

About
Autism
IN CHILDHOOD



Parent to Parent

connect • inform • support

Developed by Parent to Parent NZ Inc for its
Care Matters services.

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CARE MATTERS

LEARNING & WELLBEING

Kia ora



If you are reading this, it is likely a child in your care has just received a diagnosis of autism spectrum disorder (ASD), commonly known as autism.

We've compiled this booklet with input from autistic people, parents and professionals to provide you with information about autism and how it can affect children's experience of the world around them.

It has been designed as a practical tool to educate and empower you and your family.

*This document is a general overview current at the time of writing. This information has been provided for education/information purposes only. It is not intended or implied to be a substitute for advice, diagnosis or treatment from registered health professionals. Every care has been taken to ensure its accuracy. If you have any questions or would like further information please contact **Parent to Parent** on 0508 236 236 or email national@parent2parent.org.nz*

In this booklet we use identity first language. Identity first language is preferred by the autistic community as it celebrates the unique strengths and identity that being autistic offers an individual.

Not all autistic people choose to be referred to in the same way. If you are unsure, ask the individual what they would prefer.

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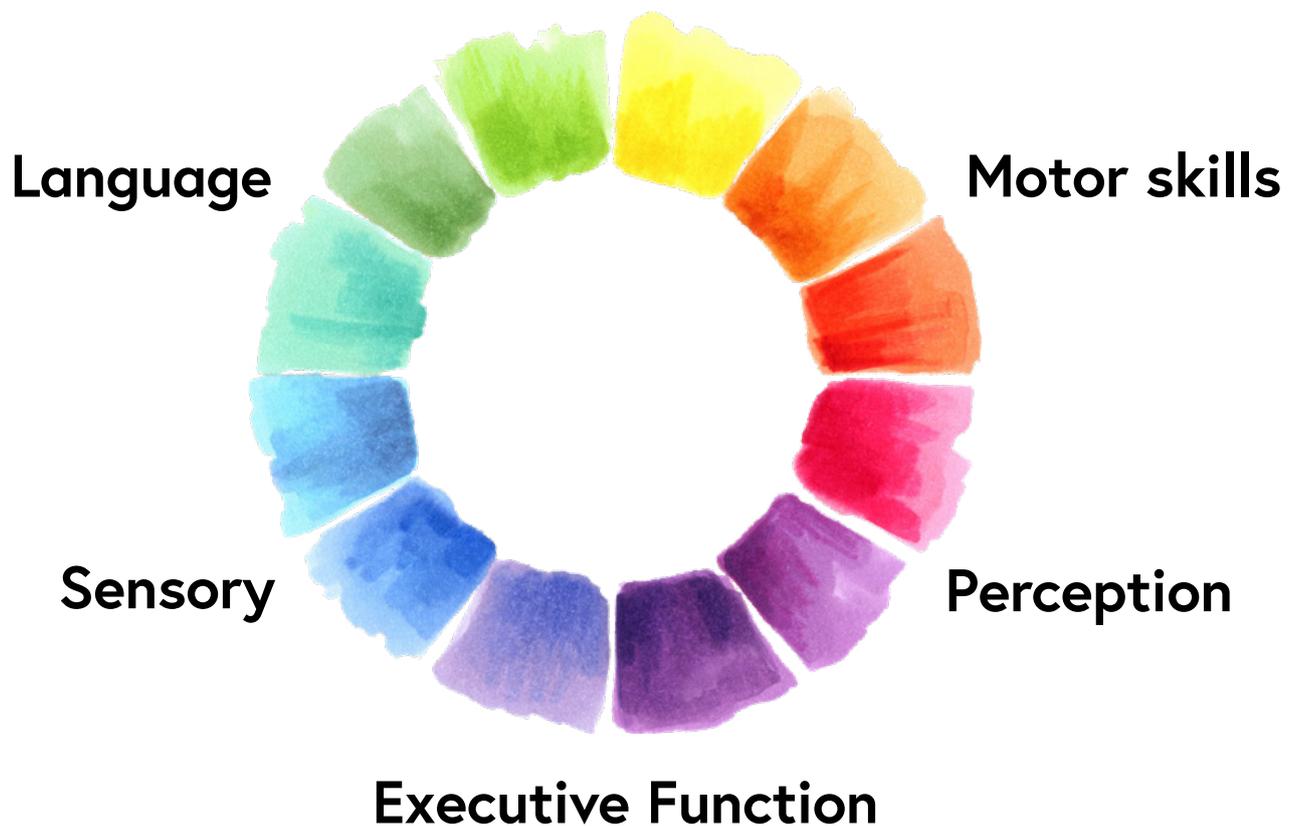


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What is autism?

Autism affects communication and social interaction as well as thinking and behaviour. It is not a disease or illness, and it cannot be treated or cured. It is better to think about autism as a brain difference which is fundamental to who a person is.

Autism is a spectrum condition. This means that each person on the autism spectrum will have a different set of characteristics in each area of the autism spectrum.



Autistic people have strengths and challenges in different areas which affect their lives differently. No two people on the autism spectrum are the same. However, for someone to be diagnosed as autistic, they must display, or at some point in their life displayed:

- 1 Impairments in social communication and social interaction, and
- 2 Restricted, repetitive patterns of behaviour, interests or activities – this includes sensory sensitivities.



Takiwātanga is the Māori word for autism.

Translated it means: **In my/his/her own space and time.**

What does autism look like?

Autism will look very different for each child who is diagnosed. However, in order to meet the criteria for a diagnosis it is likely that the individual will have a number of the traits in the autism spectrum which may be expressed or observed as follows:

Communication

- Late to develop speech and language
- May have no language at all
- Have difficulties understanding others
- Need extra time to process verbal communication
- Find it hard to communicate what is wanted or needed
- Use props or another person's hand to convey a message
- Use an unusual tone, pitch, or accent
- Repeat sounds, words or phrases (known as echolalia)
- Language may be used in an unusual way (such as being overly formal or academic)
- Finding non-verbal communication challenging, such as the inability to read, understand or respond appropriately to facial expressions, body language and gestures
- May find following instructions challenging and can take information and instructions very literally

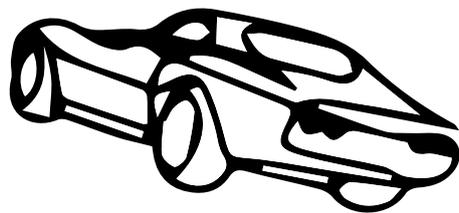
Social Interaction

- May not join in with play with other children
- Prefer to play with younger children rather than their same-aged peers
- Appear disinterested in other children or people
- Prefer to play alone or do solitary activities
- Less interested in pretend or make believe play compared to their peers
- Unlikely to bring objects to share or show other children or adults
- Find social situations difficult due to communication differences
- Display a lack of understanding for social rules or etiquette (e.g, have difficulty knowing if someone is joking or don't follow the usual social rules)
- Experience difficulty in understanding or processing emotions, thoughts or actions of oneself and others.



Restricted and repetitive patterns of behaviour

- A strong preference for routine and order
- May get upset when routines are interrupted or changed
- Transitioning between activities and into new environments may be difficult due to preference for routine
- May have difficulties starting or stopping tasks
- Have a special interest which autistics enjoy talking about a lot, or spend a lot of time doing
- Behaviour (including challenging behaviour) may be used as a way to communicate
- Appear clumsy or have poor motor skills
- Make repetitive movements or sounds (commonly known as stimming), e.g, hand flapping
- Find problem-solving or organisation challenging due to executive functioning difficulties





The senses and autism

Not all autistic people will have sensory sensitivities, but some will have many. The way you support your child with their sensory sensitivities will depend on the unique way they experience the world around them.

It is quite common for autistic people to have one or more sensory sensitivities, (now recognised in the DSM 5 under restricted and repetitive patterns of behaviour).

Autistics may be hyper or hyposensitive to certain stimuli, e.g, be affected by a dog barking but not bothered by loud music, or find all loud sounds unpleasant but seek out interesting smells.

Sensitivities can be fluid where they change day-to-day or are dependent on the environment.



Sight

Autistic people may have difficulty following objects, or have a strong dislike to bright lights. They may also enjoy bright colours and prefer visual learning material.



Hearing

Loud noises may be painful and autistics may have trouble concentrating when there is background noise. Certain background noises which may seem insignificant to a non-autistic person (e.g keys on a keyboard, or the buzz of electrical equipment) can be extremely aggravating or painful for an autistic person.



Smell

Some smells may make autistics feel sick. Autistics may also seek out smells or sniff objects to gain a better understanding.



Taste

A strong like or dislike for particular tastes or may only eat certain textures or colours.



Touch

Certain clothing may be too scratchy to wear. Some autistic people like tight clothing and tight hugs, whereas others find this painful. May have a favourite texture, or enjoy feeling different textures.



Balance (vestibular)

The sense which tells us where we are in relation to other objects, and how our different body parts are moving. Autistics may appear clumsy or uncoordinated, they may also be particularly agile. Some people may enjoy spinning in circles, while others find this makes them ill.



Body awareness (proprioception)

May appear clumsy as they may bump into people or objects due to an inability to understand their place in relation to what is around them. May also have difficulty recognising their own strength (such as pressing too hard on a pencil when writing)



Interoception (Internal cues)

Interoception is regarded as the eighth sense and is how a person recognises and responds to their internal cues, e.g, thirst, hunger, pain, temperature, illness and bowel movements. People who experience difficulty with interoception will be unable to determine what a funny feeling in their stomach is caused by, e.g, sickness, hunger or needing to use the bathroom.

Strengths and abilities in autism

There are many strengths to being autistic.

Thinking, moving, interacting, sensing and processing differently to non-autistic people can be challenging, but many autistic people display a range of strengths and abilities.

These might be strengths when compared to non-autistic children, or individual strengths within your child's own set of skills. Some of these strengths may include:



VISUAL SKILLS

Thinking and learning in visual ways



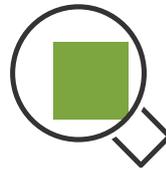
CREATIVE

Thinking creatively and having unique solutions to problems



MEMORY

Memorising and learning information quickly. May remember facts for a long time



ATTENTION TO DETAIL

Being precise and detail orientated. Enjoying or paying attention to the things most people ignore



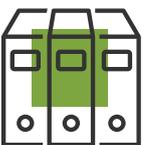
KINDNESS

Kindness and acceptance of difference. Less likely to be judgmental or to discriminate



INTEGRITY

Exceptional honesty. Trustworthy, and does not have a hidden agenda



ACADEMIC

May excel in academic areas such as science, engineering and mathematics as they are technical and logical subjects that do not rely heavily on social interaction Learning to read at a very early age (hyperlexia)



One of the strengths of my autistic son is that unlike most non-autistic people, he is egoless. He doesn't brag or seek the spotlight. He doesn't view himself as more special or important than anyone else.

Our autistic son does not judge or discriminate against people. In his eyes everyone is equal. He doesn't care about what type of car you drive, the job you have or the way you look, in fact social beliefs and expectations are unimportant to him.

One of my son's strengths is that he is able to use movement to improve learning and to self-regulate when he is feeling overwhelmed. Movement (walking, bouncing on trampoline or yoga ball) helps to calm himself and give balance to his physical, mental and emotional states. He wasn't taught to do this and instinctively knows when he needs to do it without prompting or instruction.

Our autistic child has a positive impact on neurotypical people because of the way he sees the world. He offers people a new view on their perception, beliefs and their expectations.



RELIABILITY

Punctual and great at maintaining schedules and routines



OBSERVATIONAL

Strong observational skills. Learns by looking/doing and self-evaluating



CONCENTRATION

Ability to concentrate for long periods of time (hyper-focus)



EXPERTISE

May have in-depth knowledge about a topic of interest or high skill levels in a particular area



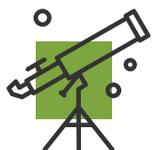
CRITICAL THINKING

Capability for alternate problem solving. Ability to think outside the box



JUSTICE

A strong sense of justice and fairness



PERSPECTIVE

A fresh sense of wonderment. Unique way of seeing the world



DECISIVE

A clear idea of what one likes and doesn't like. Sees things black and white, no grey areas



PERFECTIONISM

A drive for perfection and order. Very responsive to structure



TENACITY & RESILIENCE

Strength and determination, self-motivated. Not to be underestimated

Creative work

Artists with autism

Bricharne Hastie

Bricharne is an artist from Rotorua who learned to speak with a picture communication system (PECS), so has always loved art.

With a natural talent for painting, she creates pieces that resonate the work of Jackson Pollock and his contemporaries. It's an abstract style and one that develops and evolves over

time, but one that has been well received both here and overseas, with works sold to New Zealand and global buyers.

With help from a funded art tutor she has held several art exhibitions, and also has a following on her Facebook page ASD Art for Me where images of her work are uploaded.





A stitchbird also known as Hihi.



A tui perched on a branch.



Pukeko.

◀ Sophie Bouda

Sophie is from a small rural village in the Waikato. She loves to create digital art and 2D animation and also loves reading or writing a good story. Sophie is currently stretching herself by learning traditional painting and sketching. Her three cats are her best buddies and she is the cat whisperer in the household.

Bethany Hughes

Bethany is a writer, nature lover, and artist from Invercargill. When she's not writing, reading about the adventures of other animal lovers, or exploring the native bush, Bethany loves to draw and paint. Her favourite subjects to draw are dragons and birds; and her preferred media are pencil, ink, and watercolour.

You can read about each bird and their positive traits that Bethany relates to her own experience with Asperger's at our website: www.parent2parent.org.nz/the-birds-aspergers-and-me/



A Southern Cassowary, Red-throated Hummingbird, European Bee-eater, Northern Royal Albatross, New Caledonian Crow and a common Sandpiper

Common difficulties affecting daily life for autistic people

Anxiety

Anxiety is an intense and often overwhelming feeling of worry, nervousness, or unease about something with an uncertain outcome. It also has varying physical effects on our bodies, such as increased heart rate and sweaty palms. Often it results in people avoiding situations, preferring sameness, rigid thinking, social withdrawal, repetitive movements or noises, and sometimes anger or meltdowns.

Many autistic children meet criteria for an anxiety disorder. For those who don't, anxiety is still a common experience in their everyday lives and can make it difficult to make friends, focus at school or complete everyday tasks.

Theory of mind

Theory of mind is defined as the ability to understand your own and other people's beliefs, desires, intentions and emotions.

It is also the ability to understand that others' thoughts and feelings are different to your own. Research has shown autistic people have a significantly decreased ability to do this, which can explain some difficulties they experience with social interactions and communications.

Executive functioning

Executive functioning is a set of mental skills controlled by the frontal lobe in the brain. It affects our ability in two key areas – organisation and self regulation. Autistic people often have challenges organising, prioritising, problem solving, accessing working memory, thinking flexibly and self-monitoring, eg, difficulty following more than one instruction.



The causes and prevalence of autism

The exact cause of autism is unknown.

Research strongly suggests genetic components, as there are often familial links and differences in brain functioning.

Many environmental causes have been researched but none have been definitively found to be a cause.

Research has shown that vaccinations, trauma and poor parenting **do not** cause autism.

Prevalence is the proportion of a population found to have a condition.

Unfortunately, New Zealand does not collect prevalence statistics.

As a result there is no Māori or Pasifika data available. The most up-to-date research in America suggests:

- Somewhere between 1 in 40 and 1 in 59 children are diagnosed on the autism spectrum
- Autism is 4 times more common in boys than among girls
- Autism occurs in all racial, ethnic and socioeconomic groups

Research shows differences between boys and girls with autism.

Girls without severe difficulties are often misdiagnosed, completely missed, or diagnosed much later than boys. The reasons for this are:

- The standard tests used for diagnosing autism fail to capture the unique presentation in girls.
- Girls are more sociable – more likely to have best friends and enjoy socialising.
- Social masking – girls employ coping strategies to 'mask' their social and communication difficulties. These may include stereotyped responses, rote learning of conversational phrases and social behaviours, and using scripts.
- Girls are good at imitation.
- Autistic girls tend to have more imagination than autistic boys.
- Often autistic girls have the same interests as typically developing peers.
- Girls have fewer repetitive behaviours than boys.

Links to articles

- <https://www.altogetherautism.org.nz/gender-differences-in-autism/>
- <https://www.altogetherautism.org.nz/research-offers-fresh-clues-as-to-why-girls-evade-detection/>
- <https://www.altogetherautism.org.nz/quirky-girls/>

Diagnosis

Why is diagnosis important?

A diagnosis can be a positive and liberating experience. Having a diagnosis provides an opportunity to better understand who your child is and how to recognise and manage your child's needs.

With accurate information about your child's diagnosis and how it may contribute to their support needs, you and others in your child's life can better advocate for those needs to be met.

Getting a diagnosis

The process of getting a diagnosis for autism in New Zealand can vary between regions, depending on your District Health Board. The process is also different depending on the age of the person being referred.

If you have concerns about your child's development the process for a publicly funded autism assessment is as follows:

1. Book an appointment with your GP – your GP can refer your child for assessment and complete a full medical examination to rule out any underlying conditions
2. Referral to appropriate organisation – This is often done by your GP. Referrals can also be made by a psychologist, Resource Teachers, Learning and Behaviour (RTLs), teachers, speech-language therapists, public health nurses, Plunket nurses
3. Assessment appointment – you will be contacted by the organisation who receives your referral about an appointment (note: often there is a considerable wait time for these appointments)
4. Autism assessment – an experienced clinician (or team of clinicians) will carry out your child's assessment. This usually consists of multiple appointments ideally across a range of different settings. The clinician might speak to you and your child, and also teachers, professionals or other family members involved in your child's life.

Depending on the outcome of the assessment, you may then be referred onto other services, for example ASD coordinators, speech language therapists etc.

The diagnostic process can for some be very difficult, it can feel like your child, you, your family, your parenting, lifestyle and coping skills are discussed on a level of detail which can feel intrusive. It is important you and your child are well supported through this process.

For more information on how autism is diagnosed Download How is ASD diagnosed?

<https://www.health.govt.nz/system/files/documents/publications/how-asd-diagnosed.pdf>

Typical responses to diagnosis

It is normal to have strong emotions when your child gets an autism diagnosis. Some people might feel sadness, grief and anger. Others may feel relief. Most parents tell us getting through the first few days and finding out more information about what autism is makes them feel more positive.

Try to remember that having a diagnosis does not change who your child is.

Know that you are not alone and will adjust to this new reality over time. There are many ways you can get support in these times, such as through Parent to Parent's support parent network or free information service.

Disclosing the diagnosis

Your child

There is no right or wrong time to tell your child they are autistic. It is your choice as a parent when and how to disclose the diagnosis to your child. You know your child best.

Some things to consider are, is your child ready? Are you ready? Have you had enough time to process the diagnosis and understand what autism is? Are you ready for questions your child may have, or do you know where to get information to answer their questions? How are you feeling about the diagnosis? If you seem tense or uneasy about the diagnosis, your child may pick up on this and feel their diagnosis is a 'bad thing'.

It is important when you discuss your child's autism diagnosis with them, that you stay positive and try to use a strengths-based explanation. Setting a positive tone about each family members uniqueness is a great starting place for discussing differences with children.

Each family member will have different likes, dislikes, strengths and challenges. Autism is just a term which describes a particular set of strengths, challenges, and brain differences.

Some parents might feel concerned about sharing their child's autism diagnosis with them for fear they may react badly or see their diagnosis as a weakness. Rather, adults on the autism spectrum have found the opposite is true. Giving your child information about their diagnosis can help them to understand, accept and appreciate their uniqueness to understand their needs and to advocate for those needs to be met.

If you would like more information about talking to your child about their autism diagnosis, contact Parent to Parent for a free information pack.





Siblings

You may choose to let siblings know about your child's diagnosis. How and when you tell them will depend on their age and learning style.

Pre-schoolers need short clear explanations for their sibling's differences, such as "Joe can't talk like you and I, he asks for what he wants by pointing", or "Jess doesn't like playing with the stuffed toys like you do".

School-aged children will understand a more detailed explanation for behaviour such as "Joe can't understand how you might feel right now".

They may understand and use the word autism to explain difficulties their sibling faces, and ask questions about how is autism caused or whether they can catch it.

Pre-teens and teenagers may benefit from reading autism resources for their age group (ask Parent to Parent), and discussing how their sibling's unique behaviours fit into the diagnosis. This age group is likely to ask more questions about how autism may affect their sibling's future.

Your child's school

You may choose to disclose the diagnosis to your child's school. When teaching staff are aware of the diagnosis, they can understand your child better and make adjustments including:

- Change the environment to accommodate sensory needs
- Facilitate communication and social interaction with peers
- Adapt teaching strategies to enhance learning for your child, e.g, using a special interest, or presenting information visually
- Implement rules and routines to make transitioning between tasks, activities and classes easier.

It may be helpful to arrange a face to face meeting with the school to discuss your child's challenges, strengths and needs.

You could provide the school with reports from the team who assessed your child (i.e, psychologist, occupational therapist, speech and language therapist) as it is likely they discussed your child's strengths and difficulties, and made recommendations. You could also invite them to the meeting.

You have the right to check in with your child's teacher to assess their progress regularly. You may choose to speak with new teachers each year. If your child struggles with transitions it may be helpful to plan for this ahead of time, including both the current teacher and the new teacher in the planning.



Parent to Parent's information officers can design an information pack you can share with educators containing clear information on what autism is, classroom accommodations and teaching strategies.

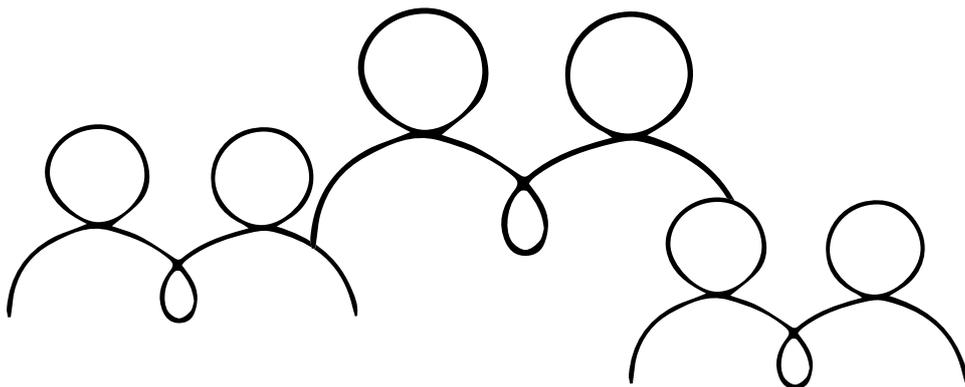


Brian and Betty Pulefolau established the Pasifika Autism Support Group (PASG) in South Auckland and most recently in the greater Wellington region.
Photo: Melissa Palmer / Nectar Photography

Extended family & friends.

You may want to tell your extended family so they understand you and your child better. Again, if you give them a copy of this book it may increase understanding and their ability to support you and your child. It may also help

them understand you better as a parent, and how you've adapted your parenting style to suit the needs of your child. The *What does ASD look like?* quick card is a great resource for friends and family, and free from Parent to Parent.



So we have a diagnosis, where to from here?

After receiving an autism diagnosis, there may be services and financial support available for you and your child. The following is a brief guide to some of the support that may be on offer for you.

Needs Assessment and Service Coordinators (NASC)

Contact your local Needs Assessment and Service Coordination Organisation (NASC) for a needs assessment. NASCs are organisations who work with disabled people or people living with a long-term condition and their family or whānau to determine an individual's strengths and support needs and outline the different support services which may be available.

Click here to find your local NASC organisation <https://www.health.govt.nz/your-health/services-and-support/disability-services/getting-support-disability/needs-assessment-and-service-coordination-services>

Financial support

Different financial support may be available depending on the needs of your child. Talk with your health professional, ASD coordinator or NASC organisation about what financial support you may be entitled to.

You can also go to the Work and Income website for more information on the type of financial support available.

<https://www.workandincome.govt.nz/eligibility/health-and-disability/index.html>

Learning support before school

Early intervention support is provided by the Ministry of Education and may be available to you depending on your child's needs and the area where you live.

For more information on Early Intervention Support see the Ministry of Education's website: <https://parents.education.govt.nz/learning-support/early-learning-support/services-and-support-available/#early-int>

Learning support at school

Most children with additional learning needs will receive support from their school. Many schools have a Special Education Needs Coordinator (SENCO) or a Learning Support Coordinator (LSC). Talk to your child's teacher and the support staff (as mentioned above) about supporting your child's learning needs.

Learning support at school when your child has significant support needs

Ongoing Resource Scheme (ORS) funding is available to a small number of children with the highest level of needs (approximately 1 in 100 students). This funding provides support options for specialists, teacher aids, as well as classroom tools, modifications or technologies to support learning.



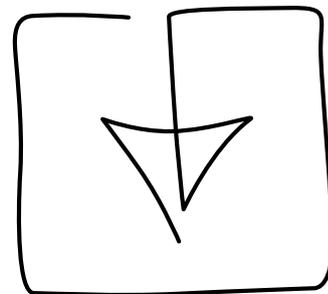
Social support

It is very important to build a strong support network around you when you are caring for a child who has extra support needs. The support that you get from family and friends can be instrumental to your adjustment and overall wellbeing as a parent or caregiver.

Peer support and local support groups can also be really helpful. Contact your local Parent to Parent Regional Coordinator for a list of support groups in your area. Parent to Parent can also connect you with a trained support parent.

Go to our website for a list of contact details:

<https://parent2parent.org.nz/contact-us/>



To find out more about ORS funding check the Ministry of Education website here:

<https://parents.education.govt.nz/learning-support/secondary-school-learning-support/services-and-support/#ORS>

Therapies and supports

Many therapies and supports can be beneficial to help manage some of the associated emotional, behavioural, social and mental health challenges an autistic person may face.

There are a range of different therapies and supports for autistic children. These can include behavioural supports, educational supports, medicinal support, alternative therapies, individual and family-focused supports, or a combination of these.

It is important that any therapy or support you are considering for your child empowers them to be their best autistic self. Therapies that promote normalising autistic people, or modifying or suppressing intrinsic autistic behaviours should be avoided.

Because autism is a spectrum disorder, the assistance a person might need should be based on an individual's strengths and support needs, rather than on their diagnosis. Some autistic people may need a lot of help in their daily lives, others need less. For example, one autistic person may have excellent verbal communication but require support with everyday tasks such as brushing teeth, using the bathroom etc. Whereas another autistic person may need special technology and assistance to help them communicate, but not have any difficulties carrying out everyday tasks.

Choosing the right therapy or support for your child is a complex and personal decision that needs to take into account the rights of the person receiving the therapy, the effectiveness, safety, time, money and energy required to implement the support.

Some therapies and supports have more evidence to say that they work than others. Some therapies or supports are based on science and have evidence-based research to prove that they work, and are safe for the person receiving them. Unfortunately, there are many therapies which target parents and caregivers of autistic children that do not have evidence to show they work. Some of these therapies may also be dangerous.

Therapies and supports along with being evidence-based need to correspond with the values, preferences and ethical principles of parents, care givers and the autistic individual.

Please contact us if you would like to know the evidence base for any therapies or interventions.

What to ask service providers

1

What is the goal of this therapy? Or what specific area of difficulty is it intended to target?
(consider whether the goals align with your views and goals for your child and your whanau)

2

Are there any scientific papers saying this therapy/support is effective?

3

How will we know if the therapy/support is working?
What will the benefits be? and what will they look like?
How will they be measured?

4

How long will the therapy/support take? How will we know when it has worked? and when we can stop?

5

What are possible side effects? and how will we measure and monitor these?

6

How difficult is it to implement the therapy/support correctly?

A note on interventions from the NZ Autism Spectrum Disorder Guidelines:

The New Zealand Autism Spectrum Disorder Guideline states:

Given individual and family differences, no one method or style of intervention/therapy is likely to be effective for all autistic children and intervention/therapy will need to be adapted to individual needs. Accordingly, parents, families and whānau of young autistic children should be supported to:

- Learn about autism as it affects their child, and adapt the home environment and routines accordingly
- Develop routines within the home that work for both the child and the family and whanau
- Ensure that behaviours that are 'cute' in young children do not develop into problem behaviours for people of an older age
- Develop methods of communication that can be used inside and outside the home
- Give their child opportunities to mix with other children, learn social skills, and develop friendships
- Seek referrals for specialist services (e.g. speech and communication therapy, behaviour support, occupational therapy, clinical psychology), if they need assistance to help their child develop skills or to prevent or manage problem behaviour.

Positive behaviour support and techniques

Therapies and supports based on behaviour modification principles are popular, however there is some controversy around therapies that have a foundation in applied behaviour analysis (ABA). Specifically, whether these types of therapies are helpful or harmful.

Positive behaviour supports can be successful in teaching new skills and increasing autonomy and independence. However, they should not be used to suppress autism related behaviours in order to 'fit in' or appear 'normal' (for example, to increase eye contact, or to suppress non-harmful stimming behaviours). The focus with

these types of supports should be on trying to figure out why an individual is exhibiting a behaviour, not on changing behaviours to make an autistic child appear non-autistic.

Understanding why a behaviour is occurring, can help those supporting an autistic person to figure out unmet needs and put supports and strategies in place to meet them.

Note: it is important to examine who decides which behaviours are and are not functional or problematic. Parents, caregivers and autistic people themselves should be empowered to drive these decisions rather than professionals.

**A**

Antecedent

preceding in time or order;
previous or pre-existing

B

Behaviour

C

Consequences

ABCs

The ABC's of behaviour refer to the process of establishing why or when behaviour occurs and is known as a functional assessment of behaviour.

A functional assessment of behaviour involves recording information about the behaviour each time it occurs such as, when it happens, who is around when it happens, what happens directly before the behaviour occurs and what happens directly after the behaviour has occurred.

Generally, there are four main functions of behaviour which are:

- **Social attention**

Behaviour to gain attention from another person. Attention may be in the form of laughing at them, playing, comforting or scolding. Some children prefer any attention (even if it is negative such as being told off) rather than none.

- **Tangible items** and preferred activities
Engaging in behaviour to get access to an item or activity. For example, a child hits another child to get a toy truck.

- **Escape or avoidance of activities or people**

Behaving in a way to get something removed from their environment.

For example, child A hits child B, and child B moves away from child A.

- **Sensory sensitivities or input**

Behaviour that rewards their senses by providing or removing sensory input.

One child may rock back and forth because it is enjoyable and provides sensory input, while another child might yell loudly to block out other noises.

Examples of ABC's and associated functions

Antecedent	Behaviour	Consequence	Function
The teacher places James' work in front of him on the desk	James sweeps his work and pencil onto the floor	The teacher tells James to go to time out	Escape or avoidance - James does not have to do his schoolwork.
Hana is at the supermarket with her mum	Hana starts screaming at the checkout	Hana's mum buys her a chocolate bar to keep her quiet	Tangible item - Hana gets chocolate for screaming.
Nick and his dad go to a busy mall	Nick gets upset and covers his ears	The environment is now quieter for Nick	Sensory sensitivities or input - Noise is reduced.
Susan has fallen over in the playground and a teacher is helping her	Amber pushes another child in the playground	The teacher stops helping Susan and tells Amber to go to time out	Social attention - Amber got attention for pushing.

Examples of possible interventions

Behaviours	Solutions
James is avoiding his school work	<p>Provide easier work for James.</p> <p>Set up a peer-mentor for James.</p> <p>Ask him to pick up his work and carry on with the task, i.e, do not reinforce behaviour).</p>
Hana throws tantrums at the supermarket	<p>Give her a distraction, e.g, to carry a toy around the supermarket.</p> <p>Provide reinforcement for good behaviour (five supermarket trips without a tantrum = a treat).</p> <p>Withhold the chocolate bar.</p>
Nick is covering his ears in a mall	<p>Take him to the mall when it is not so busy.</p> <p>Provide ear muffs, or ear phones with calming music playing.</p>
Amber is pushing children to get attention	<p>Give Amber attention for positive behaviour such as helping other students.</p> <p>Give Amber a job when someone is hurt such as getting a plaster from the school office.</p>

Communication supports

One of the core criteria for an autism spectrum diagnosis involves a persistent difficulty with social communication and social interaction. Therefore, many autistic children may require the use of communication supports to build their communication and interaction skills.

Communication is not just about spoken language, there are many other visual and other cues we rely on to help us understand what a person is saying. For example, tone of voice, a person's facial expressions, their body language, gestures, eye contact, and the context in which they are saying it.

Tools which support all aspects of communication can be greatly beneficial for autistic people.

Speech language and communication therapy

Speech-language therapy addresses challenges with language and communication. It can help autistic people improve their verbal, nonverbal and social communication.

Speech and communication support usually starts with an evaluation by a qualified speech language therapist (SLT). Whether the person is verbal or non-verbal, SLT's are specialised in creating a profile of a person's communicative strengths, skills, and abilities, which includes assessment of comprehension, or what a child or young person understands. From here, the SLT can develop a programme of support which is based around supporting inclusion, enabling participation, and creating social opportunities.

Check out this article for more information on the role of a Speech Language Therapist

<https://www.altogetherautism.org.nz/communication-connection-challenge-become-better-listeners/>



Alternative and augmentative communication tools



Alternative = instead of

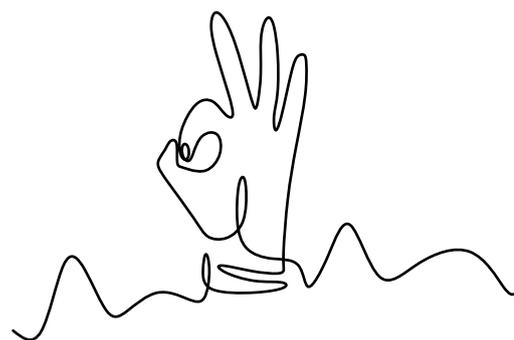


Augmentative = in addition to

Alternative and augmentative communication (AAC) systems are tools which are used to add to existing ways of communication or to give people new and different ways of communicating. This can involve both unaided and aided systems.

Unaided systems

These AAC systems don't require any equipment, rather they involve the use of hand gestures and signs (e.g. NZ sign language) to both support speech and communication or as the main way of communicating.



Aided systems

These AAC systems can be low-tech or high-tech.

Low tech systems use equipment's like cards, boards or books with photos or pictures that represent tasks or objects. Children can use these tools to understand what a person is saying, to ask for what they need and to answer other people's questions.

High tech systems use speech-generating devices. Usually, this involves speech apps or software used with tablets or specific communication devices which usually involve letter or picture keyboards which translate into computer generated words.

Check out this article here for a mother's perspective on her autistic daughters' journey with AAC

<https://www.altogetherautism.org.nz/be-an-ally-not-an-advocate/>



Visual supports

Visual supports are a communication tool that can be particularly helpful for autistic people. Visual supports can make communication physical and consistent, rather than fleeting and inconsistent like spoken words can be.

Visual supports can help with communication, social interaction, thinking and behaviours, as well as helping with executive functioning tasks such as prioritising, organising and time management.

Most autistic people can benefit from using visual supports regardless of their age and ability. This is because autistic people are generally visual learners and often excel at visual spatial skills.

Types of Visual Supports:

- Pictures and photographs
- Symbols
- Written words and scripts
- Short videos
- Calendars and timetables
- Drawings
- Safety signs and labels

Areas where visual supports may be beneficial include:

- Structure and routine, e.g, timetables and schedules
- Transition and change between activities, new places or special events

- Helping with the sequencing order of things that need to occur, e.g, the First/ Then shows what a child needs to do first (generally a less-preferred activity) to receive a desired consequence (something they enjoy)
- Instructions and reminders
- When making choices
- Introducing them to new activities/ situations
- When learning social skills
- Sharing information
- Understanding and interpreting emotions – their own and others
- Starting and stopping activities
- General knowledge
- To help with behaviour, e.g, when to stop, what's appropriate
- For praising
- Locating people and places
- Communication
- Independent living skills, e.g, breaking tasks down, cooking
- Structuring the environment, e.g, safety issues, boundaries.

Social stories™

Social stories are another social learning and communication tool which support the exchange of information between parents, caregivers, professionals and autistic people of all ages.

As previously mentioned, one defining characteristic of autism is difficulty with communication and social interactions, including problems with understanding, interpreting and responding to different social situations.

Social stories™ are developmentally appropriate, individualised short stories of a particular situation, event or activity. They can be used to teach a wide range of skills specific to an individual's needs, and include relevant information about what to expect and how to respond in particular situations.



How to create a Social story™

1. Picture the goal – identify the purpose and what the child needs to understand to achieve the goal (e.g, understanding why it is important to wash your hands or cover your mouth when you cough).
2. Gather information about the individual, including age, interests, attention span, level of ability and understanding. Also collect information about the situation you want to describe in your social story, eg, *Where? What? When? Who? How? Why?*
3. Use the individual as the main character
4. Make sure the story is personalised so the individual can relate to what is being said
5. Be specific about different settings you use in the story
6. Be specific when describing other characters
7. Write dialogue appropriate to the individual (mirror words they use or are familiar with).
8. Repeat the important points you are trying to convey in the story
9. Involve the individual in the construction of the story
10. Involve the individual with illustrations or use photographs of familiar people, places and things.
11. Expose the individual to the story a number of times and be prepared for it to not work straight away.

Example 1

Bed time

The day time is when I play.

When it is night time I go to bed.

My bed is where I sleep.

My bed is very comfortable and cosy.

When I sleep in my bed I feel very rested.

I have more energy the next day.

I should stay in bed all night.

This will make me feel like I am in a good mood in the morning.

Then I can play again in the morning.

Example 2

Calming myself down

This story will teach me how to calm myself down.

When I am feeling upset, angry or worried I can try three things to help me.

1. I pause and stop and think before I do anything
2. Then I can practise taking three deep breaths to relax and calm myself down.

I can close my eyes and picture a flower and a candle.

I can breathe in deeply through my nose like I am smelling the flower.

Then I can hold my breath and count to three very slowly in my head.

Then I can breathe out slowly from my mouth like I am blowing out a candle.

I can do this three times to help me feel calm inside.

3. Then I can think of something I like.

These three things will help me calm myself down.

Inspired by a social story written by George Timlin

Autistic behaviour

Learning about your child's behaviour and why it may occur can have real meaningful benefits for your child, as well as for your connection to them as their parent or caregiver. Common autistic behaviours which can often be misinterpreted include:

- Stimming
- Meltdowns

What is a meltdown?

Meltdowns are an involuntary response to overwhelming and over-stimulating environments and situations. It is important to note that meltdowns are not tantrums; the most distinguishing difference being meltdowns are uncontrollable, while tantrums are voluntary or purposeful to manipulate a situation to achieve a desired outcome.

The key is to recognise the signs in the build-up stage and intervene to prevent the meltdown. Meltdowns are not pleasant experiences for anyone involved and can leave a family feeling exhausted.

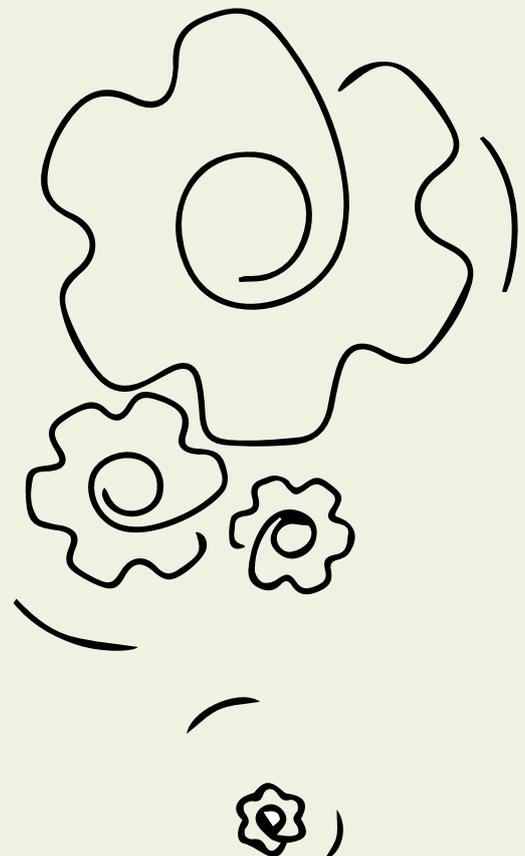
Buildup: This is also known as the anxiety and defensive stage. It usually consists of physical, verbal and behavioural signs. This is the best stage to intervene in a number of ways including limiting instructions, redirecting, a break, a sensory tool or physical activity.

Meltdown/shutdown: This is when behaviour becomes explosive and uncontrolled. There is no point trying to reason in this stage. The number one priority is safety for the child and those around them.

Recovery: This is also known as tension reduction. Each person will act differently at this stage. It generally consists of either withdrawing or sleeping. Children may feel a lot of guilt, shame and remorse from these outbursts.

There are three stages to a meltdown:

- The build-up
- The meltdown/shutdown
- The recovery



What is stimming?

For an autistic person, stimming usually refers to repetitive or rhythmic behaviour this is commonly expressed through body movements, including:

- Hand flapping
- Finger flicking or clicking
- Body rocking
- Hair pulling
- Feet flexing
- Spinning and twirling
- Necklace playing

It may also be expressed through vocalisations, including:

- Muttering
- Grunting
- Stuttering
- Whistling
- Singing
- Repeating the same word or phrase over and over

Why do autistic people stim?

Most autistic people report their stims act as a self-regulatory coping mechanism which help them to feel calm and in control. Is it likely that the reasons autistic people stim will be different for different people. However, stimming might occur because of:

- **Anxiety** – stimming can help to reduce anxiety by focusing their attention on the stim and producing a calming change in their body

- **Over powering thoughts** – Stimming can help to focus a persons concentration by soothing intense thoughts and feelings and help them to regain a sense of control
- **Sensory relief** – stimming can calm a person when they are experiencing sensory overload, it can also help to stimulate their senses when they are in a sensory lacking environment
- **Communication** – stimming can serve as a way for a person to communicate their mood, they may have a particular stim for when they are happy and excited, and another stim if they are stressed or bored.

Occasionally a person's stim may involve self-injury, or injury to others, in these instances a person may require support to reduce or adapt their stim.

We celebrate our autistic son's stims, as it gives us a visible and definitive understanding of how he is feeling in a moment. As a whanau we have learnt to recognise our son's stims and what they mean and what he is trying to communicate. His stims are a combination of hand flapping and vocal stims whether he is happy or upset. The difference is the intensity in which he stims. When he is happy, he flaps his hands with hands open and arms out and vocalises joyful, excited noises. When he is experiencing strong negative emotions, he flaps his hands more rigorously, keeping them closer towards himself and vocalises more distressed sounding noises. We like that his stimming is his way of communication with the world around him, he just expresses himself through his body rather than his words.

Strategies at home

Many of the challenges associated with autism can lead to problem behaviours. There are certain strategies you can implement at home, at school and other areas where necessary.

The following is a brief introduction to these different strategies, many of which can also be used as preventive measures.

You may see there are a number of different strategies that can be applied to particular problems. What works for one child will not work for all children. Strategies will also depend on the age and stage of the child.

Common difficulties autistic people experience and evidence-based strategies.

Difficulty with change or transitions

- Visual and or verbal prompting before change occurs
- Visual schedules
- Diaries and calendars
- Timers for activities
- 'First-Then' boards
- Social stories and scripting about transitions

Speech and communication

- Give one instruction at a time
- Avoid colloquial phrases that can be taken literally such as 'Jump in the car'
- Avoid jokes and sarcasm
- Give more processing time for questions and instructions (without repeating it)
- Use alternative or augmentative communication
- Use visuals
- Speech & language therapy

Sleep difficulties

- Establish a bedtime routine (calming and relaxing activities, no screens, and regular bedtimes)
- Check sensory sensitivities (are the blankets too itchy? is the room too light?)
- Practise meditation and relaxing techniques
- Professional / medical help

Anxiety and self regulation

- Strategies to anticipate change
- Breathing and relaxing exercises
- Practise meditation
- Teach emotions (5-point scales can be a useful tool)
- Teach triggers and signs of stress
- Talking to someone
- Asking for help or to have a break
- Professional / medical help

Education and school

- Speak with your child's educators
- Look out for sensory needs
- Allow extra time for work
- Give clear instructions
- Give visual instructions
- Set Individual Education Plans (where needed)
- Teach asking for breaks/help
- Swap to visual-based activities to demonstrate understanding
- Ensure playground support if needed

Social skills and interactions

- Teach social rules and etiquette
- Social scripts / social stories
- Prompts (conversation starters)
- Video modelling
- Reinforcement
- Social skills training

Sound hypersensitivity

- Ear plugs, ear phones or ear muffs
- Move workstation away from noise
- Avoid crowds or large group activities

Light sensitivity

- A baseball cap, sunglasses, or tinted glasses to block bright lights
- Change household lights to warm or cool tones (dependent on preference) or use dimmers
- Move school desk from well-lit area

Touch sensitivity

- Remove tags from clothes
- Pick clothes in chosen material
- Have a piece of cloth/ribbon or string in pocket for sensory needs
- Educate extended family that waving hello is better than hugs

Picky eating

- Occupational therapist assessment for sensory sensitivities
- Medical check-up to ensure child is getting enough vitamins and nutrients
- Consider taste and texture (how can you change these?)
- Increase new foods slowly and set small goals (i.e. sight, touch, lick, chew, swallow)

Meltdowns

- Learn triggers and identifying behaviours
- Teach calming strategies
- Encourage regular breaks
- Avoid or limit situations which trigger a meltdown response

Behavioural difficulties

- Positive Behaviour Support (PBS)
- Establish clear rules around behaviour
- Record what occurs before and after the behaviour (ABC recording)
- Teach alternative behaviours
- Professional services such as Explore
<https://www.healthcarenz.co.nz/service/explore-specialist-advice/behaviour-support-services/>

Self-care

- Assess sensory experiences
- Establish routines
- Use visual schedules and social stories

Note: This is not a complete list of common difficulties or evidence-based strategies.

A large, stylized white graphic of a hand holding a heart, set against a light green background with abstract white shapes. The word "Summary" is written in a green, cursive font with a brushstroke underline.

Summary

Getting an autism diagnosis can be a difficult time for some parents – for others it may be a relief as they finally understand what is going on.

No matter where you fit in, now is the time to seek out assistance from your local NASC, work out what skills and strengths your child has and which ones they may need help with.

We've provided information in this booklet for teaching new skills and supporting behaviour, as well as how to help with sensory needs and communication – common difficulties in autism.

Parent to Parent and Life Unlimited, funded by the Ministry of Health, provide evidence-based information at any time, and on any topic when requested by you, your extended family, or anyone in your network.

Parent to Parent NZ was formed in 1983 by parents and professionals who saw value in parents supporting parents when faced with the unique joys and challenges of parenting a child with a disability or health impairment.

These challenges not only affect the home lives of parents/caregivers, brothers and sisters, but the wider family/whānau, and out further into their communities.

Parent to Parent's main services are free, confidential, and not offered by any other organisation in NZ.

- Tailor-made information and support on anything connected with disability and health conditions.
- Workshops for parents new to the world of disability
- Training volunteer Support Parents who have 'been there' as parents of children with disabilities
- Connecting new parents to trained Support Parents
- Camps and workshops to support the siblings of children with disabilities
- Workshops for families and professionals to learn how to be heard and advocate for a child's educational and living needs
- Workshops for families – older siblings and parents/whānau – to plan lifelong care for their family member with a disability.

Parent to Parent's national office and its regional offices also provide the services Altogether Autism and Care Matters.





Parent to Parent

connect • inform • support

parent2parent.org.nz • 0508 236 236