



Autism

Best practice guidelines

Recommended supplement: Social model of disability

Content warning

Violence against autistic people, ableism, abuse, and eugenics are mentioned.

Definitions

Autism is a neurodivergent disability that can affect social interaction, communication, behavior, sensory sensitivity, mental processing, motor skills, and language in varying ways. It is considered **neurodivergent** because it is a different neurological experience—not necessarily a deficit or something unfavourable.

It is officially known as **autism spectrum disorder** within the Diagnostic Statistical Manual (DSM) 5 (a broad resource used for the diagnosis of different disabilities and mental health issues). The idea of the ‘autism spectrum’ is incomplete, as the characteristics and symptoms of autism don’t present in particularly consistent combinations. This makes for a wide range of possibilities in how an autistic person may present.

In previous versions of the DSM, there were several different diagnoses that could be given to autistic people. These included: Asperger’s syndrome; autistic disorder; childhood disintegrative disorder; and pervasive developmental disorder not otherwise specified (PDD-NOS). These have now been combined into the umbrella diagnosis of autism spectrum disorder.

This means it’s even more important to recognise that any two autistic people are likely to relate strongly, but also have notable differences in their neurodiversity.

Diagnosis

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Some people within the autistic community have an **official diagnosis** from a doctor or psychiatrist. A person may get this diagnosis as a child, as a teenager, or as an adult. Having an official diagnosis may allow a person to be eligible for certain services, supports, or accommodations in different places.

Other autistic people may be **self-diagnosed**. This means they have identified the characteristics of autism within themselves, but have not received an official diagnosis from a doctor or psychiatrist. A person may self-diagnose at any age as well, but children and teenagers as a whole usually need significant guidance from adults in their life to make decisions about their health and wellbeing.

Someone may self-diagnose for several reasons: they may not want the stigma or baggage that comes with an official label; they may not be able to afford to see a doctor or psychiatrist to get a diagnosis; or they may live in an area where they do not have access to someone who can diagnose them professionally.

It is important to acknowledge the diagnostic criteria and common presentations of autism are mostly representative of white, cisgender, straight autistic men. Autistic women and autistic people of other marginalised genders; autistic queer and trans folks; autistic people of colour; and autistic people with mental illness or other disabilities may not receive an official diagnosis as frequently as white, cisgender, straight autistic men for this reason.

Both official and self-made diagnoses are valid, and people with either sort of diagnosis can identify as autistic or consider themselves part of the autistic community.

Community

In the autistic community, autism is generally not viewed as a deficiency; but as a different—and equally valid—way for human brains to function. Quite often, it is embraced as a core component of a person's identity. What makes it troublesome is that the statistical majority of people's brains work another way, and societal structure and norms are built to support non-autistic people with little regard for autistic people. This relates to the **social model of disability**.

Many allistic people have advocated for using **person-first language** when referring to autistic people. This means using 'person with autism' instead of 'autistic person' when referring to someone who is autistic. However, most autistic people prefer **identity-first language**, such as 'autistic person' or 'I'm autistic', because they consider their autism to be an integral part of who they are. This is why throughout the guide, identity-first language has been used.



When speaking on behalf of any disabled or neurodivergent group use what actual disabled people—with the relevant disability or neurodivergent condition—suggest. This is especially when talking about a specific disabled person, ask them how you should talk about them.

Organisations and symbolism

There are many different organisations within the world who claim to support autistic people. Some are more geared towards supporting parents, families, and caregivers of autistic people, sometimes at the expense of the autistic person themselves. An easy way to check is to find out whether the people on the board of directors, or who are in leadership positions of the organisation, are autistic people. Many of the organisations most commonly known to non-autistic people are those organisations who don't have any autistic people on their board or within their leadership.

Organisations led by autistic people include:

- Autistic Self Advocacy Network (ASAN)
- Autistic Women and Nonbinary Network
- The ICAN Network

There are certain symbols perpetuated by non-autistic-led organisations, which are widely despised by autistic people for what they represent. This is usually because they further the idea that autistic people are broken and need fixing, or because they have links to a particularly harmful non-autistic-led organisation.

Some more positive symbols include the infinity symbol, or the hashtag #ActuallyAutistic. These won't always guarantee the quality of the content, or signal a red flag when they are not present, but they can act as a guide if they are there. These may change over time, and new symbols may be developed.

Experience

It's important to remember that every autistic person has a different experience of being autistic. They will look, sound, communicate, understand, move, and behave in a way that is unique to them and their own autistic experience.

A spectrum between high and low functioning level has often been used to categorise autistic experiences. This concept lacks nuance around what functioning means and looks like in a person's life,



instead prioritising what autistic people can or cannot do within a world not designed for them and their experiences.

Autism can present in myriad ways and the degree to which these experiences manifest—both outwardly and inwardly—varies from person to person. This guide will look at each in some more detail, while recognising they all interact with each other to contribute to a holistic autistic experience for each individual.

Social interaction and empathy

There are many preconceptions about autistic people and their ability (or lack thereof) to socialise and experience empathy.

The neurotypical human social experience has many layers and complex structures and processes, which are usually highly context-sensitive and not clearly explained anywhere. Non-autistic people often communicate with a lot of implied subtext, which they assume the other people they interact with will understand and process in a neurotypical way. An autistic person will not process this in a neurotypical way, because their brain is not neurotypical, meaning they may miss a lot of the implied subtext and contextual clues unless these are made explicit. This may make it very challenging for an autistic person to navigate social interactions with non-autistic people, particularly as the social fabric of society is built for non-autistic people.

Some autistic people may create and use social scripts to support themselves in their communications with non-autistic people. A social script is a set of things to say in a particular social situation.

Before we look at autistic people and empathy, it's important we identify some different types of empathy to ensure a nuanced exploration of the topic.

Affective empathy usually refers to the innate ability to feel what another person or living thing is feeling. Autistic people often have very high levels of affective empathy, and experience extreme physical and psychological pain at the thought of people experiencing suffering.

Cognitive empathy usually refers to the skill of working out what another person or living thing is feeling or thinking. Non-autistic people usually have an easier time learning this skill, because their brains are more wired to process complex symbolic concepts or read between the lines to decipher what someone is actually intending to communicate.



Compassionate empathy combines the recognition of someone else's situation with a desire to help. Autistic people may have difficulty finding which help is useful for the person or creature needing assistance, but usually do experience a desire to help.

Communication and language

Autistic people may communicate in ways that appear unusual or strange to non-autistic people, and may interpret what people communicate to them in a different way that most non-autistic people expect. It is important for non-autistic people to consider how they phrase things when speaking with autistic people, and what avenues of communication are available.

Many autistic people interpret language very literally, and may struggle to understand the meaning behind metaphors or symbolic language use. Similarly, autistic people may find a long, complex set of directions or instructions to be overwhelming, or may process the same instructions better in a written or visual format.

Some autistic people may have a tone of voice that appears unusual to non-autistic people. It may be a different tone or pitch, or may contain inflections and emphasis at different stages. Additionally, some autistic people may engage in echolalic speech. This means they repeat a particular phrase or word to themselves. This may be as a form of self-stimulation, self-regulation, or communication.

Some autistic people may appear minimally communicative to non-autistic people because they do not use verbal speech, or do not have an established nonverbal or nonspeaking communication technique. This does not mean they cannot understand their world and their interactions, nor that they cannot communicate their needs, wants, intentions, and opinions to others. We need to recognise that communication comes in many forms, and to understand that a particular behaviour may act as a form of communication for an autistic person.

Some autistic people are nonspeaking. This means they do not communicate by speech, and instead may use sign, written language, picture exchange communication systems, or text to voice communication systems. Sometimes, this is referred to as 'nonverbal'. However, many autistic people do not feel this accurately and respectfully defines communication without speech, and prefer to use the term nonspeaking.

A non-speaking autistic person can still be intelligent, communicative, and sociable, and can want to communicate with others to express themselves, communicate a need or want, to socialise and connect with others, and to advocate for themselves or others. It is common for non-speaking autistic people to



be misrepresented as not being able to understand their world, or not able to form and have opinions, intentions, needs and wants, or not being able to form friendships and connections.

You can support autistic people to better understand and engage in communication within your workplace, event, or game by using plain language, straightforward instructions, and by providing this information in multiple formats (pictures, verbal, written). It is important to have options for communicating within your workplace, or event, or game context, that are not reliant on speech. This enables non-speaking people to fully participate in and learn from the communication.

Behaviours may also play a role in how an autistic person communicates. For someone who does not have an established communication system (verbal, nonverbal, speaking, or nonspeaking), they may perform certain behaviours which communicate their needs, wants, feelings, experiences, and opinions. It is important to look at what a behaviour—particularly a challenging or difficult behaviour—may be attempting to communicate to us, rather than simply writing it off as a problem.

Sensory sensitivity

The way an autistic person experiences their senses may be very different from how a non-autistic person experiences their senses, even if they are within the same physical space or experiencing the same thing. As the world is usually built for the sensory needs of a non-autistic person, autistic people may experience sensory overload or discomfort within spaces.

Autistic people may experience sensory input more intensely than non-autistic people. This means that certain sounds, sights, smells, or tastes that a non-autistic person may find unobtrusive or mild may be extremely overwhelming, painful, frightening, or exhausting for an autistic person. When these sensory experiences accumulate without a release or an opportunity to take a break, it can lead to sensory overload. This causes an autistic person to be unable to function, focus, or self-regulate in a high-sensory environment.

Common sources of such sensory input which may contribute to sensory overload include: background noise; fluorescent lighting; fragrances and perfumes; cleaning products; intense, pungent, or otherwise sharp foods and drinks; flickering lights; alarms; sirens; and other innocuous background noises. An autistic person may also be overly sensitive to physical sensations, such as the feeling of clothes on their skin; the touch of another person in a hug or handshake; or the sensations of heat and cold. This can also contribute to sensory overload.



Conversely, an autistic person may seek out more extreme sensory inputs because they naturally experience a very low level of sensation from that sensory input. For example, an autistic person may seek out a strong physical sensation, or seek out a particular noise or sight. They may also seek out experiences which provide strong vestibular sensory input, which refers to the sensations of where their body is within space, and how they are balancing. The seeking out of such sensory experiences can be a form of self-stimulation (stimming), or may act as a way to regulate their brains and bodies.

Cognitive processing

Autistic people think differently to non-autistic people. This means they may interpret situations differently, and have different thresholds for becoming overwhelmed and coping with changes in routine.

They may also require additional energy for performing executive functioning tasks—like starting or stopping an activity or task or making decisions.

Motor skills and physical movement

Autistic people may move in a way that appears unusual to non-autistic people. This may include a different gait or walking style to most non-autistic people; difficulty with coordinating complex movements; needing additional time and support to start or stop certain movements; and having a different level of awareness of where their body is within a space.

Some stims involve motor movement. These may include: moving their hands, arms, feet, or legs; rocking back and forth; walking in a repeated pattern; or using a fidget tool. These movements may appear to be aimless to a non-autistic person, but they may serve a regulatory function.

Meltdowns and shutdowns

An autistic meltdown refers to a high-energy outburst to relieve emotions and overstimulation. It may involve screaming or making other loud noises; hitting or other physical movements; or hurting oneself (Davies 2019). There may be a build up to an autistic meltdown, or it may occur almost instantaneously.

An autistic shutdown is a response to the same high levels of emotions and overstimulation, but one that is focused inward rather than outward. The brain protects the self by shutting off its ability to perceive and interpret different sensory input.

Masking



Masking refers to an autistic person's ability to hide parts of what they do, what they say, and how they think so that other people do not know they are autistic. It is easier for some autistic people to mask than it is for others, and it is easier to mask some ways of behaving, communicating, or thinking than others. Some people may mask to avoid experiencing ableism or discrimination within a particular environment, such as a workplace, school, or event, while other may mask a part of their autistic experience they feel ashamed of or think other people will not appreciate.

Masking is exhausting for autistic people, because it involves constantly hiding parts of their natural ways of thinking, doing, and being. This means they cannot be their authentic self, which can contribute to depression, low self-esteem, anxiety, self-harm, and suicide.

Some therapies that have been used with autistic people involve teaching them how to mask. These are often done to make things easier or more comfortable for allistic people, or to avoid making changes to a world not built for autistic people. Many autistic people are against these therapies being used, particularly on more vulnerable members of the autistic community (nonspeaking autistic people, autistic children and young people, queer autistic folks, autistic people with intellectual disability or mental health conditions, and autistic people of colour).

Autistic-friendly spaces

There are many misconceptions around how autistic people are able to work, socialise, and exist in spaces within society. Autistic people are able to do any type of work, attend any type of event, and socialise in any way they wish—but many will struggle to perform well and thrive because the environments are built for non-autistic people.

It is important to consider how to build your environment so it is autistic-friendly and disabled-friendly as soon as practicable—don't leave it until an autistic or disabled person joins the space. There is no one 'presentation' of what an autistic person will look like. Therefore, there may be people you do not realise are autistic within the spaces you build or participate in. We need to design spaces so that they are inclusive and suitable for autistic people, even if the assumption is that no autistic people currently use the space.

To do this, we may need to make accommodations to existing spaces or processes, or to have environments designed in an autistic-friendly way. A foundation of respect for those who sound, act, think, and look different is fundamental, alongside strong, straightforward communication procedures to undercut any misunderstandings.



Some further points to consider within such spaces include:

- allowing autistic people to self-stimulate ('stim') to control their sensory processing and prevent sensory overload: for example, by using fidget toys, listening to music
- providing a quiet space where autistic people can take breaks or stim away from others
- allowing casual dress codes, so autistic people can wear comfortable clothing that does not cause excessive sensory triggers
- working with autistic people to determine schedules that work for them
- clearly communicating changes ahead of time
- allowing people to have their cameras or microphones off during virtual meetings, to minimise the need for masking
- ensuring the space has non-flickering lights and options for different lighting in different spaces
- using non-fragrant cleaning products to minimise olfactory overload
- ensuring the space has room for excess noise to escape
- clear policies around discrimination, harassment, and bullying
- clear procedures for what happens if someone is hurt, harassed, bullied, or excluded by others within the space
- providing clear instructions in written, visual, and spoken forms

The accommodations they need within each of these environments may vary, and they may change from day to day, or hour to hour. It is important for autistic people to have options within each of these environments so they can select what they need to best engage, exist, and thrive within these spaces.

Representation

The most important strategy for appropriate, accurate, and respectful representation and inclusion of autistic people is to communicate with autistic people themselves. Historically, autistic people had little voice in what their advocacy, support, and representation was. Often, these were centred on the family members and caregivers of autistic people. Such support and representation often focuses on the challenges placed on family members and caregivers and how difficult their life is because they care for an autistic person, and leaves autistic people to be viewed as an accessory, burden, or something to be fixed.

The stories and perspectives told within the media reinforce this. From autistic people being referred to in unfavourable, harmful ways, to people highlighting the impossible challenges faced to bring autistic



people into the current built-for-allistic world, to the extreme of a person's autism has been used to justify their murder by a caregiver, this is repugnant and dehumanising for autistic people.

When seeking to create authentic, accurate, and respectful autistic representation and inclusion, it is best to engage with autistic individuals themselves. This may be through watching content on YouTube or TikTok by autistic creators; following autistic advocates and other autistic people on Twitter; researching under common hashtags like #AskingAutistics and #AskAnAutistic; and reading blogs, articles, and resources created by autistic people. Hiring autistic people, either as a member of your team or as a consultant, can allow you to access a more in-depth, personalised set of advice and recommendations.

Autistic-coding

Someone who is autistic-coded will share traits that are commonly associated with autistic people, but not have an explicit description or label of being autistic. Just as an employee should not need to disclose that they're autistic to be accommodated in the workplace, characters who are autistic-coded should still be treated with respect and care. When autistic-coded characters in fiction are mocked, demonised, dehumanised, harmed, or excluded, it can reinforce the idea that real autistic people with those traits should be treated similarly.

Common autistic-coded traits that are stigmatised in media include:

- an adult living with their parents or depending on their parents to do day-to-day tasks
- a person having interests that are seen as 'weird' or 'creepy' but aren't actually harmful (for example, collecting dolls)
- a person having difficulty maintaining their hygiene
- an adult with childish behaviours (for example, holding a stuffed toy)
- a person who is a picky eater
- a person who has socially unacceptable stims (for example, rocking back and forth or humming repeatedly)

It is important to recognise that giving characters these traits is not a bad thing. Instead, recognise and steer clear of turning traits like these into punchlines, and make sure that you are writing full, rounded characters rather than using autistic coding for comic relief. Furthermore, it is important to remember that just because a person (fictional or not) displays one, some, or all of these traits, they cannot instantly be labelled as autistic.

There is a recent trend of deliberately autistic-coded characters being confirmed as autistic outside of their canonical stories, but this autistic-ness not being labeled or addressed within the fiction itself. This



can be frustrating for autistic audiences, as it reinforces the idea that autism is shameful, controversial, and should not be addressed or discussed within today's world. It is important for creators to actively seek to acknowledge autistic people as valued, useful, and included members of their worlds—with the text itself, not quietly in external contexts.

Stereotypes and tropes

Autistic people are often represented in the media through stereotypes. These usually perpetuate some harmful assumptions about autistic people, and cast them in an unfavourable light.

Sometimes autistic people are portrayed as lacking humanity, or lacking emotions. This trope can contribute to the harm of real-life autistic people, and continues a stereotype that dehumanises a group of people. Additionally, some autistic characters are depicted as having exceptionally poor social skills, being rude and hurtful, and being unable to make friends.

Other instances depict autistic people as having exceptional, beyond-this-world abilities, or of having hyper-intelligence in one particular area. While on the face of it this may seem like positive representation, these 'autistic superpowers' are still used to fetishise and ostracise autistic people. Furthermore, this may contribute to real-life autistic people being used, abused, or manipulated by those who wish to have control over the abilities of autistic people.

Many autistic people do not want a cure, and view themselves as different, not less than. This is true for many disabled people—they don't feel a need to be fixed, because what they are is not deficient. Fictional stories, and the general discussions around autistic people in real life settings, often centre on autistic people being cured, or fixed, or learning to overcome their autism and be more neurotypical. While some disabled or autistic people may desire to not be disabled or not be autistic, these stories are often not created for disabled people or autistic people. They are more likely created for non-disabled, non-autistic people who are afraid of becoming disabled or autistic, or who view being disabled or autistic as something wrong, bad, broken, or burdensome.

In some instances, fictional worlds assume that autistic people do not exist at all within the setting because of magical cures, genetic editing, and similar technologies. This reinforces the notion of allistic people being the default, normal standard for people and creatures within such fictional worlds, and invalidates the experience of autistic people living today. Instead, creators can consider how autistic people, or people with autistic traits, can fit into their new world. This may include: new rules, processes, and systems that make it easier or harder for autistic people to live their lives; new technologies or



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equipment that assist or hinder autistic people; and different attitudes and perspectives of autistic people by those in the society they live in.

A world where autistic people—or any disabled people—are removed from existence is a world built on **eugenics** (which refers to the concept of creating a 'better' human species by only allowing certain types of humans to reproduce). It is important to consider the implications of creating such a world within your fiction, and to recognise and research the real-world harm it may cause autistic, disabled, and neurodivergent people.

Resources

Amaze

<https://www.amaze.org.au/>

General information about autism and support for autistic people.

The Art of Autism: Autistic People and Empathy

<https://the-art-of-autism.com/autistic-people-empathy-whats-the-real-story/>

Information about empathy in autistic people.

Autistic and Unapologetic: What is Autistic Shutdown?

<https://autisticandunapologetic.com/2020/05/16/exploring-autism-what-is-an-autistic-shutdown-autistic-catatonia/#autisticShutdown>

Information about autistic shutdown.

Autistic Self-Advocacy Network: About Autism

<https://autisticadvocacy.org/about-asan/about-autism/>

General information about autism and support for autistic people.

Autism Wiki: Shutdown

<https://autism.wikia.org/wiki/Shutdown>

Information about autistic shutdown.

Raising Children: DSM-5 and Autism Diagnosis:

<https://raisingchildren.net.au/autism/learning-about-autism/assessment-diagnosis/dsm-5-asd-diagnosis>

Information about how autism is diagnosed and the diagnostic criteria in the DSM-5.

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Would Aspie: A Different kind of Tired—Autistic Shutdown

<https://wouldaspie.org/autistic-shutdown/>

Information about autistic shutdown.

References

Davies, S. 2019. 'Handling Meltdowns as an Autistic Adult'. *AutisMag*. Accessed 30 December 2020 from <https://www.autismag.org/news/handling-meltdowns-as-an-autistic-adult/>

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