



Consultation Response

Learning Disability, Autism and Neurodivergence Bill

The Scottish Commission for People
with Learning Disabilities

April 2024



Learning Disability, Autism and Neurodivergence Bill Consultation SCLD response – April 2024

Background

The Scottish Commission for People with Learning Disabilities (SCLD) is an independent charitable organisation and human rights defender, working to uphold, protect and raise awareness of the human rights of people with learning disabilities.

Our vision is of a fairer Scotland where people with learning disabilities live full, safe, loving and equal lives. We influence the development of policy, practice and legislation with a focus on human rights, leadership and evidence. We are respectful, inclusive, collaborative and pioneering.

Our organisational outcomes are:

1. People with learning disabilities champion and defend their own and other people's human rights, and lead the work to improve policy, practice and legislation.
2. People with learning disabilities are confident about what they can achieve and use their voices to lead, participate and influence change.
3. Practitioners and service providers learn from shared experiences resulting in improved practice and services, informed by human rights standards, data and evidence.

Introduction

The Scottish Commission for People with Learning Disabilities (SCLD) welcomes the opportunity to respond to the Scottish Government's Learning Disability, Autism and Neurodivergence (LDAN) Bill consultation. We believe that the LDAN Bill offers a once in a generation opportunity to develop bespoke legislation which helps to transform the lives of people with learning disabilities in Scotland.

Before proceeding with the Bill, the Scottish Government must carefully consider why such a Bill is required despite some existing good policy and legislation.

It is critical that we all understand that people with learning disabilities are not asking for anything special or additional with regard to the realisation of their human rights.

Despite decades of good intentions, and a wide range of existing legislative provisions and good policy, people with learning disabilities in Scotland continue to experience daily denials of their human rights. They experience multi-layered trauma, exclusion, stigma, and poor outcomes. They experience barriers to accessing rights across a wide range of domains including active citizenship, full engagement in civil and public life and a lack of access to justice, independent living, education¹, employment², relationships³, and family lives⁴.

Furthermore, SCLD believes that discrimination and human rights abuses against people with learning disabilities have, in some instances, become 'hard-wired' in policy and legislative approaches and service delivery frameworks.

This is despite the fact that the barriers that exist for people with learning disabilities go completely against the United Nations Convention on the Rights of Persons with Disabilities (CRPD)⁵ which requires that people with disabilities are entitled to enjoy all human rights on an equal basis with others to enable their full and effective participation in society. Critically, this requires not only promotion of rights but also the active removal of barriers which prevent the full and equal enjoyment of human rights⁶.

Despite the requirements for our governments to comply with the CRPD, the Human Rights Act 1998⁷, and the Equality Act 2010⁸ in all aspects of policy and law, transformative change has not yet been forthcoming. SCLD believes that the continued pathologising and 'invisibility' of people with

¹ [ENABLE \(2016\) #IncludED in the Main?! 22 steps on the journey to inclusion for every pupil who has a learning disability](#)

² [McTeir et al \(2016\) Mapping the Employability Landscape for People with Learning Disabilities in Scotland](#)

³ [SCLD \(2018\) Safe and Healthy Relationships: Empowering & Supporting People with Learning Disabilities](#)

⁴ [SCLD \(2018\) Children's Rights: Consultation on incorporating the UNCRC into our domestic law in Scotland](#)

⁵ [Convention on the Rights of Persons with Disabilities | OHCHR](#)

⁶ [Convention on the Rights of Persons with Disabilities \(2006\)](#)

⁷ [Human Rights Act 1998 \(legislation.gov.uk\)](#)

⁸ [Equality Act 2010 \(legislation.gov.uk\)](#)

learning disabilities has a central role to play in the collective failure to deliver change.

In the most horrifying instances, people with learning disabilities have been denied their right to life due to a public failure to intervene, such as in the case of Margaret Fleming⁹.

For the LDAN Bill to succeed these fundamental truths and issues must be accepted and reflected on. We must learn why the failures outlined above have become systemic and are considered acceptable. Importantly we must understand why current accountability and regulation mechanisms have proved wholly inadequate in realising the rights of people with learning disabilities.

If the above learning is embraced, SCLD believes the LDAN Bill could help to reshape Scotland's legislative framework in order to ensure that the human rights and well-being of people with learning disabilities are respected, protected and fulfilled and that the societal barriers and disadvantages they experience are addressed. Without this reflective learning process, we fear the Bill's impact will be limited.

To succeed, we believe the LDAN Bill must have a clear vision which sets out a goal of achieving a Scotland where people with learning disabilities, autistic people and neurodivergent people can live full, safe, loving and equal lives.

SCLD believes the LDAN Bill must advance equality for people with learning disabilities, autistic people and neurodivergent people. In line with the Equality Act 2010 and the Public Sector Equality Duty, the LDAN proposals must help to:

- advance equality and diversity.
- remove or minimise disadvantage.
- meet the needs of people with learning disabilities.
- encourage increased participation of people with learning disabilities.
- tackle prejudice, promote understanding and contribute to a more equal society.

⁹ [Margaret Fleming Significant Case Review published - Inverclyde Council](#)

SCLD notes the recommendation in the UN’s fourth Universal Periodic Review (UPR) of the UK to “Ensure that all new legislation remains in line with the United Kingdom’s international human rights obligations (Cyprus).”¹⁰ The LDAN Bill is an opportunity to deliver on the recommendation of the UN Human Rights Council.

The LDAN Bill must make commitments in legislation which are both ambitious and well resourced, to directly address the discrimination experienced by people with learning disabilities in Scotland. Furthermore, the LDAN Bill must dovetail with existing domestic and UK law, international human rights conventions and future human rights law in Scotland.

In this way, SCLD believes the LDAN Bill, together with the Scottish Human Rights Bill, the National Care Service Bill and the Mental Health and Capacity Law reform agenda, present an opportunity to reframe the legislative landscape which impacts the lives of people with learning disabilities and has a central role to play in protecting and respecting the social, economic, and cultural rights of people with learning disabilities.

The need for change is urgent. People with learning disabilities cannot continue to experience discrimination and human rights abuses on a daily basis. The collective failure of public authorities to deliver for people with learning disabilities has gone on for too long. SCLD believes that action is required now and that the LDAN Bill offers a significant opportunity to deliver long-awaited transformational change.

It is also important to state that lack of funding must not be used as an excuse to fail to reform the law, culture and practice. This response has been written in full understanding of the financial challenges facing the country. However, the progressive realisation of people with learning disabilities’ human rights must be a priority.

Moving forward, the development of the LDAN Bill and its implementation must continue to be co-produced by people with learning disabilities. It is pivotal that they have a central role in shaping not only the legal reform but

¹⁰ Recommendation 43.33, Report of the Working Group on the Universal Periodic Review, pub 9th January 2023 <https://www.ohchr.org/en/hr-bodies/upr/gb-index>

also the culture change required to deliver positive outcomes and genuine transformation in the lives of people with learning disabilities across Scotland.

Developing SCLD's Consultation Response

SCLD has committed significant organisational resources to responding to the LDAN Bill Consultation. Since it was published in December 2023 we have:

- Produced a suite of accessible and informative resources to assist people and organisations to respond¹¹.
- Shared these resources with over 8,500 people and organisations.
- Presented on and discussed the consultation at webinars and workshops attended by over 350 people with learning disabilities, other allies and stakeholders.
- Facilitated two webinars focussing on the consultation, attended by 180 people, during February 2024.
- Actively sought the involvement and engagement of people with learning disabilities through our existing engagement Boards and Panels – Include For Good, the Expert Group, the Human Rights Lived Experience Board and the Digital Navigators Board.

All of our learning from this work has been distilled down into this response. We also draw on a wide range of evidence and data gathered over the last 20 years and have used this to inform the points made wherever possible.

Unfortunately, we did not have the organisational resources to respond to the full consultation document in detail. We therefore prioritised our response to focus on a number of key areas which we believe are of significant importance to the lives of people with learning disabilities, their family carers and their allies. These priorities were agreed in partnership with people with learning disabilities and discussed in all of our engagement work.

¹¹ [Learning Disabilities, Autism and Neurodivergence \(LDAN\) Bill consultation - Information - SCLD](#)

As a result of this prioritisation process our response focusses on the following sections:

- Reach and Definitions
- Overarching Themes:
 - Statutory Strategies
 - Mandatory Training in the Public Sector
 - Inclusive Communications
 - Data
 - Independent Advocacy
- Health and Wellbeing
- Housing and Independent Living
- Complex Care and Coming Home
- Employment
- Accountability

SCLD has also supported other national groups and organisations to develop their own independent submissions to this consultation – these are:

- Include For Good – in partnership with our 10 Rapporteurs
- Restraint Reduction Scotland
- PBS Community of Practice
- Digital Navigators Board

In concluding this section of our response, we wanted to highlight our commitment to co-production with people with learning disabilities. Lindsay Kinloch, who is an individual human rights defender and has worked closely with the Scottish Government as part of the LDAN Bill Lived Experience Panel (LEAP) gave some opening remarks at both of our recent LDAN webinars. Lindsay's speech is available here:

[Learning Disability, Autism and Neurodivergence Bill Consultation Events February 2024 - Introduction by Lindsay Kinloch on Vimeo](#)

Part 1: Reach and definitions: who should the Bill include?

What do you think?

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

SCLD agrees with Proposal 3 to include specific conditions only in the Bill and disagrees with Proposals 1 and 2.

We are concerned at the prospect of learning disability being subsumed into the terminology of ‘neurodivergence’. We believe this would be contrary to an established identity in Scotland, and the UK¹².

People with learning disabilities, including members of SCLD’s Include For Good Rapporteurs, have told us that ‘neurodivergence’ is not a term that they are familiar with or identify with. The Rapporteurs were also clear that they are not a homogenous group but a diverse group of individuals with many different identities, interests and needs. Not all members of the group wanted to be defined by their disability, but they did believe it was important that learning disability is visible and clearly defined in the Bill.

At the same time, for some, ‘learning disability’ has become an important and positive identity which people with a learning disability have claimed for themselves and is reflected in how public services are designed, delivered and funded in Scotland¹³. A growing number of people with learning disabilities see it as an identity to be proud of, similar to people who identify as belonging to other minority groups¹⁴.

As a minority group, people with learning disabilities experience many forms of trauma, exclusion, stigma, poor outcomes, and barriers to accessing their human rights across a whole range of issues.¹⁵

¹² GB wide history consistent with powers and focus of the EHRC are at <https://www5.open.ac.uk/health-and-social-care/research/shld/timeline-learning-disability-history>

¹³ Examples include <https://www.nhsggc.scot/hospitals-services/learning-disability-services/> and <https://www.nhshighland.scot.nhs.uk/your-services/all-services-a-z/learning-disabilities/> Also section 181 of the Health and Care Act 2022 <https://www.legislation.gov.uk/ukpga/2022/31/section/181/enacted>

¹⁴ As evidenced in the reports on the UK under the Council of Europe’s Framework Convention for the Protection of National Minorities <https://www.coe.int/en/web/minorities>

¹⁵ [The State of Our Rights, SCLD \(2023\)](#)

The mandate of the UN Special rapporteur on Minority Issues acknowledges the problems:

Minorities in all regions of the world face serious threats, discrimination and racism. They are frequently excluded from taking part fully in the economic, political and social life of their countries. Today, minority communities face new challenges, including legislation, policies and practices that may unjustly impede or even violate minority rights.¹⁶

The intersectionality of discrimination and its pernicious impact is documented by the Council of Europe which reminds us of what discrimination actually is:

“Discrimination occurs when a person is treated less favourably than other people in a comparable situation, only because they belong to or are perceived to belong to a particular group, and where such treatment cannot be objectively and reasonably justified.¹⁷

SCLD has amassed a significant amount of evidence which shows that people with learning disabilities are a population for whom rights are ‘most at risk¹⁸’ – that is, they experience more discrimination than many other people but a remedy is out of reach. This discrimination is partly due to their ‘invisibility’ as a population – their needs are not routinely considered by people who make policy, legislation, design services and agree funding¹⁹.

SCLD believes that this ‘invisibility’ would become even more entrenched if learning disability was to be encompassed within the catch all terminology of ‘neurodivergence’. This would be a policy and operational change resulting in exclusion. In our opinion, there is a real risk that it would result in people with learning disabilities (already a significantly disadvantaged group who are least able to advocate for themselves) becoming even more overlooked in decision-making and at risk of further exclusion and marginalisation.

¹⁶ <https://www.ohchr.org/en/special-procedures/sr-minority-issues>

¹⁷ <https://www.coe.int/en/web/gender-matters/intersectionality-and-multiple-discrimination>

¹⁸ [The State of Our Rights, SCLD \(2023\)](#)

¹⁹ [Fraser of Allander Institute \(2021\) Invisible no more](#)

At present, existing definitions of learning disability in Scots law are outdated and project a negative impression of people which is inconsistent with international human rights law²⁰. For example, the Mental Health (Care and Treatment) (Scotland) Act 2003 lists 'learning disability' under its definition of 'mental disorder'. Many people with learning disabilities find this stigmatising, offensive, and degrading. Their view is upheld, historically, by domestic research and international human rights law²¹.

As the consultation document recognises, the LDAN Bill presents an opportunity to establish new legal definitions for people with learning disabilities, autism and neurodivergent people.

The legislation offers an opportunity to set out definitions that are aligned with how people with learning disabilities identify and refer to themselves. SCLD believes this presents an opportunity for people with learning disabilities to enjoy a positive identity and become more visible in society and understood to be equal and enjoy the rights already set out in the Human Rights Act 1998 (HRA)²².

SCLD believes it is important that the LDAN Bill sets out who the legislation applies to and how it is equally enjoyed in line with section 14 in the ECHR on protection from discrimination which is given domestic effect through the HRA. SCLD is mindful of interpreting section 35 of the Scotland Act 1998²³ to ensure this falls within devolved competence.

We believe that a great strength of the CRPD is its rejection of a medical model of disability and its recognition of people with disabilities as active members of society who are capable of claiming their rights, making decisions about their own lives and holding duty bearers to account – the social model of disability.²⁴ SCLD are also advocates of a Human Rights Based Approach (HRBA) which seeks to remove barriers to inclusion and

²⁰ <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>

²¹ For example in 2013 <https://www.gov.scot/publications/keys-life-improving-quality-life-people-learning-disabilities/pages/4/> and in 2019 the Rome Review

https://www.researchgate.net/publication/342314047_Final_report_of_Scotland's_Independent_Review_of_Learning_Disability_and_Autism_in_the_Mental_Health_Act

²² Section 1(a) <https://www.legislation.gov.uk/ukpga/1998/42/section/1>

²³ <https://www.legislation.gov.uk/ukpga/1998/46/section/35>

²⁴ A GB wide definition for example <https://www.inclusionlondon.org.uk/about-us/disability-in-london/social-model/the-social-model-of-disability-and-the-cultural-model-of-deafness/>

include participation²⁵ in contrast to the medical model which focuses on impairment to justify why disability can serve as a barrier to full participation in civil, political, social, economic, cultural life and the right to a clean, healthy and sustainable environment which was recognised by the UN in 2022²⁶.

Therefore, SCLD believes that learning disability must be visible on the face of the LDAN Bill and that it is pivotal that the Bill includes an up-to-date definition of learning disability which is aligned with the CRPD²⁷ and the social/human rights model of disability.

SCLD believes this approach is consistent with the Concluding Observations on the UK from the UN Committee on the Rights of Persons with Disabilities, published in 2017.²⁸

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

The Include For Good Rapporteurs were clear that this up-to-date learning disability definition should be easily understood by all. The language used must be clear, free of jargon and should not require any explanation. They felt the definition needs to be a positive one rather than being deficit focussed. They also felt the definition needs to recognise the range and diversity of support needs of people with learning disabilities.

It is also pivotal that people with learning disabilities are central to discussions around the up-to-date definition of learning disability. The Include For Good Rapporteurs stressed that this process of change will take time and needs careful planning to be fully co-produced with people with learning disabilities.

The Include For Good Rapporteurs also felt it is important that the Bill retains its title of 'Learning Disability, Autism and Neurodivergence (LDAN) Bill'. They identified language as being important and felt that in this way

²⁵ 2010 SHRC at https://www.scottishhumanrights.com/media/1409/shrc_hrba_leaflet.pdf

²⁶ <https://news.un.org/en/story/2022/07/1123482>

²⁷ The CRPD defines 'persons with disabilities' as including those 'who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'.

²⁸ Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland pub 3rd October 2017.

everybody can identify themselves of the face of the Bill. Indeed, SCLD believes that the acronym LDAN has considerable power and that there is the opportunity for it to become part of the normative language in Scotland e.g. LDAN inclusive employer, LDAN training.

We also believe that there is potential for people with learning disabilities to coalesce around the LDAN term and for it to be a force for inclusion as it allows them to see where they fit into the wider spectrum both as individuals and a group similar to LGBTQI+. We do not believe this would be the case if the umbrella term used in the Bill and, subsequent policy and practice, was neurodivergence.

Key Points:

1. SCLD is concerned at the prospect of learning disability being subsumed into the terminology of 'neurodivergence'. This contradicts an existing and established national identity which is reflected in service design, delivery and funding of learning disability in Scotland and GB²⁹.
2. SCLD believes that ignoring a national identity would result in people with learning disabilities (a significantly disadvantaged group who are least able to advocate for themselves) becoming even more overlooked in decision making and at risk of further exclusion and marginalisation.
3. SCLD believes that it is pivotal that learning disability is visible on the face of the LDAN Bill and that the Bill includes an up-to-date definition of learning disability which is aligned with the CRPD and the social/human rights model of disability.
4. This up-to-date learning disability definition should be clear, easily understood, positively expressed and co-produced by people with learning disabilities.

²⁹ <https://www.legislation.gov.uk/ukpga/2010/15/contents>

5. We believe the Bill should apply to people who have a diagnosis of learning disability and those who are self-diagnosed or self-identify as having a learning disability.
6. SCLD believes that the acronym LDAN has considerable power and could be a force for inclusion similar to LGBTQI+. We see potential for people with learning disabilities to coalesce around the LDAN term as it allows them to see where they fit into the wider spectrum both as individuals and a group.

Overarching Themes

Section 1: Statutory Strategies for Neurodivergence and Learning Disabilities

What do you think?

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

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

SCLD believes that a national strategy is needed to provide a shared vision and implementation priorities that public service providers can work towards achieving. However, we are less convinced by the consultation proposal to take a broad approach covering both learning disabilities and neurodivergence.

In our view and from our experience over the last twenty years, the acknowledged identity of learning disability in Scotland and across the UK³⁰ and the particular challenges and barriers experienced by people with learning disabilities, as a population for whom rights are most at risk³¹, requires a distinct strategic policy approach.

As already discussed, we are concerned that ‘neurodivergence’ will become the predominant terminology, and moreover, the main focus of policy, strategy and service provision. People with learning disabilities are a distinct group, who are included in the guidance underpinning the UK Equality Act (2010). People with learning disabilities are recognised by the EHRC as experiencing particular discrimination with their needs often overlooked³². We believe legislating to enable the terminology of “neurodivergence” to dominate will result in people with learning disabilities

³⁰ <https://www.gov.uk/government/publications/learning-disability-applying-all-our-health/learning-disabilities-applying-all-our-health> and https://www.bih.org.uk/media/dxvh12x1/guide_mental-health-human-rights-practitioner-guide_learning-disability.pdf and <https://www.nhs.uk/conditions/learning-disabilities/> and <https://www.nhsfife.org/services/all-services/occupational-therapy/adult-learning-disabilities-occupational-therapy/>

³¹ [The State of Our Rights, SCLD \(2023\)](#)

³² <https://www.equalityhumanrights.com/media-centre/news/ehrc-taking-action-improve-treatment-disabled-benefit-claimants>

becoming increasingly invisible in policy making in Scotland and at risk of further exclusion and marginalisation.

On that basis, SCLD believes a new ten-year national Learning Disability Strategy is required in Scotland. The Bill should require the LDAN Strategy to be presented on a periodical basis to Parliament to interrogate, review and monitor its delivery independently.

We believe that there are several key elements of a successful national strategy. First and foremost, people with learning disabilities must be equal partners at every stage of strategy development from agreeing the vision to oversight of the delivery. We believe that this process should revolve around the four principles of co-commissioning, co-design, co-delivery and co-assessment.

We believe that the learning, from Scotland's most recent national strategy the Keys to Life, is that without a truly co-produced approach and buy-in from national and local stakeholders, then a national strategy will fail to have the impact or lead to the transformative change that people with learning disabilities in Scotland deserve and demand.

Furthermore, it is pivotal that the national strategy is founded on a Human Rights Based Approach which consists of Participation, Accountability, Non-discrimination and equality, Empowerment and Law.³³

Law is understood to include the Equality Act 2010, the Human Rights Act 1998 (HRA), the UN Convention on the Rights of the Child (Incorporation) (Scotland) Act 2024³⁴ as well as international human rights treaties ratified by the UK Government which are not yet incorporated into domestic law: the International Covenant on Economic, Social and Cultural Rights (ICESCR), the UN Convention on the Rights of Persons with Disabilities (CRPD), the Convention on the Elimination of All Forms of Racial Discrimination (CERD) and the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW).

³³ <https://www.scottishhumanrights.com/projects-and-programmes/human-rights-based-approach/>.

³⁴ It is noted that human rights are included in other legislation passed by the Scottish Parliament such as the Social Security (Scotland) Act 2018 sets out principles in Section 1 which includes 1(b) "social security is itself a human right and essential to the realisation of other human rights".

<https://www.legislation.gov.uk/asp/2018/9/section/1/enacted>

We believe, it is critical that the national strategy supports and re-enforces the realisation of people with learning disabilities' rights in existing domestic law as well as seeking to advance rights in the other international treaties with a particular focus on the CRPD.

Indeed, we believe the strategy should be underpinned by the CRPD and geared towards its delivery and implementation to support positive outcomes for people with learning disabilities.

We believe some key areas of focus for the strategy should include but not be restricted to:

- [Article 5 – Equality and non-discrimination](#)
- [Article 8 – Awareness-raising](#)
- [Article 12 – Equal recognition before the law](#)
- [Article 13 – Access to justice](#)
- [Article 15 – Freedom of torture or cruel, inhuman or degrading treatment or punishment](#)
- [Article 16 – Freedom from exploitation, violence and abuse](#)
- [Article 19 – Living independently and being included in the community](#)
- [Article 21 – Freedom of expression and opinion, and access to information](#)
- [Article 23 – Respect for home and the family](#)
- [Article 24 – Education](#)
- [Article 25 – Health](#)
- [Article 27 – Work and employment](#)
- [Article 28 – Adequate standard of living and social protection](#)
- [Article 31 – Statistics and data collection](#)

A successful national strategy must also be accompanied by a detailed and prioritised action plan. This action plan must support minimum core human rights obligations and include key performance indicators alongside agreed timelines and responsibilities.

There must also be agreed lines of accountability for national and local bodies' delivery of the strategy. We believe this should include a duty

within the LDAN Bill which requires all local authorities, HSCPs and other relevant bodies to report progress on all areas within the national strategy.

Furthermore, to be successful, it is critical that the national strategy and the action plan which supports strategy implementation are adequately and sustainably resourced.

It is important to note that Section 6 of the Human Rights Act 1998 includes a compliance duty on those delivering services of a public nature which includes charities and private sector delivering services. Therefore, any action plan should mirror this legal duty.

Lastly, the funding for strategy development and, critically, strategy implementation must be detailed in a realistic and costed Financial Memorandum accompanying the LDAN Bill.

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.

SCLD supports a legislative requirement for local learning disability strategies. Currently, there is no legal requirement for national or local learning disability strategies and while some Health and Social Care Partnerships (HSCPs) and other public sector organisations have a local learning disability strategy, many do not.

In our view, there is a requirement for local strategies that include how the need and outcomes of people with learning disabilities will be accounted for and met fully. In doing so, people covered by the strategies and the Bill in general should expect consistency of support and services wherever they live.

We believe local strategies should be produced and led by IJBs/HSCPs on a five-year basis. IJBs/HSCPs should take an integrated approach and engage all the providers of devolved public services such as health, housing, social work, police and education and the voluntary sector.

To achieve this in practice, there needs to be much better coordination and crossover between departments and services than exists at present. It is necessary to ensure that local learning disability strategy timescales align with external planning cycles of other agencies and services to ensure that

people with learning disabilities are not overlooked in these processes. For example, strategic housing and independent living outcomes for people with learning disabilities should align and dovetail in both local learning disabilities strategy and the Local Housing Strategy.

Furthermore, we believe some key elements that a successful local strategy should include are:

- People with learning disabilities being equal partners at every stage from agreeing the vision to oversight of the delivery.
- Existence of guidance covering a range of topics to inform local strategy development.
- A strong vision statement and focus on strategic outcomes.
- A clear crossover and link to the national strategy.
- A requirement to review local strategies on a five-year basis.

Local strategies should have a clear vision statement and lay out what the key drivers for change are to inform the development of strategic outcomes and actions to be taken forward. In 2019, SCLD published *Developing a Learning Disability Strategy: Guidance*³⁵. This document was co-produced with 12 Health and Social Care Partnerships and is a resource for HSCPs, local authorities and health boards when planning their local strategies.

We believe there should be a duty in the LDAN Bill for the Scottish Government to undertake a similar process to produce statutory guidance to inform local strategy development.

Lastly, we believe there is a requirement to introduce an accountability mechanism, potentially through a Commissioner or Commission, which has a statutory duty to review local strategies and the effectiveness of their implementation. We believe this mechanism can provide people with a route to accessing their rights and given the multiple actors with responsibility for delivering the strategy act as a designated authority.

Key points:

7. Considering the particular challenges and barriers experienced by people with learning disabilities, as a population for whom rights are

³⁵ https://www.sclld.org.uk/wp-content/uploads/2019/06/Learning-Disability-Strategy-Guidance_website_.pdf

most at risk, SCLD believes a distinct learning disability strategic policy approach and ten-year national strategy is required.

- 8.** People with learning disabilities must be equal partners at every stage of both national and local strategies.
- 9.** The national strategy should be founded on the PANEL principles, underpinned by the CRPD and geared towards its implementation.
- 10.** There is a need for a detailed, prioritised and adequately resourced action plan with agreed timelines and responsibilities.
- 11.** There is a need for agreed lines of accountability for national and local public bodies delivery of the strategy.
- 12.** The funding for strategy development and strategy implementation must be detailed in the Financial Memorandum.
- 13.** HSCPs should take an integrated approach to strategy development and engage all the providers of devolved public services.
- 14.** Local learning disability strategy timescales should align with external planning cycles of other agencies and services.
- 15.** The LDAN Bill should place a duty on the Scottish Government and partners to co-produce guidance to inform local strategy development.
- 16.** There is scope for an accountability mechanism which has a duty to review local strategies and the effectiveness of their implementation and impact. This could be a Commissioner or Commission.

Section 2: Mandatory Training in the Public Sector

Proposal 1: Mandatory Training for Public Services

What do you think?

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

Yes, SCLD supports a programme of mandatory training for public service providers in Scotland.

We believe that mandatory disability awareness training should be embedded within the public sector including health and social care, education, early years childcare, housing and criminal justice as a legal requirement. Training should also be embedded within relevant services in the voluntary and private sectors.

SCLD is clear that there is a need for greater awareness and understanding of learning disability across Scotland. The consultation document recognises this necessity, especially when people with learning disabilities, autistic people and neurodivergent people are trying to access help, support and services and to exercise their human rights.

The awareness raising duties placed on the Scottish Government under Article 8 of the CRPD include “to adopt immediate, effective and appropriate measures” which includes “Promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities.”³⁶

Article 26 of the CRPD also places duties on the Scottish Government to take effective and appropriate measures to enable people with disabilities to develop, attain and maintain maximum ability, independence and participation through the provision of appropriate services and programmes³⁷.

However, whilst awareness training is currently available to some public sector professionals, undertaking this training is optional. In addition, the training is not necessarily developed or delivered by people with lived

³⁶ https://treaties.un.org/doc/Publication/CTC/Ch_IV_15.pdf

³⁷ [UN Convention on the Rights of Persons with Disabilities](#)

experience. Furthermore, the content and quality of the training can vary between areas and services.

In England, the Health and Care Act 2022³⁸ introduced a requirement for Care Quality Commission (CQC) registered service providers to ensure their employees receive learning disability and autism training appropriate to their role. This is designed to ensure the health and social care workforce has the right skills, knowledge and understanding to provide safe, compassionate and informed care to people with learning disabilities and autistic people.

The Oliver McGowan Mandatory Training on Learning Disability and Autism³⁹ is the UK Government's preferred and recommended training for health and social care staff. The training is delivered in two tiers and the NDTi has positively evaluated both the impact of the training⁴⁰, and the process of involving people with learning disabilities and autistic people in the development and delivery of the training.⁴¹

SCLD would support a similar programme of mandatory LDAN awareness training for the health and social care workforce. The Scottish Government will need to consider how delivery of this training links with the development of the National Care Service. Furthermore, SCLD believes the mandatory training must extend to the health and social care workforce that sits within the voluntary and private sectors.

It is critical that this training is co-designed and co-delivered by people with learning disabilities. One member of SCLD's Expert Group said:

'The training must transfer the theoretical to the practical.'

Key points from the NDTi evaluation of the involvement of people with lived experience in the design and delivery of the Oliver McGowan Training in England include:

³⁸ [Health and Care Act 2022](#)

³⁹ <https://www.e-lfh.org.uk/programmes/the-oliver-mcgowan-mandatory-training-on-learning-disability-and-autism/>

⁴⁰ [Evaluation of the Oliver McGowan Mandatory Training Trial in Learning Disability and Autism - Final Report - NDTi](#)

⁴¹ [Oliver McGowan Mandatory Training Trial in Learning Disability and Autism Evaluation: Experts by experience report - NDTi](#)

- People needed the right support to participate effectively in the design of the materials. This varied from person to person.
- Having the right mix of people involved in the design process was crucial – as well as those with personal expertise of a learning disability or autism, clinical experts, training experts and family members were highly valued and considered essential.
- It is important to involve people early. Later involvement hindered people’s engagement.
- There is a need to support trainers consistently with preparation and delivery.
- There is a need to develop training skills in people with lived experience who have not delivered training.
- There is a need to invest time in developing story-sharing skills.
- There is a need to ensure equal and fair payment for all trainers.

SCLD believes the learning from the NDTi evaluation should inform the Scottish Government’s assessment of costs to develop, trial, evaluate and deliver mandatory LDAN awareness training in Scotland.

We also believe it is pivotal that the training includes content focused on human rights, an understanding of trauma informed approaches when working with people with learning disabilities as well as an understanding of Positive Behaviour Support (PBS) for people with learning disabilities who have the most complex support needs.

However, SCLD does not believe that mandatory LDAN awareness training should be restricted to health and social care settings. Indeed, we would support a wider programme of mandatory LDAN awareness training for across the public service workforce, such as police and prisons as well as early years and education sectors. People with learning disabilities currently experience systemic discrimination and human rights denials every day and we believe mandatory training could be critical in helping address this in the medium to long-term.

SCLD would urge the Scottish Government to be clear within the Bill how the mandatory training will be delivered, who it will be delivered by and how it will be resourced.

Furthermore, the funding for the design, delivery, and outcomes-based evaluation of the training must be included in the LDAN Bill's Financial Memorandum. This must include development and delivery costs, and the cost of backfilling staff time.

With development costs in mind, it is important to consider that some materials have already been developed which could be incorporated into a training programme for Scotland. This includes a series of online learning modules by NHS Education for Scotland on improving healthcare access and experiences for people with learning disabilities⁴². The Scottish Social Services Council also have a suite of online learning resources for registered social service workers⁴³ which could potentially be adapted to include content greater content on learning disability, autism, and neurodivergence.

Key points:

- 17.** SCLD supports a programme of mandatory LDAN awareness training for the health and social care workforce. This would equalise provision between Scots' and English Law.
- 18.** It is critical that this training is co-designed and co-delivered by people with learning disabilities.
- 19.** The training should include a focus on human rights⁴⁴, trauma informed approaches and an understanding of PBS.
- 20.** SCLD would support a programme of mandatory learning disability awareness training for the wider public sector workforce.

⁴² [NHS Education for Scotland | NES](#)

⁴³ [Digital learning - Scottish Social Services Council \(sssc.uk.com\)](#)

⁴⁴ It is noted that section 3 of the Scottish Commission for Human Rights Act 2006 already allows the independent SHRC to deliver human rights education, training and to "charge reasonable fees".

<https://www.legislation.gov.uk/asp/2006/16/section/3>

- 21.** Learning from the NDTi evaluation should inform the Scottish Government's assessment of costs to develop, trial and evaluate and deliver mandatory LDAN awareness training in Scotland.
- 22.** It is important to consider that some materials have already been developed which could be incorporated into a training programme for Scotland.
- 23.** The Scottish Government should be clear within the Bill how the mandatory training will be delivered, who it will be delivered by and how it will be resourced.
- 24.** Funding for design, delivery, and outcomes-based evaluation of these training programmes must be included in the LDAN Bill's Financial Memorandum.

Section 3: Inclusive Communications

What do you think?

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

Proposal 1: Alternative means of communication

Yes, SCLD believes that providing alternative means of communication is critical in supporting people with learning disabilities to make informed choices, have control over their own life and enjoy their rights. Inclusive communication includes all forms of communication, whether written, verbal or visual and refers to a whole communication environment where everyone feels included because information is provided and delivered in a way they can understand best⁴⁵.

The Equality Act (2010) makes it unlawful for public authorities and others to discriminate against 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.

Article 9 of the CPRD requires that appropriate measures be taken to identify and eliminate barriers to accessibility including information, communication and other services⁴⁶. Furthermore, Article 21 requires that all appropriate measures be 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 choice⁴⁷. The HRA give effect to Articles 10 and 14 of the ECHR, so the right to form an opinion by receiving and imparting information and ideas must be equally enjoyed. Therefore, the LDAN Bill can introduce measures to ensure this existing right is equally enjoyed.⁴⁸

⁴⁵ <https://inclusivecommunication.scot/>

⁴⁶ [UNCRPD Article 9 - Accessibility](#)

⁴⁷ [UNCRPD Article 21 – Freedom of expression and opinion, and access to information](#)

⁴⁸ The Universal Periodic review of the UK took place in November 2022 and the outcome of the review included 43:20 “Remain committed to fully implementing the European Convention on Human Rights (Germany)” pub 9th January 2023 <https://www.ohchr.org/en/hr-bodies/upr/gb-index>

SCLD supports placing a duty on public bodies to provide better access to alternative means of communication on request where the offered means of communication will not work for them. This duty should include publicising people's right to make this request and to receive accessible communication and information as per the Equality Act 2010.

However, we are also mindful that the LEAP raised the difficulty, and unfairness, of people being expected to request alternative communication, and felt that the onus should not always fall on disabled people. Therefore, we believe that there should also be a duty on health and social care professionals to ask for people's preferred method of communication at the first point of contact and for this information to be shared across settings through a 'health and social care passport' such as PAMIS digital passports.

An existing example of good practice is DES Inclusive Comms hub⁴⁹ which promote inclusion and accessibility in both its content and structure. SCLD believe there is scope for this to be further developed, promoted and funded to maximise its reach across Scotland.

SCLD would also support the LDAN Bill making provisions for an Accessible Information Standard. In England, all organisations that provide NHS care and/or publicly funded adult social care are legally required to follow an Accessible Information Standard. The Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting a wide variety of information and communication support needs.⁵⁰ SCLD believes there is a requirement for a similar Standard for public services to be enforceable in Scotland with mandatory guidance on producing accessible information and developing inclusive communication and duties for its implementation and impact to be reviewed.

In addition, SCLD believes there is potential for the proposed statutory local strategies to monitor and report on how the specific communications needs of people with learning disabilities are being met.

⁴⁹ [Home Page - Welcome to the Inclusive Communication Hub](#)

⁵⁰ [NHS England » Accessible Information Standard](#)

Proposal 2: Easy-read

Easy-read is an important means of making written information more accessible for many people with learning disabilities.

SCLD supports better access to easy-read versions of all public facing communications and documents made by public authorities.

Specifically, we believe the LDAN Bill should clarify situations where easy read versions must be available e.g. appointment letters within the NHS and primary care settings.

We would support a broad duty on public bodies to make easy-read versions 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 Police Scotland, the Scottish Courts and Tribunal Service, the Crown Office Procurator Fiscal Service and the Scottish Prison Service to automatically provide information in easy read.

However, easy-read is not a panacea in terms of inclusive communication. It is important to acknowledge that easy read is just one way of making information more accessible to people with learning disabilities. Other formats, such as Talking Mats, video or voice notes, will also help some people. For many people with learning disabilities, Zoom is more accessible than Teams and will be their preferred form of communication. Furthermore, while easy read will suit some people with learning disabilities, it will be inaccessible to others.

Therefore, SCLD believes there should be a further duty placed on public bodies to provide communication and information in a range of formats to maximise inclusivity in line with existing requirements of the Equality Act 2010.

Key Points:

- 25.** SCLD supports placing a duty on public bodies to provide better access to alternative means of communication on request. This duty should include publicising people’s right to make this request and to receive accessible communication and information.
- 26.** There should also be a duty on health and social care professionals to ask for people’s preferred method of communication at the first point of contact.
- 27.** SCLD would support the Bill making provisions for an Accessible Information Standard to be enforceable in Scotland.
- 28.** SCLD believes there is potential for the proposed statutory local strategies to monitor and report on, how the specific communication needs of people with learning disabilities are being met. This approach enables an equally consistent approach to the [Gaelic Language \(Scotland\) Act 2005](#)⁵¹ and the British Sign Language (Scotland) Act 2015⁵².
- 29.** SCLD would support a broad duty on public bodies to make easy-read versions available on request and an automatic duty to provide them in certain circumstances.
- 30.** SCLD believes there should be a further duty placed on public bodies to provide communication and information in a range of formats to maximise inclusivity in line with existing requirements of the Equality Act.

⁵¹ <https://www.gov.scot/policies/languages/gaelic/>

⁵² <https://www.legislation.gov.uk/asp/2015/11/contents>

Section 4: Data

What Do You Think?

SCLD has long advocated for improvements to data on the lives of people with learning disabilities. Article 31 of CRPD is clear that appropriately disaggregated statistics and data are imperative to ensure that legislation and policy are formulated in a way that ensures the rights of people with disabilities, including learning disabilities, are respected, protected, and fulfilled.

The importance of data gathering was identified by the UN Human Rights Council in its recommendations following the 2022 Universal Periodic Review (UPR) of the UK: “Take measures to improve data collection on gender-based violence, including disability disaggregated data when reporting such violence (Croatia)”.⁵³

Currently, the data being collected and published about the lives of people with learning disabilities in Scotland is not good enough. This situation long pre-dated COVID-19 but was brought into sharp focus during the pandemic when it became apparent that there was not adequate data on how COVID-19 was affecting people with a learning disability in Scotland.

This lack of data made it difficult to accurately report the death rate of people with learning disabilities from COVID-19 in Scotland. Furthermore, the time it took to do the required data linkage to understand the impact of COVID-19 on people with learning disabilities made it more difficult to make the case for them being prioritised for vaccines.

The pandemic illustrated the lack of routinely collected data on people with learning disabilities in Scotland. This is a systemic issue and very little has been done to address the situation since then.

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

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

⁵³ Para 43.212 <https://www.ohchr.org/en/hr-bodies/upr/gb-index>

SCLD does not believe it is necessary to wait for the LDAN Bill to create a Commission(er), or add powers to an existing commission(er), in order to better collect and look at data on people with learning disabilities. SCLD believes it is possible to strengthen current data collection procedures, to disaggregate meaningful data about people with learning disabilities in line with the requirements of the CRPD.

The Scottish Government's Chief Statistician is currently responsible for ensuring adherence to the [Code of Practice for Statistics](#) and setting Scottish standards for statistical classification, methods and reporting. SCLD believes that it is within the Scottish Government's power currently to make recommendations to – and indeed mandate - bodies collecting data to disaggregate this data to the level of individuals with learning disabilities.

This data improvement work needs to start with ensuring consistent understanding of what is meant by learning disability across data collections, increasing the ability to link this data from different surveys, including whole population surveys, to inform policymaking and strategic planning. One option that SCLD has been pushing for, is for all population surveys to include, and consistently follow, the disability and long-term health condition question from Scotland's Census 2022.

While the status quo has clearly not led to good data on people with learning disabilities, careful consideration must be given as to whether moving the responsibility for this data outside central government is advisable, or whether improvement can be made with more focussed activity within current structures.

Proposal 2: Placing duties on some relevant public bodies to collect data on neurodivergent people and people with learning disabilities

Proposal 3: Placing duties on some relevant public bodies to provide returns to the Scottish Government regarding local data on people with learning disabilities

SCLD would be supportive of placing mandatory duties on current Learning Disability Statistics Scotland (LDSS) data providers to collect and submit data about people with learning disabilities to [Public Health Scotland](#) through the LDAN Bill. However, significant investment will be required to ensure that the data being collected at local level is of good quality and fit

for purpose in relation to service planning, delivery and monitoring of outcomes. Simply mandating the re-starting of the LDSS collection in its current guise would not be worthwhile.

Importantly, consideration needs to be given as to how data from the newly implemented annual health checks is collected and utilised.

SCLD would also be supportive of placing duties on other bodies to collect data on people with learning disabilities, if this were done as part of a wider equalities data improvement project. Bodies that collect equalities data could be mandated to disaggregate their disability data by impairment type in line with the CRPD.

Pivotaly, these proposals need to be supported by significantly enhanced analytical resources. Current analytical support in this policy area is almost non-existent.

Proposal 4: Consideration of the development of a Scottish version of the LeDeR programme

SCLD is not opposed in principle to a Scottish data collection based on the *Learning from lives and deaths – People with a learning disability and autistic people (LeDeR)* programme. At its heart, the LeDeR programme is intended as a service improvement programme, designed to tackle the premature deaths of people with learning disabilities in England, which is a laudable and necessary aim. However, it is unclear whether the programme in England has led to significant improvement in health and care delivery for people with learning disabilities or had addressed the major inequalities they experience.

Critics have identified that the programme was under-resourced from its inception in 2017, with individual NHS Trusts expected to find their own reviewers, and, fundamentally, participation in the programme remaining voluntary.

Given the swingeing cuts currently taking place across health and social care in Scotland, there is a strong argument that the twofold aims of this proposal – improving data and improving mortality – could be better tackled in other ways. Firstly, through an inequalities data improvement programme as highlighted above. This must be coupled with a serious attempt to

address the systematic discrimination of people with learning disabilities in the health service, including learning from the commonly occurring themes highlighted repeatedly by the LeDeR programme in England.

Fundamentally, if a version of LeDeR is to be introduced, it must be clear in its purpose. If this is both a service improvement initiative and an authoritative data generation programme, then it must be set up and resourced adequately to pursue and fulfil both these aims. Importantly, given that this will be a significant undertaking, it must not detract from efforts to support people with learning disabilities to live loving, fulfilling lives.

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

The Lived Experience Advisory Panel (LEAP) have made some important points in relation to data, in particular the need for it to be consistent and timely. They also highlight the importance of how to collect data from GPs.

SCLD supports their view that we need to prioritise disadvantaged groups and include people with lived experience in decisions about data collection and reporting. Another salient point is that people must be able to access and hold their own data. SCLD believes that a version of PAMIS' Digital Passport, developed with a personal data store, could be key to both allowing people to access and hold their own data, but also share it with other organisations, including for statistical data collection improvement.

Key Points

- 31.** SCLD does not believe data improvement work needs to wait for a commission(er), but rather the Scottish Government can use its current powers to mandate better data collection and disaggregation.
- 32.** Such improvements should include population surveys including and consistently following the long-term health condition question from Scotland's Census.
- 33.** SCLD would be supportive of mandatory duties being placed on bodies to collect data on people with learning disabilities as part of a wider equalities data improvement programme.

- 34.** If these mandatory duties were introduced, they must be supported by significantly enhanced analytical resources.
- 35.** SCLD is not opposed in principle to the introduction of a Scottish LeDeR programme, but it must be clear in its aims and significantly resourced to achieve improved outcomes for people and national data.
- 36.** If a Scottish LeDeR programme is introduced, it must not detract from efforts to support people with learning disabilities to live loving, fulfilling lives.

Section 5: Independent Advocacy

What do you think?

Independent advocacy can support people with learning disabilities to understand and realise their economic, social and cultural rights, and empower them as rights-holders by enabling the right to participation, routes to remedy and a better understanding of rights.

Article 12 of the CRPD is clear that people with a disability have the right to support that enables them to exercise the same legal and civil rights as other people and for this right to be protected from abuse. This includes a range of formal and informal support arrangements including independent advocacy and self-advocacy.

Proposal 1: Strengthen and improve access to existing advocacy provisions

SCLD is extremely disappointed that the LDAN Bill is not proposing a broad right to independent advocacy for people with learning disabilities and would strongly encourage its inclusion in the draft Bill.

Independent advocacy, both individual and collective, has a critical role to play in supporting people with learning disabilities to be empowered to make fully informed decisions about their lives, and about policy and law making.

It can play an integral role in helping to ensure that people with learning disabilities' human rights are respected by offering access to justice on an equal and non-discriminatory basis with others in line with Article 6 of the ECHR (which is given effect by the HRA). It does this by addressing issues of autonomy and choice, and by supporting an individual's voice and opinions to be meaningfully heard.

At present, people with learning disabilities have a right to access independent advocacy under the Mental Health (Care and Treatment) (Scotland) Act 2003. However, in many parts of Scotland advocacy organisations serve multiple populations, and there are questions about their capacity, skills and experience to meet the scale and nature of demand from people with learning disabilities. In addition, some

independent advocacy organisations are limited by their funding agreements in who they can offer advocacy to.

In the context of static or reducing budgets and increasing demand, advocacy services in Scotland have faced significant pressures with organisations increasingly having to restrict and/or prioritise requests for referrals and reduce or stop awareness-raising work⁵⁴. The Scottish Independent Advocacy Alliance (SIAA) has identified people with learning disabilities as a group for whom there are gaps in provision⁵⁵.

It is our view that it is more appropriate that the right to independent advocacy for people with learning disabilities is laid out in the LDAN Bill rather than in mental health legislation. We believe there is an opportunity to establish a more streamlined system of independent advocacy in which there is greater clarity and awareness around the right to access independent advocacy and increased consistency in the nature and availability of that provision.

For these reasons, SCLD believes, independent advocacy must be a key component of a CRPD-compliant Supported Decision-Making framework for people with learning disabilities. In line with the Rome review⁵⁶ anyone with a learning disability should be automatically entitled to support from an independent advocate unless they actively choose to opt out of this.

As part of the new Supported Decision-Making landscape, independent advocacy should form part of a suite of options including:

- Specialist SDM practitioners
- Independent advocacy organisations
- Peer support
- Unpaid carers/family/friends
- Professionals

Therefore, SCLD believes that the LDAN Bill should place a duty on the Scottish Government to develop a CRPD-compliant supported decision-

⁵⁴ [A Map of Advocacy across Scotland, SIAA \(2017\)](#)

⁵⁵ [A-Stronger-Voice-SCLD-Advocacy-Report-July-2018.pdf](#)

⁵⁶ [Independent Review of Learning Disability and Autism in the Mental Health Act \(2019\)](#)

making framework, in partnership with others, and for local areas to implement this by a certain date.

It is important that the Bill is accompanied by guidance that includes standards and duties for advocacy providers. In particular, we believe there needs to be accredited, high quality training on a range of support and communication skills for independent advocates.

The Bill should place a duty on local health and social care public bodies to commission independent advocacy organisations that have the staffing capacity and skill to provide effective independent advocacy for people with learning disabilities of any age (there may be different advocacy providers for children and adults).

SCLD recognises independent advocacy is significantly underfunded in Scotland at present, despite existing statutory requirements.⁵⁷ Therefore, widening the availability and access to independent advocacy as a key feature within support for decision-making will require a significant commitment to additional funding.

It is critical that any funding proposal for the future delivery of advocacy provision is sustained over the long term, and we believe that this requires continued and strengthened duties on local authorities and health boards to fund this provision.

The funding required to enhance the level of independent advocacy provision in this way must be fully costed in the Financial Memorandum accompanying the LDAN Bill.

Proposal 2: Improve our Understanding of Independent Advocacy

What do you think?

In the context of a new human rights framework for Scotland, SCLD sees an increasing of the role of independent advocacy for people with learning disabilities and a strengthening of the role of collective advocacy with a view to preventing court actions.

⁵⁷ [SCLD \(2018\) A Stronger Voice? A scoping study of independent advocacy for people with learning disabilities](#)

We are supportive of the call by SIAA and the Human Right Consortium Scotland (HRCS) for independent advocacy to be embedded as a core part of the overarching statutory framework⁵⁸ in which:

- There is a right to independent advocacy in Scotland in law.
- There are duties on relevant duty-bearers to provide the service and to provide information about the service to rights-holders.
- Independent advocacy is a core part of non-court and court routes to remedy.
- Independent advocacy is adequately and sustainably resourced.
- There is a public awareness raising about independent advocacy.
- There is a requirement on Scottish Ministers to include reporting in availability of independent advocacy.

SCLD believes, the LDAN Bill should stipulate that independent advocacy is available to people with learning disabilities to help them claim or defend their human rights under the HRA and acknowledge that those existing rights are amplified in the [CRPD](#). SCLD believes that advocacy provision should relate to all areas of people's lives and not be restricted to housing and gender-based violence.

Key Points:

- 37.** SCLD is disappointed that the LDAN Bill is not proposing a broad right to independent advocacy for people with learning disabilities.
- 38.** Independent advocacy must be a key component of a CRPD-compliant Supported Decision-Making framework for people with learning disabilities. The LDAN Bill should place a duty on the Scottish Government to develop this framework, and for local areas to implement this by a certain date.
- 39.** The Bill should place a duty on local health and social care public bodies to commission independent advocacy organisations that have

⁵⁸ [Putting independent advocacy at the heart of the new human rights statutory framework in Scotland \(HRCS & SIAA\)](#)

the staffing capacity and skill to provide effective independent advocacy for people with learning disabilities.

- 40.** Any funding proposal for the future delivery of advocacy provision must be sustained over the long term and we believe that this requires continued and strengthened duties on local authorities and health boards to fund this provision.
- 41.** The funding required to enhance the level of independent advocacy provision in this way must be fully costed in the Financial Memorandum accompanying the LDAN Bill.
- 42.** The LDAN Bill should stipulate that independent advocacy is available to people with learning disabilities to help them claim or defend their human rights under the HRA and acknowledge that those existing rights are amplified in the CRPD.
- 43.** Advocacy provision should relate to all areas of people's lives and not be restricted to housing and gender-based violence.

Part 3 – Specific Themes

Section 1 Health and Wellbeing

What do you think?

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

The health outcomes for people with learning disabilities are amongst the poorest for anyone living in Scotland.

Best evidence suggests that people with learning disabilities die 20 years earlier than the general population.⁵⁹ The figures in regard to childhood premature mortality are equally concerning, with a study by the Scottish Learning Disability Observatory (SLDO) finding that premature mortality from preventable illnesses is 12 times higher for children and young people with learning disabilities, compared to other children and young people.⁶⁰ For girls and young women, risk of death is 17 times higher than their non-disabled peers. The same research also found that treatable conditions contributed to many deaths, and some premature deaths were potentially preventable.

It is notable that given these findings the Scottish Government made £2 million available to HSCPs to support the delivery of annual health checks for people with a learning disability. SCLD was pleased to note that some local areas have started offering these checks. For those HSCPs that were slower at implementing this, a deadline of 31 March 2024 was set. Overall, however, implementation of these potentially life-saving checks has been delayed and while a standardised check is being utilised, the implementation approach varies between and within some local health board areas.

Despite this positive step, people with learning disabilities are still facing poor health outcomes which were exacerbated during the COVID-19

⁵⁹ [The Keys to Life: Implementation framework and priorities 2019-2021 \(www.gov.scot\)](https://www.gov.scot)

⁶⁰ [Avoidable deaths in children and young people with learning disabilities in Scotland | Our research | Scottish Learning Disabilities Observatory \(sldo.ac.uk\)](https://www.sldo.ac.uk)

pandemic. At the height of the pandemic, people with learning disabilities experienced significantly higher death rates from COVID-19 than the general population.⁶¹ Data from Scotland⁶² shows that people with learning disabilities were at least three times more likely to die from COVID-19 than the general population. For individuals with Down's Syndrome the figure was 4 times more likely to be hospitalised and 10 times more likely to die from COVID-19 than the general population.⁶³

Another significant source of anxiety for people with learning disabilities at the height of the COVID-19 pandemic was clinical decision-making in relation to access to life-saving medical interventions and the wholly inappropriate use of the Clinical Frailty Scale for people with learning disabilities.

During the initial stages of the pandemic, we know that people with learning disabilities and their families were engaged in conversations about Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) notices. In other cases, these notices were found to have been added to case notes without discussion.⁶⁴ The Scottish Parliament's Equality and Human Rights Committee⁶⁵ and the House of Commons Health and Social Care Committee⁶⁶ acknowledged that although there was never national NHS guidance for applying DNACPR notices to people with learning disabilities, notices were issued inappropriately for some individuals, thus infringing their Right to Life⁶⁷. This issue was prioritised and discussed by SCLD's Chair when he recently gave oral evidence to the Scottish COVID-19 Inquiry⁶⁸ regarding the experiences of people with Down's Syndrome and their families during the Pandemic.

⁶¹ [COVID-19: deaths of people with learning disabilities - GOV.UK \(www.gov.uk\)](https://www.gov.uk)

⁶² [COVID-19 infection and outcomes in a population-based cohort of 17,173 adults with intellectual disabilities compared with the general population | medRxiv](#)

⁶³ [COVID-19 Mortality Risk in Down Syndrome: Results From a Cohort Study of 8 Million Adults | Annals of Internal Medicine \(acpjournals.org\)](#)

⁶⁴ [Do not resuscitate orders and learning disability: where are we now? - Learning Disability Today](#)

⁶⁵ [Report on the impact of the COVID-19 pandemic on equalities and human rights \(azureedge.net\)](#)

⁶⁶ [Coronavirus: lessons learnt \(parliament.uk\)](#)

⁶⁷ [Universal Declaration of Human Rights | United Nations](#)

⁶⁸ [Impact hearing | Health and social care | 14 March 2024 \(morning session\) \(youtube.com\)](#)

As one parent/carer stated to SCLD's COVID-19 survey (2020)⁶⁹:

“Underneath all that is fear: fear of losing him to the virus if he got it – fear of death; fear of challenges to nursing him as he would be so frightened in the main hospital, he wouldn't tolerate an IV drip or a mask; fear of the virus causing damage to his lungs, the heart if he got it badly...”

Given these shocking statistics and experiences, SCLD welcomes the Scottish Government's inclusion of the commitment to improve access to good health care services and support across Scotland in relation to Health and Wellbeing in Section 1 of the Consultation.

The Right to Life is of primary and fundamental importance to everyone, and especially people with learning disabilities who have experienced such significant rights abuses. It could be argued that it is the human right on which all others human rights are built.

SCLD is actively involved in a number of the policy development processes highlighted in this section of the Consultation and has supported a significant number of people with learning disabilities in their engagement with them. These include:

- The National Care Service
- Suicide Prevention Strategy
- Mental Health and Wellbeing Strategy
- Mental Health Law Reform

Much more work is required on each of these to ensure that they fully address the human rights of people with learning disabilities and this will require resource to ensure the meaningful engagement of individuals in them.

SCLD has a growing concern that the current financial challenges faced by the Scottish Government and Scottish public authorities will be used as a reason not to either engage people with learning disabilities or develop solutions which could respect, protect and fulfil people with learning

⁶⁹ [SCLD-Coronavirus-Report-FINAL.pdf](#)

disabilities' right to the highest attainable level of physical and mental health⁷⁰.

All too often we hear that there is no funding available when we know that current funding is used to maintain people with learning disabilities in unacceptable situations. Whilst we accept that there are considerable challenges with regard to the availability of new funding, the more creative and flexible use of existing funding could deliver massive changes to people with learning disabilities' lives.

The recent report by ITV news regarding detention in hospital in England evidences this point⁷¹; the report makes the point that in one area the money used to pay for one out of area hospital placement has been used to fund a community-based emergency response team which has prevented 50 people with learning disabilities and/or autism being admitted to hospital in a one-year period. This is unlikely to be significantly different for people in Scotland.

Furthermore, SCLD believes that it is essential that all health policy development should consider the rights and requirements of people with learning disabilities.

With regard to the specific proposal made in this section we have responded to each one in turn:

National and Local Strategies – SCLD is supportive of these and has detailed our response to this under the Overarching Themes part of this response. Please see Page 12 - 17 and Key Points below.

Mandatory Training for Health and Social Care Staff - SCLD is supportive of these and has detailed our response to this under the Overarching Themes part of this response. Please see Page 18 - 21 and Key Points below.

More Accessible Communications - SCLD is supportive of these and has detailed our response to this under the Overarching Themes – Inclusive

⁷⁰ [International standards on the right to physical and mental health | OHCHR](#)

⁷¹ [Millions spent on keeping adults with learning disabilities locked up, ITV News reveals | ITV News](#)

Communications part of this response. Please see Page 22 - 25 and Key Points below.

Annual Health Checks – As detailed earlier in this section, SCLD is supportive of this development and is monitoring the role out of the annual health checks on an ongoing basis. We will be especially interested to find out if those HSCPs which were slower at implementing this have progressed it following the passing of the 31 March 2024 deadline.

Further consideration needs to be given regarding how this preventative approach can be enhanced. All health promotion activities including relationships, sexual health and parenting education must be available to everyone with learning disabilities.

SCLD believes that health and wellbeing are of such importance for people with learning disabilities it should be one of the key accountability functions detailed in the LDAN Bill. The responsibility for this might lie with a new Commission, a new Commissioner or indeed with existing Commissions through giving them additional powers. However, the priority must be to ensure that public bodies are held to account for ensuring improvements in access to health and in personal experiences of health care journeys to address Scotland's unacceptable track record on this issue.

Accessible Communication Passports – SCLD is supportive of this proposal and has long been an advocate of accessible health passports. We are very supportive of the work done by PAMIS⁷² and *mycompass*⁷³ in this area and have highlighted our support in the section dealing to this under the Overarching Themes – Inclusive Communications and Data part of this response. Please see Page 22 – 25, page 30 and Key Points below.

⁷² [PAMIS Digital Passports | PAMIS](#)

⁷³ [My Communication Passport \(mycompass.com\)](#)

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

The importance of the right to physical and mental health for people with learning disabilities cannot be underestimated. Without health people find the enjoyment of all other human rights limited to a greater or lesser extent.

We know that health outcomes for people with learning disabilities are amongst the worst for any group of people in Scotland. The premature and avoidable deaths of people with learning disabilities is a persistent and serious concern which needs to be prioritised across all Scottish Health Services.

One other key consideration is that so much of the health response in Scotland is crisis led by acute services. For people with learning disabilities, investment in their health and wellbeing on a preventative basis (similar to the annual health checks outlined in the consultation) must be enhanced if people are to be well enough to live the life they choose.

Key Points:

Local and National Strategies

- 44.** Considering the particular challenges and barriers experienced by people with learning disabilities, as a population for whom rights are most at risk³⁰, SCLD believes a distinct learning disability strategic policy approach and ten-year national strategy is required.
- 45.** People with learning disabilities must be equal partners at every stage of both national and local strategies.
- 46.** The national strategy should be founded on the PANEL principles, underpinned by the CRPD and geared towards its implementation.
- 47.** There is a need for a detailed, prioritised and adequately resourced action plan with agreed timelines and responsibilities.
- 48.** There is a need for agreed lines of accountability for national and local public bodies delivery of the strategy.

- 49.** The funding for strategy development and strategy implementation must be detailed in the Financial Memorandum.
- 50.** HSCPs should take an integrated approach to strategy development and engage all the providers of devolved public services.
- 51.** Local learning disability strategy timescales should align with external planning cycles of other agencies and services.
- 52.** The LDAN Bill should place a duty on the Scottish Government and partners to co-produce guidance to inform local strategy development.
- 53.** There is scope for an accountability mechanism which has a duty to review local strategies and the effectiveness of their implementation and impact. This could be a Commissioner or Commission.

Mandatory Training

- 54.** SCLD supports a programme of mandatory LDAN awareness training for the health and social care workforce.
- 55.** It is critical that this training is co-designed and co-delivered by people with learning disabilities.
- 56.** The training should include a focus on human rights, trauma informed approaches and an understanding of PBS.
- 57.** SCLD would support a programme of mandatory learning disability awareness training for the wider public sector workforce.
- 58.** Learning from the NDTi evaluation⁷⁴ should inform the Scottish Government's assessment of costs to develop, trial and evaluate and deliver mandatory LDAN awareness training in Scotland.

⁷⁴ [Evaluation of the Oliver McGowan Mandatory Training Trial in Learning Disability and Autism - Final Report - NDTi](#)

59. It is important to consider that some materials have already been developed which could be incorporated into a training programme for Scotland.
60. Funding for design, delivery, and outcomes-based evaluation of these training programmes must be included in the LDAN Bill's Financial Memorandum.

Inclusive Communications including Accessible Communications and Communications Passports

61. SCLD supports placing a duty on public bodies to provide better access to alternative means of communication on request. This duty should include publicising people's right to make this request and to receive accessible communication and information.
62. There should also be a duty on health and social care professionals to ask for people's preferred method of communication at the first point of contact.
63. SCLD would support the Bill making provisions for an Accessible Information Standard to be enforceable in Scotland.
64. SCLD believes there is potential for the proposed statutory local strategies to monitor and report on how the specific communication needs of people with learning disabilities are being met.
65. SCLD would support a broad duty on public bodies to make easy-read versions available on request and an automatic duty to provide them in certain circumstances.
66. SCLD believes there should be a further duty placed on public bodies to provide communication and information in a range of formats to maximise inclusivity in line with existing requirements of the Equality Act.

Annual Health Checks

- 67.** Annual Health Checks programme to continue to be funded and delivered nationally.
- 68.** Monitoring data relating to the implementation of Annual Health Checks for people with learning disabilities following the 31st March 2024 deadline should be published as soon as possible.
- 69.** All health promotion activities and services must be developed to ensure their accessibility to people with learning disabilities in line with the requirements of the Equality Act 2010.
- 70.** Health and wellbeing are of such importance for people with learning disabilities they must be one of the key accountability functions detailed in the LDAN Bill for a new accountability structure.

Section 4: Housing and Independent Living

What do you think?

Housing plays an integral role in ensuring that people with learning disabilities can lead full, healthy, and productive lives in their communities.

In 2021, the Scottish Government produced Housing to 2040 which sets out a vision for housing in Scotland and a route map to get there by 2040. *“It aims to deliver the ambition for everyone to have a safe, good quality and affordable home that meets their needs in the place they want to be.”*⁷⁵ A Housing Bill from the Scottish Government is promised in 2024.⁷⁶

In 2023, the Scottish Government issued a consultation on a Human Rights Bill which proposes to incorporate the International Covenant on Economic, Social and Cultural Rights (ICECSR) including a duty on the Scottish Government to progressively realise to the maximum extent of its available resources, under Article 2, and the right to housing, food and clothing under Article 11.

However, at present people with learning disabilities continue to face barriers to accessing suitable housing and housing support. Furthermore, many people are denied choice about where they live, who they live with and the support they receive⁷⁷.

Article 19 of the CRPD⁷⁸ enshrines the *“equal right of all persons with disabilities to live in the community, with choices equal to others”* and obliges the Scottish Government to ensure people with disabilities *“have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement”*.

However, although the CRPD gives disabled people the right to live independently and have choice and control over the decision-making process, for many people with learning disabilities in Scotland this is not the

⁷⁵ <https://www.gov.scot/publications/housing-2040-2/>

⁷⁶ [Programme for Government Statement, September 2023.](#)

⁷⁷ [Ipsos MORI \(2017\) Opportunities and Challenges for Housing](#)

⁷⁸ [UN Convention on the Rights of Persons with Disabilities \(CRPD\)](#)

reality and housing and independent living remain critical human rights issues.

The Equalities and Human Rights Commission (EHRC) have highlighted that home is a human right and is a gateway to all our rights: *“Human rights have special significance in relation to social housing. Quality of housing can have a huge impact on wellbeing. Inadequate housing increases the risk of severe ill health and disability; it can also lead to poor mental health, lower educational attainment, unemployment and poverty.”*⁷⁹

Whilst the Human Rights Act 1998 (HRA) does not provide the right to a house, Article 8 does set out the right to respect for private and family life, home and correspondence and that right should be enjoyed equally under Article 14.⁸⁰

Furthermore, the Scottish Housing Regulator’s Regulatory Standards apply to Registered Social Landlords (RSLs) and require that each landlord must *‘Have assurance and evidence that it considers equality and human rights issues properly when making all of its decisions, in the design and review of internal and external policies, and in its day-to-day service delivery.’*⁸¹

Scotland’s second National Action Plan on Human Rights (SNAP 2) was launched in March 2023⁸² and is the second strategic initiative to mainstream human rights delivery across Scotland with housing featuring thirty-two times.⁸³

Yet despite all the above policies and legal architecture, people with learning disabilities in Scotland continue to face barriers to accessing accessible, affordable and sustainable housing which meets their individual needs⁸⁴. Overcoming these barriers is crucial to people with learning

⁷⁹ 2011 https://www.equalityhumanrights.com/sites/default/files/human_rights_at_home.pdf

⁸⁰ This duty is set out in Article 1 of the ECHR which is not included in the HRA but there is a duty on Scottish Government to comply with the ECHR under Section 57 of the Scotland Act 1998.

⁸¹ <https://www.housingregulator.gov.scot/for-landlords/regulatory-framework/#>

⁸² <https://www.snaprights.info/>

⁸³ The independent SNAP 2 Secretariat has now moved into the Directorate for Equality, Inclusion and Human Rights within the Scottish Government.

⁸⁴ [Ipsos MORI \(2017\) Opportunities and Challenges for Housing](#)

disabilities' full and equal enjoyment of their human rights including the right to live independently in the community.

SCLD believes the following proposals have a part to play in improving housing outcomes and making the right to independent living a reality for people with learning disabilities.

Proposal 1: Advice, advocacy and guidance

SCLD strongly supports the development of housing advice for people with learning disabilities. We have strong evidence that people with learning disabilities require access to good-quality, accessible advice and advocacy to help them understand their options and be supported to make informed choices⁸⁵.

In our view, specialist housing advice services must take personalised approach, exploring all tenure options and considering people's wider personal circumstances and support needs alongside their accessible housing needs. Housing advice professionals must have the skills and knowledge to help and support people with learning disabilities in securing positive housing and independent living outcomes.

It will be essential that people with learning disabilities know where and how to access any housing advice, advocacy and guidance service, and that these services are designed to be fully accessible and inclusive. In addition to this, we believe housing allocations and adaptations processes should be streamlined and made easier for people with learning disabilities and their families to navigate in the first place.

SCLD also believes that an independent advocacy service can play a critical role in supporting people with learning disabilities to understand their human rights to good housing and independent living. Furthermore, it can help people with learning disabilities to have effective routes to redress when their rights have not been respected.

If adequately resourced, SCLD believes the provision of housing advice, advocacy and guidance could help ensure that people with learning

⁸⁵ [Ipsos MORI \(2017\) Opportunities and Challenges for Housing](#)

disabilities are empowered to access their rights and make choices around their housing options on an equal basis to others.

The funding for this must be detailed in the Financial Memorandum accompanying the LDAN Bill.

Proposal 2: Neurodivergence and learning disabilities strategies

SCLD supports the development of local learning disabilities and neurodivergence strategies which require local authorities to report on how independent living principles are embedded into assessment and allocation policies.

Making independent living a reality for all requires housing options for people with learning disabilities to be accessible, affordable, sustainable, and to meet individuals' varying needs. Furthermore, achieving suitable housing and support solutions must be determined through a person-centred approach and it is pivotal that people with learning disabilities have genuine choice and control in the allocations processes.

SCLD believes that local learning disabilities and neurodivergence strategies can provide a framework for the delivery of independent living for people with learning disabilities and evaluate progress against this.

They should also link in with the delivery of local strategies at a health and social care level. Indeed, independent living is not only a housing issue. We believe a much greater degree of co-operation is required between local authorities and HSCPS to ensure that people's housing, care and support needs are considered together. SCLD believes that the LDAN Bill should require local authorities and HSCPs to plan together on independent living for people with learning disabilities.

Furthermore, we believe it is critical that local learning disabilities and neurodivergence strategies link into Local Housing Strategies (LHS). The Scottish Government Local Housing Strategy guidance (2019) states it wants everyone to *“have a good quality home that they can afford and that meets their needs.”* LHS can play a key role in delivering against these priorities, supporting equality and place-making, informing housing

investment and service delivery and ensuring the delivery of the right homes in the right places.⁸⁶

However, SCLD believes that LHS must better evaluate the needs and preferences of people with learning disabilities and measure progress against these. We are concerned by the lack of choice and restriction on independent living which results from persistent challenges around the supply, availability, and accessibility of housing⁸⁷.

Furthermore, Housing Needs Demands Assessments (HNDAs) which feed into Strategic Housing Investment Plans (SHIPs) must be based on better data about people with learning disabilities requirements, to provide a stronger evidence base for an increase in the supply of accessible housing across Scotland. Furthermore, we would like to see at duty on local authorities to explicitly include plans for housing for people with learning disabilities within their SHIPs.

SCLD believes that local learning disabilities and neurodivergence strategies, and other local planning mechanisms require additional resources to enable all people with learning disabilities to realise their right to adequate housing and independent living.

Proposal 3: Mandatory training for housing professionals

As stated in an earlier section, SCLD believes that there needs to be greater awareness and understanding of learning disability across Scotland. This awareness and understanding by professionals can be crucial when people with learning disabilities are trying to access help, support and services and to exercise their human rights.

The awareness raising duties placed on the Scottish Government under Article 8 of the CRPD include *“to adopt immediate, effective and appropriate measures”* which includes *“Promoting awareness-training*

⁸⁶ [Scottish Government \(2019\) Local Housing Strategy Guidance](#)

⁸⁷ Expressing a preference and being heard engages the ECHR at Article 9, freedom of thought, conscience and religion, and Article 10, the right to form an opinion by receiving and imparting information and ideas.

*programmes regarding persons with disabilities and the rights of persons with disabilities.*⁸⁸

Article 26 of the CRPD places duties on the Scottish Government to take effective and appropriate measures to enable people with disabilities to develop, attain and maintain maximum ability, independence and participation through the provision of appropriate services and programmes⁸⁹.

In a housing context, we believe it is essential that people with learning disabilities get the appropriate support they need to make their human right to good housing and independent living a reality. We see a role for mandatory training to help housing professionals understand the housing and support needs of people with learning disabilities.

At the same time, it is important that housing professionals understand that people with learning disabilities are not a homogenous group but rather a diverse population of individuals who face particular challenges and barriers. Their housing requirements are impacted by a multitude of factors including individual preferences, age, support requirements and composition of their household.

SCLD believes that any mandatory training must be delivered in a way that reflects people with learning disabilities' diversity while also recognising them as a group who continue to need support to assert their right to independent living.

Indeed, SCLD believes that housing professionals must work in partnership to deliver suitable housing and support solutions by understanding what individuals with learning disabilities need to live their own life, and securing housing, care and support based on those needs. We are clear that there is no 'one size fits all' solution.

We believe there is a need for a more person-centred, cost-effective adaptations process which combines joint working between housing agencies, occupational therapists and health and social care staff, and

⁸⁸ https://treaties.un.org/doc/Publication/CTC/Ch_IV_15.pdf

⁸⁹ [UNCRPD, Article 26 - Habilitation and Rehabilitation](#)

enables more adaptations to be carried out which are appropriately tailored to individuals' needs.

Proposal 4: Data

SCLD believes that improved data at a national and local level is also critical. There is currently a lack of reliable data on the needs and preferences of people with learning disabilities to inform the Local Housing Strategy which set out local authority priorities.

We are concerned that local authorities frequently rely on a weak evidence base for assessing people's needs for accessible housing and related services.

SCLD is concerned about the lack of an up-to-date, large-scale data source that would facilitate more detailed assessment of people with learning disabilities' housing circumstances, needs and preferences. At present, there are significant gaps:

- Nationally collated data on the numbers of people on housing waiting lists is not disaggregated by disability.
- There is no current publicly available data on the use of housing support by people with learning disabilities.
- There is a dearth of data on whether the current housing circumstances of people with learning disabilities matches their preferences and aspirations.

SCLD believes it is necessary to improve data collection to inform projections about future demand for adaptations and new supply of both mainstream and specialist housing.

We believe improved data at a national and local level would facilitate more detailed assessment of people with learning disabilities' housing circumstances, needs and preferences. This fits with the existing duty on the Scottish Government to deliver Article 31 of the CRPD which focuses on data gathering:

- To collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention.
- To disaggregate, as appropriate, and use to help assess the implementation of their obligations under the CRPD and to identify and address the barriers faced by persons with disabilities in exercising their rights.
- To assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.⁹⁰

Key Points:

71. Despite a raft of policies and laws, people with learning disabilities face barriers to accessing housing which meets their needs.

72. Many people lack the necessary support to live independently and are denied choice about where they live and who they live with.

73. SCLD supports the development of specialised housing advice for people with learning disabilities which is accessible, person-centred and supports people to make choices on an equal basis to others.

74. An independent advocacy service can support people to understand their rights to good housing and independent living and help them to have effective routes to redress when their rights have not been respected.

75. SCLD supports the development of local learning disabilities and neurodivergence strategies which require local authorities to report on how independent living principles are embedded into assessment and allocation policies.

⁹⁰ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-31-statistics-and-data-collection.html>

- 76.** SCLD believes that the LDAN Bill should require local authorities and HSCPs to plan together on independent living for people with learning disabilities.
- 77.** SCLD is concerned by the lack of choice and restriction on independent living which results from persistent challenges around the supply, availability, and accessibility of housing.
- 78.** LHS must better evaluate the needs and preferences of people with learning disabilities and measure progress against these.
- 79.** It is important that housing professionals understand that people with learning disabilities are not a homogenous group but rather a diverse population of individuals who face particular challenges and barriers.
- 80.** Professionals must work in partnership to deliver suitable housing and support solutions by understanding what individuals with learning disabilities need to live their own life, and securing housing, care and support based on those needs.
- 81.** Improved data at a national and local level is critical to facilitate more detailed assessment of people with learning disabilities' housing circumstances, needs and preferences.

Section 5 - Complex Care – Coming Home

What do you think?

People with learning disabilities and complex needs who are living in out-of-area placements or in hospital settings without clinical need are being denied the right to an adequate home (Article 11, ICESCR), as well as the right to living independently (Article 19, CRPD), and in some cases their right to liberty (ECHR, Articles 5 and 14, CRPD, Article 14)⁹¹.

Article 19 of the CRPD⁹² enshrines the “*equal right of all persons with disabilities to live in the community, with choices equal to others*” and requires the Scottish Government to ensure people with disabilities including people with learning disabilities “*have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement*”.

SCLD believes that legislative measures in the LDAN Bill can engender greater accountability at a local and national level so that people with learning disabilities who have complex needs are supported to live independent lives in the community.

People with learning disabilities and complex needs require support to access their right to an adequate home and support which keeps them safe, meets their needs, promotes their well-being, and ensures they are not at risk of becoming isolated, invisible and vulnerable to abuse in institutional settings.

To that end, it is essential that people with learning disabilities who have complex care needs are supported by high quality services which enable them to lead the lives they want in their local area with support from family and the wider community. Furthermore, suitable housing and support solutions must be determined through a person-centred approach by

⁹¹ [State of our rights \(2023\)](#)

⁹² [UN Convention on the Rights of Persons with Disabilities \(CRPD\)](#)

listening to what each individual needs to live their own life and building housing, care and support based on those needs.

SCLD believes that in addition to the consultation proposals, the LDAN Bill should include a mandatory duty for HSCPs and local authorities to have a joint plan, as part of their local strategies, for moving people with learning disabilities and complex needs out of delayed discharge situations and out-of-area placements and into their own homes in their communities.

Furthermore, they should be required to demonstrate their plans and report on these on an annual basis to evidence their progress.

We also believe that increased resources are required to support local areas to provide suitable houses and accommodation and support when people with learning disabilities and complex needs are discharged from hospital.

The will and preferences of people with learning disabilities and complex needs must be at the heart of the decision-making process, in line with Supported Decision Making, as well as through consultation with their families and supporters.

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?

SCLD believes it is critical that local areas are required to keep accurate and up-to-date data on people with learning disabilities and complex needs who are in hospital, those who are in an out-of-area placement or at risk of placement breakdown.

We believe the Dynamic Support Register (DSR) is a crucial mechanism to ensure we no longer have a situation in Scotland where people are made invisible by the system. When the Coming Home report was published in 2018 it was difficult for HSCPs to know where people with learning disabilities and complex needs were. Many people had been in out-of-area placements and hospital for many years and were out of sight and forgotten.

SCLD is supportive, therefore, of the consultation proposal to strengthen the existing DSR through the LDAN Bill. We believe the LDAN Bill should place a duty on NHS Boards, HSCPs/IJBs, local authorities, and the State Hospital to maintain a DSR, and to report data from it to Public Health Scotland (PHS) to be published.

SCLD believes that this will help to ensure that there is increased visibility for people with learning disabilities and complex care and give a more accurate picture of the nature of institutionalisation in Scotland. We believe that the availability of this data at a national level can serve to influence government policy and strengthen the voice of people with learning disabilities and complex needs in Scotland who have been ignored and invisible for too long.

At a local level, the DSR will also be critical in monitoring the particular situation of individuals with learning disabilities and complex needs who are in hospital or in an out-of-area placement. It will support planning around the actions and measures which are required to enable these individuals to live in a home and community of their choice.

For example, a key feature of the DSR is the fortnightly Register review meetings which are multi-disciplinary and should be attended by the individual, if possible, and their family and/or carers. The purpose of the meeting is to discuss blocks in the system and look for potential solutions. In this way, SCLD believes that the DSR has real potential to be a mechanism for increasing accountability and requiring local areas to take specific action.

However, at present there are differences in how the DSR is being implemented across Scotland. Furthermore, we have heard that where services are commissioned for individuals, providers are often not aware that someone is on the DSR. SCLD believes more clarity and transparency is needed around who is required to attend Register Review meetings.

SCLD believes that the mandatory powers and accompanying guidance and safeguards that would result from a statutory footing for the DSR could

provide this operational clarity. Furthermore, they could provide greater authority for the DSR, increasing the profile and accountability at a local level as well as helping to ensure that a consistent approach is taken across Scotland.

Finally, SCLD believes that a legislative footing for the DSR should ensure that it is intrinsically linked with the National Support Panel to guarantee effective oversight and increased accountability for people with learning disabilities and complex needs who continue to have their human rights denied.

Which of the options for the National Support Panel (Proposal 2) do you think has the most benefits?

SCLD believes there must be full accountability for people with learning disabilities and complex care needs to ensure the delivery of high-quality, person-centred support and housing by those who have a duty to provide them.

We are supportive, therefore, of the Scottish Government's proposal for a National Support Panel designed to ensure that local areas can be held accountable for delivering this person-centred support and housing for people with learning disabilities and complex needs.

SCLD believes there are advantages in both a legislative panel conducting individual reviews (Option A) and a legislative panel conducting peer reviews of local processes (Option B).

We believe that the particular strengths of Option A are that it would be an oversight panel with a national perspective on the Register focusing on individuals whose situation is identified as 'Red.' It would have the power to review individual cases and data and could offer support and share good practice. It would also have the ability to hold people to account, require information and evidence from public bodies and make recommendations with mandatory powers. SCLD believes that this would give the individual review panel real 'teeth'.

The downside of this model is that while the panel would have powers to investigate individual cases, in practice it is likely that only a small number of people with a learning disability and complex care needs would get an individual review. However, all local areas could use the learning from the case reviews to improve the experience of other people with learning disabilities and complex care needs.

Alternatively, we see the particular strengths of Option B as having the ability to Peer Review local systems and processes and crucially the power to require local areas by law to make the recommendations from the Peer Review happen. This could include recommendations around a wide range of issues including commissioning appropriate accommodation and services, securing and financing support packages and identifying suitable support providers. It could also concern the support plans of people with learning disabilities and complex needs or any issues or concerns such as the use of restraint and/or high levels of behaviours perceived as challenging.

However, on balance SCLD believes that Option A, an individual review panel, is preferable. We believe that an exclusive focus on systems and processes is potentially shortsighted and is likely to dehumanise the problem. There is a need to focus on people and the creative and bespoke solutions and particular input that they require to live independent lives in the community.

We would, however, caution against the long-term desirability of establishing separate accountability structures for people with learning disabilities and complex needs. We believe in the medium term there could be potential for a hybrid model, with a panel that does individual reviews and area reviews, to be accommodated within a new or existing Commission or other regulatory body.

Key Points:

- 82.** SCLD is concerned that people with learning disabilities and complex needs who are living in institutional settings without clinical need are being denied basic human rights.
- 83.** LDAN Bill should place a duty on local public bodies to have a plan to move people into their own homes in their communities and to report on these annually to evidence progress.
- 84.** Increased resources are required to support local areas to provide suitable homes and support to enable people to live independent lives in the community.
- 85.** The will and preferences of people with learning disabilities and complex needs must be at the heart of decision-making.
- 86.** A statutory duty for the Dynamic Support Register will help to ensure that there is visibility for people with learning disabilities and help to influence government policy.
- 87.** At a local level, the Register will also be critical in monitoring the number of individuals who are in hospital or in an out-of-area placement and supporting planning to enable them to live in a home and community of their choice.
- 88.** Mandatory powers for the DSR could increase accountability at a local level as well as helping to ensure that a consistent approach is taken across Scotland.
- 89.** A legislative footing for the DSR should ensure that it is intrinsically linked with the National Support Panel to guarantee effective oversight and increased accountability.
- 90.** SCLD believes that Option A, an individual review panel is preferable. We believe that an exclusive focus on systems and processes dehumanizes the problem. There is a need to focus on people and the bespoke solutions they require.

91. SCLD would caution against the long-term desirability of establishing separate accountability structures for people with learning disabilities and complex needs. We believe in the medium term there could scope for a hybrid model to be accommodated within a new or existing Commission.

Section 8 – Employment

What do you think?

Do you agree with this approach?

SCLD disagrees with the Scottish Government’s assessment that there are no legislative measures that can usefully be included in the LDAN Bill to enhance the employment opportunities of people with learning disabilities.

SCLD believes that employment must a priority area for the LDAN Bill to address given the huge inequalities that exist at present. Employment has a pivotal role to play in enabling people with learning disabilities to live full lives as active citizens contributing to their sense of well-being and value both financially and socially. However, as the consultation document highlights, employment outcomes for people with learning disabilities are poor and there is no evidence of progress being made⁹³.

Through deploying devolved powers, SCLD believes there is scope for legislative measures and actions which greatly increase the number of people with learning disabilities in paid employment through greater compliance with the Equality Act including PSED, the Human Rights Bill, ICESCR and the CRPD. Addressing the employment deficit fits in with the Scottish Government’s priorities for Scotland’s economy as well as the actions needed to maximise the opportunities for a wellbeing economy.⁹⁴ SCLD believes there should be a duty on organisations that receive public funding to have accreditation of being an LDAN inclusive employer.

In the consultation introduction, the LEAP members’ underlying principles for the LDAN Bill were acknowledged, which include: *The status quo is not an option. It is not acceptable for our community to continue to face the*

⁹³ [Fraser of Allander Institute \(2021\) Scotland’s employment landscape for people with learning disabilities](#)

⁹⁴ Scotland's National Strategy for Economic Transformation pub by the Scottish Government | March 2022 <https://www.gov.scot/publications/scotlands-national-strategy-economic-transformation/>

*discrimination and struggles that are sadly too commonly experienced by us all.*⁹⁵

However, we know that the employment rate for people with learning disabilities is scandalously low:

*With regards to employment, it is estimated that employment rates are 4-8% for people with learning disabilities and 29% for autistic people, compared with Scotland's national employment rate of 82.5% for non-disabled people and 50.7% for disabled people.*⁹⁶

The Fraser of Allander Institute has published evidence which shows that people with learning disabilities who are looking for work face multiple barriers to securing employment⁹⁷. Common barriers that people with learning disabilities experience include the recruitment process with applications forms which are complicated to understand and complete, and interview processes which are often inaccessible and do not cater for individuals' support needs or make reasonable adjustments. Indeed, the entire process of seeking and applying for work remains archaic and as such is extremely complex and confusing for people with learning disabilities.

Furthermore, people with learning disabilities also face stigma and discrimination in the workplace with managers often ill-equipped to provide effective line management. There is also a lack of clarity regarding the provision of reasonable adjustments for people with learning disabilities and their inclusion in Access to Work. Some people with learning disabilities face bullying and harassment in the workplace. Many experience very limited opportunities to progress in work while others do not enjoy some of the benefits of employment, such as the social benefits.

⁹⁵ Pg 4 <https://www.gov.scot/binaries/content/documents/govscot/publications/consultation-paper/2023/12/learning-disabilities-autism-neurodivergence-bill-consultation/documents/learning-disabilities-autism-neurodivergence-bill-consultation/learning-disabilities-autism-neurodivergence-bill-consultation/govscot%3Adocument/learning-disabilities-autism-neurodivergence-bill-consultation.pdf>

⁹⁶ Pg 10. Ibid.

⁹⁷ [Fraser of Allander Institute \(2021\) Scotland's employment landscape for people with learning disabilities](#)

Therefore, as the current persistent and pernicious discrimination in employment is significant, SCLD believes it is extremely disappointing that this section fails to provide ambition on how current laws, including the Equality Act 2010 and the Human Rights Act 1998, can be used to address the deficit in the right to employment for people with learning disabilities.

We understand that employment rights, industrial relations, and equalities legislation are all reserved matters. However, access to training and employment support for disabled persons are both fully devolved areas and offer huge scope for positive change to progress the employment opportunities of people with learning disabilities. The public sector is also an employer and can do more to equalise employment opportunities.

Furthermore, in the preamble to the UN's International Covenant on Economic, Social and Cultural Rights (ICESCR), it is acknowledged that “the ideal of free human beings enjoying freedom from fear and want can only be achieved if conditions are created whereby everyone may enjoy his economic, social and cultural rights, as well as his civil and political rights...”. Therefore, employment is part of the human rights architecture for any modern democracy and the employment section of the LDAN Bill needs to be more ambitious. It should be compliant with existing laws and also dovetail with future human rights law as is permitted under the devolved settlement set out in the Scotland Act 1998.⁹⁸

However, unfortunately, the opportunity of the forthcoming Human Rights Bill for Scotland is omitted in the employment section despite the Scottish Government proposal to ‘incorporate’ the ICESCR, into Scot’s law.

For people with learning disabilities, ICESCR⁹⁹ is a powerful tool to address the human rights deficit in employment as it places duties on the Scottish Government to “to undertake to ensure the equal right of men and women to the enjoyment of all economic, social and cultural rights.”

⁹⁸ <https://www.legislation.gov.uk/ukpga/1998/46/contents>

⁹⁹ ICESCR is developed further in General Comments such as the right to work in General Comment no. 18, General comment No. 23 (2016) on the right to just and favourable conditions of work and General Comment No. 20 on Non-discrimination in economic, social and cultural rights.

This includes Article 6¹⁰⁰ “ the right to work, which includes the right of everyone to the opportunity to gain his living by work which he freely chooses or accepts” and requires the Scottish Government to take appropriate steps to safeguard this right.¹⁰¹ Article 6 (2) also sets out the steps to be taken by the Scottish Government to achieve the full realization of Article 6 which “shall include technical and vocational guidance and training programmes, policies and techniques....”

Moreover, Article 7(1) is the right of everyone to the enjoyment of just and favourable conditions of work and Article 7 (a) – (d) sets out the duties of the Scottish Government to deliver just and favourable conditions of work for everyone including fair remuneration¹⁰².

CRPD is also pivotal for people with learning disabilities. It includes non-discrimination and employment rights and as this treaty has been ratified by the UK, all laws and policies in Scotland should comply with it. Articles 26 and 27 set out rights and duties on employment¹⁰³ recognising the right of persons with disabilities to work on an equal basis with others. This includes the right to a work environment that is open, inclusive and accessible to persons with disabilities.

The CRPD states that persons with disabilities have the right to an adequate standard of living and social protection in line with Article 28. However, a considerable concern for people with learning disabilities is the failure of the state to adequately support people with learning disabilities to realise this right¹⁰⁴.

While many organisations have outlined the case for devolving employment law¹⁰⁵ SCLD is concerned with what powers the Scottish Government already has, to address the discrimination evidenced in employment. We believe the LDAN Bill must set out a strategic and legal roadmap to

¹⁰⁰ [ICESCR, Article 6](#)

¹⁰¹ <https://www.ohchr.org/en/instruments-mechanisms/instruments/international-covenant-economic-social-and-cultural-rights>

¹⁰² [ICESCR, Article 7](#)

¹⁰³ <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>

¹⁰⁴ [State of our rights \(2023\)](#)

¹⁰⁵ <https://reidfoundation.scot/2024/02/devolving-employment-legislation/>

address discrimination and positively encourage and enable people with learning disabilities to enjoy the right to work.

Research by the NDTi¹⁰⁶ found that factors which most helped people with learning disabilities into employment included accessible recruitment processes, trainee/internship schemes, employment support and voluntary work experience.

Additionally, factors that supported people with a learning disability to stay in paid work include a supportive employer, in-work employment support, help to travel to work, good communication, right person for the right job and support for the employing organisation.

Good quality supported employment can play a pivotal role in providing in-work and ongoing support to people with learning disabilities in the workplace. It can provide effective support to both the employing organisation as well as individuals with learning disabilities.

The 2021 'Review of Supported Employment within Scotland'¹⁰⁷ found that there is a complex mixture of local and national provision of supported employment with high variability in access rates. The review clearly showed a considerable opportunity to improve access to supported employment for people with learning disabilities and autistic people.

The subsequent report made nine recommendations, including improving disaggregated data collection to drive consistency and oversight of supported employment provision and a Scottish Supported Employment Guarantee to provide funding and set targets for local areas.

SCLD is frustrated that the Scottish Government's Supported Employment Review¹⁰⁸ recommendations (2021) have not yet been implemented. SCLD believes the LDAN Bill provides an ideal opportunity to provide a statutory footing for the standards and delivery of supported employment in Scotland.

¹⁰⁶ [NDTi \(2022\) Research about work and learning disability](#)

¹⁰⁷ [The Review of Supported Employment within Scotland \(2021\)](#)

¹⁰⁸ [The Review of Supported Employment within Scotland \(2021\)](#)

We believe the LDAN Bill should include a duty for the Scottish Government to create Supported Employment Quality Standards as well as a duty on public services and private services carrying out public functions to comply with these standards once they are developed.

Moreover, we believe the LDAN Bill should include a duty for the Scottish Government to develop a learning disability and autism employment plan for the Scottish Government, NHS Scotland, and Local Authorities.

SCLD believes the above employment plan must include targeted actions to support people with learning disabilities to have the aspiration, confidence, and skills to seek, secure and progress in work.

Additionally, there must be support for employers to be confident about employing people with learning disabilities, to be aware of the benefits of creating a more diverse workforce that includes people with learning disabilities and to be aware of their legal duties to make reasonable adjustments including inclusive and accessible recruitment, selection and retention practices.

The employment plan should also include learning disability awareness raising training delivered with people with lived experience of learning disability. This training should be for employers and employees as well as support workers and job coaches.

Once fully developed the employment plan should then be implemented and monitored.

SCLD also believes there should be a duty on organisations that receive public funding to have accreditation of being an LDAN inclusive employer.

Finally, we believe there should be a duty on employers to disaggregate their data on the disability pay gap to show the pay gap for people with learning disabilities.

Key Points:

- 92.** Employment must a priority area for the LDAN Bill to address given the huge inequalities that exist at present.
- 93.** It is extremely disappointing that the consultation fails to link with current economic and employment strategies and action plans.
- 94.** The consultation fails to provide ambition on how current laws, including the Equality Act 2010 and the Human Rights Act 1998, can be used to address the deficit in the right to employment for people with learning disabilities.
- 95.** The LDAN Bill needs to be more ambitious and compliant with existing laws and dovetail with future human rights law.
- 96.** The LDAN Bill must set out a strategic and legal roadmap to address discrimination and positively encourage and enable people with learning disabilities to enjoy the right to work.
- 97.** The LDAN Bill should include a duty for the Scottish Government to create Supported Employment Quality Standards as well as a duty on public services and private services carrying out public functions to comply with these standards.
- 98.** The LDAN Bill should include a duty for the Scottish Government to develop a learning disability and autism employment plan for the Scottish Government, NHS Scotland, and Local Authorities.
- 99.** SCLD believes there should be a duty on organisations that receive public funding to be accredited as an LDAN inclusive employer.
- 100.** We believe there should be a duty on employers to disaggregate their data on the disability pay gap to show the pay gap for people with learning disabilities.

Part 4 – Accountability

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.

SCLD supports Option 1 or Option 2:

SCLD does not have a fixed view on the exact model of any new accountability mechanism. However, we are convinced that the LDAN Bill must provide new resource and powers to help target and address areas where rights are not being met and to hold Government and public bodies to account.

Accountability and access to justice are fundamental pillars of a fair and equitable society. They ensure that individuals have the means to seek legal remedies and support to uphold their human rights. However, currently people with learning disabilities are often unaware of their human rights and experience barriers to accessing justice and holding public bodies to account.

SCLD believes change is required, to increase the availability of effective and accessible remedies, both in practice and in law, so that people with learning disabilities can be empowered to uphold their rights. Furthermore, we believe that for people with learning disabilities to secure their rights public bodies must be held to account for their actions.

SCLD's Include For Good Rapporteurs were clear that accountability is needed to make sure the LDAN Bill leads to genuine change. Many of the Rapporteurs have experience of being involved in previous work that was intended to improve the lives of people with learning disabilities e.g. Keys to Life Strategy yet they feel that little has changed. One Rapporteur said that *"Holding people to account allows us to make improvements."* The Include For Good Rapporteurs felt strongly that there needs to be accountability across all areas of the LDAN Bill.

SCLD believes one way to help achieve this could be through a new LDAN Commission or Commissioner with a remit to ensure that the human rights

of people with a learning disability, autistic people and neurodivergent people are protected. However, we would also be supportive of better resourcing and increased legal duties for an existing public body such as the Scottish Human Rights Commission (SHRC).

The Include For Good Rapporteurs identified various advantages to the Commission/Commissioner model. This included having someone to stand up for the rights of people with learning disabilities and who could support people to realise their rights. Overall, they were less keen on the idea of a single person commissioner and felt that a Commission, comprising a group of people, would be preferable as it could be more diverse and include people with learning disabilities. They also thought it could be more powerful in supporting human rights and have a stronger voice. The Rapporteurs drew similarities with their own seminal work in holding leaders and organisations to account across Scotland.

The Rapporteurs also identified the Scottish Social Housing Charter model as an effective model for accountability that fully involves the people at all levels¹⁰⁹. They felt that if the LDAN Bill used this model of accountability, then people with learning disabilities would be involved in reviewing the services that are provided by all public bodies. This would mean that people with learning disabilities' voices would be heard by the Commission or Commissioner when service providers are assessed against the standards in the Charter. One Rapporteur said:

“There needs to be a Charter for the LDAN Bill. It needs to help organisations to think about how they can make improvements to what they do so things work better for us.”

SCLD is less concerned with the exact structure of any Commission and more concerned that any new powers must be co-produced and exercised in partnership with people with learning disabilities, not for them.

¹⁰⁹ [Scottish Social Housing Charter \(2022\)](#)

The Rapporteurs were also clear there should be people with lived experience in the Commission. They said holding others accountable *“puts us in the driving seat, not passengers sitting quietly in the back.”*

We need people who know what it’s really like. People who have learning disabilities.

“People in power need to be in our space to hear from us, to have their attitudes shaped by our experiences. They are learning by listening to us.”

In our view, any new powers should be delivered through a co-production model, whereby a Board of people with learning disabilities and neurodivergent people are appropriately trained and supported to oversee and enact them in accordance with the legislation.

This must be much more than an advisory group. It is critical that people with learning disabilities are fairly represented in this process and are given equal opportunities to discharge their duties. This must include accessible and inclusive communications to enable their effective participation. It will also be necessary to ensure that these measures are enacted and sustained.

In terms of specific duties, SCLD believes that any new Commissioner or Commission or extended powers for an existing commission should focus on the current gap in accountability and enforcement of people with learning disabilities’ rights. We believe that any new powers should address access to justice and holding public bodies and the Government to account. This should include monitoring how the duties in the LDAN Bill are being implemented, conducting investigations on these issues, and providing regular reports on this.

Furthermore, we believe that increased accountability should include holding the Government to account through new powers and duties to review areas of law, policy and practice and then publish an opinion. It should also include providing reports and evidence to the Scottish Parliament and making recommendations based on this.

SCLD further believes that a Commissioner or new or existing Commission should hold public bodies to account by having powers and duties to conduct inquiries and formal investigations into specific issues, supports or services. As part of this it should have powers to compel the production of information held by public bodies and to interview their office holders alongside duties to publish reports of inquiries and investigations and make recommendations.

We believe a Commissioner, or new or existing Commission must also have the power to take individual cases and bring court proceedings. This should include the powers to access information linked to cases and to recommend penalties, such as fines, for public bodies.

It is essential that any Commissioner or new or existing Commission is independent of Government and that its powers and duties are set out in the Bill. In addition to this, we believe the Bill should set out how any Commissioner or new or existing Commission would be appointed and make sure that people with learning disabilities and neurodivergent people have a central role in the appointment process.

As the consultation recognises, there are already several Commissions and Commissioners in Scotland which have remit to consider people with learning disabilities and neurodivergent people including the SHRC, EHRC and Children & Young People's Commissioner. It is important that any Commissioner or new or existing Commission's powers and duties do not duplicate or overlap with existing mandates.

SCLD believes that agreements should be put in place between any Commissioner or new or existing Commission and about how they would work together with other Commissions. The legislation that established the SHRC included provisions to promote co-operation with others and prevent unnecessary duplication of existing activities.¹¹⁰

Furthermore, we believe the Paris Principles ('Principles Relating to the Status of National Human Rights Institutions') which set out the minimum

¹¹⁰ [Scottish Commission for Human Rights Act 2006 \(legislation.gov.uk\)](https://legislation.gov.uk)

standards that NHRIs must meet to be considered credible and to operate effectively¹¹¹ provide an excellent framework to underpin any new body.

In addition to the potential powers and duties that could be included in a new or existing commission, SCLD believes the Scottish Government should also legislate for individuals to have access to legal services to challenge in situations where the duties in the LDAN Bill and other relevant legislation are not being met.

Furthermore, we believe the Scottish Government should consider introducing a statutory duty as part of the LDAN Bill which requires all local authorities, HSCPs and other public bodies in Scotland to report progress to the Scottish Government against all areas in the LDAN Bill. This could be achieved by producing an annual Learning Disability, Autism, and Neurodivergence Scheme similar to the United Nations Convention on the Rights of the Child (UNCRC) Bill's Children's Rights Scheme¹¹² and the Public Sector Equality Duty¹¹³.

Key Points:

- 101.** Change is required so that individuals can be empowered to uphold their rights and hold public bodies to account.
- 102.** SCLD's Include For Good Rapporteurs felt strongly that there needs to be accountability across all areas of the LDAN Bill.
- 103.** SCLD believes this could be achieved through a new LDAN Commissioner or Commission or an existing Commission.
- 104.** SCLD's Include For Good Rapporteurs were clear that there should be people with lived experience on the Commission.
- 105.** They also identified the Scottish Social Housing Charter model as an effective model for accountability that fully involves people.

¹¹¹ [Paris Principles - GANHRI](#)

¹¹² [United Nations Convention on the Rights of the Child \(Incorporation\) \(Scotland\) Act \(legislation.gov.uk\)](#)

¹¹³ [Public sector equality duty - GOV.UK \(www.gov.uk\)](#)

- 106.** SCLD believes that any new powers must be co-produced and exercised in partnership with people with learning disabilities.
- 107.** Any new powers should be delivered through a co-production model, whereby a Board of people with learning disabilities and neurodivergent people are trained and supported to oversee and enact them in accordance with the legislation.
- 108.** Any new powers should address access to justice and holding all public bodies and the Government to account. This should include monitoring how the duties in the LDAN Bill are being implemented, conducting inquiries and investigations into specific issues, supports or services and publishing regular reports.
- 109.** It should also include the power to take individual cases and bring court proceedings.
- 110.** There should be provision for individuals to access to legal services where the duties in the LDAN Bill are not being met.
- 111.** Include a statutory duty as part of the LDAN Bill to require all local authorities, HSCPs and other public bodies to report progress against all areas in the LDAN Bill.

The following organisations have endorsed and support SCLD’s response to the Learning Disability, Autism and Neurodivergence (LDAN) Bill consultation.

THE AITEAL TRUST
(Registered Charity SC060559)

The Aiteal Trust



**British Institute of Learning Disabilities
(BILD)**



CEMVO



Cornerstone



Crossreach



DFN Project Search



Down's Syndrome Scotland



Enable Glasgow



Ewart Communications



Hansel



Horizon Housing



Indepen-dance



Kindred Scotland



Mainstay Trust



The Mungo Foundation



My Commpass



Newlands Park Community Tennis Centre



Positive and Active Behaviour Support Scotland (PABSS)



People First (Scotland)



Kate Sainsbury

Mother, Wife, Friend, Supporter,
Founder of Appletree Community.



Louis Sainsbury, Person with Disabilities. Lead Researcher for 'Louis's story: The Story of Appletree'



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Stakeholder Participation Group