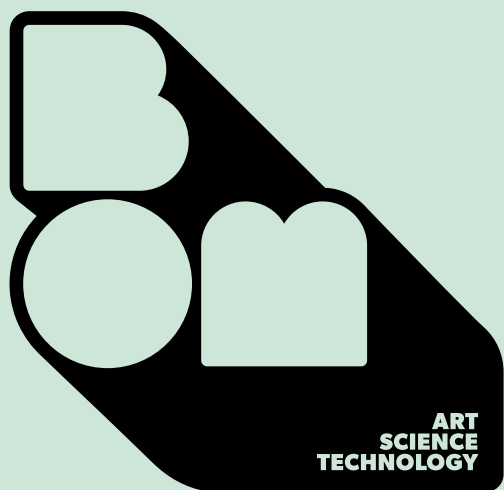


Am I Autistic ?



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A note about the author Sonia Boué (she/they).

Sonia Boué is a multiform artist. She is also a writer on autism and art, and a consultant for neurodiversity in the arts. She specialises in neuro-inclusive practice-led research.



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Foreward

BOM is a centre for art, technology and science, dedicated to creative innovation with purpose. We explore how technology can be used as a tool for change, to make society a better place. Our interests and expertise are in neurodiversity and technology, how technology can help disadvantaged communities, and how it can address environmental challenges.

BOM's programmes have been supporting autistic adults to access and thrive in the digital and creative industries since 2018. During this time, we have worked with WEBworks, an autistic-led initiative that mentors and supports autistic artists and develops autism-led projects. They have supported us on our own learning journey as we've become more neurodivergent aware, providing guidance and a safe environment for autistic people to access digital skills and professional support. WEBworks have also supported us as a team, as we've come to understand our own neurodiversity.

Over the years that we have been running programmes with autistic people we have found that the majority of our participants are just beginning their journey to understanding their neurodivergence and have a need to investigate similar elements in the lead up to diagnosis. As an adult on the beginning of a neurodivergent discovery, finding support and guidance can be limited, overwhelming and create even more barriers. We wanted a way to share the incredible resources, sign posts and support that WEBworks have shared with our participants, which may be helpful to others embarking on a diagnosis.

AM I AUTISTIC? has been written by WEBworks founder Sonia Boué for you to use as a point of reference to inform pre-diagnosis. It is a booklet which allows you to 'dip in and out', to find the elements of guidance that you need. There are many links to other people's lived experience throughout the book to provide autistic voices from a wide range of backgrounds.

As a pre-diagnosed, self-identifying neurodivergent black woman, the process of collaborating on this project with Sonia Boué has illustrated first-hand how the 'awakenings' from AM I AUTISTIC? has helped join the dots of a life lived masked.

Chloe Lawson
Engagement Manager, BOM

Introduction

We are living through a time of evolution in understanding about autism. Across the globe adults are finding out more about it and wondering, could this be me?

This booklet has been written to provide information, guidance, and reassurance before a diagnosis or self-identification of autism. Informal but informative, it offers key information and answers some of the many questions you may have. This publication provides insights from an autistic perspective, drawing on my extensive research and experience of mentoring autistic people.

However, we have a saying in autistic circles – once you’ve met one autistic person you’ve met one autistic person – and this booklet is one autistic person’s view. I am very conscious, not only of my heritage as a white autistic woman, but also that any other autistic person would have written it another way. There can be no one definitive guide.

For this reason, I have provided many links to content created only by autistic people or trusted allies. I have also tried to avoid links which include disrespectful language wherever possible. Links to the National Autistic Society (NAS) website have been cited where access to more formal information will be helpful. I have also signposted where you can find more content on social media via specific hashtags.

Welcome

I'm so glad you made it to these pages because discovering that you are autistic as an adult can feel like working your way through a maze! Each autistic person is unique, so there are as many ways of being autistic as there are autistic people. Autism is our normal, and this often doesn't match what we think we know about autism as portrayed in the media and popular culture.

Identifying that you are autistic as an adult often comes at the end of a long and lonely road. You may have other diagnoses and/or misdiagnoses. Realising autism could make sense of things can be a eureka moment. It can also be an anxious time and feel overwhelming.

The aim of this booklet is to encourage your curiosity and offer reassurance that experiencing a swirl of mixed emotions is natural. You will read about common experiences and gain insight into autistic culture to help you on your way.

What Is Autism?

If all autistic people are different, what is autism? This is a very good question! We do share characteristics but getting to grips with how they might manifest for each one of us is a journey.

I find clinical descriptions of autism to be quite alien. I don't see myself reflected and I find the language offensive. The following two links have been written by autistic people. They are accurate and use respectful language.

'What is Autism?' by Dr. Nick Walker

<https://neuroqueer.com/what-is-autism>

'About Autism' Autistic UK

<https://autisticuk.org/resources/about-autism>

To find out what autism means for you it will help to learn about the experiences of other autistic people.

My go to resource is **'The Thinking person's guide to Autism'**

<http://www.thinkingautismguide.com>

My go to blog is **'Autism and Expectations'** by Rhi Lloyd-Williams

<https://utistrhi.com>

You can find my personal blog

<https://soniaboue.wordpress.com>

The following links also offer a range of autistic voices in multiple formats, to get you started. You will soon find many more!

#ActuallyAutistic hashtag on Twitter will connect you to many authentic community voices

‘All the Weight of Our Dreams: On Living Racialized Autism’ is an anthology of poetry, essays, short fiction, photography, paintings, and drawings by autistic people of colour, featuring 61 writers and artists from seven countries

‘All The Weight of Our Dreams’ online resources page

<https://autismandrace.com/resources>

‘Asperger’s and Me’ a documentary about Chris Packham is available on BBC iPlayer

<https://www.bbc.co.uk/programmes/b09b1zbb>

@autistic_therapist for quality information about autism and emotions on Instagram

https://www.instagram.com/autistic_therapist

‘Douglas’ is a stand up comedy show about autism by Hannah Gadsby is available on Netflix

‘Explaining Humans: What Science Can Teach Us About Life, Love and Relationships’, by Camilla Pang, Penguin Books

‘I feel Different’, is a short animation exploring the untold stories of autistic girls and women in their own words

<https://www.bbc.co.uk/programmes/p08z30ky>

National Autistic Society interview with Tom Moran celebrates Gay Pride Month

<https://www.autism.org.uk/advice-and-guidance/stories/celebrating-pride-month-tom-moran>

‘Shy Radicals: The Antisystemic Politics of the Militant Introvert’
by Hamja Ahsan, Book Works

‘The Secret Life of a Black Aspie: A Memoir’ by Anand Prahlad
University of Alaska Press

‘The Electricity of Every Living Thing: One Woman’s Walk with Asperger’s’ by Katharine May Trapeze Books

@neurodivergent_lou provides useful and informative content about being diagnosed as an adult on Instagram

https://www.instagram.com/neurodivergent_lou

@neurocurioustherapist for quality insights on autistic experience and emotions on Instagram

<https://www.instagram.com/neurocurioustherapist>

‘Odd Girl Out : An Autistic Woman in a Neurotypical World’
by Laura James, Bluebird

Getting Started

Staying Safe Online

I've learned the most about being autistic from spending time on social media platforms. I've also made friends and gained work by hanging out online but occasionally I have also encountered conflict and misinformation. As a newcomer to autistic forums you may feel anxious. Here are my top tips for staying safe online.

1. When posting content it helps to avoid generalisations and to make it clear that you're speaking only for yourself. This is respectful and helps avoid disagreement and critique.
2. Some subjects are sensitive and it's thoughtful to use trigger warnings. You can do this by writing trigger warning or TW at the top of your post or comment.
3. Conflict can flare up quickly online. It's okay to mute, unfollow or block people from your timeline. You don't have to engage with triggering situations. It is completely okay to walk away.
4. Writing online is publishing in legal terms. Your comments are usually public unless you select a privacy setting. The boundaries between sharing in private and in public can get confusing when online conversations escalate quickly. Be aware that online platforms are social spaces and it can be hard for us to read the room in the moment. It can help to think through your boundaries with the help of someone you trust.

5. Check out filter options on social media platforms and apply them to trigger words and topics you don't want on your timeline.

6. Respecting other's language preferences and also knowing about language can help you avoid critique when posting content.

7. Finally, it is totally okay to 'lurk' online. Lurking is the term used to describe people who view social media without posting or commenting.

About Language

When it comes to identity, the golden rule about language is that it's a personal choice. It is entirely up to you. It's also good practice to respect the choices of others, even when we disagree.

While some of us feel it is important not everyone is interested in language or feels that it impacts their lives.

Language about autism is complex, evolving and the subject of much disagreement. Autistic identity is both personal and a social justice issue and there is a lot to unpack. Knowing more about the language will help you understand the deeper issues and work out how you chose to define yourself.

Knowing about language can also help you avoid triggering or otherwise unhelpful situations. Understanding subtle differences in the language could help you work out whether a group, organisation or situation may not be for you.

Ableism

Ableism is discrimination and social prejudice against disabled people both in words and actions ranging from social exclusion to social injustice.

Among the many harms of ableism, it is often manifest in the belief that disabled people are lesser than non-disabled people, including the assumption that we are 'broken'. Ableist attitudes include stereotypical generalisations using the language of disability as a slur.

Autism communities vs autistic communities

Autism communities - are usually groups, organisations and services for autistic people. They are usually not organised or led by autistic people.

Autistic communities - are organised and led by autistic people.

This language difference can be coded and relates to the issue of person first language vs identify first language.

The rise of autistic advocacy has challenged the previous status quo. Disagreements about language centre on how autism is perceived and whether our agency and rights are respected. The two links provided below give a deeper insight into this issue from autistic perspectives.

NeuroClastic Collective blog post '**The Difference Between the Autism Community and the Autistic Community**'

<https://neuroclastic.com/the-difference-between-the-autism-community-and-the-autistic-community>

Neurodivergent Rebel short video '**The Difference Between the Autism Community & the Autistic Community**'

<https://neurodivergentrebel.com/2020/01/24/the-difference-between-the-autism-community-the-autistic-community>

Autistic vs With Autism

Discovering that you are autistic is often a process of learning and unlearning, which can include language. I have included a link to my own reflections about this, written back in 2017.

Person first language - autism communities have tended to use person first language, namely to say that a child or a person has autism, or that they are a child or person with autism. Some individuals also adopt this language about themselves.

Identity first language - autistic communities use identity first language, which means we say that we are autistic because autism is the core of our identity.

The National Autistic Society (NAS) has updated guidance on how to talk and write about autism

<https://www.autism.org.uk/what-we-do/help-and-support/how-to-talk-about-autism>

Dr Chloe Farahar has created a 15 minute video about why identity first language is a social justice issue

<https://www.youtube.com/watch?v=Oiwm6mPNZXk>

‘The Sound of Stigma: a journey across the rope bridge’ is a blog post by Sonia Boué

<https://soniaboue.wordpress.com/2017/03/27/the-sound-of-stigma-a-journey-across-the-rope-bridge-autismacceptance>

Discovery and Identification

Discovery and **identification** are options for describing the process of finding out that you are autistic without using medical language.

I credit American artist and researcher Dr. Annette Foster with introducing me to the term discovery, which can be used in place of diagnosis. Such alternatives are helpful for those who feel the term diagnosis pathologises autistic identity. To pathologise means to treat something as medically abnormal.

Neurodiversity

The language about neurodiversity can be quite confusing. Here we will unpick the subtle differences between words that sound extremely alike.

Neurodiversity paradigm - the term originates from the work of autistic rights advocates but the neurodiversity paradigm is not a movement in itself.

The neurodiversity paradigm is inspired by the concept of biodiversity. Neuro is latin for nerve used to refer to the brain and its cognitive functions, including thinking styles. Diversity simply means variety. Combining these words has allowed us to think about neurological difference as “a diversity of minds” ¹essential to the survival of humanity as a whole.

¹ Toward a Neuroqueer Future: An Interview with Nick Walker.

<https://neuroqueer.com/toward-a-neuroqueer-future>

Neurodiversity movement - this term describes a global political and social justice movement which seeks to shift the perception and treatment of neurodivergent people away from the medical model (or pathology paradigm ²).

Neurodivergence - a term used to describe a natural variety of minds and brain functioning which differ from the majority or so-called 'norm'. Neurodivergence therefore means thinking and experiencing the world differently.

Neurodivergence does not relate exclusively to autism. It includes a range of profiles which can be inherited, acquired and/or mental health related.

Neurodivergent - a term used for individuals whose brain function and thinking style differs from the majority or so-called 'norm'.

Neurodiverse - this refers to a mixed group of neurodivergent and neurotypical people. Neurodiverse also applies to the human species as a whole. Therefore individuals are not neurodiverse, but the term is often misused in this way.

Neurotypical - this refers to people who are not neurodivergent. Some people also use the term neuromajority.

² Toward a Neuroqueer Future: An Interview with Nick Walker.
<https://neuroqueer.com/toward-a-neuroqueer-future>

The following three links are key resources relating to the history, facts and language of autism and neurodiversity.

‘A Neurodiversity Facts And Myths Primer’ is an article by Shannon De Roches Rosa

<http://www.thinkingautismguide.com/p/so-youre-doing-story-about.html>

‘Neurodiversity: Some Basic Terms & Definitions’ by Dr. Nick Walker

<https://neuroqueer.com/neurodiversity-terms-and-definitions>

‘NeuroTribes: The Legacy of Autism and How to Think Smarter About People Who Think Differently’ by Steve Silberman, gives a detailed history of autism and the neurodiversity movement.

Spectrum and On The Spectrum

On the spectrum - Considered an advance in its time, this phrase has become associated with the myth that everyone is a little autistic which is unhelpful to understanding autism. It is also associated with the use of ‘high functioning’ and ‘low functioning’ labels which are now considered ableist.

In a recent Twitter call out, as part of my research for this booklet, I found the overwhelming majority of autistic people who responded disliked, and often strongly objected to this term. Some autistic people liked it and felt comfortable using it, as it can make social situations easier to manage. Personal preference is all.

About Being Autistic

The following section will provide insights into some of the common features of autistic life that no-one ever told you about when you were growing up.

Decompression and Recovery Time

Is it hard to get through your day?

Autistic people often need decompression and recovery time due to differences in the way we process ordinary everyday social contact and our sensory environment, among other factors.

It might sound obvious that the need for decompression would be linked to a build up of pressure but it can be hard to process exactly how much we are affected by what seem like 'ordinary' pressures.

Without decompression we can easily become overloaded by sensory stress, neurotypical social demands and masking autism (see below). Before a diagnosis, we don't know why everyday life is so challenging, yet pressure can be felt bodily, resulting in physical discomfort, increased sensory sensitivity and autistic meltdowns .

Decompression often requires time alone and periods of reduced sensory stimulation, with dimmed lighting and noise cancelling headphones, for example. Many of us have go-to decompression routines, such as listening to particular music or a favourite and predictable activity imbued with a feeling of security. Decompression routines can also include bodily pressure such as weighted blankets

or the bodily release of immersion in water. The list is endless and can include creative pursuits and outdoor activities.

Stimming (see below) is also a decompression support and can help reduce the need for longer decompression activities. Once we know why we need strategies like stimming to decompress, we can work to reduce the stresses in our lives and make sure we get regular decompression as it is an important tool in supporting our wellbeing.

The National Autistic Society has provided a useful guide on issues relating to decompression called '**Autistic fatigue - a guide for autistic adults**'

<https://www.autism.org.uk/advice-and-guidance/topics/mental-health/autistic-fatigue/autistic-adults>

Executive Function

Do you struggle to get the basics of life done?

Executive function is another way of describing the ability to make things happen. This is something many people take for granted, yet is surprisingly complex. To make things happen you need to be able to plan, organise, initiate and act in a sequential and coordinated manner. For many autistic people this is challenging and can affect our ability to get many ordinary day to day jobs done. The following link gives a good insight into the ways executive function challenges can affect our lives.

‘Executive Functioning Problems: A Frustrating Aspect of Being Autistic’ by Finn Gardiner

<http://www.thinkingautismguide.com/2017/10/executive-functioning-problems.html>

LGBTQ+ and Neuroqueer

LGBTQ+ identities are found to be more prevalent in the autistic population, meaning that we are more likely to have overlapping intersectional identities. Neuroqueer is an identification which encompasses these intersections. An interview with Tom Moran (link below) gives insights into one experience of being gay and autistic.

Gender diversity describes a variety of gender identities. The following link is to an article confirming the results of a large series of studies, which confirm a higher prevalence of gender diversity within the autistic population than is the case for neurotypical people. The NAS suggests more research is needed to understand why.

Spectrum News <https://www.spectrumnews.org/news/largest-study-to-date-confirms-overlap-between-autism-and-gender-diversity>

The same goes for sexuality. We are less likely to identify as heterosexual and more likely to identify with a diverse range of sexual orientations, including lesbian, gay, bisexual, pansexual, asexual and aromantic, among others.

Neuroqueer is not only an identity, it also seeks to explain how and why neurodivergence intersects with LGBTQ+ ³

BBC Radio 4 ‘My non-binary life’ podcast

<https://www.bbc.co.uk/programmes/p06y51dp/episodes/player>

‘Neuroqueer: An Introduction’ by Dr. Nick Walker

<https://neuroqueer.com/neuroqueer-an-introduction>

‘I Don’t Feel Like a Gender, I Feel Like Myself: Autistic Individuals Raised as Girls Exploring Gender Identity’ Marianthi Kourti and Andrea MacLeod

National Autistic Society interview with Tom Moran celebrates Gay Pride Month

<https://www.autism.org.uk/advice-and-guidance/stories/celebrating-pride-month-tom-moran>

‘Working with Autistic transgender & non-binary people’ Marianthi educates Aucademy’s Katie & Annette

<https://youtu.be/s29X1-mi4bk>

‘Working With Autistic Transgender And Non-Binary People’
edited by Marianthi Kourti Jessica Kingsley

³Toward a Neuroqueer Future: An Interview with Nick Walker.

<https://neuroqueer.com/toward-a-neuroqueer-future/>

Masking and Unmasking

Do you blend to fit in, adopt people's accents and mimic their gestures?
Do you tend to get peopled-out?

The term masking describes the social camouflaging some autistic people use to manage difficult social situations and there are times when masking is the only way to stay safe. Masking is not something we're necessarily conscious of, though we can be. It is a natural adaptation which is complex and highly individual and also manifests in a wide range of cognitive processes and behaviours.

Masking arises from the need to avoid social exclusion, bullying and discrimination, but it's a survival mechanism which is known to be damaging to our mental wellbeing in the long run ⁴. Masking can be like acting in some ways, except that it is exhausting and can lead to poor mental health. This is because our own needs and preferences are suppressed in order to fit in and avoid immediate harms. We might 'pass' as neurotypical, but we lose agency and our sense of self.

Masking can be so exhausting that we need to take time to recover after being with other people (see decompression above). Not only is it draining but it can also lead to alterations in mood as we try to make sense of why we can't manage neurotypical social expectations.

Unmasking refers to presenting more 'naturally' as an autistic person. However, long-term masking can make it difficult for us to know what our 'natural' is. Unmasking autism can feel daunting because we fear the social consequences. There is also more to unmasking than simply disclosing our identity, it has to do with how we behave and present ourselves.

While there can be many layers of unhelpful social learning to process and unravel, our confidence often grows as we unmask to ourselves. What follows is that we begin to make social choices around more genuine needs.

It may be that you don't mask, and you have experienced conflict and exclusion as a consequence. Diagnosis will help in understanding why this has been a pattern in your life.

The book **'Autism and Masking: How and Why People Do It, and the Impact It Can Have'** by Felicity Sedgewick, Laura Hull, Helen Ellis, is a very detailed, readable and useful resource.

'Masking when you have autism can help you blend in, but you might not be doing yourself any favours' by Nick McAllister

<https://www.abc.net.au/news/2020-12-20/masking-when-you-have-autism-is-more-common-than-you-think---an/12999102?nw=0>

Meltdowns, Shutdowns and Autistic Burnout

Related yet distinct, meltdowns, shutdowns and autistic burnout are all responses to living in a neurotypical world. Autistics vary greatly in how we experience them. Once we know we're autistic we can do a great deal to minimise these experiences and manage the causes.

Meltdowns

Do you have a reputation for 'flipping out', 'losing it' or 'coming down like a ton of bricks'?

⁴Trigger warning for clinical language. Is social camouflaging associated with anxiety and depression in autistic adults? <https://molecularautism.biomedcentral.com/articles/10.1186/s13229-021-00421-1>

We place a lot of value on control. If you don't know the causes, experiencing meltdowns can feel humiliating and seriously dent your self-esteem. You may feel childish and unworthy while others look on with 'superior' calm. Supermarket Meltdowns is a book I could write!

While adult autistics are often shamed and made to feel ashamed, meltdowns are natural reactions to intolerable environmental and social stresses.

Quite often we can be unaware of a build-up of pressure and a meltdown happens after we've actually been working really hard to stay in control. Social judgement is entirely misplaced and unjust.

Shutdowns

Do you sometimes lose functional capacity, become speechless and unable to make choices and carry out ordinary tasks? Do you need to retreat to recover?

Shutdown literally means a form of physically and / or emotionally shutting down and can vary greatly in severity and time needed to recover.

In my experience shutdowns are sudden temporary responses to a situation which cannot be processed in the moment. We may simply have run out of road for our capacity to cope with events and are overwhelmed. Shutdowns can result from a range of stresses that are not just sensory or environmental factors. Pervasive social bias' including systemic and everyday ableism can cause us to shutdown.

Doing nothing but the things that nourish us, resting, and gaining space to process helps

Autistic Burnout

The causes of autistic burnout are cumulative and can be a longer term issue, requiring dedicated time and space to recover. Key symptoms can be overwhelming exhaustion, anxiety and low mood.

We may experience burnout due to prolonged pressure to mask our autism and conform to neurotypical expectations. It can be hard for neurotypical people to understand exactly how alien many cultural practices and 'norms' are for a lot of autistic people.

Again we've run out of road. The causes can be so individual and specific but commonly result in burnout when we can no longer sustain the extraordinary efforts required for a certain pace of life and the demands of the neurotypical world.

Spectrum News have provided a useful explainer about autistic burnout <https://www.spectrumnews.org/news/autistic-burnout-explained/>

Sensory Processing

Sensory processing can be a big part of our lives. It is thought that we are less able to filter sensory information than neurotypical people. This is also sometimes referred to as information processing. Many autistic people experience sensory sensitivities but not all of us do. Others actually find it hard to process sensation.

Therefore, some of us need more input and are sensory seeking, while others can experience sensory overwhelm when confronted with certain busy environments like shopping centres and crowded supermarkets, for instance.

Sensory processing issues can manifest in defensive strategies we may not even be aware of. Particular sounds and smells can inflict acute physical discomfort causing us to react strongly in the moment, and / or background sensory input can build up and become overwhelming over time.

Sensory sensitivities are not always consistent and can be dependent on environmental fluctuations, not always discernible to others. Our bodies can be so sensitive to temperature, light, sound or smell, that we can 'flip out' over what seems like nothing to neurotypical people.

Until you know about sensory deregulation such incidences can be bewildering, and the cause of shaming, when they are the result of intolerable sensory stress.

Challenges with sensory processing are what decompression was invented for. Once we know how to protect ourselves and take care of sensory stress in a way that suits our processing style, we can significantly improve our wellbeing.

Stimming

Do you twirl your hair, fidget with your keys or pace while cleaning your teeth? These activities are universally relatable. They can also be a form of stimming.

For many autistics stimming is a necessity. The term refers to repetitive 'self stimulatory behaviours' also known as stims. Stimming can be central to our ability to regulate our bodies and emotional lives and can take many forms.

Conventionally, stimming has been associated with flapping, rocking, and vocalisations. However, stimming is infinitely varied and as personal to each one of us as a signature. In fact, stimming is so poorly understood that you may not recognise your own stims until you find out more.

Stimming has many benefits, such as helping manage anxiety and overwhelm, so that we feel grounded and can stay in control. It can be playful and express excitement, fascination and joy. Stimming also keeps us focused when we need to concentrate and be a means of communication in itself. It can be shared in a group or played as a game of call and response with another autistic person. Far from being weird, meaningless or inexplicable, stimming can connect us to others and there's an intense joy to be found in sharing stims. Stimming therefore is a language in itself and an autistic way of being social. It is also an art, as in Sam Metz's beautiful Drawing as Stimming project.

For joyful examples of group stimming you can listen to the BBC Radio 4 '1800 Seconds on Autism' podcast episode called '**A Mexican Wave of Flapping**'.

<https://www.bbc.co.uk/programmes/p08dqrk4>

See also '**Drawing as Stimming**' (Instructional Video), by Sam Metz.

<https://www.sammetz.com/videos>

Thinking About Diagnosis

In the run up to seeking diagnosis you may need to work your way through fear and worry, due to the prejudice and discrimination that still befalls autistic people, despite progress made by the neurodiversity movement. This is often called stigma but is actually ableism.

A Word About Stigma

Stigma arises from neurotypical social bias and can be extremely harmful to our mental health. Significantly, it can also make it hard to talk about thinking you might be autistic. Stigma is also why others sometimes tell us that a label may be 'damaging' for us rather than a support. This might seem to come from a place of kindness but is actually a barrier to access. It is also an example of ableism, however unwitting it may be.

Actually, autism is a protected characteristic in law. Formal diagnosis brings rights under the Equality Act 2010, and there is a growing understanding about what we need in schools and workplaces. As mentioned above, there is also a global neurodiversity movement working to counter prejudice and discrimination. Our community also celebrates World Autistic Pride Day (18th June).

In many ways, stigma is simply the social and emotional impact of systemic injustice. Change will be more forthcoming when we call it what it is.

‘Why we should be fighting *prejudice* toward autistic people, not autism stigma’, is an interesting video talk by Dr Chloe Farahar deconstructing the language of stigma
<https://www.youtube.com/watch?v=hQrUckturTU>

‘The word ‘stigma’ should not be used in mental health campaigns’, is an article that explains the problem with the word stigma in a related context
<https://www.theguardian.com/healthcare-network/2014/oct/10/stigma-should-not-used-mental-health-campaigns>

About Internalised Stigma

Autism stigma can also get inside your head, which is what we mean by internalised stigma (this can also be called internalised ableism).

Without meaning to, we may have absorbed pervasive prejudice about autism before we reach a better understanding. This can manifest in directing hateful thoughts towards ourselves reflecting normative social views. Normative means the expectation to conform to dominant standards, usually of behaviour.

We can be quite harsh on ourselves if we don’t recognise this dynamic. Our self-esteem suffers and self-confidence can become extremely fragile. Breaking this cycle is important for wellbeing.

Aucademy is an online learning and community platform offering the kind of contact and content that you may need in order to think about autism in new and positive ways.
<https://aucademy.co.uk>

We hope that all of the links provided in this booklet will add to your understanding and help break negative thought loops.

Do seek professional support if you're struggling with internalised stigma and your mental health is affected.

Appropriate and specialist support can be hard to find, so I have been especially pleased to find a directory of neurodivergent therapists in the UK.

<https://neurodivergenttherapists.com/directory/>

About Stereotypes

People unfamiliar with autism tend to base their understanding of it on popular culture. A series of tropes, such as the maths geek lacking in empathy or non-speaking savant, have dominated public perception.

Such stereotypes are not only inaccurate, they are also harmful. Stereotypes act as a barrier to reaching a point of self-recognition that could change your life. Accurate representation is essential to understanding exactly how autism can be you. Once you crack this nut you begin to understand that autism is not at all what you imagined it to be.

We are making progress and beginning to see a range of autistic people in the public eye, as more of us step forward to claim autistic identity as a right.

About Diagnosis

We're now ready to talk about diagnosis. Having worked through stigma and stereotypes, we also need to navigate patchy and inconsistent healthcare systems. This can be daunting.

I recommend identifying one person or more who can help you through it. There are also useful resources online.

The National Autistic Society has provided a comprehensive and detailed guide to accessing a diagnosis

<https://www.autism.org.uk/advice-and-guidance/topics/diagnosis/pre-diagnosis>

Gender Bias

There has been a significant gender bias since autism was identified in the 1940s. The result has been that women and girls have flown under the radar in our thousands.

This Guardian Newspaper article gives a good summary

<https://www.theguardian.com/society/2018/sep/14/thousands-of-autistic-girls-and-women-going-undiagnosed-due-to-gender-bias>

The tide is now turning as more is known about how we can present differently due to socialisation and other factors, with many more women and girls being diagnosed.

Do I Need a Diagnosis?

You may wonder whether you need a diagnosis. Friends and family may also doubt the value of a late diagnosis. A common response is to think that you've managed so far without one, so why bother? This thinking comes from an uninformed neurotypical perspective.

There is now a wealth of testimony from adults to indicate that diagnosis significantly improves our quality of life. Whether you self-identify or seek a formal diagnosis, self-blame can be left aside and a process of recovery can begin.

You may also wonder whether you need a diagnosis to confirm that you are autistic. This is an individual choice but can also depend on whether formal diagnosis is accessible to you.

Self-Diagnosis

Self-diagnosis is also sometimes termed self-identification or self-discovery. Self-diagnosis is widely accepted in the autistic community because it provides a much needed access solution.

It can prove hard to get a GP referral. NHS waiting lists and the expense of a private consultation are also potential barriers.

The **National Autistic Society report, Diverse Perspectives (2014)**, suggests it's more difficult for Global Majority/non-white communities to obtain autism diagnoses.

Whilst these inequities remain, it will be important for some autistic people to self-diagnose. Here are some common reasons for self-diagnosis:

- Not being able to access formal diagnosis (for whatever reason, including anxiety)
- Not needing the external validation of a formal diagnosis
- Not needing a formal diagnosis to secure accommodations
- Needing to reject the medical model of autism
- Not needing certainty or closure on previous misdiagnosis
- Having a network that supports self-diagnosis

Formal Diagnosis

The certainty of a formal diagnosis is important for some of us. Formal diagnosis should provide a document you can refer back to as needed, which allows you to process and assimilate your challenges.

Here are some common reasons for seeking a formal diagnosis:

- Needing external validation
- Needing formal diagnosis for access to services and accommodations in education and the workplace
- Needing certainty and / or closure on previous misdiagnosis
- Needing to prove your identity with a formal diagnosis to family and friends

Anxiety About Diagnosis

It is completely natural to feel anxious about seeking an autism diagnosis. The diagnostic process can feel like one great leap in the dark.

To prevent anxiety becoming a barrier, it helps to seek as much information as possible ahead of time. Clinicians and diagnostic teams will be aware of the challenges of anxiety and should be willing to offer reassurance and support with the process.

The National Autistic Society has provided a useful guide to the diagnostic tools currently in use

<https://www.autism.org.uk/advice-and-guidance/topics/diagnosis/diagnostic-tools/all-audiences>

It should be possible to discover which tool will be used by your diagnostic team or clinician, and to find out more about it. It can help to reduce anxiety by visiting the location ahead of time where practical. Some of us need to make copious notes and make lists to take with us in case we find talking difficult. Having the supportive presence of someone close to you can also reduce anxiety.

Some common reasons for anxiety about diagnosis:

- Fear of stigma and worries about how to tell people you're autistic
- Fear of not being believed
- Fear of the diagnostic process itself
- Fear of going to a new place
- Fear of meeting and talking to new people
- Not knowing for certain that we will get a diagnosis

I have supported many people in the run up to diagnosis. Ultimately, I think the time has to feel right. A diagnosis lands best when it is welcome news. Many of us reach a crunch point where the need to know overrides our anxiety.

You can listen to Fern Brady talk about her recent autism diagnosis on the BBC Radio 4 '1800 Seconds on Autism' podcast

<https://www.bbc.co.uk/programmes/p097ykp6>

Assimilating Diagnosis

Getting to grips with what autism means for you can feel like peeling the layers of an onion. Each layer brings a whole new level of understanding. Diagnosis is therefore often a beginning rather than an end point. While there may be bumps in the road, there is a great deal of joy to be found in finally getting to know what you really need out of life.

Diagnosis often leads to greater self-acceptance. You may ask where the grit and determination came from to manage the challenges for so long. Actually, you probably made it through because you're autistic, and a good diagnostic process should be affirming and even celebratory. However, what happens next, and the process of assimilating a diagnosis is little spoken about or recognised as needing support.

Many of us seek out autistic company (both in real life and online) to help us adjust. Autism is more common than was previously thought and there is a strong genetic component. Many of us find autism runs in the family once we know more about it. We are also often drawn to one another, and we can therefore find that we have autistic friends, as yet undiagnosed. We may not be as isolated as we sometimes feel.

Also, with so many online resources we can begin to feel more connected. There's a community out there for everyone.

Aucademy is my go to for a safe, positive and welcoming community which is accessible on multiple platforms

<https://aucademy.co.uk>

It must also be said that a supportive network or community doesn't need to hinge around autistic identity. The key will be to find spaces in which you feel welcome and accepted as you are. For some of us, finding a common interest group is more important than finding our autistic tribe. Autism can become a real focus in your life, or something you put to the back of your mind. There is no right or wrong way to assimilate a diagnosis.

Finding Acceptance

People sometimes respond by saying that an autism diagnosis will make no difference in how they think of you, and that nothing has changed. No doubt intended as a declaration of friendship, this minimises the importance of a diagnosis for you.

Genuine acceptance comes from those who seek to understand what autism means for you and show a willingness to support you with issues such as sensory stress or overload. A diagnosis can sort out who your real friends are and help you find new ones who are genuinely supportive.

Adapting ourselves to neurotypical social 'norms' is usually exhausting and leads to burnout. Diagnosis can enable you to change this dynamic and discover your true social preferences. Pressure to socialise neurotypically is not acceptance.

Am I Disabled?

Under the The Equality Act (2010), autism is regarded as a mental impairment. The language of impairment is inherently problematic, but the status of autism as a protected characteristic is herein enshrined.

Yet, autistic people identify in many different ways. Some feel autism is a disability while others don't. We may need to work through internalised ableism.

However, there can be many reasons why an autistic person does or doesn't identify as disabled. We often have multiple identities to uncover which can take time, and it's a personal journey.

Inclusion London have provided a definition and summary of **'The history of the social model of disability'**, which includes updated thinking.

<https://www.inclusionlondon.org.uk/disability-in-london/social-model/the-social-model-of-disability-and-the-cultural-model-of-deafness>

The Autistic Scholar has written an article about **'The social model of disability and autism'**

<http://www.autisticscholar.com/social-model-neurodiversity>

'Am I Disabled?' An article by Joanne Limburg

<https://aeon.co/essays/what-does-it-mean-to-consider-yourself-a-disabled-person>

'Three Bodies' is a short film directed by Dorothy Allen-Pickard, commissioned by Molonglo. It follows the journey of three people — Joy Addo, Sonia Boué and Kat Hawkins

<https://vimeo.com/530154245>

Celebration

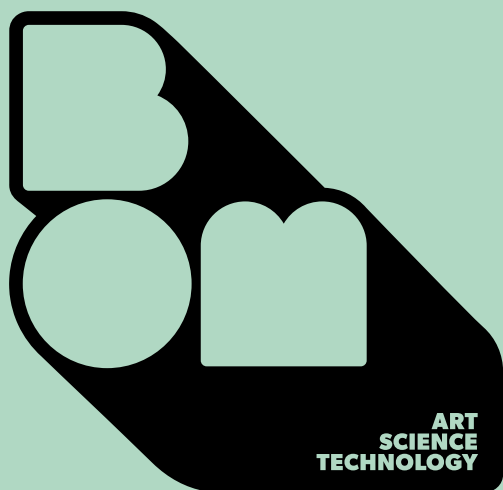
Too much of the narrative about autistic lives has been shaped by a somewhat negative clinical picture of our deficits. Yet autistic people are to be found in all walks of life and our lives can be as joyful and purposeful as any other.

There is no greater feeling than autistic flow, when we are riding on hyper focus and able to channel our passions and inspirations.

The joy of unfettered stimming is unparalleled. We are often deeply connected and loyal to those we love and trust and have an instinct for non-human connectedness too.

While the challenges are real and more progress in societal understanding is needed, knowing you are autistic will bring you new understanding and connect you to a wider community of knowledge and thought. You are no longer alone.

Every autistic person deserves a celebration and congratulations for getting through life's struggles unrecognised. I now celebrate my diagnosis day and I hope that (whether you are formally diagnosed or self-identity) you will too.



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