

Autism Informed Services

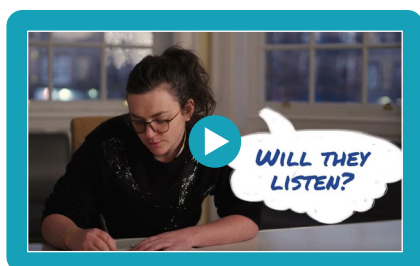
This ebook is intended to be an informed level professional learning resource for all NHS professionals working in adult services or with adults. This includes mental health services.

Features
the lived
experiences
of autistic
people

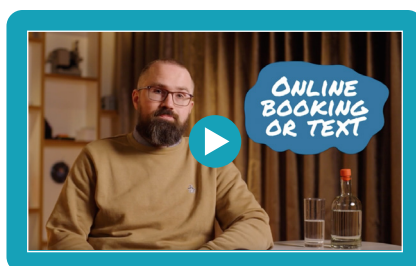


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Introduction

Autism, mental health, and access to services

There is a clear need for improvements to life experiences and health outcomes for autistic people.

Recent research highlights that:

The average life expectancy for autistic people is **54 years**.

Up to **79% of autistic people** experience co-occurring mental health conditions, with a lifetime prevalence of 40% for depression and anxiety.

23% of people with anorexia are autistic.

Autistic people are **9 times more likely** to die by suicide.

Although autism is a lifelong condition, the average age of diagnosis for autistic adults in Scotland is **31 years**.

It is thought that as few as **29% of autistic adults** are employed.

There is an under-identification of autistic people which means these numbers may not reflect the true number of autistic people.

Autism is not a mental health condition in itself, but mental health issues are common due to being autistic in a society designed for the non-autistic majority and lack of acceptance, understanding and right type of support.

In taking steps to address these inequalities, autistic people must be at the heart of identifying and planning to better meet needs.



If you want to improve, here's what you need to know.'

All quotes included are from autistic people.



Towards Transformation

In March 2021, the Scottish Government published an autism and learning/intellectual disability transformation plan called 'Towards Transformation'. It set out to address inequalities and make sure that progress is made in transforming Scotland for autistic people and people with learning/intellectual disabilities.

The Scottish Government and the Convention of Scottish Local Authorities (COSLA) acknowledge there is more to do to make sure that autistic people and people with a learning/intellectual disability can live their lives to the full and be a rightly valued and integrated part of our communities.

A collaborative and innovative leadership and engagement plan was introduced. People with lived experience were at the centre of this to make sure that change and improvement is led by the people who will see the benefit in their daily lives.

Access to mental health services was identified in the Towards Transformation Plan as being of critical importance. In 2021, Assenti Research undertook [research](#) with 154 autistic adults about experiences of access to mental health services in Scotland. Separate research was carried out with parents and carers of autistic adults and/or adults with learning disabilities. The research findings formed the basis of the work that was prioritised for lived experience groups.

The Scottish Government also asked the National Autism Implementation Team to [review the published literature about Mental Health in Autistic Adults](#). The study found that very little research is undertaken by or in partnership with autistic people and there are some useful findings about prevalence (how common autism and co-occurring conditions are) and considerations in terms of re-thinking evidence and what outcomes are important.

Access to good quality health care on a basis equal to others is a human right.

Working group

A working group was set up. As stated at the start of this section, this working group developed co-produced informed level professional learning resources for all NHS professionals working in adult services or with adults.

The group focused on developing resources based on recent lived experience of people in Scotland and the Assenti Research report. The group consensus is that there are a lot of medical professionals who misunderstand autistic people and their needs.

Often professionals:

1. Do not know enough about autistic people and miss key signals.
2. Or believe they do know about autistic people, but their knowledge is outdated, inaccurate or misinformed.
3. Require up to date professional learning to know what they can do in practice to improve experiences of autistic people in health care settings.

The group believes that having health professionals who are autistic themselves is very impactful, it can break stereotypes and highlight the barriers that autistic people experience to accessing healthcare.

The content of this ebook was created by this working group.

Experiences of seeking mental health support

The research undertaken by Assenti Research in 2021 provided rich information about the experiences and views of autistic people.

Within NHS services, it was rare for respondents to feel that they had ever experienced a service which was autism informed. This was seen as a baseline requirement.

Many respondents went further to say that there was a need for autism specific services, that being autistic in and of itself was not a mental health condition but that there was a need for services that recognised and could respond to their needs as autistic individuals.



It is insulting and distressing to be told by a neurotypical (NT) counsellor how I am feeling – how could they possibly know?



Some respondents had been told by primary and/or secondary health services that there was no mental health support for autistic people. In some cases, this meant that they were not referred on by GPs at all and in others it meant that they were pushed to participate in Cognitive Behavioural Therapy or group therapy which was clearly not working and on occasion was further negatively impacting mental health.



There are no services for autism, plenty for mental health but nothing that fits us. I get the impression my GP doesn't know what to do with me so it's a case of 'ok we've tried psychotherapy and that didn't work, we tried the counselling so let's try psychiatry'.



Impact of difficulties

The impact of the difficulties experienced by people responding to the research included:

- Only seeking help when reaching crisis point.
- Significant mistrust of health professionals and very low expectations of what help might be available to them – therefore less likely to seek future support.
- Lack of mental health support was seen as a life limiting factor e.g., not being able to maintain employment/studies, problems with relationships, not being able to live independently.
- For some respondents, their experience of ‘support’ only served to further traumatise them and make their mental health worse with several reporting contemplating suicide.

The experiences described here mirror findings across the literature and indicate a lack of appropriate mental health support for autistic people. Lack of understanding and support is associated with an increased risk of suicide.



It's really important we are consulted and involved in the process – so co-designing services from day one. When you consult with neurodivergent people, the input we give covers neurotypical people as well so if you design with neurodivergent people in mind, you're making services better for everyone.



More joined up thinking. Autism falls with learning difficulties but if you don't have a learning difficulty then where do you go because autism isn't a mental health condition.





Involve autistic people in the design and facilitation of programmes tailored to our foremost needs, linking physical and mental health. Some of the challenge is recognising how we feel and adapting processes to us.



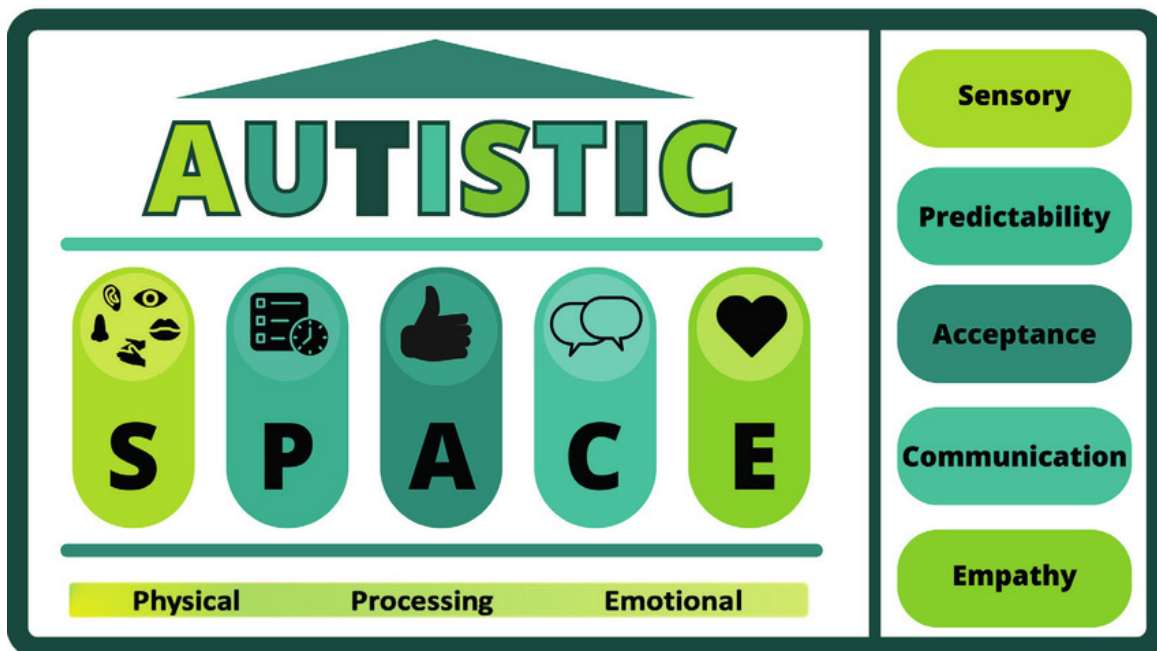
Priority for improvement:

Autism informed professionals within adult mental health services

It was clear from the research, consultation, and discussion that all people working in and with health services need to be better informed about the needs of autistic individuals. This includes but is wider than primary care and GP practices.

The information from autistic people highlighted priority areas for improvement. One of these was the need for universally autism informed professionals within adult mental health services.

The Autistic SPACE Framework



The challenges and solutions highlighted by autistic people in Scotland are similar to those reported in other countries. Autistic Doctors International are a group of autistic health professionals working to address health inequalities. They have created a [framework](#) to help professionals think about ways to support autistic patients.

This useful information highlights the need for health professionals to consider Sensory needs and preferences, Predictability, Acceptance, Communication supports and adaptations and Empathy.

Their publications provide more information about adaptations linked to each of these themes.

Sections 2 to 6 describe the things the working group would like mental health practitioners to know and the things that would help.

The embedded films feature autistic people describing these key messages.

Autistic masking and health services



Watch
the film

It is important to know about autistic masking when seeing autistic patients or patients who could be autistic.

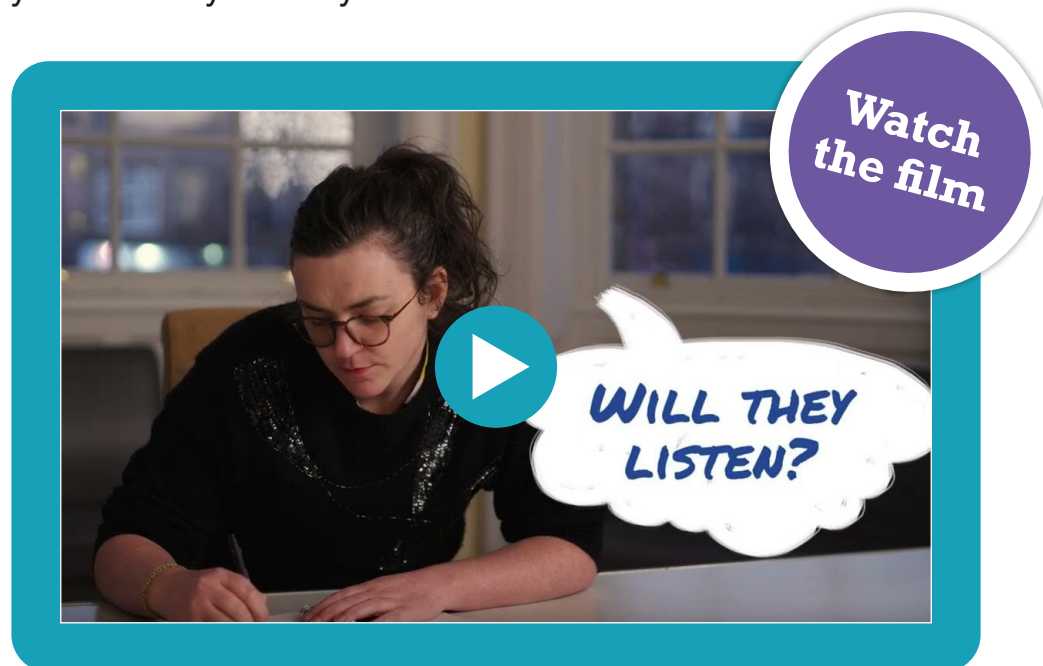
What is masking?

- Autistic masking involves covering up or suppressing natural ways of being, internal feelings, ways of moving, body language, and impacts how an autistic person responds to sensory and social experiences.
- Masking is a survival mechanism, a way of self-protection, an attempt to meet others' expectations to reduce the chance of being judged or not accepted.
- Masking is sometimes a deliberate decision, but often it is unconscious.
- Masking is not unique to autistic people but is also seen in other minorities or oppressed groups.
- Autistic people may cover up their sensory experiences by masking, a conscious or unconscious effort to fit in.

What are the implications of masking?

Masking is tiring and stressful and can lead to burnout. It can lead to erosion of self-identity and trauma through the layering of masks over time and ignoring or dismissing your own needs. For autistic people it can feel unsafe to unmask and respond authentically.

Not being accepted for who you are over time comes at a significant cost to mental health leading to depression and even suicidality. Masking means others often make assumptions about you and think you are okay when you are not.



As a health practitioner what can you do?

These are the things that would help:

- Be aware of the significance of masking and the impact it can have on the mental health and wellbeing of autistic people.
- Be aware that how someone presents does not necessarily convey their actual experience. For example, an autistic person can seem okay on the surface and have a tsunami of emotions happening inside.
- Don't make assumptions. Be humble and curious.
- Ask specific questions to understand how the person's experience impacts them, e.g.:

“How have you been able to manage daily care tasks?”

“Have you been able to participate in your usual favourite interests?”

- Believe what the person tells you. Incorrect assumptions by practitioners can lead to missed or incorrect diagnosis.

- Help to make environments in your practice that are accepting, validating and supportive, and this may reduce the need for autistic people to mask.

However, remember it is not easy for autistic people just to take off the mask, due to unconscious masking, layering of masks over time and bad experiences in the past.

Further reading and resources



- Article by Dr Amy Pearson on [Beyond masking and supporting autistic authenticity.](#)
- Preprint of an article on autistic masking ['Masking is life': Experiences of Masking in Autistic and Non-Autistic Adults.](#)
- The National Autism Implementation Team produced a [Guide to Autistic Masking](#) with autistic people.
- This article by the autistic advocate Kieran Rose describes [autistic burnout.](#)

Social interaction and communication with autistic patients



Watch the film

There are some barriers to successful meaningful interaction with autistic patients. Communication is a two-way street; the focus shouldn't always be on autistic people adjusting to the medical setting.

Natural ways of communicating may look different for autistic patients, including facial expressions, body language, and eye contact. Autistic people may stim (previously described as self-stimulatory behaviour) by making repetitive movements or sounds. It is important not to form judgements based on behaviour.

The impact of anxiety and stress may cause difficulties and provoke unexpected or undesired responses that may be difficult to understand.

An autistic person asking direct questions, not responding to questions or not making eye contact should not be interpreted as them being deliberately rude.

There may be a double empathy problem at appointments. Double empathy is when people with different perspectives, such as autistic and non-autistic people, interact and they can find it hard to understand each other which can lead to a breakdown in communication.

Watch
the film



As a health practitioner what can you do?

These are the things that would help:

- Anticipate differences. Don't expect or force an autistic person to interact like a non-autistic person. Autistic people might need to fidget, stim or laugh at times considered 'inappropriate'.
- Listen to the autistic person like they matter.
- Be willing to bend and adapt processes.
- Foster a psychologically safe environment – many autistic people are likely to people-please if they do not feel like they are in a safe space.
- Understand what a good life looks like for the individual not in comparison to non-autistic norms.
- Be aware that autistic people can feel pressure to demonstrate progress in treatment.
- Don't touch without permission. Make sure there is informed consent before touch is used with a patient.
- Be aware that some autistic people are not able to speak when they are dysregulated. Expect this, offer a pen and paper and slow everything down.
- Avoid using buzzwords and jargon.



- [My health passport](#) is a resource for autistic people who might need hospital treatment.
- The National Autism Implementation Team created this animation with autistic people about effective communication – [More Than Words: Supporting effective communication with autistic people in healthcare settings](#).
- This video with Damian Milton explains the [Double Empathy Problem](#).

“

I think the biggest thing in my experience has been that people generally don't have the patience or understanding for my ways of communication. When I've had mental health support with someone that does have patience, it's been incredible because we're able to work together to identify my emotions and figure out practical ways to help me.

”

Sensory differences and processing



Watch the film

Autistic people experience things differently in terms of how information is received, interpreted, and responded to.

This can mean:

- Autistic people can experience different senses more or less intensely than non-autistic people, and this varies over time.
- Autistic people often lack an automatic filter of incoming sensory information and have to work hard on interpreting it and focussing on what is relevant.
- Difficulty recognising and interpreting internal states such as hunger is common (interoception difficulties).
- Difficulty recognising and interpreting emotions (Alexithymia) is also common.
- Sensory differences can also impact how autistic people experience pain.
- When an autistic person is not believed about their sensory experiences or is unable to understand what they feel, it can be invalidating and can lead to trauma.
- Ongoing sensory overload can result in a meltdown. This is an automatic physiological response such as fight or flight. Meltdowns are not intentional behaviours or an autistic person being oversensitive.
- Sensory stress can also cause some autistic people to experience situational mutism, where they are unable to speak in certain situations.

Watch
the film



As a health practitioner what can you do?

These are the things that would help:

- Be aware that many hospital and mental health environments are unfamiliar, unpredictable, and often have noises, lights and smells that create a sensory nightmare for autistic people.
- Offer a quiet space to engage so that the background sensory input is at a minimum.
- Allow the autistic person to do what is needed to self-regulate, manage sensory load, and just feel okay (e.g. stimming, moving, taking a break).
- Allow more thinking and processing time for interactions. Pace things out and break down information, this does not mean slowing-down-the-way-you speak.
- Help reduce the processing load by making things predictable, being clear, saying what you mean and meaning what you say.
- Check any information that has been shared has been understood (and this goes both ways).
- Ask follow up questions. We are more likely to open up when asked a question again.
- Check the person understands what happens next and any advice given.
- Follow up in writing the key information the autistic patient needs to take away.

- Offer alternative approaches to meet an autistic person's needs, for example one to ones, autistic groups, digital communication, or creative therapy.

Further reading and resources



- Autism Understanding Scotland created a [Sensory profile](#) that might help communication with autistic patients. There is also an example of how to use it and [guidance](#).

Appointments: things to know and do



Watch
the film

Making appointments can be very difficult for autistic patients and they will often avoid it. The appointment experience itself can also be very difficult for autistic people. Therefore, thinking about accessibility is essential. For example, many autistic people struggle to or can't access the telephone.

Often autistic patients need to self-advocate about appointments at a time when they are least likely to be able to.

As a health practitioner what can you do?

These are the things that would help:

- Provide autistic-led training on autism understanding to all reception staff.
- Allow for autistic communication preferences and needs – such as by providing alternatives to using the phone to make appointments by using email or text bookings systems, and clear written communication.
- Provide clear information in advance to increase predictability e.g. information about directions, transport, photographs (locations and people), what to expect when they arrive, set waiting time expectations, how long will the appointment take, who they will see, what will be asked/discussed, and what happens next.
- Provide appointment reminders.
- Allow longer time for appointments.
- Offer alternative options without a patient having to suffer, complain, or quote legislation.

- If there are any changes or delays to the appointment, ask all staff to clearly communicate this to patients.
- Think about the waiting area and ask patients what changes might help such as telling people how long they will be waiting for or offering to turn off the radio.
- Make sure all signposting is clear.

Where waiting lists are long there should be communication about the expected waiting time, self-care suggestions, information about how to get help quicker if things get worse.



Further reading and resources



- Another working group in this workstream has developed posters and a film for GPs and practice staff. These are linked to on the NHS Education for Scotland [Turas](#) platform and on the [Different Minds](#) website.
- Autism Understanding Scotland created this [Autism Appropriate Environment Checklist](#) that could be used.
- This article relates to autistic [experiences of hospital appointments](#).
- This article describes [communication mode preferences](#) in the autism community.

Different identities and intersectionality



Watch
the film

Intersectionality is the word used to describe how an individual can experience a variety of identities. For autistic people this might be around neurodiversity, race, gender, class, sexuality, faith, disability, or other things.

This will be unique to each individual.

The experience of cultural and neurodevelopmental intersectionality cannot be inferred from physical appearance alone or put into categories. It is important to look at the whole person.

More than half of autistic people have co-occurring conditions. Common conditions include medical issues, such as epilepsy, hypermobility or sleep disorders; developmental diagnoses, such as language delay; mental health conditions, such as anxiety or depression; additional neurodivergent conditions such as ADHD and genetic conditions including Fragile X Syndrome.

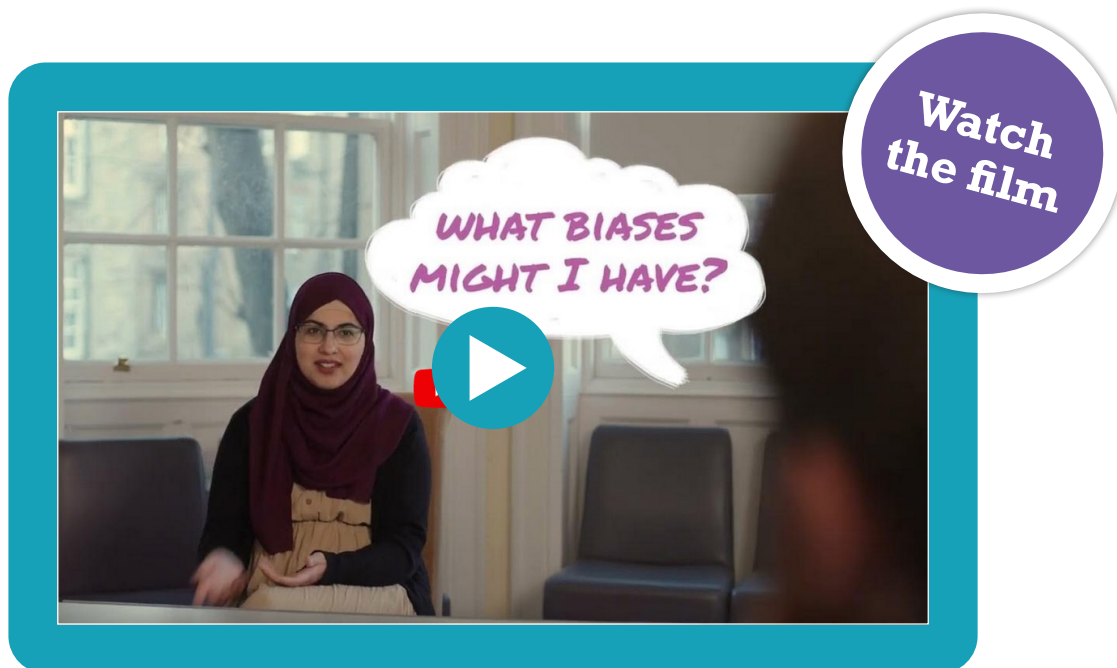
Cultural minority status is about more than just ethnicity and bias against differences can be shown in various ways.

As a health practitioner what can you do?

These are the things that would help:

- Don't put everything down to a patient being autistic – be aware of the risk of diagnostic overshadowing.

- Be curious about the patient’s cultural background.
- Be aware of your own biases and take proactive steps to address them.
- Be aware that things like social class, language, speech, and accent affect how people are perceived.
- Don’t make assumptions about someone’s background in making treatment advice and in general interaction (certain things might not be possible such as suggesting community activities).
- Autistic patients often prefer questions to statements. Be aware that plenty of autistic patients don’t want to open up about their different identities.



Further reading and resources



- This research is an example of a condition which is prevalent in autistic people but is often overlooked **Neurodivergent people more likely to experience pain, due to hypermobility.**
- This article explores the role of **intersectionality** in how autistic identity is understood.



Autistic wellbeing

It is important to understand that what is important for autistic wellbeing and quality of life can look different to non-autistic people.

Health professionals should be open-minded about what an autistic person's normal can or should look like.

Mental health practitioners should make sure that the views, goals, and targets are those of the autistic person themselves rather than based on neuro-normative expectations. Approaches should be personalised to include what is important for the individual.

Research suggests the following may play a role in supporting autistic wellbeing:

- Positive autistic social identity
- Peer support and connection to autistic community
- Access to passions and interests
- Feeling accepted, understood, and supported
- Agency and autonomy
- Appropriate support for co-occurring conditions
- Trauma informed practice

Poor mental health can manifest in autistic people in different ways which creates a risk of misdiagnosis.

Further reading and resources



- Autistic well-being: [A scoping review of scientific studies from a neurodiversity-affirmative perspective.](#)

- This paper discusses how [autistic quality of life](#) is conceptualised.
- This paper is about the [Foundations of Autistic Flourishing](#).
- This post describes autistic joy and [what is important for autistic wellbeing](#).
- This article summarises research on [Positive autistic social identity](#).
- This research article is on [understanding mental health problems experienced by the autistic population](#).
- This post is on [Adult Misdiagnosis](#).



What could you do next?

Thank you for reading this ebook. These could be your next steps:

Reflect on the content of this ebook and see where you can make positive changes in your practice.

Identify areas of priority, many of the things suggested relate to mindsets and attitudes rather than wholesale changes or expensive resources.

Involve autistic people, their representative organisations, and their advocates in plans for service improvement.

Access autistic co-produced and/or delivered training.

Have autistic peers be part of any resource sharing.



Reading and resources

These resources all were led by or produced with the involvement of autistic people.

Autistic mental health

- Assenti Research undertook [research](#) with autistic adults in 2021 on access to mental health services in Scotland.
- The National Autism Implementation Team [reviewed the published literature about Mental Health in Autistic Adults](#) in 2021.
- Autistic Mutual Aid Society Edinburgh (AMASE) carried out a survey and produced a report in 2018 titled [‘Too complicated to treat?’ Autistic people seeking mental health support in Scotland](#).
- This presentation from 2021 on [Autism and Mental Health](#) by autistic researcher George Watts includes sections on social communication and sensory differences.
- This article by the autistic advocate Kieran Rose describes [autistic burnout](#).
- The risk of [mental health misdiagnoses](#) in autistic people is described in this article.
- This article is on [Risk markers for suicidality in autistic adults](#).
- This research article is on [understanding mental health problems experienced by the autistic population](#).

Approaches to support

- The National Autism Implementation Team organised a webinar for professionals in 2023 on [‘Reflections on Cognitive Behaviour Therapy and Autistic Thinking’](#).

- This article describes [communication mode preferences](#) in the autism community.
- Ehlers-Danlos Support UK have produced a [Ehlers-Danlos Syndromes GP Toolkit](#).

Guides and resources

- Another working group in this workstream has developed posters and a film for GPs and practice staff. These are linked to on the NHS Education for Scotland [Turas](#) platform and on the [Different Minds](#) website
- Autistic Doctors International SPACE [framework](#) is designed to help professionals think about important ways to support autistic patients.
- The National Autism Implementation Team created a [Guide for GPs on Adults with Neurodevelopmental Differences](#).
- The National Autism Implementation Team created this animation with autistic people about effective communication – [More Than Words: Supporting effective communication with autistic people in healthcare settings](#).
- The National Autism Implementation Team created this [poster](#) with autistic people for healthcare settings.
- These co-produced guidelines for communicating well with autistic people in healthcare settings were published in England in 2022_ [More than words: Supporting effective communication with autistic people in health care settings](#).
- There is an Autistic led online course on Future Learn titled [Autistic Health: Improving Access to Healthcare](#).
- The Developmental Disabilities and Mental Health Lab at York University, Canada have produced a [Mental Health Literacy Guide](#) for Autism which has some resources in it.
- My [health passport](#) is a resource for autistic people who might need hospital treatment.

General

- Article by Dr Amy Pearson wrote this article on [Beyond masking and supporting autistic authenticity](#).

- This is the preprint of an article on autistic masking [‘Masking is life’: Experiences of Masking in Autistic and Non-Autistic Adults](#).
- The National Autism Implementation Team produced a [Guide to Autistic Masking](#) with autistic people.
- This video with Damian Milton explains the [Double Empathy Problem](#).
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- This article explores the role of [intersectionality](#) in how autistic identity is understood.
- This paper [details the barriers to healthcare](#) for autistic people.
- This post is on [Adult Misdiagnosis](#).
- The Scottish Government worked with autistic people to create this ebook titled [Different Minds](#).

Autistic wellbeing

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- This paper is about the [Foundations of Autistic Flourishing](#).
- This post describes autistic joy and [what is important for autistic wellbeing](#).
- This article summarises research on [Positive autistic social identity](#).
- This article describes how [autistic happiness](#) may not always be recognised as such by others.

INSPIRING SCOTLAND



Scottish Government
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