The Health and Social Care Alliance Scotland (the ALLIANCE)

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HEALTH AND SOCIAL CARE
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people at the centre

Learning Disabilities, Autism and Neurodivergence (LDAN) Bill Consultation Response

21 April 2024

Introduction

The ALLIANCE welcomes the opportunity to respond to the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill consultation.

We believe that the LDAN Bill has the potential to make significant change if it meaningfully listens to and implements what people with learning disabilities, autistic and neurodivergent people genuinely want and need.

There is a wealth of evidence that disabled people are amongst the most excluded and discriminated against groups in Scottish society; the implication is that existing legal protections are not working.

The ALLIANCE believes that people don't have human rights until everyone has human rights.

As all aspects of Scottish society need to adapt and change to be more inclusive for people with learning disabilities, autism and neurodivergence, we are glad to see that the LDAN Bill consultation reflects many elements of life that people experience and encounter.

The Bill should explicitly embed the social model of disability, intersectionality, human rights based and person centred approaches. To ensure that people covered by the Bill are viewed and treated as equal in all aspects of life, the LDAN Bill should be aligned with and channel the full range of human rights as contained in the United Nations Convention on Persons with Disabilities (UNCRPD).

We were encouraged to see the Scottish Government's efforts to co-produce the Bill, and communicate its contents in varied and accessible ways to communities that the LDAN Bill is for.

However, we heard from members and people with lived experience that they felt unable to give us meaningful feedback due to feeling overwhelmed by the length of the consultation document. The information included should have been broken down into smaller booklets for understanding and processing. We believe that this will have excluded people from responding to the consultation, whether they are people with learning disabilities, autism and neurodivergence or not.

Reach and definitions: Who should the Bill include?

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

The ALLIANCE agrees with Proposal 2: "People who are Neurodivergent'/ 'Neurodivergent People'

We agree with the Scottish Government's proposal 2, with the caveat that learning disabilities and autism also remain within the title of the Bill as 'neurodivergence' is not a term that people with learning disabilities and not all autistic people identify with or are familiar with.

As stated by the Lived Experience Advisory Panel (LEAP), 'Neurodiversity' means everyone, including neurotypical people or people who do not have learning disabilities, autism or neurodivergence, and is not an appropriate definition for who this Bill is for.

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

The ALLIANCE does not agree with Proposal 1: 'People who are Neurodiverse'/ 'Neurodiverse People'.

The term 'neurodiversity' encompasses the infinite differences within and between people's minds[1]. People whose processing fits within any society's concept of normalcy are Neurotypical, whereas people whose processing diverges from socially constructed 'norm' in any way are

‘Neurodivergent’. Many neurodivergent people identify as disabled and face the societal barriers.

We elaborate on our answer in the following question.

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

By clearly defining learning disability, autism and neurodivergence within the Bill, it will create visibility and inclusion through positive identification. We likewise believe that explicit reference in the coverage should be made to people with Down’s Syndrome and people with profound and multiple learning disabilities (PMLD). Equating neurotypes with each other is problematic as they are not the same, and each person have wholly individual experiences.

Yet, it is important to note and reflect in the Bill, subsequent memorandums and guidance that often people with learning disabilities, autism and neurodivergence experience co-occurring disabilities or comorbidities. For example, around 32.7% of people with a learning disability also have a diagnosis of autism[2].

To ensure the protection of people with learning disabilities, autism and neurodivergence, the Bill must explicitly embed a human rights based approach, and specifically align with the United Nations Convention on Rights of Persons with Disabilities (UNCRPD)[3]. The UNCRPD imposes positive obligations on states to respect, protect and fulfil the human rights of people with learning disabilities, autism and neurodivergence.

The Convention follows decades of work by the United Nations to change attitudes and approaches to persons with disabilities. It challenges the idea of viewing persons with disabilities as “objects” of charity, medical treatment and social protection towards viewing persons with disabilities as “subjects” with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society[4].

The other extremely relevant United Nations Framework is the UN 2030 Agenda for Sustainable Development that includes the Sustainable Development Goals (SDGs)[5]. Disability is referenced in multiple parts of the SDGs, specifically in the parts related to education, growth and employment, inequality, accessibility of human settlements, as well as data collection and the monitoring of the SDGs.

We agree with our member, the Scottish Commission for People with Learning Disabilities (SCLD), in supporting the recommendation by the National Taskforce for Human Rights Leadership[6]. They recommended that the UNCRPD should be incorporated into Scots law in such a way that ensures effective protection and realisation of rights in people's everyday lives.

We believe that incorporation of the UNCPRD into domestic Scottish law will act as the bridge between policy intent and lived experience, ensuring that systems consistently deliver rights, as well as prevent the most serious human rights violations[7].

As stated by the United Nations[8]:

- Disability is a natural part of human diversity that must be respected and supported in all its forms.
- Disabled rights have the same rights as everyone else in society.
- Impairment must not be used as an excuse to deny or restrict people's rights.

Evidence throughout this report shows negative attitudes and discrimination persist and were perceived to be worsening during pandemic[9]. In 2021, almost three quarters of discrimination enquiries to the Equality Advisory Service where advisers felt that discrimination is likely to have occurred concerned disability[10]. Almost all respondents (96%) to the 2021 UNCRPD survey said there is discrimination and negative attitudes towards disabled people in Scotland today. Disabled people, including LGBT+ people and those from Black and Minority Ethnic (BAME) backgrounds, report experiencing intersectional discrimination[11]. However, availability of intersectional data remains limited.

We are glad to see the Scottish Government's commitment to co-producing the Bill with the Lived Experience Advisory Panel (LEAP). The ALLIANCE believes the current title, reach and definitions contained within the Bill should be decided upon via co-production with people with lived experience. People with learning disabilities, autism and neurodivergence must be involved and leading at every stage in decisions that affect them.

We urge the Scottish Government to continue using and widening this approach to developing all future policy and legislation that will impact people with learning disabilities, autism and neurodivergence. Although the LEAP is a positive development, it is not representative of people within these communities, it is a small snapshot of some experiences.

Further, the ALLIANCE are concerned that whilst the Scottish Government is making efforts to "co-designing" legislation and policies with people with learning disabilities, autism and neurodivergence, they must be included at the very beginning of the process so they are 'co-producing the co-production', or rather designing how they should and want to be involved.

Indeed, we heard from members of the LEAP who said that during the meetings they felt that the Scottish Government struggled to acknowledge the points of view of people with learning disabilities.

In the *Seen, Heard, Included* project, our member PAMIS and Downs Syndrome Scotland concluded that if meaningful "codesign" is to take place with the group of individuals who live with People with Multiple Learning Disabilities (PMLD), it is crucial that an understanding of their lives is gained in order to avoid any misconceptions that might interfere with the engagement process[12].

People with learning disabilities, autism and neurodivergence have had poorer health outcomes, poorer educational opportunities, been generally excluded from the world of work and that it is widely recognised that they have often been denied the human rights that other citizens are able to access.

A reason for poor life outcomes is that policymakers, duty bearers and service providers have focused on impairment itself and “treating” a condition, rather than seeing the person.

We recognise the varying views of our members and that there will not be full consensus on who should be included within the reach of the Bill. This is why there must be flexibility to allow people to choose how they define themselves and their identities, and for such flexibility and choice to be embedded within public services, the third and private sector.

We agree with the Scottish Government’s proposal 2, with the caveat that learning disabilities and autism also remain within the title of the Bill as ‘neurodivergence’ is not a term that people with learning disabilities identify with or are familiar with.

As stated by the Lived Experience Advisory Panel (LEAP), ‘Neurodiversity’ means everyone, including neurotypical people or people who do not have learning disabilities, autism or neurodivergence, and is not an appropriate definition for who this Bill is for.

The term ‘neurodiversity’ encompasses the infinite differences within and between people’s minds[13]. People whose processing fits within any society’s concept of normalcy are Neurotypical, whereas people whose processing diverges from socially constructed ‘norm’ in any way are

‘Neurodivergent’. Many neurodivergent people identify as disabled and face the societal barriers.

By clearly defining learning disability, autism and neurodivergence within the Bill, it will create visibility and inclusion through positive identification. We likewise believe that explicit reference in the coverage should be made to people with Down’s Syndrome, People with profound and multiple learning disabilities. This is because we have heard from ALLIANCE members that it appears that the people they work for who are supposed to be covered by the LDAN Bill are not fully included in the act as their disabilities are not defined. It is important to note that equating neurotypes with eachother is problematic as they are not the same, and each person have wholly individual experiences.

For example, People First Scotland noted that nowhere in existing legislation is there a definition of intellectual impairment. Instead there has been the simple adoption of intellectual impairment as one of a number of “mental disorders”[14].

The new legislation must accept and acknowledge that an intellectual impairment is not a disease, illness or mental disorder but a permanent condition of impaired intellect or cognition. It must also offer a definition which is robust and which accords with other international definitions and respects the dignity of who will carry the label.

Likewise, Dyslexia Scotland wanted to highlight that whilst there was a Dyslexic member on the LEAP, a definition of dyslexia is not contained within the consultation document or Bill. The Scottish Government, Dyslexia Scotland and the Scottish Parliament’s Cross-Party Group on Dyslexia defined Dyslexia[15].

In fact, having a learning disability, being autistic or neurodivergent is an important identity for many people as it can validate their feelings and experiences. It in tandem, has become an identity to be proud of, and to have acknowledged.

Yet, people with autism have reported that the diagnosis process is still too stressful and difficult a journey, often taking far longer than is acceptable, and that efficient, accessible post-diagnostic services are not available in all parts of Scotland[16].

To resolve the unmet need in pre and post diagnosis support for autism, it was recommended that the Scottish Government, COSLA and local authorities should undertake an audit of service provision throughout Scotland, together with health and social care, housing, employment and education.

Additionally, it is important that the Bill is designed to support people with learning disabilities who also have sensory impairments – particularly given the high incidence rates of Deafness, Deafblindness and Visual Impairment amongst people who have learning disabilities.

We recommend that that the Bill mentions that the term “Sensory Loss” is not acceptable to everyone who is Deaf, Deafblind, or who have Visual Impairments, and further work should be done to ensure that language reflects people’s preferences.

Sensory impairment is a significant issue among neurodivergent people. Additionally, people with autism and learning disabilities are significantly more likely to develop a sensory impairment. The Foundation for People with Learning Disabilities stated that around 1 in 3 people with a learning disability also have a sensory impairment, with many of these going undiagnosed[17].

There is also evidence that older people in Scotland are more likely to develop a hearing impairment. The *See Hear Strategy* demonstrated that 70% of those who develop a hearing impairment were over 70[18]. This demonstrates that older people are significantly more likely to develop a sensory impairment over time. More recent figures show that these patterns are only growing more acute, with an ageing population.

Whereas, the RNID suggested that 20% of the UK population have a hearing loss, with around 12 million adults[19]. This equates to around 1 million in Scotland. They estimate that this affects 40% of over 50's and 70% of over 70's. They project the total UK figures to rise to 14.2 million adults by 2035, largely due to the aging population.

It is important to note the labelling that people with lived experience have experience in relation to their disabilities, autism or neurodivergence. They have been told that their disability is "not complex" or "too complex" or that they are "not disabled enough" which has previously led them to being excluded from accessing or receiving support,

Alongside this, the LDAN Bill provides an opportunity to establish new legal definitions and ways that people identify and refer to themselves. For instance, current definitions in Scots Law are outdated and use stigmatising and discriminatory language. People with lived experience can find this offensive and degrading.

However, definitions should not require formal diagnosis for people to be included within the scope of the Bill. A requirement of diagnosis should not act as a gatekeeper to accessing support and services. Research shows that people who self-identify as autistic or neurodivergent face difficulties in being referred and assessed for formal diagnosis[20].

In relation to the Scottish Government's proposal to include specific conditions within the Bill could result in an overreliance of diagnosis and medical terminology. This could lead to greater exclusion for those not defined within the Bill and detract from the use of the social model of disability.

Unfortunately, despite the Scottish Government's shift to implementing the Social Model of Disability within its policy developments, learning disabilities, autism and neurodivergence are still medicalized under the diagnostic criteria[21].

Establishing criteria is clearly important for clinicians, however diagnosis relies on accurate assessment, understanding and interpretation as individual presentation is rarely straightforward and can often be subtle. Accessing a diagnosis later in life can be a fraught process as the availability of skilled diagnosticians can be limited[22].

In fact, it was found that the top priorities of autistic people living in Scotland focused on issues with implication for the everyday lives of autistic people across their lifespan[23]. For example, the top five priorities were concerned with mental health and wellbeing, identifying and diagnosing autistic people, support services, knowledge and attitudes towards autistic people and issues impacting autistic women.

It would be helpful to use a person centred and strengths-based approach to definitions, focusing on abilities rather than deficits and describing barriers. This approach is not based on a person's diagnosis but rather the person's needs, wishes and condition.

The Scottish Government, through this legislation, must establish the foundation for an entirely new paradigm in how to think about intellectual impairment and intellectual impairment. It must identify people who are intellectually impaired as full citizens and whole human beings who have all the needs and aspirations of any other citizen, regardless of degree of impairment. Services, from the youngest age and earliest opportunity must address the need for intellectually impaired persons to develop to their fullest potential and to see themselves as human beings with all the rights that other human beings have.

We believe that the Scottish Government must align the LDAN Bill with the UNCRPD, especially as the Scottish Government has committed to incorporating the convention into Scots Law.

With increasing the remit of diagnoses to self-identification, we strongly recommend that the Scottish Government increases the resources to enable people to access support and services. The Bill must have a financial memorandum showing the costs and financial implications of the Bill and its proposals.

For example, in the review of the Autism Strategy, the Cross-Party Group on Autism found that one-third of autistic people did not receive support following diagnosis[24]. Indeed, several local authorities, NHS Boards and Health and Social Care Partnerships (HSCPs) failed to provide adult diagnostic pathways. Arguably, agencies should have been given an alternative, long-term central funding stream to continue the successful initiatives that positively impacted Autistic people.

Sustainable funding must be put in place either centrally or locally to ensure that post-diagnostic information, advice and guidance support services are available where needed.

Health and Social Care Partnerships should include specific Key Performance Indicators to record, collate and publish autism diagnosis waiting times so we have an accurate countrywide picture of how long people are waiting and where improvements are needed.

Statutory Strategies for Neurodivergence and Learning Disabilities

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

The ALLIANCE agrees with all of the Scottish Government's proposals. We believe that proposal 2 should introduce a requirement for all, not just some, public bodies to produce local strategies that include how the need and outcomes of people with learning disabilities, autism and neurodivergence will be accounted for and met fully. In doing so, people covered by the strategies and the Bill in general can expect consistency of support and services wherever they live.

We believe that the proposals to introduce statutory strategies, guidance and reviews could be a positive development. However, there must be actions incorporated, and a duty/requirement to implement such actions, to ensure that the strategies do not become tokenistic and rhetorical without implementation.

As with the LDAN Bill itself, national and local strategies must be designed and produced by the people they are written for. As stated by the disability movement “Nothing about us, without us”. If people with learning disabilities, autism and neurodivergence are not included or seen by the strategies, it is unlikely the actions within them will have any real and impactful effect.

A review of national and local strategies must take place to ensure appropriate scrutiny. We believe that this could be included under the responsibilities of a new or existing commission or the proposed legislative review panel. For reviews to be effective, evaluation measures such as outcomes should be developed for a clear route for public bodies to work towards. Reviews must include and be co-produced and led by the people using the support and services.

The strategies should take a human rights based, person centred and outcomes focus approach. If such strategies are developed they should demonstrate how they will proactively and preventatively support people with learning disabilities, autism and neurodivergence.

As elaborated on in our section on Inclusive Communication, accompanying guidance must be proactively provided in multiple alternative accessible formats, not just EasyRead, and in be translated into multiple languages.

We elaborate on our answer in the following question.

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

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

As mentioned within the consultation document, the Scottish Government has introduced and published multiple strategies, policies and legislative documents related to people with learning disabilities and autism. For instance, these include the *Keys to Life, A Fairer Scotland for Disabled People, with an Employment Action Plan, The Scottish Strategy for Autism, the Learning/intellectual disability and autism: transformation plan*[25]*.*

However, there has been critique of the effectiveness and implementation of previous strategies. We urge the Scottish Government to take on and implement these learnings, so any strategies associated with the LDAN Bill are effective and work for people with learning disabilities, autism and neurodivergence.

Yet, during the consultation on the second *Keys to Life implementation framework*, the Scottish Government was told that insufficient attention was paid to the health needs and outcomes of people with Learning Disabilities[26]. It was suggested that the Strategy was a 'tick-box' exercise disconnected from People with Learning Disabilities reality of services[27].

Otherwise, a review of the *Scottish Autism strategy* identified that progress in the 10 years had been unsatisfactory with 'limited impact' and 'the host of activities and projects had not led to real change'[28].

Since the Strategy ended, the *Learning/Intellectual Disability and Autism Towards Transformation Plan* was published[29]. The Plan specifically states that autistic people’s voices will be integral to their work. Given the specific social, political, and cultural context in Scotland, an appreciation of the research priorities of autistic people would be of significant value for informing future Scottish policy and autism research.

In the review of the *Scottish Strategy for Autism* it was recommended that strategies must be created with the full involvement of autistic people and families. Only by putting a wide cross-section of autistic voices at the centre of any future approaches will the desired progress be made.

Further, in the UNCRPD Shadow report, it was found that many of these actions were output led rather than outcomes. In addition, there was little or no baseline evidence to determine impact. The Scottish Government published a final progress report which showcases delivery of new policies but lacks detail of gaps closing between disabled and non-disabled people across many areas [30].

Similarly, it appears that limited progress has been made to BSL learning needs[31]. For example, the most recent progress report on the BSL plan says in relation to Action 13: Work with partners to determine the best way of enabling families and carers to learn BSL so that they can communicate effectively with their D/deaf or Deafblind child in the crucial early years (0-8 years). According to the report, forming a partnership to take this action forward has been challenging and that the Scottish Government intends to ‘identify key partners to progress this action further’.

We know that reasons behind ineffective implementation of strategies include vague, misunderstood, voluntary, or poorly coordinated implementation; inadequate solutions; limited resource (money, attention, staffing) investment; vetoing of decisions; lacklustre policy actor support; and socioeconomic conditions, such as the Covid-19 pandemic and cost of living crisis, affecting implementation support [32].

We also know that these reasons are amendable. We believe that the guidance provided by SCLD on *Developing a Learning Disability Strategy* is an excellent exemplar of how strategies should be developed, implemented and measured on both a national and local scale[33].

At the ALLIANCE we are concerned that existing strategies do not reflect representative population of people with learning disabilities, autism and neurodivergence. For the LDAN Bill and subsequent strategies, an intersectional approach is needed. This is due to the fact that often in published strategies women, ethnic minorities and even people with certain disabilities or impairment are not contained within its remit. If intersectionality is not recognised, policymakers will cause further inequalities[34].

We would like to highlight a concern that these strategies will just add to a complex policy landscape, duplicating what has already been committed to, without the tools and resources to implement already stated actions. We believe that this can be remedied if such duties, tools and resources are implemented with appropriate funding and evaluation and data gathering methods.

As stated by our member SCLD, key elements to a national and local strategy are:

- People with lived experience are equal partners at every stage from agreeing the vision to oversight of delivery.
- A detailed, prioritised and adequately resourced action plans with agreed timelines and responsibilities.
- Agreed lines of accountability for national and local delivery.

For the LDAN Bill and related strategies to have appropriate scrutiny, we believe that an accountability mechanism should be put in place to review its implementation and effectiveness. As stated in other section proposals this could be in the form of a new or added to the responsibilities of an existing commission or a legislative review panel to hold Ministers, Health Boards and local authorities to account.

Currently responsibility for ensuring effectiveness for people with learning disabilities, autism and neurodivergence falls within the gaps between central government, local government and health boards. Ultimately, however, it should be decided who is responsible for when actions within strategies are not implemented effectively.

In addition to this, we believe in reviewing the quality of the strategies, people with lived experience should be involved in checking the quality of the strategies to scrutinize its contents and also its progress. If people with learning disabilities, autism and neurodivergence are leading on such process they must be compensated for their time and energy.
Funding for strategies, and the commitments within them should be ringfenced solely for support and services for people with learning disabilities, autism and neurodivergence. When discretion or flexibility is allowed for when providing resources to bodies such as local authorities, we know that people with learning disabilities, autism and neurodivergence are not prioritised and instead money is placed where there is the most pressure or is most visible. This funding must be detailed in the accompanying financial memorandum to the LDAN Bill.

Mandatory Training in the Public Sector

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

The ALLIANCE agrees with the proposal.

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

However, we know that training within services and when implemented as its own siloed solution is not an effective strategy for improving the lives of people with learning disabilities, autism and neurodivergence on a societal level and in the long term. It must be accompanied by and delivered jointly with the other proposals suggested within the consultation document and our response.

We elaborate on our answer in the following question.

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

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

The ALLIANCE believes that mandatory training is just a small part of what is needed to make lives better for people with learning disabilities, autism and neurodivergence. However, we would recommend that the Scottish Government make clear within the Bill how training would be delivered, who it would be delivered by and how the training would resourced.

Indeed the *See Hear Strategy* also notes that many people with sensory loss could be "dealt with through effective mainstream service provision" and that if "service staff have an awareness of the needs of people with sensory loss and appropriate skills/training to deal with these needs, then a wide range of these staff should be able to not only identify needs relating to sensory impairment, but also assess and provide simple solutions"[35]. Within it, training was identified as one of the potential levers for change.

Individuals with sensory impairments also have specific communication requirements. For example, information on conditions and medication must be explained clearly to people with sensory impairments, particularly as it can be more challenging for them to know how to administer this. However, people with sensory loss are currently missing from the consultation document. Subsequently, the proposed mandatory training should also cover visual impairment awareness and hearing impairment awareness training.

Additionally, the ALLIANCE found that many people wanted to see greater levels of training for staff on sensory awareness and skills. In our research, 46% of respondents saw this as one of the most important issues they wanted to see addressed[36]. This was the second most important issue on health and social care provision according to disabled people.

In our *Mapping Sensory Loss Awareness Training Across Scotland* paper, we found that there is no agreed definition of Sensory Loss Awareness training, that delivery is infrequent, training is largely unaccredited, that online delivery has decreased since the pandemic, evaluation methods vary or it doesn't take place and there is inconsistent involvement of people with lived experience of sensory loss at all stages of training development and delivery[37].

Although the findings are related to Sensory Loss Awareness training, we believe that the following recommendations could be applied more widely when also tailored to people with learning disabilities, autism and neurodivergence[38]:

- National Task Group
  A National Task Group could address the urgent requirement to determine what constitutes awareness training and ensure people with lived experience are involved; and develop a National Awareness Training Quality Framework and tiered awareness training programmes – with consistent aims, objectives, core programme components and robust evaluation methods. A national, collaborative approach via a National Task Group would utilise resources more effectively, ensure quality assurance and bring accreditation to a non-accredited arena.

- National training programmes

The aims, objectives, learning outcomes and core components of sensory awareness training are broadly similar regardless of whether focused on agency client group(s) or on Vision, Deaf or Deafblind people. However, there are nonetheless, differences that may lead to mixed messages. A national, tiered, awareness training menu of programmes would reduce any inconsistencies. It would also enable a consistent approach to review and refresh as approaches change and, for instance, language moves on. It would enable any training programmes to drive and keep pace with societal change.

- Quality assurance and accreditation
  The bulk of sensory loss awareness training currently delivered is not accredited. The lack of a quality framework and quality assurance is of concern and requires attention. Resource and capacity constraints place accreditation beyond the reach of most third sector organisations, particularly those operating at a local level, who, are more likely to be engaged in awareness training development and delivery. However, as noted previously, a National Task Group, collaboratively involved in development of a quality framework and accreditation would support organisations to deliver accredited training.

  Some national and local organisations have developed their own e-Learning resources. Such developments are resource and time intensive, particularly for organisations operating at a local level. In the research, many training providers emphasised that they adapt awareness training to meet the needs and time constraints of organisations requesting training. These adaptations again create and add further diversity to the plethora of provision, with a lack of quality assurance. Furthermore, with no quality framework in place, the organisation-centred approach to training development introduces further diversity and potential for mixed messaging. Collaborative development of Awareness Training Programmes and materials at a national level, would support delivery of a consistent message.

  For example, See Hear Highland Education and Learning Service (SHHELS) accredited Vision, Deaf and Deafblind e-Learning modules are accredited and widely available on the Turas platform. They are well used by a number of training providers, particularly HSCPs, as this provides a means of access to training for Home Care staff, potentially a transient workforce. The Vision and Deaf modules, developed in 2016, would benefit from refresh and update to reflect the social model of disability and a rights-based approach. Review and refresh of these modules could possibly be an initial task of a National Task Group.

- Appropriate training informed and led by people with lived experience

  It is crucial that development and delivery of sensory loss awareness training is informed and influenced by the voice of lived experience. Currently, it seems that much of this involvement is tokenistic, inconsistent and reliant upon voluntary involvement.

  We know that the most effective disability training is that which has been co-produced and co-delivered by people with lived experience.

  Given that 66% of people with sight loss of working age are not in paid employment, it is refreshing to observe that one third sector organisation that participated in the survey is moving from a volunteer development and co-delivery training model to one where people are paid for their time and given status as a commissioned trainer. Non-disabled people would not be expected to develop materials and co-deliver training programmes on an ongoing basis, free of charge. The impetus to change things for the better and to challenge and change the status quo is often viewed as sufficient ‘reward’ to engage people with lived experience.

  While it is vital that people with lived experience inform and influence the development and delivery of training, these individuals should have the background, skills and experience to contribute in an equitable manner. For instance, A significant number of training providers referred to the use of simulation exercises as integral components of awareness training programmes. These involve participants conducting tasks while wearing a combination of simulation spectacles, sleepshades and ear-defenders. These are also considered to be effective. However, consideration should be given to such practices, which can be regarded as at odds with the social model of disability and a rights-based approach. Indeed, some disability activists and researchers are opposed to the use of simulation exercises, considering them to provoke fear in some participants or hilarity, where sensory loss becomes the butt of the joke.

- Evaluation
  A national, consistent, evaluation structure is required where the impact of attendance at sensory awareness training is evidenced at six and 12 months post course. This will then generate an evidence-base to influence future training developments. Furthermore, it may create an evidence-base of any differential impact of online or face-to-face delivery. Currently, providers consider face-to-face to be a more effective mode of delivery. However, there is a lack of data to evidence this.

  The majority of sensory loss awareness training is delivered free of charge, with See Hear funding cited as supporting free delivery. In some respects, this is positive, as a number of organisations no longer have budgets for staff training. However, the Equality Act (2010) expects service providers to take an anticipatory approach, ensuring staff are trained and have, at least, basic sensory awareness. We suggest this requires training with a robust audit trail.

  Development of training at a national level, a refresh and update of e-Learning modules, and development of online assessment to provide employers with a robust audit trail, is potentially an untapped opportunity.

Funding for design, delivery and outcomes based evaluation of training programmes, and costings for people with lived experience's time and work, must be included in the LDAN Bill's Financial Memorandum.

Inclusive Communications

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

The ALLIANCE agrees with all of the proposals.

The ALLIANCE believes that there are substantive rights in the CRPD that should have a duty to comply as well as a duty to have due regard. This includes article 9 on the right to accessibility of the physical environment, transportation, information and communication, and services open to the public[39].

The ALLIANCE agrees that there should be a legal duty on the public and voluntary sector to proactively provide information and communications in a range of formats. There should also be better access and availability to this information. Further all local and national strategies should contain a duty to proactively provide alternative formats of communication, and include all public bodies.

We believe that this could be included within a Scottish version of an Accessible Information Standard, not solely for NHS but all bodies working with and supporting people with learning disabilities, autism and neurodivergence. However, the Scottish version of the Accessible Information Standards must be effectively implemented and build upon the England version as it is not without a need for improvement.

To elaborate, a review was conducted *NHS Accessible Information Standards* (AIS)[40]. Although the sets out clear steps needed to take to meet information and communication needs, significant actions were required to implement the AIS in full.

The following priorities were highlights to address gaps in implementation and add accountability necessary:

1. Training: public bodies, services, staff and volunteers must be informed of the AIS, its importance and how to meet it.

2. Record systems: a flag must be available and used to alert staff through a prominent notification on someone's records. It should also transfer to referrals or handover documentation. The flag should notify staff, when an appointment is made or the record updated, what actions to take to meet the individual's needs. The system should be capable of actioning alternative formats, for example sending an email or a large print letter.

3. Alternative contact methods: Providers must not rely solely on phone systems for contact. Alternatives must be in place to meet patients' needs.

4. Contracts: Information accessibility must be written into provider contracts and monitored as part of minimum commissioning standards. This means:
   - Embedding access costs in tenders and contracts
   - Accessibility is included as part of inspections, along with enforcement timelines and annual reporting

5. Dedicated Lead: An AIS lead in each service who is responsible for implementation and review.

6. Development: Providers should also review their existing services alongside people with lived experience.

7. Accessible complaints procedures: Including more accessible methods of promotion and availability in a range of alternative formats.

8. Email and Text Suggestion: The majority of patients responding to this survey indicated that email and text message would be preferred methods of contact with their GP surgery. Providing and promoting these options could be a simple and cost-effective measure.

9. Data oversight: Allow patients to access their own records and make amendments to their accessible communication needs, in person or via NHS Health Access/Online portal.

10. Video Relay Service: BSL interpreters should be made available remotely via VRS and VRI, on-demand, 24/7 to provide communication support at short notice or in cases where agency provisions fail.

It is highly important to remember that accessible information must be provided in a range of different formats. For example, Easy Read files do not always work for people with visual impairments due to the use of images which can cause some issues with screen reading software. Word documents also tend to be more accessible than PDF files.

We also know that people with learning disabilities, autism and neurodivergence also struggle to express themselves verbally, or may have little or no spoken language at all or experience situational mutism. However, there are many other ways to communication such as using sign language, Makaton, visual prompts, text, gestures etc.

People need timely access to high quality, targeted information in accessible and individually tailored formats (e.g. hard copy and digital; face-to-face; foreign languages; large print; Braille; Easy Read; BSL; electronic notetakers; captions; Alt-text) at every stage of their journey through SDS no matter their age, disability, gender, religion, socioeconomic status, ethnicity, or cultural background.

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

We would not agree with proposal 2 if it were introduced without other alternative formats accompanying it.

For instance, there appears to be emphasis on EasyRead as the main channel for inclusive communication. A distinction should be made between EasyRead and inclusive communication. EasyRead is just one format of inclusive communication.

Is there anything else that we should consider in relation to inclusive and accessible communication?

Accessible and inclusive communication should follow the Six Principles of Inclusive Communication, and should be public available in multiple inclusive formats including Community Languages, British Sign Language (BSL), Braille, Moon, Easy Read, clear and large print, and paper formats. The ALLIANCE recommends involving relevant experts – including BSL and language interpreters – at the earliest opportunity to ensure communications and information provision is inclusive for all[41].

The Six Principles are:

1. Communication accessibility and physical accessibility are equally important
2. Every community or group will include people with different communication support needs
3. Communication is a two-way process of understanding others and expressing yourself
4. Be flexible in the way your service is provided
5. Be flexible in the way your service is provided
6. Keep trying

Every body and service must ensure that different communication needs are inclusive. For example, many people use Augmentative and Alternative Communication (AAC). People who use AAC told the Scottish Government that help from specialists is invaluable, extra time is needed as conversations may be longer, and that communication can be tiring. To be aware of this, services must be person centred, to recognise and understand that every individual must be treated equitably.

Work carried out by the ALLIANCE demonstrated the issues that some people with sensory impairments have faced when seeking accessible information. In *My Support, My Choice: Blind and Partially Sighted People's experiences of Self-directed Support and social care*, one respondent described how their social worker did not realise how important accessible information was to promote greater independence[42]. They stated:

> *"I was not given anything in the form that I could read." Instead, the participant's social worker "decided it was up to [them] to read things out to me."*

People with sensory impairments must have greater access to accessible information. If this is not provided, their rights are infringed.

Similarly, in the ALLIANCE's *My Support, My Choice People with Learning Disabilities experiences of Self-directed Support and Social Care* respondents highlighted issues with and barriers to communication[43].

Issues and barriers included requiring more high quality information earlier, not being provided accessible information or documents even after requesting it, difficulty obtaining information on how to lodge complaints, a need for different channels for communication such as online chat functions, freephone support lines and direct email addresses to professionals and a lack of follow up to check understanding.

In interviewed we were told that good conversations require effective communication, access to information, prompt decisions, and good future planning. Unfortunately, 37% of people who responded to our research said that they were either “very unhappy” or “unhappy” with communication related to their care.

To illustrate, we were told about issues with communications formats, transparency and understanding:

“I was never told my options, I was never told about SDS, I only found out about it on YouTube. I started challenging once I learnt my rights but they shut the door on me. They told me they have no money but that’s not my problem. The social worker treated me like an idiot. When I spoke to a social worker last year I said I wanted to leave the support group […] they told me I can’t. Then they told me to get a PA but they won’t support me with that.”

“She [social worker] put words into my mouth. She thought I wasn’t capable to choose what I wanted [to choose] and what outcomes I wanted. And I said, ‘No, I can choose what I want, I’ve got a voice. Why are you putting things into my mouth?’ So, that was the difficult part of it.” When asked what is needed to stop this practice, the interviewee outlined the importance of allowing plenty of time for discussion and supported decision making (rather than social workers making decisions for people): “Just be with the person and go through the complete assessment. If people struggle then yes, I can understand that [social workers guiding a decision]. But if you are capable of saying what you want to do with that budget and what outcomes you need, then that is completely different – you can do that! I was really shocked with her.”

“I find it challenging when the communication is not clear, and when written communication is unclear. I like things written down. And the lack of transparency, those would be the main challenges”[44].

In relation to complaints, we recommend that the complaints systems should be available for access and use for people with sensory impairments, as well as people with learning disabilities, autism and neurodivergence. Where the consultation document states ways in which people can make complaints, screen reader friendly information must also be provided.

Research from the ALLIANCE and others has shown significant issues in the handling of social care complaints, which have acted as barriers to the realisation of human rights of people who access social care[45].

The LDAN Bill must ensure that there is a robust complaints system in place to enable people to effectively challenge any issues they are experiencing. We recognise that the Scottish Public Services Ombudsmen currently have responsibility for this, however, improvements must be made, and the ability to refer to an accountability mechanism must be accessible if a person's rights are not met in the first instance[46].

Based on research by the ALLIANCE and others, we propose the following in relation to complaints handling by public bodies for people with learning disabilities, autism and neurodivergence[47]:

- Everyone should have access to an easy to access, transparent, and fair complaints system.
- Any complaints system should follow human rights-based approaches, and be co-produced with rights holders.
- Complaints handling processes should not just consider the procedural aspects of a decision, but also whether fundamental rights were protected and that there was due regard to the rights holders' dignity throughout.
- Public bodies (and staff) should pro-actively and regularly inform

people who use their services about how they can challenge decisionand access complaints procedures and independent oversight, and that they can do so without fear of adverse consequences.

- Public bodies (and staff) should proactively signpost people to independent advocacy and advice services, highlight the benefits independent advocates offer, as well as providing reassurance regarding their independence.

- People should always have access to independent advocacy, advice and support, including interpreters and translators, for complaints and associated meetings, if they desire.

- Public bodies should maintain regular communication during the informal stage of challenging a decision and provide support (e.g. resources) for individuals asked to discuss formal challenges.

- Sources of mental health support should be made available to those pursuing challenges.

- Formal complaints processes should be timely and quick wherever possible.

- Processes should use plain, jargon-free, English.

- All information should be readily accessible in a range of accessible formats, e.g. BSL, Easy Read, Moon, etc.
- There should be clarity and transparency about the process and what it includes, including an indication of the general time frame to expect informal and formal complaints to take.

- Robust, disaggregated equality and human rights data should be gathered and used to monitor and analyse complaints, measure public bodies' accountability, and contribute towards progressive realisation of rights.

Data

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

The ALLIANCE agrees with proposals 1 and 4.

We elaborate on our answer in the following question.

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

The ALLIANCE queries proposals 2 and 3 due to the fact that only “some” public bodies would have to collect data and provide returns.

Alongside, there is only reference to people with learning disabilities and neurodivergence. There is no mention of autism or autistic people- they must be explicitly referenced and included within this section of the LDAN Bill.

As detailed in the ALLIANCE’s response to the Scottish Government’s consultation on the Equality Evidence Strategy 2023-25, intersectional analysis, co-production, and connecting public bodies, health and social care data are important in enabling Scotland to develop robust, evidence-based policy and practice that is responsive to the needs and requirements of the population, including seldom heard groups and those disproportionately and adversely affected by the COVID-19 pandemic and cost of living crisis[48].

In relation to placing duties for data collection on public bodies, such duties need to be backed with a plan to enhance analytical resources, improve guidance production, methods and quality assurance processes[49]. We also agree that there must be investment into analytical capacity to collate and analyse any data collated. This currently appears far too limited, and opportunities to collaborate should be explored instead of silo working.

Disaggregated data gathering and intersectional analysis, including monitoring personal outcomes, is essential to develop fully realised policies and practices that prioritise equal access to support and services for everyone. Such work should follow human rights principles of equality, non-discrimination, participation and accountability.

Improvements to data collection should begin with the tightening of definitions and enabling consistency of cross data collections to connect data across bodies and services. This would make it easier to draw out evidence-based insights to inform policy and decision making.
To avoid gaps and improve analysis, we recommend that there should be a duty for systematic and robust data gathering by local and national public bodies on people with learning disabilities, autism and neurodivergence, disaggregated by all protected characteristics, as well as other relevant socio-economic information like household income and the Scottish Index of Multiple Deprivation (SIMD).

Equalities monitoring data should be gathered, including demographic groups outwith the protected characteristics, to ensure a robust human rights based approach – so the rights of those who are potentially most at risk of inequalities, and have least access to services, are protected. For example, this may include (but is not restricted to) unpaid carers, care experienced people, survivors of trauma and/or abuse, and victims of crime.

It is important that this collection of data on people's experiences is regular, sustained, and spans the entire population of people accessing services and support in Scotland (longitudinal and national data collection). The questions to capture people's experiences should allow for personalised, qualitative responses as well as quantitative data analysis, and should be developed in co-production with people who access services and their families and unpaid carers. Decisions taken based on evidence from data collection and analysis should be clearly communicated to the public, people accessing care, and the workforce.

This prioritisation of both qualitative and quantitative data is essential if people's personal outcomes and rights are to be monitored and measured with a view to ensuring continuous improvement and progressive realisation of people's rights. A mixed methods approach that embeds a human rights based approach would help to ensure that appropriate weight and priority is given to people's experiences alongside nationwide statistics.

Such data should be published regularly, on a quarterly basis, and made available to the public (after following standard research ethics around anonymity for respondents), with a duty placed on Ministers, local authorities and HSCPs to respond to any evidence of poor outcomes or inadequate access for people. Analysis of results should be published and available to the general public on at least an annual basis and include intersectional analysis to monitor how policies are working in practice for different population groups across Scotland. This would enable targeted action to ensure everyone has access to high quality services and support.

We believe that although the proposal on developing a Scottish Learning Disability Mortality Review (LEDER) is worthwhile, it seems that solely looking at health inequalities through a mortality and death perspective is limited as health inequalities perpetuate throughout the life course and efforts should made to spot and find solutions to them without people with learning disabilities, autism and neurodivergence having to die to inform policy. Alongside this we think it appropriate that resources should be given to generate data through the Annual Health Checks (of which we consider in more depth in the following section). Data collated from the checks can then inform the suitability, shape and scope of the Scottish LEDER programme. Relevant organisations should be appropriately and sustainably resourced to carry out this data collection and analysis at national and local levels including a new or existing Commission, review panels, third and independent sector.

If a Commission were created or added to they must have responsibility and powers to be able to push for enhancements to current data collection which could include the Official National Statistics. Responsibility should also link in with the Government's Chief Statistician. This analysis should include use of Equalities and Human Rights Impact Assessments as practical tools to inform policy and assess its impact.

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

The Scottish Government knows that it does not have enough information on the lives of people with learning disabilities, autism and neurodivergence. Alongside this, progress in this area has been slow.

Whilst we acknowledge former policies that have been put in place for people with learning disabilities and autism, they will not be truly and wholly effective for the population as the data is limited and only provides a partial view. Without this data they do not know what is happening to people and what could make their lives better. Or in other words, current data limitations can "restrict evidence-based policy making and planning"[50].

We note that the Scottish Government has previously said that "the costs and challenges of collecting and analysing data, and intersectional data in particular, are considerable"[51]. However, we believe that in improving the gathering and analysis of data, targeted policy interventions can be truly effective in improving the lives of all people including those with learning disabilities, autism and neurodivergent.

In our *My Support My Choice* research it was demonstrated that there are concerning gaps in national and regional data gathering and analysis around social care. Disaggregated data gathering and intersectional analysis is essential to develop fully realised policies and practices that prioritise equal access to support and services for everyone, following human rights principles of equality, non-discrimination, participation and accountability[52].

A significant reason why equalities data needs improving is down to protected characteristics being treated in a boxed-in, siloed way[53]. There needs to be a concerted effort in improving understanding of intersectionality, how it impacts people's experiences, and how different characteristics interact. For instance, no one is just a disabled person. We believe that there should be specific duties to gather and use intersectional data to advance equalities for people with learning disabilities, autism and neurodivergence[54].

A significant development from the *Same As You* strategy was the formation of the SCLD. From 2008, the SCLD's eSAY Project (now Learning Disability Statistics Scotland (LDSS) collected information on people with learning disabilities known to local authorities to support local and national policymaking and to monitor the progress of the *Same as you*[55]. By collecting the data in this way, several issues arose. Firstly, by only collecting people 'known' to local authorities, hidden populations would be not supported or registered by services[56]. Secondly, local authority data was insufficient because the recording of up-to-date information was limited and inconsistent[57]. As a result, data sent to the Scottish Government for policy implementation would not be accurate or reflect the needs of people with learning disabilities.

If LDSS were to be restarted it would need to be scrutinized and reviewed, to improve its data collection methods. For instance, the people and groups it is collected on must be broken down into additional characteristics and include people with learning disabilities, autism and neurodivergence, to find those not already known or shown in the system.

Data should be considered alongside the other overarching themes such as inclusive communications. For example, if people cannot take part in surveys or share their insights due to data collection methods being inaccessible then the data that is needed cannot be collected.

Data sharing should also not be restricted to health and social care staff working directly for Community Health and Social Care Boards or local authorities. It is important that third sector organisations providing services to people should have access there is truly integrated sharing and understanding. Likewise access to data and the assessment of appropriate access should be decided upon and led by the person whose data it belongs to.

In our *My World, My Health* project, exploring how people living in Scotland felt about data use in public health services. One of the key conclusions was as follows[58]:

"An overwhelming majority of our participants stated that the individual whose data is collected, processed, and shared should be in control of how this is done. It was also argued that there needs to be rigour in the use of data, in line with the individual's consent. Furthermore, the purpose of the data processing should be for the benefit of the individual or wider society. There should be no adverse effects to individuals whether they opted-in or -out of sharing data."

We recommend that legislation should be developed in line with the 9 Core Principles for good practice in data collection and digital systems for healthcare, from the My World, My Health project.

Independent Advocacy

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

The ALLIANCE agrees with the proposals, with amendments suggested below.

However, in relation to proposal 1, we recommend that a right to advocacy should be considered in relation to people with learning disabilities, autism and neurodivergence. A right to advocacy is vital so that people who need in whatever service they are using don't fall through the gaps and are unable to access support.

Advocacy is crucial in helping people navigate barriers to realising their rights and accessing services and justice.

Right to advocacy is a human rights issue. The UNCRPD states that the disabled person is ‘the decision maker; the support person(s) explain(s) the issues, when necessary, and interpret(s) the signs and preferences of the individual’[59]. It recognises that in some circumstances disabled people will require support with decision-making to realise their autonomy and citizenship rights[60].

Advocacy in domestic law in tandem with the UNCRPD enables equal recognition, facilitating access to justice for disabled people at both individual and systemic levels. Before the UNCRPD, however, supported decision-making and advocacy were promoted through social movements of disabled people to ensure their voices were heard, to both protect and realise their civil rights: captured by the saying ‘nothing about us without us’[61].

We believe that there must be a provision within the Bill guaranteeing a right to advocacy for people with learning disabilities, autism and neurodivergence. This should be provided alongside provision of rights advice and inclusive communication to make sure that everyone is able to access their rights equally[62].

Further, although any advocacy provided should be independent from public bodies and services, the default advocacy type should not be independent advocacy as it is too narrow. Instead, different advocacy models should be targeted for use for the most appropriate service and where it would have the most benefit. For instance, collective advocacy is appropriate to support groups to address systemic human rights issues, whereas individual independent advocacy and citizen advocacy should be provided to those who experience the greatest barriers to having their rights realised. Indeed, people with learning disabilities, autism and neurodivergence benefit specifically from longer term partnership and community, which is locally based and grass roots.

Early involvement of independent advocacy contributes to prevention and has a potential role in contributing to early intervention and preventative spend[63]. Much of the current provision of independent advocacy is directed by funders towards statutory interventions, such as mental health tribunals, adults with incapacity meetings, and adult support and protection case conferences, which are all reacting after an incident has occurred. As a result, much of the population does not get access to advocacy.

The *Mental Health (Care and Treatment) (Scotland) Act 2003* gives a statutory right to access independent advocacy to anyone with a mental disorder. This currently includes people with a learning disability and autistic people. This is the only statutory right to advocacy for adults with learning disabilities.

As it currently stands, the right and entitlement to advocacy is dependent on being labelled as having a "mental disorder". This term is currently being reviewed for amendment to not incorporate people with learning disabilities. If and when it is amended, and no longer applies to people with learning disabilities, they should not lose their right to access advocacy, and local authorities, HSCPs and third sector, should continue to have the duty to advise on the right to advocacy and to secure the provision of advocacy through public funding.

In our *My Support My Choice* research, people with learning disabilities told us that they accesses independent advice and advocacy services for a range of reasons[64]. However, we were also told that provision is inconsistent across Scotland especially in rural areas, the highlands and islands.

These included access to information, access to needs assessment criteria, assistance to develop a support plan, mediation with social work professionals, support for appeals and advice on employer related issues. In addition various forms of advocacy were mentions including local user-led service organisations, independent advocacy, solicitors, national legal aid organisations and carers' centres.

Respondents told us that[65]:

"I would advise people to try to get as much information/advice from organisations other than social work as to how the process of SDS is supposed to be carried out. In my experience, it depends on how good the social worker is at SDS".

"Get independent advice and speak to other people who have it. We always get told 'you can't have that' and then meet someone else who has it!".

"Get advocacy support and know what you're entitled to as council will not be forthcoming with support".

Further, when asked whether access to independent advocacy made Self-Directed Support (SDS) easier for them, over half "strongly agreed". Similarly, when asked whether access to independent information and support made SDS easier for them, 78% of respondents with learning disabilities "strongly agreed".

They also highlighted that the third sector was vital in assisting support. However, an interviewee told us that their local authority had planned to cut the budget for the local organisation, forcing people to access alternative services far away, but due to the need of local users it was able to continue operating just with alternative revenue streams.

There is clear evidence of the provision of advocacy leading to better outcomes for people. The ALLIANCE found this when delivering the Welfare Advocacy Support Project, targeted at people going through assessment for Personal Independence Payment (PIP) and Employment and Support Allowance (ESA) in four pilot areas in Scotland[66].

Additionally, our member, the Scottish Independent Advocacy Alliance's (SIAA) proposed the following to increase access to advocacy:

- Ensure that those with current rights to independent advocacy in Scots law can access it.
- Utilize different models of independent advocacy including collective advocacy to support groups to address systemic human rights issues.
- Provide individual independent advocacy and citizen advocacy first to those who experience the greatest barriers to having their rights realised.
- Progressive realisation of rights should be supported by sustainably increasing access to independent advocacy so that eventually it can be accessed by anyone with a human rights issue. This should be done in consultation with existing grassroots and local independent advocacy organisations and groups.

To enable this, public bodies, health and social care services, the third and voluntary sector should be given training and information on advocacy and advice services so they can appropriately signpost and refer and recognise the value of such services.

Alongside this, and as referred to in our previous question, a part of advocacy is making sure everyone can understand and access their rights. A significant part of this is providing inclusive communication. As a starting point, information should be made publicly available in plain English and free from jargon.

Accessible information should follow the *Six Principles of Inclusive Communication*, and should be publicly available in multiple inclusive formats, including Community Languages, British Sign Language (BSL), Braille, Moon, Easy Read, clear and large print, and paper formats. The

ALLIANCE recommends involving relevant experts – including BSL and language interpreters – at the earliest opportunity to ensure communications and information provision is inclusive for all.

For proper implementation, sustainability of the advocacy sector is vital with adequate resourcing, training, quality and improvement monitoring otherwise there is a real risk that rights holders will not have access to independent advocacy and independent advocacy organisations will not be able to provide their essential services and expertise. For example, the SIAA *Advocacy Map: Sustainability of Independent Advocacy in Scotland* report highlights that the demand for independent advocacy has significantly increased and is outstripping resource, resulting in a position that is not sustainable for the future[67]. Additionally, 71% of respondents identified groups with an unmet need for independent advocacy.

Health and Wellbeing

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

The ALLIANCE agrees with the proposals.

We believe that the Scottish Government already has the policies and tools in place to make change and improve the lives, health and wellbeing of people with learning disabilities, autism and neurodivergence.

We would also like to note that most of the proposals are not new to us, our members or people with lived experience. The reason we note this is that although these have already been committed to by the Scottish Government, they either have been delayed, haven’t taken effect or the way in which they have been implemented means that people with learning disabilities have not reaped the intended benefit of them.

Everyone has the right to health and to have access to healthcare. However, these groups experience unequal access, assumed ill health, diagnostic overarching and limited shared decision-making. It is imperative that barriers to healthcare and health inequalities are responded to, and that existing problems are not perpetuated.

Through our Investigating Knowledge and understanding of the Right to Health report, we found that there is[68]:

- A lack of understanding in relation to the Right to Health, that this is particularly acute for underrepresented and marginalised groups, that health information is often inaccessible.
- A shortfall in understanding by NHS staff and services of people's entitlement to the right to health.
- No accessible recourse for people whose human rights are not being met, despite the Scottish Government's promise to incorporate human rights into legislation in Scotland.
- A need for policy action to address those social and economic determinants of health that have a negative effect.

We recognise the impact of austerity and funding cuts on the healthcare systems and services. However, the system as is stands is not equitable or available to all. Equity of access to services, from the point of access, needs to be ensured for all; this can only be achieved if a knowledgeable and skilled workforce is available to support people who access services, and by taking a preventative approach that is not crisis-led.

According to the UNCRPD Survey, 82% of respondents felt disabled people still struggle to access the health care they need[69]. There remain treatment backlogs due to services being suspended or reduced during the pandemic makes it likely that people will be waiting a long time to get the treatment they need[70].

To combat this, healthcare and services should use a human rights based approach, and the LDAN Bill should reference relevant human rights policy and legislation, including legally binding international treaties like the International Covenant on Economic, Social and Cultural Rights (ICESCR). When there is no mention of human rights or there is an apparent discretion towards the application of human rights, they can be easily be ignored or pushed to the sidelines.

If the strategies proposed are published, we urge the Scottish Government to create actions with a human rights based, person centred and outcomes focused approach using an intersectional lens. Such strategies must also be co-produced with the people they are written for. There must also be actions within it with a focus on using preventative care and tackling health inequalities.

We believe that the proposals to introduce statutory strategies, guidance and reviews could be a positive development. However, there must be actions incorporated, and a duty/requirement to implement such actions, to ensure that the strategies do not become tokenistic and rhetorical without implementation.

As with the LDAN Bill itself, national and local strategies must be designed and produced by the people they are written for. As stated by the disability movement "Nothing about us, without us". If people with learning disabilities, autism and neurodivergence are not included or seen by the strategies, it is unlikely the actions within them will have any real and impactful effect.

A review of national and local strategies must take place to ensure appropriate scrutiny. We believe that this could be included under the responsibilities of a new or existing commission or the proposed legislative review panel. For reviews to be effective, evaluation measures such as outcomes should be developed for a clear route for public bodies to work towards. Reviews must include and be co-produced and led by the people using the support and services.

Additionally, although involving people in their healthcare using shared decision making (SDM) is promoted through policy and research, unfortunately its implementation in routine practice remains slow[71]. Person centred care and the inclusion of patients in decisions has been shown to increase patient engagement and satisfaction, decrease unwanted health service variation, and improve outcomes for disadvantaged patients[72]. Shared decision making is an ethical imperative.

As referenced in previous sections, data is key to knowing which actions are needed for strategies to enable the most effective support and interventions to reach people with learning disabilities, autism and neurodivergence. There is currently an under identification of people with learning disabilities, autism and neurodivergence's health needs and outcomes[73].

One way of gathering such data is by implementing the proposal on Annual Health Checks (AHCs). However, we are concerned by feedback from ALLIANCE members and members of the public that the implementation of AHCs has been delayed[74].

Internationally, research supports health checks for identification of treatable health conditions, however in the quality of health checks varied[75]. It evidence that primary care practices where development of services for people with learning disabilities is passively endorsed, may be less likely to proactively implement service improvements. People with learning disabilities were sometimes unaware they could have a health check, and aligned with previous research this highlights the role of direct support staff and importance of training on the health needs of people with learning disabilities.

Training is vital in reducing barriers to primary care for people with learning disabilities[76]. In accordance with this, training the broader teams including receptionists, sharing good practice via demonstrating annual health checks and targeted support for practices, were found to contribute to increasing health checks and service improvement.

UK-wide guidance highlights the value of learning disability champions, and practitioners with the role were key to driving primary care improvement and innovation, through training, data collection and support for practices less experienced in the care of people with learning disabilities[77]. A bespoke, flexible and personalised service (eg, the receptionist knowing your name), went some way to addressing barriers faced by people with learning disabilities in primary care.

Additionally, an alternate study found that where there had been slow progress in implementing AHCs was attributable to: uncertainty over who was eligible; limited awareness in general practices about the legal duty to make 'reasonable adjustments' to facilitate access; limited awareness of AHCs and their potential benefits amongst carers and adults with intellectual disabilities; and in some cases scepticism that AHCs were either necessary or beneficial[78].

Accordingly, to assist in the implementation of AHCs, we recommend that[79]:

- Potential strategies are published to increase implementation within local and regional areas
- There is strategic leadership within organisations and an embedding of actions to reduce health inequalities in strategy documents,
- The use of good quality data to create a benchmark against which to measure progress reinforce the importance of implementing health checks.
- Data on people with learning disabilities, autism and neurodivergence is improved, updated and validated. Where primary care services do not have this data, alternate support services should be enabled and empowered to signpost and refer people to receive Annual Health Checks.
- Reasonable adjustments, such as inclusive information and flexibility in delivering health checks, should be put in place to ensure that health checks are accessible.

In relation to the proposal on Patient Passports, we agree that patient passports allow for needs and preferences to be communicated in an accessible way as demonstrated in our member PAMIS' innovative Digital Passports[80].

Indeed, the PAMIS digital passports provide person centred and citizen owned approach and insights into people with learning disabilities lives, provide practitioners with a better understanding of how to meaningfully engage and make a valuable contribution to those living with learning disabilities.

Effective communication and understanding between people with learning disabilities and health care workers could also be supported by the introduction of citizen owned digital passports as standard. These would hold vital health care information about the person as well as any support needs, allowing individuals to share this with health care and other staff when they chose.

Further, studies outline the benefits of using digital personal health records in improving the quality-of-service delivery to patients[81]. Digital personal health records help reduce miscommunication between patients and nurses and help other nurses provide continuity of care with information sharing. These findings also emphasize that the development of health passports needs to be planned systematically to ensure their use and ensure consumers receive optimal benefits[82]. Empowering people in maintaining health is an important element of life continuity and well-being, so that they are an active participant[83].

We believe that PAMIS' Digital Passport tool should be used as a template for the development of the Scottish Government's Patient Passports as it was recognised as a gold-standard resource in helping children and young people overcome exclusion.

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

The ALLIANCE’s *Five Ambitions for the Future of Health and Care* outlines five key themes for achieving transformational change[84]. These are focused on ensuring everyone’s rights and dignity are respected, leading courageously, reimagining how we invest in social services, measuring success based on personal and rights based outcomes, and sharing power and addressing imbalances among individuals, sectors and policy makers. We would urge that the LDAN Bill reflect these Five Ambitions to encourage everyone involved in healthcare to think ambitiously about the future of our public services, and what is needed to support everyone to thrive.

In addition, we would also recommend that there is explicit reference to equality and intersectionality. Taking an intersectional approach to policy and practice means recognising that some people experience infringements of their rights because of inequality and discrimination related to their characteristics or how their characteristics intersect and taking action to mitigate and prevent this[85]. In addition, achieving outcomes will not look the same in practice for everyone receiving treatment and accessing services.

A way for equality and intersectionality to be applied practically is for there to be consideration made to applying the Availability, Accessibility, Acceptability and Quality (AAAQ) framework to policy and [86]. Additionally, the PANEL (Participation, Accountability, Non-discrimination, Empowerment, Legality) principles can be applied to incorporate human rights within the Bill[87]. These support work and services to be person centred, and ensure support is targeted at the people who need the most help.

We are concerned that specific actions to tackle health inequalities referenced. Health inequalities are unjust health differences that occur between social groups[88]. Their fundamental causes lie in the socio-political power relations between population groups and social classes, and in the variations in the distribution of power, money and resources that result. These, in turn, result in differences in environmental and individual resources (e.g. the quality and availability of employment, housing, transport, access to services, and social and cultural resources).

There is increasing evidence from a variety of sources that people living with learning disability suffer disproportionately from health problems and are more susceptible to a range of illnesses and disease processes than is seen in the general population[89]. It is also apparent that their health needs are greater and more frequently unmet.

Indeed, people with learning disabilities have more health need than the general population and those health needs are different and require more specialized services. There is evidence of poorer outcomes and less effective health interventions for people with learning disabilities in Scotland. For example, people with learning and intellectual disabilities die up to 20 years earlier than the general population, often from avoidable causes[90]. It was found that respiratory disorders are a leading cause of death among people with learning/intellectual disabilities including preventable and treatable conditions such as pneumonia and aspiration, for example due to swallowing problems.

Such health inequalities are perpetuated by barriers to accessing healthcare. These barriers are experienced disproportionately by people with learning disabilities, autism and neurodivergence. For example, people living in rural areas experience barriers to accessing health care because of a lack of accessible and affordable) public transport[91]. Attitudinally, people have said that the atttitudes of health care staff was a barrier to accessing treatment as they feel ‘fobbed off’ and like their expertise of their own condition is not valued. In addition to this, although a greater proportion of LGBT+ people are disabled, there is a lack of understanding within health and other services of the needs of this group. LGBT+ young people said there was a tendency for doctors to attribute any health issues to age or LGBT+ status[92].

Further, such barriers to reaching equal health, for example, may include clinicians attributing lower levels of intellectual and social functioning to the person with learning disability[93]. This means they may be less likely to offer screening or assessment or to prescribe treatment routinely offered to the majority of the population. This is an example of 'diagnostic overshadowing' by which clinicians unintentionally focus on the background of learning disability to explain the presence of more immediate health problems. Not offering screening or testing and so depriving people of the potential benefit from aids or adaptations leads to even more difficulties for people with already poor communication skills, which in turn exacerbates their presenting condition and reduces overall quality of life.

In terms of communication barriers, there is a lack of choice and availability of inclusive communications in healthcare. For instance, there is limited availability of interpreters in health care settings, people have not been informed of changes or updates in health care, and disabled asylums seekers struggled to access healthcare due to limited information and staff not knowing what they are eligible for[94].

Additionally, people with sensory loss are not having their rights to accessible information met by NHS Boards which resulted in patient confidentiality being breached due to individuals having to rely on others to read appointment letters on their behalf[95].

Such unequal access is further demonstrated with the fact that children and young people with learning disabilities and autism have been sent to England or treated in inappropriate settings because there are no dedicated NHS mental health inpatient units in Scotland[96].

In relation to children and young people, we feel that their health and wellbeing must be incorporated within the LDAN Bill. This must be aligned with the United Nations Convention on the Rights of the Child, and as a result human rights based, outcomes focused and intersectional. For example, Black and Minority Ethnic (BAME) children are more likely than white children to have missing or incomplete information in their development review[97]. As BAME children are consistently less likely to have ‘no concerns’ in their development reviews, any gaps in information could mean that support needs of these children are not being identified[98].

During a consultation on the *See Hear Strategy*, we heard from people with lived experience of deafness, sensory loss and dual sensory loss on what they want to experience in health care services and their interactions with healthcare professionals[99]. Although much of the feedback centred on the need for better sensory awareness and communication skills, it reflects a wider problem, and the concerns that people genuinely have and don’t feel are being met.

For example, participants told us:

“I had a bad experience at [name of hospital and location]. I’d had a little operation for a cancer on my face to get stitches out. The doctor who did the operation was great, but… I tell people straight away I’m very Hard of Hearing – but I went into this room, and there was a young foreign doctor, and he was facing away from me and I said ‘I’m sorry I can’t hear you I’m deaf.’ And he just turned away and pointed to the bed. And all he did after that was point. I just felt awful, like a lot of people assume if you’re deaf you’re not the full shilling.” (Focus group participant)

“For example, if I attend a health appointment and [an interpreter] pitches up, and I say, ‘I don’t need an interpreter, this is a private matter, this is gender specific.’ I say, ‘I don’t want an interpreter for this.’ And they say, ‘no, you need an interpreter.’ And I say, ‘no, it’s my choice, not the NHS!’”

“Medical staff need more training to deal with partially sighted people.”

“Better access to working loop systems in all public buildings, reception areas; better communication in GP surgery reception areas.”

“Some focus on supporting mainstream services to offer support where people cannot access specialist support.”

“Timely access to Audiology services would contribute to "living a good life”

“My experience of health care is that it treats people as ‘the eye’ and not the whole person”[100].

People highlighted the value and power in developing and implementing preventative approaches to health and healthcare that address the social and commercial determinants of health:

“I would like to go swimming on my own regularly but it’s only possible in a lane with a rope so I know I’m not veering off too far. Could pools and gyms have people to help? At the gym, it’s difficult to transition from one machine to another. They could allocate specific times to people with sight loss. They have sessions for people with sensory issues e.g. reduced noise. Exercise is social and important for mental health, you make friends when you go to these places”[101].

It was highlighted that healthcare encompasses physical and mental health:

“I’ve had sight loss my whole life, [then] my sight deteriorated, and I had to stop going to work. I became very depressed, and there was a long waiting list for support through the GP. With [third sector organisation] I didn’t wait very long – it was a life-saving service after having to give up work. I was home alone while my [partner] was at work. The GP didn’t know what to do; they were inexperienced. It felt useless. I didn’t want to be on antidepressants. With [third sector organisation] there was quick access which made a difference. GPs need to know about different help and facilities available for people with sight loss. I had guide service before

getting a guide dog and a refresh of white cane training to learn new routes. I felt human again, I'd felt so low and down"[102].

Approaches to addressing health inequalities have fallen into three broad categories[103]:

1. A focus on improving the health of the most disadvantaged groups.
2. A focus on reducing the gap between the best and the worst off.
3. A focus on reducing the entire social gradient

According to NHS Health Scotland, a way to reduce the steep social gradient in health, actions must be universal, but with a scale and intensity that is proportionate to the level of disadvantage. Methods include proportionate universalism, realistic medicine and value based health and care.

It is likely that to maximise health inequality reductions, redistributive policies, such as progressive taxation, will be required in order to change the gradient itself. In practice, a combination of different approaches will be required to maximise population health and minimise health inequalities.

Recently, there has been the introduction for the Assisted Dying for Terminally Ill Adults (Scotland) Bill. The purpose of the Bill would be to allow terminally ill people to request assistance from a registered medical practitioner to end their life. In the context of the pandemic, and the use of Do Not Resuscitate (DNR) orders on disabled people, loss of support and increasing negative attitudes and discrimination, disabled people's organisations are very concerned about the introduction of legally assisted suicide but have few resources to robustly challenge campaigns for assisted suicide[104]. Whilst the ALLIANCE agrees with individuals rights to choose protections must be placed within the Bill so that such orders are not use to target people with learning disabilities, autism and neurodivergence.

Healthcare for people with learning disabilities, autism and neurodivergence is been of a much lower standard than the rest of the population. This is reflected in mental health care. Disabled adults are more likely to have experienced an increase in moderate to severe symptoms of depression[105]. Autistic people and people with learning disabilities have disproportionately high rates of mental health issues[106]. Similarly, the mental health of people with sensory impairments was disproportionately impacted during the pandemic[107]. Although the worst of the pandemic over, access and availability to services and supports for mental health has decreased, in part due to waiting times and lack of understanding of learning disabilities, autism and neurodivergence.

We believe that the LDAN Bill must include actions to reflect the unmet needs of people with learning disabilities, autism and neurodivergence.

Mental Health and Capacity Law

Do you agree with this approach?

Yes, we agree with this approach.

Please tell us why?

We recognise the reasoning behind the Scottish Government’s approach to Mental Health and Capacity Law, the ALLIANCE considers the introduction of the LDAN Bill provides and opportunity to change the law to enable the proposals put forward.

This is hugely important to people with Autism and learning disabilities. First and foremost autism and learning disabilities are not mental health conditions, however the strategies sit within the Minister for Mental Health’s portfolio.

According to SCLD, the notion that learning disability and mental health are the same thing is not uncommon. Sadly, such confusion also obscures the fact that the incidence of mental ill health amongst people with learning disabilities is unacceptably high[108].This is due to the stigma and isolation which still persists in relation to people with learning disabilities, and which all too often has a detrimental effect on their physical health too.

Subsequently the perpetuation that all people with learning disabilities, autism or neurodivergence might be more vulnerable or lack capacity to make choices for themselves leads to them having their independent and decision-making taken away from them.

Further, current laws in Scotland reinforce the ideas that people with learning disabilities, autism and neurodivergence are a drain on society, need to be looked after or separated. To illustrate, the *Mental Health (Care and Treatment) (Scotland) (2003)* allows the detention, supervision and compulsory "treatment" of those classified as having a "mental disorder"; the *Adults with Incapacity Act (2000)* allows legal capacity to be removed and a substitute decision maker be appointed solely on grounds of being "mentally disordered"; the *Criminal Procedures (Scotland) Act (1995)* allows an offending person to be denied a trail and detained based on being deemed "mentally disordered".

The Mental Welfare Commission investigated detentions under the Mental Health (Care and Treatment) (Scotland) Act 2003 between 1 March 2020 and 28 February 2021. This study found that detentions increased by 9.1% during this time (in comparison to a five year average increase of 5% year on year). The lack of Mental Health Officer consent in emergency detentions during this period was also highlighted as a major concern, with consent present in 43.8% of cases, a drop of 7.8% when compared with the average from the previous five years[109].

In addition, social circumstance reports dropped from previous years, another safeguarding process that appears as retrogressive, which in turn can be understood as a diminishing of access to human rights. Also of serious concern was an increase in detentions of visible minorities. This again highlights serious issues of multiple discrimination impacting on the human rights of disabled people in Scotland.

This is reflected in the fact that 56% of respondents to the UNCRPD survey felt that DDP's right to make their own decisions is not protected. A large minority were not sure (30%)[110].

For instance, there is a tendency for guardianship applications for people with learning disabilities to be uniformly granted[111]. However, Lack of resources for regulatory body means monitoring of guardianships is compromised[112]. alongside there being no mechanism for people to reject appointed guardians[113]. This is demonstrable as the number of people subject to a guardianship order increased by 60 between 2019/20 and 2020/21[114]. The Coronavirus (Scotland) Act 2020 introduced 'stop the clock provisions' to delay the expiry of guardianship orders during the pandemic, extending orders in force during this time by 176 days.

Research from People First also raised serious questions with regard to substitute decision making[115]. This research published in 2017 showed evidence of an overwhelming tendency for guardianship applications relating to people with a learning disability being uniformly successful. This has created an environment where substitute decision making occurs across a wide range of decisions, dehumanising people as they are informed that they are not allowed to make decisions for themselves[116].

While capacity has been contested legally, and some decisions may need advocates, the PANEL principle of participation should enable people to have involvement in all decisions. A focus on mental capacity (understood as capacity to make decisions independently), as opposed to that of people's ability to co-produce decisions, further entrenched this inequality.

High legal costs for both applicants and the State are creating further barriers in these processes.

Of further concern is the ability of the Scottish Government, local authorities and public bodies to ensure that guardianships are working as they should be. The monitoring of these guardianships is compromised by what appears to be a lack of resources of the regulatory body. There is no current mechanism for people to reject appointed guardians, which emphasises a gap between the recognition in law between disabled and non-disabled people.

This leads to a situation where it is possible that a disabled person is placed in a guardianship arrangement that they do not want, and where, due to a lack of State redistribution of resources, their Guardianship can proceed free from regulatory oversight. These factors raise serious concerns as to whether all disabled people do in fact enjoy equal recognition before the law.

Specifically the Mental Health Act was designed in such a way that keeps patients in hospital, perpetuating their label of 'dangerous', even after illnesses have been treated.

Unfortunately, this was starkly illustrated during the pandemic. For example, detentions under the Mental Health Act increased by 10.5% from 2019 to 2020, compared to the five year average increase of 4.5%[117]. Additionally, the consent of a mental health officer in emergency detentions was not given in over half of cases. From an intersectional perspective, detentions also perpetuated racial inequalities as higher numbers of BAME people were detained compared to the rest of the population.

The Mental Welfare Commission studied in detail 10% of all discharges from hospitals to care homes from March to May 2020. Of the 457 cases, the Commission found 20 of these cases were considered 'clearly unlawful'[118]. In addition, in 78 out of 267 cases that involved power of attorney, those working in the hospital discharge lacked full awareness of the powers held by attorneys and guardians. In order for this human right to be upheld, it is essential that all involved with these processes fully understand the legal rights of the people involved, and the responsibilities of themselves as duty bearers. The report also noted that the issues raised were not exclusively the result of the pandemic.

Further the Rome Review, the Scott Review and the Baron review recommended that the Scottish Government use and apply the UNCRPD's definition of disability[119]. This definition change would amend the meaning of 'mental disorder' within the 2003 Act and remove disabilities from it. However, the Rome Review also left room for people with autism and learning disabilities to be detained even if they don't have a mental illness[120]. Thie is despite finding that people with learning disabilities' and autistic people's right to health had either not been met, was limited, or harmed.

Despite the ongoing Scottish Mental Health Law Review of mental health law and practice, Disabled People's Organisations (DPOs) report that adults with learning disabilities are not being included in the Review's discussions on supported decision-making[121]. If priority is given to the clinicians and medical professionals within this decision making space, people with learning disabilities, autism and neurodivergence are further excluded, and the medical model takes precedence and diminishes the progress that the social model of disability has made in raising disabled people's experience and voices.

The Scottish Government and Scottish Parliament should act on the findings from the Independent Review into Learning Disability and Autism within the Mental Health Act and legislate to end detention in hospital on the basis of disability[122].

Social Care

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

Yes, we agree with the Scottish Government proposals as a starting point.

Please refer to previous sections in answer to these proposals.

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

Is there anything else that we should consider in relation to social care?

We believe that all of the proposals contained within the Learning Disabilities, Autism and Neurodivergence Bill consultation document are agreeable. There should also be the inclusion of people with sensory impairments within the Bill.

Social care has seen incredible pressures in funding over the last decade, evident over the last decade. The COVID-19 pressure being one of them. In 2020-21, around 1 in 25 people in Scotland were reported as receiving some form of social care support[123]. According to the Scottish Government, in line with their commitment to increase social care spend by 25% by 2026, the budget for 2022-2023 allocated £1.6 billion for social care and integration[124].

Audit Scotland have set out stark warnings that there are ‘huge challenges’ facing the sustainability of social care. Key challenges include funding settlements and workforce planning. There are currently 209,690 people working in social care in Scotland— this represents 8% of the total employment in the country. This means that the sector is not only key to the health and wellbeing of Scottish society, but to the Scottish economy too. The profession is not well resourced and a ‘typical’ contract for someone providing frontline social care is precarious, has low pay and poor working conditions. It is important to also note in this context that around

84% of the workforce are women. The result is that staff turnover and vacancies remain high. The highest rates of vacancies were reported in housing support, care at home services, care homes for older people and care homes for adults (60%, 59%, 55% and 48% respectively).

Research from Inclusion Scotland sets out the reality that disabled people face when accessing services with 9 in 10 feeling that they were often treated unfairly due to their disability or impairment when accessing services[125]. Just over 80% noted that this feeling was due to the attitude of service providers, and 72% mentioned that the design of services was an issue. The report also sets out how lack of control over services impacted on their experience, alongside invasive questioning when accessing services[126]. The non-discrimination and equality standard of the PANEL principles is not evident in such accounts.

Self-directed Support (SDS) and social care are underpinned by the fundamental principles of choice and control and the human rights principles of equality, non-discrimination, participation and inclusion. The goal of the SDS legislation was to shift the balance of power from people who provide services towards those who access them. In this way, people were to become pro-active agents instead of passive recipients of care. Social care should ensure every person in Scotland can reach their full potential.

This means a system of social care which addresses the problems faced by individuals, in the communities they live, before they arise. Consequently when effectively implemented, SDS has positive outcomes but there is a lack of consistency in SDS provision[127].

Much of the critique stems not from SDS itself, but its implementation, and particularly the different rates of implementation across Scotland's 32 local authorities. Scottish Care research called for greater collaboration and human rights based approaches to implementation, spaces for dialogue surrounding the issues of implementation and further analysis of how much SDS has actually changed the delivery of social care[128].

Given the strong association between good support and wellbeing, our members agree with the recommendations in the Independent Review of Adult Social Care. Specifically, people must be able to access support at the point they feel they need it, to allow a greater emphasis on prevention and early intervention[129].

Self-directed support (SDS) assessments should explicitly consider what people need to support their wellbeing. We are supportive of the suggestion that any 'unmet need' for individuals is recorded and fed back into strategic commissioning processes. In addition, provision needs to be put in place to make sure people are supported to make informed choices. There should be an obligation on local authorities to fully discuss SDS options with people, in a way that is suitable for their communication needs, including access to independent advocacy where this is appropriate

The review also recommended the re-opening of the Independent Living Fund Scotland (ILFS) to new applicants. An additional investment of £32 million was suggested. A re-opened ILFS would provide welcome and early progress pending the longer-term development of a National Care Service. The ALLIANCE welcomes the recent announcement of the re-opening of the Fund, with an initial investment of £9 million[130].

As mentioned in previous sections, social care and SDS must be aligned with the UNCRPD, so that people with learning disabilities, neurodivergence and autism are also at the forefront of decision-making.

However, we know that there are issues within the current social care system preventing people accessing and receiving social care services. This is in line with the findings in our *My Support, My Choice* research[131].

There are varying levels of access to and provision of services across Scotland. Concerns about a postcode lottery, highlighted over ten years ago in the *Christie Commission*, and more recently in *My Support My Choice, the Independent Review of Adult Social Care in Scotland*, and the work around the National Care Service (as well as investigations into specific service delivery in the National Audiology Review), will come as no surprise[132].

Alongside this, where people have limited access to social care provision and packages in their area, there is a lack of portability of care packages and plans that makes it difficult for disabled people to move to difference local authority areas.

In our research *My Support My Choice,* we asked respondents whether they felt that SDS had improved their social care experience. 72% of respondents “strongly agreed” or “agreed” that it had improved their experience:

“Keep your eyes on the outcome that you are hoping to achieve. The assessment is time consuming and a bit overwhelming but tell the social worker everything relevant. Check the draft assessment and make sure that it is accurate. For us, Self-directed Support is the perfect solution.”

“When an accurate budget is put in places and the right services purchased SDS is a godsend that really works. My autistic son who also has learning disabilities is working with trained autism practitioners who are working on social skills and independent living skills to prepare him for when his parents are no longer around. This is done in a fun way that encourages the best from him”.

However, others had negative experiences relating to difficulties with paperwork, assessment processes and insufficient budgets:

“We didn’t have any choice in the matter, as we were told it was happening and that was that. Try to make sure you are given as much information about choices as possible and sufficient to make your decision.”

“Don’t! Awful system, the stress I’ve had for over four years and to this day still don’t have a proper plan in place or enough of a budget or care package in place.”

“Don’t hold your breath. Process takes ages, too many long forms with stupid questions. Wait ages for SW [social worker]. Then pushed into PA option as its cheaper for local authority. That’s if you can meet criteria.”

In SLCD’s Wellbeing survey, they found that a fundamental aspect of self-determination is having the right support in place to empower people to make informed choices and live the lives they want. Support is a fundamental pillar of *The keys to life*[133]. The strategy outlines that people with learning disabilities should expect to have the right support in place to meet their everyday needs, as well as any needs that they may have because of their learning disability. Indeed, our findings show that not having the right support in place to do the things they wanted to do in their free time was very strongly related to low levels of life satisfaction.

“Some days if my support gets cancelled and can’t do the things I want to do I don’t feel happy at all, but most of the time I feel quite happy”[134].

Some people with learning disabilities and autism are not receiving adequate person centred support. Good quality, adequate support via SDS can be instrumental in improving people’s quality of life and plays an important role in ensuring they enjoy their rights to independent living and equal participation in society. The impact of not providing rights based, person centred care can be devastating, resulting in severe isolation and loneliness and mental ill-health.

It is therefore vital that people are treated with dignity and respect in all interactions with health and social care professionals and that assessments and support are adequate and tailored to people’s requirements and way of life, taking into account all clinical, dietary, religious, cultural, or any other considerations based on protected characteristics and other self-identities.

Health and social care staff should consider the possibility of mental health crisis when changing packages and eligibility criteria and be able to arrange reassessments and signpost support services where needed. Targeted work is needed to ensure person centred, rights based support continues in the transition from child to adult social care, and to ensure people with learning disabilities are given a free, meaningful and active role in decision making about whether to share their support or not.

Reductions in SDS budgets and tightened eligibility criteria can pose serious risks to people with learning disabilities on low incomes who access or are trying to access social care. It can result in having to manage without support or share support, impact negatively on mental and physical health, lead to exclusion from community life, and place unacceptable demands on family and friends to assume roles as unpaid carers.

Further, work is needed to better inform people with learning disabilities about SDS. It would be helpful to widen the pool of professionals who are informed about SDS and can encourage people with learning disabilities to access it. Making more use of health and education professionals would be particularly valuable, as well as building on the existing expertise of social workers, independent advice and support organisations. Greater use of health professionals in the process would also help to strengthen the integration of health and social care.

Additionally, people with learning disabilities require better advance information and support to feel prepared for their needs assessments. Comprehensive, high-quality information in a wide range of accessible formats should be proactively provided to people about the four SDS options, carers' assessments and support plans. Overall satisfaction with advance information about all SDS options could be improved, particularly Options 2 (the person directs the available support) and 4 (a mix of the other options). The benefits of earlier high-quality information include: early intervention before people reach crisis point, and reduced demands on staff time because people are better prepared for discussion and assessments.

The ALLIANCE have recently conducted a report on accessible information on Self-directed Support, and one participant discussed the issues with not having information clearly explained[135]:

> *“The first time […] it was explained very quickly to me. I didn’t understand the full information, it really went over my head, I just stood there. It looked like I wasn’t understanding, I wasn’t taking it in. [...] I was trying to understand the information that I do have a mild Learning Disability, but the information was given to me too quickly. I was asked, ‘do you understand the information?’ and I didn’t understand it.”*

We recommend that the Scottish Government make the commitment to ensure that effective support and costs associated is provided for to ensure that people with sensory impairments are fully catered for by social care.

We urge the Scottish Government to explicitly embed equality, human rights and co-production into this section of the Bill. Additionally, social care is not just something that sits with adults, but should include children and young people and elderly people. Approaching social care intersectionally, targeting those who have been most disadvantaged or marginalised, such as women and ethnic minorities would mean that social care can reach everyone who need it.

The ALLIANCE suggests that services such as ALISS (A Local Information System for Scotland) could also be embedded within the LDAN for how people access support and resources. ALISS helps people in Scotland find and share information about services, groups, activities and resources that help them live well. We believe that people should be able to easily access information about what is available in their community. Organisations and local groups can share information about what they offer, and people –

including health and social care professionals and the general public – can find information about what is available near them.

One of the key issues that allows a disagreement over policy intentions and reality of service delivery is fragmented and disparate data collection and publication in many areas of health and social care (but mainly in social care)[136]. Disaggregated data gathering and intersectional analysis is essential to develop fully realised policies and practices that prioritise equal access to SDS/ social care for everyone, including people with learning disabilities, that follow human rights principles of equality, non-discrimination, participation and inclusion.

To avoid gaps and improve analysis, we recommend systematic and robust data gathering by local and national public bodies on people who access SDS, disaggregated by all protected characteristics, including age, gender, sexual orientation, ethnicity, and religion, as well as socio-economic information like household income and Scottish Index of Multiple Deprivation (SIMD).

As recommended by our members, we recommend the following to design and deliver social care for people with learning disabilities, autism and neurodivergence:

- Meaningful engagement of people with learning disabilities at every step on the way including in the development of legislation.
- Embedding an equalities and human rights approach to the provision of support and care which is EQIA (Equality Impact Assessment) assessed and focuses on providing flexible support which empowers individuals.
- A clear and consistent approach to the regulation of care and support including a fully accessible mechanisms of complaint for people with learning disabilities.

Housing and Independent Living

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

The ALLIANCE agrees with the proposals.

We also believe that commitments must be made to provide adaptive, accessible, sustainable and affordable housing for all, with everyone person being given choice and flexibility.

With the cost of living crisis, and the housing crises in our major cities, social housing is particularly pressured, with long waiting lists.

Disabled people’s rights to independent living are enshrined in the UN Convention on the Rights of Persons with Disabilities. The rights within the Convention recognise that disabled people are the experts in their own lives, and are best placed to identify and determine the housing and support they require[137].

Appropriate and accessible housing is the cornerstone of independent living and can transform people’s lives for the better. Yet, disabled people are still living in inaccessible housing or housing that does not meet their needs[138].

Strategic planning processes and housing allocation policies should consider the particular needs of people with learning disabilities. It is crucial that people with learning disabilities have the right information to make informed choices about where they live.

We are concerned by the lack of choice and the restriction on independent living which arises from challenges in supply, availability, and accessibility of housing. Housing and support should tailored with a person centred approach.

For example, many disabled people in Scotland do not live in a home that meets their needs. There is a severe shortage of accessible and adapted houses to buy or rent in Scotland and this can prevent disabled people living independently, working, accessing the support they need and being included in their communities. Recent research from Inclusion Scotland has found that[139]:

- 86,000 households in Scotland that include a disabled person need an adaptation but do not have one.
- 68,000 households in Scotland include a disabled person who has great difficulty getting up and down the stairs.
- 53,000 households in Scotland include a disabled person who struggle to access or use the bath/shower.
- 21,000 households in Scotland include a disabled person who can't leave their house because of stairs to the house.

As stated by our partner, SCLD, it is important to embed a 'housing options approach' where advice is personalised and explores all possible tenure options, and accounts for wider personal circumstances and support needs alongside accessible housing needs[140].

In relation to the proposals please refer to previous sections for more detailed answers as they also applicable here.

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

Is there anything else that we should consider in relation to housing and independent living?

We believe that these proposals could have a positive impact on people seeking housing and independent living.

Some people have been able to access individual tenancies, however due to austerity measures and current crises, tenancies for individuals are unlikely to continue.

Subsequently, people with unmet housing needs are four times more likely to be unemployed than those whose needs are met, or those who are disabled but do not need accessible housing.

People face continued barriers to finding the right home for them. These include:

- Experiencing injury or ill-health directly as a result of being inaccessibly housed.
- Waiting years for a suitable house or adaptation.
- Being stuck in hospital as a delayed discharge, in residential care against their will or being inappropriately discharged into an inaccessible home.
- Finding it impossible to find an accessible home to buy.
- Facing problems getting an adaptation.
- Having problems adapting a private let.

In 2019, 15% of households with a disabled member said their house was not fully accessible. For people living in local authority housing, this was almost a quarter (24%)[141].

Previous reports have also shown that many people with learning disabilities are living in unsuitable homes; whether they have been housed in an out of area placement, far away from family, in group living with people they do not get on with, or simply in a house that does not suit their needs[142].

There is a chronic shortage of accessible and adapted housing[143]. We know that the Scottish Government has committed to creating a new cross tenure accessibility standard for all new homes by 2025-26[144].

The Equality and Human Rights Commission (EHRC) found that there were four main categories of negative effects families living in unsuitable housing in Scotland. The cumulative scope of these negative experiences highlights the mental and physical stresses placed upon disabled people when they face significant barriers to accessing suitable housing. Benefit reductions, and associated eligibility assessments, often had negative consequences for those with mental health conditions. They were also seen as adding significant complexity to the pursuit of adequate housing[145]. The consequences of financial barriers, unavailability of housing, and inadequate support are shown to have been harmful to participants' wellbeing.

A high proportion of homeless applicants have health and social care needs[146]. however, due to limited data there is insufficient information on what proportion of the homeless population have learning disabilities, autism or are neurodivergent, or to what extent their needs are being met.

No-one should feel or be pressured to move into residential care against their wishes – particularly not as a result of a desire to reduce funding for support via SDS[147]. All resources should be maximised and options exhausted to enable people with learning disabilities to remain – with appropriate support – in their own homes for as long as possible, if that is what they wish.

To improve the availability of housing options and choice, additional resources will be required. However, to know what is needed and to inform local housing strategies, the availability of intersectional and disaggregated local and national data must be improved on the current housing provision/state, needs and preferences of people.

In SCLD's wellbeing survey, someone told them[148]:

"I would like my own home, but need a lot of support. I have been on waiting lists for over 20 years and am still waiting."

This issue also affects young people transitioning to adulthood. Although the transition to adulthood is closely associated with greater independence, there are a number of obstacles to achieving this. There appears to be inadequate support for young people to manage their own disability/condition(s) and to live independently. Housing is also often poorly planned, and young people may struggle to secure their own home.

Complex Care – Coming Home

Should there be a statutory duty upon the relevant public body or bodies (Integration Authority, Health Board, Local Authority) to hold a Dynamic Support Register? (Proposal 1)
Please tell us more.

We agree that the LDAN Bill should ensure that Local Authorities/HSCPs should strengthen Dynamic Support Registers (DSRs), to keep area information up to date and ensure there is visibility of people with learning disabilities and complex care needs.

Likewise, this will be critical in monitoring the number of people who are being detained or are in out of area placements, and supports actions to enable them to live in a home or community of their choice.

Which of the options for the National Support Panel (Proposal 2) do you think has the most benefits? Please tell us more.

Option B: Legislative Panel Conducting Peer Reviews of Local Processes.

We believe that a both Option B and are valuable proposals however we feel that despite the desire for speed and efficiency reviews should have legal power behind them to encourage necessary change.

Are there any other options that you think we should consider?

Whilst there has been a shift away from institutional living for disabled people, many are still expected to live with their parents, and when their parents die or this option is not possible, they are place in shared accommodation with people they have not chosen to live with. Some people with complex needs and behaviours are still placed in locked institutions and are being detained inappropriately.

In continuing the application of the medical model, and “treating” people with learning disabilities, autism and neurodivergence, it fails to highlight the obligations of duty bearers to prevent people’s human rights from being breached under the UNCRPD. The Scottish Government must take a human rights and person centred based approach to this policy matter to ensure everyone can have full inclusion and participation in their community.

According to the UNCRPD, disabled people[149]:

1. Must 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.
2. Must have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.
3. Must have equal access to and use of community services and facilities for the general population that are responsive to their needs’.

People with learning disabilities, autism and profound and multiple needs are at continued risk of being detained in institutional settings, due in part to significant shortage of community support, resources and housing options. This is otherwise known as ‘delayed discharge’.

Further the Scottish Government should adjust its terminology usage to move away from the concept of people with learning disabilities and autism needing to be cared for, that they are passive or vulnerable. Indeed, for many disabled people the framing of being institutionalised is equated to "care" is deemed patronising and oppressive[150].

In addition to this, the Scottish Government has reported that Positive Behavioural Support should be provided for autistic people with challenging behaviour[151]. The use of Positive Behavioural Therapy has been criticised by autistic people's organisations as being a form of Applied Behaviour Analysis[152]. Alongside this, there is concern about the use of psychotropic medication and restraint on autistic people, and 'very long delays' in discharging autistic people from hospital[153].

Further, a joint stakeholder submission from a number of organisations and individuals detailed a number of common concerns on the Coming Home Implementation Report [154]:

- For every person in a hospital/Assessment and Treatment Unit or out of area placement there are equal numbers, if not more people, with similar support needs living at home with their family or being supported by a provider organisation (or a combination of both) in the community. This was the case even when the long stay hospitals were operating.
- People are frequently admitted because of service failure or family crisis. These are not health issues.
- Having a learning disability and/or being autistic are not medically treatable conditions.
- An identifying characteristic of this group of citizens is that they have been singularly ill served by the health and social care system.
- The right level of support, delivered in a way that iteratively evolves to meet changing needs, and the will and preferences of the person, is foundational

People living in assessment and treatment units said that they would like to live in the community. In Scotland, there were 1,243 people on local Dynamic Support Registers (DSRs). In relation to this figure[155]:

- 455 were classified as urgent
- 171 people were in hospital, 130 people recorded as an inappropriately out of area placement and 154 people recorded as at risk of support breakdown
- There were a further 144 recorded as enhanced monitoring and 644 people in appropriate out of area placements.

This is despite the Scottish Government having published an implementation plan that includes measures to reduce delayed discharge and provide care closer to home.

To enable people to ‘come home’, with accommodation and appropriate support, there must be increased resources in each local authority area. To know what resources and support are needed, plans must be co-produced with people who are and have been detained, their families and carers. Likewise, local authorities/HSCPs should have plans developed to demonstrate and report on moving people out of hospitals, the support and services that have been put in place, and showing the outcomes of doing so. This can be enabled by improving data collection on people who are detained.

The Scottish Government and local authorities have a duty to ensure that disabled people in institutions have the opportunity as soon as possible to live in community-based accommodations with support services until they can have their own living arrangements.

Additional value would be gleaned from soliciting contributions from those who currently support people to live good full lives, despite current systems that add unnecessary complexity. Working in co-production, with support from all directly involved, would identify solutions that are person led rather than professional directed.

We also recommend that the Scottish Government address the recommendations contained within the Stakeholder Submission on Common Concerns within the LDAN Bill[156].

Relationships

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

The ALLIANCE agrees with all of the proposals.

However, we recommend the inclusion of and reference to autistic people and autism within the proposals.

Health and social care staff, teachers, support workers, social workers and other staff must adopt a human rights approach to their work, which recognises the central importance of relationships to people's wellbeing.

This will include access to good quality relationships, Sexual Health and Parenting education for young people with learning disabilities and training for service and support staff. Staff should also support people to capitaliseon opportunities to maintain existing relationships and develop new ones. In doing so we need to acknowledge and move away from a culture within services that tends towards risk aversion rather than risk enablement.

Additionally we recommend that social care and Self-directed Support are appropriately resourced so that it can provide opportunities for people with learning disabilities, autism and neurodivergence to live how they want.

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

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

As with other sections within this Bill, everyone has the human right to a private and family life and the right to choose. There is the duty to enable people to enable and power people to exercise these rights with the least restrictive means possible. In addition to this, relationships should be looked at through a human rights, person centered and intersectional lens, and embedded as such within the LDAN Bill.

Social relationships are recognised as an important part of individual wellbeing. Relationships in all forms are recognised in *The keys to life* as being of key importance to people with learning disabilities and essential for their wellbeing[157]. Likewise, choice and flexibility are fundamental tenets of Scottish social care and Self-directed Support.

People with learning disabilities continue to experience barriers to having adult relationships because they have been viewed as “child-like” or “vulnerable” or lacking capacity to make such a decision[158]. Further barriers include to having and sustaining relationships include[159]:

- Some staff and family members prevent people from being in a relationship, or make it very difficult to stay in a relationship. Sometimes this happens on purpose but sometimes it is not intended.
- People with learning disabilities themselves have limited knowledge about sexuality and keeping safe. Although there are accessible resources and services, people providing services, families, and people with learning disabilities are often not aware of these.
- Lack of money and transport to go out, visit partners, and go on dates.
- Intimate relationships are not seen as a priority when commissioning services; unless there are concerns about risks and safeguarding.

Additionally, our member Dates-n-Mates told us that due to institutionalization and segregation some people they support don't know the terms for their own anatomy because they had not been taught, due to people thinking it was insignificant to them. This has repercussions on a person's health, wellbeing, relationships, safety etc.

In line with the Self-directed Support principles, there needs to be a continued cultural shift in choice and control to enable and empower people to have a social life.

SDS is a tool that enables people to socialize, be involved in their communities, make friends and build relationships on their own terms. However, one troubling pattern that was raised by some people with learning disabilities during *our My Support My Choice* research was that people were being asked to share their support (typically for social activities or completing tasks such as weekly shopping) with another person with learning disabilities – who they did not necessarily know or have any desire to socialise with[160].

As stated in the Feeley Review, a significant part of enabling people to live their lives how they want is reforming the system so that support for people to do what they want is consistent, available and accessible whenever they need[161]. This will involve resourcing the social care and third sector so they have staff recruited and retained to empower the people they support.

A result of people not being able to socialise how they want was demonstrated in the *Stay Up Late* campaign[162]. *Stay Up Late* is a charity that enables adults with learning disabiltiies and autism by campaigning to end inflexible support and recentreing care and support around what matters. Members of *Dates-n-Mates* told us that they have been removed from activities by the support workers because their shift had ended.

We believe that people have the right to form their own social relationships and friendships with people – and, separately, to have appropriate social care supports.

We have heard of situations from our members where a couple has set up home together and they have had children, they are often not allowed to care or rear them. In fact, children are removed from parents with a learning disability at a much higher rate than for other people[163].

This disproportionately impacts disabled women (particularly those with learning disability) with children as they experience greater intervention from social services[164]. A new programme adopted by one Scottish local authority, provides support to women who have had, or are at risk of having, children removed from their care on condition that they use long-lasting contraception[165]. The programme is run by the charity 'Pause' which aims to "encourage women to take responsibility for their actions".

People should be supported to care for their children, with teams, structures and finances put in place enable them to stay together and create a family if and when they choose too. In some cases, supplemented parenting may be required where support comes from someone other than a child's parents in the areas if advice, guidance, help with homework etc.

We recognise that some people may not succeed in having an intimate relationship or living in the same home, however this reflects wider society and the lives of most citizens.

Academic studies have shown that self-determination is correlated with improved quality of life for people with learning disabilities. Choice is an important factor in people's wellbeing[166]. In particular, having little to no choice over what people did with their free time was very strongly related to low levels of life satisfaction.

In SCLD’s wellbeing survey it was found that a very strong relationship between not being able to see friends as much as people liked, and low levels of life satisfaction[167]:

“My support often gets cancelled and I often feel lonely living on my own. A communal area that I am able to meet others would be good and help when I feel I want someone to talk to as often our office is too busy.”

Disabled young people often lack confidence with regards to social situations and personal relationships, are disproportionately likely to suffer from social isolation, and report that they lack opportunities to be active members of their community[168]**.**

In line with best practice, transition support and planning should support young people’s psychosocial development to establish healthy adult relationships. It has been observed, however, that young people in Scotland lack such opportunities, and that there is little attention paid within research and practice to romantic and sexual relationships[169].

We recommend that further research is conducted on relationships for people with learning disabilities, autism and neurodivergence to enable best practice and guidance.

Access to Technology

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

The ALLIANCE agrees with all of the proposals.

However, we urge for the inclusion of and reference to autistic people and autism within this section of the Bill and related proposals.

In relation to the proposal on training, please see our response on Mandatory Training.

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

Is there anything else that we should consider in relation to access to technology?

Access to technology and digital services should be focused on the best outcomes for the person, not the needs of a service or sector. We know that access to technology can open up people's worlds.

Although the pandemic accelerated moves to online services. Indeed, The Connecting Scotland programme was set up during the pandemic to provide support and equipment for digitally excluded people. By 2021, it had supported 40,000 households[170]. There were also positive initiatives introduced including the Connecting Scotland programme and the Near Me service.

However, with the loosening of restrictions came a return to inaccessible practices. For example:

"The quick creation [of Near Me consultation options] and then almost immediate destruction of accessibility I had for a brief eight months [once lockdown ended and services went back to only offering face-to-face] was so jarring. It's clearly possible these things can be done for folk like me: it's just... nobody particularly wanted to"[171].

Digital exclusion is particularly acute in older Deaf BSL user women and deaf and hard of hearing women who struggle to access appropriate support to get online[172].

Additionally, many people with sensory impairments face challenges accessing technology, resulting in digital exclusion. People with sensory impairments should also be entitled to support and training to ensure digital inclusion.

Broadly, disabled people are still less likely to use the internet, and are still excluded because of lack of technology, connectivity and confidence, and alternatives to digital[173]. For example, statistics show that disabled people are more than four times as likely to have never used the internet compared with non-disabled people[174]. Further, a qualitative evaluation of the UK Government's Digital Lifeline programme suggests that around 35% of people with learning disabilities do not have digital skills for life, compared to 21% of the general population[175].

One way to enable people with sensory impairment to access to technology is for websites should be made accessible such as being compatible with screen reading software and the option of larger text and captions, and embedded BSL. To ensure digital inclusion for everyone, it is important that website developers are supported to make necessary changes.

We also believe that these systems must be tested by people with living experience of these challenges to ensure that they work effectively. As found through our Human Rights Principles for Digital Health and Social Care, we were told[176]:

"Do not dictate what we need to us – let us tell you, and then you help us deliver it".

The ALLIANCE, in partnership with Scottish Care and VOX, developed five principles for a human rights based approach to digital health and social care[177]:

1. People at the centre – people should have access to inclusive and flexible digital services that meet their needs, rights, preferences and choices, with support if appropriate.
2. Digital where it is best suited – people should be involved in deciding how, where and when dgital is used in health and social care, and co-

create rights based digital services to ensure they are appropriate and effective.

3. Digital as a choice - People should be able to make an informed choice between using digital or non-digital health and social care services – and to switch between them at any time – without compromising the quality of care they experience.

4. Digital inclusion, not just widening access - People should have access to free training and support to develop the skills, confidence and digital literacy they require to make a meaningful choice whether to access digital health and social care services.

5. Access and control of digital data - People should have access to data held about them by health and social care services and have control over this data and how it is used.

We recommend that the five principles are embedded within the LDAN Bill.

Employment

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

The ALLIANCE agrees with the approach. However, we believe more can be done.

In response to the UNCRPD survey, 88% of respondents said that disabled people still find it difficult to find and keep a job in Scotland[178].

In A Fairer Scotland for Disabled People the Scottish Government have committed to reducing barriers to employment for disabled people, including people with learning disabilities, autism and neurodivergence, and to reduce by at least half, the employment gap between disabled people and the rest of the working age population[179].

The disability employment gap remains significant at around 32.8 percentage points[180]. Further, data shows that just 22% of autistic adults are in any kind of employment[181]. This disproportionately affects young and BAME disabled people as they are less likely to be in employment than non-disabled and white peers[182].

Alongside these statistics, the disability pay gap is significant. In 2019, for every £1 that a non-disabled employee earned, a disabled employee earned £0.83 on average[183].

A reason for this is that there remains discrimination and stigma towards disabled people in employment. For example, in relation to people with learning disabilities, autism and neurodivergence who experience sensory loss, it was found that 26% of people would not be comfortable managing someone with a hearing loss[184].

Many people with learning disabilities, autism and neurodivergence are receive social security payments, either from Social Security Scotland or Department for Work and Pensions (DWP). People need flexibility and a system supports them to personalise their approach to work.

It is challenging enough for people with learning disabilities to find and maintain employment. However, for those with a combination of learning disabilities and sensory impairment, this would be an especially difficult combining the lack of opportunities with limited capacity for learning with the additional barriers faced by people with a sensory impairment. The Bill must consider people who have a combination of sensory impairment and learning disabilities.

Disabled people have said that the model of employment support in Scotland needs to meet their aspirations for not just a job but career progression, be based on evidence, be fit for the future and serve more disabled people across Scotland than it does at present.

Educational institutions should prepare all students to take on employment, and tailor any qualifications to an individual's strengths so they can leave with a qualification and work skills.

For example, People First Scotland recommend that qualifications could be divided into separate components so that someone can qualify if they struggle with one of the course elements and employers could be encouraged to employ specialists who might focus on a narrower range of tasks[185]. They provide the example of a hairdressing and barbering course being split into tasks such as hair washing, hair conditioning and blowdrying and each task becoming its own smaller qualification.

We welcome the Scottish Government’s proposal to train job coaches. However, we believe this could go a step further and state that courses and work should be accompanied by vocational and employment support services for people with learning disabilities, autism and neurodivergence.

For example, Inclusion Scotland deliver their *We Can Work internship programme* because they know that many disabled people want to work but the inflexibility of the workplace and difficulty accessing support can be a barrier to finding suitable employment[186].

We believe that disabled people should have the same employment opportunities as non-disabled people at every level, which might include extras employment support services to do so. As noted in the *Review of Supported Employment within Scotland* local provision of employment support services varies[187].

We agree with the *Review of Supported Employment,* which amongst others, recommended that the Scottish Government and local authorities:

- reduce variability of access across different Local Authority areas;
- steps are taken to design a Scottish “Supported Employment Guarantee”

- Steps are put in place to drive consistency and oversight of supported employment provision through data collection. This would include access, outcomes and information on the needs and disabilities of individuals accessing support, including through Fair Start Scotland
- supported employment quality standards and an assurance approach for Scotland is developed. Establishing a steering group of providers, commissioners, national government, employers and people with lived experience can support this work.
- work continues to support the professionalisation of the supported employment workforce
- a national supported employment infrastructure programme is developed and commissioned.
- employers are encouraged to deliver more support to people with disabilities
- options are explored with DWP to allow supported employment providers to claim Access to Work directly
- exploring how “anchor institutions”, such as NHS Scotland, Scottish Government and Local Authorities, can increase the number of jobs available for people with disabilities
- making changes to Fair Start Scotland contracts to remove the requirement for 16+ hours of work, and to require data reporting of the disabilities of individuals accessing supported employment

Social Security

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

The ALLIANCE agrees with all of the proposals.

We agree with the Scottish Government’s proposals and acknowledge that the Scottish Government is limited in what it can achieve in this achieve due to reserved powers.

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

Is there anything else that we should consider in relation to social security?

As part of the Scottish Campaign on Rights to Social Security (SCoRSS), the ALLIANCE has contributed to a shared vision for a new social security system for disability payments based on six core principles. The Scottish Social Security system should[188]:

1. Have a clear purpose
2. Be human rights based
3. Support equal participation in society and independent living
4. Be adequate
5. Provide whole-of-life support
6. Interact well with future social security developments and is well connected to other services.

To echo our response to the Social Security (Amendment) (Scotland) Bill we call on the Scottish Government to go beyond the planned independent review of Adult Disability Payment and undertake an independent review of disability and carer payments more widely[189].

Importantly, the future development of the Scottish social security system should be co-produced with and consider the particular needs of people with learning disabilities.

A way of doing this is by taking a human rights based approach to the development of social security for disabled people is necessary, focussing on removing the barriers to people's rights to equal participation in society and independent living. This should replace the current medical and needs-based models. It should draw on the wealth of international conventions and jurisprudence to fully realise the right to social security for disabled people. Supported decision-making, such as independent advocacy, should be at the heart of this approach.

It is critical that social security for people with learning disabilities, autism and neurodivergence supports their right to independent living. The eligibility criteria and descriptors for this payment can accurately capture the impact of learning disability on day-to-day life[190]. However we suggest that eligibility criteria and assessment processes should be reviewed to enable this.

Alongside this, people with learning disabilities across Scotland should be able to access specialist employability support which is uniquely tailored and offers practical assistance to help them find, sustain and progress in work of their choosing.

With the continued impact of the cost of living crisis energy costs are increasingly and disproportionately high[191]. As a result, poverty rates remain higher for disabled people. In 2017-20, 23% of households with a disabled person were in poverty, compared to 17% in a household without disabled members[192]. The poverty rate increases to 29% when disability related benefits are not included in household income[193]. To illustrate disabled people were at higher risk of food insecurity pre-pandemic and half of households using foodbanks included a disabled person[194].

Poverty is being exacerbated by social care support charges and ILF “available income” charges[195]. Where there was a disabled person in the household this increased to 29% of children living in relative poverty, and 22% in severe poverty[196]. We are concerned that the Scottish Government has made little progress in reducing poverty in the last decade and is not on track to meet its child poverty targets[197], despite welcome measures, such as the introduction of the Scottish Child Payment.

We recognise that social security is partially reserved to the UK Government. It is important to note however that the negative impacts of reserved benefits contribute to health inequalities, poverty, employment, dignity and choice. For example, there is increasing evidence that Universal Credit and sanctions negatively impacts people's mental health[198]. Contributing to this, was the struggle for disabled people to get advice and advocacy support, and the inaccessibility of telephone assessments and appeal hearings.

Ensuring the adequacy of payments is particularly important considering the outsized impacts of first the COVID-19 pandemic and then the cost of living crisis on disabled people, people living with long term conditions, and unpaid carers. A pressing issue of adequacy relates to the upcoming Pension Age Disability Payment. The ALLIANCE recently contributed to and supported calls led by Age Scotland for the payment to include a mobility component, and would like to see action on this as a priority[199].

Whilst estimates vary, it would appear that the social security support provided by disability assistance may not bear a good relation to the extra costs associated with an impairment if a person is to be able to fully enjoy their right to equal participation in Scottish society.

We recommend that the Scottish Government take a human rights budgeting approach, to appropriately reflect the extra costs associated with overcoming disabling barriers

Justice

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

The ALLIANCE agrees with all of the proposals. However, we believe that further legislative action is required.

We believe that with the introduction of the Hate Crime and Public Order (Scotland) Act, hate crime law will be modernised to extended offences applicable to disabled people. This is extremely pertinent as there was an increase in the number of disability hate crime charges between 2019/20 and 2020/21[200]. This is the highest number of charges reported since this aggravation came into force in 2010. However, there remains a lack of intersectional data and evidence on hate crime and how reporting on these crimes will be improved and enabled.

Adding an intersectional lens, disabled LGBT+ people are more likely to experience a hate crime than non-disabled LGBT+ people[201]. Yet, this may be due to an to an underreporting of intersectional discrimination in other groups.

This is also the case when it comes to gender based violence and domestic abuse. Data and evidence must be improved in this area to allow for targeted and specialist interventions, support and services to be implemented.

Which of these proposals do you not agree with (if any), please tell us why? Is there anything else that we should consider in relation to justice?

Under the *Criminal Procedures (Scotland) Act (1995),* offenders with a “mental disorder” are excused from standing trial and, if found to have committed the act, they are removed from the criminal justice system, and diverted into the mental health and forensic treatment where compulsory “treatment” is given or they are detained and put under the care of psychiatrists.

In such a situation, people with learning disabilities will often agree to what they are accused of, and no effort is made to understand why the act was done or if there were extenuating circumstances or justifiable explanations. Although this is contrary to the requirements of the European Convention on Human Rights and the UNCRPD, any human rights violation is denied because the process is defined as a medical treatment and detention rather than imprisonment. People who are put into this process are likely to be detained for longer but are prevented from moving back home is due to a lack of appropriate housing and community support.

In addition to this, we know that there is a lack of support for people with learning disabilities, autism and neurodivergence in the justice system. When information is known about an accused person's impairment, this is not always passed to others in the system, meaning adjustments are made inconsistently[202]. Indeed, there is little evidence that adjustment provisions for 'vulnerable witnesses' are being used[203].

Exacerbating the lack of access to reasonable adjustment is the fact that costs associated with and for reasonable adjustments are not covered by legal aid[204]. For example, BSL users requiring the use of interpreters when dealing with lawyers, of which there is a lack of availability of interpreters in courts and police stations anyway[205].

As with health and social care, there should be a duty on the justice and social work system to gather information on adjustments need for people with learning disabilities, autism and neurodivergence and proactively share them. Further guidance and mandatory training should be developed for the Scottish judiciary on disability, autism and sensory awareness, supporting people needing adjustments and existing or new adjustments that should be put in place for them.

For example, as with other sectors there was a quick shift to digital technology to enable continued working and service provision. However, Increased adoption of audio-visual technology and remote trials in the criminal justice system acts as a barrier to understanding and communication for disabled people[206].

We recommend that the legislation guarantees that everyone in Scotland has the right to a fair trial in a court of law regardless of disability. However, in the same instance, there should be mandated reforms of the court and criminal justice process to account for and implement reasonable adjustments for each person. For example, people with learning disabilities should serve sentences appropriate to and addressing their offence in a prison system or setting which is a safe environment for them, instead of their offences being medicalised in a hospital setting.

In conjunction with lack of access to reasonable adjustments, disabled people experience barriers to getting advice. Such barriers include lack of availability, inaccessible information and buildings, not being listened to, costs, lack of legal aid and discriminatory attitudes[207]. A right to advocacy would people to fully understand and access their rights in a complex system as detailed in our previous answer to the questions on Independent Advocacy.

Our members have also reported issues with access to Legal Aid for people whose first language is British Sign Language (BSL). Although interpretation for BSL or other languages is paid for if Legal Aid has been granted, it is not paid for initial pre-claim discussions which creates additional barriers to justice.

For Legal Aid (as well as more widely) information should be accessible and inclusive communication processes should be considered at the outset. As a starting point, information should be made publicly available in plain English and free from jargon. Accessible information should follow the Six Principles of Inclusive Communication, and should be publicly available in multiple inclusive formats, including Community Languages, British Sign Language (BSL), Braille, Moon, Easy Read, clear and large print, and paper formats. The ALLIANCE recommends involving relevant experts – including BSL and language interpreters – at the earliest opportunity to ensure communications and information provision is inclusive for all.

Restraint and Seclusion

Do you agree with this approach?

No.

Please tell us why?

We agree that the misuse of restraint, seclusion and other restrictive practices is unacceptable for anyone.

However, in addition to legislation being introduced for all children, young people and adults, there should be a dedicated duty to prevent this misuse for people with learning disabilities, autism and neurodivergence specifically because they are at more risk of both being subject to such restraint but also because of their historical invisibility in this area both in education but also social care, healthcare and the justice system. Additionally, we would like to highlight *The Scottish Mental Health Law Review* (SMHLR) recommendations to make the reduction of coercion a national priority over a period of years (recommendation 9.1), including a proposal for legislation to establish a national register of restraint and appoint a public body with oversight for collecting and publishing data on trends (recommendation 9.12)[208].
Research found that the lives of people with mental ill health, autistic people and people with a learning disability had not been improved in terms of unacceptable practice.

Further, in relation to children and young people, an investigation by the Children and Young People's Commissioner for Scotland found that restraint and seclusion appear to be used more frequently on disabled children in schools[209].

SCLD were told by parents issues that arose in Early Learning and Childcare (ELC) settings for their children. One interviewee explained that they had removed their child from a special needs playgroup due to the use of inappropriate physical restraint. The parent felt that mainstream nurseries as well as some specialist nurseries were not accommodating to the needs of neurodiverse children, but instead focused on trying to recondition them to be neurotypical[210].

To illustrate, there are still too many people in mental health inpatient services. They often stay too long, do not experience therapeutic care and are still subject to too many restrictive interventions, which cause trauma. Families have reported clearly that the pain and harm for them and their family member continues[211].

The lack of community services, which can provide early intervention, crisis support and support for people living within their communities, means that people are more likely to end up in hospital. Additionally, for many people, the right housing is not available, nor the right support in place. This means that people are more likely to be living in unsuitable conditions, which then break down, which can lead to hospital admission. People end up moving around the system from one service to another because their needs are not being met.

We believe that any use of restraint and seclusion should be monitored and reviewed. Additionally, the outcomes of the person restrained should be noted to demonstrate the impacts of such use. This reflects the Rome review recommendation (Recommendation 7.6) that the use of detention, restraint or seclusion, and any other limits to liberty, should be monitored consistently for those with learning disabilities or autism across all public services[212].

The ALLIANCE knows that changes must be co-produced at system level, provider level and at an individual level. Families' views should not only be listened to, but acted on, so that people can have the right care and support that they need and want, to be able to lead their best lives.

In line with the *Coming Home* report, we believe that their recommendations should be implemented to monitor and investigate the use of restraint including a National Support Panel and Dynamic Support Registers[213].

We further recommend that:

- People with a learning disability and or autistic people who may also have a mental health condition should be supported to live in their communities. This means prompt diagnosis, local support services and effective crisis intervention.

- People who are being cared for in hospital in the meantime must receive high-quality, person centred, specialised care in small units. This means the right staff who are trained to support their needs supporting them along a journey to leave hospital.

- There must be renewed attempts to reduce restrictive practice by all health and social care providers, commissioners and others. We know in absolute emergencies this may be necessary, but we want to be clear – it should not be seen as a way to care for someone.

- There must be increased oversight and accountability for people with a learning disability, and or autistic people who may also have a mental health problem. There must be a single point of accountability to oversee progress in this policy area.

Transport

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

The ALLIANCE agrees with the proposals.

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

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

Transport is vital for people to live independently, access services, meet their needs and have control over their lives and what they do.

Yet there are barriers to people using public transport, especially those in rural areas and the Highlands and Islands. Within this section of our response we have included evidence on transport specifically, but also on inclusive design, accessible information, travel, climate chance initiative and public spaces as we believe these areas are all interlinked.

The ALLIANCE believes that there are substantive rights in the CRPD that should have a duty to comply as well as a duty to have due regard as part of the forthcoming Scottish Human Rights Bill. This include article 9 on the right to accessibility of the physical environment, transportation, information and communication, and services open to the public[214].

We are concerned that due to the exclusion of people with learning disabilities, autism, neurodivergence and sensory loss, well intentioned schemes in Scotland have failed to take account of the impact they will have on their lives. This was particularly prominent during the pandemic around interim public transport and passenger assistance[215].

Additionally, we know that Transport Scotland has introduced the Scottish Accessible Transport Alliance and local Access Panels to co-produce ideas to break down barriers. However, due to a lack of resources such ideas have not been able to be progressed.

For instance, schemes like ‘Spaces for People’ have meant that many disabled people have been increasingly excluded from public spaces with some finding it impossible or difficult to (safely) navigate town and city centres[216]. Some disabled people have said it makes it unsafe for them. Indeed, some pavements have been changed which don’t have dropped kerbs. One-way systems and use of inaccessible spaces during pandemic did not consider the needs of disabled people[217].

In terms of public transport:

- Issues with wheelchair access on buses persist – people cannot book wheelchair spaces and confidently plan journeys[218].

- Almost half (45%) of train stations are inaccessible (meaning there is no step free access)[219].
- From 2021, ScotRail's passenger assist booking time changed from two to one hour[220]. There is also a 'turn up and go' option. However, other train operators across the UK, including from and to Scotland, require assistance to be booked six hours in advance[221].
- Plans for more unstaffed train stations could make the 'turn up and go' option unavailable to many people[222].
- Accessible transport is particularly lacking in rural areas, which impacts on people with learning disabilities, autism and neurodivergence's participation and access to services[223].
- There is inconsistent provision of audible and visible information in stations and on-board local bus and coach services across the UK and Scotland[224].
- There are difficulties locating and accessing public toilets, and a lack of information about accessibility of public places, can prevent learning disabilities, autism and neurodivergence from travelling[225].

Additionally, people with learning disabilities, autism and neurodivergence should have concessionary travel passes without the need for entitlement to be based on the label of "mental disorder", as detailed in answer to previous questions.

Training for transport staff is key to support people navigating spaces which can be overwhelming. We believe that training for public transport staff should also include training on disability and sensory awareness. People with visual impairments and hearing impairments must have the same access to public transport as other neurodivergent people.

We believe that provision of talking buses is essential to ensure people with visual impairments are able to independently travel to where they need to be, without fear of getting lost. Guide dogs state that only 19% of services in the UK currently offer this service, with the majority in London[226].

Drivers should also develop knowledge of the local area and be able to assist customers where this is not the case.

Multiple methods of communication must be adopted to ensure that people with a visual impairment as well as those who are deaf or have a dual Sensory loss are properly represented. Whilst many of these systems are already in operation in some of the larger cities, these must be expanded to ensure equality for everyone, including in rural areas, the highlands and islands.

Whilst the national entitlement card scheme is useful, it is important that the implementation of this is consistent across Scotland. Whilst it covers free bus travel, local authorities have different rules regarding free travel for companions on trains. People with sensory impairments often require a companion to be able to travel. Therefore, travel for companions should be free right across Scotland.[227].

Customers should also be notified when Passenger Assistance journeys may be affected, due to cancellations or disruption.

As with previous sections, transport plans and strategies must be co produced with people with lived experience from the outset. Additionally, an accessible way to complain and feedback in relation to accessibility concerns should be made available and accessible.

Education

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

The ALLIANCE agrees with the proposals.

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

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

Children who have learning disabilities, autism and neurodivergence are often segregated into separate “special schools” or are in mainstream schools but experience exclusion, are placed in separate classes or meals. Although there is a presumption of inclusion within legislation and policy, implementation is consistent and is not being put fully into practice[228].

Around 60% of respondents to the 2021 UNCRPD survey said that disabled adults and children are not fully able to take part in education in Scotland today[229]. The UK Government currently has a reservation under this Article which states that disabled children can still be educated in special schools.

Most children with additional support needs are educated in mainstream schools but the number of pupils being educated in special schools has been rising since 2018. Most recent statistics show that there were 7,599 pupils in special schools[230]. There is not always a clear distinction between special schools and special units or classes within a mainstream school.

Everyone belongs in mainstream schools and the system should provide supports where they are useful for children and young people to have equal opportunities. This means that education and any additional support should be person centred and tailored to the learning needs of children and young people, whilst providing them with the same curriculum, guidance and resources as their counterparts.

The Additional Support for Learning (Scotland) Act 2004 places duties on local authorities to identify, meet and review the needs of children and young people who have additional support needs (ASN), which includes disabled children. It gives children and young people, parents and carers a number of rights, including rights to ask for additional support needs to be identified and planned for; to receive advice and information about their or their child's additional support needs.

However, disabled children still less likely to achieve Curriculum for Excellence levels and leave school with qualifications[231]. A review of the implementation of additional support for learning found that 'Additional Support for Learning is not visible or equally valued within Scotland's Education system'[232]. An action plan to address the findings of the review was published in 2020[233].

Disabled children and young people often receive messages about not being able, not managing, needing to be looked after and being at risk if they are included fully. They also internalise messaging that they are not worth the investment of time and resources to learn and manage.

Further, disabled children are considerably more likely to be excluded – the rate is almost double that of non-disabled children[234]. Autistic children are missing school due to formal and unlawful exclusions. Some children are put on a part-time timetable to manage their behaviour[235].

There is additional concern that due to the COVID-19 pandemic and its ongoing consequences, disabled children's education and development has been negatively impacted because of the disruption[236]. Indeed it is likely that the education attainment gap will increase for disabled young people because of long-term impact of school closures[237].

Children and young people, their families and carers should have the choice to access mainstream education on an equal footing to their peers throughout their educational journey. Including children and young people at the earliest age in all classes is an effective way to promote inclusion, acceptance of difference and change in attitudes.

The Scottish Government, Education Scotland and partners should progress the commitments from the 'Autism in Schools' working group and crucially introduce a baseline of autism knowledge into the Initial Teacher Education framework.

Disabled children experience bullying at school. However, Scottish Government does not collate bullying data at a national level. We believe alongside this data set, intersectional data should be monitored collected and reported on with an outcomes focus for child with ASN.

Children and Young People – Transitions to Adulthood

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

The ALLIANCE agrees with this proposal in relation to transitions to adulthood.

We believe this transition should be as straightforward as possible, with young people and families at the centre of decisions that affect their lives. The Scottish Government, COSLA and partners should ensure there is a focus on improving the transition from child to adult services for people with learning disabilities, autistic and neurodivergence young people[238].

Principles into Practice is a framework to improve the experiences of young people aged 14-25 who need additional support to make the transition to young adult life, and their parents and carers[239]. It helps everyone involved in supporting young people and their families to implement *Principles of Good Transitions 3*, which is Scotland's national benchmark for excellent practice.

In *My Support My Choice* we found that there are concerning gaps in national and regional data gathering and analysis around social care[240]. Disaggregated data gathering and intersectional analysis, including monitoring personal outcomes, is essential to develop fully realised policies and practices that prioritise equality of experience for disabled children and young people as they transition to adulthood[241]. Such work should follow human rights principles of equality, non-discrimination, participation and accountability.

To avoid gaps and improve analysis, we recommend the Bill should create a duty for systematic and robust data gathering by local and national public bodies, disaggregated by all protected characteristics, as well as other relevant socio-economic information like household income and the Scottish Index of Multiple Deprivation (SIMD) should be included in legislation at regulation level, in line with the principles of consent, choice and ownership.

The questions to capture people's experiences should allow for personalised, qualitative responses as well as quantitative data analysis, and should be developed in co-production with disabled children and young people who access services, their families and unpaid carers. This prioritisation of both qualitative and quantitative data is essential if personal outcomes and rights are to be monitored and measured with a view to ensuring continuous improvement and progressive realisation of people's rights. A mixed methods approach that embeds a human rights based approach would help to ensure that appropriate weight and priority is given to people's experiences alongside quantitative data

However, we are concerned that there are not more proposals related to disabled children and young people within the Bill especially as tackling Adverse Childhood Experiences and childhood inequalities can be a preventative measure to improve their lives for when individuals reach adulthood.

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

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

To achieve effective implementation, the ALLIANCE recommends that the Bill is underpinned by human rights and a rights based approach. To ensure the Bill is meaningfully grounded in human rights, the ALLIANCE recommends aligning it explicitly with internationally recognised human rights treaties, including the United Nations Convention on the Rights of the Child (UNCRC) and the United Nations Convention on the Rights of Disabled People (UNCRPD).

Explicitly embedding human rights within the Bill ensures that we are actively upholding children's rights and provides a robust legal basis to challenge practice which is inconsistent with those rights.

This is a necessity as 62% of respondents to the 2021 UNCRPD survey said that they did not think children's rights are protected. 22% said they were unsure[242].

In 2018 the ALLIANCE facilitated an engagement event exploring transitions in social care and self-directed support (SDS). Participants outlined core issues with the transitions process including a lack of timely planning, preparation and support, and high levels of bureaucracy or 'red tape'. One participant compared the transition period to a "Jenga block … whereby the pieces of their life were removed without appropriate alternatives in place" leading to feelings of being a "hindrance on their family". It was also noted challenges faced during transition periods can be long lasting.

As stated in the consultation document, there is consistent evidence that positive transitions can be enabled by, for example, early and sustained transition planning, Family involvement in planning and decision-making, the provision of clear and accessible information and adequate services, resources and staffing.

Within institutional transitions, advanced planning with young people and their families again occupies a central place in transition-smoothing[243]. This in turn relies on clear inter and intra agency communication and coordination, with a keyworker ensuring continuity and coordination from the perspective of disabled young people. Trust and positive relationships are also central to effective transitions, so introductory sessions and consistency of staffing are essential. There is some evidence that the integration of health and social care could help to lessen the challenges associated with transitioning, though this will likely require concerted planning.

Yet, disabled young people's educational, professional and personal outcomes also appear to lag behind those of their non-disabled counterparts. This is in part due to concerns around transition planning being exacerbated since the pandemic[244]. For example, nine out of ten parents and carers reported that their young person did not have a transition plan in place[245].

Additionally, ALLIANCE members are concerned with the complex policy landscape that currently exists. Efforts must be made to ensure alignment between these. For example, the transitions into adulthood for disabled young people and the UNCRPD.

Many ALLIANCE members who work with children and families as they transition into adult services describe a similar disconnect and lack of joined up support planning and communication taking place. We support the principles into practice framework development by the Scottish Transitions Forum and partners, and suggest that this work and learning should be applied.

Alongside this, we have been told by members that they are concerned about how children with additional support needs (ASN) will transition to adult services. For instance, if someone has self-diagnosed, rather than receiving a formal diagnosis, this needs to be recognised and accepted by adult services so that support can be accessed.

It is important to recognise that transitions to adulthood will also require a culture shift at ground level to ensure disabled children and young people's outcomes are at the heart of planning across services and to enable effective collaboration between services, including education, health, and social care. The Bill must therefore be accompanied by robust guidance and implementation to ensure rights are upheld and that disabled children, young people and families are informed and empowered to make decisions about their future.

Accountability

Which of the 5 options set out above do you think would best protect, respect and champion the rights of neurodivergent people and people with learning disabilities? You can select multiple options if you wish. Please give the reason for your choice(s).

Option 1, option 2, option 3, option 4, option 5.

The ALLIANCE agrees that either option 1 or option 2 in combination with the other options would be best to protect, respect and champion the rights of neurodivergent people, people with learning disabilities and autism.

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

A body independent from the government should be given the powers and responsibility to assess, monitor, review and implement all aspects of new legislation and policies in relation to people with learning disabilities, autism and neurodivergence.

Our members feel that if an entirely new body or an existing body are given these powers, then it must be given sufficient time, responsibility, power, resources, funding and direction to ensure that people covered by the LDAN Bill and their rights are protected and actions associated can be implemented and delivered fully.

For instance, it was found that autistic people, families, carers and professionals believe that there is a concerning lack of accountability when it comes to implementation at a local level. Respondents to the review of the *Scottish Strategy for Autism* fed back that support they or family members desperately needed and were entitled to, was not forthcoming and that there was a feeling of powerlessness with little or no route to challenge.

Additionally, the review recommended that a commissioner should be established in law tasked with ensuring that good policy and laws are implemented appropriately at a local level and have a very tangible and positive impact for autistic people and families throughout Scotland[246].

The PANEL principles of legality and accountability are also relevant to some views that were shared. In PANEL, 'legality' means recognising that rights are legally enforceable entitlements set out in national and international law. 'Accountability' requires appropriate laws, policies and procedures for redress if rights have been breached, and therefore effective monitoring of human rights standards.

For instance, in Scotland, there is a Scottish Commission for People with Learning Disabilities (SCLD) but it is a third sector rather than a statutory body and as such does not have the same powers or responsibilities as other Commissioners such as the Children's Commissioner, the Information Commissioner, the Mental Welfare Commission Scotland, or the Scottish Human Rights Commission.

We are also mindful however, of the large number of separate proposals for Commissioners being made by different bodies, with the risk of duplication, overlapping mandates and without a strategic direction to what should or should not have its own Commissioner. We note that the SHRC has proposed that some of these functions might be added to its current mandate, potentially by adding specific Commissioners or 'rapporteurs' within the SHRC.[247]

We recommend that the Scottish Government consider a potential Learning Disabilities, Autism and Neurodivergence Commission or Commission further, as part of a strategic approach to Scotland's commissioner landscape, including as a standalone body or a potential dedicated 'rapporteur' or champion within SHRC as detailed in our response to the Scottish Parliament Finance and Public Adminstration Committee's Inquiry.[248]

Additionally, it should be legislated that any new powers or body created should be co-designed by people with lived experience, and be accountable to them, by actively supporting people with learning disabilities, autistic and neurodivergent people to engaging with its work on an ongoing basis. This should include proactively reaching out to people and Disabled People's Organisations (DPOs), and providing the funding and administrative support to enable them to engage.

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces, Libraries and Access Panels are also members.

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.

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