

# Talking about autism

Guidelines for respectful  
and accurate reporting on  
autism and autistic people

# About this toolkit

**The media has an important role to play in shaping and reinforcing community understanding of and attitudes towards autism.**

Media stories can challenge public misconceptions and myths about autism, give autistic people a platform to share their stories and experiences in a positive way, help the general community to understand autism better, and foster greater acceptance of autistic people...or they can do the opposite – reinforce myths and inaccurate stereotypes, and perpetuate negative attitudes.

This toolkit has been created by Amaze to provide journalists and media professionals with evidence-based information and practical advice for sensitive and accurate reporting on autism.

These guidelines have been developed in collaboration with and informed by the experiences of autistic people and their families.

## About Amaze

Amaze is the peak body for autistic people and their supporters in Victoria. Amaze raises awareness and influences positive change for people on the autism spectrum and their families/supporters. Amaze provides independent, credible information and resources to individuals, families, professionals, government and the wider community.

### **Our social impact goal for 2040:**

A society that respects the dignity of every autistic person and provides real opportunities for them to participate and contribute.

## Media contacts

Contact the Amaze media team to gain expert comment for your story. Our team can connect you with our CEO, autistic people, their families, researchers and clinicians as required.

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# About autism

Autism is a neurodevelopmental condition that affects the brain's growth and development, and has characteristics that appear in early life.

Autism is not an illness or disease, it is a lifelong disability: people are born autistic and remain so all their lives. Amaze use the terms 'autism' to refer to this group of conditions including autism, ASD and Asperger's.

The term 'spectrum' is used to describe the range of characteristics and abilities found in autistic people, as well as developmental changes, such as improvement in language ability, which might occur over time. The spectrum does not refer to a 'scale' of autism severity as no such scale exists.

No two autistic people are alike. Everyone experiences autism in different ways, and has different support needs. However, almost all autistic people will exhibit the following traits in some form: difficulty with social communication and interaction, and restricted, repetitive patterns of behaviour, interests or activities.

Autism affects the way that individuals are able to interact with other people, and they may find the world a confusing place.

Autism may be present with other conditions. For example autistic people may also be diagnosed with an intellectual disability, language delay, epilepsy, Attention Deficit Hyperactivity Disorder, anxiety or depression.

In practical terms this translates into each autistic person having diverse needs for support in different areas of daily life to enable them to participate and contribute meaningfully in their community.

Amaze approaches its work with autism from the perspective of the **social model of disability** – that disability is caused by the way society perceives and accommodates people with a disability, rather than by a person's condition. This is in contrast to the **medical model of disability** that says people are disabled by their impairments or differences. Under the medical model, these impairments or differences should be 'fixed' or changed by medical and other treatments, even when they do not cause pain or illness. Amaze believes in reshaping society to better accommodate the needs of autistic people, not in changing autistic people so that they better fit society.

# Principles for reporting on autism

When reporting on autism it's vital to respect the dignity, independence and strengths of autistic people. Autism is not a deficit, affliction or tragedy — it's a unique skill set, perspective and way of living.

**Portray autistic people as real people.** Autistic people have jobs, families, talents, opinions and faults, like everyone else. Autistic people are not a separate class, and they should be represented as part of the community.

**The stories of autistic people should never be used as 'inspiration porn'.**

Like anyone, autistic people can be inspirational – but be careful not to imply they are inspiring just because they are autistic. Autistic people don't exist to motivate non-autistic people or help them to feel better about their lives. Describing an autistic person as 'heroic' or 'brave' just for completing everyday activities reduces them to an object of inspiration rather than an individual who is just trying to live their life. It also suggests that their disability is a hardship they need to overcome.

An easy test to determine if you are sensationalising the achievements of an autistic person is to ask yourself 'Would I use this descriptor if they weren't autistic?'

**Avoid generalising experiences of one autistic person to everyone who is autistic.** Each autistic person is unique and experiences autism differently.

**The language we use is powerful.**

Language helps change attitudes towards autism. On pages 7–9 of this toolkit, we have some recommended language; however, it's important to recognise that there are differing views within the autism community about how to describe autism. Always ask the autistic person how they would like to be represented and what terminology they feel most comfortable with.



# Common autism myths

## **Autism can be cured**

Our research shows that this is one of the most common misconceptions about autism: 30-55% of Australians agree/are unsure that autism can be cured. People are born with autism and it's a lifelong condition. It cannot be cured or prevented, and people do not grow out of it.

## **Autism is a mental illness or disease**

Autistic brains are simply 'wired' differently to neurotypical brains. Autistic people are not mentally ill (although mental illness commonly co-occurs with autism), nor do they have a disease.

## **Vaccines or emotionless parenting cause autism**

The fact is, there is no specific cause of autism.

The myth that vaccines, particularly the MMR vaccine, cause autism has long been debunked by medical science. However this misconception remains – our research shows that 12% of Australians agree/are unsure that vaccines cause autism.

Parenting style can certainly influence how an autistic child is able to cope with the world, but it is definitely not the cause of autistic behaviour.

## **Autistic people do not experience empathy**

Autistic individuals feel as much, if not more, empathy than others. However they may have trouble detecting emotions from unspoken interpersonal communication like body language or tone of voice. When emotions are communicated more directly, people with autism are much more likely to feel empathy and compassion for others, but they may express it in ways that are harder to recognise or have trouble expressing it.

## **Autistic people are violent**

There is no evidence that autistic people are more violent than those without autism. In fact, autistic people are more likely to be the victims of violence than perpetrators. If aggressive behaviors are shown by an autistic person, they are most likely caused by frustration, physical and/or sensory overload, or similar issues.

### **Only boys are autistic**

The current estimated ratio of autistic boys and men, to autistic girls and women, is 3:1. However girls and women are more likely to be misdiagnosed, or diagnosed later, than boys and men.

The ongoing systemic failure to identify and diagnose autistic girls and women results from a lack of recognition and understanding across sectors of the differences in how autism presents in girls and women compared to boys and men, as well as historic gender biases in autism screening and diagnostic tools.

### **Autistic people are anti-social**

Autistic people may need support with social skills or interact differently with the world around them, but most autistic people enjoy having friendships and other meaningful relationships.

### **All autistic people have outstanding talents**

The characteristics of autism vary significantly from person to person. Some autistic people have extraordinary memories, but most don't. Forget the Rain Man stereotype – like all people, autistic people have diverse and varied strengths.

### **Autistic people are intellectually disabled**

Many autistic people also have an intellectual disability, however others have an Intelligence Quotient (IQ) within the typical range or higher.

### **Autistic children need to go to special schools**

While some autistic students do attend special school, many go to mainstream schools – i.e. public and private schools for typically developing children. Amaze's position is that all autistic students should have access to an education system that provides an inclusive culture and a multi-faceted, individualised needs-based approach that is tailored to their strengths and unique learning styles.

# Autism language

## **Asperger's**

A form of autism that is usually characterised by high intellect, social and communication challenges, a strong focus on particular interests, and sensory sensitivity. Asperger's is pronounced with a hard 'G', not with a soft 'G' (as in purge). Asperger's is no longer recognised by the DSM-5.

## **Autism spectrum disorder (ASD)**

A group of conditions that includes autism, autistic disorder and Aspergers. Can be used interchangeably with autism.

## **Autistic**

Many people with autism prefer autistic to describe them and their autism instead of 'on the spectrum' or 'with autism'. The preference of 'identify-first language' is becoming more widespread, especially within the autistic community. Note: Whilst this is the preferred choice of language, it is best to ask any individual how they would like to be identified and described.

## **Autistic community**

Refers to the collective community of autistic people.

## **Autism community**

Refers to a range of people that may include autistic people, their friends and family, advocacy groups, researchers, autism supporters, or people who work in the autism field.

## **Meltdown**

The result of sensory or information overload that results in the autistic person becoming distressed and unable to cope. A meltdown is not a tantrum or something that can be controlled.

## **National Disability Insurance Agency (NDIA)**

The independent Commonwealth agency responsible for implementing the NDIS.

## **National Disability Insurance Scheme (NDIS)**

A Commonwealth scheme that aims to provide individualised packages of support to people with disability, and enable choice and control over the design and delivery of those supports. Some, but not all, autistic people are eligible for the NDIS.

## **Neurodiversity**

The diversity of human brains. It is similar to other forms of natural diversity, such as ethnic, cultural, sexual, or gender diversity. The adjective 'neurodiverse' is used the same way one would use a phrase like 'ethnically diverse'. As such, individuals should not be described as 'neurodiverse'.

## **Neurotypical**

A label for people who are not on the autism spectrum. Because this term is typically only used in the autism community it may not be applicable in mainstream media.

## **Sensory sensitivity**

Acute awareness of light, sound, texture, touch, taste or smell, commonly experienced by autistic people.

## **Stimming**

Behaviour that many autistic people engage in to calm, comfort, soothe and regulate themselves when they are becoming overwhelmed or anxious. Some of the ways autistic people 'stim' is by rocking back and forth, twiddling, using fidget spinners, holding toys or repeating words.



<b>Consider this...</b>	<b>Instead of this...</b>	<b>Because...</b>
Autistic person	Person with autism Person on the autism spectrum On the spectrum	Research from the UK, as well as feedback Amaze has received from the Australian autistic community, shows a preference for identity-first language, i.e. 'autistic', as it places autism as intrinsic to a person's identity and helps promote autistic pride and self-acceptance. Always ask the autistic person what they prefer.
Is a (insert job title or other descriptor that conveys their humanity)	Is a hero Is an inspiration	Framing an autistic person's identity as inspirational suggests that it is surprising that autistic people can achieve great success.
Is autistic	Is a victim of autism Suffers from autism	While autism can have its challenges, every autistic person is an individual whose life is valuable and rich. Autistic people have many different strengths and abilities and see autism as something to be celebrated
Has achieved	Has overcome the odds/ adversity to achieve	It implies that people are limited by autism and unable to achieve success.
Disability	Disease Illness	Autism is diagnosed as a disability. It's neither a disease, nor an illness.
Low/high support needs	Low/high functioning Mild/severe autism	The terms 'high functioning' and 'mild' invalidate the difficulties an autistic person may experience, and the terms 'low functioning' or 'severe' may ignore their strengths and capabilities. Autism is a spectrum, not a scale.
Typically developing children	Normally developing children	Autistic children may show different patterns of development to neurotypical children but they are not abnormal.
Supported by their family	Is a burden on their family	The term 'burden' invalidates the strengths and independence of the autistic person and implies that their family feels encumbered by providing them with support.

# Autism: the facts

## Prevalence

- Approximately 1% of the population are autistic. (ABS SDAC 2015 – *Autism in Australia*)
- In 2015 there were 164,000 autistic Australians, yet there is no lifelong population data to provide an accurate figure, and is estimated to be higher than this figure. (ABS SDAC 2015 – *Autism in Australia*)
- Currently, three times as many males are diagnosed as females. (Loomes et al 2017)

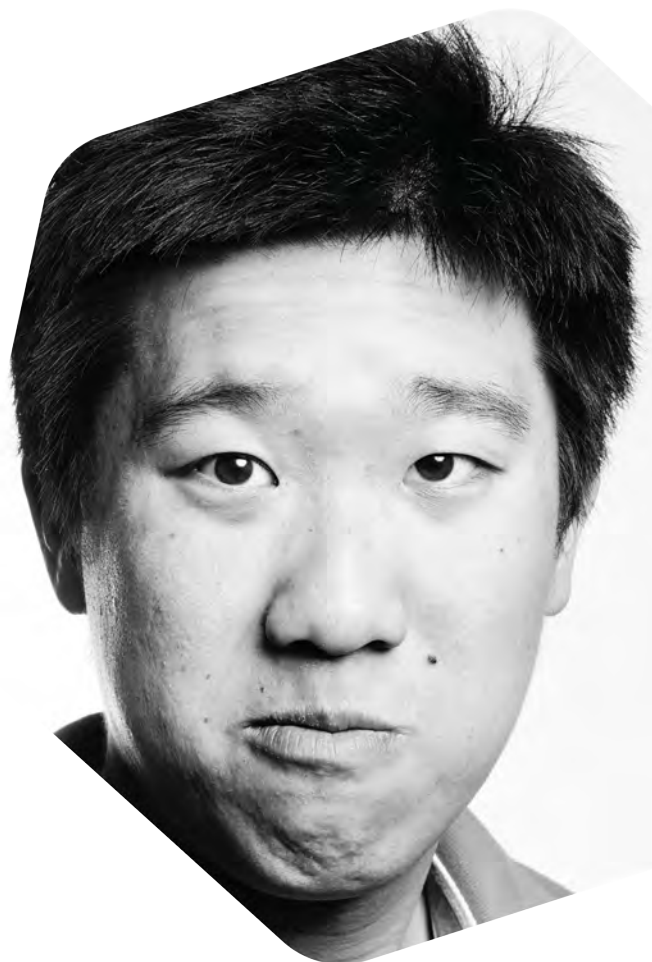
## Community attitudes towards autism and experiences of autistic people

In May 2018, Amaze released the results of two ground-breaking research studies looking at general awareness, knowledge and understanding of autism and social isolation in Australia. Both the autistic and non-autistic community was surveyed.

### Key findings:

- Nearly all Australians (98%) have heard of autism, and 86% of people have contact with an autistic person. One in five people has an autistic friend, and one in four has an autistic relative.
- Yet despite the widespread awareness and personal connection, only 29% of respondents said they know how to support an autistic person. And when the researchers asked the same question of autistic people, only 4% of them believed people in the community knew how to support them.
- 52% of autistic people report feeling socially isolated and 40% of autistic people sometimes feel unable to leave their home.
- Autistic people report high levels of negative day-to-day interactions: 81% have been stared at, 61% have experienced people 'tutting' at them or shaking their heads and 48% have been avoided or shunned.
- Australians overwhelmingly agree that autistic people are discriminated against (84%) and almost eight in 10 Australians (78%) believe autistic people have difficulty making friends.

Find more statistics here: [www.onethingforautism.com.au/get-the-facts](http://www.onethingforautism.com.au/get-the-facts)



## Assessment and diagnosis

- There is no nationally consistent standards for autism assessment and diagnosis in Australia. (Autism CRC 2017)
- There is significant evidence that many autistic children can be reliably diagnosed by the age of 24 months; however, many people are not diagnosed with autism until adulthood. (Guthrie et al 2013)
- Waiting times for diagnosis can range from one week through to two years, with longer waits occurring in the public system and in regional, rural and remote Australia. (Taylor et al 2016)
- People may incur up to \$2750 in personal costs to access an assessment. The median cost is \$580. (Taylor et al 2016)

## Education

- 97% of autistic students experience educational restrictions. (ABS SDAC 2015 – Autism in Australia)
- Autistic students are four times more likely to be bullied than other students (Autism and Education in Australia, Roberts 2015).
- Autistic students are significantly more likely than their typically developing peers to be suspended or excluded, to suffer depression and anxiety and to under-perform academically relative to their level of intelligence. (Barnard et al 2000; Kim et al 2000; Ashburner et al 2010)
- 44% of autistic children need more support or assistance at school than they are receiving. (ABS SDAC 2015 – Autism in Australia)
- 35% of autistic students do not go beyond Year 10 compared to 18% of people without disability. (ABS SDAC 2015 – Autism in Australia)

## Employment

- In 2015, the unemployment rate for autistic people in Australia was 31.6%. This is three times the rate of people with disability, and almost six times the rate of people without disability. (ABS SDAC 2015 – Autism in Australia)
- A survey conducted by Amaze of the Victorian autism community in 2016 found that only 50% of respondents had been able to find employment, with 94% reporting that they had not received enough support to help find a job.

## Mental health

- Approximately 50-70% of autistic people experience co-occurring mental health conditions, most commonly depression, anxiety disorders and/or obsessive compulsive disorder. (Foley and Troller 2015)

## NDIS

- People with autism account for 29% of NDIS participants – the largest diagnostic group in the scheme. (NDIS 2018)
- In the 0-7 age group, autism accounts for 50% for all NDIS participants. (NDIA 2016)

# Interviewing autistic spokespeople

A guiding principle in the disability community is 'Nothing about us without us'. When reporting on autism, aim to give autistic people a voice and the opportunity to share their experiences first-hand.

## Preparing for an interview

Along with your usual pre-interview research and preparation, there are a couple of things you should consider when preparing to interview an autistic person.

### Briefing

Autistic people like predictability so spend some time explaining in detail exactly what will happen in the interview. For example, where you'll meet, how to get there, how many questions you have, how long the interview will go for. Allow time for the interviewee to ask questions about the process.

### Interview format

Aim to make the interview as comfortable as possible for the autistic person. Ask how they would like to conduct it: some may prefer to meet in-person, respond to interview questions over email, or answer questions with support from a family member/carer. Some autistic people find it uncomfortable or difficult talking on the phone so do not rely on this as the only way to interview someone.

Bright lights, loud sounds and crowds can be overwhelming. If interviewing someone in-person, ask what adjustments to the physical environment would make them feel most comfortable and plan accordingly. If possible, ensure there's a quiet space available in case the interviewee feels overwhelmed.

### Scheduling

Give the interviewee as much notice as possible and avoid changing plans and details at the last minute as this can cause anxiety. If plans do change, take the time to explain the new plan and ensure they understand.

Allow longer than usual for an interview. The autistic person may require more time than others to process the questions and form a response.

## During the interview

Here are some key things to keep in mind during the interview:

- Be on time – autistic people are most calm when they can stick to a schedule.
- At the beginning of the interview go over the details of what will happen, even if you have previously explained this.
- Every autistic person will view their disability differently. Ask them how they would like their autism to be described and their preferred terminology.
- Ask for consent if you need to encroach on the interviewee's personal space, for example, to mic them up.
- Some people may feel uncomfortable making eye contact. This does not mean they're not listening or engaged.
- Use clear, direct language. Autistic people can be very literal – avoid sarcasm or idioms.
- Aim to give the interviewee time and space to respond. Pose questions that contain one idea/concept at a time.
- The person may have trouble keeping up with the conversation or get confused with lots of information. If they don't understand what you're saying, be prepared to re-phrase a question or repeat instructions.
- Make sure you focus on the interviewee during the interview, even if a carer, friend or family member tries to speak on their behalf. It is important that the autistic person feels heard.
- Respect the level of personal detail that someone is willing to divulge. Like anyone, autistic people have a right to privacy and the autonomy to choose what parts of their story they want to make public.

## Where to find spokespeople

Contact the Amaze media team to gain expert comment for your story. Our team can connect you with our CEO, autistic people, their families, researchers and clinicians as required. Call 03 9657 1600 or email [communications@amaze.org.au](mailto:communications@amaze.org.au).

Amaze proactively engages with the autism community. If our spokespeople cannot provide the commentary you require, we can put you in touch with someone who can.

# Image guidelines

How autistic people are represented in film and photos is just as important as the language used to describe them.

This following provides some considerations for the visual representation of autism and autistic people:

- Use photos that portray the autistic person in a way that is positive and respectful, not as a victim, someone to be pitied, or 'inspiration porn'.
- Try not to photograph or film the person in isolation. Unless this is key to the story, show them as a part of the community.
- Try to photograph the autistic person in a way that highlights their unique character, personality or interests – just as you would with any other interviewee.
- Avoid using images that reinforce stereotypes of autism as mysterious or negative e.g. article images that use puzzle pieces, or depictions of people hidden, blurred or in the dark.



# Further resources

## **Amaze Position statements:**

[www.amaze.org.au/about-us/policy/position-statement](http://www.amaze.org.au/about-us/policy/position-statement)

## **Real stories of autistic people**

[www.onethingforautism.com.au](http://www.onethingforautism.com.au)

[www.spectrospective.com.au](http://www.spectrospective.com.au)

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