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Karen Adam MSP Convener Equalities, Human Rights and Civil Justice Committee

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Learning Disabilities, Autism and Neurodivergence (LDAN) Bill

I am writing to you following the meeting of the Equalities, Human Rights and Civil Justice Committee on 03 December 2024 regarding the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill, and, in response to your follow up correspondence dated 05 February 2025.

I write firstly to thank you again for inviting me to speak to the Committee and for helping to raise awareness of the inequalities and poor outcomes that LDAN groups can experience. I believe very strongly that we need to change our approach, and I am committed to leading that change through the LDAN Bill and allied work that the Scottish Government is progressing in partnership with others.

Lived experience and stakeholder input and engagement

At the Committee meeting in December, I explained that I had carried out a series of meetings with stakeholders and the Bill Advisory Panels, including the Lived Experience Advisory Panel (LEAP), to reassure them of my ongoing commitment to the Bill and to discuss how we should continue to work together during the next phase of development. Shortly thereafter, we held an event for the three Bill Advisory Panels to continue that discussion and to take stock of the progress we had made together. This has included the development of our consultation proposals and an inclusive and accessible consultation exercise which resulted in nearly 900 responses, including many from individuals.

During this year we will continue to work with our Bill panels and stakeholders to progress the development of the Bill.

Any additional public consultation

Although feedback on the consultation was largely positive, I have heard through our Bill Panels that a second public consultation, similar to the first, would not be welcome. I appreciate that the consultation document was lengthy, however, I felt it was important to reflect on all of the important issues that had been raised with us. I appreciate that this,







therefore, required a substantial amount of time and resource to be able to digest and provide a response.

We are listening to that feedback and have been exploring alternative approaches, including new ways of working with the Bill Panels. The incredible response to the consultation exercise was in no small part due to the dedication and resources that our stakeholders put into helping us publicise and support people to respond. I am very grateful for their dedication to supporting these groups.

However, we will not make a final decision about whether a second public consultation exercise will be required, and, if so, how it will differ from the first, until later in the process. We will seek the views of the Bill Panels as part of that decision making process.

Allied work being progressed alongside the LDAN Bill

I recognise that the Bill is not a singular solution and that there is work we can do now to address the inequalities and poor outcomes experienced by neurodivergent people and people with learning disabilities. Some of that work is directly linked to the Bill and some encompasses the wider work of the Scottish Government and is not linked directly to a need for legislation. I have provided an update below on the topics that the Committee has raised.

Data

The Scottish Government commissioned the Scottish Learning Disabilities Observatory (SLDO) to carry out a study with Local Authority Social Work Departments to explore and strengthen data and evidence around local approaches to supporting parents with learning disabilities including scoping the extent to which children are maintained within the birth family. The study will also incorporate a small literature review and will involve people with lived experience on a small steering group to quality check responses from local authorities. We are expecting to see first drafts of the finished report by the end of March 2025.

I also note in your letter your interest in getting regular updates on data development to support and evidence improvements in outcomes over time for people who will benefit from the LDAN Bill and wider policy work. We recognised in the Bill consultation that it was crucial that we build on and enhance data measurements and indicators – this complements the evidence we hear from people with lived experiences. This also includes making good use of existing data, as you note, through the Coming Home Dynamic Registers and this is covered separately below.

Gender-based violence

As I set out at the evidence session, I regard the broad issue of gender-based violence as a serious one, with specific issues for women and girls with learning disabilities. The Scottish Government recognises that disabled women and girls are at greater risk of violence than non-disabled women and girls, and women with learning disabilities are more likely to experience sexual abuse than other disabled people.

Our Equally Safe Delivery Plan contains a commitment to deliver the Scottish Government; s Gender-Based Violence and Learning Disabilities Steering Group Action Plan.







We are continuing to attend the Gender-based Violence and Learning Disabilities steering group to support delivery of the group's action plan and have also begun planning for other deliverables in our Equally Safe delivery plan, identifying where engagement with women and girls with LD is required. Through our Delivering Equally Safe fund, we are providing £498,750 to Central Advocacy Partners and £343,036 to the Scottish Commission for Learning Disability over 3.5 years to carry out projects which focus on learning-disabled groups of women and girls. Central Advocacy Partners deliver 1:1 advocacy to learning-disabled people over 16 who are experiencing gender-based violence, whilst funding to the Scottish Commission for Learning Disability ensures that women and girls with learning disabilities, and the services who support them, better understand and are more able to recognise, report and tackle GBV.

We will continue to engage with women and girls with learning disabilities to ensure that their needs are recognised, included, and acted upon throughout Equally Safe delivery, and within wider policy and practice.

With regards to the Committee query on care workers (disclosure checks and regulation) beyond the standard Disclosure Certificate which shows criminal convictions, Disclosure Scotland also runs the Protecting Vulnerable Groups (PVG) scheme which helps ensure people who are unsuitable to work with children and protected adults cannot do regulated work. The PVG Scheme is a membership scheme and Disclosure Scotland continuously checks members' criminal history information. It also keeps lists of people barred from regulated work. PVG Scheme membership will last for five years before an individual would have to renew.

In addition, the Scottish Social Services Council, the regulator for the social work and social care workforce, publishes the SSSC Codes of Practice which set out the standards of practice and behaviour expected of everyone who works in social services in Scotland. As well as spanning all aspects of working within social work and social care, the Codes of Practice for workers directly stipulates that workers must protect and promote the rights and interests of individuals and carers. :

The SSSC Codes of Practice for Employers set out that employers will maintain a culture and have systems in place to support workers to meet the codes of practice, including leading and managing in a way that promotes kind and compassionate practice. Where someone falls short of the standards, the SSSC investigate concerns and take action if appropriate to ensure that people on their Register meet the standards of character, conduct and competence necessary for them to do their job safely and effectively in line with the SSSC Codes of Practice.

Annual health checks

On annual health checks for people with learning disabilities, the Scottish Government is providing funding to NHS Boards to deliver this important policy. Health checks are now being delivered to thousands of people across Scotland, and this is already yielding positive results. We know that this is an ambitious programme of work and Boards have faced challenges in delivering annual health checks within the expected timescales. Whilst there is good progress in some areas, progress in other areas needs to improve and this requires leadership and commitment at a local level.







I wrote to Chief Executives of all NHS Boards in January of this year reiterating the importance of annual health checks, setting out my expectations for delivery in 2025-26 and requesting that all Boards have delivery plans in place to increase and improve delivery. Annual Health Checks are now also included in NHS Boards' 2025-26 Annual Delivery Plans, and this will underpin accountability.

Ongoing support is provided by the Scottish Government to NHS Boards via the National Implementation Group and the Data Programme Board and Officials will continue to work closely with NHS Boards.

Evidence from completed annual health checks, shows that they have identified undetected and treatable health conditions and have ensured onward care, support and treatment is provided. They are also identifying a high level of unmet health need and gaps in services for people with learning disabilities. Onward referrals to secondary care pathways for individuals have been reported in some Boards in as many as 70% to 80% of cases, with an average of around 40%. This includes referrals to GPs, Dental, Audiology, Cardiology, Podiatry, Social Work, OT, Ophthalmology, Dietician, Learning Disability teams, neurology and urology.

Delayed Discharge and "Coming Home"

It is vital that we reduce delayed discharge, but I am particularly concerned that people with learning disabilities should not spend any longer in hospital than medically necessary. The Coming Home programme is a priority for this Government, and I want to be absolutely clear that a hospital cannot ever be a home – it is not a long term solution. Discharge planning should begin at the point of admission. It should provide high-quality care and support for people with learning disabilities and/or who are autistic to live in their home communities wherever possible.

Our programme continues to support the use of Dynamic Support Registers to help with local planning and provide national data and visibility of those with complex needs. We are working with COSLA, NHS Boards and Healthcare Improvement Scotland, alongside people with lived experience, to build on our investment into NHS Boards. We will continue working with partners to support community-based solutions that avoid, or limit future hospital use so that people are able to access the care they need and live within their own communities.

We are providing enhanced focus on Coming Home in partnership with COSLA and local partners to ensure people are able to access the care they need and live within their own communities. This is why we provided £20m of additional support and investment to health and social care partnerships to deliver improvements. Progress has been made, for example there has been a 61% reduction in the number of people on the Dynamic Support Register classed and being inappropriately out area since publication began in September 2023. However, it is clear that further work and strong local leadership is required.

Diagnosis and Assessment

We are working with NHS Boards and Local Authorities to improve services and support for neurodivergent people – including improving access and reducing waiting times. As you know, patient care and service delivery are the statutory responsibility of local health and social care bodies. We allocated £123 million to NHS Boards last year to improve the quality and delivery of mental health and psychological services, including neurodevelopmental







services, for both adults and children and young people. NHS Boards decide how to use funding to implement national policies to ensure that their local population have the highest quality of care and treatment at the right time and in the right place.

Actions the Scottish Government is taking to improve diagnosis and support for neurodivergent adults in Scotland include funding the National Autism Implementation Team (NAIT) to support local health and social care bodies across Scotland to design and improve neurodevelopmental diagnostic services. We have been working with NAIT to look at how we can improve the approach to diagnosis and support, and we tested adult neurodevelopmental pathways in four HSCP areas, one of which was Highland. The results of this work, including a final report, have been published. The Scottish Government accepted all 10 of the report's recommendations, and we are taking work forward to implement these.

We are also working closely with all NHS Boards to help improve their performance across CAMHS and Neurodevelopmental services, including to reduce their waiting times. We are seeing positive signs of improvement across the CAMHS waiting list compared to the previous year. The overall CAMHS waiting list decreased by 20.8% in the previous year (from 5.344 in Sept 2023 to 4.231 in Sept 2024).

The Scottish Government has commissioned NHS Education for Scotland (NES) and NAIT to provide a range of professional learning about Autism and ADHD. This includes training on assessment and support and workshops for clinical teams to put new learning into practice. NAIT has established a new neuro affirming community of practice, which provides leadership to the Adult Neurodevelopmental Professionals network to build relationships and support and combine expertise as work progresses.

We will also continue to work with NHS Boards, local authorities and partners to improve access to support and diagnosis, by supporting local partners to develop, enhance and redesign existing local neurodevelopmental services, and implement the National Neurodevelopmental Specification for Children and Young People. Through the Adult Autism Support Fund, the Scottish Government invests £1 million a year to provide support to autistic adults. Formal diagnosis is not required to access the support provided and we know that 78% of autistic adults supported have reported improved wellbeing as a result.

For broader financial context, the 2025-26 Budget will provide a record £21.7 billion for Health & Social Care this year. This includes £16.2 billion for Health Boards - a 3% cash uplift and real terms increase on their baseline funding. It will also deliver record funding of over £15 billion for Local Authorities, a further 4.7 per cent real terms increase.

Submission from People First

Finally, thank you for sharing the supplementary submission you received from People First. I consider that 2 of the 3 questions are covered in the material above, however with regards to the specific question they pose below:-

How does the Scottish Government reconcile Article 12 of the UNCRPD on equal recognition before the law with Scots law that still says that substitute decision-making can happen?







The Scottish Mental Health Law Review (SMHLR) stated in its final report:

"We accept that some processes are required to authorise decision-making on behalf of someone where they cannot do this themselves, even with significant support, whilst at the same time still trying to maximise and give effect to the person's will and preferences on an equal basis with others. This requires a range of measures to cover situations where a person is unable to indicate their will and preferences at a given time which is integrated with supported decision-making."

In July 2024, the Scottish Government published its <u>Adults with Incapacity (AWI) Amendment Act: Consultation.</u> The aim was to gather opinions on updating the AWI Act ahead of broader reforms that may be implemented over the next 5 to 10 years, as outlined in our response to the SMHLR. The consultation focused on changes to AWI law. But for these changes to be truly effective, we first acknowledged that changes in practice and in particular the need to embed Supported Decision Making (SDM) across the health and social care sector were necessary.

Scottish Government also plans to create a baseline for the current state of SDM, which will inform the development of a training and support model. This will be designed in collaboration with individuals who have relevant experience, including those who use the legislation, carers of individuals affected by it and practitioners.

More broadly and in line with the Mental Health and Incapacity Law Reform programme, our overall aim is to ensure that the human rights protections of all those impacted by mental health and capacity legislation are built on and enhanced as far as possible. Mental health legislation is based on rights and principles which provide for rigorous safeguards in respect of individuals' human rights where compulsory treatment is necessary. We want to ensure that any potential change to our framework continues to provide safeguards and provision of services. Safeguards include a right to independent advocacy and an efficient and independent Mental Health Tribunal which grants and reviews orders for compulsory treatment. Our legislation promotes patients' rights and provides for support to patients in expressing their will and preferences.

Most people who use mental health services receive treatment without being subject to an order or certificate under the Mental Health (Care and Treatment) (Scotland) Act 2003 ('The 2003 Act'). For some individuals however, compulsory treatment is used to provide the person with medical treatment to alleviate suffering and for the protection of both the person and others. Compulsory treatment is only allowed under mental health legislation in Scotland in very strict circumstances.

A person cannot be made subject to compulsory care and treatment solely on the basis of a learning disability. The 2003 Act requires that a person can only be made subject to compulsory measures or treatment under the 2003 Act if certain conditions are met;

- the person has a mental disorder;
- because of the mental disorder, the patient's ability to make decisions about the provision of medical treatment is significantly impaired;
- it is necessary to detain the patient in hospital for the purpose of determining what medical treatment should be given to the patient or giving medical treatment to the patient;







- if the patient were not detained in hospital there would be a significant risk to the health, safety or welfare of the patient or to the safety of any other person; and
- the granting of an order or a certificate is necessary.

In terms of forensic services, it is a court that determines whether a forensic order is appropriate, the alternative may be a custodial sentence. In making its decision a court has to have regard to the nature of the offence and the alternative means of dealing with the offender.

The issue of the definition of 'mental disorder' within the 2003 Act is complex and sensitive. We recognise the concerns of many people with a learning disability, autistic people and organisations who advocate for or on behalf of them. The work considering compulsory care and treatment under the 2003 Act started in November 2023. This included particular consideration of how the 2003 Act operates in respect of those with learning disability and autism, with a view to developing potential options for change. We undertook information gathering and engagement workshops which focussed on accumulating evidence to inform the development of options for amending the definition of "mental disorder", as well as consideration of the system of compulsory care and treatment and its application to those who fall within the scope of that definition. We are now working to analyse the evidence gathered through the workshops and wider engagement with a view to potentially consulting on initial reforms in 2025.

Other Issues

A couple of other issues were raised during the session as follows:

- Progress on Autism Assessments and related shortages of psychiatrists and waits for gender dysmorphia assessments
- CAMHS performance in NHS Tayside

As these did not appear in your letter, please let me know if you would still like an additional response on those issues.

I hope this is helpful and I look forward to further opportunities to engage with the Committee on the Bill and associated policy work.

Kind regards,

Maree Todd, MSP
Minister for Social Care, Mental Wellbeing and Sport





