

Navigating Your Child's Autism Diagnosis

A guide for parents and families of autistic children

Written by Emma Reardon





I wish I knew that it would all be ok; that the diagnosis report was a snapshot of where he was at developmentally at that point in time; that he's navigating a different developmental trajectory which is ok. And most importantly, he would lead an incredible life and enrich so many just being his magnificent self

- Alana Lenart, Parent





It's great you are here! Receiving a diagnosis of autism for your child is a big event in your journey as parents. It can be a time when you feel a number of different emotions such as shock, anxiety, guilt, anger, worry and even relief. All these feelings are natural and okay!

The aim of this guide is to support and empower you to learn more about autism and your incredible child. In this guide you'll find:

- · Information that will deepen your understanding of autism
- · Support to help you in your role as parents
- Information about professionals who can support you and your child
- Information about supports and practices that are neurodiversity-affirming and evidence-based, and will nurture and celebrate your child for the unique and amazing person that they are!
- Some links to further information that you may find helpful on your parenting journey

How to use this resource:

You probably have hundreds of questions running through your head at this very point in time. On the 'Contents' page of this guide, you'll find a list of headings that describe the topics to be discussed. You might wish to read the guide from start to finish in full. Or, there might be sections that are more important to you right now that you want to explore straight away. If so - start there!

The guide is yours to use as you wish, in whatever way is most helpful for you.

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What is Autism?

As you may already be aware, searching for information about autism can be overwhelming and tricky to understand! As a parent, you'll probably want to learn all there is to know about autism, so here is a good place to start!

When you learn more about autism, you'll gain a better understanding of your child and you may find you feel a greater sense of wellbeing in your role as a parent.

Sometimes, people within our community and our own families can have different ideas about what autism actually is, and this can be really challenging. It can make you feel isolated or stigmatised by your child's autism diagnosis. Education and knowledge is key to understanding more about autism and your child, and will help you to feel more prepared and empowered on your journey.

Negativity does not have to be associated with an autism diagnosis!



"Autism refers to differences in how people participate in, and experience the world around them."

These differences can relate to:

How a child communicates and participates socially

Your child may interact and form connections with others differently. They might communicate in different ways. You might notice that:

- they really enjoy playing alone instead of with other children or in a group
- they might have preferences for how they play (like lining up toys, sorting objects)
- they could have differences in how their speech develops
- they might interact socially in ways that are different, such as using eye contact differently when communicating with others
- they may use social gestures and body language differently
- they may use speech mainly for the purposes of requesting rather than engaging in ongoing back and forth communication

How they experience the world around them

Your child might experience the world around them differently to others. These differences often relate to sensory experiences (how our brain processes information from our senses). You might notice that:

- your child has a deep and specific interest or interests (such as trains, trucks, vehicles, dinosaurs or certain topics)
- they might really enjoy particular sensory experiences and engage in them repetitively (swinging, spinning, touching certain objects, eating the same preferred foods)
- they may look to avoid certain sensory experiences (loud noises, crowds or certain clothing)
- · they might prefer having a set routine
- they may repeat words or phrases in their speech (echolalia)

This is not a comprehensive list of characteristics -every child is different!

Every child experiences Autism differently!

Autism is a difference that should be accepted and supported - it is part of who a person is. Autistic children have their own unique strengths and needs. Our thoughts and ideas about autism will influence how we view autistic children, so having a view based in acceptance of uniqueness and celebrating your child's strengths is really important.

Remaining positive and optimistic will be an important part of your journey.

Talk about your child in a positive, hopeful and optimistic way - how we speak matters!



I'm feeling a lot of emotions right now...

The time following your child's diagnosis may be tricky for you to navigate as parents, and you may have found that you're experiencing stress, fatigue, relationship challenges and even concerns about finances. You have probably discovered that your day to day life has changed a lot as you adjust to caring for your autistic child. It may take time for you to process these changes and to work through the range of emotions that you may be feeling. It can be very overwhelming. It is important to remember however, that the diagnosis your

child has received can provide you with more of an understanding of them and this can help you to best support your child.

Amongst all of these emotions, It is really important to try and focus on having a positive mindset, and here is why:

Research actually shows us that our mindset can have a huge impact in supporting us to cope with parenting an autistic child. Try to nurture a mindset focused on the following:

- being flexible sometimes things won't go to plan, thats okay!
- emotional acceptance it's okay to feel how I'm feeling!
- understanding autism continuing to learn about autism
- positive beliefs about autism understanding that autism is a part of who my child is!

This will support you to positively manage your role as a parent.

Remember that it is also important that you take time to tend to your own needs, you need to look after yourself to best support your child.

Please do not feel alone.

You are not alone in these feelings!



How can I best support my child?

You are reading this guide because you want to learn more, research and do the absolute best for your child - all parents of autistic children want what is best for them. There are many different types of supports and services available. Some children will require more support than others. You may feel overwhelmed at the amount of information at your very fingertips. If you have googled "autism" you will have come across thousands of pages of information - so how can you choose what is trustworthy and what is not?.

Collaborating with the right professionals to support your child will be really important in understanding the huge amount of information available and working out what is reliable information, and what is not. Understanding what evidence-based practice is, will also be important in determining appropriate support for your child.

There are significant factors to consider when making decisions about WHO to ask for support and deciding on what types of professionals (and approaches) will work best for your child and family. When searching for professional help, there are some questions you might like to think about:

- Is this professional appropriately qualified (see section 'Who can help me support my child'), and do they have appropriate experience in working with autistic children?
- Are the strategies that have been recommended based on CURRENT, neuro-affirming approaches? (See the section about neurodiversity affirming approaches).
- Are YOU being listened to, and are you involved in the decisions being made about your child? Are your child's need prioritised? YOU KNOW YOUR CHILD BEST! These are important factors that will protect your child from being exposed to negative practices that could actually be harmful.

Who can best support my child?

Obtaining information from health and education professionals who understand your family and individual child's needs, and who can help you to find evidence-based supports is really important. There are a number of professionals who will have the proper qualifications and knowledge to support your child (see the first table for a list of some of these professionals and what areas of development they can assist your child with).

In planning and providing support for your child, professionals should:

- combine the best available evidence (research) with their own professional knowledge and experience with,
- what's most important for your child and family, and,
- explain their choice of supports with you and your child to help you to understand why they have been selected and the benefits of these supports.

Having formal supports delivered by professionals who work together with YOU as parents, is crucial.



Professionals who can provide support for autistic children.

Professional	Can provide support concerning your child's
Occupational Therapist	Sensory Processing, motor skill development, self-care and everyday living skills.
Physiotherapist	Physical development related to movement and motor skills.
Psychologist	Cognitive development, social and emotional wellbeing, self-esteem and identity, social development.
Audiologist	Hearing
Dietician	Health related to eating and mealtimes
Social Worker	Family relationships, resilience and functioning.
Speech Pathologist	Speech, language, literacy, social communication and swallowing.
Developmental Educator	Holistic development across several developmental domains related to participation and wellbeing.
Early Childhood Teacher	Personal, social, physical and academic skills in the early years.

Supports should be chosen with the involvement of you, your child and family, and take into account your unique circumstances.

What is a neurodiversity affirming approach?

An approach that advocates for awareness and acceptance of different ways of doing and being. It's ok to be different and we should celebrate our differences!

Hints that an approach or professional is neurodiversity affirming:

- a child's unique strengths will be acknowledged and celebrated
- neurodiversity-affirming language (difference NOT deficit) will be used
- · you, your family and your child will be involved each step of the way

Top tips to remember:

- Navigating appropriate information can be difficult, especially online.
 Ask for support from neurodiversityaffirming professionals! Support should be guided by your child and family's needs.
- Familiarise yourself with what evidence-based practices are.
- Formal and informal supports are both important. Informal supports are just as, if not more important, and these might look like finding a wonderful support worker or parenting group to connect with you and your child.

We can learn a lot from autistic people! Autistic adults speak about how important it is to receive support that is:

- focused on a person's strengths
- inclusive
- accepting and understanding of being different



What are evidence based practices?

Evidence-based practices are approaches and supports that have been widely researched and found to be helpful in supporting autistic children. Some relevant evidence supported practices specific for young autistic children can be found in the table below. You might like to ask health and educational professionals working with your child about these practices (and others) to help your child work towards their goals.

Name of evidence based practice	What does it look like?	What can this practice support?
AAC (Augmentative and Alternative Communication)	Using different forms of communication like sign language or technology-based speech devices.	Communication skills, social development and play skills.
Exercise and movement	Physical movement like sport, martial arts, yoga or other mindful movement activities.	Communication skills, social development, play skills, cognitive skills and motor development.
Modelling	Working together to show a child (or demonstrate) a particular skill.	Communication skills, social development, play skills, independence and motor skills.
Naturalistic intervention	Using a child's interests in play and day to day routines and activities to support their development.	Communication skills, social development, play skills, cognitive skills, independence, motor skills and wellbeing.
Peer-based instruction	Learning from other children in small group settings.	Communication skills, social development, play skills.
Social narratives	Stories written to support a child to understand new routines, social settings and new situations.	Communication skills, social development, play skills, independence.
Visual supports	Pictures or photographs that give a child information about activities or routines. These might look like visual schedules.	Communication, social development, play skills, cognitive skills, supporting a child in preparation for school, independence.

Accessing the NDIS

There may be financial costs associated with receiving a diagnosis of autism for your child related to accessing supports and services. The National Disability Insurance Scheme (NDIS) provides funding to eligible children to assist in supporting them to grow and learn.

The NDIS Early Childhood Approach helps children younger than 6 with developmental delay or children younger than 9 with disability to access support. To find out more about the Early Childhood Approach, you can visit:

www.ndis.gov.au/understanding/families-and-carers/earlychildhoodapproach-children-younger-9

To find out more information about accessing the NDIS, you can contact your local NDIS office. To locate your closest office, you can visit the link below to search according to your location:

www.ndis.gov.au/contact/locations

The NDIS website has a lot of information available to support you to understand how it operates and if your child might be eligible for funding. You can access the website here:





This is a lot of information to process!

I think I might need support for myself, or for my family.

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What can I do?

At this point in time, you may be feeling really overwhelmed. It is also very important that you receive the support you need to manage your wellbeing and take care of your child. You may find as you reach out and speak more about your child's autism diagnosis that there are other families who are also experiencing what you are.

Reaching out to your social network is important! Your social network might include:

- a partner
- family who are supportive, understanding and accepting of your child's diagnosis
- other families who have an autistic child or children
- · online support groups

Having good support and working with appropriate professionals is very important, and this can be especially helpful if you are feeling isolated from your own family members or community as a result of your child's autism diagnosis. **PLEASE REACH OUT** – there is amazing help available! Most parents find parental support groups to be one of the best ways to find further information and receive emotional support. In the section 'Links to resources', you can find links to parent support groups.

You might like to reach out to more formal supports such as specialised counselling services for parents of autistic children. Check out the link below:

Alana Lenart Counselling - www.alanalenart.com.au

In Conclusion...

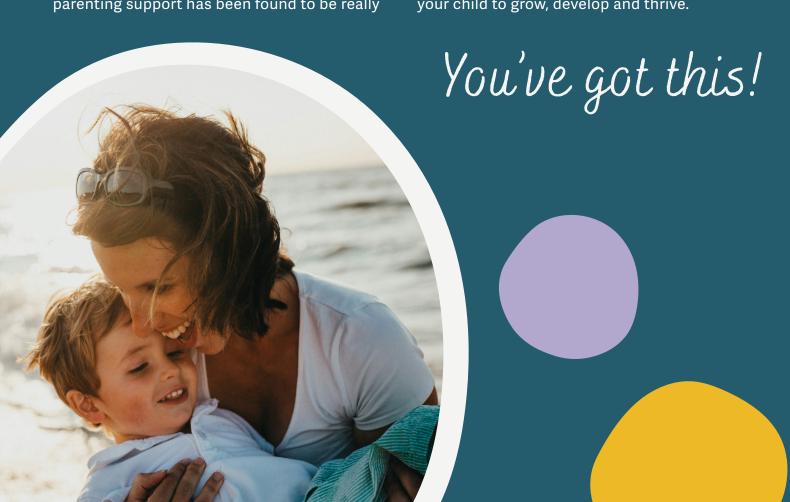
Some important things to remember... Accept your child for the incredible person they are!

Your journey and your child's journey are unique. When receiving a diagnosis of autism for your child, understand that it can take time to process this information and that is okay!

All your feelings are valid!

There is support available for your child AND family, and reason to be optimistic and positive about the future. Reaching out for parenting support has been found to be really

helpful when working through the time after your child's diagnosis. Look to connect with professionals who are neurodiversity affirming and up to date with the most recent research regarding autism. They should promote and advocate for practices that celebrate your child's unique strengths and also take into account your family context! Your continued journey of learning and discovery will support your child to grow, develop and thrive.



Links to resources

There are a number of wonderful resources available to support your journey as parents of an autistic child.

Reframing Autism

Reframing Autism is a charity run by autistic people, for autistic people and their families. It contains a wealth of information about autism. The information is informed by the lived experience and research of autistic people. You can visit the Reframing Autism Webpage to access specific support for parents of autistic children.

www.reframingautism.org.au/service/i-am-a-parent/

Children's Books About Autism

There are a number of books that have been created to support children in their understanding of autism, and which you might find helpful as parents:

www.reframingautism.org.au/service/autistic-childrens-books/

www.aspect.org.au/blog/8-best-childrens-books-about-autism

Aspect Australia

Aspect Australia is an organisation dedicated to celebrating and understanding autistic people. They have a number of fact sheets available that can help you to understand more about autism and debunk some common misconceptions about autism.

www.aspect.org.au/about-autism/fact-sheets

Amaze

Amaze seeks to create a more autism inclusive Australia. They have a dedicated parent section on their website that includes links to Autism Connect (a national autism helpline), understanding the NDIS and parent support groups.

www.amaze.org.au/i-am-a-parent-or-carer/

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