# Equalities, Human Rights and Civil Justice Committee

## Learning Disabilities, Autism and Neurodivergence (LDAN) Bill

### Engagement with Autistic Disabled People’s Organisations – 25 March 2025

- Aurora Autistic Consulting
- Autistic Mutual Aid Society Edinburgh (AMASE)
- Autism Rights Group Highland (ARGH)
- Autistic Voices Advocating Together for Autonomous Rights (AVATAR)
- Diversified
- Scottish Ethnic Minority Autistics (SEMA)

### Presentation by Aurora Autistic Consulting - An introduction to the importance of timely access assessments, pre, during, and post diagnostic support

Scotland is undergoing an intense crisis when it comes to Autism and ADHD assessment.

Pathways across the country are under threat, and those remaining open face incredibly long waiting lists – Edinburgh GPs are reporting up to a 25-year waiting list for ADHD assessments, and long waiting lists are being used as an excuse to close some pathways down. While most of the assessment pathways facing closure have been for adults, just last week it was reported that CAMHS at Ninewells Hospital are now only accepting referrals for Autism assessments if the child also has a mental health condition.

These backwards steps in the care of the Autistic community are threatening Autistic lives. Not having access to an assessment and the positive affirmation it can bring leaves Autistic people in limbo unable to move forward constructively. My own assessment story is not unique and I am happy to share it as an example. When I myself was waiting for an Autism assessment 7 years ago, I desperately hoped that I belonged to the Autistic community, That it would be a place I could find kinship and understanding. But having thought that before and been wrong I could only dip my toe into the water so to speak. It wasn’t until I was able to get the official confirmation that I am Autistic that I felt confident enough to properly embrace the Autistic community and culture, that I was able to fully explore my Autistic identity, or that I was able to start giving myself a break and put in the kinds of supports I needed to have a good quality of life. Until then I didn’t feel like I could.

I was assessed at a time when Autistic people in my area only had access to an assessment where there was evidence of poor mental health so I was repeatedly turned down for 6 months. I was not in a mental health crisis at the beginning of that time, but I most certainly was at the end. The uncertainty, lack of community, lack of belief that I could be Autistic from some friends and wider family, and neuroaffirming support, and the thought that I might never know one way or another drove me into deep Autistic burnout which affected not only myself but my family too. Had I been able to access an assessment in a timely manner, I wouldn’t have had to put myself or my family through that. The lasting effects of burnout cannot be overstated, especially when it was in this case entirely preventable, and directly caused by lack of access to assessment.

Expecting families to wait until our children hit crisis point is unconscionable. Autistic children have it hard enough accessing school, navigating friendships, going to extra curricular activities etc. Leaving them vulnerable in this way can have a significant negative impact on all areas of their life, and their future prospects. We must also consider that only getting assessed due to crisis means that their Autistic identity is strongly wrapped up in negative associations, making it far harder to embrace Autistic identity. We shouldn’t have to fail in order to get support but this is exactly what’s happening.

Locally the decision to close the Autism assessment pathway was made based on a report which severely underestimated how it would affect our community. During a recent meeting with the lead author of the report we had to argue strongly that it would have the most negative impacts on racialised Autistic people as this had not been accepted in the report. There was no acknowledgement of the impact the closure of the pathway would have on addiction or eating disorder services, and the report seemed to suggest that we could all access the third sector for mental health support as it acknowledged our local NHS services were not trained to support us properly. When I asked where exactly we could go to access trained mental health professionals we were not given a single option. There are no representatives from the Autistic community involved in their short lived working group to set up a cheaper pathway, and the HSCP staff could not understand why this would be important, even after I shared that I attended every meeting setting up the existing pathway, and how that helped ensure it was more neuroaffirming, easier to access, and a better experience for those who went through it. Shockingly the decision was made with the acknowledgement that it could well increase suicides within the Autistic community.

Without acknowledgement of the full impact, it is impossible to fully calculate the additional cost to existing services and therefore verify if losing the pathway will in fact save them money or if it will be a false economy. These decisions are being made without any consultation or input from the Autistic community which is absolutely unacceptable.

While choosing to put yourself forward for an assessment or not is an entirely personal decision, not having a formal assessment to prove you are Autistic can hamper us across all areas of life. It makes it far harder to be taken seriously as an Autistic person even by close family. And the further away we are from the most stereotypical ideas about who can be Autistic the harder that is. Racialised people, women, genderqueer people, all find it much harder to be accepted without a formal diagnosis. This means it’s much harder for us to then access support in education, employment, and out in the community. If we are masking hard as a trauma response, as so many of us do, then other people just cannot see the need to provide us with the supports we need. This leaves us more vulnerable to unemployment, costing the state even more money.

Additionally, we may not even know what we are entitled to legally or have had the opportunity to explore our expression of being Autistic to really understand what being Autistic means to us. The lack of good Autistic led pre and post assessment support continues to hamper our community. And while the Minister will talk about the funding out there for Autistic Adult support, it must be acknowledged that this - like access to a good neuroaffirming assessment - is a postcode lottery with nothing suitable in my area for Autistic people like me.

What desperately we need are Neurodevelopmental Pathways as standard in every health board. Where one self-referral can allow us to be assessed to see if we are Autistic, ADHD, dyslexic, OCD, etc without having to continually go from pillar to post fighting for referrals and waiting years on end to finally get the answers to our questions about who we fundamentally are. These pathways must be created with the Autistic and wider Neurodivergent communities to ensure it meets our needs at the design stages. This must be partnered with neuroaffirming pre, during, and post diagnostic support focused on understanding our strengths, learning how to advocate for our rights, and accepting this new understanding of ourselves. Not having this is placing undue stress on services and costing Autistic lives.

# Preliminary Analysis of Diagnosis and Assessment Survey data

## AMASE, ARGH, SEMA, Scottish Autism - March ‘25

### Quantitative Data

Our survey told us:

- 50% of the sample described the referral process as hard or very hard
- 62% reported a significant lack of information during the process
- 65% stated they were not made aware of pertinent support services during the process
- 40% of the sample reported experiencing financial hardship due to the cost of obtaining a private diagnosis
- Only 30% reported a positive impact on their wellbeing after the process

### Qualitative Data

Access to diagnosis

- Gatekeepers to diagnosis, such as GP’s, are often bound by obsolete understandings of autism
- People often ended up seeking a private diagnosis which led to financial hardship in many cases

During the diagnostic journey

- People were left in limbo, sometimes for years, met with silence, with no sense of how long a process would take, or what was happening.
- This silence created high levels of uncertainty, stress and anxiety
- The process was not always well explained when it did happen, and people awaiting diagnosis were given very little information

Post-diagnosis

- Receiving a diagnosis was affirming and validating of people’s experiences, and key to their identity
- However diagnosis opens a new avenue of challenges that are met with inadequate information
- Post diagnostic support was often inadequate or non-existent

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### Presentation by Autism Rights Group Highland (ARGH): Autistic access to healthcare

Access to healthcare is a subject which is deeply personal to me, so I am grateful for the opportunity to speak here today. If you are familiar with the LDAN consultation, then you will be only too aware of the challenges we, as autistic people, face when trying to access adequate healthcare and the devastating outcomes which directly result from being unable to do so.

Autistic individuals are more likely to experience poor health due to a high incidence of comorbidities and increased mental health challenges, yet we face considerable barriers when it comes to accessing healthcare. Some of these barriers, as discussed within the consultation, are a lack of knowledge of autism amongst healthcare providers, a lack of the provision of necessary adjustments required to access healthcare in the first place, and issues arising from communication and sensory differences. The impact these barriers have is clearly reflected in figures which reveal poorer health outcomes and a shortened life span. Life expectancy drops by an average of 16 years, between 50 and 95% of autistic people experience mental health problems compared to a figure of 25% within the general population, and autistic individuals are around nine times more likely to die by suicide. Furthermore, we find existing inequalities in healthcare, such as socioeconomic background, ethnicity and, as in my case, gender, are amplified where autism is present. It is clear the current system is failing to meet the needs of patients based on disability and urgent action is required to rectify this.

The response to the consultation recognised annual health checks as one of the most popular proposals for addressing the health inequalities faced by the autistic community. By providing prompting and removing some of the challenge and uncertainty surrounding appointments, annual health checks would provide an opportunity for early health interventions and result in improved physical and mental health outcomes; a preventative approach which would take pressure off services in the long-term. This ties in with the Scottish budget health and social care aims of preventing ill health and tackling health inequalities. Annual health checks are already being rolled out for those with learning disabilities and, while I understand this is not going as smoothly as planned, it does indicate that this action could be applied in relation to autism without the need to wait for a bill to be passed. The need for these health checks to be carried out by a doctor with an understanding of autism would also provide an opportunity to embed mandatory training. If applied in conjunction with the additional support of a liaison nurse, this would go some way towards bridging the communication gap and improving the standard of care.

Expanding the role of Learning Disability Liaison Nurses to include autism was another possibility raised in response to the consultation. As an existing service, with the potential to address several of the issues highlighted within the consultation, this is certainly an idea worth consideration. As well as ensuring that necessary adjustments were in place, a liaison nurse would be able to assist with the implementation of patient passports by ensuring that they were kept up-to-date and not ignored by medical staff. Further to this, a liaison nurse would provide a necessary safeguard and advocate for those seeking medical care as much of the harm we experience is hidden, a reason why so many of us avoid seeking medical attention where possible.

As with any approach, the two proposals outlined would need to be applied as standard across the NHS to avoid the post-code lottery approach to care we currently experience, especially in rural areas. It is also worth noting that access to healthcare is reliant on access to diagnosis, an issue which must be included in any future bill as failure to provide diagnostic services actively denies the existence of autistic people. My hope is that discussions around the LDAN Bill will lead the way to a more educated and inclusive health system which is rooted in preventative care, but the urgency to put ideas into action cannot be overstated and I worry that by tying outcomes to the progress of the bill we are missing out on the opportunity to make these desperately needed changes a reality.

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### Presentation by Autism Rights Group Highland (ARGH): Behaviourist approaches

I have worked in settings where behaviourist approaches were used to supposedly support people in distress. I speak here from that background but also as an autistic person, as a community representative and as all of us here I speak to a topic that effects not only our wider community but family and friends.

We are concerned about the growth of behaviourist approaches such as Positive Behaviour Support (or PBS), a framework that uses Applied Behaviour Analysis (referred hereafter as ABA), particularly in health and social care, as well as in education.

Our ultimate aim would be to see the use of PBS banned in Scotland.

PBS was developed to deal with challenging behaviours of people deemed to have a learning (or intellectual) disability. In practice it is used on many different disabled people who are considered at risk of "challenging behaviours" (what should be called distressed behaviour) or whose behaviour is considered to be socially impeding, say simply because it looks different or because staff and others dislike a persons actions, do not understand them and would prefer the person to have a more neuronormative presentation.

PBS claims to improve quality of life, to be aligned with human rights, evidence based, to reduce restrictive practice (such as restraint) and not be harmful. However, there is no or poor quality evidence supporting any of these claims, and in fact there is increasing evidence otherwise.

Despite this there has been widespread buy-in to PBS in Scotland. To illustrate, the 2018 Coming Home Report, that looked at getting people out of hospital, commissioned by Scottish Government and authored by a UK PBS lead made extensive recommendations for PBS that were endorsed by Scottish Government: that the model of support should be PBS, that PBS should be embedded into policy and practice, with mandatory PBS training, partnering PBS with a University, PBS training for all Health and social care workforce.

A number of these recommendations have now or are being implemented, including funding of a PBS Community of Practice to disseminate PBS widely, establishment of Glasgow University PBS dept and problematic PBS training materials have been prepared and are available freely for all on the NHS Education Scotland and the Scottish Social Services Council (SSSC) websites.

We are not aware of any Disabled People's Organisations that support ABA and PBS worldwide and the Scotland Civil Shadow report on UN CRPD (2022) noted PBS was not supported by Autistic People's Organisations.

Human rights organisations have reported that ABA and PBS do not align with human rights under the UN CRPD. This was the conclusion of Ireland's Joint Disability Committee for example who noted "behavioural interventionist therapies are ultimately founded on modifying disabled people's behaviour to meet goals decided by others; often to conform more closely with neurotypical communication, behaviour and/or norms and therefore ….cannot uphold the UNCRPD principles of autonomy, dignity, right to identity and freedom from non-consensual or degrading treatment"

We have never seen a PBS plan that was not problematic and a focus on independence - people do things for themselves, rather than a focus on autonomy is missing when it should be a core component of any support.

I should also add:

We had been keen and had requested that PBS was included in the LDAN Bill consultation - it was not.

Sources:

- Ireland's Joint Disability Committee on the rights of disabled people reported on page 24/25 that ABA and PBS do not align with UN CRPD
- Scotland Civil Shadow report on UN CRPD (2022) p33 noted PBS was not supported by Autistic People's Organisations
- The 2022 State of the Nation report published by UK PBS states "there has not really been a robust evaluation of a PBS framework in a UK setting to date".
- Work done by ICARS in their 2023 report on restraint and seclusion and Prof John Taylor's seminar on Transforming Care and PBS in 2022 provided evidence that in England where there has widespread investment in PBS for longer it is not working.

The nature and extent of the issues and lack of support by Disabled People's Organisations of PBS can be seen in the AMASE PBS paper prepared by disability advocates.

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### Presentation by Autistic Mutual Aid Society Edinburgh (AMASE): Education

### Teacher Training

(Zero autistic led, or any at all for that matter. No statutory training required). Some specific services are also inappropriate (eg recommending isolation rather than changing the environment);

What is available is not autistic led or neuro affirming; Education Toolbox is ableist. NAIT (Circle resources - also not appropriate - very neuronormative; Often use one size fits all; Nothing about autistic communication); We Were Expecting You (not really able to be meaningfully involved in development and rollout);

Need to actually explain UNCRC, Equality Act, UNCRPD;

### Bullying

Tends to be neuronormative in approach, and often gaslights autistic people; Often told 'to build resilience';

### Environment

Often not looked at in terms of school as a whole; eg open plan schools; lighting; noise; Headteachers and SMT are often obstructive - no mandate for making sure they are (not overseen and followed through);

Education and Reasonable Adjustments; This put up on schools are also not suitable/not neuro affirming; Need to actually explain UNCRC, Equality Act, UNCRPD;

### Support

Limited and delayed; Often pushed out if they don't fit a specific mould; Often looks heavily Behaviourist - triggers often not looked at; Don't always give appropriate tools; Speech and Language Therapists, and Ed Psychs almost never have the appropriate training (and no requirement to keep up to date); Depends on Child Services, Education Authority and LA approach - postcode lottery like Social Care; Social Work also very little to no training; All this is worse in areas of high deprivation;

### Additional Support Centres/ASN

Quiet/Sensory Rooms - loss of access; Inappropriate and segregating; Othering; cheap; Fences; Often physical based not ND people for example;

### PBS/ABA

See above

“Should be happy with ‘good enough for now’”

Accountability Issues

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### Presentation by Autistic Mutual Aid Society Edinburgh (AMASE): Social Care in Scotland

Social Care, the aim of which is to provide physical, emotional and social support to help people live as independently as possible. It is rooted in the Independent Living Movement and Disability Rights. It mostly revolves around services which can range across 6 areas: Personal Care, Nursing Homes, Supported Accommodation, Support with Daily Living Tasks, Occupational Therapy, and Support Engaging in social and community activities.

Its focus is to support individuals with disabilities, older people, people with long-term (and terminal conditions) and family carers. It is meant to be underpinned by Health and Social Care Standards, which revolve around: Dignity and Respect, Compassion, Inclusion, Responsive Care, and Support and Wellbeing.

Assessment is done via Social Services in local authorities. Every individual would be deemed as being able to receive Social Care can opt for SDS.

There are a range of issues that autistics and other neurodivergent groups encounter when seeking social care.

**First understanding need** – met and unmet. Unmet need must be measured too. Link to theories of independence and its relation to supported decision making and empowered lives. Unsuitability of ‘work’ as a defining metric for need (misunderstanding of autistic (and ND) being and culture).

**What is a meaningful life** – by only meeting need when it has reached an extreme crisis point, you devalue and pathologise autistics.

**Costing** – how support is costed, at present, is approached as a zero sum, with no appreciation of the benefits, be they non-economic or otherwise.

**SDS** – often used as a cost cutting exercise, no professionalisation, no acknowledgement of need to be professional (recognition as an employer of a team!), hourly rate restrictions, restrictions via contractual obligations, lack of ability to source suitable providers or individuals.

**Providers/PAs** - geo-blocking; difficulty sourcing suitable providers/candidates (behaviourism, not actually trained by autistics); pay and funding differentials; professionalisation; differences between rural and urban settings.

**Day services** – inappropriate (often riddled with behaviourism, ableism, and infantilisation), underfunded.

**Assessment** – limited over time by LA by increasingly strict rules not in the spirit of Compassion, Inclusion, Wellbeing. Now often ‘extreme crisis’ and the absolute legal minimum. This minimum hours assessment often means even this goes unmet due to small hours. Assessment not done by trained professionals

**Rights** – little to no understanding of right, both as per Equalities Act, and prospective obligations under other human rights mechanisms (especially ignorance of the UNCRPD). This is across the public, private and third sector, as well as those needing support themselves. For example, what supported decision making should be, ABA/PBS being antithetical to Human Rights.

**Focus** – focusing on ‘work’ simply commodifies and dehumanises autistics and devalues the breadth of human experience. There is often a focus on neuro-normative lifestyles further othering and dismissing the autistic experience and our culture.

**Institutions** - problems with Coming Home Report (already mentioned), lack of suitability, prevalence of abuse; what is a good model?

This is a very high-level overview of some of the key issues surrounding social care, that barely scratches the surface. It also creates an unnecessary barrier to both problematising the issues and formulating solutions, as they are systemic in nature and go beyond the false barrier of ‘social care’. For example, there is little to no acknowledgement of the continuing cling to Kantian Dualism, leaving MH compartmentalised and separate from physical health.

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### Presentation by Autistic Voices Advocating Together for Autonomous Rights (AVATAR) – employment and access to work

Employment is something of a hot topic give recent debates over benefits and the government's drive to get more disabled people into work. We know that in the UK only 31% of autistic adults are employed and only 16% of autistic adults are in full-time paid employment. The research also shows that 77% of unemployed autistic adults want to work so it's important to explore why these people have not been able to access employment.

Autistic people face discrimination at all stages of recruitment and workplace experiences across all sectors. Many of the problems autistic people face are attitudinal which creates both direct and indirect discrimination. These are often linked to a lack of autism understanding and ongoing beliefs in false stereotypes about autistic people.

A lack of appropriate support creates barriers to employment when autistic differences such as sensory and communication differences are not understood and reasonable adjustments are not made by employers. Stigma plays a significant role in barriers to employment. Many autistic people fear disclosing as autistic in the workplace as this often leads to discrimination. However, without being able to disclose to their employers they are not able to access reasonable adjustments or other support and so they are forced to continue masking their distress at work which often contributes to burnout and leads to ill health, needing to take time off from work and difficulties retaining employment.

Where people do manage to disclose and ask for support in the workplace employers are often fearful that accommodations will use more resources than are available. While some autistic people will require more support and adaptations to make the workplace accessible, often the changes which are needed are small and inexpensive but can make a huge difference to autistic employees. The application of a little knowledge can go a long way such as recognition that a person's ability to make normative eye contact during a job interview is not necessarily a reflection of their ability to do their job. One of my colleagues was struggling to prioritise all the email she had coming in and so her workplace implemented a colour coded triage system so it was immediately obvious which emails were the most urgent.

In order to get more employers to make changes such as these we need services like job coaches, mentors and employability programmes to understand the unique needs of autistic people in the workplace. Currently, where such services are available they do not have enough availability and have not been designed with or for autistic people. There is often a false believe that because such supports to access work are nominally available nothing further needs to be done because people should just use these extant services. However, the inaccessibility of these services due to their often limited or outdated knowledge about how to support autistic people means there are still many people falling through the gaps.

Autistic people report very mixed experiences of trying to access Access to Work with some describing it as ironically completely inaccessible to autistic people. Access to Work is only available to people who are already in employment and is only designed to fund things which would not be considered reasonable adjustments. We see similar difficulties when autistic people undergo needs based assessments where these are often carried out in unhelpful ways because the people conducting these assessments do not have appropriate autism knowledge.

People sometimes assume that when autistic people face discrimination in the workplace that they are able to seek redress via employment tribunals. While technically this may be true the fact is that most autistic people are too busy just trying to survive daily life and do not have the spare time and energy it would take to access the employment tribunal process. There is not enough support available to help people uphold their rights in this area and yet again the ability of the tribunal to treat autistic people fairly is dependent on them having a good understanding of autistic experiences.

This summary is only scratching the surface of the problems but I hope it's clear that when 77% of unemployed autistic adults want to work but haven't been successful in gaining employment that there's something wrong with the current system, the supports that are in place aren't fit for purpose when it comes to supporting autistic people and this needs to change.

## Asking Scottish Government to confirm their ongoing commitment to upholding the human-rights of disabled people

Last week I attended a lecture on 'Neurodiversity in the age of late fascism' by Dr Robert Chapman who is a leading philosopher and social theorist. They demonstrated how clearly world politics is edging closer and closer to fascism, and how much of a concern this is as the UK seems to be following trends set in the US around things like DEI. I have Dr Chapman's permission to reiterate some of the points they made which I think have bearing on our discussions.

Firstly, the success of the Neurodiversity Movement isn't based on mass collective power. There is no one central social movement, it has come about through lots of small organisations, like those represented here today, lobbying for change. As such it depends on a mixture of existing law and policy, for example making the Equality Act applicable in neurodivergent contexts. However, the successful implementation of the values of the Neurodiversity Movement also depends on liberal political consensus, a consensus across politics (and society more widely) that things like inclusion and human rights *are* desirable outcomes. The idea that the neurodiversity paradigm could and should impact on policy is premised on policy makers caring about scientific and humanistic research. The fact is that late fascism does not care about truth or rights.

In light of the recent Green paper proposing benefit cuts we're seeing a lot of rhetoric from Westminster which is not based on truth or rights. We are seeing people in positions of power making statements that portray disabled people as lazy scroungers and making decisions based on ideas which aren't true, e.g. the idea that making PIP harder to access will help disabled people into work when PIP is not a work-related benefit. I get PIP and I work, if my PIP is stopped or reduced I will actually be able to work less. These misleading ideas are being shared with the public and will only serve to increase stigma, some UK politicians are very clearly demonising disabled people and suggesting we are taking money away from the 'hard working taxpayers'. There are obvious parallels with the way disabled and other marginalised groups have been demonised historically.

We know that even where things like PIP are devolved in Scotland it seems very likely that decisions like this at Westminster will go on to have a negative impact on people in Scotland. These worrying trends are not just one or two areas, we’ve heard about so many areas today where autistic people’s human rights are being trampled and it’s easy to see why many of us are fearful that this might continue unchecked. We are afraid we might continue to lose our rights to things like equality just as we are seeing happen to people in the US. We are scared that our human rights are slowly but surely being eroded as world values are changing.

I really hope this is something that should go without saying, particularly given the purpose of this committee to uphold Equality, Human Rights and Civil Justice, but we need some reassurance that the committee will ensure that Scottish government do care about the truths we’ve shared with you today and will ensure decisions made at Holyrood are informed by scientific and humanistic research.

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### Presentation by Autistic Voices Advocating Together for Autonomous Rights (AVATAR) – Autistic interactions with the Police and the Criminal Justice System

I need to start with a trigger warning for mention of suicide and sexual assault.

We know autistic people regularly come into contact with police and the wider Criminal Justice System (CJS), either a victim, witness or suspect. However, stereotyping still plays a huge role in the way autistic people are treated within the CJS, people often make assumptions based on misleading stereotypes like the idea all autistic people have no empathy for others and so they believe that autistic people might be more likely than others to commit a crime even though there is no evidence for this in the research. In fact, some studies show autistic people are more likely to be law abiding than non-autistic people. Despite this we know that autistic people are over-represented in the prison population, with studies showing around 4% of the prison population is autistic (interestingly that number is closer to 5% for female prisoners) compared to prevalence of around 1% in the general population. These are just the autistic people we know about, there are likely to be a lot more people such as older adults who are far less likely to have been recognised as autistic than younger people.

In terms of victimisation, we know that autistic people are 4 times more likely to experience disability related hate crime than other disabled people but 48% of these crimes are never reported. We know that 44% of autistic people will experience some sort of victimisation during their lifetime.

Despite these alarming figures police and others within the CJS are not well equipped to support autistic people. In a study that looked at autism understanding in police officers in Scotland 82% of police officers said they found it difficult to meet the communication needs of autistic people. We know that simple things can make a huge difference if only people are aware of the impact of things like the sensory distress that bright lights or loud noises such as police sirens cause for many autistic people. The noise of emergency vehicle sirens is a key factor in why I have chosen to live in a very rural area, being in a city where these are more frequent causes me physical pain.

We know that Police often misunderstand autistic non-verbal communication such as different levels of eye contact or visible signs of anxiety and can misinterpret these, often with devastating consequences. I know several people who have experienced sexual assault and not been believed by the police because they were seen as ‘too calm’ when reporting it. I know of an autistic young woman with a learning disability who had been taught using behaviouralist approaches that she was not allowed to shout out, therefore when she was assaulted she did not shout out which again caused the Police to doubt her account.

It is well established that in stressful situations autistic people might shut down and have huge difficulties processing what is happening and what is being communicated to them. Research has shown that when interviewed by the Police some autistic people say what they think the officer wants to hear or will agree with inaccurate statements in order to please the authority figure without truly understanding the consequences of these actions.

Unless Police and others within the CJS are properly trained these issues pose a real risk to autistic people’s human rights particularly in terms of things like equality of access to justice. There’s a clear need for more training but there’s no need to reinvent the wheel there are already resources like high quality autism training that has been co-produced with autistic people and autistic police.

We need to remember that Police are often in contact with people when they are at their most vulnerable, recently one of our members was in contact with police as there were fears that she might attempt suicide and the lack of appropriate autism knowledge meant that the way she was treated by police made an already awful experience so much worse for her. When I spoke to local police the other day to invite them to a free autism professional training event we are running (which they are unlikely to attend) I asked whether they were aware of the autism specific training resources available to police and they said they did not know these existed.

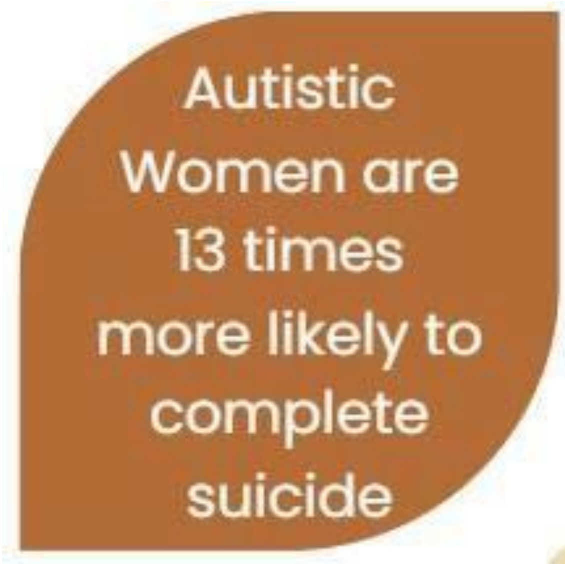
We need to find ways to ensure that everyone from police to prison officers to court clerks to victim support to judges and magistrates have the right knowledge to enable them to do their jobs without creating additional risks to autistic people.

# Learning Disability, Autism and Neurodivergence Bill

**Lessons from the Bill & Consultation - Actions and consequences**

- Lived experience organisations expertise were not taken seriously
- LEAP Group were given limited time
- DPOs were not consulted on the wording and format of the consultation
- 100 page document that was repetitive and strenuous to comprehend, visually not accessible esp for dyslexic/ ADHD/Mears Irlene.
- Disenfranchised the intended audience
- Translation - Lack of understanding and action, limited time, in the name of ‘affordability’
- Time period was discriminatory – Published just before Christmas and closing just after Ramadan
- Discrepancy between the long version and the short version

# Mental health



Autistic Women are 13 times more likely to complete suicide

6 in 10

More than 6 in 10 autistic people have considered suicide

3 in 10

More than 3 in 10 autistic adults have attempted suicide

8 in 10

Almost 8 in 10 autistic adults have a mental health condition

https://www.autistica.org.uk/our-research/research-projects/understanding-suicide-in-autism

'Suicide or deliberate self-inflicted harm' identified as the most common category of death in autistic children without a learning disability

**Compared to white people: Black women are more likely to experience a common mental illness such as anxiety disorder or depression, older South Asian women are an at-risk group for suicide, Black men are more likely to experience psychosis, and Black people are 4 more times likely to be detained under the Mental Health Act.**

https://www.youngminds.org.uk/parent/blog/autism-and-intersectionality/

https://www.mind.org.uk/about-us/our-strategy/becoming-a-truly-anti-racist-organisation/facts-and-figures-about-racism-and-mental-health/

https://www.autismcentreofexcellence.org/autistic-children-suicide-data-2/

https://www.rethink.org/advice-and-information/living-with-mental-illness/ethnic-minorities-and-mental-health/ethnic-minorities-and-mental-health/#:~:text=Black%20women%20are%20more%20likely,under%20the%20Mental%20Health%20Act.

# Equalities, Human Rights and Civil Justice Committee

## Learning Disabilities, Autism and Neurodivergence (LDAN) Bill

### Engagement with Autistic Disabled People's Organisations – 25 March 2025

### Breakout Group 1 – notes

- **ABA/PBS (behaviourist approaches)**
- **Education**
- **Social Care**

**In terms of behaviourist approaches - can you provide a bit more detail on that, your own experiences and how it has affected you?**

- Behaviourist approaches suppress negative behaviours and reward good behaviour. This is traumatic because it's suppressing autistic people and forces them to be a certain way that is not natural to them.
- Behaviourist approaches are prevalent throughout support systems even if it's under another acronym.
- PBS (Positive Behaviour Support) is a rebrand of ABA (Applied Behaviour Analysis). It is based on effectively last century ideas about "dog training". Today, dog trainers don't use this approach because it's deemed to not be good for dogs but yet it's deemed ok to use on people with autism or a learning disability.
- One of the participants spoke about their experience with behaviourist approaches and described electroshock devices being used to punish "bad" behaviour.
- It's a punishment system if you don't behave in a way that is deemed to be normative.
- The approach is self-referential, it has no basis in science.
- It is a basis for conversion therapy.
- People with a learning disability are not always assessed for autism, so it's being used on people with a learning disability without them being assessed to check if it's suitable.

- Autistic people shouldn't be "trained" to be neurotypical. Most autistic people are happy being autistic and don’t want to be neurotypical. Autistic people have their own community and culture, which is empowering.
- These approaches increase masking in young people, which is exhausting and leads to burn out. Young people are flying under the radar because they’re not coping and are burnt out.
- ABA/PBS looks at outcomes rather than underlying causes of behaviour.
- These approaches do not think about how to help autistic people just how to hide and disguise autism.
- Support for young people shouldn’t be about suppressing who they are or hiding neurodivergence.

**How important is an early diagnosis?**

- One of the participants spoke about how they thought getting their diagnosis would mean that their school would want to help and support them. They had been told by the school that without a diagnosis they didn’t need support. However, when they got their diagnosis, it didn’t necessarily help them get the support they needed.
- One of the participants spoke about how a getting a diagnosis helps the individual understand themselves better and not feel like they’re doing something wrong.
- The assessment process that is currently used for diagnosis needs to be reviewed. It needs to be designed by those with lived experience who have real understanding of what it is like to be neurodiverse.

**What can be done in the areas of Education and Social Care without the Bill?**

- A Commissioner isn’t the way to go and legal guidance isn’t enough.
- Social care and support – needs professionalising especially in terms of PA’s (personal assistants). We need a more national approach rather than local for many aspects of it. However, differing approaches might be necessary in urban and regional areas.
- Without a diagnosis everything becomes a mental health issue.

- The money spent on a new Commissioner could be used to support autistic people instead. There are Commissioners in other Bills who would cover our rights.
- To have a specific Commissioner is a waste of money.
- From a young person’s perspective the Bill was not accessible.

# Equalities, Human Rights and Civil Justice Committee

## Learning Disabilities, Autism and Neurodivergence (LDAN) Bill

### Engagement with Autistic Disabled People’s Organisations – 25 March 2025

### Breakout Group 2 – notes

- **Access to health and social care support**
- **Employment support including access to work support**

- There are barriers for autistic people, from the recruitment stage – eg in terms of the communication in job adverts and during interviews, and in terms of communication in the workplace and whether the environment is accessible.

- Employers need neuro affirming policies and may benefit from training staff. Any training should be given by autistic people.

- Being on a waiting list for a diagnosis causes stress, which can impact on mental and physical health. In terms of seeking support for mental health, there is nothing that is directed towards to the autistic experience of depression or mental health. This has an impact on employment prospects.

- It was also highlighted that there is variation in terms of support for autistic students across the university sector and it would be helpful to have more neurodivergent people working in student support.

# Equalities, Human Rights and Civil Justice Committee

## Learning Disabilities, Autism and Neurodivergence (LDAN) Bill

### Engagement with Autistic Disabled People's Organisations – 25 March 2025

### Breakout Group 3 – notes

- **Mental health**
- **The criminal justice system**
- **Access to assessment, diagnosis support and post-diagnosis support**

#### Mental health

- The importance of a timely diagnosis and its preventative benefits was highlighted. It was pointed out that patients presenting at eating disorder clinics are often subsequently diagnosed with autism.

- It was stressed generally that there was a need for a more proactive approach in mental rather than one that responds to crisis.

- An preventative approach would ultimately be far better it was proposed. Not only will it vastly improve the lives of autistic disabled people, but it will also ultimately provide cost savings to the public sector.

- It was also highlighted that this preventative approach should be a key element of post-natal care and that a higher and more consistent level of training for those providing maternity care is needed.

- Mandatory high quality and consistent training for GPs was also proposed as members of the group shared their experiences of GPs not being able to properly understand how to engage with autistic disabled people and how they might present. For example, not understanding that autistic disable people might not demonstrate pain in the same way as neuro typical people.

#### The criminal justice system

- It was stressed that there was a need for a significant improvement in training across the public sector to understand how to support autistic disabled people. It was argued that there is a need for national consistency too.

- It was suggested that this could lead to significant improvements for autistic disabled people.

- Participants provided examples of their experiences in the criminal justice system. For example, they noted that their responses to being a victim of a crime such as domestic violence do not necessarily conform with the responses the police would expect to see and accordingly they are not believed by the Police. In turn, this results in autistic disabled people not reporting subsequent instances of violence and not trusting the Police.

- It was also pointed out that there is significant under diagnosis in the prison population and that diagnosis in that system could have life changing benefits. In particular the strong link between addiction and autism was highlighted.

### Access to assessment, diagnosis support and post-diagnosis support

- Pathways for children and adults to assessment are being closed.

- Children and adults are losing significant parts of their lives while they wait for an assessment. They can’t move forward until they receive that assessment, diagnosis and subsequent support.

- In some cases people are completing suicide while still waiting for assessment, diagnosis and support.

- Without a diagnosis autistic people are not able to understand who they are.