

**INQUIRY INTO FOUNDATIONAL AND DISABILITY
SUPPORTS AVAILABLE FOR CHILDREN AND YOUNG
PEOPLE IN NEW SOUTH WALES**

Organisation: Uniting NSW.ACT

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Select Committee on Foundational and Disability
Supports Available for Children and Young People in New South Wales

30 April 2025

Uniting NSW.ACT Response to NSW Inquiry into Select Committee on Foundational and
Disability Supports Available for Children and Young People in New South Wales

Uniting NSW.ACT contributes to the work of the Uniting Church in NSW and the ACT, through social justice, advocacy, community services and spiritual care. We provide services for people through all ages and stages of life, and drive solutions to systemic issues so people experiencing disadvantage can live their best lives.

We welcome the opportunity to respond to the NSW Government Inquiry into foundational and disability supports for children and young people with disability and developmental delay. We believe that this is a significant opportunity to introduce supports to improve outcomes for all children and young people in NSW, including those who are most vulnerable.

We have extensive experience supporting children, young people and families in NSW and the ACT across a wide range of service systems. We note that this Inquiry has been established following the release of multiple important reports including the NDIS Review, Productivity Commission Inquiry into Early Childhood Education and Care and the NSW System Review into Out-of-home Care. We have not replicated these findings within our response but strongly urge the Inquiry to adopt these recommendations in the final report.

More broadly, we believe that the delivery of foundational supports must include specific strategies and initiatives which address the needs of vulnerable children and young people who are currently not receiving the support they require to thrive. This includes children experiencing disadvantage, children from a trauma background and children in out-of-home care. Without targeted and co-designed planning, these children will continue to be left behind their peers.

We have also provided examples of our programs and initiatives which we believe provide useful insight into how foundational supports can be delivered. We would welcome the opportunity to share our experience as a provider or more information about these programs if it would assist in the Inquiry.

If Uniting can assist you with any further information, please contact Clare Lawrence, Principal Policy Officer

Yours sincerely,

Dr Andrew Montague
Director Communities
Uniting NSW.ACT

Head Office
ABN 78722 539 923
Level 4 / 222 Pitt Street
Sydney NSW 2000

PO Box A2178
Sydney South NSW 1235

T 1800 864 846
E ask@uniting.org

Access to resources and supports

Awareness of disability and developmental delay

Early detection and identification is the first step in ensuring that children and young people are able to receive the supports that they need. This requires that parents and carers have access to information to recognise signs of normal and delayed development and feel empowered to raise their concerns.

This awareness is not consistent across all communities and families and can lead to signs of disability and developmental delay being missed. A Uniting staff member explained a common situation among new parents:

*So you're a new mom with this baby and you think that's how every child behaves, right?
You don't know what you don't know.*

The NSW Health “Blue Book” is an important resource which provides families with information about developmental milestones for babies and toddlers. The Blue Book is currently available in 18 languages in addition to English. Given the diversity of communities and families in NSW, we recommend that the NSW Government review if this is sufficient to meet the needs of culturally and linguistically diverse families.

We also note that the Multicultural Health Communication Service (MHCS) has a range of resources which have been translated into nearly 90 languages. We commend this work however our staff report that there is limited awareness of these resources in some culturally and linguistically diverse communities. We urge the NSW Government to continue to fund the work of the MHCS to engage with communities and share information about child health and wellbeing.

Recommendation:

- That the NSW Government review the translation of Blue Books and consider opportunities for additional languages to meet the needs of culturally and linguistically diverse communities.

Diagnosis

Families of children and young people with indicators of disability or developmental delay face significant costs in accessing services and in particular, in undertaking diagnostic assessments with specialists such as speech therapists, occupational therapists and psychologists. Additionally, public waiting lists for diagnostic assessment are often long and result in children missing out on the critical window for early intervention.

Despite this, a formal diagnosis is often required in order to receive supports through other service systems such as early learning, education and the NDIS. For families who are unable to afford these costs, children do not receive the support they need including early intervention support.

This creates a growing discrepancy between families who can afford to access private specialist services including diagnostic assessments and those who cannot. Families who are reliant on publicly funded services are left behind due to lengthy waiting lists and the critical window of opportunity for early intervention is missed.

Recommendation:

- That the NSW Government expand access to diagnostic services through increased investment in family and child wellbeing programs and develop a strategy to address the existing waiting lists.

Stigma associated with disability and developmental delay

There is also an ongoing stigma associated with disability and developmental delay which can prevent some families from accessing support. Our staff report that this is particularly damaging for mothers from culturally and linguistically diverse backgrounds who fear that signs of disability and developmental delay are a reflection on their parenting skills and avoid disclosing their concerns outside the family. This stigma becomes a barrier to seeking help and further information.

There's a shame of, well, I can't go and see someone because I don't want anyone to know something's wrong or they internalise it and go, oh, it must be something I'm doing.

This also has legal implications for children and families who are applying for permanent residency and other visas in Australia. Under Australia's Interpretive Declaration in relation to the Convention on the Rights of Persons with Disabilities, the Australian government can deny permanent residency on the basis of disability. As a result, families applying for visas are reluctant to pursue a formal diagnosis as it may be used to deny their application.

We appreciate that changing attitudes towards disability and developmental delay is a complex ambition which will require systemic change across the community. However, we believe that without a commitment to attitudinal change, the proposed foundational supports will not be successful.

Recommendation:

- That the NSW Government co-design outreach and peer support initiatives with culturally and linguistically diverse communities which aim to reduce stigma and increase awareness of signs of disability and developmental delay.

Flexible and accessible supports

When children and young people become eligible for services, it can be difficult to access supports which are flexible and accessible. For families without a car or those who live in an area with limited public transport, travelling to appointments can be costly and time-consuming. Equally, many of our families do not have the financial capacity to reduce their work commitments to attend appointments which are only available between 9am-5pm, Monday to Friday. Families with multiple children also face challenges for appointments where parents are expected to participate in therapy.

A staff member shared the experience of a parent of a child in early learning who was eligible for services:

We had a parent who said to us "We have speech [therapist funding] but the times that they can give me, I can't make it because to make that time, I've got to take time off work. I can't take time off work because that affects everything else".

We have seen the benefit of co-located services or supports which can be delivered in settings where children already attend such as schools or early learning services. These minimize the need for families to travel, reduce barriers to access and supports access to specialist services. For example, our early learning services facilitate therapist appointments for children within their services. Similarly our Wellbeing4Kids program (discussed further within this response) provides insights into how technology can be used to reduce barriers to supports.

The NSW Government should consider opportunities to co-locate specialist services in natural settings such as schools, early learning and health services. Other options include in-home services or online appointments which enable families to receive supports without travelling. This should also include ways to facilitate access through non-traditional hours such as weekends to support working parents to attend appointments.

Recommendation:

- That the NSW Government commit to reducing barriers to services for children and

families through co-location of supports and flexible solutions such as online or home-based supports.

Child centred services

As an organisation, Uniting provides supports to children and young people across a range of systems and service types. In our experience services must be specific and tailored to the needs of children and young people, rather than attempting to implement a one-size-fits-all approach across all ages.

For example, our counselling staff told us that children and young people cannot simply be treated as smaller versions of adults:

You wouldn't expect a kid to sit on the couch for an hour and talk like you would with an adult. We need to make sure that these services fit the needs of the actual child or young person.

Children and young people require unique programs and initiatives (such as play therapy) and should be involved in the design and implementation of foundational supports.

Recommendation:

- That the NSW Government co-design the delivery of foundational supports with children, young people including initiatives which are specifically focused on the unique needs of children.

Navigational supports

The complexity of navigating service systems in Australia is well-known and documented, as evidenced by recent reports including the NDIS Review, Productivity Commission report into Early Childhood Education and Care and Disability Royal Commission. We do not intend to replicate their findings here.

Our broad comment is that systems and services currently exist in the middle of a maze which prevents families from reaching the supports they need. They are based on inherent assumptions about parental literacy, access to technology and capacity to understand varying criteria, apply for supports and engage with services. Our staff member told us:

So that's this assumptions that families have access to all of this, you know, technology and these are the people who are fluent in English, right?

We believe that navigational supports should underpin the future of foundational supports. They provide an effective solution which reduces barriers to early intervention, provide opportunities for capacity building within families and result in improved outcomes across communities experiencing disadvantage.

Navigators who are connected to local communities provide information about services and walk alongside families to reduce barriers to applying for and receiving supports. This is particularly critical in families and communities who are currently not engaging with services such as culturally and linguistically diverse groups and families experiencing disadvantage. Without navigational supports, the barriers can be insurmountable and children and young people with disability and developmental delay miss out.

We believe that local providers are well placed to deliver foundational supports which are responsive to the needs of the particular community that they serve. Flexible and adaptable models of navigation ensure that providers have the ability to tailor their services and engage with families through different channels. An example of our navigation program to support families access early learning is provided below.

Case Study: Links to Early Learning

Uniting's Links to Early Learning (L2EL) supports families who are facing difficulties when it

comes to their child attending an early learning service such as preschool or child care through navigational supports. The program connects parents to quality options, and aims to help preschool-aged children access early learning in the year or two before they start school.

The L2EL program offers support in a number of ways, including:

- Helping families to find the service that best suits them and their child including ensuring that it is accessible, culturally appropriate and meets the unique needs of the child.
- Assisting with navigating systems including applying for subsidies, completing paperwork and engaging with translation and interpretation services.
- Supporting transitions to early learning services including facilitating conversations with educators, sharing information and planning for a successful transition period.
- Connecting families with other support services within the community to build capacity, their specific needs and develop a network of support.

L2EL has demonstrated success in supporting children and their families who are currently excluded from early learning to access the services that they require to thrive. This includes a significant number of families with children with additional needs, developmental delay and disability. The benefits of L2EL extend beyond preschool attendance and help to create empowered and connected families.

Recommendation:

- That the NSW Government fund navigational supports which are delivered by providers with knowledge of local communities and experience supporting children, young people and families.

Supporting families and carers

Parents and carers of children and young people with disability and developmental delay are often overlooked in the provision of disability related services. These services are often only focused on the disability related needs of the child with disability or developmental delay, failing to include the families and carers who provide day-to-day support. For example, the NDIS will only fund supports for the child to access services and will not include assistance for upskilling parents to support their child's development.

As a result, our staff report that families and carers feel like they are on the "outside" of disability supports looking in, rather than valued partners in their child's journey. Children and young people with disability do not exist in a vacuum but rather as a part of a family and community. Embracing the strengths of their broader system ensures that the child or young person has the support to learn and grow.

Valuing the role of parents and carers as teachers

Parents and carers of children and young people with disability should be valued as their child's first teacher and respected for the role that they play in supporting their child's development. While a child may spend several hours a week with specialist therapists, they spend significantly more time with parents and carers.

Currently, there are limited resources available to support parents and carers of children with disability to meet the unique needs of their child and facilitate their learning in day-to-day life. General parenting resources often do not account for the experience of children with additional needs, leaving parents without support.

Peer to peer support services and programs such as supported playgroups allow parents to learn how to support their child in their daily life in a supportive and flexible environment. Our supported playgroups (discussed further within this response) provide an example of how this

looks in practice:

There are learning opportunities every day and we help families to make the most of them. It's the small things like going to the shops with mum to buy some apples or tea and biscuits with grandma. We teach parents how to use these for learning and when they all add up, it makes a significant difference in the child's life.

Foundational supports should recognise the importance of parents, carers and families and include information and supports which enable them to build confidence and caring skills. Examples of programs may include supported playgroups, peer-to-peer learning and socialising, providing parenting resources and access to specialists who deliver education specifically for parents of children and young people with disability and developmental delay.

Recommendation:

- That the NSW Government consult with parents and carers throughout the design of foundational supports to identify service gaps and solutions.
- That the NSW Government fund and scale programs which upskill parents and carers of children and young people with disability and developmental delay.

The role of a village

Our services report that families feel increasingly isolated when parenting and caring for their children and that the “village” of informal supports which was such an important part of parenting in previous generations, is difficult to find. This includes access to parents groups, playgroups and other structured and unstructured activities which facilitate networking and socialising. Having a village also allows families to compare their child's development with others of a similar age and spot signs of delayed or different development. Further, parents have the opportunity to learn from peers and share advice to common challenges.

One staff member told us:

The isolation some of our mothers feel [is a problem]. I know that as a mum when my girls were young, there were mothers groups you could join, a hundred if you wanted! Now it all seems to be online and parents are more isolated. Whereas when you're in real life, it is easier to have those conversations of look, I'm really struggling to put my child to sleep.

Supported playgroups should also form a critical part of foundational supports for young children and families with disability and developmental delay. In addition to the benefits of playgroups and socializing, they allow families to learn from facilitators with experience supporting the unique needs of their child and connect with other parents who are navigating similar journeys with their children.

Case Study: Supported Playgroups

Playgroups are often the first step that parents have into the community and engaging with community services. They are a critical early intervention tool which increases a parent's skills, knowledge and understanding and improves their ability to care for their child. At Uniting we provide supported playgroups in disadvantaged areas which give parents a safe and supportive environment to socialize, learn and engage with services.

Supported playgroups act as a contact point which enable families to engage with staff who have experience with children with varying needs. They provides an opportunity for a staff member to identify signs of developmental delay and provide referral pathways for services and supports within their local community.

Our supported playgroups also include information and capacity building supports, including guest speakers from services such as counselling and domestic violence which allow parents to learn in a safe setting. Discussions about local supports and services from diagnosis to health services to early education are a normal part of discussion and reduce the need for parents to

seek this information independently.

They also enable parents to learn child-focused parenting skills which build their relationship with their child and are appropriate for their needs. For children with disability and developmental delay, this is particularly critical as general parenting supports may not be relevant or applicable to their circumstances.

Recommendation:

- That the NSW Government increase funding for a network of supported playgroups which are delivered by providers with local community connections and are integrated within the broader social services system including referral pathways.

Trauma and disability

During consultation, our staff spoke extensively about the needs of children and young people who experience trauma but do not have a defined disability. This cohort of children come from complex backgrounds including domestic and family violence, refugee and asylum seeker families, neglect and maltreatment, and other negative life events.

The evidence shows that children who have experienced trauma are less likely to meet their developmental milestones on time, more likely to demonstrate behaviours of concern and to be behind their peers at school. The Blue Knot Foundation notes that some children with repeated experiences of childhood trauma are diagnosed with Attention Deficit Hyperactivity Disorder (ADHD), Oppositional Defiant Disorder (ODD), truancy and aggression however often their underlying trauma is not recognised or acknowledged.¹

Despite this, there is limited or no support for children and young people who experience trauma and who show signs of developmental delay or display challenging behaviours. Children from a background of trauma require specialist services such as psychology, speech therapy and occupational therapy but these are often only available to children with a diagnosed disability. A staff member told us

Take a child who has grown up in an environment with drug and alcohol addiction and domestic violence. That child has trauma but without a diagnosis, you can't get the supports they need. We have to have some kind of diagnosis like autism, just saying "it's trauma" isn't enough to get in the door.

As a result, the family either cannot access services or is forced to pursue a diagnosis of disability or developmental delay, even if it may not be an accurate reflection of the child's circumstances.

Additionally, our staff report that there are very few professionals with the skills and expertise to navigate the complexity of intersecting trauma and developmental delay. This means that children with a trauma background do not receive the support they require which reflects their complex needs.

The reliance on formal diagnosed disability and developmental delay has excluded children with trauma backgrounds from services, despite being one of the most vulnerable cohorts in our community. This has also occurred as a result of a service gap where disability supports are the only pathway for children and families to access specialist services.

Foundational supports must include consideration and consultation with children, young people and families from trauma backgrounds. Without specific actions which address the needs of this cohort, children most in need will continue to be left behind. The intersection between trauma, disability and developmental delay is complex and nuanced but failing to

¹ Blue Knot. *Impacts of trauma*. Available at <https://blueknot.org.au/resources/coping-strategies-impacts-and-healing/impacts/>

recognise children and young people from trauma backgrounds as a group requiring specialist services would mean continuing this systemic neglect.

As such, we believe that there must be three complementary actions taken to ensure that the delivery of foundational supports includes the needs of children with trauma backgrounds and have outlined these below.

Recommendation:

That the NSW Government:

- Consult with children, young people and families with experiences of trauma to develop and fund programs which are specific for this cohort of children and provide access to child-centred, trauma informed support within local communities. These programs should be closely connected to other service systems including health, justice, child protection and education.
- Expand eligibility for specialist services to include experiences of childhood trauma where a child is demonstrating signs of delay or behaviours of concern.
- Adopt a leadership role in supporting children and young people with trauma backgrounds by engaging with service providers, lived experience representatives and researchers to develop resources to support specialists to better understand the intersection between trauma and disability and provide trauma-informed support. This may include resources for health, early education and community service professionals.

The needs of children, young people and carers in contact with the out-of-home care system

We recognise that the 2025 NSW Government System Review into out-of-home care (OOHC) (System Review) made extensive findings and recommendations relating to the delivery of child protection services in NSW. We endorse the need for reform which ensures that children and families receive the support they need to thrive. We do not intend to provide our recommendations for reform in the OOHC sector within this response but would be happy to provide more information to the Inquiry.

Prevalence of disability

Children and young people with disability are disproportionately represented in the OOHC system. The System Review found that as of 30 June 2024, 18 per cent of children in out-of-home care were recorded as having a disability and 49 per cent of children and young people in residential care were recorded as having a disability (noting that 10 per cent had a disability status of 'not stated'). It also noted that actual rates are likely to be higher as there are no systematic processes to screen for or diagnose disability on entry to care.

As a result, foster carers are often the first people to notice signs of disability and developmental delay which represents a missed opportunity for early detection and intervention. Relying on foster carers to notice and respond to signs of developmental delay is inadequate and can create delays in accessing critical services.

Recommendation:

- That the NSW Government include strategies to improve screening for disability and developmental delay in the broader system reforms in out-of-home care.

Trauma and complex behaviours

We know that children and young people in OOHC face unique challenges and enter care from a background of trauma. As previously discussed, the existing system fails to recognise the impact of trauma on the way that children and young people develop. This is compounded for children and young people in contact with the OOHC system who have been removed from families and

who are already at increased risk of poorer outcomes across the lifespan including education, health, mental health, contact with the justice system and homelessness.

Children and young people in OOHC have access to some counselling services through community health however staff report that there can be a long waiting lists, services may not be available in the local area and are often are time limited.

In addition to the lack of support for children and young people from trauma backgrounds, there is also inadequate support for foster and kinship carers. This includes education on indicators of disability and developmental delay, support navigating diagnosis, early intervention and supports as well as providing care which meets the specific needs of the child. One of our staff members told us:

Unless they've had children of their own with similar needs or disabilities, they often have no idea where to start and once they start working in the realm of services and the NDIS, it is such a maze. And I've found that carers become hugely overwhelmed and confused.

We know that upskilling and supporting carers will enable children in OOHC to thrive. The same staff member also shared positive examples of where carers have been supported to deliver trauma and disability informed care:

What I have seen work well is a consistent, loving carer. A carer who has access to the supports, resources and tools that they need and has the skills to support that child or young person when it gets tough. They show the child time and time again that I'm here, I'm not going away and I won't be pushed away. The difference it makes for that child is huge.

These children and young people are the direct responsibility of the NSW Government who must be more assertive in providing services which meet the needs of some of the most vulnerable children in the state.

Recommendation:

- That the NSW Government ensure that the delivery of foundational supports includes specific strategies to engage with and support children and young people in contact with the child protection system. This should include targeted measures to upskill and support foster and kinship carers.

The importance of early learning

We note that the Productivity Commission into Early Childhood Education and Care has provided extensive analysis about the experiences of children with disability and developmental delay in early learning. We refer the Inquiry to those findings which we are strongly support, including the importance of restructuring and investing in the Inclusion Support Program.

Recommendation:

- That that NSW Government advocate for the Australian government to implement the findings of the Productivity Commission in relation to the experience of children with disability and developmental delay in early learning.

Identifying and responding to signs of developmental delay

Early learning educators play a significant role in detecting and responding to indicators of disability and developmental delay. For many families, this is the first contact with professionals who are able to observe the child over an extended period of time, recognise signs of delayed development and establish trusted relationships with families.

Uniting's early learning services are embedded in the communities that we serve and our staff have established relationships with local health professionals including child and family health

services. This enables us to make warm referrals and share information (with family permission). However, our work in supporting children and families to access services is not funded and we believe is not consistently undertaken across the sector.

We would also urge the NSW Government to avoid developing a reliance on early learning as a screening tool and instead ensure that it forms part of a broader system of checks and points of contact where signs of disability and developmental delay can be identified at the earliest opportunity. Analysis completed by Uniting shows that one in ten children are currently not attending early learning, most of who are from groups experiencing disadvantage.² Relying on early learning as the primary tool for screening would therefore result in these children missing out.

Exclusion from services

At Uniting, we are committed to accepting and supporting all children including in our early learning services. Unfortunately, in our experience, families of children with disability and developmental delay are experiencing rejection and exclusion from some early learning services due to their additional needs. This experience creates stigma where parents are less likely to disclose their child's needs with their next centre, in fear of their enrolment being rejected. An early learning educator told us:

Every year we get two or three families who either haven't told us about the diagnosis and then once we start having a chat with them they go, oh yeah we have a formal diagnosis. Is that going to change our place? And we say, no not here it won't. But there are so many families who have bad experiences with early childhood services... It's something we have to acknowledge as a barrier because if families are being rejected by the people who are supposed to be helping them, it doesn't give them much hope.

We recognise that a significant reason that early learning services reject enrolments is because the current system for supporting children with additional needs in early learning is inadequate (we refer to the findings and recommendations of the Productivity Commission).

Children and young people experiencing poor mental health

Children and young people with mental health are often excluded from the conversation about disability, despite the debilitating impact that mental illness can have on their functioning and wellbeing. In particular, there is a lack of services for children under the age of twelve who demonstrate signs of mental illness, for example headspace services are for young people aged 12-25. Further, the Child and Adolescent Mental Health Services (delivered through NSW Health) provide important and essential services however they are responsible for supporting children and young people "with a range of difficulties that seriously impact on their mental health and emotional wellbeing".³ This leaves a service gap for children demonstrating indicators of early stage mental health concerns.

This focus on serious or acute care is a consistent experience across our services. It means that children and young people are unable to access support until their mental wellbeing deteriorates to the point of being eligible for higher levels care.

There are examples of positive programs which address both service gaps that we believe have potential to make lasting change in the lives of children and young people with mental illness. These should be reviewed, scaled and funded on an ongoing basis. Early engagement reduces the need for more resource intensive support, improves outcomes across a range of domains including education and improves quality of life.

² Uniting (2024). *Patterns of attendance in early learning*.

³ NSW Health (2023). *Child and Adolescent Mental Health Services*. Available at <https://www.health.nsw.gov.au/mentalhealth/Pages/services-camhs.aspx>

Case study: Wellbeing4Kids

Wellbeing4Kids is an early engagement program for children under 12 years of age and their families who are experiencing mild to moderate mental health supports. It offers 12 free therapy sessions per calendar year and is funded by the Hunter New England and Central Coast Primary Health Network.

The program offers a range of therapeutic models which meet the needs of each child, establishing individual treatment plans which also engage with the child's caregiver and family. The program is also deeply connected to the local community, including co-locating programs within community and neighbourhood centres to reduce barriers to access. This enables staff to establish referral pathways for both families entering the program and creating networks of support for when they complete the program.

Wellbeing4Kids co-designed a unique outcome measurement tool with children which helps capture the areas of their life that they would like help with including feelings, behaviour, focus, kindness and friends. While 80 per cent of children at the start of the program report difficulties in all five areas, this drops to 20 per cent after completion.

A review of the program found that 80 per cent of parents reported "a lot" of improvement in their child's emotional wellbeing three months after completing the program and 89 per cent of parents believe that they have a greater understanding of their child and their needs.

The compounding impact of disadvantage

At Uniting, we support children and young people with disability and their families across multiple services systems, many of which are not disability specific such as our early learning, intensive family support, family counselling and parenting programs. Many of these families are experiencing compounding disadvantage including poverty, domestic and family violence, housing instability and mental illness.

Maslow's hierarchy of needs is evident in these families. While they care deeply about their child's development, the most immediate priority is ensuring that they have a safe place to sleep and food to eat. We know that in 2024, almost one in six children in NSW live in poverty which rises to one in four in areas experiencing other forms of disadvantage.⁴ Families with an adult or child with disability are significantly more likely experience living in poverty. The impact of inaccessible systems and barriers to support is magnified in these families who are already experiencing disadvantage.

One staff member provided an example of a mother of several children, including one with potential (but undiagnosed) developmental delay who was leaving a relationship with significant domestic and family violence. This mother faced significant challenges accessing safe housing, navigating the justice system, supporting her children to continue their schooling, and affording food and other essentials. While she recognised that her child was showing signs of developmental delay, she did not have the resources to pursue a diagnosis or attempt to access services.

Another provided an example of a family with a child with disability who was facing housing instability and potential homelessness. The staff member commented

When the family doesn't know where they will be living next week, how can they be expected to search out and find resources, attend expensive specialist appointments and navigate the complexity of programs like the NDIS?

These families love and deeply care about their children but face incredible challenges in

⁴ NSW Council of Social Services (2024). *Lasting impacts: The economic costs of child poverty in NSW*. Available at <https://www.ncoss.org.au/2024/11/child-poverty-costs-nsw-60-billion-a-year-hurts-us-all/>

meeting their basic needs in a cost-of-living crisis. We appreciate that it is not within the scope of this Inquiry to make recommendations to address the cost of living crisis and other areas of disadvantage. However we urge the Inquiry to make findings relating to the impact of compounding disadvantage on children and young people with developmental delay and disability and their families.

Recommendation:

- That the Inquiry find that children and young people with disability and developmental delay and their families face compounding disadvantage which negatively impacts their ability to navigate systems, receive services and support healthy development and that it is the responsibility of governments at all levels to address systemic disadvantage.

Intersection with the health system

In addition to the early learning system, the health system often represents the first point where signs of disability and developmental delay can be identified. For many families, engaging with a child and family health clinic or General Practitioner (GP) is a key step in identifying and responding to signs of developmental delay.

Primary healthcare

General Practitioners play an important role in identifying signs of developmental delay and providing pathways to diagnosis and services. Unfortunately, increased costs and waiting lists have created barriers for families in developing ongoing and trusted relationships with their GP. For example, the 2024 *Health of the Nation* report found that the average out-of-pocket cost for attending a GP was \$45. For families experiencing disadvantage, this creates a barrier to seeking care.

Our staff also report that families find it difficult to develop a longterm relationship and continuity of care with a GP. Increasingly, families attend medical centres where there are a rotating number of GPs with shared responsibility for patients. This has meant that fewer families have a “family doctor” but rather see whichever GP has availability. As a result, parents and carers do not always feel comfortable disclosing their concerns about their child’s development or feel supported to ask questions.

Families have also reported negative experiences when disclosing their concerns to GPs including feeling dismissed or not being taken seriously. Staff in our services have reported that some local GPs in their communities seem to have a poor understanding of the indicators for disability and developmental delay in young children.

We echo our previous recommendation for the NSW Government to invest in accessible and free pathways to diagnosis which would enable families to seek support through different systems. We appreciate that the funding and delivery of primary healthcare is generally the responsibility of the Australian government and therefore not within the remit of this Inquiry and as such we have not made recommendations about this concern.

Recommendation:

- That the NSW Government and NSW Health engage with peak medical bodies to support ongoing professional education in recognising and responding to indicators of disability and developmental delay.

Child and family health services

Child and family health services represent a critical resource for families, particularly in the younger years. Our staff report that child and family health nurses can provide a safe, non-judgmental and accessible environment for families to receive development checks and referrals onto early intervention services. Unfortunately, our staff also report that there are

critical shortages in areas of highest need. For example, in South-Western Sydney our early learning service reported that there is a single child and family health nurse available for their Local Health District despite the high number of children and families requiring support. Families are therefore unable to receive the support they need or face waiting lists for accessing services.

Recommendation:

- That the NSW Government and NSW Health commit to increasing the availability of community health nurses in areas of highest need including ongoing outreach and engagement with community services.

Children, young people and families who fall through the gaps

We know that the current system does not adequately support all children and young people with disability and their families. Gaps in services, inaccessibility of supports, lack of holistic care and disjointed systems can result in children and young people with disability not receiving the support they need.

Failing to provide evidence-based early intervention services has a significant impact on the lives of children and young people with disability. Our services report that these children become disengaged from services including school refusal and disengagement from education. A Uniting counsellor described a common situation:

They're dropping out of school, school avoidance, school refusal. High levels of anxiety and it stops them from growing and learning and engaging with their peers. And it's very, very hard when children start to disengage and avoid school. Very hard to do therapy and counselling when children have lost trust in the adults around them which is essentially what happens if we don't intervene early.

In the most extreme cases, children with disability and developmental delay are relinquished into voluntary out of home care because their families are unable to provide the support they need at home.

Research conducted by the NSW Bureau of Crime Statistics and Research found that young people with disability are overrepresented both in the number of young people in contact with the criminal justice system and the youth detention system. Critically, it found that a higher proportion of young offenders with disability had their first contact with disability-related services at a later age compared with the total disability cohort.

These outcomes can only be avoided by ongoing, targeted and co-designed initiatives and programs as well as structural reform to address siloed service systems.

Regional and remote communities

Workforce shortages

Regional and remote communities face workforce shortages across key service systems including health, mental health, education and disability services. As a result children and young people with disability and developmental delay in these communities face longer wait lists, reduced service choices and limited availability of services. For example, in Port Macquarie, our OOHC staff report that there are less than three available pediatricians who can diagnose developmental delay. The ongoing and intense need for these services means that children are often only seen once and for a short period of time.

Families can also face geographic challenges in travelling to services, creating additional costs, complexity and time requirements for engaging with supports.

We believe that there are opportunities to consider how services can be delivered in innovative and flexible ways which meet the needs of regional and remote communities. We have provided

a case study of our Wellbeing4Kids service which works collaboratively with children, families and schools to reduce barriers to access.

Case study: Telehealth4Kids

The Wellbeing4Kids program established Telehealth4Kids (TH4K) which designed for children under 12 years of age and their families to access therapy via digital means. These are children and their families who live remotely and in regional areas who cannot access face to face models of therapeutic supports, as well as children who are experiencing school refusal and post COVID anxiety and mental health difficulties.

TH4K allows children to receive services in settings which meet their needs, for example:

- Undertaking play therapy at school with the clinician participating online. The clinician will send resources including activities to the school ahead of time so that the session can be interactive, despite the geographic distance between the clinician and child.
- Calling the clinician while on a “mindfulness walk” to practice techniques for managing anxiety in a space where the child feels calm and safe.
- Participating in therapy sessions from their living room, removing the need for the child and their parents to travel long distances to attend sessions.

The TH4K program won the Technology in Health award at the Hunter New England and Central Coast Primary Health Network 2023 Primary Care Quality and Innovation Awards Night.

Funding, innovation and service delivery

The delivery of foundational supports in NSW will require collaboration between the Australian government, NSW government and community services sector. While not in the terms of reference, we would like to make a general comment about the need to ensure that foundational supports are delivered effectively and meet the needs of communities.

Most importantly, foundational supports should be designed in consultation with children, young people and their families as well as the service providers who provide critical supports which enable them to thrive. The sector is willing and motivated to work with government to codesign solutions and deliver services which are locally based and tailored to the needs of communities. Uniting is eager to contribute to this process however possible.

More broadly, funding structures must enable providers to deliver comprehensive and locally responsive supports including funding for consultation, service delivery, evaluation and review. We believe that these should be a minimum term of five years to ensure that providers have adequate time to develop deep community connections and adapt programs as needed. Funding agreements should also allow providers to reflect, change and restructure supports as needed including funding for evaluation activities. Without specific allocations for evaluation and review, there is a risk that providers deliver programs which are ineffective or fail to meet the needs of communities.

We believe that the NSW Government has the opportunity to make generational change in the lives of children and young people in NSW through the delivery of foundational supports. This Inquiry is a welcome first step in listening to children, young people, families and the sector however the consultation and engagement must continue through the design and delivery of supports.