

Submission
No 56

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

Organisation: Down Syndrome NSW

Date Received: 27 April 2025

24 April 2025

Ms Abigail Boyd MLC
Deputy Chair
Select Committee on Foundational and Disability Supports Available for Children and Young
People in New South Wales
Parliament of New South Wales
Macquarie Street
Sydney NSW 2000

Dear Ms Boyd and Committee Members,

Submission: Inquiry into Foundational and Disability Supports Available for Children and Young
People in NSW

On behalf of Down Syndrome NSW, I am pleased to submit our response to the Inquiry into
Foundational and Disability Supports Available for Children and Young People in New South
Wales.

As a trusted, long-standing advocacy and support organisation, Down Syndrome NSW plays a
critical role in supporting children and young people with Down syndrome, their families and
carers, and the broader health, education and community service systems.

Our submission highlights the need for a human rights-based, inclusive approach to
foundational supports, the importance of needs-based access, and the essential role of
specialist organisations in delivering trusted, effective, community-led supports.

We welcome the opportunity to contribute to this Inquiry and would be pleased to provide any
further information or participate in public hearings if required.

Thank you for considering our submission.

Yours sincerely,

Deborah Begg
General Manager

Down Syndrome NSW



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

Introduction

Down Syndrome NSW (DSNSW) welcomes the opportunity to contribute to this Inquiry.

Foundational supports must be delivered early, timely, and based on a human rights approach, not dependent on assessments and NDIS eligibility. However, before any reforms can be effectively implemented, it is critical that a clear, shared definition of foundational supports is established with the community, families, and advocacy organisations.

Access must be based on functional needs at the time of access, not diagnosis alone, ensuring children and young people receive the right support at the right time. Timely intervention and advice will reduce the need for longer-term supports. Wherever possible, foundational supports should be integrated into mainstream service systems, with specialist organisations like DSNSW resourced to work alongside them.

Alignment with NDIS Review and Disability Royal Commission

The design of foundational supports must align with key principles from the NDIS Review and Disability Royal Commission, particularly:

- Upholding the human rights of children and young people with disability;
- Ensuring easy and equitable access;
- Investing in early intervention as a critical protective factor;
- Promoting a truly inclusive society where children with disability and their families belong and thrive.

The Critical Role of Systemic Advocacy

Systemic advocacy is essential to ensure that gaps are identified and solutions implemented at policy and practice levels.

Continued investment in systemic advocacy is essential to:

- Identify emerging gaps early;
- Develop education, supports and programs to address those gaps;
- Hold systems accountable for rights-based, inclusive service delivery;
- Build the capacity of people with disability and families to advocate for themselves.

Seamless Pathways Across Services

General and Targeted Foundational Supports must work in an integrated and consent-based way, avoiding fragmentation and duplication. Families should not have to retell their stories multiple times.

A seamless system would:

- Promote warm referrals and sharing of information with consent;
- Link health, education, early childhood, and disability services in a coordinated way;
- Ensure families are supported by trusted peer workers or support staff who can guide them through accessing the right services;
- Reduce transition gaps between service types and life stages by providing ongoing, consistent support.



Navigating NDIS pathways are complex and difficult for families of children with Down syndrome, and the ECI pathway through the NDIS has KPIs for organisations who deliver the program for them that include numbers of people referred for NDIS plans and referred away.

To ensure that those who need to progress down that pathway get the support they need, a process of support from foundational supports needs to also be considered.

Health System Gaps and Needs

It is regularly reported that the first experience of future parents and new parents of a child with Down syndrome with the health system is negative and can be traumatic.

Children with Down syndrome often have complex health needs from birth, including cardiac, respiratory, hearing, feeding, and endocrine issues. The health system is not universally equipped to meet the needs of parents or children with Down syndrome, and where available, long waiting lists mean access to support is often delayed.

This means:

- Limited access to GPs, paediatric specialists, allied health services, and diagnostic services;
- Significant travel requirements for basic health assessments or specialist care.

In regional, rural and remote areas, these gaps are amplified.

Foundational supports must prioritise health inclusion by:

- Providing positive post-diagnosis and postnatal support to families;
- Offering ongoing health education and peer support;
- Strengthening timely access to community nursing and allied health services, including mobile and telehealth services for remote areas;
- Educating health professionals including, but not limited to; maternity teams, nurses, GPs, paediatricians, geneticists — in best practice for disability-inclusive healthcare;
- Embedding self-advocacy and peer-led health education;
- Promoting inclusive communication training for health professionals, co-designed with people with Down syndrome.

DSNSW supports families and health professionals through a range of foundational activities, including:

- The Congratulations Initiative, providing positive, inclusive postnatal and prenatal engagement and peer connection;
- Family capacity-building workshops and information sessions, helping families build skills and knowledge to navigate health systems;
- Information and referral support for families seeking appropriate services and resources;
- Education sessions for health professionals and students, improving understanding of Down syndrome, communication skills, and inclusive healthcare practices.

Education System Gaps and Needs

Mainstream and supported education settings are not adequately equipped to educate students with Down syndrome. Authentic choice for mainstream education can only be made by parents when mainstream settings are truly inclusive. Teachers often struggle to access the support they need to ensure that individual learning goals



for students with Down syndrome are met, while also working to deliver curriculum outcomes across the whole classroom.

This is even more pronounced in regional and remote communities where:

- Schools are smaller and isolated;
- Specialist support units are rare;
- Access to allied health and inclusion expertise is limited.

Key gaps include:

- Lack of curriculum adaptation to diverse learning needs;
- Insufficient training in inclusive practices for teachers and aides;
- Gaps in positive behaviour support and transition planning.

Transition to school is a critical milestone for children with intellectual disabilities, particularly those with Down syndrome. While some support exists outside of the NDIS — such as transition-to-school plans developed by preschools and schools, and support from state-funded inclusion programs — these services are often fragmented, inconsistent across regions, and in many cases come too late or require significant advocacy to access.

Waitlists for paediatricians, therapists, and specialised transition support can exceed 6–12 months, particularly in regional and remote areas, leaving families without the timely support they need to make informed choices.

There is a notable absence of structured, systemic support to assist schools and educators in preparing for the enrolment of students with intellectual disabilities. This gap is even more pronounced when considering the specialised knowledge and strategies required to effectively support the unique learning profiles of students with Down syndrome. The lack of targeted professional development and resources leaves many teachers feeling underprepared to meet these students' needs.

As highlighted by the NSW Department of Education, while inclusive education is a priority, there remains a need for more comprehensive support and training for educators to effectively implement inclusive practices. This results in unnecessary anxiety for educators, inconsistent access to adjustments, and poor continuity of learning for students. Many families report that they feel they must "fight" for a place in their local school, and that transition becomes a test of persistence, not readiness.

In our communications with educators in schools, several gaps in the existing system are identified:

- **Limited School-Based Support:** While the NDIS provides funding for therapies and support services, it often lacks direct, school-based interventions that are crucial for students with Down syndrome;
- **Inadequate Professional Development:** There is a scarcity of specialised training for educators to effectively support students with Down syndrome, leading to challenges in implementing inclusive education practices;
- **Insufficient Regional and Remote Access:** Families and schools in regional and remote areas frequently face difficulties accessing specialised services due to geographical constraints and limited availability of professionals.

At Down Syndrome NSW, we provide a targeted, online foundational support model that fills this gap effectively and equitably. Through our free "Starting School", "Transition to High School", and "Unlocking Potential" workshops (among others), individualised phone and email support, and co-designed resources (including visual



storybooks, transition checklists, and teacher tip sheets), we support families to make confident choices and equip schools to welcome students with Down syndrome.

Our Education Team has developed a comprehensive school program. We work directly with all schools in New South Wales to support the education of students with Down syndrome. We strive to ensure that remote and regional schools have the same model and level of support as metropolitan schools.

Support includes (but is not limited to):

- Family and Staff Meetings
- Specialist Collaboration
- Curriculum Support
- Classroom Observations
- Professional Learning
- Resource Provision
- Ongoing Support
- Regional Outreach
- Research Translation
- Network Building

This model is already achieving outstanding outcomes — easing the transition process, reducing stress for families and schools, and ensuring children with Down syndrome start school with the best possible foundation for success.

Diagnostic Services: Access, Gaps, and Improvements Needed

Timely and accurate diagnosis is critical to early intervention success. However, families report delays in accessing diagnostic services.

Families should not have to rely on or wait for diagnosis to receive foundational supports.

Systemic improvements needed:

- Expand access to diagnostic services, including tele-assessment options;
- Increase training for primary health and community health workers to recognise developmental concerns early;
- Provide funded support for families post-diagnosis to access services without delay.

Supporting Regional, Rural, and Remote NSW

Families in regional, rural, and remote areas must not be left behind. Foundational supports must:

- Be accessible via face-to-face, telehealth, and outreach models;
- Build local capacity through partnerships with community-based organisations;
- Incentivise specialist workforce attraction and retention outside metropolitan centres;
- Fund culturally safe and place-based service models.

Culturally and Linguistically Diverse (CALD) Communities

Children and young people with disability from culturally and linguistically diverse (CALD) backgrounds face additional barriers when accessing foundational and disability supports.

These barriers include language difficulties, cultural misunderstandings, stigma, lack of accessible information, and limited knowledge of available services.

Foundational and disability supports must be designed and delivered in a way that responds to these needs.



This includes funding:

- Accessible, translated information about disability services and foundational supports in a wide range of community languages;
- Culturally safe services, including appropriate training for mainstream health, education, and community staff;
- Programs that utilise CALD families with lived experience to connect with and support new families;
- Programs that actively address stigma and discrimination that CALD families may experience when seeking disability supports;
- Outreach efforts to CALD communities through local events, religious and cultural networks, and ethnic media.

Workforce Issues

Foundational support reforms must consider:

- Building a skilled and diverse workforce that reflects the communities it serves;
- Investing in targeted training around disability inclusion, cultural safety, and working in rural and remote contexts;
- Supporting career pathways for people with disability, including as peer support workers and advocates;
- Supporting career pathways for carers.

Workforce shortages — particularly in regional NSW — are critical barriers that must be addressed through incentives, training, and sustainable employment models.

The Role of Down Syndrome NSW in Foundational Supports

Foundational supports provide essential early and lifelong building blocks for children and young people with disability and their families. They promote early intervention, build inclusive communities, and reduce reliance long term supports, and crisis-driven services.

Down Syndrome NSW plays a vital role in delivering both general and targeted foundational supports. Our work spans information, early intervention, peer support, systemic advocacy, and building inclusive practices across mainstream services.

DSNSW plays a vital role through:

- Information, advice, and referrals for families and individuals;
- Education and early intervention programs, including pre- and postnatal support;
- Peer connection and support groups across life stages;
- Family capacity-building workshops and information sessions;
- Play-based early childhood groups and community engagement opportunities, supporting toddlers and young children with Down syndrome and their families.

In addition to providing direct supports to families, DSNSW plays a critical role in building inclusion across mainstream service systems. We work alongside health services, education settings, and community organisations to promote inclusive practices, deliver professional training, support curriculum adaptation and positive behaviour approaches, and advocate for system-level changes that enable children and young people with Down syndrome to thrive.



Through partnerships, community education, and advocacy, DSNSW strengthens the capacity of mainstream services to be welcoming, accessible, and effective for all.

Much of this work is made possible through a combination of funding sources. While systemic advocacy is supported through ongoing advocacy funding, many of our foundational programs rely on short-term project funding or philanthropic support. With recurrent targeted funding, DSNSW could significantly expand the scale of these programs to reach more children with Down syndrome, their families, and mainstream and community services across New South Wales.

Recommendations

1. Commit to sustained investment in systemic advocacy organisations like DSNSW.
2. Develop a clear, shared definition of foundational supports based on functional need.
3. Prioritise regional, rural and remote access through outreach, telehealth, and place-based services.
4. Ensure culturally safe, accessible services for CALD families across health, education, and community systems.
5. Integrate diagnostic services early and close to community to enable faster access to supports.
6. Build a diverse and skilled workforce equipped for disability inclusion and rural service delivery.
7. Invest in specialist, peer-led foundational programs alongside mainstream offerings.
8. Anchor reforms in a human rights model, ensuring participation, belonging, and equity.
9. Ensure seamless pathways between General and Targeted Foundational Supports and mainstream services.
10. Continue to engage DROs and specialist organisations in all aspects of reform design and delivery.