





Down Syndrome
Australia

Early years





This document has been produced by
Down Syndrome Australia.

Down Syndrome Australia is the peak body for people with Down syndrome in Australia. Our purpose is to influence social and policy change, and provide a national profile and voice for people living with Down syndrome. We work collaboratively with the state and territory Down syndrome associations to achieve our mission. Our vision is an Australia where people living with Down syndrome are valued, reach their potential, and enjoy social and economic inclusion.

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The content of this booklet has been put together from the resources that the state and territory associations have developed over many years.

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Overview

The early years of life are extremely important for the development of every child. For children with Down syndrome, providing the right supports and interventions during the early years can help build a strong and healthy future and ensure that the child can reach their full potential.

No two children with Down syndrome are the same. Each child will have different strengths and areas where they need a bit more help. Your child with Down syndrome will learn and master new skills but may need more time and support to do so.

The right therapies will help communication, social skills, independence and mobility. Support may include physiotherapy, occupational therapy, speech and language therapies and information and support for the family. For each child, the right mix of therapies and interventions will be individual.

This resource provides information for families about early intervention, development, and supports in the early-years. It also provides information about the NDIS and accessing support through the Early Childhood Early Intervention approach. It is not necessarily meant to be read in one sitting and families may find one or more of the topics to be of interest at a particular point in time. We have also provided information about where to go to get more information on each of the topics.



Early Intervention

During the early years of life, children achieve the basic skills that lay the foundation for future progress. Children with Down syndrome typically face delays in certain areas of development, so early intervention is beneficial in helping them reach their developmental milestones. Early intervention can begin any time after birth, but the earlier it starts, the better.

Early childhood intervention services are designed to enhance the way infants and toddlers develop. However, most learning will occur at home between visits to professionals, not during the sessions. The main goal of early childhood intervention services is to help you understand and meet the developmental needs of your child and to put into place strategies to assist their development.

When families and therapists work together as a team, the best outcomes can be achieved for the child with Down syndrome. The therapists are not able to do all the work, they only spend a small amount of time with the child. Whilst they may be experts in child development, they do not know each child as well as the parents do, and they don't know initially what strategies will work best for that child and the family. The best approach, leading to the best outcomes for your child, is for professionals and parents to pool their knowledge and expertise and work together.

The most common early intervention services for children with Down syndrome are physiotherapy, speech therapy and occupational therapy. There may sometimes be other professionals involved. Often a holistic approach, where therapists are working together to achieve specific goals with the child is beneficial, rather than multiple therapists working in isolation.

Early intervention information can be found on the Reimagine Australia website. www.re-imagine.com.au

Development

Children with Down syndrome are all different and whilst there may be some developmental and health issues that are more common for a child with Down syndrome, it is important to look at your child as an individual and respond to their individual needs as they arise.

Perhaps the most important factor in the development of children with Down syndrome is the attitude of the people around them. It is important to set high goals and believe they can reach them, celebrate every success (even the little ones!) and give lots of encouragement along the way. Connecting with other families can also be helpful in sharing strategies, ideas and different approaches.

Further information about communication, language development, sensory issues and physical development is outlined. Helpful tips and strategies have been included in this guide as well as links to other useful resources and supports.

Communication, speech, language and development

Children with Down syndrome often experience delays in the development of their speech. Most children with Down syndrome will use their first word around the age of two to three. Generally, this may mean they have fewer words and may speak in shorter phrases than their peers. They may also have problems in using their communication skills to meet all their needs. For instance, children with Down syndrome may find it more difficult than their peers to use language to initiate conversations with friends, to indicate toilet needs, or to gain attention, and may use non-verbal means of meeting these needs.

Evidence suggests that the use of key-word signing can play an important role in supporting language development. Key word signing is the use of signs and natural gestures to support communication and language development of children and/or adults with communication delays or difficulties. It helps language development by using signs and

words together to promote understanding and using visual strategies to convey messages. Parents can take courses in key word signing or may be supported by their speech therapist to learn some of the basic signs.



In addition to speech delays, some children with Down syndrome may experience some difficulties with articulation or pronunciation. There are physical factors which can contribute to this.

The nasal passages and sinuses are smaller and the roof of the mouth is small and high which reduces the size of the mouth cavity. Speech therapists can assist children with improving articulation.

The tendency to have smaller nasal cavities, can also lead to more frequent ear infections and fluid accumulating in the inner ear, a condition commonly referred to as glue ear. These conditions can lead to hearing loss which can contribute to speech delays. Usually these ear conditions can be treated through the insertion of grommets or hearing aids. If you notice your child is having difficulty hearing or has had repeated ear infections, a hearing test is advisable. If left untreated, hearing issues can lead to problems with language development and learning.

Speech therapy is an important part of early intervention. Speech therapy is a way to provide strategies and support to help children to develop their language and speech skills. Speech therapists (sometimes called speech pathologists) help to develop early communication and understanding.

Working with a speech therapist can be beneficial even before a child starts to talk. There are many pre-speech and pre-language skills that must be acquired before your child says their first words. These include:

- the ability to imitate and echo sounds
- turn-taking skills – learned through games such as ‘peek-a-boo’
- visual skills – looking at the person speaking and visually following objects
- auditory skills – listening to music and speech for lengthening periods of time, or listening to speech sounds
- tactile skills – learning about touch, exploring objects in the mouth
- oral motor skills – using the tongue, moving lips
- cognitive skills – understanding more about his environment and ability to make things happen.

A speech therapist can help with these and other skills, including breastfeeding and eating solid foods, which can help strengthen your child’s jaw and facial muscles to help their future communication skills.

Tips to promote communication skill development:

- Listening: talk to your little one, listen to music and musical mobiles, sing nursery rhymes and copy their sounds.
- Looking: look at toys, books, mobiles and lights.
Watch themselves in the mirror or watch you pulling faces, making funny noises, singing, smiling or talking.
 - Games involving their body such as: rock-a-bye baby, round and round the garden, this little piggy, peek-a-boo, waving bye bye.
 - Having a good time: being with family and friends, kissing, cuddling, massage, laughing.

Social skill development

Linked to communication and language development is the development of social skills and behaviour. As with all children, children with Down syndrome can be well behaved in some situations, but other situations may be more difficult. Sometimes difficulty with communication can lead children to act out in order to try to communicate their needs.

Children with Down syndrome may be delayed in social development compared to their peers, so it is important to adjust any expectations accordingly. Some of the social behaviours parents strive to develop include:

- cooperation
- manners
- sharing
- joining in activities
- listening
- making friends
- respecting others.

Behaviour can vary between situations, according to the expectations involved. Children with Down syndrome, like all children, benefit from a consistent approach, which includes positive reinforcement of behaviour for the right age and stage of their development.



Some strategies that can help to support the child with Down syndrome develop their social skills are:

- Emphasise and praise positive behaviours rather than giving attention to misbehaviour.
- Practise taking turns at home.
- Break instructions down and give one at a time.
- Role play social situations with your child.
- Encourage the child to look at people when they are communicating, or when someone is communicating with them.
- Learn key word signs and teach others involved with your child key word signing so they can communicate.
- Search for helpful apps that model appropriate social behaviour, e.g. Model me going places.

Children learn the most at home from family members, so displaying and reinforcing positive social behaviours within your house is the best approach.

Remember, being a parent of a toddler can be hard work and tiring! If your child's behaviour is troubling you, there is help and support out there. Contact your local Down syndrome association or the parent helpline www.kidshelpline.com.au/parents/issues/how-parentline-can-help-you for further advice and strategies.

The Carer Gateway also provides information and support www.carergateway.gov.au



Sensory processing

Some children with Down syndrome will also have sensory processing issues. Sensory processing issues relate to differences in how children process and act upon information received through the senses, which in turn can create challenges in performing everyday tasks. Sensory processing issues can lead to clumsiness, behavioural problems, anxiety and depression, if not addressed. Sensory issues can involve sensitivity to light, noise, smell, temperature and textures, or the need for more sensory input than other children.

Sometimes, challenging behaviour can be dismissed as a 'part of having Down syndrome', however, it is important to identify any contributing issues that can be addressed such as communication difficulties or sensory issues.

Occupational therapists (OT) can do an evaluation and work with the child with Down syndrome in regard to any sensory issues that are being experienced. They can provide families with strategies on how to support any differences in how the child processes sensory input.

OTs can also help children build their skills in independence. When the child is small, the therapist may focus on developing their fine motor skills. This will include activities such as opening and closing things, picking up and releasing toys of various sizes and shapes, stacking and building, manipulating knobs and buttons, experimenting with crayons and other manual skills. Occupational therapists also help children to learn to feed and dress themselves, and teach skills for playing and interacting with other children.

Physiotherapy/physical development

Physiotherapy is important for children with Down syndrome who have low muscle tone. A physiotherapist works with the family and the child to help achieve developmental milestones. Physiotherapy helps children develop their gross motor skills and identify areas of strength, and areas where the child needs support. Physiotherapists can assist by teaching families physical, interactive activities and strategies to help the child understand and master the environment as well as learn, communicate and develop social skills.

Mobility

Children with Down syndrome may be delayed in walking and can have problems with co-ordination and gait, due to having reduced muscle tone. Low muscle tone is where the length of a resting muscle is slightly longer than typical. This means that there are fewer points where the muscle fibres can attach and generate pull on the muscle. As a result, the muscle needs to go through a greater range of motion, requiring more energy to be used for movement, which in turn means a child will fatigue more quickly.

Children may benefit from physiotherapy and/or occupational therapy to help increase mobility. The child should be encouraged to join in the full range of physical activities including running, skipping, climbing, bike riding and ball games.

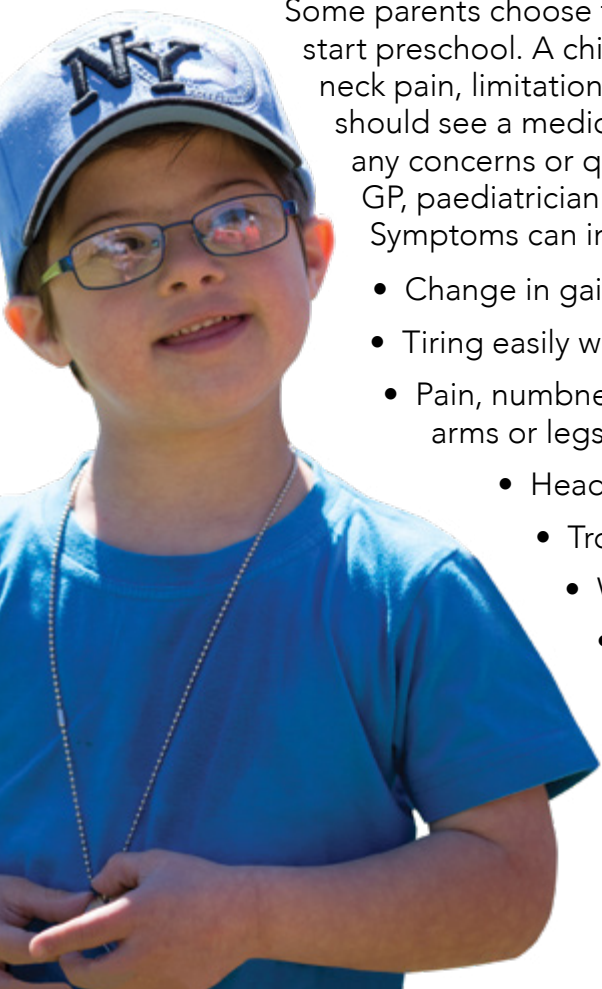
There can be a looseness of the ligaments at the top of the spine in Down syndrome. This is called Atlanto-Axial Instability. This condition can be diagnosed through x-rays. However it's important to respond to any signs of atlanto-axial instability as the screening provided by x-ray is at one point in time and does not predict any future problems.

Some parents choose to have their children tested before they start preschool. A child with Down syndrome experiencing neck pain, limitation of movement or change of gait should see a medical professional for advice. If you have any concerns or questions about these issues, ask a GP, paediatrician or physiotherapist for further advice. Symptoms can include:

- Change in gait
- Tiring easily when walking
- Pain, numbness or tingling in the neck, shoulders, arms or legs
- Head tilting to one side
- Trouble moving the neck or holding it up
- Weakness in the arms or legs
- Loss of bladder control.

For more information about atlanto-axial instability please visit:

<https://www.massgeneral.org/children/down-syndrome/atlantoaxial-instability-aa>



Fine motor skills and dexterity

Some children may need extra practice with fine motor skills. This can apply to cutting, drawing and other activities. An occupational therapist or physiotherapist can work with you and your child to learn games that help improve dexterity. Some examples could be requiring the child to pick up small objects using their finger and thumb, or playing with tongs and tweezers to pick up objects.

Toilet training

As with all other areas of children's development, there is a huge variation in the age at which children with Down syndrome achieve independent toileting and a similar range in the length of time, effort and energy that has to be put in by parents to achieve it. There is no single fail-safe way in which to toilet train. There are a range of strategies to help your child get ready to use the toilet regularly.

The steps below provide some ideas about how to approach toilet training.

1. Determine readiness

Toilet training works best when the child has shown signs of readiness beforehand. These may include an interest in using the toilet, staying dry for a period of time or telling you when they have gone. You can encourage your child in this early stage by discussing being wet or dry, showing them the toilet, or changing their nappy in the toilet or bathroom area. You may want to use picture books or visual aids to encourage the child to learn each step of the process.

2. Identify barriers

It is important to identify any specific barriers that your child might be experiencing in regards to learning to use the toilet. A few examples include:

- Some children with sensory issues might become frightened by the noise of the toilet flushing.
- Low muscle tone may make it harder for the child to feel the need to go to the toilet. It may also mean constipation.

- Disposable nappies can make it harder for kids to know when they are wet. Putting undies under the nappy or removing the nappy altogether could help that awareness.
- Communication and speech delay can make it harder for a child to express the need to use the toilet. Combining a sign with the word and introducing it early, whenever you change the nappy, can give children a tool to use down the track.

3. Identify motivators

Think about what your child loves and make them available near the toilet area. For example, leave screen time on the iPad for sitting on the toilet. Having a special reward only reserved for a success on the toilet is another option.

4. Embracing the accidents

One of the biggest barriers to embracing toilet training is the constant cleaning up. Put in place strategies to protect carpets or sofas so that accidents are not met with frustration, which could in turn make the experience a negative one for the child.

5. Decide on a routine

Consistency is key – whichever method you decide to work with. Make it a pleasant experience for the child. It is important to modify strategies along the way if they are not working or are proving to be counterproductive.

Some useful resources about toilet training can be found at:

<https://dsagsl.org/wp-content/uploads/2017/06/Toilet-Training-Guide.pdf>

<https://www.chp.edu/our-services/down-syndrome/podcasts/toilet-training>

NDIS Early Childhood Early Intervention approach

The NDIS have developed an Early Childhood Early Intervention (ECEI) approach to provide support to children who will benefit from early intervention.

Children with Down syndrome who are under the age of 7 are automatically eligible for these supports. Down syndrome is included in 'List D' which is a list of conditions which require no further assessment for access to the scheme.

The Early Childhood Early Intervention organisation will work with your family to develop a plan for therapy and support that focuses on goals that relate to the child's age, development and social skills.

Find out more about Early Childhood Early intervention on the NDIS website:
www.ndis.gov.au/understanding/families-and-carers/how-ecei-works-step-step-process

Find an Early Childhood partner in your area:
www.ndis.gov.au/contact/locations



The process for families to access ECEI services through the NDIS is as follows:

- The ECEI organisation contacts you or you contact the ECEI organisation through the NDIS.
- The family meets with ECEI partner to discuss the child and their family's needs.
- The ECEI partner works with the family to develop the best supports for the child and family. This could include speech therapy, occupational therapy as well as other supports.
- The ECEI partner also helps a child and their family if they need more intensive supports. Children with Down syndrome are automatically eligible for these more intensive supports. The ECEI partner will complete a support plan and submit it to the NDIS for approval. Once the plan is approved, the family can choose the early intervention provider(s) they wish to work with and the support begins.
- Plans will be reviewed every 12 months or when requested by the family if there is a change in circumstances. The review is a time to discuss how the child is going, identify other areas of need and tailor the plan to better meet the child's needs.

Making contact with the NDIS or ECEI partner

Families who have been accessing some services or support through different programs may be contacted by the ECEI organisation to start the conversation on the child's needs. In other cases, families might need to contact the NDIS directly to start the process.

Find an Early Childhood partner in your area:

www.ndis.gov.au/contact/locations



Getting plan ready

Families often find it helpful to do some work in advance of their first meeting with the Early Childhood partner to gather information.

This could include:

- Making contact with your local Down syndrome association or a trusted organisation locally.
- Gathering any recent reports or information about supports or interventions.
- Documenting what informal supports you already have in place (family members, friends, community organisations, sporting groups).
- Documenting what formal supports you currently access (speech therapy, OT, physiotherapy etc.).
- Thinking about how you currently manage everyday activities. What other supports are needed?
- What are some of the child's goals over the next 12 months? What goals do you have for your child?

More information

You can access more information about NDIS from a number of different places.

- NDIS – The NDIS website provides information about NDIS access. www.ndis.gov.au
- NDIS and ME Facebook group is a closed Facebook group for families of people with Down syndrome. It provides an opportunity to learn from peers and to get further information about NDIS – www.facebook.com/groups/1462085080755993
- The Down syndrome association in each state and territory – www.downsyndrome.org.au/about-us/our-federation/
- Disability Loop – www.disabilityloop.org.au provides stories, news and information about NDIS in an easily accessible format
- www.carersaustralia.com.au has a peer support program where parents can speak with other parents who have already been through the NDIS planning process.

Childcare and schools

Starting in the early childhood setting

Choosing a child care environment is a big decision for parents, perhaps more so for parents of a child with Down syndrome.

It is important to meet with key staff and communicate openly about your child and what their strengths are and where they need some additional support. It is important to be comfortable that the childcare you have chosen understands how to provide the support your child needs, while also including them with other children.

After a decision about which child care setting is appropriate, families can work with the early childcare provider to put in place adjustments to best support the child. Some possible ways to prepare for the transition and ensure staff have appropriate skills include:

- Your allied health therapist to visit the centre and provide information to staff about how to support your child.
- A speech therapist to visit with the staff in your room and provide some strategies they might like to use (including providing training on a few key word signs if your child is using these).
- Arrange for your local Down syndrome association to provide information or training with staff.
- Sharing with the staff communication strategies that the family utilise, like sign language, is really important to ensure consistency and a smooth transition.
- Put together a document that outlines your child's strengths and areas where they need support.
- Have a longer orientation program to help your child settle in the new environment.
- Using a communication book can also be a great tool between families and child care settings to share information.
- Encourage your centre to explore inclusion support funding if necessary.

Supporting your child to adjust

There are some simple things you can do to make sure your child is as ready as possible. Talk with the child about 'school' or 'day care' and use people's names to show familiarity. Taking some pictures of the early childhood setting and showing them to your little one before they transition can also be helpful. Where possible, establishing and supporting friendships in the setting may also be really useful to try to support your child in feeling comfortable and safe.

Starting school

Starting school is a major milestone for any child. There are a range of things for families to consider at this time, including:

- selecting a school
- understanding your rights in regards to education and disabilities
- preparing your child for the transition
- ongoing support at school.

Selecting a school

Choosing a school for your child can be a difficult task and it is a very personal decision for families. Your child has the right to access mainstream education. Some families choose specialist schools, some decide on mainstream education, while others choose to home-school their child. It can be beneficial to visit the schools that you feel you could consider. If you are able to visit a number of schools, you will start to get a feel for what your priorities are, in finding the right place for your child.



You can find a range of transition to school resources on the DSA Resource Hub www.downsyndrome.org.au/blog/resource-category/education/

A child with Down syndrome is more likely to experience success in a school where inclusion is embraced and supported as part of the school culture, and where the different learning needs of all the students are acknowledged and properly addressed. Providing information to the school about Down syndrome is a way of increasing the teachers' and students' understanding about Down syndrome.

Legal rights and education

The rights of people with Down syndrome are protected through the *Disability Discrimination Act 1992*. The Disability Discrimination Act outlines Australia's international law obligations under the *Convention on the Rights of People with a Disability* (CRPD).

In specific regard to education, the Disability Discrimination Act states that a school can not:

- Refuse or fail to accept the person's application for admission as a student.
- Deny the student access, or limit the student's access, to any benefit provided by the educational authority.
- Develop curricula or training courses that have content that will either exclude the person from participation, or subject the person to any other detriment.



Preparing your child to start school

Some tips to help prepare your child for starting school are:

- Talk about school positively with your child.
- Get your child to practice carrying their school bag and using their lunch box. It is important to encourage them to be as independent as possible.
- Practice getting dressed in the new school uniform and wearing school shoes before the first day.
- Visit the school and familiarise your child with the school environment.
- Arrange to meet the key staff, including office staff, so they can get to know your child.
- Consider the orientation arrangements the school has and discuss any adjustments to this with the school.

Supports within the school

Many of the social and therapy based adjustments outlined above are relevant to the transition to school. When entering the education system, the curriculum adjustment becomes important along with becoming part of the school community. While everyone wants their child to experience success in school, it is also important to note that academic success is not the key to being able to lead an ordinary life.

Children with Down syndrome have a specific learning profile with strengths and weaknesses. Being aware of the factors that facilitate and inhibit learning will allow educators to plan and implement meaningful and relevant activities and programmes of work. Communication with educators about not only the curriculum adjustments, but also building social connections in the school community is very important.

More detailed information and advice about transitioning to school can be found at:

www.downsyndrome.org.au/voice_dec_2015.html

www.downsyndromevictoria.org.au/DSV_Documents/Choosing_a_school.pdf

Further Information and support

All Means All – www.allmeansall.org.au

Education section of the Community Inclusion toolkit –
www.downsyndrome.org.au

Associations

National: 1300 881 935

New South Wales

Down Syndrome NSW

T: 1300 881 935

E: admin@dsansw.org.au

W: www.downsyndrome.org.au/nsw

Victoria

Down Syndrome Victoria

T: (03) 9486 9600

Toll Free 1300 658 873

F: (03) 9486 9601

E: info@dsav.asn.au

W: www.downsyndrome.org.au/vic

Queensland

Down Syndrome Queensland

T: (07) 3356 6655

E: office@downsyndromeqld.org.au

W: www.downsyndrome.org.au/qld

South Australia

Information Service South Australia (Down Syndrome Australia)

T: 1300 344 954

F: (08) 8346 4521

E: infoSA@downsyndrome.org.au

W: www.downsyndrome.org.au/sa

Western Australia

Down Syndrome WA

T: (08) 6253 4752

E: admin@downsyndromewa.org.au

W: www.downsyndrome.org.au/wa

Tasmania

Down Syndrome Tasmania Inc.

T: 1300 592 050

E: info@downsyndrometasmania.org.au

W: www.downsyndrome.org.au/tas

Northern Territory

Down Syndrome Association NT

T: (08) 8985 6222

W: www.downsyndroment.com.au

Australian Capital Territory

ACT Down Syndrome Association Inc.

T: (02) 6290 0656

E: admin@actdsa.org.au

W: www.downsyndrome.org.au/act



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