Submission: Thriving Kids

Ensuring a strong voice for all people with Down syndrome, their families and carers

October 2025

DOWN SYNDROME NEW SOUTH WALES

About Down Syndrome NSW

The Down Syndrome Association of NSW was established in 1980 by parents of young people with Down syndrome. As the children of the founding members grew to adolescence and adulthood, so too our services extended to all life stages. We now provide information and support, advocacy, capacity building workshops, training in schools, community participation programs, pre-natal expert advice, new parent resources and support and specialist employment preparation and connection.

We are an enthusiastic team of professionals with expertise in our relevant fields of service provision, support and advocacy. Some of us have lived experience with a family member with Down syndrome, some bring a range of expertise and industry experience. We are here to support you – all working together to help our members with Down syndrome achieve their full potential.

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Introduction

Down Syndrome NSW (DSNSW) is the peak body for people with Down syndrome and their families across New South Wales. We provide information, support, and advocacy to promote the rights and wellbeing of people with Down syndrome.

We recognise that the Thriving Kids initiative is aimed at supporting young children with mild to moderate developmental delay and autism. Children with Down syndrome have a permanent and significant disability and will require lifelong supports and services under the NDIS. However it is important that the views of people with Down syndrome, their families, and their supporters are represented in the development of policies and services such as the redesign of supports for children that include changes to access to the NDIS that affect their lives.

Reforms to NDIS access, and the establishment of additional supports outside the NDIS, must be carefully designed with input from early childhood early intervention experts and families.

Down Syndrome NSW supports any program that provides more children with responsive early childhood developmental supports. In preparing this submission, DSNSW has consulted with and endorsed the submission by Children and Young People with Disability Australia, and consulted with Down Syndrome Australia.

In their early years, children with Down syndrome significantly benefit from inclusion with their peers in local play-based groups, childcare, preschools, and primary schools—when provided with evidence-based additional support for skill building necessary for meaningful participation and inclusion. As with all young children, there is wide diversity of abilities among children with Down syndrome. Their inclusion must therefore be supported in a range of mainstream and other services with responsive resources.

In preparing this submission, DSNSW has considered the Thriving Kids Inquiry Terms of Reference, with a focus on:

- the effectiveness of current (and previous) programs and initiatives that identify children with developmental delay
- equity and intersectional issues
- mechanisms to allow a seamless transition through mainstream systems for all children with mild to moderate support needs.

Recommendations

1. Ensure a flexible and integrated early childhood support service system.

The Thriving Kids initiative must clearly integrate with other early childhood services and programs and the NDIS to create support pathways that can both include the child in regular mainstream activities, Thriving Kids initiatives and respond to their specific individual learning needs.

It is essential that children with Down Syndrome are enabled participate in regular activities and to attend local playgroups, local childcare, local preschools and local primary schools while receiving the more specific evidence based supports they might need to maximise early years development.

Because of the wide range of abilities among children with Down syndrome, particularly in infancy and early childhood, many may present with mild to moderate developmental delay alongside other indicators and conditions associated with Down syndrome. Some may also present with early indicators of autism. It is critical that children with Down Syndrome who need the same supports as Thriving Kids can equitably access those supports, and not be segregated even further from their age peers.

DSNSW is concerned that, without flexible and integrated pathways, children could be inappropriately channelled between service systems without consideration of their individual needs. We therefore advocate that all programs for young children be integrated into a well-considered continuum of support, aligning boundaries and using a flexible approach so that no child falls through the gaps.

In advocating for a flexible and integrated early childhood early intervention support service system, questions remain in the design of the Thriving Kids program. These questions include:

- New Medicare claim items covering allied health have been announced as part of Thriving Kids. Will these also be available to children on the NDIS pathway, including children with Down syndrome?
  - How will this affect access to state allied health services for children with Down syndrome?
  - How will these interact with therapy and allied health in NDIS plans?
  - How will Medicare Chronic and Complex Care Plans work alongside NDIS plans? For example, is the NDIS intended to commence when Medicare runs out? If so, how will continuity of support be ensured between funding models?

- Will reforms to the NDIS pathways for eligible children be designed in parallel with the Thriving Kids pathway

How will Thriving Kids align its entry criteria, eligibility assessments, and progress assessments with the NDIS, so that children do not fall through gaps at entry or during program participation?

- How will Thriving Kids identify and refer children who need specific therapies and supports (e.g. speech therapy, hearing supports, or vision supports)? Research shows early identification of such needs is critical, as they can significantly contribute to developmental delay and require prompt, evidence-based intervention to achieve positive outcomes.

2. Ensure that any new early childhood program does not segregate children with Down Syndrome in access to early childhood supports and services.

Hard boundaries between early childhood programs can only serve to separate children and could result in reduced outcomes for the individual child and their family.

Pathways into Thriving Kids should not result in closed doors for children with Down syndrome who meet the Thriving Kids criteria. Nor should service providers that provide Thriving Kids exclude children with Down syndrome if those are the most appropriate supports needed for that child. However, the funding sources for those appropriate supports could vary.

If service organisations align exclusively with specific programs, children with Down syndrome could be driven into a segregated tertiary[1] service system with few opportunities for inclusion in local services or with peers with different needs. DSNSW sees lifelong benefits from early inclusion in local communities. Failure to prioritise inclusion could lead to lower developmental gains and higher long-term support needs.

Children with Down syndrome need both mainstream experiences to develop their social skills and to learn to function in regular settings, as well as more targeted tertiary evidence based early childhood early intervention supports to improve individual developmental outcomes depending on the capacity of the individual child.

[1] Primary services for all children (e.g. general community and facilitated playgroups and general parenting support programs); Secondary services for children in population groups at risk of poor developmental outcomes (e.g. children in socially disadvantaged population groups such as locations or cohorts with significant percentages of children developmentally at risk as identified in Australian Early Development Census data); Tertiary highly targeted evidence based models of early childhood early intervention supports for children with significant developmental delays arising from disability and or chronic health conditions, that focus on improvements in individualised developmental goals

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There are no gaps between programs for young children so that families can access the services and support they need most and that will most benefit each young child at each developmental stage.

All early childhood intervention programs must allow children to move between programs where needed, stepping up or down in support, so families can access what is most beneficial at each developmental stage.

DSNSW is concerned that poorly integrated programs may push families into fragmented service models (e.g. multiple uncoordinated office based visits to speech therapists, physiotherapists, occupational therapists, psychologists, etc.).

Instead, DSNSW advocates for an evidence based Family Centred Practice approach with a multidisciplinary allied health team approach with a key worker assigned to a child and their family. This model delivers a combination of individualised community based interventions delivered in the child's regular settings of the home, in groups, childcare, preschool and primary school, with additional targeted group play based strategies facilitated by allied health and specialist developmental educators that build specific skills for children to be able to be included successfully in community settings. These evidence-based approaches are vital for closing developmental gaps for children.

This evidence-based Family Centred Practice multi-disciplinary team/key worker model will result in

- A measurable reduction in developmental gaps for the individual child
- More effective use of evidence based early childhood early interventions that both build skills for successful inclusion and target individual developmental goals
- Building the capacity and confidence of parents and family as their child's first developmental teachers
- Advancing the knowledge base, capacity and confidence of mainstream supports such as childcare educators, group facilitators and teachers in preschool and primary school, where the child with developmental delay attends.

3. Ensure that children with Down syndrome who need any of the services/supports available under Thriving Kids can access and use these services.

Beware of creating parallel service systems for children with similar developmental and support needs, based solely on diagnosis. The focus should be the needs of the child

thereby creating more efficient, effective and integrated service systems that provide better outcomes for children, regardless of sources of funding.

A diagnosis of Down syndrome should not automatically channel children into only specialised segregated services and supports. It is critical for positive developmental outcomes for children with Down Syndrome that they have access to both inclusive local supports and when assessed as needed targeted specialised evidence based early childhood early intervention programs.

4. Ensure genuine co-design with experienced parents and families, with disability and other advocates, and with community based experts.

DSNSW strongly advocates for co-design, to:

- to ensure programs will work for those they are intended to reach and impact
- to ensure that First Nations children and families have access to services in ways that most respond to their cultural and developmental needs
- to ensure that children from culturally and linguistically diverse backgrounds have access to appropriate services
- that children and families in regional and remote areas can receive the early childhood services they most need in ways that suit them
- that Thriving Kids is aligned on a well considered integrated continuum of primary, secondary and tertiary supports including NDIS to ensure that children can access the most appropriate supports at the right time
- that other support systems, e.g. health, child protection etc, that can impact early childhood, and families have been considered in the design of the new program so that no child is left behind.

Conclusion

DSNSW understands that Thriving Kids is in its very initial stages of design. We encourage the Department of Health, Disability and Ageing to commit to co-design and consultation at every stage of the design and implementation of the new program.

DSNSW would welcome further input into Thriving Kids at ongoing stages of its progress. Further we would welcome feedback on the questions posed in this submission.

DSNSW thanks the Department of Health, Disability and Ageing for the opportunity to provide this submission to the Inquiry into the Thriving Kids initiative.

About Down Syndrome

Down syndrome is a genetic condition, sometimes referred to as Trisomy 21. It is the most common genetic disability. There are approximately 13,000 people in Australia with Down syndrome. The birth rate in Australia for Down syndrome is one in every 1,100 births. Evidence tells us that 9 out of 10 pregnancies in Australia are terminated if Down syndrome is detected.

Most people have 23 pairs of chromosomes, making 46 in total. People with Down syndrome have 47 chromosomes in their cells, having an extra of chromosome 21.

People with Down syndrome have:

- Areas of strengths and other areas where they need support;
- Some level of intellectual disability;
- Some characteristic physical features;
- Increased risk of some health conditions;
- Some developmental delays and learning difficulties.

Down syndrome is a genetic condition, it is not an illness or a disease. It is nobody's fault. There is no cure and it does not go away.

In the 1950's (not that long ago), the life expectancy for people with Down syndrome was as low as 15 years of age. In recent times, progress in medical and social sciences has improved the quality of life enjoyed by people with Down syndrome. In Australia today, the life expectancy or Down syndrome averages 60 years of age.

Whilst this is a milestone to be celebrated, it also presents us with the first generation of people with Down syndrome who will, in the main, outlive their parents. This creates an even greater need for representative associations like Down Syndrome NSW to provide critical services, supports and advocacy at all stages across the lifespan.

With the right supports, people with Down syndrome are able to live full and active lives in their communities. From education, to employment, to community participation, to relationships and housing options, people with Down syndrome enjoy the same needs and aspirations just like everyone else. However, achieving these goals can be harder for people with Down syndrome, with some level of support needed to help them achieve the kind of life that most people take for granted.

Down Syndrome NSW proudly works with passion to support all people with Down syndrome to live inclusive, valued and active lives.

Our Important Work: Down Syndrome NSW

We provide services and supports currently to all people with Down syndrome in NSW, their families and carers across the full lifespan including:

- Information and support;
- Library and resources;
- Workshops and training;
- Parent support networks and regional hubs;
- Prenatal and early years resources and support;
- Inclusive education support, teacher training and behaviour management;
- Transition to school, school years and teens support and advice;
- Post school years transitions
- Community engagement and participation for children, teens and adults;
- Accessibility support to participate in events and access infrastructure.
- Health, sexuality and ageing advice, advocacy and support;
- Guardianship and wills resources;
- Self-advocacy, capacity building and mentoring;
- Individual advocacy support, advice and resources;
- Systemic advocacy, policy submissions and research.
- Community capacity building, awareness, inclusion and social capital.

We work to promote and represent the views of people with Down syndrome, their families and carers in all that we do. We are governed by a Board comprised of parents and family members.

We work with government and our partners to support an inclusive, vibrant and diverse Australia where every person with disability is heard and valued.

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