**CONSULTATION RESPONSE:**
**LEARNING DISABILITIES, AUTISM, and NEURODIVERGENCE BILL**
Scottish Families Affected by Alcohol and Drugs
25/03/2024

## Introduction

Scottish Families Affected by Alcohol and Drugs (Scottish Families) is a national charity that supports anyone impacted or concerned about someone else's alcohol or drug use in Scotland (www.sfad.org.uk). In responding to this consultation, we aim to bring light to the voices and experiences of family members who are affected by the alcohol or drug use of someone who is neurodivergent or who may be neurodivergent themselves. Our response also includes insights from young people impacted by parental substance use, as well as Scottish Families staff.

The Learning Disabilities, Autism, and Neurodivergence Bill is an expansive piece of legislative work. It encompasses not only nearly twenty diverse areas where improvements must be made for people who are neurodivergent, have autism, or have a learning disability – it also encompasses issues related to intersectionality, such as experiences of gender-based violence or imprisonment of neurodivergent people.

In the bill there is no mention of substance use, and in the midst of a drug deaths crisis and rising alcohol deaths in Scotland, it is vital that treatment and support services are made more accessible – especially to people who may have previously felt marginalised or unsupported. The impact that co-occurring neurodivergence and substance use has on families in Scotland has been brought up repeatedly across our support areas. The lack of tailored and non-stigmatising support for neurodivergent people using substances or neurodivergent people caring for someone who uses substances has had negative repercussions in a variety of public settings – including drug and alcohol services, GP offices, Accident and Emergency services, criminal justice settings, child and adolescent mental health services, adult mental health services, and schools. The intersection of neurodivergence and substance use needs to be addressed more thoroughly within research and service provision in order to make treatment and care more accessible, reduce stigma, and promote better outcomes[1]. As one staff member summarised:

> "I think it has a massive impact. Already, those who are neurodivergent struggle to exist and flourish in our societal systems and structures, so families are already fatigued from attempting to support someone who has always needed additional help. Adding alcohol and drug use makes it so much harder for the families as often communication is a challenge, as well as impulse control, fixations and other traits often seen in neurodivergent people. Because there are no clear support measures or treatments in place for people with both neurodivergent diagnoses and alcohol or drug use, families are left with a really unique and difficult struggle."

The failure to break stigma, provide specialist support, and uphold human rights significantly reduces the quality of life of neurodivergent people *and* people who use substances – two groups that

[1] Haasbroek, H., Morojele, N. (2022). A Systematic Literature Review on the Relationship Between Autism Spectrum Disorder and Substance Use Among Adults and Adolescents. *Rev J Autism Dev Disord* **9**, 1–20. https://doi.org/10.1007/s40489-021-00242-1

already experience poor mental health and isolation[2][3]. The themes within the LDAN Bill we are focussing on are: Mandatory Training, Inclusive Communications, and Health and Wellbeing. Input from families indicates that these are problem areas when it comes to co-occurring neurodivergence and substance use, where a lack of knowledge around the needs of this group of people results in poor practice and engagement.

Our hope as an organisation is that the LDAN Bill will have positive impacts on the care and support that people who are neurodivergent and who use substances or are impacted by someone else's substance use receive. Substance use and neurodivergence is a topic that we are currently exploring within Scottish Families, and we would be happy to further engage with the Scottish Government on this work.

## Consultation Response

### Mandatory Training

Training around the needs and experiences of people who are neurodivergent needs to be more wide-reaching and consistent. While this training should be mandatory for professionals in health and social care, it should also be extended to the justice system and the education system, as families have brought up experiences of poor practice and exclusion stemming from a lack of understanding around their loved one's needs. A general lack of understanding around neurodivergence paired with stigma around drug and alcohol use further complicates support, with families, according to one staff member, "feeling that their loved ones haven't been given the correct support or aren't supported enough". Insights from other Scottish Families staff included:

> "There seems to be a struggle to get an initial diagnosis for most people but when substance use is in the mix there is also a barrier where medical professionals do not take the possibility of neurodivergence seriously as they make a judgment that the behaviours displayed are linked more with the substance use than anything else underlying."
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> "There is a lack of support from other professionals- leaving families in the dark."
>
> "We see impacts upon the families' confidence in the ability of support and recovery services to provide an appropriate, inclusive and accessible service to loved one's who are neurodiverse."

This is reflected in families' responses to whether their loved one's needs were handled appropriately by services, to which family members expressed either "No" or "I don't know". Communication, the reasons why a person who is neurodivergent may use drugs or alcohol, and patient and carers' rights were some of the areas where misconceptions and poor handling affected support for people who use substances and their families. One family member stated:

> "We feel shut out and our rights as carers infringed. We are still the first port of call of our son when he is upset or worried. He is deemed to have capacity but it is not all or nothing."

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[2] Chapman, L., Rose, K., Hull, L., and Mandy, W. (2022), "I want to fit in… but I don't want to change myself fundamentally": A qualitative exploration of the relationship between masking and mental health for autistic teenagers. *Research in Autism Spectrum Disorders*, 99. https://doi.org/10.1016/j.rasd.2022.102069

[3] Scottish Government (2022). "Co-Occurring Substance Use and Mental Health Concerns in Scotland: A Review of the Literature and Evidence". https://www.gov.scot/publications/co-occurring-substance-use-mental-health-concerns-scotland-review-literature-evidence/documents/

Mandatory training should be considered for public-facing staff, and this training should extend beyond health and social care to encompass the justice and education sectors.

**Inclusive Communications**

We agree with all of the proposals set out in this section, as communication with public authorities – especially the NHS and the criminal justice system – is an issue families experience. Inconsistent or inaccessible communication can lead to anxiety and conflict, as one family member recalled:

> "Services underestimate the mild LD [learning disability] and think that our loved one had understood information. He is quite skilled to act as if he had. This may lead to miss appointments. Services may not remind him of appointments, causing unnecessary anxiety for him thinking he has to go court on the wrong day and also got phoned when he had to be there. This had led to his anxiety taking over, restraint, being handcuffed and taken to psychiatry. This could have been prevented if he had been informed of the appointment at court."

As the consultation itself states, inclusive communications are an important part of reducing barriers to health and social care.

**Data**

We agree with the consultation that collecting sufficient data is necessary to policy making that ensures that the needs of people who are neurodivergent are met and their human rights are upheld. We also agree that data collection and analysis should involve lived experience and intersectionality. More research needs to be undertaken to understand the link between – and impact of – neurodivergence and substance use. A few young people gave insight into why this work is important:

> "I think it's self-medicating, being undiagnosed with no support – they turn to it for comfort. My family member had no support growing up so turned to it for comfort. I think it's a major thing and I think it needs to be looked into. There's a lot of stigma around being neurodivergent and the whole drugs thing. I think if people were diagnosed earlier there wouldn't be such a problem."

> "I know with a few of my own friends, it could relax them or help them cope a wee bit better with what's going on. It probably just relaxes their mind in a way and relaxes them faster than what someone else might use to cope, to help them understand. I think it's stronger in young people, it's easier for them to get it. A lot of YP turn to it whether they're neurodiverse or not to cope with their mental health instead of talking. It's an escape from reality. People aren't doing enough to help, concentrate on more people who struggle with things like that and research more on how to help."

As mentioned by the young people, research into co-occurring neurodivergence and substance use can help us understand why someone might be using substances. It could also help us to identify issues within services and society that might be worsening already problematic relationships with substances, as well as solutions to providing more relevant and sustainable support.

More insight is needed around what is working and what is not working for people who are neurodivergent and using substances, as well as for their families. There should be duties placed on relevant public bodies to collect and report data, and use that data to inform or improve service design. Furthermore, there should be more investment in research regarding neurodivergence and

substance use, to bolster a currently limited evidence base around the experiences, needs, and challenges of people who are neurodivergent and use substances, as well as their families.

**Health and Wellbeing**

Insight from families and from Scottish Families staff shows how the lack of support for people who are neurodivergent and using substances impacts health and wellbeing. Families often recall a lack of multidisciplinary and integrated care when it comes to their loved one. As one staff member wrote:

> "There seems to be a struggle to get an initial diagnosis for most people, but when substance use is in the mix there is also a barrier where medical professionals do not take the possibility of neurodivergence seriously as they make a judgment that the behaviours displayed are linked more with the substance use than anything else underlying. This can be frustrating and frightening for families, especially if impulse control and ability to make rational decisions are in play, the risk to life is greater when poly-substance substance use is used to manage symptoms of something underlying."

This results in measures being taken by services to address one particular issue that neglect other existing needs of people seeking support -- to a point where harm is experienced within families. Prescribing practices for people who have ADHD and also use drugs are examples of this, where services avoid or withhold prescriptions such as Ritalin because the patient uses other stimulants, such as cocaine:

> "It can make the problem feel more overwhelming and prevent their loved one getting help with their neurodivergence e.g. won't prescribe ritalin if using cocaine" (Scottish Families Staff Member)

> "My grandson was using cocaine, and as a result has had his ritalin stopped. Now he has no medication for his ADHD. He has to abstain from cocaine for 6 months." (Family Member)

> "When he was 16, he was referred for an ADHD assessment. This took one year to complete. He was found to have ADHD but due to his drug use, which had escalated to street Valium, cocaine, and alcohol, CAMHS made the decision to wait until he entered adult services before medication should be offered to him. This would take a further 18 months." (Family Member)

Issues arise when no alternative support is available or accessible for the person using drugs. Families recall a vicious cycle where their loved ones who are neurodivergent use substances to mask, to cope with symptoms or feelings, or to feel "normal", and, as a result, are not able to receive support for mental health, substance use, or other needs. The onus of supporting and caring for that person as they either continue to use drugs or go through withdrawal in order to access mental health services is then placed onto families alone. One family member who wrote about her experience as a carer for her son, who has autism, ADHD, and uses substances, described this system as one of "non-care":

> "From my own experience and that of other mothers, it seems that ASD/ADHD and other behavioural issues lead to a higher incidence of drug and alcohol use as a coping mechanism. The mental health services, both child and adult are not designed for these young people. We sincerely need to look at another option for these young men (and occasionally women). The system of non-care in CAMHS may in fact be leading to escalating drug use and ultimately drug deaths. This just isn't good enough."

The way current systems of treatment address substance use as if it is isolated from mental health and social factors impacts families just as it impacts people who use substances, since families are often left being passed from pillar to post or with nowhere to turn at all. The same family member mentioned above recalled the impact of caring for someone who is neurodivergent and uses substances – without adequate support:

> "I am the main carer for my son... I have Osteoarthritis in my knees and Fibromyalgia which is an auto-immune disorder that causes pain, fatigue, and sleep disturbance. I genuinely believe that this is due to a stress and trauma response to living this way for such a long period of time."

As with many family members we support, caring full-time for her son has affected her physical health, as well as her work life, and she also mentioned how substance use has impacted the well-being of her other children and neighbours.

When asked about the impact of experiencing poor care, another family member responded:

> "Put my blood pressure through the roof, so affected my illness."

Statutory strategies, mandatory training for workforce, inclusive communications, patient passports, and annual health checks are, in theory, vital to reducing barriers to health and social care for people who are neurodivergent or have a learning disability. However, they need to be implemented consistently across all areas.

Furthermore, more needs to be done to bridge communication between health and social care services and to provide access to holistic treatment and care. People are being excluded from services with no recourse to other forms of support, and this is having an impact on the health and wellbeing of people who are neurodivergent – and their families. Multidisciplinary and whole-family support is much needed across all areas in Scotland, and should not be left to a postcode lottery. These are not new recommendations, but they have yet to be fully implemented in Scotland.

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