

# Autism and substance misuse

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# Why is this an important topic?

Autism is a way of being that affects how a person perceives and reacts to the world. This includes socially, physically and emotionally. It is far more prevalent than generally thought. (The NHS Information Centre 2012). It is thought that approximately 1% of the population are autistic.

Contrary to previous opinion, there is increasingly strong evidence that some autistic people have an increased risk of substance misuse, and the same is likely to be true for people with autistic traits but without a diagnosis. (Butwicka. A et al. 2017)

# The NAS says:

“If you are autistic, you are autistic for life; autism is not an illness or disease and cannot be 'cured'. Often people feel being autistic is a fundamental aspect of their identity.

Autism is a spectrum condition. All autistic people share certain difficulties, but being autistic will affect them in different ways. Some autistic people also have learning disabilities, mental health issues or other conditions, meaning people need different levels of support. All people on the autism spectrum learn and develop. With the right sort of support, all can be helped to live a more fulfilling life of their own choosing.”

## Nick Walker says:

“Despite underlying neurological commonalities, autistic individuals are vastly different from one another. Some autistic individuals exhibit exceptional cognitive talents. However, in the context of a society designed around the sensory, cognitive, developmental, and social needs of non-autistic individuals, autistic individuals are almost always disabled to some degree.”

# Professional understanding of autism

The way that professionals understand autism, and its relationship to substance misuse, is fundamental to autistic people getting appropriate support. There are many definitions and models of autism, from the increasingly contested traditional pathology model to the more recent neurodiversity paradigm, which positions autism as a naturally occurring difference with strengths as well as deficits.

# Health inequalities in autism

Autistic people report consistently worse experiences of healthcare settings than neurotypical people, feeling that their autism is not understood by professionals. (The Westminster Autism Commission. 2016) This is likely to include substance misuse and mental health services.

- **74% of autistic people surveyed felt they received a 'worse' or 'much worse' health service than people who are not autistic.**
- **75% of autistic people felt that health professionals 'rarely' or 'very rarely' understood their autism, and how it affects their physical and mental health.**

And...

**Autistic people die an average of 16 years earlier than the general population. For autistic people with comorbid learning difficulties, the gap is 30 years.**

(Autistica, 2016. 'Personal Tragedies, Public Crisis.')

# Why might autistic people use substances?

There is little research available about the reasons *why* autistic people might use substances. Many of the reasons will be the same as for people who are not autistic. Reasons for substance misuse specific to autism could include wanting to reduce the intensity of sensory experiences, dealing with social or generalised anxiety, or as a response to stress or trauma. Autistic people are particularly vulnerable to exploitation and abuse, especially as children. (Fisher, M.H. Et al, 2013)



# How can we best help?

As with anybody, supporting an autistic person to deal with the underlying reasons for their substance misuse will make it easier for them to reduce or stop. Supporting autistic people to replace their substance use with things that fulfil the same function for them as drugs or alcohol could be a particularly important intervention.

Every autistic person is different. When working out how to best support somebody, you should ask them about how their autism affects them and what adjustments they think will help them use the service. You should focus on strengths, including those which are specific to autism.

# Suggestions for adjustments



# Social communication

Autistic people may struggle with typical communication, especially when distressed or with new people, and may have learned to mask how they are feeling, including not showing pain or distress. Some have atypical affect including unusual patterns of speech, and can be intermittently verbal or non verbal. Autistic people may be anxious about meeting new people, or seeing healthcare professionals. Minimising assumptions about an autistic person's experiences and having open dialogue can help to work out what adjustments someone might require in order to establish and maintain communication.

# Sensory processing differences

Many autistic people experience sensory input with more or less intensity than people who are not autistic, and may be differentially sensitive to a range of things including sound, light and physical sensation.

Think about what might help?



# You might have thought of:

- **Appointments at times when the service is less busy**
- **Quieter rooms**
- **Dim lighting**
- **Giving options for communication such as email or text**
- **Giving plenty of personal space**
- **Ensuring a person feels comfortable using their own processing or self soothing methods such as repetitive movements, which are sometimes called 'stimming'.**

# Information processing differences

Many autistic people process written and verbal information differently to people who are not autistic. Autistic people may sometimes find it harder to process information when they are stressed or rushed, but may be particularly good at processing information in a context that works for them. Autistic people can have trouble quickly changing topic and may find it easier to focus on a single task or idea at a time, but may be particularly good at following through a plan once it is made.

What might help?





# You might have thought of:

- **Allowing time to process information**
- **Checking that the client has understood information**
- **Giving the client a written summary of keywork, plans and future dates in a preferred format**
- **Suggesting that they are accompanied by a friend or carer if they think this would help**
- **Giving documents suitable for dyslexic or visually impaired clients if necessary**

# Some other considerations



# Missed diagnosis

It is important for professionals to know that autism can go unnoticed, both due to autistic “masking”, where autistic people have learned to adapt their behaviour to minimise their experiences and fit in, and due to misunderstanding of the wide range of ways that autism affects people. This is especially the case for autistic women. (Bargiela. S et al. 2016)

# Misdiagnosis and misunderstanding

Autism is sometimes misdiagnosed as a mental health problem such as a 'personality disorder', which can lead to inappropriate treatment being offered. Co-occurring physical, neurological and psychological problems get missed in autistic people, because they are assumed to be inherent to autism. (Dudas. R.B et al. 2017)

Clients who think that they could be autistic should be supported through referral to specialist neurobehavioural teams for proper assessment and diagnosis, following NICE guidance.

# Healthy habits

Autism may make it harder for clients to engage in healthy habits, such as getting sufficient sleep, exercising, eating well, taking medication as prescribed and organising and planning. Autistic clients should be supported to build their wellbeing in a way which works for them.

# Homelessness

For homeless clients, we should consider that autism could be a risk factor for homelessness, and a barrier to getting off the streets. Clients should be encouraged to discuss how their autism affects them with other professionals such as housing workers if possible. (Homeless Link 2015)

# In summary

As with any patient or client, care planning for an autistic person should be done **with** the autistic person, and should be person centred and holistic. Autism is varied and complex, and poorly understood by many professionals, and the public. As professionals we should be seeking to understand our clients and their needs collaboratively, with creativity and curiosity, and being clear when we don't understand.