

About Autism



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Published by Parent to Parent NZ for its Alogether Autism and Care Matters services partially funded by Care Matters

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This publication is reviewed every six months, in January and July

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CARE MATTERS
LEARNING & WELLBEING

INFORMING • EMPOWERING • CONNECTING
**ALTOGETHER
AUTISM**
THROUGH KNOWLEDGE AND EXPERIENCE

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 people living with autism, professionals and parents, to provide you with information about autism and how it can affect children's behaviours, communication and sensory experiences.

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 will use the terms 'person with autism' and 'autistic person' interchangeably. Autistic communities often express preference for the term 'autistic' as it celebrates the unique strengths and identity that being autistic offers an individual.

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What is autism?

In 2013 the fifth Diagnostic and Statistical Manual for Mental Disorders (commonly known as the DSM-5) introduced the diagnosis Autism Spectrum Disorder (ASD: Autism) which was previously four different diagnoses in earlier editions.

- ▶ **Autistic Disorder**
- ▶ **Asperger's Disorder**
- ▶ **Childhood Disintegrative Disorder**
- ▶ **Pervasive Developmental Disorder not otherwise specified (PDD-NOS)**

It is recognised that autism is a spectrum, meaning that everyone has unique strengths and challenges.

Autism is a lifelong developmental condition that affects each individual differently both cognitively (thinking and behaviour) and socially (communication and social interaction).

People with autism have strengths and difficulties in different areas which affect their lives differently. No two people on the spectrum are alike. However, for someone to be diagnosed with autism, they will have a difficulty or delay in two main areas of functioning:

It's important to remember that abilities can change over time. We may have the ability to complete a task in one situation, but not in a new environment. This is true for people with autism who usually find change challenging.

People with a delay or difficulty in only one of these two areas are unlikely to meet the criteria for ASD, however, they will likely benefit from the same supports a person with a diagnosis of ASD has in place. For this reason, interventions should be based on an assessment of an individual's strengths and difficulties, rather than diagnosis.

- 1 Communication and social interaction
- 2 Restricted and repetitive patterns of behaviour.

What is Asperger's?

Asperger syndrome (AS) is also known as Asperger's Disorder (AD) or simply Asperger's.

Before 2013 it was a separate diagnosis –related, but different to, autism. The changes to the DSM-5 saw it removed as a separate diagnosis and placed within Autism Spectrum Disorder.

Asperger's was thought to be a distinct diagnosis due to the timing of diagnosis, intelligence levels, how the condition progressed and the overall impact on one's life. The reason Asperger's was removed as a separate diagnosis and included under the spectrum of autism was because the core features are in the same areas of functioning. Combining the diagnosis under a spectrum allows for the acknowledgement of the very different and unique presentations throughout the autistic population.

Since the change in 2013, many resources are no longer Asperger's specific as it's recognised on the autism spectrum, however, older resources labelled either Asperger's or high-functioning autism will be still relevant.



What does autism look like?

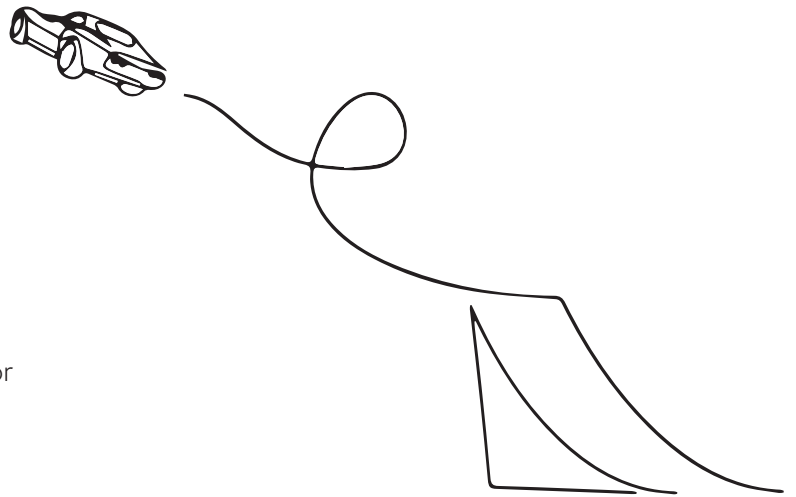
Difficulties or delays may be expressed or observed as follows:

Communication

- Delayed in speech and language
- Have difficulty understanding others
- Need extra time to process verbal communication
- Find it hard to communicate what they want
- Use props or another person's hand to convey a message
- Use an unusual tone, pitch, or accent
- Repeat sounds, words or phrases said by someone else (known as echolalia)
- Language may be used in an unusual way (such as being overly formal or academic)
- Show difficulty in non-verbal communication, such as the inability to read, understand or respond appropriately to facial expressions, body language and gestures
- Difficulty following instructions 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 difficulties
- 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 for polite behaviour)
- 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, or difficulty starting or stopping tasks
- Have a special interest which they 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 unusual movements or sounds (commonly known as stimming), e.g, unusual movements near their eyes or face
- Find problem-solving or organisation challenging due to executive functioning difficulties.

Sensory

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

They 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 change day-to-day or are dependent on the environment.

The senses and autism



Sight

People with autism may have difficulty following objects, or have a strong dislike to bright lights.



Hearing

Loud noises may be painful and they may have trouble concentrating when there is background noise.



Smell

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



Taste

A strong like or dislike for particular tastes and may appear fussy with different textures of food.



Touch

Certain clothing may be too scratchy to wear. Some autistic people like tight clothing and tight hugs, whereas others find this painful and are oversensitive to the touch of others.



Balance (vestibular)

May experience difficulty with balance and have poor coordination. Some enjoy spinning in circles while others find this makes them ill.



Body awareness (proprioception)

May appear clumsy as they are always bumping into other people and objects due to an inability to understand their place in relation to what is around them.



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.

Common difficulties affecting daily life for autistic people

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 people with autism have a significantly decreased ability to do this, which can explain some difficulties they experience with social interactions and communications.

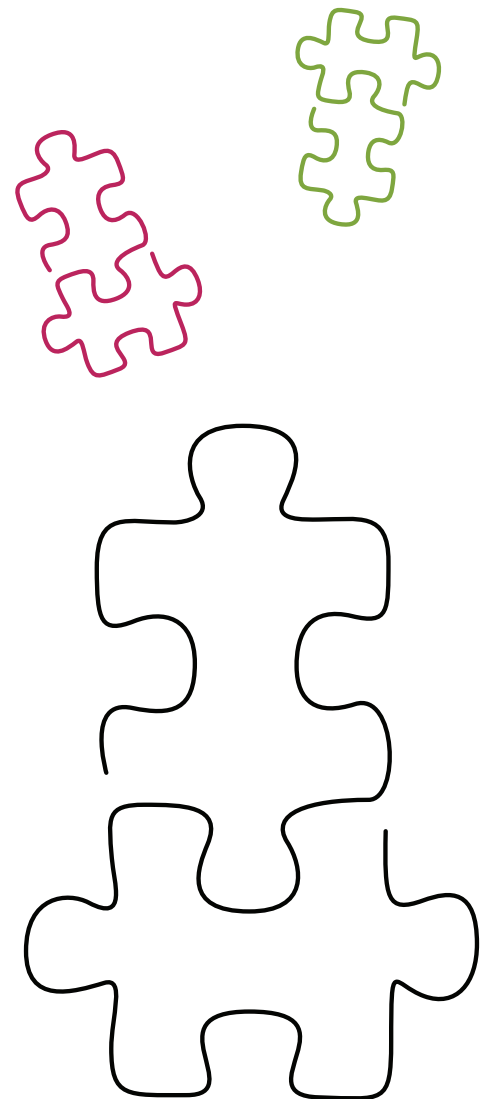
Executive functioning

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. People with autism often have problems organising, prioritising, problem solving, accessing working memory, thinking flexibly and self-monitoring, eg, difficulty following more than one instruction.

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.



Creative work

Artists with autism

Bricharne Hastie

Bricharne is a 20-year-old 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

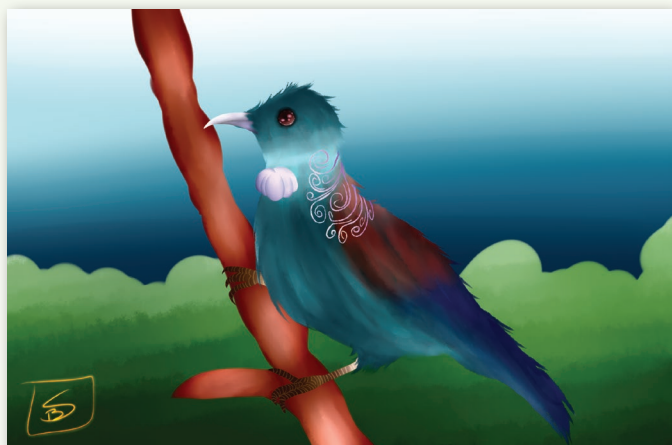
time, but one that has been well received both here and overseas, with works sold to New Zealand and global buyers.

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, and [instagram.com/asdartforme](https://www.instagram.com/asdartforme) where images of her work are uploaded.





A stitchbird also known as Hihi.



A tui perched on a branch.



Pukeko.

Sophie Bouda

Sophie is a 15-year-old 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 16-year-old 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

Strengths and abilities in autism



People with autism may display a range of strengths and abilities that can be directly related to their diagnosis, including:

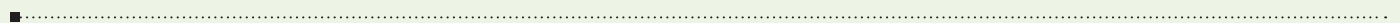
- Learning to read at a very early age (known as hyperlexia)
- Memorising and learning information quickly
- Thinking and learning in a visual way
- Having an excellent sense of direction
- Logical thinking ability
- May excel in academic areas such as science, engineering and mathematics as they are technical and logical subjects that do not heavily rely on social interaction
- Having an extraordinarily good memory (remembering facts for a long time)
- Being precise and detail-orientated
- Exceptional honesty and reliability
- Being dependable in regards to schedules and routines
- Being punctual
- Strong adherence to rules
- Able to concentrate for long periods of time when motivated
- A drive for perfection and order
- A capability for alternate problem-solving
- A fresh sense of wonderment.

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 it is probably somewhere between 1 in 40 and 1 in 59 children. 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 are:

- The standard instruments 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 girls have the same interests as typically developing peers.
- Girls have fewer repetitive behaviours than boys.

Diagnosis

Why is diagnosis important?

A diagnosis can be useful because it allows a label to be given to something you may have been trying to understand for some time. Diagnosis may also open a door to knowledge by allowing you a specific term to use to search and gather information required.

Diagnosis allows you access to resources, support and assistance.



Typical responses to diagnosis

Caring for a family member who has diverse needs requiring support is an experience few families or whānau anticipate or plan for.

The diagnostic process can also be 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.

When a diagnosis is made with older children and adolescents, there needs to be discussion about what they should be told, when, and by whom.

The diagnosis itself, whether you've been expecting it – or even hoping for it – can be a shock. A common reaction is difficulty remembering any of the discussion after the diagnosis was made.

You can contact the person/people who did the diagnostic assessment to arrange a follow-up appointment, and ask questions you might have had after the diagnosis.

Doubt about the accuracy of the diagnosis or about the competence of the clinician(s), anger, grief and despair are also common.

Other people experience a great sense of relief, as there is now an explanation for their experience, although this relief can then give way to anxiety about what the future may hold.

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 Altogether Autism service.

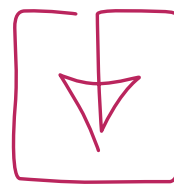
Getting a diagnosis

The assessment pathway for autism in New Zealand varies considerably depending on a range of factors, including the situation of the person requesting the diagnosis and regional services available to them. Ideally, diagnosis will involve a multidisciplinary team, but this is not always possible.

Where diagnosis rests with a sole practitioner, it is essential they have specialist autism knowledge.

The New Zealand Autism Spectrum Disorder Guideline provides detailed guidelines for best practice. It acknowledges "there is currently inconsistent and inequitable access to assessment and diagnosis" (p.18).

However, the *Guideline* offers clear recommendations for best practice diagnosis, and should be consulted.



Download the free guideline

www.health.govt.nz/system/files/documents/publications/asd-guideline-apr08.pdf

Download its companion book **How is ASD diagnosed?**

www.health.govt.nz/system/files/documents/publications/how-asd-diagnosed.pdf

Diagnostic assessment will vary considerably depending on the age of the person being diagnosed, but should include:

Minimum

Informed consent, discussion with family, interview, observations (ideally in a range of settings) screening and self-reports.

Medium

The above, plus interviews with significant family members, and a review of historical documents.

Comprehensive

The above using 'gold standard' ASD tests, plus consideration of as many of the following components as possible/indicated:

- Detailed health, developmental and behaviour history
- Comprehensive file review including transitions, peer relationships
- Medical evaluation including vision and hearing
- IQ and cognition skill assessment (by a psychologist)
- Mental health assessment (with consideration of comorbidities and differential diagnoses)
- Adaptive functioning
- Neurological assessment (including epilepsy)
- Communication (ideally by a speech and language therapist)
- Sensory, motor and perceptual assessment (ideally by an occupational therapist)
- Social competence
- Family strengths/needs (often by an ASD services coordinator from your regional DHB)
- Comorbidities.

Diagnosis is a process and not a single event, and families should always know how and who to contact for follow-up appointments, and to have the information repeated and clarified. They should be assured of their right to ask questions, to query both the accuracy of the diagnosis and the competency of the clinician(s), and to have resources and materials to digest in their own time.

Disclosing the diagnosis

Your child

There is no right or wrong time to tell your child they have autism. It is your choice as a parent to disclose the diagnosis to your child or not. 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? If you seem tense or uneasy about the diagnosis, your child may pick up on this and feel their diagnosis is a 'bad thing'.

Picking the right way to disclose also depends on your child. If they can understand verbal communication well and will learn from a discussion, then that may be a good option. You could also pick up some videos, or visual pictures if your child is more of a visual learner to supplement and aid discussion.

Be prepared for your child to have a range of reactions to the diagnosis. They may go through different stages of processing it, such as a depression or grieving period where they ask questions like 'why me?', ask you to 'make it go away', or they may experience denial.

They may also just accept the diagnosis; "I always knew I was different", and be happy to have a label that explains their quirks or helps them understand themselves.

An older child may be able to use it to help themselves such as understanding that visual supports may enhance their retention of information.

They will likely have a lot of questions. It's OK to not have the answer to every question your child has about their diagnosis, or how it may affect them in the future – just reassure them your support will be there all the way!





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 siblings' difficulties, 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 Altogether Autism information pack you can share with educators containing clear information on what autism is, classroom accommodations and teaching strategies.

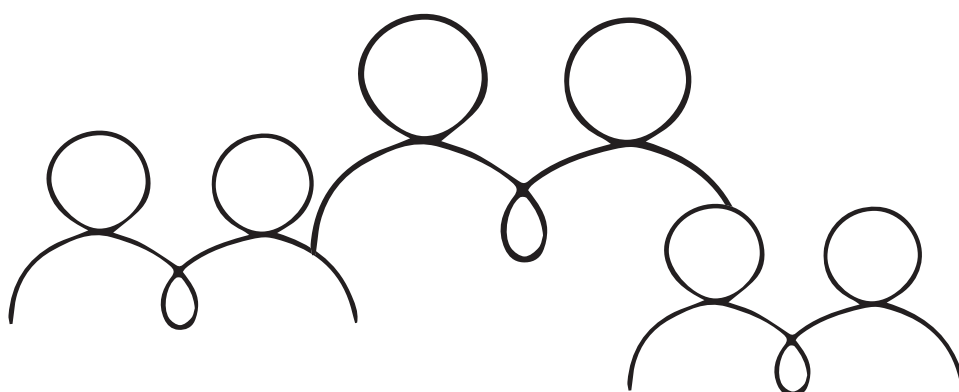


Brian and Betty Pulefolau established the Pasifika Autism Support Group (PASG) in South Auckland and most recently in the greater Wellington region.
Photo: Melissa Palmer / Nectar Photography

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?

Needs Assessment and Service Coordinators (NASC)

After receiving a diagnosis it would be beneficial to identify your local Needs Assessment and Service Coordination services.

NASCs are organisations in different areas contracted by the Ministry of Health to work with disabled people and their family or whānau.

The role of the NASC is to determine the individual's strengths and support needs, outline the different support services available in your area, and determine your child's eligibility for Ministry-funded support services. The needs assessment will look at abilities, resources, goals and needs, and identify which areas are most important to maximise wellbeing and independence.



Whangarei/Northland:

NorthAble-Matapuna Hauora
(09) 430 0988

Auckland:

Taikura Trust
(09) 278 6314 or 0800 TAIKURA
(824 587)

Gisborne/Tairāwhiti:

Life Unlimited Charitable Trust
(06) 863 2836

Waikato:

Disability Support Link
(07) 839 8883

Tauranga/Bay of Plenty:

Support Net Kupenga Hao Ite Ora
Tauranga
(07) 571 0093

New Plymouth/Taranaki:

Access Ability Taranaki
0800 758 700

Hawke's Bay:

Options Hawke's Bay
(06) 870 7485

Whanganui:

Access Ability Wanganui
0800 758 700

Palmerston North/Mid Central:

Currently piloting a systems transformation. If you live in the MidCentral area contact Mana Whaikaha:

www.manawhaikaha.co.nz
0800 626 255
info@manawhaikaha.co.nz

Masterton/Wairarapa:

Focus
(06) 946 9813

Lower Hutt and Upper Hutt/ Hutt Valley:

Life Unlimited
(04) 569 3102

Wellington/Capital & Coast:

Capital Support
(04) 230 6400

Nelson/Nelson-Marlborough:

Support Works
(03) 539 3976

Christchurch/Canterbury:

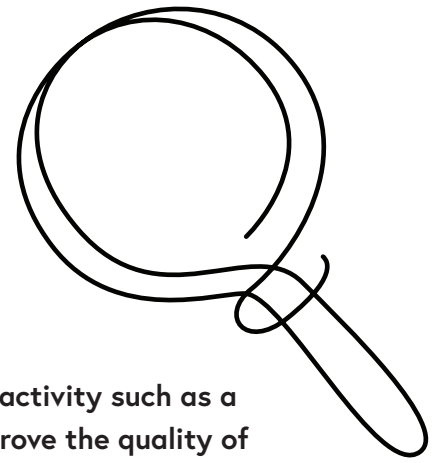
Life Links
(03) 365 9593

Otago/Southland:

Access Ability Otago, Southland
0800 758 700

This information is subject to change. The systems transformation will be reviewed in 2020.

Strategies and Interventions



An intervention for autism is defined by Research Autism as "any kind of activity such as a treatment, a therapy or the provision of a service that is designed to improve the quality of life for people on the autism spectrum".

Interventions can be behavioural, educational, medical, alternative, individual, family-focused, or a combination of these.

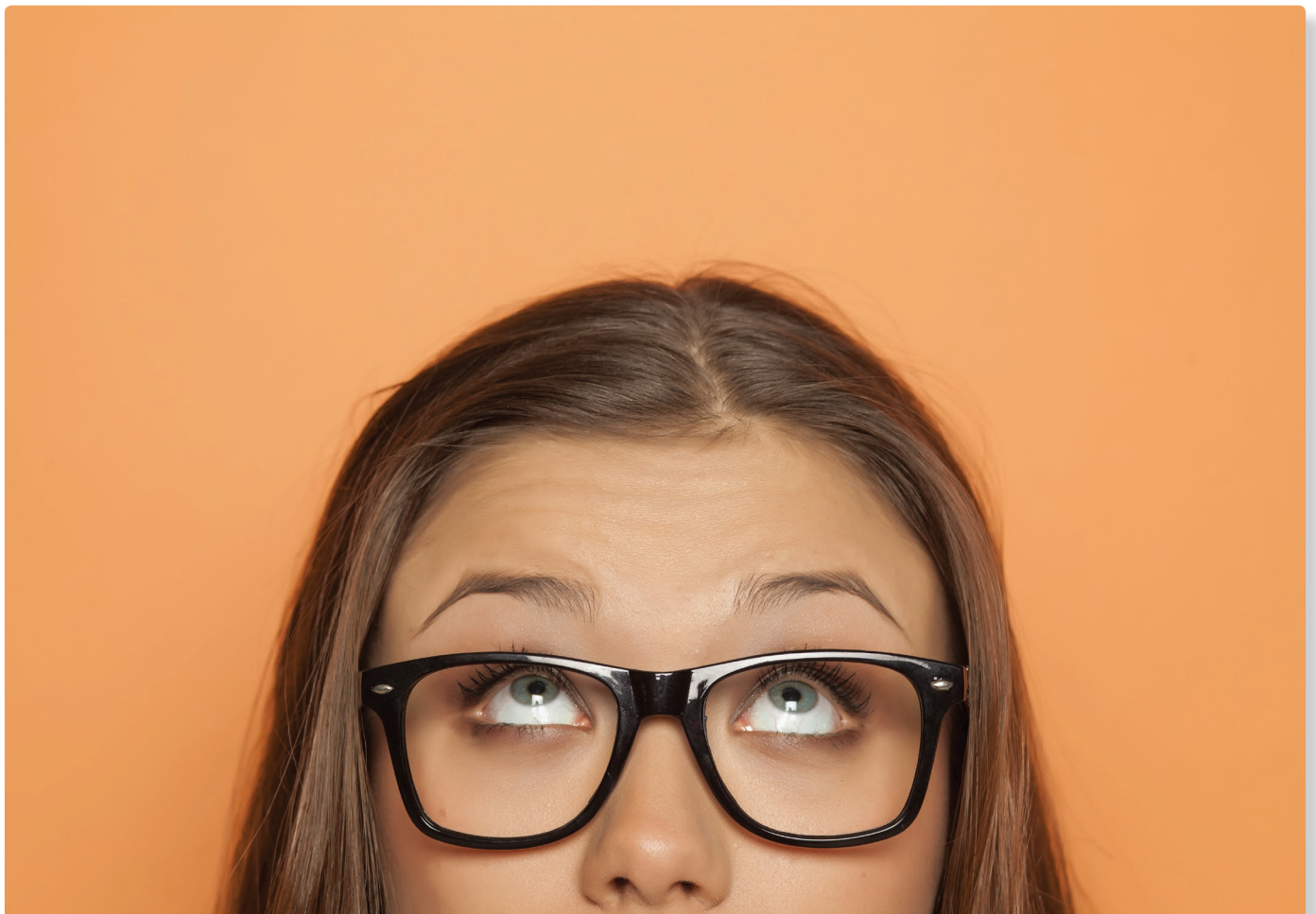
Choosing an intervention is a complex and personal decision that needs to take into account the rights of the person receiving the intervention, the effectiveness, safety, time, money and energy required to implement.

Interventions should be implemented after careful consideration of the child's strengths

and difficulties. Some interventions may work for one child, but not another.

Research into the effectiveness and safety of an intervention forms its evidence base.

A Google search of 'autism' and 'intervention' gives over 34 million results, however, what is most popular and appears first may not be evidence-based and be ineffective at best and harmful at worst.



What does evidence-based mean?

Professionals (eg, nurses, occupational therapists, psychologists) are obligated to practice in an evidence-based way. The American Psychological Association defines evidence-based practice as "the integration of the best available research with clinical expertise in the context of patient characteristics, culture and preferences".

This means professionals should use particular methods for evaluating whether an intervention is working, take into account the current understanding of what is being treated, and use the best available research to help guide treatment decisions.

When an intervention has been studied extensively and proven effective, people may say it is 'evidence-based'. It should still be implemented as part of evidence-based practice to be effective.



What is a 'fad' intervention?

Fad interventions are not based on science and their effectiveness is not researched. Some are pseudo-scientific – they seem based on science, but when examined the research or evidence does not follow scientific rules.

Unfortunately, many fad treatments became popular despite there being no evidence base for them. Some can be dangerous.

Please contact us if you would like to know the evidence base for any intervention.

Why does autism attract 'fad' interventions?

There are a number reasons, for example (but not limited to):

- Parents of children with autism often see their child struggling and experience significant grief. In times of desperation they want something to make life easier for their children and themselves
- People with autism can often have advanced skills in some areas if a gain in skills occurs when a fad intervention is in place, the intervention may falsely be given credit
- Another reason is pressure to select and begin using an intervention even if the evidence behind it is only anecdotal, because research shows early intervention is important.

What to ask service providers

1

What is the theory or rationale for this intervention?

2

Are there any scientific papers saying this intervention is effective?

3

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

4

How long will the intervention 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 intervention correctly?

Positive behaviour support and techniques

Positive Behaviour Support (PBS)

Positive Behaviour support is an evidence-based approach which aims to increase a person's quality of life, and meet their individual needs. It includes teaching new skills, decreasing challenging behaviours and increasing social inclusion, autonomy and independence.

Challenging behaviour is often a sign someone's needs are not being met. The aim is to figure out why they are behaving in a particular manner, and understand what needs are not being met. You can then respond effectively before behaviour escalates and put strategies in place to address their needs.

Primary prevention is emphasised in PBS. This means figuring out unmet needs and putting supports and strategies in place to meet them, identifying situations where skills may be lacking and teaching the skills and minimising environmental stressors. Strategies may include: making changes to the individual's environment, improving communication options, building relationships and increasing active engagement in pleasurable activities. Information is gathered and analysed to increase understanding on what is happening for people (see following section on ABC's) and plans are put into place to decrease challenging situations and behaviours and increase quality of life.

NB: If any extreme, violent behaviour puts you or others including your autistic child in danger, seek professional help immediately.

Applied Behaviour Analysis (ABA)

One of the most effective, well-researched interventions available for autism, and available throughout New Zealand, ABA comprises techniques based on evidence and data collection.

ABA techniques can be used in the home, at school or in the workplace to teach new skills, change problematic behaviour and encourage an infrequent behaviour to occur more often. It is used with children with autism to increase or teach communication and language skills, social skills, play skills, and self-help skills, and to reduce aggression, self-injury or harmful self-stimulatory behaviours.

ABA therapy takes behavioural techniques and applies them in a more structured way with a specific goal in mind. The first step is an assessment of strengths, needs, likes and goals.

Strengths are needed so the practitioner knows what level the child is currently at in terms of ability. Needs are assessed to determine what skills would be beneficial for the child to learn (i.e. a better way to communicate what they would like instead of displaying aggression). Likes are important as the practitioner needs to be aware of what may be an appropriate reinforcer (which increases the likelihood of behaviour). Goals are important as they benefit the child and improve their quality of life.

The programme should address a wide range of questions such as:

- What behaviour needs to change?
- How will this change benefit the child?

- What is the baseline of that behaviour? E.g. how often is that behaviour occurring?
- What new skill will be taught ?
- What prerequisite skills does the child have?
- What steps will we need to take?
- How will it be measured?

Once goals have been identified, the intervention can be designed and then implemented sometimes by professionals and sometimes by family members. .. Data is usually monitored by the supervising practitioner, and changes to the programmes are made accordingly.

It is essential when looking at ABA to establish the reasons why behaviour is being addressed. It is key that it is in line with the child and family goals or serves a practical purpose and not just to make someone "fit in" or appear "normal".

Social skills training

Social skills training aims to improve the child's reading and understanding of nonverbal communication, such as eye contact, body language, tone of voice and facial expression.

It may also focus on perspective-taking (seeing things from another perspective), problem-solving and understanding social rules.

It aims to teach the child how to assess and understand situations, and the most appropriate responses.

Social skills training can occur one-on-one with a therapist, or in a small group. Sometimes it will include outings where skills learned in sessions can be practised in real-life scenarios (e.g, buying products from a store).

Social skills training may also be a specific programme to target a particular skill deficit, or as a part of a larger social skills unit, and may be incorporated into an ABA programme or similar.

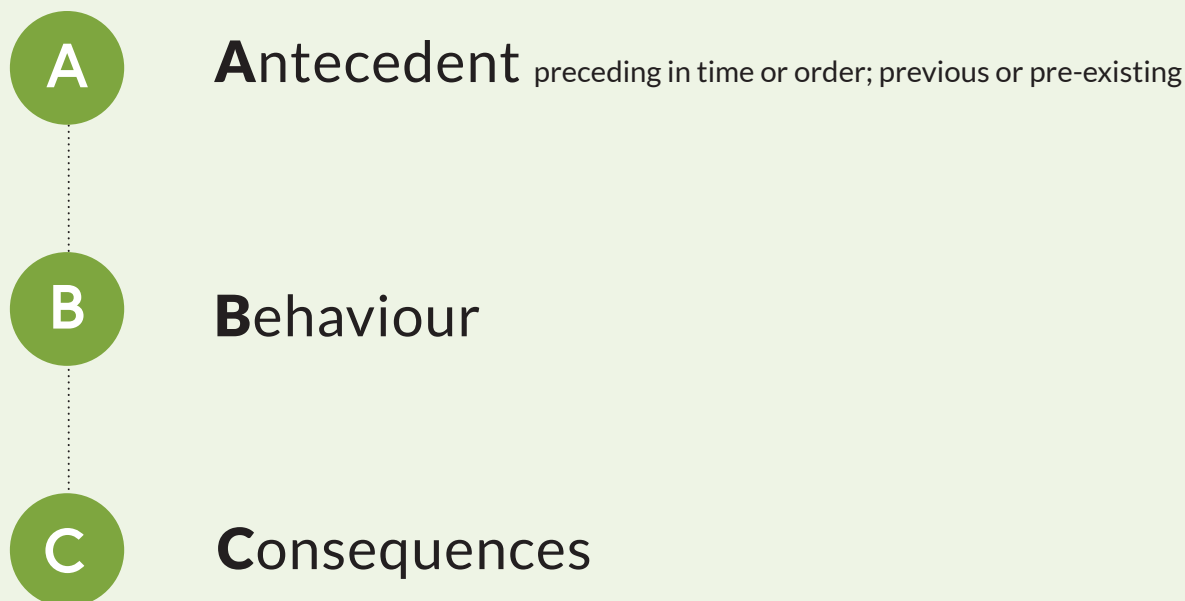
Cognitive-Behavioural Therapy (CBT)

CBT is an emerging therapy for autism and is a combination of cognitive (thinking) and behavioural (doing).

It focuses on being aware of thoughts and emotions, and changing harmful behavioural or thinking patterns. It may also involve or include mindfulness, meditation and learning new coping skills.

CBT has been very effective in treating many mental health issues, and research is looking at how CBT may be useful for autistic people as it has been proven effective to treat co-occurring anxiety and depression in individuals with autism, as well as social and communication skills.

Good practice guidelines mention that CBT may need to be adapted to suit autistic people, for example the practitioner needs knowledge in autism, be able to provide information on autism, as well as change the way the therapy is conducted in terms of information and tasks presented and structure (Insight Research Ltd, 2016).



ABCs

All behaviour occurs for a reason. ABCs refers to establishing why or when behaviour occurs, and is known as a functional assessment of behaviour.

After multiple observations of behaviour, you can begin to form hypotheses or theories on why it may occur and under what circumstances it is likely to occur.

There are four main functions of behaviour – social attention, access to tangible items or preferred activities, escape or avoidance of activities or people, and sensory sensitivities or input. These functions identify what reinforces behaviour, and why that behaviour keeps occurring.

Reinforcement here is not necessarily given to the person, but may be a result of other environmental factors.

- **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 ABCs and associated functions

A ntecedent	B ehaviour	C onsequence	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 of school work
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 in the form of chocolate
Nick and his dad go to a busy mall	Nick gets upset and covers his ears	The environment is now quieter for Nick	Sensory relief
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	Amber got attention for her behaviour

Examples of possible interventions

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

Relaxation techniques

Anxiety is a common experience for people on the spectrum. It can be highly debilitating and stressful for people. Teaching children to be aware of these feelings at an early age and to engage in calming techniques can be very beneficial for them and the family.

There are many different relaxation strategies which can be a start for helping children manage their anxiety, such as deep breathing, positive thinking, and redirection to more pleasant/calming activities, listening to music, swinging or jumping. Some of these will depend on the individual's particular likes and dislikes.

Reinforcement

Reinforcement refers to the process of strengthening behaviour. A reinforcer is a consequence of a behaviour that increases the likelihood of that behaviour occurring again.

Reinforcers may be given by people or may just occur as a result of the behaviour naturally. For example, a parent may give praise to their child for brushing their teeth (given reinforcer in the form of praise) or a child who is cold puts on a sweatshirt which stops them from being cold (the removal of cold reinforces the behaviour of putting on more clothes when cold).

Reinforcement is a simple yet effective behavioural technique that can be applied in almost all situations, such as increasing a socially desirable behaviour (e.g. using manners) or when encouraging a new skill (e.g. tying shoelaces). Reinforcement means looking for behaviours you would like to see happen more, and rewarding these.

Common reinforcers include praise, giving a tangible item or favourite food, giving access

to an activity, or sensory based reinforcement such as a tickle.

What would be reinforcing for a child depends on their individual likes, interests and level of ability. If something is not increasing the behaviour it is not reinforcing. Reinforcement works best when given immediately after the desired behaviour, and when it occurs every time. It can be faded out when necessary. For more information on the use of reinforcers contact Parent to Parent.

Token systems

Token systems are a way to reward positive behaviour. Reinforcers are symbols or tokens that can later be exchanged for a larger item, or access to an activity for instance, after they receive 10 tokens they may go to the park. Token systems generally work best for children on the spectrum who understand the relationship of tokens representing a highly desired reward. An example of a token system is a star chart - good to use for autistic people as a visual representation of their goal, what is expected of them and how far away they are from reaching it.

Token systems are most effective when used regularly – and when there are plenty of opportunities to gain a token. If a child only earns one token a week, and it takes 10 tokens to earn a new video game, that child may lose interest in the desirable behaviour required.

Visual supports

These are common in everyone's life – we use calendars, lists, maps, road signs and other visuals on a daily basis. For example if you were in an unfamiliar shopping centre and needed to find a bathroom, you would look for a toilet symbol.

Visual supports can be helpful for autistic people for 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 they are generally visual learners tending to excel at visual spatial skills.

Visual schedules have the potential to increase positive interactions and behaviours, help the child cope with change and anxiety, and overall increase your child's wellbeing.

A visual support is also a tool to communicate with people who have difficulty understanding or using language, and it could be a real object such as a timer, photographs, written words, drawings, pictures, symbols or lists.

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.

Scripting

Scripting is a technique which provides children with verbal or written descriptions about specific skills or situations.

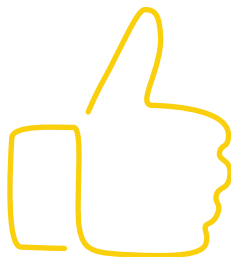
It serves as an outline of what is going to occur, or what is required. The rationale behind scripting is to help the learner anticipate what may occur at given times, and give them the opportunity to mentally prepare for the situation – resulting in decreased anxiety.

Additionally, it may provide opportunities to cope with change. When an activity or a situation is changed (as happens in the real world), scripting allows for the new information to be added, potentially reducing anxiety.

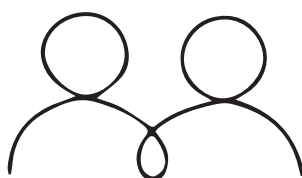
When using a visual support, make sure it's appropriate for your child's needs, and take into account that some children with autism have trouble generalising – they may not get into a white car after being shown a picture of a blue car.



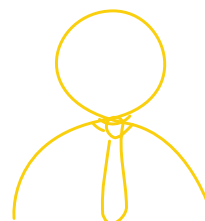
I can give a thumbs up to say **“Hey that’s cool bro”**



I can say **“Hi”** when I meet somebody new



At 8am, get dressed and go to the mall with my big brother to buy a present for dad for Fathers Day.



Social stories™

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 with autism 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

Alternative and augmentative communication tools



Alternative = instead of



Augmentative = in addition to

A number of communication supports are used as tools to increase communication, particularly when your child does not communicate verbally. These include picture exchanges, technology, sign language, etc.

General tips for success

Structure

- Limit choice – too much choice may result in anxiety
- Try to make the environment as predictable, structured and organised as possible. Ideally the child will know what is expected of them, when and for how long
- Breaks in between activities, particularly between periods of focus, concentration and intense self-regulation.
- Check they have understood – some children take longer to process instructions
- Be consistent – if you say there will be a consequence, make sure you follow it through
- No surprises! Let them know when you're making changes. Use the visual schedule and script to communicate the change (rather than just tell them). Communicate simply, clearly and concisely.

Clear rules and consistency

- Don't rely solely on verbal communication – use visual supports or write it down
- Keep it simple – don't crowd or overload with information
- Allow processing time and personal space
- Take notes of what the 'build-up stage looks like' and intervene at this point – prevention is the key.



Teaching skills

- Break it down into small units
- Check prerequisite skills
- Reinforce often
- Create situations for success and to gain reinforcement
- Increase motivations by starting easy and building up confidence first
- Master the skill in one environment before moving into teaching the skill in a new environment.
- Recognise the ABCs
- Take into account communication difficulties
- Get help when you need it!

General

Dealing with behaviour

- Set clear expectations
- Be consistent with expectations and consequences
- Teach self-regulation
- Focus on the positive – reinforcing good behaviour makes it more likely to occur again, leaving less time for problematic behaviours
- Keep positive
- Choose your battles
- Take care of your self
- Advocate for your child
- Educate others
- Make time for siblings
- Reach out for help when you need it.
- Make self-esteem building a priority

What is a meltdown?

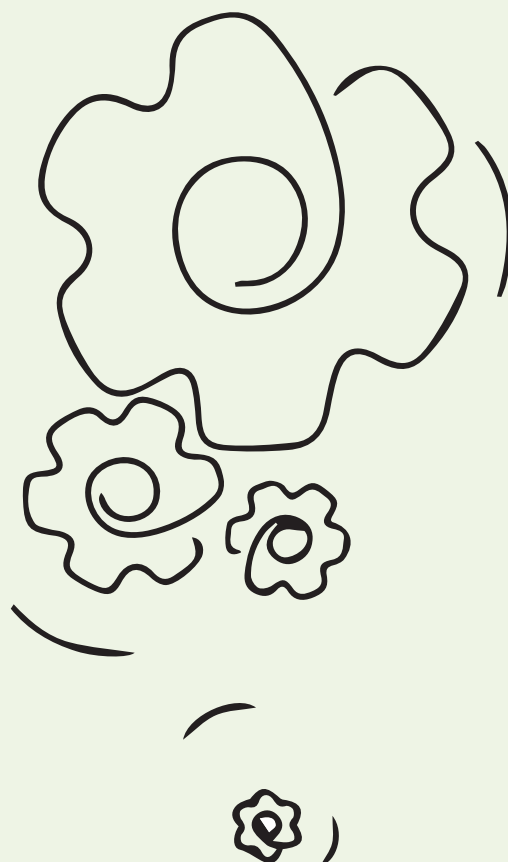
Meltdowns are an involuntary response to overwhelming and over-stimulating environments and situations. It is important to note that meltdowns are not tantrums; the most distinguishing difference being meltdowns are uncontrollable, while tantrums are voluntary or purposeful to manipulate a situation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

There are three stages to a meltdown; the build-up, the meltdown/shutdown, and recovery. 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.

Rumbling: 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 toy or physical activity.

Rage: Also known as acting out. 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.



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 statements that can be taken literally
- 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	<p>Speak with your child's educators</p> <p>Look out for sensory needs</p> <p>Allow extra time for work</p> <p>Give clear instructions</p> <p>Give visual instructions</p> <p>Set Individual Education Plans (where needed)</p> <p>Teach asking for breaks/help</p> <p>Swap to visual-based activities to demonstrate understanding</p> <p>Ensure playground support if needed</p>
Social skills and interactions	<p>Teach social rules and etiquette</p> <p>Social scripts / social stories</p> <p>Prompts (conversation starters)</p> <p>Video modelling</p> <p>Reinforcement</p> <p>Social skills training</p>
Sound hypersensitivity	<p>Ear plugs, ear phones or ear muffs</p> <p>Move workstation away from noise</p> <p>Avoid crowds or large group activities</p>
Light sensitivity	<p>A baseball cap, sunglasses, or tinted glasses to block bright lights</p> <p>Change household lights to warm or cool tones (dependent on preference) or use dimmers</p> <p>Move school desk from well-lit area</p>
Touch sensitivity	<p>Remove tags from clothes</p> <p>Pick clothes in chosen material</p> <p>Have a piece of cloth/ribbon or string in pocket for sensory needs</p> <p>Warn extended family that waving hello is better than hugs</p>
Picky eating	<p>Occupational therapist assessment for sensory sensitivities</p> <p>Medical check-up to ensure child is getting enough vitamins and nutrients</p> <p>Consider taste and texture (how can you change these?)</p> <p>Increase new foods slowly and set small goals (i.e, sight, touch, lick, chew, swallow)</p>
Meltdowns	<p>Learn triggers and identifying behaviours</p> <p>Teach calming strategies</p> <p>Encourage regular breaks</p> <p>Avoid or limit situations which trigger a meltdown response</p>
Behavioural difficulties	<p>Positive Behaviour Support (PBS)</p> <p>Establish clear rules around behaviour</p> <p>Record what occurs before and after the behaviour (ABC recording)</p> <p>Teach alternative behaviours</p> <p>ABA therapy / Behavioural therapy</p> <p>Professional services such as Explore</p> <p>www.healthcarenz.co.nz/explore-specialist-advice/</p>
Self-care	<p>Assess sensory experiences</p> <p>Establish routines</p> <p>Use visual schedules and social stories</p>

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

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 a 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 changing behaviour, as well as how to help with sensory needs and communication – common difficulties in autism.

Parent to Parent's free Altogether Autism service provides evidence-based information at any time, and on any topic when requested by you, your extended family, or anyone in your network.



Writers



Rebecca Armstrong *MAppPsy (1st Hons)*

Rebecca has a Masters in Applied Psychology and is a researcher for Parent to Parent and Altogether Autism where she answers complex information requests, liaises with the Professional Expert Group and Consumer Reference Group, and is involved in developing and facilitating PRISM – Altogether Autism's tailor-made workshops for professionals working with people on the spectrum. Rebecca is also studying to become a clinical psychologist through the graduate programme at the University of Waikato. Her previous experience includes working with children with autism, facilitating anxiety and depression peer support groups and tutoring general, experimental and cognitive psychology at the university. Rebecca has been involved in a number of volunteer positions and is currently a board member of Evolve – anxiety and depression peer support group.



Tegan Andrews *MAppPsy (1st Hons)*

Tegan is a former researcher for Parent to Parent and Altogether Autism, and current doctoral student at the University of Waikato. As a researcher she answered complex information requests and wrote for the Altogether Autism Journal. She also facilitated Prism workshops for professionals. Tegan has been a tutor at the University of Waikato for the past four years, teaching general psychology, behaviour analysis, research methods and assessment. Prior to this, she worked as a behavioural therapist using techniques to facilitate the development of social skills in children with autism.

► **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 over 3600 different 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 11 regional offices also provide the services Altogether Autism and Care Matters.



► **Altogether Autism was started in 2007 by Parent to Parent and Life Unlimited.**

It provides free evidence-based information and support for people living with autism, families who have loved ones with autism, and to professionals working with people with autism.

The information it provides is tailored to any query, and its researchers can investigate more complex questions.

Altogether Autism also has two external consultancy groups: The Consumer Reference Group which is made up of autistic adults and parents with children of all ages on the spectrum; and the Professional Expert

Group which is made up of professionals who work with people on the spectrum including psychologists, psychiatrists, educators, lawyers and health professionals.

Altogether Autism also offers Prism professional development workshops to any group such as schools, disability organisations, police, psychologists and employers. Workshops are tailored to introduce participants to strategies and tools for working with someone on the spectrum.



► **In 2015 the Ministry of Health launched two new national services to support family carers, delivered by not-for-profits SAMS (Standards and Monitoring Services), Parent to Parent, and Carers New Zealand.**

The services, developed by carers for carers, assist people who support people with disabilities nationwide.

SAMS' and Parent to Parent's Care Matters learning and wellbeing service is available online at carematters.org.nz, supported a free phone service. The website provides up-to-date information to assist carers, while learning and training is available face-to-face and online. Resources cater to people who have visual impairments and are accessible via online desktop and mobile devices.

The Care Matters freephone 0508 236 236, operated by Parent to Parent, connects callers to its existing network of local knowledge and support, and its facilitators – many of whom are carers who have walked in the same shoes. Care Matters also funds Parent to Parent's SibSupport programme and Champion Your Needs workshops.

The freephone also directs carers to sources of respite care at Carers NZ's National Relief Care Matching Service, a partnership with MyCare Ltd. Often family carers struggle to find relief carers so they can have time out. This service matches disabled people and family carers with relief carers in their area, online and through its 0800 777 797 number.



Parent to Parent

connect • inform • support

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