

Introduction to autism



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A contemporary view of autism

"The better part of a decade ago, I remember sitting and talking with a psychologist as my son was being screened for autism. There was such a heavy focus on all the things that he 'couldn't do', with

so much chatter about 'putting in work now so he could catch up to his same-aged peers'. This news about his likely diagnosis was presented in such a sombre way, like it was meant to mark some great upheaval in my life. It really gutted me because I didn't see him in the same way the psychologist did. If you asked us both to describe him, we would have been painting completely different pictures. I would have focused on his superenquiring mind, his problem-solving

over the last decade. Things that were very much on the periphery 10 years ago such as Autistic co-production, the social model of disability and double empathy, have all become front and centre when thinking about Autism. Instead of focusing on what an Autistic person can't do, we are far more strengths focused.

skills, amazing memory and deep love of the Wiggles. Sure, he was nearly three and only had a few words and phrases, but I understood him and he understood me, and I figured we could just build on that emerging skill for him to be able to use out there with the rest of the world. I also saw so much of myself in him. The quirks that exist in him are largely things he shares with me (funny that). If autism was the thing that coloured the way he experienced the world, and largely makes him who he is (which is the most loving, sweet, good human), I just didn't see it as a negative thing. The messaging at the time was just so negative, and inaccurate.

Thankfully, this messaging has started to change over the last decade. Journal articles opening with 'Autism is a neurodevelopmental disorder characterised by [insert list of deficits]' are being phased out. There is a stronger focus on strengths and Autistic characteristics are being viewed as differences, as opposed to deficits. Another big change has been the inclusion of Autistic voices. My daughter was diagnosed as Autistic recently and instead of what she 'couldn't do' the psychologist spoke to how she could do things in her own way, there was a focus on how to support her growing into the best version of her Autistic self, and her diagnostic report notes her extreme skill in particular areas. Her report and my description of her match pretty well.

It is with these changes in mind that this introduction has been created. To give a snapshot of what autism is, from a more contemporary lens."

Ainslie Robinson, Aspect Senior Working in Partnership Officer and Autistic mother 2024

Differences versus deficits

Autism is a condition that affects how a person thinks, feels, interacts with others, and experiences their environment. Whilst the diagnostic title of autism spectrum disorder (ASD) includes the word 'disorder', more people are moving toward thinking of autism as a collection of differences in the way people communicate, socialise, think, behave, process information and input sensory information, that are a natural and necessary part of human diversity that is not better or worse, just different.

A popular analogy used to describe autism is that of 'PC versus Mac'. Neither are inherently better or worse, they are just different. Autism is associated with some co-occurring conditions that can make life more difficult for Autistic people.

When thinking about these inherent differences of autism, it is also worth considering whether typical developmental milestones are an



Figure 1: PC versus Mac platforms

appropriate and relevant tool for measuring an Autistic child's development. An example of this is by 4–5 years of age, as determined by a typical developmental chart, a child should be able to 'play imaginatively' (for example playing in the home-corner, dressing up, cooking). An Autistic child at the same age may prefer to sort toys using a variety of methods, which demonstrates scientific thinking. Both are valid forms of play, and this concept of 'different not incorrect' can be generalised across a variety of developmental areas, such as speech versus Augmentative and Alternative Communication (AAC).



"When my son was about 3, his cousin who was 2 years older, challenged him to a running race. His cousin picked a starting line and said, "Ready, set, go!" Off they raced...in completely different directions. What was clear is that his cousin had technically won the race because he got to the pre-determined finish line faster, but my son was likely running faster. My sister and I looked at each other and giggled. What became clear that day was my son was running his own race. He is really great at running; his track is just different."

Autistic mother

Autistic children should not be considered as catching up to their peers, because they aren't running the same 'race'. Their track is different – they develop differently and it is not fair to use milestones for typically developing children to track progress.

Neurodiversity

Neurodiversity as a concept describes how all people have brains that are different from each other. These brains offer different strengths, different ways of thinking, and how humanity as a whole is better off for having this diversity. This is similar to the term 'biodiversity' and how natural environments thrive when there is diversity of flora and fauna. The implication for 'different thinkers' such as Autistic people and ADHDers, is that their brain and way of thinking has value, just like everyone else.

Neurodivergent

Neurodivergent refers to people who have brains that operate differently to what is considered typical. Some common forms of neurodivergence include, but are not limited to:

- Autism
- ADHD
- Dyslexia
- Tourette's
- Synaesthesia
- Obsessive Compulsive Disorder
- Bipolar Disorder

Autism is individual

Autism presents very differently from person to person, and as they say, If you've met one person with autism, you've met one person with autism. For some, autism can be very disabling and they will require quite significant supports throughout their entire lifetime. For others, many of their support needs could be ameliorated by a kinder, more inclusive world, and there is every experience in between.

If you've met one person with autism, you've met one person with autism.

Also, support needs are not stagnant. They may change over time, or be context or environment specific. Support needs can also change from day-to-day depending on an Autistic person's level

of 'spoons. Spoon Theory is a metaphor that is used to describe the amount of mental or physical energy a person has available for daily activities and tasks. More information on Spoon Theory can be found below.

- Aspect video
- The Spoon Theory written by Christine Miserandino

Strengths and interests

Just as with everyone, Autistic people can have areas in which they excel. This may be in academics or it may be in a very specific area, such as:

- memory and recall of facts
- reading, deciphering, recalling spoken or written language
- mechanics and/or visual-spatial ability
- mathematical calculation
- calendar calculation
- music
- visual arts
- performing arts
- athleticism and ball skills (throwing and catching).

Many Autistic people will have uneven developmental profiles, meaning that they will have areas where they excel and others that present challenges.

Autistic thinking tends to lend itself to some specific strengths, such as novel ways of problem solving, process thinking, logical thinking, precision, detail focused, honesty, reliability, intense focus and excellent memory. Also, whilst there certainly are many Autistic people who have strength in areas such as IT and mathematics, there are also many with strengths in creative fields such as drama, literature, visual arts and music.

Interests and passions

Another common characteristic of autism is having focused interest in a particular topic or topics. What makes this different from a typical interest is the level of intensity, with some individuals spending exceptional amounts of time and energy on their interests. Some quite stereotypical interests include dinosaurs, Lego, Marvel, Disney, transport and video games, but interests can also include things that are very specific such as vacuum cleaners, bins and whitegoods. These interests are really important to the individual, are hugely motivating and can bring a lot of joy. Unless a

focused interest is taking up an amount of time that impinges on their quality of life, it is not a problem.

From a practitioner or parent perspective it is important to understand Autistic strengths and interests, because they are an invaluable tool to motivate and engage, but arguably more importantly, necessary for quality of life.



"When I started teaching, I wish I had of known more around engaging Autistic students by utilising their strengths and interests, as well as ensuring their sensory needs are met. A student can't begin to engage if they aren't well-regulated, and special interests are such an easy way to get a student motivated."

Teacher, 16 years' experience

Sensory

Autistic people process the sensory world differently. This can bring great joy, but the world can also be stressful and overwhelming.

Hypersensitivity and hyposensitivity

Autistic people often have differences in how they process sensory information, and as with other

characteristics of autism, is experienced individually from person to person. Some Autistic people are hyposensitive to sensory input, meaning they need a lot of that input for it to register and some are hypersensitive, meaning sensations register as more intense than typically expected.

- People with a hyposensitive profile may need a lot of added sensory input as well as sensory breaks to feel well-regulated and comfortable.
- sensory input throughout their day overwhelming

Those with a hypersensitive profile may find the and may benefit from individualised accommodations (for example. headphones, sunglasses or a quiet room) to support self-regulation.

There are some people who have a mixed sensory profile depending on the sense and particular type of input.

"The world is too loud, too fast, too bright. I am always stressed and sometimes overwhelmed."

Aspect Think Tank member

Stimming

Often Autistic people will 'stim' as a way of self-regulating. 'Stimming' is an abbreviation for self-stimulatory behaviour and refers to the repetitive movements or noises that individuals may make. Some of the more common types of stimming include hand-flapping, finger-flicking, rocking, spinning or flicking fingers near ones' face.

"A lot of people assume that me stimming means something bad is happening, but I often also stim to experience or express sensory joy! A great example is on airplanes, the deep pressure you feel during take-off is like heaven to me and I will often be happy flapping along with the sensation. When someone tries to tone down or replace my happy stims it can take all of the joy from the experience."

Emma Beardsley,
Autism Friendly Consultant

for Autistic people to reduce anxiety and self-regulate, so it is important not to try and stop someone from stimming, unless the movement could potentially lead to injury.

Whilst much is made of the challenges Autistic individuals can experience from differences in sensory processing, the opposite side of that coin is rarely discussed. For some people their differences in sensory processing can be a great source of joy, for instance experiencing music and art in an intensely beautiful way. It's not all itchy clothing tags and overwhelming sounds.

Communication and social situations

Double Empathy Theory

Autistic people are considered to have less sophisticated social skills. The Double Empathy Theory, originally coined by Damian Milton in a 2012 paper, posits that communication misunderstandings are actually a two-way street and not unique to autism. Essentially, Milton theorises that mismatches in communication partners' contexts lead to break downs in communication. This is supported by newer studies that have looked at communication between Autistic and non-Autistic communication partners. In one study, both Autistic and non-Autistic participants had difficulty understanding the others' facial expressions and mental states. Yet, non-Autistic people are not expected to attend social skills training to partially bridge this communication gap.

Communication

Communication is a shared responsibility. This means that non-Autistic people must also adapt and learn to communicate with Autistic people, in a way that produces the best outcomes for all.

Verbal communication ability is varied across the autism spectrum. Some individuals may never use speech as their primary mode of communication, some may have a speech delay and others may have typically developing speech. It is important to note that whilst some Autistic people may never have speech as their mode of communication, it is not the only valid form of communication, and all Autistic people have the capacity to learn a form of communication.

Different modes of communication include speech, sign language, text-to-speech, text messaging, chat function on apps, writing things down or using pictures, Augmentative and Alternative Communication (AAC), or any combination of any of these. For some, the ability to speak is dependent on a variety of factors, and they may supplement speech with other modes of communication. In addition to this, some Autistic people may have differences in how they process auditory information, in that it may take longer to process information. This may require communication partners to allow a little more processing time during a conversation.

Communication is stronger when visually supported – as it reduces the need for processing verbal information. An autism-friendly environment adapts communication to the way that works best for an Autistic person, through the provision of visual supports, resources and time to process information.

Other differences in communication include:

- a desire to have purposeful conversations as opposed to small talk
- a dislike for tedious social scripts
- a preference for literal communication.

This however is individual, and it is important to understand a person's communication preferences.

Social situations

Traditionally, Autistic people have not been thought of as sociable people. This simply is not true, as a sense of connection and belonging is important for everyone. Autistic people are often very social beings, though their friendships can look different and should not be held to other people's standards. Also, for many, socialising can take quite a lot of effort so can be somewhat taxing, even if enjoyable.

"By most people's standards I am probably a terrible friend. I don't know how often I am meant to call/text, how to organise catch-ups, or how to 'hang out' at someone's house. I am terrible at knowing how to maintain friendships, so as a result I have very few close friends. But regarding those friends I do have ... the ones who don't mind my quirks; they are incredibly important to me, I am loyal to a fault, and if they need someone at 2am for literally anything ... I am there every time."

Autistic person

Eye contact

One of the common characteristics observed in Autistic people is differences in eye contact. For some Autistic people they may not do eye contact at all. For others it may be reserved for people they are very close to. Some Autistic people may seem to be staring off into the distance, whilst others may look around whilst communicating. For many Autistic people, eye contact feels very intense. In the past, it has been considered best practice to teach and demand eye contact when communicating, however this is incredibly taxing and often gets in the way of actually paying attention to the conversation.

"It's so awful when teachers single you out and demand you look at them when you are talking. I can't concentrate if I am worrying about looking at their eyes. You don't listen with your eyeballs, you listen with your ears."

Nine-year-old Autistic person

Self-identity

Social model of disability

Traditionally, autism has been viewed through the deficit model of disability. When undergoing a diagnosis for autism, the diagnostician is essentially checking to see if the person displays a certain amount observable behaviours indicative of autism. These behaviours through a traditional lens, have been viewed as deficits requiring remediation. So, all of the 'problem of autism' existed within the person, and to fix that 'problem' it was viewed the person needed to be shaped.

The social model is the more contemporary lens autism is now viewed through and it focuses on the things in the world that are disabling. The easiest way to make this really concrete is to think about someone who is reliant on a wheelchair for accessibility. Consider what it would be like as that person entering a building with a flat entrance, wide corridors, and an elevator, rather than having

to enter a building that has a couple of stairs and a broken elevator that nobody has bothered to fix and they have to get to the fifth floor. That same person is far more disabled in one circumstance than the other.

Applying this to autism, in a typical classroom in a mainstream class in Australia, an Autistic student is going to be far more disabled if the classroom presents sensory challenges – there is a lot of group work that is not facilitated well, ambiguity of instructions, reliance of verbal communication, lack of routine and a disorganised environment. In a well-supported classroom that student will still be Autistic, but they will be less disabled by what's around them – spending less cognitive and emotional energy managing an uncomfortable or unpredictable environment and more time engaged in class activities. The social model does not magically ameliorate all challenges of autism but it does go a long way.

Masking

Masking, also known as camouflaging or adaptive morphing, is when someone attempts to hide their Autistic characteristics in an effort to blend in with people around them.

It's important to note that everyone masks to some degree. An example of masking that most people do is the difference between one's work persona and what they are like at home. What is different for Autistic people is frequency and reason.

Many Autistic people feel as though they must mask 24/7 at home, at school, at work and in community. The reason Autistic people mask is not just to assimilate into the world around them but is also a matter of safety and to remain hidden from harm. Over a lifetime, masking becomes exhausting. Not being able to behave in a way that's natural is exhausting. In addition, being told that many of your natural behaviours need to change is really damaging to one's self-esteem.

Autistic burnout

Some Autistic people, in response to living in environments or having to meet expectations without accommodation, can experience Autistic burnout. Autistic burnout is a result of chronic life stress, when demands exceed an Autistic person's capacity to cope. An Autism CRC study, <u>Investigating autistic burnout (#AutBurnout): Final Report</u> (2021), defines it as "a severely debilitating condition that comes from the fatigue from masking, cognitive overload, unaccommodating environments and other stressors or change". Other than significant mental and physical exhaustion, Autistic burnout can be characterised by interpersonal withdrawal, increased sensory sensitivities and reduced executive functioning, which can significantly impact an Autistic individual's capacity to process information, remember, plan and perform basic self-care.

A common point of confusion in understanding Autistic burnout is that it can often be misrepresented as just a reflection of general life stressors, job-related stress or no different from

neurotypical experiences of burnout. Although these might be additional contributing factors, Autistic burnout is defined by the unique stress of masking or camouflaging, and living in an unaccommodating neurotypical world.

Preventing Autistic burnout can in itself be a difficult process that invites the opportunity for an Autistic person to develop the self-compassion and acceptance to exist outside neurotypical expectations for the preservation of self. Creating autism-friendly environments where Autistic individuals can engage in deep rest and self-care can positively contribute to an Autistic person's health and wellbeing.

Self-efficacy and self-esteem

Autistic people are often reported to have lower self-esteem than non-Autistic people. Many Autistic people report that they have to try much harder to get the same, or sometimes less result. When thinking about self-esteem within the context of the double empathy problem, it's easy to see how this can occur. When you are told your whole life that your natural way of existing is incorrect and should be changed by masking who you are, this is not only exhausting but impacts significantly on a person's self-esteem.

"Everybody is a genius, but if you judge a fish by the ability to climb a tree, it will live its whole life believing that is stupid."

Albert Einsteir

"We have to try ten times harder. People don't know that. It consumes a

Aspect Think Tank

"I would like teachers, OTs and other people working with Autistic people to think about how they would like to be treated if it were them."

Sibling of an Autistic person

Autism-positive culture

"Within my role and my personal life, I have had the privilege of hearing a lot of peoples' stories about their experience with autism. One theme that is constant and heart-breaking, is the feeling of shame and stigma that still gets attached to autism. I have encountered families who hide their child's diagnosis from everyone including schools, community, extended family members and sometimes even their child. I understand that comes from a place of good intention, as there are still people who perceive autism as a big, scary disorder rather than a neutral way of existing that can be supported and accommodated. Parents aim to protect their children, they don't want them to feel different. A lot of people conflate different with 'bad'.

The problem with this is that most Autistic people already feel like the odd one out from a really young age. Without understanding why, we feel so different to the other people, we just end up feeling like broken versions of everyone else. The very best thing to come from my own diagnosis was the gift of self-esteem. Finally, after 30-something years of feeling like a disappointment to everyone around me because I wasn't able to do life 'properly' (whatever that is), I had a reason for why I felt so different. I was able to give myself grace for the things I couldn't do.

Over the years, my feelings about this have evolved further. Now it's not just about giving myself grace for the things I can't do, it's realising that it's not that I can't do things, rather that I do things differently and sometimes even better ... just in a different way.

In short, if someone knows they are Autistic, and also knows that means their existence isn't sub-par, then life is just ... better. Infinitely better."

Autistic staff member

What does an autism-positive culture look like?

- Environments are adapted to be autism friendly in order to support Autistic people to be as well-regulated as possible.
- There is an understanding of and accommodation of individual sensory needs.
- individualised self-regulation skills (including stimming) are encouraged.
- Eye contact is not insisted on or taught.
- There is understanding of, respect for and encouragement of Autistic communication, listening and socialising skills.
- Support is available for Autistic people to understand typical communication, listening and socialising skills, to enable them to interact more broadly, whilst not promoting these as superior skills.

- Support of provided to develop self-advocacy skills.
- Calm and safe spaces for self-regulation are provided.
- Autism-positive language (i.e. language that does not describe autism as inherently negative) is adopted and used.

Common co-occurring conditions

More often than not, autism co-occurs with other conditions.

ADHD

Current literature suggests that 50–70% of Autistic individuals have ADHD as a coexisting condition (Hours et al., 2022). Whilst there is an overlap of characteristics between these two conditions in terms of attention and impulsivity, there are characteristics of ADHD that are distinctly different and may require supports that are not covered by typical autism-specific supports, for example the Autistic need for structured and routine versus an ADHDer seeking out novel experiences. See below for more information on ADHD.

- Aspect: <u>Autism & ADHD</u> fact sheet
- Aspect: <u>Understanding ADHD</u> fact sheet
- Aspect ADHD in girls and women fact sheet
- ADHD Australia
- <u>ADHD Foundation</u>
- Health Direct
- Royal Children's Hospital ADHD information sheet

Dyslexia, dyscalculia, specific learning disability

Various learning disabilities such as dyslexia, dyscalculia and specific learning disability are not an inherent part of autism, nor are they caused by it. It is important to note however, that they are more common in Autistic individuals – when working with Autistic students/participants it is worth noting that this could be a possibility. See below for more information on these areas.

- Auspeld
- SPELD NSW
- <u>Dyslexia Association Australia</u> (also provide information on dyscalculia and dysgraphia)
- <u>Dyslexia SPELD Foundation</u> (also provides information on dyscalculia and dysgraphia)

Mental health and trauma

Current literature suggests that more than 70% of Autistic people have a coexisting mental health condition, including depression, anxiety, eating disorders, schizophrenia, post-traumatic stress disorder (PTSD) and borderline personality disorder (BPD). The reasons these conditions are so prevalent in the Autistic community is largely believed to be sociological, and due to the experiences of living life in society as a neuro-divergent person.

Intellectual disability

It is common for people to conflate intellectual disability with autism, however this is not the case, with approximately two-thirds of Autistic individuals having average or above-average cognition. It is also worth noting that cognition can be difficult to accurately measure due to communication differences that can be present for Autistic people. This means intellectual disability is a relatively common co-existing condition within autism. For more information on intellectual disability go to Council for Intellectual Disability.

Medical conditions

Postural orthostatic tachycardia syndrome (POTS), Ehlers Danlos, gastrointestinal issues, and epilepsy are all significantly more common with Autistic people than non-Autistic people.