



"My Autistic Self"



“My Autistic Self”

Our latest campaign - "My Autistic Self" - features interviews with a diverse group of autistic individuals and their personal autism experiences. Here we share their stories in an attempt to help the neuro-typical community understand how certain characteristics and traits are essential for the autistic adult or child in relieving stress and exhaustion.

Real-life experiences from our students, teachers, therapists and parents covered topics such as stimming, masking, sensory sensitivities, non-speaking communication, shutting down, and floating focus.

The objective with all of our campaigns is to drive greater autism awareness and understanding. We believe that it is only by educating others that we can provide an insight into the exclusion, stress and exhaustion many autistic individuals face every single day and drive greater understanding, awareness and acceptance.

Autism Unlimited exists to support and empower autistic children, adults, and their families. We partner with them to find solutions and provide educational and life skills training.

From bespoke education for children, to independent living skills and career guidance for adults, we ensure that all of the people we support, find their passion, a route to their dreams and a rich and fulfilled life.

Learn about how these characteristics and traits manifest themselves and read their insightful stories [here](#).

Contents

- **Masking**
 - a definition
 - what our interviewees had to say
 - key data
- **Sensory Sensitivities**
 - a definition
 - what our Interviewees had to say
 - key data
- **Non-Speaking**
 - a definition
 - what our interviewees had to say
 - key data
- **Stimming**
 - a definition
 - what our interviewees had to say
 - key data
- **Floating Focus**
 - a definition
 - what our interviewees had to say
 - key data
- **Shutting down**
 - a definition
 - what our interviewees had to say
 - key data
- **Summary**



Masking



Masking is about suppressing certain behaviours and habits in order to fit in with the expectations of people around you.

Masking can include mimicking and mirroring the behaviour of those around us, such as copying non-verbal behaviours, developing complex social scripts to get by in public situations.

It can be unconscious or conscious, and it might be something you can't just "take off" even when you're on your own because you are too busy worrying about how you feel you ought to behave.

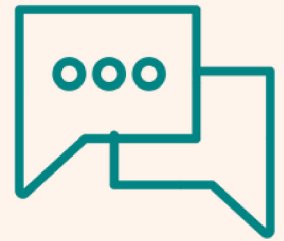
Signs of autism may present differently in women and they're more likely to camouflage their traits because of increased social pressure to fit in. This can include forcing eye contact and facial expressions, preparing jokes beforehand and hiding behaviours deemed as socially unacceptable.

Signs that someone is **masking** their autism include:

- copying or mirroring the facial expressions, actions and behaviours of others,
- pre-empting responses to people, perhaps by writing them down or practising them,
- suppressing physical symptoms and fidgeting.

Masking can lead to autistic burnout and mental health problems down the line.

Masking - what our interviewees said



Willow

There are few people that Willow feels comfortable unmasking around, including their boyfriend and sometimes a friend. However, they do recognise and emphasise the importance of channelling your true emotions in one way or another.

As Willow told us: “I would say that you shouldn’t mask because that’s not going to help. You need to get it out in some way, but I generally put all my emotions in a drawing, or a song and I feel like anyone who masks emotions should find a hobby that they can get it all out. I generally pick a topic that is bugging me in that particular moment in time...and once it’s in a song it doesn’t matter anymore.”

By using different creative mediums like writing, drawing, and dancing, Willow expresses these feelings – and encourages others to do the same.

Becs

Becs, who is the Training Coordinator at Autism Unlimited, recently received a diagnosis, and soon learned she had been **masking** most of her life without ever realizing it.

She said: “I felt inherently that I was different, and it felt like everyone else knew what they were doing, and I had no idea.” This meant suppressing certain behaviours that she felt made her stand out. This included looking at how other people were acting and speaking and trying to emulate their behaviour.

It can also involve suppressing self-soothing behaviours, which may be perceived as different, such as **stimming**.

As Bec explains: “It’s a constant analysis of everything that’s happening around me and it’s exhausting. The only time where I feel I don’t have to mask is when I am on my own. I am trying to unmask more around people I’m comfortable with, such as my family, but it also feels quite conflicting because they’ve only known me as Becs and the person I present to them.



Masking is a coping strategy to help me to avoid negative judgement and social exclusion.

Masking - did you know?

It is thought that 94% of autistic adults have masked at some point in their lives (Sedgewick et al., 2022).

70% of autistic adult participants reported that they consistently camouflage (Cage & Troxell-Whitman, 2019).

Studies are now beginning to find how detrimental to our mental health **masking** can be (Bradley et al. 2021; Hull et al. 2019).

Due to societal norms and expectations autistic women "mask" their autism more often than men. (National Institutes of Health)

Sensory sensitivities



Sensory sensitivities can often be referred to as over responsiveness or hyper reactivity.

Autistic people may experience sensory differences which impacts their ability to engage in everyday activities. They may be over-sensitive or under-sensitive to specific sights, sounds, smells or textures.

This can be a positive thing but can also cause distress or discomfort. Autistic people are sometimes over sensitive to things like noise, crowds or temperature and avoid these. Other autistic people are under sensitive to sensory information (hyposensitivity) and they seek out sensory experiences, like wearing tight-fitting clothing, or looking for things to touch, hear or taste, or rub their arms and legs against things.

Some can have both over sensitivities and under sensitivities in different senses, or even the same sense. For example, they might be oversensitive to some sound frequencies and under sensitive to others. They may be over sensitive to bright lights but are unable to recognise any smells.

Sensory sensitivities can sometimes seem worse when people are stressed or anxious. Sensitivities can also make people feel stressed and anxious.

Sensory Sensitivities - what our interviewees said



Archie

Archie's sensory processing differences mean that he struggles with loud noises.

He said: "I don't like loud noises, especially sudden loud noises that start off quiet and progressively get louder and louder." Schools, workplaces, and other public settings can be difficult to navigate due to their unpredictable and noisy nature, which quickly becomes overwhelming. Fire drills that come with no warning can be especially challenging, "When it did go off, I just got quite scared and I either just hid under a table and didn't leave, or I just ran out the nearest door just because I hated it."

Some individuals use support strategies such as ear defenders to help them manage the sensory input. Archie uses his own little earbuds that help him cope in loud environments by reducing the impact of the noise.

Archie concluded: "If you see someone that you think might be overreacting to something, it is probably not overreacting. They probably either just don't like it or associate something bad with it."

Georgia

Georgia's story is about how **sensory sensitivities** with different foods and materials can create challenges for her in everyday situations. Her biggest sensitivity is with food and how it smells, tastes and feels, which attracts judgement from others and can make it very difficult to eat in company, with those who don't understand.

Going out to eat was always a struggle as her fellow diners would not understand why it took so long for her to decide what to eat and insisted that she try something new.

She said: "I'm very much labelled as a fussy eater. I quite like bland food and I don't like a lot of flavours and textures and things like that."

She continued: "People kind of like judge you 'Oh, you're so fussy. Why don't you just try it? It's not going to kill you.'" If she subsequently decided not to eat anything and grab something afterwards, it was seen as socially unacceptable, further adding to her anxiety.



Sometimes when noises or the atmosphere gets too much for me I go for a walk.

Sensory Sensitivities - did you know?

Recent studies suggest prevalence of **sensory sensitivities** in 69% to 90% of autistic people (NHS England 2022).

Sensory sensitivities means your senses take in too much or too little of the environment around you.

Sensory sensitivities are as individual as the person experiencing them.

Up to 16% of the population will experience **sensory sensitivities** at some time in their life. (National Institute of Health)

Non-speaking

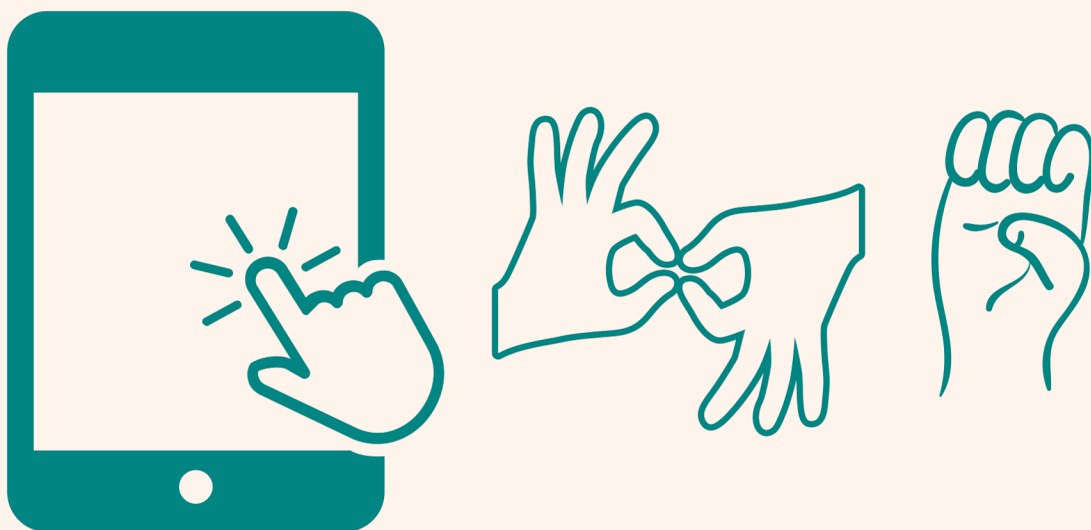


Non-Speaking or **non-verbal** means the autistic person is not currently able to communicate recognisable words using their voice.

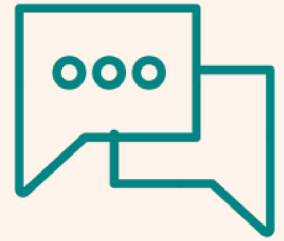
This doesn't mean that they don't understand the words that are spoken to them or that they overhear. Nor does it mean that they can't communicate at all. By using Alternative and Augmentative Communication (AAC) such as body language, hand signing, sounds, pictures and/or technology or writing they are able to get their message across. Much communication is also be achieved with facial expressions and gestures.

Just because somebody is non-speaking, it does not necessarily mean that they will never speak. Individuals can begin to use spoken words at various ages.

Some, who are minimally or partially speaking or verbal, often use a combination of all the various methods to express themselves. In many instances, these options are just as effective as speaking.



Non Speaking - what our interviewees said



Max and Riley's story

Jamie is a parent to Max and Riley, two **non-speaking** boys at Portfield School. She said: “**Non-speaking** to me means that the boys can't say any words that can be understood by anyone. They make a lot of noises which maybe make sense to them but nothing that we can attribute to words at the moment.”

Every individual is different and communicates in their own way – and the same applies to those who are **non-speaking** like Max and Riley.

Although Max grew up without any speech, he can now say 'dad' and 'up' after working with his Speech and Language Therapists and Teachers.

She continued: “People tend to think if you're **non-speaking**, you're unintelligent and sort of talk in front of you like you're not there.”

Max's understanding has improved as he's gotten older. When people are having conversations in front of him, he seems to understand what's going on.“

He is extremely bright and he can communicate in two other ways with signing and with his iPad. From someone who was born not having any form of communication, he has now learned two, and is working on a third which I think you have to be quite intelligent to do.”

By accommodating and accepting differences in communication, everyone can feel further included in society, make meaningful connections and benefit from more opportunities.

Jamie concluded: “I don't know if they'll ever talk, I think it's a never say never. I've heard stories of people in their thirties and forties who have been **non-verbal** or **non-speaking** and start talking. That's great to us but talking would be the icing on the cake.”



Just because someone is **non-speaking** doesn't mean they can't hear or understand what's going on.

Non-Speaking - did you know?

An estimated 25-35% of autistic children are considered **non-verbal** (Healthline).

There are 31 million people worldwide who are **non-speaking** (Communication4All).

Many children with **non-speaking** autism have above average intelligence.

Communication can come in many forms, which are just as valid as speaking.

Stimming



Stimming or self-stimulating behaviour includes arm or hand-flapping, finger-flicking, rocking, jumping, spinning or twirling, head-banging and complex body movements.

Although **stimming** varies from person to person, the reasons behind it may be the same:

- for enjoyment,
- an attempt to gain sensory input, e.g. rocking may be a way to stimulate the balance (vestibular) system; hand-flapping may provide visual stimulation,
- an attempt to reduce sensory input, e.g. focusing on one particular sound may reduce the impact of a loud, distressing environment; this may particularly be seen in social situations,
- to deal with stress and anxiety and to block out uncertainty.

It includes the repetitive use of an object, such as flicking a rubber band or twirling a piece of string, or repetitive activities involving the senses (such as repeatedly feeling a particular texture).

Repetitive behaviours can be a major part of life for many autistic children and young people. They can be an essential way of regulating emotion and providing someone with a source of comfort or enjoyment that enables them to carry on with their day.

Stimming - what our interviewees said



Tyler

Tyler is a train enthusiast who relies on specific **stimming** behaviours, such as fiddling with paper straws and spinning around in circles, for comfort and joy. He describes **stimming** as a 'somewhat involuntary action' which keeps him occupied. He doesn't give it too much thought – it's almost an automatic response which focuses his attention to just one thing.

He said: "It helps with brain stimulation. I guess that's why they are called stims, short for stimulation." Paper straws are a big part of Tyler's life and a useful support tool for day-to-day activities.

"I have really big boxes and bags full of them. Basically, every place I frequently go to, they help me visualise the things I see in my brain."

He added: "I've met people who also like trains, I've met people with my name, I've met other people with autism...But spinning is definitely one of the things unique to me." "Most people are actually really fascinated by it. They just find it incredible to know that one of my pastimes, one of my stims, one of my things that I like to do is spinning around really fast."

Cayden

Cayden has relied on **stimming** since a young age, scrunching and un-scrunching different items, such as paper, and using fidget toys to help self-regulate and manage his sensory challenges. Sometimes, he will find himself playing with a zip on his hoodie for entertainment, or subconsciously fiddling with his fingers to cope with sensory information in his surroundings.

At his old school, he would always play with paper for sensory relief - to the annoyance of his teachers. **Stimming** is often misunderstood as 'bad behaviour', when in reality, it can be very beneficial and shouldn't be discouraged unless harmful.

He added: "It's safe to say though, that the sensory issues have gone from the upper torso to the lower torso because I've now got restless leg syndrome...it's just non-stop. Even when I sleep, it's non-stop."

When behaviours like **stimming** and conditions such as restless leg syndrome are not understood, they might be perceived as unusual and met with judgement.



If you see people doing something unusual, don't judge them.

Stimming - did you know?

In a study of 100 autistic adults, 72% of people had been told not to stim at some point (Stewart, 2015).

75% of autistic participants said that they did not always stim in their preferred way, because they think other people do not consider it socially acceptable (Goldsmiths 2021).

84% of autistic adults said they had been told not to stim or to stop a repetitive movement.

Social pressure was given as a reason for suppressing **stimming**, and this suppression had a negative effect on emotions and cognition (Goldsmiths 2021).

Floating focus



Floating focus happens for some autistic people when they find it difficult to focus on one thing for a long period of time. They adapt what is known as a **floating focus** where they appear detached and uninterested in the world around them.

Distractions in the external environment can also make it difficult to concentrate and it can be a challenge to tune out any distractions. This helps them to avoid over stimulation and is especially true if the subject is not of any interest to them.

Additionally, focus and concentration can be affected by external factors, such as the environment and stress levels. A noisy, overwhelming, or unpredictable situation can make it difficult for an autistic person to concentrate. Likewise, high levels of anxiety can make it more challenging to focus on tasks or activities.

Whether it's children at school or adults in the workplace, challenges with maintaining focus can impact day-to-day life. Everyone is unique and their experiences vary widely – while some people may struggle to focus, others can become fixated on certain topics for a long period of time. If something is of interest, individuals might channel a high level of attention and concentration to that area.

Floating Focus - what our interviewees said



Mimi's story

For Mimi, staying focused and filtering out distractions can be a struggle. Her mind starts to drift away unconsciously, derailing her train of thought.

She said: "I sort of go into a daydream world and it can be so easy and so quick and sometimes I don't even realise it's happened."

This change can be completely random and out of her control. Different factors in the environment can take away her focus, and this can escalate until she's immersed in a wholly new and often irrelevant subject.

She continued: "I could be in a meeting, and I can see, oh, there's a stain on that curtain...I wonder how that got there? And all of a sudden, I'm thinking about how people made curtains in the 1800s."

Holly's story

Holly has ADHD, which is characterised by a difficulty sustaining focus and a short attention span. As a result, Holly's mind often wanders between different topics.

She said: "We're different thinking people, we've got different points of view. It affects everyone differently, the only way I can describe it is like a computer that doesn't have all its updates or the latest software."

Everyone is unique and their experiences vary widely – while some people may struggle to focus, others can become fixated on certain topics for a lengthy duration. If something is of interest, individuals might channel a high level of attention and concentration to that area.

She added: "We need to stop making people feel like they have the wrong personality and that the personality they have is the way to go."



I sort of go into a daydream world and it can be so easy and so quick.

Floating Focus - did you know?

90% of Autistic people reported having internal conversations or an inner world.
(NeuroClastic)

Focussing on an area of interest for an extended period, is often described as being “in the zone.”

Sensory inputs, such as lights, sounds, and smells, can make it difficult to concentrate.

Around 3 in 10 autistic adults have ADHD, meaning they have difficulty sustaining focus and a short attention span.
(Medical News Today)

Shutting down



Shutdowns are a muted response to extreme overload or stress. When an autistic person goes into shutdown mode, there are a few common signs:

- being completely silent,
- unable to communicate in any way,
- withdrawing to a quiet, dark space to get away from the cause of their shutdown,
- not being able to move from where they are because they're thinking too much about the cause of their shutdown,
- lying down on a flat surface, being completely still.

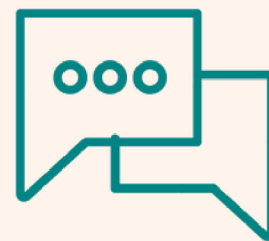
Many autistic people experience higher levels of stress and anxiety, which can make things even more difficult. If this becomes too much, they need to release their anxiety. For some this means shutting down completely and for others, who reach crisis point, it may be a physical manifestation of their anxiety.

Shutdowns tend to be more discreet than a crisis situation and can go unnoticed and both are the autistic person's response to a stifling situation.

Common triggers may include:

- too many demands placed on the autistic person, especially if they are not related to each other,
- unexpected changes in plans or routines,
- sensory overload. Social overload (being exposed to too much social interaction, this is particularly relevant to shutdown).

Shutting Down - what our interviewees said



Mimi

Mimi said: “**Shutting down** is almost like...the glass frosts in front of you. You’re sort of in this glass box and you can’t see through. Everything is happening around you but you’re in this state.”

“So for me, that includes not being able to verbalise my thoughts, and suddenly the lights are brighter and the sounds are louder...And I start to feel all the threads in my clothes, on my skin.”

She faces an increased sensitivity to her surroundings and there’s too much information to process at one time. When this happens, it helps to find a quiet room where she can seek refuge from the stimuli and begin to recover.

She continued: “It’s like you can hear they’re saying words at you, but it’s just bouncing off. It’s not going in, your brain is not processing it at all.” “It’s sort of like a TV going into standby mode in a way. So you’re still on, and the light’s still on, but the screen is black.”

By shutting off her sensory channels and withdrawing into her own world, Mimi’s brain attempts to manage the overload and create a layer of protection. It can no longer process further information and shuts down to isolate the environment. This is her coping strategy. Shutdowns are an internal way of dealing with overwhelming situations whereas reaching crisis point tends to have a more physical reaction.

Both can be extremely distressing experiences – and what each person needs in that moment will be highly individualised.

“I wear sunglasses indoors. I quite like plushies, so I’ll have one of those or sensory toys. I love to fiddle with my hands, so anything like that helps with not **shutting down**.”



Usually when I shut down, it’s because I’ve gotten overwhelmed sensory-wise.

Shutting down - did you know?

47% of autistic people fall into the severe anxiety category based on GAD diagnostic criteria.
(National Autistic Society)

50% of autistic people said anxiety had a high impact on their ability to get on with life.
(National Autistic Society)

Shutdowns' are a muted and discreet responses to highly stressful situations.

Too much information, can overload the brain and overwhelm the individual.

Summary and Conclusion

Stimming, masking, floating focus, shutting down, non-speaking.

What do all these things have in common, they are all related to autism:

Stimming refers to self-stimulating behaviors, such as flapping hands or rocking back and forth, that can help regulate sensory input.

Masking involves hiding one's autistic traits in order to fit in with neurotypical people.

Floating focus is a tendency to become deeply absorbed in a particular task or interest.

Shutting down is a response to overwhelming sensory input or emotional stress, in which a person may become unresponsive or non-communicative.

Non-speaking refers to individuals who do not use spoken language to communicate, or who have limited verbal communication abilities.

Sensory sensitivities means your senses take in too much or too little of the environment around you. Autistic people may experience sensory differences which mean they may be over-sensitive or under-sensitive to specific sights, sounds, smells or textures.

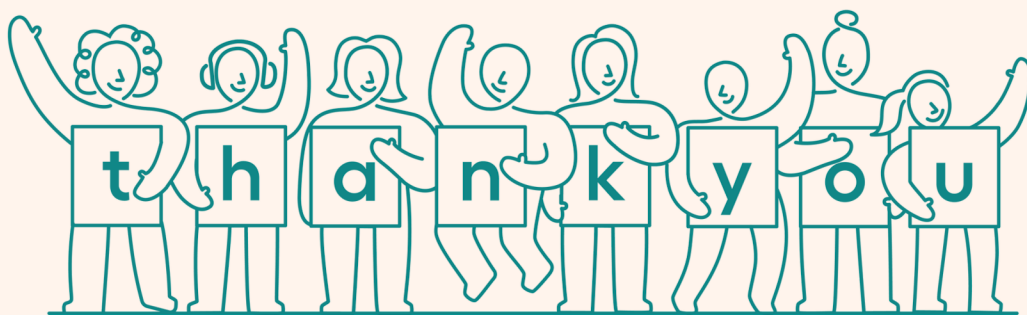
When interacting with individuals who may be neurodivergent, such as those who are autistic, it is important to have an open mind and not to judge without understanding their circumstances. Rather than seeing their differences as a negative, we should celebrate and embrace them as a valuable contribution to our collective understanding and creativity.

If you have a question or don't understand something, don't be afraid to ask. By doing so, we can foster a culture of inclusivity and understanding. Remember, kindness and respect are key to an inclusive world.

VISIT OUR WEBSITE

www.autism-unlimited.org/my-autistic-self/

TO READ AND WATCH THE INSPIRATIONAL STORIES



We would like to say a big thank you to everyone who took part in the "My Autistic Self" campaign.

If you would like to find out more about the work we are doing or take part in future campaigns please email: enquiries@autsim-unlimited.org or call 01202 483360

