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Autism and Addiction

Let me introduce myself. My name is Tania Browne, I'm an alcohol and addiction researcher at the University of Stirling, and at the sprightly age of 46 I found out I was autistic.

Now, this is hardly a dramatic revelation. In fact, it's increasingly common here in the UK. Many people from past generations, like me, have slipped through the diagnostic net. In recent years there has been an increasing demand for diagnosis of people with suspected Autism Spectrum Condition (ASC) in adult mental health services (Crowley *et al*, 2018).

There are several reasons why we adults with ASC may not have been diagnosed in childhood. Firstly, until recently there was quite simply a lack of awareness in the educational and health care communities. Autism wasn't recognised in the DSM until 1980, and Asperger Syndrome in 1994 (though it's worth noting that in the latest edition of DSM, Asperger Syndrome has been removed as we realise the broad variety of autistic adults and their "spiky" profiles*).

Some of us are misdiagnosed with other conditions for long periods of time until one day, the penny drops; obsessive-compulsive disorder, ADHD, and (in my own case) bipolar disorder are all common, and women especially are often misdiagnosed with borderline personality disorder. Our parents may have thought there was something a bit "odd" about us, but they may have been unwilling to pursue a diagnosis due to the stigma and discrimination that autistic people still face. There is also a racial bias in diagnosis. A study in the USA in 2007 found that white children were over twice as likely to be diagnosed with an ASC than their African American peers. These children had very similar symptoms, but were more likely to be diagnosed with ADHD (Mandell *et al,* 2007)

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Many of us will have been considered a little "shy" or "introverted" as children, but without what many people think of as the "classic" symptoms of autism. Our problems dealing with the world might only have become apparent as we grew into adulthood and faced social demands in the world of work, and the need for executive functioning skills (skills such as timekeeping and the ability to organise yourself). It's now thought that women in particular learn "masking" skills to conceal their autism, especially mimicking small-talk, rehearsing expected conversations, and having more "feminine" special interests (Cage and Troxall-Whitman, 2018).

There has been a lot of talk in the media about how diagnosis of ASC is increasing, and from this some people deduce that the condition itself is on the rise. However, there is no evidence to support this – the illusion is created by changing rates of diagnosis, rather than an increase in autistic people. There has only been one large scale study in the world measuring prevalence of autism in adults. In 2011, Terry Brugha and colleagues at the University of Leicester found that while the prevalence of autism in the population was not age dependant, the rate of existing diagnosis *did* correlate with the age of participants. In other words, autism rates are pretty constant over time, it's just that we're better at spotting it than we used to be. Brugha's best estimate was that around 1 in 75 people of all ages are on the autism spectrum. In their conclusion, he and his colleagues write that:

*"In our clinical experience, providing….social care to adults with a diagnosis of ASD leads to improvements in quality of life and reductions in the inappropriate use of high-cost hospital services….. A great deal more research should be directed at the epidemiology and care of adults with this condition." (*Brugha *et al,* 2011*)*

This last quote is important, because the general health of autistic adults has rarely been studied and, as I've discovered during my own research, there's barely any published evidence at all about autistic adults and addiction to alcohol and drugs. The assumption that an autistic person would rather read a nerdy website all night in their room than party hard might prevent people, including medical staff, from suspecting substance use in autistic teens and adults. In my case they'd be

absolutely right, but everyone is different. As the saying goes “If you’ve met one autistic person….. you’ve met one autistic person.” The fact is that autistic people can, and do, use alcohol and drugs. Even the briefest scan of Reddit autism forums will show many discussions among those who self-experiment with cannabis, cocaine, and MDMA to see if it alters their personal “symptoms”, as well as those who are seeking advice as they drink to combat their loneliness. Of course, this doesn’t necessarily lead to addiction, but if combined with other conditions such as depression and anxiety it can be a slippery slope.

Though screening for a substance use disorders is common for many mental health conditions, it is not routine for those with ASC. Arnevik and Helverschou (2016) surveyed previously published scientific studies, and identified only 18 examining the association between ASC and substance use disorders. The results of these showed rates of adults diagnosed with ASC with substance use problems varied widely between 0.7% and 36%. However all of the identified studies were on small, specialised populations, such as offenders and patients in mental hospitals. The samples were also predominantly male, which makes drawing comparisons and establishing a good estimated rate difficult.

A population-based study trying to establish the rate of substance use disorders in a general population of autistic adults was not published until 2017. In a Danish study of over 26,900 individuals, Butwicka and colleagues documented a doubled risk of alcohol and substance use-related problems among autistic adults when compared to the general population. A population study such as this had never been done previously, and provides stark contrast with the studies of niche samples gathered by Arnevik and Helverschou. It suggests that prevalence of substance use disorders in autistic people may be much higher than previously estimated – something that I myself am keen to study further.

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There are several good reasons why we should make the effort to establish the rates of autistic people having problems with alcohol and drugs, and to further study the links between autism and addiction;

- the perceived "protective factors" of autism are overstated
- depression is strongly linked to substance use, and a higher proportion of autistic people experience depression and anxiety than in the general population
- Social isolation and anxiety are shared common factors in both ASC and substance use disorders
- There is a significant discrepancy between need and support for autistic adults

Let's go through these points in turn.

Perceived "protective factors" of autism are overstated

The protective factors of an autism diagnosis may appear to outweigh the risk of alcohol and substance use. For example, many might assume that autistic people tend to be strict rule-followers, and the idea of social boundaries or breaking the law would be unthinkable. Sensory processing sensitivities could make the taste of alcohol unpleasant and the concept of snorting, smoking, or intravenous drug use abhorrent (Kunreuther and Palmer, 2017). The assumption that an adult with ASC doesn't want to socialize or feel accepted may prevent primary care staff from suspecting substance use in autistic adults.

It has sometimes been argued that there is no link between autism and substance use disorders, and some studies identify autism as a protective factor for alcohol or drug addiction (*eg.* Ramos *et al*, 2013). However, such studies often use young people in specialist care settings, and not those in general education. Kunreuther and Palmer (2017) point out that if an autistic adolescent is in a mainstream school, then the desire to "fit in" may still lead to experimentation with alcohol and substance use. More and more children diagnosed with ASC are being 'mainstreamed', so are

more readily vulnerable to social situations, peer pressures, relationship issues, and school (and employment) successes and failures. This is important, as alcohol and substance use disorders in adulthood frequently begin in adolescence (Levy and Sundaram, 2018).

Clarke and colleagues (2016) also note that there is a significant discrepancy in past studies regarding substance use in autistic adults. Most studies didn't factor in any kind of desire for social interaction, but in their own thematic analysis of 8 interviews they found that the theme of social difficulties dominated their overview. The desire to "fit in" with their peers appeared to be an important motivator in the participant's use of substances including alcohol, cannabis, codeine, cocaine, and MDMA.

Depression is strongly linked to substance use. A higher proportion of people with ASC experience depression and anxiety than in the general population

A systematic review reported by Rydzewska and colleagues suggest that depression, bipolar disorder, schizophrenia, suicidal thoughts and behaviour, and non-affective psychosis are more common in autistic adults than other people (Rydzewska *et al*, 2019).

In their 2018 study, Wang and colleagues note that there is a well established connection between depression and substance use in neurotypical people. They suggest a mechanism through which the stress of stigma relating to mental illness may lead to "emotional dysregulation", and maladaptive coping strategies such as alcohol and drugs. Wang and colleagues suggest that this stigma undermines self-esteem, increases isolation, and deters people from seeking help – this may equally be a factor when considering the stigma of autism, especially when seeking diagnosis as an adult (Kunreuther and Palmer, 2017). However, it's important to note that Wang and colleagues also acknowledge the line of causation may be the other way around – substance use might lead to emotional dysregulation and maladaptive coping.

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Symptoms of anxiety and depression are commonly reported by adults diagnosed with ASC, and this can make core autism symptoms worse and lower a person's quality of life. Hollocks et al (2019) reviewed a total of 35 studies of anxiety and depression in autistic adults published between 2000 and 2017, and found a pooled estimate of *current* anxiety and depression of 27% and 23% respectively in clinical studies. This was considerably higher than would be expected, based on estimates of 1–12% in the general population. The finding was similar for pooled *lifetime* estimates of anxiety (42%) and depression (37%). Hollocks and colleagues also found that specific anxiety disorders, particularly social phobia and obsessive compulsive disorder (OCD), were more common in autistic adults.

Murray and colleagues (2019) found that 46% of 205 British adults who received a diagnosis of ASC in adulthood reported symptoms that reflected moderate or severe anxiety and/or depression. Cassidy and colleagues found that in a large sample (n=374) of newly diagnosed British adults 66% had contemplated suicide, significantly higher than both the general population (17%), and patients with psychosis (59%). Further, 35% had attempted suicide, higher than previous estimates of attempted suicide in general (2.5%) and university (10%) populations (Cassidy *et al*, 2014). A later research paper from Cassidy suggests unique contributors to suicide in autism when compared to the general population, which need to be addressed in addition to important well-known factors such as mental health, employment, and living arrangements (Cassidy *et al*, 2018).

In Sweden, Bejerot and colleagues (2014) discovered a higher rate of self-reported social anxiety in 50 autistic adults when compared to the general population. A systematic review of 25 papers also found strong links between autism and social anxiety (Spain et al, 2018).

Social anxiety can produce a higher risk of problem drinking and drug use, particularly when autistic adults are accustomed to using masking behaviours. Masking is defined as camouflaging particular aspects of one's behaviour from others to "pass" in social situations, and is common in autistic people navigating the

non-autistic world (Bargiela *et al* 2016; Cage and Troxell-Whitman 2019). Peer influence has been shown to be a predictor of alcohol use among college students and young adults. Perceived norms are considered a strong predictor of alcohol use and alcohol related negative consequences among young adults (Villarosa *et al*, 2016).

While the studies above can be seen as a first step in furthering our understanding, the sampling and methods chosen are extremely homogenous. None of the studies included adults with ASC tendencies but without diagnosis, or adults who had not been in contact with clinical services, This means that they may not fully represent adults with ASC in the whole population. They might possibly be of value in clinical practice settings, but they have limited value to an understanding of the relationship of autism to anxiety and depression in the wider community.

Social isolation and anxiety are shared common factors in both ASC and substance use disorders

Many adults with ASC and related mental health issues report a sense of loneliness and social isolation. Todd and colleagues (2004) defined ‘social exclusion’ as having housing problems, being unemployed, having a lower education level and being isolated (ie living alone). All of these factors regularly occur as a result of the executive functioning problems frequently reported by autistic adults, leading to a more chaotic lifestyle than the general population (Hollocks et al, 2014).

Drake et al (2002) noted that the biological emphasis formerly placed on investigating people dually diagnosed with substance use disorders and mental health disorders meant that vital issues such as social networks, boredom, poverty, dysphoria and expectations of drug effects were neglected. The reasons may be complex, but the desire to fit in with peers plays a key role in substance use among those with psychiatric disorders. Boredom, loneliness and stress have been cited as key reasons why people with mental disorders may use (and relapse into using)

substances (Laudet et al, 2004). Participants in Laudet's study also mentioned other reasons why they used substances – to increase happiness, energy, and emotions, and to reduce feelings of anxiety and depression.

Agwu et al (2016) note the role of social capital in substance use disorders, defining social capital as a multidimensional concept "operationalised as economic, cultural, and social assets, civic engagement, solidarity, trust and reciprocity." Importantly, Kunreuther and Palmer (2018) suggest that becoming involved in drinking and drug subcultures may be a way for autistic people to gain social capital among other marginalised groups when they feel rejected by mainstream culture.

Clarke et al (2016), in their interviews with 8 adults with ASC, come to the conclusion that some socially oriented adults with ASC feel isolation and a lack of connectedness, and will use substances to aid communication with others, and to gain a sense of social inclusion. Clarke and colleagues conclude that *"…contrary to the protective factors of autism contained within earlier literature, the presence of… [ASC]…leaves an individual as vulnerable to the development of SUD as the wider population, and perhaps arguably more so."*

There is a significant discrepancy between need and support for autistic adults

It's now widely recognised that ASC is severely underdiagnosed in the adult population, and that as a direct result of this there is very limited support available for newly diagnosed adults. Similarly, adults diagnosed with ASC during childhood '*find themselves "falling off a cliff" into unstructured and overwhelming adult environments for which they lack the tools for successful integration*' (Wallace *et al*, 2016). All physical and mental health outcomes for autistic adults are poor, which puts them at risk for alcohol and other substance use.

The autistic advocate John Elder Robison writes that outcomes for autistic adults range from institutionalisation to seamlessly "blending" into the community. This means that there's a wide range of implications for support and services (Robison,

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2019). There's still a great deal of stigma attached to an autism diagnosis which, combined with a distinct lack of post-diagnostic support and services, may discourage people who suspect that they're autistic from seeking psychiatric confirmation. Robison further points out that if the currently undiagnosed community have similar outcomes to those *with* a diagnosis, the implications for future health outcomes and the need for tailored treatments are sizeable if we consider Terry Brugha's prevalence estimate of 1 in 75 people in the UK.

The lack of monitoring and social support networks for autistic adults may ultimately be a major factor in drinking and other substance misuse, and it's an issue that needs to be addressed. But how?

Adults with ASC may be under-served in mainstream addiction services

Arnevik and Helverschou (2016) point out that little is known about successful interventions for autism and substance use disorders. They postulate, in fact, that typical interventions may do more harm than good. Forced involvement in group sessions or community based programmes could make autistic people anxious and cause them to drop out. This could lead to further feelings of failure and alienation in autistic adults, leading to more substance misuse…. a self-perpetuating cycle that would be very hard to break.

Attwood (2018) agrees with this general view, stating that rehabilitation services often rely on social living and group therapy and activities and provide limited opportunities for personal space and solitude. Autistic people might need solitude, guidance, and support in the social and disclosure requirements of group therapy. They may have difficulties recognizing social and personal boundaries, converting their thoughts and feelings into speech, knowing when to talk in a group, and understanding how to show that they acknowledge the experiences and emotions of other group members with substance use issues who may not be autistic.

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Much investigation still needs to be done to establish the scale of the problem of autistic people with alcohol and substance use problems. What studies have been done are on small niche populations, which are too varied to provide a comparison even between themselves, and certainly not representative of the adult autistic population in general. What's more, the only existing population study focuses on adults who have received a diagnosis, when it is known from Brugha that a large proportion of autistic adults don't have an official diagnosis.

The next steps are therefore to establish

- A clearer picture of a general community prevalence of SUDs among autistic adults
- An initial scoping picture of the rate of alcohol and substance use among people who are not officially diagnosed, but who suspect they have ASC
- The experiences of treatment so far; or if treatment has not been sought, the perceived barriers to seeking help
- How clinicians may be able to tease apart the often mixed presentations of ASC and SUDs, in order to provide more tailored effective treatments

Research already shows that autistic adults are more likely to report unmet medical needs and dissatisfaction with their care than the general population (Nicolaidis *et al.,* 2012) as well as barriers in accessing medical care (Raymaker *et al.,* 2017). Additionally, only 38% of GPs report having had any training in ASC, and even those who have report a lack of confidence in caring for their adult patients with autism spectrum conditions (Unigwe *et al,* 2016). However, little has been published on how to improve healthcare access and delivery for autistic adults. As the adolescent and adult populations with autism spectrum conditions continue to grow, it becomes increasingly important that we seek a better understanding of their health care needs (Rydzewska *et al*, 2019; Robison, 2019).

In a series of focus groups and an online survey of almost 2000 stakeholders, Pelicano and colleagues found almost unanimous disappointment that autism research is still primarily limited to the basic science – neural and cognitive systems, genetics and other potential risk factors. As one autistic adult said, "it represents the priorities of neurotypical people, not autistic people" (Pelicano *et al,* 2014). All stakeholder groups agreed that much more research is needed in in services and support, and they unanimously called for evidence based services and interventions.

Any research on alcohol and substance use disorders would contribute to such an evidence base, for both the development of brief interventions directed at autistic adults, and for more effective and "user-friendly" recovery services. There is clearly a need for specialist staff within community mental health and addiction services who have received training in the core issues surrounding autistic adults, and it has even been suggested that a model of "ASC hub" workers be adopted. This would co-ordinate autistic people's mental health and recovery with psychosocial supports such as future life/career planning, further education and independent living skills (Crowley *et al,* 2018).

In a 2018 paper about the co-production of research, Sue Fletcher Watson and colleagues describe activities necessary to build a culture where autistic people and their allies can have meaningful roles in research. These included changing the language describing autism, modifying or identifying physical spaces to enable autistic participation, and adapting the structures and bureaucracy of academia to facilitate autistic involvement and leadership in research. A similar approach needs to be taken by the medical profession and addiction services, to provide a more autism friendly space for those seeking help with problem alcohol and drug use. The health of autistic people, and in some cases even their lives, may depend on it.

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