

Go To Guide

Autism and your child 0–6 years





This booklet was developed by
South West Autism Network (SWAN)

We are grateful for the input from autistic individuals and their families who shared their expertise to make this a useful and practical resource for families of young children.

Thank you to everyone who has contributed to its development.



Government of **Western Australia**
Department of **Communities**



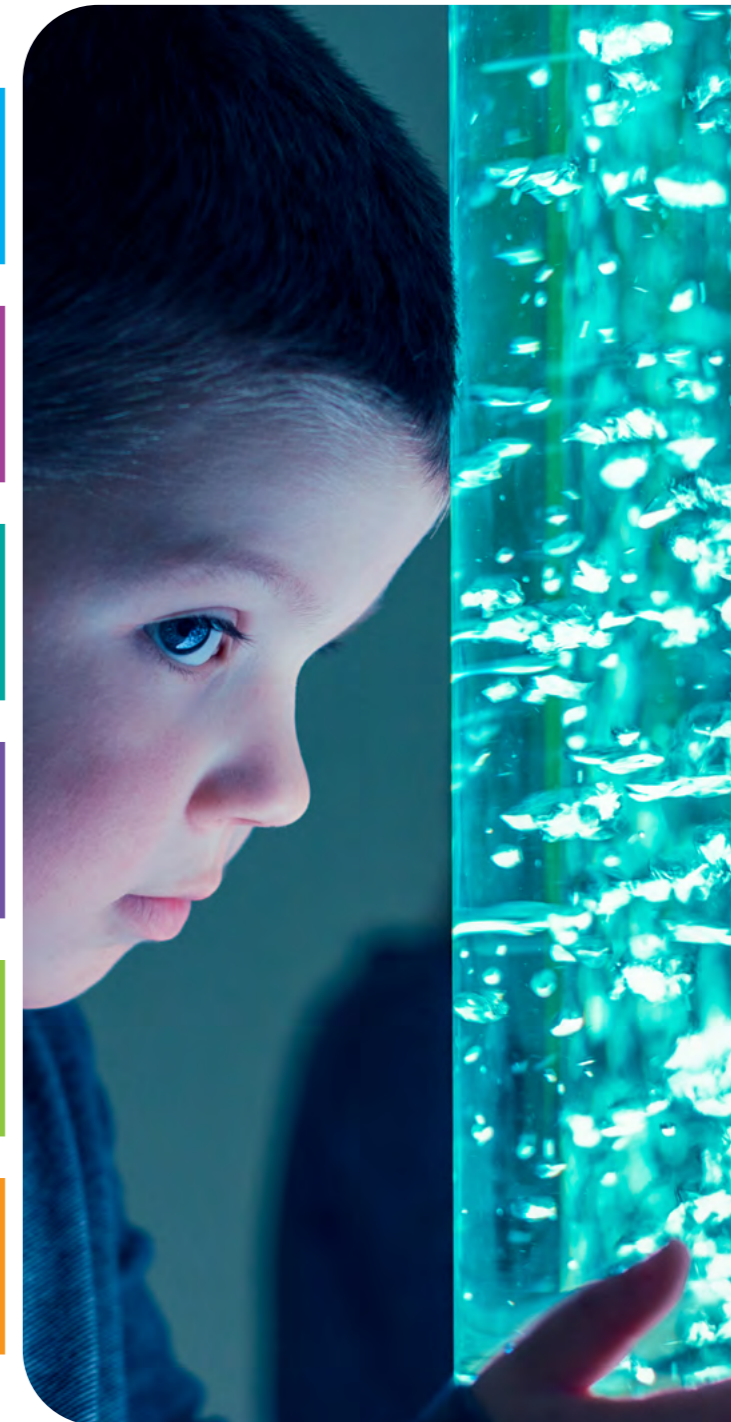
Australian Government
Department of **Social Services**

This project is an NDIS Information, Linkages and Capacity Building (ILC) initiative, jointly funded by Department of Communities (Disability Services) and Department of Social Services (DSS). For more ILC information and resources please visit:

- Department of Communities (Disability Services):
swanautism.org.au/dss-ilc-resources
- Department of Social Services:
swanautism.org.au/dss-ilc-program

Contents Page

About SWAN	4
About this booklet	5
Getting a Diagnosis in Western Australia	6
Support Services	12
Health	24
Early Childhood Education and Starting School	32
For Further Information	50



About SWAN

The South West Autism Network (SWAN) supports autistic people and their families in the south west region of Western Australia.

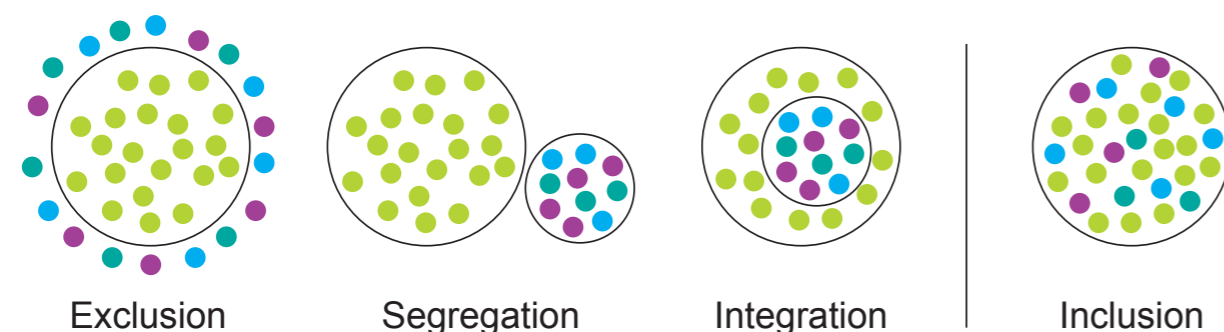
We provide:

- information, resources, and peer support (online, phone or face-to-face)
- social media groups
- accessible information via website and e-newsletter
- a free resource library for members
- training and workshop opportunities
- fun skill-building group programs for children and young adults
- social events such as our Family Christmas Party

SWAN's staff and Board of management includes autistic adults and family members. This gives us an understanding of the experiences of autistic people and guides us in providing the information, services and support people need.

Our vision is to empower autistic people and people with disability in south west WA and beyond. We are a Disabled Persons and Families Organisation (DPFO) and use person-centred language. Most autistic adults prefer to be described as an 'autistic person' rather than 'person with autism', and SWAN uses the language preferred by autistic people.

At SWAN, we believe in inclusion as the truly fair way to honour and respect the rights of all people.



SWAN is a not-for-profit organisation with tax-deductible status. Our services are funded through government grants and the generosity of people who make donations and provide ongoing sponsorship.

Go to our website to learn more about SWAN, join as a member or find out how you can get involved. www.swanautism.org.au

“High quality inclusion is not just about ‘being there’ or attending a mainstream or universal setting, but about creating environments that provide opportunities for ALL children to actively engage in ALL activities”

Denise Luscombe, Chair ECIA WA/NT 2015

The early years of life are important for the development of every child. The right support during these early years can help autistic children to develop their individual strengths and capacity. Parents who receive good information and support are better equipped and more confident in their role.

About this booklet

This booklet begins with information and guidance for parents just starting the process of getting a diagnosis. The rest is useful for parents whose child already has a diagnosis and are looking for more information to help them support their child through the early years.

There is information for families about therapies available through NDIS Early Childhood Early Intervention, financial entitlements and other supports you might need in the early years. This booklet provides information about health services, childcare, getting ready for school, support for parents and where to find more information and services. We've also included information on your child's rights and where to get help when you need it.

This booklet is the first of a series that SWAN has produced for different ages and stages of life.



How to use this booklet

Parents using this resource will be at different stages and some will be looking for specific information. Some will want to read the whole booklet first, while others will want to look first at certain topics that are of more interest at the moment. It's up to you.

As well as providing information, we have also included some blank templates and a Notes page. You can use these to map out and record important information about services and supports, so it becomes a handy personal resource.

If you have any comments about the booklet, or need further information, please get in touch with us at SWAN by emailing info@swanautism.org.au.

Getting a diagnosis in Western Australia

In WA, a child aged 0-12 years is assessed for autism by two out of three professionals using the Diagnostic and Statistical Manual of Mental Disorder, version 5 (DSM-V-TR). The three professionals are:

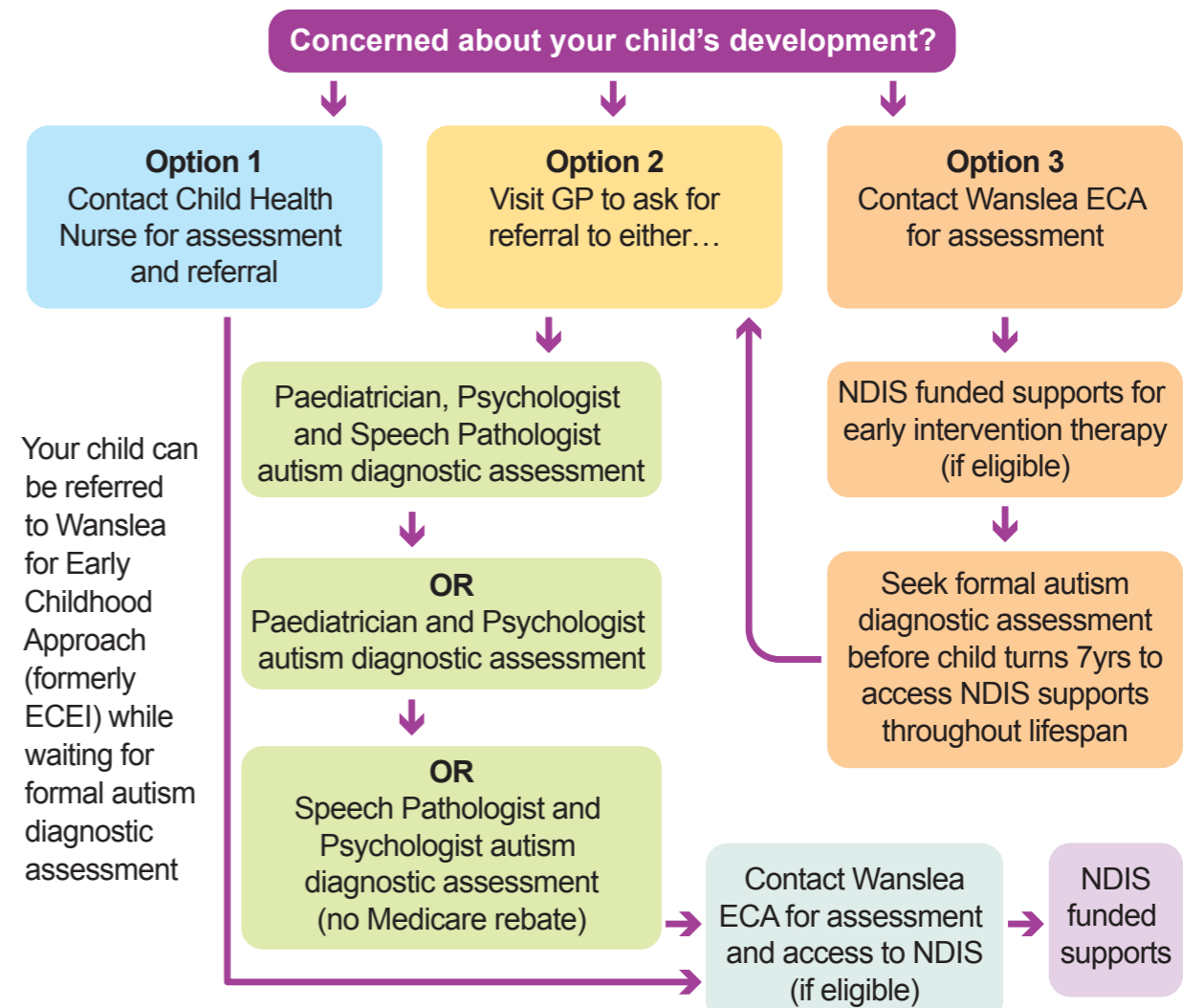
- Paediatrician
- Speech Pathologist
- Registered or Clinical Psychologist (must include psychologist)

Please note, not all qualified professionals carry out autism diagnostic assessments. Also, the diagnosing professionals and processes are different between children and adults.

The process for diagnosing autism varies between different Australian states and territories. If a person was diagnosed outside WA, they may need to be re-assessed to meet the criteria for support in the WA Education system.

Here's how it works

If you are a parent worried about your child's development, here are the different options and steps involved in getting a diagnosis.





The traditional autism diagnostic process in WA starts with an appointment with either your GP or Child Health Nurse to talk about your concerns. Your child needs to go to the appointment with you. The GP or Child Health Nurse can refer your child to see a paediatrician. You can choose which paediatrician, or they can recommend one. The paediatrician's office will contact you to book an appointment. If you don't hear from them within two weeks, it's a good idea to contact them directly.

The paediatrician will carry out an assessment of your child. If they believe your child needs further assessment for autism, they will refer your child to a speech pathologist and a psychologist for them to do a formal autism diagnostic assessment. These assessments can be done either through the public or private systems.

- Public: diagnostic assessments are free, but the waiting period for children aged 0 to 6 years is around 6 to 12 months. For children over 7yrs old, the waiting period is up to 2 years. Public autism diagnostic assessments are carried out by the Department of Communities – Disability Services OR the State Child Development Centre (Perth families only).
- Private: the waiting period for a private autism diagnostic assessment is usually around 1 to 4 months, and you will need to pay a fee for the assessments. You may be able to claim some small rebates from Medicare or private health insurance. Please contact the speech pathologist and psychologist before the appointments to find out about their fees and any rebates.

The speech pathologist and psychologist work together to carry out their autism assessments and to write a formal diagnostic report. You may then have a follow-up appointment with the paediatrician to confirm the diagnosis, if they haven't written a letter beforehand stating their opinion that your child meets the criteria for autism.

The diagnostic assessment can be completed by Psychologist and Speech Pathologist (without Paediatrician), but there is no Medicare rebate available this way.

Children with developmental delay aged 0-6yrs can access Early Childhood Early Intervention (ECEI) through the National Disability Insurance Scheme (NDIS). Wanslea is the ECEI provider for WA. To access this, you can:

- Fill out an NDIS Access Request Form and ask your GP, paediatrician, or allied health therapist to fill out the Supporting Evidence Form which can be downloaded from the NDIS website swanautism.org.au/ndis-access-request. Both forms need to be emailed to NAT@ndis.gov.au, or dropped off at your nearest NDIS or Wanslea office. OR
- Contact Wanslea by phoning 1300 969 645 or emailing ndis@wanslea.asn.au

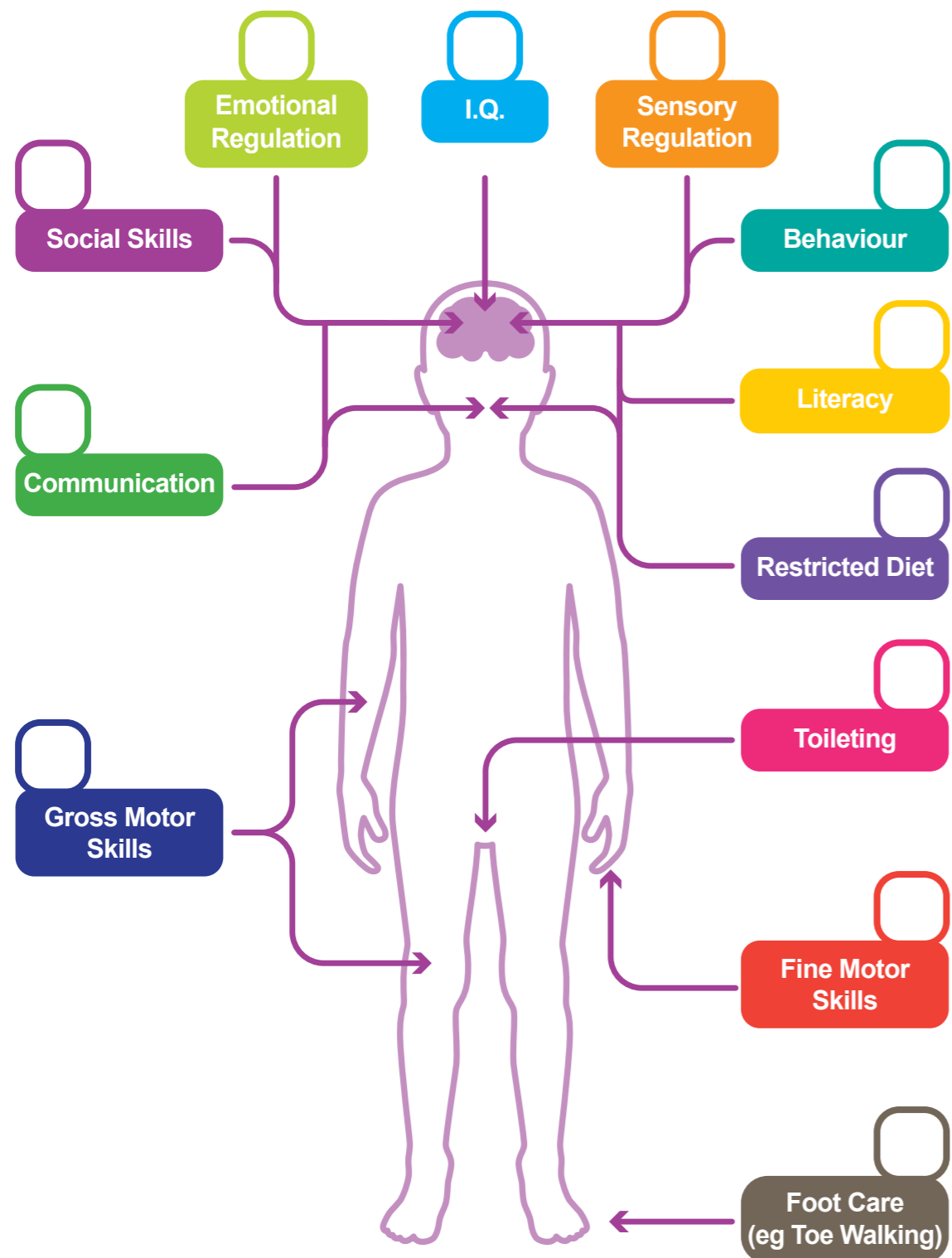
Children aged 0-6yrs don't need to have a formal diagnosis to be eligible for ECEI, but there does need to be evidence of developmental delay. Your child will be able to get NDIS funded ECEI therapy services until they turn 7 but will need a formal diagnosis by the age of 6 years for continued access to NDIS supports throughout their lifespan.

You can find out more information about Wanslea here:

swanautism.org.au/wanslea-early-childhood-approach



What Does Your Child Need Support With?



You can use this diagram to think about what your child may need support with. This will be useful when you have your meeting with Wanslea.



Handy Hint – Collecting evidence and information

You will probably be asked similar questions by the GP, paediatrician, therapists, and other services about your child. You will also receive lots of forms, reports, and paperwork. The best way to keep track of it all is to:

HELPFUL TIPS



- Create a file where you can store everything in one place. Take print copies with you to appointments with your paediatrician, therapists and ECEI.
- Write down your concerns about your child. You can also use video to show the health professional your concerns.* *Remember to keep any notes and videos private – your child will be an adult one day, and the internet is forever.
- Collect supporting evidence of your child's needs from a variety of sources. e.g., letters or reports from day care, school, therapists.
- Store digital backups of important reports and paperwork in the cloud. Dropbox, Google Docs and OneDrive are some options.
- Never assume the health professional you are meeting has all your information. Take print copies with you, just in case.

Support Services



One of the most valuable sources of support when your child has a disability is other parents who are going through similar experiences. Not only for emotional support but for the sharing of everyday useful information, recommendations, and ideas. Many parents find the connections they make early on through support groups become enduring friendships as their children grow.

SWAN

As a member of SWAN, you can join our closed Facebook Peer Support Group to connect with other parents and autistic adults, as well as follow our public Facebook page for news and information. You can also contact us for information, referral, and support, including about NDIS. We have a directory of support services on our website, but you can also contact us for help to find what you need.

- Website: www.swanautism.org.au
- Email: info@swanautism.org.au
- Phone or SMS: 0499 819 038 or 0476 315 694

Carer Gateway

As the parent of a young child, you probably don't think of yourself as a 'carer', but you can still tap into a range of services and opportunities offered on the Carer Gateway. These include professional counselling (online, phone or in person), online skills courses and self-guided coaching.

You can find more information about the Carer Gateway here: swanautism.org.au/carer-gateway

Carers WA is the contact and provider for the Carer Gateway in WA: swanautism.org.au/carer-gateway-WA

Family Support

Family and friends

Some parents find their extended family and friends to be great supports. If there are people you would like to contact sometimes for practical help or emotional support, check that they are happy for you to do this. Keep their contact details handy for when you need them.

Advocacy Support

Sometimes, if you are having problems with the NDIS or with other services such as education or health, you might feel you need someone who can give you good advice and practical help.

You may get some help from family, friends, and your peer support networks, but sometimes you might want more formal help from an advocacy organisation. Advocacy organisations provide free advocacy support.



What can advocacy help me with?

If you have a problem, an advocate can give you advice to help you decide what to do. They may also provide practical support such as someone to go to meetings with you to sort out problems and make sure your child's rights are respected.

Where can I get advocacy support?

SWAN is a free service and may be able to help you in some situations. We work with people with disability and their families to improve knowledge and understanding about the NDIS, mainstream, and disability services, and can attend meetings with you as an advocate if needed. It can be helpful to speak with a peer support organisation like SWAN before important meetings, to help you prepare. If you know more, and feel prepared, you will feel more confident in meetings to advocate for your child.

Here are some other organisations that offer advocacy support.

Advocacy WA

Advocacy WA is an organisation based in Bunbury, but they also have offices in other major towns and operate across the southwest of WA. It is a free service for people with disabilities, and parents can contact them on behalf of their child for advocacy support.

You can find out more about Advocacy WA and how to contact them here:

swanautism.org.au/advocacy-wa

Sussex Street Community Law Services

Sussex Street Community Law Services is a free legal service based in Perth for low-income and disadvantaged people in the community, including people with disabilities. The WA Disability Discrimination Unit is part of the Sussex Street Community Law Services. They provide information and advice to people living anywhere in WA (including the southwest) who feel they have been discriminated against because of their disability. You can find out more about Sussex Street Community Law Services and how to contact them here:

swanautism.org.au/sussix-street-comm-law

Developmental Disability WA (DDWA)

DDWA also provide free advocacy, and have expertise in advocacy across health, education, disability services (including NDIS), justice (including guardianship), access, recreation and housing.

You can find out more, and contact them here:

- Website: swanautism.org.au/ddwa-ind-advocacy

As well as being able to get individual advocacy support, there are national and state advocacy organisations that advocate to the government on issues that are important to people with disabilities. Some also offer a range of information resources. There is a directory of Australian disability advocacy organisations here: swanautism.org.au/afdo-advocacy

Children and Young People with Disability Australia (CYDA)

Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disabilities aged 0 to 25 years. CYDA has information on NDIS, inclusive education, and much more. swanautism.org.au/cyda

People With disability WA (PWdWA)

PWdWA provides non-legal individual advocacy to help people with disabilities speak out, express their views, and uphold their rights.

swanautism.org.au/pwdwa

Advokit

Advokit is a simple, pop-up website produced by Disability Advocacy Network Australia (DANA) and Inclusion Australia during COVID 19. It is designed to help you with the advocacy resources you need during the pandemic and beyond.

swanautism.org.au/advokit

Financial Support



Centrelink Payments

Most parents of autistic children will be eligible for some financial assistance from Centrelink / Services Australia. However, you don't get any allowances or payments automatically when your child has a diagnosis, you have to apply for them.

The rules and application forms may change from time to time, so it's important to look at the current information and use current application forms. The payment starts from the date Centrelink receives your application, not the date your child is diagnosed, so it's a good idea to apply as soon as possible. Here are some payments you may be entitled to:

Carer Allowance

Most parents of children diagnosed with autism will qualify for Carer Allowance from Centrelink. This is a fortnightly supplement to help with costs related to the disability. The allowance includes a Health Care Card in your child's name, which entitles them to low-cost prescription medications. The allowance is income-tested but the cut-off rate for the combined family income is \$250,000. Check the Centrelink website for current information:

swanautism.org.au/sa-carer-allowance

Carer Payment

Carer Payment is a means-tested fortnightly payment sometimes known as the Carer Pension. This is a payment for people who can't support themselves because they provide constant care to someone who has a disability, illness or is frail and aged.

Carer Supplement

This is a once-a-year payment automatically paid to people who receive Carer Allowance or Carer Payment.

Child Disability Assistance Payment

This is a once a year payment automatically paid to people who receive Carer Allowance for a child under 16 years.

Carer Adjustment Payment

This is a one-off payment if your child is aged under 7 and gets a severe illness or has a major disability.



To Do Checklist

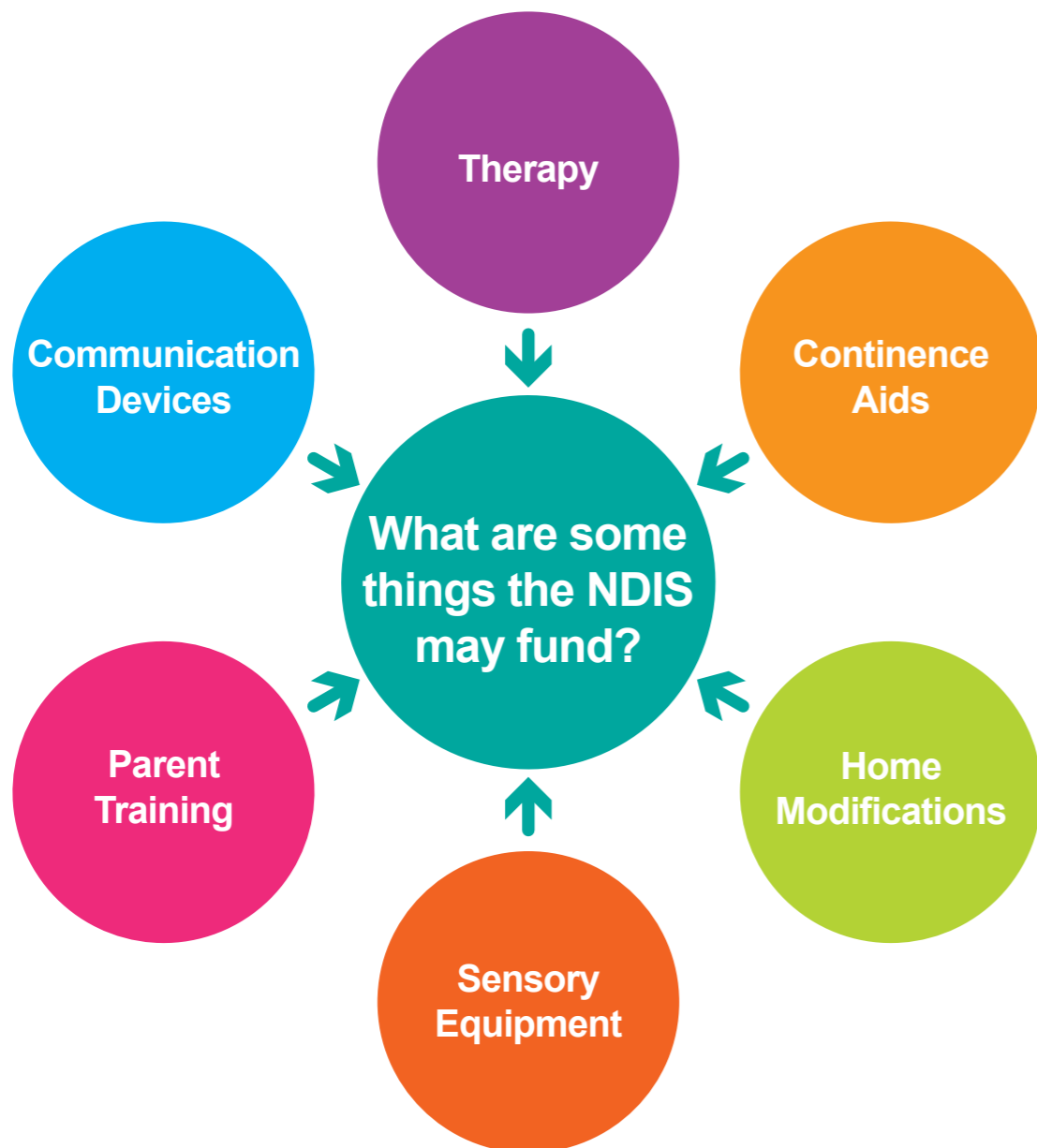
Services Australia (Centrelink)

Check eligibility for:

- Carer Allowance
- Carer Payment
- Carer Supplement
- Child Disability Assistance Payment
- Carer Adjustment Payment (CAP)



You can find more information here:
swanautism.org.au/sa-carer-payment



Supporting your child's development

National Disability Insurance Scheme (NDIS)

Early Childhood Early Intervention (ECEI)

The NDIS ECEI program supports children aged 0 to 6 years with developmental delays to access early intervention to help their development. The NDIS works with organisations called Partners in Community to deliver the program. In WA, the ECEI Partner in Community is Wanslea.

What is Early Intervention?

It's an approach designed to help each child achieve their best outcome through therapy services, to help them learn and develop their skills. Early intervention also helps families learn how to support their child's development. The NDIS worked with leading Australian early intervention practitioners and researchers to design the approach which aims to provide the best support in the early years of life to help them be included in everyday community life.

What is an Early Childhood Early Intervention (ECEI) Partner?

The role of ECEI Partners is to work with you to identify your child's individual support needs and goals and work out what supports will be best for your child and your family. They will then draft a plan of supports to help them towards their goals, which goes to an NDIS delegate to approve. They will explain the plan, give you information about services in your local community and help you to link with the services you choose. They will also monitor and review your child's progress towards their goals.

In Western Australia, Wanslea is the NDIS Early Childhood Early Intervention Partner. You can contact Wanslea by phoning 1300 969 645 or emailing ndis@wanslea.asn.au

The Wanslea offices in the southwest are located as follows:

Wanslea - Bunbury
Unit 1, 28 Carey Street,
Bunbury WA 6230

Wanslea – Busselton (co-located in the APM Communities office)
Shop 13, 69 Prince Street,
Busselton WA 6280



NDIS Social Media support networks

Here are some online groups you can join to share or find information with other NDIS participants and families:

- NDIS in WA Peer Support Facebook group
- NDIS Grassroots Facebook group
- NDIS Self-Management Hub Facebook group

You can also find peer support on a range of things including NDIS online by joining:

- SWAN Group – South West Autism Network Facebook group
- Disability Peer Support South West WA Facebook group



Your Rights - NDIS

People who receive NDIS funding and supports have a number of fundamental rights. This includes the right to quality services to meet their needs, the right to choose and control their services, the right to be safe when using services, and the right to make complaints.

The NDIS Quality and Safeguarding Commission is the organisation responsible for upholding people's rights and taking complaints relating to the NDIS.

swanautism.org.au/ndis-participant-rights



Therapy

What kinds of therapies might your child need?

Every child is different and needs different kinds of support. Some therapies work to help a child's development by teaching skills, while others may focus on providing positive behaviour support. Your child's NDIS plan will include funding for assessments, therapy, and parent training in a section of their NDIS plan called Capacity Building - Daily Living. You will be able to choose therapists to assess your child's needs, and work with them during the year to build their skills. Here are some of the different kinds of therapy:

Speech Pathology

If your child needs help with speech, communication, and comprehension, you and your child can work with a Speech Pathologist (sometimes called a speech therapist). They can also help children who have difficulties with feeding/eating.

Psychology

Psychologists help children with understanding and managing their emotions, learning social skills and interaction, staying safe, and positive behaviour support. They also help parents with understanding their child's needs, and how to support them.



Occupational Therapy

Occupational Therapists help children to develop skills for daily life such as eating, dressing and toileting so they can become more independent. This involves supporting the child with their fine and gross motor difficulties, sensory issues (e.g., over-sensitivity to noise, light, smell, and touch), organisation skills and information processing.

Physiotherapy

Autistic children sometimes also experience difficulties with low muscle tone, low core strength and gross motor skills such as sitting, crawling, and walking. Physiotherapy can help to improve these early skills so that children can go on to master more complex skills such as balancing, riding a bike, skipping, and ball skills; all skills that help children to take part in activities and sport with other children.

Podiatry

Many autistic children toe-walk. Spending a lot of time toe-walking can cause problems with feet and ankles, such as the Achilles tendon becoming too short as they grow. Podiatrists and physiotherapists can both help with improving foot and ankle flexibility and strength.

Alternative therapies

Alternative therapies are therapies that are outside of conventional medical and allied health practice. You might see these advertised online, or well-meaning people may tell you about them. However, the benefits are generally not supported by rigorous scientific testing, and some are actually harmful.

Evidence Based

When you're choosing a type of therapy, it's important to look for 'evidence-based' approaches - that is, interventions that have scientific evidence to show they work for autistic children. Seeking advice from autistic adults who have experienced these therapies can be helpful. Be cautious and use your judgement when considering interventions that haven't been scientifically tested. It's also important to remember that NDIS will only fund therapies and interventions which are evidence-based.

Here are some other terms you will probably come across relating to therapy.

Child and Family-centred Approach

Therapists will work in partnership with families to better understand their unique circumstances, and to help parents decide what strategies will best suit their child and their family. You should always be involved in setting goals and talking about how you can work towards them.

Multidisciplinary Team Approach

Each type of therapy is a 'discipline'. Multidisciplinary means that your child sees two or more different types of therapists who each work with your child as part of a team (e.g. Speech Pathologist, Psychologist, and Occupational Therapist). In multidisciplinary therapy, the therapists share what they know about your child and what therapy they are doing with each other, to make sure that your child's needs are understood, and that therapy is holistic.

National Guidelines for Best Practice

Early Childhood Intervention Australia have produced these guidelines that set out the requirements for high-quality early childhood intervention. This can be especially useful when you want to check if a therapy service is providing your child with a quality service.

swanautism.org.au/ecia-national-guidelines



Health



When you have a young child, it's good to know how the health system works before you need it urgently. This section contains some basic, useful information and links to help you find what you need in the health system, as well as some information specifically around disability and health.

The WA Health System

Western Australia's health system is a mix of different services. Some are provided by Australian and State Governments, and some by private healthcare providers.

The Healthy WA website provides a lot of information about the different kinds of services that make up the health system in WA. They explain what these services are and give links to more information.

The link below gives you an overview of the system and covers some useful information on public and private healthcare, choosing to be a public or private patient, health insurance and different types of hospital care – inpatient or outpatient.

swanautism.org.au/doh-wa-health-overview

General Practitioners (GP)

Unless the situation is life-threatening, your local doctor (GP) is the first person you should contact when your child is unwell or has a minor injury. It's a good idea to build a relationship with a GP so that they get to know your child as a person, and understand their disability and any ongoing health conditions they may have.

Finding a GP

To find a GP in your local area use the following link and enter your postcode - swanautism.org.au/doh-wa-service-finder

GP Services

As well as going to your GP when you are sick, GPs provide some services to help you stay well, identify health problems, and manage your care. These services can include annual health assessments and GP-managed health plans.

Talk to your GP about regular health checks for your child and any Medicare-funded health and allied health programs they are entitled to contact your private health insurance provider (if applicable). Find out which services you are covered for such as occupational therapy, speech pathology, psychology, physiotherapy as applicable.



GP Managed Health plans

People with disability are usually eligible for GP managed health plans. The GP can set up a team care approach and make referrals to other health and allied health practitioners such as therapists. You can do this even if you have therapy in your NDIS plan.

swanautism.org.au/doh-disease-mgmt

Health Check-ups

People with intellectual disability can have a full health check-up with their GP every year, with a Medicare rebate. Medicare calls this an annual “health assessment for people with an intellectual disability”. Here is the link to information about the Medicare-covered annual health assessment:

swanautism.org.au/doh-medicare-assessment

HealthDirect

If your child is unwell or injured, and you’re unsure what to do, you can contact HealthDirect 24 hours a day for free advice by phoning 1800 022 222.

You can also visit the HealthDirect website to check symptoms, find information about health, and find a health service near you.

swanautism.org.au/health-direct



Emergency

In an emergency, you may need to call an ambulance for your child or visit the nearest hospital Emergency Department.

If you need urgent treatment for a serious injury or illness call 000 for an ambulance.

Emergency departments in public hospitals provide free emergency care to anyone who needs immediate treatment for a serious injury or illness.

You don’t need an appointment to go to an emergency department. They are open 24 hours a day, 7 days a week.

In the Perth metropolitan area, WA Health emergency department doctors and nurses are always on duty. Country hospitals and nursing posts can arrange emergency services.

This link gives you the name of each Emergency Hospital and the average amount of time you need to wait to be seen by medical staff.

swanautism.org.au/doh-wa-emergency

In Country WA, hospitals and nursing posts provide or can arrange emergency services. Ambulance services or the Royal Flying Doctor Service can also help you access these services. You can find health services information for your area by using the National Health Services Directory:

swanautism.org.au/doh-wa-service-finder

This is the link to search for your closest GP, Emergency Department, Pharmacy, Mental Health, and Hospital Service. Enter your postcode and choose the type of service you need.

swanautism.org.au/doh-wa-service-finder



Supporting your child in an emergency

Emergency visits to hospital can be very frightening for young autistic children. It's important to tell health professionals that your child is autistic, so that they can better support their needs. Some things which may help your child cope with health treatment are:

- Bringing a comfort item with you, if you have time.
- If your child uses a communication system, bring it with you.
- Asking ambulance staff to turn internal lights and sirens off (if appropriate).
- Ask emergency department staff for a separate room (if available), and for the lights to be dimmed.
- Ask medical staff to demonstrate medical treatments on mum, dad, or a toy, to help your child understand what will be done to them.
- Use your smart phone to search for videos or social stories about medical procedures, to help your child understand what will happen. Make sure that you watch any videos first, to make sure they are helpful rather than scary.
- Ask medical staff to carefully explain to your child what will be done to them, before doing it.
- Take snacks that your child likes in case they get hungry (just check with emergency department staff that its ok to eat first).
- Activities to keep them occupied – books, games etc.
- Charging cords for any electrical devices (i.e., iPad, phone).

Hospital Admission Forms

You can download these forms and use when your child is going to hospital, either urgently or for a planned admission. Families can complete the forms, to be sure important information is seen by the treating professionals and is in the medical record.

swanautism.org.au/ddwa-hospital-forms

Medicare

Through the Helping Children with Autism (HCWA) program, a child aged 0-13yrs can be referred by a paediatrician or psychiatrist to the following allied health services for a Medicare rebate:

- Up to 4 diagnostic/assessment services from psychologists, speech pathologists, occupational therapists, audiologists, optometrists, orthoptists, or physiotherapists to assist the referring Dr with diagnosis, treatment, and management.
- Up to 20 treatment services from psychologists, speech pathologists, occupational therapists, audiologists, optometrists, orthoptists, or physiotherapists (available up to age 15yrs, as long as the referral is made before the child's 13th birthday).

These are the maximum number of services you can claim a Medicare rebate for, and don't renew each year. You can find out more here:

swanautism.org.au/doh-wa-helping-children-autism

Medicare also provides a Safety Net to help people with high medical costs. If your out-of-pocket medical costs reach the threshold between 1st January and 31st December each year, you will receive a higher amount back when claiming from Medicare.

Find out more here:

swanautism.org.au/medicare-safety-nets

NDIS and Health

NDIS doesn't cover services that are seen as the responsibility of the Health system, but there are some health-related supports that can be included in an NDIS plan. So it can be confusing and hard to work out which treatments and therapies are covered by which system.

Here is what the NDIS and Health have agreed on:

swanautism.org.au/ndis-health



Disability Discrimination Act



Your Rights – Health

All Australians including people with disabilities of all ages, have legal rights when it comes to health services. This is covered by the Disability Discrimination Act and also by the Australian Charter of Healthcare Rights.

Australian Charter of Healthcare Rights

The Australian Charter of Healthcare Rights describes the rights of patients and other people using the Australian health system. These rights help to make sure that, wherever and whenever care is provided, it is of high quality and is safe.

The charter applies to all health settings anywhere in Australia, including public hospitals, private hospitals, general practice, and other community environments. It allows patients, consumers, families, carers, and service providers to have a common understanding of the rights of people receiving health care.

You can find the charter here:

swanautism.org.au/healthcare-rights

Here is a Guide for Patients and Carers about the charter:

swanautism.org.au/guide-patients

Making complaints about health services in WA

You can make a complaint about health services if you've had your rights denied or you feel that you've received bad care. It's a good idea to try first to resolve the problem with the health professional involved, but if that's not possible, or you need some advice or help, talk to the patient liaison officer or representative at the health care service.

Health and Disability Services Complaints Office (HaDSCO)

You can also contact the Health and Disability Services Complaints Office. HaDSCO is a WA independent statutory authority providing a service to help you resolve complaints relating to health, disability, and mental health services.

Here is information about how to make a complaint about a health service:

swanautism.org.au/wa-health-complaints

Patient Opinion Australia

You can share your experience on the Patient Opinion website. It is an independent service that aims to help make health services better.

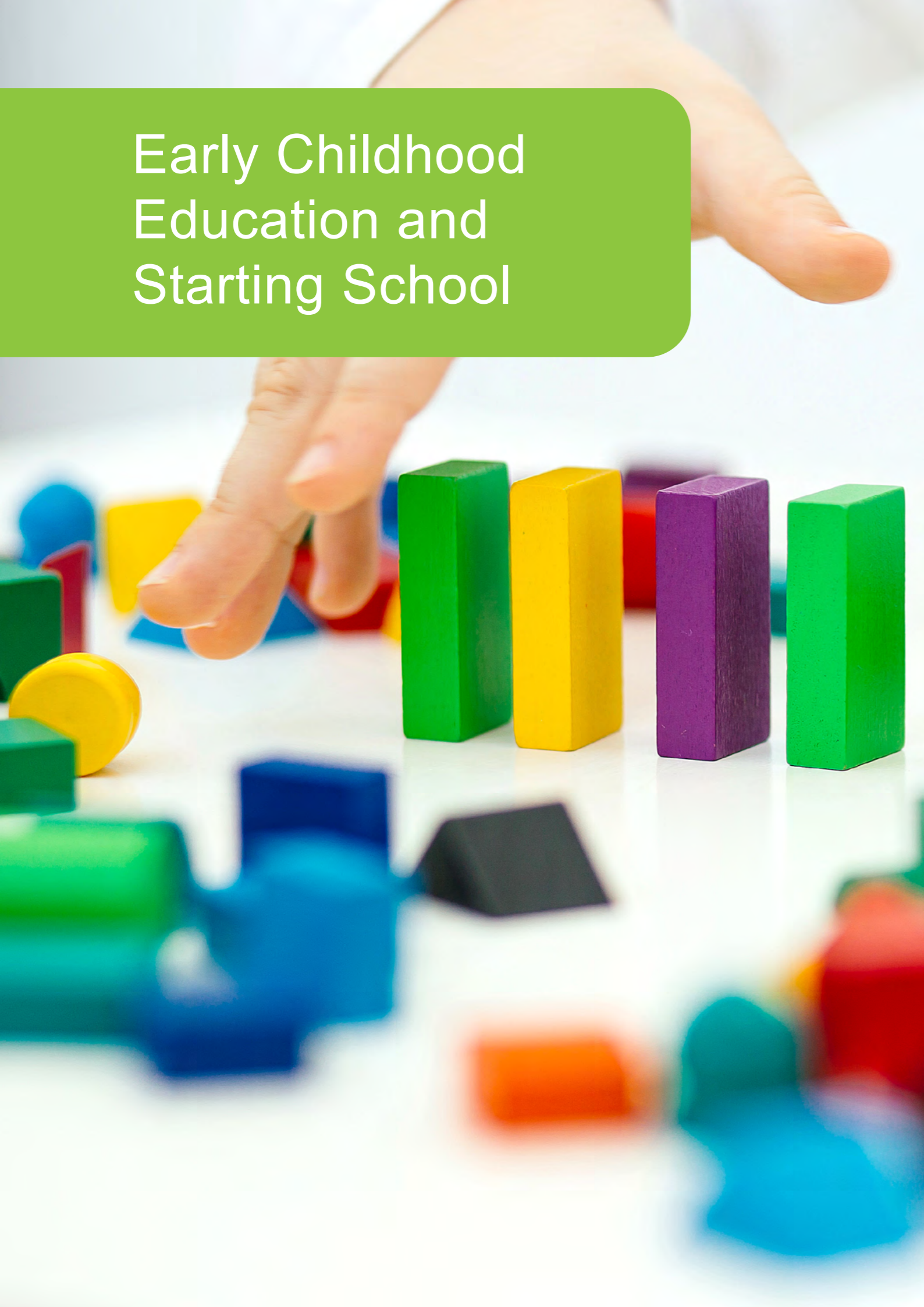
Over 50 health services and organisations are currently subscribed to Patient Opinion Australia. These include hospitals and hospital networks, primary health networks, mental health services, community health centres, government departments, and other health not-for-profit organisations.

Here's how it works:

1. Go to the Patient Opinion website: swanautism.org.au/care-opinion
2. Share your story of using a health service
3. We send your story to staff so that they can learn from it
4. You might get a response directly from the health service such as an apology, an offer to discuss your complaint, or be asked to advise how to improve their service
5. Your story might help staff to change services



Early Childhood Education and Starting School



Choosing an Early Childhood Education and Care setting is a big decision for all parents, and more so when you have a child with a disability. There are all the usual things to consider, such as seeing that the setting is safe and well run. But you also need to know the childcare provider can give your child the supports they need to be included in learning alongside other children.



It is important to visit the centres you are considering and talk to key staff about your child, their strengths, and where they need some extra support. Ask them:

- How do they practice inclusion?
- What do they do to help all children to participate and feel they belong?
- What kinds of support can they provide? and
- Will they need assistance to support your child?



Preparing for Childcare



Here are some ways you can help the childcare service to be ready and have the information and skills they need to support your child:

- Ask your child's therapists to visit the centre to talk to staff, giving them information and some strategies they can use to support and communicate with your child.
- Write out your child's strengths and the areas where they need more support. You could do this as a One Page Profile so that all staff can easily see the main information about your child. See page 45 on One Page Profiles.
- Use a communication book to help with everyday communication between home and the childcare centre.
- Understand that it may take your child longer to settle in, so be prepared to spend more time there at first, or to pick up your child early.

Inclusion Support Program (ISP)

The ISP is a free service that helps childcare services to overcome barriers so that all children can be fully included. If an early education and care service feels they will need it, they can ask for extra support. The WA Inclusion Agency (WAIA) employs a team of Inclusion Professionals to provide tailored support and advice to early childhood education and care services. The childcare service sends WAIA a Request for Inclusion Support form, along with a signed parent permission form.

WAIA will then visit the childcare service and meet with staff and develop a strategic plan that sets out the best supports and actions that are needed to overcome the barriers to inclusion. Services can also apply for funding for extra staff and can borrow specialist equipment if it is needed. It is very important that childcare services keep families informed about the inclusion support they are providing. Families can talk to the service directly, and with the Inclusion Professional at the centre, or you can call the WAIA Helpline on 1800 119 247.

Here are some things you can do to help your child get ready for childcare:

- Go to the centre with your child just to visit, so they can meet people and see what happens there. Take some photos while you're there, to look at and talk about later. You can ask the centre for photos of the staff who will be working with your child as well.
- Talk with them about going to childcare and the fun things they will do.
- Talk about the people there, using their names if you can, so they begin to feel familiar.
- Talk about when they will go, who will take them and who will pick them up.

Starting School

There's a lot to think about when it comes to choosing a school for your child. So it's a good idea to start thinking about it early and take it step by step.

Thinking about the kind of life you want for your child is a good place to start. Most families will say they want their autistic child to have the same opportunities as other children and grow up to have a fulfilling life like anyone else. This usually means a happy life that includes friendships and relationships, a job they enjoy, the chance to keep learning, having their own place, making their own decisions, and really belonging in a community that values them.

It can be daunting to think ahead, but it's good to have a vision for the future. It helps to set the scene for thinking about possibilities and helps with making decisions in line with that vision.

Choosing a school

This section has the main things to think about when you are choosing a school for your young child. Some families, especially if they have older children at school, will already know which school they want their autistic child to attend. This information will still help with preparing your child for school and may be useful when things don't always go according to plan.

Your child's legal rights

Hopefully, you won't need to use legal information, but it is always useful to know about education rights just in case.

According to law, Australian children with disabilities, in every state and territory, have the right to access and participate in education on the same basis as children without disabilities.

The law that covers these rights is the Commonwealth Disability Discrimination Act 1992. The Act also has Education Standards that set out what schools and other education providers must do.

Schools and other education providers must not treat children with disabilities differently from other children. This is discrimination. They must also provide 'reasonable adjustments'. This includes things such as support staff, equipment, materials, modifications, and other things each child needs to support them to learn. This does not mean being told your child should learn in a separate learning environment because that is where the specialist support is located. Children with disabilities have the right to the supports they need to learn alongside other children in mainstream settings.

If the school you choose will not accept your child into the mainstream or provide the support they need, you can get support from an advocacy organisation to negotiate with the school. You can also get help to make a formal complaint to the Australian Human Rights Commission.

Knowing these rights gives you the knowledge and confidence that you can approach any school in any system and know that by law they must treat your child the same as any other child.

Making decisions about schooling

Here is a step-by-step process to help you gather the information you need and make decisions.



Step 1: School Systems in WA

There are four schooling system options to consider – Government, Catholic, Independent, and Home-schooling.

It is important to find a school that not only suits your child but fits in with your family. When you are making a decision about which school systems you might consider, think about:

- Your philosophy on education. Do you want a private or public school, same-sex or coeducational?
- Your religious beliefs.
- The financial cost of each system and your family's circumstances.

Talk to friends, relatives, and other parents to hear what they say about different schools, but you and your family need to be happy that the school you have chosen is a good match.

Here are some websites with further information about each system.

Department of Education swanautism.org.au/dept-education

Every child from Pre-primary to Year 12 is guaranteed a place at their local public school. There are 'catchment areas' for most schools, so where you live can determine which school your child is able to attend.

Catholic Education of WA swanautism.org.au/catholic-education-wa

You don't need to be Catholic to go to a Catholic school. But, it is important to put your child's name on the waiting list as early as possible if this is your preferred option.

Association of Independent Schools

swanautism.org.au/Independent-schools-wa

Each independent school is different, so you need to look at each school's website to find out information about that school and how to enrol.

You don't need to follow a particular religion to enrol in most independent schools, but it is important to put your child's name on the waiting list as early as possible, if this is your preferred option.

Home-based learning swanautism.org.au/home-education-wa

This website has information about home-schooling, the legal requirements, the curriculum range, and assessments required. It is also a support network for families who are home-schooling.

Legal requirements and registration for home schooling process is on the Department of Education website.

The SWAN website also has an article about home schooling options.

There are also different types of placements within the different school systems.

School of Special Educational Needs: Disability (SSEND)

SSEND provide support to public schools to make sure that students with disability are able to access the curriculum, as well as their peers, can. Services include:

- Advice and training for staff
- Intensive student support
- Assistive technology e.g., mobility equipment, hardware and software

Mainstream

This is a regular classroom where students of all abilities learn together. The teacher will provide work of an appropriate level for different students, and also have whole-class activities. Each student with disabilities should have their own Individualised Education Plan (IEP). The teacher should have assistance from other staff in the classroom to ensure students get the support they need. Children in public mainstream settings have access to visiting teacher (SSEND) support, and most schools will also allow your child's therapists to visit them at school to provide additional support. It's a good idea to check with the school that they will allow therapists to visit before you enrol your child.

Note: Private mainstream schools do not have access to support from SSEND and may not provide an Education Assistant (EA) if your child needs one. Private schools are funded differently for these types of supports. Make sure that you ask about how your child's needs will be supported if you are considering enrolling at a private school.

Some mainstream schools may also have an education support class within them.



Education Support Centre

These are clusters of classrooms specifically for children with a disability on the same grounds as some mainstream primary schools. The centres have their own staff including their own principal and teachers who work with children in the centre as well as some support in the regular school.

Education Support School

This is a separate school for students with disability. There is often on-site therapy and nursing available.

Step 2: Finding the Best Match for Your Child and Family

Schools need to be a good match educationally, practically and financially.

Think about your family situation.

- Do you have other children already at school? Do you want all your children to be at the same school?
- How far can you travel to get to school?
- Do pick up and drop off times fit with your work and other things you have to do?
- Are you prepared to pay school fees?

Think about your child.

- What are their strengths? What are they good at?
- What do you think they need to experience and learn?
- What learning situation do you think will work best for them?
- What are their likes and dislikes? What motivates them?

Think about the school situation.

- What type of school would suit your child?
- What class size would be best?
- What support do they need in the school?
- What support do they need in the classroom?

Step 3: What Do I Look for in a School?

When you are researching schools, you are:

- Collecting as much information as you can to get a good idea of whether this school will be able to provide a great education for your child.
- Trying to get a feel about whether this school is a positive and welcoming place to be.
- Finding out if the school is flexible, and willing to work with you to support your child.

Contact the school and ask to arrange a visit to see the school and classroom. Ask to talk to the teacher as well as the Principal and/or Learning Support Coordinator and the office staff. This will give you more information and help you get a better feel for what the everyday school experience will be like.

The key things that you are looking for are:

- School staff with a positive attitude.
- Staff willing to be part of a team approach.
- Staff willing to learn how to support your child's learning and inclusion.

Step 4: Enrolment

There will be forms to fill in, and you will need to provide some documents. Ask the school how to do the enrolment and what documentation you need to show them.

You will need to confirm the place, and potentially pay a deposit. Ask when this needs to be done. If you don't hear back from the school, get in touch to make sure the placement is confirmed.

Prepare a package of information for the school and your child's teacher. This could include an information booklet about your child, a One Page Profile, and anything that could be useful such as medical information, contacts for therapists and so on.

Talk with the school about extra support they may need to arrange in time for your child to start school.

- Will they need equipment and/or Education Assistant support time?
- Do staff need any specific training?
- Do you want therapists to work with the school?
- Assist with information required for any funding application. For example, the school will need a copy of your child's diagnostic report to apply for funding for an Education Assistant.



TIP: Keep all paperwork in a file so that you can find it easily and refer back to it if needed. Keeping a back-up copy of this paperwork in the cloud is also a good idea.



Step 5: Helping Your Child Get Ready for School

1. Show your child the school environment before school starts. Take photos of the classroom, playground, office, library, and assembly areas. Then you can look at the photos and talk about what happens in each of these places in the weeks before they start school.
2. Create a visual schedule of the morning routine, including going to school. Your therapists can help you with this, or you can search for examples using Google.
3. Help your child be as independent as possible. Let them practice getting dressed/undressed, opening food containers, putting things in and out of their school bag. Visual schedules can help with learning what to do.
4. Does your child recognise their written name? If not, mark their possessions with something that they will recognise as their own, as well as their name.
5. If your child needs to change uniform in school (e.g., for sports) and can't tell the back from the front or inside from outside, sew a small piece of fabric or put a mark on the back inside seam of all clothes and help them to use it to help with dressing correctly.
6. Buy shoes with Velcro fastenings rather than laces or replace the laces with flat elastic and leave them tied up permanently.
7. Let your child practice eating their lunch from a lunchbox during the holidays. Pack food that they can open independently. For example, greaseproof paper or a paper bag instead of clingwrap? If they can't open small packets or bars, it will be easier if you snip them open a little.

Do they know which food is for recess and which is for lunch? Think about having two colour-coded containers so they know which is which.



8. Teach your child to drink from a water fountain. If you give them a juice pack, then puncture the plastic wrap on the straw so they can take it out easily. If they have a drink bottle with a screw top, teach them to open and close it.
9. If your child is likely to 'wander', buy an identity bracelet with their name and your mobile number engraved on it. It may never be needed but it will give you some peace of mind. If your child cannot cope with a bracelet, you could add your phone number to the name labels in their clothes.
10. If you know who is going to teach your child next year, get to know them in advance and discuss the start of the year. Give them a one-page profile or booklet about your child. Staff are at school for two days before students start so if you don't know who the teacher will be, contact the school two days prior to school starting. You can organise to bring your child for a visit before students start, so they can meet their teacher, see their classroom, desk etc.
11. Establish a form of constant communication with the class teacher and education assistant (if applicable). You need to know what is happening each day so that you can talk to your child about their day. A communication book is a good idea so that you can swap information between school and home and back to school.
12. Remember that your child's teacher may feel as uncertain as you did when you first discovered your child has a disability. Give them time to adjust and get to know your child as an individual (at least the first half of the first term). Share any useful information with them and let them know about any training they can do.



13. If your child's teacher has taught an autistic student before (including an older sibling), the teacher may assume that they are well prepared. However, as the saying goes, 'if you've met one autistic person, you've met ONE autistic person'. You may need to explain to them that all autistic kids are different, and that autism affects everyone differently. Offer to meet with them in the first few weeks of term, to discuss your child's needs, and how to support them.
14. The first day of school can be very chaotic, for teachers and students alike. If your child finds crowds and noise overwhelming, you may consider starting school on day 2 or week 2, when things are a little more settled.
15. Do not over-commit yourself on rosters to help in the classroom. Your child will learn to become independent more easily if you are not there. However, you can volunteer your time to help at school as you would for any of your other children.

(Adapted from Down Syndrome Australia's and other ready for school checklists)

If your child is happy to go to school, be pleased and remember that the learning process takes time. Remember, no child will learn to read and write on their first day at school.

School is a big transition. Your child may need extra support and time to rest. Don't overload your child with activities after school as they need to relax and play, the same as any other child.



Step 6: Working with the School

Perhaps the most important factor when it comes to your child's education is working in partnership with the school and its staff. An effective partnership involves good communication, sharing of knowledge, respect, and being able to work in different but complimentary ways towards a common goal.

Getting to Know Your Child

The teacher will appreciate information about your child as soon as possible, and definitely by the start of school. This helps them to understand the support your child needs, how to communicate with them, what interests and motivates them, dislikes, and triggers, and how to include them in the classroom. Teachers also need to know about any health issues and therapy goals.

You can help by putting together some information about your child. There are different ways of doing this. Some parents put together a booklet of information about their child, and some create a One Page Profile.

One Page Profiles

A one-page profile is a great way to communicate important information about a person all in one easy-to-find space.

You can use them in all kinds of settings to help support people of all ages. For example, you might create a child's first one-page profile when they are just about to start going to childcare. Starting kindy, pre-primary or school are also good times to create or update your child's profile.

Because the information is all on one page, this means that anyone reading it can quickly see what is most important to know about the person. The one-page profile is a good ongoing reference for teachers, child care workers, and other support staff, and helpful for new or relief staff so they don't have to read lots of information before they can start their work.

Each one-page profile has the following categories of information in it:

- Name of the person
- What is important to me
- What people like and admire about me
- How I want to be supported

How to Make a One Page Profile

There are lots of downloadable templates you can use. You can make your own but be sure it has the same categories of information as we've listed above. These have been shown over many years to be the most effective.

Sometimes parents work by themselves to write their child's profile. With a very young child, this is fine, and parents do know their children and the support they need well. But as your child gets older, it is better to ask other people who know them well to take part in writing the profile. You might be surprised that other people often add some very positive and useful information that you might not have known or thought about. Older children and adults can either write their own or get help to create or contribute to their profile.

One-page profiles need to be updated regularly so that the information is current. It's a good idea to put the date on the profile.

This website has lots of helpful information on creating a one-page profile:

swanautism.org.au/wordpress-profiles

Profile Example

Photo of Nathan

One Page Profile

What Is Most Important To Me?

-
-
-
-
-
-

What People Appreciate About Me

-
-
-
-
-
-

What You Need To Know To Support Me

-
-
-

Profile Example



Nathan 's
One Page Profile

What Is Most Important To Me?

For Example

- Having fun
- Friendships
- Rewards
- Playing with Rockets
- The colour green

What People Appreciate About Me

For Example

- My cheeky smile
- My determination
- My sense of humour
- How kind I am
- My creativity

What You Need To Know To Support Me

For Example

- Sometimes I need Mrs Jones or Mr Ando to help others understand me when I am Talking
- I need an adult to go to the toilet with me as I sometimes struggle on my own



Communication

It is really important to have regular, open communication between you and your child's teacher and education assistant (if they have one), if you are going to have an effective partnership. You can share useful information, celebrate achievements and deal with small problems before they become big problems. This is especially important when your child is very young and/or doesn't use speech to communicate.

Parents need to know what happened at school so that they can encourage their child to talk about the day and liaise with therapists to address any issues. Teachers need to know if there is anything at home that is either something positive to talk about with your child or that might be affecting their learning.

Most parents and teachers find that a communication book between home and school is the easiest way to keep up two-way communication about daily details. You can just use a small school exercise book. Often the teacher will provide this, or you could supply one if preferred. It need only take a few moments for a teacher to write that it was a good day, to ask a question or report an achievement. Parents can write a quick thanks, let the teacher know their child could be tired, sad, excited for some reason or, give other information that the teacher can use to chat with your child. Talk to your child's teacher before or when school starts, and work out a system that works for everyone.

When your child is ready to start school, read SWAN's booklet for children aged 7 to 12 years. This includes more practical information to help you during your child's primary school years.

Education and the NDIS

Although the NDIS can fund a range of specialised supports for school-aged children with a disability, it will not fund anything that should be the responsibility of the education system. Schools must continue to provide 'reasonable adjustment' for students with disabilities so that they can learn on an equal basis with other children.

The NDIS will fund allied health and other therapy supports such as speech therapy, OT, and other allied health depending on what each child needs because of their disability. These can be provided at school.

The school will work with you to develop your child's educational goals and create an Individual Educational Plan (IEP). Therapy plans should be consistent and directly related to the outcomes in your child's IEP.

Here is a summary of what NDIS funds and what education systems can fund for children with disabilities.

NDIS funds:

- Self-care at school related to the student's disability, such as support with eating.
- Specialised training of teachers and other staff about the specific personal support needs of a student with disabilities.
- Specialist transport required because of the student's disability (does not replace parental responsibility).
- Transportable equipment such as a wheelchair or personal communication devices.
- Therapies a family and school have agreed may be delivered during school time but are not for educational purposes.

NDIS

Education systems fund:

- Teachers, education assistants, and other supports e.g., Auslan interpreters.
- General support, resources, and training for teachers and other staff.
- Therapy delivered in schools for education or training purposes, such as allied health practitioners helping teachers and trainers adjust curriculums.
- Aids and equipment to make curriculums accessible, such as modified computer hardware, software, Braille textbooks, other accessible information formats.
- Adjustments to buildings such as ramps, lifts, accessible toilets, and hearing-loops.
- Transport for educational or training activities such as excursions, field trips and sporting carnivals.
- Day-to-day supervision of students at school, including behavioural support.

EDUCATION SYSTEMS

You can find more information on the NDIS website:

swanautism.org.au/ndis-other-govt-svs

For Further Information



NDIS

The NDIS website contains lots of information to help you no matter what stage you are at. There are booklets you can download, videos and Easy Read information. You can begin at this page:

swanautism.org.au/ndis-home

From here, you will find information and videos to explain each stage.

Planning Resources

NDIS

This NDIS page has booklets to help you understand the NDIS, develop some goals for your child's NDIS plan, get ready for a planning meeting and use NDIS plans and funds to find and purchase services and supports.

swanautism.org.au/ndis-participants

Autism Queensland

Autism Queensland has a Family Goal Setting Tool to help families identify and prioritise goals for their child as well as the family's needs for information, support, and ways of participating in their community. SWAN has copies of this resource at our office that families can borrow.

swanautism.org.au/autism-qld-family-goal-setting

Association for Children with a Disability

Association for Children with a Disability have a free downloadable pre-planning workbook to help you prepare for NDIS plan meetings.

swanautism.org.au/acd-ndis-planning-workbook

Developmental Disability WA (DDWA)

DDWA's 'Making Changes through Goal Setting', is a step-by-step workbook to guide you through a series of questions to help set goals for your child and create a road map to help your child achieve the goal.

swanautism.org.au/ddwa-goal-setting-booklet

Down Syndrome WA

Down Syndrome WA's pre-planning workbook is for people with any kind of disability and any age to prepare for NDIS plan meetings.

swanautism.org.au/down-syndrome-resources

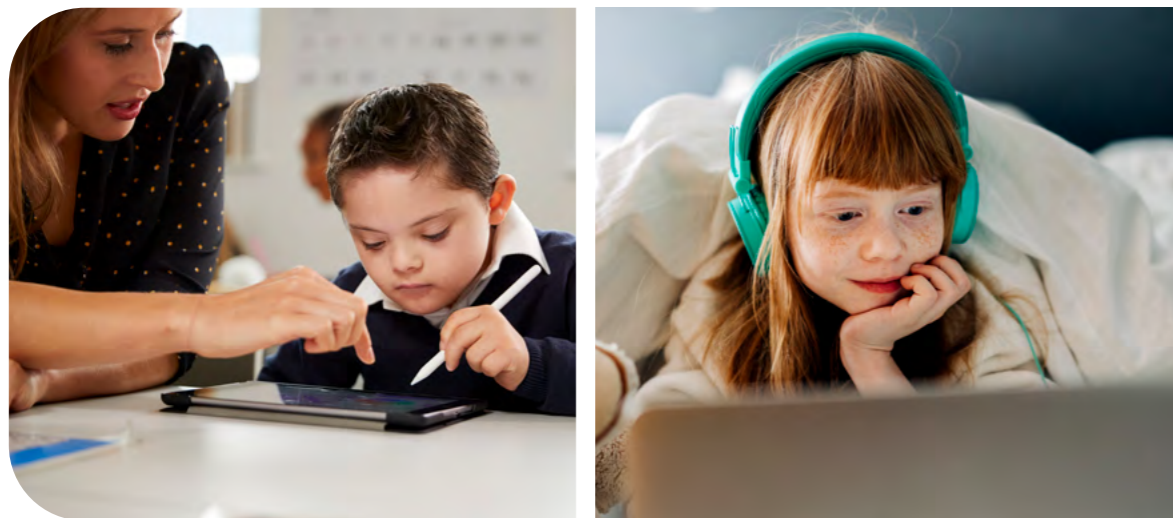
Early Childhood Intervention

Developmental Disability WA and Early Childhood Intervention Australia have produced this guide for parents to help you understand and use early intervention therapy to support your child's development.

Every Possibility

This guide for parents aims to provide you with information to help you make decisions and get the help and therapy services needed to build your child's skills to participate in family, school, and community life.

swanautism.org.au/flipsnack-ecei-parent-guide



Assistive Technology

Assistive technology (AT) includes all kinds of equipment and technology to support people with disabilities. Each child is different, but some of the kinds of AT a young child with autism might need could be a communication device (AAC/PODD), apps, or sensory equipment such as sensory clothing.

NDIS will fund some AT if it relates to a person's disability and is needed to help them in their daily lives.

swanautism.org.au/ndis-assistive-tech

Apps

Here are some links to lists of Apps for iPads and other devices that you may find useful to support your child's development.

AutismApps is an Autism Association of WA website. It provides comprehensive advice on complex communication, devices, and Apps that they have reviewed.

swanautism.org.au/autism-wa-apps

Indigo Australasia (formerly Independent Living Centre)

Indigo provides a range of services including assessments and advice on communication technologies and other kinds of AT including sensory equipment.

swanautism.org.au/indigo-comm-solutions

swanautism.org.au/indigo-assistive-tech

They also have a searchable online equipment database.

swanautism.org.au/indigo-equipment-database

Sensory equipment

SWAN has a list on its website of companies that offer sensory equipment and clothing.





Inclusion

Children and Young People with Disability Australia (CYDA)

Children and Young People with Disability Australia (CYDA) has produced a range of fact sheets on inclusion.

swanautism.org.au/cyda-fact-sheets

All Means All

All Means All is the Australian Alliance for Inclusive Education, working to implement an inclusive education system and remove the barriers that limit the rights of some students, including students with disabilities, to access full inclusive education in regular classrooms in Australian schools.

All Means All has produced an Inclusion Toolkit to guide parents in supporting their child's inclusive education journey. You can download it here:

swanautism.org.au/ama-for-parents

School Inclusion Parent Network (SIPN)

SIPN is a network of families supporting each other to navigate the school years and promoting inclusive education. SIPN has an active Facebook group that provides information, support, and connection.

swanautism.org.au/ama-sipn

Developmental Disability WA

Planning Choices

This Handbook is designed for parents of children with disabilities who want to learn how to access an ordinary, typical life for their son or daughter. It looks at understanding your child's development and helps you plan and make choices with your child to support them to reach their potential.

swanautism.org.au/ddwa-choices

Thinking Ahead

This is a very practical handbook with a wealth of knowledge and tips to help you advocate for your child at school.

swanautism.org.au/ddwa-thinking-ahead

Personal Learning Support Plans Used in Education

This booklet is about Personal Learning Support Plans; this is an umbrella term covering various kinds of plans your child may have at school. For example, an Individual Education Plan (IEP), Behaviour Support Plan, Transition Plan and so on. The booklet explains the benefits of personal support plans, how they are developed and used, and contains examples.

swanautism.org.au/dept-education-personalised-learning



