

Talking about autism

Guidelines for respectful
and accurate reporting on
autism and autistic people

Summary

Talking about autism is a toolkit with guidelines for the media on reporting about autism and autistic people. The media has an important role to play in shaping and reinforcing community understanding of and attitudes towards autism.

Some key points to remember when reporting on autism:

- 1. Use appropriate language:** When reporting about autism and autistic people it is important to use respectful and accurate language. Consider using identity-first language, such as 'autistic person' instead of 'person with autism' as this is becoming more widespread in the community. Never use outdated language that can reinforce misconceptions about autism.
- 2. Avoid objectifying autistic people or using their stories as 'inspiration porn':** Portray autistic people as real people. Autistic people don't exist to motivate non-autistic people or help them to feel better about their lives.
- 3. Feature autistic voices:** When reporting about autism, give autistic people a voice and the opportunity to share their experiences first-hand.
- 4. Use respectful photos and images:** Always show an autistic person as being part of the community. Avoid using images that reinforce stereotypes of autism as mysterious or negative. Use the rainbow infinity symbol instead of puzzle pieces.
- 5. Dispelling the myths of autism:** There are many myths and misconceptions about autism and this is damaging to autistic people. Amaze can provide research and evidence-based facts.

Contents

About this toolkit	4
Find out about using this toolkit, the work Amaze does and who to contact for your next story	
About autism	5
Describing autism and understanding how to report about it	
Principles for reporting on autism	7
Reporting about autism is about ensuring the dignity, independence and strengths of autistic people	
Common autism myths	8
Debunking the common myths associated with autism	
Autism language	10
Common terms to help understand autism better	
Interviewing autistic spokespeople	13
How to conduct an interview with an autistic person	
Image guidelines	15
Autism: the facts	16
Research and evidence-based facts about autism and autistic people	
Further resources	18
References	19

About this toolkit

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

Media reports can challenge public misconceptions and myths about autism. They present 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.

However, inaccurate reports have the potential to be damaging by reinforcing myths and false stereotypes, perpetuating negative attitudes, or using incorrect and hurtful language.

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

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

About Amaze

Amaze has been providing support to autistic people and their families/carers for over 50 years. Amaze increases understanding of autism and influences positive change for autistic people and their families/supporters. Amaze provides independent, credible information and resources to individuals, families, professionals, government and the wider community. Amaze delivers [Autism Connect](#), a free national autism helpline.

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 communications team to gain expert comments for your story. Our team can connect you with our CEO, autistic people, their families, researchers and clinicians as required.

Amaze communications team

Phone: (03) 9657 1600

Email: communications@amaze.org.au

About autism

Autism is a neurodevelopmental disability with traits appearing early in life.

Autism is not an illness or disease, it is a lifelong disability. People are born autistic and remain so all their lives. Autism is part of a group of conditions referred to as autism spectrum disorder (ASD). ASD became the official diagnosis in 2013 and includes Asperger's syndrome and pervasive developmental disorder not otherwise specified (PDD-NOS).

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 'linear scale' of autism severity as no such scale exists. The spectrum looks more like the illustration below. Autism consists of many different traits or ways in which the brain processes information.



Illustration: Developed from the autism app wheel created by Mark Coppin in 2012

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 narrow, repetitive patterns of behaviour, interests or activities.

Autism changes the way that individuals interact with other people, and autistic people may find the world a confusing place.

Autism may be present with other conditions. For example, autistic people may also be diagnosed with intellectual disability, language delay, epilepsy, attention deficit hyperactivity disorder (ADHD), anxiety and/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 different 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 10–12 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.

Remind your audiences that support is available. Amaze has launched Autism Connect, Australia's national autism helpline: 1300 308 699. It is available for autistic people, their friends and family, and the broader community. Amaze encourages you to include details of the helpline at the end of reports regarding autism.

Common autism myths

MYTH: Autism can be cured

FACT: People are born autistic and it's a lifelong condition. It cannot be cured or prevented, and people do not grow out of it. 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.

MYTH: Autism is a mental illness or disease

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

MYTH: Vaccines or emotionless parenting cause autism

FACT: 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 and 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 autism.

MYTH: Autistic people do not experience empathy

FACT: Autistic people feel a range of empathy levels just as non-autistic people do. However, autistic people may have trouble detecting emotions from unspoken interpersonal communication like body language or tone of voice. When emotions are communicated more directly, autistic people are much more likely to feel empathy and compassion for others. They may have trouble expressing it or they may express it in ways that are different or harder to recognise.

MYTH: Autistic people are violent

FACT: There is no evidence that autistic people are more violent than non-autistic people. 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.

MYTH: Only boys are autistic

FACT: 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 can present in girls and women compared to boys and men. This is in addition to historic gender biases in autism screening and diagnostic tools.

MYTH: Autistic people are anti-social

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

MYTH: All autistic people have outstanding talents

FACT: 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.

MYTH: Autistic people are intellectually disabled

FACT: Intellectual disability isn't an autistic trait, however many autistic people do have co-occurring intellectual disability. Autistic people should not be assumed to have intellectual disability. Regardless, all autistic people must be treated with equal respect.

MYTH: Autistic children need to go to 'special schools'

FACT: While some autistic students do attend specialised schools, 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.

MYTH: Everyone is a little autistic

FACT: Only autistic people are autistic. Autism is a neurodevelopmental disorder and people are either autistic or not autistic. The autism spectrum is not a linear scale of 'not very autistic' to 'very autistic'. The autism spectrum refers to the diversity of traits of autistic people.

Autism language

Asperger's

Asperger's 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 (Diagnostic and Statistical Manual of Mental Disorders, which contains descriptions, symptoms and other criteria for diagnosing mental disorders). This means that Asperger's is no longer given as a diagnosis in Australia.

Note: Some people still identify as having Asperger's. It is best to ask an individual how they would like to be identified and described.

Autism spectrum disorder (ASD)

The DSM-5 lists Autism Spectrum Disorder as the umbrella diagnosis for four previously separate categories of autism. These were autistic disorder, Asperger syndrome, childhood disintegrative disorder and pervasive developmental disorder-not otherwise specified (PDD-NOS). Autism and autism spectrum disorder can be used interchangeably.

Autistic

Many autistic people prefer autistic to describe them 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, for individuals, it is best to ask 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.

Masking

Masking is the camouflaging of autistic traits to fit in. Many autistic women and girls mask, however it isn't just limited to them. All types of autistic people have the potential to mask their traits. Masking is much more common in people from marginalised groups including LGBTQIA+ people and people from culturally and linguistically diverse backgrounds.

Meltdown

The result of sensory or information overload that results in an 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. Autistic people make up 35% of NDIS participants.

Neurodivergent

A label for someone or a group of people who's brain is 'wired' differently to the majority. This label is generally inclusive of autism, ADHD, epilepsy and many more. Note: It is best to ask an individual how they would like to be identified and described.

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 neurodivergent. Because this term is typically only used in the neurodivergent community it may not be applicable in mainstream media.

Sensory sensitivity

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

Shutdown

Shutdowns are similar to meltdowns but they are the result of an autistic person internalising their distress. During a shutdown, an autistic person either partially or completely withdraws from the world around them.

Stimming

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

Consider this...	Instead of this...	Because...
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 autism should be seen as something to be celebrated.
Has achieved	Has overcome the odds/ adversity to achieve	It implies that people are limited by autism and unlikely 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' ignore 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.

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. Send questions to the interviewee ahead of time to help them prepare and stick to those questions.

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. 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. Autistic people may need more time to process what's being said.

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 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 and respected.
- 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 communications 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.

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.
- Instead of a puzzle piece, use more autism-positive symbols such as the neurodiversity rainbow infinity symbol. Many autistic people find the puzzle piece imagery offensive. Autism is not a puzzle that needs to be solved.



Autism: the facts

Prevalence

- Around 1 in 100 Australians are autistic.
- In 2018 there were 205,200 autistic Australians. However, there is no lifelong population data to provide an accurate figure, and so the population is estimated to be higher than this figure. (ABS SDAC 2018 – 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



Assessment and diagnosis

- There are 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 \$2,750 in personal costs to access an assessment. The median cost is \$580. (*Taylor et al 2016*)

Education

- 92.3% of autistic students experience educational restrictions. (*ABS SDAC 2018 – 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 non-autistic peers to be suspended or excluded, to experience 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*)
- 45.9% of autistic children need more support or assistance at school than they are receiving. (*ABS SDAC 2018 – Autism in Australia*)
- 32.4% of autistic students do not go beyond Year 10 compared to 15.4% of people without disability. (*ABS SDAC 2018 – Autism in Australia*)

Employment

- In 2018, the unemployment rate for autistic people in Australia was 34.1%. This is three times the rate of people with disability, and almost eight times the rate of people without disability. (*ABS SDAC 2018 – Autism in Australia*)
- In an Australian-first study conducted by Amaze, 53.9% of unemployed autistic Australians stated they have never held a paid job despite having the skills, qualifications and desire to join the workforce.

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

- Autistic people account for 35% 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*)

Further resources

Amaze position statements

www.amaze.org.au/about-us/policy/position-statement

Real stories of autistic people

www.onethingforautism.com.au

www.spectrospective.com.au

Autism Connect - National autism helpline

Phone: 1300 308 699

Email: info@autismconnect.org.au

Webchat: www.amaze.org.au/autismconnect/

Media contacts

Amaze communications team

Phone: (03) 9657 1600

Email: communications@amaze.org.au

References

- Ashburner, J. et al 2010, Surviving in the mainstream: Capacity of children with Autism Spectrum Disorders to perform academically and regulate their emotions and behaviour at school. *Research in Autism Spectrum Disorders*, 4(1), 18-27
- Australian Bureau of Statistics 2018, Autism in Australia. Survey of Disability, Ageing and Carers: Summary of Findings. See <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#autism-in-australia>
- Autism CRC 2017. The diagnostic process for children, adolescents and adults referred for assessment of autism spectrum disorder in Australia' -Draft version for community consultation. Available at <https://www.autismcrc.com.au/get-involved/participatestudy/national-guideline-now-open-community-consultation>
- Barnard, J. et al 2000, Inclusion and autism: Is it working? London: The National Autistic Society
- Foley K and Troller J 2015. Management of mental ill health in people with autism spectrum disorder. *Australian Family Practitioner*, 2015;44:11;p. 784 – 790.
- Guthrie, W., et al (2013). Early diagnosis of autism spectrum disorder: stability and change in clinical diagnosis. *Journal of Child Psychology and Psychiatry*, 54(5), 582–590. Available at http://www.researchgate.net/publication/232318674_Early_diagnosis_of_autism_spectrum_disorder_stability_and_change_in_clinical_diagnosis_and_symptom_presentation; Zwaigenbaum L et al (2015) Early Identification of Autism Spectrum Disorder: Recommendations for Practice and Research *Pediatrics* Oct 2015, 136 (Supplement 1) S10-S40; DOI: 10.1542/peds.2014-3667C
- Kim, J. A. et al 2000, The prevalence of anxiety and mood problems among children with autism and Asperger Syndrome. *Autism*, 4 (2), 117-132
- Loomes R et al 2017. What is the Male-to-Girls/women Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis. *J Am Acad Child Adolesc Psychiatry*, vol 26, no, 6, pp. 466-474
- NDIA Quarterly Report to COAG 2017-2018 Q3
Available at: <https://www.ndis.gov.au/medias/documents/dashboard-national-mar-18-pdf/dashboard-national-march-18-pdf.pdf>
- NDIA 12th Quarterly Report to COAG 2015-16 Q4
Available at: <https://www.ndis.gov.au/about-us/information-publicationsand-reports/quarterly-reports>
- Taylor, L., Brown, P., Eapen V et al (2016). Autism Spectrum Disorder Diagnosis in Australia: Are we meeting Best Practice Standards? Autism Co-operative Research Centre, Brisbane.