**Learning Disabilities, Autism and Neurodivergence Bill: consultation – SAMH Response**

**About SAMH**

SAMH (Scottish Action for Mental Health) is Scotland’s mental health charity. We’re here for your mental health and wellbeing, providing local mental health support and always accessible information. We listen to what matters in each local community and campaign nationally for the changes that make the big and little differences in life. Now more than ever, we need to make change happen. We’re standing up for Scotland’s mental health.

Please note that, as the Citizen Space platform does not enable the inclusion of footnotes or hyperlinks, a fully referenced version of this response is available on our website at www.samh.org.uk

**Definitions: Which of these proposals do you agree with (if any), please tell us why?**

Note: for the purposes of this consultation response, we have adopted the language used by the Scottish Government in the consultation, referring to ‘neurodivergent people’ and ‘people with learning disabilities’ throughout.

Language and definitions are important. People need to be comfortable with, and see themselves in, the language and definitions used to describe them and their needs. We know that in the past, and even in law now, language – such as ‘mental disorder’ – has been used in mental health which has been unhelpful and served to increase stigma. While there are differing preferences and opinions within the neurodivergent and autistic communities, which are themselves continuing to develop, Scottish Government should be cautious about codifying in legislation language that the communities it is hoping to support may find stigmatising.

When it comes to terminology of this type, the views of those with lived experience – those the terminology seeks to describe – should be given the most weight. The term ‘neurodiversity’ was collectively coined[[1]](#footnote-1) to express a wide range of conditions where individuals have different nervous systems, and therefore express themselves and experience the world in different ways. Definitions should stay away from ideas of right/wrong or normal/abnormal.

We know that language does not stay still and can change over time. It may therefore be worth the Government considering specifying a secondary power within the Bill to review language further down the line, so that the appropriateness of the language used can be updated as norms and preferences evolve.

**Strategies: Which of these proposals do you agree with (if any), please tell us why?**

We are broadly supportive of all the proposals relating to strategies. However, we also note that for strategies to be effective they need to be adequately resourced, as well as aligned with other strategies. There must be appropriate leadership, governance, and measurement and evaluation. It will be important that any strategies emerging from this legislation are cognisant of, and aligned with, the existing mental health strategy, suicide prevention strategy and self-harm strategy.

Figures vary but find that at a minimum 11% of autistic adults had thought about suicide during their lifetime, and up to 35% had planned or attempted suicide.[[2]](#footnote-2) While figures are a wide range, even the lower end of this range 11% is unusually high compared to the general population which is estimated to be around 5%[[3]](#footnote-3) thinking about suicide at any one time. Autistic people are more at risk of dying by suicide.[[4]](#footnote-4) Research undertaken in Sweden found people with autism were most at risk of suicidal behaviours when they also had ADHD. While both men and women with ASD had increased risk of suicidal behaviours, the study found women were at higher risk than men.[[5]](#footnote-5).

Similarly, available data seems to find a relationship between ADHD and suicide[[6]](#footnote-6) in all age groups. A 2020 review of research found that almost all studies considered found an association between ADHD and suicidal behaviour or suicide attempts in children and teens[[7]](#footnote-7).

The Suicide Prevention Strategy already has existing actions around neurodivergence which must be progressed, as well as recognising these actions as being relevant to multiple strategies – including any strategy emerging from this Bill.

Self-harm is also higher in those with ADHD and emotional dysregulation[[8]](#footnote-8) which is present in both ADHD and autism. It has even been suggested that young women presenting to A&E having self-harmed should also be screened for ADHD[[9]](#footnote-9).

We know that neurodivergent people are one of the priority groups in the self-harm strategy, which we welcome, and would urge that a separate strategy on autism and neurodiversity will not mean that focus should not be taken away from this group in the implementation of the current self-harm strategy or in future iterations.

There is more work to be done to fully understand the links between mental health and neurodivergence, but a useful first step to help those on the ground would be to make sure that existing strategies, including on mental health and self-harm, align with any strategy that is a product of this Bill.

**Mandatory training: Do you agree with this proposal, please tell us why?**

We agree that mandatory training would be useful for those working in health and social care as well as teachers. However, training needs to be relevant, regularly refreshed, and designed with those with lived experience. Creating measures of how effective training has been in creating new workplace cultures and use outside of the training room to change working practice would ensure training helps make meaningful change.

Anecdotally we often hear that neurodivergent people have been misdiagnosed with a mental health problem. This can result in them having treatments for mental health problems, which are not able to deal with the core issues the person is experiencing, and can cause frustration and stress, which can be a factor in developing mental health problems.

Therefore, while mental health problems are not the same as learning disabilities, autism or neurodivergence, we suggest that a good understanding of all three across health and social care would be helpful in ensuring that people are getting the right support, from the right practitioners at the right time.

**Data: Is there anything else you want to tell us?**

We believe that data collection exercises relevant to neurodivergent and autistic people and people with learning disabilities should also include clearly defined information on their mental health, including mental health diagnoses, in order to support greater understanding of neurodivergent and autistic people and people with learning disabilities’ mental health needs.

For instance, we hear anecdotally that in some areas the CAMHS waiting list have a very high proportion of people seeking a neurodivergent or autistic diagnosis. As those with mental health problems and neurodivergent people rely on the same workforce for diagnosis and support we need to understand people’s needs better to properly support workforce planning and development.

We also hear anecdotally that autistic and neurodivergent people can be misdiagnosed as having mental health problems. Additionally, there is wide public confusion around the intersection of mental health problems and autism and neurodivergence with many people thinking they are the same thing. This means that there is sometimes a lack of clarity for organisations who aim to support people with mental health problems or learning disabilities, and autistic or neurodivergent people. Improved data collection could have a positive effect on service planning as well as better understanding of the needs of people with learning disabilities and autistic and neurodivergent people when it comes to access support for mental health problems, understanding the intersection between their mental health and learning disability or neurodivergence, and designing neuro-affirming services.

We would go further and stress that there is a need for more research around learning disabilities, autism and neurodivergence and mental health. We hear anecdotally that some mental health approaches can be less than optimal for autistic and neurodivergent people, and greater understanding would enable the mental health sector to do more to support those autistic and neurodiverse people and people with learning disabilities who are also living with mental health problems.

**Health Passports/checks: Which of these proposals do you agree with (if any), please tell us why?**

We agree that annual health checks for anyone who is at higher risk of physical illness appears sensible. However, by not including mental health explicitly in the health checks there is a risk of under-serving people whom the Bill aims to help. As we detailed in the question on strategies, there is a significantly higher likelihood of suicidal ideation, self-harm and suicide attempts in autistic and neurodivergent people.

We should be mindful of “minority stress”[[10]](#footnote-10), which is the stress that people within minorities encounters because of the discrimination and prejudice they face. Internalised minority stress includes expectations of rejection and discrimination, concealment of minority identity, and internalisations of negative dominant cultural attitudes, beliefs, stereotypes, and values.

While stress is not a mental health problem in its own right, it can make existing mental health problems worse or lead to the development of mental health problems. Statistically we know that neurodivergent people have higher levels of suicidal ideation, anxiety and depression. This is one of the reasons why we call for any LDAN strategies to be aligned with other strategies on mental health.

We note that the Scottish Government is proposing a system similar to the advance statements used in mental health. While in principle advance statements are positive, they do currently suffer from low uptake. Our understanding is that one of the reasons for this, besides low general awareness, is a lack of confidence among people who might choose to use them that they will be followed or even acknowledged by health or care professionals. It will be important to make sure that from the start there is confidence that any proposal similar to advance statements will be respected and play a meaningful role in the provision of people’s care and support. It is worth noting that the Mental Health Law Review has recommended a move away from the language of advanced statements and towards supported decision making. There may be value in ensuring that terminology across systems is aligned to minimise the risk of confusion.

**Employment**

We offer Individual Placement and Support (IPS) services in several local authority areas[[11]](#footnote-11),[[12]](#footnote-12). IPS is an innovative, international and highly successful[[13]](#footnote-13) economically viable[[14]](#footnote-14) service model that assists those with severe and enduring mental health problems to find and retain work. Research has found that IPS services also work well for those who have other or multiple barriers to employment, and we are calling for high fidelity IPS to be rolled out across Scotland.

High fidelity IPS is likely to be able to assist neurodivergent people and people with learning disabilities to find and retain work and we would encourage further exploration of this, and recommend the Scottish Government implement the recommendations of the review of IPS[[15]](#footnote-15) to ensure that everyone who needs it can access an IPS service.

1. [The neurodiversity concept was developed collectively: An overdue correction on the origins of neurodiversity theory - Monique Botha, Robert Chapman, Morénike Giwa Onaiwu, Steven K Kapp, Abs Stannard Ashley, Nick Walker, 2024 (sagepub.com)](https://journals.sagepub.com/doi/10.1177/13623613241237871) [↑](#footnote-ref-1)
2. [Systematic Review of Suicide in Autism Spectrum Disorder: Current Trends and Implications | Current Developmental Disorders Reports (springer.com)](https://link.springer.com/article/10.1007/s40474-018-0133-6) [↑](#footnote-ref-2)
3. [samh.org.uk/about-mental-health/suicide](https://www.samh.org.uk/about-mental-health/suicide) [↑](#footnote-ref-3)
4. [Individual risk and familial liability for suicide attempt and suicide in autism: a population-based study - PubMed (nih.gov)](https://pubmed.ncbi.nlm.nih.gov/31238998/) [↑](#footnote-ref-4)
5. [Individual risk and familial liability for suicide attempt and suicide in autism: a population-based study - PubMed (nih.gov)](https://pubmed.ncbi.nlm.nih.gov/31238998/) [↑](#footnote-ref-5)
6. [Attention-deficit/hyperactivity disorder and suicide: A systematic review - PMC (nih.gov)](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5371172/) [↑](#footnote-ref-6)
7. [Long-Term Suicide Risk of Children and Adolescents With Attention Deficit and Hyperactivity Disorder—A Systematic Review - PMC (nih.gov)](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7779592/) [↑](#footnote-ref-7)
8. [Self‐harm as the first presentation of attention deficit hyperactivity disorder in adolescents - Ward - 2021 - Child and Adolescent Mental Health - Wiley Online Library](https://acamh.onlinelibrary.wiley.com/doi/full/10.1111/camh.12471) [↑](#footnote-ref-8)
9. [Self‐harm as the first presentation of attention deficit hyperactivity disorder in adolescents - Ward - 2021 - Child and Adolescent Mental Health - Wiley Online Library](https://acamh.onlinelibrary.wiley.com/doi/full/10.1111/camh.12471) [↑](#footnote-ref-9)
10. [Minority stress theory: Application, critique, and continued relevance - PMC (nih.gov)](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10712335/) [↑](#footnote-ref-10)
11. [samh.org.uk/about-us/individual-placement-and-support-ips-services](https://www.samh.org.uk/about-us/individual-placement-and-support-ips-services) [↑](#footnote-ref-11)
12. [IPS\_infographic\_2019.pdf](file:///C:/Users/Mairi.CampbellJack/Downloads/IPS_infographic_2019.pdf) [↑](#footnote-ref-12)
13. [IPS\_Fidelity\_reviews\_summary.pdf](file:///C:/Users/Mairi.CampbellJack/Downloads/IPS_Fidelity_reviews_summary.pdf) [↑](#footnote-ref-13)
14. [SAMH\_IPS\_Final\_20161011\_1.pdf](file:///C:/Users/Mairi.CampbellJack/Downloads/SAMH_IPS_Final_20161011_1.pdf) [↑](#footnote-ref-14)
15. [Fair Start Scotland - individual placement and support review: findings - gov.scot (www.gov.scot)](https://www.gov.scot/publications/review-ips-delivery-within-fair-start-scotland-findings-recommendations/) [↑](#footnote-ref-15)