

**Sight Scotland**

Call for views: Consultation on the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill

April 2024

**About Sight Scotland**

At Sight Scotland we’re tackling vision loss together. Our mission is to reach everyone in Scotland with sight loss – where and when they need us. We are here for everyone affected by vision loss in Scotland. We offer support and advice, campaign for equal rights and fund medical research.  We provide learning, care, accessible formats and support blind and partially sighted people in their communities.

Our services include The Royal Blind School and education outreach services in mainstream schools, residential care for children and adults, the provision of formats which enable equal access to the written word for people with sight loss, emotional support and information to anyone living with or impacted by sight loss through our support line and community service, and expert rehabilitation and mobility training to enable people to regain independence after sight loss.

To get free support you can call Sight Scotland on 0800 024 8973. You can also get in touch by emailing us at help@sightscotland.org.uk, or by visiting our website Sightscotland.org.uk.

**Sight Scotland's response to the Consultation on the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill**

**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 can see benefits within proposals 2 and 3.

Proposal 2 allows for a wide range of people to be included by the legislation - reflective of the wide range of learning difficulties and learning disabilities, in line with the social model of disability. There is a concern that reference to specific conditions within the Bill could mean the Bill covers only those with a diagnosis and medical terminology. This has the potential to exclude people not specifically defined, undermining the social model of disability.

While the argument can be made that listing specific conditions is too narrow an approach and could risk people being excluded from the provisions and rights stipulated in the legislation, proposal 3 gives explicit recognition of groups of people who have often been overlooked, meaning their needs related to their specific condition can be better included.

A focus on neurodivergence could mean training provided is too generalised and not detailed enough to specific conditions. Neurodivergence is not a term that that people with learning disabilities and not all autistic people identify with or are familiar with. We therefore support calls for learning disabilities and autism to remain within the title of the Bill.

While the need for a formal diagnosis should not be a barrier to accessing support and exercising rights, often in the current policy landscape (despite moves to implementing the Social Model of Disability), a formal diagnosis is necessary to access support. We believe it is vital that major improvements are made to the diagnostic path to reduce waiting times so that people can receive a formal diagnosis in a timely manner. This is especially true for people seeking a diagnosis later in life. A whole systems approach must be adopted to avoid scenarios where a person would be covered by the Bill under the definitions set out in proposal 2 but would be excluded from accessing services due to needing a formal diagnosis.

The differing definitions of 'learning disability' is concerning and we advocate for a consistent approach to be adopted that reflects present views of how people identify. It is important to consider that each person is different, even if they have the same condition.

The report ‘What Are Learning Disabilities? How Common Are Learning Disabilities? Sally-Ann Cooper, Angela Henderson, Myrthe Jacobs, Elita Smiley Scottish Learning Disabilities Observatory, 29.2.16’ notes “there are several definitions of learning disabilities, and some definitions require the person to have an intelligence quotient less than 70” and “when a

person has a clear genetic cause for their learning disabilities such as Down syndrome, they are unique from all other persons with Down syndrome.”

Including definitions of learning disability, autism, and neurodivergence within the Bill will foster visibility and inclusivity through affirmative identification. We agree with Down Syndrome Scotland’s position that there should be explicit acknowledgment of individuals with Down Syndrome and those with profound and multiple learning disabilities (PMLD). Each individual's experiences are unique and this must be clearly set out.

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

Proposal 1.

We feel this does not meet the aims of the Bill and who it is intended to apply to.

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

It is important to note that many people can have a learning disabilities and/or be neurodivergent have visual impairment. Evidence shows people with autism and learning disabilities are significantly more likely to develop a sensory impairment. The Foundation for People with Learning Disabilities stated that around 1 in 3 people with a learning disability also have a sensory impairment, with many of these going undiagnosed.

The Bill should be designed to support people with learning disabilities who also have sensory impairments – particularly given the high incidence rates of Deafness, Deafblindness and Visual Impairment amongst people who have learning disabilities.

We echo the recommend by the ALLIANCE that that the Bill mentions that the term “Sensory Loss” is not acceptable to everyone who is Deaf, Deafblind, or who have Visual Impairment. This should be adhered to ensure the language used is reflective of people’s preferences.

The estimated number of People with Learning Disabilities in the population with Visual Impairment (excluding blindness) in Scotland by 2026 is set to be 8,493. With blindness is 1,181. Source: "The Estimated Prevalence of Visual Impairment among People with Learning Disabilities in the UK" Eric Emerson & Janet Robertson.

In the report ‘Prevalence of mental health conditions, sensory impairments and physical disability in people with co-occurring intellectual disabilities and autism compared with other people: a cross-sectional total population study in Scotland’ 2020, Kirsty Dunn, Ewelina Rydzewska, Michael Fleming, Sally-Ann Cooper found, "with regards to sensory impairments, of the 36 matched youth with intellectual disabilities with and without autism, 38.9% with autism reported having visual problems compared with 50.0% without autism" and "an intellectual disabilities register study reported that 95 of the 368 (25.8%) adults with intellectual disabilities who had visual impairment also had markers for autism, compared with 422 of 2674 (16%) of those who had normal vision" and "46 of the 60 (76.7%) of the adults with intellectual disabilities and congenital blindness also had markers for autism compared with only 36 of the 67 (53.7%) with normal vision."

Moreover, people with learning disabilities are 10 times more likely to have serious sight problems than other people and are at greater risk of developing dementia at a younger age, particularly people with Down’s Syndrome. Source: Alzheimer’s Society (2020c). “This is me”. London: Alzheimer’s Society. Available from: www.alzheimers.org.uk/thisisme (Accessed 7/5/20) and Barnett, K. Mercer, S.W., Norbury, M., Watt, G., Wyke, S., & Guthrie, B. (2012). Epidemiology of multimorbidity and implications for health care, research and medical education: A cross sectional study. “The Lancet”, 380(9836), 37-432.

This must therefore be considered in the Bill, especially with regards to inclusive communication, education and transition (discussed later in this response). Intersectionality and consideration of comorbidities is key to view a person as whole and how multiple conditions may impact them.

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# **Part 2: Overarching Themes**

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## **Section 1: Statutory Strategies for Neurodivergence and Learning Disabilities**

The Scottish Government has previously produced national strategies on learning disability and separately on autism.  Following the COVID pandemic, a joint plan produced in partnership with Convention of Scottish Local Authorities (COSLA) was published covering both learning disabilities and autism – the *Towards Transformation* Plan.  The Scottish Government continues to work to this plan pending decisions on the shape and content of the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill.

Scottish Government strategies are scrutinised by the Scottish Parliament and stakeholders. There is currently no formal or legislative requirement for either national or local strategies specifically for neurodivergent conditions or learning disabilities.

**What can the LDAN Bill do?**

The Scottish Government is proposing to take a broad approach covering neurodivergence and learning disabilities.

We recognise that approaches to previous strategies and polices have been single condition focussed even although many people have more than one condition.  Although there will always be a need for some distinct policies according to certain conditions, we think a wider neurodivergent approach is more appropriate in terms of recognising the whole person rather than single conditions and recognising the crossover in the way services and supports are delivered. This includes the workforce delivering them.

There should also be a clear recognition that neurodivergent people and people with learning disabilities should be treated equally whatever condition or combination of conditions they have.

**Proposal 1**: Introduce a requirement for a national strategy on neurodivergence and learning disabilities to be produced by the Scottish Government.

**Proposal 2**: Introduce a requirement for local strategies to be produced by some public bodies, for example health and social care partnerships, local authorities, and other public bodies.

**Proposal 3**: Introduce guidance that could cover a range of topics to be included in national and local strategies.

**Proposal 4**: Ensure that there is a requirement to review strategies, for example every 5 years for example.

**Proposal 5**: Ensure that people with lived experience have to be involved in the development of the strategies.

**Proposal 6**: Consider whether any new accountability mechanism introduced by the Bill should have a duty to review national and/or local strategies and their effectiveness.

**What Do You Think?**

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

We agree with Proposals 1-6.

A national strategy is key to coordinate specific strategies already in place. A cohesive framework is needed to uphold the actions of local and condition specific strategies to tie these together, building on existing work in this area. This would ensure a more joined-up approach compared to separate strategies. A national strategy would also be an opportunity to establish clear priorities and outcomes to be achieved. Furthermore, a national strategy would promote awareness and understanding of neurodiversity among policymakers, educators, employers, and the general public. This increased awareness can help reduce stigma and discrimination, leading to a more inclusive and supportive society for individuals with neurodivergent conditions and learning disabilities.

Local strategies informed by a national strategy can help to deliver the priorities and outcomes intended to uphold the rights of neurodivergent and those with learning disabilities in their communities. Local contexts are important as needs can vary across Scotland. This way public bodies can tailor their approach to address specific needs in that area, delivering services and support matched to people’s needs.

Development of strategies must be led by people with lived experience. This participatory approach can ensure that the strategies are truly responsive and meet the specific needs of these communities. There is also scope to share best practices between local authorities and health boards.

We welcome guidance to accompany national and local strategies. This should include guidance on how visual impairment, can impact a person with a learning disability and/or is neurodivergent. This should be informed by the Scottish Government’s See Hear strategy.

An accountability mechanism would provide an opportunity to monitor and evaluate the implementation of national and local strategies and highlight areas in need of improvement and best practice. This would enable policy makers to make informed decisions about adjustments or enhancements to the strategy to better meet the needs of people with learning disabilities and/or neurodivergent. Accountability mechanisms also help to ensure transparency and accountability in national government and local government actions.

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

N/A

**Is there anything else that we should consider in relation to strategies?**

We note the commonly reported gap between policy and practice so there must be accountability to ensure strategies are implemented to achieve real life outcomes.

There has been many strategies over the years, including Keys to Life, A Fairer Scotland for Disabled People, with an Employment Action Plan, The Scottish Strategy for Autism, the Learning/intellectual disability and autism: transformation plan; Scottish Autism strategy; the Learning/Intellectual Disability and Autism Towards Transformation Plan, yet criticisms have been made that little action or positive change has resulted from these initiatives. There is a lack of detail as to how these actions have helped to achieve equality between disabled and non-disabled people. As the ALLIANCE highlights, the UNCRPD Shadow report, found that many of these actions were output led rather than outcome led.

Finally, we strongly believe the LDAN Bill has to take an intersectional approach. Existing and past siloed strategies don’t reflect the reality of many people with learning disabilities, autism and neurodivergence – failing to recognise the role and impact of gender, race, age, other disabilities including visual impairment.

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## **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?**

Sight Scotland agrees with this proposal to make training mandatory for public facing staff in some public services and believe this should extend to other public sector areas.

This is important to ensure consistency of treatment, staff knowledge and service user expectations when they engage with public sector services/functions. More detail is needed to set out how the training will be delivered, who will deliver it (including using the skills of professionals in the third sector), and how this will be funded in the financial memorandum, and how this training will be accredited and it’s quality is assured.

Opportunities for continuous development are important too to embed the culture of greater awareness.

We discuss further other comments regarding mandatory training and visual impairment.

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

N/A

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

Greater awareness and meaningful understanding of learning disabilities and neurodivergence is essential to ensure people's rights are upheld. It is important autism specific issues are not neglected. We note the roll out of the Autism Training Framework and would recommend good practice approaches from this are replicated and poor practices are avoided in future mandatory training.

Guidance should be provided on how other disabilities, such as visual impairment, can impact a person with a learning disability and/or is neurodivergent and this should be included in any training. The Scottish Government’s See Hear Strategy highlights that greater staff awareness of people with visual impairment having the appropriate and necessary skills to respond to these needs can “not only identify needs relating to sensory impairment, but also assess and provide simple solutions”. This includes understanding a person’s communication preferences and requirements. People with visual impairment should lead and inform this training.

Mandatory training must cover visual impairment awareness. The ALLIANCE found in its research that 46% of respondents saw this as one of the most important issues they wanted to see addressed. This was the second most important issue on health and social care provision according to disabled people.

**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 strongly agree with Proposals 1-4.

Proposal 1: Alternative means of communication.

It is essential that people are asked from their outset what their communication preferences are and that this is adhered to. This includes if communication needs to be sent in braille, large print, colour contrast and/or audio.

We echo the point by Down Syndrome Scotland that it shouldn’t be an expectation on the individual to request an alternative method of communication, rather public bodies should ask what a person’s communication needs and preferences are. This is in line with the

Equality Act. We also support the idea of a ‘Communication Passport’.

Proposal 2: Easy-read.

We agree with this and advocate for these to be provided in large print. It should be noted that the use of images in easy-read files (especially in PDF format) are not compatible with screen readers. Efforts must be made to ensure there is accurate image descriptions accompanying all images used and documents are made available in word formats as these are more accessible that PDF files.

Proposal 3: Neurodivergent and learning disabilities strategies.

We agree with this.

Proposal 4: An enforceable Accessible Information Standard for Scotland.

We strongly advocate for a statutory obligation to provide for an Accessible Information Standard to be enforceable in Scotland. Accessible communications is vital to ensure people with visual impairment can access information - especially issues pertaining to their personal circumstances and health - in a way they can understand and comprehend.

This is reinforced by article 9 of the Convention on the Rights of Persons with Disabilities (CRPD) on the right to accessibility of the physical environment, transportation, information and communication, and services open to the public. A legal duty should apply to not only the NHS but other public and voluntary sector bodies involved in supporting

people with learning disabilities, autism and neurodivergence. We’d like to see this duty go beyond this audience and be a standard all public bodies must follow. More proactive approaches should be taken to provide information in alternative formats as standard practice without a person having to requests this. We elaborate on this below.

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

Sight Scotland echoes the view of the ALLIANCE that Easy Read alone does not equate to inclusive information. It is simply one format of inclusive information.

**Is there anything else that we should consider in relation to accessible information?**

Proposal 4: An enforceable Accessible Information Standard for Scotland.

We note the point raised in the consultation paper that it refers to "a culture where inclusive communication and accessible information is considered the norm, thought about proactively by public authorities, and provided automatically in reasonable circumstances without the need to request" We echo this sentiment and call for this to be included in the mandatory training proposals, as well as public awareness campaigns, so embed this approach so that asking about someone's communication preference is automatic from the outset. A statutory duty would help to reinforce this message.

## **Section 4: 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.

It is important that the population of neurodivergent people and people with learning disabilities are visible in topic specific data collections where these are of particular interest, for example, employment data.

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

In order to achieve the desired outcomes, organisations often need to link different pieces of data to paint a full picture. However, a barrier to being able to do this is that there needs to be a legal basis for some types of data to be collected, including personal data. The Bill could provide an opportunity for data to be collected in particular circumstances if that would be beneficial to neurodivergent people and people with learning disabilities.

**Proposal 1: Developing a commission(er) with responsibility for data collation**

Within the section entitled “Accountability”, there is discussion on the possible creation of a new Commission or Commissioner, or adding to the remit and powers of an existing body. If a Commission or Commissioner (or other relevant accountability model) is created, their functions could include responsibilities for collecting and analysing data on neurodivergent people, and people with learning disabilities.

Additionally a body could have powers to make recommendations to other organisations collecting data to disaggregate their data to the level of neurodivergent people, and people with learning disabilities.

There are some other options that would need to be developed further, however, to help us with this, we would like to know your views on the following:

**Proposal 2:** Placing duties on some relevant public bodies to collect data on neurodivergent people and people with learning disabilities where this would be helpful for better understanding of the needs of these groups, their experiences, informing service design and improvement, and to allow for evaluation of measures to improve outcomes for these groups.

**Proposal 3:** Placing duties on some relevant public bodies to provide returns to the Scottish Government regarding local data on people with learning disabilities and neurodivergent people, where this would be helpful for better understanding of the needs of these groups, their experiences, informing service design and improvement, and to allow for evaluation of measures to improve outcomes for these groups.

**Proposal 4:** Consideration of the development of a Scottish version of the Learning Disability Mortality Review (LeDeR) programme. This helps reduce inequalities in care for people with a learning disability. It could reduce the number of people dying sooner than they should.

**What Do You Think?**

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

Proposal 1: Developing a commission(er) with responsibility for data collation.

We agree. Consideration must be made to the current Bill proposed by Jeremy Balfour MSP to create the post of a Disability Commissioner for Scotland. If this Bill is successful thought must be given as to how the Commissioner would collaborate and ensure responsibilities are clearly defined and not replicated.

Proposal 2.

We agree with this proposal, but would make this a requirement, not only “where this would be helpful.”

Proposal 3.

We agree with this proposal, but would make this a requirement, not only “where this would be helpful.”

These proposals (2 and 3) would help to fill the gap of the lack of available data to evidence and measure the outcomes of current initiative to uphold the rights and support people with learning disabilities and/or who are neurodivergent. The collection of reliable and long term data will inform future policy design and planning, including service delivery. Autism or autistic people must be explicitly referenced and included within this section of the LDAN Bill.

We agree with LEAP that "current data collection and analysis should involve people with lived experience and include looking at intersectionality". We call for this to included people with visual impairments.

We argue that all public bodies should have to collect data and provide returns. The data collected must be available to the people it is about. They should be informed as to the purpose of the data collection and how this will be used.

Proposal 4. LeDeR

We believe this would help to understand where grievances and poor practice has occurred, increasing accountability. This builds on existing work by PAMIS to establish, as practice, a review of someone with profound and multiple learning disabilities (PMLD) death. We would suggest that LeDEr is not limited to assessing a person’s life upon their death, but also during regular intervals during their life. This would help to ensure the person is able to provide their own feedback about their life and is an opportunity to highlight issues of concern.

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

N/A

**Is there anything else that we should consider in relation to data?**

Disaggregated data and intersectional analysis is essential. The analysis of this data should help to better inform policies and practices to deliver the best support and uphold people’s rights. Intersectional data helps to understand a person as a whole and how they experience the world. Too often equalities data is collected under each protected characteristic. This does not provide an accurate or full picture of how a person’s characteristics interact and influence each other and how society responds.

As such, it should be noted that data on the number of people who are sight impaired or severely sight impaired is not collected nationally. Establishing a commission(er) with responsibility for data collation could be an opportunity to develop data collection on sight loss and visual impairment, alongside data on neurodivergent people, and people with learning disabilities.

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# **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.

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## **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?**

Sight Scotland agrees with proposals 1-5.

We are supportive of initiatives to create conditions for people with learning disabilities and neurodivergent people to access support and services when they need them, helping to prevent illness and improving overall health and wellbeing.

We note there are already Scottish Government initiatives and policies in place aimed at improving the lives, health and wellbeing of people with learning disabilities, autism and/or who are neurodivergent. The proposal suggested must be implemented and we would go further to call for this to intersect with other areas of healthcare. In the context of eye healthcare and visual impairment, it is important to ensure services are joined up with efficient referral pathways. Early identification and intervention can lead to better outcomes, as it allows for timely support and guidance tailored to the individual's needs.

As discussed previously in our response, inclusive communications is paramount.

We support the use of Promoting a More Inclusive Society (PAMIS)’s Digital Passports and agree these should be used as a template for the development of the Scottish Government’s Patient Passports. Feedback and evidence has found these to be highly regarded by users. These set out the full needs of a person and the person is the driver of the information that is included, providing them agency over their health, wellbeing, support and care. It is a useful tool for practitioners to best understand how to engage appropriately with someone with learning disabilities. This further promotes inclusive communication detailing how a person would prefer to be communicated with. It could act as a first point of reference for someone to learn about the passport holder’s health, care and support needs. Moreover, a digital version of the passport would allow for records to be updated more easily and shared with multiple practitioners and healthcare professionals when necessary.

We are encouraged by the annual health check roll out across Scotland. There must be greater efforts to ensure those who are eligible are aware of their entitlement to this and the benefits of this. We call for the annual health check to include an eye health care assessment (on top of the universal right to a free eye health check) given the prevalence of sensory impairment of people with autism and/or learning disabilities.

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

N/A

**Is there anything else that we should consider in relation to health and wellbeing?**

Being born a visual impairment or developing an eye condition later in life can result in different outcomes of how health inequalities can manifest and lead to disparities in overall health and well-being. This is especially acute when interacted with learning disabilities, PLMD, autism and/or being neurodivergent.

Feelings of isolation, depression, and anxiety are common among those with visual impairments due to reduced social interactions and restricted opportunities. Through our own research we found 90% of respondents had some experience of loneliness. The survey indicated causes of loneliness which result specifically from vision impairment.

Accessing information about health and wellbeing is vital so that someone can receive support. Yet, people with visual impairment can often have a negative experience of this. For example, sending letters in small print meaning a patient can’t read an appointment letter. They are then left with no option to ask someone to read it on their behalf, compromising their confidentiality.

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## **Section 8: Employment**

Employment can help people to feel valued and contribute to more independent living. While employment should not be seen as the only option to be a valued member of society, opportunities and choices to work are important for everyone.

The Scottish Government is focused on supporting those furthest from the labour market to progress towards, enter, and sustain employment. We are committed to high quality, fair and inclusive work and employability support.  However, we know that many neurodivergent people and people with learning disabilities continue to face barriers to employment.

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

Disabled people face some of the most persistent labour market barriers, which is why we have committed to at least halve the disability employment gap by 2038. We agree that more needs to be done to support people with learning disabilities and neurodivergent people to access fair and sustainable employment, particularly in light of the available data which suggests these groups achieve some of the poorest labour market outcomes, even compared to wider disability groups.

**However, given the work that is currently ongoing, and our limitations on changing the law in this area, we are not currently proposing any legislative changes.**Instead, we intend to explore the following in order to promote and encouraging more inclusive approaches:

* Under our Fair Work First approach, the recipients of public sector grants and contracts can be challenged in new ways to work towards meeting the Fair Work First principles. This includes taking action to create a more diverse and inclusive workplace. We can highlight to employers that it is best practice to ensure they undertake disability equality training, including more specialist training for line managers on individual impairments, such as neurodivergence and learning disabilities, where this would enable appropriate support and reasonable adjustments to be provided to staff.
* Training for job coaches on neurodivergence and learning disabilities in the workplace: we are taking forward the Review of Supported Employment within Scotland (2021), which recommended that work continues to support the professionalisation of the supported employment workforce, including ensuring it is well equipped to provide appropriate support to people with learning disabilities and neurodivergent people.
* We will review the language within impairment level (employability) data that the Scottish Government collects on employability to ensure it is consistent with the language individuals and professionals use.

**What Do You Think?**

**Do you agree with this approach?  Please tell us why?**

While it has been stated legislative changes cannot be made, we remain concerned these proposals do not go far enough to address the underlying causes of unemployment rates of neurodivergent people, people with autism and people with learning disabilities.

The ALLIANCE points out that a reason for the disability employment gap stems from discrimination and stigma. For people with learning disabilities, autism and neurodivergence who experience sight loss it is often feedback that employers don’t know how to best support them with their communication preferences or what adaptions can be made. As such, encouraging and recommending actions under the Fair Work First principles is positive, but without enforcement and accountability, the process to close the unemployment gap will take longer. Specialist, mandatory and continuous training is essential, and we believe should be a requirement for all employees.

Further uptake of the Disability Confident employer scheme, BASE and the PSP would encourage and support other organisations to recruit and retain disabled people and those with health conditions. While the Disability Confident employer scheme is a UK Government scheme, the Scottish Government should assess how it can encourage more employers in Scotland to sign up to the Disability Confident employer scheme and any additional actions which can be taken to support the scheme. This includes further promotion of the Scottish Union of Supported Employment (SUSE), the lead partner in the Disability Employment Gap Public Social Partnership (PSP), to get more organisations to take up the training on offer. Renewed efforts are needed to support employers who are willing, but perhaps unsure, to make changes to their employment practices.

Having a disability or disabilities should not be a barrier to accessing quality work, skills development, career progression or fulfilment at work, yet disabled people are more likely than non-disabled people to be unemployed or in low paid work. It is also important to consider the intersecting characteristics of those furthest from the job market. We need more data to determine how different characteristics impact each other, e.g. someone with sight loss who is also a lone parent, and therefore what actions need to be taken to create equal opportunities for employment in varying circumstances. Developing Scotland’s Fair Work policy and implementing current Fair Work commitments should be informed by timely data on Fair Work which reflects the changes caused by the pandemic.

Retention and adaptations in the workplace are areas where more action is needed to ensure fair work across all sectors. Although some employers have good competence around what adaptations or changes can be made to include disabled people in the workplace, there are knowledge gaps and/or misconceptions about what structural changes are needed.

Attitude change towards hiring and supporting persons with disabilities should also be considered. Employers generally report positive attitudes towards persons with disabilities, but this doesn’t always translate into practice. One reason for reluctance can be the associated cost of adapting the workplace, but with an increase in home working because of the pandemic, employers are realising how being flexible in work location is beneficial to both them and their employees. Studies have shown that employers have reported multiple benefits from accommodating workers with disabilities, including retaining qualified employees, avoiding costs associated with hiring and training new employees, and increased business profitability/efficiency. Despite this, more needs to be done to expand support Fair Work practices among employers who may not see this as a priority right now.

## **Section 13: Education**

This section relates to children and young people in early years, primary and secondary school education settings. Higher and Further Education and University education is considered within the scope of another section of the consultation, called Children and Young People -Transitions to Adulthood.

Neurodivergent children and young people, and children and young people with learning disabilities should be able to reach their full potential and live happy and fulfilling lives. Without the right learning experiences and support, these children and young people are likely to be disadvantaged, their quality of life adversely affected and their aspirations unreached. This can be particularly felt by children and young people with profound and multiple learning disabilities for whom specialist education is the most appropriate option.

Neurodivergent children and young people, and children and young people with learning disabilities, their families, and organisations that represent them have consistently raised concerns that these groups are not having their right to education fulfilled and are missing out on reaching their full potential, which may contribute to poorer outcomes in adult life.

In Scotland, the education system aims to be fully inclusive. There is a legal presumption that children will be educated in mainstream schools except for in exceptional circumstances.

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

An independent review of additional support for learning legislation found that the legislation is not deficient. However, it found a gap between the policy intention of the legislation and its implementation. Since then, a Additional Support for Learning (ASL) Review Action Plan has, and is currently being, progressed. This work is being done in partnership with Convention of Scottish Local Authorities (COSLA) and the Association of Directors of Education in Scotland (ADES).  Whilst there is a comprehensive and robust action plan in place to address the implementation gap, the following proposals could potentially be explored in relation to the Bill:

**Proposal 1: Strategies and reporting requirements**

The 2000 Act imposes duties on education authorities and schools to plan and report annually on the measures that they are taking to address the key priorities of the National Improvement Framework (NIF). The statutory guidance to support these legislative duties is currently being reviewed. We could consider whether to create a new requirement for education authorities and schools to include in their plans and reports an articulation of how the specific needs of neurodivergent pupils and pupils with learning disabilities have been considered and are being met.

We could consider whether to require that Children’s Services Plans Annual Reports should include specific consideration of neurodivergent children and young people and children and young people with learning disabilities.

**Proposal 2: Mandatory training for teachers, practitioners and other educators**

We have set out proposals for a mandatory training requirement for health and social care staff, and are seeking views on whether this should extended to other public sector areas. Therefore, we could explore:

(a) whether there is a need to set out anything in legislation regarding the training requirements for student teachers, given the recently updated Standard for Provisional Registration;

(b) whether there is a need to set out anything in legislation regarding the training requirements for student Early Learning and Childcare (ELC) practitioners; and,

(c) whether there is a need for a mandatory training requirement for teachers, practitioners and other educators on learning disabilities and neurodivergence as part of their Continued Professional Development (CPD).

**Proposal 3: Data**

The overarching themes section of this consultation sets out broad proposals relating to data and invites views.

Current Additional Support Needs (ASN) data reflects that children and young people have a wide ranging spectrum of learning needs.  Within this, there is disaggregated data available on some conditions but not others. For example, there is disaggregated data available on learning disabilities, autism and dyslexia but it isn’t available on Attention Deficit Hyperactive Disorder (ADHD), and Fetal Alcohol Spectrum Disorder (FASD), Dyscalculia and other neurodivergent conditions.

To better understand all neurodivergent children and young people and their experiences and outcomes in relation to education this data could be collected and published. This would allow for reporting on the attainment gap of these groups, school leavers and positive destinations, and to understand the size of these populations and any trends. There may also be a need for data on the use of part-time timetables.

**What Do You Think?**

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

Sight Scotland agrees with proposals 1, 2 and 3.

As a provider of specialist education through the Royal Blind School in Edinburgh we routinely include in our plans and reports of how the specific needs of neurodivergent pupils and pupils with learning disabilities have been considered and are being met. This is essential as the pupils attending the school full-time or through split placements have a disability and/or a learning disabilities and/or are neurodivergent. Combined, these factors impact a young person’s educational experience and their learning, so it is essential we report on this to assess best practice and areas for improvement. To meet the needs of all learners across Sight Scotland’s education services there is a detailed and individualised approach to support. This ensures their education entitlement and that they are able to thrive within their learning environment. National systemic change is required to effectively assess, track and monitor the outcomes for learners with additional support needs.

With regards to mandatory training, we agree that more needs to be done to ensure the workforce, including learning practitioners at all levels, are supported to develop their skills to ensure neurodivergent children and young people, and children and young people with learning disabilities, can reach their full potential and live happy and fulfilling lives. This is critical in the context of the presumption of mainstreaming. On this premise, education and learning should offer full support to all children and young people ensuring this is person centred and adapted and delivered to meet their needs and equal access to learning.

Training must be continuous and practitioners and teachers must be given the adequate time and full support to undertake this as part of their CPD. This is evident as sited in the

Education Institute for Scotland’s report on ASN in 2018, noted that “87% strongly disagreed or disagreed when asked if they had sufficient time to undertake professional development opportunities.”

We further note concern at the findings from the Morgan Review that “98% of the education workforce felt that initial teacher training did not adequately prepare teachers for teaching children and young people who have ASN.” It is critical that student trenchers have access to practical training and consideration should be given to allow student teachers undertake placements in special schools, including Grant-aided schools to give students the opportunity to spend time with neurodivergent pupils and/or pupils with learning disabilities and/or other disabilities.

Moreover, we would argue that the expertise across the wider Independent Specialist sector is underutilised and undervalued as a training support to the wider education system. The sector is open to support colleagues across education services and more could be done to widen the reach of the expertise within these specialist establishments. Consideration to how the specialist sector could contribute and support the work of the RICS could be a simple and opportune starting point for this.

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

**Is there anything else that we should consider in relation to education?**

Improved intersectional data collection and analysis is imperative to be able to deliver quality education for people with learning disabilities, autism and/or those who are neurodivergent and who have visual impairment.

The Visual Impairment Network for Children & Young People (VINCYP) whose aim is to improve the care for children and young people with a visual impairment, involving professionals working in health, education and social work, parents/carers of children and young people with a visual impairment and voluntary sector organisations, is a key partner to develop this intersectional data. Currently, the clinical audit system (CAS) database contains information which aids the planning of services by providing an accurate number of children with visual impairment as well as supporting visual impairment research. Currently, data is logged about children and young people with visual impairment and top co-morbidity conditions including learning disability, epilepsy, autism, down’s syndrome and ADHD. Further attention should be given to gather information relating to PMLD and neurodivergence and ways to further strengthen the gathering of this data.

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## **Section 14: Children and Young people – Transitions to Adulthood**

The term ‘transitions to adulthood’ will mean different things to different young people, and as such will be achieved in many different ways and timescales. In their Principles of Good Transitions,The Association for Real Change (ARC) Scotland refer to this as the period when young people develop from children to young adults. This is not a single event, such as leaving school, but a growing-up process that unfolds over several years and involves significant emotional, physical, intellectual and physiological changes. Transitions also impact on the family of, or those who care for, the child or young person.

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

In their Stage 1 Report on the Disabled Children and Young People (Transitions to Adulthood) (Scotland) Member’s Bill, the Education and Skills Committee noted that many people have described the current legislative landscape as being complex, cluttered, and difficult to navigate for young people and their families, and, in some instances, for the professionals working to support them.

The Committee’s report concluded that “… the Committee is not yet convinced that introducing further legislation in an already cluttered and complex legislative and policy landscape will resolve the issues…”. Rather, there was thought to be a “significant implementation gap between the [existing] intended policy and the experiences of children and young people.” In the Stage 1 debate on the general principles of the Bill, on 23 November 2023, the Bill fell and so will not become law.

Transitions is a period of development which can involve changes in every area of life such as housing, employment, social care, education, transport and relationships. We therefore expect some of our overarching and specific consultation proposals, which covers all of these areas and more, to contribute towards improving outcomes for neurodivergent young people and young people with learning disabilities making the transition to adulthood. This also includes our proposals around inclusive communications, mandatory training, independent advocacy, and statutory strategies for learning disabilities and neurodivergence.

Specifically in relation to data, we will consider whether our approach ensures that disaggregated data for neurodivergent young people and young people with learning disabilities is made available to:

* enable us to better understand and measure the extent to which these young people are experiencing a positive and supported transition to young adult life;
* ensure the visibility of these young people;
* help inform the work that will take place under a National Transitions to Adulthood Strategy; and,
* help to inform the development of services to meet the needs of these young people when transitioning to adulthood.

**What Do You Think?**

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

We note that there are no specific proposals regarding Transitions to agree or disagree with. We are concerned there has been oversight in this regard to offer proposals on the overarching themes detailed in other sections of this consultation (Statutory Strategies, Mandatory Training, Inclusive Communications, Data and Independent Advocacy).

As stated previously in this response, intersectional data collection and analysis is imperative to gain a better understanding of a person’s circumstances, support needs and preferences.

Transitions must be considered as an issue in and of itself that starts before a person moves into adult services. We agree with the literature review of what a positive transition can look like, yet the common experiences of many have had a negative impact on the young person.

Currently, there are significant levels of disparities in provision across local authorities, therefore having a national legislation is important to provide a minimum basic legal requirement to end any postcode lottery in the delivery of support and ensure equality of access. We believe the Bill must be accompanied by guidance on how to ensure disabled children and young people’s voices are heard in the planning of support and care so that they and their families are actively included, informed, and empowered to make decisions about their future.

While it is encouraging to see a focus on transitions via the National Transitions to Adulthood Strategy in the programme for government in 2021, statement of intent in September 2023 to be followed by further consultation in 2024, we note there has already been a significant amount of work undertaken to establish the key concerns, challenges and best practices of transitions. We would urge the Scottish Government to focus on implementing the key actions and recommendations identified to bridge the policy to practice gap. One of the key issues that is well evidenced is the provision and availability of services. Urgent action and investment are needed to deliver upon the recommendations and proposals already presented. To support this, the LDAN Bill can be the vehicle to gather intersectional data that will help to develop and establish practices that best support a young person through their transition to adulthood.

It is essential to achieve meaningful change, there must be a cultural shift as well as change at a system level. To achieve this, the LDAN Bill but must be led by a human rights-based approach. We support wider calls for a proposal to introduce a local authority transition plan for every disabled child and young person. We believe this will help to ensure better outcomes and a smoother transition process for young disabled people that upholds their dignity and respect. A single plan removes duplication and therefore reduces confusion for all involved. Data gathered via the LDAN Bill would help to support this initiative.

We agree with the ALLIANCE, that there should be systematic and robust data gathering by local and national public bodies, disaggregated by all protected characteristics, and should also include children and young people with visual impairment. How the data is gathered too is important. Accessibility is key and any questioned should be asked in line with inclusive communication standards discussed in this response, co-produced and informed by lived experience.

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

**Is there anything else that we should consider in relation to Children and young people – Transitions to adulthood?**

A parent of a young person who resides in our residential living centre, commented:

“As a parent carer and for past 7 years going through the transition stage with my son from the age of 14, I am fully supportive of this Bill. Sadly, the social work/care system is broken, not fit for purpose. We live in a postcode lottery; we have local councils not accountable to how they treat disabled children and their families when they are moving to adult services. Disabled children and young disabled adult’s lives are just as important than non-disabled people. They should, with the right support, be able to achieve to their highest level, whatever level that may be. Their wellbeing and quality of life should not be calculated by £ signs. Invest in them and they can, and will, contribute to society in a variety of ways, not just financially.”

As noted in the consultation document, "while employment should not be seen as the only option to be a valued member of society, opportunities and choices to work are important for everyone." Before work is often education, which is an important part of transitions. Attention should also be paid to the routes to quality work, including access to higher education. Despite blind and partially sighted people excelling in a wide range of careers, people with sight loss are still underrepresented in the workplace. Blind and partially sighted students face a number of barriers both in further and higher education. These barriers largely centre around a lack of support, a lack of accessible equipment or formats and issues around transport or accessible accommodation. The Thomas Pocklington Trust investigated colleges across the UK, including in Scotland, and found that only 2 out of 10 were compliant with disability accessibility regulations. This means 80% of colleges across the UK are breaching legislation requiring them to provide information and learning in accessible formats.

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# **Part 4: Accountability**

Throughout our early work we have heard many different views on how people think their rights can best be enforced. One thing most people with learning disabilities and other neurodivergent people agree on is that they often have trouble knowing what their rights are and being able to properly access their rights. Most people would like to see more accountability to make sure rights are not ignored.

When thinking about accountability, people like different models – some people want to see a new body to enforce rights and some people want to see greater accountability within existing public bodies or a specific role within an existing human rights body, such as the Scottish Human Rights Commission.

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

The Bill can be used to ensure that there is improved accountability for the delivery of rights. There are different ways to do this and we have set out some options.

**Option 1: A new Commission or Commissioner**

A Commission or Commissioner could be set up to help people secure their rights. A Commissioner is one person whereas a Commission might have a board with several people on it.

Either of these would be set up to be independent of Government and its powers and duties and appointments process could be set out in the Bill. These could include the following:

* Consult and involve neurodivergent people and people with a learning disability in the appointments process and work programme,
* Promote human rights,
* Conduct research,
* Hold the Government to account,
* Hold public bodies to account by conducting inquiries and formal investigations,
* Power to bring court proceedings,
* Publish an annual Strategic Plan and financial accounts,
* Collate and publish data and report regularly to the Scottish Parliament on key outcomes for neurodivergent people and people with learning disabilities,

**Option 2: Better resourcing and additional duties for an existing Commission or Commissioner**

Neurodivergent people and people with learning disabilities already come within the remit of the Scottish Human Rights Commission (SHRC), the European Convention on Human Rights (EHRC), the Children and Young People’s Commissioner and other more specialist bodies like the Scottish Public Services Ombudsman (for public service complaints) and the Mental Welfare Commission.

However, these bodies cover the needs of a broader range of people than those with neurodivergence or learning disabilities.  This means that they have to take decisions on where to spend their resources and time and prioritise some issues over others. We know that the needs of people with learning disabilities and neurodivergent people are often not being met even though these bodies are doing many good things. But there is not a specific focus on these groups.

Rather than setting up a new body we could look to our existing bodies and provide additional resources and potentially powers and duties that would allow them to play a more comprehensive role in upholding the rights of neurodivergent people and people with learning disabilities.

We would need to decide which body could best do this. The Bill could amend the legislation that established the body chosen.

**Option 3: Champions and Advocates within Public Bodies**

Scotland has many public bodies whose roles are central to the experiences that neurodivergent people and people with learning disabilities have in their daily lives as they have responsibility for administering many key areas of life such as education, health and social care, and justice.

This option could involve having people with lived experience of neurodivergence or learning disabilities, or people selected by people with lived experience of neurodivergence or learning disabilities, raising awareness of rights within public bodies and promoting a culture where the rights of neurodivergent people and people with a learning disabilities are upheld.

Public bodies include local councils, healthcare providers like the National Health Service (NHS), the Police and many other bodies.

We could explore the potential for the Bill to make provision for this role to be appointed within all Scottish public bodies and could clarify the remit and appointments process.

**Option 4: Better resourcing for existing Disabled People’s Organisations who support neurodivergent people and people with a learning disability**

When we refer to Disabled People’s Organisations (DPOs), we mean those organisations that are led by disabled people themselves. They are directly connected to the communities that they support.

In Scotland, many DPOs receive funding from local councils or the Scottish Government.  DPOs include Autistic People’s Organisations (APOs) in Scotland (there are several) and People First, which is an organisation led by people with learning disabilities.

This option would mean better resourcing of existing DPOs to allow them to support and advocate for the rights of neurodivergent people and people with learning disabilities.

Although the Scottish Government and other organisations already fund DPOs, including some APOs and People First, funding can be limited or directed at particular projects or policies.  We know that DPOs work very hard on behalf of the people they represent and have knowledge and understanding of the issues that often come from their own experiences.

**Option 5: S****upporting good practice through standards, guidance and practical tools and investing in co-production**

This could involve us working continuously with people with lived experience (like the Lived Experience Advisory Panel (LEAP)) to produce national standards and guidance to help people understand the needs and wishes of neurodivergent people and people with learning disabilities and uphold their rights.

It could include providing guidance to schools, universities, councils, healthcare providers, the police, and others. However, we already do this kind of work and there are still many serious issues experienced by people with learning disabilities and neurodivergent people. This guidance, and accompanying tools, could help people within these organisations understand how to respect the rights of neurodivergent people and people with learning disabilities.

**What Do You Think?**

**Which of the 5 options set out above do you think would best protect, respect and champion the rights of neurodivergent people and people with learning disabilities? You can select multiple options if you wish.**

Option 1

Option 2

**Please give the reason for your choice(s).**

Options 1 and 2 provide for the most robust accountability mechanisms with the necessary and appropriate powers to hold public authorities to account. We currently support the Members Bill to establish a Disability Commissioner for Scotland. It is important this is independent from Government with the appropriate and necessary powers to evaluate, review and monitor the implementation of any new legislation and policies in relation to people with learning disabilities, autism and neurodivergence.

Consideration must be given to Proposal 2 to ensure an existing Commissioner had the capacity and expertise to advocate for the rights of people covered by this Bill.

Proposals 3, 4 and 5 are welcome but hold no accountability powers. These initiatives have value though and should be established alongside a Commissioner.

**Are there any other options we should consider? Please give details.**

Nicoletta Primo
Policy and Campaigns Lead
nicoletta.primo@sightscotland.org.uk