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

Organisation:

United Nations Youth Australia 25 April 2025

Date Received:



31 March 2025

The Secretariat Select Committee on Foundational and Disability Supports Available for Children and Young People in New South Wales NSW Parliament House, Sydney

Dear Committee Members,

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

UN Youth Australia appreciates the opportunity to provide this submission written by some of our young volunteers on behalf of the over 4000 young people that we engage with every year.

UN Youth Australia welcomes the opportunity to contribute to this critical inquiry. This submission draws on the voices and lived experiences of young Australians who have engaged with our national consultation program, the Listening Tour, including participants across New South Wales.

As Australia's largest youth-led organisation, UN Youth Australia's engagement with young people enables us to amplify their needs, hopes, and policy priorities. In partnership with the Department of Foreign Affairs and Trade, our 2025 Listening Tour has already reached over 1,000 young people from diverse cultural, geographic, and socioeconomic backgrounds - including those from First Nations communities, rural and remote regions, and youth with disability. These conversations underscore that equitable access to early childhood and disability supports is not only a policy imperative - it is a matter of dignity and justice.

Young people repeatedly told us that access to support services in NSW is defined not by need, but by postcode. We heard from students who travel hours each week to access education and healthcare. From families unable to secure therapy due to workforce shortages. From Deaf young people are denied interpreters because they "speak well." From young carers burnt out by bureaucratic systems that misunderstand neurodiversity. And from children with complex disabilities who rely on music therapy to communicate - yet whose supports were nearly cut due to a pricing review that ignored their voices.

This submission examines the role and effectiveness of existing supports, identifies barriers to access, and outlines recommendations to improve services for children and young people in NSW. Our insights are drawn from extensive research, consultations with young people and families, and a commitment to advocating for a more inclusive and equitable support system.

# The Role of Services and Supports in Child Development, Health, and Wellbeing

Early childhood intervention services are essential for identifying and addressing developmental concerns as early as possible. Research consistently shows that early intervention improves cognitive, social, emotional, and physical outcomes, leading to greater independence and long-term success. Key areas of impact include:



- Early Identification and Intervention: Timely support prevents small developmental concerns from escalating into lifelong challenges.
- Parental and Caregiver Support: Providing education and resources enhances caregivers' ability to support their child's needs.
- Educational and Social Inclusion: Ensuring access to appropriate supports enables children to participate fully in education and community life.
- Long-Term Economic and Social Benefits: Investing in early intervention reduces long-term reliance on disability support systems and health services.

# Types of Services and Supports Available and Measures to Improve Access and Effectiveness

# 1. Medical Services

- Paediatricians, child psychologists, and specialist medical practitioners play a critical role in diagnosing and managing developmental disorders.
- Enhancing telehealth services can bridge accessibility gaps in regional and remote areas.

# 2. Community Nursing and Allied Health Services

- Occupational therapy, speech pathology, physiotherapy, and behavioural therapy support children with developmental challenges.
- Expanding workforce training and incentives for allied health professionals in underserved areas will enhance service reach.

# 3. NDIS and Disability Support Services

- The National Disability Insurance Scheme (NDIS) provides crucial funding for children requiring sustained intervention.
- Streamlining the NDIS application process and reducing wait times will improve access.

# 4. Early Childhood Education and Intervention Programs

- Preschool and childcare inclusion programs support children's early learning and development.
- Additional funding for early childhood educators to receive training in special education would strengthen early intervention strategies.

# 5. Service Delivery Models in Metropolitan, Regional, Rural, and Remote NSW

(a) Metropolitan Areas



Services are more readily available, but demand often exceeds supply, leading to long wait times. For example, in 2023, the NSW Department of Health reported that children in Sydney could wait up to 18 months for an autism assessment through public health services, delaying access to essential supports. Such delays can result in missed developmental windows, increased stress for families, and the need for more intensive support later in life. Addressing these gaps requires increased funding for providers and streamlined referral processes to reduce bureaucratic hurdles. For example, families in Sydney often face waiting periods of six months or more for specialist paediatric assessments and allied health services, delaying critical interventions. Increasing funding for more providers and reducing bureaucracy can improve service delivery.

# (b) Regional and Rural Areas

A shortage of healthcare professionals limits access. For example, in some rural NSW towns, families may wait over 12 months for a paediatric assessment or therapy services due to the lack of available specialists. According to the Australian Institute of Health and Welfare (2022), there are only 20.5 allied health professionals per 100,000 people in rural areas, compared to 40.7 per 100,000 in metropolitan regions. This disparity significantly impacts timely access to critical interventions. Incentivising professionals through scholarships, rural placement programs, and increased salaries can improve availability.

#### (c) Remote Communities

Geographic isolation presents unique challenges. In some remote Indigenous communities, children must travel hundreds of kilometres to access basic healthcare services. A 2023 report by the Royal Flying Doctor Service found that Indigenous children in remote NSW have 30% less access to paediatric services than their metropolitan counterparts. Mobile health clinics, community-led initiatives, and culturally appropriate services for Indigenous communities can address service gaps by bringing essential care directly to families.

#### 6. Recommendations for Improvement

(a) Expanding Funding and Workforce Development

More investment is required to recruit, train, and retain professionals in all areas, with a focus on regional, rural, and remote communities.

(b) Enhancing Digital and Telehealth Solutions

Strengthening digital infrastructure to support telehealth services will increase accessibility.

(c) Improving Coordination Across Sectors

Integrating medical, educational, and community-based services will create a seamless support network for children and families. A 2022 study by the NSW Auditor-General found that fragmented service delivery leads to duplicated assessments and delays in care. Establishing centralised case management systems and better inter-agency collaboration will enhance efficiency and reduce the burden on families navigating multiple systems.



(d) Addressing Socioeconomic and Cultural Barriers

Subsidising services for low-income families and ensuring cultural competency among service providers will enhance inclusivity.

#### (e) Community-Led Solutions

Empowering local communities, particularly Indigenous communities, to develop and manage culturally appropriate services will lead to more effective interventions.

However, families across NSW continue to face significant barriers in accessing these services, particularly in rural and regional areas where availability is limited. Addressing these barriers requires a coordinated and well-funded approach to service delivery.

#### 6. Therapies - particularly Art and Music

Music therapy is not simply a recreational activity - it is a recognised, evidence-based therapeutic support that plays a critical role in the lives of children and young people with disability. For many, particularly those with complex communication needs, sensory processing challenges, or non-verbal presentations, music therapy serves as a vital tool for expression, emotional regulation, social connection, and confidence building.

In consultations with Sound Expression Music Therapy Centre and families across New South Wales, urgent concerns were raised regarding proposed changes to NDIS pricing structures that threaten the viability of music therapy services. These changes have, at times, reclassified music therapy as an "activity" rather than a therapeutic intervention - an administrative decision that erases its clinical and developmental value.

Families spoke of the unique and irreplaceable impact music therapy has on their children. For some, it is the only space in which their child can engage meaningfully, connect with peers, or regulate overwhelming emotions. Reclassifying or underfunding music therapy denies these children access to a form of care that acknowledges their strengths, honours their identity, and supports their holistic development.

Moreover, such changes risk reinforcing a deficit-focused approach to disability support, undermining the social model of disability and ignoring the lived experience of children and families. A therapy that allows a child to feel joy, find their voice, or be part of a community must be recognised as essential - not optional.

The Committee is urged to ensure that allied health supports such as music therapy are protected, properly valued, and made accessible to all children who benefit from them. This includes embedding qualitative feedback and lived experience into evaluation frameworks, and recognising that measurable progress does not always take the form of test scores or clinical outputs - but sometimes, a song, a shared rhythm, or a smile.



# The role of diagnostic services, existing gaps and barriers, and measures to improve effectiveness, availability and access of such services

# 1. The Role of Diagnostic Services

(a) Support and Early Intervention

Diagnostic services play a crucial role in the early identification and intervention of various disabilities, including but not limited to Autism, ADHD, intellectual disabilities, learning disabilities, and physical disabilities. Early intervention is essential as it leverages the brain's neuroplasticity during the critical early years, enhancing cognitive, social, emotional, and behavioural functioning. Research indicates that children who engage in early intervention programs are more likely to reach important developmental milestones and excel academically.

Importantly, early diagnosis is also key to the well-being of young people with disabilities as it fosters self-understanding and acceptance, encouraging self-advocacy. It enables timely and appropriate interventions, connecting them with professional practitioners and support systems that address their unique needs in education, workplaces, and personal lives. Early diagnosis also prevents secondary mental health issues, improves long-term outcomes, and reduces stigma. In NSW, reducing wait times and making diagnostic services more affordable and accessible, including through telehealth, are essential measures.

(b) Connection with Professional Practitioners

Effective diagnostic services facilitate connections between young people and professional practitioners, ensuring timely and accurate diagnoses. This connection is vital for developing tailored intervention plans that address the unique needs of young people with disabilities.

(c) Holistic Support in Education Institutions, Workplaces, and Personal Lives

Diagnostic services provide holistic support by integrating medical, educational, and social services. This comprehensive approach ensures that young people with disabilities receive the necessary accommodations and support in educational institutions, workplaces, and their personal lives. For example, individuals with intellectual disabilities benefit from personalised educational plans and workplace accommodations that consider their cognitive and social needs.

- 2. Existing Gaps and Barriers
- (a) Long Wait Times in the Public Sector

One of the significant barriers to accessing diagnostic services is the long wait times, particularly in the public sector. This issue is especially pronounced for mental health services such as psychiatry, where wait times can exceed three months. The average wait time for public mental health services in NSW is approximately 8 weeks, however anecdotally, many have waited upwards of 6 months for treatment.

(b) High Costs for Private Referrals



The high costs associated with private referrals and the provision of extensive reports, NDIS referrals, and ongoing therapeutic treatments pose a significant barrier to accessing diagnostic services. In NSW, the cost of private diagnostic assessments can range from \$1,500 to \$3,000.

# (c) Lack of Understanding of Various Disabilities

There is a notable lack of understanding of various disabilities, including intellectual disabilities, learning disabilities, and physical disabilities. This gap in knowledge can lead to misdiagnoses and inadequate support for young people with these conditions.

(d) Gender Bias in Early Intervention

Gender bias in early intervention is another critical barrier. Research indicates that girls are often underdiagnosed or misdiagnosed, particularly with conditions like ADHD and Autism.

#### (e) Gap in Support for 'Twice-Exceptional' Neurodivergent Individuals

There is a significant gap in support for individuals who present with 'twice-exceptional' neurodivergence, meaning they have both high abilities and disabilities. These individuals often fall through the cracks of the existing support systems.

# (f) Limited Support in Schools

Support in schools is often only provided for students who are failing to meet learning goals, leaving many students with disabilities without the necessary support to thrive. In NSW, only 30% of students with disabilities receive adequate support in mainstream schools.

(g) Gaps for CALD, Rural, Queer and Gender Diverse, or Lower SES Young People

There are substantial gaps in support for culturally and linguistically diverse (CALD), rural, queer and gender diverse, or lower socioeconomic status (SES) young people. These groups often face additional barriers to accessing diagnostic services due to the intersectional barriers present across the healthcare system.

# (h) Lack of Integration Between Medical and Educational Teams

The lack of integration between medical and educational teams means that young people and their families often bear the burden of advocating for themselves. This situation is exacerbated by a lack of time, resources, and specialist knowledge. Despite robust referral letters, means of contact or care team coordination, often a young person or their family is required to navigate their care themselves. It would be more beneficial to ensure each young person's care is holistic and guided by their individual needs.

#### 3. Measures to Improve Effectiveness, Availability, and Access

(a) Increased Availability of Diagnostic Services

Diagnostic services should be more readily available to reduce wait times and ensure timely diagnosis. This includes increasing the number of professionals and facilities offering these services.



# (b) Affordability and Multiple Means of Treatment

Making diagnostic services more affordable and offering multiple means of treatment, such as telehealth, can significantly improve access. Telehealth, in particular, can bridge the gap for individuals in rural or underserved areas. In NSW, telehealth consultations have increased by 40% since 2020.

#### (c) Holistic Approaches to Psychiatric Diagnosis

Psychiatric diagnoses should incorporate more holistic approaches, creating robust care teams and plans that address all aspects of a young person's life and necessary accommodations. For example, integrating mental health services with educational and social support can provide a more comprehensive care plan.

# (d) Access to Services in All Areas

Ensuring access to diagnostic services in all areas, not just central metropolitan regions, is crucial. This can be achieved through mobile clinics, telehealth services, and increased funding for rural health initiatives.

#### 4. Examples of Best Practices for Holistic Care

# (a) Enhanced Legal Support and Advocacy

A holistic approach to disability care includes advocating for legal protections that promote equal access to healthcare, education, employment opportunities, and other essential services. Legal support helps protect the rights and interests of individuals with disabilities.

# (b) Improved Quality of Life

Holistic care addresses all aspects of an individual's life, improving their overall quality of life. This includes physical health, emotional well-being, and social integration. For example, personalised care plans that involve family members and community resources can create a robust support network.

#### (c) Better Treatment Outcomes

A holistic approach to disability care improves treatment outcomes by considering the interconnected aspects of a person's life. This includes integrating medical, psychological, and social services to provide comprehensive care. For example, post-diagnosis a young person should be equipped with connections to services such as Occupational, Speech, or Physical therapy providers, and feel empowered to access these services. Members of a care team must communicate effectively, so appointments and referrals are an effective use of time and money.

#### (d) Individualised Care and Support



Holistic care emphasises individualised care plans that consider the unique needs and preferences of each person. This approach fosters autonomy and dignity, leading to more meaningful outcomes and higher satisfaction.

# Measures to implement recommendations of the NDIS Review Final Report and the Disability Royal Commission Final Report in relation to foundational supports

The NDIS Review Final Support emphasises the need for government funded support that is accessible and increased in scope. This is great, but can also be extended and implemented further:

1. As per Action 1.1, National Cabinet should design, fund, commission, and expand supports. These supports should include:

- Psychological, emotional, and financial support services for parents and guardians, including but not limited to financial counselling, housing support, clinical psychologist sessions
- Accessible online information about other support services, referral process, and eligibility requirements that are easy to understand

2. As per Action 1.3, the redesign should be performed with consultation and input of young people with disabilities and their parents/guardians, as well as medical and educational experts

3. As per Recommendation 2, young people who are not eligible for NDIS should be able to access the broadened support systems, Medicare, and other essential services with ease, to reduce stress and ensure quality of life

4. As per Recommendation 3, providing a fair and consistent pathway,

- Other structural societal barriers must be acknowledged and then addressed, to ensure existing inequalities do not restrict access to services. To do this
  - (a) Cultural training, anti-sexual harassment and sexual (and other abuses) abuse training, MHFA training, etc. should be provided to frontline workers, with a specific focus on how young people with disabilities can be impacted by such issues
  - (b) All information must be presented in accessible formats, including audio options, easy to read English, and be translated into multiple languages for people from CALD backgrounds

5. As per Recommendation 9, information on NDIS schemes for children starting from nine years old can be displayed and provided at schools, so parents are aware of such systems of support

6. The Disability Royal Commission Final Report includes goals such as enabling autonomy and access, and, achieving inclusive education, employment, and housing

- Access can be improved through increased access and information on financial support services, housing services and programs, and other essential services that cover young people's basic needs
- Information on services, and provided at services, should be accessible and easy to understand. This includes access to multilingual disability support workers

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7. Improving the experience of First Nations people with a disability

- This can only improve alongside other government and societal actions and initiatives that address racism and embedded structural inequalities. However, measures that can work towards improvement for young First Nations people with disabilities include:
  - 1. Having First Nations social and medical support workers, or workers trained in cultural awareness and safety
  - 2. Providing information on services in First Nations languages

#### Conclusion

Children and young people with disabilities deserve timely, high-quality, and accessible support services that enable them to reach their full potential. While NSW has made progress in providing foundational and disability supports, significant gaps remain, particularly in diagnostic services, workforce availability, service coordination, and accessibility for marginalised communities.

UN Youth Australia urges the Select Committee to prioritise the reforms outlined in this submission. and work towards a more inclusive and effective support system for children and young people with disabilities.

We welcome the opportunity to further contribute to this inquiry and advocate on behalf of young Australians.

Yours sincerely,

<u>With contributions from:</u> Satara Uthayakumaran - Australia's Youth Representative to the United Nations Ruby Abercromby - New South Wales Youth Representative Listening Tour Coordinator

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# Supporting Material:

Agency for Clinical Innovation (ACI), "Consumer Enablement and Life Contexts," *NSW Health*, 2023, <u>https://aci.health.nsw.gov.au/projects/consumer-enablement/life-contexts/specific-needs</u>.

Australian Institute of Health and Welfare (AIHW), "Health of Young People," *AIHW Reports*, 2022, <u>https://www.aihw.gov.au/reports/children-youth/health-of-young-people</u>.

Healthy Primate, "The Power of a Holistic Approach in Disability Care," *Healthy Primate*, 2023, <u>https://thehealthyprimate.org/the-power-of-a-holistic-approach-in-disability-care/</u>.

Heart 2 Heart Healthcare, "The Role of Early Intervention in Developmental Disabilities," *Heart 2 Heart Healthcare Blog*, 2023,

https://www.h2hhc.com/blog/the-role-of-early-intervention-in-developmental-disabilities.

MJA Insight+, "Needs, Strengths: Supporting Child Health in Remote Australia," *MJA Insight+*, October 17, 2022,

https://insightplus.mja.com.au/2022/40/needs-strengths-supporting-child-health-in-remote-australia/.

NSW Health, "Principles for Holistic Mental Health Care," *NSW Health*, 2022, <u>https://www.health.nsw.gov.au/mentalhealth/psychosocial/principles/Pages/holistic.aspx</u>.

NSW Health, "Youth Health and Wellbeing Assessment Guideline," *NSW Health*, 2022, <u>https://www.health.nsw.gov.au/kidsfamilies/youth/Pages/yhw-assessment-guideline.aspx</u>.

NSW Parliament, *Health Outcomes and Access to Services*, Report No. 57, PC 2, 2023, <u>https://www.parliament.nsw.gov.au/lcdocs/inquiries/2615/Report%20no%2057%20-%20PC%202%20-%20Health%20outcomes%20and%20access%20to%20services.pdf</u>.

Oliver Pearson and Rachel M. Smith, "Health Services for Aboriginal and Torres Strait Islander Children in Remote Australia: A Scoping Review," *ResearchGate*, 2023, <u>https://www.researchgate.net/publication/367630971\_Health\_services\_for\_Aboriginal\_and\_Torres\_Strait\_I</u> <u>slander children in remote Australia a scoping review</u>.

Royal Flying Doctor Service, "Close the Gap Day 2023," *Flying Doctor*, 2023, <u>https://www.flyingdoctor.org.au/news/close-gap-day-2023/</u>.

University of Sydney, "Average Wait Time for Autism Assessments in Children Is over 3 Years," *Brain and Mind Centre*, February 6, 2023,

https://www.sydney.edu.au/brain-mind/news-and-events/news/2023/02/06/average-wait-time-for-autis m-assessments-in-children-is-over-3-y.html.