

Autism and substance misuse

A briefing for professionals

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Surrey and Borders Partnership

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Why is this briefing important?

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.¹

There is increasingly strong evidence that some autistic people have an increased risk of substance misuse,² and the same is likely to be true for people with autistic traits but without a diagnosis.³

Autistic people experience disproportionately poor health outcomes and high early mortality for a range of reasons, including comorbid physical and mental health problems.⁴

- **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.**⁵

Furthermore, autistic people report consistently worse experiences of healthcare settings than neurotypical people, feeling that their autism is not understood by professionals. This is likely to include substance misuse 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.**⁶

This briefing aims to help substance misuse professionals update their understanding of autism, adapt how they work with autistic people, and feel empowered to ensure their services are working for neurodiverse clients.

¹ The NHS Information Centre (2012). *Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey*. Leeds, NHS Information Centre for Health and Social Care.

² Butwicka, A et al. (2017). Increased Risk for Substance Use-Related Problems in Autism Spectrum Disorders: A Population-Based Cohort Study. *Journal of Autism and Developmental Disorders*. 47(1): 80-89

³ De Alwis D. et al. (2014). ADHD symptoms, autistic traits and substance use and misuse in adult Australian twins. *Journal of Studies on Alcohol and Drugs*. 75 (2): 211-221.

⁴ Hirvikoski, T. et al. (2015). Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry*, 208(3): 232-8

⁵ Autistica (2015): *Personal Tragedies, Public Crisis*, <https://www.autistica.org.uk/downloads/files/Personal-tragedies-public-crisis-ONLINE.pdf> accessed 16/12/18.

⁶ The Westminster Autism Commission. 2016. *A Spectrum of Obstacles* https://westminsterautismcommission.files.wordpress.com/2016/03/ar1011_ncg-autism-report-july-2016.pdf Accessed: 28.9.18

The complexity of defining autism medically and socially

- **80% of GPs reported that they needed more guidance and training to be able to identify and support autistic patients.⁷**

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 paradigm⁸, which positions autism as a naturally occurring difference with strengths as well as deficits.

The National Autistic Society 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.”

Although the National Autistic Society describes autism as a disability⁹, autistic people may not identify as disabled.

Nick Walker, an autistic academic 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.¹⁰”

⁷ National Audit Office (2008) *Survey of General Practitioners in England on the subject of autism* https://www.nao.org.uk/wp-content/uploads/2009/06/0809556_gp.pdf accessed 10/12/18

⁸ Neurodiversity: Some Basic Terms & Definitions:

<http://neurocosmopolitanism.com/neurodiversity-some-basic-terms-definitions/> accessed 18/12/18

⁹ National Autistic Society: *What is Autism* <https://www.autism.org.uk/about/what-is.aspx> accessed 22/10/18

¹⁰ What is Autism? <https://www.thinkinclusive.us/what-is-autism-a-definition-by-nick-walker/> accessed 20/12/18

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.¹¹ Autism is also sometimes misdiagnosed as a mental health problem such as a personality disorder¹², 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.

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.

How can we better meet the needs of autistic people who are misusing substances?

There is little research available about the reasons *why* autistic people might use substances. Many of which 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.¹³

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. When building a support plan, you should focus on strengths, including those which are specific to autism, rather than starting with an assumption of impairment. In mental health¹⁴ and substance misuse¹⁵, strengths based approaches such as motivational interviewing are successfully used across the NHS. To apply a strengths based approach with an autistic client requires identification of their strengths.

¹¹ Bargiela, S et al. (2016). The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype. *Journal of Autism and Development Disorders*. 46(10): 3281-94

¹² Dudas, R.B et al. (2017) The overlap between autistic spectrum conditions and borderline personality disorder. *Plos One*. <https://journals.plos.org/plosone/article/related?id=10.1371/journal.pone.0184447> accessed 28/12/18

¹³ Fisher, M.H. Et al, (2013) Differences in Social Vulnerability among Individuals with Autism Spectrum Disorder, Williams Syndrome, and Down Syndrome. *Research in Autistic Spectrum Disorders* 7(8): 931–937

¹⁴ Tse, S. et al, (2016). Uses of strength-based interventions for people with serious mental illness: A critical review. *International Journal of Social Psychiatry*. 62(3): 281-91.

¹⁵ Carroll K.M. et al, (2006). Motivational interviewing to improve treatment engagement and outcome in individuals seeking treatment for substance abuse: A multisite effectiveness study. *Drug and Alcohol Dependence* 81(3): 301–312.

Adjustments

The following suggestions for adjusting the way we work are adapted from the NICE guidance¹⁶ on supporting autistic adults, and National Autistic Society resources¹⁷. Adjustments that an autistic person will find useful are likely to change over time as the person changes, especially during the period after diagnosis if somebody is diagnosed as an adult, as this can be a period of rapid figuring out.

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 differently sensitive to a range of things including sound, light and physical sensation.

Things that might help:	<ul style="list-style-type: none">- 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'.
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Autistic people may find some treatment settings, such as groups, unpleasant and difficult for reasons related to their sensory experience, and the intensity with which they process social information. Take this into account when planning support.

¹⁶ Clinical guideline [CG142]

¹⁷ National Autistic Society, *Sensory differences*. <https://www.autism.org.uk/sensory> accessed 22/10/18

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,¹⁸ but may be particularly good at following through a plan once it is made. As well as the communication measures that would help anybody, autistic people may also benefit from:

- **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**

Other considerations

Whilst it may be useful to speak to a person who knows an autistic client well such as a parent, partner or friend, never assume that a person who is not autistic will understand an autistic person's needs better than the autistic person themselves.

It is important to bear in mind common comorbidities and how they may interact with autism. For example, there is a high prevalence of Attention Deficit Hyperactivity Disorder symptoms in autistic people¹⁹. If an additional diagnosis is suspected, clients should be supported to have this investigated.

For homeless clients, we should consider that autism could be a risk factor for homelessness, and a barrier to getting off the streets.²⁰ Clients should be encouraged to discuss how their autism affects them with other professionals such as housing workers if possible.

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.

¹⁸ Murray, D., Lesser, M., & Lawson, W. (2005). Attention, monotropism and the diagnostic criteria for autism. *Autism*, 9(2): 139–156.

¹⁹ Rommelse, N. et al. (2010), Shared heritability of attention-deficit/hyperactivity disorder and autism spectrum disorder. *European Child & Adolescent Psychiatry*. 19(3): 281-95.

²⁰ Homeless Link (2015), *Autism and Homelessness: a briefing for frontline staff*. <https://www.homeless.org.uk/our-work/resources/autism-homelessness> accessed 10/12/18.

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.

Additional resources

There are a range of resources available to support healthcare professionals working with autistic clients. Misleading information and poor research about autism frequently appears. Professionals should evaluate the quality and integrity of information and advice they read, and ensure that it is based on good research, and ideally developed by or with input from autistic people. Much of the literature is focused on autism in children, not the varying and complex ways it can affect adults.

Some selected links are included below, and are current as of 10/10/2018.

Guidance around developing autism specific clinical skills, including assessing and taking into account sensory needs (Royal College of Nursing)

https://rcni.com/sites/rcn_nspace/files/RCNi-Autism-Booklet-2015.pdf

Person centred care planning (National Autistic Society)

<https://www.autism.org.uk/professionals/health-workers/person-centred-planning.aspx>

Autism: Improving access to social care for adults (Social Care Institute for Excellence)

<https://www.scie.org.uk/autism/>

Autism Spectrum Disorders Toolkit (Royal College of GPs)

<http://www.rcgp.org.uk/clinical-and-research/resources/toolkits/asd-toolkit.aspx>

Autism and Homelessness: A Frontline briefing. (Homeless Link)

[https://www.homeless.org.uk/sites/default/files/site-attachments/Autism%20&%20Homelessness Oct%202015.pdf](https://www.homeless.org.uk/sites/default/files/site-attachments/Autism%20&%20Homelessness%20Oct%202015.pdf)

Elearning modules (payment required) from the British Psychological Society

<https://www.bps.org.uk/news-and-policy/three-adult-autism-awareness-e-learning-modules-relaunched>

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