ABOUT AUTISM

A guide to autism in childhood

ALTOGETHER AUTISM
TAKIWĀTANGA

Parent to Parent®
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Kia ora

If you are reading this, it is likely a child you know has just received a diagnosis of 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 whānau.

This document is a general overview current at the time of writing and 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:

Altogether Autism on 0800 273 463 or www.altogetherautism.org.nz

Parent to Parent on 0508 236 236 or www.parent2parent.org.nz

In this booklet, we use identity-first language 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. You can also refer to the Autism New Zealand Terminology resource, which outlines some of the language preferences of the Autistic community: https://autismnz.org.nz/autism-new-zealand-terminology-guide/

With special thanks to our families featured throughout the photography and quotes in this booklet.

Contents

Section one

What is autism?

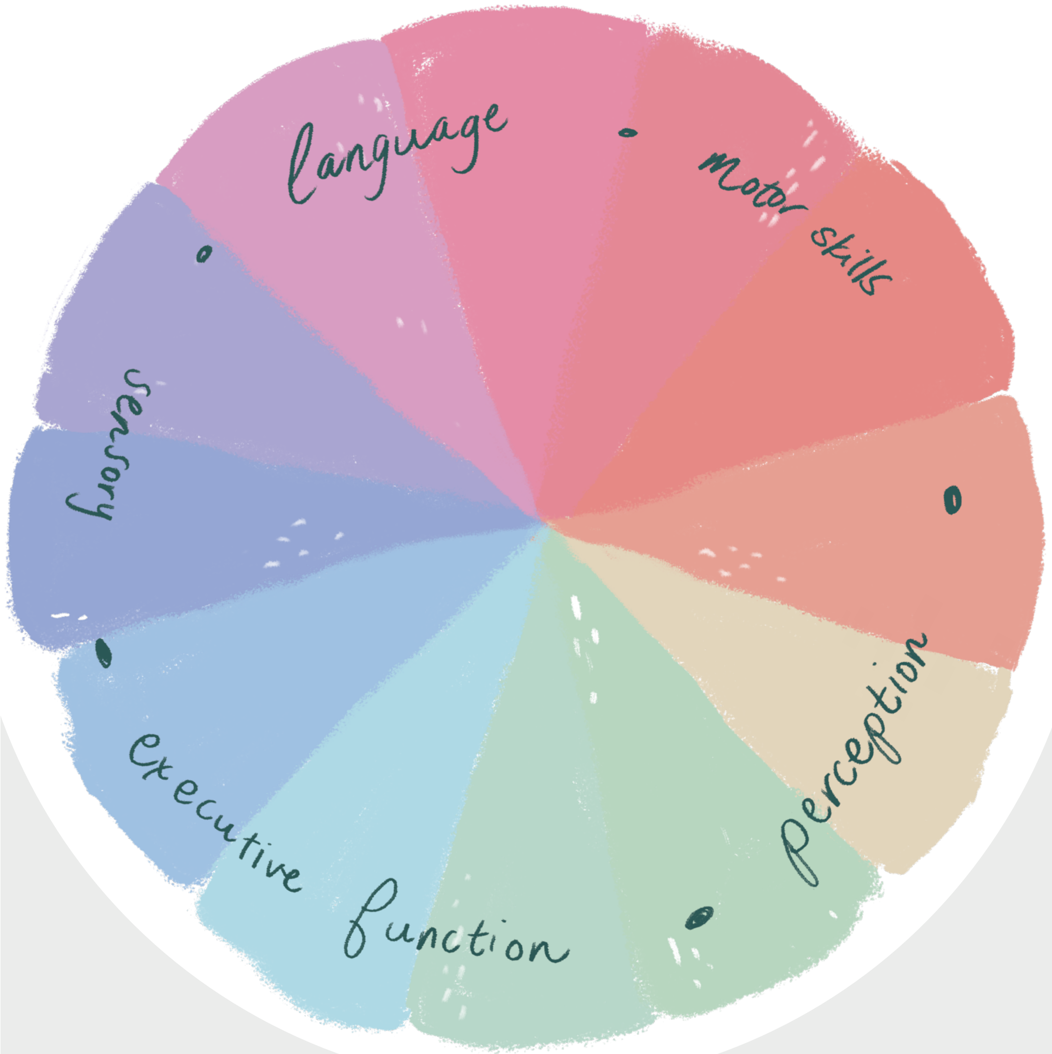
Autism is a brain difference that is fundamental to who a person is. It affects the way a person develops in childhood, the way that they think, and the way they live their life. All Autistic people are unique, but some of the areas where Autistic people develop differently to non-Autistic people include:

- Communicating
- Socialising and interacting with others
- Thinking and processing
- Sensing and perceiving the environment
- Moving, playing, and having fun

Autism is not a disease or an illness, and it cannot be treated or cured. Instead, autism is a different way of 'being' in the world—a source of strength, diversity, and beauty. We understand these differences in the way brains work and the way people think as neurodiversity.

Neurodiversity

Neurodiversity is the idea that everyone's brain works differently and no one 'type' of brain is inherently better or worse than any other type of brain. Some people, because of the way their brains function, can conform to dominant norms of behaviour; these people are described as neurotypical. People whose brains function differently are described as neurodivergent. Neurodivergent is a broad umbrella term which includes autism, Attention Deficit Hyperactivity Disorder (ADHD) and specific learning disabilities. It also includes mental health conditions, intellectual disability, and traumatic brain injury.



Autism is a spectrum

It is important to understand that the autism spectrum is not linear. As shown in the image above, each Autistic person will have a different set of characteristics across each area of the autism spectrum. Therefore, the spectrum does not go from 'more' Autistic to 'less' Autistic, or from 'higher functioning' to 'lower functioning'. Instead, an Autistic person's needs and experiences can change from one day to the next, depending on the environment they are in and how well they are able to cope with day-to-day demands.

/ Takiwātanga /

Functioning labels do not capture the complexity and variability of an Autistic person’s experience.

These characteristics shape Autistic lives in many ways; no two people on the autism spectrum are the same. However, for someone to be diagnosed as Autistic, they must display:

- Differences in social communication and social interaction; and
- Restricted, repetitive patterns of behaviour, interests, or activities—this includes sensory sensitivities.

Communication

It is also common for Autistic people to have differences in the way they use language. Some Autistic people may not use spoken language at all, preferring to communicate through body language, forms of sign language, or electronic devices that support communication. These methods of communication are collectively known as Augmentative and Alternative Communication, or AAC. Others may use speech, but not as frequently or fluently as non-Autistic people or they may use more complex language than most non-Autistic people. Some Autistic people may also need extra time to process and respond to spoken language.

Takiwātanga

A te reo Māori term for autism is Takiwātanga. Takiwātanga derives from the saying "Tōku/Tōna anō takiwā", meaning "in his/her/their own time and space." Takiwātanga is a part of human diversity and focuses on the strengths of our taonga placing them in the context of their whānau. Takiwātanga acknowledges that individuals are unique; they move at their own frequency and pace and may have alternative routes to achieving tasks.

> **“For my whānau Takiwātanga is a beautiful kupu. There is no indication of deficit in the word therefore it doesn’t minimise the mana of our son, unlike some medical terminology. Our whānau apply the meaning of the kupu as an overarching concept of how we want our son’s rhythms, values, and preferences valued by health professionals, educators and support services that come into his life.”** He Taonga Takiwātanga Nā te whānau Ashcroft

Takiwātanga was crafted by rangatira and te reo expert Keri Ōpai. Keri created Te Reo Hāpai, a te reo Māori glossary for use in the mental health, addiction, and disability sectors. It was created to provide a glossary of positive terms through a Te Ao Māori lens. Takiwātanga is underpinned by Te Ao Māori understandings of diversity and celebrates and encompasses traditional perspectives of Te Ao Māori approaches to health and disability. A copy of the glossary can be found online here: https://www.tereohapai.nz/

Te Ao Māori worldview of Takiwātanga

A Te Ao Māori perspective and approach to Takiwātanga can be found in: Kōrero tuku iho; Pūrākau; Whakataukī; Te Reo Māori; Tikanga Māori; Māori hauora models; and traditional practices such as karakia, rongoā māori and maramataka.

This is a body of knowledge that has been passed down through many generations and captures the wisdom of our tūpuna/ancestors to provide guidance for whānau on how they can lead positive lives through a Te Ao Māori worldview. It is important to note that different iwi and hapu may have different tikanga/traditions or language/kupu around autism and neurodiversity.

These videos provide further information https://www.youtube.com/@kanorau or you can contact Kanorau https://kanorau.org.nz/

“Takiwātanga is a philosophical approach to understanding our son’s uniqueness. Rather than looking at our son as ‘different’, Takiwātanga celebrates his uniqueness. Takiwātanga embraces a Māori worldview to understanding and acknowledging our son’s diverse needs and his way of life. Kei wētahi, kei wētahi anō, he kanorau, he rereke, tōna ake ahua, tōna ake mana, tōna ake mauri – each and every person has their own uniqueness, presence and life essence.” Anonymous

“Kei roto i te ao Māori te rongoā hei mirimiri i te hinengaro me te wairua. Rongoā Māori is a traditional healing system that incorporates several forms of traditional therapies that are grounded in mātauranga Māori. We have used rongoā as a means of therapy for our son to assist with sleeping as this was a form of connection not only with our son, but with our ao Māori. We use rongoā rakau (herbal remedies), mirimiri (physical therapy) and waiata Māori in our night-time routine to assist with calming our son and preparing him for wā moe and it has helped tremendously!” Anonymous

Autism is different for each child

Autistic differences

Autism will look different for each child who is diagnosed. Some of the differences we might see in an Autistic child include:

Communication differences

- Taking longer to develop speech and language
- Speaking less or not at all
- Finding it difficult to speak in certain settings but speaking fluently and easily in others (this is termed situational mutism)
- Preferring written to spoken communication modes
- Needing extra time to process verbal communication and/or instructions
- Finding it hard to communicate their wants or needs
- Interrupting or staying quiet because it's hard to work out when it's their turn to speak
- Returning to previous parts of a conversation
- Using props or another person's hand to convey a message
- Echoing or repeating sounds, words, or phrases (known as echolalia)
- Using language in an unusual way (for example, some Autistic people use more formal or academic language)
- Speaking in an unusual tone, pitch, or accent
- Preferring literal, direct use of language, as opposed to language that is more figurative or abstract
- Preferring clear, non-ambiguous communication, as opposed to indirect communication through facial expressions, body language, and gestures
- Saying yes or agreeing to things to cover up their confusion
- Over-analysing the conversations they have with others

Differences in social interaction

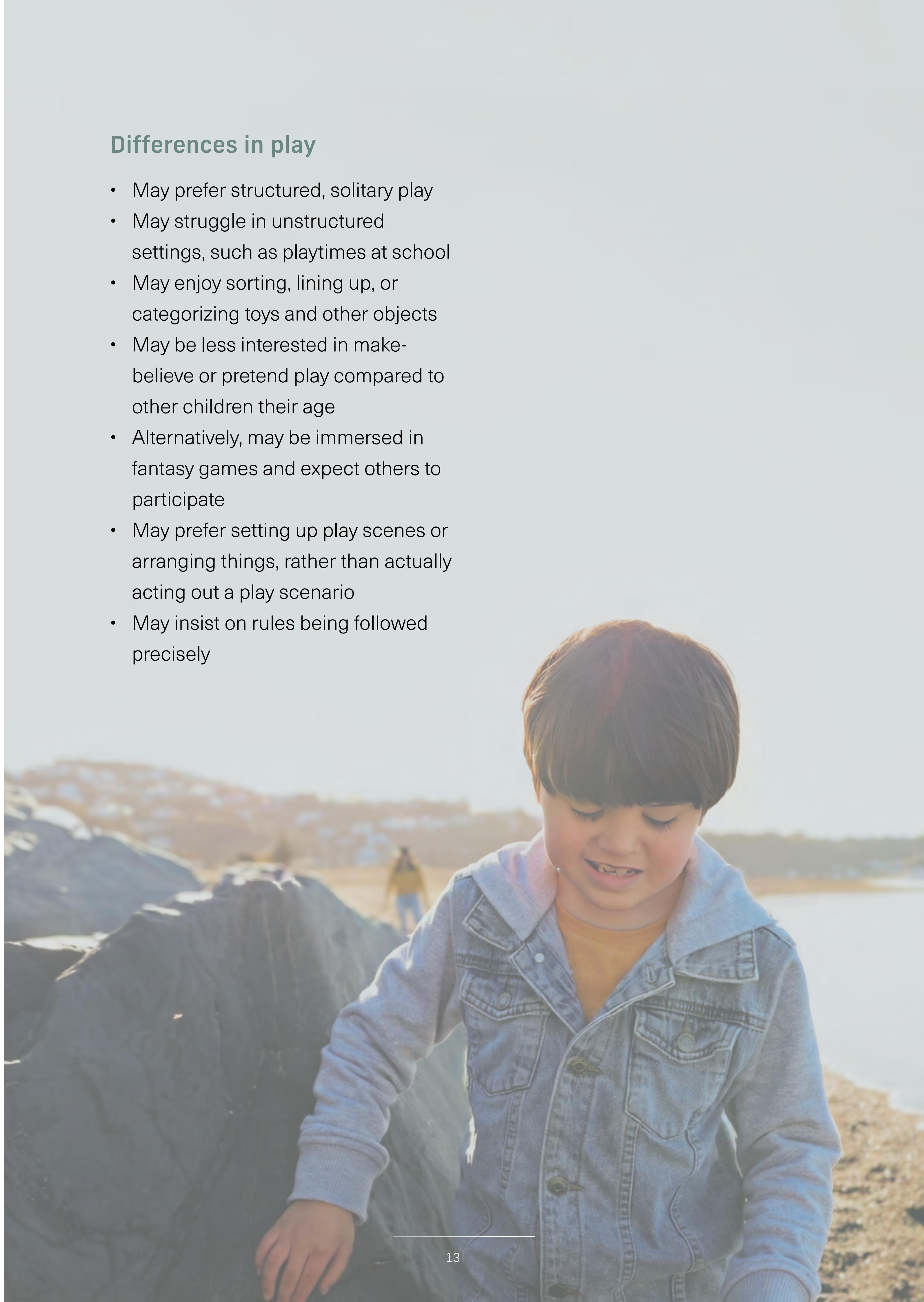
- May not show or respond to conventional signs of social interest (e.g. may not use eye contact or standard greetings)
- May feel anxious in social situations or appear shy and introverted
- Might be less likely to initiate interactions with others
- Often plays alone
- May have only one friend and struggle to understand why this friend wants to play with anyone else
- May rely on a more extroverted friend to guide them
- May find social situations difficult or tiring
- May struggle to work out the intentions of others (e.g. whether someone is joking, bullying them, or is upset with them)
- Interactions with others may be focused on shared interests
- May prefer to play with children who are a lot younger or a lot older than they are
- Finds it hard to recognise, interpret and talk about emotions (termed alexithymia)
- May prefer the company of animals or being in nature to being around people
- May copy the speech, behaviour, and dress of others to fit in
- Worries about making social mistakes

Strong interests

- Has a strong, specific interest, or several strong, specific interests
- Talks a lot about this interest, or spends a lot of time doing it or learning about it
- Can recall a lot of detail and facts about their interest
- Life can feel like it revolves around this interest
- Can be totally absorbed in an interest for a long period of time (months/ years), and then suddenly the interest may change to something else

Differences in play

- May prefer structured, solitary play
- May struggle in unstructured settings, such as playtimes at school
- May enjoy sorting, lining up, or categorizing toys and other objects
- May be less interested in make-believe or pretend play compared to other children their age
- Alternatively, may be immersed in fantasy games and expect others to participate
- May prefer setting up play scenes or arranging things, rather than actually acting out a play scenario
- May insist on rules being followed precisely



Prefers structure and routine

- Feels a sense of safety from routine and order
- Gets upset when routines or rules are interrupted or changed
- Finds it hard to transition from one activity or environment to another
- Prefers familiar activities and environments
- May ask a lot of questions prior to going somewhere for the first time
- May have difficulty in environments with a lot of activities/distraction

Sensory

- Has differences in the way they sense and perceive their environment
- Might be hypersensitive (over-sensitive) to sounds, smells, light, tastes, textures, or touch
- Might be hyposensitive (under-sensitive) to sounds, smells, light, tastes, textures, or touch
- May not be as aware of sensations happening inside their own body (known as interoception), e.g. pain, hunger, or tiredness

Motor skills

- May make repetitive movements or sounds such as humming or hand flapping (commonly known as stimming)
- Uses stimming to express emotion or likes and dislikes
- May have difficulty with fine and gross motor coordination
- May have difficulty mapping out where their body is in space (known as proprioception)
- May have difficulty with balance and movement (vestibular system)

Anxiety

- May spend a lot of time worrying about bad things happening
- May have trouble sleeping due to worries or nightmares
- May overthink social situations
- May be preoccupied with safety and avoid taking risks
- May need a lot of support in situations that can be unpredictable, e.g. going to a birthday party

The cause 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 found to be a definitive cause.

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

Unfortunately, New Zealand does not collect prevalence statistics (the proportion of a population found to have a condition). Because of this, there is very little data available concerning the Aotearoa population. However, research conducted overseas tells us:

- It is estimated that 1 in 36 children is diagnosed as Autistic
- Autism is between 3-4 times more likely to be diagnosed in boys than girls
- Autism occurs in all racial, ethnic, and socioeconomic groups

/ Kōtiro / as a girl

Girls are often misdiagnosed, completely missed, or diagnosed much later than boys. This may be because the standard tests for diagnosing autism fail to capture the way autism presents in many girls. The first instances of autism, which were identified in the 1930s, were all boys with specific characteristics, significant language delays, and prominent, restricted interests. These interests were often of a particular type. For example, many of the earliest instances of autism involved boys who were extremely interested in trains, numbers, or machines. Because the diagnostic criteria for autism were built on these early examples, they developed in a male-centric way.

Interests

While Autistic girls also typically have intense, specific interests, these may not be the ones that clinicians look for in relation to autism. Autistic girls may have interests that are more socially acceptable or common, such as an interest in celebrities, makeup, music, art, animals, or social justice.

Masking

Understanding masking and camouflaging may also be important in identifying autism in girls. Studies show that many Autistic girls employ coping strategies to conceal (or mask) their social and communication difficulties. These may include stereotyped responses, rote learning of conversational phrases and social behaviours, imitating the way others dress, speak, or interact, and using social scripts. Many Autistic boys also use these strategies.

Autistic masking involves disguising or covering up natural preferences, feelings and reactions to fit in with others. Whether conscious or unconscious, it can be hugely tiring and affect your child's well-being and day-to-day life.

> **"Masking for my girl looks like letting everybody else make the decisions and do everything that they want and holding in her thoughts and feelings. Then when she's at home she'll let out a lot of frustration."**
> Anonymous

Section two

Autism diagnosis

Why is diagnosis important?

Getting an autism diagnosis can be a positive and liberating experience for both the child and the adults around them. Having a diagnosis provides an opportunity to better understand who your child is and how to recognise and support 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.

How diagnosis can help

"It helped the picture fit together and I could understand better the reasons why things were so challenging for her." Anonymous

"It helped us find strategies that would support him and then support us as a family. Because we knew why, we could tailor the support to meet his needs." Anonymous

"There were two things that diagnosis helped with. One was to just stop me from overthinking everything that was going on with her. The other was to have some way of explaining what was happening to others. People were judging her and putting labels on her, calling her shy, defiant, and manipulative. Diagnosis helped other people to understand and shift the lens of how they saw her." Anonymous

Getting a diagnosis

The process of getting a diagnosis of autism in Aotearoa can vary between regions. The process is also different depending on the age of the person being referred for a diagnosis.

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

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.

Referral to assessment services

This is often done by your GP. Referrals can also be made by psychologists, Resource Teachers of Learning and Behaviour (RTLBs), teachers, speech-language therapists, public health nurses, and Plunket nurses.

Assessment appointment

You will be contacted by the service that receives your referral about an appointment (note: often there is a considerable wait time for these appointments).

> **"My daughter wouldn't do any of the things that he [the assessor] was asking her to do. She shut down and kinda sat there..... I had to ask the GP to write a letter as she wasn't eating. I had to go back to the kindy to get them to write the letters to the assessor. It was a bit drawn out for us. I had to do a lot of the work myself. "** Anonymous

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, your child, teachers, professionals, or other family members involved in your child's life. A multidisciplinary assessment is the gold standard for autism diagnosis in Aotearoa, so you can expect involvement from medical professionals, psychologists, psychiatrists, speech-language therapists, and occupational therapists.

Referral to services

Depending on the outcome of the assessment, you may then be referred to other services, for example, Autism Coordinators, speech-language therapists, etc.

Our Altogether Autism article gives tips on how to prepare for an autism assessment. https://www.altogetherautism.org.nz/how-to-prepare-for-a-diagnostic-appointment/

Typical responses to diagnosis

The diagnostic process can be difficult for some families. It may feel like your family is being judged and discussed at a level of detail that seems intrusive. It is important you and your child are well supported through this process.

It is normal to have strong emotions when your child gets an autism diagnosis. Some people might feel sadness, panic, confusion, guilt, or anger. Others may feel validated, excited, or relieved. After the initial processing period, and once they have accessed more information about autism, most parents feel more positive.

Your child is the same person

While you may have a lot to process, it's important to remember that your child is the same person they have always been. Nothing has changed because your child has been Autistic since they were born. Now, however, you have new knowledge and resources that you can tap into as you support your child, and a new community that your child belongs to.

You are not alone

While parenting an Autistic child can feel isolating, know that you are not alone; there are other parents you can connect with to support you in your journey. During these times, you can receive free support from Parent to Parent's network of Support Parents or the free Altogether Autism information service.

https://parent2parent.org.nz/how-we-help/support-parent-network/

https://www.altogetherautism.org.nz/information-hub/request-information/

Every whānau will have a different experience, so if you are struggling with strong, difficult emotions, please go easy on yourself. Your emotions are valid and deserve to be acknowledged and worked through. They may even come and go over the years as you navigate different parts of life with your child.
If you are the primary caregiver, it is important to seek out ongoing support and opportunities for respite for yourself.

To be able to support your child, you first need to look after yourself.

https://parent2parent.org.nz/about/contact-us/

https://www.disabilitysupport.govt.nz/carers

/ Whakaaro / thoughts

“Once he was diagnosed, it was intense relief. It sort of puts your mind on another path. What can we do now? It put us in the right direction. The validation that it wasn’t all in my head. I pushed for that support for my child so I felt like a good mum rather than a ‘bad mum’ or someone making big things out of little things.” Anonymous

“What I had heard about autism wasn’t good. But I was like, if this is autism, autism is beautiful... This is my son.” Mum of Autistic 10-year-old son

“It gave me confidence.” Anonymous

“It’s fear of the unknown. You sort of have an idea in your head of what life is going to be like and then it’s all thrown up in the air. Which it is anyway with neurotypical kids...” Anonymous

“For me as a mum, it meant that I needed to improve my internal state to be able to support my Jackson’s emotional state. Prior to his birth I was fairly limited in my feelings, my compassion, how much I loved and how to advocate for myself. My son is 13 years old now, so I have worked on all of these areas and it’s been a positive in our life. I am a stronger person and a stronger parent to him.” Jackson’s mum

“We’re a little bit further along in our journey... You see these things you never saw before and are exposed to things you would never be exposed to—you overcome these challenges that at the time seem so overwhelming and impossible and then you do it and I’m such a better version of myself than I could ever have even imagined because I’ve done this.” Mum of Autistic 10-year-old son

Talking about the diagnosis

With your child

Research shows that conversations about autism that begin when a child is young can help them think about autism in a positive way. You know your child best, so we encourage you to thoughtfully consider:

- Is your child 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'.

Setting the scene

A good way to set the scene for conversations about autism is to talk about difference and diversity in general. We can start by talking about the many ways humans differ from each other, from physical differences like hair colour or physical disabilities that require the use of a wheelchair, to personality differences or brain differences. It may be easier to start with differences that children can see. When children are comfortable and embrace difference they can understand that autism is just another example of natural human diversity.

Talking about autism

When talking about autism with your child, it's a good idea to use a positive tone and focus on their strengths. A conversation where you appreciate each family member's uniqueness is a great starting point for discussing differences with children. Each family member will have different likes, dislikes, strengths, and challenges. Autism is just a term that describes a particular set of strengths, challenges, and brain differences.

Normalise challenges

It's important to acknowledge your child's challenges too, rather than brushing over them. It is okay if a child needs extra support in some areas—this is a very common human experience throughout our lifetimes. Normalising this can help your child accept all parts of themselves without guilt or shame.

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. However, most Autistic adults have found the opposite is true. For many Autistic people, receiving a diagnosis is a huge milestone—a gift to be celebrated. Most likely, your child already knows they are different to other children. While it might take your child some time to accept and come to terms with an autism diagnosis, they will eventually come to value this knowledge about themselves. Giving your child information about their diagnosis can help them to understand, accept and appreciate their uniqueness, and to advocate for their needs to be met.

Siblings

Once you have talked to your child about their diagnosis, you may choose to let siblings know. How and when you tell them will depend on their age, personality, and their relationship with their sibling. Pre-schoolers need short, clear explanations of their sibling's differences, such as "Joe doesn'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 needs alone time in his sensory room because he is overwhelmed right now." They may understand and use the word autism to explain difficulties their sibling faces and ask questions about how autism is caused.

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

Support for siblings

Siblings play a special and important role in the lives of their Autistic brother or sister. They can be a great source of fun, care and support, but playing this significant role can also lead to feelings of increased worry and isolation. Siblings may need their own support as they navigate their family member's diagnosis. Parent to Parent offers services, resources, and community support for the siblings of Autistic children. These can be accessed on the Parent to Parent website. https://parent2parent.org.nz/how-we-help/sibsupport-nz/

Your child's school

It is a good idea to share your child's diagnosis with their school. When teaching staff are made aware that your child is Autistic, they can understand your child better and make adjustments, including:

- Changing the environment to accommodate sensory needs
- Facilitating communication and social interaction with peers
- Adapting teaching strategies to enhance learning for your child, e.g. using a special interest, or presenting information visually
- Implementing rules and routines to make transitioning between tasks, activities, and classes easier
- Applying for in-class support such as teacher aide hours, Resource Teacher of Learning and Behaviour (RTLB), Ministry of Education (MoE) funded occupational, speech or physiotherapy interventions, Ongoing Resourcing Scheme (ORS) funding, and assistive technology

You can contact Altogether Autism for information to share with your child's educators.

"Once we had a diagnosis I sent an email out pretty quickly because her teachers at kindy were making her do things like go around in a circle where everyone had to say hi to everybody, and that was stressing her out."
Anonymous

Extended family & friends

You may want to tell your extended whānau, so they understand you and your child better.

If you give them a copy of this booklet it may increase their 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.

Section three

Understanding autism

Supporting positive Autistic identity

A lot of work has been done in recent years to improve the way we think and talk about autism. This began with the neurodiversity movement of the late 1990s which challenged the belief that autism is a disease to be cured, or a tragedy to be mourned. The neurodiversity movement reframes autism as a form of neurodivergence—a difference among many differences in the way human brains work. According to this model, autism is simply a unique way of thinking, processing, communicating, and perceiving the world—a natural form of diversity that has intrinsic worth and value. It exists alongside many other ways of being in the world, some more common than others. It does not need to be judged, pitied, fixed, retrained, grown out of, or changed.

Why we need positive Autistic identity

Although the way we talk about autism has become a lot more positive and accepting, Autistic identity remains a battleground. Most Autistic children and adults experience exclusion and discrimination in their daily lives, which may affect their sense of self. Autistic ways of being in the world, preferences, and ways of communicating are not always fully understood by non-Autistic people and are often subject to judgement or misinterpretation. In too many situations, Autistic people are simply not allowed to be themselves.

With this in mind, there is a powerful need for language, practices, and habits that actively help Autistic children and adults to build a positive Autistic identity, both as individuals and as members of a larger community.

It can take time to build a positive identity, but as the parent of an Autistic child, there is a lot you can do to support your child. Here are a few ideas to get you started.

Start at home

The relationships that we have within our families are hugely important to our sense of identity. For most people, it is in the home that we first learn that we are valuable individuals worthy of respect, inclusion, and love.

Wherever you can, ensure that your home is a place where autism is welcome—where Autistic preferences, communication styles, and habits are practised, celebrated, and understood. This doesn't mean that you can't have boundaries, but as long as your child isn't harming anyone or anything, home should be a place where they can be free to be their true Autistic selves. Where possible, you could make sure that visitors to your home are on board with this as well.

Embrace your child's interests

Embracing your child's interests is a powerful way to connect with them and to affirm their Autistic identity. Allow them the freedom to engage with their interests and encourage them to share ideas and information with the rest of the whānau. For many Autistic people, interests are the centre of their lives and their greatest source of joy. There is nothing wrong with this—they do not need to be taught to focus on relationships instead.

Affirm their strengths and abilities

Your child has unique strengths and abilities. Some of these may be strengths they share with other Autistic children, such as the following:

- Learning to read at a very young age (known as hyperlexia)
- Memorising and learning information quickly
- Thinking and learning in a visual way
- Logical thinking ability
- Excelling in academic subjects that interest them
- Having an extraordinarily good memory (being able to remember facts for a long period of time)
- Being precise and detail-oriented
- Exceptional honesty and reliability
- Being dependable in terms of schedules and routines
- Having an excellent sense of direction
- Being very punctual
- Having a strong adherence to rules
- An ability to concentrate for long periods of time when motivated
- A drive for perfection and order
- A capability for alternative problem solving
- A rare freshness and sense of wonderment
- Having strong intuition, e.g. able to use natural instincts over reasoning
- Having hyper-empathy for both living and non-living things
- An ability to connect with the natural world

Other strengths may be more specific to your child, their interests, and the environment they are in. Affirming your child's strengths is critical to building your child's positive Autistic identity. Your child needs to feel that they are capable, worthy, and that they have something of value to contribute to the world.

/ Tautoko / advocate

Advocate for your child

Parenting an Autistic child often means becoming an advocate. You are probably already doing a lot of advocating for your child as they move through the health care system, school system, your social circle and society at large.

In advocating for your child's right to full participation in these systems and the wider community, you are showing your child that they are worthy of inclusion. In explaining their Autistic needs and preferences to others, you are telling them and others that Autistic ways of doing things are meaningful, logical, and valuable.

It can be difficult to go against the grain and take a stand for your child with professionals and other people who feel that it is the Autistic child who needs to change. But every time you do this, you are helping your child to develop a positive Autistic identity.

Teach your child simple self-advocacy skills

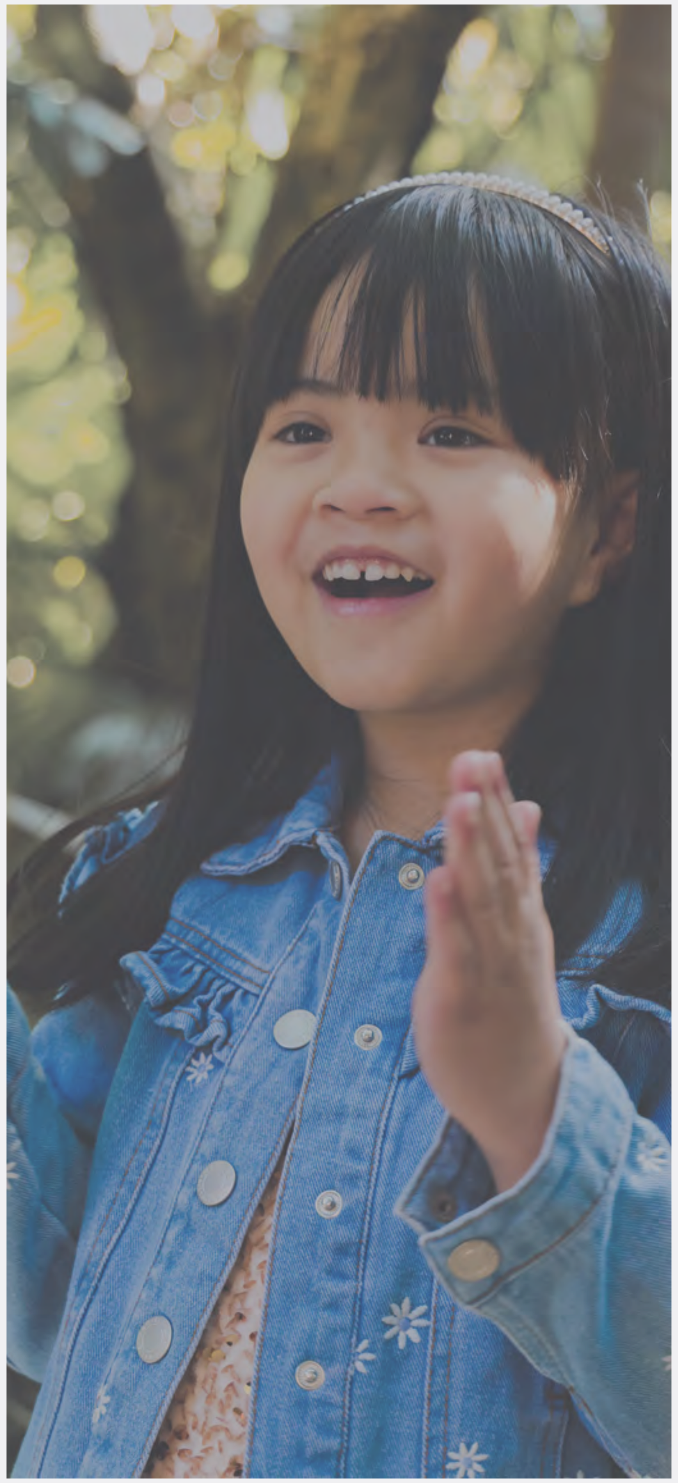
Autistic children are never too young to begin advocating for themselves. Often, if you look for it, you will see that they are already advocating in their own way. To support your Autistic child to advocate for themselves:

- Ask them about their likes, dislikes, goals, and preferences.
- Listen to their ideas and respect their choices.
- Help them find a means of communication that works for them, such as Augmentative and Alternative Communication (AAC).
- Listen and respond to their cues.
- Offer accommodations to help them cope with difficult situations.
- Teach them phrases such as "I don't like that," "Stop," "I don't want to do that," and "No." Listen when they use them.

Teach your child about autism

Teaching your child about autism goes a long way in helping them build a positive Autistic identity. There are several children's books that explore and normalise Autistic traits and tendencies through the lived experiences of Autistic children. Words, pictures, stories, and references that describe our experiences can become powerful containers for our identities. When we have a name for something, we can talk about it with others. When we connect with an example or a story, it can become a 'hook' to hang our own stories and memories on—something that we use to explain ourselves and make sense of ourselves in our own minds. Helping your child access these 'hooks' is a crucial component of building their Autistic identity.

Use these stories and references at home wherever you can and make them part of your family's vocabulary.



Some good children's books that you may want to check out are:

Some Brains, by Nelly Thomas,
The Brain Forest, by Sandya Menon, and
Remarkable Remy, by Melanie Heyworth.

You can also find more books here:
https://notanautismmom.com/2021/08/25/inclusive-childrens-books-on-autism-and-neurodiversity/

https://www.altogetherautism.org.nz/childrens-books-about-autism/

Ask Autistic people

Autistic people cannot build a positive sense of identity on their own. Your child needs to have connections and contact with other Autistic people, whether this is through the internet, art, books, movies, or in real life. Autistic adults who grew up before the internet have expressed repeatedly that meeting other Autistic people was the turning point in their journey towards self-acceptance. While all Autistic people are different, there is often a lot we can connect on and a lot we wouldn't understand about ourselves without exploring our experiences together.

Autistic adults, teens, and other Autistic children can be an invaluable source of knowledge, perspective, and expertise. There are plenty of professionals who specialise in autism and other developmental conditions, but unless these professionals are Autistic themselves, they can never offer you the wisdom of lived experience as an Autistic person.

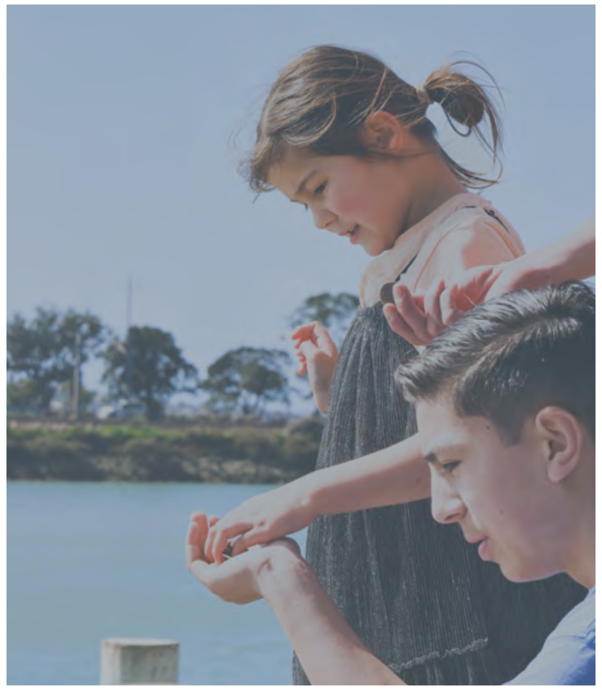
Autistic people communicate differently

It is not always easy for non-Autistic people to understand Autistic people. Often, Autistic experiences, emotions, and interpretations are misrepresented or 'lost in translation'. A lot of things that Autistic people do can look one way on the outside, but when you ask what they were thinking or feeling, you might find that their intentions were quite different from what you were expecting. This is why it is so helpful to access the Autistic community and talk to Autistic people. They can help you navigate some of the challenges that are common to Autistic people and support you to understand and work with your child.

Autistic adults can be found on online blogs, YouTube, and Facebook support groups. Many have also authored books. Here are a few useful resources created by Autistic writers and speakers:

I am Autistic, by Chanelle Moriah
Different, not Less, by Chloe Hayden
Welcome to the Autistic Community, by the Autistic Self Advocacy Network.

"When I was young and didn't know I was Autistic, I used to become borderline obsessed with other Autistic people I met. Just because I guess I knew there was something similar about them and me. I think that's something that can help Autistic children accept their diagnosis... recognising that they are like this other [Autistic] person, especially if it's someone that they admire." Anonymous



Encourage them to express themselves

Having an alternative means of self-expression is also extremely useful in helping your child develop a positive identity. Communicating through music, art, photography, writing, sport, or other creative pursuits can support self-advocacy and help your child make sense of their experiences. Many Autistic people use the arts to explore and express their identities.

Learn about ableism

Ableism is the internalised belief that disabled people are somehow inferior, shameful, or 'less than'. Sadly, this is something that almost everyone grows up with, as we encounter prejudiced attitudes and negative portrayals of disability in society.

Attitudes to disability are improving, and acceptance is growing. But there is still a lot of work to do around ableism and often, that work starts at home. After your child receives a diagnosis, it may be helpful to look at the beliefs that you have about autism and disability in general. Where do you think they come from? Most likely, you picked them up from people around you, especially the people you spent time with when you were young. These beliefs are not your fault, but by bringing them into conscious awareness, you can begin to challenge and change them.

Some of the ways ableism can show up include:

- Feeling embarrassed by your child
- Wishing they would stop stimming in public
- Wishing your child would be more like other children
- Trying to get your child to speak when they prefer other modes of communication, such as using a tablet
- Wanting your child to follow social conventions and 'fit in'

These feelings are natural and common, and they are not something to feel guilty or ashamed about. They may never fully go away. That said, you have a wonderful opportunity to give your child the gift of full acceptance—acceptance of their unique Autistic self. Working through ableism is crucial to building a supportive, affirming relationship with your child.

"It is the biggest barrier, regardless of funding or whatever you have; ableism is the biggest barrier in people's minds to get inclusion in society. So much emphasis is placed on ability—and judgement... It's still completely acceptable for people to ring up and say sorry your son can't participate because of their ability... I've stopped apologising for my son's autism, for meltdowns. He has the right to be who he is. We all have needs, different needs." Mum of Autistic 10-year-old

The senses and autism

Many Autistic people have sensory sensitivities. The way you support your child with their sensory sensitivities will depend on the unique way they experience the world around them.

Hyper- or hypo-sensitivity

Your child may have unusual responses and reactions to specific things in their environment, such as the sound of a dog barking or the texture of an item of clothing. These responses may be heightened, which would indicate hypersensitivity, or dampened, which would indicate hyposensitivity. Some Autistic children may, for example, have lower sensitivity to pain or to sounds that occur in the background when they are very focused on something. It is normal for Autistic people to have combinations of hypersensitivity and hyposensitivity, where they enjoy and seek out some sensations but dislike others. Sensory sensitivities are sometimes fluid, changing from one day to another. They may be more impactful in certain environments than in others. Sensory sensitivities are often highly specific to the individual. Some Autistic children, for example, may be distressed at the sound of a motorbike or a fire alarm but enjoy listening to loud music.

Sensory sensitivities can affect the way information is perceived and processed across all the senses. They may be heightened when the child is stressed or anxious, and they may also be the cause of stress and anxiety. Here are some of the common areas where Autistic people may experience sensory sensitivities and differences.

Body awareness (proprioception)

Autistic people may have some difficulties mapping out where their body is in space, and how each of their body parts is moving. This can lead to clumsiness and bumping into people or other objects around them. It can also lead to a fear of heights or certain kinds of motion.

Fine motor skills (such as handwriting) can also be affected. It can be difficult for some Autistic children to work out how much force to use to complete a task, which can be a source of frustration.

Some Autistic children are exceptionally agile and flexible. In some cases, hyper-flexibility can be a sign of Ehlers-Danlos syndrome.

Balance (vestibular)

Autistic people often have differences with their vestibular system, which controls our sense of balance. This can result in extreme motion sickness, fear of heights, and avoidance of certain kinds of activities. Other Autistic children enjoy vestibular stimulation and like to move, rock, and spin a lot.

Hearing

Loud noises may be painful or abrasive for Autistic people and can sometimes trigger panic and anxiety. Other sounds, especially repetitive sounds or background noise can also be uncomfortable and disruptive. Some Autistic people have described how they are particularly aggravated by everyday sounds such as the buzz of electrical equipment or the tapping of keys on a keyboard—sounds that most non-Autistic people would not notice or would be able to filter out. Alternatively, Autistic people may also really enjoy certain sounds. These could include specific pieces of music, vocal stims, or low ‘rushing’ sounds like the sound of thunder or a waterfall.

Taste

It is common for Autistic children to have strong preferences around food and taste. This may mean that they only eat food of a certain texture or colour, or that they tend to stick to foods that are familiar and safe. In many cases, when Autistic children restrict the kinds of foods they will eat, they are attempting to manage and organise the intensity of taste sensations. Tasting something unexpected or feeling an unusual or unwanted texture in the mouth (such as an unexpected chicken bone) can be very upsetting and off-putting.

Some Autistic children also enjoy putting non-food objects in their mouths to explore the taste and texture. This is called pica.

“Food is the biggest challenge. My daughter will only eat cereal, bread, smoothies, maybe chips, that’s pretty much it. I have to bring her own food with us anywhere we go otherwise she won’t eat anything at all. She’ll run away from the food at the table at Christmas dinner because she can't stand how it smells.” Anonymous

Misophonia

Misophonia is a condition where certain sounds produce an intensely negative reaction in the listener, often of fear, rage, or disgust. Misophonia is more common in Autistic people and may result in intense aversions to specific sounds. Some of the sounds that can set off misophonia include repetitive beeping or ticking, the sound of people chewing or breathing, or the rustling of paper.

Touch

Autistic people may be hypersensitive to some kinds of touch. You may find that your child dislikes feeling labels inside of clothing, clothing that feels ‘scratchy’ or restricting, or the seams inside their socks. They may not want to touch you or others affectionately and may not want other people in their space.

Alternatively, some Autistic people enjoy touch and may like rough play with others. Some like deep-pressure hugs but dislike light touches.

Smell

Some smells may make Autistic people feel sick. Common smells that are especially triggering include spicy food, perfumes or shampoos, or chemical smells such as gasoline. For many Autistic people, aversion to these smells can lead to avoidance of certain people and places.

For other Autistic people, some smells may be very enjoyable. They may like to linger on a smell, or approach and sniff a person or object that smells good to them.

Interoception (internal cues)

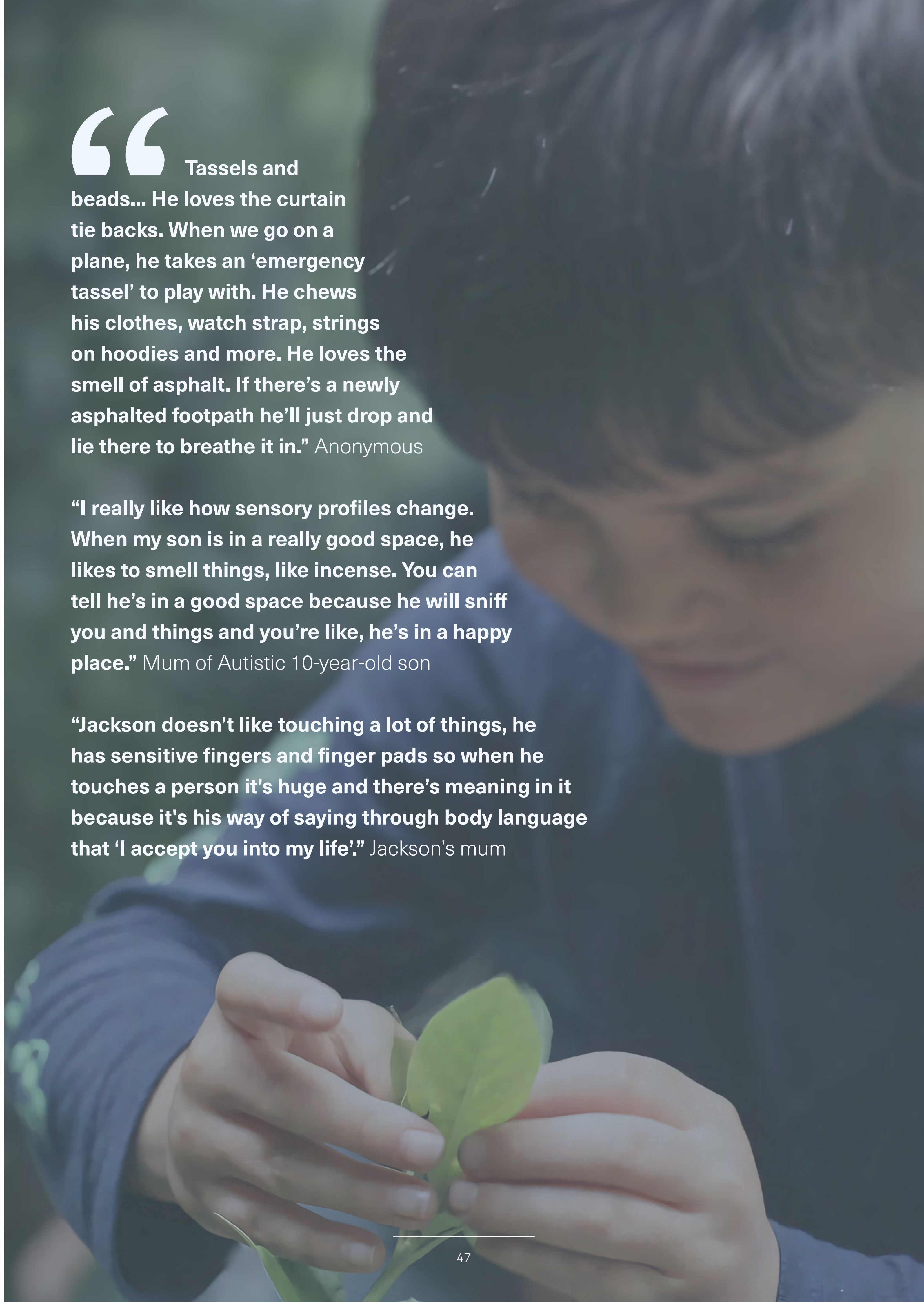
A person is using interoception when they recognise and respond to their internal cues, such as thirst, hunger, pain, temperature, illness, and bowel movements. Autistic people may have difficulty identifying these cues and may sometimes not notice that they are hungry or need to use the bathroom.

Stimming may be one way that Autistic people access interoception. For example, an Autistic person might stim to gather more feedback about how they are feeling, to magnify physical sensations from their nervous system, or to work out what part of their body is in pain or feels different.

Sight

Some Autistic children enjoy bright colours and are fascinated with visual patterns or stimuli. They may explore this by spinning or twirling objects, turning lights on and off, or arranging objects in a particular way. Many, but not all, Autistic children prefer visual learning material and activities.

Autistic people may also have an aversion to bright lights or sunlight and have difficulty tracking moving objects. Some Autistic children may need a darkened room after a day of being exposed to light at school, for example.



> **“Tassels and beads… He loves the curtain tie backs. When we go on a plane, he takes an ‘emergency tassel’ to play with. He chews his clothes, watch strap, strings on hoodies and more. He loves the smell of asphalt. If there’s a newly asphalted footpath he’ll just drop and lie there to breathe it in.”** Anonymous

> **“I really like how sensory profiles change. When my son is in a really good space, he likes to smell things, like incense. You can tell he’s in a good space because he will sniff you and things and you’re like, he’s in a happy place.”** Mum of Autistic 10-year-old son

> **“Jackson doesn’t like touching a lot of things, he has sensitive fingers and finger pads so when he touches a person it’s huge and there’s meaning in it because it's his way of saying through body language that ‘I accept you into my life’.”** Jackson’s mum

Stimming

What is stimming?

The term stimming comes from the clinical phrase ‘self-stimulatory behaviour’. Stimming usually refers to repetitive or rhythmic body movements such as:

- Knee bouncing
- Tapping a pen
- Humming or singing while doing a task

All children and adults, including non-Autistic children and adults, stim. They may do this out of boredom or restlessness, because of their mood or emotions, or for no reason at all. For Autistic people, however, stims may take on special significance, serving as a form of emotional expression and communication. Autistic people tend to stim more frequently, intensely, and noticeably than non-Autistic people. As well as the above, some common stims are:

- Hand flapping
- Finger flicking or clicking
- Body rocking
- Hair pulling
- Feet flexing
- Spinning and twirling
- Twirling an object

Stimming may also take the form of vocalisations, such as:

- Muttering
- Grunting
- Whistling
- Humming
- Singing
- Repeating words or phrases

Why do Autistic people stim?

The reasons Autistic people stim are likely different for different people. Many Autistic people tell us they stim to help them regulate, or to express their emotions. Stimming can help a person feel calm and in control, or it can be used as a display of joy and excitement. It may also happen for no reason other than that the Autistic person enjoys doing it. Here are some common reasons that Autistic people stim:

- Anxiety: stimming can help to reduce anxiety or distressing thoughts by re-focusing attention on the stim. It can also produce calming sensations and help reassure the Autistic person that they are in control.
- To release or re-direct energy.
- Sensory relief: stimming can calm a person when they are experiencing sensory overload.
- Sensory stimulation: stimming can also help to stimulate the senses when the Autistic person feels deprived of sensory input.
- 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, the person may require support to adapt their stim. Otherwise, stims should be accepted and celebrated as natural and valid Autistic communication. Stimming is an important part of Autistic life and should not be suppressed or discouraged.

> **“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 whānau 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 his 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 to himself and vocalises more distressed-sounding noises. We like that his stimming is his way of communicating with the world around him, he just expresses himself through his body rather than his words.”** Jackson’s mum

Your Autistic child may need support with…

Anxiety

Anxiety is an intense and often overwhelming feeling of worry, nervousness, or unease about something with an uncertain outcome. It has varying physical effects on our bodies, such as an 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 intense emotional distress and overwhelm.

Anxiety looks different for each child

For some children, it may be associated with anger and uncontrollable outbursts as the child frantically tries to assert control.

Many Autistic children meet the 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.

Autistic children may have difficulty recognising when they are feeling anxious, and/or communicating this to others around them. Signs that may indicate your child is struggling with anxiety can include:

- An increase in stimming
- Heightened sensory sensitivity
- Withdrawal and avoidance (e.g. unable to attend school)
- Difficulty sleeping
- Emotional outbursts

/ Manawapā / anxiety

Strategies to help manage anxiety

Recognising when your child is experiencing anxiety and understanding the triggers is key. Once you have worked out the things that make your child feel anxious, you can figure out strategies to manage the anxiety in those situations. Strategies might include:

- Modifying the environment to reduce sensory overload
- Planning for transition times and changes to routine
- Encouraging the use of relaxation activities
- Using visual tools to support your child in anxious situations
- Utilising sensory toys/activities
- Teaching and supporting children with emotional regulation and how to recognise anxiety in themselves

"I guess anxiety looks like wanting to do something and not being able to do it. Watching people do things and then standing off to the side crying because you want to join in, but it's just too scary... Lots of stop, start, one step forward, one step back." Anonymous

"My son has a lot of anxiety around times and logistics... 'What are we doing? How am I getting there? What's for dinner?' The first thing when he bursts into our room in the morning at 7am: 'What's for tea?'" Anonymous

"For us anxiety is shown as aggression and anger, and it's often misread, so people try to treat the anger and bad behaviour which then triggers the anxiety more." Mum of Autistic 10-year-old son

"Our son masks around other people but we as parents can see the little signs that he is so anxious inside. People often don't get it and say, 'but he looks fine.' As soon as we are alone, like in the car, the overwhelm is shown in complete shutdown or sometimes demands, crying or screaming." Anonymous

"Anxiety looks like retreating to her room and into herself, so she internalises her anxiety. It's never exhibited as challenging behaviour, or aggression towards us; it's all internal which is perhaps why we missed it for so long." Anonymous

"Outings really drain her. When she has to leave the house for something, and she puts all her energy into managing the anxiety and masking and going out into the outside world, then afterwards we know that she'll need a lot of quiet time and rest and time on her own. She might be in her bedroom for a day or two afterwards and we will barely see her." Anonymous

"What I have to check is my own anxiety about my son's anxiety. The majority of the time he is fine and there's no problems because all the anxiety strategies are in play. So, keeping my anxiety in check is important... Also, always have a plan B in case things go pear-shaped." Jackson's mum

Social misunderstandings

When we socialise with others, we depend on being able to understand our own and other people's beliefs, desires, intentions, and emotions. We tend to find this easy when we are socialising with people who are similar to ourselves but may struggle to connect with people from very different backgrounds, with life experiences and ways of thinking that are not like our own.

The double empathy problem

Your Autistic child may find that they do not naturally understand the thoughts and feelings of non-Autistic people, and that non-Autistic people do not naturally understand their thoughts and feelings. This is because Autistic people and non-Autistic people often think and process information in very different ways.

Autistic researcher Damien Milton describes this as the 'double empathy problem'[1]. It can lead to frequent social misunderstandings, communication breakdowns, and often to rejection and prejudice.

How to support your child

There are some things that you can do to help your child understand others and make sure they are understood. For example, your child may need other people to communicate more directly and explicitly about what they are thinking or feeling, as it may be hard for them to guess or work it out on their own. They may also benefit from the opportunity to explain their own intent, or to have a trusted support person explain it for them if they are unable to do so. Non-Autistic people in your child's environment should be taught about Autistic ways of communicating so that they do not misjudge or misunderstand them.

Both Autistic and non-Autistic people can learn a lot from discussions about what other people could be experiencing in a particular situation. Exploring the reasons why a person may be acting in a certain way or what thoughts or feelings might be behind what is being said can help create a climate of mutual respect, collaboration, and understanding.

Executive functioning

Executive functioning is a set of cognitive skills controlled by the frontal lobe of the brain. It affects our ability in two key areas—organisation and self-regulation. Autistic people often have challenges with organising, prioritising, problem-solving, accessing working memory, thinking flexibly, and self-monitoring.

Supporting executive function

There are several ways you can support your child's executive functioning. Visual schedules or lists of tasks that need to be completed may be a helpful reminder for a child who tends to forget routine tasks. You can also use timers to signal that it's time to move on to the next activity soon by having the timer go off 10, 5, and 2 minutes before a transition.
If your child struggles to remember information as it is presented to them, you could encourage them to write notes or draw a picture that will help jog their memory. They might want to carry around a notebook or a tablet to help with this. If they find it difficult to follow a lot of steps at once or to complete a task that involves several steps, you can help them by breaking the task down into smaller steps and checking in with them after they have completed each one. Again, this can be done visually or in writing to support your child's processing.

You can find more information about using visual supports in the 'Communication supports' section of this booklet.

[1] Milton, D. E. (2012). On the ontological status of autism: The 'double empathy problem'. Disability & Society, 27(6), 883-887.

Understanding behaviour

As they go through life, children often face situations that they struggle to cope with. These could be short-term situations or events, recurring situations, or phases of life that are challenging. When they are struggling to cope, Autistic children, like other children, often exhibit signs of stress and overwhelm. They may withdraw to a safe space, stop speaking, refuse to do an activity, lose interest in learning, run away, hit or hurt themselves or others, or protest by crying and screaming.

If your child is showing these signs, it is essential to understand the reasons underlying their behaviour. Then, you can work out what to do to support your child in these challenging situations.

Behaviour is the tip of the iceberg

In this analogy, the behaviour is the tip of the iceberg that is visible above the waterline, while a much larger part of the iceberg remains hidden below the waterline. The larger, hidden part is made up of the underlying factors that influence behaviour—factors that are beyond the child's control. These factors could include anxiety, pain, tiredness, loneliness, trauma, fear, sensory overload, frustration, or a lack of appropriate skills to complete a required task. Such factors may not be immediately obvious to others, but the behaviour serves as a signal to alert us that the child is struggling and in need of support; behaviour functions to communicate the child's deeper feelings and experiences to the outside world.

A person's behaviour is not always what it seems

Changing the lens

It is easy to assume that a child is 'behaving badly' when they hit, scream, run away or refuse to cooperate. But this is an over-simplification that does not take the child's experience and perspective into account. Often, they are struggling with something that we are not even aware of, or something that we don't understand. If we start by exploring why the child may be behaving in this way, we can begin to make changes to support them, such as adjusting our expectations and modifying the environment.

Some of the invisible struggles that children may experience include:

- Dealing with expectations that they cannot meet
- Barriers to communication
- Difficulties expressing themselves
- Difficulties understanding others
- Being asked to complete tasks that they do not have the skills or tools to complete
- Regulating complex or intense emotions, such as frustration or disappointment
- Sensory needs not being met
- Having to face things they are afraid of or uncomfortable with
- Having to meet social expectations or participation requirements

Rather than being judged and punished, children who are struggling should be supported to succeed. This may require making changes to the child's environment or routine or providing extra help with challenging tasks and activities. As Dr. Ross Greene[2] says, ***kids do well when they can***. They want to earn the approval and recognition of others and do not enjoy failing or getting into trouble.

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[2] Greene, R. (1998). The Explosive Child [Fifth Edition]: A New Approach for Understanding and Parenting Easily Frustrated, Chronically Inflexible Children. Harper Paperbacks.

"It's taken us a while to figure out that an increase in annoying/provoking family members, refusing to do things, minimally speaking, and walking off means that our daughter is feeling overwhelmed rather than behaving 'badly'.

"Sometimes it goes further than this. We know our daughter to be kind and thoughtful, so when her behaviour becomes aggressive and destructive, we know that she is beyond overwhelmed. Though it's not always possible to figure out what has caused the overwhelm, it does mean that we form more of a plan around what we can do as a family on this journey to adjust things so that they hopefully work for everybody." Anonymous

The effects of the nervous system on behaviour

The nervous system is the unique two-way communication system between the body and the brain. Through the nervous system, the state of the body influences the brain and the way that we feel, behave and think. As Dr. Mona Delahooke[3] points out, we cannot understand what is going on in the brain without understanding what is going on in the body.

Fight, flight or freeze

When a child is in an environment where they feel safe and loved their nervous system will be in a calm and steady state, and they will be in an optimal position for learning. When they are in a situation that *feels* challenging, dangerous, or stressful, however, they may experience a heightened state known as fight, flight or freeze. Some signs that a child is in fight, flight or freeze include:

- Lashing out at self or others
- Throwing objects or damaging property
- Running away
- Hiding
- Becoming silent and withdrawn

We might also refer to these heightened states as overwhelm, meltdowns or shutdowns. Usually, children do not go straight to fight, flight or freeze from a state of calm. There will be a period of build-up before a child gets to this point and becomes overwhelmed. During this period of build-up, we might see:

- Anxiety
- Defensiveness
- Withdrawal
- Negative self-talk
- Comments that express frustration
- Physical tension
- Tension in relationships with others

If you can identify these signs before they escalate to nervous system overwhelm, you may be able to help your child relax and self-regulate. You might want to encourage them to take a break from what they are doing, reduce instructions and demands, minimize sensory distractions and stressors, or engage them in an activity that they enjoy.

Once they reach a state of fight, flight or freeze, however, your child's reactions are physiological and may be beyond their control. A child in this heightened state is a child in survival mode, which is not an optimal state for thinking or acting rationally.

Co-regulation

As most children lack the skills required to emotionally self-regulate, they need the support of a calm and compassionate adult to help them move back towards a state of calmness and safety. This is called co-regulation.

Co-regulation could involve being present with the child until they are able to regulate themselves. The adult models the process of calming down by breathing deeply and speaking quietly. The adult may also empathise with the child to help them feel understood, by saying something like "You really wanted to keep playing Minecraft. It's really hard to stop playing." Alternatively, with some children it can be better to be silent and talk it through later on.

The way you co-regulate with your child will depend on their unique needs and preferences, as well as the needs and preferences of the adult involved. It is important to find a way of co-regulating that feels comfortable for both people.

When a child has repeated experiences of a calm and trusted adult co-regulating with them, they tend to feel safer, more relaxed, and more comfortable. Conversely, when adults respond to fight, flight or freeze behaviour with anger, punishment and consequences, this only increases the child's feelings of stress, fear and frustration at being misunderstood.

[3] Delahooke, M. (2019). Beyond Behaviors: Using Brain Science and Compassion to Understand and Solve Children's Behavioral Challenges. PESI Publishing.

Ways to co-regulate with your child:

lower your body position

reduce environmental noise

model deep breathing

go for a walk outside, together

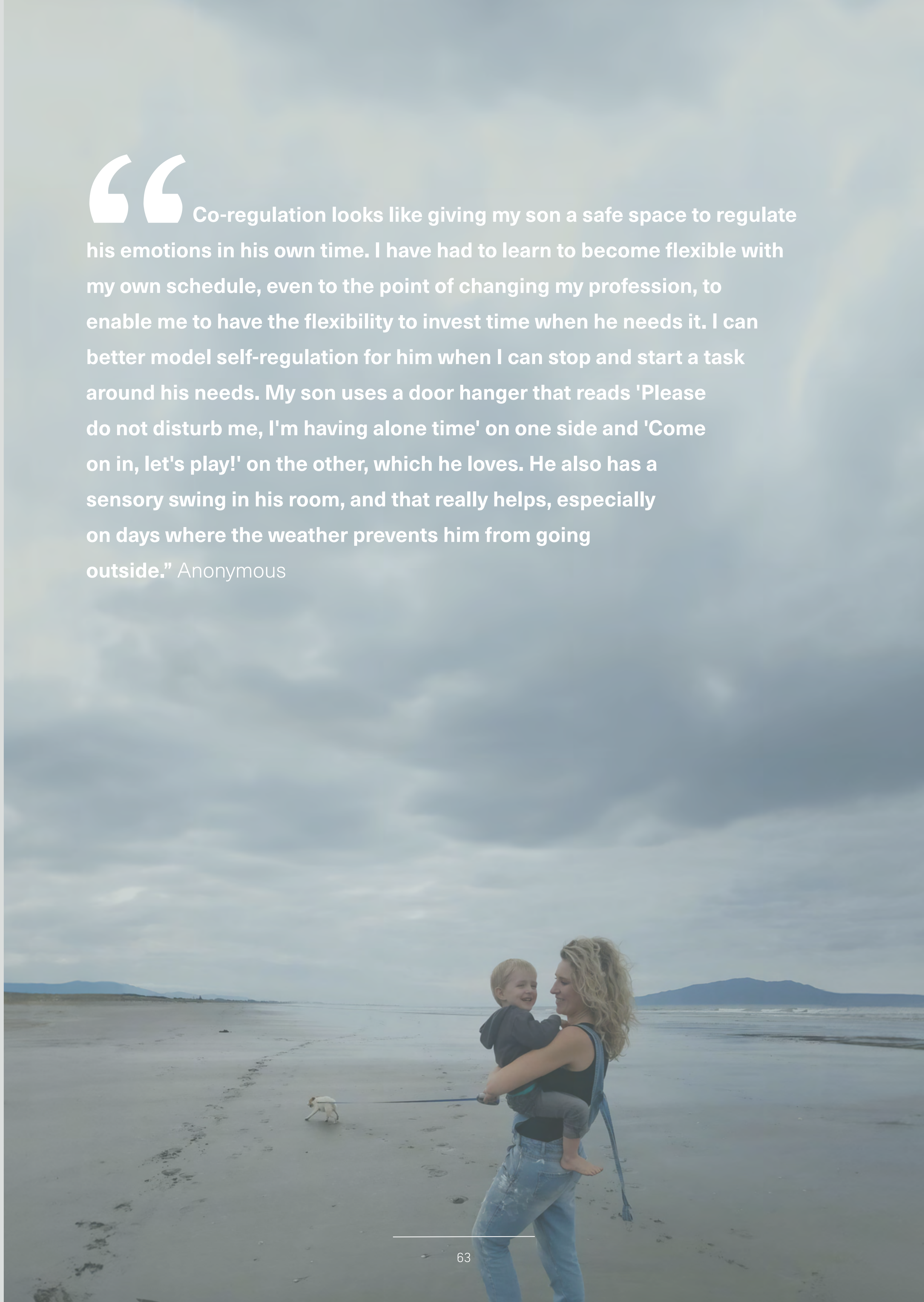
offer deep pressure

encourage a sensory activity

move your bodies, together

darken the environment

soften your speech, facial expression and body language



> **“Co-regulation looks like giving my son a safe space to regulate his emotions in his own time. I have had to learn to become flexible with my own schedule, even to the point of changing my profession, to enable me to have the flexibility to invest time when he needs it. I can better model self-regulation for him when I can stop and start a task around his needs. My son uses a door hanger that reads 'Please do not disturb me, I'm having alone time' on one side and 'Come on in, let's play!' on the other, which he loves. He also has a sensory swing in his room, and that really helps, especially on days where the weather prevents him from going outside.”** Anonymous

Practical tips

If your child is showing signs of distress and overwhelm, it may help to consider the following in supporting your child:

- Keep a diary for one to two weeks. When you observe behaviour that indicates distress or overwhelm, write down what happened. Make a note of where you were at the time, who was there, and what happened before and after. This will help to identify any patterns and triggers.
- Rule out any medical or dental concerns that may be causing your child pain or discomfort.
- Consider their physical comfort and wellbeing: are they hungry or tired?
- Look at the situation from your child's perspective and think about what they might be trying to communicate to you. Is there a task that they are expected to complete that they do not have the skills or abilities for? Are they in a social environment that is causing them to feel overwhelmed? Do they have sensory needs that are not being met? Are they anxious or needing a break from the demands of their daily routine?
- Think about the changes that could be made to your child's environment and routine, and/or the additional supports that could be provided. Take a collaborative approach, including your child and other relevant adults in these discussions and plans.
- Talk to Autistic people about what is happening and see if they have any suggestions or similar experiences. You can find groups of Autistic people on Facebook. Many Autistic teens and adults have also written blogs that can be found online.
- Consider what strengths your child may be able to draw on in working through these challenges and support them to access those strengths.
- Work out a co-regulating practice with your child to help them learn to self-regulate. Each child is unique, so you will need to learn what works best for them. Some children may prefer minimal words spoken in a calm, quiet voice, a firm hug or no/limited touch. Others may like to retreat to a quiet, darkened space with their favourite sensory toy.
- Focus on building a strong, trusting relationship with your child. Spend time with them doing things they enjoy.
- Choose your moments carefully! When your child feels calm, this is the time to gently communicate about expected routines, challenging situations, and future plans. Do not try to communicate about these things when your child is in a heightened state—it is not possible for the brain to learn when the body is in distress.
- Take care of yourself: to be able to support your child, you need to look after yourself too. Take a few minutes to check yourself before responding, and a few deep breaths.
- Look into opportunities for regular time out or respite for yourself, so that you are in a stronger position to cope with the challenges of day-to-day life.

"Co-regulation with my daughter on one day is going outside together and spending time with our various animals—enjoying how cute they are, laughing at their funny characteristics. On another day, it can be purposefully watching a funny media clip together, wrestling, or squeezing her tightly. Other times, if things have got a bit more overwhelming for her, then co-regulation is us parents not talking, not touching her, not going near her, not making any demands on her, and instead just being in the nearby vicinity so that we are 'around'." Anonymous

Section four

Services & supports

If your child has been diagnosed as Autistic, you may be eligible for disability support services and financial support. This may include:

Government funding from Disability Support Services (DSS)

Depending on your personal circumstances, examples of services that may be available include support to enable carers to access respite, funding for home modifications, behavioural support, and housing/living support options. To find out if you are eligible for support, you will need to contact your local Needs Assessment Service Coordination organisation (NASC), as discussed further below.

Financial support from Work and Income New Zealand

Depending on your personal circumstances, examples of support may include the Child Disability Allowance or the Supported Living Payment, and the Disability Allowance. To find out if you are eligible for support, you will need to contact your local WINZ office.

You can find further information on this important topic in the following link: https://parent2parent.org.nz/resource-hub/?topics=funding

You can also:

- Read the information available on the following websites:
  - www.disabilitysupport.govt.nz
  - www.workandincome.govt.nz
- Request personalised information from Altogether Autism: https://www.altogetherautism.org.nz/information-hub/request-information

Introduction to the NASC

To find out if your child is eligible for any DSS-funded support services you will need to contact your local NASC.

NASCs work with disabled people and their families to determine an individual's strengths, support needs and goals, and outline and allocate different support services that the individual may be entitled to. Each region in Aotearoa has its own NASC, many of them have different names. An introductory guide to the NASC can be found here: https://parent2parent.org.nz/resource-hub/?topics=funding

Although the specific processes and terminology used by each NASC may vary slightly from region to region, the general process is as follows:

1

Referral to the local NASC

You can self-refer, or a professional (GP, Paediatrician, Specialist) can refer you.

Visit this webpage to find your local NASC: https://www.disabilitysupport.govt.nz/disabled-people/assessment-and-funding/needs-assessment-services

2

Needs assessment

If your referral meets eligibility criteria and is accepted by the NASC, the NASC will contact you to arrange a time to meet. The purpose of this meeting—often referred to as a needs assessment—is for the NASC to learn more about your child, their goals and what support is needed to live their life.

3

Service coordination

The NASC will determine if your child is entitled to receive any government-funded disability support services, based on the information you provided during the needs assessment. The NASC will also consider if there are other services or organisations that you can access for support.

4

Outcome

The NASC will advise you in writing if any funded support services have been allocated to you. They may also advise of other relevant information or support services that you may wish to access. If you feel that the NASC has not accurately understood your child's support needs and/or if you feel that the supports that have been allocated are not appropriate, please discuss this further with the NASC.

Therapeutic supports

Simple adjustments

There is a lot we can do to support Autistic children in their daily lives. We can learn about how they experience the world, what sensory sensitivities or anxieties they may have, and what their preferred ways of communicating are. We can then make simple adjustments to daily routines, environments, and the way we communicate with them.

Therapies

There will be stages or aspects of an Autistic child's life where more formal support, such as therapy or medication, is needed. Some of the therapies that may be offered to Autistic children include:

- Speech-language therapy
- Occupational therapy
- Music, art and physical therapies
- Psychological support
- Communication support
- Behavioural support
- Medication (e.g. for anxiety)

When choosing a support or therapy, several things should be considered.

Do choose therapies that:

- Affirm your child as an Autistic person and empower them to be their best Autistic self.
- Embrace a positive view of autism as a valuable form of neurodiversity.
- Have a strong scientific backing, and a solid record of evidence-based research that proves they are safe and effective.
- Are accepted by communities of Autistic people, and compatible with their lived experiences and views.
- Are child-centred. All therapies for children should prioritise their best interests, respect their right to be involved in daily decisions, and include them in goal setting and planning.
- Are family-centred, and respect the needs, preferences, values, and cultural perspectives of the whānau.
- Are individualised, based on your child's specific strengths and support needs.

Unfortunately, there are therapies and autism interventions that target parents of Autistic children but are ultimately harmful and unsafe. They often lack an established research or evidence base.

Avoid therapies that:

- Offer a one-size-fits-all treatment for autism or another diagnosis.
- Try to 'normalise' or 'fix' an Autistic child or make them more like non-Autistic children.
- Try to modify or suppress natural Autistic behaviour, such as stimming.
- Encourage non-Autistic norms, such as making eye contact.
- Attempt to change Autistic behaviour through a system of rewards and consequences.
- Use seclusion or restraint.

Choosing a therapy or support for your child is a complex decision. The therapy needs to take into account your child's right to live as their best Autistic self. It should consider their support needs, the values and needs of the family, the effectiveness and safety of the therapy, and the time, money and energy required to implement it.

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

Points to discuss with service providers

When exploring a new support or therapy for your child, it may be helpful to consider the following questions. You could talk about these with the service provider or think about them yourself:

- What is the goal of the therapy or support?
- Is there evidence that this therapy/ support is safe and effective?
- What do Autistic people say about this therapy?
- Does the service provider embrace autism as a valuable form of neurodiversity?
- How long will the therapy/support take?
- How will we know when it has worked and when can we stop?
- What will the benefits be?
- What are the possible side effects and how will we measure and monitor these?
- Are the steps to implement the therapy or support practical and achievable?
- How will the therapy accommodate my child's unique needs and the needs and values of our whānau?
- Is there a check-in/evaluation process, in consultation with the family, whereby the approach may be modified to better suit my child's needs?
- Does the service provider have up-to-date knowledge of autism?
- Is their practice space accommodating of my child's needs (for example, sensory needs)?
- Can they put you in contact with any whānau they have worked with to hear their experiences?

Any service provider should be using an evidence-based approach and should be willing to collaborate with you and your child. They should provide the support and therapy that best meets your child's unique needs and the needs of the wider family. This means working with (not against!) your child's neurology.

You can also check that a therapy or an intervention is in line with the ***Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau (Third edition)*** https://www.whaikaha.govt.nz/about-us/policy-strategies-and-action-plans/nz-autism-guideline.

Part 4, Recommendation 7 of the Executive Summary (or *Good Practice Point 4.3.13* in the Guideline) makes recommendations for ethical practice involving the mental health and wellbeing support of Autistic people. These recommendations are summarised below, or you can read them in full by downloading the documents at the link above.

- Understand that behaviour is communication
- Accept the person as authentically Autistic
- Be strengths-based
- Be person-centred
- Do not encourage masking
- Encourage and facilitate the use of supports and adjustments
- Presume competence and potential
- Provide access to communication supports (i.e. AAC devices, signing, quiet spaces)
- Do not use seclusion and restraint
- Work collaboratively with whānau and other professionals
- Regularly check for consent
- Monitor progress of support provided
- Commit to the dignity, human rights and civil liberties of the Autistic person

Communication supports

Non-Autistic people tend to communicate through spoken language, gestures, body language, and facial expressions. These are the things that people tend to look to if they want to work out what someone wants or needs. Autistic children, in contrast, may use styles and modes of communication that are less common. These could include typing to communicate, echolalia (echoing or repeating sounds, words, or phrases), using visual supports, verbal or vocal stimming, or using electronic devices. They may require support around communication to make sure they are understood by others, can access learning, and are able to build meaningful relationships.

"It feels counterintuitive at times but embracing your child's unique way of communicating will allow them to flourish." Parent of unreliably speaking 11-year-old Autistic son

“My daughter has a bell that she rings when she wants to talk and also when she doesn’t. She’ll ring it and then she’ll say, “Okay, talking time’s finished,” and she rings the bell again and that’s the end, which means she wants to be left to herself. She made it herself at school. She loves how it sounds.” Anonymous

There are several tools available to support Autistic communication, such as core boards and other visual supports, sign language, and electronic devices or tablets. We talk more about these in the following pages.

Speech-language therapy

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

Speech and communication support usually starts with an evaluation by a qualified speech-language therapist (SLT). Whether the person is speaking or non-speaking, SLTs specialise in creating a profile of a person's communicative strengths, skills, and abilities. This may include assessment of receptive language (what the child or young person understands), as well as expressive language (their use of spoken and written language). From here, the SLT can develop a programme to support inclusion, enable participation, and forge social opportunities.

This article has more information on the role of a speech-language therapist: https://www.altogetherautism.org.nz/communication-connection-challenge-become-better-listeners/

"For me the SLT is building rapport to support our family with our own goals." Parent of unreliably speaking 11-year-old Autistic son

Non-speaking Autistic people

It is estimated that around 25-35% of Autistic people do not use speech as their primary means of communication. Some may be 'non-speaking', others 'minimally speaking', and some 'unreliably speaking.' These individuals can be said to have complex Communication Support Needs (CSN).

When talking about this population of Autistic people, it's supportive to use terms that reference speaking and speech, rather than terms like 'non-verbal'. This emphasises the fact that these individuals often do use verbal means to communicate, they just may not do so through conventional speech.

"I rely a lot more on body language than what's coming out of his mouth because he can't always verbally say how he is doing or how he is feeling." Mum of an Autistic 10-year-old son

Advocating for non-speaking Autistic people

Autistic people with CSN are particularly vulnerable to exclusion and even abuse. Their style of communication may not be recognized as meaningful or legitimate, and they are often dismissed as incapable or incompetent. Many are sidelined and ignored, while others are subjected to unacceptable therapies and practices to which they cannot protest. Some are not taught to read and write.
If your child is non-speaking, this does not mean they cannot communicate. This is where parents can be such an amazing resource for their children, as they are often the first to notice and draw out their child's strengths and abilities. In these cases, it's important to explore the use of alternative communication tools for your child. These tools are life-changing for many Autistic people.

"Accepting and affirming your child's chosen method of communication is the way to build trust and connection. If I could go back, I would compare my child's communication with others less and celebrate it more for it's complex, creative and unique wonderfulness." Parent of unreliably speaking 11-year-old Autistic son

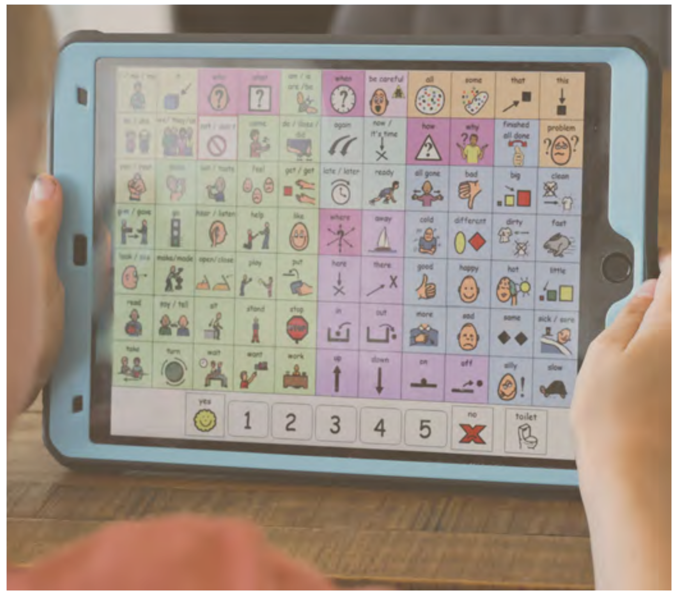
Augmentative and alternative communication tools

Augmentative = in addition to
Alternative = instead of

Augmentative and Alternative Communication (AAC) systems are tools that are used to add to existing ways of communicating, or to give people new and different ways of communicating. They may be used by both speaking and non-speaking individuals. It is common for Autistic people to use multiple modes of communication.

Visual Communication

Some AAC systems involve mostly visual supports, such as boards, cards, or an electronic library of pictures and photos. To communicate, children point to images that represent the items they need or would like to draw attention to. Other people can also point to images to explain what they mean, or to signal what to do next. These pictures can also be used to answer questions. Core boards, which display a range of symbols associated with core words that we use in everyday communication, are an example of a visual communication support.



"The core board pictured here is probably the one most widely used in New Zealand, which is provided by The TalkLink Trust to their clients."
Spotlight on Core Boards - Altogether Autism https://www.altogetherautism.org.nz/spotlight-on-core-boards/

Language boards

Language boards are also becoming popular. Language boards are boards where letters and numbers are laid out on a card, and the user points to the letters one by one to spell words. This is known as ***Spelling to Communicate***.

Facilitated Communication

Sometimes, an Autistic person may require the support of another person to use an AAC system, such as a language board. This can involve a communication partner who provides physical support at the person's back or elbow to help them remain focused on the board. Physical support is gradually faded out as the person becomes more confident. This is called Facilitated Communication (FC) or the Rapid Prompting Method.

There has been some controversy around the use of Facilitated Communication and its derivatives. While further research is needed and debate is ongoing, we recognise the lived experience of Autistic individuals who communicate via FC.

Electronic AAC

Other AAC systems, such as ***Proloquo2Go***, rely on the use of tablets, apps, or software. These may involve speech-generating devices, where the person types or selects written words that the computer repeats aloud. Many of these systems can use both picture and text-based keyboards to give the Autistic person lots of options to choose from.

It can be difficult to find the right AAC system for your child and get it set up in a way that they can use. AAC is a new and still somewhat limited technology, and more work needs to be done to make it broader and more functional. Working in partnership with a speech-language therapist may help with this. You can also contact ***TalkLink Trust***, a nationwide service that helps disabled people find the right kind of assistive technology to support communication. There is also a wonderful Facebook community for AAC users and their parents, where you can ask questions and troubleshoot problems: https://www.facebook.com/groups/456220758119314/

Rights to communication

Access to Augmentative and Alternative Communication is a basic human right for children who do not communicate in typical ways. This is set out in the UN Convention on the Rights of Persons with Disabilities, which says:

"... to enable persons with disabilities to live independently and participate fully in all aspects of life, State parties [or countries that signed the convention, including New Zealand] shall take appropriate measures to ensure to persons with disabilities access [...] to information and communications, including information and communications technologies and systems."

All individuals should have the opportunity to express themselves, to share and exchange information, to make and advocate for their own decisions, and to participate in learning and the community. In this sense, AAC systems are a cornerstone of Autistic self-determination and mana.

Check out this article for a mother's perspective on her Autistic daughter's journey with AAC: https://www.altogetherautism.org.nz/be-an-ally-not-an-advocate/

"There is a serious lack of resources out there, you will, sadly, need to become the expert on your own."
Parent of unreliably speaking 11-year-old Autistic son

Visual supports

Many Autistic people have strengths around visual thinking and excel in visual-spatial tasks. Visual supports are often used to help Autistic people communicate, interact, plan, and manage tasks.

These supports can transform fleeting and inconsistent spoken words into physical and consistent communication. Some examples of visual supports include:

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

Visual supports may be useful to:

- Express needs, preferences, and ideas
- Depict routines, timetables, or schedules
- Help explain what will happen next
- Signal transitions or changes between activities, places, and events
- Give instructions and reminders
- Offer choices
- Introduce new activities/situations
- Share information
- Represent the child's emotions or the emotions of others
- Explain safety information
- Give feedback or praise
- Locate people and places
- Support independent living skills by breaking tasks down, such as the steps in cooking a meal

"We've got a timetable on the fridge with our routines displayed. He now has a phone, and he uses an iPad and a calendar. So, when we've got events that are for the whole family, I put them on a Google calendar, so he sees them there... It feels like another level of effort to do the visuals, but it is worth it. It doesn't have to be high-tech. We've got a little whiteboard."
Anonymous

Social stories

Social stories are another communication tool that supports the exchange of information between parents, caregivers, professionals, and Autistic people of all ages.

Social stories are developmentally appropriate, individualised short stories that depict a particular situation, event, or activity. They can be used to introduce new situations, explain confusing or stressful encounters, or help children explore their own emotions and experiences.

Ryan's social story:

Getting ready for school

Ryan knows that it is a school day when Mummy helps him to make his bed.

Changing the date helps Ryan to ground himself in the new day.

Eating breakfast gives Ryan strength for the day.

Laying the clothes out helps Ryan to get dressed on his own.

Watermelon flavoured toothpaste is Ryan's favourite.

Ryan puts his shoes on and now he is ready for school!

In a social story, the child is usually the main character. The story may refer to familiar environments or people. Photos of these people and places can be used to construct the story.

For example, you might want to make a social story for a child who is anxious about starting school. You could include pictures of what you will do in the morning before the child starts school, such as packing a bag or eating breakfast. Then, you could show a picture of the school gate. You could use a photo to show saying goodbye to a parent or caregiver, and a picture of the teacher and the classroom where your child will be going.

Creating respectful social stories

While they can be useful in certain situations, there is a problematic history of social stories being used to dismiss Autistic feelings, perspectives, and experiences in favour of neurotypical interpretations. If you are constructing a social story for your child, make sure to include them in the process. If they are anxious about something, acknowledge and accept their feelings. For example, in the first day of school example above, you might want to include a comment such as, “Ben is worried and stressed about all the changes that are happening. He isn’t sure what school will be like.”

Social stories should also respect Autistic ways of being in the world. This means they should not be used to encourage children to be more like their peers, or to push them to participate in activities that may not be suitable for them. Stories about whole-body listening, joining in with social activities when the child prefers playing alone, or other norms around classroom behaviour, should be avoided.

Here is a great tip sheet on how to create social stories: https://www.facebook.com/story.php/?story_fbid=232722036333487&id=100087870753308

Checklist of strategies

As they grow, your Autistic child will encounter situations that may need to be modified to accommodate their needs. The following is a brief overview of some evidence-based strategies you may find helpful to support your child.

Bear in mind that what works for one child will not work for all children. Strategies will also depend on the age and stage of the child.

Anxiety

- Prepare your child for changes in advance, and help them map out what these changes will look like
- Stick to routines and plans where possible
- Reduce demands and stimulation
- Try breathing and relaxation exercises
- Practise meditation
- Practise mindfulness
- Give support with understanding emotions
- Give support with identifying triggers and signs of stress
- Talk to a support person
- Ask for help or to have a break
- Seek professional/medical help

Light sensitivity

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

Speech and communication

- Give one instruction at a time
- Give more processing time for questions and instructions (without repeating yourself)
- Use Augmentative and Alternative Communication
- Use visuals
- Speech-language therapy

Touch sensitivity

- Remove tags from clothes
- Pick clothes in their preferred material
- Provide toys/sensory jewellery to support stimming
- Educate extended family that waving hello is better than hugs

Sleep difficulties

- Establish a bedtime routine (calming and relaxing activities, regular bedtimes)
- Check sensory sensitivities (Are the blankets too itchy? Is the room too light?)
- Practise meditation and relaxation techniques
- Seek professional/medical help if needed

Sound sensitivity

- Earplugs, earphones, or earmuffs
- Move school desk away from noise
- Avoid crowds or large group activities

Social skills and interactions

- Support friendships with children who share your child's interests
- Help your child meet other Autistic children and adults
- Recognise that Autistic friendships may look different—they may not always have friends their own age and may spend more time with those friends online than in person. Autistic people may also prefer the company of animals/nature instead
- Teach and support self-advocacy skills
- Talk to people in your child's life about autism and how your child experiences the world

Difficulty with change or transitions

- Visual and/or verbal prompting before a change occurs
- Visual schedules
- Diaries and calendars
- Times when activities will start or finish
- Social stories about transitions

Emotional regulation

- Understand your child's triggers
- Practise calming strategies
- Encourage regular breaks
- Avoid or limit situations that are stressful for your child
- Help them regulate with you (co-regulation)
- Provide lots of opportunities to work off energy (exercise, exploration, fun play with your child)
- Help your child use art, music, or writing to work through their emotions if they want to

Picky eating

- Occupational therapist assessment for sensory sensitivities
- Medical check-ups to ensure your 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)

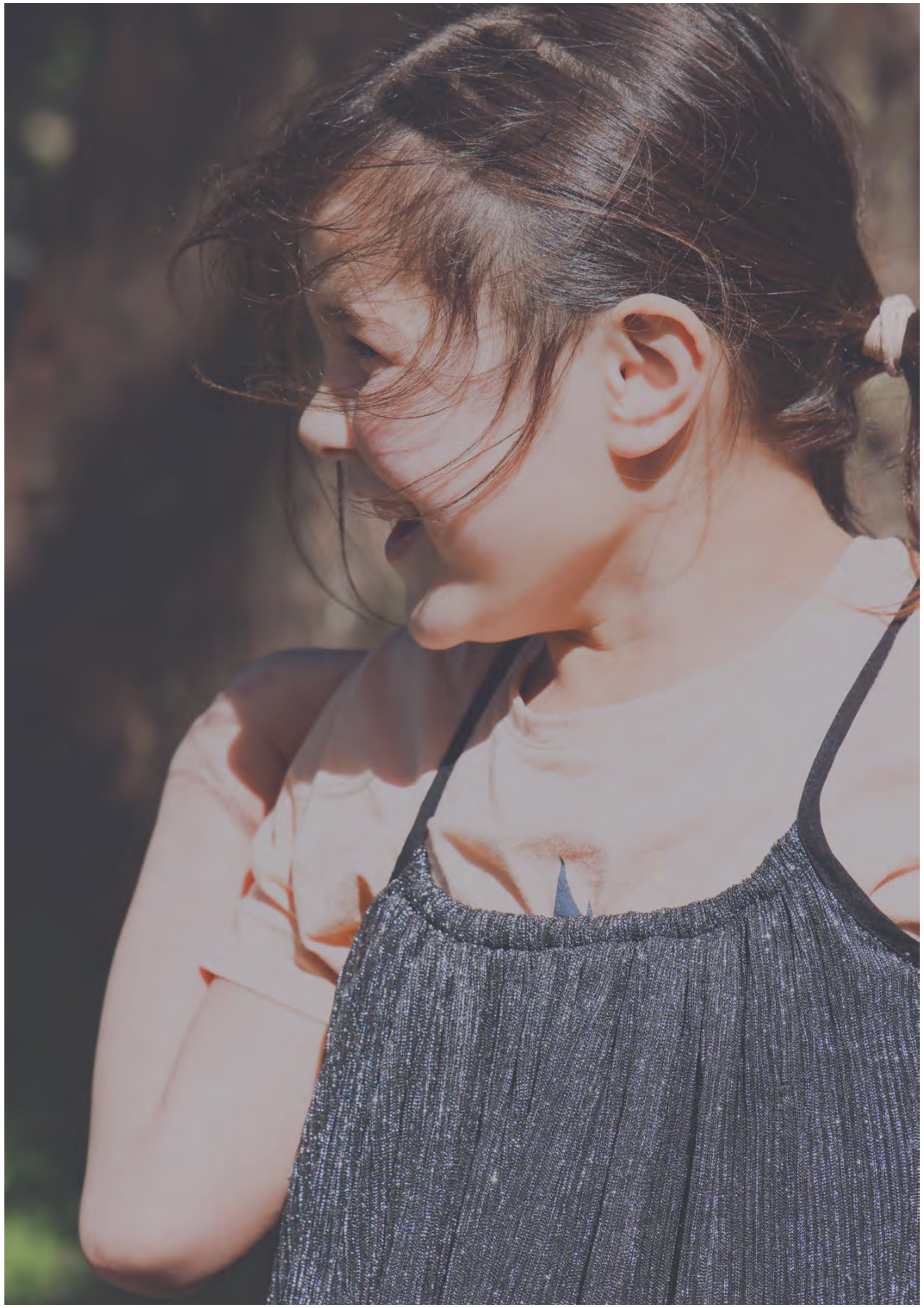
Self-care

- Make sure your child gets regular sensory breaks
- Make sure your child has plenty of time to engage with their interests
- Respect their choices, boundaries, and priorities
- Help them build a positive Autistic identity

Education and school

- Prioritise the home/school partnership
- 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
- SENCO/LSC/RTLB

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



Section five

Your child in education

The education that your child receives should be inclusive and cater to their unique learning needs.

The right to an inclusive education is set out in several key documents, including the Education and Training Act 2020, the United Nations Convention on the Rights of Persons with Disabilities, the United Nations Convention on the Rights of the Child, and the New Zealand Disability Strategy. Here is an excerpt from the New Zealand Disability Strategy:

"Education is provided in a way that supports our personal, academic and social development, both in and out of the formal schooling system. This includes making sure that those of us who use different languages (in particular New Zealand Sign Language), and other modes or means of communication, have ready access to them to achieve and progress. Information will be made available at the right time to those who support us, both when we are young or for those of us who need on-going support. This will help us succeed – whatever our individual education pathway may look like.

"We are treated with respect and dignity by those around us in the education system, including our peers and those who teach and support us. The love and expertise of our families and whānau and their wish to see us succeed in education will be honoured without question. As we move on to tertiary and life-long learning, the transition periods are smooth, with the right information and supports available at the right time – particularly when our needs or situations change."

Tips for navigating your child's education

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 where you live.

This service is free, but there are often lengthy waiting lists to receive it. If your child is aged 2-5 and has received a diagnosis of autism or is likely to receive one soon, speak to your child's early childhood service to get the ball rolling with early intervention as soon as possible.

The early intervention service involves speech-language therapists, occupational therapists, kaitakawaenga (Ministry of Education employed Māori cultural advisors), and early intervention teachers. Your child's development across home and school settings will be considered, and an ***Individual Plan (IP)*** may be created in partnership with you and your family. Your child may be assigned an education support worker to help implement the IP. The Ministry of Education website has more information on early intervention support: https://www.education.govt.nz/parents-and-caregivers/early-learning/learning-support

Learning support at school

Your child may be entitled to receive learning support at school. All schools have a ***Special Education Needs Coordinator (SENCO)*** or a ***Learning Support Coordinator (LSC)***. As a first step, talk to your child's teacher about the support you believe your child needs. Their teacher is also likely to have ideas about what support might be needed. You can then ask the teacher to speak with the SENCO/LSC, or you can talk to them directly.

Learning support at school when your child has significant support needs

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

To find out more about ORS funding, check the Ministry of Education website here: https://www.education.govt.nz/education-professionals/schools-year-0-13/learning-support/apply-ongoing-resourcing-scheme-school-students

Individual Education Plan (IEP)

An IEP is a written document that specifies how your school-aged child will be educated. It is intended to empower your child and to help make education more accessible for them. It includes goals and learning outcomes that your child is working towards, strategies to support their achievement, and modifications to classroom learning that will be made. An IEP is typically created during a meeting involving the child's class teacher, other education staff such as the SENCO or RTLB, you as your child's parent, and other members of your child's whānau. Your child should also be present if they want to be—their voice is important in creating a successful plan.

There is more information about creating an IEP here: https://parent2parent.org.nz/resource-hub/individual-education-plan/

Focus on a collaborative approach;
'How can WE do this?'

Communication with teachers

Children do best when their parents and teachers have a positive relationship built on open communication. Here are some ideas and resources to help you build a successful partnership with your child's teacher, and to help you explain what your child needs in the classroom:

- Create a printable sheet that summarises your child's likes, dislikes, learning preferences, strengths, sensory needs, and triggers. Share this with your child's teacher and other teaching staff. Include strategies and tips that work for your child.
- Get to know your child's teacher and other school staff such as the SENCO/LSC and participate in school activities wherever you can.
- Early in the school year, make a plan with the teacher around how and when you will communicate with them (via phone/email, once a month/three times a term).
- With your child, develop a vision for your child's education. Share this with their teacher. Think about what goals your child would like to accomplish, and what participation might look like for them. This vision will also become part of your child's IEP.
- At times of transition, for example when your child moves to a new class or a new school, make a plan with school staff around how to support them.
- If you have concerns for your child's safety at school, or if they are likely to try to escape from school, set up a Safety Plan with your child's teacher at the beginning of the school year. Make plans to review this regularly.
- With the teacher, identify areas where additional support may be needed. Try to gauge their approach to inclusion by asking questions, coming from a place of curiosity. You could use your child's IEP as the basis for this discussion, or just talk about things you have noticed yourself.

- Teachers may vary in their knowledge and understanding of how to support an Autistic child. Share resources with the teacher that help explain how Autistic children think and learn. Where possible, choose resources that have been created or selected by Autistic people, as these will most accurately represent your child's experience. The Ministry of Education guide to autism and learning is an excellent place to start for educators. It can be accessed here: https://inclusive.tki.org.nz/guides/autism-and-learning/. You could also encourage your child's teacher to contact Parent to Parent or Altogether Autism for more tips and ideas.

Here is a link to further information on how to advocate for your child's rights in education: https://parent2parent.org.nz/resource-hub/five-top-tips-for-advocating-for-your-childs-right-to-education/

Other school professionals

Your child's teacher is not the only person in the school setting that can help you plan for your child's learning. Other key figures that may be able to support you include:

- Your school's Special Education Needs Coordinator (SENCO) / Learning Support Coordinator (LSC)
- Resource Teachers of Learning and Behaviour (RTLBs)
- Resource Teachers of Literacy, if your child struggles with reading (RTLit)
- Specialists in vision, hearing, or physical disabilities. If your child has an impairment in one of these areas, supports should be placed within the school to meet these additional needs
- Local Ministry of Education Learning Support representatives

The learning environment

Your child has a right to an inclusive education and to reasonable accommodations in the classroom. The exact supports that your child requires will depend on their unique learning style, sensory profile, and other support needs. Some supports that may be made available to Autistic learners include:

- Communication devices such as visual supports or AAC devices
- Modifications to the seating area: seating the child in the area of the classroom that is most comfortable for them—perhaps away from bright lights, loud noises, or other sensory triggers
- Timetable modifications to allow for breaks, quiet time or different start or finish times
- Breaks in the timetable where the child has a choice of activity
- Extra time to complete work or tests
- Voluntary access to a quiet space or sensory room (note that students should never be placed in involuntary or punitive seclusion)
- Sunglasses or headphones to block out light and noise
- Objects that help the child regulate their body, such as a bean bag, rocking chair, or fidget toy
- Opportunities during the school day to engage with interests (e.g. Lego club, projects around a topic of interest)
- Alternative options for involvement in group work or assemblies (e.g. offering the choice to work with just one person; staying in the classroom or sitting at the side during assemblies)
- Access to technology that supports learning, such as a computer or iPad
- A printed schedule or timetable to show what is coming next
- Choices and options around how to demonstrate understanding (e.g. visually rather than in writing)
- Executive functioning tools such as a diary or list to help keep track of homework
- Alternatives to mainstream learning, such as Te Kura (the Correspondence School), homeschooling, and specialist schools

Watch Parent to Parent's Neurodiversity Series for more tips: https://parent2parent.org.nz/resource-hub/neurodiversity-video-series/

Managing tricky situations at school

At times, you may run into difficulties or conflict around the way your child's needs are accommodated at school. Below are some tips for managing these situations.

Conflict with teachers or other students

A helpful way to begin to resolve a conflict with a teacher or another student is to understand as much information as you can around what happened. Talk to your child or spend time with them to get a sense of their perspective. Listen to the views of anyone else involved. Write down the main events neutrally and factually.

Then, consider things from the teacher's point of view. Is there something the teacher doesn't know about your child or about your whānau that might help explain or encourage solutions? Would it be beneficial to share some of the resources available to help them understand autism? It may be helpful to show them the iceberg analogy on page 57 and discuss how the behaviours being seen are not the whole story.

When talking with the teacher be specific about your concerns and focus on solutions that you and your child's teacher can implement. Try to keep the discussion factual and remember you have a shared interest—your child's education. Talking to the teacher in person may help in discussing the situation thoroughly. It will probably be helpful to take notes about what has happened that you can refer back to later. You may want to take along a support person who can do this for you.

You will also want to be solution focused. Have some solutions ready that you feel would be supportive for your child and family. Show that you want to work collaboratively and listen to suggestions and advice by asking the teacher, "What do you think?" or, "What have you done in the past for other families in this situation?".

School refusal/School can't

Another challenge that parents frequently report is school refusal. School refusal is also known as 'school can't'. This is to emphasise that not attending school is not a choice the child is making, but something they are currently unable to do. This can be confusing and frustrating for parents, especially if the child is unable to articulate why they do not want to attend. If your child doesn't want to go to school, this is often due to factors such as anxiety, overwhelm, exhaustion, or unmet needs. Your child may have had negative experiences at school and may now have built up a negative association with school. Alternatively, they may dislike school because it involves a lot of unknowns.

You can support your child by listening to their feelings and working proactively with the school to put accommodations into place. Some families eventually end up on a different educational pathway to mainstream education, such as homeschooling, health school, Te Kura, or specialist schools. For these families, alternative settings are a better fit for their child.

In navigating these challenges, it may help to talk to other parents who have had similar experiences. These parents can be accessed through the Parent to Parent Support Parent Network, your school, or online forums such as the VIPS-Equity in Education Group on Facebook: https://www.facebook.com/groups/vips4equity

Mā te wā

“The assessment process was hard for us all. For my son, and for us as his parents. Our family desperately needed information and tools to guide us through the diagnostic process and onwards, but we didn’t know where to start.

"This comprehensive, strengths-based guide to autism aims to support and empower children like my son as they navigate a new diagnosis, along with their families and the people around them. We hope this resource will be a guiding light to you in the weeks, months, and years to come.” Member of the About Autism publishing team

No matter where you are in your journey, we encourage you to identify your child's skills, strengths, needs and challenges and make a plan to support them.

We’ve provided information in this booklet on teaching new skills, understanding behaviour, and how to accommodate your child’s sensory and communication needs. Remember that you are not alone—there are many people to support you and your whānau in your journey.

Parent to Parent New Zealand

For more than 40 years, Parent to Parent has supported families and whānau to hold and realise a strong vision for their disabled, neurodivergent, or health-impaired family member.

Founded in 1983 by a small group of parents and professionals who dared to imagine better lives for disabled people, our grassroots organisation now offers pan-disability, peer-to-peer services right across New Zealand.

Today, our 14 branches help thousands of families of disabled Kiwis find connection, information and support to navigate through their experiences with disability.

Parent to Parent's main services are free and confidential:

- Tailor-made information and support on anything connected with a disability, neurodivergence, or health condition from our Support & Information Team (qualified researchers with family or personal experience of disability).
- Connection to a trained volunteer Support Parent to gain the wisdom of experience from another parent or carer who gets what you're going through.
- Support groups, workshops, courses and events designed to support you and your family and make connections with other parents and carers in your area.
- SibSupport NZ: camps and day events to support the siblings of children with disabilities.

Parent to Parent also provides the services of ***Altogether Autism*** and ***Care Matters.***

Your Way I Kia Roha

Your Way I Kia Roha is a charitable trust offering information, support, and equipment to enable disabled people to thrive, living the lives they choose in their communities. Your Way | Kia Roha's family of brands, include ***Journey Together, Imagine Better, Altogether Autism***, and ***Mobility Centre.***

The organisation began in 1979 as the Disabled Living Centre (Waikato) Trust Inc. In 1997 the operating name was changed to Life Unlimited Charitable Trust to reflect the wider scope of services that were provided.

In June 2021, Life Unlimited merged with the charitable trust, Access Ability, which provided the Needs Assessment and Service Coordination (NASC) service in Otago, Southland, Whanganui and Taranaki, and the Local Area Coordination (LAC) service in Otago / Southland. Imagine Better (advocacy, research and training) and Journey Together (delivering Local Area Coordination in Bay of Plenty) were wholly owned subsidiaries of Access Ability and became part of the whole organisation.

In recognition of the significance of Life Unlimited and Access Ability merging, in late 2022 the charity became known as ***Your Way | Kia Roha*** **–** a new name to go forward.

Altogether Autism was started in 2007 by Parent to Parent and Your Way | Kia Roha.

Our free ***Altogether Autism*** service (a shared service provided by ***Parent to Parent*** and ***Your Way | Kia Roha***) provides evidence-based information at any time and on any topic when requested by you, your whānau or anyone in your network. The information provided by *Altogether Autism* is tailored to any query and its researchers are on hand to investigate more complex questions.

Altogether Autism also has two external consultancy groups: ***The Consumer Advisory Group***, which is made up of Autistic adults and parents with Autistic children, and the ***Professional Advisory Group***, which is made up of professionals who work with Autistic people, including psychologists, psychiatrists, educators, lawyers and health professionals.

Altogether Autism also offers professional development workshops to any group such as schools, disability organisations, police, psychologists and employers. Workshops are tailored to the learning needs of professionals working with Autistic people.

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**If this
is autism,
autism is
beautiful.
This is
my child.**

Mum of Autistic 10-year-old