



[www.downssa.asn.au](http://www.downssa.asn.au)

## GETTING STARTED

### THE EARLY PATHWAY FOR NEW BABIES WITH DOWN SYNDROME

#### INTRODUCTION

[Down Syndrome South Australia](http://www.downssa.asn.au) (DSSA) is pleased to support families and individuals with Down syndrome and other chromosomal abnormalities throughout their lives. Our support includes:

- Ante-natal and post-natal information and support
- Group information and support through early childhood
- Specialist supports around transitions to childcare, pre-school/kindergarten and school as well as life transitions
- Consultant support and key-worker support to assist families and individuals to build capacity to learn, grow and thrive in their communities

These services are also available to, and suitable for, families and individuals with developmental delay, intellectual disability and other chromosomal differences.

DSSA links with our professional learning and development arm, Learning4All, to provide information and education to families, friends, educators and carers. Workshops include topics that are both specific to Down syndrome and those that are experienced by children with developmental delay.

#### STEP 1: SEEK SUPPORT AND INFORMATION

Read through your DSSA Baby Pack. These are distributed by most hospitals, or available by request at **E:** [info@downssa.asn.au](mailto:info@downssa.asn.au) **Ph:** 8245 4600.

Included in this pack is 'A Guide for New Parents', a booklet produced by Down

Syndrome Australia. The booklet provides useful information and answers to many questions.

The Down Syndrome Australia website <https://www.downsyndrome.org.au> provides information on many topics and resources in Easy Read and other languages.

Contact Down Syndrome SA on 8245 4600 or [info@downssa.asn.au](mailto:info@downssa.asn.au) if you would like personalised support from our staff.

#### STEP 2: APPLY FOR ACCESS TO THE NATIONAL DISABILITY INSURANCE SCHEME (NDIS)

The NDIS is the funding source for early intervention and disability services in Australia.

The Partner in the Community (Partner) has been engaged by the NDIA to deliver the Early Childhood Early Intervention approach in South Australia. The Early Childhood Early Intervention (ECEI) approach supports children aged 0 to 6 years who have a disability or developmental delay, and their families or carers.

Visit the Early Childhood Early Intervention Partner website <https://dhs.sa.gov.au/ndis> to learn about getting started. It is recommended that you commence this process as early as possible as it is often many months before individualised early intervention funding is allocated.

Experienced staff will be happy to assist you with the intake process. **Ph:** 1800 931 190  
The Partner will help you to get information and to work out your child's support needs, and to link you to the services and support you need to build your and your child's capacity.

You will need to provide details of parents and child. Have your Centrelink details (CRN) available. If you have updated this record with your child's birth details, it may be sufficient information. Without updated Centrelink details, you will need to apply for a birth certificate to verify your child's identity and provide this information.

Have the document that states a diagnosis of Down syndrome for your child. This may be a doctor's letter or a copy of the discharge summary.

A diagnosis of Down syndrome, along with meeting the NDIS eligibility criteria relating to residency, should ensure eligibility for early intervention services.  
<https://ndis.gov.au/people-disability/access-requirements.html>

The National Disability Insurance Agency/Partner will send out an Access Request Form for you to complete and return. Email this form back; keep a copy and a record of the date of return.  
**E::**[ECEI.SouthAustralia@ndis.gov.au](mailto:ECEI.SouthAustralia@ndis.gov.au)

You will receive a letter confirming your child's access to the NDIS.

From the time of confirmation of Access (eligibility) to receiving a planning appointment, and then a plan (funding), there is often a wait of many months. We recommend that you start this process as soon as possible.

If you have specific concerns about your baby's needs, your GP or paediatrician is your best contact. You may be eligible for a Medicare health care plan to support some subsidised early intervention prior to NDIS funding.

### STEP 3: CONNECT TO LOCAL SUPPORTS

While you are waiting to receive NDIS funding supports, you and your baby can access many community-based programs and explore government services. These supports will form a large part of you and your child's community life. Most are free (government or locally

funded) or very low cost. Supports include:

#### **Down Syndrome SA** Early Intervention Parent Support and Information Group

**P: 8245 4600** or **E: [info@downssa.asn.au](mailto:info@downssa.asn.au)**

An information and support group meeting twice a term at various metropolitan community locations. Meet other families with babies to pre-schoolers, learn about various topics related to raising your child and what is available in your community, ask questions, problem solve and share. Let us know if there is something in your community that you would like us to explore with you; a new playgroup, café, park, council run baby activity, reading or song group.

<http://www.downssa.asn.au/index.php/our-services/early-intervention>

#### **Facebook groups**

T21 Mum Australia Network <https://www.facebook.com/t21mum/> is a great place to start. Through here you can be linked to other (SA based) closed Facebook groups and connect with other families.

#### **Child and Youth Health**

<http://www.cyh.com/>

Services include the Parent Helpline, Universal Contact Visit, Family Home Visiting, Day Service, Breastfeeding support, Torrens House, Health Checks, Universal Neonatal Hearing Screening, Disability, Parenting Groups, Aboriginal and Multicultural services.

#### **Contact details**

**Business hours:** Mon - Fri, 9am - 5pm

**P:**1300 733 606 for appointments  
(line open 9am - 4.30pm, Monday to Friday)

**All hours::**Parent Helpline: 1300 364 100

There are Early Childhood Intervention Coordinators available across the state.

All Child and Family Health Services are free and statewide. Qualified nurses, medical staff, social workers, physiotherapists and Indigenous Cultural Consultants provide them.

## Department of Education and Child Development (DECD) services:

DECD is a state government funded service providing not only schooling, but early education services in your local community.

Children's Centres offer playgroups (often run or supported by therapists), parent information sessions, Occasional Care, and many other services. Look for a timetable on your local centre's website.

<https://www.decd.sa.gov.au/parenting-and-child-care/child-care/services-and-programs/childrens-centres/find-childrens-centre>



Kilparrin is a statewide support service for students from birth with vision and/or hearing impairment and additional disabilities.

Support from Kilparrin is accessed via direct parent referral accompanied by medical evidence of sensory impairment (vision and/or hearing) and verified additional disabilities. They provide a visiting support teacher service at no cost.

**Email** [dl.1372.info@schools.sa.edu.au](mailto:dl.1372.info@schools.sa.edu.au)

**Phone:** (08) 8277 5999

**Web:** [www.kilparrin.sa.edu.au](http://www.kilparrin.sa.edu.au)

Learning Together at Home is a government funded play-based learning service. Enquire about this service at your local children's centre

### Carer's Support

Register by calling **1800 052 222**

### Time for yourself or help in an emergency

It's okay to admit you need a break from the challenging role of being a carer. We can help you to explore options and plan flexible respite that best meets both your needs and the needs of the person for whom you are caring.

If you become unwell, are admitted to hospital, or feel exhausted and need to restore your health, emergency respite options are available

To discuss what options are relevant to you and available in your area, contact the Commonwealth Respite and Carelink Centre on: **1800 052 222**

Emergency respite is available **24** hours a day **7** days a week.

**Local council services** eg. Library services and baby groups, Toy Library services

Explore what your local council funds in your community. These services are for everybody!

### Play groups in your local community

<http://playgroupsa.com.au/>

## The Australian Department of Human Services

<https://www.humanservices.gov.au/individuals/subjects/after-your-baby-born#a2>

<https://www.humanservices.gov.au/individuals/subjects/payments-families#a4>

### Health Services

Maintain contact with the public hospital/community service where your baby was born, to access allied health, nursing support, lactation consultants, social work etc if available.

### Raising Children Network

The Australian parenting website: provides comprehensive, practical, expert child health and parenting information and activities covering children aged 0-15 years. [raisingchildren.net.au](http://raisingchildren.net.au)

### MyTime

MyTime groups provide facilitated peer support for mums, dads, grandparents and anyone caring for children with disability, developmental delay or a chronic medical condition. Socialise and share ideas and information with others who understand the rewards and intensity of caring for a child with

special needs. For more information, please visit the MyTime website <https://www.mytime.net.au/>

## Childcare

Childcare is available for all children to support your child's social and general development, your own wellbeing and/or return to work. There is federal funding to support children with additional needs in childcare. The Centre director can apply for this funding. You can find out about the childcare subsidy <https://www.humanservices.gov.au/individuals/services/centrelink/child-care-subsidy> and look into local Centres and Family Day Care should you so choose. If you would like support in transitioning your child to childcare or negotiating challenges, DSSA staff can assist you in navigating this process.

## Start exploring early intervention services

What is early intervention? What services might be useful to me? Where and how do I find these services?

The Early Childhood Intervention Australia (ECIA) website provides information and resources which are relevant and reflect current best practices.

<https://www.ecia.org.au/For-Families/What-is-Early-Childhood-Intervention-ECI->

Look into therapy services in your local area and beyond. This downloadable booklet from the ECIA website is a great resource:

'Choosing **Quality** Early Childhood Intervention Services and **Supports** for Your Child: What you need to know' <https://www.ecia.org.au/For-Families/Choosing-Quality-ECI-Services-Supports-booklet>

Prior to NDIS funding becoming available, you may be able to access some services through Community Health or health systems, using a Medicare Health Care Plan or private health insurance to subsidise some services.

## STEP 4: GETTING STARTED WITH YOUR NDIS FUNDING

When you have received your NDIS plan:

**Discuss** the plan with your planner so that you clearly understand how it works and what it means. This is part of the planner's role.

**Check** that you have access to the NDIS online portal (via MyGov <https://my.gov.au/LoginServices/main/login?execution=e2s1>) before you receive your plan handover.

**See** the NDIS website <https://ndis.gov.au/> for instructions on accessing the portal. You will require an access code that your planner can provide.

**Make contact** with DSSA ([support@downssa.asn.au](mailto:support@downssa.asn.au)) or 8245 4600 if you would like to engage with a staff member who can provide Key Worker support using some NDIS funding from your plan. Using a Key Worker gives you:

- Support in planning out how you want to spend your funds
- Assists you in linking and coordinating therapists/educators and providers
- Helps to build your capacity to navigate early intervention services and supports
- Support at key times in the plan year (eg. Preparing for plan review near the end of the plan).

## STEP 5: REMEMBER YOU ARE NOT ALONE

ECIA (<https://www.ecia.org.au/>) use the picture below to describe the team around the child. You, your family, friends, neighbours, local community, community services, health team, therapy team, education supports and many more are part of this team and will provide supports at different stages and times in your child's life. There are many supports and services for you too.

Talk to your GP about adult health and counselling services or call a helpline Eg. Relationships Australia **1300 364 277** or **1800 182 325**, Beyond Blue **1300 22 4636**, Lifeline **13 11 14**

