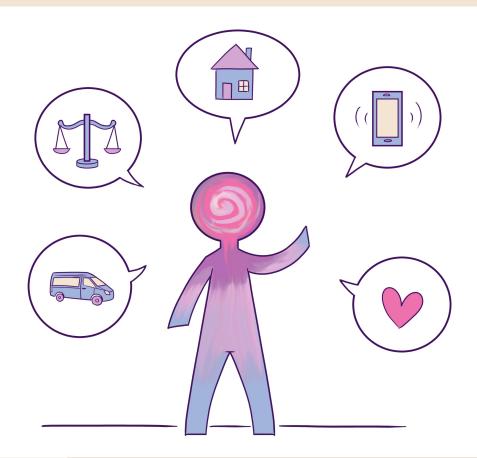


Learning Disabilities, Autism and Neurodivergence Bill:

Consultation



Ministerial Foreword

"Neurodivergence and learning disabilities are part of the natural diversity of human expression. We do not need curing, we just need acceptance."

Member of the Lived Experience Advisory Panel (LEAP)

People with learning disabilities and neurodivergent people are unique individuals, who, like all of us, have potential to develop, skills to offer, and vibrant lives to lead connected to their families and communities. They may think differently and see and experience the world differently. This shouldn't cause them to be marginalised, stigmatised, disadvantaged, abused and excluded, as the evidence set out in this consultation, and the contributions we have received from people with lived experience, sadly and clearly demonstrate.

Scotland's diversity is our strength. We are committed to building a country that ensures equality of opportunity for all by embedding equality, inclusion and human rights into everything that we do. It is evident that much more needs to be done and that this work is needed to provide the focussed attention that these groups, who have at times been overlooked and made to feel invisible, need and deserve.

We have been dedicated to taking a human rights based approach to the development of this consultation. It has been co-designed with people with lived experience at the heart of it, through our Lived Experience Advisory Panel (LEAP). I am incredibly grateful for the work and contributions made by LEAP members whose ideas, knowledge, expertise, and energy is woven throughout this document – including the wonderful covering page which was designed by a LEAP member.

We have also worked closely with our Stakeholder and Practitioner Panels in the development of this consultation. These Panels include organisations and charities representing the views of a wide range of people and a range of practitioners from the organisations which provide support and services to them.

We now want to stimulate a public discussion and provide everyone with an opportunity to tell us about where they think rights could be better protected, respected and championed for people with learning disabilities and neurodivergent people. It is crucial that we get this right and that we consider these issues carefully to make real, groundbreaking improvements to people's experiences and outcomes, seizing the opportunity to be innovative whilst focusing on delivering sustainable person-centred public services.

This document presents the key themes we have heard so far, but there may be others that we should consider. We are inviting views on who the proposed Bill should apply to and have set out a range of proposals on overarching themes, such as inclusive communications, data, and mandatory training in the public sector; as

well as a range of proposals on specific themes, such as health and wellbeing, social care, education, and transport.

I recognise, however, that legislation in and of itself is not enough to build the inclusive and equal society that we aspire to. This proposed Bill is not a singular solution. We therefore continue to prioritise other vital work in partnership with COSLA and local authorities, the NHS, other agencies, and the third sector, which is described in detail throughout this document.

This proposed Bill presents a unique and world-leading opportunity to help create a society where being neurodivergent or having learning disabilities is as accepted as being neurotypical. As has been articulated so well in the LEAP Co-Chair Foreword, which follows, all of Scotland can benefit by strengthened protection and respect for the rights of these groups.

I would therefore like to invite views from as many people as possible on the proposals set out in this consultation. I am confident that, together, we can build a fairer Scotland for all. We want to hear from you in a way that suits you best which is why we are inviting responses in writing, audio, video, or at our events online and inperson across the country.

Finally, I would like to express my gratitude to the many people who have worked in partnership with us and who have dedicated a significant amount of their time and energy to this process so far. In particular, I would like to thank the members of the LEAP, Stakeholder and Practitioner Panels.





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

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Lived Experience Advisory Panel (LEAP) Foreword

This public consultation marks what we hope will be a significant milestone on the journey towards the fair and inclusive society Scotland aspires to be. Never before has such an ambitious and far-reaching piece of proposed legislation been focused on recognising and promoting the rights of our community of people with learning disabilities and neurodivergent people. If we get this right, Scotland has the opportunity to become a leading light, not just in the United Kingdom, but across the world.

From the outset, the Scottish Government has sought to place the voice of those with lived experience at the heart of this process. For many of us on the LEAP, it has been the first time we have been able to have our voices heard and to share the daily struggles and experiences that underline why this proposed Bill is such a crucial piece of legislation.

It has been a real honour to work with such a diverse and passionate group of people on the LEAP – each with their own unique story, background and perspective on the issues we have discussed. This consultation paper has been shaped by our many months of discussions. We are grateful to the Scottish Government for involving us so committedly.

Despite the diversity of views among LEAP members, we are all agreed on the following underlying principles that underpin this opportunity:

- 1. The status quo is not an option. It is not acceptable for our community to continue to face the discrimination and struggles that are sadly too commonly experienced by us all.
- 2. **There must be accountability.** We need a new mechanism to hold people and organisations to account and to uphold our rights. The form this takes will be informed by the responses to this public consultation.
- 3. **People with lived experience must be included.** For too long, decisions that impact us have been made without us. Once this proposed Bill passes into law, those with lived experience must have a significant role in its implementation and evaluation.
- 4. What benefits us, benefits all. Whilst this proposed Bill focuses on the learning disabled and neurodivergent communities, all of Scotland can benefit in promoting and supporting our rights. As has been shown by the unique insights and innovative ideas offered up by the LEAP to date, by enabling and empowering us to fully participate in society, Scotland can unlock a vast amount of talent and potential which will benefit everyone not just us!

This public consultation is not just a formality but an essential step in having our human rights respected and protected. Your feedback, your stories, your expertise, and your lived experiences will shape the content of this proposed Bill and inform future policy – please share your thoughts openly, honestly, and constructively and encourage others to participate too.

Alongside the Scottish Government, the members of the LEAP urge you to seize this unique opportunity to help define the Scotland we all aspire to build here and now, and for generations to come.

Thank you.



Hannah Roussel
Co-Chair of the LEAP



Jim Gault Co-Chair of the LEAP

The language we use: "neurodivergent people and people with learning disabilities"

We recognise that different people have different preferences in terms of how they are described. In this paper we seek to respect those preferences. However, we accept that the terminology may not suit everyone.

When speaking of neurodivergence, we use identity-first language such as 'neurodivergent person' or 'autistic person', as this was preferred by the majority of such people with whom we interacted during our scoping work¹ for the Bill.

When speaking of learning disabilities, we use person-first language such as 'people with learning disabilities', as this was the preference of the majority of such people with whom we interacted during our scoping work.

We understand that for some, 'neurodivergence' refers to individuals whose brain processes are different from those of others in society. Under this model, when we use 'neurodivergent people' this refers generally to: people with learning disabilities, people with learning difficulties such as dyslexia, autistic people, and a wide variety of people whose neurology is different by virtue of ADHD, Fetal Alcohol Spectrum Disorder (FASD), and other conditions.

We know that not everyone is comfortable with the word neurodivergence. Some people with learning disabilities have particularly told us this. In an attempt to balance these viewpoints, we will use the term 'neurodivergent people and people with learning disabilities' throughout this paper.

This term should also be understood as referring to all age groups, including children and young people as well as adults.

We will continue to seek guidance and feedback on the terminology that we use throughout the Bill development process to ensure that we are as inclusive and respectful as possible.

¹ Learning Disability, Autism and Neurodiversity Bill: Scoping Analysis 2022 (www.gov.scot)

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Introduction

"...We must ensure equality of opportunities for all – reaffirming our commitment to embedding equality, inclusion and human rights into everything we do.

We will use the powers of devolution to their maximum to deliver services and improve the lives of the people in Scotland... As a Government we will be unapologetic about supporting those in greatest need. We will use every power at our disposal to protect the vulnerable in our society." ²

First Minister, Humza Yousaf MSP

We know that people with learning disabilities and neurodivergent people can be amongst the most vulnerable and disadvantaged in our society. This needs to change and it is why the objectives for the Bill are to better respect, protect and champion the rights of these groups to deliver a fairer Scotland for everyone.

This consultation brings much needed focus to help us move towards a society where neurotypical and neurodivergent people, and people with learning disabilities, all have their needs met and their choices respected.

What do we know about neurodivergent people and people with learning disabilities?

Although detailed or comprehensive data collection and reporting on learning disabilities and neurodivergence is poor in some areas, from the data that is available we estimate that these groups comprise 10-15% of the population, with some conditions commonly co-occurring. The individual figures below are likely underestimates. For example, the data that is available shows the following:

- The 2011 Census reported that 0.5% of Scotland's population have learning disabilities.³
- The Scottish Government commissioned a study to assess the prevalence of autistic people which estimated that at least 1% of the population is autistic.⁴
- However, autism diagnosis in children and young people is increasing year on year. In 2022, 3.6% of the school population identified as having additional support needs were autistic, indicating that the 1% estimate for adults is an under-representation.⁵

² Equality, opportunity, community: New leadership - A fresh start (www.gov.scot)

³ Population | Census 2011 Information | Scottish Learning Disabilities Observatory (sldo.ac.uk)

⁴ The Microsegmentation Of The Autism Spectrum - Economic and research implications for Scotland (www.gov.scot)

⁵ Overall pupil population, excluding ELC, was 705,874 <u>Classes and pupils - Schools in Scotland 2022: summary statistics - gov.scot (www.gov.scot).</u> Number of pupils with additional support needs, excluding ELC, was 25,855 (Table 1.8, Pupil census 2022) <u>Pupil census supplementary statistics - gov.scot (www.gov.scot)</u>

- It is estimated that 3-4% of the UK population has ADHD.⁶
- There are few reliable sources of data on FASD. However, the University of Salford published research in 2021 indicating that 1.8-3.6% of the UK population may have FASD, but that the prevalence rate may be higher.⁷
- In terms of learning difficulties, it is estimated that up to 10% of people in the UK have dyslexia⁸, and 6% have dyscalculia⁹.
- Neurodivergence and learning disabilities often co-occur, for example:
 - it is estimated that 37.2% of autistic people have a co-occurring learning disability;¹⁰
 - o 50% of individuals with FASD are estimated to also have ADHD;¹¹ and,
 - ADHD and learning disabilities can also commonly co-occur.¹²

There is good evidence of the significant inequalities and challenges that these groups experience. For example, research indicates that:

- People with learning disabilities in Scotland die on average 20 years earlier than the rest of the population, which is largely preventable.¹³
- Adults with learning disabilities are twice as likely to die from preventable illnesses than the general population, and were over three times more likely to die from COVID-19.¹⁴
- Autistic people die on average 16 years earlier than the general population.¹⁵
- Autistic people are 9 times more likely to die by suicide. As many as 66% of autistic adults had thought about suicide during their lifetime, and up to 35% had planned or attempted suicide.¹⁶/¹⁷
- People with FASD who are not diagnosed in early life are at high risk of having a lower life expectancy than their peers, estimated at 34 years.¹⁸
- People with ADHD are five times more likely to attempt suicide which rises to 1 in 4 for women with ADHD.¹⁹

⁶ Prevalence | Background information | Attention deficit hyperactivity disorder | CKS | NICE

⁷ Prevalence of fetal alcohol spectrum disorder in Greater Manchester, UK: An active case ascertainment study - McCarthy - 2021 - Alcoholism: Clinical and Experimental Research - Wiley Online Library

⁸ Dyslexia - British Dyslexia Association (bdadyslexia.org.uk)

⁹ About dyscalculia - British Dyslexia Association (bdadyslexia.org.uk)

¹⁰ Mental health in autistic adults: A rapid review of prevalence of psychiatric disorders and umbrella review of the effectiveness of interventions within a neurodiversity informed perspective - PubMed (nih.gov)

¹¹ Comorbid Mental Disorders in Fetal Alcohol Spectrum Disorders: A Systematic Review - PubMed (nih.gov)

¹² <u>college-report-cr230---attention-deficit-hyperactivity-disorder-(adhd)-in-adults-with-intellectual-disability.pdf</u> (rcpsych.ac.uk)

¹³ Research projects | Our research | Scottish Learning Disabilities Observatory (sldo.ac.uk)

¹⁴ Rates, causes, place and predictors of mortality in adults with intellectual disabilities with and without Down syndrome: cohort study with record linkage | BMJ Open

¹⁵ People with autism die 16 years earlier on average, says charity | The BMJ

¹⁶ Systematic Review of Suicide in Autism Spectrum Disorder: Current Trends and Implications | Current Developmental Disorders Reports (springer.com)

¹⁷ Common etiological factors of attention-deficit/hyperactivity disorder and suicidal behavior: a population-based study in Sweden - PubMed (nih.gov)

¹⁸ Life expectancy of people with Fetal Alcohol Syndrome | Journal of Population Therapeutics and Clinical Pharmacology (jptcp.com)

¹⁹ Common etiological factors of attention-deficit/hyperactivity disorder and suicidal behavior: a population-based study in Sweden - PubMed (nih.gov)

In terms of family and community, research indicates that:

- 66% of autistic people in Scotland say that they feel socially isolated.²⁰
- Social isolation and loneliness remain a reality for many people with learning disabilities.²¹ 52% of people with learning disabilities occasionally, sometimes, or often felt lonely.
- Autistic people are bullied more frequently than non-autistic peers (46-96% prevalence rates).²²
- 5% of people with learning disabilities lived with a partner compared to 56% of the general population, and 3% were married compared to 47% of the general population.²³
- Between 40% and 60% of parents with a learning disability have their children removed from their care due to being assessed as unable to provide an adequate standard of parenting.²⁴

With regards to employment, it is estimated that employment rates are 4-8% for people with learning disabilities²⁵ and 29% for autistic people,²⁶ compared with Scotland's national employment rate of 82.5% for non-disabled people and 50.7% for disabled people.²⁷ The Office for National Statistics has also reported that the employment rate for 'severe or specific learning difficulties' is 26.2%.²⁸

In terms of education, we know that 4.6% of exclusions in Scotland are of autistic learners, which is higher than the overall percentage of learners who are autistic (3.6%).²⁹ The majority of applications to the Health and Education Chamber of the First-Tier Tribunal are consistently for autistic learners.³⁰

With regards to justice, research indicates that:

- Communication disorders among young offenders have a prevalence rate of 60-90%³¹.
- A Scottish Prison Service pilot carried out in 2016 showed that 39% of prisoners had a learning disability or difficulty.
- Whilst there is no reliable data on FASD prevalence within the prison population in the UK, FASD is thought to be overrepresented and under-recognised in criminal justice settings.³² International research indicates that youths with FASD are 19

21 Relationships matter for people with learning disabilities - SCLD

²⁰ Too much information (autism.org.uk)

²² The National Intimate Partner and Sexual Violence Survey: 2015 Data Brief — Updated Release (cdc.gov)

²³ Relationships matter for people with learning disabilities - SCLD

²⁴ A systematic review of interventions to promote social support and parenting skills in parents with an intellectual disability - PubMed (nih.gov)

²⁵ New research on learning disabilities in Scotland | FAI (fraserofallander.org)

²⁶ Outcomes for disabled people in the UK - Office for National Statistics (ons.gov.uk)

²⁷ Supporting documents - Labour Market Statistics for Scotland by Disability: January to December 2022 - gov.scot (www.gov.scot)

²⁸ Outcomes for disabled people in the UK - Office for National Statistics (ons.gov.uk)

²⁹ Overall pupil population, excluding ELC, was 705,874 <u>Classes and pupils - Schools in Scotland</u> <u>2022: summary statistics - gov.scot (www.gov.scot).</u> Number of pupils with additional support needs, excluding ELC, was 25,855 (Table 1.8, Pupil census 2022) <u>Pupil census supplementary statistics - gov.scot (www.gov.scot)</u>

³⁰ Needs to learn Annual Report AW.indd (healthandeducationchamber.scot)

³¹ Annual report 2012-13 | Children's Commissioner for England (childrenscommissioner.gov.uk)

³² Understanding the Mental Health Needs of Scotland's Prison Population (www.gov.scot)

times more likely to be in prison than youths without FASD, and, our stakeholders have consistently told us that people with FASD are over-represented in the justice system.³³

- Global rates of gender-based violence suggest that 90% of women with learning disabilities have been subjected to sexual abuse, with 68% experiencing sexual abuse before turning 18.³⁴
- Those higher in autistic traits are 1.4 times more likely to have experienced childhood sexual abuse compared to those with few autistic traits (40% vs. 27%), and 1.7 times as likely to have experienced physical or emotional abuse (24% vs 14%).³⁵

The Scottish Government and COSLA's Towards Transformation Plan³⁶ highlighted that people with learning disabilities and autistic people continue to face stigma when trying to access services to which they are entitled. Such stigma can lead to exclusion from services, or else unequal treatment when services are provided.

For example, we know that stigma concerning autism and mental health has resulted in some autistic people not receiving support to which they are entitled; as one autistic person put it, "GPs [can blame] the mental health of people on their autism and so [do] not [provide] support". Another autistic person reported that their "school just thinks I'm being over-dramatic, they don't take me seriously, very patronising. They know I'm autistic and they just use it as an excuse".

Elsewhere in the UK, large numbers of autistic people are targeted because of autism-related stigma. For example, of autistic respondents to a UK government review of the Autism Act 2009,³⁷ 87% had 'sometimes' or 'often' experienced bullying, 75% had 'sometimes' or 'often' experienced discrimination, and 52% had 'sometimes' or 'often' experienced harassment.³⁸

People with learning disabilities face both social and health inequalities, which place them at an increased risk of mental health problems.³⁹ A contributing social factor is stigma: negative stereotypes held by society about people with learning disabilities, which often lead to prejudice.

We know that just under a third (32%) of respondents in the 2017 British Attitudes Survey⁴⁰ thought that disabled people are not as productive as non-disabled people. This belief may be a factor which contributes to the disparity in

³³ Fetal alcohol spectrum disorder prevalence estimates in correctional systems: a systematic literature review - PubMed (nih.gov)

³⁴ <u>Unequal, Unheard, Unjust: But not Hidden Anymore – new report launched at Scotland's Learning</u> Disability and Gender-Based Violence Conference 2023 - SCLD

³⁵ Healthy Relationships on the Autism Spectrum (HEARTS): A feasibility test of an online class co-designed and co-taught with autistic people - PMC (nih.gov)

³⁶ Learning/intellectual disability and autism: transformation plan - gov.scot (www.gov.scot)

³⁷ The Autism Act 2009 applies only in England, and not in Scotland. <u>Autism Act 2009 (legislation.gov.uk)</u>

³⁸ <u>Summary of findings from the government's review of the National Autism Strategy 'Think Autism': call for evidence - GOV.UK (www.gov.uk)</u>

³⁹ Standing up for Myself (STORM): Adapting and piloting a web-delivered psychosocial group intervention for people with intellectual disabilities - ScienceDirect

⁴⁰ Disability Perception Gap | Disability charity Scope UK

employment rates between people with learning disabilities and the general population.41

We also know that stigma can lead to hostility towards people with learning disabilities, in some circumstances potentially contributing to abuse. 42 The Scottish Commission for People with Learning Disabilities (SCLD) has produced a short film that documents people with learning disabilities' experiences of hate crime. 43 We also know that, in England and Wales in the year ending March 2019, disabled people were more likely to be subjected to physical violence than non-disabled people, and that disabled women were more than twice as likely to have experienced domestic abuse than non-disabled women.44 Whilst we do not know the exact statistics relating to people with a learning disability within this dataset, we can extrapolate both from this dataset and from what we know otherwise about the experiences of people with learning disabilities that they, too, are more likely to experience violence and criminal actions.

For example, the SCLD research suggests that 1 in 3 adults with learning disabilities experienced sexual abuse in adulthood and that the UK had a prevalence of 34.1%. International studies demonstrate that people with a learning disability may be 10-12 times more likely to experience sexual assault than their non-disabled peers.⁴⁵

We also know that people with learning disabilities are often excluded from teaching in school and other settings about Relationships, Sexual Health and Parenthood.⁴⁶

People with learning disabilities and neurodivergent people can think differently and see and experience the world differently. That shouldn't cause exclusion, stigma, stereotyping, abuse, aggression and disadvantage. However, these groups can be among the most stigmatised, vulnerable and socially excluded in our society. As one LEAP member put it:

"I was not born vulnerable. I have been made vulnerable because of the attitude and behaviour and prejudices of others throughout my whole

Whether it's the bus conductor who gets irritated with me because I just need a bit more time to get to my seat, or the school teacher who placed me at the back of the class because I was 'holding everyone back', or the staff in my GP practice who think I'm a pain because I keep contacting them – they just see my learning disability."

Sadly, stigma can become internalised in the people who experience it. This is associated with higher levels of psychological distress and lower quality of life. 4748

⁴¹ Stigma and discrimination - research and statistics | Mencap

⁴² Seminar Review - Stigma and People with a Learning Disability - Cerebra.

We are More - a film about hate crime on Vimeo

Disability and crime, UK - Office for National Statistics (ons.gov.uk)
 Unheard-Unequal-Unjust—But-not-Hidden-web-version.pdf (scld.org.uk)

^{46 &}lt;u>Unheard-Unequal-Unjust—But-not-Hidden-web-version.pdf</u> (scld.org.uk)

⁴⁷ Self-reported stigma and symptoms of anxiety and depression in people with intellectual disabilities: Findings from a cross sectional study in England - ScienceDirect

⁴⁸ Public stigmatisation of people with intellectual disabilities: a mixed-method population survey into stereotypes and their relationship with familiarity and discrimination - PubMed (nih.gov)

We also know that stigma has an intersectional element. This means that attitudes and assumptions concerning things like ethnicity, culture, gender identity, and the like can interact with and influence disability stigmas, making things even harder for neurodivergent people and people with learning disabilities to achieve respect within their societies and cultures, and to access the services that they need. Attitudes and assumptions prominent within certain social and cultural groups can also influence disability stigmas. For example, we know that 'particular groups with higher levels of religious faith may be more likely to stigmatise.⁴⁹

Our approach to developing proposals with neurodivergent people and people with learning disabilities

In our 2021 Programme for Government,⁵⁰ we committed to carrying out scoping work for a Bill. That work took place between May and July 2022 and involved a series of events to consider how people with lived experience viewed the Bill and to discuss potential key elements, including the role of a Commission or Commissioner. We ran 30 different events with 18 different stakeholder organisations, including people with lived experience of learning disabilities or neurodivergence. An analysis of the findings from our scoping work was published earlier this year.⁵¹

We have been committed to taking a human rights based approach to ensure that this consultation and the proposals contained within it were fully co-designed with people with lived experience.

To enable this, we established three Bill panels to support the development of consultation options. This included a Lived Experience Advisory Panel (LEAP), a Stakeholder Panel; and a Practitioner Panel.

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

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

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

Individual meetings with the three panels took place from February to September this year. Whilst the scoping report informed our Panels' discussions initially, the LEAP has led the way on the themes that were to be explored in this consultation, and the resulting proposals.

⁵⁰ A Fairer, Greener Scotland: Programme for Government 2021-22 (www.gov.scot)

⁴⁹ Autism stigma and the role of ethnicity and culture

⁵¹ Learning/intellectual disability and autism: transformation plan - gov.scot (www.gov.scot)

We have been committed to a partnership approach with the LEAP and to find new ways of working together for genuine and ground breaking engagement in the policy process. This has included the LEAP co-designing and co-producing this consultation paper.

How the Bill fits with the other rights-based work we are progressing

The Bill is part of a system of rights-based work that we are currently progressing. In developing this consultation and its proposals we have aimed not to duplicate or add more complexity to this landscape. Where this other work is relevant to the themes in this consultation, it is noted and discussed at the individual sections. This Bill can therefore be seen as working in harmony with this other work, whilst providing proposals to bring more focus to people with learning disabilities and neurodivergent people within that work where it may be needed.

The other pieces of rights-based work we are currently progressing includes:

International human rights

Whilst the UK has signed and ratified various international human rights treaties and conventions, which means the UK has consented to be bound by them, these rights are not directly enforceable in domestic law. This is because internationally recognised human rights are not enshrined in Scots law. This means that the rights in these unincorporated international human rights instruments cannot be relied on in Scotland to challenge public bodies in court or by regulators if there is a failure to take actions to uphold these rights or if actions are taken to undermine them.

We are, however, progressing the following two pieces of legislation:

a Human Rights Bill for Scotland, which will be introduced during the current Parliamentary year. A consultation on proposals for the Human Rights Bill closed on 5 October 2023. The Human Rights Bill will incorporate a wide range of internationally recognised economic, social and cultural human rights belonging to everyone in Scotland, into Scots law within the limits of devolved competence.

The aim of incorporating these rights in the Bill is to help better secure a life of dignity for everyone, particularly those who are most marginalised and disadvantaged. We want the Bill to help tackle inequality by improving how public authorities consider human rights and protected groups (including disabled people) when delivering services in areas devolved to Scotland, such as health, education and housing.

The proposals for the Bill are ambitious and we are seeking to provide a single framework in which all rights can be read, applied and interpreted together against the relevant international law from which they come. The proposals in the Bill would mean that for the first time in our domestic legal framework, duty bearers have to comply with the rights in the International Convention on Economic, Social and Cultural Rights (ICESCR) and the right to a healthy environment, and actively consider the rights in the Convention

on the Rights of Persons with Disabilities (CRPD) (alongside other treaties for the protection of women and those who experience racism) when making decisions and delivering public services. The model of incorporation differentiates between the treaties given the overarching need to provide a framework which is coherent, consistent and competent – although the Scottish Government is committed to considering its approach to CRPD rights whilst balancing those overall aims.

The rights and duties will be supported by strengthened improvements for how everyone can access justice when rights are infringed and robust planning and reporting duties on public authorities. These will be crucial in ensuring the Bill can provide the transformative culture change for human rights based delivery of public services that we want it to.

Details of these treaties and proposals are in the Human Rights Bill consultation document.⁵²

the United Nations Convention on the Rights of the Child (UNCRC) (Incorporation) (Scotland) Bill. This Bill will, if passed, incorporate the UNCRC into Scots law within the limits of devolved competence.⁵³ The UNCRC is an international human rights treaty that covers all aspects of children's lives. The Bill sets out several things to make sure that incorporation works, such as that the Scottish Government must publish a Children's Rights Scheme to show how they are meeting UNCRC requirements and explain future plans for children's rights. Certain listed authorities must report every three years on what they have done to meet the UNCRC requirements and give better or further effect to children's rights.

The UNCRC applies to everyone under the age of 18. It recognises that all children and young people have rights and contains four underpinning principles around: non-discrimination; the best interests of the child; the right to life, survival and development; and respect for the views of the child. More specifically, Article 28 recognises that children and young people have the right to education on the basis of equal opportunity. This includes both primary and secondary education and includes the option of technical or vocational training.

We have already provided non-statutory guidance to public authorities on giving effect to the UNCRC.⁵⁴

Given that these two Bills will aim to incorporate high-level treaty-based rights, the LDAN Bill could potentially add to the increasingly developing rights system, providing more focus on people with learning disabilities and neurodivergence and more specific legal rights and obligations in respect of these specific populations, in specific circumstances.

⁵² A Human Rights Bill for Scotland: consultation - gov.scot (www.gov.scot)

⁵³ The Scottish Parliament. 2023. United Nations Convention on the Rights of the Child (Incorporation) (Scotland) Bill Overview | Scottish Parliament Website

⁵⁴ Children's Rights and the UNCRC in Scotland: An Introduction (www.gov.scot)

- The establishment of a National Care service (NCS) and the National Care Service (Scotland) Bill. We are committed to delivering the NCS to improve quality, fairness and consistency of provision that meets individuals' needs. It is part of our broader work to provide sustainable person-centred public services that tackle inequalities. We are working with people with lived experience and frontline workers to co-design the detail of the NCS. Services will continue to be planned, designed and delivered at a local level, with input from those with lived experience, creating a person-centred, outcome-focused approach to care.
- The Mental Health and Capacity Law Reform Programme. Earlier this year, we published a response⁵⁵ to the independent Scottish Mental Health Law Review (SMHLR).⁵⁶ The SMHLR was tasked with considering ways to better realise and protect human rights through our mental health, incapacity and adult support and protection legislation. It also looked at ways to remove barriers to care and support for people currently covered by the legislation. The Review's final report recommended a series of changes to legislation, policy and practice.

In our response, we committed to establishing a new Mental Health and Capacity Law Reform Programme to co-ordinate and drive further change and improvement over time in line with the Review ambitions. This programme will modernise our legislation to enhance the protection of people's rights. It will also seek to bring about improvements across mental health services and strengthen accountability for upholding and fulfilling human rights.

- The Public Sector Equality Duty (PSED) Review. The Equality Act 2010
 ("Equality Act") provides a legal framework to protect the rights of individuals and
 advance equality of opportunity for all. Section 149 places a duty on public
 authorities, and others who exercise public functions, to have due regard to the
 need to:
 - eliminate discrimination, harassment and victimisation and any other conduct that is prohibited under the 2010 Act;
 - advance equality of opportunity between persons who share a protected characteristic and those who do not;
 - and to foster good relations between persons who share a protected characteristic and those who do not.

This is known as the Public Sector Equality Duty (PSED).⁵⁷

The Scottish Ministers have used their available powers to encourage equal opportunities to support compliance with PSED by placing detailed requirements on Scottish listed public authorities through the Equality Act 2010 (Specific Duties) (Scotland) Regulations 2012 ("the SSDs").

The SSDs support Scottish listed public authorities to improve performance of the PSED by requiring them to: report progress on mainstreaming equality; propose and publish equality outcomes; assess policies and practices from the

⁵⁵ Scottish Mental Health Law Review - Our Response (www.gov.scot)

⁵⁶ Scottish Mental health Law Review [archived] (nrscotland.gov.uk).

⁵⁷ Public sector equality duty

perspective of equality; and publish employee information on pay and occupational segregation.

Responsibility for oversight of compliance with the Equality Act, including compliance with the SSDs, rests with the Equality and Human Rights Commission (EHRC). The EHRC has issued guidance on how the SSDs should be applied in practice.

The SSDs aim to help public authorities to meet the PSED. In order to demonstrate due regard to the matters set out above, institutions must do the following:

- Report on progress on mainstreaming the PSED into all functions
- Develop and publish a set of equality outcomes that cover all protected characteristics (or explain why not all protected characteristics are covered)
- Assess the impact of policies and practices against the needs of the PSED
- o Gather and use information on employees
- Publish gender pay gap information
- Publish statements on equal pay for gender, race and disability
- Have due regard to the PSED in specified procurement practices
- Publish information in a manner that is accessible

We are reviewing the PSED in Scotland and are phasing in changes to improving the regulatory regime. Our next steps include delivering on two key regulatory changes:

- 1. revising the current pay gap reporting duty to include reporting on ethnicity and disability pay gaps; and
- 2. introducing a new duty on listed public bodies in relation to their use of inclusive communication.

Further legislative changes will be considered over the longer-term.

• **Getting it right for every child (GIRFEC)**. With the right support at the right time, every child and young person in Scotland can reach their full potential. GIRFEC⁵⁸ is our national approach to promoting, supporting and safeguarding the wellbeing of all children and young people, providing a consistent framework and shared language which puts their rights and wellbeing at the heart of the services that provide support to them and their families.

The GIRFEC National Practice Model seeks to help practitioners consider ways they can help improve wellbeing for a child or young person. It provides a framework to structure and analyse information consistently to take account of a child or young person's needs, identify their strengths and any challenges they face, and consider the most appropriate offer of timely, holistic support. Children, young people and families should be supported to fully participate in discussions as the assessment of need is made; and be at the heart of any planning, including receiving accessible information on the decisions reached and why.

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⁵⁸ Getting it right for every child (GIRFEC) - gov.scot (www.gov.scot)

- The Promise. Our ambition is for all children to grow up loved, safe and respected so that they can reach their full potential. Keeping The Promise will ensure this ambition is turned into a reality for all care experienced children and young people. Our Implementation Plan⁵⁹ sets out the range of actions across the different parts of Government that contribute towards Keeping the Promise by 2030.
- Getting it right for everyone (GIRFE). Getting it Right for Everyone (GIRFE) is a proposed multi-agency approach to health and social care support and services from young adulthood to end of life care, building on GIRFEC. ⁶⁰ It is currently being co-designed. Our GIRFE approach will help inform whole system working, define the adult journey and respect the role that everyone involved has in providing support planning and support. GIRFE will put the person at the heart of every decision about their own health and social care.

How the consultation sections are set out

Each of the sections in this paper is focussed on one main topic. Most sections are set out in the following way:

What we heard

Here we set out what we heard about the topic from our scoping report, stakeholders, and the research that is available to us or that we have undertaken.

What did LEAP think?

Here we set out what the LEAP told us about the topic and their lived experience of it. LEAP's suggestions for change are also included.

Where do we want to get to?

Here we set out our ambitions and vision for the outcomes we want to see.

What happens now?

Here we set out what rights and duties already exist in relation to the topic, as well as current practice. This information is included because LEAP members told us that without knowing what rights and duties may already exist, or what systems and processes are currently in place, they would not be informed enough to engage and participate to their full potential, or to provide meaningful and informed responses. We agree with this and so have set out detailed information for each topic to enable respondents to this consultation to be more informed and able to participate.

What can we do about it?

Here we set out what we and our partners are already doing to improve things for people with learning disabilities and neurodivergent people.

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⁵⁹ Keeping The Promise to our children, young people and families (www.gov.scot)

⁶⁰ Getting it right for everyone (GIRFE) - gov.scot (www.gov.scot)

• What can the LDAN Bill do?

Here we set out proposals for what the Bill might be able to do to improve things for people with learning disabilities and neurodivergent people.

• What do you think?

Here we ask questions for you to respond to, so that we can understand your views.

Part 1: Reach and definitions: who should the 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 we know

In Scotland, along with the rest of the UK, disabled people are protected against discrimination, harassment and victimisation by the Equality Act 2010 ("the Equality Act"). The Equality Act also requires public authorities and others to make reasonable adjustments for disabled people in areas like education and employment, to assist them to engage with these on an equal footing to non-disabled people.

Neurodivergent people and people with learning disabilities are covered by the Equality Act, if they can align their presentations with the definition of disability under the Act. Under the Equality Act, a person has a disability if they have a physical or mental impairment that has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities. 61 'Long-term' in this context means 12 months or more. 62 Official guidance accompanying the Equality Act specifically includes Attention Deficit Hyperactivity Disorder (ADHD), learning disabilities, Down's Syndrome, dyspraxia, and autism as disabilities. 63

There are also existing laws applying in England that have been made to help specific groups of neurodivergent people and people with learning disabilities. These include the Autism Act 2009 and the Down Syndrome Act 2022. However, neither of these Acts provide specific definitions for autism or Down's Syndrome. Neither Act applies to Scotland.

Many neurodivergent people and people with learning disabilities report that they do not receive the support and protection from discrimination to which they are entitled. For example, as part of a review of the Autism Act 2009, autistic people reported that they were told by professionals they would not be found eligible for support because autism is not automatically considered a disability under the Equality Act.⁶⁴

Furthermore, existing definitions within Scots law may project a negative impression of neurodivergent people and people with learning disabilities. For example, the

62 Definition of disability under the Equality Act 2010 - GOV.UK (www.gov.uk)

⁶¹ Equality Act 2010 (legislation.gov.uk)

⁶³ Disability: Equality Act 2010 - Guidance on matters to be taken into account in determining questions relating to the definition of disability (HTML) - GOV.UK (www.gov.uk)

⁶⁴ <u>Summary of findings from the government's review of the National Autism Strategy 'Think Autism': call for evidence - GOV.UK (www.gov.uk)</u>

Mental Health (Care and Treatment) (Scotland) Act 2003 ('The Mental Health Act') lists 'learning disability' under its definition of 'mental disorder'.⁶⁵ We accept that this term is seen by many as stigmatising and offensive towards people with lived experience, and the LEAP were of the view that it is upsetting, degrading and insulting.

The Independent Review of Learning Disability and Autism in the Mental Health Act (the Rome Review) suggested that the inclusion of learning disability under this definition led to people with learning disabilities being detained unnecessarily, and in violation of their rights. The Review recommended that autism and learning disabilities should be defined in a new law, and this is discussed further at another section of this consultation on 'Mental Health and Capacity Law'. The Review recommended that a new law use the following definitions:

'An autistic person is a person who has a professional diagnosis of autism'.

'A person with intellectual disability is a person who has a professional diagnosis of intellectual disability'.

The term 'intellectual disability' is often used as an alternative to 'learning disability'.

The LDAN Bill presents an opportunity to establish legal definitions for various communities under Scots law. Specifically, it presents an opportunity to set out definitions that are aligned with how such people prefer to represent and refer to themselves.

Whatever definitions we use in the Bill, we will also need to think about how we keep them up to date and future-proof the legislation. There may therefore be a benefit in the Bill containing a power to make future changes to definitions by regulations.

The Scottish Government is committed to the social model of disability. Unlike the medical model, where an individual is understood to be disabled by their impairment, the social model views disability as the relationship between the individual and society. In other words, it sees the barriers created by society, such as negative attitudes towards disabled people, and inaccessible buildings, transport and communication, as the cause of disadvantage and exclusion, rather than the impairment itself. The aim, then, is to remove the barriers that isolate, exclude and so disable the individual.⁶⁷

Because the social model of disability focuses on impairment, it allows people to be recognised as disabled even if they do not have a formal diagnosis. The key consideration is how people are impaired by social and built environments. Definitions focused on impairment rather than diagnosis could, therefore, better help public bodies in Scotland to identify and remove relevant barriers that create such impairments.

⁶⁶ The Independent review of Learning Disability and Autism in the Mental Health Act Final Report - [Archived] (nrscotland.gov.uk)

⁶⁵ Mental Health (Care and Treatment) (Scotland) Act 2003 (legislation.gov.uk)

⁶⁷ Defining disability - A Fairer Scotland for Disabled People: delivery plan - gov.scot (www.gov.scot)

What we have heard

Our scoping work on the Bill ⁶⁸ helped us to obtain insight on this issue from people with lived experience of neurodivergence and learning disabilities, alongside organisations that work with and advocate for them. People expressed a range of views:

- There was consensus amongst participants in the scoping work that the Bill should cover people without a formal diagnosis of any of the conditions that this Bill might cover.
- Many people supported a Bill with a wide coverage, covering the full range of neurodivergent people as well as people with learning disabilities.
- Some people were less supportive of the reach of the Bill being as broad as this. They expressed concern that too broad a reach would not effectively target the needs of any individual or group.
- Some people wanted to name specific conditions within the Bill to ensure that
 the groups associated with these conditions were sufficiently visible and
 supported.
- People expressed strong preferences for language associated with the social model of disability, rather than a medical model, to be used throughout the Bill.
- There was broad support for terms such as 'neurodiversity' and
 'neurodivergence'. However, people wanted language to be as inclusive as
 possible, and to be adaptable to social changes. Some people with learning
 disabilities find the terms 'neurodiversity' and 'neurodivergence' unhelpfully
 vague.

What did LEAP think?

- 'Neurodiversity' means everyone, and was not an appropriate definition for who
 this Bill was for. 'Neurodivergence' was broadly welcomed as a term, though not
 as familiar to people with learning disabilities.
- Limiting the coverage of the Bill to a subset of specific conditions would limit the Bill's impact, but naming some conditions (in addition to a broad definition of neurodivergence) could help ensure visibility for marginalised groups.
- Down's Syndrome should not be defined separately to learning disabilities. This
 is because Down's Syndrome is a genetic condition which can cause the people
 in whom it develops to have a learning disability. People with Down's Syndrome
 are commonly included in the broader category of people with a learning
 disability.

⁶⁸ Learning Disability, Autism and Neurodiversity Bill: Scoping Analysis 2022 (www.gov.scot)

- It would be helpful to use a person-centred and strengths-based approach to
 definitions, focusing on abilities rather than deficits and describing barriers. This
 approach could look similar to the one adopted in Sweden, where legislation was
 passed in 1993 for People with Certain Functional Impairments⁶⁹ to protect the
 rights of people in need of wide-ranging support. The legislation is not based on
 a person's diagnosis but rather the person's needs, wishes and condition.
- People with Down's syndrome and people with profound and multiple learning disabilities (PMLD) should both be explicitly referenced in the coverage and definition of the Bill.

Where do we want to get to?

- The clear reach of the Bill and its provisions makes a difference in Scotland to how neurodivergent people and people with learning disabilities are seen and treated.
- Neurodivergent people and people with learning disabilities feel more visible as a result of the Bill and are clear about who it applies to.
- Everyone providing support or services, such as healthcare, education, and care, to neurodivergent people and people with learning disabilities are clear about their duties under the Bill and who this applies to.
- People without a formal diagnosis are clear about how the Bill may or not apply to them.

What definitions already exist?

Beyond the definition of disability in the Equality Act, existing definitions covering neurodivergent people and people with learning disabilities in Scotland are not in law.

We have previously used various definitions for neurodivergent people and people with learning disabilities. Whilst none of these have been placed into law, this Bill could provide an opportunity to do so:

Our Keys to Life Strategy⁷⁰ defines learning disability as:

"a significant, lifelong, condition that started before adulthood, which affected their development and which means they need help to: understand information; learn skills; and cope independently."

The Scottish Commission for Learning Disabilities uses a similar definition:

"a learning disability is significant and lifelong. It starts before adulthood and affects a person's development. This means that a person with a learning disability will be likely to need help to understand information, learn skills and live

⁶⁹ Act concerning Support and Service for Persons with Certain Functional Impairments | Independent Living Institute

⁷⁰ The Keys to Life: Implementation framework and priorities 2019-2021 (www.gov.scot)

a fulfilling life. Some people with learning disabilities will also have healthcare needs and require support to communicate."

The Scottish ADHD Coalition defines ADHD as:

"a neuro-developmental disorder which interferes with the way a child develops in, and interacts with, his or her environment. ADHD is a long term disorder which in most cases persists into adulthood."

The FASD Network UK defines Fetal Alcohol Spectrum Disorder as a term used to describe the permanent impacts on the brain and body of individuals prenatally exposed to alcohol during pregnancy. It can result in a range of physical, mental, emotional and behavioural impacts.

The National Autism Implementation Team identifies neurodivergence as cogitative (brain) functions that fall outside of what is seen/perceived by society to be 'normal'.

Our National Neurodevelopment Specification⁷¹ provides the following definitions:

"Neurocognitive functions are selective aspects of brain functions – the ability to learn and use language, the ability to regulate attention, emotions, impulses (including movements and spontaneous utterances), social behaviours, and process sensory stimuli. Like height, these traits may be significantly genetically influenced, and are present from birth. Like height, the statistical normal range changes, dependant on age. The societal norm for a selective neurocognitive function is defined by the general population and may be variably and narrowly defined."

"A Neurodevelopmental disorder is a term reserved for those who present with a 'functional' impairment in day to day life due to difference in one or more neurocognitive functions which lie at the extreme of, or outwith the normal range."

"Neurodivergent describes individuals where a selective neurocognitive function falls out with the prevalent range."

With regards to clinical guidance, the International Classification of Diseases 11th edition (ICD 11) is established by the World Health Organisation and defines what medical staff are looking for in relation to conditions which require care, support and potentially treatment. An example from it is the definition of 'autistic spectrum disorder':

"Autism spectrum disorder is characterised by persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive, and inflexible patterns of behaviour, interests or activities that are clearly atypical or excessive for the individual's age and sociocultural context."

⁷¹ Children and young people - national neurodevelopmental specification: principles and standards of care - gov.scot (www.gov.scot)

What can the LDAN Bill do?

There are 3 different potential approaches for the Bill, as follows.

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.

This is a broad term that can encompass both innate differences, such as autism and dyslexia, and acquired alterations to brain functioning such as people with an acquired brain injury.

'Neurodivergent' and 'neurodivergence' are therefore 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 dyslexia, dyspraxia and dyscalculia, autistic people and people with Down's Syndrome, ADHD, and FASD.

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.

Finally, 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.⁷²

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.

⁷² Education (Additional Support for Learning) (Scotland) Act 2004 (legislation.gov.uk)

However, under this approach, if a condition was not specifically listed and defined then that population would be excluded and so would not benefit.

This is why it may be important for the Bill to 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 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?
- 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 this topic?

Part 2: Overarching Themes

This part sets out key themes that are relevant across many areas of life and are central to what we think we should do.

Section 1: Statutory Strategies for Neurodivergence and Learning Disabilities

The Scottish Government and COSLA have previously produced national strategies on learning disabilities and autism respectively. 73/74 These strategies were the focus for the development of policies nationally and locally. Following the COVID pandemic, a joint plan was published in partnership with COSLA covering both learning disabilities and autism – the Towards Transformation Plan⁷⁵. We continue to work to this plan pending decisions on the shape and content of the Bill.

Our strategies have been scrutinised by the Scottish Parliament and stakeholders. We commissioned an independent review of the Autism strategy⁷⁶ and the Scottish Parliament's Cross Party Group on Autism also published a review called "The Accountability Gap".77

There is currently no formal or legislative requirement for either national or local strategies specifically for neurodivergent conditions or learning disabilities.

The Autism Act 2009⁷⁸ introduced a requirement for a UK Government strategy for improving services for autistic adults in England, underpinned by legally binding guidance to councils and the NHS in England. This strategy, and associated guidance to public bodies, are issued by the Secretary of State for Health and Social Care. The Department of Health and Social Care (DHSC) has since published 3 adult autism strategies.

The Rt Hon Dr Liam Fox MP introduced a Down Syndrome Bill as a Private Members' Bill to the House of Commons on 16th June 2021. The Bill completed its Parliamentary journey in April 2022, becoming the Down Syndrome Act 2022.⁷⁹ The Act instructs the Secretary of State for Health and Social Care to 'give guidance to relevant authorities on steps it would be appropriate for them to take in order to meet the needs of persons with Down Syndrome in the exercise of their relevant functions'. The relevant authorities to which the Act and guidance applies include the NHS, Councils in England, and schools in England. This Act is not yet in force.

79 Down Syndrome Act 2022 (legislation.gov.uk)

⁷³ Keys to life: implementation framework and priorities 2019-2021 - gov.scot (www.gov.scot)

⁷⁴ The Scottish Strategy for Autism - gov.scot (www.gov.scot)

Tearning/intellectual disability and autism: transformation plan - gov.scot (www.gov.scot)

⁷⁶ Scottish Strategy for Autism: evaluation - gov.scot (www.gov.scot)

⁷⁷ Scotland Cross Party Group on Autism publishes report – 'The Accountability Gap'

⁷⁸ Autism Act 2009

Local Strategies

Health and Social Care Partnerships have a duty under the Public Bodies (Joint Working) (Scotland) Act 2014⁸⁰ to produce a strategic plan. This should include how the needs of the local population will be addressed, including accounting for particular protected characteristics and circumstances.

Whilst we have encouraged local strategies for learning disabilities and autism, HSCPs currently take different approaches. We met with 22 HSCPs between November 2021 and November 2022 to discuss local approaches. At that time, of those 22 HSCPs, 16 had an autism strategy and 12 had a learning disabilities strategy. Several more did have strategies in development. There was only one joint strategy. Individual strategies can be found on the different HSCP websites.

What can the LDAN Bill do?

We are proposing to take a broad approach covering learning disabilities and neurodivergence.

We recognise that approaches to previous strategies and polices have been single condition focussed even though 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 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. Therefore, we could:

- **Proposal 1**: Introduce a requirement for a national strategy on learning disabilities and neurodivergence 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.
- **Proposals 5**: Ensure that people with lived experience have to be involved in the development of the strategies.

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⁸⁰ Public Bodies (Joint Working) (Scotland) Act 2014

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

What Do You Think?

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

Section 2: Mandatory Training in the Public Sector

What we heard

One of the key themes we have heard through our scoping exercise, and from stakeholders and the LEAP, is that that there needs to be greater awareness, understanding, and training on learning disabilities and neurodivergence. In particular, there is a need for this when these groups are trying to access help, support and services and to exercise their rights.

It is thought that better awareness of the needs and experiences of people with learning disabilities and neurodivergent people will help to reduce stigma and also improve their access to the services and support available to them, improving overall outcomes for these groups.

Whilst there can be training options available to public sector professionals to help them better understand and communicate with people with learning disabilities and neurodivergent people, undertaking this training is not a statutory requirement 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 NHS or social care, the police and prisons, can choose to do training or not, if it is available to them. It is also not available consistently across different public services or delivered to a set standard. It can therefore vary in quality and effectiveness.

There are some examples of good practice where there is a focus on disability awareness training in some public sector areas, in a way that is tailored to specific roles, such as some examples seen across transport (as discussed in another section of this consultation).

We have heard that there is a particular need for increased awareness, understanding and training across the health and social care workforce. In England, the Health and Care Act 2022⁸¹ introduced a new legal requirement for all health and social care service providers registered with the Care Quality Commission (CQC) to provide employees with training appropriate to their role on autism and learning disabilities. In England, the UK Government's preferred and recommended training for this purpose is called the Oliver McGowan Training.⁸² We have heard that people would like a similar requirement for training in Scotland. One of our LEAP members told us that:

"Like many other autistic people, I struggle with expressing pain. I can't express pain on a sliding scale, so when my doctor asks me what my pain level is on a scale from 1 to 10, I can't answer. This means my pain has often been dismissed or not been taken seriously, leading to misdiagnosis and prolonged pain in the past.

Cont...

⁸¹ Health and Care Act 2022 (legislation.gov.uk)

The Oliver McGowan Mandatory Training on Learning Disability and Autism | Health Education England (hee.nhs.uk)

"Doctors who rely on body language and tone when making diagnoses can miss important symptoms when assessing me. As an autistic person, I don't express these things in the way they expect. This can cause them to not take me seriously when I tell them about my symptoms.

I'm not good at verbal communication. Thinking of answers in the moment can be challenging for me, so I have to prepare a list of my symptoms when going to the doctor and practice what I'm going to say. Some doctors view this with suspicion and accuse me of sounding "too rehearsed". They think I'm trying to trick them.

I need doctors to understand my differing communications needs so I can receive the same level of care as everyone else.

Autistic people face a documented barrier to healthcare access, and the difficulties in communication is one of the main reasons."

Another example from LEAP members on why training should be mandatory is the experience of people with learning disabilities when presenting at hospital in pain or in a health emergency. It can often be their experience that health professionals and clinicians can overlook the presenting health issues, believing that the symptoms or behaviours are to do with a person's learning disability without looking at anything else that could be wrong. This is called 'diagnostic overshadowing'.

Feedback from consultation on the National Care Service highlighted that social care staff think that "There is a need for more consistent and appropriate training to develop the essential skills for a variety of roles, and ensuring the time for development is also crucial"83

Besides our work on the National Care Service, the need for awareness raising and training for public sector staff on learning disabilities and neurodivergence has featured consistently across our work, including:

- Complex Care (Coming Home Report)⁸⁴
- Our Mental Health Strategy⁸⁵
- Mental Health and Capacity Reform including the Rome report⁸⁶ and the Scottish Mental Health Law Review⁸⁷

⁸³ National Care Service - valuing the workforce: regional forums - findings summary - gov.scot (www.gov.scot)

⁸⁴ Coming Home Implementation report

⁸⁵ Mental Health Strategy 2017-2027

⁸⁶ The Independent review of Learning Disability and Autism in the Mental Health Act Final Report [Archived] (nrscotland.gov.uk)

⁸⁷ Scottish Mental Health Law review Final Report [Archived] (nrscotland.gov.uk)

What did LEAP think?

- Disability awareness training is needed across all of the public sector, and training specific to neurodivergence and learning disabilities is also needed as part of this or in addition to it. Some training is outdated and isn't developed by or delivered with lived experience.
- There is a need to always include people with lived experience in developing and delivering training. Mandatory training should be co-designed, coproduced and co-delivered with lived experience groups.
- Lived experience trainers should be able to access appropriate support for training delivery as well as appropriate payments for training work undertaken.
- There is a need for trauma informed, neurodevelopmentally informed and culturally sensitive approaches.

Where do we want to get to?

- Public sector staff who work directly with members of the public have confidence and skills in being able to understand the needs of neurodivergent people and people with learning disabilities, resulting in improved services and communication and reduced health inequalities.
- Neurodivergent people and people with learning disabilities feel listened to, valued and understood by public sector staff who are take account of their individual needs

What happens now?

In our Towards Transformation Plan⁸⁸ there is a commitment to explore establishing mandatory autism training and learning disability training for all NHS staff.

We currently fund NHS Education for Scotland (NES) to engage with NHS Boards on the Autism Training Framework⁸⁹. The framework provides training on a tiered pathway from "autism-informed" to "expertise in autism" and is available online to all NHS and Social Care staff to ensure they have knowledge of autism in a way that is tailored to their role.

NES has also developed online learning for staff working with people with learning disabilities. This provides an education and training hub designed to meet the needs of staff on a range of topics including trauma, health inequalities, behaviours perceived as challenging, and improving psychological care and support.⁹⁰

The National Autism Implementation Team (NAIT), funded by the Scottish Government, is a practitioner researcher partnership based at Queen Margaret

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⁸⁸ Learning/Intellectual Disability and Autism Towards Transformation (www.gov.scot)

⁸⁹ sct0117216030-3 asd training framework cov_final.pdf (scot.nhs.uk)

⁹⁰ Learning disability | NHS Education for Scotland

University. It has produced professional learning materials on autism for schools and early years establishments.

We have also provided funding to support the establishment of a FASD Hub in Scotland with the aim of providing support, training and advice to families, carers and professionals supporting children affected by FASD. Funding has also been provided to the Fetal Alcohol Advisory Support and Training Team (FAASTT) to allow the delivery of training to improve knowledge, attitudes and confidence in professionals working with individuals with FASD⁹¹.

Our Leadership and Engagement work on Mental Health and Accessing Services is currently underway, led by autistic people and people with learning disabilities. These lived experience leaders create resources and training to inform and support health and social care staff to increase awareness, understanding and skills. The resources are being piloted between October and December 2023 in some GP practices, NHS 24 and the Scottish Ambulance Service.

Currently, under the Patient Rights (Scotland) Act 2011, Scottish Ministers must publish a Charter of Patient Rights and Responsibilities⁹² that summarises the existing rights and responsibilities of people who use NHS services and receive NHS care in Scotland and what you can do if you feel that your rights have not been respected.

The 2011 Act gives patients the right to receive healthcare that:

- considers their needs;
- considers what would most benefit their health and wellbeing; and,
- encourages them to take part in decisions about their health and wellbeing, and gives them the information and support to do so.

The Charter states that:

- When accessing and using NHS services in Scotland I have the right to safe, effective, person-centred and sustainable care and treatment that is provided at the right time, in the right place, and by the most appropriate person; and, as part of this.
- My needs, preferences, culture, beliefs, values and level of understanding will be taken into account and respected when using NHS services

What can the LDAN Bill do?

Whilst there are training resources available across the public sector, including in health and social care, undertaking this training is not currently mandatory, or a statutory requirement. This can lead to inconsistency in the experience of neurodivergent people and people with learning disabilities, which has been reflected in the feedback we have received from the LEAP and others with lived experience.

92 The Charter of Patient Rights and Responsibilities - Revised: June 2022 (www.gov.scot)

⁹¹ Home - Fetal Alcohol Advisory Support & Training Team (ed.ac.uk)

The need for better understanding and knowledge through consistently applied and available mandatory training has been a key theme raised with us.

We know that 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; and,
- 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 therefore 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. This is discussed in more detail in other sections of this consultation.

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? If so, please tell us why?
- If you disagree with this proposal, please tell us why?
- Is there anything else that we should consider in relation to this topic?

Section 3: Inclusive Communications

What we heard

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 supports 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. Using inclusive communication is essential because it recognises that different people use many different ways of understanding and expressing themselves. 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.

Example: we have heard that autistic people and people with learning disabilities are more likely to breach their bail conditions, the consequence of which can be further restriction on their liberty. We have been told that this is more likely because neurodivergent people and people with learning disabilities aren't always appropriately supported to understand their bail conditions, rather than those conditions being deliberately breached.

The profound importance of using inclusive communication was clear during the COVID-19 pandemic, when vitally important public information needed to be quickly available and understood by all. The pandemic exacerbated the disproportionate impact on individuals and groups who already experience disadvantage.

The Scottish Parliament's Equalities and Human Rights Committee 2021 Report⁹³ on the impact of the pandemic on equalities and human rights, noted that respondents felt the needs of disabled people were not considered in the information and guidance provided by the Scottish Government and public services, which had direct consequences on people's lives.

What did LEAP think?

 LEAP members often feel like they aren't respected, and can feel angry and frustrated when interacting with public authorities and the professionals who work for them.

⁹³ Equalities, Human Rights and Civil Justice Committee

- LEAP thought that public authorities in Scotland do not meet their legal obligations around inclusive communications in practice and need to do more.
- LEAP members often commented on negative experiences accessing healthcare, feeling that:
- Inclusive communications are crucial when interacting with doctors for example, autistic people may not be able to express how bad their pain is.
 - o doctors who rely on body language and tone when making diagnoses can miss important symptoms if they aren't expressed in the expected way.
 - the rules for phoning in to get a GP appointment are confusing and complex and create a lot of anxiety with people being worried they will be "scolded" if they get it wrong.
 - The right to request alternative forms of communication should be upheld in every situation.
- It can be difficult to interact with professionals and other people working in public authorities (such as doctors, police and social workers) as they don't have enough understanding of neurodivergence and learning disabilities. LEAP would like those professionals to have a better understanding of their different communication needs, and their rights to accessible information.
- The information provided by public bodies and service providers is often difficult to read and understand, unclear or unnecessarily complex. LEAP would like alternative formats to be automatically provided wherever possible, rather than the responsibility being on them to request alternative formats. This includes easy-read versions.
- During the COVID pandemic, public authorities and services were able to offer a
 variety of communication methods when accessing services, such as online and
 telephone appointments. LEAP members felt this made services more
 accessible to them. They would like this to continue to be best practice and seen
 as a way that allows them to access their rights around inclusive
 communications.

One of our LEAP members told us that:

"I struggle to make appointments with my doctor because the rules for phoning in are so confusing and complex. There are certain times and days you have to phone to get appointments, but nobody explains this to you. I'm scared to be scolded for phoning at the wrong time, so I often don't even try."

Where do we want to get to?

We are committed to improving and embedding inclusive communication proportionately within the Scottish Government and across the public sector. In March 2021, we published our suite of Equality Outcomes for 2021-25 under the

Scottish Specific Duty Regulations (SSDs),⁹⁴ which focus on tackling significant inequalities in society. The SSDs are discussed further below. One of those outcomes is focused on inclusive communication and states:

"By 2025, inclusive communication will be embedded in the approaches of public bodies, with an increased proportion of people in Scotland reporting that their communication needs are being met when accessing public services" ⁹⁵

For people with learning disabilities and neurodivergent people, we want:

- 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 alternative formats.
- Professionals who work for public authorities and service providers are knowledgeable and confident when communicating with a range of neurodivergent people and people with learning disabilities.
- When inclusive information is not automatically provided, it is easy for neurodivergent people to request alternative formats, methods of communication and adaptations that work best for them as individuals.
- Neurodivergent people, and people with learning disabilities, are able to communicate with professionals who work for public authorities and service providers and feel heard, respected and understood.

What happens now?

Inclusive information and communication is promoted through various pieces of legislation and policy, as follows.

The Equality Act 2010 ("the Equality Act")

The Equality Act makes it unlawful for public authorities and others to discriminate against, harass or victimise employees and people who use services. It requires public authorities and others to make reasonable adjustments for disabled people to avoid disadvantage and is clear that reasonable adjustment can include provision of information in an accessible format.

The Public Sector Equality Duty (PSED) – Scottish Specific Duties Regulations

As discussed in the introduction, we have been reviewing the effectiveness of the PSED regime and, in March 2021, published a report which identified issues and areas for improvement. We then made commitments to embed inclusive communication, and consulted on ambitious proposals for change relating to the SSDs, as well as the wider

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⁹⁴ Equality outcomes 2021-25

⁹⁵ Public Sector Equality Duty: specific duties in Scotland

environment for implementation so that the regime can be made tangible for everyone in Scotland.

We are introducing new SSDs to ensure inclusive communication is embedded proportionately across the work of listed authorities when they are communicating with the public.

This inclusive communications duty would sit alongside Scottish Government's other work to embed inclusive communication across the public sector, such as developing national standards, best practice, and a monitoring system for the effectiveness of this.

The Social Security (Scotland) Act 2018 ("the 2018 Act")

The 2018 Act⁹⁶ contains an example of a specific duty being placed on a public authority regarding inclusive communication. Section 4 of the 2018 Act states that the Scottish Ministers must have regard to the importance of communicating in an inclusive way as part of their duty to keep under consideration what steps they could take to ensure that individuals are given what they are eligible to be given through the Scottish social security system.

The 2018 Act explains that 'communicating in an inclusive way' means communicating in a way that ensures individuals who have difficulty communicating (in relation to speech, language or otherwise) can receive information and express themselves in ways that best meet each individual's needs.

The Public Sector Bodies (Websites and Mobile Applications) (No. 2) Accessibility Regulations 2018⁹⁷

In general, these Regulations place a duty on public sector bodies, including the Scottish Government, to make sure that their website or mobile applications are accessible. This means making them perceivable, operable, understandable and robust to an internationally recognised accessibility standard. In general, a public sector body responsible for delivering public services via a website or app must:

- evaluate the accessibility of websites and apps;
- fix identified accessibility issues; and
- publish an accessibility statement that explains to users the level of accessibility of the website, or mobile app.

The Patient Rights (Scotland) Act 2011 ("the 2011 Act")

The health care principles as set out in the 2011 Act⁹⁸ include reference to accessible information. Under section 5 of the 2011 Act, NHS bodies must, in performing their health service functions, uphold the health care principles in so far as they are relevant to the function being performed.

⁹⁶ Social Security (Scotland) Act 2018

⁹⁷ The Public Sector Bodies (Websites and Mobile Applications) (No. 2) Accessibility Regulations 2018

⁹⁸ Patient Rights (Scotland) Act 2011

The Health and Social Care Act 2012 ("the 2012 Act") – Accessible Information Standard

Whilst the 2012 Act is not applicable in Scotland, Scottish Government Guidance to NHS Scotland on Learning Disability Employment provides that the Accessible Information Standard⁹⁹, produced under section 250 of the 2012 Act, is seen as best practice for NHS Scotland Boards to help implement their duties under the 2010 Act. Whilst it is seen as best practice, it is not legally enforceable in Scotland.

The 2012 Act provides that organisations that provide NHS or adult social care have a legal duty, under section 250 of the 2012 Act, to make reasonable adjustments to improve access for disabled people.

Getting it right for every child (GIRFEC)

As noted in the introduction, GIRFEC¹⁰⁰ is our national approach to promoting, supporting and safeguarding the wellbeing of all children and young people, providing a consistent framework and shared language which puts their rights and wellbeing at the heart of the services that provide support to them and their families.

The GIRFEC National Practice Model seeks to help practitioners consider ways to help improve wellbeing for a child or young person. Children, young people and families should be supported to fully participate in discussions as the assessment of need is made and be at the heart of any planning, including receiving accessible information on the decisions reached and why.

What can we do about it?

The Scottish Government is progressing two initiatives to better protect and uphold rights around inclusive communication and information, as follows.

International Human Rights

The Convention on the Rights of Persons with Disabilities (CRPD)¹⁰¹ includes article relevant to inclusive communications and Articles 9 and 21 are particularly relevant.

Article 9 requires that appropriate measures are taken to identify and eliminate barriers to accessibility including information, communication and other services. This includes physical barriers. Article 21 requires that all appropriate measures are taken to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice.

As noted in the introduction, we are progressing a Human Rights Bill for Scotland to incorporate a wide range of internationally recognised human rights belonging to everyone in Scotland into Scots law, within the limits of devolved competence.

⁹⁹ Accessible Information Standard – Overview 2017/2018

¹⁰⁰ Getting it right for every child (GIRFEC) - gov.scot (www.gov.scot)

¹⁰¹ A Human Rights Bill for Scotland: consultation, June 2023

The Public Sector Equality Duty Review (PSED) – new Scottish Specific Duty Regulations (SSDs)

As discussed in the introduction, we have been reviewing the effectiveness of the PSED regime and, in March 2021, published a report which identified issues and areas for improvement. We then made commitments to embed inclusive communication, and consulted on ambitious proposals for change relating to the SSDs, as well as the wider environment for implementation so that the regime can be made tangible for everyone in Scotland. 103/104

We are introducing new SSDs to ensure inclusive communication is embedded proportionately across the work of listed authorities when they are communicating with the public.

This inclusive communications duty would sit alongside our other work to embed inclusive communication across the public sector, such as developing national standards, best practice and a monitoring system for the effectiveness of this.

Complaints Systems

Inclusive communications should also extend to complaints systems. Complaints systems start with individual organisations and many public organisations also come within the jurisdiction of the Scottish Public Services Ombudsman (SPSO) which means you may take a complaint to them if you are not happy with how you have been treated by an individual organisation and you have already complained to that organisation directly and used any appeal process.

Organisations within the jurisdiction of the SPSO must comply with complaint handling principles approved by the Scottish Parliament and, where the SPSO has issued one, with any model complaints handling procedure (MCHPs) applied to them.

The complaints handling principles approved by Parliament reference the need to be user-focused (recognise the needs of individuals) and accessibility¹⁰⁵. Most of the MCHPs contain a requirement to demonstrate how certain legal and other rights are being met. The MCHPs require public reporting of complaints statistics, performance and learning by the organisation.

The SPSO publishes summaries of case decisions online. Their cases include complaints by people with learning disabilities, people with dyslexia, ADHD and autistic people. Some complaints are related to the condition people have. Overall over 50% of people complaining to the SPSO declare a disability. Complaints upheld include from autistic people about treatment by healthcare providers.

¹⁰² Equality Outcomes and Mainstreaming Report 2021: Mainstreaming Report (www.gov.scot)

Public Sector Equality Duty (PSED) Review Consultation (www.gov.scot)

Public Sector Equality Duty - operation review: consultation analysis - gov.scot (www.gov.scot)

¹⁰⁵ Scottish Public Services Ombudsman Statement of Complaint Handling Principles <u>principles</u> (spso.org.uk)

In 2023-24, 1,012 users of the SPSO service answered a question identifying conditions: 70 people refer to a developmental disorder, 105 to a learning difficulty and 112 to a learning disability.

The SPOS has produced guidance around vulnerability.¹⁰⁶ However, complaints to the SPSO must be in writing, as set out in legislation, and so there may be a need for more flexibility around the method of complaint within individual organisations. Within the NHS, for example, there is a patient advice and support service (PASS) which offers support for people to make complaints. The PASS website has accessibility tools and the service itself allows for home visits.¹⁰⁷

We think that it is important that neurodivergent people and people with learning disabilities are able to make complaints in the same way as anyone else – with access to accessible and easy read information, with the ability to make complaints in different ways (and not necessarily in writing) and with confidence that their needs will be met.

We think this needs more work and consideration to establish how far existing complaints systems meet the needs of neurodivergent people and people with learning disabilities.

What can the 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 SSDs, in order to assist public authorities to understand and meet their particular needs. The provision of more accessible information links also to our proposals in the mandatory training section, which considers whether there should be a requirement for training for certain professionals in certain public sectors or services. 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.

¹⁰⁶ Scottish Public Services Ombudsman Complaints with Vulnerabilities Guidance <u>VulnerabilitiesGuidance.pdf (spso.org.uk)</u>

¹⁰⁷ PASS | Patient Advice and Support Service Scotland (pass-scotland.org.uk)

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 NHS Boards and 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. Local strategies could therefore be required to include consideration of, and reporting on, how the specific communications needs of neurodivergent people and people with learning disabilities have been 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?
- 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 this topic?

Section 4: Data

What we heard

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.

We have previously committed to improving the routinely collected data on autistic people and people with learning disabilities through the Towards Transformation Plan. Many of the actions in this Plan commit to developing or monitoring our picture of people with learning disabilities and autistic people. Action 9 highlights our ambitions to deliver these improvements working with our partners, however, it is acknowledged there is a long way to go to fully capture the life experiences of these groups through nationally collected and analysed data.

The lack of available evidence has been repeatedly mentioned in reports addressing the well-being of neurodivergent people and people with learning disabilities, such as the Fraser of Allander Institute's report¹⁰⁹ on data on the lives of people with learning disabilities in Scotland. This lack of data can restrict evidence-based policy making and planning.

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 did LEAP think?

- There is a lack of consistent and up-to-date data on neurodivergent people and people with learning disabilities to improve the visibility of these populations. We should improve data collection on key issues for neurodivergent people and people with learning disabilities, including health and wellbeing outcomes.
- An organisation should be made responsible for the collection of data, ensuring it is fit for purpose and published regularly.
- Current data collection and analysis should involve people with lived experience and include looking at intersectionality and particularly disadvantaged groups (eg delayed discharge patients, prisoners etc).
- There should be consideration of how to collect data from GPs.
- Data should be used to monitor and evaluate experiences and highlight gaps.
- People should have the opportunity to understand and contribute to the decisions around data collection and reporting.

¹⁰⁸ Employment - <u>Learning/intellectual disability and autism: transformation plan - gov.scot (www.gov.scot)</u>

¹⁰⁹ Data on the lives of people with learning disabilities in Scotland | FAI (fraserofallander.org)

- People should have the right to access their own data, but there are instances of services not allowing this.
- The Census should include questions which better capture neurodivergence.

Where do we want to get to?

- We collect sufficient and adequate data and measure outcomes to properly inform the development of national policies.
- We collect the right kind of information and data to know how many people with learning disabilities and neurodivergent people need local supports and services and what they need.
- Definitions of neurodivergent people, and people with learning disabilities, in data collections, are correct.

What happens now?

There are opportunities currently in terms of data sources which identify people with learning disabilities and neurodivergent people, some of which are currently being used for policy making and some of which could be improved by changing demographic questions in data collections.

Most barriers to better data across the public sector, especially for equalities, are wider than just neurodivergent people or people with learning disabilities. Specific issues centre around correctly identifying people, naming and definitions, and maintaining correct records.

The data collected about autistic people and people with learning disabilities is inconsistent. For some data sources, people have to self-disclose (say whether they have a condition) and this can lead to inconsistency too.

Scotland's Equality Evidence Strategy¹¹⁰, covering the years 2023 to the end of 2025, was published on 24 March 2023. The strategy states that we know there are gaps in the equality evidence base. The publication includes a three-year plan to make improvements.

We fund multiple bodies to research outcomes for people with learning disabilities and autistic people. This includes the Scottish Learning Disability Observatory (SLDO), Scottish Commission for People with Learning Disability (SCLD), the National Autism Implementation Team (NAIT) and the Fetal Alcohol Advisory Support and Training Team (FAAST).

¹¹⁰ Scotland's Equality Evidence Strategy 2023-2025 - gov.scot (www.gov.scot)

Relevant reports from the work of these bodies include SCLD's How's Life report, 111 SLDO's mortality reports, 112 and NAIT's neurodevelopmental pathways report. 113 These reports have been helpful snapshots on specific topics and have impacted on national policy making. However, there is a need for routine data collection that lets us know if there are changes over time, allowing monitoring rather than snapshots.

Learning Disabilities Statistics Scotland (LDSS)¹¹⁴ is one of the best sources of data we have on people with learning disabilities. It is based on national and local authority level figures.

LDSS only collects data on people with learning disabilities and there is a need to review the questions to ensure they are fit for purpose. Additionally, there are issues in terms of the completeness of the returns from local authority areas. Due to issues with returns, data protection and prioritisation during the pandemic, LDSS has not been published over the last 3 years. However, work is underway to review LDSS and restart data collection and publication.

In England, the LeDeR programme¹¹⁵, funded by NHS England and NHS Improvement, was established in 2017. It aims to:

- Improve care for people with a learning disability and autistic people.
- Reduce health inequalities for people with a learning disability and autistic people.
- Prevent people with a learning disability and autistic people from early deaths.

LeDeR summarises data on the lives and deaths of people with learning disabilities and autistic people in annual reports. Once LeDeR is notified of someone's death, their case is referred to a reviewer in the person's local area. The reviewer will contact the multiple people (including family member / carer and the person's GP) to talk about the person's life and death, usually within 6 months. A LeDeR review looks at key episodes of health and social care the person received that may have been relevant to their overall health outcomes. The reviewer will send the completed review to the local governance group or panel with the areas of learning, good practice and concern. The group or panel will decide on actions to take, who will take these actions, and the help they need to reduce health inequalities and stop people dying too young from preventable causes.

What can we do about it?

Work is currently ongoing to review and restart the LDSS data collection. We have also undertaken an exercise to assess the data and evidence collected across Scotland to identify the priority gaps. This assessment has informed the development of a data action plan that we and our partners will take forward to

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¹¹¹ Methods-Report-October-2020.pdf (scld.org.uk)

¹¹² Life expectancy of people with learning disabilities | Our research | Scottish Learning Disabilities Observatory (sldo.ac.uk)

¹¹³ NAIT Adult Neurodevelopmental Pathways report - gov.scot (www.gov.scot)

¹¹⁴ Learning Disability Statistics Scotland, 2019

¹¹⁵ LeDeR

address gaps and improve our understanding of people with learning disabilities and autistic people across Scotland throughout their lives.

Through our extensive work with people with lived experience we collect a great deal of qualitative data which informs our policy work. This includes a Leadership and Engagement project which is an opportunity to bring people with lived experience together with people responsible for providing services nationally and locally. Working with our partners at Inspiring Scotland and the Learning Disabilities Assembly, we have also undertaken exercises to gather the voices of people with lived experience through surveys and focus groups. We are currently working with autistic people and people with learning disabilities to implement the findings of this work.

In May 2022, we announced Annual Health Checks for adults with a learning disability aged 16 and over across Scotland. Each Health Board area will offer every eligible person a first check by 31st March 2024. We have funded the Scottish Learning Disability Observatory to undertake research with SPIRE and PHS to use the data collected as part of this work to identify how many people with learning disabilities are registered with GPs.

We set out our Health and Social Care Data Strategy¹¹⁶ in February 2023. Together with COSLA, we are committed to developing a nationally consistent, integrated, and accessible, electronic social care and health record. The integrated record will support people to tell their story only once and ensure that staff have the right information at the right time to deliver the right care. This record, including the requirements of this record, will be co-designed.

What can the 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 Elsewhere in this consultation, at 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.

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¹¹⁶ Health and social care: data strategy - gov.scot (www.gov.scot)

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 LeDeR programme. Similar to Child Death Reviews, a programme could be established to ensure when someone with a learning disability dies, that a review happens to identify why they died and share the learnings of how it could have been prevented. Teams would need to be established to undertake this work, including the appropriate training. We would use examples of good practice to share across the country. 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?
- 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 this topic?

Section 5: Independent Advocacy

Independent advocacy can play a key role in helping people to secure their rights. An independent advocate will help someone's voice be heard. This can help people to make choices about their services and supports. There are different kinds of independent advocacy and this includes **collective advocacy** when people are supported to come together to talk about their experiences and challenge discrimination.

What we have heard

We know that neurodivergent people and people with learning disabilities often don't know what their rights are - but they know and experience when things are not working in practice. People often have rights they don't know they have or, where they know about them, they aren't sure how to access those rights. Neurodivergent people, and people with learning disabilities, can struggle to be heard.

Independent advocacy is one way that people can receive help to understand and access their rights. Other things are also important - like accessible communications and complaints systems, professionals who are trained in working with neurodivergent people and people with learning disabilities, and access to legal representation.

The right to independent advocacy in the Mental Health (Care and Treatment) Scotland Act 2003 ("the 2003 Act")¹¹⁷ applies to every person with a 'mental disorder', a term that is interpreted broadly to include autistic people and people with learning disabilities. It is the duty of local authorities and health boards to make services available.

The 2003 Act does not specify the circumstances under which the right should apply, however, Mental Health Officers have duties to inform patients who are receiving compulsory care and treatment of the availability of services and to help them to access these as required. In practice, therefore independent advocacy services may be most frequently provided in these circumstances.

People have told us that they want more rights to accessible independent advocacy that is clearly signposted and available across the country.

What did LEAP think?

- A right to independent advocacy would help neurodivergent people and people with learning disabilities, secure their human rights.
- There are a number of barriers and prejudice experienced and independent advocacy could help people obtain justice.
- The Bill should provide a right to independent advocacy in a range of settings including health and social care, education and training, employment, benefits and housing.

¹¹⁷ Mental Health (Care and Treatment) (Scotland) Act 2003 (legislation.gov.uk)

- The right should state that independent advocacy should be provided by individuals with specific training on neurodivergence and learning disabilities. It should be individual advocacy and not collective advocacy.
- If a Commission/er is to be created, they should be responsible for ensuring the provision of an independent advocacy service for neurodivergent people and people with learning disabilities.

Case Study

"One of the most damaging myths about autistic people is a belief that we aren't interested in having relationships. How would there be autistic people in the world if there weren't autistic/neurodivergent families everywhere? We fall in love, just like anyone else, and sometimes love ends. I am autistic and have an autistic child. I separated in 2019, just before the pandemic. This is a snippet of my journey through the complexities of being neurodivergent, and how I had to face a crisis within a crisis, in a world that fails to understand our everyday needs and challenges.

In the midst of my separation, I found myself confronted with a myriad of responsibilities, from managing my own life to advocating for my autistic child, to managing a degree, to moving homes, and all of this with the COVID-19 pandemic as a background.

I desperately needed help yet when I approached Social Work and various other departments within the local authority, I was met with indifference and a surprising lack of understanding of autism given the remit of these bodies. Seemingly, we weren't struggling enough to be granted help. I lost count of the times I told our story to people on whose checklists we didn't tick the right boxes.

Ever since he had started primary school I had struggled to convince head teachers of my son's needs. By P6 he had had enough and left school due to relentless bullying and lack of adaptations. The class environment, with its sensory overload and social complexities, had become unbearable for him. The teachers struggled to understand why my child faced difficulties at school, assuming he was "rebellious" or "lazy". He became home-educated at the end of 2019, and after the lockdowns ended he decided he didn't want to go back to school.

The isolation I've felt in the last three years has been suffocating.

Something that is not often talked about is the effect of trauma and social isolation caused by being different, other, always. As well as I and my son being the only known autistic family in the neighbourhood, I am the only foreign born in this area of a very tight knit rural community.

.../continued

I grew to hate the word resilience. I felt overwhelmed and had to drop out of my university course. All NHS mental health practitioners had to offer was CBT, which isn't effective for autistic people. Social workers downplayed our needs and rejected my application for SDS, because the assessment failed to pick up on obvious aspects, like sensory and emotional difficulties that I as an adult experience on a daily basis. The energy required to navigate these challenges was overwhelming, and our struggles are far from over.

My experiences underscore the urgent need for specially trained advocates who could bridge the gap between neurodivergent individuals and decision-makers who lack understanding. We shouldn't be left to self-advocate in times when self-advocacy is the most energy consuming, burdensome, of tasks."

Where do we want to get to?

Neurodivergent people and people with learning disabilities:

- know what their rights are;
- are communicated with in a way that is inclusive and accessible to help them secure their rights; and,
- can access support when needed, including independent advocacy.

What happens now?

There are different approaches to free independent advocacy in Scotland. There are some rights in law, in addition to the 2003 Act, but they can be set out differently:

- A right to advocacy for a disabled person accessing Scottish social security entitlements where help is needed to engage effectively with the process as set out in section 10 of the Social Security (Scotland) Act 2018.¹¹⁸
- A duty to ensure that advocacy support is available and free of charge when someone is going to a Tribunal held under the Education (Additional Support for Learning) (Scotland) Act 2004¹¹⁹ or when a child attends a children's hearing under the Children's Hearings (Scotland) Act 2011.¹²⁰
- There can be a duty to provide information about available advocacy services
 e.g. as set out in the Social Care (Self-directed Support) (Scotland) Act 2013¹²¹
 and for children referred to a Children's Hearing as set out in the Children's
 Hearings (Scotland) Act 2011.
- There is a duty on Scottish Ministers to develop and publish advocacy service standards in the Social Security (Scotland) Act 2018.

¹¹⁸ Social Security (Scotland) Act 2018 (legislation.gov.uk)

¹¹⁹ Education (Additional Support for Learning) (Scotland) Act 2004 (legislation.gov.uk)

¹²⁰ Children's Hearings (Scotland) Act 2011 (legislation.gov.uk)

¹²¹ Social Care (Self-directed Support) (Scotland) Act 2013

- There is a duty to allow advocates to take part in discussions or make representations on an individual's request in the Education (Additional Support for Learning) (Scotland) Act 2004.¹²²
- There is a duty for a local authority to consider the importance of providing advocacy under the Adult Support and Protection (Scotland) Act 2007¹²³ where they need to intervene to protect an adult at risk of harm.
- Independent advocates are also available to children and young people with additional support needs aged 12-15 in school under "My rights, my say".

This means that, whilst there are some rights in law, particularly for people with learning disabilities and autistic people, they are not consistent. It can also be difficult to obtain an independent or specialist advocate in practice due to funding constraints and the limited availability of advocates.

Under the 2003 Act, the duty to provide advocacy to autistic people and people with learning disabilities is placed on local authorities and Health Boards collaborating together – independent advocacy must be available and appropriate steps taken to make sure people can use the service.

The Mental Welfare Commission¹²⁴ reported this year (2023) on how Health Boards and local authorities are performing in terms of their duty to provide independent advocacy services. They noted that, whilst some progress had been made, the Covid 19 pandemic had impacted the availability of staff to deliver advocacy services and not enough advocacy was available. There had been few increases in funding and there was an ongoing need to strengthen advocacy for children and young people. Recommendations included the need for strategic plans and the level and terms of funding.

The Scottish Mental Health Law Review¹²⁵ also made recommendations about independent advocacy and the 2003 Act. It stated that only around 5% of people who have the right to independent advocacy actually access it. The Rome Review of the 2003 Act included a range of recommendations around advocacy for people with learning disabilities and autistic people. It particularly recommended that advocacy be provided on an opt out basis and that non-instructed advocates should be available to those with severe communication disabilities.

What can we do about it?

We are looking at how we can improve rights through the availability of independent advocacy through our policies on:

- The creation of a National Care Service through the National Care Service (Scotland) Bill (the "NCS Bill"); and,
- Our response to the Scottish Mental Health Law Review.

¹²² Education (Additional Support for Learning) (Scotland) Act 2004

¹²³ Adult Support and Protection (Scotland) Act 2007 (legislation.gov.uk)

TheRightToAdvocacy2022_April2023.pdf (mwcscot.org.uk)

¹²⁵ Scottish Mental Health Law Review – Final Report [Archived] (nrscotland.gov.uk)

Section 13 of the NCS Bill¹²⁶ as introduced states that "The Scottish Ministers may by regulations make provision about the provision of independent advocacy services in connection with the services that the National Care Service provides."

Proposal 1: Strengthen and improve access to existing advocacy provisions

We want to take time to make sure that there is more consistency around our approach to advocacy and we want to involve people with lived experience in helping us to design this. To do this, we will:

- work with the Scottish Independent Advocacy Alliance, other organisations and people with lived experience to help identify how best to strengthen rights and access to provision; and,
- develop a consistent definition of 'Independent Advocacy'.

This work will take place across the Scottish Government and we will ensure that it includes specific consideration of the rights of neurodivergent people and people with learning disabilities. How we legislate for advocacy for these groups will depend on the proposed changes in the NCS Bill and to mental health legislation, including whether people with a learning disability or autistic people remain covered by provisions within the 2003 Act.

This means that we are not currently proposing a broad right in this Bill to independent advocacy for neurodivergent people and people with learning disabilities. However, we think there are some other things we could explore in the Bill especially since the right to advocacy under the Mental Health Act only applies the duty to the State Hospital, Health Boards and local authorities (although Health and Social Care Partnerships may in some cases be carrying out this duty) and only applies to a subset of neurodivergent people (as people with a "mental disorder" under the legislation includes people with learning disabilities and autistic people).

Therefore, we could:

- Provide a power in the Bill that allows us to make regulations around the
 provision of independent advocacy for neurodivergent people and people with
 learning disabilities whilst further discussions take place about how to improve
 this.
- Include a provision in the Bill that places a duty on all public bodies to ensure that all neurodivergent people and people with learning disabilities are given information about advocacy and how to appoint their own independent advocate to support them.

Proposal 2: Improve our Understanding of Independent Advocacy

We will also in the meantime identify and gather evidence on specific circumstances where a right to independent advocacy could make a difference.

¹²⁶ National Care Service (Scotland) Bill – Bills (proposed laws) – Scottish Parliament | Scottish Parliamen

For example, we know that there are some circumstances where additional support could help, as follows:

• Evidence from a research published by the Scottish Commission for Learning Disabilities¹²⁷ suggests that where women with a learning disability have been subject to gender-based violence they struggle to access support due to discrimination and stereotyping. There can be significant barriers to accessing support and to effective support when people are able to come forward. Professionals may not recognise that someone has learning disabilities and if they do they may not have any relevant training in how to support them.

"Women with learning disabilities can also be fearful of Adult Support and Protection and Child Protection processes and this can stop them from disclosing violence and abuse. Women can face negative attitudes about their ability to parent as a result of reporting abuse. Although some women may benefit from the provision of an appropriate adult where they make a complaint, this is not consistent."

 The Equalities and Human Rights Commission, in its Inquiry report into housing for disabled people in 2018, recommended that local authorities should ensure that people with learning disabilities have access to good-quality, accessible advice and advocacy when discussing housing options and to help them navigate complex systems.

We could consider whether the Bill could provide some specific legal rights to free independent advocacy in these circumstances, as well as others.

What Do You Think?

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

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¹²⁷ Unheard-Unequal-Unjust—But-not-Hidden-web-version.pdf (scld.org.uk)

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

What We Heard

"Hard to reach", "lack of engagement/failed to engage", "did not attend", "non-compliant" "hypochondriac" are some of the ways that neurodivergent people and people with learning disabilities can be described or labelled in health care. We also heard that people with learning disabilities are often referred to as having 'challenging behaviour' when what is happening is a failure in communication.

Too many neurodivergent people and people with learning disabilities feel failed by a system they have tried to engage with, due to lack of understanding. This has fostered distrust and disbelief in the accountability of services. This can often lead to negative outcomes and a decline in quality of life. People with learning disabilities and neurodivergent people experience poorer health outcomes than the general population which can be preventable.

People with learning disabilities have some of the poorest health outcomes of any group in Scotland and die on average 20 years earlier than the rest of the population, which is largely preventable, according to research. Research also indicates that adults with learning disabilities are twice as likely to die from preventable illnesses.

The life expectation for people with Profound and Multiple Learning Disabilities (PMLD) is further reduced. There are still many premature deaths of people with PMLD caused by the lack of reasonable adjustments to facilitate their survival, causing delay or problems with diagnosis or treatment. People with PMLD exhibit a different pattern and higher frequency of health disorders which, coupled with communication challenges, lead to barriers in accessing and receiving healthcare.

Mortality is high among people with PMLD, with over 20% dying in a 10 year period¹³¹. The principal causes of death arise from epilepsy, respiratory problems and difficulties in eating and drinking.

The key issue for effective health care for people with profound and multiple learning disabilities is good communication between the family, carers and all those involved health professionals. The importance of listening to the families and carers and

¹²⁸ Research projects | Our research | Scottish Learning Disabilities Observatory (sldo.ac.uk)

Rates, causes, place and predictors of mortality in adults with intellectual disabilities with and without Down syndrome: cohort study with record linkage | BMJ Open

¹³⁰The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study - PubMed (nih.gov)

Policy, service pathways and mortality: a 10-year longitudinal study of people with profound intellectual and multiple disabilities - PubMed (nih.gov)

respecting their knowledge and experience must be acknowledged by all health staff. Partnership working should also be strengthened between health professionals from the community, including allied health professionals who have specialised knowledge of persons with PMLD, and health professionals in the acute sector.

There is a need for effective procedures to be in place between GPs and other community health professionals so that in the event of an emergency admission all health staff are able to respond appropriately to the needs of the person with PMLD. There is a need to ensure sufficient training for health professionals on communication and learning disabilities in general and people with PMLD in particular.

The available evidence indicates that autistic people die on average 16 years earlier than the general population.¹³² There are many possible reasons for this gap, including poor professional understanding of autism among health and care staff, which can result in autistic people having signs of illness, or their needs, overlooked.

Autistic people are also at a higher risk of suicide than non-autistic people. Figures show that as many as 11-66% of autistic adults had thought about suicide during their lifetime, and up to 35% had planned or attempted suicide. ¹³³

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

Reasonable adjustments should ensure that the needs of neurodivergent people and people with learning disabilities are included in all health services and preventative health screening programmes, and in the design and delivery of specific services and supports.

As part of the development of our Leadership and Engagement Framework, the mental health of Neurodivergent People and People with Learning Disabilities was selected as the first topic to be address by people with lived experience.

Several strands of research were carried out around mental health services and supports including peer research by our autistic and learning disability lived experience groups, as well as supporting academic literature reviews. 134

Key findings from the research across both groups identified shared issues around: diagnosis and/or lack of diagnosis of mental health issues; barriers and poor access to mental health services and a fundamental need for ongoing support.¹³⁵

¹³² Premature mortality in autism spectrum disorder | The British Journal of Psychiatry | Cambridge Core

Anxiety and Depression from Adolescence to Old Age in Autism Spectrum Disorder - PubMed (nih.gov)

¹³⁴ Literature Reviews: Research Summary: Mental Health in Autistic Adults written by NAIT, and Learning/intellectual disabilities mental health evidence review written by The Observatory

¹³⁵ Assenti Research reports – <u>Autistic Community Report</u> and <u>Parents and Carers Report</u> The Assembly's report on their <u>mental health services</u> workshops and priorities.

What did LEAP think?

- There is a need for guidance and mandatory training for health and social care staff that is kept up to date. Implementation of training should be monitored.
- Annual health checks being implemented for people with learning disabilities must be implemented consistently without a 'postcode lottery'.
- There should be a choice about how to attend an appointment online appointments should be made available where appropriate.
- In terms of mental health care, therapies and staff may not be neurodivergent informed, including in relation to learning disabilities. This can compound trauma.
- There is a need for trauma informed, neurodevelopmentally informed and culturally sensitive approaches.
- There is a need for timely access to diagnosis, better diagnosis guidelines and better signposting to support.
- There is a need for data on understanding and managing the demands placed on people when looking for diagnosis and other supports.

Where do we want to get to?

- Neurodivergent people and people with learning disabilities have improved health and wellbeing, live longer lives and are able to choose to be active members of society.
- The health and social care workforce is knowledgeable and skilled in treating neurodivergent people and people with learning disabilities.
- Neurodivergent people and people with learning disabilities access health care, services and supports without undue stress and the risk of traumatising or retraumatising experiences.
- Neurodivergent people and people with learning disabilities are empowered with knowledge and understanding, choice and control over their health care and treatment.

What rights do people have?

There are legislative rights in place though they are not specifically for people with learning disabilities or neurodivergent people:

 The Patient Rights (Scotland) Act 2011 (The Charter of Patient Rights and Responsibilities)¹³⁶

¹³⁶ The Charter of Patient Rights and Responsibilities

- The National Health Service (Scotland) Act 1978)¹³⁷
- The Health and Social Care Standards prepared under the Public Services¹³⁸
- Reform (Scotland) Act 2019¹³⁹
- National Health Service (Scotland) Act 1978¹⁴⁰

What happens now?

National Care Service Bill – we remain committed to delivering a National Care Service (NCS) to improve quality, fairness and consistency of provision that meets individuals' needs. We are working with people with lived experience and frontline workers to co-design the detail of the NCS. Services will continue to be planned, designed and delivered at a local level, creating a person-centred, outcome-focused approach to care.

Health and Social Care Data Strategy – in partnership with COSLA, we are committed to developing a nationally consistent, integrated, and accessible electronic social care and health record. The integrated record will support people to tell their story only once and ensure that staff have the right information at the right time to deliver the right care.

Suicide Prevention Strategy - we are considering inequalities and diversity to ensure we meet the suicide prevention needs of the whole population whilst taking into account key risk factors, such as poverty and social isolation.

Mental Health Strategy Delivery Plan – this includes our current commitments to both annual health checks and the development of adult neurodevelopmental pathways for better diagnosis and support.

Dementia Strategy - we will have an enhanced focus on equalities, working with others to help minimise the structural barriers to participation, diagnosis, treatment, support and care, regardless of ethnicity, race, sex, gender reassignment, sexual orientation and additional disability or neurodivergence.

Racialised Health Inequalities - we are implementing the recommendations made by the Expert Reference Group on Covid-19 & Ethnicity in 2020.¹⁴¹ As part of this, we are building understanding of and commitment to addressing racialised health inequalities, taking an anti-racism approach. Action to date includes the establishment of the Racialised Health Inequalities in Health & Social Care Steering Group, and the development of an action plan with commitments across health and social care.

Lived Experience leadership and engagement on mental health and accessing services – we have brought together and are supporting lived experience groups of autistic people and people with a learning disabilities to create their own resources

¹⁴⁰ National Health Service (Scotland) Act 1978

¹³⁷ National Health Service (Scotland) Act 1978

¹³⁸ Health and Social Care Standards: my support, my life

¹³⁹ Planning (Scotland) Act 2019

Expert Reference Group on COVID-19 and Ethnicity: recommendations to Scottish Government - gov.scot (www.gov.scot)

for health and social care professionals. The aim of this work is to increase professionals' awareness of these conditions and what is needed to support these groups to access support and services. The resources are being tested and evaluated between November 2023 and January 2024 within a variety of settings, including primary care GP practices, NHS 24 and the Scottish Ambulance Service.

Adult neurodevelopmental pathways – the National Autism Implementation Team (NAIT) is supporting NHS Boards and HSCPs to develop adult neurodevelopmental pathways. We funded a series of pilots around adult pathways for support and diagnosis. The report was published in March 2023 and we have accepted and are working on the recommendations.¹⁴²

Neurodevelopmental pathways for children and young people - there is a separate neurodevelopmental pathway for children and young people. In 2021 we published the National Neurodevelopmental Specification for Children and Young People: Principles and Standards of Care¹⁴³ which sets out seven standards for service providers to ensure that children and young people who have neurodevelopmental profiles receive the right support.

What can the 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

The overarching themes section sets out proposals for statutory strategies. We are proposing legislative requirements for these 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

The overarching themes section sets out proposals around mandatory training. Earlier in this section, we set out that 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, the UK Government's preferred and recommended training for this purpose is called the Oliver McGowan Training.¹⁴⁴

¹⁴² NAIT Adult Neurodevelopmental Pathways report - gov.scot (www.gov.scot)

¹⁴³ Children and young people - national neurodevelopmental specification: principles and standards of care - gov.scot (www.gov.scot)

¹⁴⁴ The NHS Constitution. (2023) <u>The Oliver McGowan Mandatory Training on Learning Disability and Autism | Health Education England (hee.nhs.uk)</u>

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

The overarching themes section sets out proposals on inclusive communications. 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. This could mean being able to request an online or telephone meeting rather than face to face, or other forms of communication.

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 NHS Boards and 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 Statements¹⁴⁵ that can be used by people with mental health conditions, or it could be based on PAMIS's Digital Passports.¹⁴⁶

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 significantly poorer

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¹⁴⁵ Advance Statements | Mental Welfare Commission for Scotland (mwcscot.org.uk)

¹⁴⁶ PAMIS Digital Passports | PAMIS

health outcomes of people with learning disabilities, annual health checks will provide a mechanism to mitigate risk, monitor delivery of treatment, and measure impact. The rollout of health checks is backed by significant evidence of the benefits this can have. We want to consider including the delivery of annual health checks as a specific legal duty in the Bill.

Autistic people, people with FASD and 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 of 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?
- 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 this topic?

Section 2: Mental Health and Capacity Law

What we heard

Current mental health, capacity and adult support and protection legislation in Scotland can, in certain circumstances, apply to autistic people and people with learning disabilities.

The law uses the term 'mental disorder', as defined within the Mental Health (Care and Treatment) (Scotland) Act 2003 (the "Mental Health Act")¹⁴⁷. We accept that this term is seen by many as stigmatising and offensive towards people with lived experience. However, it is used in this document to reflect the language of the legislation, where needed.

We have heard strong views from some individuals and organisations that people with learning disabilities and autistic people should not fall within the definition of 'mental disorder'. This is because life-long conditions cannot be 'treated' in the same way that mental illness can. The condition may be managed, and the person may be supported, but there is no treatment that can lead to the person no longer being autistic or having learning disabilities. Many learning disability groups have said that the inclusion of learning disability in the definition of mental disorder means they feel they are stuck in a system that is not designed to meet their needs.

We also note that, in England and Wales, the UK Government has proposed to change mental health legislation to limit the scope of detention to remove those with autism and learning disabilities from some, but not all, powers under their mental health legislation.¹⁴⁸

What did LEAP think?

- People should not be 'locked up' under mental health legislation in Scotland on the basis that they are autistic or have learning disabilities. The LEAP finds this wholly unacceptable.
- Learning disabilities and autism are lifelong conditions and are not curable, and they are not a mental health issue.
- Neurodivergence and learning disabilities are part of the natural diversity of human expression. We do not need curing, we just need acceptance.
- Autism and learning disabilities should not be considered a mental disorder, which is upsetting, degrading, and insulting and the LEAP believes this disrespects the human rights of people with learning disabilities and autistic people.
- LEAP believes that medication is used too quickly under the Mental Health Act and sometimes before a mental health issue is identified or properly diagnosed. LEAP also believes things escalate too quickly, just because a person has a learning disability.

¹⁴⁷ Mental Health (Care and Treatment) (Scotland) Act 2003

¹⁴⁸ Reforming the Mental Health Act: summary - GOV.UK (www.gov.uk)

- LEAP members don't accept the label 'challenging behaviour'. More often than not, disruptive episodes are a consequence of a communication failure and, sometimes, it's about exercising our right to be heard.
- LEAP believe that more importance should be placed on Supported Decision
 Making to actively involve the individual in the decision-making that impacts their
 freedom and their human rights.
- Autistic people often find inpatient mental health wards distressing and detrimental to their mental health instead of beneficial.
- One LEAP member referred to their experience of being detained under the Mental Health Act on a number of occasions over two decades and having experienced significant harm. Psychiatric medications they were prescribed caused pregnancy complications. This resulted in brain damage to their child causing significant physical and learning disabilities. They said that these potential harms should be considered where compulsory treatment and detention happen.

Where do we want to get to?

We want to update and modernise our mental health and capacity legislation to enhance the protection, respect and championing of people's rights.

What is the current position in law?

Mental health and capacity law in Scotland is comprised of the following legislation, together with relevant secondary legislation:

The Adults with Incapacity (Scotland) Act 2000 ("the AWI Act")

The AWI Act provides for interventions to be made in an individual's life where they are unable to make decisions for themselves because of incapacity due to a mental disorder or an inability to communicate. Interventions can include decisions made about a person's care, welfare, living arrangements, restrictions on those living arrangements and financial decisions providing the person responsible for effecting the intervention is satisfied that the intervention will benefit the adult, is the least restrictive option, and such benefit cannot reasonably be achieved without the intervention. Guardianship Orders and Power of Attorney Orders can be secured under the AWI Act.

The Mental Health (Care and Treatment) (Scotland) Act 2003 ("the Mental Health Act")

The Mental Health Act provides for the compulsory assessment, treatment, care, and support of people with mental illness or mental disorder. It is used when individuals are unable to make their own decisions about treatment or if they do not want, but still need, treatment, care and support. The Mental Health Act applies to children and young people as well as adults.

The Adult Support and Protection (Scotland) Act 2007 ("the ASP Act")

The 2007 Act¹⁴⁹ provides for interventions to be made to protect adults at risk. For the purposes of the ASP Act, an adult at risk is a person who is unable to safeguard their own well-being, property, rights or other interests; who is at risk of harm; and because they are affected by disability, mental disorder, illness or physical infirmity is more vulnerable to being harmed than adults who are not so affected. Harm can include physical, financial, sexual or psychological abuse, and neglect and discrimination. Interventions can include protection orders: assessment orders, removal orders or banning orders.

Definition of 'mental disorder' and applicability to people with learning disabilities and autistic people

The criterion of 'mental disorder' is set out in the Mental Health Act¹⁵⁰. This definition is also used as criterion for possible intervention under the AWI Act and the ASP Act. 'Mental disorder' is currently defined under s.328(1) of the Mental Health Act as:

- a. Mental illness
- b. Personality disorder
- c. Learning disability

Although not specifically listed, autism has historically been understood as being encompassed within the definition of mental disorder.

An individual cannot, however, be made subject to compulsory measures for care and treatment under the Mental Health Act only because they meet the criterion of mental disorder. For example, before a compulsory treatment order can be made, all of the following conditions must also be met:¹⁵¹

- The patient has a mental disorder;
- That medical treatment is available which would likely (a) prevent the mental disorder worsening or (b) alleviate any of the symptoms of effects or the disorder;
- If the patient were not provided with such medical treatment, there would be a significant risk to (a) the health, safety or welfare of the patient; or (b) the safety of another person;
- That because of the mental disorder the patient's ability to make decisions about medical treatment is significantly impaired; and,
- The compulsory treatment order is necessary.

"Treatment" under the Mental Health Act for "mental disorder" includes:

- Nursing
- Care
- psychological intervention

¹⁴⁹ Adult Support and Protection (Scotland) Act 2007

¹⁵⁰ Mental Health Act 1983

¹⁵¹ Mental Health (Care and Treatment) (Scotland) Act 2003 (legislation.gov.uk)

- habilitation (including education, and training in work, social and independent living skills)
- rehabilitation.

Similarly, under the AWI Act an intervention can only be made if the intervention will benefit the adult and the benefit cannot reasonably be achieved without the intervention. The intervention should be the least restrictive option in relation to the freedom of the adult and the past and present wishes of the adult, so far as they can be ascertained, must be taken into account in determining if an intervention is to be made.

What has happened so far on this issue?

Mental Health and capacity law in Scotland has been subject to two major reviews in recent years: the Rome report¹⁵² and the Scottish Mental Health Law Review (SMHLR)¹⁵³.

The Rome report, on learning disability and autism within the Mental Health Act, was published in December 2019. It recommended removing learning disability and autism from the definition of 'mental disorder' and creating a separate law to provide support and equity in law for these groups. The report recognised that, nevertheless, if someone had a mental illness over and above their lifelong condition which brought them within the remit of mental health law then the law would apply to them in the same way as to any other person.

The SMHLR reviewed mental health, capacity and adult support and protection legislation in Scotland and reported in September 2022. It observed that the diagnostic criterion of mental disorder has been criticised as being a violation of the CRPD anti-discrimination requirements in relation to the right to exercise legal capacity (Article 12) and the right to liberty (Article 14). However, it was observed that for detention to be lawful under Article 5 of ECHR, it must fall within one of the specified categories where detention is allowable. This means that, in the language of the ECHR, an individual must be of 'unsound mind', and it was noted that the Winterwerp¹⁵⁴ ruling has determined that lawful psychiatric detention requires objective medical evidence of a 'true mental disorder'.

The SMHLR recommended a different approach to the Rome report. Early on in its work, the SMHLR made the decision that a reformed mental health and capacity legal framework should have a new, positivist purpose, which has at its heart the aim of enabling people's rights rather than removing them. Accordingly, it was recommended that the law should be as inclusive as possible in its scope and include autism and learning disabilities.

It was recommended that the gateway to access the rights anticipated by new legislation should be wide enough to ensure those in need of help and support can

¹⁵² The independent review of Learning Disability and Autism in the Mental Health Act. p.16. [Archived] (nrscotland.gov.uk)

¹⁵³ Scottish Mental Health Law review Final Report [archived] (nrscotland.gov.uk)

¹⁵⁴ Winterwerp v Netherlands 6301/73 [1979] ECHR 4 - Mental Health Law Online

access it appropriately, and such access must not be conditional on an 'incapacity test' or other similar threshold being met.

Consequently, the two reports have left us with two different recommendations on the way people with learning disabilities and autistic people should be included within mental health and capacity legislation in Scotland.

In terms of supported decision-making, the SMHLR recommended a new framework for human rights, supported decision-making and autonomous decision-making. It made a strong argument to further the development of supported decision-making in Scotland to try to achieve this and secure the best outcomes for people who lack capacity. In our response, we noted our agreement that the voice of those using services should be strengthened.

We recognise that supported decision-making is an important part of shifting the way in which the system fulfils people's rights. That is why we have committed to take forward as part of our first priorities under the Mental Health and Capacity Law Reform Programme work to review and build on existing practices, working with partners to support the development and roll-out of effective supported decision-making practices and approaches. Based on learning and evaluation from this work we will consider whether a national framework approach is needed.

We know that independent advocacy can be instrumental in supported decision making. This is why we have also committed to working with the Scottish Independence Advocacy Alliance, its members and organisations providing advocacy services, as well as people with lived experience of accessing services, to help identify and address gaps and improvements in provision.

What can the LDAN Bill do?

The proposed purpose of the LDAN Bill is to better protect, respect and champion the rights of neurodivergent people and people with learning disabilities. The LDAN Bill could, therefore, propose to make changes to mental health and capacity legislation in Scotland as it relates to autistic people and people with learning disabilities. Those changes could be to:

- (1) specifically remove learning disability and autism from the scope of mental health and incapacity legislation; or,
- (2) change "mental disorder" to a term that is not stigmatising or offensive.

However, we are not at this time consulting on any proposals for legislative change in this area. This is not because we do not think it is important but because more work needs to be carried out to consider how we balance the different recommendations of the Rome report and the SMHLR.

We know that people with learning disabilities and autistic people have been asking for change in this area for a long time. We therefore need to consider what we can do to address these concerns and what this would mean in practice, including any consequences to the rights and protections the Mental Health Act provides to people

¹⁵⁵ Scottish Mental Health Law Review - Our Response (www.gov.scot)

with learning disabilities and autistic people who are currently treated under this legislation.

We know that people took time to make their views clear to both the Rome review and the SMHLR. We are not asking for those to be reiterated. We now want to develop options and consider whether there is an evidence-base for potentially making changes, ahead of wider reform. We need to more fully understand the consequences and implications of any changes, including any unintended consequences, to ensure that people with learning disabilities and autistic people still have appropriate rights, protections and support where needed.

For example, if we were to remove learning disability and autism from the current definition of mental disorder, we need to understand what this means for some of the people who are currently receiving care and treatment under the Mental Health Act.

A short-term piece of work is being prioritised as one of the first actions under the Mental Health and Capacity Reform Programme. That work will consider the current definition of mental disorder within the Mental Health Act and the approach to compulsory care and treatment and safeguards. This will include, amongst other aspects, consideration of whether learning disabilities and autism should continue to fall within the definition, along with updating the language of the definition.

The outcome of this work may lead to a change in the law. The LDAN Bill may be an appropriate place to make those changes, however, that will be determined once the work has concluded.

Initial work on this has begun with a scoping workshop held in November this year to help inform the design of the workstream. This included people with lived experience, the organisations and people that represent them, and practitioners. We will continue to fully involve people with lived experience in the process as we develop any proposals for future consultation.

What Do You Think?

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

Section 3: Social Care

What we have heard

For those people who need it, social care, social work and community health are vital supports that enable people to live fuller lives connected to their local communities.

Based on figures from the Independent Review of Adult Social Care (the work that led to proposals for a National Care Service), around 21% of the social care budget (£780m) is invested in services for people with learning disabilities.

People with learning disabilities and neurodivergent people are more likely to present with care and support needs compared to some other groups and those needs may be perceived as more complex by the people providing the services. Without the right support from care practitioners, people are much more likely to need hospital care. This applies in particular to those with complex care needs.

In 2021, the Fraser of Allander Institute published a report on Scotland's adult social care system for people with learning disabilities.¹⁵⁶ It suggested that not enough is being done in Scotland to deliver social care and support for adults with learning disabilities to enable them to live safe, secure and fulfilling lives.

The key findings of that report include that, the pandemic has been detrimental to the support relied upon by people with learning disabilities and there remain fears that support will not return to the same level it was before the pandemic. The report also found that there are a lot of positive assets in Scotland's social care system for people with learning disabilities. This includes the many dedicated people who work in the sector, and the many creative solutions that have helped improve lives.

The Independent Review of Adult Social Care in Scotland reported in 2021.² It explored the current system of care in Scotland and set out proposals for reform in light of the previous First Minister's announcement that a National Care Service for Scotland would be established.

One of the Review's findings was that in 2019/20, £58m was spent on out-of-area care home placements for adults with learning disabilities, for reasons other than choice, at a median cost of £87k per placement.

The Review reported on several key themes including: access, eligibility and assessment, structure and design of services, planning, commissioning and procurement, workforce and other issues.

We also heard the following themes from people and organisations who have engaged with us so far:

 Positive fulfilment rather than meeting problems – people have a consistent sense of services being built to meet and resolve 'problems' focusing on individuals' deficits, rather than their strengths. The opportunity a National Care

¹⁵⁶ Evidence on Scotland's adult social care system for people with learning disabilities

- Service presents to proactively support and enable a person to develop and build on their strengths and lead fulfilling lives is recognised.
- Involvement in communities both practitioners and advocacy organisations highlighted the need for social care support to also enable participation where possible.
- Exacerbated need the adverse impacts of the pandemic on access to social care support, and on the need for such support for neurodivergent people and people with learning disabilities, means that making a positive change is more important than ever.
- Unsuitable accommodation there is a need to recognise the housing challenges people with complex care needs face (this is explored in a separate section "complex care needs and coming home").

What did LEAP think?

- There should be mandatory training and guidance for social care staff, and qualifications for specialist practitioners working with neurodivergent people and people with learning disabilities.
- There is a need for monitoring and evaluation of how well the needs of neurodivergent people and people with learning disabilities are met, and the impact that services are having. Evaluation of where there may be gaps in the provision of services, or where better links need to be made.
- Better signposting and awareness of social care support available for neurodivergent people and people with learning disabilities.
- Care must be person-led to the greatest possible degree, including through selfdirected support.
- Specialist provision for those with complex care needs is delivered across Scotland.
- There is a lack of day opportunities available now, which used to be in place before the pandemic. This is vital to decreasing loneliness and isolation and enabling people to make relationships and feel part of their community.

Where do we want to get to?

- The ambitions of the National Care Service are delivered for those neurodivergent people and people with learning disabilities who need it.
- Neurodivergent people and people with learning disabilities have improved health and wellbeing, live longer lives and are able to choose to be active members of society.
- The health and social care workforce is knowledgeable and skilled in treating and caring for neurodivergent people and people with learning disabilities.

- Neurodivergent people and people with learning disabilities can access care, services and supports through the new NCS without undue stress and the risk of traumatising or retraumatising.
- Neurodivergent people and people with learning disabilities are empowered with knowledge and understanding, choice and control over their care.

What happens now?

There are some legislative rights in place though they do not specifically reference neurodivergent people or people with learning disabilities.

In relation to social care, the Social Care (Self Directed Support) (Scotland) Act 2013, and statutory guidance¹⁵⁷ sets out a number of rights in relation to how self-directed support should work including for neurodivergent people and people with learning disabilities (adults and children) who access support services. Professionals must:

- treat supported people with dignity and respect at all times, including when they first assess someone for support;
- offer the four SDS options and explain what each of them mean in a balanced and impartial way, and how they would work for the supported person's unique circumstances;
- make sure that supported people have a say in planning what their support looks like and that they have as much involvement as they want in decisions about their support;
- make sure that supported people have enough information to understand what is available and to make the choices which are right for them; and,
- make sure that supported people have opportunities to challenge and ask
 questions about any aspect of their support, and are given enough time to
 understand and participate in decisions.

Other relevant legislation includes:

- The Carers (Scotland) Act 2016¹⁵⁸
- The Mental Health (Care and Treatment) (Scotland) Act 2003¹⁵⁹
- The Adults with Incapacity (Scotland) Act 2000¹⁶⁰
- The Children (Scotland) Act 1995¹⁶¹

¹⁵⁷ Social Care (Self-directed Support) (Scotland) Act 2013: Statutory Guidance (www.gov.scot)

¹⁵⁸ Carers (Scotland) Act 2016 (legislation.gov.uk)

¹⁵⁹ Mental Health (Care and Treatment) (Scotland) Act 2003 (legislation.gov.uk)

¹⁶⁰ Adults with Incapacity (Scotland) Act 2000 (legislation.gov.uk)

¹⁶¹ Children (Scotland) Act 1995 (legislation.gov.uk)

What can we do about it?

Getting it right for everyone (GIRFE)

As noted in the introduction, GIRFE is currently being co-designed and will be at the heart of our work on health and social care policy. GIRFE is a proposed multiagency approach of support and services from young adulthood to end of life care, building on GIRFEC. Our GIRFE approach will help inform whole system working, define the adult journey and respect the role that everyone involved has in providing support planning and support. GIRFE will put the person at the heart of every decision about their own health and social care.

The National Care Service Bill ("NCS Bill")

The NCS Bill is currently progressing through the Scottish Parliament.¹⁶³ Its aim is to improve the quality and consistency of provision of integrated community health, social work and social care services, with human rights at the heart of it. The final shape of the NCS is being developed through co-design with people with lived experience.

Decisions on whether the scope of the NCS includes children's services and justice services will be subject to further detailed consideration and evidence gathering with key partners.

Following initial support from Scottish Ministers and COSLA leaders, discussions have taken place on the basis of a proposed model of shared accountability which means that Scottish Ministers, Local Authorities and NHS Boards will each have their own responsibilities to fulfil within a new national framework. Under this proposal, local authorities would retain service delivery functions, staff and assets. This would improve the experience of people accessing services by introducing a new structure of national oversight to drive consistency of outcomes, whilst maximising the benefits of a reformed local service delivery.

The NCS Bill enshrines our commitment to embedding equality and human rights in the NCS through the NCS Principles. The Principles recognise care and community health services as essential to the realisation of fundamental human rights, and that these services will have equality, non-discrimination, and the dignity of the individual at their heart.

The NCS will be delivered in a person-centred way that respects, protects, and fulfils the human rights of people accessing care support and their carers.

The NCS Bill and work associated with it will bring significant change. The LDAN Bill proposes to recognise the elements where we think more can be done specifically for neurodivergent people and people with learning disabilities.

As part of taking a human rights based approach, we are already working to deliver a range of policies to further realise human rights in the NCS including:

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¹⁶² Getting it right for everyone (GIRFE) - gov.scot (www.gov.scot)

¹⁶³ National Care Service (Scotland) Bill

- Developing a NCS Charter of Rights and Responsibilities to empower people to claim their care specific rights
- Establishing a complaints and redress process for the NCS that delivers a fair, accessible and consistent complaints process
- Creating a comprehensive approach to independent advocacy support for the NCS
- Developing a consistent approach to inclusive communication;
- Seeking to understand where services for those with specialist and/or complex care needs may be best met through a national 'Once for Scotland' approach

What can the Bill do?

The Bill could take additional action in the following areas for neurodivergent people and people with learning disabilities. These proposals all relate to the overarching themes section of this paper.

Proposal 1: Neurodivergent and learning disabilities strategies

As discussed in a previous section of this consultation, we are proposing legislative requirements for these strategies in future. For local strategies, we could ask Integration Authorities and local authorities to set out how they and organisations they commission will take into account the needs of neurodivergent people and people with learning disabilities in their workforce planning and workforce training, as well as how they are meeting requirements around inclusive communications and accessibility.

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

In England, the Health and Care Act 2022¹⁶⁴ introduced a new legal requirement for all health and social care service providers registered with the Care Quality Commission (CQC) to provide employees with training appropriate to their role on autism and learning disabilities – the Oliver McGowan Training.¹⁶⁵

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

Proposal 3: Inclusive communication and Accessibility

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 will not work for them. This could mean being able to request an online or telephone meeting rather than face to face.

165 The Oliver McGowan Mandatory Training on Learning Disability and Autism | Health Education

England (hee.nhs.uk)

¹⁶⁴ Health and Care Act 2022 (legislation.gov.uk)

We also propose 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, such as a duty on NHS Boards and HSCPs to require appointment letters to automatically be produced in easy read.

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.

What Do You Think?

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

Section 4: Housing and Independent Living

What we heard

Appropriate housing for neurodivergent people and people with learning disabilities is crucial in helping them to live safe and independent lives. Whilst most people live in mainstream housing, for some people accessible or supported housing will be the most appropriate option.

Unsuitable housing can have a negative impact on neurodivergent people, people with learning disabilities, their families and their carers, including impacting on mobility, mental health, social isolation and a lack of employment opportunities.

Appropriate housing is therefore an essential requirement of independent living. It supports health and wellbeing allowing neurodivergent people and people with learning disabilities to live safely, offering greater choice and control over their lives. It can consequently save on health and social care costs in the future, and so it is thought to be better to build accessible housing from the outset rather than having to make adaptations at a later stage.

People with learning disabilities and neurodivergent people tell us that they want to be treated with dignity and respect by services, including in relation to housing. ¹⁶⁶ They say that good-quality and timely housing advice and support services are extremely important in supporting them to live independently in a home of their choice within their community.

We know that there is currently only a small amount of specialist supported housing available, which makes up 1% of total housing stock with the vast majority of it in the social rented sector, which limits choice.¹⁶⁷

In 2018, the Equalities and Human Rights Commission produced a report, ¹⁶⁸ examining whether the availability of accessible housing, and the support services associated with it, fulfilled disabled people's rights to independent living. The Inquiry found that, at that time, many disabled people lived in homes that did not meet their requirements. It called for urgent action to ensure that future housing supply is accessible for everyone.

The report highlighted that, at that time, 61,000 people needed adaptations to their home, 1% were fully accessible for wheelchair users, and 10,000 people were on housing waiting lists.

In particular, the report noted that concerns were raised that people with learning disabilities are not always able to exercise choice and control over who they live with, who can visit and when. This was for a range of reasons such as:

• the emphasis on the online application process

¹⁶⁶ Keys to life: implementation framework and priorities 2019-2021 - gov.scot (www.gov.scot)

Housing to 2040 (www.gov.scot)

housing-and-disabled-people-scotland-hidden-crisis-long-summary.pdf (equalityhumanrights.com)

- lack of support from housing providers, such as a reluctance to provide information in accessible formats, such as easy read
- lack of specificity in advertisements for accessible properties
- lack of assistance with applications from housing provider

The report called for local authorities to ensure that people with learning disabilities have access to good-quality, accessible advice and advocacy when they are discussing housing options, to help them navigate complex systems.

The report also noted evidence that housing professionals in local authorities were at that time not sufficiently aware of the adaptations that people with sensory impairments, learning disabilities or autism might require – and that the focus was on physical disabilities.

A more recent 2022 report from the Scottish Commission for Learning Disabilities working with IPSOS MORI¹⁶⁹ highlighted the particular challenges faced by people with learning disabilities in being able to choose where and how they live. These barriers are thought to be similar to those faced by other disabled groups: availability of appropriate housing, lack of housing advice and support, legal barriers and discriminative attitudes.

The report found that around a third of people with learning disabilities live independently (35%). 52% of young adults aged 20-34 still lived with parents compared to 27% in the general population. And, around a third (35%) had not chosen where they lived.

What did LEAP think?

- Housing and support allows neurodivergent people and people with learning disabilities to live independently and much more could be done.
- Neurodivergent people and people with learning disabilities are unlikely to know about their housing rights and what this means for them. There is a need for clear and accessible information about any rights to housing and independent living and the options available to them.
- Securing adaptations to homes can be a lengthy process and being able to advocate for what they need, knowing who to talk to or where to go when problems arise is a challenge. The adaptations system needs to be quicker to meet people's needs, with more support available including advocacy.
- Neurodivergent people and people with learning disabilities can sometimes be misunderstood as being incapable of living independently, when straightforward support is often all that is required.

¹⁶⁹ My-Home-My-Community.pdf (scld.org.uk)

 There needs to be more data and information available on neurodivergent people and people with learning disabilities and their housing needs.

Case Study: As an neurodivergent person I have experienced homelessness on numerous occasions especially as a result of hospital admissions or domestic abuse (GBV). I continue to have an unsettled living situation as an older person, often having to move on due to being unable to manage my home situation or not having my needs as an neurodivergent person met. Most recently in June this year I had to move out of Housing Association retirement housing in Edinburgh as my landlords were unable to recognise or make any adjustments for my autism. All social landlords and councils should have LDAN strategies and provide training for their staff. - LEAP Member

Where do we want to get to?

- Neurodivergent people and people with learning disabilities understand their rights around housing and to independent living, and are empowered to access and exercise those rights.
- Neurodivergent people and people with learning disabilities have clear and effective routes to redress when they feel their rights have not been respected.
- Neurodivergent people know where to go for housing advice and support, and are able to easily access services, independent advocates and housing officers.
- Housing systems and processes, in particular allocations and adaptations, are streamlined and made easier for neurodivergent people and people with learning disabilities to navigate – avoiding unnecessary bureaucracy and delays.
- The supply of accessible housing across Scotland is increased.
- Housing services are knowledgeable and have the training they need to communicate and engage with neurodivergent people.
- Relevant public authorities should set clear policies to address the housing needs
 of neurodivergent people and people with learning disabilities, which promote
 access and inclusion.

What happens now?

Existing housing rights and standards are set out in a range of legislation and guidance covering a wide range of housing-related policy and practice. This includes the following:

- Homelessness: the law relating to homeless persons is found in the Housing (Scotland) Act 1987 which places a number of duties on local authorities;
- Tenancy Rights: the law regulating private residential tenancies is found in the Private Housing (Tenancies)(Scotland) Act 2016; the law regulating assured

- and short-assured tenancies is found in the Housing (Scotland) Act 1988; and the law regulating social tenancies (Scottish secure and Short Scottish secure tenancies):
- Housing Standards: for tenanted properties the repairing standard¹⁷⁰ in the Housing (Scotland) Act 2006 will apply; for all residential properties whether tenanted or otherwise, the tolerable standard in the Housing (Scotland) Act 19087 will apply which is discussed in one of the next paragraphs;
- Planning including housing strategic planning: the law relating to the
 development and use of land is found in the Town and Country Planning
 (Scotland) Act 1997, as amended, and in supporting secondary
 legislation. They include a number of requirements relating to housing,
 particularly for the national planning framework and local development plans;
 for example on how planning will contribute to outcomes that improve equality,
 eliminate discrimination and meet the housing needs of older people and
 disabled people.
- Regulation of the Housing Sector: the "Tolerable Standard" is the basic standard of human habitability, introduced in 1969 and added to periodically since then. Local authorities are required to have a strategy for ensuring that houses which do not meet the Tolerable Standard are closed, demolished or brought up to standard in a reasonable period, and they have broad discretionary powers to assist homeowners with work needed to meet the standard. The Tolerable Standard is required as part of the minimum standard for social landlords (the Scottish Housing Quality Standard 171), and as part of the Repairing Standard for private rented homes.

From April 2015, all social housing must comply with the Scottish Housing Quality Standard (SHQS). Social landlords in Scotland are already required by law to meet the Tolerable Standard which forms part of the SHQS. The performance of social landlords is monitored by the independent Scottish Housing Regulator (SHR).

The SHR publishes accessible information about the performance of each social landlord against the Scottish Social Housing Charter.¹⁷² The Charter requires that social housing providers must work towards a set of outcomes, including ensuring that tenants are provided with information on how to obtain support to remain in their home (including adaptations). The SHR's most recent report found that compliance with the SHQS fell to 75% in March 2022 from 87%.¹⁷³

We are committed to ensuring that every private tenant in Scotland is able to live in a safe and good quality home and that the condition of private rented sector properties are the right standard to help ensure a fair deal for all private tenants. Where the requirements of the Repairing Standards are not being met, tenants can apply to the First Tier Tribunal (Housing and Property Chamber) (FTT) for a determination. Local Authorities have powers to apply to the Tribunal on behalf of vulnerable tenants.

¹⁷⁰ 2. Repairing Standard Overview - Repairing standard: statutory guidance for landlords - gov.scot (www.gov.scot)

¹⁷¹ Improving housing standards - Social housing - gov.scot (www.gov.scot)

¹⁷² Scottish Social Housing Charter November 2022 - gov.scot (www.gov.scot)

¹⁷³ National Report on the Scottish Social Housing Charter - Headline Findings - 2021 -2022 | Scottish Housing Regulator

Practical Issues such as how to access help to adapt or improve your home

Section 71(2)(e) of the Housing Scotland Act 2006 requires that local authorities must have a Scheme of Assistance which sets out the support that is available to a person who requires adaptations to their home. There are housing support services which are commissioned at local level and are often provided as part of a support package that may also include social care. The following guides provide further information:

- Funding adaptations to the home: a guide for housing association tenants
- Funding Adaptations to the home: a guide for local authority tenants
- Funding adaptations to the home: a guide for private tenants
- Funding adaptations to the home: a guide for homeowners

Housing advice services are offered at a national and local level by third sector organisations such as Shelter and Housing Options Scotland.

What can we do about it?

We are progressing a number of initiatives to better protect and uphold rights around housing and independent living, as follows.

Housing to 2040

Housing to 2040¹⁷⁴ is Scotland's first long-term housing strategy, published in March 2021. It sets out our vision for how we want housing and the communities of the future to be, with actions on how to achieve that. This includes all aspects of housing and independent living for disabled and older people.

The aim of Housing to 2040 is to ensure everyone has a safe, good quality and affordable home that meets their needs in the place they want to be. Some of the actions include:

- Reviewing the Housing for Varying Needs, the social housing design guide, and creating a Scottish Accessible Homes standard (SAHS).¹⁷⁵ The SAHS will raise the baseline level of accessibility, adaptability and usability of all new homes to meet the needs of different people. It will apply to homes delivered through the Scottish Government's Affordable Housing Supply Programme. It will also propose updates to building standards and guidance.
- Increasing the supply of accessible and adapted homes and improving choice.
- Streamlining and accelerating the adaptions system.
- Providing help to disabled home owners who want to move to a home that better meets their needs.
- Reviewing housing legislation undertaking a comprehensive audit of our current housing legislation to help us assess how well current legislation protects marginalised groups and people with protected characteristics, and help us

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¹⁷⁴ Housing to 2040 (www.gov.scot)

Enhancing the accessibility, adaptability and usability of Scotland's homes: consultation - gov.scot (www.gov.scot)

- determine the best and most effective means of making the right to an adequate home a reality.
- Providing a new Rented Sector Strategy which will take an equalities-led approach to addressing the current gaps in housing options for people with protected characteristics, with a specific focus on addressing the needs of disabled people and others.
- Embedding a person-centred approach that aligns housing and health and social care services.

Independent Living Fund

We are reopening the Independent Living Fund on a phased basis, with an initial £9 million in 2024-25 to enable up to 1,000 additional disabled people with the most complex needs to access the support they need to live independent lives. This will add to the support already being provided by the current Fund to nearly 2000 disabled people in Scotland with the most complex needs. We are working with disabled people's organisations and other stakeholders to co-design the reopened Fund, including developing eligibility criteria that will ensure funding is targeted at those who need it most.

International Human Rights

The International Convention on Economic, Social and Cultural Rights (ICESCR)¹⁷⁷ provides the right to Adequate Standard of Living which includes the right to adequate housing.

The Convention on the Rights of Persons with Disabilities (CRPD)¹⁷⁸ recognises the barriers faced by disabled people in accessing their human rights, such as in relation to adequate housing and inclusion in the community. Articles 19 and 28 of the CRPD articulate several rights for disabled people relevant for housing, and support for living independently:

- equal opportunity to choose place of residence and not obligated to live in a particular living arrangement
- equal access to housing and community services/facilities
- access to assistance and in-home, residential or other support services to support living in the community
- right to adequate housing as part of an adequate standard of living
- equal access to social protection, poverty reduction, poverty assistance and housing programmes

As noted in the introduction we are progressing a Human Rights Bill for Scotland as well as the United Nations Convention on the Rights of the Child (UNCRC) (Incorporation) (Scotland) Bill, to incorporate a wide range of internationally recognised human rights belonging to everyone in Scotland into Scots law, within the limits of devolved competence.

¹⁷⁶ Programme for Government 2023 to 2024 - gov.scot (www.gov.scot)

¹⁷⁷ International Covenant on Economic, Social and Cultural Rights | OHCHR

¹⁷⁸ Convention on the Rights of Persons with Disabilities | OHCHR

Housing Bill

Whilst Scotland already has the strongest rights for homeless households in the UK, we are taking steps to further strengthen this. As set out in the 2023 Programme for Government¹⁷⁹ we will bring forward legislation in this Parliamentary year (2023/24) to deliver a New Deal for Tenants, including the introduction of long-term rent controls for the Private Rented Sector, creating new tenants' rights, and introducing new duties aimed at the prevention of homelessness.

What can the LDAN Bill do?

The Bill could provide a stronger focus on how public authorities' duties around housing and independent living can best be met for people with learning disabilities and neurodivergent people. Some or all of the following could be explored further for possible inclusion in the Bill, or other work.

Proposal 1: Advice, advocacy and guidance

Adequate housing advice, support and advocacy were thought to be necessary to enable neurodivergent people and people with learning disabilities to access their rights to housing and independent living. There is already an advice service available, Housing Options Scotland, however this is not an independent advocacy service.

Whilst another section of this consultation deals with independent advocacy, this could include consideration of the introduction of specialist advocacy services for housing support.

Proposal 2: Neurodivergence and learning disabilities strategies

Strategies are discussed in the overarching themes section of this consultation where we propose legislative requirements for national and local strategies in future. We could require strategies produced by local authorities to set out how independent living principles are embedded into assessment and allocations policies, to ensure real choice and control.

Local Authorities must currently produce Local Housing Strategies. We could consider whether these must also set out how the needs of neurodivergent people and people with learning disabilities are met, and to evaluate their progress.

With regard to Integration Authorities, we could consider requiring that their neurodivergent and learning disabilities strategies must: set out how housing, care and health services are integrated; describe the supports available to people to help them live independently; and, evaluate progress against this.

¹⁷⁹ Programme for Government

¹⁸⁰ Housing Options Scotland | Right Home, Right Place

Proposal 3: Mandatory training for housing professionals

Proposals for mandatory training in the public sector are set out in the overarching themes section of this consultation. We propose introducing a statutory requirement for learning disabilities and neurodivergence training for professionals who work in health and social care settings as set out in the overarching themes section. We could consider extending this requirement to housing service professionals.

Proposal 4: Data

Proposals in relation to data are set out in the overarching themes section. We could consider the following in relation to data collection specifically in relation to housing and independent living:

- Relevant public bodies, such as local authorities, to improve the way data is collected and shared, on the requirements of neurodivergent people, and people with learning disabilities, and their housing needs.
- Collection of data on how many people with learning disabilities are considered not to have access to appropriate housing.

Proposal 5: Inclusive communications

Proposals in relation to inclusive communications are set out in the overarching themes section. We think there is likely to be a need for some documents in relation to housing to be available in easy read formats.

What Do You Think?

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

Section 5: Complex Care – Coming Home

What we have heard

We know that some people with learning disabilities who have more complex care needs spend a longer time in hospital than is medically necessary often due to a lack of appropriate community support. This is called delayed discharge. We also know that some people are living away from their home, communities and families even though they did not choose to. This is often called living in an inappropriate out-of-area placement.

We know that this is completely unacceptable and we want to change it. We have been working to improve this for people with learning disabilities and complex care needs and this is often called the *Coming Home* programme.

We have heard from people with learning disabilities and complex care needs that they want to be supported to live in their own homes and communities, and want to be involved in the decision making process around this.

We have heard that there are existing barriers within local areas and public bodies, including local authorities, Integration Authorities and Health Boards, which sometimes make it difficult for action to be taken in order for people with learning disabilities and complex care needs to live at home.

What did LEAP think?

- LEAP members were concerned about the number of people, especially those
 with learning disabilities, who experience delayed discharge from hospital and felt
 that these people's rights were not being upheld and that they were being let
 down by public bodies.
- One LEAP member said that they know from experience about the staffing challenges that the NHS faces and that increasing accountability through the LDAN Bill could help with this.

Where do we want to get to?

- People with learning disabilities who have complex care needs, and the people supporting them, know that their choices and wishes are at the heart of the decision making process.
- People with learning disabilities, who have complex care needs, know that they are supported by the best possible services to enable them to lead high quality lives with their family and their community, where they experience personalised support in their own home, consistent with international human rights standards.
- Local staff (e.g. Learning Disability services) know who is in hospital or in an outof-area placement (or at risk of being admitted to hospital or placed in an inappropriate out-of-area placement) and what actions are required to best enable them to live in a home and community of their choice.

 There is full accountability for people with learning disabilities and complex care needs to ensure that appropriate, person-centred services are delivered by the public bodies who have a duty to provide them.

What happens now?

We are currently carrying out work to address these issues. Alongside people with lived experience, COSLA and key stakeholders, we are progressing the programme of work called *Coming Home* which aims to significantly reduce delayed discharge and inappropriate out-of-area placements for adults with learning disabilities and complex care needs. The work is based on the recommendations set out in the Coming Home Implementation Report ('the Report').¹⁸¹

The key recommendations in the Report said that the Scottish Government should:

- Introduce a Dynamic Support Register to improve planning and monitoring of those who are admitted to hospital and those in inappropriate out-of-area placements
- Establish a National Support Panel that provides professional advice to Health Boards, Integration Authorities and local authorities and provides recommendations on how to resolve complex cases
- Establish a Peer Support Network for professionals from Health and Social Care Partnerships, clinicians, commissioners, social care providers, housing organisations, local authorities, family members, third sector organisations and other relevant stakeholders to provide an informal group for people to share best practice

What can we do about it?

We think that the LDAN Bill could potentially strengthen some parts of the Coming Home work to make sure that the vision is achieved.

We prioritised work on the Dynamic Support Register and launched this across Scotland in May 2023. This improves the monitoring of the experiences of people with learning disabilities and complex care needs who are in hospital, who are in out-of-area placements and/or whose current support arrangements are at risk of breaking down. This underpins all of the Coming Home work. It ensures that there is visibility for this population. We think that legislation could help with this recommendation.

We are establishing a Practitioner Peer Support Network through Healthcare Improvement Scotland (HIS). The group is collaboratively supporting practitioners to work together to improve local processes and case management. We do not think that there is a need to legislate for this group.

¹⁸¹ Supporting documents - Coming Home Implementation: report from the Working Group on Complex Care and Delayed Discharge - gov.scot (www.gov.scot)

We have been progressing scoping work on the National Support Panel. We think that legislation could help with this recommendation.

Part 1: Dynamic Support Registers

What happens now?

Currently, Integration Authorities each use and operate a local Dynamic Support Register. These were set up in May 2023 and are backed up by a Memorandum of Understanding, which is an agreement between the Scottish Government and COSLA, signed by the Minister for Social Care, Mental Wellbeing and Sport and the COSLA Health and Social Care Spokesperson. Although this agreement is in place, it is not currently the law that Dynamic Support Registers have to be used.

The local Dynamic Support Registers record information about people with learning disabilities and complex care needs who are in hospital, who are in out-of-area placements or whose current support arrangements are at risk of breaking down. Integration Authorities report data from their Register to Public Health Scotland (PHS) who analyse and publish this information twice a year.

The Dynamic Support Registers are not simply records of people with learning disabilities and complex care needs. They are a way to help professionals know what they need to do so that people are best able to live in their home communities. They contain information about what action needs to be taken to find or build a suitable home and they help professionals collaborate with the right people and organisations to do this. We have provided guidance and support to make sure that the Dynamic Support Registers are used properly. People with lived experience helped to design and develop the Dynamic Support Registers and guidance.

What can the LDAN Bill do?

Proposal 1

We want to strengthen the Dynamic Support Registers and the processes around them through the LDAN Bill so that it becomes law for the relevant local public body (Integration Authority, Local Authority, Health Board) to hold these. This would help to ensure that there is visibility for people with learning disabilities and complex care needs on a national level, and that a consistent approach is taken.

Each area would be required to have a Dynamic Support Register, and to report data from it to PHS for it to be published. It is important to note that personal information about people on Dynamic Support Registers is not published, and none of the data that is published nationally identifies the individuals that it is about.

Further consideration would be given to:

- who would be included on the Registers
- which public bodies would have statutory duties, and
- the guidance and safeguards to be put in place to ensure that the Registers are used properly

If we do not make this a law, then Integration Authorities could decide to monitor people in a different way. It could also be more difficult to ensure that sufficient planning and early intervention is being put in place.

Part 2: National Support Panel

The National Support Panel recommendation in the Coming Home Implementation Report is about improving accountability for people with learning disabilities and complex care needs to ensure that effective work is being carried out to reduce delayed discharges and inappropriate out-of-area placements for this population.

The Report says that the primary purposes of a National Support Panel should be:

- to work with Integration Authorities and partner organisations by providing support and expertise for their decision making and solutions for individuals in a collaborative forum
- to provide checks and balances to ensure that people with learning disabilities are receiving the best care in the most suitable environment
- to understand and hear from families and individuals about their individual circumstances

What happens now?

There is not currently a way for people with learning disabilities and complex care needs who are facing inappropriate hospital stays or out-of-area placements to have their case reviewed by experts.

Health and Social Care partnerships, health boards and local authorities are responsible for commissioning and delivering local health and social care services. When people are unhappy with the health or social care service they receive, they can make formal complaints through the NHS Complaints process or to their local authority respectively. In both cases, the Scottish Public Service Ombudsman can provide an independent say on any complaints. People could also pursue legal proceedings to challenge a decision that has been made by a public body, for example through a judicial review.

People who are subject to delayed discharge may be treated in terms of measures in the Mental Health (Care and Treatment) (Scotland) Act 2003 ("the Mental Health Act") including Compulsory Treatment Orders (CTOs). The primary role of the Mental Health Tribunal for Scotland ("the Tribunal") is to consider and determine applications for compulsory treatment orders (CTOs) under the Mental Health Act and to operate in an appellate role to consider appeals against compulsory measures made under the Mental Health Act. The Tribunal also plays a monitoring role by periodic review of compulsory measures. The Mental Welfare Commission provides an independent oversight of this process.

We are currently considering reforms to the Tribunal process proposed in the Scottish Mental Health Law Review (SMHLR). 182 Some of these issues were also

¹⁸² Scottish Mental Health Law review Final Report [Archived] (nrscotland.gov.uk)

explored in the Independent Review of Autism and Learning Disabilities in the Mental Health Act (the Rome review).¹⁸³

What can the LDAN Bill do?

Proposal 2

The National Support Panel ("the Panel") should work with and support the new Dynamic Support Registers and Peer Support Network and we think there are different ways to do this. We want to consider different options, including whether we should make the Panel statutory in the LDAN Bill.

The Coming Home Implementation Report recommended a National Support Panel that could understand and hear from families and individuals about their individual circumstances.

One way to do that is to establish a panel that would look at every individual case. It would need to review each person regularly and provide advice to the relevant Integration Authority, local authority and/or Health Board on each case. There would be issues to consider around powers and duties and the interaction with the role and functions of existing bodies like the Mental Welfare Commission.

Although we have thought about this, we do not think it would work in practice due to the length of time it would take a panel to consider every case. We would need several panels to make this work and we would need to use our small pool of experts in Scotland to do this, therefore taking them away from their other jobs supporting people. We think this would make the situation worse for people who need quick solutions.

We have set out below the options we think could work under proposal 2.

Option A: Legislative Panel Conducting Individual Reviews within Defined Parameters

This type of Panel would be made up of sector experts who have current knowledge of the Scottish approach to complex care, and who are committed to a human rights based approach. We would recruit or appoint people with lived experience, housing and social work expertise to the Panel. The panel will likely also need legal and clinical expertise.

This type of Panel would have a function allowing it to conduct investigations into individual cases on a discretionary basis. The Panel could have a broad scope of the type of cases that it could investigate and there would be some flexibility built into this. For example, this could be a list of potential circumstances that may give rise to a review or investigation. The Panel members might decide that an investigation into a certain case, and the recommendations and findings that come from that investigation, would provide a good example of what can be done to address complex barriers or issues.

¹⁸³ The Independent review of Learning Disability and Autism in the Mental Health Act Final Report [Archived] (nrscotland.gov.uk)

This would mean that not everyone with a learning disability and complex care needs who is in hospital or an out-of-area placement would get an individual review. However, Integration Authorities, Local Authorities and Health Boards would be able to use the findings and learnings from the Panel's example individual case reviews to improve their practices.

The Panel would be reviewing fewer cases and therefore the demand on the Panel and its members would be reduced to a manageable level.

It would be important to ensure that the work of this type of Panel, including how individual cases are selected as examples, is consistent and fair. It would also be important to ensure that the learning that is shared from any example individual case review is anonymised and does not contain any identifiable information about the people involved.

This type of Panel would require the powers to:

- review individual data;
- require information and evidence from public bodies; and,
- make recommendations, potentially with consequences for non-compliance.

There would also be other things to consider, including:

- how this Panel would crossover with existing processes such as investigations by the Mental Welfare Commission or inspections by the Care Inspectorate, and how to make sure it isn't duplicating any of this work;
- whether there would be an appeal mechanism;
- what types of decisions or recommendations the Panel could make;
- what the timescales for the Panel reviews would be; and,
- if there would be penalties for not complying with the decision of the Panel.

Benefits

- The Panel would be legislative, so relevant public bodies (Health Boards, Integration Authorities, local authorities) would be required by law to participate in individual case reviews.
- All Health Boards, Integration Authorities and Local Authorities would be able to benefit from the learnings and findings of the example individual case reviews.

Potential drawbacks

- Only a small number of people with learning disability and complex care needs on a Dynamic Support Register would be individually reviewed by the Panel. However, this would show how the Panel would expect all similar cases to be handled.
- It might be difficult to decide which individual people's cases would be investigated by the Panel.

- It might be difficult to recruit or appoint experts to be on the Panel because they would have to take time out of their existing professional roles.
- It would take longer to set up than a non-legislative Panel.

Option B: Legislative Panel Conducting Peer Reviews of Local Processes

Another option for a legislative Panel would be one that conducts Peer Reviews of Local Processes.

This Panel would consist of a group of experts who could provide checks and balances through a model of peer reviews. It would be made up of a 'bank' of expert members, including people with lived experience, who could be brought in to conduct peer reviews of the work and processes of Health Boards, Local Authorities and Integration Authorities in relation to this population.

This process would involve the Panel going to a local area and reviewing the relevant public bodies' systems and processes in relation to complex care needs, to identify key challenges and issues. This review could be through site visits or job shadowing.

The Panel would then provide recommendations or decisions based on the peer review that the Health Board, Local Authority and Integration Authority would have to implement in order to improve their practices around complex care. The Panel would provide follow up support and would monitor progress.

The Panel might review systems and processes related to:

- Commissioning appropriate accommodations and services
- Securing and financing support packages
- Identifying suitable support providers
- The support plan in the person's current placement
- Any issues or concerns, for example the use of restraint, high levels of behaviours perceived as challenging or serious risk factors

This Peer Review Panel would identify issues which affect all individuals with complex care needs, and potentially find ways to improve local processes and structures that could help to improve the system for everyone.

This panel would be legislative, so the relevant public bodies (Health Board, Local Authority, Integration Authority) could be required by law to participate in a peer review of their processes and structures. They could also be required by law to implement the recommendations made by the Panel.

Although this type of Panel would not be able to review individual cases as part of their role, their reviews would have a significant impact on those individual people and their outcomes.

There are also a number of other considerations about this type of Panel that would have to be made, including:

- how this Panel would crossover with existing processes such as investigations by the Mental Welfare Commission or inspections by the Care Inspectorate and how to make sure it isn't duplicating any of this work
- how the relevant data and information could be shared with the Panel
- what the criteria would be in order for an area to be picked for a review

Benefits

- The Panel would be legislative and therefore public bodies would be required by law to participate in peer reviews
- Public bodies could be required by law to implement the Panel's recommendations
- The strategic support by the Panel would help public bodies make better progress
- Improving systems and processes within the relevant public bodies will improve care, treatment and support arrangements for all of the people in that area

Potential drawbacks

- The Panel would not have the powers or resources to look at individual cases
- It might be difficult to recruit or appoint experts to be on the Panel because they would have to take time out of their existing professional roles
- It might be difficult to create a culture of fully open and reflective practice within a legislative context and people may not participate fully
- It would take longer to set up than a non-legislative Panel

Option C: Non-legislative Panel Conducting Peer Reviews of Local Processes

A non-legislative National Support Panel Conducting Peer Reviews of Local Processes would work in the same way as the Panel described in Option 2, however it would not be legislative.

This type of Panel would carry out peer reviews as above, providing checks and balances and offering support to relevant public bodies (Health Boards, Local Authorities, Integration Authorities) to improve their systems and processes.

Because this Panel would be non-legislative, it could be set up more quickly than a legislative one. However, it would not be the law for Health Boards, Local Authorities or Integration Authorities to participate in peer reviews. The peer reviews would be voluntary, with the option of local areas being able to request a review, and would take a 'critical friend' approach which means the Panel would be supportive but would also be able to ask difficult questions, take an objective view and provide honest feedback in order to address complex issues. Health Boards, Local Authorities or Integration Authorities would not be required by law to implement any recommendations made by the Panel.

In addition, the Panel would not have statutory functions so would be limited in its ability to investigate any individual cases, and have access to certain information in relation to individuals.

There are also a number of other considerations about this type of Panel that would have to be made, including:

- how this Panel would crossover with existing processes such as investigations by the Mental Welfare Commission or inspections by the Care Inspectorate, and how to make sure it isn't duplicating any of this work
- how the relevant data and information could be shared with the Panel
- what the criteria would be in order for an area to be picked for a review
- if there would be any escalation processes if relevant public bodies declined to take part in a review

Benefits

- Provide strategic support to public bodies who are face barriers to providing appropriate support for people with learning disabilities and complex care needs
- Improving systems and processes within relevant public bodies would improve care, treatment and support arrangements for all the people in that area
- Learning from each review could be shared nationally
- An non-legislative structure may be the best way to enable fully open and honest conversation and peer learning
- A non-legislative panel could be set up quicker than one that requires legislation.

Potential drawbacks

- The relevant public bodies (Health Boards, Integration Authorities, local authorities) would not be required by law to participate in reviews
- Public bodies would not be required by law to implement any recommendations made by the Panel
- The Panel would not be able to look at individual cases
- It might be difficult to recruit or appoint experts to be on the Panel because they would have to take time out of their existing professional roles
- Because the Panel would be non-legislative, it might have a lesser impact as public bodies and service providers would not be held to account for this population by law.

What Do You Think?

- Should there be a statutory duty upon the relevant public body or bodies (Integration Authority, Health Board, Local Authority) to hold a Dynamic Support Register? (Proposal 1). Please tell us more.
- Which of the options for the National Support Panel (Proposal 2) do you think has the most benefits? [Option A, Option B, Option C]. Please tell us more.
- Are there any other options that you think we should consider?

Section 6: Relationships

What we heard

Children, young people and adults that have a learning disability or are neurodivergent have the right to the same opportunities as anyone else to live satisfying and valued lives and to be treated with the same dignity and respect. They should be able to develop and maintain relationships and get the support they need to live a healthy, safe and fulfilling life. However there are a range of barriers that prevent some neurodivergent people and people with learning disabilities from being included in society and having healthy relationships on an equal basis compared to neurotypical people. This often causes loneliness, social isolation, poor mental health, and trauma.

Research indicates that, for autistic people, one third experience contact sexual violence, physical violence or stalking by an intimate partner, and one third of secondary school children experience bullying. It also indicates that autistic people are bullied more frequently than non-autistic peers (46-96% prevalence rates). For women, research indicates that those higher in autistic traits were 1.4 times more likely to have experienced childhood sexual abuse compared to those with few autistic traits (40% vs. 27%), and 1.7 times as likely to have experienced physical or emotional abuse (24% vs 14%). Many autistic people report challenges making and maintaining friendships, and have lower quality friendships than non-autistic peers.¹⁸⁴

A 2020 survey¹⁸⁵ conducted in Scotland found that social isolation and loneliness remain a reality for many adults (aged 16+) with learning disabilities. It found that there is a lack of intimate relationships for the vast majority of respondents, higher levels of loneliness, lower levels of happiness for those who did not see their loved ones as often as they liked, and higher levels of loneliness overall than seen in the general population. In particular, it was found that:

- 5% lived with a partner compared to 56% of the general population
- 3% were married compared to 47% of the general population
- People living in mainstream accommodation were more likely to be in a relationships than people in supported accommodation, and people in medical settings and care homes least likely
- 52% occasionally, sometimes or often felt lonely. 9% often felt lonely, compared to 5% of the general population.

In 2023, a we commissioned a report conducted by Scottish Commission for People with Learning Disabilities (SCLD) reported on the experiences of women and girls with learning disabilities who have experienced gender based violence: Unequal, Unheard, Unjust: But Not Hidden Anymore.¹⁸⁶

¹⁸⁴ Healthy Relationships on the Autism Spectrum (HEARTS): A feasibility test of an online class codesigned and co-taught with autistic people - PMC (nih.gov)

¹⁸⁵ Relationships matter for people with learning disabilities - SCLD

¹⁸⁶ Unequal, Unheard, Unjust: But not Hidden Anymore – new report launched at Scotland's Learning Disability and Gender-Based Violence Conference 2023 - SCLD

When looking specifically at learning disabilities, global rates of gender-based violence suggest that 90% of women with learning disabilities have been subjected to sexual abuse, with 68% experiencing sexual abuse before turning 18.¹⁸⁷ The report found that women with learning disabilities continue to experience high barriers to support and justice following experiences of gender-based violence and abuse due to discrimination and stereotyping. They also encounter significant barriers to reporting crimes, including limited access to safe spaces and appropriate adults, and not being believed or taken seriously. It also found that professionals may not recognise that someone has learning disabilities and if they do they may not have any relevant training in how to support them.

Other research has found that access to Relationships, Sexual Health and Parenthood (RSHP) education is not equal¹⁸⁸ and that people with learning disabilities are often excluded from teaching in school and other settings about RSHP. One of the reasons for this is that current RSHP materials aren't always provided in accessible formats.

Another reason was thought to be stigma and discrimination, with professionals and others assuming that some neurodivergent people and people with learning disabilities don't, or don't want to, have romantic and sexual relationships. This puts people with learning disabilities at risk as they don't get the same information and education as others. This can make it challenging to identify and respond to incidents of gender-based violence and abuse.

Other research estimates that between 40% and 60% of parents with a learning disability have their children removed from their care due to being assessed as unable to provide an adequate standard of parenting.¹⁸⁹

A 2016 report commissioned by the Scottish Government, conducted by SCLD, explored the support needed for parents with learning disabilities. ¹⁹⁰ This followed the refreshed Scottish Good Practice Guidelines for Supporting Parents with a Learning Disability in 2015. ¹⁹¹

The report noted good progress towards better supporting people with learning disabilities to parent, as well as providing recommendations to further remove barriers. It provided evidence that parents with learning disabilities can and do become "good enough parents" who love their children and want to be the best parents they can be, with the right support. However, the support needed to do so is resource intensive, likely to be long term and likely to be intensive as children reach particular developmental milestones.

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^{187 &}lt;u>Unequal, Unheard, Unjust: But not Hidden Anymore – new report launched at Scotland's Learning</u> Disability and Gender-Based Violence Conference 2023 - SCLD

¹⁸⁸ Safe-and-Healthy-Relationships-UPDATED_SCLD_130618.pdf

A systematic review of interventions to promote social support and parenting skills in parents with an intellectual disability - PubMed (nih.gov)

¹⁹⁰ Parenting-Report-FINAL-14.11.16.pdf (scld.org.uk)

¹⁹¹ Supported_Parenting_web.pdf (scld.org.uk)

The report concluded that unless extensive support is available for the whole family, parents with learning disabilities would be unlikely to have their children living with them. It recommended that the solution is the provision of jointly-funded multi-disciplinary teams that take a whole family approach and are well trained in working with people with learning disabilities. Several other recommendations were provided relating to better data collection to establish accurate prevalence rates, an accessible information strategy, access to independent advocacy, awareness raising and specialist training.

More recently, a pilot parenting project has been implemented to develop Shared Lives services for parents with a learning disability. 192 It evidences that positive outcomes can be achieved with the right support, enabling parents with learning disabilities to parent their children in a home they live in together.

What did LEAP think?

- LEAP members thought that they should have equal access and support to make and maintain relationships with friends, family, and the community. They stated that they should have a right to choose where they live and who they live with. They should not be moved away from their families and communities.
- People should be able to express their gender and sexuality freely. They
 particularly pointed out that they shouldn't have their gender expression or
 identity invalidated because of their learning disability or neurodivergence. They
 also highlighted the intersection of neurodivergence and LGBT identities and the
 increased risk of mental health issues and suicide rates in both of these groups.
- More support is needed for neurodivergent parents, and that their needs should be recognised when interacting with services on behalf of their children and families in settings such as school and healthcare.
- Any approach towards eliminating violence towards women, girls, and people
 assigned female at birth needs to be preventative and empowering. Any
 education surrounding this should specifically recognise the differences
 neurodivergent people and people with learning disabilities may have with
 reading social and/or sexual cues.

Where do we want to get to?

 Neurodivergent people and people with learning disabilities are supported to make and maintain healthy relationships, express their gender and sexuality, and live well in their communities.

 Parents with learning disabilities and neurodivergent parents, carers, and families are given the support they need and their children are not unfairly removed from their care.

¹⁹² Evaluation-Supported-Parenting-in-Shared-Lives-Scotland-2023.pdf (sharedlivesplus.org.uk)

- Neurodivergent people and people with learning disabilities have equal access to RSHP education.
- Access to justice and specialised support is provided where neurodivergent people and people with learning disabilities experience gender-based violence and abuse

What happens now?

Our vision is that, where it is possible "Every child lives in a safe and loving home where families are given support to overcome difficulties and stay together." This is our commitment as reflected in The Promise Implementation Plan. ¹⁹³ We recognise that this involves universal holistic family support, at the right time, and more intensive targeted help if it is needed so that people can continue to care for their children where it is safe to do so.

GIRFEC underpins our commitment to providing all children, young people and their families with this help and support through a consistent framework and shared language for promoting, supporting, and safeguarding their wellbeing.

We have supported the development of Scottish Good Practice Guidelines for Supporting Parents with a Learning Disability. 194 These guidelines provide guidance on supporting people with learning disabilities who are parents, placing those parents and their families firmly at the centre and in control.

The Guidelines are for the information of health, social work, education and third sector services. In the 2016 report referenced earlier, it was found that 87% of respondents were aware of the guidelines and that 79% used them in their everyday practice. It was thought that the guidelines had influenced their practice, with a focus on ensuring that it is non-discriminatory and safeguards the rights of parents and their children.¹⁹⁵

The guidelines were thought to have proved useful in raising awareness of the particular issues faced by parents with learning disabilities and have promoted "an acknowledgement that the parent's rights are as important as the rights of the child". However, it was acknowledged that the participants were those more likely to have an awareness of the guidelines and so the survey results should not necessarily be taken as an indication that they are widely used across all services.

Article 8 of the European Convention on Human Rights, incorporated into UK law by the Human Rights Act 1998, provides that everyone has the right to respect for private and family life. Article 12 of that Convention, also contained in the Human Rights Act 1998, protects the right to marry a partner and to have a family. This means that Governments must ensure that those with disabilities, including people with learning disabilities and neurodivergent people, can marry and have

Parenting-Report-FINAL-14.11.16.pdf (scld.org.uk)

¹⁹³ Keeping The Promise to our children, young people and families (www.gov.scot)

¹⁹⁴ Supported_Parenting_web.pdf (scld.org.uk)

relationships on an equal basis with others without any interference or arbitrary restriction.

The Equalities and Human Rights Commission's guidance for public authorities on how the 1998 Act relates to what they do and how they do it, notes that the concept of 'family life' is broader than the traditional family and can include various relationships such as between siblings. ¹⁹⁶ It also provides the following case study which is included here to demonstrate how Article 8 rights could be relied upon:

Case Study: London Borough of Hillingdon v Steven Neary (2011)

This was a case involving a 21 year old autistic man with learning disabilities who lives with, and is cared for by, his father, Mr Neary. Steven requires constant support and supervision, and Mr Neary was helped by an extensive care package provided by Hillingdon Council. In 2009, the local authority accepted Steven into respite care for a few days, but subsequently kept him there for a year, despite Mr Neary's insistence that Steven was best placed with him.

The case judgment focused on the unlawfulness of Steven's detention under Article 5 (the right to liberty), but also found Hillingdon council to be in breach of the right to respect for family life under Article 8, by failing to consider the human rights implications of keeping Steven away from his family for a long period of time.

One aspect of the Article 8 breach was based on the council's failure to listen to Mr Neary's complaints. The court said that: "Hillingdon's approach was calculated to prevent proper scrutiny of the situation it had created. In the weeks after Steven's admission, it successfully overbore Mr Neary's opposition. It did not seriously listen to his objections and the suggestion that it might withdraw its support for Steven at home was always likely to have a chilling effect. Once Mr Neary's resistance was tamed, the question of whether Steven was in the right place did not come under any balanced assessment."

There is also a range of legislation which contributes to preventing and tackling violence against women and girls, although none specifically reference people with learning disabilities or neurodivergent people. These include:

- Vulnerable Witnesses (Scotland) Act 2004
- Protection of Children and Prevention of Sexual Offences (Scotland) Act 2005
- Sexual Offences (Scotland) Act 2009
- Domestic Abuse (Scotland) Act 2011
- Forced Marriage etc. (Protection and Jurisdiction) (Scotland) Act 2011
- Children and Young People (Scotland) Act 2014
- Victims and Witnesses (Scotland) Act 2014
- Human Trafficking and Exploitation (Scotland) Act 2015
- Domestic Abuse (Scotland) Act 2018
- Prohibition of Female Genital Mutilation (Scotland) Act 2005

¹⁹⁶ Homepage | EHRC (equalityhumanrights.com)

- Female Genital Mutilation (Protection and Guidance) (Scotland) Act 2020
- Domestic Abuse (Protection) (Scotland) Act 2021

International Human Rights

The UNCRC sets out the international human rights standards for children up to the age of 18. Article 6 of the UNCRC recognises that all children and young people have the right to survive and the right to develop. State parties should do as much as they can to make sure children and young people can live in conditions that don't impact negatively on their physical and mental wellbeing in order that they can grow and develop.

Under Article 12 of the UNCRC every child and young person who is capable of forming their own views has the right to express those views freely in all matters that affect them, with those views being given due weight.

In addition, Article 23(1) of the UNCRC specifically recognises that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community. Therefore state parties (under article 23(3)) must "ensure children must have special access to [...] services to ensure social integration and individual development, including his or her cultural and spiritual development".

Article 23 of the CRPD is particularly relevant as it provides that state parties shall take effective and appropriate measures to eliminate discrimination against disabled people in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others.

As noted in the introduction we are progressing a Human Rights Bill for Scotland as well as the United Nations Convention on the Rights of the Child (UNCRC) (Incorporation) (Scotland) Bill, to incorporate a wide range of internationally recognised human rights belonging to everyone in Scotland into Scots law, within the limits of devolved competence.

What can we do about it?

Our Towards Transformation Plan¹⁹⁷ committed to establishing a Gender Based Violence Steering Group which would develop an action plan to reduce incidences of violence and empower women and girls with learning disabilities and autistic women and girls (including people assigned female at birth) to have safe and loving relationships.

To inform this work, we funded SCLD and People First (Scotland) to undertake research and report on women with learning disabilities' experience of gender-based violence. The resulting report, recently published, made twelve recommendations about how to tackle violence against women and girls with learning disabilities.¹⁹⁸

¹⁹⁷ Learning/intellectual disability and autism: transformation plan - gov.scot (www.gov.scot)

¹⁹⁸ Unequal, Unheard, Unjust: But not Hidden Anymore – new report launched at Scotland's Learning Disability and Gender-Based Violence Conference 2023 - SCLD

These recommendations are currently being considered by the Steering Group as part of the action plan.

We recently consulted on draft statutory guidance on the Delivery of Relationships, Sexual Health and Parenthood (RSHP) Education in Scottish Schools. 199 The draft guidance states that "[t]here are some misconceptions that children and young people who require additional support are not, or will not, be sexually active... those who require additional support, including those with a learning disability, must be included in RSHP lessons", and that "[c]hildren and young people with a learning disability or who require additional support may require more bespoke learning activities and this should always be discussed with parents/carers and children/young people".

What can the LDAN Bill do?

We believe that children, young people and adults who are neurodivergent or have a learning disability have the right to the same opportunities as anyone else to live satisfying and valued lives and to be treated with the same dignity and respect. They should be able to develop and maintain relationships and get the support they need to live a healthy, safe and fulfilling life.

There are various initiatives underway to help make improvements, as discussed in the previous paragraphs. However, there are still barriers and challenges to overcome. We could explore the following in relation to the Bill to help strengthen that work specifically in relation to people with learning disabilities and neurodivergent people.

Proposal 1: Access to Independent Advocacy

Another section of this consultation discusses independent advocacy. We would like views on any specific circumstances where a right to independent advocacy could make a difference. For relationships, this could include:

- (a) where a parent with learning disabilities is at risk of their child being taken into care; and,
- (b) where a neurodivergent person or person with learning disabilities have disclosed gender-based violence or abuse. This would aim to enable them to access justice and support (as recommended in Unequal Unheard).

Proposal 2: Data

The overarching themes section sets out some broad proposals on data and and we have asked for views on particular circumstances in which better data collection and sharing (with careful consideration of confidentiality and data security), would be helpful in order to better inform service design, policies, and to enable progress to be

¹⁹⁹ Consultation on draft Statutory Guidance on the Delivery of Relationships, Sexual Health and Parenthood (RSHP) Education in Scottish Schools - Consultation on draft Statutory Guidance on the Delivery of Relationships, Sexual Health and Parenthood (RSHP) Education in Scottish Schools. - gov.scot (www.gov.scot)

evaluated and monitored. For relationships, we could consider data collection on the following:

- (a) Data collection and reporting on gender-based violence affecting women with learning disabilities (as recommended in Unequal Unheard).
- (b) Data collection and reporting on the number of parents with learning disabilities in Scotland, including where their children have been removed from their care. This acknowledges that there is currently a lack of knowledge of this population which may impact on the availability and range of services provided.

Proposal 3: Inclusive communications

We have made some proposals on inclusive communications in the overarching themes section of this consultation and have asked for views on particular situations where a strengthened right to and focus on inclusive communications would have an impact. For relationships, we could explore the following:

- (a) Where a person with learning disabilities is at risk of having their child removed from their care. This could include information automatically being provided in easy-read, and support provided by professionals who have specialist training in learning disabilities.
- (b) Where a neurodivergent person, or person with learning disabilities, has disclosed gender-based violence or abuse and is interacting with the justice system. This could include information automatically being provided in easyread, and support provided by professionals who have specialist training in learning disabilities.

Proposal 4: National and Local Strategies

Proposals are set out in the overarching themes section on national and local strategies for learning disabilities and neurodivergence. For relationships, we could explore whether those strategies should include the following:

- (a) Local authorities to set out how a multi-disciplinary team and Whole Family Approach is being implemented to proactively support neurodivergent parents and parents with learning disabilities, including reporting on and evaluating this approach.
- (b) Local authorities to set out how RSHP education is provided to all Additional Support Needs learners.
- (c) Local authorities to set out how they provide services to neurodivergent people and people with learning disabilities to enable them to be active and involved in their communities. This could include evaluating the impact of these services.
- (d) If extended to Police Scotland: Police Scotland to set out how people with learning disabilities are provided with specialist support to report crimes, including gender-based violence and abuse.

Proposal 5: Accountability

Another section of this consultation discusses various proposals and options for increased or more focussed accountability. This includes proposals for a new Commission/er specifically for neurodivergent people and people with learning disabilities, as well as considering changes to the power and remit of existing bodies.

If a new or existing body had powers of investigation they may be able to investigate ongoing and historic cases of child removal from parents with learning disabilities, based on their disability.

What Do You Think?

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

Section 7: Access to Technology

What we heard

Over recent years digital access has become increasingly important to the way we live our lives. It is important to stay connected with family, friends and our communities, as well as being able to access learning and employment opportunities online. Digital inclusion therefore plays a key role in a person's independence. The pandemic made the importance of digital access even more critical, due to many services moving online.

In many cases this has been very successful and for many people it has made things more accessible. However, for those who are digitally excluded the opposite is true. We know that people with learning disabilities are at particular risk of being digitally excluded. Digital exclusion is one of the ways that people with learning disabilities are excluded from society, and this is mirrored in the lack of investment in learning disability specific specialist technologies.

Through our work on the Towards Transformation Plan, we heard about people being taken advantage of online. We also heard about the removal of WIFI and devices from people with learning disabilities due to other peoples' assumptions about their capacity to use them.

There is a need for security, awareness and training in terms of how to use technology and how to use technology safely. Skills and confidence play a pivotal role, often acquired through training and practice. We know that both family and professionals who work with people with learning disabilities and neurodivergent people play a key role in assisting individuals to use digital spaces effectively.

Since the pandemic we know that there has been an increase in technology use, which has highlighted further the need for enhanced confidence and skills, particularly in the use of communication platforms.

As digital technologies advance, developments must be consciously designed to address the needs of those who are already digitally excluded, including people with learning disabilities, or there is a risk of furthering the digital divide that already exists.

What did LEAP think?

 Digital access is an area where improvements could be made and is important in enabling participation in society and to reduce isolation and loneliness.

 Some people can access technology, with support, and the bill could increase availability of this support. More information and data is needed on use of technology by LDAN people and the Bill could achieve this.

Digital inclusion and participation of people with intellectual disabilities during COVID-19: A rapid review and international bricolage - Chadwick - 2022 - Journal of Policy and Practice in Intellectual Disabilities - Wiley Online Library

- Barriers to digital access are availability, cost, permission and usability and we need to consider the needs of older LDAN groups and those who have poor internet connection in remote areas.
- Education is important to help protect LDAN people and help them to learn how to spot false information so they can make informed decisions. Controls and strict security settings could help with this.
- Software that increases digital access for LDAN groups is very useful however is
 often only available through school or work. This should be made more widely
 available e.g. through community services.

Where do we want to get to?

- Digital inclusion for all Scottish citizens, including those who are most at risk of being digitally excluded, such as people with learning disabilities and neurodivergent people.
- Increased confidence and safety for people who are at risk of being vulnerable online

What happens now?

Our Digital Strategy 2021²⁰¹ aims to promote digital inclusion for all of Scotland's citizens to thrive and flourish in a digital society. The work under this strategy aims to ensure that everyone has equal access to public services or is able to maximise their life opportunities through education, employment or entertainment.

The vision of our Connecting Scotland Programme²⁰² is a fairer, more equitable Scotland, enabled by digital access for all.²⁰³ It was established during the pandemic, and initially aimed to provide devices, connectivity and training to digitally excluded households so that they could stay connected to friends and family, as well as access public health advice.

During Phase 2 of Connecting Scotland in the Winter of 2020, 5000 disabled people, older and socially isolated people were supported, including people with learning disabilities. This meant that these groups could be more involved in online discussions and became more digitally included.

Actions to achieve our overall vision for digital access aim to reduce the number of people that currently do not have the essential digital skills or confidence to participate in a digital society. To achieve this, we have created a partnership with the public, private and third sectors.

Connecting Scotland therefore aims to bring all digital inclusion organisations under one alliance where resources, expertise and knowledge is shared in a collective

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²⁰¹ A changing nation: how Scotland will thrive in a digital world - gov.scot (www.gov.scot)

²⁰² Connecting Scotland

²⁰³ Connecting Scotland - gov.scot (www.gov.scot)

manner to build the digital capacities of our nation, rather than pursuing success independently.

Some third sector organisations have used the funding provided under the Connecting Scotland programme to purchase devices for people with learning disabilities and to provide training in how to use them.

The continuation of a digital way of working following the pandemic has meant that some third sector organisations continue to provide training for disabled people, including people with learning disabilities. These organisations include Linking Education and Disability (LEAD) Scotland, Glasgow Disability Alliance and People First Scotland.

The Digital Scotland Service Standard²⁰⁴ sets out criteria that organisations delivering public services should work towards. This includes the theme of 'meeting user's needs' to 'design and deliver inclusive and accessible services which meet the needs of users, providing a service that everyone can use – including disabled people.

A digital service should be accessible to everyone who needs it, including services only used by public servants. There are regulations that require and promote the need for accessibility that protect the civil rights of people with disabilities. The most recent of these and aimed at digital services is the Public Sector Bodies (Websites and Mobile Applications) (No. 2) Accessibility Regulations 2018²⁰⁵. The Regulations aim to ensure that services provided by public sector bodies are accessible to people with disabilities

What can we do about it?

The Connecting Scotland programme resumed delivery in August 2023, with Lending Device Library funding opportunities available in partnership with the Scottish Council for Voluntary Organisations (SCVO).²⁰⁶

The programme's focus is on delivering kit and connectivity devices to library and social housing organisations through grant funding. Up to £400,000 in funding will be awarded to successful projects, with organisations able to apply from August 2023.

This funding will allow organisations to expand their digital capacity through the provision of additional kit and connectivity, supporting them in reaching out to more digitally excluded people across Scotland. SCVO will regularly report to the Scottish Government on the status and progress of the projects. An evaluation of the programme will conclude in March 2025.

Connecting Scotland has also begun work on a Digital Inclusion Alliance (DIA) with public, private and third sector organisations to develop a cohesive approach to

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²⁰⁴ <u>Digital Scotland Service Standard - gov.scot (www.gov.scot)</u>

The Public Sector Bodies (Websites and Mobile Applications) (No. 2) Accessibility Regulations 2018

Fund-Details-Lending-Libraries.pdf (scvo.scot)

digital inclusion in Scotland. The DIA platform will develop a collaborative approaches to effectively help and support digital excluded people across Scotland.

While we make progress to ensuring everyone is digitally included, we recognise that it is important that there are opportunities for people to be involved in policy making in ways that are not digital. We therefore recognise the need to ensure that these opportunities are maintained as we continue forward.

What can the LDAN Bill do?

An earlier section of this consultation paper discusses, and makes proposals for, bringing a greater focus to how public authorities' duties around inclusive communication can best be met for neurodivergent people and people with learning disabilities. By enabling better inclusive communications, we would expect this to have a positive impact on increased digital access.

Proposal 1 - We could also consider how to ensure that training is available to people with learning disabilities in digital skills and online safety.

Proposal 2 - We could gather clear data on the number of people with learning disabilities and neurodivergent people accessing and using technology.

Proposal 3 - We could make more support available to directly help people with learning disabilities and neurodivergent people access and use technology.

What Do You Think?

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

Section 8: Employment

What we heard:

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.

In 2016, we committed to halving the Disability Employment Gap, outlining the initial steps that would be taken to achieve this by 2038 in A Fairer Scotland for Disabled People: Employment Action Plan²⁰⁷ (2018). The latest full year data estimated the employment rate for disabled people aged 16 to 64 at 50.7 per cent.²⁰⁸ This was significantly lower than the rate for non-disabled people (82.5 per cent), and represents a disability employment gap in Scotland of 31.9 percentage points.

It is estimated that employment rates are 4-8% for people with learning disabilities²⁰⁹ and 29% for autistic people²¹⁰, compared with Scotland's national employment rate of 82.5% for non-disabled people and 50.7% for disabled people.²¹¹ The Office for National Statistics has also reported that the employment rate for 'severe or specific learning difficulties' is 26.2%.212

We have heard from neurodivergent people and people with learning disabilities, that they often feel excluded from the world of work. We have also heard that they want support to find work and hold down a job so they can contribute to, and feel part of, society.

What did LEAP think?

- Workplaces are often not neurodivergent and disability-conscious or adaptive to people's individual needs. This includes during recruitment as well as in the workplace.
- There can still be a lot of stigma in the workplace and it should be challenged.
- There is a lack of clarity on what reasonable adjustments are and look like in individual circumstances, and there needs to be more consistency in the

²⁰⁷ A Fairer Scotland for Disabled People: employment action plan - gov.scot (www.gov.scot)

²⁰⁸ Supporting documents - Labour Market Statistics for Scotland by Disability: January to December 2022 - gov.scot (www.gov.scot)

New research on learning disabilities in Scotland | FAI (fraserofallander.org)

Outcomes for disabled people in the UK - Office for National Statistics (ons.gov.uk)

²¹¹ Supporting documents - Labour Market Statistics for Scotland by Disability: January to December 2022 gov.scot (www.gov.scot)

Outcomes for disabled people in the UK - Office for National Statistics (ons.gov.uk)

understanding and implementation of reasonable adjustments as it was felt that "reasonable" gave employers too much leeway to refuse.

- A booklet should be written to explain what reasonable adjustments mean and made available to all employers in Scotland. There should be a clearer way to monitor adjustments and to challenge when requests are rejected.
- Employers should consider what could be done to make workplaces and job
 roles more autism/disability friendly for everyone rather than there just being a
 focus on the right to request reasonable adjustments.
- There is a need for employers not to employ neurodivergent people as a tick-box exercise but to recognise their strengths and engage in ongoing development to avoid them being underemployed. Additionally to not assume every neurodivergent person is the same.
- Public sector contracts should include a requirement around having employees
 that are neurodivergent people or people with learning disabilities. Or, there
 should be a need to have accreditation of being an inclusive employer for
 organisations that receive public funding.
- Full-time work often is not accessible (even with adjustments made). A higher number of part-time and flexible roles available, including through supported employment programmes, would address the employment gap.
- There was agreement to the Scottish Government's separate proposals for a new duty on employers to report on the disability pay gap. It was thought that this data should be disaggregated to show the pay gap for neurodivergent people and people with learning disabilities.
- Employers should be doing more to be inclusive and adaptive, including greater accessibility in the recruitment process. Competency based interviews may not work for neurodivergent people or people with learning disabilities.
- Employers and employees (as well as support workers and job coaches) should be trained to work alongside neurodivergent people and people with learning disabilities.
- Employers should have business strategies and policies suitable for neurodivergent people and people with learning disabilities and these strategies need to be monitored and controlled.
- There should be better information sharing and promotion of work-related support such ashttps://www.gov.uk/government/collections/disability-confident-campaign²¹³ and Access to Work²¹⁴.

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²¹³ Disability Confident employer scheme - GOV.UK (www.gov.uk)

²¹⁴ Access to Work

- LEAP members were concerned that the social security benefits system disadvantages people with learning disabilities who want to get work (the 16 hours cap)
- The experience of people with learning disabilities is that they can often
 experience bullying at work and their opportunities to progress are generally very
 limited.
- LEAP members feel the entire system of trying to get into employment is extremely complex and confusing and that it needs to be streamlined and made much more learning-disability friendly.

Where do we want to get to?

- A workplace culture of inclusivity, understanding and acceptance, where there is no stigma surrounding neurodivergence or learning disabilities.
- More neurodivergent people and people with learning disabilities in employment.
- Reasonable adjustments being more easily understood, with neurodivergent people and people with learning disabilities feeling knowledgeable and empowered to request reasonable adjustments.
- Reasonable adjustments effected quickly and appropriately.
- Recruitment exercises being more accessible and inclusive.
- Data on employability services and employment support should be disaggregated to the level of condition (eg neurodivergent or learning disabilities), to ensure we know that people with learning disabilities and neurodivergent people are being supported into employment proportionately to the general population and that employment is sustained.

What happens now?

The Equality Act provides a legal framework to protect the rights of individuals and advance equality of opportunity for all. Section 149 of the Equality Act places a duty on public authorities in the exercise of their functions and others who exercise public functions to have due regard to the need to:

- eliminate discrimination, harassment and victimisation and any other conduct that is prohibited by or under the 2010 Act:
- advance equality of opportunity between persons who share a protected characteristic and those who do not;
- and to foster good relations between persons who share a protected characteristic and those who do not.

This is known as the Public Sector Equality Duty (PSED).²¹⁵

The Scottish Parliament's power to legislate on equalities is limited, as equal opportunities are generally reserved to the UK Parliament. For example, this means that the Scottish Ministers do not have the power to introduce a protected characteristic that has the same status as the protected characteristics in the Equality Act 2010.

The Scottish Parliament also does not generally have the power to legislate on employment and industrial relations, which is reserved to the UK Parliament in the 1998 Act.

Although the subject matter of the Equality Act is largely reserved, Scottish Ministers have used their available powers to support compliance with the PSED by placing detailed requirements on Scottish listed authorities through the Equality Act 2010 (Specific Duties) (Scotland) Regulations 2012 (SSDs).

The SSDs support Scottish listed authorities to improve performance of the PSED by requiring them to: report progress on mainstreaming equality; propose and publish equality outcomes; assess policies and practices from the perspective of equality; and publish employee information on pay and occupational segregation.

Responsibility for oversight of compliance with the 2010 Act, including compliance with the SSDs, rests with the Equality and Human Rights Commission (EHRC). The EHRC has issued guidance on how the SSDs should be applied in practice.

Our commitment to at least halve the disability employment gap to 18.7 percentage points by 2038 (from 37.4 percentage points in 2016 baseline year) aligns with the intention and ambitions of both the Equality Act and the CRPD.

The Equality Act requires employers to provide reasonable adjustments to disabled employees. We are taking action to improve the recruitment and retention of disabled people. This has included, for example, establishment of a dedicated Workplace Adjustments team, and introduction of an Employee Passport.

One reasonable adjustment that may be particularly beneficial to many disabled employees is flexible working. Whilst we cannot place a legal requirement on employers to provide this, given that the subject of employment and industrial relations is reserved to the UK Parliament, we are encouraging flexible working arrangements through our Fair Work policy approach with employers. If a person has a disability, illness or health condition that means they need support to do their job that is over and above a 'reasonable adjustment', they may be eligible for support through the Access to Work scheme, which is run by the UK Government's Department for Work and Pensions.

Where someone is considered disabled under the 2010 Act, employers must also provide reasonable adjustments during the recruitment processes.

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²¹⁵ Public sector equality duty

The Equality Act also enables employers to make use of positive action in relation to recruiting and promoting people with protected characteristics. Additionally, it is not unlawful for an employer to treat a disabled person more favourably in comparison to a non-disabled person, for example guaranteed interview schemes for disabled applicants.

What can we do about it?

We are simplifying the employability system through the implementation of No One Left Behind.²¹⁶ It has a crucial role in achieving the vision for economic transformation and tackling child poverty; and aims to deliver a system that is more person centred, tailored and responsive to the needs of people of all ages who want help and support on their journey towards and into work. In particular, No One Left Behind aims to support people with health conditions, disabled people (including neurodivergent people and people with learning disabilities) and others who are disadvantaged in the labour market.

Whilst employment and industrial relations is generally reserved to the UK Parliament to legislate on, under the 1998 Act the Scottish Ministers have power to put in place arrangements to assist disabled people and people at risk of long term unemployment who are in receipt of reserved benefits to select, obtain and retain employment. In the case of those at risk of long-term unemployment, the assistance must be provided for at least a year.

In the absence of powers to amend employment rights and industrial relations legislation, we are taking a strategic approach and using the levers we do have available to promote Fair Work practices across the Scottish economy. The actions we will take to progress this agenda are set out in our refreshed Fair Work Action Plan.²¹⁷ This incorporates actions on tackling the gender pay gap, the disability employment gap, and is complemented by our Anti-Racist Employment Strategy²¹⁸.

Actions relating to disabled people's employment include:

- Investing almost £1m into our Public Social Partnership, which is working to improve the recruitment and retention of disabled people by developing and testing support for employers.
- Delivering all-age, person-centred, tailored employability services to those further from the labour market, including disabled people and those with health conditions, through a combination of locally designed services (No One Left Behind) and our national employment service (Fair Start Scotland).
- Providing tailored pre-employment and in-work support, which are both entirely voluntary with no threat of social security sanctions. This includes the provision of specialist support through either Supported Employment or Individual Placement and Support.

²¹⁶ No One Left Behind | Employability in Scotland

Fair Work action plan: becoming a leading Fair Work nation by 2025 - gov.scot (www.gov.scot)

Anti-racist employment strategy - A Fairer Scotland for All - gov.scot (www.gov.scot)

- Reviews of Individual Placement and Support and Supported Employment.
 Review recommendations are being taken forward through the next phase of development of our employability services.
- Establishing a Scottish Access to Work Stakeholder Forum, led by a Disabled People's Organisation, to engage and provide direct input to DWP.
- Application of Fair Work First²¹⁹ principles to public sector spend including action by employers to create a more diverse and inclusive workplace. Since 2019, this has been applied to over £4bn of public sector spend.

In terms of the visibility of people with learning disabilities and autistic people in the data reporting under Fair Start Scotland, we have mainstreamed this through the recently published Employability Shared Measurement Framework²²⁰. The Framework covers activity under the No One Left Behind approach. This data will allow us to better measure the reach of our services for people with learning disabilities and autistic people, and the opportunities and outcomes we are supporting them to access.

In line with our commitment to person-centred services, the experience of users is a critical measure of success. As part of our programme of evaluation work outlined above we are considering opportunities to evaluate the experiences and outcomes of autistic people and people with learning disabilities where possible.

As discussed in the introduction, we are also reviewing the PSED in Scotland and intend to deliver on two key regulatory changes - revising the current pay gap reporting duty to include reporting on ethnicity and disability pay gaps, and, introducing a new duty on listed public bodies which will seek to ensure inclusive communication is embedded proportionately across their work when they are communicating with the public.

By extending the current requirement for pay gap reporting to disability and ethnicity, we believe that this can encourage public bodies to take more effective action on equality issues affecting their disabled and ethnic minority staff. Following a public consultation²²¹, we found that most of the respondents were largely in agreement (93%) that listed authorities should publish ethnicity and disability pay gap information.

Whilst we think that pay gap reporting is vital, some stakeholders have suggested that it has some limitations. It is thought that reporting statistics alone can be of limited value without contextualising the data, as this would highlight only part of the story. We are therefore considering this feedback as we take forward reforms, to ensure that meaningful change is achieved.

Regulation 11 of the SSDs provides that "In carrying out its duties under these Regulations, a listed authority may be required to consider such matters as may be specified from time to time by the Scottish Ministers." We are exploring how we

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²¹⁹ A12 Fair-Work-First-Policy-Statement V1 2021 Final.pdf (article12.org)

²²⁰ for-publication-shared-measurement-framework-updated-december-2022.pdf (employabilityinscotland.com)

²²¹ public consultation

might use this power to highlight issues which would have an immediate impact on public bodies' progress in equality mainstreaming, such as making more effective use of intersectional equality data in policy making.

What can the 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 will explore the following in order to promote and encourage 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
 undertake disability equality training, including more specialist training for line
 managers on individual conditions, 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,²²² 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 condition level (employability) data that the Scottish Government collects on employability to ensure it is consistent with the language individuals and professionals use, to ensure that we are collecting and reporting data in a consistent way.

What Do You Think?

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

Supported employment: review report and Scottish Government response - gov.scot (www.gov.scot)

Section 9: Social Security

What we heard

Social security is a human right and is essential to the realisation of other human rights. None of us know when we might need it. It is a shared investment to help build a fairer society, together. Social security is key for disabled people, including neurodivergent people and people with learning disabilities, to gain independence from families, boost their social participation and support their ability to live with dignity. It can enhance the productivity, employability and economic development of disabled people. And, ultimately, help to tackle inequalities and allow every person in Scotland to live with dignity, fairness and respect.

We know that people with learning disabilities and neurodivergent people are less likely to be in employment and are therefore more likely to need social security support. For those who are in employment, we know that they may also need social security support if they are unable to work full time, or to help with the additional costs of being disabled.

Neurodivergent children and young people, and children and young people with learning disabilities, and their families, may also need support with the additional costs of their conditions.

The latest full year data estimated the employment rate for disabled people aged 16 to 64 at 50.7 per cent. This was significantly lower than the rate for non-disabled people (82.5 per cent), and represents a disability employment gap in Scotland of 31.9 percentage points.²²⁴

It is estimated that employment rates are 4-8% for people with learning disabilities²²⁵ and 29% for autistic people²²⁶, compared with Scotland's national employment rate of 82.5% for non-disabled people and 50.7% for disabled people.²²⁷ The Office for National Statistics has also reported that the employment rate for 'severe or specific learning difficulties' is 26.2%.²²⁸ The National Autistic Society has said that 77% of unemployed autistic people want to work.²²⁹

What did LEAP think?

 There shouldn't be a limit of 16 hours per week of employment, after which certain social security benefits are taken away. This limit can make it very difficult to find employment.

²²³ Social Security in Scotland: consultation - gov.scot (www.gov.scot)

Annual population survey (APS) QMI - Office for National Statistics

New research on learning disabilities in Scotland | FAI (fraserofallander.org)

Outcomes for disabled people in the UK - Office for National Statistics (ons.gov.uk)

²²⁷ Supporting documents - Labour Market Statistics for Scotland by Disability: January to December 2022 - gov.scot (www.gov.scot)

²²⁸ Outcomes for disabled people in the UK - Office for National Statistics (ons.gov.uk)

New shocking data highlights the autism employment gap

- Learning disabilities, and other neurodivergent conditions such as autism are lifelong conditions. It is undignified and stressful having to be re-assessed for certain benefits. This shouldn't happen.
- The social security rules and processes should either be simpler, or more support should be provided to help people understand their right to social security and how to apply.
- The eligibility criteria for disability payments does not seem to be right. In
 particular, there is uncertainty about whether a diagnosis of a neurodivergent
 condition, such as autism, ADHD or FASD, or a diagnosis of learning disabilities,
 is needed. It was thought that a diagnosis should not be needed because there
 can be long waiting times for diagnosis.
- Transitions into and out of employment need to be managed better without cliff edge losses of certain benefits and quick restarting of those benefits is required if employment doesn't work out which can often be the case.
- The barriers to accessing and understanding rights to social security need to be better understood and addressed. Better communication and information are needed.

Where we want to get to

- Our social security system supports people in line with the values of dignity, fairness and respect.
- Clear information and guidance is available on the right to social security and how to apply, including for people without a formal diagnosis.
- People who are eligible for social security benefits are provided with proactive support wherever possible, and people who are eligible receive the benefits they are entitled to.
- There are better transitions into and out of employment.

What happens now and what can we do about it?

International Human Rights

Social security is a human right that is protected by a range of international human rights laws and standards:

- Council of Europe Code of Social Security
- Article 12, European Social Charter
- International Labour Organisation Convention No. 102
- Article 9The International Covenant on Economic, Social and Cultural Rights (ICESCR)

As noted in the introduction we are progressing a Human Rights Bill for Scotland as well as the United Nations Convention on the Rights of the Child (UNCRC) (Incorporation) (Scotland) Bill, to incorporate a wide range of internationally recognised human rights belonging to everyone in Scotland into Scots law, within the limits of devolved competence.

The different types of Social Security Benefits

Some social security benefits are delivered in Scotland by Social Security Scotland. However, the majority are delivered by the UK Government, through the Department for Work and Pensions (DWP).

The Scotland Act 2016²³⁰ gave the Scottish Government additional powers, including to deliver certain benefits, and provides powers to top up certain reserved benefits (those that the UK Government delivers). In addition, it gave the Scottish Government powers to create certain new benefits. The Social Security (Scotland) Act 2018 ("2018 Act")²³¹ sets out the framework for most of the benefits to be delivered that the Scottish Parliament has so far legislated for. There are other devolved forms of social security assistance that are delivered outwith the 2018 Act powers, for example, Best Start Foods under regulations made under the Social Security Scotland Act 1988, and grants payable from the Scottish Welfare Funds under the Welfare Funds (Scotland) Act 2015.

Our Charter²³² sets out what people should expect from the new social security system and how we will take a human rights based approach. It was created with people with lived experience and not for them, and a defining feature of our human rights approach to social security is that every aspect of the new system has been designed together with the people who know the system best – those who access and rely on services.

Social Security Scotland currently delivers 13 different benefits in Scotland, including:²³³

- five Family Payments, including the Scottish Child Payment;
- two Disability Benefits: Adult Disability Payment (ADP) and Child Disability Payment (CDP):
- two Carer Benefits;
- two Heating Benefits;
- Funeral Support Payment; and
- Job Start Payment.

ADP and CDP are not means-tested. This means that they are paid regardless of a person's income or financial position, so employment status is not taken into account. ADP will not stop if a person works over 16 hours, or enters into employment. CDP will not stop if a child or young person's parent or carer's

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²³⁰ A Fairer Scotland for Disabled People: delivery plan - gov.scot (www.gov.scot)

²³¹ Social Security (Scotland) Act 2018 (legislation.gov.uk)

²³² Social Security Scotland - Our Charter

²³³ Social Security Scotland - Benefits

employment or income status changes, of if the young person enters into employment.

Carer Support Payment, which will replace Carer's Allowance in Scotland, has limits on the amount carers can earn while receiving the benefit, as an income replacement benefit. Earnings rules for the benefit will mirror Carer's Allowance on launch to avoid a 'two tier' system which would disadvantage some carers but we are considering feedback from carers, support organisations, and our previous public consultation on changes we could make in future to provide more flexibility for carers who are able to, and want to, take on paid work alongside caring.

However, the key social security benefits that neurodivergent people and people with learning disabilities are likely to rely on are the responsibility of the UK Government. This includes Income Based Employment and Support Allowance (ESA), New Style ESA, Universal Credit and Tax Credits. The DWP is, however, in the process of migrating people from Income Based ESA and Tax Credits to Universal Credit. This process is due to complete for Tax Credits by 2025 and ESA by 2029.

New Style ESA can only be awarded if a person is working less than 16 hours, or they do not earn more than £167 a week and have paid class one or class two National Insurance contributions in the last two full tax years before a claim is made.

No new claims can be made for income based ESA and interested persons will be signposted to claim Universal Credit.

Universal Credit can be awarded even if a person works over 16 hours a week. It is, however, means-tested.

Working Tax credit can only be awarded to a disabled person if they already get Child Tax Credit and work at least 16 hours.

Overall, this means that some of the concerns raised by the LEAP cannot be addressed by the Scottish Government. This includes concerns relating to: the 16 hours limit of employment per week; cliff edge loss of benefits when entering employment; and concerns around being able to quickly reapply for benefits if employment doesn't work out.

We continue to call upon the UK Government to make changes to reserved benefits which impact on people in Scotland. For example, calling on the UK Government to legislate for an essentials guarantee to be applied to the rates and uprating of reserved benefits. Doing so would link the rates of benefits to the cost of essential items such as food and fuel, as well as ensuring that no-one's benefit would fall below this level as a result of any caps or limits, government debt or sanctions. As well as the implementation of an essentials guarantee, we are currently calling on the UK Government to make the following changes to Universal Credit:

- abolish the two child limit;
- end the widespread use of sanctions, following clear evidence that they do not work;

- scrap the young parent penalty which ignores the reality that, regardless of age, housing, food and utilities cost the same for everyone; and
- replace advance loans with non-repayable grants.

Adult Disability Payment (ADP)

Following a phased pilot rollout, ADP opened for new applications across Scotland in August 2022. For people in Scotland who currently receive Personal Independence Payment (PIP) or Working Age Disability Living Allowance (WADLA) through the DWP, their payments are automatically transferring to Social Security Scotland without interruptions to people's payments. Our ADP policy position paper was published in March 2022.²³⁴

Our priority is the safe and secure transfer of these payments, which means that we are not immediately making fundamental changes to the existing benefit structure or rules. However, we have made a number of improvements to provide disabled people with a far more positive experience compared to PIP.

ADP is not means-tested and is not taxed. It will also rise with inflation. On 01 April 2023, ADP was increased by 10.1% in line with inflation. It can be a passport to other types of support, such as Blue Badge, Housing Benefit, Carer's Allowance, Universal Credit and exemption from the benefit cap.

ADP has been co-designed with stakeholders and disabled people to ensure that the values of dignity, fairness and respect are embedded throughout. The application process was designed with individuals and disability organisations so that as many people as possible can understand, apply for and receive the benefits they are entitled to. Applications can be made in a way that suits people best: online, by post, over the phone or face-to-face. Local delivery staff are available to provide one-on-one support to disabled people throughout the application process, at a time and place which is most suitable for the person applying.

There are no DWP style assessments with medical examinations, such as asking clients to 'touch their toes'.

Disabled people are asked, where possible, to provide one piece of supporting information from a professional with their application. In order to make the application and review process as easy as possible for people, Social Security Scotland can obtain supporting information from professionals on the person's behalf. Social Security Scotland also accepts supporting information provided by third sector organisations who support an individual in their day-to-day life. Disabled people are encouraged to apply for disability assistance even if they do not have any supporting information to hand.

People can access Short-term Assistance while they are challenging a decision after a review to reduce their entitlement, which does not need to be repaid if their review is unsuccessful.

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²³⁴ Adult Disability Payment: policy position paper - gov.scot (www.gov.scot)

Eligibility is not based on a person's diagnosis of a particular condition. Instead, it is based on the impact a person's condition has on their daily life. This approach means that individuals who face barriers accessing a diagnosis or input from medical professionals will not be disadvantaged within the social security system.

We have introduced indefinite awards for people with the highest level awards where they have needs which are highly unlikely to change. This will help to avoid the stress and anxiety associated with reviews while providing long-term financial security to people. Indefinite awards will support people to lead their lives more independently and fully.

ADP as it currently stands does not represent the limit of our aspirations for disability assistance in Scotland. We are in the process of establishing an independent review of ADP to consider what further changes and improvements could and should be made in the future.

The independent review will examine the current eligibility criteria and people's experiences of the first year of ADP. The review will make recommendations ensure the benefit continues to meet the needs of disabled people, in accordance with the principles set out in the 2018 Act. The Chair will be independent of Government and will also consider the most appropriate ways of engaging with a wide variety of audiences. The independent review will secure the input of disabled people and stakeholders, with opportunities for participation throughout.

Child Disability Payment (CDP)

CDP was launched in Scotland in November 2021 and is available to children from 3 months to 18 years old who have care and/or mobility needs as a result of disability. CDP is designed to mitigate some of the additional costs of caring for a disabled child or young person. Our CDP position paper²³⁵ was published in February 2020.

CDP was co-designed with disabled people and other stakeholders to ensure that our values of dignity, fairness and respect are embedded throughout. It was the first benefit anywhere in the UK where applicants could apply online, as well as by phone, post or face-to-face.

It is not means-tested or taxed and will rise with inflation. On 01 April 2023, CDP was increased by 10.1% in line with inflation. It can be a passport to other types of support, such as a Blue Badge, Housing Benefit, Carer's Allowance, Child Tax Credit, Universal Credit and exemption from the benefit cap.

Whilst over 80% of people surveyed told us that CDP helped make a difference to their lives²³⁶, we are continuing research to look for ways to improve and enhance the service for the people of Scotland. As described in the Evaluation Strategy²³⁷ for devolved disability benefits, a series of evaluations are planned. These involve asking individuals, staff, and stakeholders about their experiences which will allow us

Supporting documents - Devolution of disability benefits: evaluation strategy - gov.scot (www.gov.scot)

²³⁵ Child Disability Payment: position paper - gov.scot (www.gov.scot)

²³⁶ Social Security Scotland - Client Survey: Child Disability Payment

to understand what is going well and identify next steps. We will be commencing work to evaluate CDP to ADP journey from Nov 2023 onwards.

Independent advocacy, support and guidance

The Social Security (Scotland) Act 2018 places a legal requirement on Scottish Ministers to ensure that independent advocacy services are available to anyone who identifies as disabled and requires support to claim Scottish social security entitlements.

The Social Security Independent Advocacy Service launched in January 2022 and is delivered by VoiceAbility²³⁸. The service supports disabled people to access and apply for Social Security Scotland assistance, and builds on our human rights based approach, increasing accessibility and supporting people to be more involved in the processes and decisions which affect them.

It is a free service and is available to anyone who self-identifies as a disabled person who requires support. It is available throughout the whole process for seeking support; from the point of application through to any request for redetermination and appeals.

A referral pathway has been established between Social Security Scotland and VoiceAbility, allowing for direct referrals into the advocacy service.

Promoting benefit take-up and user research

Ensuring that people access all of the social security benefits they are entitled to is a fundamental priority for the Scottish Government. The 2018 Act establishes a legal duty on the Scottish Ministers to promote benefit take-up. As part of our duties under the 2018 Act we must periodically publish a Benefit Take-up Strategy. The latest Benefit Up-Take Strategy²³⁹ was published in 2021 and sets out the principles which shape our approaches to promoting benefit take-up across the suite of devolved payments.

Part of our work to promote benefit take-up includes tackling stigmatising narratives and challenging negative perceptions around benefit receipt. Through user research, we look to better understand how to address stigma and ensure that Scotland's social security system is designed with input from the people who will use it.

Co-design with people with lived experience

We have put clients' needs at the heart of the design and improvement of all our social security systems and services. This user-centred approach has been central to the design and delivery of social security from the very outset, and now continues with Social Security Scotland using a range of clients' feedback on their experiences to continuously improve the service.

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²³⁸ VoiceAbility | Advocacy and involvement

Social Security (Scotland) Act 2018: benefit take-up strategy - October 2021 - gov.scot (www.gov.scot)

Despite this, we are aware that there are groups of people with lived experience that are less likely to be represented on these panels, and who face substantial barriers in accessing social security support. As such, we established the "Seldom heard Voices" research programme²⁴⁰ to address this gap. In line with commitments set out in the Benefit Take-Up Strategy, we will continue to explore opportunities to work with these groups, ensuring that valuable, bespoke methods are considered to support seldom-heard communities to access their entitlements.

Inclusive communication

The 2018 Act included a specific duty on the Scottish Ministers, and therefore Social Security Scotland, regarding inclusive communications. Section 4 of the 2018 Act states that the Scottish Ministers must have regard to the importance of communicating in an inclusive way as part of their duty to keep under consideration what steps they could take to ensure that individuals receive the support they are entitled to through the Scottish social security system.

The 2018 Act explains that 'communicating in an inclusive way' means communicating in a way that ensures individuals who have difficulty communicating (in relation to speech, language or otherwise) can receive information and express themselves in ways that best meet each individual's needs.

Social Security Scotland, in its Corporate Plan²⁴¹, sets out that the organisation is committed to inclusive communication and want to make it as easy as possible for people to access the support they are entitled to. Social Security Scotland will aim to communicate with people in the ways they prefer, and staff will be trained to help them do this.

To assist with this, and to inform service design, extensive research with users was undertaken.²⁴² However, in recognising that further improvements should be made²⁴³ an Inclusive Communication Action Plan 2022-25 was prepared and is being progressed to increase accessibility and participation.

Reserved benefits - ESA and Universal Credit

The Department for Work and Pensions published Transforming support: the health and disability White Paper alongside the Spring Budget on 15 March 2023²⁴⁴. This included an aim to make "the [benefit] claim journey more of a two-way conversation", communicate decisions in a simple and compassionate way and get more decisions right first time.

The white paper outlined plans to abolish the Work Capability Assessment. This assessment helps determine whether someone is entitled to extra amounts in

242 Social Security Experience Panels: Inclusive Communication - Report (www.gov.scot)

²⁴⁰ Social Security Experience Panels: publications - gov.scot (www.gov.scot)

²⁴¹ Corporate Plan 2020-2023 (socialsecurity.gov.scot)

²⁴³ Social-Security-Scotland-Governance-Executive-Advisory-Body-Meeting-30-20220628-30.2a-Inclusive-Communication-Cover-Paper.pdf (socialsecurity.gov.scot)

²⁴⁴ Transforming Support: The Health and Disability White Paper - GOV.UK (www.gov.uk)

Universal Credit and ESA, as well as any work-related requirements people must meet as a condition of their entitlement.

What can the LDAN Bill do?

The previous paragraphs discuss that some of the issues that the LEAP wished to be explored or changed are not within the power of the Scottish Government or the Scottish Parliament to change. Some of the issues that LEAP wished to be explored or changed are already being actioned through the new Social Security system for Scotland.

We could, however, explore the following in relation to the LDAN Bill, to bring more focus and understanding to the needs of people with learning disabilities and neurodivergent people:

Proposal 1 National and Local Strategies

National and local strategies are discussed in the overarching themes section of this consultation. We could consider requiring Social Security Scotland to report on, and evaluate, how its inclusive communication strategies have taken into consideration the needs of people with learning disabilities and neurodivergent people.

Proposal 2: Mandatory training for social security staff

Proposals are set out in the overarching themes section for mandatory training for health and social care staff and we invite views on whether there are other public sector areas this should extend to.

With regard to Social Security Scotland, we are aware that there is likely to be a significant proportion of people with learning disabilities and neurodivergent people who are eligible for social security, given the employment rates. We could therefore explore whether there is a need for training on learning disabilities and neurodivergence to be a statutory requirement for some Social Security Scotland staff.

Proposal 3: Data collection

We have set out broad proposals on data in the overarching themes section. To better understand neurodivergent and learning disabilities groups and their needs, including how many people are accessing social security benefits, current data reporting could be disaggregated further. For example, current data reporting on ADP in Scotland has a category for "autism and other developmental disorders" but does not report on learning disabilities, ADHD, FASD or other conditions separately.

²⁴⁵ Social Security Scotland - Adult Disability Payment: high level statistics to 31 July 2023

What Do You Think?

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

Section 10: Justice

What do we mean by Justice?

The intention is that this section will cover both the civil justice system (including the civil courts and tribunals) and the criminal justice system. Where necessary, it is clarified which proposals would just extend to the criminal justice system and which would apply to both the criminal and civil systems.

Some justice agencies, such as the Scottish Prison Service, are not involved in the civil justice system. In addition, there is no accused person in the civil justice system and there are some hearings in the civil justice system (e.g. child welfare hearings) where evidence is not taken.

A word about Youth Justice

Most of what appears in the rest of this section relates to people aged 18 and over. Scotland is already doing a lot to address issues for younger people in the justice system. This includes a rights respecting approach that aligns with the UNCRC. For example, we have:

- A youth justice vision and priorities²⁴⁸ including:
 - all children being able to access services to address trauma, abuse, neglect and communication needs
 - o Early intervention and support including trauma informed approaches
 - o Better data and evidence
- Recommendations from The Promise on justice, including through provisions outlined within the Children (Care and Justice) (Scotland) Bill²⁴⁹
- Standards for youth justice
- A youth justice Improvement Board
- A secure care pathway and standards

Under the Youth Justice Improvement Board²⁵⁰ an implementation group looking at addressing the priorities within the Youth Justice vision around children's rights has been established. This includes looking at the speech, language and communication needs of children. The standards for youth justice also include supporting children to understand their needs and behaviours.

Some areas across Scotland are looking to develop youth courts. This includes consideration of the language used in court and recognising and addressing speech, language and communication needs.

²⁴⁶ Youth justice strategy: progress report - gov.scot (www.gov.scot)

²⁴⁷ United Nations Convention on the Rights of the Child (UNCRC): how legislation underpins implementation in England - GOV.UK (www.gov.uk)

²⁴⁸ Youth justice - gov.scot (www.gov.scot)

²⁴⁹ Children (Care and Justice) (Scotland) Bill – Bills (proposed laws) – Scottish Parliament | Scottish Parliament Website

²⁵⁰ Youth Justice Improvement Board - gov.scot (www.gov.scot)

The Scottish Children's reporter developed a disability toolkit in 2021²⁵¹ for use by practitioners that allows for the identification of additional needs in the children's hearing system.

We provided funding to secure centres in 2022/23 to allow secure providers to support children with neurodivergent needs. The latest published social work statistics showed that in 2021/22²⁵² there were 67 residents in secure care and 31% of young people in secure care had a known disability.

The Health and Education Chamber of the First Tier Tribunal deals with cases relating to additional support needs for children, and has considered these needs in the design of the Chamber. It has:

- Developed the Needs to Learn First-Tier Tribunal for Scotland (Health and Education Chamber) website for children to access information about how to make claims and references and what to expect as the case goes on;
- Developed a My Voice! Form for children to put across their views in relation to their case:
- Developed an accessible, purpose-built suite of hearing rooms for additional support needs cases to help children participate in their hearings, alongside visual guides for children to prepare them for visiting the suite; and
- Developed cards to help children participate in their hearings (for example, stop/go cards).

What We Heard

Currently there is a lack of reliable data for neurodivergent people and people with learning disabilities who have contact with the justice system.

People with adverse childhood experiences (ACEs) can be more likely to have contact with the criminal justice system as victims, witnesses or perpetrators of crime and this can include neurodivergent people and people with learning disabilities who have experienced trauma. People with less understanding of legal issues find it much harder to access the services and information they need to resolve their issues. Those who say their lives are limited greatly by disability are particularly vulnerable.

Clan Childlaw published an animation from children and young people called Alright²⁵³ about their experiences of legal representation, what they want from lawyers and from care and justice settings.

The SOLD (supporting offenders with learning disabilities) network²⁵⁴ aims to reduce offending and improve support for offenders with significant communication needs. The network is funded by the Scottish Government and led in partnership by People

police station: easy read - gov.scot (www.gov.scot)

²⁵¹ Development and piloting of a children's disability toolkit - SCRA

²⁵² Secure care accommodation - Children's Social Work Statistics Scotland: 2021 to 2022 - gov.scot (www.gov.scot)

²⁵³ 'Alright?' - An animation by Clan Childlaw - Clan Childlaw ²⁵⁴ Your Rights when you are at the Police Station - Letter of rights - your rights when you are in a

First, ARC Scotland and the National Autistic Society. SOLD members have reported that they often feel confused and anxious as they cannot understand what is going on. SOLD reports that there is a lot of anecdotal evidence in terms of the increased likelihood of neurodivergent people and people with learning disabilities coming into contact with the criminal justice system.

Offenders data²⁵⁵

- A report by the Children's Commissioner in 2012²⁵⁶ showed communication disorders among young offenders of 60-90%;
- A Scottish Prison Service pilot carried out in 2016 showed 39% of prisoners with a learning disability or difficulty.
- The 2019 SPS prisoner survey found that within the prisoner responses (30% of prisoners on the survey date responded), prevalence rates were reported as including Autism (4%), ADHD/ADD (8%), Dyslexia (7%), Dyspraxia (1%) as well as high rates of depression (39%) and anxiety/panic disorders (29%)]
- The Coates review into education in prison (England) stated that one-third of prisoners self-identified as having a learning difficulty and/or disability in 2014/15 (Coates, 2016)

A review of neurodivergence in the criminal justice system in July 2021 in England and Wales by Inspectorate Services²⁵⁷ found:

- 5–7% of those referred to liaison and diversion services have an autistic spectrum condition (ASC).
- Within prisons the prevalence of autistic 'traits' or 'indicators' could be around three times as high (16% and 19% respectively).
- Around a quarter of prisoners were thought to meet the ADHD diagnostic criteria (Young et al, 2018).

The review found evidence of good local partnerships and heard about many simple adjustments that could be made but these were patchy, inconsistent and uncoordinated. More effective assessment of need, adaptation of services and better training of staff was needed to support those with neurodivergent conditions, wherever they are in the criminal justice system. The report made six recommendations, including the introduction of a common screening tool; collection of screening data; use of simple adjustments including on communications; and, awareness raising and specialist training which should be mandatory for frontline staff. The UK Government is taking forward this work and reporting on it regularly.

A report by the Equality and Human Rights Commission - Inclusive Justice: a system designed for all²⁵⁸, looked at the experiences of adult accused people with a cognitive impairment, mental health condition, or neuro-diverse condition in the criminal justice system in England, Wales and Scotland to determine if people could

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²⁵⁵ Prison population: social care needs - gov.scot (www.gov.scot)

Annual report 2012-13 | Children's Commissioner for England (childrenscommissioner.gov.uk)

²⁵⁷ Neurodiversity in the criminal justice system: A review of evidence - His Majesty's Inspectorate of Constabulary and Fire & Rescue Services (justiceinspectorates.gov.uk)

²⁵⁸ EHRC Inclusive justice a system designed for all (equalityhumanrights.com)

participate effectively. Key findings were around a lack of understanding due to inaccessible information and lack of knowledge, a lack of reliable data on the prevalence of vulnerable people entering the system and a lack of a reliable method of identifying vulnerabilities. Recommendations made included:

- Address gaps in the collection, monitoring and analysis of disability data for defendants and accused people.
- The Scottish Government should agree a long-term aim of a health-led screening and assessment process to identify needs.
- The Scottish Government should create a system to ensure appropriate collection and sharing of information on identified needs and recommended adjustments across health, social work and justice.
- There should be improved training including within initial professional qualification training for law students and as a mandatory element of continuing professional development for those working in criminal law.

What did LEAP think?

- There should be a requirement on the Scottish Prison Service to report publicly on people with learning disabilities and neurodivergent people currently held in prison.
- Training in relation to disabilities, learning disabilities and neurodivergence for Police Scotland and all public bodies in the Justice system should be mandatory.
- Data should be published on the number of neurodivergent people and people with learning disabilities employed by public bodies in the system.
- We should change the meaning of "mental disorder" within mental health legislation so that it doesn't include autistic people and people with learning disabilities. This issue is discussed at another section of this consultation.

Where do we want to get to?

- Neurodivergent people and people with learning disabilities are better identified at any key point of contact within the civil and criminal justice system, and information is passed on to other relevant partners.
- People with learning disabilities and neurodivergent people are given access to accessible and inclusive information throughout the civil and criminal justice system.
- Neurodivergent people and people with learning disabilities who need additional support have confidence that this will be identified. Access to an Appropriate Adult and advocacy support will always be considered.
- That partners in the civil and criminal justice system have a better understanding of the impact of learning disabilities and neurodivergence on an individual.

- People are diverted from the criminal justice system where it is appropriate, and any underlying needs are addressed in an effective way.
- People working in the civil and criminal justice system have confidence, based on training, that they can effectively identify and work with neurodivergent people and people with learning disabilities.

What Happens Now?

We published our vision for justice in Scotland in 2022,²⁵⁹ a vision for a just, safe and resilient Scotland that is person centred and trauma informed. Elements of this strategy are important for neurodivergent people and people with learning disabilities and there is an emphasis on prevention and improving mental and physical wellbeing, including:

- a new trauma framework for staff;
- an Equally Safe two year delivery plan;
- Work with partners to Keep The Promise;²⁶⁰
- A new health and wellbeing strategy for prisons.

Our National Strategy for Community Justice was published in June 2022²⁶¹ and has a focus on four national aims relating to diversion and early intervention; the provision of robust and high quality interventions; responsive services which meet the needs of individuals; and strong leadership and partnership working. A delivery plan was published in June 2023 to ensure implementation and drive towards actions at a national, as well as local level. This sits alongside the vision for youth justice²⁶².

The Public Sector Equality Duty (PSED), as discussed in the introduction, requires certain public bodies, including the Scottish Government and Scottish Courts and Tribunals Service to have due regard to the need to (among other things) eliminate discrimination across the protected characteristics in the exercise of their functions, including disability.

The SOLD network and the National Autistic Society (NAS) have produced helpful materials, including:

- A guide for defence solicitors representing clients with communication support needs²⁶³;
- A guide for support workers²⁶⁴; and,
- Easy read guides including on arrest and going to court²⁶⁵.

²⁵⁹ The Vision for Justice in Scotland - gov.scot (www.gov.scot)

²⁶⁰ Keeping the Promise implementation plan - gov.scot (www.gov.scot)

National Strategy for Community Justice - gov.scot (www.gov.scot)

²⁶² Justice for children and young people - a rights-respecting approach: vision and priorities - gov.scot (www.gov.scot)

²⁶³ Practice-Guide-Defence-Solicitors-SOLD.pdf (soldnetwork.org.uk)

SOLD 4_V03_Final_PRINT.indd (soldnetwork.org.uk)

You are under arrest: an easy read guide (soldnetwork.org.uk)

- Guides for parents and carers and autistic adults; and
- Guide for police officers and professionals.

The SOLD User group is made up of adults with a learning disability who have been involved in the criminal justice system. The group supports people with communication support needs, including learning disability. In April 2022 there was a national conference called 'I wish I could be back in prison: Community based support for offenders with communication support needs.' This focused on how people with a learning disability are at increased risk of offending if support to achieve equal access to protective factors (such as good housing, employment, education, meaningful relationships) is not provided. SOLD members have delivered training to several agencies across the justice system.

Human Rights Bill

As part of the Human Rights Bill consultation, we sought views on strengthening access to justice (both non-court and court) for rights-holders, which could include people with learning disabilities and neurodivergent people, where their rights have been potentially infringed under the Bill by a public authority. The proposals we are currently considering in relation to judicial access to justice are mostly relevant in the civil court system and seek to lessen the burden on individuals seeking justice through courts and to recognise judicial remedies as an important part of making sure the Bill has a positive impact for rights-holders.

Data

There is a lack of data available to tell us what happens to neurodivergent people and people with learning disabilities in both the civil and criminal justice systems.

Currently there are issues with needs being identified if they come into contact with the criminal justice system. The current practice of identification relies on individual police officers' ability to recognise neurodivergence or a learning disability. This determines whether their condition and its impact is recorded in the Standard Prosecution Report sent to the Crown Office and Procurator Fiscal Service (COPFS). This in turn limits the information available to inform the use of suitable interventions and support which enables neurodivergent people and people with learning disabilities to fairly engage with the justice system.

Appropriate Adults

Appropriate Adults is a statutory scheme of communication support available to vulnerable people over 16 years old suspected of committing an offence, victims and witnesses as part of police procedures. An Appropriate Adult should be requested by a police officer where the person appears, due to mental disorder, to be unable to sufficiently understand what is happening or communicate effectively with police. The role of an Appropriate Adult is to help the person understand what is happening, and facilitate effective communication between the person and police. Local authorities are responsible for ensuring that Appropriate Adults are available. The criteria are set out in law in the Criminal Justice (Scotland) Act 2016 and the Criminal Justice (Scotland) Act 2016 (Support for Vulnerable Persons) Regulations

2019. The definition of mental disorder for these purposes is drawn from the Mental Health (Care and Treatment) (Scotland) Act 2003 ("the Mental Health Act"). Mental disorder currently includes people with a learning disability and autistic people. However, the police will also request an Appropriate Adult where they identify that anyone has a communication need.

In court, special measures can be requested for witnesses who are vulnerable by way of mental disorder (in the meaning of the Mental Health Act). One of these special measures includes having a supporter in court. The supporter is there to support the vulnerable witness when giving their evidence.

A vulnerability assessment is carried out by the police in custody but this covers many aspects of mental and physical health and has only one question related to communication which focuses on difficulty reading and writing.

It may be difficult for the police to always identify the need for an Appropriate Adult for neurodivergent people and people with learning disabilities

We provide guidance to local authorities on the provision of Appropriate Adults²⁶⁶. Following a review of the guidance and in collaboration with partners, we expect to publish an updated version in 2024.

There is a recommendation in the Scottish Mental Health Law Review²⁶⁷ that intermediaries should be introduced to the justice system, subject to review and assessment of the Appropriate Adult service and independent advocacy. Crossgovernment work is now underway to assess the implications of this and the other recommendations in the report.

Advocacy

An independent advocate is in addition to and different from an Appropriate Adult and can also be provided.

Although advocacy is available to people with learning disabilities and autistic people under the Mental Health Act, anecdotal evidence suggests that it is often not available and professionals working in the civil and criminal justice systems don't have enough knowledge about its availability or how it should work alongside the Appropriate Adult system in criminal justice.

Diversion from Prosecution (DfP)

DfP is a process by which prosecutors working for the Crown Office and Procurator Fiscal Service (COPFS) can refer a case to the appropriate Local Authority, and partner agencies, as a means of addressing the underlying causes of alleged offending when this is deemed the most appropriate course of action. It can be considered in any case where the person reported to COPFS has an identifiable need and where it is assessed that DfP is the most appropriate outcome in the public

²⁶⁶ Appropriate Adults: guidance for local authorities - gov.scot (www.gov.scot)

Scottish Mental Health Law review Final Report [Archived] (nrscotland.gov.uk)

interest. It is for prosecutors to make the decision on whether diversion is appropriate.

It is the responsibility of the Police to submit relevant information in relation to the alleged offence(s) together with any information on accused/victim/witness disability including a learning disability, where known, to COPFS in the form of the Standard Prosecution Report. If prosecutors consider that DfP is appropriate, they may refer a person to the local authority for a DfP assessment. In most cases, a report is returned to COPFS and a prosecutor will determine whether to proceed with the DfP, or whether alternative prosecutorial action (if any) is appropriate. If DfP goes ahead this will usually be for about 3 months, but this is not a fixed period and may be extended. National Guidelines on Diversion from Prosecution were published in April 2020 and are currently under review.

Referral to the Children's Reporter

The Lord Advocate issues guidelines to the Chief Constable regarding the reporting to Procurators Fiscal of offences alleged to have been committed by children. It is the responsibility of the police, following the Lord Advocate's Guidelines, to decide to whom an offence shall be reported. A case is "jointly reported" where it is reported by the police to the Procurator Fiscal and the Children's Reporter in terms of the Lord Advocate's Guidelines. Although the decision regarding the jointly reported case is for the Procurator Fiscal, such a decision shall not be taken until the Children's Reporter has provided relevant information and views regarding the most appropriate decision.

When the outcome of the consideration of a jointly reported case is that the child will be referred to the Children's Reporter in relation to the offence, that decision cannot be reconsidered. The Scottish Children's Reporter Administration (SCRA) will take forward the referral, taking into account the particular needs and circumstances of the child. The children's hearings system is not a justice system, but one based in welfare needs. SCRA has developed a bank of resources to help neurodivergent children and those with learning disabilities through the hearings system.

Victims and witnesses in court

The Criminal Procedure (Scotland) Act 1995 (as amended by the Vulnerable Witnesses (Scotland) Act 2004 and the Victims and Witnesses (Scotland) Act 2014) makes provision in relation to special measures for vulnerable witnesses. Where there is a significant risk that the quality of evidence given by a person will be diminished because of mental disorder, the witness is deemed to be vulnerable and may be entitled to special measures when they give evidence. Examples of special measures include giving evidence by TV link or evidence being recorded in advance.

Under the Vulnerable Witnesses (Scotland) Act 2004, as amended by the Victims and Witnesses (Scotland) Act 2014, special measures may also be available in civil cases as well as in criminal justice cases.

Forensic Mental Health Inpatient services

We are aware that people in Forensic Mental Health in-patient services who have a learning disability or are neurodivergent, have specific and sometimes highly complex needs.

The Independent review into the Delivery of Forensic Mental Health Services²⁶⁸ made a number of recommendations to address the specific needs of these populations of people. We issued a response²⁶⁹ in October 2021.

We agree that collaboration between forensic and general mental health services is required to put the needs of people with learning disabilities and neurodivergent people at the forefront. We consider that alignment with the ongoing work to implement the recommendations of the Coming Home report ²⁷⁰ is crucial to achieve the best outcomes for people with learning disabilities, as discussed in another section of this consultation.

There is currently ongoing work to improve strategic planning and governance of forensic mental services and specific populations will be considered as part of this and any future service delivery based on needs assessment.

The State Hospital

People are only detained in the State Hospital for as long as they require care and treatment. A diagnosis of autism or a learning disability in itself is not a cause for detention in the State Hospital, as discussed in another section in this consultation relating to mental health and capacity law.

What can we do about it?

Data and identification of Neurodivergence and learning disabilities

Good data is necessary to understand how many neurodivergent people and people with learning disabilities are going through the different parts of the civil and criminal justice system and if this is proportionate to the rest of the population. A routine and reliable procedure for better identifying neurodivergence and learning disabilities on arrest, or those in police custody or in prisons, would significantly improve our understanding of the prevalence of people entering the criminal justice system and within the prison population.

Better data and identification allows planning for the provision of the right supports, analysis of offending behaviour, and the impact of interventions.

The second priority action of the National Strategy for Community Justice is to: "Improve the identification of underlying needs and the delivery of support following arrest by ensuring the provision of person-centred care within police custody and

²⁶⁸ Independent Forensic Mental Health Review: final report - gov.scot (www.gov.scot)

²⁶⁹ Independent Review into the Delivery of Forensic Mental Health Services: Scottish Government response - gov.scot (www.gov.scot)

²⁷⁰ Coming home: complex care needs and out of area placements 2018 - gov.scot (www.gov.scot)

building upon referral opportunities to services including substance use and mental health services."

Public Health Scotland is working in collaboration with the Scottish Prison Service and prison NHS teams to deliver a health and wellbeing surveillance system that links a variety of prison and health data sets to inform on disease burden and outcomes for the prison population in Scotland. Mental health is a key area of interest and there are plans to scope out future analyses on the prevalence of neurodivergent conditions, learning disabilities and FASD.

This is dependent on access to prison primary care and mental health data of sufficient quality and would rely on clinical diagnosis being available.

Together with COSLA, we are committed to developing a nationally consistent, integrated and accessible electronic social care and health record as part of the new National Care Service. The integrated record will support people to tell their story once and ensure that staff have the right information at the right time to deliver the right care including when individuals enter custody settings.

Diversion from Prosecution (DfP)

A Joint Review of Diversion from Prosecution was carried out by HM Inspectorate of Prosecution in Scotland, HM Inspectorate of Constabulary in Scotland, HM Inspectorate of Prisons for Scotland and the Care Inspectorate, with a report published in February 2023²⁷¹. The review made 34 recommendations and found a need to:

- improve the quality of information submitted by the police to COPFS to assist appropriate decision making by prosecutors;
- improve communication between all parties;
- ensure the processes for managing diversion across agencies are as effective and efficient as possible; and,
- increase the take-up of diversion by accused persons. While diversion is voluntary, more could be done to tackle the level of non-engagement in the diversion assessment process.

The review also noted that:

"There were also examples of people being assessed as unsuitable due to their mental health or learning disability. The suitability assessment did not make clear if this was reflective of the capacity of the accused person to engage in the intervention, the availability of an appropriate intervention or simply the presence of these issues. Depending on the reason, this may call into question the equity of access to diversion from prosecution for those with particular protected characteristics."

²⁷¹ Joint review of diversion from prosecution (prisonsinspectoratescotland.gov.uk)

Victims and Witnesses

We are progressing a range of measures to improve the experiences of victims and witnesses in the justice system. This includes legislation and is set out as follows.

Victims, Witnesses, and Justice Reform (Scotland) Bill

We have introduced the Victims, Witnesses and Justice Reform (Scotland) Bill (VWJR), which is currently at Stage 1 in the Scottish Parliament²⁷².

The Bill aims to put victims and witnesses of crime at the heart of the justice system. The Bill has been informed by the work of the Victims Taskforce²⁷³ and the victim and survivor advisory board to the Taskforce, and Lady Dorrian's Review on Improving the Management of Sexual Offence Cases²⁷⁴. Key parts of the Bill include

- establishing a Victims and Witnesses Commissioner;
- establishing a sexual offences court as a court distinct from existing court structures, which will enable complainers to give their best evidence while minimising potential for re-traumatisation;
- criminal justice agencies being required to have regard to trauma informed practice and this being embedded including through standards, rules and procedures; and,
- enhancing special measures in civil cases.

A Victims and Witnesses Commissioner is proposed as an independent voice for victims and witnesses, to champion their views and encourage Government and criminal justice agencies to put victims' rights at the heart of the justice system. The Commissioner will have a duty to monitor compliance with standards of service and the Victim's Code for Scotland, and to promote best practice, but will not have a power to intervene in particular cases.

Independent review of the Victim Notification Scheme

The Victim Notification Scheme (VNS) provides eligible victims with information about the release of an offender or patient in the forensic mental health system, and with the chance to make representations as part of decisions on release. We commissioned an independent review of the scheme in 2022; the review's report²⁷⁵ (including an easy read version²⁷⁶) was published in May 2023. We are considering the terms of the review's report on the Victim Notification Scheme in collaboration with partners, and intend to publish a formal reply as soon as possible.

274 Improving-the-management-of-Sexual-Offence-Cases.pdf (scotcourts.gov.uk)

²⁷⁶ Victim Notification Scheme (VNS): independent review - easy read - gov.scot (www.gov.scot)

²⁷² Victims, Witnesses, and Justice Reform (Scotland) Bill: factsheet - gov.scot (www.gov.scot)

²⁷³ Victims Taskforce - gov.scot (www.gov.scot)

²⁷⁵ Section 11: How much is the VNS used? - Victim Notification Scheme (VNS): independent review - gov.scot (www.gov.scot)

People at Heart

The First Word are a specialist communications agency who have been commissioned to improve victim experience of the criminal justice system - by ensuring communications with them are clear, person centred and trauma informed. They have created People at Heart, a person-centred, trauma-informed approach to communication that puts the needs of people affected by crime first. The First Word have worked with criminal justice agencies to rewrite communications, and have also created guidance, provided online training and developed digital learning for the justice agencies.

Training

Scotland has developed a trauma-informed knowledge and skills justice framework designed to help organisations commission the right training for their staff. The Framework was endorsed by the Victims Taskforce and was launched on 3 May 2023.

The framework will help justice organisations identify what their staff need to know to respond to victims and witnesses in a trauma-informed way and will inform the development of consistent training in trauma-informed practice. The next phase of work is the development and implementation of a training programme for all organisations involved in the criminal justice system.

The Learning Disability Queens Nurses developed the "Think COULD"²⁷⁷ animation. Its primary objective is to raise awareness about the diverse needs of individuals with learning disabilities, emphasising the fact that they may mask their condition, have reduced understanding of their actions, or have additional support needs. Interested individuals, organisations, and professionals working across sectors, particularly in justice are encouraged to access and share the animation widely, promoting greater awareness and understanding of the needs of people with a learning disability within the justice system.

It is acknowledged that criminal justice partners may also have been providing their own specific training on neurodivergence and learning difficulties.

Judicial training is a matter for the Judicial Institute and the Lord President, and is not a matter for the Scottish Government. However, since 2021, at the request of the Judicial Institute of Scotland, People First Scotland has delivered two training sessions a year to the Justices of the Peace (JPs). The Institute is planning on formally incorporating SOLD training to their training programme for JPs.

Prisons

We are working with SPS and NHS partners to improve health and social care within prisons. Screening for healthcare conditions takes place within 24 hours of entry to prison. On admission, as with all other conditions, any condition under the umbrella

New animation 'Think COULD' supports individuals with learning disabilities in the justice system (qnis.org.uk)

of neurodivergence would only be recorded on the basis of self-disclosure. There is scope to increase the opportunity for screening for people with neurodivergence and learning disabilities by including this as a specific consideration in the initial screening. Alongside development of clear referral pathways this would increase opportunities for people to access necessary support and services.

SPS staff are responsible for conducting a Core Screen within 72 hours of admission. The Core Screen is the initial contact for all people in custody. This provides a starting point for a full risk and needs assessment plus, identifying any immediate needs that require referrals to service providers and in order to have the best possible plan of action in place. This is especially important for very short-term prisoners. The Core Screen, in addition to wider sentence management processes, is currently under review. Currently, neurodivergence and learning disabilities may be captured if self-disclosed. People are then invited to participate in a screening process conducted by Fife College, who provide learning provision across all SPS sites.

If during this process the assessor identifies any behaviours, presentation or capacities that are indicative of a neurodivergent condition, a further referral can be made to apply a profiling tool called Do-IT. The referral process is open to all staff, not just SPS uniformed staff, and anyone may make a referral if they believe someone needs additional support. Do-It, is not a diagnostic tool, but it gives a broad indication of where an individual may need support and identifies a support package to mirror that need. The consideration of support needs is managed in a multidisciplinary context, with clear pathways should identified support or formal diagnosis be required through NHS colleagues or educational psychology.

The Scottish Health Check for Adults with Learning Disabilities

The Annual Health Checks for People with Learning Disabilities (Scotland) Directions 2023 ("the Directions")²⁷⁸, place a duty on Health Boards to ensure that an annual health check is offered to all people in Scotland aged 16 and over who have learning disabilities. The Scottish Health Check for Adults with Learning Disabilities (set out in Annex A of the Directions) must be used in carrying out the annual health check.

Health Checks are delivered by a registered nurse or registered medical practitioner and everyone eligible should be offered their first check by 31 March 2024. Health checks should be offered to people with learning disabilities in forensic and prison health care.

What can the 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 are not specifically adapted for neurodivergence or learning disabilities, but trauma focused work is a key theme that can be built upon for these groups.

²⁷⁸ Annual <u>health checks for people with learning disabilities (Scotland) directions 2023</u>

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

Improving data is a key proposal in this consultation and this includes access to better data within the civil and criminal justice systems.

Alongside this 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. This might happen on arrest or on admittance to a custody suite. We want to consider how best to ensure that neurodivergence and learning disabilities are better identified at relevant points and by relevant staff.

One way that this could happen in practice would be to identify individual needs, including communication needs, on arrest or admittance to custody. In custody, questions could be added to the vulnerability assessment that is used. Better identification would allow the information to be included within the Standard Prosecution Report that is sent to the COPFS. We might also wish to ensure that the Vulnerable Person's Database is a reliable source of information and used effectively in all cases.

The Bill could potentially place a duty on public bodies such as the Police, 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 section.

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. This also places additional costs on the criminal and civil justice systems that could potentially be avoided. Sometimes advocacy will be needed to support people to understand information and we have set out our approach to this in the overarching themes section. We also think there is a need to make more people working in the criminal and civil justice systems aware of the need for and provision of advocacy.

The approach we have set out earlier in this paper 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 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.

Training is a way to ensure that there is better understanding of neurodivergence and what it means and that people who are neurodivergent and people with learning disabilities coming into contact with the civil and criminal justice systems are dealt with appropriately whether they are a victim, party, witness or accused.

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.

We could look at mandatory training for both new and existing staff, and could utilise, for example, the existing police and prisons colleges.

Proposal 5: Advocacy

Proposals are set out in the overarching themes section in relation to advocacy. 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)

We know that for some neurodivergent people and people with learning disabilities preventative support to address offending behaviour can make a difference. Other proposals in this paper seek to ensure that neurodivergent people and people with learning disabilities have their identifiable needs addressed more effectively in future.

As with other people, neurodivergent people and people with learning disabilities may benefit from the use of DfP where they are alleged to have committed offences.

The 2023 review of DfP highlighted a range of areas for improvement. However, there is little evidence of how DfP is applied to neurodivergent people and people with learning disabilities. 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?
- 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 this topic?

Section 11: Restraint and Seclusion

What We Heard

We know that neurodivergent children and young people and those with learning disabilities can have negative experiences at school where restraint or seclusion is used in response to distressed behaviour.

We know that adults in certain settings, including hospital or care settings, may also have negative experiences as a result of restraint or seclusion being used inappropriately.

It is not acceptable for neurodivergent people and people with learning disabilities, or anyone else, to be subject to the misuse of restraint, seclusion or other restrictive practices. This can lead to increased and unnecessary distress and trauma.

Where do we want to get to?

- Neurodivergent children and young people and those with learning disabilities in schools have their needs met by people who are trained and understand how to change the environment to minimise distress.
- People with learning disabilities and neurodivergent people are not subject to restraint, seclusion or other restrictive practices unless as a last resort to keep themselves or others safe.

What rights do people have now?

Restraint and seclusion should only ever be used in schools as a last resort to prevent harm. Restraint cannot be used for disciplinary purposes in Scotland's schools. We are developing new rights-based non-statutory guidance on the use of restraint in schools which will be reviewed one year after publication. If it does not have the desired impact, legislative options will be considered. We publicly consulted on the draft guidance in 2022.

The Adults with Incapacity (Scotland) Act 2000 and the Mental Health (Care and Treatment) (Scotland) Act 2003 both set out offences regarding ill treatment or neglect that must be considered with any use of restraint.

There are also regulations under the Public Services Reform (Scotland) Act 2010 about the use of restraint by care providers.

The Mental Welfare Commission has published guidance on restraint – Rights, risks and limits to freedom.²⁷⁹

²⁷⁹ RightsRisksAndLimitsToFreedom_March2021.pdf (mwcscot.org.uk)

What can we do about it?

We have committed to exploring options for legislation in this area that would apply equally to all schools (education authority, independent and grant-aided). This includes the option of statutory guidance.

Daniel Johnson MSP, working with Beth Morrison and her campaign on behalf of her son, "Calum's Law", has conducted a public consultation on draft proposals for a Member's Bill which proposes introducing statutory guidance and other controls around the reporting of all instances of restraint and seclusion in schools, inspections and publication of data. The proposals also include training for school staff.

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

There is a recommendation in the Rome report²⁸⁰ (Recommendation 7.6) that the use of detention, restraint or seclusion, and any other limits to liberty, should be monitored consistently for those with learning disabilities or autism across all public services.

The Scottish Mental Health Law Review (SMHLR)²⁸¹ also made a series of recommendations to make the reduction of coercion a national priority over a period of years (recommendation 9.1), including a proposal for legislation to establish a national register of restraint and appoint a public body with oversight for collecting and publishing data on trends (recommendation 9.12).

In response to the SMHLR we have committed to establish a Mental Health and Capacity Law Reform Programme to take forward the Review's ambitions and enhance the protection of human rights across the mental health system. Consideration of what is required to reduce coercion and restrictive practices is an early priority for this work, which will take a staged approach to reform.

We also currently fund the Restraint Reduction Scotland Network based at the Scottish Commission for Learning Disabilities which has 140 members and will continue to work to eliminate the misuse of restraint, seclusion and other restrictive practices, and promote and support good practice.

We are committed to taking forward the following in relation to restraint and seclusion:

Children

 Following our analysis of consultation responses on the draft physical intervention in schools guidance, we will work with partners on our working

²⁸⁰ The Independent review of Learning Disability and Autism in the Mental Health Act Final Report [Archived] (nrscotland.gov.uk)

²⁸¹ Scottish Mental Health Law review Final Report [Archived] (nrscotland.gov.uk)

group to make any final amendments to the draft guidance, ahead of its final publication.

- Work with partners on the working group to support the implementation of the guidance. This includes raising awareness of the new guidance amongst staff, children and young people and their families; providing advice on any subsequent changes that may be required to existing local authority or school level guidance; and supporting the monitoring of the use of restraint at a local level. The working group will also consider whether further resources may be required to support implementation.
- We will evaluate the effectiveness of the new guidance one year after publication.
- Alongside the publication of the new guidance, and in line with our original commitments, we are exploring options to strengthen the legal framework in this area, including placing the guidance on a statutory basis.

Adults

- As part of our Mental Health and Capacity Law Reform Programme, we will scope a programme of work to further reduce the use of coercion and restrictive practices, including seclusion and restraint over time.
- Our first delivery plan will be published in early 2024 and will set out the initial activities that will be taken forward to progress this commitment and the milestones that will be achieved.

What Do You Think?

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

Section 12: Transport

What we have heard

We know that accessible travel can enable people to enjoy a better quality of life, feel more connected to their community and reduce social isolation. However, we understand that there can still be barriers to transport and travel for disabled people, including people with learning disabilities and neurodivergent people.

Not being able to travel easily, comfortably and safely will impact many areas of life such as employment, education and access to health, social care and day services, and basic needs like getting shopping and socialising.

The National Transport Accessibility Steering Group (NTASG), together with the Mobility and Accessibility Committee for Scotland, (MACS) bring people with lived experience close to the heart of transport policy making in Scotland.

The NTASG co-produced Scotland's Accessible Travel Framework (ATF)²⁸² including an easy read version²⁸³ together with Transport Scotland. Both the NTASG and MACS provided input to the development and implementation of Transport Scotland's two Annual Delivery Plans (2019²⁸⁴ and 2021²⁸⁵) under the ATF.

The NTASG and MACS are clear that there needs to be accessible methods of providing feedback to transport operators. We understand that it is key to involve disabled people, people with learning disabilities and neurodivergent people early in the design and development of travel operations and services to make them truly accessible and inclusive.

When co-producing the ATF, disabled people told Transport Scotland they wanted:

- more disabled people to make successful door-to-door journeys, more often;
- disabled people to be more involved in the design, development and improvement of transport policies, services and infrastructure;
- everyone involved in delivering transport information, services and infrastructure to help enable disabled people to travel; and
- disabled people to feel comfortable and safe using public transport this includes being free from hate crime, bullying and harassment when travelling.

Through our engagement on the LDAN Bill with neurodivergent people and people with learning disabilities, we have heard examples of difficulties that can sometimes be caused by lack of staff and other people's awareness of invisible disabilities, and the anxieties surrounding using public transport that this can cause.

²⁸² Going Further: Scotland's Accessible Travel Framework (transport.gov.scot)

²⁸³ Going Further: Scotland's Accessible Travel Framework Easyread (transport.gov.scot)

transport-scotland-communications-corporate-publications-accessible-travel-annual-external-delivery-plan-2019-2020-120720191634.pdf

²⁸⁵ Scotland's Accessible Travel Framework - Annual Delivery Plan 2021-22 | Transport Scotland

Members of the National Improvement Network (NIN), a group supported by ARC Scotland and authors of the Charter for Involvement, prepared a report²⁸⁶ on the issues they have getting out and about in June 2023. It set out the challenges around transport specifically for neurodivergent people and people with learning disabilities, which include:

- reliability of public transport
- behaviour of other passengers
- cuts in services
- unhelpful drivers
- anxiety

"Sometimes when I get on a crowded bus or train I can get very anxious and can have panic attacks"

The barriers to travel were described as follows:

- worries and lack of confidence
- difficulty getting the right support
- having access to toilets
- availability of public transport
- being able to afford trips; and
- accessibility of the transport information

"Bus companies change routes and don't tell us. They say look up the website but some of us can't do that."

The Scottish Commission for People with Learning Disabilities (SCLD) also gathered lived experience views in their consultation for the report: A Connected Scotland: Tackling social isolation and loneliness and building stronger social connections.²⁸⁷ The report underlines how critical transport services are to enabling people with learning disabilities to be fully included in society. It was thought that the following would help increase access and inclusion:

- Better accessible information about transport services and timings;
- Awareness raising and training for transport staff;
- Removal of physical barriers to transport;
- Better transport provision for those living in rural communities; and,
- Travel training as part of the curriculum for people with learning disabilities at schools and colleges.

A charity focusing on bringing neurodivergent people and people with learning disabilities together for social events (Get Together) told us of the frustrations from its members when there are no evening services and they can't attend the events that the charity runs. Their service users are sometimes unable to go out socialising or go to concerts as there is often no way to get home.

²⁸⁶ Getting Out and About: Experiences of Travel – ARC Scotland

A Connected Scotland: our strategy for tackling social isolation and loneliness and building stronger social connections - gov.scot (www.gov.scot)

What did LEAP think?

- Transport is a vital part of being fully included in society. This includes being able
 to form and maintain relationships, access education and employment, and
 attend appointments. More needs to be done to ensure accessibility and
 inclusivity for neurodivergent people and people with learning disabilities.
- People with learning disabilities often have to plan much more in advance to make a simple journey. This can mean they have less freedom and choice.
- It is frustrating having to re-apply for concessions when, for people with learning disabilities, their disability is a lifelong condition.
- Need for greater promotion of the various frameworks that are available. These should be better publicised within neurodivergent communities.
- Support workers and carers are often vital in assisting neurodivergent people and people with learning disabilities access and use public transport. Training should be made available to them also to enable the best level of support.
- Service restrictions are particularly relevant in rural communities where certain transport and/or routes may stop after 6pm, or are so infrequent that the only means of travel is by taxi.

Where do we want to get to?

- A Scotland where all disabled people, including neurodivergent people and people with learning disabilities, can travel with the same freedom, choice and dignity and opportunity as other citizens. This is our vision as set out in the ATF.
- More neurodivergent people and people with learning disabilities are able to make successful door-to-door journeys, more often.
- Neurodivergent people and people with learning disabilities are more involved in the design, development and improvement of transport plans and services.
- Everyone who provides transport information and services will help make it easier for neurodivergent people and people with learning disabilities.
- Neurodivergent people and people with learning disabilities feel comfortable and safe using public transport and are not be bullied and harassed when travelling.

What happens now, and what are we doing about it?

Our vision for transport is delivered by Transport Scotland, as the national transport agency for Scotland. Accessibility and inclusion are at the heart of the National Transport Strategy,²⁸⁸ sitting within the "Reduces Inequalities" priority, which

²⁸⁸ National Transport Strategy (NTS2) - Delivery Plan - 2020 to 2022 | Transport Scotland

describes that we will provide fair access to services which will be easy to use and affordable to all.

Since the ATF was launched, targeted Delivery Plans were published in 2019²⁸⁹ and 2021,²⁹⁰ and a new Delivery Plan is currently being prepared. A progress report²⁹¹ and easy read ²⁹² has also been published to reflect the impact of the pandemic on delivery of the ATF and on everyone's access to travel and Disability Equality Scotland was recently commissioned by Transport Scotland to undertake an evaluation of the impact of the ATF.

The ATF and Delivery plans cover an array of topics, including: infrastructure, ticketing, staff, training and assistance, information, and key issues for specific transport operators.

These actions and commitments from Transport Scotland are designed to uphold the rights of disabled people to live a life of equal opportunities like any other citizen. This is in recognition of the fact that, under the Equality Act 2010²⁹³, public sector organisations must ensure that reasonable adjustments are made to enable access to disabled people.

Whilst good progress has been made, some actions are still being progressed. This is because some of the issues will take longer than others to resolve and may need revisiting over time. Some of the issues remain reserved to the UK Government.

Some of the key actions from the ATF and delivery plans are set out in the following paragraphs. Whilst the actions refer to disabled people, this includes neurodivergent people and people with learning disabilities.

Staff Training, Disability Awareness and Attitudes

The Accessible Travel Annual Delivery Plan 2021-22,²⁹⁴ sets out that there are a number of training modules being used across different transport modes but that disabled people have stressed that this training needs to be consistent, updated regularly, delivered by certified trainers and enable people to refresh their training at appropriate intervals. Training also needs to include information in relation to assistance tools/cards that disabled people use such as the Thistle Assistance Card and sunflower lanyards.

In December 2020, the UK Government Department for Transport created the REAL (Respect, Empathy, Ask, Listen) disability equality training programme to improve the transport sector's confidence and skills in delivering inclusive journeys for disabled passengers.²⁹⁵ This programme was developed in collaboration with people

²⁸⁹ transport-scotland-communications-corporate-publications-accessible-travel-annual-external-delivery-plan-2019-2020-120720191634.pdf

²⁹⁰ Scotland's Accessible Travel Framework - Annual Delivery Plan 2021-22 | Transport Scotland

Scotland's Accessible Travel Framework 2019 – 2020 Delivery Plan Progress Report (transport.gov.scot)

²⁹² scotlands-accessible-travel-framework-delivery-plan-progress-report-easy-read.pdf (transport.gov.scot)

²⁹³ Equality Act 2010 (legislation.gov.uk)

²⁹⁴ Accessible Travel Annual Delivery Plan 2021-22 (transport.gov.scot)

²⁹⁵ Inclusive Transport Leaders Scheme - GOV.UK (www.gov.uk)

with lived experience of disability and has been shared across all modes of transport in Scotland.

As part of the revised Accessible Travel Policy guidance published in July 2019, the Office of Rail and Road introduced enhanced obligations on train and station operators to provide up to date, regular disability awareness and equality training to their staff by July 2021. This is to enable frontline staff in Scotland to be trained to communicate more effectively with disabled passengers, and understand the challenges they may face when travelling/.

Similarly, the Civil Aviation Authority who oversee and regulate all aspects of civil aviation in the UK, require that all employees, including management, receive necessary training that is developed in partnership with forums of people with disabilities.

Good practice exists across the country, including CalMac's recently updated Disability Awareness training programme to include Hate Crime, and their work with Promoting a More Inclusive Society (PAMIS) on training staff on their newly installed Changing Places facilities. Additionally, NorthLink Ferries are undertaking training to ensure that staff are familiar with current legislation and safety procedures, including weekly drills, covering the actions necessary to assist all passengers in an emergency situation and have an on-going programme of disability awareness training for their personnel.

In recent years, Transport Scotland has taken forward the following actions:

- Undertaken a survey with all local authority areas to understand the training provided to taxi and private hire car drivers.
- Worked with bus operators to explore and understand the training provided to bus drivers and station staff.
- Promoted and facilitated disability awareness training schemes through the NTASG, ensuring that training is being undertaken by key transport providers.
- Worked with Disability Equality Scotland, Police Scotland, and People First Scotland as they develop disability awareness and hate crime training in formats tailored to the needs of transport operators.

Inclusive information and journey planning

Transport Scotland funds the Accessible Travel Hub, hosted by Disability Equality Scotland, which provides information, articles and guidance about accessible travel in Scotland.²⁹⁶

An example of good practice is that CalMAC is working with the National Autistic Society to create "story boards" detailing journey processes for major and small vessels. CalMac and NorthLink Ferries have also introduced a "Recite Me" function which reads the content of all documents on their website.

Certain aspects of the provision of audible and visible information on-board local bus and coach services across the UK are reserved. In 2018, the UK Government

²⁹⁶ Accessible Travel Hub | Scotland's one-stop-shop for accessible travel information and resources

consulted on plans to require the provision of audible and visual information on board local bus and coach services and the Public Service Vehicles (Accessible Information) Regulations 2023²⁹⁷ came into force in October 2023. Individual provisions of the 2023 Regulations are being implemented gradually.

Transport Scotland is progressing the following to make or encourage improvements around inclusive information and journey planning:

- Promoting a more inclusive approach to communication and raising awareness
 of technology and initiatives that ensure passengers can access timely and up to
 date information that suits their needs.
- Continuing work with Traveline Scotland, Disability Equality Scotland and Scottish Government Digital to ensure the digital travel information needs of disabled people have been considered.
- Working with transport operators and Disability Equality Scotland to enhance and promote the information on the accessible travel hub.
- Procuring the next generation of data management and online services contract
 to ensure continued delivery of a 'one true source' of travel data as committed to
 in our 2019 Programme for Government. The service aligns with our objectives
 to facilitate modal shift to more sustainable public transport and is being
 developed together with disabled people.

Passenger assistance and accessibility

The Thistle Assistance Card²⁹⁸ and app was developed by the South East of Scotland Transport Partnership (SEStran) to make using public transport easier for older people and those with disabilities or illness. It is supported by all seven Regional Transport Partnerships, Transport Scotland, the Scottish Government, Transport Operators and disability groups (including Royal National Institute of Blind People (RNIB), Scottish Accessible Transport Alliance (SATA), and Disability Equality Scotland).

The Thistle Assistance card and app let transport operators know if someone needs extra support. Awareness raising has taken place in the form of 'A little help goes a long way' campaign on the Thistle website²⁹⁹ and across social media. This programme aims to highlight where there is need for assistance for those with hidden disabilities, including neurodivergence and learning disabilities. This can be used in conjunction with Sunflower lanyards³⁰⁰ which are also recognisable to staff and the public and should be used in a respectful way to identify vulnerable people who may require assistance.

Traveline Scotland aims to provide accessible travel information and journey planning, via their website and apps. Ticket booking services ensure there are no

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The Public Service Vehicles (Accessible Information) Regulations 2023 (legislation.gov.uk)
 Thistle Assistance | Thistle Assistance | Thistle Assistance | Your Travel Companion - Discreet public transport support at your fingertips

²⁹⁹ Thistle Assistance | Thistle Assistance Thistle Assistance | Your Travel Companion – Discreet public transport support at your fingertips

³⁰⁰ What is the Hidden Disabilities Sunflower? (hdsunflower.com)

higher costs if internet not used. Local Travel Centres are available to assist people in person with booking travel and planning trips.

A passenger assistance app was launched by the Rail Delivery Group (RDG) in May 2021 which makes it easier for people to request assistance for their train journeys.³⁰¹

At the start of April 2021, Scotrail reduced its notice period for assistance booking to one hour. This compares with many other UK train operators still requiring 6 hours' notice.

Transport Scotland provides funding to the Ferries Accessibility Fund for improvements to our ferries and ports which has enhanced the ferry travelling experience of disabled people, including those that have hidden disabilities. Projects have included improvements to ferry terminal access and surrounding infrastructure such as: accessible doors, changing places toilets, and staff training.

In recognition of the fact that travel is a door to door journey, work on Clear Pathways initiative aims to ensure that streets and pavements are kept accessible for disabled people. The Transport (Scotland) Act 2019³⁰² set a national prohibition on pavement parking. There is also work taking place to create new guidance on inclusive street design in town centres and busy street areas. This work is being developed in consultation with representatives from disability and equality stakeholders and a public consultation will launch in early 2024.

There is work ongoing to ensure that street signs, wayfinding signage to transport hubs and journey planning are improved to enable passengers to complete their journeys, particularly at interchanges.

The Civil Aviation Authority produce annual accessibility reports which set out the work being done across Scotland's airports.³⁰³ Airports operate independently but demonstrate examples of good practice, such as creating quiet rooms for autistic passengers, creating autism-champions and seeking Autism-friendly accreditations.

Hate Crime Charter for Transport

Disability Equality Scotland developed the Hate Crime Charter in 2021³⁰⁴ in partnership with Transport Scotland, Police Scotland, the British Transport Police, South-East Scotland Transport Partnership (SEStran) and People First. This was formally launched in October 2022 by the Minister for Transport and is supported by a broad coalition of transport operators across all transport modes as well as transport authorities and law enforcement. The Charter provides a nationally recognised system to encourage transport providers and members of the public to support zero-tolerance approach to all forms of hate crime on public transport.

³⁰¹Technology To Simplify Assisted Travel | PassengerAssistance.com

³⁰² Transport (Scotland) Act 2019 | Transport Scotland

³⁰³ Airport performance report (caa.co.uk)

Tackling Hate Crime on public transport | Transport Scotland

Concessionary travel

Concessionary travel is available for eligible disabled people on buses across Scotland. Criteria for this is led by eligibility for the concession scheme³⁰⁵ in addition to eligibility for the National Entitlement card³⁰⁶.

The National Entitlement Card scheme also allows for free travel for companions where required by eligible disabled people of any age (including children under 5).

Blue Badge scheme

The Blue Badge scheme³⁰⁷ supports those with a disability to lead independent lives. The badge provides parking concessions for on-street parking, allowing badge holders to park close to where they need to go. Transport Scotland is responsible for national policy and legislation which sets out the framework for the scheme and provides support to local authorities to help them deliver it.

Recent reviews of the Blue Badge Code of Practice have amended eligibility criteria to include hidden disabilities, including distress when travelling and for those with conditions which results in lack of awareness around traffic.

Taxis and private hire

Transport Scotland works with local authorities and the UK Government to help improve the accessibility of taxis and private hire cars. In recent years, this has included conducting a survey with all Scottish local authorities to gather information on disability awareness training and the numbers of accessible vehicles. Transport Scotland and MACS has written to each local authority to raise awareness to the Accessible Travel Framework and the UK Government Department for Transport's guidance on access to taxis and private hire vehicles for disabled users.³⁰⁸

The UK Parliament recently passed the Taxis and Private Hire Vehicles (Disabled Persons) Act 2022³⁰⁹ which amended the Equality Act to place new duties on taxi drivers, PHV drivers and operators. It requires local authorities to maintain and publish lists of wheelchair-accessible vehicles. We also recently published an updated best practice guide for Licensing Authorities in Scotland in respect of taxis and private hire cars (PHC),³¹⁰ which includes a chapter on accessibility for disabled people. Through Disability Equality Scotland, Transport Scotland supports the provision of information on taxis and PHC on the Accessible Travel Hub.

The National Bus Travel Concession Scheme for Older and Disabled Persons (Eligible Persons and Eligible Services) (Scotland) Order 2006 (legislation.gov.uk)

³⁰⁶ Eligibility and Conditions for the 60+ or Disabled Traveller (transport.gov.scot)

³⁰⁷ Blue Badge scheme | Transport Scotland

Access to taxis and private hire vehicles for disabled users - GOV.UK (www.gov.uk)

³⁰⁹ Taxis and Private Hire Vehicles (Disabled Persons) Act 2022 (legislation.gov.uk)

Taxi and Private Hire Car Licensing - Best Practice for Licensing Authorities and Taxi and Private Hire Car Operators (3rd Edition) (www.gov.scot)

What can the LDAN Bill do?

The discussion in this transport section sets out that an ambitious and wide ranging programme of work is underway to make improvements for disabled people when travelling, and that this work is being informed and influenced by people with lived experience of disabilities.

Whilst some aspects of transport are reserved to the UK Parliament and UK Government, there are some areas which we could explore in relation to the LDAN Bill as follows.

Proposal 1: National and Local Strategies

Regional transport Partnership's (RTPs) were established to strengthen the planning and delivery of regional transport so that it better served the needs of people and businesses. They publish regional transport strategies specific to each region, supported by a delivery plan. RTPs bring together local authorities and others to take a strategic approach to transport in each region of Scotland. We could consider requiring RTPs to set out in their transport strategies how the specific needs of neurodivergent people and people with learning disabilities are being considered and met through travel information systems and accessibility initiatives.

We could also consider a requirement to set out in RTP travel strategies how staff across different modes of transport are being trained in disability awareness, how that training incorporates specific training on neurodivergence and learning disabilities, and the uptake of this.

Proposal 2: Mandatory training

Various actions and commitments around disability awareness training for transport staff are in place or are currently being progressed but is not a statutory requirement and is not necessarily consistent.

We have also set out in a previous section proposals for mandatory training for public sector staff on neurodivergence and learning disabilities, primarily in relation to health and social care staff, and have invited views on whether this requirement should be extended to other public sector areas. We could consider extending this requirement to transport staff in Scotland.

What Do You Think?

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

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 in this consultation, called Children and Young People -Transitions to Adulthood.

What we heard

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.³¹¹ 2

In Scotland, the education system aims to be inclusive. There is a legal presumption that children will be educated in mainstream schools other than in exceptional circumstances.³¹²

The Education (Additional Support for Learning) (Scotland) Act 2004 ("the ASL Act") sets out rights, duties and obligations for children and young people with additional support needs (ASN) for learning. A person has ASN if 'for whatever reason' they are unlikely to be able to benefit from school education without additional support ("School education" includes Early Learning and Childcare). This broad meaning of ASN in practice includes children and young people with learning disabilities and neurodivergent children and young people, who require additional support to benefit from school education. Other reasons that children and young people may have additional support needs include, for example, if they have a hearing impairment, if they are a young carer or if they are adopted.

The most recent pupil census statistics shows that in 2022, 241,639 pupils had identified with ASN needs (34.2% of the school roll), compared with 69,587 in 2010 (10.3% of the school roll).³¹³

The ELC census in 2022 showed that 16,500 child registrations were for children with ASN (18% of total registrations), compared with 15,020 registrations and 16% of total registrations in 2017.³¹⁴ (Comparisons cannot be made with 2010 data for ELC as changes were made in 2017 as to how additional support needs were recorded.)

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³¹¹ Not included, not engaged, not involved (NAS), Building Blocks (SCLD), and IncludED (ENABLE)

³¹² Standards in Scotland's Schools etc. Act 2000 statutory guidance - gov.scot (www.gov.scot)

³¹³ www.gov.scot/publications/pupil-census-supplementary-statistics/

³¹⁴ Early learning and childcare statistics - gov.scot (www.gov.scot)

In relation to outcomes for pupils with ASN, the percentage of school leavers with ASN from mainstream secondary schools in an initial positive destination is consistently lower than for pupils without ASN.³¹⁵

Additional support for learning is an issue that has been raised in evidence regularly with the Scottish Parliament. In 2017, the then Education and Skills Committee undertook a short inquiry on how it was working in practice.³¹⁶ It reported³¹⁷ that there had been an "exponential" increase in the recorded incidence of children with ASN in Scotland, beyond many people's expectations, and was encouraged by figures on positive outcomes for those with ASN. However, a number of concerns and recommendations were raised, including: the observation that there is a gap between policy and practice; in relation to lack of resources; inconsistent approaches in different local authority areas; the attainment gap; provision of specialist and appropriately trained teaching staff; advocacy and information; and, co-ordinated support plans.

We consequently established the Morgan Review of Additional Support for Learning, which reported in 2020.³¹⁸ The Review did not find any deficits in ASL legislation or policy itself but observed that the challenge is in translating the policy intention of that legislation into thousands of individual responses for individual children and young people who face different learning barriers. The Review concluded that ASN is not equally recognised and that pupils' achievements are not equally valued within Scotland's education system, and that, therefore, its implementation is inconsistent and does not ensure that all children and young people who need additional support are being supported to flourish and fulfil their potential.

The Review made several themed recommendations, including in relation to resources, workforce development and support, and leadership and strategic planning.

More recently, the Scottish Parliament's Education, Children and Young People Committee begun another inquiry into ASN, with views invited by 31 December 2023.³¹⁹ The Inquiry will focus on:

- the implementation of the presumption of mainstreaming;
- the impact of the COVID-19 pandemic on ASN; and
- the use of remedies set out in the ASL Act.

In relation to teacher workforce training, the Education Institute for Scotland's report on ASN in 2018³²⁰ noted that, at that time, teachers expressed serious concerns about their access to professional learning on ASN: 87% strongly disagreed or disagreed when asked if they had sufficient time to undertake professional

³¹⁵ Support for Learning: All our Children and all their Potential (www.gov.scot)

Additional Support Needs in School Education - Parliamentary Business : Scottish Parliament

How is Additional Support for Learning working in practice?

³¹⁸ Support for Learning: All our Children and all their Potential (www.gov.scot)

³¹⁹ Additional Support for Learning (ASL) | Scottish Parliament Website

³²⁰ Additional Support for Learning in Scottish school education: exploring the gap between promise and practice,

development opportunities. The Report noted that access to specialist qualifications on ASN had been eroded and that teachers who engaged in professional learning on ASN did so voluntarily and in their own time.

The Morgan Review subsequently noted that, at that time, 98% of the education workforce felt that initial teacher training did not adequately prepare teachers for teaching children and young people who have ASN. The Review also noted that there was, at that time, minimal requirement for focus on additional support for learning as part of Initial Teacher Education (ITE).

Probationary teachers in their first year of teaching told the Review that their only awareness had been a "short input on legislation" relating to ASN and that they felt ill prepared in terms of knowledge, understanding and practice skills.

In its final report, the Review highlighted concerns about both ITE and Continued Professional Development (CPD), noting a reduction in specialist staff available in school to provide specialist training and the ability of school staff to take time out from other work pressures to train. The Review recommended that:

- all teacher education and development includes nationally specified practice and skills development in supporting learners with additional support needs as a core element:
- all teachers understand what additional support needs are. They are clear about their role in supporting the identification of additional support needs and the need to adapt their teaching to ensure a meaningful learning experience for all their learners; and,
- there should be a first teaching qualification in additional support needs available during ITE.

In relation to Co-ordinated Support Plans (CSPs), the Education and Skills Committee³²¹ noted in a 2017 report that the use of CSPs had declined and expressed concern as access to many of the rights in ASN legislation depend on statutory support being in place.

What did LEAP think?

LEAP members provided the following views and suggestions for improvement:

- There should be a right to inclusive education.
- There should be more focus and better training on neurodivergence and learning disabilities in Initial Teacher Training. This should be part of the core curriculum. There should also be neurodivergence and learning disabilities training for teachers as part of their Continuous Professional Development ("professional update training"). Current training isn't in-depth enough, or condition specific.
- Education plans aren't followed in practice. There is a need for increased accountability.

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³²¹ How is Additional Support for Learning working in practice?

- Whilst there is a right to support in the education setting, this is not being felt in practice. Better accountability is needed.
- There should be improved access to online learning and other alternative learning methods.
- The education system should be holistic in its support of the whole person, not just academic learning. There should be an ability to gain qualifications through experience instead of traditional exams.
- Assessments for specialist staff in classrooms are inconsistent and seem to be made on the basis of available resources rather than the needs of the child or young person. There is a need for more consistency and accountability.
- ASN legislation is not being implemented appropriately in practice due to resources and funding. This infringes the rights that children and young people have.
- There is a need to record and publish data on part time timetables for neurodivergent people and people with learning disabilities.
- It was thought that there is an issue with girls and people assigned female at birth often being un-, mis-, or late-diagnosed and so are unable to benefit from ASN educational school support.
- There were concerns that there may be extensive use of exclusion, and restraint, in Scottish schools (to note that restraint is discussed in a separate section of this consultation).
- The ability to access advocacy should be made available earlier in the process, before a Tribunal. This is a lengthy process and there is likely to be less need for a Tribunal if children, young people and their families were able to access advocacy earlier.
- Meany LEAP members with learning disabilities noted that they are still affected by traumatic school experiences and that there should be a redress mechanism for this.
- Concerns were raised about Positive Behaviour Support, which some LEAP members thought was a form of Applied Behaviour Analysis.
- Children, young people and their families should be educated on the rights to education.

Where we want to get to

 An education system that ensures all children and young people have the same opportunity to thrive and succeed, including those who are neurodivergent or have learning disabilities. An education system that is comprised of teachers, practitioners and other
educators who are confident and well trained to educate neurodivergent children
and young people, and children and young people with learning disabilities.

What happens now?

Various policies and legislation aim to provide access to and accountability for children and young peoples' rights to education.

Co-ordinated Support Plans (CSPs)

A CSP is a statutory plan and is intended to co-ordinate support between education and other agencies for children and young people with significant multiple and complex needs. It is not intended to provide support for the majority of children and young people. The ASL framework also utilises Individualised Educational Programmes and Child's Plans as part of the planning process to meet children and young people's needs, as discussed in the following paragraphs.

The Education (Additional Support for Learning) (Scotland) Act 2004 ("the ASL Act") and Code of Practice

The ASL Act³²² provides the legislative framework for identifying and addressing the additional support needs of children and young people who face a barrier, or barriers, to learning. It gives them, and their parents and carers, a number of rights and it places duties o local authorities in the exercise of their education functions.

This includes rights to: ask for ASN to be assessed and planned for; placing requests in respect of children and young people with ASN; advice and information about their or their child's ASN; be part of discussions about decisions being made on ASN; access dispute resolution procedures, including mediation; be informed about the outcome of requests under the Act and the reasons; have decisions reviewed; request a CSP or review of an existing plan; have views noted in a CSP; and, access redress through the First-tier Tribunal Health and Education Chamber ("the Additional Support Needs Tribunal"). There are also statutory rights to advocacy and other support services.

There are duties placed on education authorities including that they must: make adequate and efficient provision for ASN and to identify ASN; in certain circumstances, provide additional support to children under school age who have been identified as having ASN; provide parents of children with ASN with certain information; provide a CSP to those children and young people who need one; and, provide independent and free mediation services, and arrangements for resolving disputes.

There is also statutory guidance, in the form of a Code of practice.³²³ The Code explains the duties on education authorities and other agencies to support children and young people's learning who have ASN. Education authorities and agencies

Education (Additional Support for Learning) (Scotland) Act 2004 (legislation.gov.uk)
 Supporting Children's Learning: Statutory Guidance on the Education (Additional Support for Learning) (Scotland) Act 2004

must have regard to the Code. Relevant authorities include local authorities and health boards, Skills Development Scotland, all colleges of further education and all institutions of higher education in Scotland. Those authorities must ensure that their policies, practices, and information and advice services take full account of the legal requirements of the ASL Act.

Education (Disability Strategies and Pupils' Educational Records) (Scotland) Act 2002 ("the 2002 Act")

Under the 2002 Act, education authorities have duties to develop and publish accessibility strategies to: increase pupils' access to the curriculum; increase access to the physical environment of schools; and, improve communication with pupils with disabilities.

Funding

Local Authorities are responsible for managing their budgets and allocating the total financial resources available to them, including in relation to education. Local Authorities manage this based on local needs and priorities, having first fulfilled their statutory obligations and the jointly agreed set of national and local priorities. The latest Local Authority finance returns indicate that spending on ASL reached a record high (in real terms) spend of £830m in 2021/22. This includes ASL spending within early learning and childcare, primary, secondary and special school sectors.

In addition, we have invested funding of £15m per year since 2019-20 to help Local Authorities respond to the individual needs of children and young people. We also provide over £11m each year to directly support pupils with complex ASN and fund services to support children and families.

Scotland's Strategy for the learning provision for children and young People with complex additional support needs 2017-2026

This Strategy³²⁴ outlines the long-term changes we are making to the way in which services are delivered in order to improve children and young peoples' experience of education. The Strategy is focussed on children and young people with complex ASN being supported to learn in their local communities.

The 2023 National Improvement Framework and Improvement Plan ("the NIF")

The 2023 NIF and improvement plan³²⁵ sets out the vision and priorities for Scottish education that have been agreed across the system, and describes the national improvement activity that is currently, or will be, undertaken to help deliver those key priorities.

³²⁴ The Right help at the right time in the right place: strategy for the learning provision for children and young people with complex additional support needs 2017-2026

³²⁵ Achieving Excellence and Equity: 2023 National Improvement Framework and Improvement Plan (www.gov.scot)

The Standards in Schools etc. Act 2000 ("the 2000 Act")

The 2000 Act³²⁶ and accompanying statutory guidance³²⁷ makes provision about standards in Scotland's schools. It does this primarily by setting out duties and rights in respect of education and a framework for improvement and raising standards.

Inclusive Education

A number of legislative provisions support inclusive education in Scotland, including:

- Section 1 of the 2000 Act sets out that "it shall be the right of every child of school age to be provided with school education by, or by virtue of arrangements made, or entered into, by, an education authority.";
- Section 2 of the 2000 Act provides that it is the duty of an education authority to secure that education is directed to the development of the personality, talents and mental and physical abilities of the child or young person to their fullest potential. And, Section 2(2) provides that education authorities shall have due regard to the views of the child, so far as is reasonably practicable. This provision is reflective of aspects of Article 29 of the UNCRC, as discussed later in this section.
- Section 15 of the 2000 Act provides the presumption that education is provided in mainstream schools;
- As described above, the ASL Act sets out rights and duties relating to the
 provision of additional support for learning for those who are, or are likely to be,
 unable to benefit from school education without it. This framework supports the
 provision of education in mainstream schools wherever possible; and,
- The Equality Act provides that reasonable adjustments must be made to remove or reduce a disadvantage relating to a person's disability in the delivery of public services, including education.

Independent advocacy, advice and support

All children and young people have the right to be involved in decisions about the support they receive at school.

Section 14 of the ASL Act provides that where a child, young person, or their parent wishes to have an advocate then the education authority must comply with their wishes unless they are unreasonable. Section 14A of the ASL Act provides that the Scottish Ministers must secure the provision of an advocacy service to be available free of charge, in respect of proceedings before the Additional Support Needs Tribunal.

My Rights My Say³²⁸ is a childrens' service supporting children aged 12-15 to exercise their rights under the ASL Act. They provide advice and information, advocacy support, legal representation and a service to independently seek childrens' views about the support they receive with their learning.

³²⁶ Standards in Scotland's Schools etc. Act 2000 (legislation.gov.uk)

³²⁷ Guidance - Chapter 4: Plans and reports - Standards in Scotland's Schools etc. Act 2000 statutory guidance - gov.scot (www.gov.scot)

³²⁸ My Rights, My Say (myrightsmysay.scot)

Reach³²⁹ is a website dedicated to children and young people aiming to help them feel supported, included, listened to and involved in decisions at school. It has information and advice for pupils about their rights to; practical tips for all sorts of school problems; young people's real life stories; and positive examples of pupil participation.

ENQUIRE³³⁰ is the national advice and information service on additional support for learning for families, teachers, practitioners, education authorities and others caring for or working with children and young people with additional support needs. They operate a telephone helpline and publish resources on their website.

Let's Talk ASN³³¹ is the national advocacy and legal representation service supporting parents, carers and young people (16+) with a right of reference to the Additional Support Needs Tribunal in exercising their rights.

Teacher workforce training

Initial Teacher Education

The Standard for Provisional Registration (SPR),³³² is the benchmark of competence required of all student teachers at the end of their initial teacher education (ITE) who are seeking provisional registration with the General Teaching Council for Scotland (GTCS). The SPR was updated in 2021 and sets out the professional knowledge and understanding that student teachers are required to demonstrate, including additional support needs. This covers learning on neurodivergence and learning disabilities.

The GTCS's Guidelines for Accreditation of Initial Teacher Education (ITE) Programmes in Scotland state that student teachers should be exposed to key areas such as additional support needs, including Autism, ADHD, ADD, and others.³³³ These are the standards that universities offering courses in teaching must meet in order to be accredited by the GTCS to provide ITE programmes.

A set of baseline materials for autism and neurodivergence was developed by ITE providers and stakeholders in 2019. These are used by all ITE providers and GTCS will only accredit programmes that have embedded these materials. For example, the GTCS Autism Guidance on Meeting the Needs of Autistic Learners.³³⁴

In April 2023, the Measuring Quality in Initial Teacher Education (MQuITE) report was published.³³⁵ This was a six year, Scottish Government funded study which involved co-investigations from all 11 university providers of ITE along with the

³²⁹ Reach - understand children's rights to education and support in Scotland

Enquire - The Scottish advice service for additional support for learning

Let's Talk ASN - National Advocacy Service for Additional Support Needs - Enquire

³³² standard-for-provisional-registration.pdf (gtcs.org.uk)

³³³ ITE-Programme-Accreditation-Guidelines.pdf (gtcs.org.uk)

professional-guide-meeting-needs-autistic-learners.pdf (gtcs.org.uk)

³³⁵ Measuring Quality in Initial Teacher Education: Final Report (strath.ac.uk)

GTCS. The project tracked ITE graduates over 5 years. Teaching students with ASN was highlighted as an area where more professional learning was needed. Professional learning

The Scottish Universities Inclusion Group designed and published the National Framework for Inclusion which provides a tool for teachers at all stages of their career to reflect on their inclusive practice, in the context of the GTCS Professional Standards for Registration.³³⁶ This was last updated in August 2022.

A range of free professional learning opportunities are currently available to all teachers, and other educational professionals, to understand their professional duties and support their knowledge, understanding and practice on ASN. Regional Improvement Collaboratives and local authorities also provide a range of context specific opportunities. Education Scotland's Inclusion, Wellbeing and Equality Officers facilitate sessions, share information and signposting for ASN to the national NQT Stepping Stones professional learning programme and the Middle and Senior leadership programmes. Some examples of learning for all educational professionals include:

- the Autism Toolbox;³³⁷
- CIRCLE train the trainer materials for Early Learning and Childcare, primary and secondary education;³³⁸ and,
- Education Scotland online modules based on CIRCLE and Autism Toolbox content.³³⁹

To ensure all educators can access free high quality support, Education Scotland has also recently published a new national Inclusion, Wellbeing and Equality Professional Learning Framework.³⁴⁰ Some of these resources were specifically developed so that they can be used by universities that provide ITE.

Fully registered teachers can also gain registration in ASN if they hold an appropriate ASN qualification. Currently, over 700 teachers have GTCS registration in additional support needs.

ELC workforce training

The National Standard³⁴¹ for funded ELC sets out the quality criteria that all providers will be required to meet to deliver the funded entitlement to ELC. In line with 'Criteria 6: Inclusion', settings must comply with the duties under the Equality Act and so must not discriminate in offering a service. Duties under the Equality Act apply both to funded ELC and to privately purchased ELC.

OLCreate: Education Scotland - Inclusion and Equalities (open.edu)

^{336 &}lt;u>Scottish Universities Inclusion Group and GTC Scotland launch third edition of National Framework for Inclusion - The General Teaching Council for Scotland</u>

Home | Autism Toolbox Autism Toolbox

³³⁸ Education | ThirdSpace

³⁴⁰ Informed Level | Inclusion, Wellbeing and Equalities Professional Learning Framework | Resources | Education Scotland

National Standard for early learning and childcare - Early education and care - gov.scot (www.gov.scot)

Settings must also provide appropriate support, including making any reasonable changes to the care and learning environment, to ensure that children with ASN, including disabilities, do not face a barrier to them accessing a full range of experiences and meets their individual needs. In line with the National Standard, we expect local authorities and settings to work together to support children with ASN to access their funded ELC hours.

Supporting children with ASN has now been introduced as a standalone unit within the Scottish Qualification Authority's (SQA) Next Generation Higher National Childhood Practice award pilot which is currently underway. Supporting children with ASN is also included in the pedagogy unit, with meta-skills embedded throughout the course, and a specific ASN meta-skills outcome is required. In addition, longer-term work led by the Scottish Social Services Council (SSSC) to review the National Occupation Standards (underpinning the registerable qualifications for ELC practitioners), will scope existing ASN learning content to identify any gaps and inform change in this area.

Since 2020, we have funded a suite of continuous professional learning (CPL) modules for ELC practitioners including 'Building confidence in identifying and responding to ASN' and 'Supporting the development and progression of children's early language and literacy'. These resources are being embedded in the SSSC's Open Badge learning scheme and will continue to be available free of charge.

In addition, the National Directory of CPL for ELC practitioners provides a range of further learning materials.³⁴²

GIRFEC and child's plan

As noted in the introduction, GIRFEC³⁴³ is our national approach to promoting, supporting and safeguarding the wellbeing of all children and young people, providing a consistent framework and shared language which puts their rights and wellbeing at the heart of the services that provide support to them and their families.

A personalised GIRFEC child's plan is a non-statutory plan which should be considered when those working with a child or young person and their family identify that the child or young person needs a range of extra support beyond universal provision to be planned, delivered or co-ordinated. If accepted, the child's plan should reflect the voice of the child or young person at every stage and include a clear explanation of why the plan has been created, the actions to be taken by everyone involved in the plan and the expected improvement for the child or young person.

³⁴² Your one-stop shop for quality assured continuous professional learning (CPL) dedicated to children and young people professionals. - CPL Portal (sssc.uk.com)

³⁴³ Getting it right for every child (GIRFEC) - gov.scot (www.gov.scot)

The Children and Young People (Scotland) Act 2014 and Children's Planning Services ("the 2014 Act")

The 2014 Act³⁴⁴ requires certain public authorities to report every three years on the steps taken to secure better or further effect of requirements under the UNCRC.

Children's Services Planning is Scotland's statutory partnership approach to planning and delivery of local services and support, with relevant duties set out in Part 3 of the 2014 Act and accompanying statutory guidance³⁴⁵. This aims to ensure a whole system approach is in place in each local area to improve outcomes for children, young people and families. Each Children's Services Plan is based on a joint strategic needs assessment which is undertaken to identify the needs of all children, young people and families living in that area. This should consider the needs of specific groups, such as those affected by disability, complex health conditions, poverty, or care experience.

Children's Services Planning duties require each local authority and health board to work collaboratively with local public and third sector partners to address national outcomes and local priorities, and meet the statutory aims of Children's Services Planning to:

- Safeguard, support, and promote the wellbeing of children, young people and families (the eight SHANARRI indicators)³⁴⁶;
- ensure action is taken at the earliest opportunity, and where appropriate, to prevent needs arising;
- ensure support is experienced as joined-up from the point of view of children and families; and
- constitute best use of available resources.

Each local authority and health board must publish a Children's Services Plan (CSP) Annual Report to demonstrate what progress has been made together with partners in the public and third sector, to improve wellbeing outcomes for children, young people and families living in that area. Each CSP sets out how services, supports and improvement activity will be delivered over each 3-year period across a continuum which spans prevention, universal services, early intervention and targeted or intensive support. CSPs include the provision of 'Children's Services' (for example, schools, health visiting, early learning & childcare, social work and CAMHS) as well as 'Related Services'. This includes adult services provided to parents/carers for, example, in relation to drug or alcohol use, mental health needs, disability or offending. It also includes community-based supports such as housing, welfare advisory services and recreation facilities.

The current cycle of planning runs from 2023-2026. We review CSPs and provide feedback to each CSP Partnership. We also publish a national report outlining key

³⁴⁴ Children and Young People (Scotland) Act 2014 (legislation.gov.uk)

Children and Young People (Scotland) Act 2014: Statutory Guidance on Part 3: Children's Services Planning – Second Edition 2020 (www.gov.scot)

³⁴⁶ Wellbeing (SHANARRI) - Getting it right for every child (GIRFEC) - gov.scot (www.gov.scot)

themes and areas of strength or for development. The most recent national report was published in July 2022.³⁴⁷

National Neurodevelopmental Specification for Children and Young People: Principles and Standards of Care

In September 2021, we published the National Neurodevelopmental Specification for Children and Young People: Principles and Standards of Care³⁴⁸ which sets out seven standards for service providers to ensure that children and young people who have neurodevelopmental profiles receive support that better meets their needs.

The Specification aims to ensure that children and families receive support and access to services that meet their needs at the earliest opportunity, based on the GIRFEC approach. This includes education services. For many children and young people such support is likely to be community based and should be quickly and easily accessible.

The Specification makes clear that support should be put in place to meet the child or young person's requirements when they need it, rather than be dependent on a formal diagnosis.

What can we do about it?

We are committed to Scotland being the best place in the world for a child to grow up. The National Outcome for children and young people is that "Children grow up loved, safe and respected, so that they realise their full potential". 349 As part of this, we are committed to improving the education experience and outcomes for all children and young people, including those with learning disabilities or who are neurodivergent. We are taking forward several pieces of work to improve experiences and outcomes, as follows.

Additional Support for Learning Review Action Plan

In response to the Morgan Review,³⁵⁰ we published the joint ASL Review Action Plan with COSLA and the Association of Directors of Education in Scotland (ADES).³⁵¹ The Action Plan sets out the various activities we have committed to carry out to implement the Review's recommendations.

To ensure that meaningful change is realised we have also established the ASL Project Board to oversee delivery of the Action Plan and associated workstreams. The Scottish Government, COSLA and ADES have joint responsibility of the Board. Membership includes representatives from: local government, third sector, parent

³⁴⁷ Improving outcomes for children, young people and families: review of Children's Services Plans and strategic engagement activity - gov.scot (www.gov.scot)

³⁴⁸ Children and young people - national neurodevelopmental specification: principles and standards of care - gov.scot (www.gov.scot)

³⁴⁹ National Outcomes | National Performance Framework

³⁵⁰ Support for Learning: All our Children and all their Potential (www.gov.scot)

³⁵¹ Additional support for learning: action plan - gov.scot (www.gov.scot)

groups, unions and children's groups. ³⁵² The Action Plan is under regular scrutiny by the Board to ensure delivery of the recommendations.

Since the Action Plan was first published significant progress has been made in a number of key areas, as reflected in the most recent joint progress report published in November 2022.³⁵³ We continue to work closely with partners to deliver the remaining actions and the next update will be published in Spring 2024.

Co-ordinated support plans

In the ASL Review Action Plan,³⁵⁴ we committed to refreshing the Supporting Children's Learning Code of Practice,³⁵⁵ to ensure that it fully supports schools and local authorities to fulfil their duties under the ASL Act.

The Code already provides advice on the relationship between statutory CSPs and non-statutory plans, including the Child's plan. The refresh will take account of the update of the GIRFEC Policy and Practice Guidance as well as seek to align and further clarify the relationship between plans. This work will help improve the support available for all children and young people who face barriers to their learning.

Qualifications and Assessments

The Independent Review of Qualifications and Assessment reported in June this year.³⁵⁶ The Review's aim was to ensure that all pupils in the Senior Phase (in school and college) have an enhanced and equal opportunity to demonstrate the breadth, depth and relevance of their learning. The Review specifically considered pupils who have ASN, including pupils with learning disabilities and neurodivergent pupils.

Recommendations in the final report centre around the introduction of a Scottish Diploma of Achievement (SDA) with three mandatory elements: Personal Pathway, Programmes of Learning and Project learning.

The recommendations, if implemented, would represent very significant change, and must be considered carefully and as part of the broader suite of reform to education and skills. We are taking forward detailed examination of the proposals, ensuring the Scottish Parliament and others across the system have the opportunity to engage with and shape our response. The Cabinet Secretary for Education and Skills has committed to return to Parliament to fully debate the proposals in early 2024.

³⁵² Additional Support for Learning Project Board - gov.scot (www.gov.scot)

³⁵³ Additional Support for Learning Review Action Plan – update November 2022

Additional Support for Learning review: action plan - November 2022 update - gov.scot (www.gov.scot)

Supporting Children's Learning: Statutory Guidance on the Education (Additional Support for Learning) (Scotland) Act 2004

³⁵⁶ It's Our Future - Independent Review of Qualifications and Assessment: report - gov.scot (www.gov.scot)

International Human Rights

UNCRC Article 28 recognises that children and young people have the right to education on the basis of equal opportunity. This includes both primary and secondary education and includes the option of technical or vocational training.

Article 29 sets out that a child or young person's education should help the development of their personality, talents and mental and physical abilities to their fullest potential. It should also build their respect for human rights, their parents and their own cultural identity, language and values as well as the national values of their country, and respect for others and the natural environment.

Under Article 12 of the UNCRC, every child and young person who is capable of forming their own views has the right to express those views freely in all matters affecting them, with those views being given due weight in accordance with the age and maturity of the child and young person.

The Scottish Ministers have already provided non-statutory guidance to public authorities on giving effect to the UNCRC.³⁵⁷

Article 24 of the CRPD recognises the rights of disabled people to education on an equal basis with others and requires State parties to ensure an inclusive education system at all levels.

As noted in the introduction we are progressing a Human Rights Bill for Scotland as well as the United Nations Convention on the Rights of the Child (UNCRC) (Incorporation) (Scotland) Bill, to incorporate a wide range of internationally recognised human rights belonging to everyone in Scotland into Scots law, within the limits of devolved competence.

What can the LDAN Bill do?

As discussed in earlier paragraphs, existing ASN legislation was independently reviewed in 2020 and was not found to be deficient. Rather, there was found to be a gap between the policy intention of the legislation and its implementation. Since then, a comprehensive ASL Review Action Plan has, and is currently being, progressed in line with the Morgan Review recommendations. This work is being done in partnership with COSLA and the ADES and includes scrutiny and oversight by third sector organisations, parent groups, unions and children's groups.

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

³⁵⁷ Children's Rights and the UNCRC in Scotland

NIF. The statutory guidance to support these legislative duties is currently being reviewed. ³⁵⁸ 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. This would avoid adding to the existing planning and reporting requirements which exist.

Previous paragraphs in this section set out that there is duty on each local authority and health board to publish a Children's Services Plan Annual Report which demonstrates what progress has been made to improve wellbeing outcomes for children, young people and families living in that area. We could also consider whether to require that these 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

As discussed in earlier paragraphs the Standard for Provisional Registration was updated in 2021, following the Morgan Review, and sets out the professional knowledge and understanding that student teachers are required to demonstrate including on learning theories in ASN. This includes neurodivergence and learning disabilities. And, in relation to ELC, a new SQA award is being piloted which has focussed units and outcomes on ASN.

There are also a range of free professional learning opportunities available to teachers, practitioners and other educators. However, these are currently optional which has the potential to lead to inconsistencies and variation in practice. We do not have data on how prevalent the uptake is.

We have set out proposals in the overarching themes section of this consultation 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 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 CPD.

Proposal 3: Data

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

³⁵⁸ Statutory Guidance: Standards in Scotland's Schools etc. Act 2000 (www.gov.scot)

Current ASN data reflects that children and young people have a wide ranging spectrum of learning needs.³⁵⁹ 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 ADHD, 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?
- 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 this topic?

³⁵⁹ Pupil census supplementary statistics - gov.scot (www.gov.scot) and Summary Statistics for Attainment and Initial Leaver Destinations, No. 5: 2023 Edition - gov.scot (www.gov.scot)

Section 14: Children and Young people – Transitions to Adulthood

What do we mean by "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, ³⁶⁰ 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. During this period young people progressively assume greater autonomy in many different areas of their lives and are required to adjust to different experiences, expectations, processes, places and routines. Transitions also impact on the family or on those who care for the child or young person.

What we have heard

There is well-documented evidence that the planning and support for disabled young people making the transition to young adult life could be improved.

In February 2023 we published an independent literature review³⁶¹ on the main challenges and experiences faced by young disabled people during their transition to adulthood. This considered Scottish, UK and international evidence.

The literature review set out that there is consistent evidence that positive transitions are characterised by the following:

- early and sustained transition planning
- holistic and coordinated wrap-around support
- services delivered in partnership
- designated keyworkers as a coordinating point of contact and continuity;
- person-centred support and preparation
- family involvement in planning and decision-making
- parental and familial support throughout the transition
- the provision of clear and accessible information
- adequate services, resources and staffing

"I always get really anxious to the point of feeling sick about transitions. Had to hit rock bottom to get any form of support... it felt like a tick box."

- Young Person 362

"Transitions from school can be very scary; change is a big thing to navigate, and knowing what it will entail is hard." – Young Person

³⁶⁰ Principles-of-Good-Transitions-3.pdf (arcscotland.org.uk)

Literature Review: Transitions to Adulthood for Disabled Young People

ational-transitions-adulthood-strategy-disabled-young-people.pdf (www.gov.scot)

Findings from the literature review, along with the views of disabled young people and those who support them, suggest that common experiences of transitions can include:

- stress and uncertainty for the young person;
- difficulties transferring from child to adult services;
- changes in eligibility for services, and support arrangements;
- a sharp drop in support;
- inadequate transitions planning;
- lack of clear information about the transitions process;
- lack of joined-up working (such as communication and collaboration) between services and other partners;
- inadequate account being taken of young people's capabilities, views, needs and aspirations; and,
- stress and difficulties faced by family members relating to their young person's transitions.

The Scottish Parliament's Education, Children and Young People Committee recently considered proposed legislation for transitions to adulthood in response to the Disabled Children and Young People (Transitions to Adulthood) (Scotland) Member's Bill.³⁶³ In its Stage 1 Report, published in October 2023, the Committee noted its concerns about some of the evidence it had received on the poor experiences of transitions for many disabled young people, and recognised the need to act on these issues to improve disabled children and young people's experiences of transitions.³⁶⁴

What did LEAP think?

LEAP members thought that more needs to be done to support neurodivergent young people, and young people with learning disabilities, to experience a positive transition into adulthood. LEAP members expressed concern about the sudden loss of structure and support when young people who are neurodivergent or have learning disabilities leave school. They provided the following views:

- Transition planning starts too late and is not as person-centred as it could be.
- Care-experienced young people with learning disabilities need significant additional support to transition to adulthood.
- Clinicians and professionals have insufficient awareness of existing policies and guidelines, with significant local variations.
- There might still be children and young people being admitted to adult mental health wards instead of a Child and Adolescent Mental Health Service (CAMHS) unit.

³⁶³ Stage 1 | Scottish Parliament Website

³⁶⁴ Stage 1 Report and Easy Read

- There needs to be more short break or respite care suitable for young people transitioning to adulthood that is consistently provided across Scotland.
- There was a lack of college courses available to move on to after school. Some LEAP members shared that they were offered to repeat the same course multiple times as there wasn't anything else available to them. Other members shared that they couldn't access a college course because they were already full with other people who had been repeating the same course for years. They felt that there is low aspiration and expectation of many college courses for college students for students or applicants with learning disabilities.
- There is a sudden lack of support when transitioning from school to university
 and that whilst some people are able to perform well academically, they struggled
 or had to drop out because of the lack of support provided to them. It was
 mentioned that being able to perform well academically should not be an
 indicator that support is not needed.
- Poor transitions linked to poor outcomes around employment.

LEAP members also noted some positive experiences and developments:

- One member's son who is neurodivergent and has learning disabilities had a
 positive experience of being assessed by their local social services' learning
 disability transition team, receiving funding for college support and being able to
 move into wheelchair accessible accommodation with 24/7 care.
- LEAP members were pleased that one of the deliverable identified in the Scottish Government's work programme to develop CAMHS services is the development of neuro-developmental services for children and young people. It was noted that a national specification had been published which some members thought had an excellent approach and use of language which includes individual transition plans to adulthood.

Where do we want to get to?

There are already a range of legislation, plans and policies in place that support the objective of improving transitions to adulthood, and we are committed to doing more to make the transitions journey for every young person a smoother and more positive one.

In the 2021 Programme for Government,³⁶⁵ the Scottish Ministers committed to introducing Scotland's first National Transitions to Adulthood Strategy in this Parliamentary term to ensure there is a joined-up approach so all disabled young people can experience a supported and positive transition to adult life. This commitment was reaffirmed in April 2023 in First Minister's Policy Prospectus.³⁶⁶ In this prospectus we have also committed to helping all school leavers by 2026,

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Programme for Government 2021 to 2022 - gov.scot (www.gov.scot)

³⁶⁶ Cabinet Secretary for Education and Skills - Equality, opportunity, community: New leadership - A fresh start - gov.scot (www.gov.scot)

regardless of their background, to access the transitions support they need to achieve their potential, and ensuring every young person aged 16-24 can further their education or secure a job or training place.

In September 2023 we published our Statement of Intent³⁶⁷ which is based on what we have heard through our research and engagement to date. It sets out the proposed scope, vision, and priorities for a National Transitions to Adulthood Strategy for disabled young people. This has been co-developed with an external Strategic Steering Group³⁶⁸ and some groups of disabled young people. The Steering Group also includes representatives of: parent carers; education (including further education); employment; health; social care; the third sector and local authorities.

We recently published a questionnaire alongside the Statement of Intent to gain further views from a wide range of people. We will use this feedback to develop a National Transitions to Adulthood Strategy, which we aim to consult on more widely in 2024, before publishing the final strategy.

What happens now?

As there is already a range of legislation and policies in place that support the objective of improving transitions to adulthood for disabled young people, in addition to the development of a National Transitions to Adulthood Strategy, any new proposals to improve transitions to adulthood should complement this existing framework. This includes:

The Equality Act 2010 ("the Equality Act")

The Equality Act makes it unlawful for public authorities and others to discriminate against, harass, or victimise employees and people who use services. It requires public authorities and others to make reasonable adjustments for disabled people, to avoid disadvantage.

The Public Sector Equality Duty

As discussed in the introduction, the Equality Act introduced the Public Sector Equality Duty (PSED). Under the PSED, public authorities, in the exercise of their functions, and others who exercise public functions, must have due regard to the need to:

- eliminate unlawful discrimination, harassment and victimisation and other conduct that is prohibited by the Equality Act;
- advance equality of opportunity between people who share a relevant protected characteristic and those who do not; and,

³⁶⁸ Disabled young people: National Transitions to Adulthood Strategy Strategic Working Group - gov.scot (www.gov.scot)

³⁶⁷ Supporting documents - Transitions to adulthood strategy: statement of intent - gov.scot (www.gov.scot)

 foster good relations between those who share a protected characteristic and those who do not.

Social Care (Self-Directed Support) (Scotland) Act 2013 ("the 2013 Act")

The 2013 Act seeks to ensure that children and adults are given more choice and control over how their social care needs are met. It places a duty on local authorities to have regard to the general principles of involvement, informed choice and collaboration when carrying out some of its functions including its functions under the 2013 Act. This includes assessment and planning functions under section 23 of the Children (Scotland) Act 1995,³⁶⁹ the Social Work (Scotland) Act 1968 and the Carers (Scotland) Act 2016.

We have also produced statutory guidance on Self-directed Support³⁷⁰, which, amongst other matters, provides detailed guidance on how this Act interacts with other assessment, planning and supporting duties.

Education (Additional Support for Learning) Scotland Act 2004 ("the 2004 Act)

The 2004 Act is described in more detail in the Education section of this consultation paper. The 2004 Act provides that if a child has complex needs which require the support of another public service (such as social work or health service), then a Coordinated Support Plan must be prepared. Section 12 of the 2004 Act provides for duties on the education authority to engage with any such agency or agencies as appropriate no later than 12 months prior to the young person finishing school education. It enables professionals from multiple agencies to plan together to meet a young person's needs and to co-ordinate their support.

Additional Support for Learning (Changes in School Education) Scotland Regulations 2005

These regulations govern transitions within a child or young person's school career.

Transition Care Plan (TCP) Guidance

The Transition Care Plan (TCP) Guidance, published in 2018, describes the standards required in the planning of good transitions for young people moving from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services. This approach allows flexibility for those aged 18-25 to continue their care and treatment with CAMHS where this is in their best interests rather than automatic transfer to adult services.

GIRFEC and the Child's Plan

As discussed in the introduction, GIRFEC provides a framework to ensure that everyone in Scotland can work together to support children and young people to grow up feeling loved, safe and respected so they reach their full potential. GIRFEC

³⁶⁹ Children (Scotland) Act 1995 (legislation.gov.uk)

³⁷⁰ Social Care (Self-directed Support) (Scotland) Act 2013: statutory guidance - gov.scot (www.gov.scot)

policy and guidance recognise that well planned and supported transitions are key for children and young people.

In October 2023, we published our 'Getting It Right For Every Child' Child's Plan Practice Statement.³⁷¹ This includes new guidance for transitions which outlines that particular consideration should be given to disabled children and young people.

The non-statutory GIRFEC child's plan remains an important element in the ways children's and related services can work in a co-ordinated way to support the wellbeing of children, young people and their families. The child's plan should be used to support quality transitions by enabling those involved to effectively plan for changes together, and in time, to ensure co-ordination and continuity of support.

Using the GIRFEC approach, practitioners and lead professionals should support a child or young person's wellbeing through transitions by working alongside them and their family, and other practitioners involved in transition planning. They should ensure the views and rights of the young person and family are considered in decisions throughout a transition. Effective transfer of information between services during transitions, in line with information sharing guidance, is also essential.

GIRFE

We are also currently co-designing Getting it Right for Everyone (GIRFE),³⁷² a proposed multi-agency approach to support and services from young adulthood through to end of life care. One of the key themes includes young people in transition from GIRFEC to GIRFE.

International Human Rights

The UNCRC sets out the international human rights standards for children up to the age of 18. Many of the articles are relevant to transitions. For example, under Article 12 every child and young person who is capable of forming their own views has the right to express those views freely in all matters that affect them, with those views being given due weight in accordance with the age and maturity of the child.

As noted in the introduction we are progressing a Human Rights Bill for Scotland as well as the United Nations Convention on the Rights of the Child (UNCRC) (Incorporation) (Scotland) Bill, to incorporate a wide range of internationally recognised human rights belonging to everyone in Scotland into Scots law, within the limits of devolved competence.

The Association for Real Change (ARC) Scotland's Principles of Good Transitions

We support ARC Scotland to run the Scottish Transitions Forum. This forum has around 950 members and aims to improve the experience of young people who require additional support who are making the transition to young adult life. ARC Scotland's Principles of Good Transitions³⁷³ are widely endorsed by many

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³⁷¹ Getting it right for every child (GIRFEC): child's plan - practice statement - gov.scot (www.gov.scot)

Getting it right for everyone (GIRFE) - gov.scot (www.gov.scot)

³⁷³ Principles-of-Good-Transitions-3.pdf (arcscotland.org.uk)

stakeholders with a role in supporting disabled young people's transitions to adulthood, including the Scottish Government. We promote the Principles and Principles into Practise³⁷⁴ as a good practice framework for practitioners across a range of services. We have also supported ARC Scotland to develop Compass which is an online tool to help young people in Scotland, their parents and carers, and the professionals who support them, with the transition to young adult life.

Developing the Young Workforce (DYW)

Developing the Young Workforce (DYW)³⁷⁵ facilitates the engagement between employers and schools to support young people to transition into the world of work.

Through DYW, we have continued to provide funding to Enable's 'Stepping Up' transitions programme, which connects disabled young people to fair work, education and productive activities designed to support a successful transition into adult life and work.

Independent Living Fund

The Scottish Government is reopening the Independent Living Fund on a phased basis, with an initial £9 million on 2024-25 to enable up to 1,000 additional disabled people, including children, young people and adults, with the most complex needs to access the support they need and deserve to live independent lives.³⁷⁶ This will supplement the existing work of Independent Living Fund Scotland's Transition Fund which supports young people in transition to adulthood, aged 16-25, through one year grants.

Colleges and University: support for neurodivergent students and students with learning disabilities

Institutions' duties

Each college or university has a duty under the Equality Act to make 'reasonable adjustments', to ensure that students with disabilities, long-term medical conditions or additional support needs are not placed at a disadvantage in comparison to non-disabled students. Institutions are therefore expected to ensure that these students are supported as they study in further and higher education. Each institution's support or disability services should advise students what support they can access.

The Scottish Funding Council (SFC) has, together with the Equality and Human Rights Commission, recently developed a National Equality Outcomes framework to address the most persistent inequalities in further and higher education.³⁷⁷ Under this Framework, Institutions are asked to consider and report on progress towards the outcomes as part of the 2021-25 Public Sector Equality Duty reporting cycle.

³⁷⁶ equality-opportunity-community-programme-government.pdf (www.gov.scot)

³⁷⁴ Principles into Practise PN2P and Compass – Information site

³⁷⁵ DYW - Scotland - Home

Joint call for Scotland's colleges and universities to address inequalities (sfc.ac.uk)

The SFC has committed to doing more to address specific issues faced by neurodivergent individuals, as is outlined in its Tackling Persistent Inequalities Together report, which sets out the Outcomes, to ensure the needs of this group are being met.³⁷⁸

Disability, as a protected characteristic, is included as part of this work, and the following National Equality Outcomes related to disabled students:

- The success and retention rates of college and university students who declare a mental health condition will improve.
- Disabled students report feeling satisfied with the overall support and reasonable adjustments received, including from teaching staff, while on their course.
- Disabled staff and students report feeling safe in the tertiary system.
- Where representation is not proportionate to the relevant population, increase the representation of disabled staff in the workforce and on college Boards and university Courts

Funding provided to universities and colleges

Funding is provided to Scottish universities, via the SFC, to assist with the costs incurred in providing additional materials and services for disabled students. This is called the Disabled Students Premium. For Academic Year 2022-23 this funding totalled £2.87m.

We also provide funding to colleges to support the teaching and learning of students with additional support needs. This is called the Access and Inclusion Fund. For Academic Year 2022-23 this accounted for £51.8m of the £522m that was allocated in core teaching funding to colleges.

Transitions and student support in Further and Higher Education

The Additional Support Needs for Learning Allowance is a non-income assessed allowance administered by individual colleges. It is intended to support students with disabilities or additional learning needs who are studying a course of Further Education and may have extra costs.

The Disabled Students Allowance is a non-income assessed fund that is administered by Student Awards Agency Scotland. It is intended to support disabled students and those with additional learning needs who are studying a course of Higher Education and may have extra costs because of their impairment.

Independent Advocacy, advice and support

We know that independent advocacy can be fundamental to ensuring the realisation of children and young people's rights. We have therefore increased support to Clan Childlaw, to increase their capacity; to provide advocacy support for children and young people; to develop training and materials; to work with us to help identify

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³⁷⁸ Equality and diversity (sfc.ac.uk)

areas where children's rights are not being met; and, to develop child-centred legal professional training.

We also fund a national children's service, called My Rights, My Say³⁷⁹, which provides advice and information, seeks children and young peoples' views, and provides advocacy and legal protection focussed on children and young people exercising their rights in respect of education and transition planning. We also fund The Support in the Right Direction programme which provides local independent support, advice and advocacy for all social care user groups.³⁸⁰

What can the 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.³⁸¹

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:

- (a) 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;
- (b) ensure the visibility of these young people;
- (c) help inform the work that will take place under a National Transitions to Adulthood Strategy: and,
- (d) help to inform the development of services to meet the needs of these young people when transitioning to adulthood.

³⁷⁹ My Rights, My Say (myrightsmysay.scot)

Support in the Right Direction 2024 - 2027 - Inspiring Scotland % %.
 Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill – Bills (proposed) laws) - Scottish Parliament | Scottish Parliament Website

What Do You Think?

- Do you agree with this proposal, please tell us why?
- Do you do not agree with this proposal, please tell us why?
- Is there anything else that we should consider about Children and young people: Transitions to adulthood?

Part 4: Accountability

What we have heard

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 did LEAP think?

When discussing options for accountability, the majority LEAP members decided that a new Commission model would be their preferred option because:

- They liked the idea of a board with several people who could take lead
 responsibilities for different groups of people with learning disabilities and other
 neurodivergent people. They thought it was important that a Commission should
 be overseen by a board that included people with lived experience of learning
 disabilities and neurodivergence;
- They wanted a body able to conduct investigations on individual cases;
- Parents and carers could also be represented without this diluting the views of neurodivergent people and people with learning disabilities;
- A Commission could have formal responsibilities to promote and secure rights and it was important for this to have legislative backing.

Some members thought it would better to have a specialist within an existing Commission or Commissioner body to prevent neurodivergent people and people with learning disabilities being seen as "other".

The LEAP wanted to emphasise that neurodivergent people and people with learning disabilities should be involved in the leadership and governance of any new or existing Commission or Commissioner. They thought it vital that people are able to advocate on behalf of themselves and their communities at every level of representation. This could in turn help ensure that the actions and advice of any new or existing body are fully informed by the experiences of the people whom it aims to help.

The LEAP also thought that several of the options below could be selected alongside each other. They thought that, for example, introducing champions and advocates into public bodies could complement the establishment of a new Commission. They also thought that a Commission could issue national guidance and set national standards, which is one of the other options that we list below. However, they

acknowledged that potential funding limitations could limit the selection of multiple options alongside each other.

Where do we want to get to?

- Neurodivergent people and people with learning disabilities know what their rights are
- Neurodivergent people and people with learning disabilities have confidence that their rights will be respected and upheld when they need supports or services
- Public bodies providing supports, services or information always make sure they
 are accessible to neurodivergent people and people with learning disabilities and
 respect their human rights
- When rights are not respected there is a clear route to redress and improvement.

What happens now?

Earlier this year, we conducted and published research on the role of existing Commissions and Commissioners.³⁸²

We agreed that our research would focus on in-depth interviews with five commissions, commissioners or partners. Our research sets out more detailed information about these existing Commissions and Commissioners in Scotland. They all include neurodivergent people and people with learning disabilities in their remit:

- the Equality and Human Rights Commission (EHRC)
- the Scottish Human Rights Commission (SHRC)
- the Scottish Public Services Ombudsman (SPSO)
- the Mental Welfare Commission for Scotland (MWCS)
- the Children and Young People's Commissioner (CYPCS)

Our research paper sets out more about the powers and duties of these bodies and their views on the effectiveness of their powers.

What can we do about it?

We can explore using the Bill to make better provision for neurodivergent people and people with learning disabilities to know about their rights and to be able to get support where those rights are not being protected or respected. We have set some of this out in the sections about accessible information and advocacy.

The Bill can also 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 below. This will be in addition to the existing roles of charities and disabled peoples organisations and would not replace them. The options include the following:

³⁸² 1. Introduction - Commissions and commissioners: final report - gov.scot (www.gov.scot)

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

The table below summarises some of the information about these options.

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	Option 1: New	Option 2:	Option 3:	Option 4:	Option 5:
	Commission	Better	Champions	Better	Supporting
	or	resourcing	and	resourcing of	good
	Commissioner	and additional	Advocates	existing	practice
		duties for an	within	Disabled	through
		existing body	Public	People's	standards,
			Bodies	Organisations	guidance
					and
					practical
					tools and
					investing in
					CO-
					production
Provides	Yes	Yes	No	No	Yes
consistent					
guidance					
across					
Scotland		
Can hold	Depends on	Depends on	No	Possibly, via	No
Scottish	functions of	functions of		campaigns	
Government to	Commission	Commission		and targeted	
account	or	or		legal actions	
	Commissioner	Commissioner			
Can involve	Yes	Yes	Possibly	Possibly	Possibly
people with					
learning					
disabilities and					
neurodivergent					
people in					
decisions that					
affect public					
bodies					

Can conduct formal investigations of public bodies that may not be treating people with learning disabilities and neurodivergent people well	Possibly	Possibly	No	No	No
Can inform neurodivergent people and people with learning disabilities of their legal rights	Depends on functions of Commission or Commissioner	Depends on functions of Commission or Commissioner	Yes	Yes	Yes
Can bring legal proceedings against the Scottish Government and Scottish public bodies	Possibly	Possibly	No	No	No
Can provide advice directly to people with learning disabilities and neurodivergent people	Possibly	Possibly	Possibly	Yes	No

Option 1: A new Commission or Commissioner

What would this mean?

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 could be set out in the Bill. The Bill can also set out how the Commissioner or Commission would be appointed and could make sure that neurodivergent people and people with learning disabilities were involved in the appointment process.

There are already a number of Commissions and Commissioners in Scotland which have remit to consider people with learning disabilities and neurodivergent people.

These include the Children and Young People's Commissioner. This Commissioner does a number of things, including:

- Telling people in Scotland about the rights children and young people have and helping them understand what they mean in practice;
- Looking at what powerful people in Scotland do and the laws they pass, and raising concerns with them when they don't respect children and young people's rights;
- Telling people who work with and for children and young people how to get better at respecting human rights; and
- Investigating some issues affecting children's human rights.

It also includes the Scottish Human Rights Commission (SHRC), which can:

- Publish advice, guidance and ideas;
- Conduct research and provide education and training;
- Review and recommend changes to law, policy and practice;
- Conduct inspections in places of detention;
- Conduct inquiries (under some strict conditions); and
- Intervene in civil proceedings before a court in certain circumstances.

The SHRC does **not** currently have the power to:

- Assist in claims or legal proceedings or
- Provide advice, guidance or grants linked to proceedings.

However, as part of our consultation on a new Human Rights Bill for Scotland, we are considering whether the SHRC should have additional powers. These potential new powers are discussed in greater detail below under Option 2 in this section.

The Equality and Human Rights Commission's (EHRC) also has remit to consider people with learning disabilities and neurodivergent people. Its role is to promote equality and diversity, enforce equality laws and promote and protect human rights by encouraging and promoting good practice and promoting mutual respect across Great Britain. In Scotland its functions include:

- Producing statutory guidance
- Conducting inquiries into any topic related to equality, diversity and human rights
- Conducting investigations where it is suspected an unlawful act has been committed
- Making applications to court including judicial reviews and interventions

More information can be found in our published research on the role of Commissions and Commissioners as mentioned above.

What could a Commission or Commissioner do?

Several organisations have suggested powers that a Commission or Commissioner might have. They have also made suggestions about how a new body might work

alongside existing Commissions and Commissioners in Scotland. We have set out below what the powers and duties of a new body might be. It could have all or some of these powers and duties:

Consult and involve neurodivergent people and people with a learning disability

- o Involvement in the appointment process for a Commission or Commissioner;
- Ask neurodivergent people and people with learning disabilities what issues they would like the Commissioner to address;
- Establish and work with an advisory group of neurodivergent people and people with learning disabilities.

Promote human rights

- o Provide information
- o Provide advice and guidance on specific issues
- o Provide education and training
- o Promote good practice

Conduct research

- Into specific issues where there is limited information
- o Into issues where people feel disadvantaged
- Publish information on, for example, national numbers on people with learning disabilities alongside numbers of neurodivergent people generally and people with specific neurodivergent conditions

Hold the Government to account

- Review areas of law, Government policy and practice
- Publish their opinion
- o Provide evidence to the Scottish Parliament
- Make recommendations

Hold public bodies to account by conducting inquiries and formal investigations

- o Into specific issues, supports or services
- Have powers to compel the production of information held by public bodies and interview their office holders
- o Publish reports of inquiries and investigations
- Make recommendations

Power to bring court proceedings

- o Have powers to access information linked to the case
- o Recommend penalties for public bodies, such as fines

Publish an annual Strategic Plan and financial accounts

- Co-produce this with neurodivergent people and people with learning disabilities:
- Collate and publish data and report regularly to the Scottish Parliament on key outcomes for neurodivergent people and people with learning disabilities

Potential Benefits

- Raise the profile of people with learning disabilities and neurodivergent people in our society and advocate for changes in attitudes and behaviours as well as systems and services.
- Provide a high-profile single point of contact for neurodivergent people and people with learning disabilities across Scotland, advocating for their rights.
- Specialise and keep up with the latest language, research, and attitudes. These can change quickly.
- Provide a new resource in Scotland to help target and address areas where rights are not being met and hold Government and public bodies to account.

What additional benefits might a Commission provide?

Because a Commission consists of multiple people, it could potentially represent a broader range of views more easily than a Commissioner. This might include a Board where each member could specialise in one area, such as learning disabilities, autism or ADHD, for example. Those members might be able to also act as individual champions for people in different fields. We could explore how neurodivergent people and people with learning disabilities could be represented on the Board.

Potential Challenges

- There could be duplication or a need for agreements with existing bodies. This is because there are already Commissioners and Commissions who, although they do not specialise in neurodivergence or learning disabilities, include these groups within in their remit. This includes the SHRC, EHRC and the Children and Young People's Commissioner. However, agreements could be put in place between a new Commission or Commissioner and existing ones about how they would work together.
- The Scottish Parliament would need to be persuaded that there is a need for a new public body.
- A new Commission or Commissioner would have a specific remit covering all neurodivergent people and people with learning disabilities. This means covering a wide range of issues and also representing families and carers.
- If a new public body has duties to conduct investigations and/or take some
 individual cases, this might need a lot of time and resource and could divert it
 from other activities. The same might apply to a power to provide advice and
 guidance to individuals. It is not guaranteed that a new body would have these
 powers and a case would need to be made for them and adequate funding
 provided.
- A new Scottish body can only operate within devolved powers. This might limit it
 to some extent, for example on equalities issues, but this would apply to any of
 the accountability mechanisms that could be created by this Bill.
- Some people feel the funding for a new body could be more effective spent in a different way to benefit people with learning disabilities and neurodivergent people.

Option 2: Better resourcing and additional duties for an existing body

What would this mean?

Neurodivergent people and people with learning disabilities already come within the remit of the SHRC, the EHRC Equality, 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. They also have limited opportunity to specialise in some areas. We know that the needs of neurodivergent people and people with learning disabilities are often not being met so whilst existing bodies may have been able to do many good things we know that it is not always possible to prioritise this within their overall duties.

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 people with learning disabilities and neurodivergent people.

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

We recently consulted on proposals for a new Human Rights Bill for Scotland including exploring changes to the powers of the SHRC to include: 383

- Powers to bring or intervene in civil proceedings under a Human Rights Bill; and
- An investigatory power which allows for accountability for systemic issues relating to the rights in the Bill (relating to civil matters).

In addition, it is proposed that scrutiny bodies (including the Scottish Public Services Ombudsman (SPSO)) be required to inform the SHRC of any systemic human rights issues they come across.

The SHRC itself has proposed introducing a rapporteur model in a recent report.³⁸⁴ This means some small teams within the SHRC having responsibility for a specific dedicated issue. They have suggested that one of those dedicated teams could be for disabled people. This would include, but not be limited to, neurodivergent people and people with learning disabilities. Each Rapporteurship would be proactive in securing rights and would appoint highly qualified people to act in this role.

³⁸³ human-rights-bill-scotland-consultation-june.pdf (www.gov.scot)

³⁸⁴ crossroads_what-next-for-human-rights-protection-in-scotland-shrc-june-2023.pdf (scottishhumanrights.com)

Potential Benefits

- Existing bodies have experience and powers that can help them uphold the rights of neurodivergent people and people with learning disabilities.
- This option could prevent the duplication and overlap of powers and remit that creating a new Commission/er might bring. It may reduce the likelihood that lots of new Commission/ers will be set up in future.

Potential Challenges

- Existing bodies already have a lot of work to do. It is possible that, even with
 additional resources, they would not be able to focus, or give the focus that is
 needed, on the rights of neurodivergent people and people with learning
 disabilities as much as they would like.
- Existing bodies may not have a lot of experience of working with people with learning disabilities and neurodivergent people. They may have to do a lot of learning first before they could effectively uphold their rights.
- There may still be gaps in the powers of existing bodies that some people may like a commission or commissioner to have.

Option 3: Champions and Advocates within Public Bodies

Scotland has many public bodies whose roles are central to the experiences that people with learning disabilities and neurodivergent people 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.

What would this mean?

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 NHS, the Police and many other bodies. Currently, many public bodies will have individuals appointed to their Boards to provide expertise in a variety of areas.

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.

Potential Benefits

- These champions and advocates would act as representatives of people and could quickly tell public bodies what they need to do better in live time.
- Having different champions and advocates within different public bodies would allow those champions and advocates to focus on issues specific to those public bodies.

 This option could work alongside other options, including a new or existing Commission or Commissioner. The champions and advocates could make sure change happens at a local level, while the Commission or Commissioner makes sure that it happens at a national level.

Potential Challenges

- It would not necessarily be possible to place a legal duty on public bodies to enact the suggestion of the champions and advocates.
- Champions and advocates would have to speak up on behalf of lots of different neurodivergent people and people with learning disabilities. This could be an overwhelming task for them, and they could overlook some people or groups due to their broad remit.
- The role would be focussed on specific bodies. There would be no overall
 consistent national approach or governing body looking at accountability unless
 a Commission or Commissioner was also established.

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, 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 in Scotland (there are several) and People First, which is an organisation led by people with learning disabilities.

DPOs try to help public and private bodies including local authorities, healthcare providers, education providers, people working in justice, and the Scottish Government. They help by explaining what their communities want and need.

What would this mean?

This option would mean better resourcing of existing DPOs, specifically those that are led by and support people with learning disabilities and neurodivergent people, to allow them to increase support and advocate for the rights of neurodivergent people and people with learning disabilities.

Although we 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 as disabled people (including people with learning disabilities and neurodivergent people).

Potential Benefits

- Giving more money and support to certain DPOs could allow them to grow and reach more people within the communities they represent.
- DPOs are connected to their communities and could develop direct and deep understanding of their problems.
- DPOs ensure that people's voices come first and do not need to be represented by anyone else.

Potential Challenges

- DPOs do not have any legal powers of enforcement. They can advise organisations, but those organisations do not need to listen to them.
- Some DPOs operate only in a specific geographical area. They can identify and talk about local issues, but they may struggle to reach everyone in their communities across all of Scotland.
- In Scotland the only existing DPOs established specifically to support people
 with learning disabilities and other neurodivergent people are APOs that focus
 on autistic people, and People First who support people with learning disabilities.
 This means that there are no DPOs representing other neurodivergent groups
 such as people with ADHD, FASD, and people with learning difficulties like
 dyslexia. Although many neurodivergent people may have more than one
 condition, this means that not all people would be represented through this route.
- Furthermore, differences between DPOs in, for example, the interpretation and application of relevant guidance, or even in the number of staff they have, could mean that people with learning disabilities and neurodivergent people receive different levels and quality of support depending on where they live in Scotland.
- If DPOs take different approaches to data collection regarding the people they support, it may result in the production of data sets that cannot be amalgamated to form a national picture across Scotland. However, this could be mitigated by the Scottish Government providing guidance on any data sets that would need to be collated and published, or finding an alternative solution for national data collection.
- Whilst bodies established through legislative means generally have accountability built in, DPOs would not be subject to the same level of accountability or scrutiny. They are accountable to their members, but not every neurodivergent person and person with learning disabilities in Scotland is a member of a DPO.

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

What would this mean?

This could involve us working continuously with people with lived experience (like the 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. 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.

We already do some of this kind of work, however, there are still many serious issues experienced by people with learning disabilities and neurodivergent people. We have worked with autistic people and people with learning disabilities over the last two years to identify improvements needed around mental health.

Potential Benefits

- We could set standards that are expected to be followed by public bodies across Scotland, meaning that they would be consistent between council areas and providers.
- The design of standards, guidance, and practical tools could be done with a wide range of neurodivergent people and people with learning disabilities, meaning that lots of different groups could influence them.

Potential Challenges

- Designing these standards, guidance, and tools could take a long time, and would have to be updated regularly. This means that they may not be of immediate help.
- We already deliver some of this work and will continue to do so, but this
 approach does not provide a means to enforce best practice via legal means or
 assure any additional accountability from the organisations we work with.
- Some people worry that setting standards and issuing guidance without an
 enforcement mechanism could lead to standards and guidance being treated as
 a 'tick box exercise'. They worry that nothing would change for the better
 because of this.

What Do You Think?

- Which of the 5 options set out above do you think would best protect, respect and champion the rights of people with learning disabilities and neurodivergent people? You can select multiple options if you wish.
- Please give the reason for your choice(s).
- Are there any other options we should consider? Please give details

Part 5: Next Steps

This part of the consultation sets out next steps following the publication of this document.

The consultation will run for four months and closes on 21 April 2024.

Everyone should have the opportunity to offer their views to inform the Bill. During the consultation period, we will make sure as many people as possible know about the consultation and are encouraged and supported to take part.

This will include a series of local discussion events across Scotland as well as online events. We will seek to meet with neurodivergent people and people with learning disabilities who face historic and ongoing societal barriers to having their voice heard in public consultations. We will work with organisations that represent the lived experience of neurodivergent people and people with learning disabilities to engage with as many people as possible.

We have also published accessible facilitation packs so that community groups can hold their own discussions and, if they wish, submit a group response to the consultation. We have developed accessibility resources, such as easy read versions of all sections in this document, a short guide to the consultation document, a child-friendly version, an audio version and a BSL video, that help to enable as many people as possible to get involved.

The Lived Experience Advisory Panel (LEAP) will continue to meet throughout the consultation period and over the rest of the Bill development process. LEAP members will help us put accessibility and transparency at the heart of the consultation process.

The views provided through the consultation, alongside the feedback received throughout the consultation development process, will inform the next steps in developing the Bill.

Part 6: How to Respond

We are inviting responses to this consultation by 10pm on Sunday 21 April 2024.

Some sections of this consultation may be more relevant to particular individuals than others. Therefore, you may wish to only answer the questions or sections you find most relevant.

We encourage you to submit a response, regardless of how many questions you would like to answer.

Responding online

If you are able to, please respond using Citizen Space, the Scottish Government's online consultation hub. Here you will be directed to the 'About You' page before submitting your response. Please indicate how you wish your response to be handled and, in particular, whether you are content for your response to be published. If you ask for your response not to be published, we will not publish it.

The LDAN Bill consultation on Citizen Space can be found here.

Written responses

If you are unable to respond online, please complete the Respondent Information Form and send with your completed questionnaire to:

By Post: FREEPOST – LDAN BILL (simply put form in an envelope and add address above – 3 words – all in capital letters - to post your response free from any postage costs)

Or by email: LDAN.Bill@gov.scot

You can submit any written form of response this way too, so long as you have provided answers to the About You questions on pages 1-4 of the Respondent Information Form, and in particular whether you would like your response to be published, and follow the flow of the questions, answering the questions as they are set out.

Responding by audio or video

You are welcome to submit a response in an audio clip, video, or BSL video file – please email these to <u>LDAN.Bill@gov.scot</u>.

As part of your response, you must include answers to the About You questions in pages 1-4 of the respondent information form so that we can accept your response. Please always supply a way to contact you so we can reach you if anything is missing and so that your responses can be accepted.

How your response will be handled

To find out how we handle your personal data, please see our privacy policy: Privacy - gov.scot (www.gov.scot).

All respondents should be aware that the Scottish Government is subject to the provisions of the Freedom of Information (Scotland) Act 2002 and would therefore have to consider any request made to it under the Act for information relating to responses made to this consultation exercise. However, personal data would never be disclosed.

Where respondents have given permission for their response to be made public, and after we have checked that they contain no potentially defamatory material, responses will be made available to the public at http://consult.gov.scot. If you use the consultation hub to respond, you will receive a copy of your response via email.

Following the closing date, all responses will be analysed and considered along with any other available evidence to help us understand the views and issues. Responses will be published only where we have been given permission to do so. An analysis report will also be made available.

Consultation is an essential part of the policy making process. It gives us the opportunity to consider your opinion and expertise on a proposed area of work.

Depending on the nature of the consultation exercise the responses received may:

- indicate the need for policy development or review;
- inform the development of a particular policy;
- help decisions to be made between alternative policy proposals; and,
- be used to finalise legislation before it is implemented.

While details of particular circumstances described in a response to a consultation exercise may usefully inform the policy process, consultation exercises cannot address individual concerns and comments, which should be directed to the relevant public body.

For information on how to make a complaint please visit: Make a complaint - gov.scot (www.gov.scot)



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