EHRCJ/S6/24/27/1

Equalities, Human Rights and Civil Justice Committee
Tuesday 3 December 2024
27th Meeting, 2024 (Session 6)

Learning Disabilities, Autism and Neurodivergence Bill

Introduction

The Committee agreed to hear evidence following the Scottish Government's decision to delay the introduction of the Learning Disabilities, Autism and Neurodivergence Bill (LDAN Bill).

This paper updates the previous paper with an additional section on 'Evidence heard on 26 November 2024.'

On 3 December the Committee will hear from:

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

supported by:

- Jacqueline Campbell, Unit Head, Learning Disabilities and Autism Policy, Scottish Government
- Carmen Murray, Team Leader, Learning Disabilities, Autism and Neurodivergence Bill, Scottish Government

On 26 November 2024 the Committee heard from:

- 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
- Joe Long, Director of Practice and Innovation, Scottish Autism
- Gregor Hardie, member representative, People First (Scotland)
- Susan Burt, member representative, People First (Scotland)

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.

Evidence heard on 26 November 2024

This section summarises the evidence heard on 26 November 2024. The Official Report was not available at time of writing.

Issues for people with learning disabilities

Some of the panel shared a view that there are low expectations of people with learning disabilities when they need to be treated as equal citizens. Some examples given were being able to access employment, being kept in hospitals, and incidents of hate and verbal abuse when carrying out day-to-day activities.

Gregor Hardie (People First), told the Committee about research from the Fraser of Allander Institute. It shows that while employers have a desire to recruit people with learning disabilities, they lack an understanding of how to do so. They reveal five key themes holding employers back:

- Lack of knowledge, leading to prejudice
- Lack of prioritisation
- Lack of intention and knowledge about how to recruit
- Not knowing where to start
- Perceived cost barrier

Gregor said that those things impact every aspect of the lives of people with learning disabilities "their impact reinforces the low expectations Scotland has for us".

Susan Burt (People First) agrees that employment is one part of life where people with learning disabilities are failed, but that the failure touches every aspect of life. For example, Susan said:

> "Some of us are still locked away in hospitals, the policy says that should not happen, but it still does… we still

> experience incidents of hate daily that do result in us being invisible… verbal abuse is a daily misery…while we're travelling or when we're shopping…"

Susan also said that people with learning disabilities are often given no option but to live with others, because independent living is too expensive.

Dr Simon Webster said that the Bill needs to redefine people with learning disabilities as equal citizens, "…who, without exception, are equally valuable members of our society". Dr Webster said that "Scotland's understanding of people with learning disabilities is shaped by a history which includes segregation, institutionalisation and dehumanisation".

Involvement with the Bill

Each of the organisations had been involved with the Bill in various ways.

Several of the organisations said they had been on the Scottish Government's Stakeholder Panel, and had carried out engagement work (Enable, NAS, Scottish Autism, PAMIS).

Jamie Cooke (Enable) said they worked closely with other organisations around campaigning on the Bill and engaging with activity across Scotland and through events.

Suzi Martin (NAS) spoke about the 10-year Autism Strategy for Scotland, which was found to have failed at making the systemic change needed to improve outcomes for autistic people. That led NAS to acknowledge that there is an "accountability gap" or "implementation gap". NAS worked with Scottish Autism and Enable to campaign for a commissioner for autistic people and people with learning disabilities as a means to address those gaps. A commitment to legislate was made in several party manifestos for the 2021 Scottish Parliament election, and the commitment was made in the Programme for Government 2021, both to establish a commissioner, and to legislate.

NAS worked with the other organisations throughout the process and facilitated engagement. Suzi Martin praised the LEAP (Lived Experience Advisory Panel) for its great work in advising the Scottish Government and driving the delivery of proposals.

Jenny Miller (PAMIS) said they spent a lot of time going back and looking at what people had been asking for, for the past 32 years. They found in 32 years there was limited progress, and the issues were still current.

Joe Long (Scottish Autism) said they did a lot of work to engage people in the consultation. He also pointed out that some of the single responses to the consultation were from organisations that engaged with lots of people.

Dr Webster (SCLD), said that the Bill had been the focus of their work this year, but there wasn’t enough time for people with learning disabilities to be fully engaged with it. SCLD also helped with the accessibility of the consultation, such as creating animations and accessible briefings.

Delay to the Bill

The whole panel expressed a deep disappointment that the LDAN Bill has been delayed.

Gregor (People First) said: “we were hopeful that some of the issues that People First have campaigned for over our 35 years might finally move ahead, but we remain unheard. Action not words is required.”

Jamie Cooke (Enable) expressed disappointment at the delay and said it was a chance for Scotland to be a “world leader”.

Suzi Martin (NAS) said that the Bill had the potential to be “transformative”, she said that autistic people and their families “feel let down at best, and at worst, abandoned”. Suzi said that Scotland is behind England in several areas, where they already have an Autism Act in place, mandatory training for health and social care professionals, and where disaggregated data on waiting times is published.

Jenny Miller (PAMIS) said that Covid had exacerbated inequalities “…the community are at the back of the queue, continue to be forgotten, undervalued, let down, and the promises made throughout the pandemic have been broken.”

Joe Long (Scottish Autism) told the Committee that after a lot of well-meaning legislation, multiple reviews, there has been a lot of hope invested in the LDAN Bill. People have invested a lot of time to it.

There was also a recognition that the Minister had felt some disappointment at the delay.

The difference a Bill could make

The panel shared a view that the Bill would make a positive difference to the lives of autistic people and people with learning disabilities, who Gregor and Susan (People First) described as being “bottom of the list” for years. Each organisation referred to the importance of addressing the accountability gap.

Suzi Martin (NAS) said three provisions were key in addressing systemic injustices: statutory strategies, mandatory training for the public sector, and accountability mechanisms.

Jamie Cooke (Enable) said the Bill would give the rights that already exist a legislative footing to address the accountability gap.

Joe Long (Scottish Autism) said that the difference the Bill would make would depend on its provisions. He said there needs to be accountability mechanisms, greater professional skills and understanding, and an end to crisis-led commissioning services.

Joe also spoke about the intersections with other policy work – autistic people and people with learning disabilities can be detained under the Mental Health Act on account of their neurodevelopmental profile. Organisations like Scottish Autism want to see an end to that, which the Bill could help achieve.

Jenny Miller (PAMIS) hoped that the Bill would raise the profile the rights of people with learning disabilities. She said, “There appears no repercussions for policies and guidance not being taken forward”, and it was hoped the Bill would change this.

Dr Webster said that the clear priority for people with learning disabilities is that this Bill would provide some accountability when public services are not provided or do not meet requirements.

The need for an LDAN Commissioner

Susan Burt (People First) said that an LDAN Commissioner was not their priority.

However, other panel members expressed strong support for an LDAN Commissioner, which was seen as a mechanism to provide accountability. Joe Long (Scottish Autism) said that a commissioner can hold government and services to account, and that “It needs a catalyst because the status quo is failing so many people.”

Consultation design

There was general agreement that the consultation was extensive and complex. However, it was felt that this reflected the number of challenges faced by autistic people and people with learning disabilities, and there was some appreciation that the Scottish Government understood this.

Susan Burt (People First) explained how members spent months looking at different parts of the consultation because there were so many questions.

Susan said she appreciated the accessible documents. When it is done well it is meaningful and respectful. However, there are still things missing or lost in translation.

Jamie Cooke (Enable) said they had to break down the consultation into smaller pieces which was time intensive.

Suzi Martin (NAS) said that the Scottish Government did work hard to put lived experience at the heart of the process through LEAP.

Jenny Miller (PAMIS) said it needed to be extensive, but it was also overwhelming.

Dr Webster (SCLD), said that while efforts were made on accessibility, it was still a difficult process.

Joe Long (Scottish Autism) said they were interested in the cross-cutting themes. However, he said there was a bit of disappointment that autistic people were not mentioned more in the consultation.

Thoughts on why the Bill was not introduced

There was a general view that the Bill was not introduced because people with learning disabilities are not seen as a priority, they are not important enough to be put on the agenda.

However, there was also a shared viewed that the Minister was very personally committed to the Bill.

It was generally felt that the proposals for the LDAN Bill were achievable rather than overly ambitious.

Suzi Martin (NAS) said that the reason given for delaying was that there remains a diversity of views. She disagreed with this point and said that there was strong support for statutory strategies, mandatory training and accountability. Other issues could have been worked through with the Panels.

Joe Long (Scottish Autism) said the fact that three Bills have now been delayed – National Care Services Bill, Human Rights Bill and the LDAN Bill, represents a “tranche of disappointment”. He said there is a lot of consensus on the Bill and now is the time for leadership.

Impact on the organisations

In terms of the impact of the decision to delay the Bill, it will affect those who are waiting for change and who want to feel equally valued.

Suzi Martin (NAS) said that the longer there are delays, the longer people are waiting for support, the longer they go without education and employment, the more people end up in poor and declining health, and the more people end up in institutional care instead of living in their own homes. The status quo is driving people into crisis; this has a human cost which is unsustainable on the public purse.

Jenny Miller (PAMIS) said that mortality rates for people with learning disabilities is unacceptable and needs to be addressed.

Joe Long (Scottish Autism) said that people are still excluded from services they are entitled to, and still fighting for what they’re entitled to.

Dr Webster (SCLD) said the opportunities in the Bill are now at risk, but they remain committed to progress the Bill.

How was decision communicated?

The organisations on the Stakeholder Panel received a letter from the Minister on 4 September 2024 stating that the Bill would be delayed. This was the same day as the Programme for Government was announced.

Suzi Martin (NAS) said that they received an email on 11 October 2024 from the Scottish Government’s LDAN team to confirm the Bill would not be introduced before the next Scottish Parliament election. Suzi suggested there was a bit of a vacuum as the Stakeholder Panel were told, but they had to go and communicate that news to the public.

Jenny Miller (PAMIS) appreciated that the letter was heartfelt and very personalised.

Advice for the Scottish Government

There was a sense from the panel that the Scottish Government needs to maintain momentum on the LDAN Bill’s development, and not lose all the progress that has been made. Organisations are willing to work with the Scottish Government as equal partners, but any consultation must be focused on the wording of the Bill.

Gregor Hardie (People First) said that annual health checks were promised but are not happening. He said “Do not in another 5 or 10 years apologise and act to try and explain or redress more failure. Make change now.”

Jamie Cooke (Enable) said that people need to see action, honesty, and realism from the Scottish Government. The main thing is to ensure that whatever has been captured is not lost.

Dr Webster (SCLD) said the Scottish Government will have to show people how they’ve used their responses to the consultation as they need to maintain an element of trust.

Joe Long (Scottish Autism) said that the Scottish Government needs to communicate what is happening regularly and clearly, for example, not everyone understands what “draft provisions” means. They would like to see a recognition of the consensus that already exists. He said there is currently no strategy and it’s unclear what’s coming next: “Our communities do need cause for hope, rather than despair at this point.”

Jenny Miller (PAMIS) said there is an opportunity for collaboration and agile working, the third sector needs to be an equal partner in this.

Suzi Martin (NAS) suggested there is no need to consult further. Any further consultation must demonstrate progress and must be a very focused consultation on the wording of the Bill.

Outcomes without legislation

The panel members had a range of suggestions for positive outcomes that could be achieved without legislation. There was a shared view that these outcomes require investment and should be thought of as spend that is proactive, preventative and positive.

Suzi Martin (NAS) said that access to autism assessment and diagnosis is extremely difficult in Scotland and legislation is not required to improve access. Suzi also spoke about exclusion from education and suggested that the Scottish Government does not understand the scale of it. Work could be done around training to address this, but unless it’s mandatory it’s always going to be piecemeal.

Suzi also said that the Scottish Government needs to stick to commitments it has made, such as ending of non-residential care charges. In terms of barriers, people are continually driven into crisis situations and government needs to understand that is unsustainably expensive and acknowledge that there is a return on investment by implementing preventative spend. This can be, for example, more support in schools, more comprehensive social care packages, or improved access to diagnosis.

Jamie Cooke (Enable) said there needs to be better data as it is difficult to find up to date data. He also suggested that pathways of how people get support can be improved now.

Joe Long (Scottish Autism) said, in terms of data, he would like to see an equivalent of the Scottish Learning Disability Observatory, for the autistic community. The observatory was set up to generate evidence and build understanding of the causes of poor health and health inequalities experienced by people with learning disabilities.

He also said that more investment in training is needed, and not just awareness training, so that there are people with proper specialist skills. There needs to be sustainable investment in community-based services that often prevent people from ending up in crisis. There is also a need for proactive support, advice for people, and peer support programmes. Joe said that these are things that tend to be cut, but these are things that prevent the human cost of crisis. He also said that we need to stop thinking in silos and take a whole life, whole system view.

Jenny Miller (PAMIS) spoke about the need for a workforce review, looking at payment and support and supervision of the workforce. The workforce needs to be fit and able to work with people with complex needs. Jenny referred to the research available from the Learning Disability Observatory and that thought needs to be given of how to put the evidence into practice. There is a lot that can be done, but support and coordination is required to take it forward.

Jenny also said that people with complex needs need to become an “us”, rather than a “them and us.”

Dr Webster (SCLD), referred to the Coming Home programme to reduce delayed discharges and inappropriate out of area placements and said it requires investment.

He also suggested that guidance for health and social care partnerships and local authorities could be updated.

Further issues raised:

Number of people in hospital with learning disabilities and complex care needs

Data from Public Health Scotland: Insights into learning disabilities and complex needs: statistics for Scotland (September 2024), shows that:

Considering adults registered with learning disabilities and complex care needs:

- In Scotland, at 27 June 2024 there were 1,515 people on local dynamic support registers.
- Of those, 474 were classified as urgent within the following categories:

    - 181 people in hospital, of which 84 were classified as a delayed discharge.
    - 66 people recorded as an inappropriately out-of-area placement.
    - 227 people recorded as at risk of support breakdown.

This is the third set of data, which is published quarterly. See previous quarters.

The Dynamic Support Register (DSR) was launched in May 2023, as one of the key recommendations from the Coming Home Implementation report.

As mentioned above, the DSR was launched in May 2023 and 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.

Waiting times for assessment/diagnosis of autism/learning disabilities

A Blog by SPICe on ADHD in Scotland – Prevalence, treatment and private care (September 2024) helpfully sets out the issues with waiting time data. It notes:

> “Waiting times for ADHD assessment in Scotland are not currently routinely published. Where data has been made available, it suggests lengthy waiting times for both child and adult ADHD assessment.”

Such data can only be obtained through Freedom of Information requests. The SPICe blog provides some examples:

- NHS Lothian said the average waiting time for an adult ADHD assessment in Edinburgh is 23.5 months (June 2024).

- NHS Tayside said that although it does not specifically track ADHD referrals, the current waiting time for children referred to its neurodevelopmental services is 154 weeks (May 2024).

This situation also applies to autism assessments and other assessments.

ADHD UK has developed a searchable UK-wide database of Freedom of Information request responses concerning waiting times for ADHD assessment. This resource can offer a starting point for waiting time data, but it may not reflect the most recent data.

Public Health Scotland has developed a Neurodevelopmental Pathway Trajectory tool to support NHS Boards in predicting and planning for future demand for services including ADHD assessment. However, the data generated by this tool is not publicly available.

There has been a growing demand for assessments in ADHD and autism which is likely due to increased awareness from professionals and the wider public. This is a key factor that has led to longer waiting times. A report by the National Autism Implementation Team (2023) recommended the implementation of proactive monitoring of demand and capacity to ensure timely access to support.

SPICe Research
November 2024