# Learning Disabilities, Autism and Neurodivergence (LDAN) BILL: Consultation



# Part 1: Reach and definitions: who should the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill include?

#### Who Should the Bill include?

A Bill has to set out who it will apply to and in what circumstances. This means our Bill has to say which groups of people it will apply to.

This is important because it sets out who can benefit from the Bill's provisions, and who can rely upon it to uphold their rights or seek redress for their rights being breached.

If the people included are not properly defined, the legislation won't be able to fully benefit the people it is intended for.

#### What can the LDAN Bill do?

There are 3 different potential approaches for this Bill.

#### Proposal 1: 'People who are Neurodiverse'/'Neurodiverse People'

There are differing schools of thought in academic literature about what 'neurodiversity', and 'neurodiverse' means.

We understand that it is, however, commonly accepted that 'neurodiversity' encompasses all of humanity, and does not mean 'neurological disability' or 'otherness'. 'Neurodiversity' describes a population, not individuals. A person cannot, therefore, be individually 'neurodiverse'.

If we use the term neurodiverse in the Bill then it may be too broad. It will cover the whole population including people who are not neurodivergent - 'neurotypical' people - so we don't think it is a good description to use in the Bill.

## Proposal 2: 'People who are Neurodivergent/'Neurodivergent People'

We understand that it is commonly accepted that 'neurodivergent' means having a mind that functions in different ways to the minds of the majority of people in society.

'Neurodivergent' and 'neurodivergence' are very broad terms that would allow us to capture a wide range of people within the Bill, including people with learning disabilities, people with learning difficulties such as people with dyslexia, dyspraxia and dyscalculia, autistic people and people with Down's Syndrome, Attention Deficit Hyperactive Disorder (ADHD), and Fetal Alcohol Spectrum Disorder (FASD). However, the term can also apply to people with acquired brain injuries.

We could also consider how to put some further definitions in the Bill around how we define "neurodivergent" to ensure that it does not become too wide.

Such an approach could allow us to define neurodivergence by reference to common barriers or behaviours faced or expressed by various groups. This would be similar to the approach taken by the Education (Additional Support for Learning) (Scotland) Act 2004, where a child or young person does not require a diagnosis to be able to receive support.

## Proposal 3: including specific conditions only in the Bill

We could take an approach that specifically names and defines populations of people in the Bill. This would increase the visibility of these groups and more clearly state who the Bill applies to for the benefit of those people, as well as for practitioners.

For example, we could choose to apply the Bill only to people with a learning disability and autism; add ADHD and FASD; or any combination of neurodivergent conditions. However, if a condition was not specifically listed and defined, then that population would be excluded.

The Bill could include a power that allows future changes to the Bill's definitions to be made by Regulations, as our understanding of neurodivergence and different conditions evolve. This means that, if certain conditions were left out of the initial Bill, they could potentially be added later, after the Bill has become law.

There is also a question about whether Down's Syndrome should be specified separately from broader learning disabilities – we understand that some people will support this and some will not.

#### What Do You Think?

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

We believe it's important to establish clear definitions from the outset to ensure that this Bill is effective and supports the people it was created to serve.

Of the members we spoke to, most supported Proposal 2. While Proposal 1's use of 'neurodiverse' has what some might perceive to be more positive connotations than 'neurodivergent,' it was also thought that 'neurodiverse' could be used to describe all people, perhaps unintentionally widening the application of the Bill.

#### Which of these proposals do you **not agree** with (if any), please tell us why?

While we agree that it would be useful to list specific conditions somewhere in the Bill, we feel Proposal 3 would more likely lean towards excluding people with lesser understood conditions who should be covered by the Bill.

## Is there anything else that we should consider in relation to this topic?

We seek more clarity on whether or not these definitions include self-identification, or if not, on what basis one would be defined as covered by this Bill.

#### Part 2: Overarching Themes

## **Section 2: Mandatory Training in the Public Sector**

One of the key themes we have heard through our scoping exercise, and from stakeholders and the Lived Experience Advisory Panel (LEAP), is that that there needs to be greater awareness, training on, and understanding of neurodivergent people and people with learning disabilities. In particular, there is a need for this when people are trying to access help, support and services and to exercise their rights.

Whilst there can be training options available to public sector professionals to help them to better understand and communicate with neurodivergent people and people with learning disabilities, undertaking this training is voluntary and is not necessarily developed or delivered by people with lived experience. This means that people who work in public services, such as in the National Health Service (NHS) or social care, the police and prisons, can choose to do training or not, if it is available to them. It is not consistent across different public services or delivered to a standard. It can vary in quality and effectiveness.

# What can the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill do?

Having access to staff in public services who are informed and able to understand and communicate with people effectively can make a significant difference:

- People are more likely to engage with services
- People are more likely to seek help and support at an early stage meaning crisis can potentially be avoided
- Staff will feel more confident in meeting needs successfully
- Early engagement with health and social care supports will allow a greater focus on prevention and reduce health inequalities

#### **Proposal 1: Mandatory Training for Public Services**

We want to consider how we make training mandatory for public facing staff in some public services.

In the first instance, we would like to consider implementing the same approach as in England, by placing a mandatory training requirement on health and social care staff.

However, we could also consider extending this to other public sector areas. For example, the justice system, which could include the police and prison staff, and in the education system for teachers and other educators.

Although the approach in England relates specifically to training on autism and learning disabilities, we could consider a broader approach for training to be inclusive of neurodivergence more generally, as well as learning disabilities.

As part of our approach to mandatory training we want to think about how people with lived experience should be involved.

#### What Do You Think?

## Do you agree with this proposal, please tell us why?

Mandatory training can be very useful when provided in the right context. It is particularly useful in raising awareness across what may be considered a varied workforce. We particularly support the design of such training by those with lived experience and would add that professional expertise can enhance this input. Helping a large population understand inclusive communications, for instance, is something that speech and language therapists are well trained to support, as many of their roles rely on coaching and modelling practices within multidisciplinary teams.

## Do you **not agree** with this proposal, please tell us why?

We do express concern, however, that mandatory training is used in this Bill as something that is seen to be done to address an already identified lack of awareness in the workforce without thinking about other approaches that might be more effective. We understand the importance of mandatory training but see there are significant limitations in this approach. Formal training in itself may be insufficient to facilitate behaviour change. We know from practice and research that the most effective models used by professions such as speech and language therapists incorporate coaching and modelling in context. While arguably everyone could benefit from greater awareness of the needs of neurodivergent people and people with learning disabilities, developing and implementing this widescale mandatory training programme may result in the content being more broadbrush and less impactful on certain areas of the workforce that need more support. It should be more about getting the right training for the right roles.

We are also concerned that this mandatory training would place too much emphasis on awareness rather than early identification and prevention, the latter two being critical areas that could really improve the lives of people covered by this Bill.

# Is there anything else that we should consider in relation to mandatory training?

Our initial thought is that mandatory training would be most beneficial in the justice system, but perhaps this is because there is such a low base line of understanding, even compared to health and social care settings. Should training like this be more targeted to settings that really need the support now? We don't want to see a mandatory training programme across vastly different public sector settings that becomes less effective the more you have to accommodate so much variance in application.

#### **Section 3: Inclusive Communications**

Inclusive communication means sharing and receiving information in a way that everybody can understand. For public authorities and people who provide support and services, it means making sure that they recognise that people understand and express themselves in different ways. For people who access support systems and services, it means getting information and expressing themselves in ways that meet their needs. Inclusive communication relates to all modes of communication: written information, online information, telephone, face to face.

Neurodivergent people and people with learning disabilities with communication support needs can face widespread exclusion and disadvantage. The use of inclusive communication is vital in order to allow people to know and exercise their rights, to live independently and to participate fully in life.

## What can the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill do?

The Bill could assist by providing a stronger focus on how public authorities' duties around inclusive communication can best be met for neurodivergent people and people with learning disabilities – potentially providing more specificity than the Human Rights Bill (recently consulted upon) and existing public sector duties. The provision of more accessible information links also to our proposals on training. Inclusive communication would inherently be a significant component of that training.

Although we focus on public bodies for the Bill, it will also be important to think about how we extend and promote inclusive communications to other organisations in the future. Some or all of the following could be explored further for possible inclusion in the Bill.

#### **Proposal 1: Alternative means of communication**

Provide for neurodivergent people and people with learning disabilities to request access to alternative means of communication where the offered means of communication will not work for them. This could mean being able to request an online or telephone meeting rather than face to face, or a telephone call instead of a letter, or other forms of communication.

It might also be appropriate for neurodivergent people, and people with learning disabilities, to be able to request access to a practitioner with specialist training in certain circumstances. For example, when accessing health care or when navigating the criminal justice system.

#### Proposal 2: Easy-read

Better access to easy-read versions of all public facing communications and documents made by public authorities. This could include a broad duty to make them available on request and an automatic duty to provide them in certain circumstances, such as:

- a duty on National Health Service (NHS) Boards and Health & Social Care Partnerships (HSCPs) to require appointment letters to automatically be produced in easy read; and
- a duty on the Scottish Police Service, the Scottish Courts and Tribunal Service and the Scottish Prison Service to automatically provide information to people in certain circumstances including when accused or convicted of a crime in an accessible way, including standard bail conditions.

There will be other circumstances too where an automatic duty would be important.

#### Proposal 3: Neurodivergent and learning disabilities strategies

Local and national strategies are discussed more fully in a previous section. If the Bill were to require local strategies to be produced, this could apply to local authorities, NHS Boards and integration authorities, and potentially other public bodies if appropriate. The Bill could provide the Scottish Government with power to direct what these strategies should cover and this could include how communication needs are met.

## Proposal 4: An enforceable Accessible Information Standard for Scotland

Whilst the Accessible Information Standard made under section 250 of the 2012 Act is not enforceable in Scotland, guidance sets out that it should be considered best practice in NHS Scotland organisations. The Bill could provide for an Accessible Information Standard to be enforceable in Scotland with requirements for its implementation and impact to be reviewed.

#### What Do You Think?

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

We were pleased to see inclusive communication mentioned so heavily throughout this consultation. RCSLT Scotland has campaigned for many years to embed inclusive communication practices within public services to benefit all people with a speech, language or communication need, including neurodivergent people and people with learning disabilities. We would encourage the definition of inclusive communication within this Bill to be in line with previous legislation passed by the Scottish Parliament:

"communicating in an inclusive way" means communicating in a way that ensures that individuals who have difficulty communicating (in relation to speech, language or otherwise) can receive information and express themselves in ways that best meet their needs (Good Food Nation (Scotland) Bill, 2022)

## Proposal 2: Easy Read

We agree with this proposal to increase access to easy-read documents. Speech and language therapists already work with public services to design and draft easy-read materials as required in some areas of Scotland. For this reason, we believe that there should be SLT-led development in this area, including deciding where and when automatic easy-read documents would be produced and distributed.

## Proposal 4: An enforceable Accessible Information Standard for Scotland

We agree that making an enforceable AIS in Scotland is a good idea, however, the shortcomings that have become apparent through its implementation in England need to be addressed in the development of Scotland's AIS (see below).

## Which of these proposals do you **not agree** with (if any), please tell us why?

In a broader point under inclusive communications, the Bill should allow neurodivergent people and people with learning disabilities to actively participate in communication regardless of their level of communication needs. This means more than just offering passive forms of communication, like receiving easy-read documents. Training around inclusive design is key, and SLTs and lived experience panel could greatly improve this. There are also great resources already freely available that support inclusive communication, including Communication Access UK (https://communication-access.co.uk/) – an initiative led by the Royal College of Speech and Language Therapists in partnership with a number of charities and organisations to improve the communication environment for people with communication difficulties.

## Proposal 2: Easy Read

Going back to the importance of definitions, we feel that for this proposal to be implemented properly, there needs to be an understanding across all public services of what makes a document easy-read. There needs to be quality assurance in the production of easy-read documents. Speech and language therapists have the expertise to do this but are limited by the capacity of their current roles within SLT services. Consistent professional oversight of drafting easy-read will be critical, and the best way we have found this works in practice is to integrate speech and language therapists in multi-disciplinary teams. This way, speech and language therapists can share best practice and provide oversight for other support colleagues in a way that is sustainable and provides maximum benefit to service users.

We would like further clarity on what circumstances will require automatic easy-read documents to be produced versus easy-read on request. We foresee there could be difficulties in raising awareness within the LDAN community of the fact that easy-read documents can be accessed on request. We want to empower people to access easy-read documents, but work needs to be done to get there.

Proposal 4: An enforceable Accessible Information Standard for Scotland

While RCSLT welcomes the introduction of an enforceable Accessible Information Standard in Scotland, we have identified some shortcomings, particularly in how the AIS is utilised in practice with people with a speech, language or communication need, since its implementation in England. These will need to be addressed from the outset to introduce an improved Standard for Scotland:

Key concerns with the AIS in England are:

- There is a duty on organisations providing NHS or adult social care to ask someone if they have a communication need which they may be unaware of or not wanting to disclose.
- Appropriate adjustments are often not made
- There is less focus on supporting communication and supporting people to express themselves; The AIS mainly focuses on adjustments to format.

#### Part 3: Specific Themes

This part of the consultation sets out specific themes that arose during our scoping work, and through our work with the LEAP.

# Section 1: Health and Wellbeing

Neurodivergent people and people with learning disabilities experience poorer health outcomes than the general population, which can be preventable, resulting in below average life expectancies and death caused by preventable conditions.

It is important that people with learning disabilities and neurodivergent people have good health outcomes in order to access their rights and be able to participate fully in life. Poor health creates an additional barrier for neurodivergent people and people with learning disabilities, potentially limiting or impacting their ability to be active in their communities, access employment or maintain relationships.

#### What can the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill do?

The Bill can help to create the right conditions for people with learning disabilities and neurodivergent people to access supports and services successfully when they need them, helping to prevent illness and improving overall health and wellbeing.

#### **Proposal 1: Neurodivergent and Learning Disabilities Strategies**

We are proposing legislative requirements for national and local strategies in future and we could set out what the strategies must include. For example, in relation to health care, we could ask Health Boards, Integration Authorities and Local Authorities to set out in their local strategies how their workforce planning and service planning has taken into account the needs of the neurodivergent and learning disability populations.

#### Proposal 2: Mandatory training for the health and social care workforce

We have set out proposals around mandatory training. In England, the UK Government has introduced a new legal requirement for all health and social care services registered with the Care Quality Commission (CQC) to provide employees with training appropriate to their role on learning disabilities and autism. In England, this is called the Oliver McGowan Training.

We propose to legislate for a similar training requirement for health and social care in Scotland in the LDAN Bill. However, we could take a wider approach so that the mandatory training focusses on learning disabilities and neurodivergence - not just learning disabilities and autism.

## **Proposal 3: Inclusive communications and Accessibility**

We have set out proposals on inclusive communications and this will impact on healthcare. We propose to legislate for neurodivergent people and people with learning disabilities to be able to request access to alternative means of communication where the offered means of communication is not suitable work for them. We also propose better access to easy-read versions of public facing communications and documents. This could include a broad duty to make them available on request as well as an automatic duty to provide them in certain circumstances, such as a duty on National Health Service (NHS) Boards and Health and Social Care Partnerships (HSCPs) to require appointment letters to automatically be produced in easy read.

In addition, we also propose legislating for an Accessible Information Standard for Scotland which would be applicable to NHS Scotland organisations.

We also plan to do more work to look at how far existing complaints systems meet the needs of neurodivergent people and people with learning disabilities.

## **Proposal 4: Patient Passports**

We could place a duty on Health Boards, HSCPs and Local Authorities to ensure that a person's "passport" is able to follow them through whichever care pathways they are accessing, such as a hospital or care home admission, and that these passports include important information about their needs and preferences, including how to communicate with them in an accessible way. This could be similar to Advance Statements that can be used by people with mental health conditions, or it could be based on Promoting a More Inclusive Society (PAMIS)'s Digital Passports.

Passports like these help medical professionals to know how best to support people, their preferred treatments or communication styles, and can reduce barriers and frustration when people have to repeatedly restate their needs. There is currently no statutory duty placed on patient passports and, although they are encouraged as best practice, implementation is inconsistent.

#### **Proposal 5: Annual Health Checks**

We are currently rolling out annual health checks for people with learning disabilities across Scotland. A health check will be offered to everyone who is eligible by end March 2024, backed by £2m of funding per year. Given the really good evidence of significantly poorer health outcomes of people with learning disabilities, annual health checks will make a big difference. We propose to include the delivery of annual health checks as a specific legal duty in the Bill.

Autistic people, people with Fetal Alcohol Syndrome Disorder (FASD) and Attention Deficit Hyperactive Disorder (ADHD) also have poorer physical health outcomes and/ or a lower life expectancy than the general population. There are many possible reasons for this gap, including poor professional understanding among health and care staff, which can result in these groups people having signs of illness or their needs overlooked. Without the right understanding, these groups can miss out on adjustments needed for them to engage in medical appointments which can lead to distressing experiences and avoiding seeking advice. We could include a duty in the Bill which, in effect, extends the current annual health checks for people with learning disabilities to autistic people. We could also consider extending this to people with FASD and ADHD. We would want to first gather more evidence of the need for this.

#### What Do You Think?

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

Proposal 4: Patient Passports

We support the use of patient passports. This reflects the aims of RCSLT's Five Good Communication Standards (<a href="https://www.rcslt.org/wp-content/uploads/media/Project/RCSLT/good-comm-standards.pdf">https://www.rcslt.org/wp-content/uploads/media/Project/RCSLT/good-comm-standards.pdf</a>), which advocate for communication passports that helps all health professionals understand an individual's communication needs and the support they may require.

We do have concerns, however, about equal implementation of these passports across all health boards. Our members have noted some health boards insist there is a legal basis to block passports from being used, including similar schemes such as ReSPECT. In order for the patient passports in this Bill to be truly effective, the Scottish Government will need to ensure that they will be accepted and used in all health boards.

#### Section 10: Justice

Although there is a lack of robust data, there are indications that people with learning disabilities and neurodivergent people may be over-represented in the criminal justice system and that their needs can be unidentified and unmet. This can be because of inaccessible information, lack of knowledge and lack of a reliable method of identifying people with vulnerabilities.

# What can the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill do?

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. Some of those changes are broad and not specifically adapted for neurodivergence and learning disabilities but trauma focused work is a key theme that can be built upon for these groups.

We think that there is merit in exploring the extent to which the Bill could seek to improve the position for a neurodivergent person or person with learning disabilities interacting with the justice system in the following ways.

#### Proposal 1: Strategies and a co-ordinated approach

We could consider bringing together a single national strategy that deals with neurodivergence and learning disabilities in the civil and criminal justice systems. There are many complex interactions between different parts of the justice system that would benefit from this approach and allow a clear set of priorities to be developed reflecting the other proposals below.

# Proposal 2: Data and the identification of neurodivergent people and people with learning disabilities in the justice system

It is a critical requirement to ensure that neurodivergent individuals and people with learning disabilities and their needs can be appropriately identified at key points of contact with the justice system. This is to ensure that:

- The right kind of communication is used and it is adapted for neurodivergent people and people with learning disabilities;
- Any additional impact of a situation, for example admittance to custody is understood and appropriate adjustments made such as to the physical custody environment;
- Additional supports are provided, such as an Appropriate Adult in criminal justice and access to independent advocacy;
- Appropriate information is fed into key decision points in the justice system to help provide more accurate future data.

At present the onus in the criminal justice system is often on individual police officers to recognise and flag up any additional needs. We want to consider how best to ensure that neurodivergence and learning disabilities are better identified at relevant points and by relevant staff.

The Bill could potentially place a duty on public bodies such as the Police, Crown Office and Procurator Fiscal Service (COPFS), and the Scottish Prison Service to seek to identify neurodivergence and learning disabilities when people are coming into contact with the criminal justice system. This could apply at key points such as:

- When a victim or witness comes forward
- When someone is arrested and brought into custody
- When someone is sentenced
- When someone is admitted to prison to begin a sentence

This is not about diagnosis - it is about identifying the need for support.

It may also be possible to investigate whether a common screening tool across criminal justice agencies could help.

## **Proposal 3: inclusive communication**

Inclusive communication is critical for neurodivergent people and people with learning disabilities and we have set out broad proposals around this in the overarching themes. Those in contact with the criminal and civil justice systems need to be able to fully understand the information they are being given whether they are a victim, witness, party or potential offender. If information is not accessible this can result in people being either unaware of their rights or unaware that they are at risk of breaching standard or special bail conditions. The approach we have set out earlier in this consultation on inclusive communications proposes:

- Better access to easy-read versions of public facing communications and documents made by public authorities. This could include a broad duty to make them available on request and an automatic duty to provide them in certain circumstances. For example, a duty on the Police, the Scottish Courts and Tribunal Service and the Scottish Prison Service to provide information to people accused or convicted of a crime in an accessible way, including standard bail conditions.
- Provide for neurodivergent people and people with learning disabilities to request access to alternative means of communication where the offered means of communication will not work for them. This could mean being able to ask for an online meeting rather than face to face or a telephone call instead of a letter.

#### **Proposal 4: Mandatory Training**

Proposals in relation to mandatory training are set out in the overarching themes section. We propose that the Bill provides for training on neurodivergence and learning disabilities to become mandatory for health and social care staff, and we are seeking views on whether this should be extended to other public bodies.

We could therefore consider extending the requirement for mandatory training to police, prison, COPFS and relevant courts and tribunals staff. We think that mandatory training for staff in the civil and criminal justice systems is a key element to support better identification of needs, better support and improved communications. We know that not all staff will need this but public facing staff would, and we could consider how to define this in the Bill for new and existing staff.

#### **Proposal 5: Advocacy**

We have set out our proposals on advocacy in the overarching themes section. There is currently work going on across the Scottish Government to consider a consistent approach to advocacy and this includes neurodivergent people and people with learning disabilities. We do not want to take anything forward separately on advocacy that is not informed by this work. If necessary, and if this work is not concluded, we could consider the Bill conferring a power that would enable the Scottish Ministers to make any necessary regulations on independent advocacy for neurodivergent people and people with learning disabilities, should this be required.

In addition, mandatory training could include information about the role and availability of advocacy in the civil and criminal justice systems as well as information about the Appropriate Adults scheme.

## **Proposal 6: Diversion from Prosecution (DfP)**

As with others, neurodivergent people and people with learning disabilities may benefit from the use of DfP where they are alleged to have committed offences. Better identification within the justice system and training for staff to understand how to do this could help. A requirement to identify needs should allow better information to be provided by the Police to COPFS in the Standard Prosecution Report (SPR). The SPR is the basis on which COPFS can make a decision about DfP. This will also help local authorities when they complete their DfP assessment as they would need to take this into account.

Training and awareness raising provided to professionals working in COPFS on neurodivergence and learning disabilities, how it impacts on people's lives, and how it can have an influence on offending behaviour could help with increasing consistency of decisions around DfP for these groups. This training could include the role of support in reducing the likelihood of re-offending.

#### What Do You Think?

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

Proposal 3: inclusive communication

Our research shows that at least 60% of young people who come into contact with the justice system have a speech, language or communication need, demonstrating how needed inclusive communication is to this particular population. We agree with this proposal to expand duties on relevant justice settings to adopt inclusive communication practices. We also note that rehabilitation programmes are often heavily language-based, further necessitating this inclusive communication approach.

Proposal 4: mandatory training

We agree with this proposal to extend the requirement for mandatory training to police, prison, COPFS and relevant courts and tribunals staff as there is a clear need to upskill this workforce for the anticipated high level of need in this population.