

SPICe

The Information Centre
An t-Ionad Fiosrachaidh

Learning Disabilities, Autism and Neurodivergence Bill

Introduction

The Committee agreed to hold an evidence session to consider the impact of the Scottish Government's announcement to delay the introduction of the Learning Disabilities, Autism and Neurodivergence Bill (LDAN Bill).

On 26 November 2024 the Committee will hear from:

- Susan Burt, member representative, People First (Scotland)
- Gregor Hardie, member representative, People First (Scotland)
- Jamie Cooke, Head of Policy, Enable
- Suzi Martin, External Affairs Manager, National Autistic Society Scotland
- Jenny Miller, Chief Executive, PAMIS - Promoting a more inclusive society
- Dr Simon Webster, Chief Executive, Scottish Commission for People with Learning Disabilities

On 3 December the Committee will hear from Maree Todd, Minister for Social Care, Mental Wellbeing and Sport.

Terminology

The terminology used in this paper reflects the terms used in the documents it references.

The Learning Disabilities, Autism and Neurodivergence Bill has been shortened to the LDAN Bill.

Background on the LDAN Bill

Before the Bill proposal

In March 2021, the Scottish Government and COSLA jointly published the [Learning/intellectual disability and autism: transformation plan](#).

The purpose of the plan was to:

“... shape supports, services and attitudes to ensure that the human rights of autistic people and people with learning/intellectual disabilities are respected and protected and that they are empowered to live their lives, the same as everyone else.”

The transformation plan was published a year after the first lockdowns were introduced to stem the Covid-19 pandemic. It built on people’s experience from the pandemic. There was a widely held view that the rights of autistic people and those with learning disabilities were infringed before Covid-19, and that the pandemic had exacerbated this.

Also at that time, the Scottish Government and COSLA had been working in partnership with the third sector and others on two strategies - [Keys to Life Strategy](#) and the [Scottish Strategy for Autism](#), which were both ending in 2021 and 2023.

The transformation plan set out a [list of actions](#), including the consideration of a Commission or Commissioner to help protect people's rights.

Scoping the Bill

The Scottish Government committed to the LDAN Bill in its [Programme for Government 2021-22](#) (September 2021) It said:

“To uphold and protect the rights of people with autism or learning/intellectual disabilities, we will take forward a Learning Disability, Autism and Neurodiversity Bill, with scoping work carried out in 2021-22. We will also provide an independent advocate for people to secure the protections of such a law, through a Learning Disabilities, Autism and Neurodiversity Commissioner.”

Scoping work took place between May and July 2022. This involved a series of events to consider how people with lived experience viewed the Bill and to discuss potential key elements, including the role of a Commission or Commissioner.

There were 30 different events with 18 different stakeholder organisations, including people with lived experience of learning disabilities or neurodivergence.

An [analysis of the findings from the scoping work](#) was published in February 2023.

Consultation on the Bill proposal

The Scottish Government's [Learning Disabilities, Autism and Neurodivergence Bill: consultation](#) sought views between 23 December 2023 and 21 April 2024.

In the Foreword, Maree Todd MSP Minister for Social Care, Mental Wellbeing and Sport said:

“People with learning disabilities and neurodivergent people are unique individuals, who, like all of us, have

potential to develop, skills to offer, and vibrant lives to lead connected to their families and communities.”

The Minister said that a human-rights based approach had been taken to develop the consultation. It was co-designed with people with lived experience, through the Lived Experience Advisory Panel (LEAP).

The LEAP includes 25 people with various conditions including learning disabilities, autism, ADHD, Dyslexia, Down’s Syndrome and other conditions, with some members having more than one condition. Some members are also parents to children with learning disabilities or neurodivergence.

The Scottish Government also worked closely with Stakeholder and Practitioner Panels. The Panels include organisations and charities representing the views of a wide range of people and a range of practitioners from the organisations which provide support and services to them.

The Stakeholder Panel includes over 40 office bearers from a variety of interested third-sector organisations, including Disabled People’s Organisations.

The Practitioner Panel includes representation of professionals from: Social Work Scotland, Education Scotland, NHS Scotland (various), the Mental Welfare Commission, Police Scotland, the Royal College of Psychiatrists, the Law Society of Scotland, and others.

There was also a Foreword from LEAP. They view the consultation as a ‘significant milestone’ towards a fair and inclusive society. It is referred to as ‘ambitious and far-reaching’:

“If we get this right, Scotland has the opportunity to become a leading light, not just in the United Kingdom, but across the world.”

While there is a diversity of views among LEAP members, they are **agreed on the following principles**:

1. **The status quo is not an option.** It is not acceptable for our community to continue to face the discrimination and struggles that are sadly too commonly experienced by us all.

2. **There must be accountability.** We need a new mechanism to hold people and organisations to account and to uphold our rights. The form this takes will be informed by the responses to this public consultation.

3. **People with lived experience must be included.** For too long, decisions that impact us have been made without us. Once this proposed Bill passes into law, those with lived experience must have a significant role in its implementation and evaluation.

4. **What benefits us, benefits all.** Whilst this proposed Bill focuses on the learning disabled and neurodivergent communities, all of Scotland can benefit in promoting and supporting our rights. As has been shown by the unique insights and innovative ideas offered up by the LEAP to date, by enabling and empowering us to fully participate in society, Scotland can unlock a vast amount of talent and potential which will benefit everyone – not just us!

A note on language

The consultation sets out some guidance on language and terms because different people have different preferences in how they are described.

Identity-first language, such as ‘neurodivergent person’ or ‘autistic person’, is used because this was preferred by the majority of such people during the scoping work.

Person-first language is used in reference to ‘people with learning disabilities’, as this was the preference of the majority of such people during the scoping work.

‘Neurodivergent people’ generally refers to: people with learning disabilities, people with learning difficulties such as dyslexia, autistic people, and a wide variety of people whose neurology is different by virtue of ADHD, Fetal Alcohol Spectrum Disorder (FASD), and other conditions.”

It is recognised that not everyone is comfortable with the term ‘neurodivergence’, particularly people with learning disabilities. The consultation uses the term ‘neurodivergent people and people with learning disabilities’ throughout.

What is known about neurodivergent people and people with learning disabilities?

The consultation sets out a range of information which includes:

- Neurodivergent people and people with learning disabilities represent about 10-15% of the population. Some conditions are commonly co-occurring.
- These groups face significant inequalities and challenges:
 - People with learning disabilities in Scotland die, on average, 20 years earlier than the rest of the population, which is largely preventable.
 - Autistic people die on average 16 years earlier than the general population.
 - People with FASD who are not diagnosed in early life are at high risk of having a lower life expectancy than their peers, estimated at 34 years.
- In terms of family and community
 - 66% of autistic people in Scotland say that they feel socially isolated.
 - 52% of people with learning disabilities occasionally, sometimes, or often, felt lonely.

- Employment
 - It is estimated that employment rates are 4-8% for people with learning disabilities and 29% for autistic people, compared with Scotland's national employment rate of 82.5% for non-disabled people and 50.7% for disabled people.
- Education
 - 4.6% of exclusions in Scotland are of autistic learners, which is higher than the overall percentage of learners who are autistic (3.6%).
- Justice
 - Communication disorders among young offenders have a prevalence rate of 60- 90%.
 - A Scottish Prison Service pilot carried out in 2016 showed that 39% of prisoners had a learning disability or difficulty.
 - Global rates of gender-based violence suggest that 90% of women with learning disabilities have been subjected to sexual abuse, with 68% experiencing sexual abuse before turning 18.
- Stigma can lead to exclusion from services:
 - Stigma concerning autism and mental health has resulted in some autistic people not receiving support they are entitled to.
 - Large numbers of autistic people are targeted because of autism-related stigma - 87% had 'sometimes' or 'often' experienced bullying, 75% had 'sometimes' or 'often' experienced discrimination, and 52% had 'sometimes' or 'often' experienced harassment.

- People with learning disabilities face both social and health inequalities, which place them at an increased risk of mental health problems.

Who is the Bill about?

The LDAN Bill is presented as an opportunity to establish legal definitions for various communities under Scots law. The aim is to align these definitions with how such people prefer to represent and refer to themselves.

Views were sought on the definitions in the Bill, with a focus on the social model of disability:

“The Scottish Government is committed to the social model of disability. Unlike the medical model, where an individual is understood to be disabled by their impairment, the social model views disability as the relationship between the individual and society.”

Overarching themes

Views were sought on overarching themes:

Statutory Strategies for Neurodivergence and Learning Disabilities – while there have been national strategies, there is no legislative requirement for national or local strategies specifically for neurodivergent conditions or learning disabilities.

Mandatory Training in the Public Sector - there needs to be greater awareness, understanding, and training on learning disabilities and neurodivergence.

Inclusive communications - sharing and receiving information in a way that everybody can understand. Inclusive communication relates to all modes of communication:

- written information
- online information

- telephone
- face-to-face.

Data – better data collection and reporting will enable better understanding of the requirements of people with learning disabilities and neurodivergent people throughout their life and build evidence on whether they are able to realise their rights.

Independent advocacy – this is one way that people can receive help to understand and access their rights.

Specific themes

The consultation also sought views on specific themes. This gives an idea of the breadth of the proposed Bill:

Health and Wellbeing - Create statutory strategies in the Bill, mandatory training for health and social care workforce, inclusive communications and accessibility, patient passports (which follow a person when accessing care), annual health checks (currently being rolled out for people with learning disabilities across Scotland, but the Bill could extend this to autistic people and people with FASD and ADHD).

Mental Health and Capacity Law - The LDAN Bill could propose to make changes to mental health and capacity legislation in Scotland as it relates to autistic people and people with learning disabilities. However, more work needs to be done before a decision is made on this.

Social Care - Create statutory strategies in the Bill, mandatory training for health and social care workforce, inclusive communications, and accessibility.

Housing and Independent Living - A number of initiatives are already being progressed, but the LDAN Bill could include: adequate housing advice, strategies, training for housing professionals, data, and inclusive communications.

Complex Care – Coming Home - Strengthen the Dynamic Support Register and the processes around them through the LDAN Bill so that it becomes law for the relevant local public body (Integration Authority, Local Authority, Health Board) to hold these.

The Dynamic Support Register was launched across Scotland in May 2023. It aims to record information about people with learning disabilities and complex care needs who are in hospital, who are in out-of-area placements or whose current support arrangements are at risk of breaking down. They are a way to help professionals know what they need to do so that people are best able to live in their home communities.

Relationships - People who are neurodivergent or have a learning disability should be able to develop and maintain relationships and get the support they need to live a healthy, safe, and fulfilling life.

Proposals are for independent advocacy, improved data, inclusive communication, national and local strategies, and accountability.

Access to Technology - Proposals on training for people with learning disabilities in digital skills and online safety, as well as gathering data on the number of users, and the provision of support for users of technology.

Employment - No legislative changes proposed due to ongoing work in this area, and limitations because employment is reserved.

There are some suggestions to explore more inclusive approaches, for example, in training for job coaches on neurodivergence and learning disabilities in the workplace.

Social Security - Proposes some of the cross-cutting themes – national and local strategies, mandatory training for social security staff, better data gathering on social security benefits.

Justice - There are many developments happening across the civil and criminal justice system that have the potential to be very positive for neurodivergent people and people with learning disabilities.

The Bill could require a national strategy, data on neurodivergent people and people with learning disabilities in the justice system, inclusive communication, mandatory training and advocacy.

Restraint and Seclusion - The consultation said:

“We are considering what legislative options we could take. However, we do not think that this Bill would be the right place to do this because it would need to apply to all children and young people, and not just neurodivergent children and young people and children and young people with learning disabilities.”

Transport - Some areas are reserved, but there could be national and local strategies, and mandatory training.

Education - Existing Additional Support Needs legislation was independently reviewed in 2020 and was not found to be deficient. However, there was a gap between the policy intention of the legislation and its implementation.

The Bill could provide for strategies, mandatory training for teachers, practitioners, and other educators. It could provide for data on the spectrum of learning needs.

Children and Young People – Transitions to Adulthood -

The expectation here is that other overarching and specific proposals, will contribute towards improving outcomes for neurodivergent young people and young people with learning disabilities making the transition to adulthood.

Accountability

The consultation set out options for neurodivergent people and people with learning disabilities to know about their rights and

to be able to get support where those rights are not being protected or respected.

The options were:

- Create a **new Commission or Commissioner**
- Better resourcing and additional duties for an existing Body
- Champions and Advocates within Scottish Public Bodies
- Better resourcing for existing Disabled People's Organisations who support neurodivergent people and people with learning disabilities in ensuring that their rights are upheld
- Supporting good practice through standards, guidance and practical tools and investing in co-production.

Consultation analysis on the LDAN Bill

Independent analysis (Wellside Research) of the consultation was published on 26 August 2024: [Learning Disabilities, Autism and Neurodivergence Bill: consultation analysis - gov.scot](#).

A total of 877 responses were analysed, including 609 responses from individuals/groups of individuals, and 268 organisations.

This is a very broad summary of the responses to the 61 questions provided in the [conclusions](#) to the independent analysis:

- There were a large number of responses, but the representativeness of respondents is not known, and feedback related to certain conditions and/or demographic groups risks being underrepresented.

- Respondents were largely positive about most of the proposals, with general support for the implementation of all proposals in combination in order to provide the most robust and accessible set of systems.
- Respondents stressed the importance of ensuring meaningful involvement from a wide range of people with lived experience.
- Training for public sector staff (and others), as well as the proactive provision of accessible communication were also seen as key to improving current service provision.
- The publication of strategies, reporting duties and the development of strong and robust accountability measures were also perceived as vital to ensure change happens on the ground.
- Key to the success of the proposals and measures, however, was the need to learn lessons from the current implementation gap.
- It was felt that capacity issues (including funding, staffing and staff retention issues, training, and the general availability of services/facilities) would need to be addressed to ensure the proposals can be implemented in a meaningful way.
- Some sectors (such as housing, transport and education) would also require more infrastructure-based changes (which were not covered by the proposals).
- It was also suggested that the approaches or proposals outlined for certain sectors did not go far enough, for example, employment, education, and systems to support transitions.
- It was suggested that the proposals focused largely on adults, and that greater consideration was needed in relation to children and young people.

- Barriers to diagnosis were also highlighted as a significant issue which the consultation document did not tackle. Respondents felt this was a missed opportunity and urged the Scottish Government to make provisions for this within the LDAN Bill.

LDAN Bill – next steps

Maree Todd MSP, the Minister for Social Care, Mental Wellbeing and Sport [wrote](#) to the Convener of the Health, Social Care and Sport Committee on 4 September 2024 (copied to the Convener of the Equalities, Human Rights and Civil Justice Committee).

The Bill had been expected as part of the legislative programme announced in the [Programme for Government 2024-25](#) on 4 September. Instead, the Programme for Government said that draft provisions on the LDAN Bill would be published this parliamentary year.

The Minister said in the letter, “It is our intention to publish these provisions in order to seek people’s views on our finalised proposals and how the legislation will be framed.” There was recognition that some stakeholders would feel disappointed at this news.

The Minister said that the consultation analysis showed there are strong and diverse views on some of the key issues, and that further work is required before making final decisions. Reference was also made to the evolving landscape with the proposed Human Rights Bill and the National Care Service (Scotland) Bill. However, both have since been delayed.

Reference was also made to the Scottish Parliament’s Inquiry on the Commissioner Landscape in Scotland, which has since called for a moratorium on new commissions and commissioners, until there has been a review of the system.

The Parliament has agreed to the moratorium and that the review should be completed by June 2025.

The draft Bill will take account of the responses to the consultation, and work with the Bill Advisory Panels will continue, “with lived experienced being at the heart of our process.”

Given the length and detail of the LDAN consultation, the intention is to provide a longer time for feedback on the draft Bill provisions.

**SPICe Research
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