REPORT ON PROCEEDINGS BEFORE

SELECT COMMITTEE ON FOUNDATIONAL AND DISABILITY SUPPORTS AVAILABLE FOR CHILDREN AND YOUNG PEOPLE IN NEW SOUTH WALES

At Jubilee Room, Parliament House, Sydney, on Thursday 19 June 2025

The Committee met at 9:15.

UNCORRECTED

PRESENT

The Hon. Natasha Maclaren-Jones (Chair)

Ms Abigail Boyd (Deputy Chair)
The Hon. Anthony D'Adam
The Hon. Taylor Martin
The Hon. Cameron Murphy

PRESENT VIA VIDEOCONFERENCE

The Hon. Scott Barrett
The Hon. Mark Buttigieg

The CHAIR: Welcome to the second hearing of the Committee's inquiry into foundational and disability supports available for children and young people in New South Wales. I acknowledge the Gadigal people of the Eora nation, the traditional custodians of the lands on which we meet today. I pay my respects to Elders past and present, and celebrate the diversity of Aboriginal peoples and their ongoing cultures and connections to the lands and waters of New South Wales. I also acknowledge and pay my respect to any Aboriginal and Torres Strait Islander people joining us here today. I'm Natasha Maclaren-Jones and I'm the Chair of the Committee.

I ask everyone in the room to please turn their mobile phones to silent. Parliamentary privilege applies to witnesses in relation to the evidence they give today. However, it does not apply to what witnesses may say outside of the hearing. I urge any witnesses appearing today to be careful about making comments to the media or to others after completing their evidence. In addition, the Legislative Council has adopted rules to provide procedural fairness for inquiry participants. I encourage Committee members and witnesses to be mindful of those procedures.

Mrs KYLIE IRVIN, Portfolio Manager, NDIS Western, Marathon Health, sworn and examined

The CHAIR: Could you give a bit of an overview of the challenges that families have raised with you about accessing services, particularly from rural and regional perspective?

KYLIE IRVIN: Yes, absolutely. Shall I start with my opening remarks, or would you like me to jump straight into questions?

The CHAIR: Sorry, I should have said that. Do you have an opening statement you'd like to make?

KYLIE IRVIN: Yes, I do. Thank you for the opportunity to appear today. I'd like to start by acknowledging the traditional owners of the land on which we're meeting, and I pay my respects to Elders past and present. Marathon Health was established in western New South Wales in 2015 to address gaps in high-quality, community-based health and wellbeing services for people living in regional, rural and remote areas. We now deliver face-to-face services across 75 per cent of New South Wales, and a virtual service Australia-wide. We are a non-profit organisation with a vision for empowering these communities to thrive through equitable health and wellbeing. All of our 300 employees live and work in regional New South Wales, which gives us unique insight into the challenges and barriers families living in regional, rural and remote New South Wales face.

Marathon Health is a key provider of community-based early intervention supports to children across regional, rural and remote New South Wales, and I welcome the opportunity to provide information that will support equitable access for families, no matter where they choose to live. Today I will speak from my perspective as a speech pathologist with more than 18 years experience delivering services to children living in communities such as Dubbo, Cobar, Nyngan, Lightning Ridge and Walgett. From this experience, I can testify the difference that early intervention supports and services make in a child's and family's life—if they can access them—and, unfortunately, the impact on children and families when they are unable to access these services. Over the last year, I've had the privilege to lead the co-design and delivery of the Flying Start paediatric service in collaboration with remote communities in western New South Wales.

This service provides families living in rural New South Wales with free access to a paediatrician in their local community, unlocking access to ongoing health, education, carer and social supports based on each child's needs. To date, over 60 children have accessed this free holistic assessment via paediatrician and allied health team. More than 80 per cent of these children identify as Aboriginal or Torres Strait Islander. Unfortunately, despite us being ready to scale, at this stage sustainable funding for this service has not been secured, leaving many children on wait lists and no guarantees for service. With the current foundational support reforms, and through these inquiries, I believe that we have a unique opportunity to create a system focused on collaboration, universal access, early intervention and evidence-based practice, particularly for our most vulnerable in our regions who are often overlooked.

The CHAIR: Thank you very much, and for coming to Parliament, to Sydney, to appear in person. It is greatly appreciated. And thank you also for the work that you do, particularly supporting rural and regional families. I might go back to my first question, which was around the challenges that families have identified in being able to access those services.

KYLIE IRVIN: Yes, absolutely. So there's probably a few barriers that exist out in those more rural and remote communities. Larger regional centres like Dubbo do have access to a number of different services and service provider options, but the further remote you go, there might only be one provider in the community, and they might only see children with an NDIS plan. So I guess that's one barrier, being able to meet the eligibility criteria to get the supports that you need, as well as understanding how to get into those systems when there's not diagnostic services available, and there's not those people that they can walk into the offices of and ask the questions, "Where do I find this help? My child has a developmental difference. Who can I go to for support?"

The CHAIR: You mentioned in your opening statement the Flying Start Paediatric Service, and in the submission, WARATAH for Kids. Could you outline what those two programs are? Are they self-funded, or do you get State or Federal assistance with it?

KYLIE IRVIN: Yes. I'll speak about Flying Start first, because that's one that I've been primarily, directly involved with. The funding for that initially came through philanthropy—through Variety, the children's charity—and we worked together with them to develop this model based from community need, identifying that there were many, many children in some of these remote communities who didn't have access to disability supports or early intervention supports. A big reason was they weren't able to see a paediatrician. They weren't able to meet the criteria that the NDIS requires to get ongoing supports in place. We also recognise the travel distance is a big barrier for those families living out in those communities, as well. They can't easily come into metropolitan assessment services to get those supports, so they're just staying in community and they're not able to get any access.

Sometimes what we see is those children arriving at kindergarten and having quite significant developmental delays. I'm talking about children coming to school who aren't toilet trained, maybe they haven't accessed preschool in some situations, they aren't able to communicate very well. They might have 10 words, and they're entering the kindergarten in formal schooling with that sort of level of delay, without having access to any supports. We designed this model to go out and start working in community and identifying these families and these children who need support, and bring the supports to them. We've been working with local GPs, working with child and family health nurses, with wellbeing nurses who are based in the education system to collaborate with families and get them to see a paediatrician to unlock the access to NDIS supports, education supports and things like that to get better outcomes. The Rural Doctors Network also came on board to help fund that in the last six months, as well, which has been a great help.

The WARATAH for Kids program has been funded by the Murrumbidgee Primary Health Network. It is working with GPs, allied health supports and a community-based paediatrician to upskill GPs in providing supports to early childhood, and in terms of understanding developmental milestones and referral pathways and families, and putting health workers in to help families navigate what supports they need and where to access them, and an add-on as the program has been evaluated. The newest part of the program is adding some intervention into that model as well, because we recognise that it's good and well to identify where there are developmental differences, but if you can't provide support to help children get on the way to catching up with their peers, it's really disheartening for families. Just to say your child has this diagnosis or they have this significant delay and here's some options of service providers, but they're $271.59 an hour in a remote location. You can pay privately. If you have an NDIS plan, you can do it, but otherwise there's nothing for them to access.

Ms ABIGAIL BOYD: Thank you so much for your submission and for coming along. One of the things that stuck out in your submission was this bit about how, prior to the NDIS, you had this network of allied health assistants based in preschools and schools, but that has not really been possible since NDIS came in. I think we've seen, in quite a few of the submissions, this unintended consequence of NDIS where it has led to quite a lot of fragmentation in service provision. Can you explain to us what that looked like prior to NDIS and what makes it hard now?

KYLIE IRVIN: Absolutely, yes. Prior to the NDIS there were lots of block-funded programs where we could have community-based models of service working with preschools and schools and having allied health clinicians and, in this case, allied health assistants in community, delivering supports and services that children and families needed. When the NDIS came in it very much removed those sorts of funding models and put it into specific, individualised funding packages for individual children. There are some situations where we're getting some funding through primary health networks to be able to go into small communities and work with children in those preschools—little communities, for example, maybe between 30 and 60 minutes outside of Dubbo, and working with those children. But again it's fairly individualised and there's not enough focus on capacity building, being able to run groups and working with the educators in those settings to identify children. We are doing some referral pathways where we see children with complex needs, but there's not enough flexibility or enough funding to spread around, really, since the NDIS.

Ms ABIGAIL BOYD: I've spoken to a few different people who were disability Ministers in different States and Territories at the time NDIS came in, and there seems to be a general acceptance that they thought NDIS was going to cover a lot more than what it has ended up covering, if we're only looking at one in 10 people with a disability being covered by NDIS. Now that we are focusing back again at the States providing this so-called foundational support—however we want to define it—how do you see us taking this opportunity to go back to having some of that block-funded approach where you can go out and actually run more community-wide, generalised programs to capture more people?

KYLIE IRVIN: It's quite exciting, I think—the opportunity to be able to get back to doing some of that type of work—because we have just seen these huge gaps now that come out. It's either you have an NDIS plan or you don't, and if you have an NDIS plan you're almost one of the lucky ones because you're able to unlock that access. I think it needs to be a collaboration in community. I think there needs to be a lot of consideration for what is in each individual community already, because we know that local health districts are quite stretched and they're not able to provide services in all the communities that other not-for-profit organisations might be in. I think there needs to be a real collaboration and not necessarily sitting funding in one particular agency but rather looking at what all of the services are that are available and how they can work best together.

I think it's very much having community-based locations like health linkers, allied health assistants—those sorts of positions that can work across agencies. They might sit in education or they might sit in health, and they have that frequent contact with allied health clinicians to be giving that targeted intervention when that's required for a particular child but also helping families understand referral pathways, get referrals actioned, linking them with other supports that they need—capacity-building opportunities.

Distance is also a significant barrier in our areas as well. I don't know if you know the town of Coonamble in the North West. We have a few OTs based in that office, and they might travel 400 kilometres in a round trip in a day to go out and see families in remote communities and provide services. But, again, that's usually in that NDIS model of service delivery. We're in preschools, schools and family homes and we're seeing children who have a plan, but what we can also see is lots of other children who need some supports, but we're not able to because of the rigidity of that NDIS funding model.

Ms ABIGAIL BOYD: I admit to being a critic of that market-based service approach that has come through—quite unfortunately, I think—the NDIS in a way that has led to the fragmentation, but also the making it more difficult for people to navigate and find the services that they need. Also some of the submissions have spoken about a breakdown between a lot of the private providers of services through the NDIS and the public school system. In a previous inquiry that the Chair and I were both involved in, we were looking at the experiences of children with a disability in the education system, and one of the obstacles that kept coming up was a reluctance of schools to allow speech pathologists and other allied health professionals to come into the school. Was it easier before NDIS or have those obstacles always been there?

KYLIE IRVIN: I think in some respects it may have been easier before. One of the things that the NDIS has done is it has meant that families who have been able to navigate this system have been able to access more therapy, so there are more clinicians on the ground and there are more clinicians going into schools and wanting to see children. I actually worked for ageing, disability and home care, so I was part of that before the NDIS rolled out. What we really only saw was the more severe end people with a disability, whereas I think now there is some opportunity for the moderate level of disability clients to get access, so there are more clinicians. However, in very rural and remote places, that's not the case because there's just not the providers out there. In those communities, there isn't a reluctance from the Department of Education to have clinicians coming into the schools. They're excited to have an OT or a speech pathologist come in and work with their teachers and children.

The Hon. ANTHONY D'ADAM: I want to explore something that you've raised in your submission around Medicare bills. I think you've touched a bit on this about Medicare billed services. I mean, you've raised the whole issue around the structure of the NDIS model. It's very individualised, and you're advocating for a more sort of collectivist model. I think one of the tensions was that the NDIS model was built on the premise of giving people with a disability choice.

KYLIE IRVIN: Yes.

The Hon. ANTHONY D'ADAM: If you move back to a more collectivist model in terms of foundational supports, obviously there's more rigidity and less choice. Perhaps you might want to offer some comments around that?

KYLIE IRVIN: Yes, I can. In the regional, rural and remote areas, there's probably less choice anyway because there's not the range of providers that are available in metropolitan areas. I think families would be very happy to get any kind of support in that nought to nine age group from the providers that are available in the community. I know that some Aboriginal-controlled health organisations, for instance, have found their own funding and are purchasing in allied health supports to come into community to be able to deliver some of that free community health type intervention for children and families. I think it's less about taking away choice and control in those regional, rural and remote communities. I think just having a service that can provide intervention for that early intervention age group without needing to meet all the criteria that's needed for NDIS access would be brilliant.

The Hon. ANTHONY D'ADAM: You also raise in your submission the issue around the limited availability of specialists and allied health providers. This is just an inherent problem, not just in disability but in health provision in rural, regional and remote areas. What do you think the solution is? It's the eternal problem that we face.

KYLIE IRVIN: Absolutely, it is. Marathon Health, as a not-for-profit, we are quite committed because we are so passionate about regional, rural and remote. We are quite committed to trying to develop our workforce and trying to attract graduate clinicians. We have some structured pathways for psychology interns. We supported 61 student placements in 2023-24. I think it's about investing in those workforce development career pathways for young professionals, getting them to come out to our community, giving them a really good experience and a good opportunity to see how good it can be to be out there, and then working with what's in local community as well. You don't need all of the services to be living in Walgett or in Nyngan or Brewarrina, if you have access to some of those in your larger regional centres or nearer to where those communities are, but then you have some living in community that you can build the skills and have a local workforce. I think that's probably going to lead to best outcomes.

The Hon. SCOTT BARRETT: Thank you for tolerating me being online. Ms Irvin, in your submission and in lots of other places we hear of the disparity and vulnerability in regional and remote areas versus metro areas. How big an impact is the lack of providers having on that? Is that because of the lack of providers? What are the other factors that lead to that disparity?

KYLIE IRVIN: That's a good question. It's not just the lack of providers in some of these communities that is leading to the disparity between metro and rural or remote children. Some of the families in the most remote communities that we access, they're just not engaging with health and education and preschool settings like you see in other regional settings and metro settings. Part of that might be culture. We often see they have, as a community generally, just quite a low health literacy and understanding of different systems and what they can be doing to support their child's development. There are other socio-economic factors at play as well in terms of living a far distance from their nearest preschool or services like that.

I know there is the Brighter Beginnings program that operates out through western New South Wales communities. That is really, from what we've observed, targeting those four-year-olds who are in the preschool environment and trying to make sure they screen four-year-olds in terms of capturing them then, supporting their transition to school—making recommendations to have a positive transition to school. Sometimes children aren't at preschool in the communities where we're living and working. Also, four is quite late to be trying to identify developmental concerns. It doesn't give you much time to have an impact before they get to five. There really needs to be a focus on getting in there earlier and having those points of contact with allied health earlier on in the journey to have better outcomes.

The Hon. SCOTT BARRETT: Further to that, would there be people in these communities that, first of all, aren't aware that their children do need this extra assistance, and then also that this extra assistance is available for them?

KYLIE IRVIN: There would be people, I think, that fit that category. I think that's where we find it's really great to work across as many different agencies as we can and figure out who has the local relationships with these families and try and capture them wherever they're at. So working with the Aboriginal medical centres and working with different contacts at the preschool and at the health service, and wherever they might access, to try and build capacity of other people in the community so that you don't need to rely on visiting allied health professionals. But, yes, there's a lot of work to be done in that education space in terms of building capacity of communities locally to be able to support the families who live in those towns.

The Hon. SCOTT BARRETT: You mentioned Dubbo, Cobar, Lightning Ridge, Walgett. There are a lot of communities around that. How much is the effectiveness of services lost, first of all, when you're doing these fly-in fly-out visits to smaller communities, and then is it further exaggerated when people need to travel into places like Coonamble, Walgett or Dubbo away from their home communities to access these services?

KYLIE IRVIN: We really prioritise delivering services in the places where families and children are playing, working and living. We like to do home visits. We like to do preschool visits, because we need to see what functional skills those children need. We need to see how they're communicating with their friends. We need to see how they actually behave in the environment, not in a clinic setting. We very much are the approach of we will do the travel, and we will see families in community. I don't know how that might change with the recent NDIS price review, which is making it really difficult for providers to travel because of the caps on travel and how viable that will be for providers to do that. There'll be, certainly, an increased expectation for families to travel to services, and I think what will happen is that many families won't be able to do that.

The Hon. SCOTT BARRETT: We've talked about the gaps in some of the services now because of a lack of coordination around the broader picture of it. Is there also duplication in some areas? That must lead to a fair bit of frustration, if there's an oversupply in some areas and non-existent in others.

KYLIE IRVIN: I don't think there's an over-duplication in the areas that I'm aware of. I think in our local areas we have some really nice paediatric allied health networking meetings, where we really try to collaborate, share information, service map. We discuss what communities we're visiting, who's going where and what programs we're running. We are, on a local level, really trying to meet the need of these communities together.

I don't think there's an over-duplication. I think we always say it's not a competition. There's so much work to go around in our communities. It's just let's work together to find a best fit for each individual community and family and child.

The CHAIR: I have a final question in relation to the gaps you're talking about and the pressures that may now be on families to travel to access services. What role can telehealth play in that, or does it not just work, compared to being able to be face to face?

KYLIE IRVIN: I think we place a lot of value on face-to-face intervention. In our experience, it can certainly complement face-to-face service delivery, and I think there are probably different options to be explored that do work well. For instance, if we're working with a family or a child for therapy, there needs to be somebody there with the child to support that, whether that's their family in a home environment or whether it's an educator in the preschool environment. Sometimes that is a barrier, having someone on the other end to help support the telehealth. But, I think, yes, having a local person to be able to support that telehealth is really important. You just can't replace being face to face. It's just so valuable. What we hear from the families that we work with—because there are plenty of telehealth providers around that will just do telehealth therapy. They will never come out into community and actually meet the child face to face and see the environment. The landscape out there is that they just really love the relationships that they can form with their therapists and how much that supports their therapy goal achievement.

The CHAIR: That's great.

Ms ABIGAIL BOYD: Someone came to see me recently, who was talking about the difference between learning disabilities and learning difficulty—basically the lifelong learning difficulty or disability, whatever you want to call it, in terms of dyslexia or dyspraxia and a bunch of other learning disorders. This person was talking about the need for there to be foundational supports for people once they've left school. We think about those things as something that's applying only to people while they're at school and jumping through the hoops of exams and everything else, but there's an increasing awareness that they are lifelong disabilities and there is a need for foundational support that doesn't get caught with things like NDIS. It's a little bit outside the scope of this particular inquiry, but I'm curious, do you have any thoughts on what those kinds of foundational supports could look like? Do you agree that we need to be a little bit more inclusive when we're talking about disabilities?

KYLIE IRVIN: Yes, it's an interesting concept. As Marathon Health, we provide services to people across the lifespan, so we are seeing adults in those environments after school. Again, because of the NDIS funding, it is very individualised. When we're going into community access-type programs, supported employment environments and accommodation providers, we are in there to work with one person in that environment rather than the whole cohort of people. There would definitely be merit in capacity building and upskilling the providers and the communication partners—the people who are around every day—because they have the most impact on that person's ability to do things and their functional skills. I think a lot of the things that we're talking about for the early intervention age group in terms of foundational supports could very much be applied to other age groups as well.

The CHAIR: Unfortunately, our time has expired, but thank you very much for coming and for everything you do as well.

(The witness withdrew.)

Dr NIROSHINI KENNEDY, President of the Paediatrics and Child Health Division, Royal Australasian College of Physicians, before the Committee via videoconference, sworn and examined

Dr LYDIA SO, Fellow and Developmental Paediatrician, Royal Australasian College of Physicians, before the Committee via videoconference, sworn and examined

The CHAIR: Hello, Dr Kennedy and Dr So. Please state your position.

NIROSHINI KENNEDY: I'm a developmental paediatrician based in Victoria, working across public and private settings, as well as the Aboriginal community controlled health sector.

LYDIA SO: I work in the South Western Sydney Local Health District, NSW Health.

The CHAIR: Do you have an opening statement that you'd like to make?

NIROSHINI KENNEDY: Yes, I do. The Royal Australasian College of Physicians welcomes this opportunity to appear before the select committee and strongly supports the efforts made by the New South Wales Government to improve foundational and disability supports for children and young people in New South Wales. I'd like to begin by acknowledging that I'm speaking to you today from Melbourne, on the lands of the Wurundjeri people of the Kulin nation, and I'd like to pay my respects to their Elders past, present and emerging.

The Royal Australasian College of Physicians, or RACP, represents over 28,000 Australian and New Zealand physicians across over 40 specialities, including 8,500 members in New South Wales. We have over 5,000 paediatricians and paediatric trainees nationally, of whom about 30 per cent are based in New South Wales. The Royal Australasian College of Physicians is the key training body for physicians and paediatricians in Australia. I'm speaking to you today in my capacity as president of the paediatrics and child health division of the RACP. I am a paediatrician in Victoria, specialising in developmental paediatrics. I have worked in both public and private settings, including the Royal Children's Hospital in Melbourne, where I have practised for 25 years, and over a decade in the Victorian Aboriginal Health Service, which is a community controlled Aboriginal health service in Melbourne.

My clinical work focuses very much on vulnerable children involved with the child protection and out-of-home care settings. I'm joined today by my colleague Dr Lydia So, who is a developmental paediatrician in south-west Sydney, who also has experience across both the public and private sectors. The RACP acknowledges the New South Wales Government's pivotal role in fostering inclusive environments for children with disabilities. Central to this is prioritising early intervention and integrated services. As paediatricians, we know that delays in care can lead to poorer lifelong outcomes. Systemic barriers must be addressed through clearer pathways, easier access and better support for families.

Our submission outlines 31 recommendations across eight domains, calling for a more equitable and coordinated system of early childhood and disability supports. The key priorities include strengthening early intervention as a core part of health care, expanding screening and timely diagnosis and support for underserved communities, addressing workforce shortages across sectors, improving system navigation and reducing service fragmentation and, finally, aligning the New South Wales policy with the recommendations from the NDIS review and the disability royal commission. The advice we have provided in our submission is grounded in the deep expertise of our physician members. I will now invite Dr So to speak to the New South Wales experience.

LYDIA SO: Thank you for the opportunity to be of service to the select committee. In the interest of time, I'll keep it brief. In New South Wales there are 6.8 million people aged between zero and 65, and we have 1.4 million children aged between zero and 14. That's 20 per cent. However, 43 per cent of all active NDIS participants are aged under 15. To me, this represents a cry for help. I want to acknowledge the work of my colleagues in producing this fantastic submission. It gives recommendations for what to do next. To reiterate what Dr Kennedy has said, and what our college members have said, the first 2,000 days are critical. We want early childhood intervention and support to be recognised and funded as essential care, not something that children need to qualify for through a diagnosis.

We need to strengthen access to early intervention, especially for priority populations. We need more diagnostic capacity, and the ACI clinical practice guide provides a very useful framework for this. Finally, systems need to stop working in silos. Health, education and disability sectors must collaborate. We need better coordination between NDIS and non-NDIS supports. Families can't be expected to navigate these systems alone. We risk more children falling through the gaps. Like Dr Kennedy said, we strongly support aligning reforms with national recommendations and co-designing services with those who live the experience: children, families and frontline professionals. Just as a small edit, I also work as a team leader for a developmental assessment service—

is my public role. I no longer work in the private sector. We now welcome questions from the Committee members.

The CHAIR: I might start, before handing over to the Deputy Chair. One of your recommendations is around expanding respite care services. I am interested to know where you see some of those gaps existing at the moment.

NIROSHINI KENNEDY: I might let you take that, Lydia.

LYDIA SO: Sorry, I couldn't see across the room. I was wondering if I could take that first question on notice?

The CHAIR: That is fine. I am happy for you to take any question on notice.

LYDIA SO: I'm not too familiar with the landscape for respite services, but I agree that it's very important.

The CHAIR: The other one is in relation to the mobile outreach services—whether it's also from a Victorian perspective, but also New South Wales. What services are currently available, and where do they provide that service—what areas? Happy for you to take it on notice. I understand it is a submission from organisations, so more than happy if you would like to take that on notice.

NIROSHINI KENNEDY: Lydia, are you able to comment on the New South Wales services? I can speak to, in general terms, the role of outreach services, but it may be useful to hear from you about New South Wales.

LYDIA SO: I would say that my experience is also more generalised. I'm not aware of, exactly, the landscape in terms of outreach services. Certainly, my service doesn't provide outreach.

NIROSHINI KENNEDY: Perhaps if I could just add, in general terms, we are looking at reducing barriers for vulnerable families to seek care early. Sometimes where services are located are not always accessible to families who might have difficulties with transport, who might have parents and caregivers who struggle to access services. So certainly in Victoria, in the Aboriginal community controlled health sector, outreach is a really important part of the work that we do. We take the care to the families. What that means is that we have, in the past, run screening programs at local Aboriginal kindergartens. We have run them in community centres. So in general terms, when we're talking about screening, and particularly equitable services for vulnerable groups, outreach is a really, really useful tool that we can use.

The CHAIR: My final question—Dr So, you talked about workforce shortages, particularly in certain sectors. I am interested to know what those sectors are, that you are aware of, that there are particular workforce shortages in being able to service the needs of families.

LYDIA SO: Would it be okay to add to what Dr Kennedy had said about the earlier question before I answer the workforce shortages? I did say that our service doesn't provide outreach, but actually we are embedded in the community paediatrics service and we are based across different community health centres. So I suppose, in a way, that is providing outreach. In relation to workforce, I was wondering, maybe Dr Kennedy, you might be able to talk a little bit more about that one?

NIROSHINI KENNEDY: Of course, Lydia. While I can't speak to the exact services in New South Wales, in general terms what we're hearing across Australia is there are great waiting lists for children with developmental and behavioural conditions, and the waiting lists are linked to a number of things—a growing need, but also workforce shortages across diagnostic services, treatment services, follow-up services and allied health. Certainly, there is a huge inequity, as well, in terms of access. Many families choose to use private services when the waiting lists at public services are insurmountable, but that is not an equitable option for a lot of families. And that means that the most vulnerable are missing out. Certainly there is a lot of concern amongst paediatricians about workforce shortages and the maldistribution, particularly across rural and regional areas and particularly for priority populations—so in the Aboriginal community controlled sector and in other vulnerable populations. We can certainly take this question on notice and give you some more specific data around New South Wales. We'd be happy to come back to you on that, but that's in broad terms—what we were referring to in our submission.

Ms ABIGAIL BOYD: One of the themes that has been coming through in a lot of the submissions and is also mentioned in yours is in relation to the need for an integrated service. We've spoken a lot about fragmentation of services not just between NDIS and non-NDIS but also, as you said in your opening statement, with health, education and disability. What does it look like in your mind, the ideal, integrated model? If we had a magic wand and we could create something tomorrow, what would it look like?

NIROSHINI KENNEDY: Thank you for that question. This is something that I'm really passionate about. I think when we look at the health needs of children in Australia—the growing burden of developmental and behavioural conditions and the growing mental health crisis that our children are facing—we need to deliver health care differently. We have a wonderful health system in Australia but it has been very hospital-centric. That has meant that we haven't been able to develop the sort of community-based wraparound teams that can really address the core drivers of the developmental and behavioural concerns that these children and families are facing.

When I think of what an ideal service is like, my views on this have really come from the time that I have been privileged to spend in an Aboriginal community controlled health service. We have, in Australia, for the past 40 or 50 years, this remarkable Indigenous-led model of health care that we see in Aboriginal community health services. Aboriginal community controlled health services have pioneered integrated care in Australia. They've been running this model for over 50 years and, in a way, the mainstream system is now catching on to the benefits of that model.

That model is grounded in the community. They're based in the community; they're not based in hospitals. It's grounded in primary care and screening. There is a system of annual health checks that involves screening, health promotion, increasing health literacy and building a relationship with health providers. Certainly the best integrated care models internationally have that at its core as well. You have, from there, a team-based delivery of care that follows that. That can really match the child. This is patient-centred care. For one child it may well be that what they really need is to link in with an educational liaison officer. For another family it might be about a social worker to help that family source secure housing, which is going to be, really, the key plank to that family linking in with appropriate services. For another family it might be about addressing specific speech therapy.

Really, you have this coordinated team that wraps around a child and family and the family's needs rather than what we have at the moment, which can be provider-centred care. We have one clinic that might be for a particular health condition, and people come to that clinic and get the care, but it's not really patient-centred. When we're looking at ideal models, firstly, I think what we need to do is go to Aboriginal community controlled health services, support them sustainably, fund them, help them to develop their model, evaluate them, and then support them to develop the model to the point that we can actually learn from the mainstream system.

Ms ABIGAIL BOYD: How much of the obstacle at the moment do you think is a product of everything being funded on a per-item basis as opposed to funding professionals to do everything that's required within a community, that preventative work and the outreach work and everything else? I think I fall into the trap of thinking of these magical "good old days". I don't know if they actually existed, but we hear a lot of talk about there used to be community centres with doctors who were funded to do that broader outreach, rather than having to worry about a per-patient, per-item funding model. Within the disability services space and that interaction with health, education and everything else, how much of the fragmentation is as a result of that funding model, do you think? Should we be looking towards putting in block funding now to try and build these so-called foundational supports going forward?

NIROSHINI KENNEDY: I think I agree with you. Without the right health infrastructure, it's really hard to deliver effective foundational supports, and that health infrastructure is community-based care. I think you're right: The funding models can sometimes encourage what is more siloed care, and that's something that occurs across every State. Every State's health system has addressed that in a different way. My colleague Dr Lydia So might be able to speak to the New South Wales experience, but certainly in the State that I practise in, Victoria, it's a major barrier to us addressing these problems effectively.

Ms ABIGAIL BOYD: Dr So, did you want to contribute there?

LYDIA SO: Reflecting on what you've said about the good old days, in preparing for this inquiry I actually went to look for where early childhood intervention services were. There's the Reimagine website, which used to be ECIA. They used to have a list of early childhood intervention services, and I couldn't find it. I had to go back on Wayback. I found the list for our local area, for example, Bridges for Learning or Mater Dei, and we had MECIS, which was the Macarthur Early Childhood Intervention Service, but we've stopped referring to them. Some of these providers have reoriented to the NDIS, and some I don't think exist anymore. I don't actually know how these early childhood intervention services work now, because they were based on what Dr Kennedy is talking about, this team-based, multidisciplinary approach. My concern is that, with the privatisation of ADAC, we are disincentivising or creating barriers to that multidisciplinary, collaborative approach. Like you're saying, it's this user-pays system, so that is, in a way, contributing to fragmentation of care.

The Hon. ANTHONY D'ADAM: I want to pick up on the themes that have been covered so far. Particularly, I'm interested in your recommendation 10, which is about advocating for a shift in the NDIS away from therapy-centric interventions towards promoting inclusive environments for children with disabilities in schools and communities. I wanted to pose to you—and I raised this with the previous witness—that it seems that the NDIS system architecture is premised on an individualised model and individuals making choices in a market, and that's derived from a very individualised based system as opposed to a more collective based system of provision. How do you envisage this shift actually occurring, given it seems to run contrary to the basic system architecture of the NDIS? Perhaps you might want to elaborate on how you think we would shift the NDIS away from this therapeutic-centric model.

NIROSHINI KENNEDY: That's a great question. I want to start by saying the NDIS has revolutionised support for children and adults with a disability in Australia. I have been practising paediatrics long enough to remember what life was like and what the options were for young people before the NDIS, and it certainly has been revolutionary. Having said that, it has to be a sustainable system and an equitable system, and I think that's where some of the concerns have been. That has driven a number of reviews and certainly the reflections that no doubt have come in front of this inquiry.

I think a key plank of what the NDIS set out to achieve was to increase the participation of children and adults with a disability in society, and I think a key plank of that is making sure that our community is also inclusive enough to include people with disabilities and developmental differences in the community. I think a good question that we ask of our schools, our workplaces and our communities is: How much of that has changed? I think that's what we were aiming to open a discussion about in this conversation. So, as well as focusing on the individual, we need to build a society that is more inclusive.

The Hon. ANTHONY D'ADAM: Are you suggesting that the State effectively fills the collective action gap, or do we try and encourage the individual choices that are being made by NDIS participants towards more collective approaches?

NIROSHINI KENNEDY: The detail of that is probably outside of my scope in my role here, and expertise. But in general terms I would say there is a very well established body of literature around the social model of disability and what that means in terms of the changes that need to happen in a community, and in schools and in workplaces, to make places more receptive and inclusive for people with disability. I think the point we were hoping to get across is that, as well as individual therapy, we do need to ensure that there are measures taken to ensure that the society is more inclusive and that people with disabilities can participate to their fullest.

The CHAIR: We'll now pass to Mr Barrett, who is online as well.

The Hon. SCOTT BARRETT: Dr So, you mentioned the 2,000 days and how critical they were—I presume that is the preschool days. Given the issues we're identifying as far as the identification of developmental vulnerabilities, there's also a lack of awareness about the services available to these people. What efforts and resources are needed to bring someone back on track if they get to those 2,000 days without the support that they need and without the identification of those issues?

LYDIA SO: It's a very good question. I suppose, if I can come back a little bit to that previous idea about making sure that the environments are right too, I think that is part of the responsibility. I was thinking about the ideas in a simple analogy. Thich Nhat Hanh would say, "Don't blame the lettuce." It's about the environment and the supports that we're putting around children to support and nurture them, to help with their growth and their development and their outcomes. I think we've been thinking about these ideas for a long time about how to support children. I wanted to draw attention to the paper that was produced in 2013, *Strengthening supports for children and families 0 – 8 years*. It already talked there about this tiered early intervention system.

We are using those principles of universal proportionalism to support people at different levels of that tier—so universal, targeted and intensive. Pointing out correctly the first 2,000 days is that zero to five, we do worry about children who are perhaps not getting that early intervention soon enough. In the ideal world, we would have more capacity in the tier 1 and 2 levels to identify, to screen and to provide early intervention before children get to beyond the first 2,000 days. Beyond that, we obviously still need to continue to support these children, and I don't think it's a matter of saying it's too little, too late. Certainly we would want to support every child and every family, but I think being able to have more of these wraparound supports is really important.

The Hon. SCOTT BARRETT: I asked that wondering how much of a drain past those 2,000 days is getting put on our schools and our teachers to right the ship. How much resourcing is required from our teaching staff, who are not necessarily equipped to do this? How much of a drain is it on them at this point?

LYDIA SO: I agree. I was thinking of a case example of a child who's now seven but he presented at exactly that age of five with his child protection caseworker, who was worried how he was going and about his behaviours. He had a lot of adverse childhood experiences growing up—family violence, housing instability—and just to point out that the NDIS was helpful in this instance. We initially were able to get him into early childhood intervention through community allied health, and then also NDIS was able to come in with supports.

He had his assessment through our developmental assessment service. But as he has turned seven, I think these are the concerns that we have—that he would be moving out of the NDIS, potentially, as a participant and that the therapies, for example, were able to be put into the school setting to help. That is something that we could be doing to work with Education as to actually embed allied health and supports into education. Dr Kennedy, I think you wanted to add to that.

NIROSHINI KENNEDY: That's a wonderful question. We now have decades of research from neuroscience and behavioural research that shows that the first 2,000 days are absolutely critical in determining future health, development and learning—on every health outcome—and we know that early intervention works. The return on investment for intervention early—there's something called the Heckman Curve that describes the impact of early intervention. In terms of when we're looking at the cost of services, we really should be investing early in life, in the first 2,000 days. The early childhood checks, which the college has previously provided a submission on, speak to the importance of early childhood and screening so that we're not left with children who have issues down the track that can take a lot more work to address.

The CHAIR: Unfortunately, our time has expired for this session. Thank you, Dr Kennedy and Dr So, for appearing today.

(The witnesses withdrew.)

Mr ANTONY NICHOLAS, Chief Executive Officer, Osteopathy Australia, and Immediate Past Board Chair, Allied Health Professions Australia, affirmed and examined

Mr DEAN MURPHY, Professional Officer, NSW Nurses and Midwives' Association, affirmed and examined

Ms LYN BRODIE, Chief Executive Officer, Speech Pathology Australia, Allied Health Professions Australia, before the Committee via videoconference, affirmed and examined

Ms CAROLYN O'MAHONEY, APA Titled Paediatric Physiotherapist; and National Chair, Disability Group, Australian Physiotherapy Association, Allied Health Professions Australia, before the Committee via videoconference, sworn and examined

Mrs MICHELLE OLIVER, Chief Occupational Therapist, Occupational Therapy Australia, Allied Health Professions Australia, before the Committee via videoconference, sworn and examined

Ms NICHOLE CALLAN, Child and Family Health Nurse, and Member of the NSW Nurses and Midwives' Association, before the Committee via videoconference, affirmed and examined

The CHAIR: Before we commence with questions, would any of the witnesses like to make an opening statement?

ANTONY NICHOLAS: Firstly, I'd like to acknowledge and pay our respects to the traditional custodians across the lands that we meet on today. All children and young people in New South Wales should have the right to access allied health services to support and optimise their development, health and wellbeing. For those experiencing developmental delay and disability, access to the right service, including allied health, can mean the difference between achieving goals and outcomes, and not. We thank you for this opportunity and hopefully we will be working closely with the New South Wales Government to make sure that every child and young person gets the chance to thrive.

Allied health professionals currently deliver comprehensive assessments, facilitate access to assistive technology and provide evidence-based implementations tailored to meet the unique needs of individual children and young people with developmental delays and disabilities. Evidence shows that a child's early years represent a critical development window. Once that development window has closed, achieving development outcomes is much more difficult, which we talked about in the recent evidence. Feedback from practitioners in New South Wales has made it clear that not all children and young people can access the services they need. Targeted therapeutic interventions delivered by allied health are often only available to children and families that can afford to pay privately or have access to NDIS due to lack of funded alternatives. Where services do exist, long waiting lists and delays for assessment and diagnosis can impede timely interventions. Also, workforce shortages have an impact.

AHPA recognises that New South Wales has begun investing in supports that help address these, such as Brighter Beginnings, but this needs to be supported by a broader system of accessible supports including ones that improve identification in early years. A more efficient system will require focus on improving accessibility to allied health at all stages, from early identification to supporting parents through coaching and education and developing and delivering therapeutic interventions that address physical, speech and other delays. To get that system right, the allied health sector must be engaged with collaborative co-design of future foundational and disability supports in New South Wales. Working with the Commonwealth, New South Wales will need to fund and deliver a system of foundational supports based on a nationally consistent framework.

The volume of funding will need to ensure that targeted foundation supports delivered by allied health professionals are a genuine alternative to those unable to access the NDIS or mainstream services, and that there is a choice of services for families and children. The establishment of these new foundational programs will need to define the skills, knowledge, scope, capability and needs for those different roles to ensure the best outcomes and most effective use of workforce. We can probably reflect on some of the recommendations from Professor Cormack's scope of practice work, which also helped map out how that can be utilised to maximise or optimise the workforce. To ensure children and families can access these services, new models will need to allow flexibility to engage allied health professionals including those working in primary care or the private sector. We welcome the opportunity to talk about that collaboration and welcome any questions. My colleagues online will have some great clinical examples as well.

The CHAIR: Mr Murphy, do you have an opening statement?

DEAN MURPHY: I'm happy to go straight to questions and not do an opening statement. However, there's one thing I'd like to ask. I've printed off an article. It's a two-page article from our publication, *The Lamp*, and that is a story that includes Nicki Callan, who's with us today. She was involved in a program to bring paediatric services out to the local community in the Far West. I wonder if this could be tabled and given to you today?

The CHAIR: Yes, it can. Would anyone online like to make an opening statement? No? Then we'll move to questions. I might start with a question specific to Mr Nicholas's submission. We have received evidence and heard from witnesses previously around the key worker model as being quite successful. However, in your submission, you've raised some concerns regarding it. Could you elaborate a little bit more as to why that model is not as good as something else?

ANTONY NICHOLAS: I might actually throw this to Michelle or Lyn, who may be better at answering that question.

MICHELLE OLIVER: Sure, I'm happy to jump in first, and then Lyn, if you'd like to add anything. With regards to the key worker model, it's not that it's not necessarily an effective model, but I guess what we're acknowledging is that everyone's needs are different. With really complex needs or where there's a lot of different services that are needing to be coordinated, absolutely that's valuable and beneficial. But what we don't want to see is that the key worker is in place of the expertise of, say, allied health professionals or appropriately trained professionals to provide that, whether it's screening, assessment or intervention. The key worker model definitely has a place, but a young child and a family may just need to see a speech pathologist or an occupational therapist or a physiotherapist over one or two sessions to support them, to build capacity, to do some coaching or knowledge building. It may not need that kind of broader piece. So I guess that's kind of the perspective we were talking to. Lyn, I'm not sure whether you wanted to add anything.

LYN BRODIE: No, I think you've covered it. It does come down to the flexibility and the expertise that each of the allied health professions are going to bring to the table, especially around diagnosis, that others may not be able to.

The CHAIR: That leads me to the next question, which is around that collaboration. What recommendations or advice would you have to see, both from a health perspective and education, being able to work more collaboratively, and also then in with the services that are actually already being delivered, whether they're government or NGO funded? That's to all witnesses.

ANTONY NICHOLAS: I think this is a real challenge in the fact that, as we all know, we have an incredibly fragmented health and disability sector—State, Federal, public, private, NGO et cetera—and this has added to a real complexity of getting fulsome collaboration and co-design. We've noticed that even within the NDIS. As many disability services diminished with the development of the NDIS, what that meant was a lot of allied health who focused in this area went into private practice to work through an NDIS model. And I think now there is going to have to be—which is great about this inquiry—some real consideration into those diversity of places that are offering services for early childhood and disability now, in multiple locations, because they probably are not going to exist in single "go to this centre and do that".

That would be optimal, but most of those services are gone now. So we need to think about models where there is true collaboration and co-design, which unfortunately in our health system rarely exists. It does within medical practitioners and within hospitals or tertiary settings, but rarely in primary care or in the broader environment. It's the biggest challenge in our health system, we would say, to actually engage the full health workforce who can work with health or disability.

DEAN MURPHY: I would say similarly, in the nursing workforce, speaking about the NDIS, nurses are currently more on the periphery of that, whereas, certainly, child and family health, which is my background—and Nic is on the front line there—it's somewhat limited in that nurses are often brought in for a specific purpose rather than being more central to that review process and being involved in using the tools that nurses use for screening, intervention and then appropriate referrals. So I think that needs to be looked at. In terms of access for parents to services, there's the idea that's being looked at quite a bit currently around multipurpose hubs and having different services such as nursing, midwifery, allied health, medical services and so forth, co-located. That happens to an extent, I guess, in community health centres, but obviously an expansion of that is being looked at. I'm aware of that, and it should be looked at. I think that's quite important.

In terms of the nursing and midwifery workforce, as we know, there are workforce issues in terms of attracting and retaining staff. As we know, in New South Wales nurses and midwives are the lowest paid in the country, even though the cost of living, particularly in this part of New South Wales but more broadly, is among the highest in the country. We are losing staff to other States, particularly to the north and the south of us. Nicki, can I pass over to you to speak, because I interrupted you?

NICHOLE CALLAN: Yes, thank you. I am a child and family health nurse working in western New South Wales. I've been in the nursing profession for over 30 years and, in that time, spent all of my nursing practice in rural or remote communities. My role is to complete assessments, blue book checks, immunisations and referrals as necessary, working in partnership with our families. That's quite detailed in what I do. I actually refer to the allied health team all the time. I also refer to the NDIS with the allied health team all the time. I do have barriers faced every day with our families, from being in a rural and remote community to not having any access to any services. I know of one community that has no service—no allied health service and no paediatric service.

In the west we are facing a huge crisis at the moment with neural paediatric access. These children are already disadvantaged from living in rural or remote communities and then having nil access to paediatric or allied health services. In our local community we work really hard, together with every service in the community, from our schools to our health to our GP centre, and we created a fly-in fly-out service with Little Wings, fully funded with no cost to any of our children or families—the gold standard of face-to-face delivery. It is successful. We have children being seen, children having diagnosis, children having medication to attend school and support services in place. But, sustainably, we're doing this with really limited funding.

This is a perfect opportunity for the Government to look at this and go, "You know what? This is an excellent model where all services are working together." Where there are rural and remote communities without allied health, we're working with the Fly2Health team that will help provide those allied health services, speech, OT and psychologists to these rural and remote communities. Every child deserves a right to access health care, allied health and paediatric services, and if we do not do something now, we will have poorer health outcomes, poorer education outcomes, poorer job opportunities and a financial deficit for our region. We are working extremely hard in our communities and we are doing this with one child family health nurse and one CEO of Little Wings to make an amazing difference for our communities. We have to act now. We don't have time. We don't have tomorrow. We don't have next week. Children are aging, and Australia has to stand up and take responsibility for what's happening in our rural and remote communities.

The CHAIR: Thank you for everything that you do and also Little Wings. I've got to say that I am biased, having been a registered nurse, but I appreciate everything you're doing in rural and regional areas. Are there other witnesses online who would like to add anything further on that question?

CAROLYN O'MAHONEY: I'm a titled paediatric physiotherapist, and I'm the national chair for the Disability Group with Australian Physiotherapy Association. I work in a few places. One of them is a GP practice, another one is a paediatrician's office and a third one is a paediatric physiotherapy clinic. I think, to the points you've already heard, often the children we're seeing who would fall under the foundational supports category are presenting as a movement concern or often a feeding concern. So often physiotherapists are the first practitioners they see, or the maternal and child health nursing system or lactation consultant is where these children are presenting, and it's often a teasing out of what's happening, trying to get these children support and trying to get them referrals to paediatricians. Sometimes they do come from paediatricians, but it's often a process of getting those supports in place for them.

There are many children who present who are not eligible for the NDIS but do have significant issues with feeding or moving, and it is really critical to get to them—as has been described today—before those critical developmental windows close. We know there's neuronal pruning that happens around six months of age where a lot of neuronal connections are lost in the brain. If we're not getting in and helping children move or helping them learn function before that happens, it's much harder to then retrain it and gain that back once it's been lost. We all in this industry feel enormous time pressures of helping these children when they're in these critical stages of development, knowing that if we can achieve that, we are preventing the severity of their disease, delay or condition. I just wanted to add that.

Ms ABIGAIL BOYD: Thank you all for making the time to appear and for your submissions. I have personal experience of having had one child in the UK and then having another child a couple of years later in Australia, and I experienced a very different situation when it came to nurse and midwife care in the UK. I note that in the Nurses and Midwives' Association submission there is comment around this UK health visitor model. Can you explain to the Committee what that model is and how we could implement it here?

DEAN MURPHY: In terms of the detail of the model, I'm happy to take that on notice and provide more information. However, what I understand of the model is that nurses over there have increased referral rights, for example. An issue that we come across here, particularly in rural and remote areas, is the issue of access both for nurses and midwifery to GPs, for example, or the medical profession in having to make referrals via the GP to specialist services such as paediatricians and so forth. Certainly that could be something that we could look at here because nurses working in that area have extra training, assessment tools and skills. That's something that we should look into.

That's not to replace in any way the GP, for example. Nurses are very good at referring, collaborating and communicating with GPs, but, particularly in areas where there are shortages, that can lead to significant delays in children that need to be seen. As we've heard from a number of witnesses today, particularly in the *First 2000 Days Framework,* early intervention and getting in as early as possible is vital. Another aspect in the UK, from my understanding, is being able to have certain prescribing rights related to the work that they're doing, from a limited formulary, but I'm happy to provide further information on notice.

Ms ABIGAIL BOYD: One of the themes that's been coming through in the submissions is the difficulty navigating support and services for parents and carers when they're looking at where they go. Also you don't know what you don't know. Especially if you're a new parent, you just don't have the knowledge to understand whether early intervention is required often until it's later than you would want. Certainly my experience in the UK was that the nurse that would come around and into your home would not only be checking on your child, but on you and a bunch of other things and was a very good source of referral to say, "Well, have you thought about seeing this service or there's a playgroup over here or that's something for your GP"—or whatever it happened to be. It seemed to fill that gap. Is that something of some form that you are recommending?

DEAN MURPHY: Definitely. It's already happening. My background's in child and family health nursing, and one of the central components of that role is exactly as you've described, so that is happening now. I guess the issue is that needs to be expanded, so that role could be expanded in terms of referral rights, where needed, and certainly access. The issue is twofold. If we have a staffing issue—commensurate pay, for example, with other States could help with that, increase the funding for further training for these nurses and midwives. I know it's been looked at and we're some part of the way there, particularly for undergraduate nurses in terms of paid clinical placements.

But I think that could be looked at, for example, at postgraduate level. It could be important. But until we fix the staffing issues in the nursing and midwifery area, that's going to provide an impediment to access for these families. But on the other side, there needs to be access for these nurses and midwives to refer people to. As Nicki has illustrated, in rural and remote areas in particular, that's quite an issue where they're often in a position where they've done the assessment, they know who the child or these children need referral to, but there's nothing on the other end.

ANTONY NICHOLAS: And the same probably applies exactly the same in allied health. It's that ability to refer on, particularly where there are GP shortages. That becomes the barrier for people accessing other care because it's so dependent on the GP or a medical practitioner being that next step to get anywhere else.

DEAN MURPHY: One thing I would like to add that I didn't quite get to is that nurses are quite central in terms of—and you alluded to it in your experience that nurses are often at the forefront or the front line. They're a pathway to pretty much every other service out there. Nurses and midwives working in the child and family health arena are really a great resource in that if they're central to that, then they can identify the needs of the child and identify where that child needs to go, not just for other services such as allied health, the GP, paediatricians, physio, OT, speech pathology and so forth. They have the skills to identify that to refer appropriately. But also things like services such as supported playgroups and services such as that, or just general playgroups and networking and linking families with other families and things like that.

Ms ABIGAIL BOYD: Given the importance of the involvement across allied health and education and disability services, to what extent has either the Federal or State government engaged with allied health professionals to consult on what foundational support should look like?

ANTONY NICHOLAS: This will sound slightly negative, but generally allied health are treated exactly—they're allied over there, and we'll talk to you last after we've designed the whole system. Not always, but most frequently, we have to do the, "Sorry, what about 200,000 allied health that are working across the country and all these different environments?" It is a real challenge, which is why we really appreciate being here today and talking about it at the start rather than at the end. It is a real challenge, and partly that's a challenge because we're talking about 30-plus professions, a diversity of scopes of practice, a diversity of working in tertiary care, community settings, education, private care et cetera. It's very broad.

We understand it's a challenging sector, but it's generally been where it's almost like we'll consult on this little bit here with this particular profession because they're maybe the larger profession that works in that space, but not thinking about the broader sector or that broader workforce, which is, again, why that scope of practice review and some of the other reviews going on are talking about those overlapping scopes and how we can optimise the workforce for people, particularly in areas of high need or market failure.

Ms ABIGAIL BOYD: Did anyone online want to add?

MICHELLE OLIVER: Could I just quickly jump in on that. We've been trying very hard to be proactive in this space, especially with—ever since the recommendation around foundational supports came out. There has been a lot of anxiety amongst the disability sector as well, and it's often the allied professionals who work so closely with and for young individuals and families. They're turning to us to ask questions, and we're feeling like we are being closed out of any sort of decisions or opportunities. We are very open to collaboration. We would love the opportunity to engage and be part of designing and working with States and Territories and government to look at how we can best design models to meet the needs of young people as early as possible and people out of hospitals, out of the scheme if that's not where the needs are going to be met. We are very willing to engage, but it has been challenging so far.

The Hon. ANTHONY D'ADAM: I want to ask about issues around allied health access to schools. In their submission, the royal college of physicians suggest embedding allied health in schools. I wanted to perhaps ask the witnesses about the pros and cons of that particular approach and also the issues around access as it currently stands.

ANTONY NICHOLAS: There are a couple of representatives online whose professions work quite a lot in education, so I might throw to Lyn, Michelle or Carolyn.

LYN BRODIE: Obviously speech pathologists do work in the education space quite a lot, but I have to say it's not necessarily consistent. Often it does rely on a school principal that has a real passion and is a champion. There are very diverse systems that work in. I think what we need to look at in the system is there is opportunity, certainly, for group work with a small group of children, but then there's also the need for specialist services for a child that's going to need and require other help and assistance. In fact, I did have a case study from a young child that was having a range of communication difficulties. Unfortunately, the speech pathologist wasn't able to engage in the school environment, and that caused a whole lot of issues. So we are involved, but it's very dependent on principals.

MICHELLE OLIVER: I'll just add to that as well. I think it's really varied across the country, and, unfortunately, in New South Wales there are much greater barriers. There's far less allied health employed within education in New South Wales than any other State or Territory. Certainly there are some States and Territories that are more so leading the way in terms of employing allied health within education, but we do work from a tiered system or a tiered approach to care within and across education. When we talk about education, we talk about all the way from playgroup to kindergarten to preschool, child care, primary school, secondary school and above. There's value in having allied health employed within the school system to work either directly with the child, work with the educators or work with the whole community to build capacity—whether it's about adaptive environments, coming up with strategies to support children to engage or even to come to school—but then work and learn the most out of schooling.

Then there's also the private sector, who provides support and that kind of in-reach—so a child, for example, might be working with a therapist, and part of that really collaborative or comprehensive care and holistic approach we take. We want to work with the individual within their natural environments, and school is a pretty critical place for young people. Those private practitioners often experience barriers. Education is hard because of the system—the public, there's the independent school system, and there's the Catholic school system, and they all have different approaches. As Lyn pointed out, unfortunately, it comes down to the principal, whether they have an understanding of the value, the opportunities, and want to create those pathways. That's really just not sustainable. But I would assert and urge New South Wales to look at the opportunities of employing allied health within education, because then systems can be built that can better support either individual therapy or that change or capacity building within the school community. We, as allied health, certainly don't want to take away the educator role. That's really critical. We know that it's such a challenging role at the moment. But if we can add value to support engagement, manage challenging behaviours and meet sensory need, there are great opportunities there. But we also have a whole cohort of young people who just can't go to school as well, which is incredibly concerning.

NICHOLE CALLAN: In rural and remote, where I am currently working, in 2023 we had 12 children out of 22 kids starting in kindergarten that had severe speech and other concerns. We have a massive need out in the west. The school is now working with speechies and OTs and a paediatrician to overcome this. There is a huge need. We have a high Indigenous population. We've worked with other services and resources—Dolly Parton's Imagination Library and the Indigenous Literacy Foundation—to bring books into children's homes to help these children and to really push the reading and referral rate for services. It is about community working together with all the allied health and with the paediatrician as one. We can't do this separately. We can't do this just by ourselves. We have to all work together. I believe communities will do whatever they can to help their children.

The Hon. ANTHONY D'ADAM: If we did adopt a model like this, of embedding allied health in schools, do we have the workforce to be able to implement something like that?

ANTONY NICHOLAS: It depends on the region. All the areas of probably the highest need are the places where, as we know, there will be less workforce. Partly that was also almost facilitated by the NDIS funding model, and a reduction of State-funded disability services that encouraged allied health and others to move into this private provider model that's funded by the NDIS, which meant they were restructured out of State-run or State-funded schemes and into the model that they've now moved into. But for that to work, clearly they have to be in areas of need where people either have NDIS funding or can pay, which has probably further exacerbated workforce issues. Workforce is a huge challenge for disability health care and these expansions, but there are also a lot of allied health being underutilised because of the way most funding models are structured. Most cannot use their full scope of practice because no-one other than a patient will pay them for that. So it's a barrier to patients in need.

The Hon. ANTHONY D'ADAM: What's the solution to that misalignment of resources?

ANTONY NICHOLAS: I think there are dozens. There's not one solution; there are dozens of little things that could change. That's both at State and Federal and across different ways in the fact that many allied health are basically trained to do certain things but, whether it's Medicare, the NDIS or other funding models, don't allow them to use some of those skills because a different profession may be funded to do X. Obviously, that's where consumers will go because that's where they get the subsidy from, even though there may be 20 other professions also prepared to do that.

It's also mapping what people's skills are. There's very little understanding, even within health professions, of the scopes of practice of other professions. They know some of them and they may have an idea of what it is, but there needs to be a much better understanding of the full scope and knowledge of all these different professions and their role within health care, disability or education. The overarching one is we've got this fragmented—there's the private health sector and private health insurance and what it will fund, there's Medicare, there's the NDIS, and then there are State services and NGOs et cetera. So it is incredibly complex for the average consumer to even know where to go. I think it's got to be multiple things.

For allied health, using New South Wales as an example, New South Wales has this amazing agency of clinical innovation. The only people who can access its great resources and training and other things, even though it's been government funded, are people who are employed within tertiary or public health. They don't even sell it to people outside. All those people servicing New South Wales for better health care can't get access to the great training and resources that have been funded by the Government because they're not employed within a hospital. It's very much that the department sees that health in New South Wales is who we employ within hospitals or within our systems, and not much outside that.

The CHAIR: I think Mr Barrett had one question before we conclude.

The Hon. SCOTT BARRETT: The last couple of minutes has opened up the possibility of many questions. Ms Callan, you talk about the school picking up a little bit of the load—everyone sort of chipping in together—but how much resourcing is going from the school to these areas that could or should be picked up by allied health, which is then being diverted away from some of their other functions?

NICHOLE CALLAN: I'm not quite certain about that because I only look at the nought to five space. When we were looking at getting a paediatric service and working with our allied health team in our community, we all worked together to find a solution. I'm not sure financially how much is going from the education department into allied health. I do know that the community that I'm looking at the moment has employed a speech therapist and an OT therapist. The local Rotary service is also doing a massive fundraiser to pay for speechies and OTs and paediatric service for the community. This shouldn't be up to Rotary; this should be covered by the government. This is our children that we're looking at. This is a community trying everything to help supply the OT, the speechie and the paediatric services to the local community. We have a dinner in August, and we're hoping to raise $50,000 just to start to help further the speechie and OT services in the schools and the community. It's a huge need.

The Hon. SCOTT BARRETT: Thank you for your passion and commitment to this.

NICHOLE CALLAN: Can I say one more thing? We didn't talk about our Indigenous engagement with our families. When I first started in the communities I worked for, there was a 12-month and 18-month workforce gap across the childhood health sector. I've worked really hard. I wasn't known to the community. I worked really hard with our Aboriginal health worker. We created engagement projects such as Bellies and New Life to engage our women early and to then provide ongoing referral services. What's happening is our women are being engaged while they're pregnant. They're then coming back to us for ongoing services, and they're more comfortable to access our care. Therefore, they're coming back for immunisations. We're picking up any delay early for our children, we're linking them into the NDIS, we're linking them into the paediatrician and we're linking them into the allied health team. Nurses are so well placed to be the main referral pathway for all of your services. Because child and family health nurses work directly in community, they know what's needed, know the gaps and know the mapping that's available in their communities.

The CHAIR: Unfortunately, time has expired for this session. On behalf of the Committee, I want to thank all of you for the work that you do supporting local communities but also, particularly, families and young people as well.

(The witnesses withdrew.)

(Short adjournment)

Ms SYLVANA MAHMIC, Chief Executive Officer, Plumtree Children's Services, sworn and examined

Ms KYLIE AEKINS, Parent-Peer Hub Leader, Plumtree Children's Services, affirmed and examined

Ms EMILY CASKA, Chief Executive Officer, Playgroup NSW, sworn and examined

Ms ELLEN HESTER, Individual with Lived Experience, and Administration Officer, Playgroup NSW, sworn and examined

The CHAIR: Thank you very much to everyone who is appearing today. We do have a couple of members who are online: Mr Scott Barrett and Mr Mark Buttigieg. Before we start with questions, would either of you like to make an opening statement?

SYLVANA MAHMIC: Thank you so much for the opportunity to contribute to this process. I acknowledge the traditional owners of the land on which we are meeting today. I'm here with Kylie Aekins. We are both parents of children with a disability and bring lived experience to this inquiry. My son is now 35 years old. My entire career I have spent in early childhood intervention based on my experience with him. I'm also the CEO of the community organisation that I run. It's a not-for-profit child and family organisation that has supported children with disability or developmental delays for over 40 years. We're also an NDIS provider, but today I'll be focusing on how we build capacity for families of children with developmental delay and disabilities using peer-led approaches and, in particular, our approach called Now and Next.

Since 2015 we have delivered the Now and Next program, which is a peer-led capacity building program developed and co-designed by families for families. The program equips parents to take the lead in their child's journey building their skills in goal setting, decision-making and self-direction, increasing their hope, empowerment, wellbeing and goal-achievement. It is delivered by trained parent peer workers and paid parent peer workers with lived experience. Over 2,000 families internationally, including in Australia, have participated. Foundational supports like the Now and Next program are critical for parents of children who either have an NDIS package or do not have an NDIS package.

Such programs build the capability of parents, which in turn improves outcomes for children at a much lower cost than therapy. But, as we have learned through our national evaluations, when such programs are not free, parents will prioritise therapy for their child over building their own capability. In our evaluation of 1,008 families recently—in a period of 36 months—who participated in Now and Next, they did not have NDIS funding. Many entered the program with lower levels of hope, empowerment and wellbeing and were more likely to disengage compared to our benchmark—they were more vulnerable, that is. However, when they did participate, they made more significant progress than our benchmark, showing that programs such as this work, even when the families are overcoming incredible obstacles.

We also know this approach is highly cost-effective. A cost-benefit analysis using a New Zealand Government model found that the Now and Next program delivered a return of up to $4.70 for every dollar invested, including positive returns to government. What this means is that peer-led programs like Now and Next offer real value not only for families but also for government and the wider community. They are low-cost, but they are far-reaching and lasting in benefits, making them a smart investment for government.

Peer-led programs like this also grow the workforce, which is under pressure due to the NDIS and increased reliance on therapy. Through the Parents as Peer Leaders project, for example, we supported 33 parents to become peer facilitators. Many are now working in the sector and leading in their communities, showing the untapped potential of parents as powerful contributors, not just service users, when given the right supports. We urge the Committee to recognise the importance of peer-led, non-clinical foundational supports in enabling earlier access, greater equity and long-term service sustainability and system sustainability. If we want to strengthen outcomes and reduce demand for intensive services, we must invest in building the capability of parents and make these services to those parents free.

The CHAIR: Thank you very much. Ms Caska?

EMILY CASKA: I'm actually going to go to Ellen first, if that's okay. Her voice is more important than mine.

ELLEN HESTER: Thank you for the opportunity to share with you my story and why I'm so passionate about it. I am on the NDIS. However, my life is not defined by the NDIS. When I look back to my childhood, there was no NDIS, but that didn't mean that I didn't get services and supports back then. Many of the supports for me and my family were through the State Government. My Down syndrome means that I do need some additional supports, but that doesn't mean that every person with Down syndrome has the same needs. We are people first. That cannot be forgotten in this inquiry.

My mum is a speech pathologist, and she supported me when I was young—lucky me. But every child who needs this should get it as early as possible. As a child I would also join my mum at work with other young children and babies. I would see firsthand the huge impact on children in their early years. Research shows us that the earlier the better. I remember seeing baby sign and speech tips, with parents learning together. I would help a lot as a mentor. I would show children how. All children have families, and parents and siblings are just as important to support.

When I was young, my mum got peer support from other parents, meeting together, supporting each other and sharing knowledge. I know from my experience and talking to my mum that place-based group services and supports are just as impactful and just as needed as individual therapy. That's why I'm super proud to work at Playgroup NSW, in our team of over 90 staff and 650 volunteers. We support a whopping 74,000 children and their families from prenatal to school age across 99 per cent of postcodes in New South Wales, making sure they get the very best start in life.

We are not an NDIS provider. Each year we run 26,000 playgroups and 2,000 peer support groups and parent capacity programs. The best part is they are all local and free. I am really proud to be a role model for what a great early intervention looks like, through my lived experience. Without it, my life would have taken a very different path. I would be more disabled, not enabled. I have a very full and fun life. I have three jobs—at Playgroup NSW, at the University of Sydney and at the Sydney Swans women's team. Despite what people might jump to think, none of these are supported through the NDIS. I can do this myself. I can travel to them all myself. I have a boyfriend. I have a TAFE certificate in health and fitness. I play netball and I have a great social life with my family and friends, just like my sisters.

Soon I would like to move out of home, as my next adventure. I am a great example of the opportunity that this reform brings. Get it right early to thrive later. Perfect can't be the enemy of good. Playgroup NSW is a great example of fundamental supports in action. It is ready to go, is place based and is a soft entry point for child, family and community. My friends and I who have a disability don't want to be made political. I'd just like to see all children with a disability get the best start in life, like I did, so that one day I won't be the only person with an intellectual disability sitting here before Parliament on reforms that directly affect our lives. A seat at the table is great, but wouldn't it be great to have people with intellectual disability as members of Parliament too? Let's get it right early to thrive later.

EMILY CASKA: I mean, honestly, what can you add to Ellen's? Hear, hear, from me, to have a formidable colleague in Ellen, a woman with an intellectual disability, presenting here in the House of the people and representing those voices. I think Ellen, for us, has really nailed the essence of what this is about. I won't go into too much detail, but not all children with a disability need to go to the NDIS. Unfortunately, I think we're in a system at the moment where the construct is it's the NDIS or nothing. For all the best intentions, I think that's become more exclusionary.

So, too, I think if we dig down to the layers of where we sit, not all children with a disability also need very individualised early childhood intervention. We see that every day in playgroups and in the great work that Plumtree and our partners and others do. So, too, not every child with a disability needs targeted foundational supports. There are things in the community and the general space that we know—that not every child with a disability needs to necessarily be an adult with that same disability or developmental delay, if we can get some of those early interventions right, and the social model of disability will surely tell us that. And so too, in our own context, some of those biases is not every child with a disability needs to go to supported playgroups. We really proudly run 650 community playgroups each and every week, run by parents in those local communities, and they too need to be just as inclusive of and responsive to the needs of children with a disability or with a delay.

Playgroups are absolutely one of the earliest place-based soft entry points that every child and family will access across New South Wales. Like Ellen said, we run 26,000 playgroups a year. We're in 99 per cent of New South Wales postcodes and by and large, except for some community playgroups who need to pay the bills, we are free. We are there from the earliest point, and we do also reach in, in the prenatal stages. I think with playgroups what's really unique, probably as opposed to many other models in the early years, is our co-participation model. The parent is there with the child. We absolutely love the work of ECEC and other sectors, but they're there in that co-participation model with their peers. That really, we think, is the power of playgroups and particularly the power of parent capacity building.

But beyond playgroups, as our submission shows, we also run 2,000 peer-to-peer support groups through MyTime across New South Wales every year. We also have a really dedicated parent capacity building hub. Many could probably argue that playgroups themselves, because of the evidence base that actually does sit behind them, are a parenting program and parenting capacity. But there is no way I'm about to go out to families to say that, because we want to maintain that local soft touch. We think that foundational supports are such an opportunity to finally get this right for children in this State and across this country, because we need health, disability and education to absolutely come together. When we say children with a disability, I don't mean those with a diagnosis, particularly in these early years. For us, the first 2,000 days, particularly the first 1,000 days—disability, delay, just parents saying, "I'm not really sure; my child isn't keeping up." It shouldn't be a diagnostic test.

What we're also excited about is, to my earlier point, I think we can finally bridge this long-held gap between the NDIS or essentially nothing, which so many families tell us. I think we all here know the why. I think we would really like to, and our submission focuses a lot on the how—not that I have all the solutions—because there are a lot of things and there are a lot of green shoots there to scale—obviously, playgroups being one of them. We don't want foundational supports to be another system inserted within a system. The passion, the capability, the capacity is there. It's the resourcing and the investment that actually is needed.

In this I caution as well, foundational supports—very passionate about it, but it cannot be NDIS 2.0. It cannot just be seen in the lens of the kids coming off the NDIS, and that's who foundational supports is for, because I think that would be a missed opportunity if it's just an off-ramp. But so too it can't also be seen just through critical individual early intervention, which Sylvana mentioned as well. It can't just be about diagnostic support and health-based therapies. Foundational supports have to meet the needs of all children who need assistance. As a non-NDIS provider, we would argue in what we see, particularly in our integrated Aboriginal hubs across New South Wales and other areas, there are children out there who are the most vulnerable and marginalised, who aren't even getting any services and supports, and we need to start from them, not the lens of looking at who's coming off the NDIS.

Very quickly, in terms of what's needed to make it work at a high level, the voice of children and families has to be at the centre, full stop. I think there's a lot of improvement that we need to do there. We do really want a clear and shared definition, including not just what foundational supports are, but what are those interface points, again, not just with the NDIS, but mainstream as well, because that's a bit missing at the moment. We do need a nationally consistent but locally responsive approach, absolutely. There needs to be fluidity and seamlessness for families and for us as providers. I think if you take an example of a family that might need some really targeted high-level NDIS-based services, the family also needs peer support. They might also come to a supported playgroup and also want to go to a community playgroup. How are they going to traverse those systems? How many eligibility assessments are they going to have to go through? For us as providers, how many different standards and accreditation processes are there going to be? That's a bit of a caution.

I think from a government lens in this inquiry—and I saw the briefing paper—a really solid understanding, yes, of what's being delivered now, but where's the unmet need and demand? Because I can tell you absolutely every single playgroup we have is high demand. We are not meeting the need. We could double tomorrow, without a doubt, absolutely, to the point where we've had to, in some of our playgroups, make parents register, which goes against the very ethos of playgroups. For some of them—and I know the shadow Minister attended one; that's one where we have 120 families coming sometimes, mainly from a culturally and linguistically diverse background, and we can't cope with that sort of demand. The other part is also probably on the provider side, investing in quality providers and taking a more relational commissioning approach, rather than a transactional model that we've all been under to date, and some more timing. Some of that would be very appreciated, because providers like Playgroup NSW, Plumtree and our valued partners—we need to be here to deliver them, and sustainability is needed now. It is at urgent point.

For us as well, there must be a focus on place-based, community-led and peer support models that really do link into primary and allied health, but primary and allied health can't be the first port of call. We do think that that soft entry point in community is important. Probably not surprisingly, yes, workforce development, but our lens on that, too, is the volunteer workforce. I have 650 volunteers. Again, I could double that overnight, many of whom are parents. Also, we want to see people with a disability—people like Ellen—mentoring what this looks like in the early years. There must be a focus on outcomes, and I think we're all looking at just getting it implemented. But what will it look like when it's there? What's the data sharing and the outcomes reporting, and having open datasets? Finally, we would love to see that foundational supports at both State and Federal levels have a clear agency leading it. I do absolutely love the collaborative approach and a clear Minister that's driving this.

Ms ABIGAIL BOYD: Can we just have that? Can we have all of that?

EMILY CASKA: If you could all do that, that would be wonderful.

The CHAIR: Before I hand over to the Deputy Chair for questions, I just have one that follows basically your last statement around that collaboration. We've seen a shift at a Commonwealth level, and the NDIS Minister is now under Health as opposed to the social service sector. We know governments aren't great working across different departments and agencies. How do we improve that collaboration—whether it's from the DCJ, Education or Health—but also, more importantly, with communities so it is community led and with NGOs and service providers? What needs to be addressed? That's to the both of you.

SYLVANA MAHMIC: Prior to the NDIS, there was an Ageing Disability and Home Care service funded, called the early childhood intervention coordination project. Thirteen regions across Australia got $12,000 each to have a coordination function. Each of the government departments involved with interfacing with children and services who had developmental delay or disability received that funding. That group brought together everybody in that region, regardless of whether they were government or non-government, and the whole function of it was collaboration and coordination. Each committee had a little incentive of the $12,000, and that brought people around the table to brainstorm what was going to be locally suitable, responsive to local needs. We've lost that collaboration and coordination now. Things have become much more siloed with the NDIS and with governments in New South Wales pulling out of provision of services to children and families, where there's a delay or disability, to a very large extent.

EMILY CASKA: Absolutely. Hear, hear! I remember that. I think the only thing I would add is also the voices of children and families. I think for too long the sector thinks that providers or services are on the other side of the equation to service the families, but we are the ones that they trust, so I think utilising us and our networks and through the Child and Family Supports Alliance, which we're all members of, to make sure that we are hearing the voices of children and families and giving them the information. I would like to see, as to my last recommendation, a single Minister really start to take this on. I know the Cabinet Office, Health, Education and DCJ are coming together. I did hear Anne Campbell and Gill speaking, but I think we would like as a sector and probably as a family member myself, as a sibling of someone with a severe intellectual disability, who is the go-to and who's really championing and guiding this. Across all those portfolios, I think we run the risk that this could just be quite far down the rung, because they obviously have so much else. We really want to see it land somewhere.

SYLVANA MAHMIC: I agree, Emily. With that former ECICP committee, parents were welcome to those groups. There was a parent representative, Kate McNamara, whose daughter, Bridget Kelly, is an acclaimed artist, who happens to have an extra chromosome. She was the ECICP parent rep for many years. There's absolute value in bringing families and professionals together. The work of Plumtree since 2015 has been to really demonstrate that we really need to increase the level of involvement that parents have in co-design and in service co-design within organisations and within program development. Parents can offer so much. Of course, children can as well. Our ages are birth to eight, so that can sometimes be a challenge, but the parents themselves definitely have got so much to contribute to service design. Our evidence has been to show that it's not just an idea. We have shown that it is possible to identify, train, pay and support parent peer workers within an early intervention organisation.

We feel that that model can be scaled up and we feel that that model should be one where, like in the mental health service sector, you wouldn't be able to nowadays go to a mental health service and receive professional services without a person who has lived experience of a mental health concern in that organisation. Why is it different to early childhood intervention? Wherever families land, through whatever door they enter—whether it's health, education or maternal child and family health, as we heard this morning—parents should be employed as a parent peer worker. There should be allies for parents to connect with, wherever they enter through.

Ms ABIGAIL BOYD: Thank you so much, all of you, for coming. Ms Caska, everything you said was everything that I had been thinking but unable to articulate, particularly around needing to be relational and not just transactional, being place-based and community led, and what's become the norm towards this individualised, targeted support under the NDIS versus playgroups and other community-led initiatives that adopt that social model of disability and are far more inclusive and, I would argue, are going to have better results. My understanding is that Playgroup NSW supports community-run, family-run playgroups but there are now some private players coming in offering playgroups. Can you tell us about that? Is that true? Who are the people offering those and how is that impacting on the work that you're doing?

EMILY CASKA: There are. We do both community and supported playgroups. We've been around for 50 years, so we've traversed a few levels. We are the peak body for New South Wales and the biggest community playgroup provider not just in New South Wales but across the country. The supported playgroups have also increased in recent years. We either provide them directly or we subcontract to our valued partners. On top of that, we're also the lead contractor for peer support through MyTime and parent capacity. We do all the things plus national research. Are we the only person in New South Wales that provides or contracts out playgroups? No. Do I want to be or should I be? No. That's a bit selfish.

There are lots that pop up in church groups organically or through other organisations that run playgroups. Do we think as a sector—and this is some work we've been doing—that we need to come together and better articulate the value of playgroups? Yes. In August this year we're launching the New South Wales playgroup collective to be that umbrella, but not necessarily be the owner of it all. I haven't heard of too many private for-profit providers coming into that space. I'd be keen to learn more if there are. But where we need to come together better as a sector is to better articulate the evidence base.

What is this magic model of playgroups? Where do we sit when it comes to particularly marginalised and vulnerable people—in this case, children with a disability? And what is it—we're doing some pilots as well—in our model that is that magic source for children with a disability? Ropes Crossing in Sydney is a great example of where we're parachuting in allied health, because we are hearing from families that either they can't access or the format of that individualised therapy is not working for them and it's not really building anyone's capacity. It's too transactional. And it's not a therapy session within a playgroup by any means. It has a much softer touch and benefits all in that group. So that's where we sit in the sector.

Ms ABIGAIL BOYD: I'm hearing that some of these ECEC players that would normally run childcare/early learning centres are now offering a fee-for-play playgroup. That's why I asked whether you'd been aware of that, because I thought that was quite an interesting development.

EMILY CASKA: Interesting. I haven't heard of the fee component. We know that either schools or ECEC providers will provide playgroups. Some of them we partner with, with some caution. We co-locate with schools as community centres as part of the New South Wales Government's Start Strong funding. That's been a really successful model, we find, particularly sometimes for children with a disability, so they can have that leeway into school and get familiarity. So too the parents—they can meet the teachers and the principals beforehand. But, by and large, is that the full model we're going for? No. That works for some communities; it absolutely doesn't work for others. We work with a range of ECEC and ECI disability providers that will also co-locate playgroups—again, because they are already trusted spaces or it serves as a natural segue for those families. But I'd definitely like to hear if they are charging fees and using it as a commercial model, because that is absolutely a risk. We wouldn't want to see it used as that, like a sales pipeline or a commercialised model—absolutely not. Also, overall, it needs to be underpinned by evidence and best practice.

Ms ABIGAIL BOYD: In terms of the funding and the way that people are made aware of a playgroup in their local area, did it used to be different pre-NDIS to what it is now? How do people know that playgroups exist? I wrote it down and now I can't find it but we talked before about the potential funding for communities to come together—that $12,000. Is there anything like that now? How do people find out? What are we missing out on that we had previously?

EMILY CASKA: Great question. I'll probably answer it in three parts. How are we funded? By every department known to man, Federal and State, so it is very mixed. I think, in part to my earlier point, playgroups aren't going to be the top macro policy priority in the disability department, health or education—yet we are so critical to them all, as well as communities. That funding construct hasn't necessarily changed. It's always been fragmented for the playgroup sector. Pre-NDIS, how did people know about playgroups? Probably most importantly through maternal, child and family health nurses, and probably a stronger connection to health. Is that still there? Absolutely. We also, as Playgroup NSW, have a "find a playgroup by postcode" on our website, and now we've also probably introduced the other layer of a bit warmer support. I don't want families just putting in a postcode and going off to a playgroup. How can we help them understand they might need some peer support? We've got these webinars and real wraparound the family.

In terms of how the NDIS has impacted it, I think a couple of things—I probably speak from my time with Down Syndrome NSW. We know of families in hospital who are being handed the NDIS booklet and being told, "That's where you go now." It's probably to my earlier point but that system, as well intentioned as it is, has become exclusionary so families just go down that path and wait far longer than they should for their assessments and their eligibility. If we're lucky, playgroups will pick up the pieces, as much as we're still doing all of the work that we're doing. This inherent bias, I think, has definitely crept in.

So too, parallel to it—I don't know if it's as a result of the NDIS—we have seen the growth of the supported playgroup funding and programs and agenda. Again, I get funding for those across a range of streams, federally and State. We would like to see that come back together. Again, to my introductory point—and I'll be honest, probably something that we've had to address in our own organisation—if a parent of a child with a disability calls us, we don't go, "Great, you go to PlayConnect+ because you have a child with a disability." We're being really explicit in addressing our own bias but, again, we are seeing this split that, I would argue, community playgroups for parents of children with a disability are seen as the lesser cousin, and that there is a preference for the supported playgroup model. I don't know if that's because of the NDIS, but it's that same bias that's coming in.

KYLIE AEKINS: Can I also can I talk about my experience? As a mother—my children are now 12 and 15. At the time when my son was first diagnosed, I was funnelled into a supported playgroup that had a multidisciplinary team. I didn't know what I didn't know, so I was lost in that system, and I'd fallen through gaps. That playgroup supported me. Then the rollout of the NDIS was coming, and that meant that playgroup was shut down very quickly and I was left in limbo. I was very lucky to have found a parent capacity building program led by parents at Plumtree Children's Services with the Now and Next program, and very quickly I realised that what I'd been looking for was parent capacity building. I—really, my whole family—needed parent capacity building. It's not just the parent; it's all of those people that are caring for the child.

Plumtree Children's Services were offering that through the Now and Next program. It was funded so I could do it for free. My husband and I both did it and it was life changing; it changed our whole lives. I decided that I wanted to be a parent peer worker. In that time, I came to Plumtree, I was trained and I became a family leader. That family leadership gave me skills that I could use in my everyday family life. I could also do that with other families, so I could support other families. I went to other playgroups and I talked about peer leadership and the Now and Next program. Because it was free at the time, it was able to be offered to all families. I then got to be asked to be a part of the Parents as Peer Leaders Project, and I was able then to train more family leaders and more facilitators of the Now and Next program under that 36-month project.

In that time, I got to speak to 1,008 families that didn't have NDIS funding. That really showed me how vulnerable those families are. Many of them could never access NDIS funding because they didn't fit the criteria, but they were left vulnerable and they didn't have supports in place. However, throughout the eight sessions of the program, they got to build on their empowerment, on their goal attainment, on their wellbeing and on their hope. We all need hope, and that was one of the biggest things that was created. That was delivered originally face to face. Then through COVID we got to go online.

Because it became online, that meant we got to go across all of Australia to the most vulnerable groups of people. I was speaking to people from every group in Australia. We had about 22 per cent fathers come on board, which is a very high percentage of fathers. About 38 per cent were CALD families. We also had Indigenous First Nations people. But, overall, I got to speak to some of the most remote communities that were really struggling and didn't have programs like that. Building their capacity is very rewarding for me as a parent, but it also means I get to meet these families that are really needing this foundational support. And it was through playgroups that I first started.

Ms ABIGAIL BOYD: Thank you. That's really valuable.

The Hon. ANTHONY D'ADAM: I want to ask about Now and Next. I see its funding ceased in 2024. It was initially funded under the ILC funding. It's been independently evaluated. You've got a cost-benefit analysis. Why is it not continuing to be funded through the ILC?

SYLVANA MAHMIC: I think Emily raised it. I think it's a matter of commissioning and different systems turning over from State-funded services to nationally funded services through the NDIS. Initially, we were funded through Ageing, Disability and Home Care, then through a grant through New South Wales Premier and Cabinet. That was the initial NDIS ILC funding, and then through ILC funding in and of itself. As Emily said, with the programs and playgroups that she runs, we have done what we could in the last 10 years. Now and Next is 10 years old today. It is an internationally recognised, evidence-based program. We have published peer-reviewed articles and are planning a randomised controlled trial, so the progress is continuing. But we had funding ceased in June because, up until now, the NDIS ILC program funds short-term programs. We hope that will change in the future, and we hope the evidence and the experience we have developed in Australia that is internationally world leading will continue to be funded.

Plumtree is a small to medium not-for-profit organisation. We have fundraised to provide that. We continue to employ Kylie and a couple of other parent peer workers, and we have to raise those funds ourselves. It is not an ideal situation. We feel like we have moved with that program beyond an initial stage. We feel like it is well and truly proven. With a randomised controlled trial, we'll be able to compare parents with and without such capacity-building efforts and what the impact on them is. But, since then, what we have seen is that, even though we offer the program to parents who have got NDIS funding and they could pay for the program with their NDIS funding, they don't. Parents are in an untenable and unethical position. We are asking them to choose between services that they see that their child needs—that is often therapy—and parent capacity building for themselves.

That is not an ethical decision to ask parents in this vulnerable situation to make, even just parents of children who have NDIS. As Kylie said, through our project, which targeted parents who didn't have NDIS funding, now we're sponsoring those families to carry on.

The Hon. ANTHONY D'ADAM: You've highlighted a broader issue around how it's not an appropriate question for parents to decide, but government is going to have to make the same decision, ultimately, about whether we allocate funds to allied health or to capacity building. Why is capacity building more of a priority than funding allied health? We've heard about the difficulties around getting allied health workforce in rural and remote. That's an expensive process and we have to incentivise people to go out and provide those direct services. In the choice the Government has to make, why would we prioritise capacity building over provision of those direct therapeutic services?

SYLVANA MAHMIC: Firstly, as Emily said—and, thank you, it's an excellent question—not every parent and child will need therapy. Secondly, I would liken the experience of family capacity building as not only being best for the child and family—parents are going to be their child's parent for at least 18 years. It is in the long-term interests of families and of their child that we build the capability and understanding of the family. When my son was diagnosed with a disability, therapy was the easiest thing to tackle. Eat, drink, walk, talk—that was way easier than coming to terms with what it means to have a child who has a significant disability and will have that impairment for the rest of their life.

How do you build a great life for that son or daughter? I didn't want families to have to reinvent that wheel alone. Why does every parent have to reinvent and wait that whole 18 years to try to figure it out for themselves? Now and Next programs and other such programs should be auspiced, developed and funded for free so that they're showing families how to get onto a metaphorical bridge. We want, as parents, our children at age 18 to live a life of acceptance, hope and purpose. How do they get there? Three laneways—at the moment we have one laneway, which is the services and professionally-led laneway. That is now, through the NDIS, an autobahn.

You jump into your NDIS Lamborghini and you expect to travel along from birth to 18 years and expect that you're going to be able to build a good life for your child through the use of services. That is not reality. What I have found, what other families have found themselves and what the evidence says is that we need two other laneways. We need a community laneway. We need parents to jump into the community laneway and into the parent peer-led and peer-led organisation laneway. At the moment, those two laneways are dusty, dirty and bumpy. Parents are not going to want to travel in them, because it's hard.

It is natural that parents will jump into the services laneway, but we know that staying in the services laneway is not how you're going to get your child to have an independent and inclusive life. Parents have to travel and navigate through those three laneways. They need to be paved well by government so that families can travel into them, stay in them when it's necessary and move into the other laneways when needed, rather than saying that therapy is the only thing and we have to have a service-led life. That's not the answer, and I can say that from my own parenting experience, from the thousands of parents that I've supported through the Now and Next program and also through my career of 35 years in early intervention.

KYLIE AEKINS: For myself, as a family leader, being able to live this experience with other families and talking to thousands of families in my role over the past seven years, I know that parents want to be in the lead of their own family. They want to be able to advocate effectively and know where to spend their time. Where should this time—I'm time poor. I'm busy. We need to make finances. Where do we spend our time? If we're building our own capacity, we can then ascertain what therapies our child really needs. We can be in that seat of control, supporting our child. Over time, our child will change, they will develop, and they may not need the therapies as they grow older. Those therapists might become redundant. But if we don't give parents capacity building and help them to advocate for that, then their child might always be in a system where they need care.

I see that it's empowering for parents, but it's also financially rewarding, as a whole country, that we can actually support families to build that in those early years. We know some families are going to need to have NDIS support for their whole entire life, but it could reduce the amount of NDIS funding that they need for their child as well. So I see it as financially viable to build capacity for families at the earliest point possible and to not make families have to choose. Because I know, right now, if I had to choose—I got to do it for free; it was funded at the time—I would be thinking twice, "Can we do this, because my son needs this much of his funding?"

Families aren't getting a lot of funding a lot of the time, and these really vulnerable families are thinking that funding is the answer, because they're being told that by a deficit-based model. I would be able to go into a strengths-based model when I was building on my capacity. I learned very quickly that the strengths-based model was going to give me the best outcomes for my child and for my family, and then I got to watch it do that with thousands of other families. And I see them today. We have been able to auspice two organisations that are peer led, and that's been so encouraging. I get invited in to talk as a family leader with those organisations, and they're only growing right now. That peer-to-peer connection and family leadership is growing. There is a demand by the families. They want to be able to be the ones leading and making those decisions, and they don't want to feel helpless anymore. They want to be taught how to fish rather than to ask to be fed.

EMILY CASKA: I think it's a great question. The only other lens I want to add is that every single child needs healthy, confident, thriving adults in their lives. Something we're really conscious of, too, is that not all children—particularly children with a disability, because of the over-representation—are with their parents. We also need to focus on the other adults that are in their lives, particularly foster carers, who are often left off the agenda, and building their capacity. I understand the Government has budget constraints. I don't think, though, it's an either/or—capacity building or therapy. I also don't think it's a nice-to-have—capacity building or a really targeted early intervention. Both are early interventions.

I would also argue that parent capacity building is a preventative and protective measure, far more than therapy would ever be. I think that around family preservation and some of those bigger issues we're also trying to tackle, where we know kids with a disability are, again, over-represented and shouldn't be—to that point, yes, the budget constraint, but I think there's a better way to organise it so it's not either/or in a budget context. Also, to my earlier point about how we structure this system, I'd hate to see therapy in the NDIS stream, with a needs assessment and eligibility to get that. Then parents are just structurally, not even budget wise, having to choose—is it NDIS therapy for my son or a general or targeted foundational support of peer support for myself? They should be getting both, parallel.

I think the third part for me that it raises is who's helping parents, families and the adults in these situations make those decisions of which path they should take. Because at the moment, like I said, it generally has been in the hospital—newborn baby, here's the NDIS booklet for those more individualised therapies. That's why I think getting this peer-led navigation support piece, as well, for families—meeting with other families who have walked that path and can actually tell you what it means and what the results were for them—is also important in who's helping families make those decisions. Particularly for us, child with a disability or not, we all know what it's like to have a baby in those early days. If someone tells you your kid needs 100 hours of therapy a week, you think, "Okay, you're the professional." We need to look at that, as well, in this system.

The Hon. SCOTT BARRETT: The chat around the formal parent capacity building and the peer support has been great. How does that flow in, and what's the importance of that informal community that you might have around parents with that shared lived experience? Just to set up what I'm actually asking, what does that mean for people that might live in more remote or rural areas—to follow on from the earlier metaphor that I loved—that might not have access to some of those laneways?

SYLVANA MAHMIC: What I can say is we used to deliver the Now and Next program, before COVID, mainly face to face. Building family and community, building family leadership and building collective capacity is what we're trying to do here. We're trying to develop a ground-up approach to communities and families supporting one another, because professionals come and go; it's families that are with their child. Families have told us that the most that they learn—it's wonderful hearing from professionals and getting support from professionals, but the information and support that they get from other parents who are in their situation or, in Kylie's example, paid family peer workers is so vital, and creating those connections, whether they're in person or online and remote.

Just before COVID we shifted online to test whether or not we could get out to some of these rural and remote places and give access to such parent capacity-building programs to families for whom it would not be viable to set up a group like that in their local region, because perhaps they were the only person that lived in their area for a couple of hundred kilometres. What we did before we rolled out fully online was we looked at the evidence, compared it to our benchmark and demonstrated that it did not matter whether or not you were doing such programs online or face to face. What really mattered was that you reduced the isolation by meeting other parents. How you met them—whether it was by phone, whether it was by meeting and talking with Kylie, or whether it was by joining an online group and talking and meeting with other parents who were in a similar situation to yourself—did not matter. What's important is that link that parents have to one another. They do that through playgroup; they do that when they're standing at the school gate. But for parents of children with disabilities, the barriers can be higher, and reaching out and meeting with somebody who understands what you're going through is what reduces the isolation.

EMILY CASKA: Scott, for us, I think you've hit the nail on the head. As I said at the start, not every child with a disability or their family needs a formal service or support. That's where I think, again, we'll miss the mark with foundational supports if we do just see it as that. With our community playgroups, which are funded through DSS federally, they don't just happen. We are doing some advocacy at the moment—that grant ends at 30 June next year—because a playgroup can be as simple as three parents getting together in their local community.

I don't need to overlay a whole program and training and education that they need to do, no. What I do need to help them with, because of the way things are—as our backbone support, which is why Playgroup NSW started in the first place—is their insurance. They find it really hard to find venues. We have a very remote, regional, rural group of mums. They want to rotate the playgroup around three of their farms because there's no community centre and there's no church anywhere near them. My insurer says, "No way, Emily." Similarly, I've got some Elders outside Wagga who want to convene a playgroup on country in a dried-out billabong to get that connection to culture and country. Again, my insurance is like, "No way, Emily." And so we need to make sure that—I think that's where community playgroups come in.

At the moment, like I said, I've got one single stream of funding for that through the CaPS program with DSS. But I'd love to talk to the State Government because at the moment we run 650 of them across the State each and every week, but it takes a lot of backbone work to make them happen. Again, I'm relying on, at the moment, largely parents in those communities to come to us and say, "Yes, we've got together. We want to chat." But what we're probably not doing as well as we could, because the investment isn't there, is how do I go out and incubate and reach the really marginalised, really remote ones and support them to get together, have a yarn, share their stories and not overlay a model? Like I said, yes, playgroups are a parenting program, a capacity building program, but I am not going out to say that. I really think community playgroups really come to the fore in that respect, Scott. And, yes, then we can dovetail them into more targeted supports, online supports and others.

SYLVANA MAHMIC: Scott, just to reassure you, in our last 36-month program for families who do not have NDIS, we collect data for all of our programs pre and post. Our participants came from all over Australia in accordance with ABS data. So rest assured that we were able to reach families who lived in rural, remote and very remote areas according to the proportion of the population that lives in those areas.

The CHAIR: I have one final question around funding. Plumtree, you indicated that you're now based on a sort of philanthropic model. We've now heard that the foundational supports or the Federal-State agreements have been pushed out and delayed. What is the current landscape for organisations that are no longer able to be funded through other grants that were available? And what is a potential short-term solution to address that gap and avoid organisations going under?

SYLVANA MAHMIC: I can speak of the program that we're running. We're also, as an organisation, financially very much struggling under the NDIS, but our organisation has invested 10 years of government funds so far into the development of this innovative, novel and internationally recognised parent capacity building program. Our board are committed and our organisation, our parent peer workers, are committed to providing a bridge to when reality and sense hits and hopefully foundational supports is worked out. We're trying on a shoestring to do what we can to keep the program alive and out there in the public domain so that it does not get forgotten. There's too much money and research that's gone behind it to let programs such as this fall into disarray.

However, it would be a wonderful thing if the New South Wales Government could continue to bridge a gap through programs such as Start Strong Pathways. Start Strong Pathways has been extended on numerous occasions. It funds, as Emily has said, a variety of supported playgroups, toy libraries, all sorts of inclusion supports. It's a tiny amount for the organisations. They're receiving perhaps $100,000 or $200,000. It's been extended for 18 months till December 2025. It's six months out from that extension end now. Parent capacity building initiative webinars, parent calendar events, programs, playgroups et cetera—all of that is in limbo right now because foundational supports have not been put into place. There needs to be a bridge somehow built between what is at least happening in this scarcity mode right now to help us all make that bridge over to foundational supports when it's finally funded.

EMILY CASKA: I think some funding is needed. If I just reflect on us, we've got TEI that we'll know about—well, it ends in December. We'd like to know fairly soon. That's targeted early intervention through DCJ. I've got Start Strong Pathways through the New South Wales Department of Education. We've got Connected Beginnings through the Federal Department of Education ending end of December this year. Not knowing, it's very hard to maintain the very workforce that we need. And then it does feel like we're on a bit of a six-month cycle. Then 30 June next year, I've got MyTime through DSS. That funding, at this stage, ends. And then our CaPS funding through DSS also ends.

It does feel like, as an organisation, we're on this six-monthly "What are we recommissioning for today? What are we doing?" I think the other issue is the timeliness of it. I do understand: It is this nexus. We are trying to bring together very fragmented programs, and I welcome it. We need to streamline this, and someone needs to draw a line in the sand at some point. I get it. But for us as providers, juggling that and being thrown six-month—or 12 months, if you're lucky—extensions? Yes, welcomed, but the timing of it could be a bit better, though, and not finding out a week or two prior. In some cases, for some of probably the more federal programs, we've found out three months into the year in which it's meant to be occurring, and we've had to carry that. At the scale for Playgroup NSW that we're carrying, that is significant.

Also, I think to my earlier point, stop just rolling over things. As Sylvana said, we're on quite a few rollovers now, but there has been no quantification of demand and unmet need in that. I think that's a concern that we are taking up what it is now, and Federal and State governments will bundle it into our buckets, and then that'll be enough. All of us have so much unmet need. I do think there needs to be some consideration, like with every big reform, for a foundational supports transition fund. Some of that funding needs to work now and give us that sustainability funding now, because we had it with the NDIS, and we've had it with the social sector coming out of COVID. I think that that's needed. I think, also, it comes into some of the definitions that would be nice from the Federal and State lens, even just at a high level, to understand what programs they are thinking about putting in into this mix, and maybe just a bit more of an implementation and timing road map so that we can plan ahead, because it is really difficult at the moment for us all.

The CHAIR: I'm mindful that we have run over time a little bit. We really appreciate your appearing and also all the work that you do to support families and young people as well. Thank you particularly to Ellen for coming here today. It is very important that we hear from people with lived experience, so it's great to hear from you today as well. Thank you very much.

(The witnesses withdrew.)

Mr BEN FIORAMONTE, General Manager of Children, Families and Disability Support, Settlement Services International, affirmed and examined

The CHAIR: I welcome our next witness. Thank you very much for coming today. Do you have an opening statement that you'd like to make?

BEN FIORAMONTE: Thank you for the opportunity to speak today. I'm Ben Fioramonte, general manager at SSI. If the select committee may indulge me, my speech—or opening statement, rather—will take about five minutes, and I'm happy to take any questions afterwards. Founded in 2000 here in New South Wales, SSI began as a response to the needs of newly arrived refugees. Over the years, we have expanded our services significantly, and we now support a range of communities across New South Wales, Victoria and Queensland, though we still have a strong focus on migrants and refugees. SSI delivers services each year to more than 60,000 people across almost 60 programs. We are known as an organisation that can engage communities considered by many to be "hard to reach".

As GM at SSI, I oversee local area coordination under the NDIS in Sydney and south-west Sydney, as well as out-of-home care services through our Multicultural Child and Family Program across New South Wales, Queensland and Victoria. SSI supports over 22,000 NDIS participants, including more than 8,000 children aged nine to 15 making up over one-third. Despite initial predictions of 20 per cent uptake of CALD participants under the NDIS, the current figure is under 9 per cent after nearly 10 years since rollout in 2016 following the trial.

In New South Wales out of 51,389 zero- to eight-year-olds on the scheme, only 12.4 per cent identify as being from CALD backgrounds, underscoring significant access challenges for CALD children and young people with disability. In 2021 over one-third of children aged zero to four in New South Wales were from CALD backgrounds—the highest cultural diversity in Australia. Research shows that these children are more likely to face developmental vulnerabilities at school entry, with underutilisation of early intervention services being a key factor. CALD children in New South Wales are half as likely to access these services compared to non-CALD children, which significantly impacts their long-term outcomes. Barriers such as a lack of trust in government services, language barriers, limited services and insufficient community-based support prevent families from accessing essential resources. In short, without adequate and appropriate services and a foundational support and navigator model that addresses these barriers, CALD communities will continue to sit in the dark.

Over the past decade, programs like Ability Links, Community Connectors and ILC led by specialist CALD organisations have effectively engaged diverse communities in New South Wales. They have fostered trust and access to essential supports. SSI itself has broken down barriers by delivering place-based services using a recruitment model that reflects the diversity of the communities served. However, as programs changed and disappeared over time, so has valuable data, including lessons learnt and evaluations that could be used to inform sector changes, networks and vital community connections, and a sense of stability and support for diverse communities. Short-term funding arrangements and instability of programs coming and going have hindered the sustainability of program outcomes.

A lack of statewide integration and application of lessons learnt through these services has also been problematic. However, it's also an opportunity, and one that I'd like to highlight. For foundational supports to successfully cater to the needs of children and young people with disability, the following ingredients are necessary. Firstly, there must be a statewide approach to the design, implementation, monitoring and evaluation of this program, ensuring appropriate services reach the people that need it most; and a navigation model that aligns with true local area coordination—what LAC today under the NDIS was supposed to look like, which is an evidence-based model used around the world, proven to be cost effective and outcomes driven.

To that end, SSI asked the inquiry to recommend that the New South Wales Government plays a key role in ensuring the navigators model under the NDIS caters to diverse communities by influencing Federal Government to ensure the design and implementation of navigators is co-designed by people with disability from CALD backgrounds and by CALD-specific organisations, supporting the design of navigators to be based on true local area coordination; and establishing a statewide committee to assist in the design, development, implementation and monitoring of foundational supports within New South Wales. This committee could be made up of people with lived experience, young people with disability from CALD backgrounds and CALD-specific organisations and agencies.

In closing, there are significant access issues for children and young people with disability from CALD backgrounds. SSI is committed to working with community, all levels of government and the broader sector, including peak bodies and key influencers, to deliver lasting, meaningful change. Thank you for your time, and I look forward to any questions you may have.

The CHAIR: Thank you very much. In your opening statement—I want to clarify for Hansard—when you talked about the LAC model, you're referring to the local area coordinator model?

BEN FIORAMONTE: Yes, that's right.

The CHAIR: They like, rather than having acronyms, the full details of anything. Could you outline that model and why it's been successful, particularly internationally?

BEN FIORAMONTE: Yes, absolutely. I won't claim to be an expert on the true local area coordination. Before I speak to that I will provide a little bit more clarification on the differences between local area coordination now within the NDIS and how it was intended to look during the rollout. The current model in local area coordination is very—I would say the way we would describe it is plan-based. It's very much around supporting people to gather the information for a plan. For some years we were also doing plan build. It's about implementing those plans and connecting people to community. A smaller part of what we do that is connected—and when I say a smaller part, I'm referring to the volume of work that we do—is dedicated to individual capacity building, community capacity building and really connecting people to mainstream community supports. That certainly does happen but not to the extent that it was intended to at the beginning of the rollout. True local area coordination was less about building plans and so on; it was more about building the capacity of individuals and communities.

The model that I refer to—and I'm more than happy to provide further information on this following the meeting today—is a model that really is place-based. It's about being connected and embedded within community. Typically an LAC would have a lower caseload—maybe up to 65 people that they're working with in community—and they're able to spend the time that's required to work with those individuals to build their understanding of their rights and connect them to, again, mainstream community supports, but also support them in developing innovative ideas when that may be required, for example, in building circles of support and connecting people to greater supports that they wouldn't have otherwise had. I suppose when we look at the navigator model, which is recommended as part of the NDIS recommendations—and, to be clear, we obviously aren't 100 per cent sure what navigators will look like once it does roll out—there are certainly elements of true local area coordination built into it, but there's opportunity for it to be more closely aligned to that original intent of true local area coordination, and for those two pieces to come together.

Finally, the point I would raise on this mark—and this is also why we would push for the principles and the design principles of true local area coordination to form a part of this—is those principles and that way of working greatly supports breaking down the barriers for CALD participants, CALD people with disabilities within community. It breaks down those barriers, having someone embedded in those communities to work with individuals to support them in accessing material. Right now, we've got an issue where the NDIS is quite a complex scheme and model to navigate for people in community, but when you're working with people from CALD backgrounds where English is perhaps not their first language, it becomes all the more complicated for people to get the services and supports that they need.

The CHAIR: I'm interested to know a little bit more about the gaps in the services, particularly for the CALD community. Government has indicated they're starting to do a bit of that analysis now. In your experience—and also talking to families and organisations—what do you see as some of the gaps that currently exist? What needs to be delivered?

BEN FIORAMONTE: Firstly, just to build a little bit of context, there's been a great deal of programs to date that have had a lot of success in working with people with disability, from CALD backgrounds—children and young people, of course—through ILC programs, through community connectors, through local area coordination, through community hubs that have really achieved some amazing outcomes. One of the gaps that we've got is that we haven't found a way, at least to my knowledge, to be able to pull together all the learnings that we've made, all the successes and the outcomes we've been able to achieve and the formulas for achieving that from all of these different programs. Some of them have been absolutely amazing to be able to help us to inform what foundational supports, for example, should look like. That's the first large gap that I would point out.

The second thing I'd say is that in terms of how organisations, community—the sector even—works with CALD communities and people with disability, it can be quite segmented in some ways. What I mean by that is there's a lot of providers, agencies, organisations doing some great work but in terms of what they're learning and in terms of what is needed in various geographical locations, there's not necessarily a central body that's able to connect the dots with people and organisations, for example, to be able to say, "Hey, if you're going to work in this particular location of Sydney, you need to know that there are some significant gaps here for CALD communities," or, "There's high cases of fraud or people taking advantage of people in these specific communities. You might need to be aware of that," or, "We've got low therapist support for Arabic-speaking communities in Liverpool." Whatever it may be, it would really help. This is one of the reasons why one of the recommendations we're making is, could we have some kind of a body that could act as a bit of a conduit and a connection for all organisations working with diverse communities.

One thing I also want to point out on this note is that I think as a CALD specialist organisation, one of the things that we see, and often feel, is that working with diverse communities is sometimes perceived as an afterthought when we're designing and implementing programs. That's really problematic. As an example of what I'm saying, if you look at the NDIS rollout, we started rolling out in 2016 following the trial, but two years later was when we saw the first CALD strategy. If we are going to work toward foundational supports and a new model across New South Wales—which has obviously significant amounts of diversity right across the board—I'd like to see that we're looking at this from a CALD perspective from the get-go, and that it's not an add-on component that we need to think about once we've done it. It is looked at now. In terms of a model, approach and principles, if it is benefiting people from CALD backgrounds with disabilities, and children and young people, therefore, with disabilities from CALD backgrounds, then it's helping all people, because it means we're embedded in community and we're able to give that information support to everyone.

The CHAIR: A lot of the submissions received, and the witnesses, talked more about the national support for the early years—young people, school-leaving and up to the age of 24. What role do you see the States playing in providing that support for the high school year—young people who are not on the NDIS? How does that fit into the piece?

BEN FIORAMONTE: I think that's a great question. I don't have an answer for that one, but I would say that's where there's definitely opportunity for that to form part of a consultation to work out what are the best supports for young people who are making that transition, because it is quite critical. Even if we're looking at the out-of-home care sector—people making that transition from the out-of-home care space—people with disability or certain vulnerabilities can be going through significant change and need significant amounts of support. I don't have an answer for that one, but I do think that is a critical thing to look at and to get the right people in the room to discuss it and come up with solutions.

Ms ABIGAIL BOYD: Thank you very much for coming along and giving your perspective. My question is, what did we lose when we went to NDIS, and what does this move towards foundational supports in the State again create an opportunity for, from your perspective?

BEN FIORAMONTE: If I could ask, specifically, when you talk about what did we lose, are you more referring to services or are you talking about knowledge?

Ms ABIGAIL BOYD: It's everything. We've heard from previous witnesses that, as we've moved from what we had before to NDIS, we ended up with more individualised services, a bit of a division between those on NDIS and those who aren't, but also a fragmentation of services and a lack of knowledge of how you navigate each of the services and where to go, particularly for people who are coming from another country or have just arrived. From your perspective, do you think that we've lost some of that landing and ability to network and refer people along with NDIS, and how could we change that going forward?

BEN FIORAMONTE: That's a great question. I would actually say that we've lost certain things, but we've also gained a lot too. I'll start with the former. The Ability Links program in New South Wales was actually rolled out to support that transition, and it was a great initiative by New South Wales Government to support the transition of the sector of community into NDIS. For those who aren't sure what Ability Links is, it actually does tick a lot of the boxes in terms of being very closely aligned to what true local area coordination was about. You had linkers, and we, SSI, played a key role in that, in supporting CALD communities. Some 75 per cent of our participants at that stage—for the six years that we ran it—worked with CALD participants.

The staff members that we worked with and we employed were from community. They were most often from diverse backgrounds, working in community across the State, connecting people and working with people in a very innovative way. We would do a lot of community consultations across the board to get a sense of what community needs. If there was a lack of awareness of what the NDIS was, for example, and a lack of translated materials, this might become then a program that we work on within the State or certain areas within the State to support people to get the information they need. If we found, through community consultation, there was a lack of connection across various community groups which was required, whether it be to develop a peer network of some sort to then lead toward capacity building outcomes, then that's something we would do. We'd start to work on a peer network and so on. It was quite innovative. It was very flexible.

Again, this is something I'm more than happy to provide more information on later, but we haven't had anything like that since, and the outcomes that were achieved through the Ability Links program were amazing. In fact, it was a program that didn't just work across the disability sector; it worked across all sectors. It was focused on people with disability and, for us, particularly children and young people from CALD backgrounds, but it worked across housing and education. There might have been people who, even to this day, wouldn't have been eligible for NDIS, but they needed support in gaining access to education, so we would find ways of linking them into appropriate services and supports to get them there, or link them into housing and so on. To a large extent—and this goes back to your question a little bit earlier, shadow Minister—around the world where this model has been used, it hasn't necessarily just been used in the disability sector; it has been used across multiple sectors, so you've got people joining those dots.

That is one of the things that I do feel that we've certainly lost in New South Wales—this incredible program with incredible outcomes. I think there is opportunity for us to find ways to weave that back into the future through sector changes. In terms of what we've gained, though—and this is one of the interesting things. Local area coordination today, whilst I would say that it is more plan based and focused, over the last ten years—to give a little bit of context, partners in the community are organisations across Australia who run local area coordination or early childhood services, but partners in the community—and SSI is one of them—have done some amazing community development and community capacity based projects and programs in communities across Australia. They are doing very interesting pieces of work that have been evaluated and do have recorded outcomes that, to a large degree, the sector often isn't aware of.

I think there is a lack of awareness of what has been done through these various programs. We've talked about peer networks, and this is one of the things that the partners program has been able to implement over time. There have been projects that work across the intersectionality that we see within the sector, where you have young people from CALD backgrounds with disability who also identify as being from an LGBTQIA+ community, and they're struggling to make connections or there's a lot of fear in the community around that. LAC is a program that has developed projects and events to support people who are facing these kinds of unique barriers and challenges. Again, I'll be brief. I'll be more than happy to provide more information on the type of work that it does, but a lot of these community development initiatives and activities are widely unknown, which is unfortunate.

I'd say that we have gained a hell of a lot through that process. We could also use those learnings that we've achieved across the partners program in Australia to help us to inform the future. One final thing I would say is that that's something we probably didn't take as much an advantage of in terms of the information, linkages and capacity building program that has had amazing projects across the board for many years. I'm not sure that there's ever been an evaluation process that took place to take the lessons learnt from all those different projects to help to inform us as to where are the service gaps and the need, and what type of projects have organisations run that have been highly successful, cost effective and can be replicated? I think that that is something that is a missed opportunity that we could take advantage of.

Ms ABIGAIL BOYD: That's an excellent answer. Thank you.

The Hon. TAYLOR MARTIN: Thank you for being here today. In your view, and with the benefit of your experience, how could we best improve the partnerships and relationships between government departments and CALD communities?

BEN FIORAMONTE: That's a great question. These are some examples. My mind tends to go a little bit bigger picture and a little bit further into the future here, but what I would firstly say is what we know works is when there is a relationship—and a strong relationship—between community and all layers of government, but also depending on what social issue that we may be looking at. For example, if we're looking at employment, then we'd be looking at local businesses and community leaders. But when there is that strong relationship between all these different layers, that's when we're most likely to start to see some progress—when there's buy-in and ownership across these different layers.

It's not government's responsibility to fix everything, and it can't be. There's got to be a joint relationship and joint responsibility taken to work through these things. Now, when government are working with local organisations and community-based and place-based organisations and are actually actively listening to what's going on on the ground, what's needed, what challenges are being faced and what works, that's one of the keys in this. But also working with community leaders—so it's not just community organisations; it's community leaders, and they could be religious leaders, people of high influence in specific community groups. It's also critical that they are connected.

One of the pieces of feedback that we've had in a number of different forms over many years through various community consultations that we've done across south-west Sydney and Sydney, people often say—and this is one of the disadvantages of having programs come and go, is that you lose those connections as well, quite often. What people will say is, "If you're not here and we can't see you, you don't exist. You can't help us." When there is that disconnect, that's when you've kind of lost any sense of ability to bridge that gap. One of the challenges that we're aware of in certain geographical locations—and if we were to look at Leppington in New South Wales, for example, where it's a highly diverse population and it's a great, growing area, there's low social infrastructure in Leppington at the moment. What that means is that it's even more difficult for services, organisations and certainly for government to be able to break down some of those barriers.

What is happening at the moment is that CALD communities are relying on word of mouth and what they're hearing. They're using WhatsApp platforms to communicate who to go to for this, that and the other. It can be highly effective. But if there's no connection between community organisations or government or any way of being able to use that channel as a way of sharing positive information and useful information about what to access, then it's also an opportunity for misinformation too. The final thing I'd say in response to that is, more broadly, I think that the idea of having some form of a statewide advisory committee that can work on developing a program like Foundational Supports is a great opportunity to connect all those different layers—to connect government to the grassroots. It's also an opportunity to start to build in more of a systemic and methodical approach to working with CALD communities and CALD people, and reaching those children and young people that need the supports they need.

The CHAIR: Thank you very much for coming today, and for the work your organisation does supporting families and the whole community. That concludes the morning session.

(The witness withdrew.)

(Luncheon adjournment)

Mr MATTHEW JOHNSON, President, NSW Special Education Principals' and Leaders' Association, affirmed and examined

Ms GEMMA QUINN, Chief Executive Officer, Federation of Parents and Citizens Associations NSW, affirmed and examined

Mr PATRICK DOUMANI, Member Support and Research Officer, Federation of Parents and Citizens Associations NSW, affirmed and examined

ANNABEL STRACHAN, President, Isolated Children's Parents' Association of NSW Inc., before the Committee via videoconference, sworn and examined

LIBBY McPHEE, Secretary, Isolated Children's Parents' Association of NSW Inc., before the Committee via videoconference, affirmed and examined

The CHAIR: I thank our next witnesses for coming this afternoon. For those in the room at the moment, Ms Strachan's video isn't showing. It's a black screen, but we can certainly hear you. Would anyone like to make an opening statement?

GEMMA QUINN: Thank you for the opportunity to present today. The Federation of Parents and Citizens Associations of New South Wales represents the voices of parents and carers in our public schools. We speak today not just as an organisation, but on behalf of thousands of families who are doing everything they can to ensure that their children with disability and developmental needs have a fair start in life. Our submission highlights what families across the State are telling us: They are waiting too long, travelling too far and paying too much for the essential supports their children need—if those supports exist at all. From Dubbo to the South Coast, from Western Sydney to the Northern Rivers, parents are navigating fragmented systems, with long diagnostic delays and a postcode lottery that determines access to care.

We support the vision of the NDIS review and the disability royal commission, particularly their calls for foundational supports outside of the NDIS, integrated service delivery and rights-based approaches to inclusive education. But we need to make those reforms real, especially in our schools and our regional communities. We urge the Committee to make bold recommendations and take practical action: joint investment in early supports; embedded health professionals in schools; reform of diagnostic pathways; and culturally safe and a well-trained workforce in every corner of New South Wales. Ultimately, what parents want is simple: to see their children happy, learning and included, without having to fight for the basics. With the right support, in the right place, at the right time, we can give every child in New South Wales that chance. Thank you.

The CHAIR: Ms Strachan or Ms McPhee, would you like to make an opening statement?

ANNABEL STRACHAN: We're very much the same as the P&C—very much along those same lines, so very happy to support what the P&C has just said.

The CHAIR: I'm happy for this question to go to all witnesses. It's around the transition for young people particularly from school to work, additional study, accessing other services. A lot of the submissions we've received have been very much focused on those early years, which I'm happy to touch on a little bit later, but I'm keen to hear your views about the gaps that exist at the moment to support that transition and what needs to be improved.

MATTHEW JOHNSON: I'd like to comment on that, if I can, Chair. One of the biggest challenges within our special schools and settings is for students with significant disability and complex needs. The transitions that people usually think of, going from year 12 to education, further study or work, that's something within our special schools and settings that starts in year 9, year 10, year 11 and year 12. It's a really long process to be able to work with parents on what's going to be the best outcome. But one of the challenges is that, whilst in the schools, the students are accessing a heap of support, the parents get a lot of support from us in our schools—our school counsellors, inter-agency interactions, therapists and all the rest—but it really comes to just a complete stop at the end of year 12.

It's another trauma that our parents face, because when every other mainstream year 12 parent is celebrating—hopefully—a really good ATAR or something like that, and the next phase of life, for our students with complex needs, where they go next is a lottery. Trying to find that best fit where the parent can see their child going—"Yes, that's where he belongs," or she belongs, "This is going to work for them"—is a real challenge. There are no real coordinated supports apart from our schools, and our deputy principals and executive and teachers picking up the parent and driving them around to all the various institutions and supports that they might find for their child, to be able to see which one is going to work. Again, with a lot of the submissions, it's the lack of inter-agency coordination around that. But it really is just a steep cliff that our kids face at the end of year 12. It's a huge transition, but to where?

The CHAIR: Would any of the other witnesses like to comment?

GEMMA QUINN: I would like to echo Mr Johnson's sentiment, yes, because that's certainly what we hear from parents. And I think, to take the parent lens, this is something that parents think about from early childhood, from even before the point of diagnosis. This isn't something that we get to a stage in a child's life and think, "Okay, we need to start preparing for what happens after school." But parents know that that burden falls on them because of the fragmented nature of the supports available to them, so they begin this process of trying to set up structures as a family to support their child or young person once they leave school. That is an incredibly disproportionate experience in the regions as opposed to in metro Sydney. Access to support then becomes critical. And to take the metaphor of it being a steep cliff to face at the end of school, we hear from parents that they feel like their children are very much at risk of falling off that cliff when they leave the school system if they don't take on the personal burden of making sure that child is supported and safe outside of the school system.

LIBBY McPHEE: Thanks very much for the opportunity. I just wanted to raise a couple of things here. ICPA NSW, or Isolated Children's Parents' Association, are all about equity to access to education, and I think it's a good point here that I can make that—and you talked about transition to work, transition to secondary school or beyond—we are, at the moment, calling for a tertiary drive subsidy, and that's literally to get children to university. Once they've finished year 12, whether it's been by distance education or whether they've been at boarding school, or wherever they've been, they are now facing the problems out here of getting to a university, which can be at Armidale or Sydney or wherever.

We don't have the public transport that they have in the city. These students can have an Opal card, but it's no good to them; they can't access public transport. They've got to make a huge journey, potentially overnight, to get to somewhere like Armidale, carting all their luggage: their computer, their clothes, their linen—whatever it has to be. They have to negotiate and their parents have to take them to Dubbo, potentially, to get on some sort of public transport. Then they probably have to overnight in Sydney to then make the journey to Armidale the next day. Meanwhile, they could have made a 600-kilometre trip if they'd had a car or some assistance to get across the northern part of the State. But that doesn't happen.

Unfortunately, our calls fall on deaf ears at the moment. We really hope the Government will look at that scenario and try to help these students. At the moment, if their parents can't help them, they're not able to do it. They just have to forget about the study and perhaps just go to work and not get a diploma behind them, and that's not helping these students. It's a real exclusion to what they should be allowed to have in their access to equitable education. We're hoping today that something like that might come through this foundation and this disability supports inquiry.

Also, distance education students—when they move on to secondary school, they are not able to get much support. We're calling for TP1 and TP2 schools to be made hubs so that these students can go and access the schools. They are already signed up to public education through distance education, but they have to stay at home because that's how it's been and try and do their education from the lounge room with limited internet—whatever it might be. We're asking that these children should be allowed to go to a public school within reach of them. We're talking about very remote schools here, schools where they don't have another opportunity, and distance education has been their only opportunity to study or do their schooling so far.

Obviously, when they get to secondary school, it's far more difficult for them. We're asking that they get those facilities, be it a library, some internet or an actual schoolroom to sit in. They're being taught by distance ed, so they really just need a supervisor in the room. That could even be a camera these days. There are lots of very good cameras that could keep an eye on them, and someone could be monitoring that from the office or wherever. Generally, their siblings are going to the same school. In some cases, we know these children have repeated year 6 because that's the end of their schooling. That's where it ends for them. To us that's not acceptable, and it's very disadvantaging for them. We really hope that things like this inquiry will bring that forward as well.

The other one is, of course, the preschoolers. We have them out here. They're unable to access the school buses that are travelling. We're asking for a preschool drive subsidy to get these children to a preschool, just to get some sort of free schooling before they actually go to school. Parents are having to drive anything up to 200 kilometres one way to take these kids, because they cannot access a school bus because of safety reasons. This is what we're being told. Meanwhile, their siblings are on the bus. The parents are prepared to do it, but they're doing it at their own cost. That cost is extraordinary when you start to think about it—each week to take that child into school and stay there, pick it up and take it home, meanwhile the others are on the bus. We're hoping that this inquiry will also look into a preschool drive subsidy.

The CHAIR: Just following on from that and it was touched on before about the inter-agency and government collaboration. From an early childhood perspective, we've heard about having things like hubs and allied health professionals in schools. When you're looking at young people—so not the early childhood years—how could that model work? What are some of the suggestions or solutions to be able to ensure that these young people are getting access to those services? Would a hub model work, or does it need to be more flexible or fluid?

MATTHEW JOHNSON: I'd like to comment on that, please. The hub model is, for me, the way to go, especially when there are specialist settings. For example, one of my previous schools had 150 students. Those 150 students only had two paediatricians between them all, but all of the students had to go individually to those paediatric appointments, whereas pretty much the entire cohort for that paediatrician was sitting right in my school. For students with complex needs, just the sheer stress for a parent trying to take a child into a doctor's surgery or waiting room, and possibly be 45 minutes late—for a child with significant autism it's a really, really stressful thing to do, and something that parents dread.

There are models across Australia. Queensland, for example, in their special schools have occupational therapy, physiotherapy, speech who are Department of Education employees within the school. They actually get to know that child through their full 12 years, K to 12 experience in that school. It's a consistency. Then the parents are accessing those additional supports outside of the school with the NDIS. Also, school nurses would be another fantastic thing because a lot of our school learning support officers, or teachers' aides in New South Wales, are the ones doing—sometimes suctioning—medical procedures that really are the domain of health, not education. Having that kind of model within the special schools, I think, would be incredibly beneficial to parents and especially to the students.

GEMMA QUINN: We do think that the hub model also is an effective model. We really underscore in our submission that need for consistency throughout a child's life, and to be looking at the access that a person has to particular supports and particular individuals throughout their journey of accessing support, even beyond school. That consistency needs a dedicated strategy with regard to workforce retention to make sure that when a model is set up, such as a hub model, that that gives a young person consistent access to the same continuity of care throughout their journey.

LIBBY McPHEE: I wanted to also say we totally agree with the consistency model, but we are also about the fact that we think that the students should be getting access to allied health, things like speech pathology, very early in their time. It's quite often only diagnosed when they start some sort of school. At the moment, we're finding in rural areas that they have to get onto long waiting lists. If people are coming to visit, of course, there's a real call for it so they're finding it really difficult. Parents, in some cases, are prepared to travel to a more regional centre—say, Dubbo—and visit somebody with their child for speech pathology because they realise that it's really important that they get on to it and try and access help for that student so that their learning is not impacted or affected. We're really about the fact that they should be given some support to access it in a regional centre, if that's what they're prepared to do, and just try and skip the queue and get some assistance for that child before too long, because we realise those early years are really important.

ANNABEL STRACHAN: Our waiting lists out here are up to 18 months and longer. Also, the consistency of the same person we have are not consistent. They might only be here for two months, so when the child goes again next time, it's a start again, so for those children it's very traumatic. Also, in the Department of Education, the psychologists, school counsellors can't diagnose conditions such as ADHD and autism and mental health conditions. That is the only people that we really get out in these really remote areas. It would be great if we could have some sort of allied health supporting these people.

Ms ABIGAIL BOYD: Thank you to all of you for coming along to give evidence. Something that a previous witness was talking about has been playing on my mind. They made the very good point that part of a foundational support framework should really be trying to upskill and capacity build for families. But you could also presumably argue that that should be across society, whether it's enabling teachers to deal with a range of disabilities within their classrooms or whether it's health professionals or whoever. With the introduction of the NDIS and the funding being so segregated between those who are on NDIS and the 90 per cent or something of people with disability who are not, it made me think about whether we have, in the process, lost some of that responsibility within broader society—whether it be in education, health or wherever—for continuing to upskill and capability build so that we are able to deal with people, particularly children, of all abilities and levels. Do you think there's something in that? Do you think that is a product of the NDIS, or is it something else? I'll start with you, Ms Quinn.

GEMMA QUINN: I absolutely think that that is both accurate and also that this siloed model was always going to result in that fragmentation. I think that the burden is really falling on parents from a very early age to go, "That upskilling that needs to occur for me and my family is now my responsibility." We've got parents who are having to become an expert in all sorts of areas of support for their child. That is navigating completely new territory for them. We have parents reporting that the sheer burden of trying to keep up with the number of things that they need to learn and understand to adequately support their young person is resulting in them having to reduce their capacity to work or leave work entirely. So there's also a financial cost to society as a whole, with parents having to pick up that burden because we've failed to have access to those supports in another area. A greater focus on how we address that would have economic benefits for society as a whole, because of that disconnection between parents and the workforce that results from having a child with complex needs.

Ms ABIGAIL BOYD: Does anyone else want to comment on that?

MATTHEW JOHNSON: Yes. It certainly is siloed. I've worked across a range of special schools—ones that were called behaviour schools or learning centres for students with emotional and behavioural difficulties, and then ones with intellectual disability. Each of these students were interacting with other agencies, sometimes coming in contact with police and with juvenile justice. All of those agencies were doing their role with that student, and then we were as well, but none of us knew what each other was doing. That's the real challenge. We need some kind of navigator—something that is multi-agency—to be able to look at especially high-risk students, but more broadly in your context of looking at how we get that support spread. That's what we need to have.

When you look at a lot of the students, whether it's significant disability or even trauma, most of those students or that family that's going through those challenges, most people in the street would identify that family and know that they're having trouble. We're in a society now that's very much blinkered, and you get on with your own world. We've lost a lot of that sense of community. That makes it a real challenge because, as Gemma has hinted at, as well as our friends from the Isolated Children's Parents' Association, it's not until school when all of a sudden—surprise, surprise—this child's got challenges.

The parents don't really have to confront or see that, or they might not think their child has an issue, until all of a sudden the rules-based formality of school becomes that challenge. That's five years gone—missed—where intervention and early intervention could have made the world of difference, especially for students with disability and complex needs. If we get that right then, that's a cost-effective, whole-of-society benefit because you're not starting from scratch again. That's a real challenge. What we need is some kind of coordination there.

One of the biggest problems is, too, families and schools trying to interact, simply having the time to do proper meetings and with a multidisciplinary team, because we know that that is the most effective when we have everyone from that. But that's usually schools taking their own time to ring and get those people connected, and it's another job for us and for principals in our special schools and in our mainstream schools. We constantly feel that we're doing a lot of other agencies' work and we need that help. We need that kind of hub model where everyone has got an MOU of how we work together, not just individual schools of great practice going on their own to try and solve the problem.

LIBBY McPHEE: From Isolated Children's Parents' Association of NSW, I just wanted to say we totally support what Ms Quinn and Mr Johnson have said there. In our submission we have outlined that we would like to see relevant Ministers from Health and Education working together to enable access for parents and carers of remote students to access vital allied health support through funding and/or subsidies that are not being covered by the NDIS. I think that's really important at the moment, because we know the NDIS does do it for some but, as you pointed out, there's a huge cohort out there that aren't under NDIS and therefore don't get any assistance. Those parents are left alone with those students to try and access help and navigate the challenges that they've got.

The Hon. ANTHONY D'ADAM: I wanted to ask about the existing funding streams in public education for disability. So we've got IFS and we've got low-level adjustment for disability. How do you think they should be affected by a shift to foundational supports?

MATTHEW JOHNSON: It's a really challenging area when it comes to looking at the funding for our special schools and support classes. The real funding that comes from the Government is the resource itself of staffing, so it will be the teacher and that school learning support officer on that class. Integration funding support, or IFS, as you mentioned, is only available within mainstream schools, not available within the special school. That ranges from small amounts to larger amounts, depending on the child's need. Schools will then use that targeted money within the school to be able to support the student, usually with teacher aide time, SLSO time, to be able to support their needs, or sometimes pooling it towards a resource so that there could be an additional teacher to be able to help and do withdrawal work.

As far as that impacting the foundational supports, it's a difficult thing. It's like the Nationally Consistent Collection of Data. When we're looking at that, you can only be disabled once, so you can't have multiple disabilities mentioned—it's a primary disability. That's one of the real complexities. Queensland, for example, has an extensive plus category on top of the NCCD to be able to cater for that. That's an additional funding stream that schools can apply for to be able to support that child with multiple co-morbid disability. Really, it is a challenge because with the NDIS, if that has been identified early enough, that child's got that package which can see them through. But for other students, they might not access specialist support within a support class or in a special school until later in their life. Sometimes it might be right up until the start of high school. That's the real challenge, that there's no particular funding that follows the child. It's really around triaging what that child's needs are through local placement panels and access requests, and seeing how many vacancies you've got and whether they can get in.

A lot of the time, too, parents are unaware of what is available. Sometimes the first time a parent knows that their child might have a disability is when an access or a placement panel has sent them a letter of offer for a support class. That might come as a surprise for a lot of parents as well, because they thought, "Oh, our child's having a few difficulties," but they didn't think of it as a disability. Then, once you go in, it's the assessing that takes place with our school psychologists, then external paediatricians. Unfortunately, we're in the era where if you get the label, you get the support, but if you don't get the label, it's up to the generic resources of the school.

The Hon. ANTHONY D'ADAM: Isn't that effectively what the low-level adjustment for disability is supposed to cater for—those who don't have the label?

MATTHEW JOHNSON: Within my sector of special schools, that's not a funding stream that we have access to. That is an overall resource with the school's budget within mainstream for them to be able to put that whole-of-school resource across to be able to support students, absolutely.

The Hon. ANTHONY D'ADAM: The hub model is kind of contingent on this idea of having specialist support in place, but obviously the need is contingent on the disability profile of the students in the school, and that varies over time. This is the perennial problem, which is that you've got a tension between funding for a program or tying the funding to the specific student. In terms of the hub model, there's a risk there, isn't there, that you'll have additional resources in one place and not in another where there might be the need. Do you have a comment to make about the various pros and cons of those two approaches?

MATTHEW JOHNSON: I disagree that they would be an idle resource.

The Hon. ANTHONY D'ADAM: Not an idle resource, but in terms of equity of spreading the resource fairly across the system so that everyone's got access to a minimum level.

MATTHEW JOHNSON: Essentially, students who are in mainstream schools and can access integration funding support are the students who should be in mainstream. With our special schools, we've seen over time that the complexity of need has just increased. The most complex multi-disability students are within the special school, and it is just that intense. By the nature of the department's own processes, if you get offered a support class in mainstream, that's less need. If you're getting integration funding support, that means you can be within the general school population without withdrawal, with some additional supports. When you're coming to the pointy end of the pyramid within a special school, where I'd see the hubs as the first place to go as a pilot, those employees would soon be swamped with the amount of work and the case load that they would face.

The Hon. ANTHONY D'ADAM: So you're not proposing the hub model for mainstream schools?

MATTHEW JOHNSON: I think so. It'd be beneficial. But mainstream schools have also got access to larger budgets to be able to be flexible and to innovate. We're very much stuck to that structure of being funded by staffing and our classes. We need those supports because the children deserve to have professional health support within the school so it's part of the educational process, rather than all these little silos still happening before or after school or on the weekends.

The Hon. SCOTT BARRETT: I might start with the ICPA. We heard earlier about some of the formal parent capacity building arrangements and the formal peer support. A lot of people in rural and remote areas don't have that same largesse of community, of shared experience in their areas. I just wonder what government can be doing to assist building that sense of community for those more remote people that have that lived experience and shared experience.

LIBBY McPHEE: Annabel, did you want to answer that?

ANNABEL STRACHAN: In that case, mostly, for us, the best way would be through remote allied health if we could. Royal Far West would be very helpful for us in our situation because travelling is such a long way from anywhere. Also, in some of the communities, the parents themselves are not able to help in that way. That's when it could go through the school, and the school would be able to help the children and support them through any extra learning that they needed. For us, also, the early intervention is vital because that would help so many parents know if there was any trouble and any support they could get early, rather than wait. If you go through distance education, you might be in high school before you really realise there are any problems. That's a long way down the track, and then the poor child has to go through school with all different sorts of issues.

The Hon. SCOTT BARRETT: I'd like to come back to that—unless, Ms McPhee, you had something to say about that sort of community of shared lived experience.

LIBBY McPHEE: I was, Mr Barrett. I was going to say thank you for the question. Annabel touched on it. The program is called early beginnings—or Brighter Beginnings, sorry, is the word that they use. We really want to see an extension of that program. There was the Healthy Kids Bus Stop, which had been around for years. It's had its funding withdrawn from. We are concerned that children, moving forward, are not going to get a community approach across all of those areas about some of those health things. Of course, the Brighter Beginnings is going to, supposedly, give them an early intervention, which is what Annabel has spoken about. The other thing was—within our submission we have suggested that the Department of Education ensure more accessible, school-based platforms for assessing and diagnosing any learning and wellbeing support difficulties for children living in rural and remote areas. We hope that this submission will take that forward as well.

The Hon. SCOTT BARRETT: When we're talking about missing that early intervention and that early identification, Mr Johnson, you talked earlier about sometimes feeling like you're doing the jobs of other agencies within schools. Ms Quinn, you talked about the flow-on effects of the lack of available services. If our children are missed when it comes to that early intervention, or they're not getting the services that they require, what impact is that having on our resources in the broader schooling community and the broader student body?

MATTHEW JOHNSON: I might start answering that one. It has a huge impact and workload at the school level. If the family doesn't have or hasn't accessed supports, it's then our job. I don't want to say it's a burden, but it's a workload issue of being able to connect them with supports. Also, with Indigenous families, that can be a really confronting thing when you're trying to link them up with government agencies. That might cause some trauma. They might feel like they're being judged on their parenting when you're trying to look at getting assessment for their child, and also the shame around that—and with migrant communities as well—where they don't really understand the interface of what's occurring and that we're trying to get support. Trying to manage that in a really equitable way, in a sensitive and culturally safe way, is a challenge as well.

But it's the time within that school's work hours to be able to identify the family, meet with the family, be able to meet with the child and look at their needs. When you look at the disability standards for education, the biggest time to get it right is on enrolment, to be able to really find out what the needs of that child are and what the wants of the parents are; then hooking them up with all those services; then the school trying to coordinate that and have meetings with those inter-agencies; and then trying to foster that support and keep it going so it's not just one-off interventions. That's a real workload for schools, and we're not staffed for it.

GEMMA QUINN: I'd like to pick up on that, if I may. I think that in our non-specialist public schools, in particular, the proof is in the pudding. The fact that we have teachers and parents reporting to us that they're relying on teachers to be everything from the diagnoser to a specialist agency of support tells us that we're missing something here. We have P&C associations across the State being approached by school principals and asked to contribute additional funding to the school budget to pay for SLSOs. That is indicative to me of a broken system. We have parents reporting to us, as touched on in our submission, that there is an over-reliance or a heavy reliance on an external diagnosis in order for a school to step in and offer support to a child that they themselves have flagged requires additional support. I think that is suggestive that we need to look at alternative models of funding public schools and resourcing our teachers, and additional staff to ensure that the needs of children that are being clearly identified are being met.

I think that part of that is going to need to be a look at the way we train our teachers at the university level to say, "If you are being asked to carry this burden, are we doing our job in equipping you to be able to identify the needs of every child that is going to be in your classroom?" While we have specialist schools, we know that children are presenting in non-specialist schools every single year at enrolment that have more and more complex needs, have multiple diagnoses or are not diagnosed but potentially do require multiple diagnoses. A teacher is being asked, in addition to all of the other children in their classroom—and that's not just one child who maybe has additional complex needs in that class; it can be multiple. It could be everyone, and we aren't investigating exactly what is needed there to supplement the funding to make sure we are capturing all of those children.

MATTHEW JOHNSON: If I could quickly add to that as well, with initial teacher education, there's no real part of initial teacher education where you're taught how to work with adults, and that's what our teachers are being increasingly asked to do as part of those multidisciplinary teams. It's a real skill set, being able to do that. I just wanted to add that.

GEMMA QUINN: I would echo that completely, and I think that the relationships with principals and with teachers work incredibly well in a lot of schools where the teachers and principals have developed that skill set themselves. We also see that the breakdowns in communication that result, going all the way through to a complaints-handling process, tend to be resolvable from the outset had the communication skills been built in the first instance to support a complex discussion or a challenging discussion happening between a teacher, a principal and a parent.

The Hon. SCOTT BARRETT: That will be all from me, unless Ms McPhee or Ms Strachan wanted to add something from a rural and remote perspective.

ANNABEL STRACHAN: These specialist schools—are there any regionally, or are they all in the city?

MATTHEW JOHNSON: They are mostly metropolitan or large regional.

The Hon. SCOTT BARRETT: There's one in Orange.

ANNABEL STRACHAN: Oh, one in Orange. I was just thinking we live near Dubbo and there's definitely not one there. So Orange is the only larger regional centre?

MATTHEW JOHNSON: For the west, yes.

ANNABEL STRACHAN: I think that's a sad thing too, because parents from very remote and rural areas would be able to access them if they were in these regional areas. That would make a huge difference.

The CHAIR: There being no other questions from members, I thank all of you for appearing today and for everything that you do to support young people and families.

(The witnesses withdrew.)

Dr SALLY HOWELL, President, Australian Association of Special Education NSW, and Expert Panel Member of the Institute of Special Educators [InSpEd], affirmed and examined

The CHAIR: Thank you, Dr Howell, for appearing today. Would you like to make an opening statement?

SALLY HOWELL: Yes, I was just going to kind of flag just very quickly about AASE but also a wee bit about my background. I thought it might be useful for panel members to know where my perspective on things comes from. AASE is actually celebrating its fiftieth year this year. The entire history of AASE has been around advocating for the needs of students with disabilities and special education needs in the education context. We are an organisation about—obviously, from our name—special education, even though that term has become a little bit contentious. We've never been about a special school as special education; special education to the organisation is actually specialised teaching practice. That's very much what we're committed to. AASE does have its own journal, which is the *Australasian Journal of Special and Inclusive Education*, which is one way that AASE aims to provide information about evidence-based practice and that sort of thing to the special education community. We run an annual conference, which is highly attended, bringing in people from overseas and around the country to present at that conference and have workshops. That's a little bit about the background of AASE.

But just very quickly, I thought I might also just flag with you that I've worked in the field of special education or supporting children with disabilities for some 40 years, which makes me feel terrible when I think about it in those terms. But the roles that I've had have allowed me to see a lot of different inquiries over 40 years, a lot of recommendations, a lot of ideas about what might work and what might support children and students better, some of which have been taken up and others that haven't. I have worked as a support teacher in a mainstream school. I've worked for a non-government agency providing consultancy support for children with disability enrolled across Catholic, independent and public schools. I've worked at the Department of Education head office in disability programs and I finished my career up as a principal of a special school.

If I think about things in terms of this particular inquiry and the cohort of children, being young children, I would have to say that the most rewarding part of my career was actually in the 1990s. That was when children with disability first started being included in mainstream schools. At that time it was called integration, which is no longer an acceptable term either. But the way that the Government and the Department of Education responded to that move at that time, I think, possibly does provide a model of how foundational supports can be provided in a more equitable way across schools.

That early learning program that I was part of employed an early learning consultant—which was the role I had in Western Sydney—in every region. I think at that time there were probably eight regions across the State. To be in that role, you had to have a special education qualification. In our submission that is, again, a major focus. Even just listening very briefly for the minimal amount of time I was in the room with the other speakers, it keeps coming up: How are schools actually meant to support children in the school setting? Because, let's face it, they spend a lot of time in school, and anything that we can do to help teachers with that, I think, is a really good idea.

The notion that a classroom teacher can do it on their own is just not realistic. AASE really does strongly believe that every school should have a highly qualified specialist teacher with a range of skills. If the panel were interested to look at the standards on the InSpEd site, that's what we believe key specialist teachers need to know. Included in those skills are those ones that were mentioned around collaboration, because the environment that exists today with the NDIS is a very, very different one, and it is just so vital that there is collaboration and communication between anyone who is trying to support young children in the education system. That's just a little bit about my background.

The CHAIR: Wearing both your Australian vice-president hat and with your experience at a State level, if you look at somewhere like Queensland, where they have a number of programs to support young people with disabilities in schools and it's run through Education, do you think from a New South Wales perspective that support should be coordinated through Education? Or is it something that needs to be from a Health perspective, but working in with our schools?

SALLY HOWELL: I think I do lean towards the Education coordination, from the perspective that there is a general feeling that, since the introduction of the NDIS, disability is becoming increasingly medicalised. Even the notion that children need to have some kind of medical or formal diagnosis to receive the educational support that they need in school just doesn't make a great deal of sense to me. It's children's educational needs that should be driving a lot of the support that they get. I appreciate that NDIS provides a lot outside of the education system but, yes, I'm just kind of talking from the education system. It's problematic at a school level that for some children receiving NDIS support from clinicians, the advice that clinicians are giving families is practically incompatible with the school setting in which the children actually are. It's not about the commitment of teachers—"Oh, we don't want the children."

I can give a personal example of advice coming from a clinician about the behaviour of a child who had serious self-harming injuries. The advice that the person gave to the school and the plan that was written for the child bore no resemblance to what, speaking as an experienced special educator and also working in a school context, was possible to actually do for that child. It is very problematic, the focus on recognising that specialist training can provide a really powerful and essential way of supporting parents, even to navigate what their children's needs might be. It's also a little bit problematic that when there's money attached to something, it tends to be valued much more highly. As a principal, I have experienced the situation where a child gets a $40,000 behaviour plan. Parents will place much more value on that than they will place, perhaps, on a school and a system that have been supporting their child. I would like to see greater recognition and greater coordination at a school level.

The CHAIR: My next question before I hand on is regarding the functional behavioural assessment. Could you provide a little bit of an overview of that? It's referenced in your submission.

SALLY HOWELL: Yes. When we talk about a functional behaviour assessment—and, again, some people are kind of a little bit anti because it is associated a little bit with the applied behaviour analysis approach to education. But, really, an effective functional behaviour assessment of a child actually looks at the whole environment and context of the child. You're identifying variables that kind of account for the most variance in the behaviour. When does a behaviour of concern occur? When doesn't it? What's its intensity? What are the actual variables in the environment that might lead to those behaviours?

There are things that can be done in a classroom to reduce, say, some environmental variables, but it's also looking at what is the purpose of the behaviour for the child. What has prompted the child to do that? Behaviour is viewed as being purposeful. Children are behaving for a reason. We need to understand what the reason is, and if you understand what the environmental context is and what the function of the behaviour is, then you can actually develop a plan that is perhaps going to support the child better but also provide an intervention that is going to support the child perhaps to manage their behaviour. In more modern discourse, it would be a plan that maybe helps the child self-regulate better or helps the child recognise when things are getting stressful. But you really need to understand, yes, the function of the behaviour. Why is the behaviour occurring?

The CHAIR: And, just to clarify, the assessment is all done by humans as opposed to any AI ability?

SALLY HOWELL: Yes.

The CHAIR: How do you also address any unconscious bias that may be present in the assessment process?

SALLY HOWELL: I don't think I have an answer to that one. I would say that, again, classroom teachers need the support of specialist teacher support. I don't think you need a psychologist to do it. I don't think you need an occupational therapist to do it, although you might have dialogue with everyone that the child's interacting with because you want a full picture of when or when not things might happen. But, again, a well-trained specialist teacher should be part of their training. Again, the whole notion around having really highly trained specialist teachers in schools is that they can support and even coach classroom teachers as well. In terms of bias, yes, one would hope. I guess part of your training is that you're made aware that such things exist, but that's a fairly individual matter. Sorry, I don't have a magic bullet for that one.

The CHAIR: No, that's fine.

The Hon. ANTHONY D'ADAM: I just wanted to pick up on this. Is functional behavioural assessment different to the functional assessment that the department is referring to? In our previous inquiry, we looked at this question around the gateway for accessing IFS. At the moment, it's diagnosis based. There was a suggestion from the department that they have a preference to move towards functional assessment. I'm wondering whether we're talking about the same thing. That's the first question.

SALLY HOWELL: I think probably what they're talking about a little bit more is probably a bit more consistent with the approach of the nationally consistent collection of data, which is a functional needs assessment. A child might have a disability; how does that disability actually affect their functional needs within the classroom? I would very much be in favour of every child being supported to reflect their functional need, regardless of whether they have a diagnosis of any sort.

The Hon. ANTHONY D'ADAM: How is that different, in terms of its purpose?

SALLY HOWELL: Functional behaviour analysis is really a method or an idea of looking at when there are behaviours of concern. You are looking at when those behaviours occur and what is the function of the behaviour, whereas functional needs might be that that child has a reading problem that's going to impact all these different aspects of their education. How are you going to provide an adjustment to address the child's reading difficulty?

The Hon. ANTHONY D'ADAM: Are both assessments not directed to the same thing, which is what kind of adjustments are you going to put in place to support that child?

SALLY HOWELL: Yes, I guess the outcome would be. But I would say that functional behaviour assessment is a term that is used in the research literature. There are particular parameters around it and how you actually do it. And a functional behaviour assessment definitely would result in a plan of how you are going to support the child.

The Hon. ANTHONY D'ADAM: It appears that there is some resistance somewhere around shifting from a diagnosis basis to a functional assessment. Do you have some insight as to what might be the impediments to the department shifting from that basis?

SALLY HOWELL: I haven't worked in the department for a while. I suspect—

The Hon. ANTHONY D'ADAM: Because you talked about the medicalisation. Obviously, having a functional assessment is a means to avoid that sort of medicalisation. Of course, at the moment, it's a gateway to funding.

SALLY HOWELL: And if you look at the education standards, they do talk about an imputed disability. If you have an imputed disability, that is really saying, yes, you haven't got a formal diagnosis, but it can be seen that there is something that is affecting your access to the curriculum or to whatever's going on in the classroom. What could be the department's reluctance? I suspect it may be a fear that it will just really balloon and the expectation will be that much more is provided. A very common cry—and I think I even heard some discussion when I was sitting over there—is about more SLSO time. That's not necessarily the answer. I think the department might have some concern that if you don't have diagnosis as part of the mechanism for triggering support, such as SLSO time, which does obviously have a cost, that they might be worried about that. But I would say that if you really do a good assessment of a child's needs, it's not necessarily that you need to have a teacher's aide.

Many of us in the field would even argue that sometimes the fallback position to say this child has a level this disability, and therefore they get X hours of SLSO time, is not actually the best way forward. What does the child actually need? It might not be a teacher's aide. But then even the use of teacher's aides in the classroom is a whole area that really needs to be addressed. The original idea of teacher's aides was not necessarily that the teacher's aide was going to sit next to the child with a disability and have responsibility for implementing that child's program. Part of the model was meant to be, actually, the teacher's aide could go and sit with the children who don't have need adjustments, who have been set on a particular learning task, while the teacher spends the time working with the child with the disability. But often what you see in classrooms, as more and more children are included, is that the talk about whether it's going to work or not is dependent on how much teacher's aide time there is.

The Hon. SCOTT BARRETT: I will jump in on the back of the point that was just made about the best use of a teacher aide and the fact that a teacher aide is not a student aide. I wonder how we can better utilise that point, given that we are hearing that sometimes schools' resources are being diverted into other areas that they weren't designed to handle and into areas that should be covered by allied health and those areas. How can we better utilise that teacher aide role?

SALLY HOWELL: Sorry, I am not quite understanding. Do you mind explaining what you mean by that diversion?

The Hon. SCOTT BARRETT: I want to hear more about what you were just saying. I thought you raised a really good point about teacher aides and how they can be better used. I want to hear more of your thoughts on that.

SALLY HOWELL: AASE would argue that the allocation of teacher aide time really should be as a teacher aide. As you said yourself, they're not student aides. Again, it does come back to what level of specialist support there is within the school. Is there a specialist teacher who can more effectively train teacher aides and talk to teacher aides whereby teacher aides can be used to support anyone in the classroom so that the child for whom time is being allocated does actually get teacher time? That is a concern, as I mentioned. Again, it comes down to training. We all recognise—and various reports and inquiries have found—that classroom teachers do not feel confident to take on the teaching role for many students with disabilities in their classrooms. I think if we can provide more support to build their support—whether it be through co-teaching models with a specialist teacher or through part of our initial teacher training—the effective use of teacher aides can be incorporated in that training, just so it's not the go-to. Does that answer your question?

The Hon. SCOTT BARRETT: Yes, thank you. That was a really good point that you made.

The CHAIR: There being no other questions, thank you very much for coming this afternoon, and for the work you have done over 40 years to support young people.

(The witness withdrew.)

Ms ANGELA SCARFE, Senior Policy Adviser, Australian Association of Social Workers, before the Committee via videoconference, sworn and examined

The CHAIR: Good afternoon, Ms Scarfe. Thank you for participating this afternoon. Would you like to make an opening statement?

ANGELA SCARFE: Good afternoon, and thank you for the opportunity for the AASW to address you today. The AASW sets the standards for and represents the social work profession in Australia. We have more than 17,000 members nationally, of whom 4,400 or so live and work in New South Wales. We are a self-regulating profession. The AASW is the body that sets the standards for the education, the ethical conduct and professional practice for social work in Australia. Before getting into the details about the service system in New South Wales, I want to spend some time outlining the world view of social workers and the way we go about our work, because I think it will illuminate the points that I want to say later.

As social workers, we take what's called a "person in environment" approach. We think that what matters is the interface between a person and all aspects of their environment. Our analysis takes in all aspects of these two domains. That's a person's health, their physical state, their mental state, their world view and belief system—any conditions that they are born with. But we also look at all aspects of the environment in which they find themselves—their family, their community, their social status and their economic circumstances. We refer to the process of assessing this as a biopsychosocial assessment, and this is something that takes time, and it's best done through the medium of a respectful relationship with someone.

Now, when it comes to intervening, social workers similarly cast a wide net. In terms of directly improving things for a person, we undertake direct interventions that improve their wellbeing and help them reach their full potential, but we also look at those social and environmental factors. This means that social workers often are addressing the underlying or systemic issues in a person's environment that lead to, say, discrimination, unfair treatment and disadvantage. Social workers can also advocate at this level. Often that means social workers are advocating across several service systems to see whether people are getting the services that most appropriately meet their needs.

I'm sure it won't surprise you to hear me say that social workers are found throughout the health, disability and community sectors. This means that even if social workers are not directly employed within the NDIS, many of our members are in services that intersect with it in hospitals, early childhood services, schools, child protection but also family violence and mental health. Because of what I've told you about the way we analyse all aspects of a person's situation and advocate across all systems, social workers are in a very strong position to identify how all these systems could or should be working together, complementing each other to build a unified and coherent response to all aspects of a child's situation.

We really welcomed the recommendations in the NDIS review for a reinvigoration of the service system around the NDIS. We see that as an opportunity to strengthen the holistic and strengths-based early intervention services that embody best practice in the way that you identified in your library's discussion paper. Many of our members before the NDIS worked in exactly these kinds of services, doing exactly this kind of work. This means that, from our members' experience, we can identify the elements that we think are necessary for these early childhood supports, like the ones that you described, to succeed.

One of the main ones is that all children and families, including the very vulnerable children that so many of your speakers today have been talking about, have equal access to the holistic biopsychosocial assessments for children in the context of their family and community that we've described. Access to these assessments—when I say they should be accessible, that's about their location and their waiting lists. It also means that they're free of stigma, that they're welcoming to families of all cultures and backgrounds, and that they're conducted by qualified professionals who can take time to build a relationship with a child, observe children and families together, and also who know the service system well enough to be able to formulate ideas of where that family should go. You can see that we're already talking about a locally available, strongly functioning, universal service system that's free of stigma. You mention in your paper the Brighter Beginnings assessments for children in early childhood and schools. I'm thinking of a similar kind of assessment but happening earlier—say, from the platform of maternal and child health.

You can see already that this is really, really different from that single-dimensional checklist of "Are you or are you not eligible for the NDIS or another project?", because we're talking about a multidimensional, respectful assessment. But you can already see that if someone is not eligible for the NDIS, it's up to that person to go back to another system and undergo another eligibility assessment, whereas what we're talking about and what our members would like to see is something that sits outside all systems so that people only go through this process once.

As well as a strong universal system, this also requires a thriving system of early interventional supports, both general and targeted. We see this as a really positive opportunity for improving the whole childhood service system, rather than just being a cost. For example, we know of lots of members—and I've done this work myself—providing intensive wraparound supports to vulnerable families where there's a child with a disability or with extra needs, because that kind of work can build the parents' capacity. It can also support the needs of every person in that family and help them in the way that they relate to each other.

If we can keep a family together and functioning with that sort of skilled, holistic family support—and if we can keep that family connected in its community and its employment services, schools and local sports services—we're keeping that family away from child protection, family violence, mental health, and alcohol and drug services. We see the work that this Committee is doing and the work that it opens up as a really good opportunity to lead to a really strong community services sector. The AASW would be delighted to work with you on that, and I look forward to continuing this conversation with you now.

The CHAIR: In your submission you've talked about the role of local government as well—and I must say you're one of the first I've come across to do that. Could you just outline what role you see for local government? Because a lot of the talk about foundational supports or NDIS has always been a State-Federal collaboration.

ANGELA SCARFE: Yes, indeed. I've been listening all day to your conversations, and people have been talking about hubs and place-based supports. A lot of that work of pulling services together into a holistic response relies on people knowing the service system, and local government are a really important part of the service system that we have already. Also, I think that they're a foundation that could be drawn upon more actively. For example, in the maternal and child health space, or early childhood, there are already services there, but there are already staff in some local government areas that know the area and know the community sector that's working in the area. Some local government services already have those sorts of coordinating committees that could make sure that services are not leaving any gaps and are meeting the needs of the local community, so I do see a role for local government in this.

The CHAIR: Do you have an example of some of the local government areas, whether it's in New South Wales or another jurisdiction, where that is working well and they're identifying gaps?

ANGELA SCARFE: I'm as old as the hills; I was doing work with schools and young people before the NDIS. The examples that I have—and similarly of our members—relate back to what things were like before the NDIS. The city council in which I worked did have sort of a youth coordinator position. All of us who were providing services for children and young people met regularly, and that included schools, community health and various allied health providers. We just looked at what the services were, where the gaps were, where people should be extending or strengthening their services and funding sources, how to make sure that submissions went in from people who could provide services that weren't there, and how those of us in schools and youth groups could make sure that the young people we knew of got into them.

For example, there was a city council in Melbourne's north-east that was running disability-specific services but had a little bit of money left over, and schools and youth groups knew that there were lots of young people in the area who didn't have enough to do and had a lot of time on their hands. This city council had a music studio that it was letting out to musicians and community groups, and so we decided that on one afternoon after all the after-school programs that would come, we got a youth musician and a youth worker to help young people set up rock bands. They were for young people with disability as well as young people who didn't have a disability. It wasn't a rock band for the young people with disability. They sorted themselves because some of the young people on the autism spectrum were absolutely sensational at some things.

This ran on the smell of an oily rag, with leftover money and staff who had a bit of time, and kept young people off the street. It helped their education. It was one of those beautiful little things that cost nothing and met all sorts of needs. But it was disability funding that went to the local government, so then once all that funding was pulled out of the NDIS, that program died overnight and the young people who were not eligible for the NDIS were left with nothing. It's examples like that that I just remember that worked really well. I've talked to a lot of members in the NDIS and around the NDIS in preparation for you today, and there are other examples of things like that. The one that I was talking about in my opening address was in more detail. It was with families that do have really highly specialised and complex needs, and examples of how you can wrap services around them before the children and young people get to the NDIS.

The CHAIR: The other area I want to explore a little bit more is the navigator role which has been coming up. How do you avoid that position becoming, I suppose, another layer of bureaucracy, rather than focusing on upskilling and capacity building with parents?

ANGELA SCARFE: Exactly. I have a lot of concerns when I see the word "navigator" used, because I think a lot of people are using it in different contexts with different meanings. When something's not there, it's very easy for it to become Ali Baba's cave of everything that we want to be done. Social workers are taught and use a skill that's slightly different from navigation, and that's what we call case management or care coordination. I do take your point about not being an extra layer, because we've got to make sure that the role I'm about to describe to you similarly does not become an extra layer, but it's different from navigators. Navigators sound to me like it's just sort of like pointing somebody in the right direction.

What specialised support coordination in the NDIS does and what old-fashioned case management is—and it's still done by some social workers—is taking all the services that a family is in contact with or a young person is in contact with and making sure that they not only do not work against each other but that it's stronger than cooperating. It's making them cohere into a unified, tailored response. It's not an extra layer of bureaucracy. It's not an intermediary. It's a more active making sure that everyone is in the room at the same time with the child, the young person or their family, and making sure that the family have a chance to say what they want for everyone to hear at the same time and that we're all going to do it.

There's an element of clinical governance in it. There have to be arrangements between all the agencies that are already involved with that family. It has to be funded properly because it takes time. People have to be released from their case management, from their therapeutic support. But when it works, it's like the icing on the cake. It's like the system is bigger than the sum of its parts. That's a really important role. It can be really good. It's slightly different from the navigator role, which is, I think, being envisaged as just pointing people to the right services, assuming that those services exist.

Ms ABIGAIL BOYD: Thank you very much for your appearance today. We talk about the ideal world if we had a proper set of foundational supports for people across the State, but one of the things that keeps coming up and that worries me is the workforce capacity issue. Can you talk a bit about the workforce shortage in the social work sector? What can we do if we want to be serious about it in terms of attracting more people and retaining more workers in the sector?

ANGELA SCARFE: Workforce is a huge issue. We at the AASW are members of Allied Health Professions Australia. I know you've also spoken to them. A lot of the things that I'm going to say are also applied to the other professions in AHPA. Yes, social work is a growing profession. There are real workforce challenges that we acknowledge and that we know about. The thing that is critical in terms of a social work qualification is the requirement that people do field education. That's 1,000 hours of supervised field education, and that's unpaid. For a long time, that's been our biggest challenge. But one of the changes that's come from the Federal policy recently—you possibly didn't notice that—is the ability for students on placement to then get that stipend. We are paying a lot of attention to that. We as the AASW do determine those educational standards, and we have built flexibility into our courses. They're not courses that you have to do straight through; you can take time out. We appreciate that students need to take time to support themselves. Also, we did a lot of work around the Job-ready Graduates Package to make sure that social work subjects were funded at the level that required students to pay lowest.

There are workforce challenges, we know. We know that also, even though it's a great temptation to allow people with lower level qualifications to do that work, the risk that sits around the work that social workers do means that we do [audio malfunction] the standards that we've set. We're conscious that they are high. The families that we're talking about and the children we're talking about often are on the cusp of referrals to child protection, and this can be serious. We know that families in which a person has a disability are overrepresented in family violence and drug and alcohol. It's important not to downplay the level of skill that's required because we are talking about children and young people and families at very high levels of risk.

The CHAIR: Mr Barrett, do you have any questions?

The Hon. SCOTT BARRETT: I'm pretty good, thanks, Chair.

The CHAIR: The only other question I have, which has been asked more broadly to a number of the witnesses, is about the ideal pathway of accessing or working with a family through that continuous care approach. Do you have any comments more broadly on that and what that ideal pathway would be?

ANGELA SCARFE: I don't want to sound cute and annoying, but for us it's very much that every family has their ideal according to what they want and their goals and needs. A lot of what I was saying about taking time to do assessments, using your skills and doing observation is to do with giving people the time and showing that you're trustable so that people can tell you what they want. It's very easy for us professionals to assume that we know what is best for a family. When I worked with young people, so often I realised that I had underestimated the goals and desires of the children and the young people for their lives.

I would be confronted with children and young people whose other workers thought, "Oh, this is good enough; they're doing well enough." But actually that young person had already decided what they wanted, and we were letting them down by deciding too quickly that they were on this pathway. You see it a lot in children in out-of-home care. The agencies and the foster carers think that they need to be in some kind of TAFE or academically light program. If you talk to that young person, they may well tell you that actually they're going to be a doctor or they're going to be a clinical psychologist so no-one else goes through what they went through.

We have to have a system that is flexible but strong enough for each child and young person's ideal pathway to happen for them. That's what I mean about the holistic assessment happening early. That is different from the check board, "Are you eligible for this program?" We need to be building in time for that family and that child or young person, because the child might have told their parents, and we need the parents to be safe enough to tell us what the child or family wants. If that child or family wants to be in a mainstream school so that they can go on and be whoever it is they want to be, I think that we are strong enough and flexible enough to set up a system that enables that child to be on the pathway they need.

When I say "us" and "we", I have read the paper that your library got to do for you, and I've seen what supports are already there. There are things like Brighter Beginnings—which I have already mentioned. My vision is that if Brighter Beginnings was funded to the extent that it could be, and everyone had time, the foundation could be there to find out what those children want and to set up the ideal pathway for them. I know it's annoying when people don't give you a short answer to the question but, having read your paper and having heard what other people have said to you today, I think there's a long answer to that. We can do it. I've also heard a lot of concern from the Committee and quite responsible concern from parliamentarians about allocating resources fairly across the whole State and across all your systems. It has occurred to me on a couple of occasions during the day that it might be worth pointing out that the taxpayer is already paying a lot of money for families and children whose needs were not met early enough.

Our members work with people in the mental health system, in the drug and alcohol system, in the family violence system, and in youth justice. Our members who work in youth justice estimate that half the young people in youth justice should have had a disability identified ages ago and should have had a better schooling experience than they have for a long time. I don't want to just come here and tell you that you've got to spend heaps more money. I think the foundations for a really strong early childhood system are already in existence, and they represent a reorganising of resources from the tertiary end of the system into the early end of the system.

The Hon. SCOTT BARRETT: Can I circle back, please, to some comments you made earlier about the band that the kids are involved in. We also heard earlier from Ellen about how proud she was to be part of her netball team. I could tell you stories about kids that I've played cricket with and against. I just wonder if we could spend a bit of time, because we have it, on the importance of that covert support—being part of a club or a group or a sporting organisation—and how that can be better utilised to add this support.

ANGELA SCARFE: It's everything we know about neighbourhoods and communities, isn't it? If the people who are the coaches know that one team member behaves oddly at times for a good reason, that's all that they need to know. The coach can help the team work around that. I think that in terms of the foundational supports that are being envisaged—at this stage I'm talking about the general ones, not the early childhood ones—there are those resources, and "light touch" and online. Those kind of things can really come into their own. But that gets back to the local government that I was talking about before. It may be that local government is the appropriate person to be able to say to our football teams, "Okay, there happens to be the Carer Gateway or the"—I forget what it was called, but it was in your document. "There are resources on there for all those of us who are working with young people with special needs. Look at them. These people are in our teams. It can work really well." It's not only in terms of the services that the children and young people receive; it's what they give to that team as well. The thing about the one person in the rock band who can drum like there's no tomorrow, the one bowler who can do it—that's their chance to shine, to see that, "Yes, this is what I bring."

The CHAIR: Thank you very much for coming this afternoon and for all the work that you do.

ANGELA SCARFE: Thank you so much.

(The witness withdrew.)

(Short adjournment)

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

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

The CHAIR: Welcome back, everyone. We have a couple of members of Parliament who are online as well. Would you like to make an opening statement?

CARA VARIAN: A very brief one, Chair. I'd like to start by acknowledging the traditional custodians of the land on which we are gathered today, the Gadigal, and pay my respects to their Elders past and present. I also acknowledge any First Nations people in the room or online today. NCOSS and the community service sector support the most disadvantaged people in our State. Decades of this work has taught us that vulnerable children can thrive if we support them and their families to break the cycle of poverty and disadvantage. At Ashcroft Public School in south-western Sydney, 40 per cent of children at this school are living below the poverty line. It's a community of incredible cultural diversity, with 75 per cent of the children from households where English is not their first language. That's where Olivia works, as part of the Mirrung project.

There is a young boy there; I'll call him Daniel. Daniel lives in social housing with his dad and three-year-old brother. Daniel's dad looks after the boys alone. Their mum is in prison and has been in and out of incarceration since he was born. They don't have a family GP or regular health checks, and Daniel did not go to preschool. Through the Mirrung project at Ashcroft, which is an integrated service that connects education, social services and the health system to take a whole-of-child and whole-family approach—NCOSS set this program up with the school—Daniel was given a health and development check when he started kindergarten.

The results show that he was behind across all key areas. Mirrung has put him in an intensive speech group. He has seen the Mirrung paediatrician, and his teacher has made changes to help him in class. Mirrung has worked with Daniel's dad to improve outcomes across the whole family as well. Mirrung suggested after assessing Daniel's younger brother that he was also found to have delays. He now also sees a speech therapist and goes to playgroup as often as possible, which is part of the school infrastructure as well. Daniel and his brother still have some way to go, but they have made significant progress. They will keep getting the help they need along their way to reach their full potential.

I tell this story because Daniel's story is not rare. About 70 per cent of the children that were screened through this program needed extra help to reach their developmental milestones. But after Mirrung provided this help through a coordinated health, education and social service approach that looked after the whole family, the follow-up screening showed that the number of children with delays had dropped to 40 per cent. The outcomes we see at Mirrung teach us some key things: Any support system for vulnerable children should help the whole family. It should support families where they are and respond to their unique needs. It should be easy for people to access in a single, trusted local environment, and it should give families a trusted person to guide them through the services. This is what we need to build in the development of this new system, as well as improving the existing system.

The CHAIR: Thank you for telling that story regarding Ashcroft, which does a great job. I'm interested to learn a little bit more about the supports that were provided, because the evidence that you gave just then is that not all young people who might need support need it indefinitely, and to have a reduction of 30 per cent or 40 per cent in a six-month period is huge. What types of supports were provided, whether they were intensive or just general wraparound?

CARA VARIAN: I'd make the point that I think most people on this Committee know—that there is a huge intersection between people experiencing disability and poverty. When we're designing these systems, we need to understand that there is a connection there. But I'll hand over to Olivia on the details of the interventions and support systems.

OLIVIA WRIGHT: When we screened all of our four- and five-year-olds, we discovered that 71 per cent of them were flagged as missing at least one, but more likely two or three, of the developmental milestones. At the time of doing the screening and initiating the project, we assumed it would be a case where we'll discover who has extra needs and we'll either contact NDIS or we'll refer them off to the public LHD-funded supports. Of course, the scale in the school—71 per cent—meant that with the number of children and the amount of support that was required, there was no way that we could get 40 instances of speech therapy for the number of children. The way we responded was with a patchwork approach.

We brought all of the classroom teachers into the room. We have a school-funded speech pathologist—speech therapy—in the school, we have an OT program, and we established small groups where children were taken out of classrooms and given a 10-week program with the speechie. Children were taken out of classrooms and given an intensive program with the OT. We were able to do some one-on-one supports for those children who were at the end of the spectrum and required the most support. As Cara said, we have a paediatrician in the school, so we were able to refer those to the paediatrician or out to community paeds. So it really became a patchwork and a moving feast of how to support these children. But what that meant was that we could also go in and assess after a short period of time, as you say, because we knew that some children just needed a little boost to get up to the level required for them to meet the milestones. We were able to do that constant, continuous referencing back to whether the children had made progress.

The CHAIR: To do that would have required, obviously, the school principal and the support of the teachers. How did that process come about—bringing them with you on that as part of the program?

OLIVIA WRIGHT: The way in which we work now—how we began this was the school was recognising that the scale of the problem, to use that word for want of a better word, was increasing, but also the way in which the standard processes that they'd been using for years were not working. Really, they were completely on board to look at, "Well, how can we change the way we're working?", and understanding that, if we don't integrate and bring these services into the school environment so that parents can access the services—to try and remove as many barriers as possible for families whose children were identified or flagged as needing interventions.

The teachers were on board, but they haven't had to do vast amounts of work. It hasn't changed their processes other than, for some children, it was identified that we would need in-class adjustments. But, for the most part, the only additional position we've employed in the school was an SLSO, a student liaison support officer, whose specific responsibility is to manage this program of interventions. The rest of the project really sits inside the standardised school processes, the learning and support process. But now we're very deliberate at ensuring that all of our younger students, four- and five-year-olds, are screened initially and then pushed through the standard education, learning and support process.

The CHAIR: Thank you very much for your submission. One of your recommendations is around a taskforce and looking at foundational supports. I'm mindful that the Government announced a taskforce last year and I'm interested to know the level of engagement that is expected with the sector and with others in looking at foundational supports in New South Wales and the service gaps in particular.

CARA VARIAN: At the moment we look forward to being engaged with that taskforce, but that hasn't happened yet. I think it's very important that there is co-design and equal representation from both government and non-government agencies. But I think the Mirrung project itself shows the challenges that there are just within government having the different departments working together. Part of this implementation taskforce needs to be bringing all the relevant parts of government together, including the Ministry of Health and the education department and the social services but, equally, with all of those social service and disability services that are provided. In a context at the moment where there is enormous pressure on those services because the need is outstripping the funding that is available to deliver services, it's very important that the Government considers how it can fund the participation in that taskforce, because there just isn't an ability for services to do it on top of their business as usual. The third component is to make sure that everything that we do is grounded in the experience of people that have lived experience.

Ms ABIGAIL BOYD: It's interesting. Coming into this inquiry, there was a lot of talk about funding and how much was required and where. Obviously, when you're dealing with the community services sector or education or health or anything else in the State, more funding is always welcome. But what we've heard a lot from people so far in this inquiry is that a lot of the need around foundational supports is actually about coordination, redirection and retargeting as well. To what extent do you think we could make a big difference in terms of providing the early intervention and support that people need through that smarter coordination and leveraging the facilities and skills that we already have within various parts of schools, health and community services? How much is actually just a need for there to be far more services and far more money coming into the sector? It's a big question, I apologise.

CARA VARIAN: I guess, to the first part, we talk about it in terms of access, and it's the trusted relationships that people have, to be able to go and seek help or to understand what services are available in the first place. And we see in communities all the time that that can be very hard to build. And so we would encourage this system to use the existing social infrastructure that's in place, rather than trying to build—wherever possible, to be using existing schools, neighbourhood centres, community organisations, rather than trying to build something new, because, obviously, that would be starting from a baseline that doesn't include trust that already exists somewhere else.

Then the other part of that is that the system is incredibly fragmented. The sector talks about the ping-pong effect. People will go to their trusted organisation, be sent somewhere else as a referral; they can't take them because of capacity issues; they come back; and all of that degrades that trust. I think that speaks to that issue around coordination. It's also just a very complicated system. And so, if you're not a health professional or a social service professional—and one of the things that I have found interesting about the Mirrung experience is that I think part of the motivation for those teachers to be part of it is because they felt helpless to know where to go for support, and Mirrung has shown them what's possible by connecting properly to Health and the social service sector. But there is another component of that, which is the location and the ability for people to just get to those places for support, and that's particularly difficult in regional and rural areas.

The other side around whether we just have enough volume of services—I can't express how consistently I'm hearing from people that they are finding that the needs of the communities are growing in a way that they haven't seen. Really very old heads, wise heads of the sector are actually coming to me and saying, "It's too much. I'm too tired. I can't say no anymore to my community. I'm going to retire rather than endure, because I'm overwhelmed by this." And there is a volume problem as well as a coordination problem. You will see in our submission that we do recommend a linker role to help with that navigation and that we strongly believe that it needs to be focused on areas of socio-economic disadvantage and cultural diversity. But it's both of those things. Olivia, I think you shared an experience about Swahili families and it probably demonstrates what I'm talking about.

OLIVIA WRIGHT: Yes. I agree with Cara. I think your question about targeting and using coordination is really important. And there's so much data. The AEDC data that was released this week shows where the pockets of need are for addressing children with the greater need of developmental vulnerability. But it's really got to be contextual, and therefore, even in those targeted environments, you can't just have a single approach. The story Cara's referring to is we have, completely new to the school, five families, in the last 12 or so months, who speak Swahili. Before now they've never had any children of African origin. And so there's just been no way to engage this family. Using Google Translate or any of the translation services available have got us to a sort of point of existence but nothing more than that.

One of the children of one of these families—we have great concerns about behaviour and ability to access their education, and it wasn't until last week we employed a Swahili-speaking SLSO and only for two days. It's two days a term, well within the envelope of funding in the school's budget. And she sat down and had a conversation with the mother in a way that's culturally appropriate, obviously, in language. And now we're miles ahead. We're going to refer this child to the paediatrician, and who knows what will come from that? But I think it's really important just to reiterate that it has to be targeted. I think the socio-economic disadvantages are a massive correlation with developmental vulnerabilities, but also that it has to be contextual to the place. CALD communities, regional-rural, are all going to experience different disadvantage to accessing supports.

Ms ABIGAIL BOYD: In your submission, you reference children being, I guess, taken off NDIS before they have found other supports. How common is that? How much of a problem is it?

CARA VARIAN: What I know is really anecdotal and so it's very difficult for us to tell you that this is affecting 10 or 10,000 kids, but we are hearing stories regularly through our members that the children are not able to access services because they've been taken off. There is a vacuum of information about how long they'll need to wait and who they should talk to in the meantime. It's causing a great deal of concern. How big that problem is, I'm not sure.

The Hon. ANTHONY D'ADAM: I want to delve into some of the details of the Mirrung case study. Where was the genesis of it? Was it an initiative from the school? Was it an initiative from an NCOSS partner organisation? Where did it come from? How did it come about?

OLIVIA WRIGHT: The project is philanthropically funded. It was initiated as an idea that there is a very successful model that's run out of Victoria called the Our Place schools, which are both government-funded and philanthropically funded approaches to integrating services into the school environment, into the school setting. We received some philanthropic funding to explore that same approach.

The Hon. ANTHONY D'ADAM: Who's we? Is that NCOSS?

OLIVIA WRIGHT: NCOSS, yes.

The Hon. ANTHONY D'ADAM: All right, so it was directly NCOSS.

OLIVIA WRIGHT: It was directly. It was within our interest because we were keen to see what the integration of service systems looked like in a New South Wales practice and policy setting. We worked closely with DCJ at the time to identify a community that met some criteria, which included the deep socio-economic disadvantage but also other measures that we were interested in engaging with. Metro was one of those criteria, so we landed in south-west Sydney, Liverpool and, ultimately, Ashcroft Public School. But it was a process that we both came to in the end. Ashcroft Public School, as I said, had very low school attendance. They had a lot of children. They had very low academic performance.

The Hon. ANTHONY D'ADAM: How big is the school?

OLIVIA WRIGHT: Three hundred and twenty. It's P-6, so there's a preschool onsite—a school preschool. There's a SaCC, a school as community centre, so the environment was right and met the criteria that we had proposed. As I said, there was a lot of buy-in from the school leader, the school principal, but also the DEL and the EDD. I think it was, ultimately, a mutual decision. We did a lot of research using the Transforming Early Education and Child Health research institute at Western Sydney University to understand the community, understand the community need, looking at the data across sectors, but also engaging with the community. We ran forums with, I think, up to 80 families with the students, teachers, social service organisations and, from that, built the Mirrung model. The word "Mirrung" means "belonging" in Dharug, and that emerged from the consultation with the community—that they didn't feel they belonged to anywhere.

The Hon. ANTHONY D'ADAM: How many specialists are involved in the assessment process?

OLIVIA WRIGHT: I have a great visual that I could show you. Philanthropically funded is myself, the NCOSS director role, and then a couple of—we have a Pacific islander Samoan SLSO and the Swahili-speaking SLSO. Other than that, the specialist roles are funded by either DCJ or the school. There's potentially one Health-funded role. The paediatrician is privately engaged but Medicare-funded. The speech therapist and the OT are all Education-funded specialists.

The Hon. ANTHONY D'ADAM: Is this just a one-year project?

OLIVIA WRIGHT: No. We launched in August 2022, so we're into our third year. Ideally, it'll run beyond the scope of our philanthropic funding, which ends in December this year.

The Hon. ANTHONY D'ADAM: In total, how much does the project—I'm trying to get a sense of how replicable this model is and if it's an expensive model. We can create the best possible model with the resources, but if it's not something that we can then duplicate in other needy areas, then—

OLIVIA WRIGHT: It's a fairly tricky question to answer, and one that we're grappling with at the moment. There are other examples of school-based hubs that have emerged in communities like Ashcroft. They are all funded in different ways, and they come from different parts of the community that support them. For example, in the Sydney LHD, there are nine hubs that are all funded out of community, so the LHD. We're looking to expand into a couple of schools that are getting new preschools in. With the 100 new preschools in the Liverpool LGA in the same network, I don't think that it is much more than—I don't know that we could put a number on it, to be honest, but it's not vastly expensive. We've done some very crude mapping of the schools and the areas that we believe meet the same need. While there are over 2,000 schools in New South Wales, it's probably down to 100 or 150 schools that you could potentially use an approach like this.

The Hon. ANTHONY D'ADAM: Your submission says 20 LGAs.

OLIVIA WRIGHT: Yes. I think the LGAs are identified by those that have a higher than 30 per cent child poverty rate. It was an arbitrary criteria that we've used to make that recommendation.

The CHAIR: I've got a couple of questions. You do a lot of work around mapping cost-of-living pressures and also the increasing poverty in different areas. Have you done any analysis overlapping that with the need for disability supports? If so, are there particular areas of more need than others? I understand that you might need to take that on notice.

CARA VARIAN: I am happy to take that on notice. We have our economic mapping done, and we also know that there is a correlation between people experiencing poverty and people that have disabilities. There is a higher proportion of people with disabilities in that socio-economically disadvantaged cohort. I would say it would be a fairly clear and consistent map. It wouldn't be that different from each other. But I'll take it on notice.

The CHAIR: How easy would it be to map where the services are and where those gaps in services are?

CARA VARIAN: It's something that I think the whole of the social service sector would benefit from—a more comprehensive map than currently exists.

The CHAIR: My final question is around the universal screening that used to operate. I think it was a Mount Druitt project and an Albury project. Are either of you familiar with those, which I know are no longer funded? How does that differ to the work that was done with Ashcroft?

OLIVIA WRIGHT: I think you're probably referring to CUBS, the Check Ups Before School in Mount Druitt. I might be wrong, but I think that was philanthropically funded initially and now I believe has been taken into the Brighter Beginnings program by the Western Sydney LHD. However, it still operates as it was designed. I would say it's fairly similar. We certainly are well connected with the Mount Druitt team and have modelled a lot of the way we designed our own screening program in the first year on the work that they've been doing. They also use the TeEACH research institute as their academic partner. The Albury one is different, unless I'm not familiar. The Albury program that I'm familiar with is a high school based screening program to determine mental health and homelessness. Again, I would say that I know it only from a desktop perspective.

The CHAIR: Thank you very much again for appearing and for all the work that you do.

(The witnesses withdrew.)

Ms ZOË ROBINSON, NSW Advocate for Children and Young People, affirmed and examined

Ms EMILY BACKHOUSE, Aboriginal Participation Officer, NSW Advocate for Children and Young People, affirmed and examined

Ms SONJA VUJANIC, Previous Youth Advisory Council Member, NSW Advocate for Children and Young People, affirmed and examined

Ms LAUREN STRACEY, Chief Executive Officer, Youth Action, affirmed and examined

Ms AYESHA AYAZ, Youth Action Member, Youth Action, affirmed and examined

Ms ELIZA TAIT, Youth Action Member, Youth Action, affirmed and examined

The CHAIR: Thank you very much for coming this afternoon. Would anyone like to make opening statements?

ZOË ROBINSON: I think there are opening statements all around. I want to start by acknowledging the traditional owners of the lands and pay my respects to Elders past, present and emerging. I also want to acknowledge that I feel like I've achieved a goal—to become obsolete—because there are amazing young people who you'll hear from today. I also acknowledge that in this hearing and in listening to it today, we are talking about our littlest people, who often don't have voices in things like this. I want to acknowledge all the people who appeared and lifted up some of the people who don't often get heard. That has been an incredible theme. May we only do better by our young people and our littlest learners as well. I will let Emily and Sonja read their opening statements on behalf of ACYP.

EMILY BACKHOUSE: Good afternoon, Chair and Committee members. I would also like to acknowledge the traditional owners of the lands on which we meet today, the Gadigal people of the Eora nation. I pay my respects to Elders both past and present. The land on which we all live, walk and work is, was and always will be Aboriginal land. Thank you, Committee and Zoë Robinson, for giving me the opportunity to appear today and to share my experiences of navigating the disability support services for young children. I'm a current employee of the Office of the Advocate for Children and Young People. I'm also a kinship carer for my young nephew, who has been diagnosed with complex medical needs. I knew I was going to get upset and teary so I apologise, and bear with me.

Prior to taking on the care of my nephew, I had little knowledge of the disability sector, only knowing what I knew directly from children and young people during consultation. It is important to recognise and appreciate that the services we have access to have made a very positive impact on the health and development of my nephew. However, I have also come to learn and experience the strain and demand for these services, particularly in regional areas and from an early intervention perspective. Our experience hasn't come without its challenges and jumping through many loopholes; it's a process that shouldn't be so difficult. Being a full-time working parent and kinship carer, whilst also navigating a sector with the additional complexity of out-of-home care, hasn't been easy. Nevertheless, it's worth the battle to ensure that my nephew is receiving the early intervention care he deserves to be able to increase his chances of a better quality of life.

Though I'm sure many of these will be highlighted throughout the questions, I'd like to share some insights that stand out particularly to me. One of these is the need for better communication and connection between providers. Unfortunately, I found there to be no communication between the public and private health providers, often leaving it up to families to know and remember the finer details that would typically be case-noted and shared among practitioners, especially if you're having to travel between locations to see these providers. The funding and recruitment for community health—in particular in regional areas—is leaving such strain on waitlists and the time between referrals, whether these are being self made or via the GP or a paediatrician. Children can take a month, two months or a year to be seen. I don't want to speak for others; however, there is potential that families are turning to AI to help kickstart the therapy to prevent further regression. I know because I did this, due to waiting an extensive time to be seen by a physio.

Another insight is on recognising the work of early childhood teachers, and their contributions to support children. We ourselves are very lucky to have a day care who has walked and worked hand in hand with us to ensure that they are also providing the appropriate care and supports in their environment, as well as aiding in therapy time. The last insight is on early intervention—understanding and appreciating the importance of early intervention. Despite raising concerns and knowing that something wasn't quite right from very early on, often I was being told to wait until he was two years old to start investigating into my concerns. I couldn't imagine the impact on his development if I had just let it be. We should be normalising early intervention, ideally as soon as these concerns are raised.

My hope would be that disability support services become easier to access in regional areas, that families are given opportunities to build their skills in advocacy and education and to know their rights when accessing services, to better protect themselves and the care being provided to their children. I hope that we acknowledge the unsung heroes of those who support families and their children and young people; and most importantly, and I'm sure unsurprisingly, that we provide better space for children and young people to be able to participate, to have voice and to get to make decisions and provide feedback on the care that they are receiving. Thank you.

SONJA VUJANIC: Good afternoon, Chair and Committee members. Thank you for the opportunity to speak today. My name is Sonja Vujanic and I'm 21 years old. Today I'm speaking as a carer for my brother, who has a profound intellectual disability and some of the most severe behavioural challenges seen in the State. Caring for him has been one of the greatest privileges of my life, but when adequate support isn't there, it can become exhausting and isolating. Almost every support we've tried to access—whether through the NDIS, education or health systems—has been a battle. When we do finally access help, it often disappears just as quickly as it came. Because of the severity of his behaviour, most mainstream and even specialised services turn him away. He has been rejected from respite services and disability day programs, sometimes without even meeting him, because providers aren't trained or don't have capacity to manage his behaviours. We've been told he is too complex for services that are specifically designed to support complex children and young adults. The irony is devastating.

NDIS plans look good on paper, but funding means nothing when providers won't work with young people. We've had funding for support workers that went unused because services wouldn't accept him as a client. We've had therapists cancel services mid-treatment because his behaviours were too difficult to manage. We've had to repeatedly explain his disability to systems that should already understand how lifelong and intensive these challenges are. The result is a profound lack of consistency, the very thing people like my brother need most. He thrives on routine, on people he can trust; instead, he gets turnover, gaps and instability. This is a chance to fix a system that fails those with the greatest needs. My brother is not "too hard". He is not beyond help. He is a human being who deserves support, dignity and safety—and so do the carers who fight for them every day. Thank you again for the opportunity to share my story.

The CHAIR: Thank you very much both, Emily and Sonja, for coming today, but particularly for sharing your experiences. Before we move to questions, I'll just see if Ms Stracey or either of the two of you would like to make statements.

LAUREN STRACEY: We do. Thank you so much. Good afternoon, and thank you for the opportunity for us to appear today before the Committee. I'd also like to begin by paying my deep respects to the Gadigal people, on whose land we're meeting today, and honour the traditional Elders past and present. Youth Action, for those who don't know, is the peak body that represents young people and youth services across New South Wales. We represent over 150 member organisations and have been working alongside young people for over 30 years. What we want to do is really progress the vision of a society where all New South Wales young people are supported, engaged and valued, and their rights are realised.

Our submission to this inquiry is grounded in the voices and lived experiences of young people with disability across New South Wales. Through consultations with more than 100 youth services and direct engagement with young people 16 to 24, we heard really clearly that the current system is fragmented, difficult to navigate and is often leaving young people unsupported. We want to acknowledge that there have been some transformative impacts that the NDIS has made for many, but we also recognise that it has left significant gaps, especially for young people in regional communities, Aboriginal young people, young people from culturally and linguistically diverse backgrounds, and those with complex or coexisting needs.

We see foundational supports as essential. These are really the everyday supports that help young people access education, participate in their communities, manage their health and mental health, and also find secure employment. They are the vital bridge, particularly for young people who are not yet diagnosed, are on waitlists or are ineligible for NDIS. But, right now, these supports are really inconsistent, they're underfunded and they're often not youth specific. Eliza and Ayesha will now speak to some of our recommendations. They'll be also elaborating on that in terms of their lived experience.

ELIZA TAIT: Good afternoon. My name is Eliza Tait. I'm an 18-year-old student at Blackwattle Bay Sydney Secondary College. As a young person living with a disability and navigating the education system, I know firsthand how critical foundational supports are. At 13, I was hospitalised against my will. Soon after, I was excluded from a private school, not because I lacked ability but because they lacked the will to support my needs. I was labelled too complex and too difficult, and repeatedly made to feel like I didn't belong. That exclusion hurt, but, more than anything, it made me angry—angry that systems built to serve young people were failing the ones who needed them most. What I want this inquiry to hear clearly is tying access to foundational support to formal diagnosis creates a harmful binary between those deemed eligible and those left behind. Foundational support must be youth specific, flexible and accessible before diagnosis.

AYESHA AYAZ: Good afternoon, members of Parliament and everyone here today. My name is Ayesha Ayaz. I'm 16 years old and a young person with lived experience of disability. Today I would like to advocate for more inclusive and accessible foundational supports for young people with disability. For a long time, I lived with an undiagnosed condition that significantly impacted my ability to function. It took two years to receive a diagnosis through the public healthcare system, and during that time, I wasn't eligible for any disability supports. After I finally received treatment, I had to put in a lot of work to regulate my daily life and catch up on the time I had lost. I was fortunate to access education through Sydney Distance Education High School, which allowed me to work at my own pace and access special provisions. I believe we need to offer support not just after diagnosis but throughout the diagnostic journey, and take a more inclusive approach to how we define and support disability.

Thank you for the opportunity to share my perspective and experiences. I would now like to highlight that we believe the following are essential recommendations to consider when developing a successful foundational support system. First, develop a youth disability action plan for New South Wales. This should be co-designed with young people with disability, grounded in a rights-based social model and tailored to their unique needs. Second, build a fit-for-purpose support system for young people, delivered in accessible and youth-specific community settings like youth hubs. Third, find a truly coordinated service ecosystem. Currently, families and young people bear the burden of navigating siloed systems. No-one should have to become an expert in disability education and healthcare policy to access basic support. We need services that communicate across departments, sectors and providers. Fourth, upskill the workforce that supports young people with disability. Invest in training that builds capability across services to ensure they are safe, accessible and responsive to the real experiences and needs of young people.

ELIZA TAIT: Fifth, integrate disability inclusion into education. Increase investment in mainstream education settings, including teacher training, inclusive policy and practice, and capital works so that all young people with disability can thrive in their learning environments. Despite having documentation of my support needs, I was repeatedly denied basic accommodation in school. That institutional failure contributed to a steep mental health decline and ultimately pushed me out of the HSC ATAR system. Education should be inclusive by design, not dependent on a young person's ability to fight for it, prove they're struggling enough or tolerate bullying and neglect.

Sixth, guarantee access to early intervention and diagnostic supports. Like many others, I spent years in visible distress but without access to diagnostic pathways. Research shows that girls, socioeconomically disadvantaged students and those part of a racial minority are significantly underdiagnosed and consequently cannot access support. Seventh, tackle geographic inequality head on by funding local infrastructure outreach, digital delivery and community-led response so that no young person is left behind due to postcode. Eighth, support Aboriginal people with culturally safe services. As a young person with a disability, I stand in solidarity with my First Nation peers. The disabled Aboriginal community is hurting. The death of Kumanjayi White, a young man with disability, underscores systematic racism and use of excessive force.

The CHAIR: Thank you very much, both of you, for coming today and also being so open about your experiences. We're going to ask a few questions. It's quite informal, even though we're sitting in this environment. Anything that you don't want to talk about, you can either just say, "Look, I really don't want to talk about that," or you can also say, "I'll come back to you with that." Feel comfortable chatting about anything that you would like to. I might actually start with Emily, just from a regional perspective. You mentioned you were told that there would be a two-year wait time. Was that because of lack of access to services or was it because that was the advice and they were saying, "Come back in two years. Wait and see what happens"?

EMILY BACKHOUSE: That was based on the advice. I had raised, very early on, concerns of development issues. I was told, from those practitioners, that it's not typical to intervene so early and to wait until he was two years old, until you were able to visually be able to determine and visually be able to assess what those lack of developments were. That's really unfortunate. When we're thinking about early intervention, obviously, the earlier the better. It actually took us to go and see a private paediatrician to then—when I was listened to, and then it was kind of full circle. We went and saw the private paediatrician, and then we returned to those health professionals, who then said, "Oh, they are right, and you were right", because obviously by that point we had some form of diagnoses.

The CHAIR: This is to both Emily and Sonja. I think it's fair to say both of you are quite young carers. What support is given to you to help you navigate the system, to help you in your role as carer, if any?

EMILY BACKHOUSE: I think for the both of us it's, obviously, very different experiences. I understand and I definitely accept my privilege of having DCJ as part of my support network. I would say that, so I think it's very different. But I think, also, as someone with an education like I have, it's also the support that I also rely on, and the situation might be very different for Sonja.

SONJA VUJANIC: Yes, I don't personally have any support networks that reach out to me. I do think it's also quite difficult for my parents, because they also come from a non-English speaking background. I don't think there are any specific supports for carers, in terms of my experiences. It would be more the supports available for my brother that would help them make their job easier.

The CHAIR: I'll ask a couple of questions. I might start with Eliza. You touched on having to have a formal diagnosis. I wanted to understand that a little bit more. How did that impact your education, having to wait for someone to formally diagnose you with disability or some learning challenges?

ELIZA TAIT: I didn't get diagnosed until I was 14 years old, and by this point I had experienced multiple points of education—private, public, specialised. I had been in the hospital system and so that really had affected where I was currently. I think if I had foundational support before, it might not have gotten to that stage. And I think I'm a young person, I'm a young girl from a privileged background through my race and socioeconomic area, and I still immensely struggled. So part of why I feel the need to advocate is because in our recommendations we talk about people in remote areas and we talk about Indigenous communities. They have it so much harder than people in the cities, who are still struggling.

The CHAIR: And Ayesha, you talked about the need to have a youth-specific disability action plan. What do you think would be good in that plan that would help young people?

AYESHA AYAZ: A part of that plan is that it should mainly be co-designed with young people. We would like to strongly advocate that young people should be involved in the process of creating that plan. But personally, I would like for there to be more focus on accessible services, some support systems with education and health. That would be great to see.

Ms ABIGAIL BOYD: Thank you to all of you for coming along and sharing your experiences. I might start with you, Ms Tait, because quite a lot of what you said really resonated with me. One of the things that I've been thinking a lot about today is the impact that exclusion and ableism has on the ability of young people to get the support that they need. To what extent do you think that the lack of access to services is sometimes driven by that medicalised model of disability where we need to have some sort of diagnosis before you can get ordinary support?

ELIZA TAIT: The medical model that currently underpins all our servicing is damaging young people. Behind me—I am sure he wouldn't mind me saying—one of my peers has been excluded from school due to the fact of exclusion, of bullying, of ableism. It is the same story as me. If we had services which saw us as whole people and saw us as kids and not just our disability or the fact that we don't have our paperwork, if we had more compassion in our systems to go, "This is a 13-year-old who wants to get to school. They are trying really hard and they are not able to because of this discrimination," I think it would change every kid's life with a disability in New South Wales.

Ms ABIGAIL BOYD: That's an excellent answer. Did anyone else want to talk about that as well? I worry, now that we know that only one in 10 people are on NDIS and often that is used as a gateway in order to get services and to get the support that people need, that there is now a huge number of people who are seen as not requiring the same level of support and perhaps we are, as policymakers, making it more difficult for people to get services because we are encouraging a binary, in a way. Is this lack of inclusion something that resonates with you as well?

ZOË ROBINSON: I moved forward because we talk about human-centred design and that's not what we have. We have a system where people have to find their space in that system versus—if you think about a wonderful 13-year-old who is communicating and telling you the things that they need, it is not up to us to then find where they fit in the boxes that we have created. It is up to us to say, "Okay, now we need to make sure that that can happen for you, so help us understand. If that's not possible either, let's work together and figure out how we can communicate what is needed." Human-centred design has been misused, I think. Having come from a consulting firm who made plenty of money talking about it, I think it is being misused, because we no longer put the individual, unique human at the centre of something; we ask you to fit into a system and fill in forms that make sense for a system.

But also we need to remember that there are rights to things. As a young person, you have a right to education. We are talking about an education setting and we are excluding you from that. As you well know, Ms Boyd, ACYP's view is that the reason for that better be pretty good, because that is a fundamental right that young people hold. If you take that to people who can't communicate reasons why, particularly little people and little learners, and they are not having those conversations, again it has to be a very good reason when that is something that we should create space for you to come into and have the benefit of those spaces with outcomes that matter to you. I think we have lost humans at the centre of many things, but especially when you are talking about young people who might have disability and even little learners who have undiagnosed spaces. Shouldn't we start by saying, "Let's create somewhere where you feel like you can come and then let's figure out what you need"? I think Emily said the words beautifully: Let's walk together on that.

LAUREN STRACEY: To build on that, one of the things that we heard in our consultations that some of the young people here were part of was that that whole challenge created another set of challenges that they were then having to navigate. You were having to advocate for yourself at school, and the energy that that took then impacted your mental health. You were having to pull resources from other parts of your world to be able to maintain education, which meant that you then collapsed when you got home and you weren't able to engage in family in the same ways.

Similarly, young people are also speaking to the fact that being able to engage with the supports that they needed—being able to go to your psychologist, for example, and learn some skills that might support you in another domain and then being able to go to a specialised youth space like a youth centre or a youth hub or something like that, where you have supportive adults to be able to hold you while you enacted those skills—actually meant that you got better benefit from the thing that you were accessing treatment for. If you haven't got the opportunity to generalise that and if it only happens in a clinical environment, the learning doesn't get embedded in quite the same way. There are lots of opportunities where we can broaden out what we think of in terms of this kind of support to be able to create whole ecosystems which can hold young people as they develop.

ZOË ROBINSON: Also, as Sonja said, if English isn't your first language and you have to navigate that, and you have to try to articulate what it is that you think you are seeing in a young person in your life or what you are feeling and going through in your own life, that is a complexity that I don't think that we've managed to design well in any system.

Ms ABIGAIL BOYD: I like that concept of designing whole ecosystems around children and supporting them in order for them to be able to thrive. We're looking at recommendations coming out of this inquiry as to how the Government should be viewing its role in laying out foundational supports for the future. We've heard a lot about—and you've mentioned it today—the idea of having coordination and making sure that there's someone who's there to make sure people are getting the bit of the ecosystem they need at that time. Is there also an opportunity there for those connecting, supporting hubs—or whatever we want to call them—to play a role as almost an advocate for each child in order to have their rights met? Is there an element of that that could be built in?

ZOË ROBINSON: I don't want to take away from that because I think—certainly listening to people speak today—there are amazing organisations in communities that spend a lot of time connecting and advocating and all of that. That absolutely continues, and "ecosystem" is very true. When we're thinking of it through a government and policy lens, if we start with rights and what people should have, and we design it that way, then we're not negotiating away things. We're not creating spaces where you have to almost build another avenue to advocate for it. You should be creating spaces where people can step in; that is what service is about. It is saying that we've created a space.

Everyone talks about it: youth hubs, one-stop shops or whatever you want to call them. They are places where someone can come or someone can go to that person and say, "What are the things that you need?" Then it is our role to make sure that you have those things. We still have to start with what people have a right to, as opposed to expecting it to be carried by community people, carers and individuals. We have a role and a capacity in that space to say, "Actually, we're going to do our best to enable and ensure, and we're not going to negotiate any of that away."

The Hon. ANTHONY D'ADAM: I'd like to ask Eliza, Ayesha and Sonja—and I'll come back to you, Emily—what would be the one support that your parents would have benefited from that wasn't there in your circumstances? Is there one type of support that you think would have made a big difference that wasn't there when you needed it or when your parents needed it?

SONJA VUJANIC: I think it's possibly someone there to support them who they could culturally connect with. My parents are from a Serbian background, so you can talk to caseworkers and things, but it would still feel a bit foreign at times. I also don't think there was much mental health support for them and for carers. There is a focus on how we help to support my brother, but there was no-one really supporting them. I think that would be beneficial.

AYESHA AYAZ: I would like to bring up that, personally, I would have liked to see some support regarding disability specifically and support within education. Sorry, my mind just went blank.

ELIZA TAIT: Would you like me to step in?

AYESHA AYAZ: Yes.

ELIZA TAIT: I completely agree. I think education is a really key cornerstone when kids are struggling, fundamentally. You're at school five days a week, so if you can't get there, it's really difficult. Something that my parents struggled immensely with was, when I was not enrolled in a school and didn't have access, where did I go? My previous school gave us a list of about 30 different other schools, and they were all for kids who could not speak or had very complex needs, which in my case was not what I needed. It was actually really degrading—"You can only do life skills," which just isn't the case. I think having someone to step in there and go, "Here's a space that your child can learn in," so it's not an in-between, between really complex needs and competitive academic environments with no support.

AYESHA AYAZ: I would like to speak on that now. One support that I would have liked to have seen would have been regarding diagnosis. Since my diagnosis took so long, it was mainly because we went through the public healthcare system. With private, it would have cost something around $2,000 to get that diagnosis, and with public we had to wait two years because so many people were also seeking a diagnosis. In the time that it takes, the condition can actually get a lot worse, and it can then impact mental health, education and daily life. Also, within school there was a lack of support due to academic achievement, because even though I was doing okay in school, I was missing a lot of classes and I was struggling to keep up with the workload. It was very draining for me mentally.

I remember coming home from school and not even being able to get out of the car because of how physically and mentally drained I was. Definitely some support within school with learning special provisions—I would like to strongly advocate for that for people with disability—and with diagnosis, some kind of funding or help with speeding up the waitlist. The main reason that it took so long with the public healthcare system is because there were only two doctors at that hospital who could diagnose that. So with thousands of people trying to get that diagnosis, it would have taken forever for a lot of people.

The Hon. ANTHONY D'ADAM: Emily, perhaps you could speak about the type of support that wasn't there that you needed as a carer?

EMILY BACKHOUSE: Again, I do acknowledge my privilege of having DCJ as a support network, despite the complexities that lay there. But I think for families, particularly where I'm from, the lack of support comes down to staffing. Being able to access those services within our local area is very far and thin, so having to actually transport—whether that's interstate or locally, being an hour and a half away—that's not available to every single family. I think we need to take into consideration the demand and the need versus the staffing ratios, and how we are actually supporting families within that time. Like I said, I turned to AI to utilise the smartest of AI to try to figure out how I could best support my nephew, because I don't have a background in the space that he was needing that—so trying to find ways to fill that gap without exhausting carers further, which is really important. I don't think there's enough emphasis on the impact that those waitlists are having on carers and on families, particularly those that have more vulnerability.

The Hon. SCOTT BARRETT: First of all, Zoë and Lauren, you guys could have stayed at home.

ZOË ROBINSON: Thank you. That's a good thing to hear.

The Hon. SCOTT BARRETT: It's quite an impressive panel you've pulled together. The question I'd like to ask—Zoë, you might work out where I'm going with this—is to Eliza, who talked about belonging and acceptance. Where else can you go to get that belonging or to get that acceptance? That is a question to everyone, and I'm also thinking outside the standard disability support services groups that might be available to you.

ELIZA TAIT: When I first got diagnosed, I did not see anybody else in my life that I could go to. I felt really isolated, so I actually joined a social group for my specific disability, and this was really great. Now I no longer go to them because I'm in specialised pathways where my peers have similar stories to me. But I would love to see more groups like this one to help people travel if they couldn't go on normal travel groups due to their disability, or to help them with sport and that sort of thing. They are just fundamental fun things that teenagers and kids want to get involved in, but sometimes their disability doesn't allow that.

The Hon. SCOTT BARRETT: I will open this up to everyone. Being involved in sports and those sorts of other teenage activities, how much of an outlet and a support is that for you?

ELIZA TAIT: I cannot say enough about how much I have enjoyed just being a teenager in the later part of my years. It has been amazing to not be at doctor's appointments and not be struggling at home feeling isolated. I love going to school. I love playing netball on the weekends. I love seeing my friends. They're just the things that you want every kid to experience.

The Hon. SCOTT BARRETT: Would anyone else like to add to that?

ZOË ROBINSON: I think Eliza put it beautifully in the sense that belonging is what that young person finds and chooses where they find that. It's the responsibility of those in all of the communities and spaces to ensure that there is access to a variety of spaces where it can happen. For the benefit of the young people at this Committee, I think Mr Barrett wants to talk about crochet and whether you're interested in crocheting. He seems to be pushing that in young people right now. This is the second time I feel like you're going down this path, Mr Barrett. For young people, we can't define what that space is for them in terms of where their belonging is. Our role is to enable them to be good spaces and many spaces. If they are telling us that is a space where they find their belonging, we should make sure that they have access to that and create more spaces where young people feel like they belong.

LAUREN STRACEY: In terms of belonging, one of the things that we heard in our consultation was that there was something kind of magic about youth-specific spaces that meant that young people felt that they could ask for what they needed. That was different to other spaces that they were in. There was something about the way that youth workers and the specialists who work with young people were able to make it known to them that they could say exactly what they needed, whether that's by visual cues, whether that's by the way the space is set up or whether that's by the way they engage with them. It made it really obvious to them that they belonged. When we're talking about the opportunity for increasing training and investment in training for people who are supporting young people, it's being able to invest in those kinds of things so that whenever a young person walks into a space, they can ask for exactly what they need so that they can belong. Whether that's sport or other recreation, that would be really great.

The Hon. SCOTT BARRETT: It's that covert support that I am talking about—being part of a cricket club, a netball club or, as Zoë referred to, a crochet club—where you can find your tribe, find people and find that belonging.

ZOË ROBINSON: The other thing, Mr Barrett, before we move on, is that when the work was done around social media, I would be remiss not to say that young people talked about recognising the pitfalls of social media, but it's also a place where people who cannot or aren't feeling at the right stage, or for various reasons it's not accessible for them to be in a space, can find communities online. When we talked about the social media age restrictions or when we talked about that space, we did hear from young people that, for many, it is where they can find a sense of belonging.

AYESHA AYAZ: Could I also speak on that? I am a student at Sydney Distance Education High School. When I first switched to that school, I noticed a huge change in the environment and the way that students felt when they were there. There are a lot of students there with lived experience of disability, so it made me feel very included and like I belonged, because everyone there had been through similar situations. Everyone was incredibly friendly and kind to one another. I haven't noticed any issues with bullying so far. It was quite a safe space for me. I really enjoy going to the clubs because all the teachers are very supportive. They check in on you. All the students are very friendly, and the staff members and office workers. It's a very nice environment to be in.

The Hon. SCOTT BARRETT: Starting with you, Emily, if I could, we've heard the evidence and we've seen submissions talking about how much worse conditions are for people in regional areas. I wonder if you could shed some light on why you think we are facing greater difficulties in regional areas than metro areas.

EMILY BACKHOUSE: I think the last person who appeared—my apologies, but I don't remember their name—said the need is so much greater than what we recognise. We are living in towns where, once upon a time, there were a couple of streets, one high school and one primary school. Those towns are booming. There are thousands and thousands more families that are moving to these regional areas, and we're not catering to that. We have families who are having difficulties accessing these services, who are having to outreach and to go to other locations to access these services. I'm not privy to what happens behind closed doors, and I'm not privy to a lot of things. But I think, from my experience, there's a lot of staff turnover because burnout is so, so contagious. It's something that is, I think, really affecting regional areas. The demand is there; the quality of work is most certainly there. But there is just dire need for more.

As an example, to access physiotherapy, we were on the waitlist for six months before we got a phone call. The phone call that I received was "We don't actually have this service in your area, but you currently travel to another area where you can access this service. Do you want to go there?" Of course, without a doubt, I said yes. But there are a lot of families who cannot travel to that location to access that, so their young people and their young children are then missing out. So I think it's a combination of funding, of staff turnover and maybe of communities not actually recognising that need.

Unfortunately, the flip side to that is that childcare centres and early childhood educators are the spine for that. They're really trying to recognise and support children within their environments to not let that regression keep on falling behind. That's when families are turning to things like AI to contribute to that development or are turning to private specialists who, again, can cost quite a lot of money. We're in a cost-of-living crisis, so not everyone can actually afford to go and travel but also then pay the money to see private specialists. But in small regional towns, there's a long waitlist for community health providers and for private health providers, and so you're a bit at a loss for that.

The Hon. SCOTT BARRETT: Would anyone else care to talk to why we think there's such a disparity between metro and regional areas?

AYESHA AYAZ: I think, with the cost-of-living crisis, there's probably just a lot of pressure on suburban areas. The pricing for the suburban areas is going up quite a lot, so then people who can't afford to live even in suburban areas would then move to regional areas. That could put a lot of pressure on them to have more support services for young people. Since they're not very strongly funded, there might not be as much support systems available there.

Ms ABIGAIL BOYD: Next week the Treasurer of the State will hand down a budget, and there will be funding announcements and there will often be policy announcements attached to the budget. If it was your budget, what would you want to see in there that would make the most difference in terms of creating a more supportive environment for children with disability, going into the next year or two? Imagine you've got a magic wand.

EMILY BACKHOUSE: I'm happy to go first because, obviously, I had my long list of hopes in my opening statement. But, obviously, at its very core, more support services for younger children, for early intervention that is actually early and that is actually targeted to what they need. But also, really importantly, I would really appreciate a bit of an education piece for families and for carers, to actually acknowledge and to understand their rights when accessing services and not just falling into the trap of listening to GPs and paediatricians. They do great work. But I think there's a lot of times, especially when there's such a strain, that it's so easy to just push to the side and put into the too-hard basket. I think that's happening more and more, especially with this strain on services, and so I think getting families to acknowledge and to understand where they can sit.

From my perspective as someone, again, who's very well educated and very well realmed within this kind of space, I find it very difficult to do things like NDIS applications and to fill out forms and to remember details. I think creating some sort of thing where we can build that communication between practitioners—there is no communication currently. When you're having to jump between public and private, and especially in different local health districts, that's causing even more complexity. I know there are many things in there; but I think, again, a piece around younger children—we are missing their voices and we're missing their participation. We're relying on parents, families and carers maybe a little bit too much to tell us what their young children need when they can actually tell us themselves. That would be a really nice, hopeful dream.

SONJA VUJANIC: Yes. I agree with Emily. I think some kind of way to navigate the process of accessing help, and understanding all the procedures involved, would be beneficial. I also think increasing training for disability support workers for very complex cases would be beneficial because there's a broad range of cases and no two people are the same. From my experiences, I think that would be quite helpful.

AYESHA AYAZ: I would like to say that, personally, I would like to see more NDIS funding that's inclusive to many disabilities because there are a lot of young people with disabilities who aren't eligible for NDIS either because of their age or because it doesn't impact their life enough, even though they are significantly struggling due to their disability. Not having that support could not only make them struggle a lot more but would also put stress on the parents to try to find support systems that are affordable for the young person. It can just be very difficult overall—also, teacher training to support students with disability because currently they aren't fully educated on how to support young people's needs, especially in the circumstance of disability.

ELIZA TAIT: I understand that politics is all about money and budgets, so I'd like to make a comment on something that wouldn't cost any money.

Ms ABIGAIL BOYD: Well done!

ELIZA TAIT: I think we could have NESA, and probably New South Wales as a whole, understand that people with disabilities don't necessarily have a low IQ and it's not something like, "You have a disability, so you have a low IQ." If we could have students like my peers, who are saying that they're getting straight As, but they're really struggling—an easy fix is we start recognising twice exceptionality within our education policy. There's currently no guidelines on NESA about a student who is both disabled and gifted, so having that would help a whole lot of kids who are currently dropping out.

LAUREN STRACEY: Can I jump in as well to speak from the perspective of the youth sector? We talk a lot at Youth Action about the fact that we need to take a rights-based approach to the way that we work with young people. I think that is critical and fundamental to this all, but I think we need to invest heavily in the early intervention space for the nought to five—that kind of early years—but adolescence is the second wave of neuroplasticity, so we need to have some solid investment in that space as well.

The benefit of investing in that particular developmental period is that we have these absolute legends over here who can help inform it and help co-design it. They not only bring what they know now; their childhood wasn't long ago, so they can also reflect on what they needed and what they were missing out on. Being able to have investment that is really driven by young people's voices, that has a rights-based approach and that really looks at that whole person would be fantastic to see.

EMILY BACKHOUSE: Something else that I'd like to add—and this is again based on my own experience—is some form of investment for working carers. What I'm finding—and I will just acknowledge the fact that Zoë and ACYP have been very empathetic and understanding to my situation, and I appreciate it—is that there are some working carers who do not meet many thresholds, and so then they are having to actually take unpaid leave for a certain amount of time to attend things like appointments. I'm very lucky, very fortunate. I have my time that I take to cater to my nephew and his appointments, but many families don't. Many families are single income households. Many families are relying on that single income, and so they're not able to actually take that time away. Again, I think trying to find a way—I'm not sure how. It costs money, I'm sure. But I think if we're investing in working carers better, we're actually going to be benefiting the wellbeing of carers, but also their children, who placehold of that as well.

ZOË ROBINSON: I'd love the idea of having the pen on the budget, but I think what we've heard today is—I get that we need to build things. I get that there's infrastructure that needs to be committed to. But it seems like if we nurtured the good things that are going really well, if we harnessed what people have said today and around this table about what has had a good impact on them, and we started to shift money into things that—and I don't mean this disrespectfully; I get why it happens. Perhaps we can't cut a ribbon, but what we can do is see people feel something—feel like they belong somewhere, have a space where they can go.

I feel like we shift money into those things, and we can't necessarily always articulate it, because sometimes it is about the fact that someone at this table talked about the fact that they are enjoying their teen years for the first time. Whatever we did in that space that made that possible, let's invest in that. Whatever we're doing that allows a person to care for their nephew, let's keep doing that. I think it has to look like many different things. But also I think, "Wouldn't it be amazing?" Perhaps this is a challenge. I can do this because it's my last six months and I can be cheeky. Wouldn't it be amazing if the Treasurer sat with some of these young people as they were designing a budget and tested, "Was this a good investment? Does this make sense for you? Does it make sense for people in the future?"

Ms ABIGAIL BOYD: I love that.

The CHAIR: On that final note, thank you to the four of you for coming today and sharing your experiences. It does make a huge difference. All of you are doing such an amazing job. You should be really, really proud. Thank you to both Ms Robinson and Ms Stracey for coming along and for the work that you do, particularly for young people across New South Wales.

(The witnesses withdrew.)

The Committee adjourned at 17:10.