For families who have a child with Down syndrome

The NDIS:
Where to go for further help and information

Down Syndrome Australia:
This information has been prepared by Down Syndrome Australia to help you understand how to access NDIS services to get the best support for your child’s needs. Down Syndrome Australia (DSA) is the national voice representing people with Down syndrome and their families. It consists of eight state & territory associations that provide Down syndrome support and information. You can contact DSA through these local associations.

Down Syndrome Support and Information in your state/territory
Your local state Down Syndrome Association can offer advice and information regarding your child’s development and can also put you in touch with other families to talk about your experiences and share ideas. They can help you find out what other services are offered in your state or territory, and more information and guidance regarding your child and the NDIS.

Contact your local state or territory Down Syndrome Association below for answers to any questions you may have or to talk to another parent about Down syndrome:

**Australian Capital Territory**
Phone 02 6290 0656 www.actdsa.asn.au

**New South Wales**
Phone 02 9841 4444 or 1800 811 629 www.downsyndromensw.org.au

**Northern Territory**
Phone 08 8985 6222 Email: dsant@octa4.net.au www.downsyndroment.com.au

**Queensland**
Phone 07 3356 6555 www.dsaq.org.au

**South Australia**
Phone 08 8245 4680 www.downssa.asn.au

**Tasmania**
Phone 1300 592 050 www.downsyndrometasmania.org.au

**Victoria**
Phone 03 9468 9608 or 1300 658 873 www.downsyndromevictoria.org.au

**Western Australia**
Phone 08 9368 4002 or 1800 623 544 www.dsawa.asn.au

Down Syndrome Australia is a member of the First Step Alliance
Funded by the Australian Government Department of Social Services.
What is the NDIS?

The National Disability Insurance Scheme is referred to as the NDIS. NDIS provides reasonable and necessary funding to people with a permanent and significant disability to help them achieve goals in many aspects of their life, including independence, involvement in the community, education, health and wellbeing.

The NDIS gives you choice and control over how, when and where your child’s supports are provided. The focus on early intervention ensures that your child will get the early supports they need to achieve the best possible outcome.

Roll out of the full NDIS in all states and territories (except Western Australia) commences progressively from July 2016.

The NDIS and You – Access

Your child may be eligible for support through the NDIS if:

- They are an Australian citizen, or a permanent resident.
- They live in an area where the NDIS has been rolled out.
- They have an impairment or condition that is likely to be permanent and their impairment substantially reduces their ability to participate effectively in activities or meet the early intervention requirements.

Early intervention requirements

Your child may meet the early intervention requirements if:

- They are under 6 years of age with a developmental delay and the delay means they usually need more help than other children of the same age with their self-care, communication, learning or motor skills.
- Or they have an impairment or condition that is likely to be permanent and there is evidence that getting supports before the age of 6 will reduce their ability to participate effectively in activities or meet the early intervention requirements.

Getting NDIS ready

By now you may be making choices about the services that you would like for your child. You might also be wondering how to ensure that you get the right level of support for your child’s needs. Information on eligibility and access to early intervention services through the NDIS can be found on the NDIS website.

NDIS Planning Process

Once your child is eligible for assistance from the NDIS, you will need to participate in a planning process to ensure you have the right supports for your child’s needs. On the NDIS website you will find a range of resources which will help you prepare for the NDIS and for this planning process. The NDIS Early Childhood Early Intervention approach is used to identify the type and level of early intervention support each child needs to achieve their best outcomes. So, how do you best prepare for the NDIS? You need to think about what your child’s needs are, know what funding you currently receive or need to receive and plan ways for your child to achieve their goals. Talk to your current service providers if you are using any and ask lots of questions so you can understand your current services.

Parents and carers can find further information by calling the NDIS on 1800 000 110 or visiting www.ndis.gov.au.

The following information has been prepared to help you understand the types of services and supports available to you and your child.

What is Down syndrome?

Down syndrome is the world’s most common genetic chromosomal condition and genetic cause of intellectual disability. Down syndrome is due to the presence of an extra or part of an extra chromosome, chromosome 21. For that reason, the most common form of Down syndrome is also known as trisomy 21. People with Down syndrome commonly have 47 chromosomes in their cells instead of 46.

Down syndrome is usually recognisable either before or shortly after birth and is confirmed by a blood test. However, what happens after birth is much more important than the extra chromosome in determining the outlook for a baby with Down syndrome.

A new baby with Down syndrome is first and foremost, a baby – and needs the same love and care that all babies need. He or she will grow and develop but is likely to reach developmental milestones at a slower rate.

Making the Most of the NDIS

NDIS funding allows families to decide which therapies they will access, which service providers they will use, and how often they will attend therapy sessions. These decisions are not always easy, so we have put together this list of tips to help you get started:

Be a family. The most important thing your child needs is to be a part of a loving and caring family. You will always play the biggest role in your child’s development, and early intervention services and therapies are there to support you.

Plan ahead. By planning which services and resources you will use you can ensure that your child and family have access to consistent therapy and information throughout your child’s pre-school years.

Find a balance. Don’t feel pressured to attend sessions that disrupt your family schedule or do not match your child’s individual needs.

Resources: You can also access resources, including equipment, technology, books and teaching aids.

Play is therapy too. Remember that therapy is only part of the learning for your child. You can use therapy sessions as a way to learn techniques for supporting your child’s development through everyday activities at home.

Find the right fit. You and your child may have a long-term relationship with the providers that you choose, so it’s important that you feel comfortable with your choice. Discussions with providers will help you find out what you think about them, and whether they seem ‘the right fit’ for your family. If you are not comfortable, don’t hesitate to speak up, or seek another provider. You have the right to change service providers if you choose.

Ask questions. Your questions for service providers could include:

- Have you worked with many children with Down syndrome?
- What experience do you have of working closely with families?
- What will be your long-term goal in working with me and my child?
- Do you expect to be available to continue working with my family over the next few years?
- Do the therapy sessions include the use of assistive technologies (e.g. iPads)? (where relevant)
- Are you willing to work collaboratively with other professionals who are supporting my child’s development?
- Would you be interested in training or information that can be provided by NDIA?

Speech Pathologists (“speechie” or SP) promote early exposure to communication and enhance understanding. They also assist in the development of feeding skills.

Occupational Therapists (OT) assist in the development of fine motor skills and sensory processing. Therapy intervention services will in most cases be needed throughout the early years into school and beyond.

Parents of a baby born with Down syndrome are advised to contact their state Down Syndrome Association for specific information, support and guidance.

NDIS Early Childhood Early Intervention approach

NDIS Early Childhood Early Intervention approach is the biggest role in your child’s development, their own strengths, challenges, likes, dislikes and personalities.

Early Intervention for Children with Down syndrome

Early intervention plays an important part in the development of children with Down syndrome.

For children with Down syndrome, early intervention can begin from the first few weeks after birth. It can be in the form of physical, cognitive and language therapy (including physiotherapy, occupational therapy and speech therapy).

Therapists

Physiotherapists (“physio” or PT) promote a variety of posture and movement experiences and maximise quality of movement. They aim to develop gross motor skills such as rolling, sitting, crawling and walking.

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