

DSA Early Years Strategy Submission

April 2023

Introduction

Down Syndrome Australia (DSA) was established in 2011 as the peak body and representative organisation for people with Down syndrome and their families in Australia. Our purpose is to influence social and policy change and provide a national profile and voice for people living with Down syndrome. Our vision is an Australia where people living with Down syndrome are valued, reach their potential, and enjoy social and economic inclusion. All our work is informed by the United Nations Convention on the Rights of Persons with Disabilities.

DSA and our State and Territory member organisations work together to provide all people with Down syndrome and their families with information and support. Young children with Down syndrome (0-5 years) and their families are one of our specific targeted cohorts.

DSA welcomes the opportunity to provide input into the Australian Government's Early Years Strategy. Our submission relates to the Strategy's:

- a. Structure
- b. Vision
- c. Outcomes
- d. Policy Areas
 - Antenatal
 - Health
 - Education
 - NDIS
 - Family support
 - Community attitudes
- e. Principles

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Structure

DSA agrees with the current proposed structure of The Early Years Strategy. The submission process may uncover the need for changes to the structure. We ask the Australian Government to consider a flexible structure to allow for changes resulting from consultation and the development of the Strategy.

Vision

What vision should our nation have for Australia's youngest children?

Every child has the full enjoyment of all human rights and freedoms, and the opportunities and supports to reach their individual potential in a safe and inclusive community.

Outcomes

What mix of outcomes would you like to see in the Strategy?

The outcomes we would like to see in the Early Years Strategy are outlined below. The Policy priorities to achieve these outcomes are expanded on in section d. below.

- Universal access to early childhood education and care settings, where every child is afforded supports they need for optimal development and inclusion.
- The Early Years Strategy to include the transition to school period, which for some children happens at the age of six, not five.
- Place-based, wrap-around family support available across Australia to any family wishing to access it.
- New parenting supports provided in a community location and/or online.
- A higher level of support for families whose child is born with, or diagnosed during early childhood, with a disability or developmental delay.
- Health professionals and health services are equipped to provide good health care and health outcomes for all children.
- Clearer systems and processes between the key areas of early years including health, education, community, NDIS, and other specialist systems.
- Improved community attitudes towards children with disability and other diversity.

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Policy Priorities

Our response to each of the policy priorities covers what the area is, why it should be included and what the Commonwealth should do to improve outcomes in this area. To improve coordination and collaboration in developing policies for children and families, we recommend that the Commonwealth adopt a co-design model with representative organisations.

Antenatal Period

"I would like to see expecting parents receive support and up to date facts and positive language used."

– Parent of a young child with Down syndrome, South Australia

Many prospective parents do not receive accurate and objective information before prenatal screening, or upon receiving a high chance result or diagnosis¹. The government must ensure prospective parents have the information they need to make informed decisions about prenatal screening for chromosomal conditions such as Down syndrome.

The Department of Health and Aged Care (DOHAC) has produced [Pregnancy Care Guidelines](#) that include guidelines on prenatal screening. A coordinated approach and training to support their implementation is needed.

The [National Roadmap for Improving the Health of People with Intellectual Disability](#) recommends DOHAC work with organisations such as Down Syndrome Australia to ensure accurate, evidence-based information about Down syndrome and other diagnosis is available to parents during the pre- and post-natal periods. This work needs to be prioritised to ensure prospective parents are appropriately supported. The government can act on this recommendation through the [Intellectual Disability Health Curriculum Development Project](#). This project will support universities to integrate intellectual disability health care principles and best practice into their curricula. The core capabilities and learning outcomes must include ways to discuss prenatal screening and provide up to date information that uses neutral language.

Existing health professionals also need to receive this training and information. DOHAC could promote training, such as DSA's Health eLearning program currently in development, and also ensure DOHAC's [Primary Care Enhancement Program for People with Intellectual Disability](#) training modules include this information.

¹ Constantine M, Allyse M, Rockwood T, Wall M, De Vries R. Imperfect informed consent for prenatal screening: Lessons from the quad screen. *Clinical Ethics*. 2014;9(1):17–27.

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Families need support during the antenatal period to prepare for what it means to have a child with Down syndrome in the family. The government should provide access to counselling by appropriate health professionals and support to connect to other families through Down Syndrome Australia and our State and Territory member organisations.

Health

I would like to see access to health care without diagnostic overshadowing so that each child can thrive and receive health care to meet their individual needs without assumptions being made based on quality of life.

– Parent of child with Down syndrome, ACT

People with intellectual disability, including children with Down syndrome, have significantly poorer health outcomes than the general population². Misdiagnosis, diagnostic overshadowing, lack of knowledge and training and negative attitudes are considered to contribute to these poor health outcomes.

The government needs to focus on two key areas to ensure improved health care and health outcomes for children with Down syndrome: health assessment tools and increased training and support for healthcare professionals.

Health assessment tools

The Commonwealth should adopt existing growth charts for children with Down syndrome used in other countries (e.g., USA, UK) in the short term. In the longer term, invest in developing an Australian-specific set of charts.

The Commonwealth should, in conjunction with relevant experts, develop a child-specific version of the [Comprehensive Health Assessment Program](#) (CHAP). Alternatively consider adopting the American Academy of Paediatrics Health Supervision Guidelines as a standard of care for all annual health checks involving children with Down syndrome.

Publicising and promoting the use of current or future tools to GPs and parents.

² Troller & Small (2019). Health Inequality and People with Intellectual Disability: Research Summary. [Research-Analysis-Health-Status-of-People-With-Intellectual-Disability.pdf \(cid.org.au\)](#)

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Training for health professionals

To help ensure health professionals receive appropriate training and information on supporting and treating people with Down syndrome and intellectual disability informed by people with lived experience, and expert representatives, The Commonwealth should:

- Include DSA in the development of health learning outcomes and curriculum for universities as part of the [Intellectual Disability Health Curriculum Development Project](#).
- Promote training, such as DSA's Health eLearning program currently in development, to GPs and Paediatricians on the health co-morbidities common in children with Down syndrome.
- Improve education for frontline healthcare professionals treating children with Down syndrome (for example hospital emergency staff) about diagnostic overshadowing. This includes the important role parents/carers have as those who are generally best placed to notice any critical changes in their child's wellbeing and function.
- Ensure that all paediatric healthcare facilities adopt communication training and support (e.g. augmentative, and alternative communication devices, communication boards, Auslan, Key Word Sign) so children with disability have their right to communication met. Queensland Children's Hospital currently provides this training.

Education

Children with Down syndrome, and other disabilities, often face barriers to attend their local Early Childhood Education Care (ECEC) setting. This can be direct discrimination and refusal from the centre, or children not being well supported due to the time it takes to get additional supports and lack of knowledge of staff.

The government must improve access to ECEC by:

- Making childcare free of charge for children with disability (with no work activity measures applied for caregivers.)
- Reducing the bureaucracy and time to get additional supports in place.
- Increasing awareness of the rights of the child and family and responsibilities of ECEC, including discrimination and the Disability Discrimination Act 1992 (DDA).
- Increasing awareness that the DDA does include Early Childhood Care settings, for example the Australian Human Rights Commission does not include ECEC in its summary of the DDA.

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The government should, to deliver on its obligations under the UN Convention on the Rights of Persons with Disabilities, develop a national inclusive education plan, consistent with the [Australian Coalition for Inclusive Education Roadmap](#). This plan should ensure a quality, universally accessible and inclusive system from early childhood centres, through school (including out of hours care) and post-school education settings.

The government should improve the experience of children with disability in ECEC by:

- Upskilling ECECs, and educators in diversity, inclusion, and disability. This needs to occur at training settings, such as TAFE and as professional development. Barriers are the time and cost of professional development, and it not being prioritised.
- Improving the transition from ECEC's to school, as this is currently not resourced or done well for children with Down syndrome and other intellectual disability. For example, moving from an ECEC which is often a very controlled environment to a school that has much more open space is a significant change and requires support.

A glimpse into the future of every early childhood setting or playgroup should observe children of all abilities fully included in play and learning.

- DSA State Member organisation Early Years team member

NDIS

The current NDIS Early Childhood Early Intervention approach and system is often overwhelming and confusing for parents. DSA welcomes the NDIS Review and appreciates the opportunity the Commonwealth Government has provided us to be involved. There are key areas of concern we hope the Commonwealth will consider.

Access to services, supports and equipment

The lack of availability of therapists and allied health professionals is an issue for many families and children on the NDIS. It is an issue particularly evident in the regional and remote areas. The government, via the NDIA, needs to consider how to increase the pool of professionals so that children can access the supports which they require.

Consider establishing equipment loan services

There is vast waste of resources and missed opportunities to reuse equipment that outlasts its original purchase. Before the introduction of the NDIS, there were state based equipment loan services providing equipment for children as they developed e.g., walkers, soft sitters. Now families seek to get funding for equipment they may only need for a short time (1-2 years) alongside other families seeking equipment they need on a long-term basis. This equipment then quickly becomes obsolete in a system that supports the purchase of new equipment.

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Interaction with mainstream services

There is a lack of common understanding across the range of systems supporting children with Down syndrome around whose responsibility it is to provide what support. For example, Health versus NDIS, Education versus NDIS, Family support versus NDIS. This leads to siloing, and very fragmented (if any) family support. The government needs to clarify roles and hold departments, agencies, and services to account, or allow them to effectively work together to provide the supports required for the individual

Planning and coordination

Down syndrome is still not well understood by most NDIA early childhood approach (ECA) workers and planners. We often see newborn babies with a NDIS plan with only one or two developmental domains covered, despite the syndrome having evidenced functional impact across all 6 domains. The government should invest in more training for ECA partners and require them to evidence how and when they link families to suitable support organisations.

Early Childhood Partners do not appear to be fulfilling the coordination role that the Scheme says they should (often due to extremely high caseloads). This is failing families, particularly as it is very rare to be given support coordination funding in an early childhood approach plan.

ECA partners are funded to connect and work well with peaks such as Down syndrome associations; this rarely occurs. I've not received a single referral from an ECA partner in the 3 years I've been in this role, despite previous connections to them.

– DSA State Member organisation Early Years team member

Family support

Place-based, wrap-around family support should be universally available across Australia to any family wishing to access it. Currently, many family support services are 'targeted' at vulnerable families and can carry an associated linkage or stigma in relation to those at risk of domestic and family violence and child safety risks. We know that experiences such as perinatal mental health, for mothers as well as fathers, are universally experienced, regardless of sociodemographic factors; and this is particularly so if you've received a prenatal or postnatal diagnosis of disability for your child. If an 'it takes a village' approach could be built into universally available new parenting supports (with a higher level of such support immediately available for those families whose child is born with, or diagnosed during early childhood, with a disability), this could go a long way to strengthening the wellbeing of children and their families across Australia. This could be delivered in non-stigmatizing existing locations, such as schools, libraries, community centres) and with a virtual platform for more isolated families.

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Community attitudes

In line with [Australia's Disability Strategy](#) and [Community Attitudes Targeted Action Plan](#) and [Early Childhood Targeted Action Plan](#), the Commonwealth needs to work with representative organisations to improve community attitudes toward, and expectations of, people with Down syndrome and intellectual disability.

This includes the attitudes of the general community through awareness campaigns and strategic inclusion of people with disability. It also should involve specific awareness raising among people working in mainstream services of health, education, and other areas that impact on children in their early years.

Principles

The principles that will guide policy and implementation under the Strategy should include:

- Child and family centred, acknowledging the diverse range of family structures within Australia.
- Respect for human diversity.
- Non-discrimination.
- Equality: equal opportunities and access to suitable supports as needed.
- Accessibility: removing barriers to ensure access by all children to built environments, services, and information.
- Respect for the evolving capacity of children.
- Full and effective inclusion.

In summary

Down Syndrome Australia appreciates the opportunity to be involved in such a valuable piece of work and significant initiative of the Australian Government. We recognise the development of the Strategy is just the beginning and welcome future opportunities to provide advice and action towards the implementation.

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