

Summary and analysis of comments from attendees at

# ***Not your neurotypical client: Autism, alcohol, and other substances***

An online seminar hosted by Alcohol Change UK, the Centre for Applied Autism Research at the University of Bath, and the Royal College of Psychiatrists

**Monday 6 September 2021**

This online event was attended around 270 people and the discussions covered a range of autism-related topics. Here we have sought to summarise the comments made by attendees, and draw out some themes under a series of headings:

- Reasons people drink or use other substances
- Legal and illegal drugs
- Autism and gender
- Autism and homelessness
- The role of trauma
- Difficulties accessing services
- Families and other relationships
- What would help?
- The importance of lived experience
- Comments on the value of the event.

## **Terminology**

A range of autism terminology is used in this document, as it draws on the actual words used by attendees during the event. The terms used and opinions expressed do not necessary reflect the views of the event's organisers.

## **Reasons people drink or use other substances**

One of the questions we asked attendees was what they thought were the reasons some autistic people might drink alcohol and/or use or substances, and whether those reasons were different to neurotypical people's reasons. Here are some of the responses we had:

- "Autistic people drink for exactly the same reasons NT [neurotypical] people drink!"

- “I think sometimes alcohol can provide a confidence to deal with socialising when feeling out of place and uncomfortable with group situations”
- “I was a drinker as a teenager...but mostly [because of] peer pressure and trying to be the same as everyone else...When I stopped drinking, I stopped socialising in an NT way because I couldn’t deal with the sensory overwhelm of the pub/club environment”
- “The issue of self-medication is a huge one, as the healthcare system is difficult to navigate at the best of times”.

### **Legal and illegal drugs**

There was some discussion about whether autistic people may be more likely to use alcohol rather than illegal substances. There was some agreement that this may be the case but the picture was not consistent:

- “[I work] with an 18-year-old male with ADHD [attention deficit hyperactivity disorder] and [an] autism diagnosis. He is now drinking excessively...I have discussed at length the triggers, and he just says he likes to drink, he likes how it makes him feel, and it’s legal”
- “How about the use of the internet...to buy other drugs such as Benzodiazepines? I have a group of clients who have graduated from alcohol to the use of those drugs”
- “We have seen quite a few issues around opiates and Diazepam”
- “How about addictions to prescription medication?”
- “In [my] service, I have noticed that out of nine males who misuse cocaine, six have a diagnosis of ADHD”.

### **Autism and gender**

Concerns were expressed that autism is not always recognised in children, particularly amongst girls, nor amongst women of all ages:

- “We are missed at school because we mask”
- “We are missed at school because we can hide in plain sight by masking. Choose a more capable person and stick like glue to them...Then at home it all comes out”
- “[There is] more stigma attached [to autism] as a female”
- “Masking females find it almost impossible to ask for help”.

### **Autism and homelessness**

A number of participants spoke of their experiences of autistic people being at particular risk of becoming homeless:

- “[There is] massive over-representation [of autistic people] in the homeless community. Services need to be better-equipped”
- “I work in a homelessness service, supporting a client who is alcohol-dependent and who I suspect may have undiagnosed autism”
- “There is a very high percentage of homeless people with untreated/undiagnosed ADHD and ASD [autism spectrum disorder]. I tend to approach everyone that I see now as having possible ASD”.

### **The role of trauma**

The complex relationship between autism and trauma was discussed, in particular the trauma that an autistic person may experience in a world that is far from autism-friendly. There was general agreement that some professionals’ poor understanding of autism leads them to take inappropriate approaches to addressing trauma. In particular, the idea that “we need to fix the trauma first” (before acknowledging someone’s autism) was considered unhelpful:

- “When I have tried to change the narrative, I have often had to have the discussion with professionals as [they] often think that ‘trauma’ is an alternative diagnosis/explanation; rather than ASD informing the risk of trauma, the impact, and therapeutic approach”
- “[In our breakout room, we] spoke about underlying trauma, how services across the UK are not facilitated to meet needs of autism, how clients are moved around the country to access services, and how services lack understanding of autism”
- “[There] needs to be more awareness of ND-related trauma and [the] effect of substances”.

### **Difficulties accessing services**

Unsurprisingly, many people said they had experienced difficulties accessing services, either for themselves or for people they were supporting. This often started with difficulty persuading services to understand what the issues were (and provide a diagnosis where appropriate):

- “Our greatest issue has been the difficulty around the clients getting assessed, as the diagnosis helps to inform treatment in, for example, rehab. It often takes about 18 months in local services for the clients to be assessed”
- “These clients are often misdiagnosed”

- “Adult ADHD [is] still massively under-recognised, especially in those who [have] resorted to substance use to self-medicate. Everything then just gets blamed on the drugs”
- “It would be useful for this seminar to include mental health services. I get my referrals rejected on the grounds that my clients have substance use issues. Basically, they are not interested in working with the drug services”
- “Services [are] very rigid in their approaches”
- “[I] find social workers very useless when it comes to supporting autistic adults”
- “[There’s a] need for a wider range of support services alongside alcohol and drug services to meet a wider range of needs. Too often, people will fall between the gaps [in] services”.

A number of other barriers to accessing services were mentioned:

- “Lack of staff understanding about autism”
- “Lack of awareness of autism”
- “Lack of services in the area”
- “Appointment/support location”, i.e. having to access support in a location that is not autism-friendly
- “Anxiety”
- “Shame”
- “Anxiety, especially around times of transition, e.g. starting college”
- “Anxiety/stress about prospective change”
- “ASD clients not knowing that they are welcome”.

### **Families and other relationships**

As is often the case when dealing with substance use issues, families and other relationships were seen as influential and important:

- “The issue I would like to raise is what happens when an autistic person is living with a problem drinker or individual who is using substances. We often don’t see the red flags in relationships that others would and do tend to have empathy with the underdog and we relate to the difficulties that our partner [is having] and why they use substances to cope and can be more accepting of difference than others. BUT we also find it far harder to ask for help. Support is often lacking for the partners or loved ones of substance users anyway without being autistic as well”
- “There also needs to be a recognition that a lot of us saw our parents deal with the stress of the system through the use of drink. You still see it now with parents

[saying] 'Thank goodness it's wine o'clock'. Wine o'clock can quickly turn into, 'Oh sh\*t I need a drink'"

- "In Gwent Integrated Autism Service we run a SAFE course for autistic women (and we run one for men) around relationships, keeping yourself safe, social media risks, red flags etc."
- "[At] CRAFT in Cardiff and the Vale of Glamorgan, [we] provide a group programme for families and friends with a loved one with an alcohol and/or substance concern. [It does] not specifically reflect ASD, but many family members have suggested that possibly undiagnosed ASD is a factor. The programme is about the participant[s] changing their behaviour and responses, in the hope that this would generate positive change in their loved one. Sometimes this a real challenge for participants if they feel their loved one is autistic, and the family may struggle with their behaviour/responses and want/need to keep them safe".

### **What would help?**

As well as looking at the difficulties autistic people face in accessing services, we also asked participants at various points during the event what they thought would help autistic people to avoid and/or manage problems with substance use:

- "Services seem to consider that people are difficult and challenging...[What is needed] is professionals changing their approach rather than discharging [people] from the services. It maybe that we [need to] consider the way we work, and we need to hone our skills"
- "Being more person-centred"
- "Tailoring approach/support to the individual"
- "Psychologically Informed Environments"
- "Being more focused on the person"
- "Flexibility and treatment options"
- "Being more fluid in how you treat or work with people"
- "Being willing to change systems and procedures"
- "Unconditional positive regard"
- "To have an understanding of how [substance use] affects autistic people, and patience"
- "Understanding and empathy"
- "Recognition that we don't live in an autism bubble. We are a very, very diverse community [and we] need to recognise intersectionality"
- "Occupational Therapists can play a significant role in helping individuals overcoming barriers and improving outcomes"
- "Tenancy support".

A number of people mentioned the value of online support, which may reflect in part the growth of this kind of support during the Covid-19 pandemic:

- “[There] needs to be something different to group therapies for ND persons”
- “[We need to] understand that some people may not engage or may have other difficulties with engagement”
- “[We need] flexibility with how access services, e.g. meeting online”
- “[We should] consider designated support in rehab, including online group work with others with autism”
- “Online courses where there is no need to social[ly] interact [are valuable]. This removes the shame, stigma and the risks”.

### **The importance of lived experience**

One point that was made clearly and consistently in answer to the question **What would help?** was that professionals need to understand and draw upon the experiences of autistic people:

- “I am finding it particularly helpful to hear from those with lived experience”
- “The more autistic-led input, the better. These discussions are so important, between all neurotypes”
- “Training for professionals is often very basic with regards to autism. It would be beneficial for training to be delivered and designed by individuals with lived experience”
- “Consult with people on [the] autistic spectrum and [who have] sub[stance] mis[use] issues”
- “Involve people with lived experience in the design and delivery of services”
- “[I] agree [that it is] very important to get research to the community you are researching. NOTHING ABOUT US WITHOUT US...Participatory research is the way forward”
- “Nothing about us without us!”.

Within this, there was a lot of enthusiasm for peer-support:

- “I find lived experience is so important and I love that our service allows for people with autism to have support from people with lived experience”
- “[In our breakout session] we discussed the vital involvement of peer-mentors for those in treatment, and also the potential for professionals to have someone with lived experience as a peer-mentor”

- “Peer-mentoring [is] definitely needed more”
- “Peer-support and training for organisations is absolutely essential”
- “Would more peer-support be helpful? [It] seems to work in other areas of work with autistic people”
- “[We need] training delivered and designed by autistic trainers...co-production using lived experience [and] peer-mentors with experience of addiction and substance use”.

### **Comments on the value of the event**

The feedback from attendees was universally positive, and there is clearly a great deal of enthusiasm for more collaboration working between people working on autism and those working on substance use. Here are a few examples of the comments made about the event:

- “Very enlightening”
- “That was EXCELLENT!”
- “Thank you so much for stretching how we should view issues for our clients”
- “Great sessions. A much-needed project!”
- “It’s encouraging to see so many people involved in this subject”
- “Great webinar. Look forward to more research in this field”.

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