that not only in some communities or geographies would you be less likely to access an early learning service, because of its availability, but you might also at the same time be less likely to access, or have available, services for interventions for children as well.

I'm trying to understand to what extent that is compounding challenges that children are facing, and whether the example that you gave us in south-west Sydney and in Nambucca Heads, a program like that where you're trying to assist families to access early learning, is one of the first steps in order to then help them access other services and supports. Or is that probably not going to help too much anyway because, even if you can get into an early learning centre in some areas, you may not have the right support services for interventions in that community either?

TOM McCLEAN: Yes, the oases and deserts experience—the research you're referring to is consistent with our experience. There are definitely communities that have better access to early learning and to early intervention services, and perhaps less access. For our Links to Early Learning program, the availability of a high-quality early learning service to refer to is definitely a cap or a limit to how much we can achieve. In parallel with that innovation that we're running we're also experimenting with ways of expanding access to quality early learning to address that. Those are definitely factors that come from our frontline experience, yes.

JENNY HARGREAVES: What we have found post-COVID in western New South Wales is the lack of early learning places available. As a family preservation provider, the most important step we would do with the family is to secure places in child care for the children so that they would have eyes on them, and they would be with other children, within the learning centre. There was always a priority list within early childhood centres that would hold places for children. With their lack of staffing and within—well, it's everywhere, but within rural communities, priority is given to working parents now. Those priority lists, in some instances, have disappeared. So children who were once able to access early learning cannot access it.

What would happen previously, we would enrol families in early learning centres, preschools, and the educators there—often out here they would have relations with the Royal Far West organisations similar to those, and they would pick up on anything that needed support. The OTs, they would come out from the Royal Far West and then would provide transport for those families to travel to Sydney, to the Royal Far West, for intensive treatment. Because we can't access early childhood—even preschools are having a waiting list—that means that the families are missing out. They're just falling through the gap because no-one's diagnosing any of those health concerns that they may have.

Ms FELICITY WILSON: Do either of you have any reflections on what then occurs when children start in kindergarten? Is that the point that you then have teachers and educators observing? At that point, is there an ability to access services, or are they experiencing the same issues that we see for the youngest learners?

JENNY HARGREAVES: Once they start school, enrol in school, the teachers do pick up on that. That is great, it's fantastic, but the issue for rural communities is the transport and the cost to go to a regional centre to see an occupational therapist or a paediatrician or a speech pathologist. It can be done virtually but it doesn't have the same impact. To begin with, I think face to face has to happen within the first few visits, but the parents are hesitant to travel.

TOM McCLEAN: That's consistent with our experience. When children arrive in kindergarten at school, that's when it becomes obvious that there really is an issue that needs to be addressed. The detection becomes clear at that point. But I don't think that magically there's better access to services just because the kids are at school and the teacher has identified that there's a problem. Those service barriers for accessing all of the allied health that's needed to actually address the problems are still there.

Ms FELICITY WILSON: What difference does age of intervention make for outcomes for children?

TOM McCLEAN: There are exceptions to this but, as a general principle, the earlier that you identify the problem and the earlier you start working on it, the better. There are some sorts of cognitive impairment and disability, for example, that only became apparent later in childhood but, as a general rule, the earlier the better.

Ms FELICITY WILSON: If these children aren't being identified until they're in kindergarten, do we reach a point where there's less ability to actually have successful interventions? Or will you still see successful treatment and interventions even if children are not captured until they're in primary school?

TOM McCLEAN: If you've got something specific in mind, I'm happy to take that on notice. I think that it's possible in early school to still intervene meaningfully and to change lives even then—to put people on a different trajectory—but the underlying message is that it's easier to do if you start earlier.

Ms FELICITY WILSON: I've got two small children, one still in early learning, and I think about the roles and responsibilities of early learning educators versus primary school, kindergarten and early learning—the ability to juggle the different demands of the school environment versus an early learning centre, and even the ratios of educators to children. I imagine it would be much more challenging once they're out of those early years to really be able to invest enough in kids to give them the focus and the attention and the support to get the best outcomes at that point in time. It seems quite crucial to me that we are doing what we can to get kids into that system and get those interventions in place sooner.

TOM McCLEAN: I would agree. The earlier the better, yes.

JENNY HARGREAVES: I agree with that.

Ms DONNA DAVIS: Thank you for attending today. You touched on people with temporary visas. We know that's a part of our community, both in regional areas and in metropolitan. We also have such diverse communities with language. So what in language, child health and development resources would be most effective for those communities? We've talked this morning to other people who've been here before the inquiry about the fact that we know that so many people are unable to read and are getting caught up in the system and missing out. There's an assumption that if we put something in language they'll be able to read that, but that's not always the case either. Do you have any thoughts on how we can better engage at a very early stage with these new parents?

TOM McCLEAN: It probably comes down to two things based on what I've heard from our staff. The first is trust and the second is information. Trust is not simply a matter of translating something into a community language and then hoping for the best. It actually involves people who are part of the language group or the culture being in community and communicating directly with the vulnerable, the disadvantaged, the isolated people who need help. In our experience, for example, in some of our supported playgroups—in our multicultural centre in Cabramatta and others—that set of personal relationships with the community is more important than whatever the language happens to be.

But the second is that the big systems that we use to provide care in Australia tend to be fundamentally in English, and that is a barrier. So having the resources available in language once people have decided to connect and to try to get the help they need, so that it's accessible to them—whether it's in audio or written form or whatever it might be—is an essential support to that. Our systems are hard enough to navigate as it is, and that's an extra barrier for many people.

Ms DONNA DAVIS: Thank you. You hit the nail on the head.

Ms LIZA BUTLER: Everyone has told us today about how hard it is to get early intervention staff, whether that's speech pathologists et cetera. Do you have an inter-agency group where you can coordinate and communicate with other services, work together, to be able to go, "We don't have that capacity, but you can with this child"?

JENNY HARGREAVES: Yes. Every centre that Barnardos works in—every town—we always attend inter-agency, even those we do outreach with. We do work really closely with everyone within that inter-agency. Often, though, those speechies and OTs are still providing outreach to those towns, particularly in western New South Wales. There're just positions vacant, waiting to fill. But we do work really hard within inter-agency to try and fill that gap and build those relationships.

Ms LIZA BUTLER: Does that tend to work, that between you all you can pick services up for children?

JENNY HARGREAVES: Yes, to some degree. But for most of our smaller centres, it does mean travelling to those bigger regional cities—Dubbo, Orange, those places—for the children to access those services, because most of those services would not provide outreach to those smaller communities.

Ms LIZA BUTLER: Is there something we can do to improve that? One of the earlier participants talked about a rural and remote team.

JENNY HARGREAVES: That would be fantastic. We would love that. As I mentioned earlier, we did have that partnership with Marathon Health, who are based in Dubbo, but they travelled out to our smaller—they went to Gilgandra, Warren, Nyngan, Cobar, Coonabarabran and provided that service and then came back. That did cost us a lot of money to do that. But something like that works really well because they come into the Barnardos centre—or could be wherever—while the playgroup's being held and then just work with the families and assess the children. So it's within a welcoming environment, not having to take Mum with six of her children for six hours travel to have the same assessment done. Things like that work really well.

Ms LIZA BUTLER: My next question is to Dr McClean from Uniting. In your submission, you spoke about formalising support that LHDs provide to children when they're accepted but haven't yet accessed NDIS. Can you just elaborate on that for me, please?

TOM McCLEAN: I'm aware of the reference in our submission. I'm afraid that's not something that I've got any more information on to hand, but I'm happy to take that on notice and get back to you.

Ms LIZA BUTLER: Thank you very much.

Ms FELICITY WILSON: Thanks very much. Jenny, you mentioned that the program you were running with Marathon was costly but effective and you ran out of funding. Where did the funding come from? Was it a specific grant program?

JENNY HARGREAVES: No, it was within our Barnardos funding. And we had bit of an underspend from the previous year. So we held that over and provided that service with that funding. It was State Government funding.

Ms FELICITY WILSON: Can I ask both organisations to what extent you have any commentary on funding—the level of funding, how it's provided, how it's prioritised, and where you think you need additional funding?

JENNY HARGREAVES: Within our family pres programs, we're given a certain amount of funding for brokerage for our families, and it's based on a family. Potentially, they could say, "You have $1,200 to spend on that family." But, if you've got a family of seven children and they all need allied health and they need beds, it's not going to last long. I know some other programs are funded per child, which works a lot better. It's really difficult. Then, within family support, like targeted early intervention programs, there is no brokerage to spend on families as such to provide any support with medical appointments or allied health appointments. We work really hard to secure outside funding from donors. We try to secure that funding and we use that to provide those services for our families.

TOM McCLEAN: I think our experience of brokerage is consistent. It's an essential part of any program, especially in this space. The sufficiency of that brokerage varies from program to program. I think the other challenge we face is that sometimes it doesn't matter how much brokerage there is; the services just aren't there to procure on a time frame that helps the family. If you've got a child who is four years old who you identified when they were still in early learning that they need some support but there is a two-year waitlist, they are in school before they get the support. The thin markets problem is real, no matter how much brokerage you have in some cases.

Ms LIZA BUTLER: I have a supplementary question. In regard to brokerage, did you see the amount of brokerage funding change when disability services changed over to NDIS?

JENNY HARGREAVES: Yes. I can reply to that because I used to manage a disability service, and when I managed that disability service we used to get block funding. We could provide early intervention for nought to 6-year-olds. They didn't have to have a diagnosis, but if the early childhood centre or the early intervention worker picked up that there was a speech—or if there was something that needed support, that block funding would provide assistance so we could have an assessment done by a speech pathologist or an OT. That has now gone, as such. It has left that big gap because waiting for a child to get a diagnosis, to then get a package, has left that gap, and it's expensive.

Ms LIZA BUTLER: Was that the Early Start early intervention program that you were talking about, where you could use the brokerage to get that child assessed when you thought, which we are not—

JENNY HARGREAVES: Yes. This was, like, 15 years ago.

Ms LIZA BUTLER: I know. I rolled that program out for ADHC.

JENNY HARGREAVES: Yes. ADHC had it, and it was great.

Ms LIZA BUTLER: Yes, it was.

JENNY HARGREAVES: It was that block funding that you could spend on those young children.

Ms LIZA BUTLER: And the families, and keeping that whole family together and letting them know how to do their person-centred plan.

JENNY HARGREAVES: Yes, we modelled our work with Marathon on that. They would have the assessment with the speechie, and the speechie would then come back and work with the parent and support worker to roll out that program—not to train them but to show them how to do it. They would sit and do it together. That worked really well. That was with block funding. Block funding was good.

Ms LIZA BUTLER: And that's a gap now with NDIS?

JENNY HARGREAVES: Yes, a huge gap.

The CHAIR: Did Uniting have any comment on that same question?

TOM McCLEAN: No comment.

Mrs HELEN DALTON: Was that block funding State or Federal?

JENNY HARGREAVES: At ADHC; it was State.

Mrs HELEN DALTON: NDIS is Federal.

Ms LIZA BUTLER: State rolled it out, but Federal gave the State some money and the State provided some as well. So it was both, but the State ran the service.

The CHAIR: Just to wrap up, I get to the point now where I say to you—and to extrapolate it out of your submission, into the transcript—if you were going to be making some suggestions for change or what we should be doing differently, what would you suggest we do to achieve better outcomes, in terms of children having access to these early childhood health assessments?

JENNY HARGREAVES: I think I really like that block funding model, just to provide services with that bucket of money so they can support those young children before they've actually got a diagnosis and can move into an NDIS package. I think that's really important, to have some funding for that. I think access to early childhood services and early learning is imperative. And I think we need to push harder for those vulnerable families to have access to that, rather than having to go on the waitlist like they're having to do now. And I think the idea of non-government organisations having a one-stop shop so that the families, where they feel comfortable—and you bring in the allied health, the early childhood nurse into those settings where the parents are feeling comfortable and supported, and I think you get a better response from the families, and you build those trusting relationships.

The CHAIR: Uniting, I know you had recommendations in your report. So if you want to get them on the record, talk to them.

TOM McCLEAN: Yes. We've got some recommendations in our suggestions, but I think Jenny's just summed them up perfectly. One of the challenges is to help families to access environments where they feel safe and trusted, because this isn't necessarily always an easy experience for families, to recognise and to address the fact that their child might have some sort of issue, some sort of developmental issue that needs help. The second is for better coordination between the big government systems, because there are many of them that are involved in this. It's not just the NSW Health system, which is what we mentioned in our submission. Then the third is the thing that's come up in many of our responses to your questions today, which is the underlying challenge of workforce and thin markets for many of the allied health and other things that families need in order to get the diagnoses and the help that they require.

The CHAIR: Agreed. We have heard that a bit today, and we've also heard about the massive challenge of travelling to appointments.

TOM McCLEAN: Those practical barriers are a big issue.

The CHAIR: I was thinking about, Jenny, your example about getting to the paediatrician in Dubbo. My brain just goes, "What if we took the paediatrician out to Cobar once a month and they just filled their book with appointments?"

JENNY HARGREAVES: Perfect. Yes.

Mrs HELEN DALTON: If only.

The CHAIR: If only—I know. But I don't think we get to tell paediatricians what they do and how to do it. On that note, thank you for appearing before us today. You will be provided with a copy of the transcript of your evidence for correction. Committee staff will also email you any questions that you have taken on notice from today. The Committee as a body may develop some supplementary questions that we want to send to you, as well. If any of that happens, we do ask you to turn them around in one week if that's possible. If it's not possible, please talk to us about that, and we'll work through that. But the Committee will now break for lunch and return at 1.30 p.m. Thank for again for your submissions and your time here with us this morning.

(The witnesses withdrew.)

(Luncheon adjournment)

Mr RICHARD WESTON, Chief Executive Officer, Maari Ma Health Aboriginal Corporation, before the Committee via videoconference, sworn and examined

The CHAIR: Richard, thanks for being with us again. I see you at different inquiries and it is always good to have your company and wisdom. Before appearing before the Committee today, please note that Committee staff will be taking photos and videos during the hearing. The photos and videos may be used for social media and public engagement purposes on the Legislative Assembly's social media pages and websites. Please let the Committee staff know if you have any objections. Before we start, do you have any questions about the hearing process?

RICHARD WESTON: No, thanks. I think I'm pretty right.

The CHAIR: Before we start with questions, do you want to make a short opening statement?

RICHARD WESTON: I am a Meriam man of the Torres Strait. I pay my respects to the traditional owners of the country I'm on today in Broken Hill, New South Wales, the Wilyakali people. I'm the CEO of the Maari Ma Health Aboriginal Corporation. We cover half of the region of Far West New South Wales that we know as the Murdi Paaki region. Every five years Maari Ma produces a child health profile for our region, and most of the available indicators show a disproportionate impact on Aboriginal children, and particularly those living in remote settings.

For Maari Ma Health, when we're thinking about services for children and improving outcomes for children, the focus and the outcome isn't the actual checks but more an effective child and family health service system. That system includes a competent workforce with specialist knowledge and skills, service infrastructure, clear and accessible referral pathways with targeted and intensive support services, interagency and interprofessional collaboration beyond health services, appropriate levels of funding and human resources, ongoing evaluation and performance review, and a research base.

The CHAIR: Thank you for your excellent submission. Can I start by asking you for your view about how confident you would be that you're catching all the mothers and newborn babies in that enormous area that you cover?

RICHARD WESTON: Great question. By our estimation, particularly across Broken Hill, Wilcannia and Menindee, we estimate that we see about 95 per cent of families with very young children. We have a program of maternal and infant health called Healthy Start that we've developed over the last 20 or 30 years, and we also have an Early Years education program, which provides access to vulnerable Aboriginal families. We see a large proportion of those families.

The CHAIR: Richard, in and around that Healthy Start program that you're running, and particularly the work since 2008, you have developed your own resources. Are they books and things like that to use with the family? Have you written your own materials and put that together?

RICHARD WESTON: Yes. One of the programs we have that we've developed our own materials for is called Little Kids and Books. It just came out of identifying a gap in literacy and exposure to literacy for children. We provide the books for free, but it's encouraging families, particularly parents, to read to their children. That has proved to be very popular with the families.

The CHAIR: Good job. Can I just ask about the first dot point on page 2, where you talk about the implementation of the framework that you've built. Dot point 1 says:

> Regular interactions between our health service and the child/family including 23 visits from birth to 5 years of age …

So Maari Ma coordinates 23 visits to each new baby and home and mum?

RICHARD WESTON: That's correct, yes.

The CHAIR: Wow.

RICHARD WESTON: A benchmark, I guess, for us is about ensuring that kids meet their immunisation targets, their developmental checks. We've been training our Early Years staff, which is our Early Years education side of our service, and our Healthy Start people in the ASQ-TRAK, which is the monitoring and developmental checks for Aboriginal kids. It's an Aboriginal-specific tool. So we encourage families. Our health workers get out on the ground and follow families up, and that's an important part of just really trying to ensure that kids from birth to when they start school are healthy and start on a level playing field but also that we pick up any developmental issues or health problems early on.

The CHAIR: Given that you started that around 2008, 2009, you're 15 years into it now. We're talking about high-school-aged kids right at the pointy end of that program. I think that the results that you've been able to show there, all the improvements on so many levels, is fantastic. Is there anything you would do differently? Or is there anything you're planning to do differently on that front?

RICHARD WESTON: I think that we will just keep trying to evolve and develop our service. We've started to integrate our Early Years program and our Healthy Start program into a single service that we're calling the Maari Ma Child and Family Service so it's a kind of a seamless approach. But what we're trying to do with that approach is to access the more vulnerable families that don't always get access to services. We've found that any programs we do around children, particularly our Early Years, families are really keen to engage in that. That's not only parents but grandparents. So it's a really good soft entry point for us, so we're really trying to strengthen that.

We're trying to add additional workers in there that do social work, child support—family support workers. We're really trying to develop a service, I think, that is more holistic, gives better access to those families that don't always access services when they need to and, I guess, build on that work that you mentioned. We're seeing the second and third generation of children coming through our services. Their parents have been through our programs, and now they're bringing their children back to our services.

The CHAIR: Given you go all the way down to the Victorian border, I'm going to throw to the member for Murray, Mrs Helen Dalton. You guys, undoubtedly, share some territory.

Mrs HELEN DALTON: We would, I think. Welcome, Richard. How can health professionals be supported in building trust with Aboriginal families when offering screening services? Clearly you've got a very good relationship, I suppose, with the community—and highly successful. But there must be areas where you would like to be further supported?

RICHARD WESTON: Thanks for the question, Helen. We have quite a large area, so we're just really starting to develop our services around the Balranald area. We've been building our relationship with the Aboriginal community for 30 years, and mainstream services don't always do that. We're an Aboriginal community controlled organisation. Two-thirds of our employees are Aboriginal people from within our region. We have an Aboriginal board of directors. We have a really strong relationship with the communities. I think, for mainstream providers, the best way to build your relationships or to improve services that you're providing to Aboriginal communities is to build partnerships with Aboriginal community controlled services where they exist.

I think the second bit of your question was about additional resources or what extra supports we would need. We would just like to have more investment in what we do and recognition about what we do. The idea of bringing our Early Years work and our Healthy Start work together into a single service is something that could be either invested in or at least closely looked at. We're doing that because we have a good relationship with our communities and we really want to support families to stay out of systems, like the child protection system in particular. It's often the vulnerable families that come under the notice of the out-of-home care system. Our approach isn't to become an out-of-home care provider; our approach is to work on strengthening families and strengthening communities. I think that's something worth thinking about and worth keeping an eye on to see how that works.

The reason we're doing this approach of the single child and family service is because the evidence tells us that we get better outcomes when we do that—when very young children have better access to those universal-type services. Exposure to literacy and numeracy at an early age, and that exposure to good health—immunisations, developmental checks and all those things we've already spoken about—that's what I think we can offer to the system.

Mrs HELEN DALTON: You're talking about generational support or health care. Are you seeing great results in schools? Are kids reaching their potential? Is there a correlation?

RICHARD WESTON: I can't answer that question. Well, I guess, I can. The answer I would say is that there needs to be more effort in the social determinants of health. We provide good-quality health care. We can demonstrate and measure that. But our families grow up in challenging circumstances. Things like access to employment for families and education outcomes aren't always the best, and social conditions are challenging for children and families. We would say that there's a need for more effort in what we call the social determinants of health. Things like housing, education and employment—those kinds of things would help our services to have better outcomes and improvements for families and communities overall.

Ms FELICITY WILSON: Thank you very much, Richard, for joining us and for the work you're doing. There were a few things in your submission that I was quite interested in. If you're happy to answer a few questions for me—it is not an area I have a lot of knowledge around. I have small children, so I have a lot of knowledge about early learning or aspiring to early learning and development for my own children, but I live in the city and have a very different level of access to services here. One of the areas you spoke about in the submission was the Australian Early Development Census, which I'm aware of, and you talk about the way in which that looks at some of the, shall we say, determinants of outcomes and prospects for children. And you said that you've got a huge variation across where you offer your services. But you also mentioned that the Central Darling shire doesn't have any results. Do you know why? Are they not included in the census? Do they not have access to that information?

RICHARD WESTON: I'm not sure of that, Felicity. I'd probably have to take that one on notice.

Ms FELICITY WILSON: Okay. It just really interested me because, if we're trying to make decisions about where to put government resources and programs, I think you need to have a baseline of information to understand where you need to target that to. So that was really interesting to me. Do you have even an anecdotal explanation as to why you see such a significant variation across the communities that you service?

RICHARD WESTON: Yes. I think remoteness is a big factor. Where we deliver our strongest services are Broken Hill, Wilcannia and Menindee. Wilcannia and Menindee are fairly close to Broken Hill, relatively speaking—200 kilometres to Wilcannia, 100 kays to Menindee. But then you get to places like Ivanhoe and Balranald and even the Wentworth Shire. Those places have pretty good access to services, but they're often dealing with cross-border issues. Balranald and Wentworth are right on the borders. But I just think the challenges are about remoteness. That causes a problem for families, and just the social circumstances that our families are growing up in creates additional challenges as well. Families aren't always motivated around their kids. Health and education, for some families, is not their highest priority.

So the work we're trying to do is not just provide a service to communities, but we're trying to open up important conversations and dialogue with our communities and using the leadership of our board to help us open up those conversations about where our priorities should lie, and our investment in getting better outcomes for children, mums and babies and very young children is because we think that that's ultimately where we're going to make a difference down the track. We think we can close the gap. If we can create and support healthy families and healthy children, getting kids to grade 1, without ear problems, have some numeracy skills and have all their immunisations up to date so any infections are minimised and their physical health is in good nick, they stand a better chance of having better life outcomes. That emphasis on children and creating healthy children and healthy families, we see as a long-term investment, and ultimately that, we think, will close the gap.

Ms FELICITY WILSON: We hear a lot about the challenges of remote, regional areas, obviously, accessing services, for instance, and you do speak a bit about that. You talk about your own incentive models to try and get services out there and some of the challenges of having to be funnelled out of public health care and into private, allied health services, things like that. Do you think that, if you had all of these services available, people would be accessing them? Is it more of a supply, or more of a demand, issue?

RICHARD WESTON: Great question. I think, if we had those services available, we could, clearly, offer more. We could offer it in a more timely way. But I think, whilst we need to keep developing our education and health services, we also have to address the social determinants of health, things as I mentioned before: housing, employment, education—those things are important—that have to be dealt with in parallel. If you're offering more supply or more services, we'd certainly take them.

Ms FELICITY WILSON: One of the areas we talk about quite a bit is around early learning and access to early education. You mentioned earlier the different priorities or motivations for different families or individuals. As we know, there are often issues with access to early learning, but one of the lowest areas of participation is for Aboriginal children, as you'd be aware. Do you have any insights about how we get more Indigenous children into early learning?

RICHARD WESTON: Yes, I think what we see in our Early Years program is skilled early-years educators and Aboriginal people working in that program as well—people that know the community and know the families—and also recognition that Aboriginal people just love their children. Anything to do with kids, they're into it and they'll latch onto it, but you have to provide the right access. It has to be a good environment, it has to have an Aboriginal feel to it and it has to be a safe place. There's a bunch of issues that our staff have to manage sometimes, which is sometimes inter-family conflict, so they have to be pretty sensitive about that. But families are pretty good at moderating any tensions when it's about the children. So really recognising that if you can provide good access for families and make the extended families welcome—so not just parents but it might be uncles, aunties and in a lot of cases grandparents doing that sort of caring. It has to be a safe place and it has to be a place where Aboriginal people feel welcome and where they see their children being treated well.

We just find that the community loves our Early Years team because of the way they work with the children and help them learn about play and give them access to things like Little Kids and Books and other programs. It's a really important entry point for health services into those families that have more complex issues and are challenged with access. We just keep trying to build on what we're doing, what we have done and what we do well, and try to expand our services. We are often limited. It's not just about funding; it's also having the people available or interested in that sort of work. The tyranny of distance when trying to deliver services into Wilcannia on a consistent and regular basis can be a challenge sometimes.

Ms FELICITY WILSON: You also spoke about the NDIS and said it was failing in small rural and remote areas. We've heard from other attendees that—I'm not sure if this is your experience more broadly or just with the component for early childhood—the early interventions are so crucial with timing. You refer to it as well—that you can have a 12-month wait for an appointment. You're having to wait for a diagnosis or trying to get on a plan et cetera, but there are delays to getting prompt access to interventions or supports. Do you think there should be a different way of approaching it? You talk about the Aboriginal community controlled health organisation model. Do you think there should be a different approach for children than for adults, or do you just think the NDIS is a failure across the board in those communities?

RICHARD WESTON: I think there should be a different approach for children and adults. With children, the longer you delay a service or an intervention, what's happening while that delay's occurring—whatever the issue is—is evolving or developing for the child. I think those wraparound services are really important—the allied health, psychology, community paediatrician—so trying to find strategies or develop strategies so that those services can be accessed. I think there have been some developments in the NDIS where the Federal Government's having a look at a different approach for Indigenous communities but I'm not quite sure where that's up to. We'd certainly see opportunities to develop an Aboriginal community controlled health model. Not every area, community or region has an organisation like Maari Ma that's been there for 30 years—it's well established and so there's a good foundation to build on. But where that resource exists, we should be looking at bespoke models that work for that region and work for those families. I think the NDIS has been a really important development in our health system over the last few years or however long it's been going but, if we can't access it, then we can't take advantage of the benefits of it.

Mrs TANYA THOMPSON: Felicity touched on the three topics that I wanted to talk about, which is fine. It's great that you were able to elaborate on those. I was interested in the HIPPY program—the school readiness program. I think that's a really great initiative that you're rolling out in that region. If you want to elaborate more on it, I'd welcome more information, although you did talk about it at length already. Do you think that the New South Wales Government has engaged enough with your organisation and supported you enough? If you had the Ministers in front of you, what would you ask them for? I know you said funding, but you said it's not just funding. So what in particular, if you had a wish list, would you really need to keep things moving forward?

RICHARD WESTON: Tanya, for our region, and for the area that we cover, I think it would be good to have recognition that our organisation and what we've done over 30 years is important. We're not just a not-for-profit organisation, or an NGO operating on the periphery of the system; we're really embedded in the system out here. For our region anyway, and for our organisation, there are great opportunities to develop some really interesting and innovative partnerships that could be funded and supported by the Ministry of Health, which would advance and expand what we do because it does make a difference. Our work is all based on evidence—or the best evidence available—and that's the way we've always functioned. We look at the research and we look at the evidence about what makes a difference and then we try to implement it. We try to make it happen on the ground. That's always the biggest challenge.

As well as the other things, we'd like some recognition and respect for what we do, not just as an Aboriginal not-for-profit operating on the periphery of the system but as a really sophisticated, well-functioning organisation that can make a difference. If we were given more responsibility and more access to more resources, with that recognition we could provide some pretty good programs and services that other people could learn from. We have done that for a long time.

Ms DONNA DAVIS: Thanks so much for being online today, Richard. This morning we had a different range of people talking about the benefits not only of preschools but also playgroups. You reiterated something that was mentioned this morning, which is that people aren't always motivated around their kids because they've got so many other challenges to face on a daily basis. Do you run playgroups right across? And how do you find that they help in terms of health interventions for children?

RICHARD WESTON: Yes, we do. That's part of our early years programs: playgroups. What Maari Ma has done is last year we were successful with some funding from a Commonwealth program called Connected

Beginnings, which is all about early years. It's about, I guess, trying to build closer working relationships with the early years education sector and children's health services, maternal and infant health. Maari Ma is unique because we were funded by the Connected Beginnings program to do both elements of that. In other parts of the country, those parts have been funded to separate agencies or organisations. That's really led us to this idea that we should integrate our early years education work, which includes playgroups, HIPPY programs, Little Kids and Books, Aboriginal families as first teachers and those kinds of services, with our maternal and infant health services, which we call Healthy Start, which has child health nurses, Aboriginal health practitioners supported by a general practitioner who is focused on child health, supported by visiting paediatric services and things like that.

We have a pretty strong model and because we're all in the one organisation, we can start to create a seamless model that helps those—because education and health, they have different philosophies. They're governed by different dynamics, their own politics, their own challenges in developing those different workforces. So we're working on bringing those together under one organisation to create a child and family service. We're really keen to see where it goes because we've drawn on evidence to do the thinking about that. The portfolio is being led by an Aboriginal executive manager for the child and family service. She is a school teacher by training, who then came and worked for us and did diabetes education. She's worked in a whole range of programs, including our Healthy Start program. So we've got this really interesting approach that we're taking. It's just for us to really work out how do we bring those together? How do we manage the dynamics between the two—the education people and the health people?

But really, I think what I find is that, at the centre of it all, it's always about children. When people seem to focus on what's in the best interests of children, people seem to be able to relax those kinds of discipline boundaries or whatever they are, and actually just really work together to provide really good services.

Ms DONNA DAVIS: In the delivery of services, I just wanted to touch on how, in your submission, you talk about the challenges of attracting allied health workers and health professionals—the same challenges that we know are being faced right across New South Wales with nurses and midwives. I found your suggestion very interesting about specific training through Charles Darwin University for Aboriginal health practitioners in the Far West that you used to access. What can we do to make things easier for you to be able to have local men and women trained to be able to provide those services—people who want to stay in their local communities and also support their own communities?

RICHARD WESTON: I guess what we're saying is that in addition to the deployment of masters-level courses, which is a very powerful qualification that can take a while to achieve, particularly if you're working, we think the service could be enhanced if courses actually focused on the milestone assessments. People do not necessarily have to have a masters degree or diploma to deliver milestone services and checks. That's our thinking behind the ASQ-TRAK training, which we have been delivering to our health and early education staff. We took a similar approach when we trained Aboriginal health practitioners in the past. They are not necessarily registered nurses, but there is a degree of work that they can do that takes the pressure off nurses. Nurses don't have to do everything and Aboriginal health practitioners can plug a gap. It frees the nurses up to do more complex stuff. It's a similar idea. We are really just trying to look at what the need is here. The need isn't necessarily to have someone with a diploma or a masters to do a check. We just need the people who have the knowledge.

Ms DONNA DAVIS: Yes, if you're weighing babies and measuring their height and doing basic hearing tests. I think that is very pertinent to not just Aboriginal medical services, but everywhere.

RICHARD WESTON: People are overseeing it. There are people there to make sure they are doing it right and getting the right clinical support and supervision. But there is work that local people can do.

The CHAIR: I want to ask one last question from my perspective. Do you talk to other agencies and organisations about the way that they roll out some of these initiatives to constantly improve, reframe and reshape what you are doing? Are you looking for where someone else might be doing it better so you can do it in your work?

RICHARD WESTON: Yes, we are always looking at the evidence. We have a public health unit in our organisation. We are looking at what is best practice or better practice. Anything that we can do and any learning that we can take, whether it is from the mainstream or from Aboriginal community controlled services, we will look at it, and if we think it's going to work for us then we'll try to integrate it into what we do. We are quite active like that. We're shameless in the ideas that we steal off people. Again, it is about trying to provide a good service in a pretty challenging environment and to just make a difference where we can for our families.

The CHAIR: We will call an end to it there, Richard. Thank you so much for your time and your submission. You will be provided with a copy of the transcript of your evidence today for correction. Committee staff will also email any questions taken on notice. I don't think there were any—one maybe.

RICHARD WESTON: There was one.

The CHAIR: The Committee might develop some additional questions that it might send to you. We do ask, if it is possible, that you respond to that within a week. But if that is too difficult, please talk to us and we will work through the process. Once again, thank you so much for your time.

(The witness withdrew.)

Ms NICOLE ROGERSON, Chief Executive, Autism Awareness Australia, sworn and examined

Associate Professor CATHY MORGAN, Program Lead, Early Detection and Intervention, Cerebral Palsy Alliance, sworn and examined

The CHAIR: Thank you for appearing before the Committee today to give evidence. Please note that Committee staff will be taking photos and videos during the hearing, which may be used on the Legislative Assembly's social media pages and websites. Please let the Committee staff know if you object to having photos and videos taken. Do you have any questions about the hearing process?

NICOLE ROGERSON: No.

CATHY MORGAN: No.

The CHAIR: Would either or both of you like to make a two-minute opening statement before we begin with questions?

CATHY MORGAN: I would like to. Thank you to the honourable members of the Committee for the opportunity to make this statement. I would also like to begin by acknowledging country and paying respect to the traditional owners of the land we are on today. In my 30-plus years as a physiotherapist in New South Wales—including in regional New South Wales—and now subsequently as a researcher, the most common thing parents tell me about their diagnosis journey for cerebral palsy is that, despite their concerns and suspicions, they were told to wait and see.

Historically, cerebral palsy, which is the most common lifelong childhood disability—and disability of a lifetime, actually—was thought to only be able to be diagnosed well into the second year of life. This, obviously, delays access to interventions in the key window of neuroplasticity. However, early diagnosis breakthroughs in the last 20 years mean we can now diagnose cerebral palsy with 98 per cent certainty at just three months if we use the right assessments. Early diagnosis means an opportunity to deliver evidence-based early intervention, altering the lifelong developmental trajectory of infants with CP and supporting their families, who we know to be at greater risk of mental health challenges during this period.

In spite of this, three-quarters of infants with CP are still not diagnosed until after six months of age. As laid out in the submission to this inquiry by CP Alliance and related to this inquiry's fourth term of reference, it is of critical importance that funding for early intervention programs and screening for cerebral palsy is available. In New South Wales, one in 700 infants are born with cerebral palsy. Risk factors that contribute to cerebral palsy are more prevalent in rural and regional areas and in Aboriginal and Torres Strait Islander populations, meaning vulnerable communities are even less likely to receive timely support. For these communities and for all families, we should not accept a wait-and-see approach.

This inquiry's focus on improving access to childhood developmental checks presents a significant opportunity to invest in a brighter future for all of these children by implementing a few recommendations. We're specifically asking for or recommending that we screen all infants admitted to NICUs across the NSW Health network. That's because 50 per cent of children who go on to have cerebral palsy spend time in a NICU or a special care nursery. Secondly, our long-term vision is that we actually universally screen for cerebral palsy and that these implementation processes could be embedded across all health touchpoints, including the blue book, which we've heard a lot about today. Our final recommendation is for the early diagnosis clinics that we've already started to be fully funded and expanded across New South Wales, to ensure that early diagnosis of cerebral palsy is accessible for every family, no matter where they live. Thanks very much.

The CHAIR: Thank you. Ms Rogerson?

NICOLE ROGERSON: There's so much Cathy and I have—I could insert "and autism" in so much of the early introduction, so I won't go over some of them. Suffice to say that we too have problems of families losing valuable time in the wait-and-see approach. We actually did a survey a couple of years ago. Sixty per cent of parents reported that the wait-and-see approach had prevented them from getting a diagnosis early. I'm certainly going to bring up some very new research out of the United States today that shows the effectiveness of bringing in these early childhood checks and the impact that can have on the autism community, but oftentimes we might find, with GPs, that they will often say to families with a diagnosis such as autism, because there's obviously not a blood test that one can take for autism—if a parent, particularly a first-time parent, presents with certain concerns, they're often told, "The child's a bit too young, and we'll wait and see how their development comes along." Every "wait and see; let's talk to you again in six months" is just further kicking down the road that child's ability to start absolute integral early intervention.

We know, in autism, that, the earlier we catch it, the earlier we can get children enrolled in effective early interventions and therapies, the better the outcome in the long term. So this little section here, of early childhood development, the part that we've been missing—and in my case, I've been in this space for over 20 years. We've known this for a really long time. It just beggars belief we don't really do anything to address it. We just know the earlier the better. It's as important in CP as it is in autism, so I think you're probably going to have an alliance of agreement here today.

The CHAIR: Indeed. There was alliance of agreeance in your submissions. It was a little bit like insert "autism"—

NICOLE ROGERSON: We don't know one another, I should say. We just met today.

The CHAIR: Essentially, both of your submissions really concentrated on the importance of that early diagnosis, but the absence of work being in that early diagnosis space. So my opening question to you is how specialised is the skill set required for a diagnosis to be made?

NICOLE ROGERSON: Could I go with that one first? The reason is—this is hot off the presses, and I'll happily share it—a study that has just come out of Drexel University in the United States. They did a large study across three states, in two cohorts. They took the existing staff of the early childhood screeners and gave them some training in a tool called the M-CHAT, which is the Modified Checklist for Autism in Toddlers. It has been around for many years. It's quite a straightforward series of questions that can be a really good screening tool for children that need to be referred on for other services. Obviously, they had a control group who did not. At the end of the study, they found that the group that did not have any training had only referred 39 children at risk to go on and get an assessment, whereas the teams that had the training in how to deliver the tool had 186 children referred on further.

So we just know that the staff on the ground in these centres, when they have tools—and they can be really quite simple in autism; I can't speak for cerebral palsy—are picking up young children and toddlers that may be at risk. You can't get back time you've lost, but you won't waste time investigating a child with a developmental delay. If it turns out not to be fully fledged autism in the long run, okay, great. We didn't lose any time; we just identified a child who was developing a little differently. But if we flip it on the other side and say, "Well, we don't want to make parents too nervous," or, "Mum and dad don't look like they're ready to hear that yet," that's actually the child's opportunity that they're missing.

Coming back to the blue book that I know everyone's probably talked about, when I looked at the more updated version of that now, I could see that they do a really good job of checking for 10 fingers and 10 toes and checking for hearing. But we know that the numbers of children with autism in Australia are considerable. They currently make up 35 per cent of the NDIS population. One in 91 Australian children has autism. We're talking big numbers here. So if we can impact, even by moving that diagnosis—and I should show that this research also indicates that it reduced the age at which these children were being picked up for further investigation. We know that the earlier we go, the better the outcome for those children. So a relatively minor bit of training in a pre-existing tool that's been considered to be international best standard for 30 years could be implemented and could address this quite quickly and quite inexpensively.

The CHAIR: Before I give Ms Morgan a chance to answer the same question, when you talk about that simple training, is it one day, a week, a year course, part time? How much training is required to get people up to scratch?

NICOLE ROGERSON: Less than a day. I don't have this American research on me at the moment to give you a definitive answer of how much training went in, but the M-CHAT is literally a tool that lives on the internet that we suggest parents look at now and use now. Anybody can use this. This is not proprietary software or a proprietary assessment. This was merely alerting early childhood nurses that when you're doing the screening and the checklist of all the things that little Johnny should be doing, there are a few questions that we can ask. It's a screening tool. It's not a diagnosis. It's merely saying, "This is a child we should check up on." Maybe we wait and check up again in two months or in four months, but we don't do, "See you again next year and see how you go."

CATHY MORGAN: The situation with cerebral palsy is probably a little bit different. I would say, in the past, people have been waiting for children to not do something before they started worrying about whether they had a diagnosis like cerebral palsy. What we know now is that there's an assessment called the general movements assessment that's done around three to four months of age, which has 95 per cent sensitivity for picking up CP. That assessment is video based. So, pretty much, a family can take a three-minute video with a few simple instructions and upload it, and somebody can score that remotely.

Across Australia now, every neonatal intensive care unit has trained staff. It is a 3½-day training, so it is a specialist training. We use that as a screening assessment but we also, of course, have a neuro exam and MRI, which also help to bring that information together to make a formal diagnosis. The most useful tool for screening is the general movements assessment. People are using that to some degree throughout the State. But our problem is that we only screen 10 to 15 per cent of the children who are likely to get a diagnosis of CP—small percentages.

The CHAIR: So if I'm at home, if I'm a parent, I can work through these movements—

CATHY MORGAN: No. A trained professional needs to score it, but a parent can take the video. They can take a video of their child with a few simple instructions and a trained person would look at that video and be able to say, "This is high risk for cerebral palsy. Let's bring you in for some more assessment," or, also very helpfully, "This does not look like cerebral palsy based on this video."

It's something that's in our international clinical guidelines that our team wrote in 2017. It has started to be implemented across the world. We really have done it on the smell of an oily rag here in New South Wales. It is being used, but it's not being used to capacity.

The CHAIR: Ms Davis, I'm going to go in reverse order. I'm going to shake things up.

Ms DONNA DAVIS: I don't have anything yet.

Mrs HELEN DALTON: I'm fairly gobsmacked, actually, about what you're saying. My electorate is very rural and remote. You see children slipping through the gaps. I know a little fellow who is three and non-verbal and basically hasn't had any care yet. He has to come to Sydney now for care. I think it's appalling. Now you're telling us that the screening tests are pretty easy and there are ways and means around it—

CATHY MORGAN: Absolutely.

Mrs HELEN DALTON: —and people just don't know. Is no-one listening to you? How can the gap between vulnerable children with complex developmental needs and access to support services be bridged, particularly with us, where we don't even have paediatricians? The last doctor will leave town in about five years. I haven't got a doctor. We have to be able to do a bit better than this. Obviously, you've nutted out a few things. At least give us the tools to help ourselves, really, because not many other people—well, the system is totally broken. Parents need the tools and the information so they can at least do an assessment at home. What's the road map for all of that?

NICOLE ROGERSON: I would just comment that it's not that nobody knows. It is that a lot of people know. It just lacks the leadership to implement some changes in this system. I understand that in the health system things can move glacially slow. But the frustration—certainly from my side of things—would be that we have known this for a really long time. We've been talking about these things for a really long time. It's a little bit like screaming in the void. The way that we, as an organisation, at Autism Awareness Australia, get around that is we build digital tools to go direct to families. There's one we're launching just today. We have very big digital platforms so we can get this kind of information to families. If I can't get it to the doctors or if I can't get it to the early childhood centres, I can make sure parents are better informed to know what they can ask for and to know what they should be demanding. It's to re-educate parents.

It's very difficult in certain communities, particularly for communities that find disability to be quite a cultural issue. We have to get through all of those barriers. Why it feels to me that this is so sensible is that the blue book is your first parenting guidebook. It's your first thing that is trusted from the New South Wales Government that says that these are all the things that you need to look out for. The fact that autism is missing from that has an impact at the moment that beggars belief. We need to be looking at the whole of the child, not just the 10 fingers and the 10 toes. With minor changes to some of these systems that are already in place, I think it would have a ginormous impact. It doesn't mean that I can get a doctor or a speech pathologist to your town, but I do now have parents who understand, are informed and can seek out answers for themselves.

CATHY MORGAN: If we could just start with infants who have been admitted to neonatal intensive care units or special care nurseries—17 per cent of all births are admitted to a NICU or a special care unit. If we had something embedded within NSW Health where all of those children had a QR code, people could download an app to their phone and could upload the video to a region where we had trained people—we know we can train.

I'm a trainer for the particular assessment that we're talking about. We've got two trainers in Australia, which is better than America, where they've got one. We could definitely make it happen with some investment within a digital platform that could house videos. I think that's one of the barriers—actually having a place where the videos can be stored. We do have a lot of people trained. We just need to build in a training program so that is ongoing over time.

The good thing about the general movements is that if a family who was in a NICU and was worried about their child goes home to Broken Hill, for example, and they upload that video and we see that the baby is looking like it is moving really well, we can give that good news. That way we're directing the funds for the children who actually need the follow-up to the children who actually need the follow-up.

Mrs HELEN DALTON: You could put a QR code in the blue book.

CATHY MORGAN: In the blue book, yes.

Mrs HELEN DALTON: So simple.

CATHY MORGAN: So simple. Some digital infrastructure is definitely required. We've got an app already that's only been used in research. I know the people who have built that app from Murdoch in Victoria are very keen to get funding to make that into a clinical version so that it can be used in every hospital everywhere. At the moment, you have to be in a research project in order to be able to access that app. But we know how to do it. We know what parents think. We know how often they return videos if they're in a research pilot project. We're about to start a pilot in three sites in New South Wales to see what the feasibility is of assessing every single baby from the NICU—because, at the moment, it's 10 to 15 per cent.

Mrs HELEN DALTON: Is the blue book only a New South Wales initiative?

CATHY MORGAN: Yes. Other States have something similar.

NICOLE ROGERSON: Other States have a version. This is not funny but I think in other States it's a different colour.

CATHY MORGAN: Like red.

NICOLE ROGERSON: But, no, it's the concept.

Mrs HELEN DALTON: The concept is there. I wonder how extensive information is in their blue book. Often we hear we're lagging behind in New South Wales on many things. I wonder if they are more forward thinking in other States. Do you know or not?

CATHY MORGAN: This screening isn't happening anywhere. It's really all very site specific. Whatever site has the will and the means to put resources in, it happens.

Mrs HELEN DALTON: It could save a lot of heartache.

CATHY MORGAN: That is unlike hearing, which is across the whole country. And the prevalence is the same as cerebral palsy. Every single baby is screened for hearing.

Mrs HELEN DALTON: I know in this case a family where the grandmother was saying to just wait and see and that there is nothing wrong with the child. Of course they've lost time in arguments and destroyed relationships in the family because they didn't have any access to any information or they didn't know where to go. It's a long waiting list. Now they're off to Sydney to get treatment or to get help. It's ongoing, all of this. At what cost?

NICOLE ROGERSON: To further that point, some of these things being more embedded within things like the blue book, where it helps is—we have a really tough time, even at the GP level, of getting a GP to have enough time with a child and to get to know a child well enough to be able to see if they're "developing normally". If you've got a parent who is really not alert to the fact that their child might have a problem and a GP that hasn't got time to spend with that family to know, we're losing even more time. It's not enough to just say that going to the GP might pick this up earlier or going to see a paediatrician would pick this up. That's not necessarily the case.

We know that these early screeners that could be done, if children are going to these centres, would address most of that problem. And then a parent has the results of a screening tool and they don't have to listen to the GP say, "He looks all right to me," which is a response that, frighteningly, in the year 2024, families still report that's what their GPs say. They say, "Why are you worried? You're just a slightly nervous mum," negating the fact that mum or dad are seeing that their child is not developing in the same way as either of their siblings or other children from the community. Parents often get shut down. That makes it very difficult. By formalising something, it doesn't say, "Your child has autism." It just says, "I think you should be watching this." That can save an enormous amount of time and heartache.

Mrs HELEN DALTON: I think that GPs are not really in the zone. There was that face-to-face with the clinic sister that we used to have years ago, and they interact almost fortnightly or weekly. You used to be able to go and see the clinic sister, and that doesn't exist any more. They were watching the development. Back when I had my four children, they were watching the development. You go every month or two weeks and just drop in and see. Maybe perhaps a return to that kind of system where we had a bit more interaction with a nurse or a clinic sister—or an RN, as they are called now. That might be the answer.

Ms FELICITY WILSON: Thank you very much for being here today. Professor Morgan, you were talking about the fact that you can have 98 per cent certainty of a diagnosis at just three months of age, and then you mentioned that you thought we should introduce screening for any baby in the NICU. Is that what you suggested as a first step?

CATHY MORGAN: Yes. Just to clarify, 98 per cent is when we use all the three tests that are available. The particular movement test that I mentioned, the general movements assessment, is a screening aspect of that. It's the lowest hanging fruit, if you like, because it's the one where you can take the three-minute or five-minute video, and if the infant is or isn't moving in a certain way, you can have a very high sensitivity for picking up those kids who have got movement problems.

Ms FELICITY WILSON: If you wanted the lowest hanging fruit screening for every baby in the NICU, what kind of resourcing/training would that require?

CATHY MORGAN: We would need, for every site that had a NICU, staff who are trained in how to do the assessment. The parent takes the video but the clinician scores it, so it would need a portal where the families could upload the video and somebody assigned to be scoring those each week. I imagine that means, then—well, all the NICUs actually do have trained people. I can tell you that now. The special care nurseries—quite a few of them across the country—do as well, but probably not every single one. So you could have a regional approach. Then there'd be some sort of automated system that sends out "We need to see your baby again" or "At this point, low risk for cerebral palsy based on this assessment". Obviously, there's always a disclaimer—it doesn't cover every developmental problem that could ever happen with a child, but it does screen for cerebral palsy very effectively.

Ms FELICITY WILSON: You said earlier, in response to another question, that you don't see this screening happening in any jurisdiction. It's a bit patchy. Are there examples, either in public healthcare systems or private hospitals, where they do undertake this kind of screening?

CATHY MORGAN: I would say the Grace Centre for Newborn Care at the Children's Hospital at Westmead has the biggest—

Ms FELICITY WILSON: Just where Professor Badawi is.

CATHY MORGAN: Yes, where Nadia is. That's right. They would probably screen 50 per cent of their admissions. Most of the other sites—every other NICU, in fact—would screen children who fit the Australian and New Zealand Neonatal Network criteria. That's typically 28 weeks pre-term birth and less, and probably extra infants who have, say, seizures or some sort of sentinel event around the time of birth, or a stroke. Those babies would be followed up, but really there's these moderate to late pre-term babies who we also know are at risk of cerebral palsy who we could be screening very easily.

Ms FELICITY WILSON: Would you just be screening them when they're in the NICU, or in the subsequent months with their child and family health nurses and things like that?

CATHY MORGAN: No, we would be definitely screening them at three to four months because that's when the test is the most sensitive. The strategy would be to help parents understand how to use the app on their phone, for example, and understand the process. The app that we have at the moment sends a reminder to families a couple of times when their baby is about to turn 12 weeks. We collect data at the moment at 12 and 14 weeks, if they're in these research projects. But if we build an app which is more clinically suitable as opposed to research suitable, then we could send a reminder at whatever time we wanted and it would come up on their phone. And then they could upload the video at a time when the baby is in a good mood and they haven't had to travel for four hours in a car. Then somebody can assess that remotely and then provide an answer back to the family, or a phone call if they need to have more assessment.

The CHAIR: Forgive my ignorance. If a baby is in NICU, are they typically in NICU for three months?

CATHY MORGAN: No, it can really vary. A baby could be born at 24 weeks, for example, which means they will be there until they are term equivalent, which is three months. But we take it from when they were due. The video that we want to capture is still not until they are at three months corrected age.

Ms FELICITY WILSON: Am I to take it from what you're saying that it wouldn't be a huge resource increase? You're saying that people in NICU are already trained and you've got apps. You've got families that have children that have gone through the NICU and are already interacting with health services throughout that time period anyway. Are you saying that it wouldn't be a huge resource increase to put that screening in?

CATHY MORGAN: At the moment they're screening 10 per cent on the budgets that they've got within the NICUs. If we go to screening the whole amount, they would definitely need more resources to screen more babies.

Ms FELICITY WILSON: But we have the capability within our workforce in order to do that?

CATHY MORGAN: Yes.

Ms FELICITY WILSON: Ms Rogerson, in your submission you were speaking about how crucial early intervention is—the profundity of it for changing futures for kids. What is the earliest that you could have an effective screening for autism, or an average earliest that you could have an effective screening?

NICOLE ROGERSON: It's a good question. There is no actual age. At the moment there's a research program out of Western Australia that is called Inklings and they're looking at screening babies who are the siblings of children who currently have an autism diagnosis to see if they can get a bit more of an idea. What we typically know is that children are being diagnosed over the age of four when we can reliably diagnose a child as being somewhere on the autism spectrum at around 18 months, during that time that they're potentially still going to these early childhood checks. To go back to the point that Cathy was making about the digital reminders, that's not something that happens if you haven't been in a NICU, and most of our families obviously wouldn't have.

It's interesting. I don't know how it works because my children are now adults, so I have forgotten what having small children was like. But whether it be a system that something becomes automated through either the blue book or Service NSW, once you have a child in New South Wales, the idea that you could be sent reminders, whether it be at 12 months—the same way we're kind of reminded about vaccinations. It is like a reminder to mum and dad: "You can go to your local community maternal health centre and have a check." Whereas, once a family starts getting a little bit nervous about needing an assessment for their child, they will go to the public health system, which—I don't know what the actual number is now, but it's typically a two- to three-year wait to get into Westmead children's hospital for an assessment.

A child just can't lose that amount of time. They don't have that amount of time to lose, so then families are pushed into the private sector, where diagnoses are typically between two to three thousand dollars for a private assessment—another barrier to why most families can't do it. Even by going to have these screening checks to work out whether or not this is an issue, you need to get on a waiting list, you need to have this assessment—or some great news as well, which is, "No, actually, it turns out this is fine." That's really critically important. You also have to think this is a generation of parents who are quite used to everything being on their phones. I think we need to look at the systems that we've got that were born out of years of government policy and then the system that we need that actually—it's relatively low-cost reminders and digital architecture that could help us close some of this gap.

Ms FELICITY WILSON: Our blue book developmental checks go up to four years, but that relies on you attending those appointments. I know that you referred in the Cerebral Palsy Alliance submission to the previous inquiry into new babies and parents, which I also sat on at the time. At that point, a lot of the conversation was about whether or not people were engaging with their blue books. One of the big determinants for immunisations, for instance, is the No Jab, No Pay—no participation in early learning—so there's a motivating factor to make sure you're getting your immunisation, at which point, you're going to the GP and the GP is then asking you about your blue book and doing the developmental checks because you're getting vaccinations in the centre. But you don't really get any other reminders or alerts or anything to try to encourage you to do those checks. To what extent do GPs, if that's the path you're going through, now have the training and tools to undertake that kind of first level screening? If they're getting people through the door for their blue book checks, do they know how to actually screen at that age? What would it take to upskill that workforce to ensure that they could?

NICOLE ROGERSON: In autism, no. GPs are obviously generalists. They have to be specialists in everything. Obviously there will be great GPs who understand the early signs. They might have other children or people with autism as part of their practice and they're across it, but we know that we're probably missing a lot more than we're getting. We did some work with the Australian Medical Association a few years ago where they wrote a position paper on our need to change this. But, of course, GPs have to learn so much. There's often pushback in terms of how much more education can they do. But a lot of groups understand that that is a missing part. If we had GPs as part of this army of people who know what the signs look like, it would be incredibly helpful.

Ms FELICITY WILSON: So you could screen for them, but the issue then is treatment. As you said, the waiting lists are very long in the public system and costly in the private system—but are there also long delays in the private system as well?

NICOLE ROGERSON: There can be. It very much depends on where you are and if you're willing to travel.

Ms FELICITY WILSON: What can we do about workforce capacity?

NICOLE ROGERSON: Workforce capacity is an enormous—

Ms FELICITY WILSON: Simple question, simple answer!

NICOLE ROGERSON: Yes—would you like the answer to be before I die? Look, it's obviously an enormous issue and one that we talk about with the Federal Government a bit more, because this is a capacity issue within the NDIS and it rolls into a whole range of other areas. There'll be discussion around what kinds of assessments need to be taking place and at what age. It's a much bigger piece of work there. We know that children in New South Wales that will go and have a public assessment at one of the assessment centres will absolutely get top-of-the-line, comprehensive assessment by a multidisciplinary team.

That's fantastic, but we know a few years ago the new Australian diagnostic guidelines that were done nationally said that we know, for a cohort of children with more profound and severe autism, we're probably going to be able to detect that quite quickly in the assessment, in which case we may not need a whole day of assessments because we're able to call it earlier. I think we need to build in a system that says—we need to make sure that the children who need a thorough assessment to be able to work out what we're looking at here, and whether autism might be the diagnosis or something else, will be assessed. But, for probably 30 per cent of children with autism, it's quite obvious quite quickly.

CATHY MORGAN: When it comes to cerebral palsy, I would say a lot of GPs—I would concur with Nicole—are not aware of what to look for, particularly in mild CP. The majority of children with cerebral palsy are going to walk, for example, so that can be difficult. This is one of the reasons we've started early diagnosis clinics in this State, which is a collaboration between Cerebral Palsy Alliance and NSW Health in some instances, but we do have a lot of philanthropic funding that supports those as well. The idea of that was to reduce the time waited for a family to see a neurologist, for example, which can be nine to 10 months in the public system. We get these kids in, usually within six weeks, and the original appointment is a couple of hours with a multidisciplinary team and a social worker, so that we can really support the family in total. At the moment we have three of those; they've been going since 2018. But at the moment most of the funding would come from our donors at the CP Alliance.

Ms FELICITY WILSON: Once you get through that early diagnostic centre, is there then access to services and treatment?

CATHY MORGAN: Yes. One of the next barriers for us is helping families access the NDIS if they do have a diagnosis. That can take varying amounts of time, so what we have at CP Alliance is basically a free service, called the early response service, where families with babies who are newly diagnosed or at high risk of cerebral palsy can access early intervention through CP Alliance until they get onto the NDIS scheme. Of course, that's limited by—again, it's philanthropic funding, so probably they're getting 25 per cent to 33 per cent of what is recommended as the amount of therapy. But it's one of the only organisations that's providing early intervention that's cerebral palsy specific without any other funding coming alongside.

Mrs TANYA THOMPSON: I wanted to address with Nicole the gaps with allied health professionals, community nurses and that age group. Twenty years ago, when my kids were little, the community health nurse used to visit kids when they were in preschool or day care centres and would pick things up. My daughter had a hearing problem when she was three, so that was picked up early when she was little and addressed before she started getting into school age.

I think that's been lost somewhere because the services aren't funded or there's not enough boots on the ground to pick that up. I think that might be where those gaps are now in this space with parents, but also education in regional, rural and remote areas for parents, who might feel that the first step is to go to a GP and then get referred on to a specialist and then get referred on. Then they have to wait, and then they're stuck in the NDIS merry-go-round, with that feeling of helplessness. It's all too hard and it feels like there's no hope. I've got a few families in my area that feel that way and just get stuck in that cycle. It's very disheartening and hard for families. Have you got some recommendations, or did you want to speak to that?

NICOLE ROGERSON: Yes. It's funny—when you're describing that period, there are just so many places where it could be caught and then so many places it could be missed. It's actually interesting because as I was coming here today, I looked at my own son's blue book. My son is autistic and he's 28. I still have it. What was beautiful next to his 24-month check was the community nurse in Potts Point writing, "Have told mum and dad that there are not enough single words, and it might be time to see a speech pathologist." Thank goodness that's what she wrote because then you go to see the next person, and that next person says, "Yes, we might need to investigate this even further." There are so many bits missing there. What if we didn't do the 24-month check? What if the nurse who was there didn't have a screener for children with developmental delays? It's all so terribly haphazard.

One of the ways organisations like mine try to get around this is earlier this year we launched a program called "Navigating Autism: The Early Years". We delivered a digital training platform directly to early childhood educators. We launched it in February. It was an online video module of training. We've already had 18,500 early childhood educators trained in what to look for. It's just one program. We were going directly to day cares thinking that was bang for your buck because lots of kids will be in some kind of day care or family day care. That was just one way we could go, but it obviously needs to be a multi-pronged approached; it can't just be with early childhood educators.

We built that because we saw that was a potential way to not miss these really important parts. It is dependent on families. It leaves families later on with this feeling like, "What could I have done if I had have known earlier?" No doubt you will understand that mother guilt can power the world. That's disheartening for families. They feel like they missed that time. It's particularly true for children with mild forms of autism because it may not be as obvious and they may not be picked up until they start more formal school. Those families will often go through a period of feeling like, "Wow, what could I have done if we had picked this up when they were two or three?" We can, with the right screening tools.

Mrs TANYA THOMPSON: Can you explain a bit more what the "choice and control" focus in the NDIS means? What does that mean? I'm not fluent in NDIS, so I just wanted to know what that means.

NICOLE ROGERSON: You're best not to be, really—save some grey hair! The concept for us that still leaves us a bit concerned is that the NDIS has always been built on this concept of choice and control. When you have a disability, there will be a package of funding. You can choose the best life you want for your family and how you will do that. We've always been of the opinion that, of course, everybody believes in choice and control and having agency in their own life, but we need to make sure that early intervention options are also evidence-based and valid. It's a little bit like—for instance, you wouldn't allow children in a day care centre to play with toys that were likely to break or that they could swallow. There are certain quality controls involved. We'd like the same thing in New South Wales, to make sure that families have an early intervention system that has evidence-based options for them and they're not going to spend those NDIS funds on things that are silly and not really going to help their child.

CATHY MORGAN: Hear, hear!

The CHAIR: We heard some testimony earlier today about a resistance to or a fear of getting a diagnosis. In your journeys, have you come across some families who have little ones that are probably on the spectrum or experiencing CP, but they go the other way? Or do you not tend to see those parents because they won't even come in your door in the first place?

CATHY MORGAN: Yes, there are definitely individuals who find the whole assessment and diagnostic workup incredible anxiety-inducing. Our idea for those families is to just pace the diagnostic process with what they're asking to know at a certain point of time. I think it's absolutely critical to have people like psychologists and social workers involved in these processes so that families can receive support around their own anxieties with it. I would say that is the case. However, in a recent study done by my colleagues in Victoria, where they got people using that app I mentioned to you, I would say that less than 10 per cent of the families found that a really difficult process, to know that their baby was being screened for cerebral palsy. The vast majority agreed or strongly agreed that this was something that they wanted to do for their child, even if it did create a little bit of stress for them. I think it does happen but, at the end of the day, information is power and people want the information that is relevant to their child. But they need the support, in some circumstances, to really know how to process that diagnostic moment.

NICOLE ROGERSON: I think that's very true for autism as well. Do we meet families who resist that diagnosis? Definitely. That can be particularly true for people from certain cultural backgrounds who can find the concept of disability more broadly to be difficult. It's about supporting parents. It's also about changing the narrative of what a "label" is. I think that's changed over time. We have to understand that a label describes a child at a particular point in time. It doesn't describe the whole person. It's really important, again, for organisations like ours to provide information and content to families that says, "A label is fine. It doesn't tell you anything about your child. It's still your child. It's still the one that you had yesterday and it will be the one you have tomorrow. You love them just as much." A label can just be something that alerts all of the grown-ups in this child's life that work needs to be done. We need to provide that support. A label is certainly not something to be feared, but it has been in the past. I don't think we've necessarily got on top of that yet.

The CHAIR: Following on, with culturally and linguistically diverse communities, how are your organisations working to get penetration into our CALD communities?

CATHY MORGAN: At the Cerebral Palsy Alliance, our early diagnosis clinics—the first one we set up was in south-west Sydney—are in probably the heart of areas where there is a high proportion of people from diverse communities. We would use interpreters wherever possible. We love having diverse staff as well so that when people come to our organisation they're represented. It's really through those main mechanisms, I would say.

NICOLE ROGERSON: For us, we don't have a physical centre. We're not that kind of service provider. Again, most of the projects Autism Awareness Australia is involved in tend to be digital in nature, purely because we can scale it. The barriers to access to the information are very low. We can make all of our information and resources free to families, and we can get to families wherever they happen to be. Where we think it is important is to be able to—and again, this takes money but, strangely enough, not as much as it used to, because technology is our friend—make sure that we have websites that have easy translation tools to use.

What we find for some families who are a little bit nervous about maybe going to see a practitioner or somebody about their child's disability, is you can privately ask Google anything you wanted to. A parent—oftentimes, the first thing that they're going to do about a child's development is going to be to Google or ChatGPT. We need to understand that, whilst they might not be comfortable within their communities to talk about it too early, that shouldn't deter us from making sure that we're giving them the right information as early as we possibly can to help that process for them and to get them to where they need to have a proper assessment.

The CHAIR: Associate Professor Morgan, you talked about a five-minute video clip that can be sent through and then be assessed. My question is, how many specialists do we have that can do that form of assessment? Is it a really small number, or are there dozens and dozens of them?

CATHY MORGAN: There's dozens and dozens of them.

The CHAIR: Okay.

CATHY MORGAN: I actually don't know the New South Wales number. The number in Australia is over 1,000.

The CHAIR: Typically, New South Wales has about a third of whatever Australia has.

CATHY MORGAN: Yes.

The CHAIR: I think that you referenced the point that you're one of only two people in all of Australia—

CATHY MORGAN: Two trainers.

The CHAIR: —who can train.

CATHY MORGAN: I train people, yes. Across the world, the General Movements Trust is an organisation that manages all the tutors for this particular training. It's based in Europe, but we have two trainers in Australia who run the courses. I would say that every year in Australia we run two to three courses, which cover 30 to 50 people per time. Every neonatal intensive care unit—and I can tell you this because I help them—uses this tool within the NICU, and at quite a few of the special care nurseries as well. I would say at each one of those sites there's doctors and allied-health members who are trained in how to score those assessments.

The CHAIR: How many NICUs do we have across New South Wales?

CATHY MORGAN: Eight in New South Wales.

The CHAIR: Which one is the furthest west?

CATHY MORGAN: Nepean. The most remote would be the John Hunter.

The CHAIR: Nothing over the other side of the sandstone curtain?

CATHY MORGAN: No. There are special care nurseries. There would be level 2 nurseries scattered a bit more broadly throughout larger centres.

The CHAIR: Like Orange, maybe Bathurst, Dubbo and possibly Broken Hill? So big centres out west, but not a NICU.

CATHY MORGAN: Yes. But all the neonatal intensive care units—John Hunter is the most remote, as I said, and then the rest are in the Sydney metropolitan area. So that means the babies from those centres come here. If we were going to screen everybody in a NICU, they would have met somebody who is able to screen them.

The CHAIR: Do you think in the future AI will play a role in diagnosis?

CATHY MORGAN: Definitely. We are already working on that, alongside Deakin University. They are working on machine learning for scoring movement from videos. I have just been to a summit, where we got world leaders in this space for cerebral palsy and general movements detection together. We are certainly making gains. We're now harmonising the data we're extracting from videos. There are a lot of privacy and legal things that we've got to overcome, of course, because we've got identifiable images of children. We've got to think of a way to store those. We can't just destroy them. So there are quite a few barriers, but we're pretty committed to solving them. I do think AI embedded into a phone is the way of the future, but I really think we need to start earlier than that to start screening these kids. Because as we collect videos, we're going to build the machine learning—

The CHAIR: The bank, yes.

CATHY MORGAN: —because it's dependent on data, right?

The CHAIR: Yes, 100 per cent. What about with autism?

NICOLE ROGERSON: There is very similar work that's happening internationally in this area. Whereas autism is a little bit different because it's often a behavioural diagnosis, there is research around eye tracking and a baby's ability to have joint attention that is showing early signs of promise. So I think the future is there, but I agree with Cathy that there's no need to wait and we can use some of the technology we have now. What I think is really interesting and what's changed for this generation of families is smartphones. I don't think that you need to know many new parents to realise just how many photos and videos they take of their babies, at least of baby number one. I'm not sure baby number two gets much.

The CHAIR: Ms Wilson?

Ms FELICITY WILSON: I've got four. The last one—completely.

NICOLE ROGERSON: But those videos exist. When you see a paediatrician, they would often say, "What age was the child walking?" Back in the day your answer would be "I don't know. Who knows?" Whereas now you probably know the date they take their first steps. So we already know we have a bank of videos around most children that might end up forming part of a diagnosis at some point. That's all exciting times ahead. But, goodness, we're missing some really low-hanging fruit here that could use some older assessment tools to make sure that we're getting who is here now. We don't need to wait for the technology to catch up.

The CHAIR: I think you've made that point very well today and in your submission. We genuinely appreciate your time, expertise and knowledge, and we appreciate you sharing that with us. Thank you for appearing. You will be provided with a copy of the transcript of your evidence for correction. Committee staff will also email any questions taken on notice from today and any supplementary questions the Committee may develop in the coming days. We do ask that, if possible, you return answers in about one week. If that's not possible, that's okay. Just please talk to us about that. I sincerely thank you again for all the work that you do and for spending time with us today.

(The witnesses withdrew.)

(Short adjournment)

Mr PHILIP PETRIE, Chief Executive Officer, Allevia Limited, and Chair, National Disability Services New South Wales Divisional Committee, affirmed and examined

Ms ALICE LANS, Chief Executive Officer, Noah's Inclusion Services, and Member, National Disability Services New South Wales Divisional Committee, affirmed and examined

Dr ALEISHA DAVIS, Chief Executive Officer, The Shepherd Centre, affirmed and examined

Ms ANGELIKA DALKEITH, Director of Clinical Services, The Shepherd Centre, sworn and examined

Mr DAVID BRADY, Director of Community Engagement, The Shepherd Centre, affirmed and examined

The CHAIR: I welcome our next witnesses. Thank you for appearing before the Committee today to give evidence. During this session, I ask that members and witnesses state their name before they begin speaking. My name is Clayton Barr, and I am the Chair of this particular Committee. On my left, we have Mrs Helen Dalton, who is the member for Murray. We have Ms Felicity Wilson, who is the member for North Shore, and we have Mrs Tanya Thompson, who is the member for Myall Lakes. We have been rejoined by Ms Donna Davis, who is the member for Parramatta, who has come back from what must have been a controversial Legislation Review Committee meeting.

Ms DONNA DAVIS: It wasn't controversial; it was just much longer than normal.

The CHAIR: Please note that the Committee staff will be taking photos and videos during the hearing. The photos and videos may be used for social media and public engagement purposes on the Legislative Assembly's social media pages and websites. Please let Committee staff know if you object to having photos and videos taken. As Chair, I am going to offer you the chance to make a short, two-minute opening statement before we begin the questions. I might go to the Shepherd Centre first, and then I'll go across to the National Disability Services. Would anybody like to make a start?

ALEISHA DAVIS: On behalf of the Shepherd Centre, I thank the Committee for inviting us to provide evidence here today. We are a charity based in New South Wales, the Australian Capital Territory and Tasmania that empowers deaf children to achieve a world of choice. With over 50 years of experience, we've helped thousands of children and their families develop crucial listening, speech and social skills to thrive, and we were the first to do so here in Australia. We're here today to discuss the gap in early childhood hearing screening.

In New South Wales, one in 1,000 children is born with hearing loss, identified through newborn hearing screening. There has been excellent coverage of that here in New South Wales and across Australia over the last 20 years. However, for every child that's diagnosed with a hearing loss at birth, another two children will develop hearing loss by the time they start school. Yet, there is no hearing screening program in place for these children. Evidence shows that these one in 300 children who are entering school are at risk of having hearing challenges, which puts in jeopardy their communication and personal development, and many parents are left without support or guidance or a pathway. For those who do reach out to organisations like Hearing Australia, they currently face a six-month wait for a hearing test.

The evidence indicates that most children with hearing loss detected after the newborn period do not have any known risk factors for late-onset hearing loss, so a targeted surveillance program in itself wouldn't be enough. There's a lot of work internationally that has been done on accessibility and efficiency of early childhood screening mechanisms that don't rely on specific equipment or on a specialised workforce. I note that only three submissions of the 52 that were received mentioned the need for hearing screening. While this might suggest that the issue isn't urgent, the reality for preschool children and their families is very different. It is widely accepted across New South Wales, Australia and globally of this need for early childhood hearing screening.

In closing, I highlight two points for the Committee in the terms of reference of this Committee. Without early childhood hearing screening, children in New South Wales are vulnerable and not set up to learn in the classroom. There's even a higher risk of up to 40 per cent more children in regional and remote areas and in Aboriginal communities. Preschool hearing screening is not a nice-to-have. It's a must-have to ensure that children develop their communication, educational and emotional wellbeing; ensure that teachers can support accessibility so that children can learn well; reduce demands on later therapy services and on misdiagnoses and behaviours in the classroom; minimise long-term costs to taxpayers and reduce pressure on the education, health and disability systems; and the necessity of having a navigation system post the screening that supports the pathway for diagnosis and therapy support.

In regard to paragraphs (3) and (4) in the terms of reference for the Committee, there's an experienced and trained workforce and organisations like ours here in New South Wales, and we've commenced discussions with the Sydney Children's Hospitals Foundation and can work with Brighter Beginnings, Hearing Australia and the sector to develop pilot programs, and that can really leverage on various successful implementations already in place, like the vision screening program. This can also be started in areas like south-western Sydney, which is what we've been talking about, and piloted across other areas. There is also a real opportunity with the Brighter Beginnings program to introduce the hearing screening program.

My colleagues are here today to help answer your questions—Angelika Dalkeith from a clinical perspective and from working with families, and David Brady for his insight into having a hearing loss and the difference a diagnosis makes. Many of us, as parents in this room, understand the absolute necessity for our children to hear well so they can reach their learning, developmental and communication ability. We can have a formal submission, with a literature review as well, of evidence for the Committee.

PHILIP PETRIE: Thank you to the members of the Committee for inviting National Disability Services to be represented here today in the inquiry. I am the CEO of a small NDIS-registered organisation, Allevia, which operates in the south-western Sydney region. I am a registered nurse with 43 years of experience working in community health, largely in the Hunter and Illawarra regions, specialising in disability, mental health and community health. I am also the chair of the National Disability Services' New South Wales division. I am joined by Alice Lans, who is also on the National Disability Services' New South Wales State committee. Alice is also CEO of Noah's Inclusion Services. She is a certified and practising speech pathologist and has worked with children's speech, language, feeding and development for the past 25 years in New South Wales, Western Australia and the UK. She has worked with people across preschools, schools in general, in private practice and in the not-for-profit context.

Noah's Inclusion Services is an organisation established 42 years ago in Nowra by a group of parents who were raising children with disability. Noah's support around about 2½ thousand children and families in the region between Wollongong and Narooma through a range of disability, developmental, education and family support services. It employs 100 staff who are made up of early childhood development practitioners, early childhood teachers, health professionals and family workers. Every day they work with families of young children on the child's development and help them navigate the processes and barriers to support and provide evidence-based best practice services.

National Disability Services is the peak body for disability services in Australia. We have around 300 member organisations in New South Wales and 1,100 nationally. Collectively, NDS members operate thousands of services for Australians with all types of disabilities across all age groups. Our members employ around 100,000 people nationally and provide a full range of disability services to around half a million Australians. Our vision is for an inclusive Australia where all people with disability live safely and equitably. We believe that to achieve this people with disability need to access the right supports, at the right time in their lives, from the right people.

Equally important is to ensure that support starts as early as possible in a person's life to minimise the impact of their disability and maximise their potential as a contributing member of society as they grow. Our members have identified many barriers and potential opportunities that the New South Wales Government could and should address to improve the access and delivery of safe, quality and inclusive health services for children and young people with disability. These are detailed in our submission that has already been submitted to the inquiry. I will just add that NDS is actively involved with the New South Wales State Government through a number of initiatives that have been looking at the early childhood intervention foundational supports. We will continue to support the Government as we move forward on the reforms around the NDIS.

The CHAIR: I'll start by going back to NDS. In your submission you talk about the barrier in Indigenous communities of whether the person coming in to do the medical procedure, intervention or assessment is trusted. We heard language around fear of government agencies and things like that earlier today. How is your cohort going around that difficulty in making a trusted approach for our Indigenous communities?

PHILIP PETRIE: I might defer to Alice from a practical standpoint to give you an answer to that question. I have got a few other things I will probably add.

ALICE LANS: Sure. I think it is a very multifaceted discussion. I think that one of the really significant things in building trust is consistency and being in the local place-based area that communities are living. I think one of the greatest things that we have found as a provider, but also other providers that we work with in our community—we have been working with Aboriginal communities for 20, 25 years. We will only engage with Aboriginal communities on invitation, so we have a lot of partnerships with other Aboriginal organisations. But really, when we started that work, it's about consistency and about being there long term.

What we find often is the challenges if services come in, which is what happened in our region with the introduction of the NDIS. That happens a lot, so you have a lot of providers who come in and are there for a short time. People may or may not access the services because they haven't built trust yet. Then the organisations or service provisions as well are actually not funded to be there if none are not turning up, so we're just not going to be there and so then they leave. Then it reinforces the cycle, the fact that someone is not staying. A lot of it I think is long-term service delivery, and long-term service delivery can only be provided with long-term programs and funding. That, I think, is really key. The second part, as I said, is engaging when invited by Aboriginal communities to do so, and partnering.

The CHAIR: In terms of early childhood assessments, health checks and things like that, and given that excellent description of how you develop trust, what do you see happening on the ground in terms of trying to roll out and implement some of those early childhood checks? First of all, they need to be checked and assessed before they can get a diagnosis, and then once they get a diagnosis they might tap into your services. Do you witness and see some good things being done on the ground?

ALICE LANS: Absolutely, we do. There are some great things being done on the ground, but I think that the challenges to a lot of those great things being done on the ground are very sporadic and very siloed, depending on the program and the funding that they are offering. There is not necessarily calibration in how we support families to know what is out there and how that can be supported. There are some amazing programs. There are Aboriginal-controlled organisations providing some amazing programs and there are non-Aboriginal organisations providing great programs. But I think the challenges for families are often that the processes are so complex to decide to know where to go for supports. There is not one streamlined pathway.

I think one of the biggest challenges for New South Wales is that we have, as I said, some great programs but they are being put out, layered on each other, but independent of each other and there is no true universality. When we are talking about essential screenings and consistent pathways that is a big challenge. For a lot of families that we support, when you are talking about assessment and diagnosis, and then supports and services, I guess just going back to that, even that concept has been challenged with the NDIS with the way that operates. It actually doesn't work as smoothly or seamlessly as that because of the way the programs are funded. I don't know if that answers the question or not.

The CHAIR: No, it does. It's interesting to hear about that siloing. I'm guessing when you say that, you mean within a single community, for example, Bourke or Cobar, might have all these siloed—

ALICE LANS: Generally, I mean state-based services. What is actually in communities is often very strong and very rich. There are services being provided there that are just doing the best with what they have, but they know their communities very well. I think what is tricky is that sometimes the reach of programs that are funded isn't in all places, so it does depend a bit on where you live and what's going to be available, but it also means in terms of the criteria or eligibility of children and families to access that service. It's very complicated. Because they are funded by different departments and they are funding something slightly different to get a slightly different outcome or a particular purpose, that's what government needs it to do, but it's not necessarily how families' journeys are.

So it doesn't match someone with a child who just wants to get supports for whatever it is they need at that time, and then in six months time or a year's time it might be something different and they want everything to come together at the right time in their community. But what happens is that often they don't even know that these programs are out there because they may not have transport to get to them or they may not fit into the outcome of what that program is trying to fund. Does that make sense?

The CHAIR: Yes, that's good. I do have questions for the Shepherd Centre. But in fairness, and for time, I pass to Mrs Dalton, the member for Murray, for her questions.

Mrs HELEN DALTON: It seems that we don't know what's out there in the coordination of services. So how do we instigate an audit of services in New South Wales? What's the best way to do that? I'm the member for Murray, which is the second biggest electorate, going from Griffith to South Australia, and we are rural/remote. No-one knows what's going on and there's no coordination. How do we bridge that?

ALICE LANS: I'm happy to give a very quick answer but I'm happy to hand over to other people—I don't want to take all the time. I think there are a couple of ways. It's the people in the communities asking around because people will know. Particularly the more regional and remote you go, the more people will know who to ask and who to go to. I know for a long time with DCJ, with the Targeted Early Intervention, I've been thinking that it would be really great to know who are the other Targeted Early Intervention-funded programs. They should absolutely know that, because they're funding them, so there's no reason not to know that.

There's an Aboriginal Families as Teachers program that the Department of Education is running. That is one of the programs where I think they have invested brilliantly in working with service providers, because they've created a network of service providers. So everyone who is funded under that program has opportunities to network and to know who is who. That's been a five-year funded program and that's been amazing. So there are opportunities to tap into that type of work but it's probably something like the Cabinet Office is looking to do, I'd imagine, with foundational supports and looking at what's out there. I'll let other people talk about that.

PHILIP PETRIE: NDS, in the last 12 months, has been working with providers across the State. In the consultation process that we've been going through with Department of Communities and Justice work, part of what we offered was the ability to bring a lot of providers from right across the State to the table to consult around these particular issues. In our last one that we held at the Indigenous cultural centre at Redfern, we had 50-odd people that turned up. There was a wealth of information in there from right across the State. It's not hard to get those people together. There is a push at the moment with CaFSA, which is a provider-based alliance of children and family services. That's expanding at a rapid rate and gathering momentum and members. I really don't think that it's difficult to be able to get the insights into what's going on in the far corners of the State, because the providers are so keen to share that information and be part of that consultation. It's just a matter of making the invitation.

Mrs HELEN DALTON: That sounds too simple.

PHILIP PETRIE: I know sounds simple but it is actually quite simple. I learnt so much that day in the consultation about what's going on in regional towns and what's not going on in regional towns. The negative impact that the NDIS is having—it's doing great things for some people but it's actually siloing services. It's making the services extremely transactional. It means that there are a lot of people that are missing out, because we know that, of people with a disability in this State, only a small number have actually got access to funds through that scheme. There are so many outside of it.

Mrs HELEN DALTON: From the Redfern meeting, were there any outcomes? Was there a report or—

PHILIP PETRIE: Yes, we have a report, which we can share with the Committee—more than happy to do that. The consultations continue. I understand that DCJ are actually going through an online consultation. They've gone out to all the providers for them to make submissions to try to further that. There was further consultation done with families and people with disability themselves, so it's been quite a wideranging inquiry into how foundational supports are going to look and how they are actually going to integrate with the NDIS, given that the clear insight is that the services are there.

Mrs HELEN DALTON: We just don't know.

PHILIP PETRIE: Yes.

Mrs HELEN DALTON: I don't know whether the services are really there for rural and remote areas. Do you have a comment on that?

PHILIP PETRIE: I think we'd be a bit surprised, actually. The Chair was talking about trust, and one of the issues is that people trust their own in those local communities. There is a lot of service provision that's going on which, probably if you put it there, technically is informal. It's unpaid, it's provided by the not-for-profit sector, or it's provided outside of the funding envelope for many services. I call on my daughter working out in Wentworth with the Indigenous health services out there. They do so much beyond their brief.

Mrs HELEN DALTON: Would anyone else like to comment?

ALEISHA DAVIS: I will. From a clinical perspective, I concur with all that. I think there is excellent work going on in individual communities from really very good people who want to help their communities, and professionals want to come together because it helps everyone. I think the NDIS has pushed organisations into a place where they're so focused on funding, unless there is specific funding to create these networks and to connect the dots. When there is, that's when it really works and we can work together and collaborate, develop the partnerships and help. If we don't know that the services are there, families definitely don't know that the services are there. How can we help that system to do that? I do think it comes down to there is goodwill, there is excellent capability, but how do we put all of that together?

ANGELIKA DALKEITH: Historically, having worked in the disability sector for a really long time, we did have a different community of support amongst non-government services and government-provided services. To your point, Aleisha, I agree it is very siloed at the moment and it makes it quite difficult, even for organisations, to coordinate. If you have individuals, families, with low medical literacy and low literacy levels across the board, which we find in different parts of the community, it makes it very difficult to navigate and source and understand what to do in an individual family, as well as how organisations can then support it themselves. I think everyone is doing their absolute best, and putting in a whole lot of time and effort outside the envelope is consistent with what we're experiencing as well.

Mrs HELEN DALTON: In the previous session we talked about the linker, somebody who can triage. It is the same with mental health. There are people out there—

Ms FELICITY WILSON: Brokerage.

Mrs HELEN DALTON: Brokerage, or there was a word—

Ms DONNA DAVIS: This morning they called it a "linker".

Mrs HELEN DALTON: The linker. We need that somewhere, or somehow, because they're all working in their own little part of the sandpit but no-one seems to know exactly who is doing what. But there are organisations there, and there is a real gap in all of that. Would you agree?

ALICE LANS: I think to some degree there is. Also, I was going to say to your point before, I know of at least two or three early intervention providers who had been operating in regional areas for decades who have all closed down in the past 10 years because they haven't been sustainable. That has been an issue with the NDIS because you just can't operate under that model with children and families. It was never intended to be like that. Unfortunately, we just sort of kept going and then that's what the result is. Absolutely, the intent of people working in the sectors is that they want to work across health, education, disability. They are really motivated because that's how they've always been in that sector. We want to rebuild that before we lose it completely. We want to make sure we get the threads of what is still there. I see this as a huge opportunity to get this really right in this State.

PHILIP PETRIE: The Federal Government are talking about introducing navigation to the NDIS scheme, which will replace support coordination. I think there is a real opportunity there for the States and Territories to get on board, because I think what navigation brings is the opportunity to have really well-coordinated ways of being able to support people to access the services that are available in their local areas. So I don't think it should just be confined to the NDIS.

ALEISHA DAVIS: There are definitely models in other States, particularly in hearing, for example, where there are linkages that support families through screening, through diagnosis, through into interventional supports, because families have to opt in at each stage for that. In the States where that does exist, we see very successful rates of families in support programs early, and then the outcomes are very different because that role is there. And so how we can take advantage of that within different sectors, but also widely across disability, would have a huge benefit.

Ms FELICITY WILSON: To the National Disability Services, as you'd know, we've had a number of submissions from stakeholders representing a range of physical, neurological and developmental disorders, illnesses and disabilities. We hear some consistent themes, obviously. But when we are looking at some keys areas for children around screening, diagnosis and then intervention or treatment, is there, in your experience and knowledge across the broader suite of disabilities, a perfect model that you can conjure up that would have screening that would cover off the range of different areas where we need it, even if it is not the formal diagnosis step, but that earliest level of screening that would cover off a range of different conditions or concerns? Do you think we still need to have more ad hoc specific screening happening for different disabilities or developmental issues?

PHILIP PETRIE: We both probably want to jump into this question. It's a pet topic. I go back to my days of working in Newcastle, where I was seconded to Wallsend hospital and worked in the developmental disability unit for New South Wales. We were a trans-disciplinary team that brought a range of professionals together in one place. We used to travel all over the State to provide the services, do checks, work with families, work with GPs and work in schools. The government of the day about 32 years ago decided that they would scrap that model. I believe that was probably one of the biggest mistakes that they made in that policy shift. I think there was a concern that they wanted to move away from the medical model to the social model. The reality is that it's both. You've got people who need to be socialised into a medical environment and they need to feel comfortable being part of that. That's based on relationships and they need someone who they can trust that can lead them through it and refer them to the right people. I believe that those trans-disciplinary teams hold the answer for the future.

ALICE LANS: This is something that I could talk about all afternoon, but I won't. Yes, I think there are many models that would be the perfect solution and they all involve utilising existing people, skills, providers and services. Just to give an example, I know that 10 years ago, if a child was born in Nowra hospital, our organisation would have a phone call from the maternity ward and they would say, "Come and meet with this family." One of our family workers would go and meet with them and then they would go straight into some sort of trans-disciplinary team support, which would coordinate with the GP and follow that child through with early childhood education services or health appointments or whatever they needed. You add into that screening for hearing, cerebral palsy and all the things that we have been talking about and that all the submissions have supported. Then you add in universal models and you also have parents in New South Wales having development coaching support. People would say, "There's no way you could fund that for every child". But I believe, honestly, if you did the analysis for the return on investment on that, most children will be off that program in six weeks.

We have got really highly skilled child and family nurses. We've got GPs. We've got trans-disciplinary teams of therapists. We've got specific disability organisations that have specific skills that they get referred to. At the moment, they don't get referred to the services in the appropriate time because no-one has been there to support them or pick that up. For the children who are developing typically, then they will be off on their way. The other big link is that it would have a huge impact on child protection services down the track and we would be able to offer support so much earlier. The cost of having a key worker from a team of trans-disciplinary people to support every family who has a baby in some sort of model would be an incredible return on investment in the long run. You'd only have to wait five years because you have developmental checks when they start kindergarten. You'd only have to wait five years to test that and see how that works.

Ms FELICITY WILSON: A lot of avoided cost as well.

ALICE LANS: A huge avoided cost—probably five times what you are actually spending on all of the programs that you're funding at the moment. Those programs would still exist, but they would be utilised in the more specific, targeted way that they're meant to.

Ms FELICITY WILSON: To the Shepherd Centre—I've had a lot to do with the Shepherd Centre, so these questions are probably more for the benefit of the inquiry rather than for myself. You have a very successful newborn hearing screening. I remember, when my first child was born, I took a photo and I sent it to Dave to show my little alien baby having her hearing screening in the hospital, which is incredibly successful. Many other organisations refer to that with the great wish that they could have that level of screening for the conditions that other children experience.

But, Aleisha, you also talked about children then getting into school and that there are another two children for that cohort who will also have issues with hearing. You made reference to the vision screening for four-year-olds, which I find interesting because I had a four-year-old in early learning who was never offered vision screening. I am not sure how universal it is, but I have another four-year-old, so let's see if he is offered vision screening. I am not sure yet. Do you think four years old is the right level to then screen? Do you think it is through early learning and/or preschool? What about the children who are less likely to be in early learning? We've had another conversation about early learning today and the fact that there can be that correlation between a lot of the communities where you see increased hearing loss amongst Indigenous children, for instance, and in rural and regional communities, where you actually see a lower participation in early learning as well, for instance. Do you think that's the right model? How would you get around some of those other risk factors and groups if you were to introduce that preschool screening?

ALEISHA DAVIS: Good questions. I will start and then pass across. It's been a long discussion around what is the best age for hearing screening for early childhood, and we've discussed this is in a number of committees over the years. There's an argument for doing it in school age—kindergarten checks. Some States choose to do that. The benefit of doing it earlier than that means that children can be diagnosed and set up early so they have good technology and a year of intervention supports before they actually get into the school system—we say children that can hear well can learn well—so that all of that is then there. Then it's not a new process once a child—you've experienced it—has started kindergarten and knows all of that stuff going on. Should we do it earlier than that? Around four is a good age, cognitively, for children to be able to do tests. There's some excellent, as I mentioned, technology now on tablets that can be done with smartphones and headphones.

Earlier than that, it can be less accurate, probably because they're younger children. So around three to four, I would say, is the best age to do that, but I would also suggest that it needs to be different in different communities. It's not a one-fits-all, particularly in Aboriginal and First Nations communities. We've been working with a community on the South Coast, and much of that is around middle-ear management as well and the incidences of that. It's very similar to what we heard before about what works in community. We've been developing through research, through Macquarie University, a lot of culturally safe programs, working around that middle-ear management, within those communities, that isn't necessarily in early childhood. It's not a catch-all, but the accessibility and the efficiency of doing it within an early childcare model would catch a lot of children that we're seeing at the moment going into schools with those mild and moderate hearing losses.

ANGELIKA DALKEITH: I think it's, as you say, not one model fitting everyone, and trying to think about the communities and being quite targeted within those communities. Working with organisations that are already within those settings, I think, is really important. For us, I guess we see ourselves as having an expert lens, but, as you were explaining earlier as well, there are organisations already within community that we would want to partner with that work quite well in those settings to try and capture a lot of these children and families that may not be accessing early childhood settings and preschool.

ALICE LANS: One other comment on screening, just quickly, is that something like Brighter Beginnings, which I know is a new program, is a fantastic concept and really works for a lot of centres where they're close by, and that's great. But in our region, as that rolls out, it takes a very long time and, I imagine, a lot of cost to set something like that up, and it's actually still very specifically targeted because it's only services with a certain number of children in their centre that are four-year-olds that they can come to. It's only then picking up the children whose parents have said, "Yes, that's okay." And then, after that, if they then do a speech screening, they say, "Yes, that child needs to have some more supports." Then they start at the bottom of the process of then what's needed, or there's waitlists or "Where do I even go from there? There's no community health. I can't afford private practice, and I'm not eligible for the NDIS." So, in that sense, I have a bit of a concern with the next stage. If you're investing a lot in a screening program that says it's universal but it's not really universal and then it doesn't necessarily have an outcome afterwards, I think that's one of the challenges.

And same with ear, nose and throat. We can do hearing screenings, and then we've got this problem where families can't, in our area—if they have grommets, they have to go to Wollongong, and they have to stay there for 10 days to two weeks. So a lot of our families who are casual workers won't be able to, and they have to rent up there somewhere while they're doing that, and they've got other children. They actually just don't do it, because they can't get grommets put in.

Ms FELICITY WILSON: That's looking at screening. And then, obviously, diagnosis is another step. Some of the discussions we've had with other people attending the hearing have been around treatment and supports and interventions. Aleisha, you mentioned there's a six-month wait for Hearing Australia. But what about the workforce, skills, capacity, access across the State, for instance? Is it predominantly, at this stage, medical interventions, things like grommets, or surgical interventions? Is it more like some of the programs that you run at the Shepherd Centre, for instance? What type of services need to be provided? Do we have the capacity to deliver those?

ALEISHA DAVIS: In terms of the diagnosis and the capacity for that, I really am concerned around Brighter Beginnings and children being picked up with speech and language issues. The first thing that will happen for them is they will be referred on for hearing tests as well, and then that will just push the waiting lists out even further if we're not either doing a hearing screening or addressing the diagnosis issue. Diagnosis does require specialist training and support. Organisations like ours and like others in New South Wales do have audiologists that can do it. There are funding mechanisms for that to happen through Medicare or private pay at the moment. So funding would significantly help to pull back the waitlist to get children through to have these hearing tests. From that point, then, it's typically a fitting of a device, if families choose that, to access the sounds that they need or the technology to help them hear in their learning situations. And then, typically, because they've missed out on critical periods of sound, it's on speech pathology services, so intensive support to get the speech pathology up and going, either with a local speech pathologist, once the access is sorted, or with a specialist program.

Ms FELICITY WILSON: How is that all funded? Is this normally just public hospital access? Are the devices and things like that through NDIS? Are there other ways it could be funded?

ALEISHA DAVIS: At the moment, families are paying for hearing tests, either through Hearing Australia or privately. We are seeing a number of children going to private audiologists who aren't experienced in paediatric hearing loss and a number of misdiagnoses back through the system, which isn't great. The devices themselves are funded through Hearing Australia for all children. That's federally funded. That isn't at a cost to any parent at that age. And then the intervention supports themselves, at the moment, are funded, typically, through the NDIS. Again, here comes an opportunity with the foundational supports of what that could look like for children with those greater needs going forward. So there's that capacity. Apart from that, it is parents choosing to pay for it themselves.

Ms FELICITY WILSON: Do you know what kind of proportion of children with hearing loss are also being diagnosed with other developmental issues or disabilities?

ALEISHA DAVIS: Yes. My understanding is it's about 30 per cent of children have additional needs as well as hearing loss. It's quite common to have syndromes that do have additional needs. Definitely, in our population that we see, it's been consistently around that 30 per cent mark.

Ms FELICITY WILSON: Are they more likely to have—subsequent to hearing issues, are they being diagnosed for their hearing loss because of the original diagnosis, or being diagnosed for their other concerns because of their hearing diagnosis?

ANGELIKA DALKEITH: I'd say the latter. I'd say what we probably would be seeing is an increase in behavioural concerns in children in schooling, because they have a misdiagnosis of hearing. Often what'll happen is children, starting school, having increased behavioural support needs and had an acquired hearing loss that's been missed, not checked, and therefore are falling into other categories, sometimes misdiagnosed. Good teachers often are the ones catching these little ones, who are actually saying, "Actually, the first port of call is can you get their hearing checked, please?" At that point, you will have a hearing screen check, and finding other diagnosis of a hearing loss and impact is very common for us in what we're seeing.

DAVID BRADY: A four-year-old would not know if they're hearing correctly or not. Ninety seven per cent of parents have no experience of hearing loss in their family. My parents never did. I was born deaf, so it was a bit different, but I went to school with a couple of Indigenous kids and they did not get their hearing picked up until they finished school. They were told they were lazy. They were not doing anything and they were in the back of the classroom. That's a problem because they don't know. What we're talking about here in hearing screening is that reassuring parents that that's been ticked off is probably a good thing and a bad thing.

You've ticked off that list—vision, hearing, screening. Great. If there's something else, they can go and investigate further, and then they look at other things. But the most important thing you've got to recognise is that a child doesn't know that they have a hearing loss at all, until somebody tells them. A parent doesn't know. Unless they're really good parents, which we know quite a few—they'll pick it up. But most parents wouldn't know. They will go on to something else. So I think you need to put that into consideration. They would not know until they've had the screen, and that goes to your question.

Mrs TANYA THOMPSON: David, thank you for that comment—and the previous group that was here. My eldest daughter is now 22. When she was between three and four, as she was transitioning through to kindy, it was required that they had the checks with the community nurse. They go and put the headphones on and do the hearing screening. For the life of me, I don't understand why they stopped doing that. It was invaluable because they picked up that she had a hearing problem. It beggars belief that they don't do that anymore. It should be mandatory. Anyway, I note that you do telehealth services for regional areas, and I just want to know what that looks like. How do parents or families and communities access telehealth through the Shepherd Centre?

ANGELIKA DALKEITH: We are very well resourced and had been providing telehealth way before COVID—quite successfully, in fact, as a model. For us, telehealth is very much working within therapy, but the key part for us is working with the parent as much as the child. We talk about working and extending therapy not just with a child on the seat and doing—repetitive therapy is, I think, what people would think it might be. But how do we, within your environment as we beam into your setting, support you and your family in a natural sort of way, even though it's online and it doesn't feel natural? Although I think that, in today's age, it's probably feeling a little bit more natural being online than what it would have 10 years ago.

We have very much specialised in being able to work within that model of parent-educator with their little person in their family home or natural environment, and also with other community members. It doesn't have to be a parent. We also quite clearly stipulate that it's about who is the primary caregiver. It may be a daycare setting. It may that a little person goes five days a week somewhere, and that's where we focus some of that tele-practice or provide training to itinerant health support and iterate the extension of that specialised care into that service. So we have different ways and means of working there, quite successfully.

Ms DONNA DAVIS: Thank you for being here today. One of the recurring themes today is the shortage in the workforce of allied health professionals right across New South Wales, not just regional and remote. What do you have as recommendations for us to improve the recruitment and retention of people, particularly recruitment? I know a little bit about the hearing aid industry; I used to own a hearing aid clinic. But I know that for someone leaving school, they probably have no idea that they can go and study audiometry or would even contemplate that as a career path at TAFE, let alone audiology. What do you think we should be doing to increase awareness and increase our workforce, apart from the obvious, which is money?

PHILIP PETRIE: I'm happy to take that one on first. This is a national problem; it's not just a New South Wales problem. We see competition between States and Territories around things like award rates and pay rates. We see international countries taking our professionals and providing them with great incentives to leave Australia and go and work elsewhere. I don't think we do that really well as a nation. I don't think we incentivise these people who are vital in our community.

I'm aware that at the moment we've got a violence against women problem in Australia. There's the Federal Government initiative to provide fee-free training for professionals around domestic violence and supporting people in that. There has been great take-up in that. I think that's a really good example of where we as a nation could actually make life a bit easier. We all know that going through tertiary education is an extremely expensive experience. There needs to be some incentivisation in order to encourage people to take that path. It doesn't fix the problem in the short term though.

I think the NDIS has created a massive problem in regards to where people are choosing to work. You're finding a congregation of services in the metropolitan regions, which means that going rural is unsustainable because you may only be working in a town with a cohort of about five to 10 people. You can't set up a business to do that, and the travel and all of those sorts of things are not incentivised. The NDIS, for the past five years, has not provided a pay increase or a price increase for allied health and therapy services, which has driven a lot of practitioners out of the market and into other areas where they can make a better living and set up their businesses. I think we need to look at those sorts of things to encourage it.

Ms DONNA DAVIS: Anyone else?

ALEISHA DAVIS: Yes, I have a couple of comments. It's interesting how you say children coming out of school—children and young people, including 18-year-olds. I have one who has just finished year 12.

Ms FELICITY WILSON: Congratulations.

ALEISHA DAVIS: It's a journey. My son doesn't know what an allied health professional is. When people talk about health professionals, they think of nursing and doctors. How do we showcase what that profession looks like and the incredible engagement and purpose that it brings? I think there are opportunities there as a State. I think there are opportunities in education—in how we do that and broaden the scope. I know many mature-age people who would like to go back and study and do things like speech pathology or audiology, but the cost of living means they just can't leave corporate jobs to do it. They cannot afford to pay for the university degree to do it, but they would make phenomenal allied health practitioners.

How can we support them to do something that they want to do and have a fulfilling career without the financial burden that comes with it? That's something for us to be thinking about, and then supporting some of the mechanisms around it. Every organisation in our sector has workforce as their number one risk, apart from financial sustainability. In terms of professional memberships, they're expensive for individuals to pay and organisations can't supplement that. There are specific challenges for individuals to stay in the sector. I think there could be some easy partnerships or ways that can be supported.

Ms DONNA DAVIS: Going back to the blue book, I noticed, Alice, that you mentioned speech pathology and also food—what's the correct terminology?

ALICE LANS: Feeding. Eating and drinking.

Ms DONNA DAVIS: From personal experience again, and the connection between babies and eating and their inability to suck—all those types of things and those signs in terms of potentially autism or other things—what more should we be doing in that early screening with our blue book? What other things can we add in so that we can potentially identify some of these other conditions earlier and then refer on to the appropriate places?

ALICE LANS: It's a really good question. My response to that would be that it's partly people and relationships, and partly process. I think that the situation now is that a lot of the developmental—when a child leaves hospital now, they will have a phone number to ring to then make an appointment to see the child and family nurse. It's an opt-in situation. We know that feeding is everything. If you have a newborn baby, it is your entire world. You can't do anything else if that's not going well. But I think that one of the challenges is consistency of people.

A child or a mum might have six different child and family nurses in the six visits that they might get in that first few weeks, if they opt in and if they ring the number and can connect and leave a message and get called back when they're not trying to feed the baby and organise to come to the clinic. All of those things have to happen for that to happen. I think there's a process issue in that those people may not necessarily get to know that mother and baby really well. If you have a different person doing it each time, they're not going to see the pattern or get to know that child's development and that family relationship.

I think the second part of that question is that it's a very difficult thing to—if that's the end of the child and family nurse visits, then where do you go from there? You also have to opt in and there is a QR code if you want to join a mother's group, so it's the same situation. They are very likely to drop off that pathway. So then you sit in that first little while until, if you happen to have one, a mother or mother-in-law or family member or friend happens to say, "Hey, I know where you can go. These people are really good." That's where a lot of families will fall through the gaps. We know that feeding and oral structures is one of the first indicators of later speech development and syndromes and all sorts of other things.

I think it's really another example of where you want something absolutely universal and you want to have as much consistency and relationship with someone built as you can for as long as it's needed for that child. A lot of the time there are plenty of great resources out there and there are plenty of people with amazing skills that they can bring in that space, but we need to find a way to have access to that type of model, where families are not having to do the hard work in getting there. They already have enough on in those early days.

Ms DONNA DAVIS: It seems that the box is ticked when they're tiny about difficulty feeding, difficulty feeding, difficulty feeding—"Oh, how are you going with your feeding?"—and then it just gets parked. There needs to be something that could then be followed through on. I see. It's good. These are very important things.

ALICE LANS: I was just going to say a super quick workforce comment. Also, for the workforce, I feel like the early childhood part of the NDIS has absolutely changed the workforce structure. If you look at people who typically worked in not-for-profit organisations or disability, we have no problem attracting people. They came because that's the sort of work they wanted to do or they could work in health in the hospital in community health or they could work privately. The people who worked privately did a particular type of caseload and client base. What has happened now is that there has been an enormous shift. You have a lot of people working as sole traders by themselves. The organisations who are still providing that service are having to fund under the same model that a private practitioner would have to under the NDIS. That also makes it really challenging for us. We've always wanted to have student pathways. We always supervise a lot of university students coming through and we still do that, but that is an enormous cost to us. There is no funding for that. If we didn't do it because we believe in it and because it's the right thing to do—it is losing us money.

The CHAIR: Can you just explain that a little bit more? This goes to the question about the workforce. What was that change? In terms of taking on students and helping them to get through their course and get their hours up, has that changed recently?

ALICE LANS: It has changed over the last 10 years, since the NDIS has come on board. What happens is that all of our therapeutic staff, if we have funding to work with the families in our region—and we work with them depending on where the priority is and people see as many clients as they need to. They work with families on the needs basis. Because of the way that it's funded under billable time and minutes, that means that those therapists need to work a certain number of minutes or hours for our organisation to be sustainable in the costs we have for registration and for insurance and for cybersecurity and for all the things we need to pay.

We have an NDIS hourly rate, which, as Philip said, hasn't gone up in five years, and other costs have gone up a lot. That means that every time we have a student, if we have a student from university and our therapists are supervising and mentoring that student and doing their placement for them, they are also trying to see their clients. That is time. They need to find time to support those students and do induction and HR and paperwork and all those sorts of things. There's no funding for that. If they're spending time doing that, then they're not spending time seeing clients and creating revenue. Does that make sense?

The CHAIR: Mr Brady, do you want to add to that?

DAVID BRADY: We've got one situation with the workforce—and what you mentioned is quite correct. The other thing is we also have a workforce in the early education and preschool space. They just need the tools. They need the training and the expertise from organisations to give the educators the tools to be able to give a screening test. That will offload the workforce challenges. The workforce that we actually represent are actually picking up the therapy and the follow-up process rather than at the screening point. This inquiry is about the screening, and you mentioned the workforce. The screening bit, if you can get that first, will prevent a lot of overflow going into the workforce and will actually allow the workforce from our sector to focus on the ones who actually need it the most.

But if we can get the innovation and support and we can do some training for the educators and the people in the centres to be able to do those screenings or be supported, you will find that that will increase the flow between the workforce. Right now, we're just talking about, "Oh, we should do this workforce over here." But we also forget there is a huge workforce in the child education space that could be utilised, a little bit, to actually help the workforce over here, if that were put in that way. We're talking about screening.

The CHAIR: Following on from that, how much coursework or learning, or how many professional development sessions would an early childhood teacher—who is already a teacher—need to do to become more qualified in testing for hearing?

ALEISHA DAVIS: In terms of screening, probably not very much. There is equipment now where that can be done, as I mentioned, through an app. I would say it's definitely not weeks of training, but it's days of training or even hours of training that would help them to be able to do that—particularly, even supporting children with hearing loss in the preschool. As Angelika was mentioning, there's upskilling and capability-building that we do already for early childhood teachers. We find even an hour of that per quarter or a few hours a year is helpful, and it changes some fundamental strategies that benefit all children in the classroom.

The CHAIR: Thank you for appearing before the Committee today. You will be provided with a copy of the transcript of your evidence for corrections. Committee staff will also email any questions taken on notice from today and any supplementary questions that the Committee may develop in the coming days. If we do that, we ask you to respond within one week, or seven days. If that's not possible, please talk to us about that. Again, sincere thanks for your time.

DAVID BRADY: Just one thing, Chair. You say seven days. Can we put a submission in from this inquiry to your Committee within seven days? Is that correct? If we've got some more information, can that be submitted?

The CHAIR: If you'd like to make a submission, you can make a submission at your convenience.

DAVID BRADY: Thank you.

(The witnesses withdrew.)

Professor NITIN KAPUR, RACP Paediatrics and Child Health Division President, and Paediatric Respiratory and Sleep Physician, Royal Australasian College of Physicians, before the Committee via videoconference, affirmed and examined

Dr VANESSA SARKOZY, RACP Fellow, and Developmental Paediatrician, Royal Australasian College of Physicians, affirmed and examined

Dr LOUISE WIGHTMAN, Chair, Maternal, Child and Family Health Nurses Australia, before the Committee via videoconference, affirmed and examined

The CHAIR: I welcome our next witnesses to this inquiry. Thank you all for appearing before the Committee today. Please note that the Committee staff will be taking photos and videos during the hearing. The photos and videos will be used for social media and public engagement purposes on the Legislative Assembly's social media pages and websites. Please let Committee staff know if you object to having photos and videos taken. Before we start, do you have any questions about the hearing process?

NITIN KAPUR: No.

LOUISE WIGHTMAN: No.

VANESSA SARKOZY: No.

The CHAIR: Professor Kapur, I note that you are appearing from Brisbane.

NITIN KAPUR: That's right.

The CHAIR: As such, you may not be covered by parliamentary privilege. Any defamatory statements made, therefore, will not be privileged.

NITIN KAPUR: I understand that.

The CHAIR: So please just stay away from defamation. That would be great. Would people like to make a short two-minute opening statement before we begin the questions? I will extend that offer to you first, Dr Wightman.

LOUISE WIGHTMAN: No, there's nothing further from me at this point.

The CHAIR: What about Professor Kapur or Dr Sarkozy?

NITIN KAPUR: Yes, I would like to make a quick opening statement if that's okay. Thanks, Mr Barr and the team, for giving us the opportunity to appear before this inquiry on improving access to early childhood health and development checks. The Royal Australasian College of Physicians, which I'll refer to as RACP or "the college", welcomes the establishment of the ongoing work of this inquiry. I want to start by acknowledging the Turrbal and Jagara people, who are the traditional owners of the land from which I'm speaking today. I pay my respect to Elders past, present and emerging. Our appearance today will predominantly pertain to the following terms of reference of the Committee: the significance of early intervention programs and screening in children's health and development, particularly children from vulnerable communities, and the barriers that affect access to these; and recruitment and retention of health professionals to address workforce shortages.

Before I go into any detail, I want you to get familiarised with the role of the RACP. We connect, train and represent over 32,000 medical specialists and trainees, 7,000 of which are paediatric trainees, of which I am the president. To be clear, RACP has no role in funding training positions in States, and it does not limit the number of trainees. Our college accredits these settings, and these criteria are clearly outlined on the website. We definitely acknowledge that there are significant workforce shortages in developmental paediatrics. The reasons are many and complex, including the need for part-time work, issues with Medicare and workforce shortage.

We have advocated for an increase in STP funding to CCH. Close to 90 per cent of our community child health trainees are females, and most of them work part time. This requires greater flexibility of training options as well as part-time options, which sometimes rural, remote and STP funding is unable to navigate. This need for flexibility also sometimes limits movement and relocation of trainees. The RACP seeks opportunities to collaborate with NSW Health to better understand workforce shortages and policy drivers to develop and retain regional, rural and remote workforce.

It's also well established that early years are the time when investment into prevention and early intervention is most effective. Making regular and comprehensive health checks accessible at early childhood education and care services and other community settings will ensure that children with additional needs can be identified and referred appropriately. Once identified, these developmental concerns then need to be addressed by a multidisciplinary yet integrated model of care.

Our key recommendation to improve access today for early childhood health and development checks are to prioritise and invest in Aboriginal and Torres Strait Islander leadership, to invest in and expand models of care which support children in rural and remote communities to access local intervention and diagnostic services—these models of care will need to be multidisciplinary, yet well integrated and possibly even co-located—and to invest in initiatives that support access to quality early childhood programs for all three-year-olds.

Mrs HELEN DALTON: How many trainees are specialising in paediatrics? At the moment in my town of Griffith, I think we've got one paediatrician who is on the verge of retirement, and there do not look to be any coming through. Is the training pipeline large enough to help address the paediatric staffing shortages, or is it just incentives that we've got to provide? What will encourage people to go to rural and remote areas?

NITIN KAPUR: As I've just identified, with a predominantly female workforce, sometimes it's hard for females with families to relocate to rural settings, especially when part-time work is difficult to provide in these settings. If the rural and remote hospitals can support flexible working options, that will certainly go a long way with taking these trainees to the rural settings. The other thing is your question about numbers, Mrs Dalton. There are 2,200 RACP paediatric members in New South Wales. When I say paediatric members, it's divided into trainees and our fellows who have finished their training. There are roughly 700 trainees in New South Wales and roughly 700 paediatric fellows who have completed their training in New South Wales. There are some who are dual-training in adult and AYAM, which is adolescent and young adult medicine.

Just to add to that, our paediatric training is a six-year training program, three years of which is basic training; then there is an exam, and three years is advanced training. Out of the 700 trainees that I just mentioned, there are 271 basic trainees in New South Wales and 323 advanced trainees. So in the next three years, there will be 323 new paediatricians that will be added to the workforce. RACP does not dictate the workforce. There is no entry limit to how many doctors can train through the RACP. All the jobs are governed by local jurisdictions. If there are jobs available and they're an accredited position—accreditation which is not very onerous—there is no limit to the number of paediatricians that can be trained.

Mrs HELEN DALTON: You've mentioned a few key challenges faced by the paediatric workforce, particularly women, and the need for increased specialist training programs. But you've said that there's no limit to the entry. Is that right?

NITIN KAPUR: That's right. But there needs to be jobs available, right? They can only go into job positions. If there were more jobs available from the New South Wales Government, RACP will accredit them and fill them.

Mrs HELEN DALTON: So we need positions to be funded?

NITIN KAPUR: That's right.

Mrs HELEN DALTON: That's the issue, is it?

NITIN KAPUR: That is the issue. Obviously, as a college, we not only train but we advocate for the workforce as well. RACP has advocated multiple times to the STP to have more funded positions in these rural and remote—as well as private—set-ups, especially in developmental paediatrics. That's RACP's role in advocacy.

While we do not individually advocate for Medicare items, it's well known that developmental assessment is a complex issue that takes far longer than the half an hour or 40 minutes of Medicare remuneration. We will continue to advocate for something similar to what geriatric practice has done: They've got Medicare billing items that can bill for longer consultations. We have been advocating for that in paediatrics as well.

Ms DONNA DAVIS: Following on from that response, currently, how many vacancies are there for paediatricians in New South Wales government hospitals?

NITIN KAPUR: I'll have to take that question on notice. I don't have insight into the workforce of New South Wales. That sits with the Department of Health.

Ms DONNA DAVIS: That's fine.

NITIN KAPUR: I don't know if Vanessa has the answer to that. I'm happy for Dr Sarkozy to add on if she has the answer to that.

VANESSA SARKOZY: No, I don't have that data. Those are individually held within—each LHD would have that data.

Ms DONNA DAVIS: That's cool. I didn't want to forget my questions so I rushed in. I want to thank you all for being here in person and online. I'm particularly interested in the in-depth information and support you have for the community hubs. I'm very fortunate to have a couple of community hubs in my electorate of Parramatta. This morning, we had people talking about the success of the Hive that operates in Mount Druitt. I wanted to see if you could elaborate a bit more on what more could be done to pursue that approach and how that fits with what we're looking at, which is the theme of early childhood assessments.

VANESSA SARKOZY: The college certainly supports the use of hubs. The idea of providing care where the population is breaks down a lot of those barriers in terms of access, particularly where there are concerns about engaging in purely medical encounters. It also helps raise literacy, supports families, and deals with the broader social determinants of health, which we also know are really important in those early years. In terms of being able to expand them, funding is often an issue in terms of providing workforce to those settings. They require integration of lots of different providers to make those community hubs really work. You need primary health care, social supports, NGOs, community paediatrics—and often they're based on short-term funding. That can be one of the real challenges in terms of setting them up and sustaining them. Where they're community led and responding to a community need, they can be incredibly successful in terms of providing that wraparound care for families of young children.

Ms DONNA DAVIS: In your experience, do the child and family health nurses actually attend the community hubs so that they can have appointments with some of those mothers?

VANESSA SARKOZY: The hub I'm most familiar with certainly does have outreach. There is an agreement between the LHD and the provision of those child and family health nurses to attend the hub, which then provides that linkage across between health and community.

LOUISE WIGHTMAN: I could elaborate on that. In other jurisdictions where that has occurred, it's either that the child and family health nurses are located there or they come in as well. I guess it's about that warm referral—if the child and family health nurse is doing the initial universal assessment and they're looking at the ages and stages questionnaire and whether the development is on track on not—to be able to directly contact or have a conversation with a paediatrician or allied health professional. For the family to be taken directly to there, or to be able to make an appointment there and then, and to know who that person is and feel comfortable coming into that space, then they're more likely to attend. We can address right at the time those that actually need immediate escalation or those who can wait and have an appointment.

It is sometimes also about thinking broadly about either having staff directly located there, and that's where the child health clinic will be all the time, or having, as Vanessa said, an agreement with the local LHD that a child and family health nurse will come in. It's sometimes also where a playgroup is. It might not be how we normally think of an appointment. If parents are attending a playgroup, there's a child and family health nurse available so they can pop across and have a conversation. I think it's about where parents find it accessible. Even if there is a daycare centre attached, and maybe that is where all the initial screening happens, then there is a connection into more detailed services.

Ms DONNA DAVIS: One thing that I've noticed on community chats—I'm the member for Parramatta. You go onto social media and you'll see mums having questions about their baby. Often the feedback will be to call Karitane or another private organisation, but very rarely have I seen that reference to our good old-fashioned child and family nurses. This is in new communities. This is in new suburbs that I have in my electorate where there is no clinic that's been established for 50 years and everybody knows that's that little building down the road.

These are high-rise suburbs, and I'm sure this is the same repeated across south-west and north-west Sydney. Is that something that you have experienced as well? We talked this morning about them getting the blue book when they're at hospital, but do they actually really click, get that follow-up and know that that service is there to help them?

LOUISE WIGHTMAN: I think what has diminished over a number of years is that where previously—and this is many years ago—a child and family health nurse would make the rounds of the maternity unit and drop off the pamphlet, now child and family health nurses are no longer as visible as they used to be. Social media related to each LHD—for instance, in the area where I work as a child and family health nurse, we aren't allowed to have a child and family health nursing page within the social media realm. It all has to go through one area. We're not visible, yet in another LHD the child and family health nurses are constantly posting and telling parents what is on and what's happening. That is a huge problem, as most families now are more connected to social media. So the book is there, and that's fine, but they don't go through that book and look at all the links and see where it is. The midwives are meant to say, "Your local child and family health nurse is available here."

The other thing that's happened is that child and family health services have gone to sometimes central intakes. The person rings up a number and they're put on to somebody else, who will say, "I'll look over the clinics and I'll make it there." They're relying on someone picking up the phone to make a phone call. Parents are not having the option to book online or find their local service. We haven't moved with the social media and the way new parents, or even previous parents—the one thing they do know is that there's a GP, but they'll only go there if their child is sick or if they need to have an immunisation. Some councils used to offer immunisations. Sometimes child and family health nurses used to offer that.

The other thing is that in child and family health services, parents don't often get a one-stop shop. They don't get their growth and development check and the immunisation that they need, because local health services have made the decision, "Oh, no, that's somebody else's job." So why would a parent come to there if they then have to go somewhere else to get an immunisation? GP practice nurses—some of them are child and family health nurse trained; some are not. If they go to the GP and they've got a new baby, if they can get an immunisation, they'll get a weigh and measure but they won't get a development check.

Parents also aren't aware that a development check is important. That's not publicised. That's not a conversation that parents are hearing either about "It's good to check how my child is going." We often get them coming when there's a problem. Then we begin this huge pathway of how to get that seen, when if they came earlier and we could give them some guidance and they may or may not need a referral on to a paediatrician or a speech therapist or a physiotherapist or an OT, then we would deal with that earlier and then it wouldn't be that they were two years old and not talking. So it's the visibility. There needs to be quite a big campaign. As you say, times have changed and parents aren't hearing those same messages and parents aren't aware.

Mrs TANYA THOMPSON: You both touched on telehealth briefly in your submissions. I wanted to ask, for regional areas that don't have those clinics and we have the staff shortages, where we don't have community nurses to do pop-ins and things like that, how do you feel telehealth would support early childhood health and development checks? I wanted to get your thoughts on telehealth moving into that space.

NITIN KAPUR: Do you want me to go first?

VANESSA SARKOZY: Yes, you go.

NITIN KAPUR: Thank you. RACP fully supports the expanding and integrating of telehealth into specialist services, be it child development assessment, early intervention or early assessment as well, especially in the New South Wales-funded hospitals, in the community clinics and in all GP services as well. It is well documented that satisfaction with telehealth services has been very good. So the widespread use in regional areas, especially where access is a problem, where we can ensure good internet availability, we strongly support that.

LOUISE WIGHTMAN: I would add to that. For example, I talked about an ages and stages questionnaire. Whether there was a routine check done or where their day care, for instance, said to the parents, "Your child isn't talking or walking or moving like they should," you could have a conversation with that parent where they could ask questions. Those ages and stages questionnaires could be emailed to parents for them to fill in and returned to the next nearest child and family health nurse, who could book an online appointment with the parent, go through that discussion with them about what could happen and what may be some early intervention activities they could do, and then be able to liaise with their local health provider, whether it's the GP or community nurse, to access services. So that's something that could be simply done.

Sometimes when you have to examine the child, that's quite different, but a lot of the developmental checks can be done through screening tools that parents can fill in, and then it's about having a conversation with a health provider as to what would be the next step and how could we progress this. Sometimes it can be as simple as parents not knowing the type of activities to do with their child to encourage that development, and then we don't get to a problem where we actually need major intervention.

VANESSA SARKOZY: The only thing I would add to that is that we do need to be mindful of our most vulnerable families, where health literacy, English language, IT literacy, data et cetera are a huge issue.

LOUISE WIGHTMAN: Yes, I agree.

VANESSA SARKOZY: If the bulk of the services are provided online, we will continue to miss on these vulnerable children.

LOUISE WIGHTMAN: I agree with that. We would have to give consideration that there could be a place like a hub where they could go to access that, because if you're relying on them to do it on their phone—we had issues with that at the beginning of COVID, where the expectation was everyone had a phone or had data, and that's not the case. We actually need to provide the service where those parents could access that telehealth, not rely on them to have that.

The CHAIR: We heard that earlier today as well from NCOSS, I think it was. Professor Kapur, I'm sorry if I'm asking you a question that you've already explained. I'm just struggling to exactly understand the number of paediatricians and the nature of jobs existing or work existing for those paediatricians. We've heard on a couple of occasions today that getting access to a paediatrician can take somewhere between 12 months and three years. Doesn't that indicate that there's lots of work that needs to be done and that we could have lots more paediatricians available?

NITIN KAPUR: Thanks for the question. This exact question was asked to me when I faced the Western Australian parliamentary inquiry of increased waiting times for developmental assessment, and that submission is with our submission papers as well. We explored the various reasons why there is increasing waiting time for developmental assessment. By far, the most common reason is that there is actually increased incidence of developmental concerns, increased identification of these concerns as well. We would agree that there is workforce shortage. The workforce shortage is more obvious in rural and remote, disadvantaged, and First Nations communities as well. There is no doubt that workforce is an issue.

There is no clear, easy solution to that. We have looked inward towards the RACP's training program as well to understand how we can make exposure to our trainees about developmental a little bit easier and a little bit better. I'll try to explain. Our structure is that we've got, under the paediatric training—the advanced training—a subspecialty called CCH, which is community and child health, which is quite specialised development to paediatricians. All paediatricians are well versed in doing developmental assessment, but some of the pointier ends of complex developmental assessment is done by developmental paediatricians.

There is huge demand, as I had addressed previously, for part-time work. Even though the number going into the training are, say, 100, just as an example, when they come out at the other end most of the trainees want to work a minimal number of hours. The output is much less than what the input is, and it's very difficult to predict what hours a trainee might want to work when they enter the training program of six years. That creates a bit of an issue as well. We have identified that. Remuneration is always an issue. Medicare hasn't kept up with the amount of time that paediatricians and GPs all have to take in these developmental assessments.

Developmental assessment is not easy. It's a complex field. It is not a simple diagnosis. It is not just diagnosing a single medication, and the Medicare remuneration has not kept up with this kind of change. Hence, the interest in doing these kinds of training programs has gone down as well. It's not as if we are trying to gatekeep people wanting to do paediatric training; that is absolutely not the RACP's role. We only accredit the situation so that the quality of training is good. I may ask Dr Sarkozy to add to that as well.

VANESSA SARKOZY: Just to reiterate: You can only train in paediatrics if you have a job. So the numbers of trainees are limited by the number of roles. You need to have passed your exam, you need to do your annual accredited—you need to pass through the training, but you can't train unless you have an RACP accredited position. The number of trainees actively training is dictated by the number of positions. The bulk of those positions happen in LHDs and are hospital based, with some of those positions now being funded by STP and those with a focus on rural, regional or private settings or Aboriginal services. So there is a finite number of trainees that can go through. Many are females, as we've pointed out, but even our male trainees are not always wanting to work full time.

I think there is a shift in how generations choose to work and how they achieve their balance in life. There are complexities around the length of training. If you are part-time during training, it takes longer to train because the amount of training is fixed—for example, you must have 36 months in community child health. If you are doing that part-time, even if it was at 0.5 FTE, that is six years not three. Then there is the capacity to be able to find a post when you are finished that meets you and your family's requirements. I also add in terms of sending our trainees to rural and regional settings that the feedback from trainees is there are often difficulties in terms of their families.

I think a lot of these positions were set up with the expectation that you would be a single person going out; the accommodation may or may not be provided for you as a single person. It is much harder to move a family, a partner, children, even pets. Those sorts of issues impede on people's capacity. The quality of accommodation, the availability of accommodation and, particularly for this cohort—if you think about the age group we're talking about, they have families with young children—their capacity to access child care when they go out for 12 months to rural and regional settings, all of those things impact on a trainee's capacity to go out to those positions and get that training, and then it impacts on their decisions going further down the line.

Ms DONNA DAVIS: I come from a regional background. Something that I have observed is with professionals coming to regional areas is that when their children get to a certain age, unless they are prepared to send them to boarding school, there is often a tendency for people to want to move back to metro areas for schooling. Is that the reality?

VANESSA SARKOZY: I think with paediatricians, who are usually in slightly larger towns, that is perhaps less of an issue. But certainly, I think all of us make plans for our whole family. The capacity to access quality education, our partners et cetera all makes a difference.

Ms DONNA DAVIS: Helen talked about the paediatrician who was about to retire. Does someone actually have to retire before that position is available? If there was the knowledge that someone was planning to retire on 25 November 2025, would it be better if that knowledge freed up a spot for the future, rather than somebody having to retire before the actual vacancy exists?

VANESSA SARKOZY: Would you call that contingency planning?

Mrs TANYA THOMPSON: Succession plan?

VANESSA SARKOZY: Succession planning is an important part of filling roles. When we talk about trainees, all of those things are important and also having career progression—if you go train in a rural LHD where all of your senior colleagues are in their 30s and 40s, there is no job for you unless there is going to be an expansion in staff specialist roles going forward, then you come back because there is no job for you there.

The CHAIR: Thank you for all of that. I am sorry, I might be a bit slow; I still don't quite understand. Surely NSW Health and all of our LHDs are trying to accumulate, catch and vacuum up as many practitioners as they can get their hands on. Is that not happening?

LOUISE WIGHTMAN: My experience, having worked in regional towns—not necessarily in New South Wales—is, particularly in the child and family health area, even in a regional setting where I work, if they can reduce the numbers as someone leaves, they do. I guess the big thing that I'm hearing from my colleagues as well is that one of the things we are not funding is the early intervention and prevention. We are not funding primary health care. We are not funding the community health sector. That funding has disappeared rapidly over the last 10 to 15 years. The funding from health services goes into acute areas. If there is any left over, we'll think about primary health and early intervention. One of the huge issues is that, in the area that I work, we have a six-week waiting list for families to get a clinic appointment to have the blue book check—the routine checks that were in there. They have a six- to eight-week wait, they forget about it, they can't remember, and then they think, "Oh, yes, I'll have a check," but they can't get one.

We have asked for enhancement of our numbers, but we need the data to say that people want that. But we can't get that data, because if people don't book an appointment, we can't get that. Also, our data collection, our CHIME records, how we record all of these things—those systems don't allow for us to pull data off to match how many births versus how many people have actually had a check versus who is missing out. None of the systems talk to each other. Even within New South Wales there are three different community health electronic medical records that don't talk to each other. It is getting the information through. We don't know who is out there.

As a child and family health nurse, we offer them a universal health check at the beginning, when they come home with their baby. That doesn't necessarily mean we can book them in for the next one or the next one, and then parents go, "Well, I don't really know whether I need to have this. I'll just wait until my child is sick and then I'll go to the GP. Actually, I'm not going to the GP now because it is too expensive and I don't get bulk-billed." So until I get to preschool or school and we do that first health check or the first development check in the early check of children going into—that brings out our AEDC data, then they go, "Oh my goodness! This child has so many issues. Now we need to get them into NDIS." And then that is a whole other process. The system is trying to shrink the workforce, not expand the workforce.

NITIN KAPUR: There are just not enough funded developmental childhood training positions in the metropolitan area or in the rural area. We have canvassed for years to have STP and other avenues to fund these positions. In truth, there is just not enough money. Sorry, I had to cut you off.

Mrs TANYA THOMPSON: Do you think digitising the system from the start, from birth, with the blue book and making that a digital footprint all the way through to try to capture it all from the start would make things easier? Given that we all live on the device—I would say 90 per cent of particularly New South Wales would live on the device—do you think there is an opportunity there to collaborate it all together? And therefore there would be reminders. Or you've done your universal check at birth, then you can have the notification sent through at this age or this step or that step, to streamline things.

LOUISE WIGHTMAN: There is work being done with Healthy Beginnings that's trying to engage people in that service. They will get reminders of when they should have a check and that, but it hasn't been rolled out all across New South Wales. The problem is that there will be a new model like that—there is work being done on a digital health record book. I think New South Wales is doing the zero to five part of it, another State is doing the adolescent and then there is a pregnancy digital health record as well. But it could be 10 years in the making before that ever comes to fruition. And then if we have families, particularly in, say, the north and south of our State, who work across borders, that presents an issue that then they go to a different health service. One of the things—I am not sure if you know—is that while we have a personal health record book for each child, none of the States in Australia match.

Mrs TANYA THOMPSON: Yes, I am aware.

LOUISE WIGHTMAN: So, it's even that. I think, having that digital record that parents do, that would be more helpful for—when I am thinking of our more vulnerable populations—those children who get taken into out-of-home care. Often, the blue book is lost in that transition. They are our vulnerable populations, and they don't always get developmental checks, even though you would think that would be a priority. But that's not necessarily a priority. And then, if they want to be prioritised, where do they go?

VANESSA SARKOZY: I do think the electronic blue book and the statewide electronic medical record, which is now currently underway, will be a bonus. I think that will be a really positive thing, particularly if those two digital spaces are going to talk to each other, which is what I understand is the plan. And if we could bring in primary care, that would be fabulous.

Mrs TANYA THOMPSON: Further to that, I think it has to be on a national level because you have Medicare sitting at the top and you can't have different States with different things. People do travel across the border for work or move interstate. It is too clunky. You can't have mum and dad at the top and the brothers and sisters are all not talking to each other. It doesn't make sense. There are too many gaps and people fall through them. Anyway, that's a whole other inquiry, I think, right?

LOUISE WIGHTMAN: I'd just like to make another comment. I think we're also starting at the wrong end. Development checks are important, but if we did the early intervention right from pregnancy, right through in that early time—as Dr Kapur said, we are seeing more of it because children are having a more complex start to their life. In utero it's complex and then, as they step out, as they're born, then it becomes complex and then that complexity increases. So that's the other thing: We are not at the early intervention and we are not at the preventative end, which is even more important.

The CHAIR: Dr Wightman, could you expand on what you just said about, even in utero, babies—embryos—are having more complex experiences?

LOUISE WIGHTMAN: Yes. If a parent has mental health issues then they have high levels of cortisol that are rushing through their body, complex medication. That baby has been exposed to all of that stress and duress. If the parent is in a domestic or family violence relationship, that baby is being exposed to all that distress as well. If their parent has drug and alcohol issues, if they're homeless, if they're not getting good nutrition, that baby is exposed early in utero. So they are small for dates; they might be born early. Already the complexity is happening and we don't have enough services, from a social and emotional perspective, to look after those families so that it doesn't add to their complexity when they're ex utero.

If they've still got those experiences once the baby is born—if the parents don't have a house, if they're concerned about food, even simple things like that, or they've had a very traumatic birth—that baby becomes at risk. But it doesn't reach the threshold of risk where the Department of Communities and Justice gets involved. They are simmering at that level where their family situation is not okay and, therefore, their opportunities and what they need to do—like, if a family can't even read to their baby or hold their baby when it's crying, that baby is already experiencing mental health issues, as an infant. Then that complexity increases as they grow.

VANESSA SARKOZY: Which brings us back to the hubs.

LOUISE WIGHTMAN: Absolutely.

VANESSA SARKOZY: So being able to have that wraparound care that goes from early parent training, family support and linkage with services would give those families a much more optimal start and enhance that child's developmental trajectory going forward.

Mrs TANYA THOMPSON: Yes, which then takes us to long-term retention of staff for continuity of care, right?

VANESSA SARKOZY: Ideally, for those relationships.

Mrs TANYA THOMPSON: You've got the same person—

VANESSA SARKOZY: And trust.

Mrs TANYA THOMPSON: Right back to trust.

The CHAIR: We have heard, and we've got submissions, that some marginalised groups are actually quite afraid of government agencies and departments, because their experience historically has been that you start to get reported for some of this stuff and then, all of a sudden, you are separated from your children. Can I ask all of you, is there anything in the New South Wales blue book—Professor Kapur, I'm not sure how familiar you are with the New South Wales one.

NITIN KAPUR: I'm not.

The CHAIR: Is Queensland's maroon?

LOUISE WIGHTMAN: It used to be red, yes.

The CHAIR: Is there any glaring omission currently in the list of things that we should be checking our youngest children for?

VANESSA SARKOZY: I think the blue book is a really robust document; it's just underused.

LOUISE WIGHTMAN: The only thing I would say is that when we removed the four-month check—there is that big gap between six-to-eight weeks and six months—we have removed the opportunity for parents to connect in that time. That's when sometimes things start to go wrong. It's got really good information in it. It's got lots of questions for parents to prompt them to think about what's happening for their baby, but they don't really know. They get this book, and it's not seen as a tool for them to use. It's something that needs to get filled in, and then they forget about it and it's only for immunisation. If they are connected to Centrelink and they say, "We are going to cut your payments off if you don't have an immunisation", they go and get an immunisation. It's a lot about the parents understanding how we can support. That's where hubs would be good that are not seen as a government agency but as local community and conversation and the opportunity to learn from peers and from Elders. I think it is that whole aspect of nurturing the parent to nurture the child.

The CHAIR: We're going to finish up a bit early. Everyone gets an early mark. Thank you for appearing before us today. You will be provided with a copy of the transcript of your evidence for corrections. Committee staff will also email any questions taken on notice from today and any supplementary questions that may be developed by the Committee. If we do that, we ask that you try to turn that around in one week if that's possible. But if it's not, please just talk to us and we'll figure it all out. That concludes our public hearing for today. I thank all witnesses who appeared today. I also thank the Committee members, Hansard, the staff of the Department of Parliamentary Services and Committee staff for their assistance. I thank you all. It has been a wonderful day. Thank you to our last round of witnesses. We really appreciate your incredibly important and valuable time and wisdom.

(The witnesses withdrew.)

The Committee adjourned at 17:20.