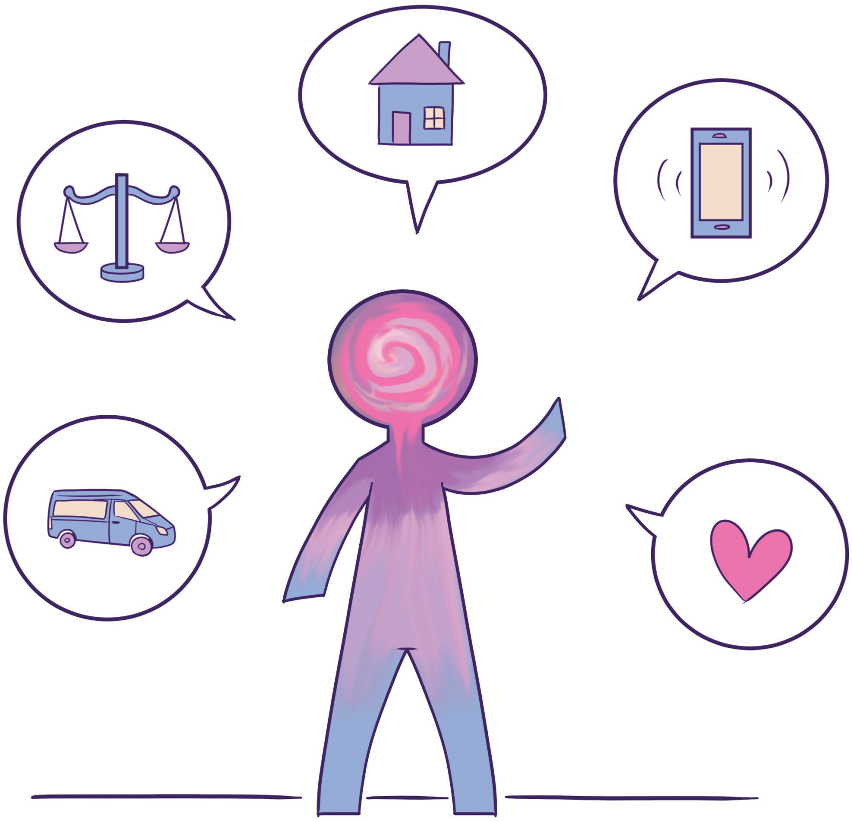
Scottish Government
Riaghaltas na h-Alba

Learning Disabilities, Autism and Neurodivergence Bill: **Consultation Analysis Report**



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Acknowledgements

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Executive Summary

Introduction

The Scottish Government undertook a public consultation on the creation of a new Learning Disabilities, Autism and Neurodivergence (LDAN) Bill. Proposals covered a wide range of overarching themes and sector specific issues. The consultation ran for four months, from December 2023 to April 2024 and asked 61 questions. A total of 877 responses were analysed, including 609 responses from individuals/groups of individuals, and 268 organisations.

The main findings from the analysis are outlined below. Where specific proposals were set out in the consultation, these are presented below based on levels of support for each, i.e. the most popular proposals are outlined first through to the least popular. Where all proposals within a section received largely similar levels of support, their presentation reflects the order they were set out in the consultation. As most questions were open-ended questions, feedback was mainly qualitative in nature and accurate numbers and percentages cannot be provided to quantify all findings.

Feedback and views tended to be mixed within respondent groups, with views also echoed across a wide range of respondent types. As such, the findings largely reflect the views of multiple respondent typologies (across both individual typologies and organisational sectors).

Recurring Feedback

A number of common issues were identified and discussed by respondents, including:

- The need to include those with lived experience in designing, delivering and evaluating any changes, strategies and guidance, inclusive communication, training, and/or data collection, analysis and reporting;
- The need for staff training, both in learning disabilities, autism and neurodivergence, and around inclusive communication and other proposals/ measures;
- The need for accessible communication and information to be proactively provided and to go beyond Easy Read options;
- The need for advocacy support to be provided, to have consistency in advocacy workers, and for them to have appropriate learning disability and neurodivergence training;
- Concern over funding and resources/staffing, and how each of the proposals would be delivered given the currently stretched finances and staffing problems across public sector services;
- The need for robust accountability and real consequences for services not delivering on strategies or legal requirements;

- A need for clarity around what the LDAN Bill sought to achieve that was not (or should already be) covered by existing legislation, such as the Equality Act, the Human Rights Act, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), and the United Nations Convention on the Rights of the Child (UNCRC), among others; and
- That legislative change may not be the most appropriate way to achieve the desired proposals or changes.

Across most of the sections covered by the consultation, large proportions of respondents supported all proposals that were outlined and/or felt that all proposals should be implemented in combination to develop the most robust and impactful solution.

Part 1: Reach and Definitions

Respondents were asked who should be eligible for support and what language/terminology should be used in the Bill. Overall, 735 respondents provided comments at this section and the most preferred option was to use and include **'People who are Neurodivergent'/'Neurodivergent People'**. Just over half of those who responded at this section preferred this option. This was considered to be accurate and clear; broad enough to be inclusive of all those targeted by the Bill; to not require a formal diagnosis; to reflect needs and a social model of disability; and was future-proofed to accommodate new and evolving conditions. Some respondents questioned whether the term 'neurodivergent' would be commonly understood or interpreted, and others were concerned that the broad nature of this option could result in an unmanageable increase in demand on services/for support.

Around a third of respondents indicated a preference for **'including specific named conditions only'** and felt this would avoid any ambiguity or confusion over eligibility; that it would improve understanding of different conditions; facilitate condition-specific tailored support; and allow finite resources to be directed towards those in greatest need. In particular, those with Down's Syndrome, and their family, friends, carers and support/representative organisations, supported this option. The main concerns were that this option risked excluding relevant conditions, and that it placed too much focus on formal diagnosis.

Very few respondents supported the option to use and include **'People who are Neurodiverse'/'Neurodiverse People'**, mainly because it was felt that the term 'neurodiverse' was inaccurate and too broad.

There was also discussion around the name of the Bill, and in particular, whether autism (among other conditions) should be named. Similarly, respondents debated which conditions would be protected by the Bill, with questions over whether this would include people with mental health conditions, acquired brain injuries, dementia, etc. Several respondents stressed that the Bill should not dilute the identities and needs of people with different conditions, and stressed that it was important for individuals to recognise themselves within the Bill.

Part 2: Overarching Themes

Section 1: Statutory Strategies

The consultation document set out six proposals in relation to the development of statutory strategies for neurodivergence and learning disabilities. Overall, 619 respondents provided feedback at this section with the main views being:

- **to involve people with lived experience in the development of strategies** - this was the most strongly supported individual proposal, seen as being key to developing relevant, meaningful and impactful strategies. Respondents argued there should be "Nothing about us, without us!" stressing the need for meaningful involvement and co-creation, and involving a wide group of people, covering all conditions, demographic backgrounds, and a range of geographic locations.

- **development of a National Strategy** - to provide a national standard and consistency across the country, thus avoiding the development of regional or sectoral variations. Only a small number of respondents explicitly disagreed with a national strategy, generally due to a perception that this would be too broad, end up "paying lip-service" to the issues, and would not be impactful.

- **reviewing strategies** - respondents generally felt that building in regular review periods was a positive step which would allow progress to be evaluated, and help to ensure that strategies remained relevant, up-to-date and reflected the latest research, understanding and developments.

- **duty to review strategies and effectiveness** - respondents expressed strong desires for robust accountability to be built into any strategy model on the basis that ineffective accountability mechanisms would lead to services simply paying lip-service to strategies, without any real and meaningful changes for service users. Several wanted requirements to be enshrined in law, with robust consequences for not fulfilling these.

The idea of **local strategies for some public bodies** attracted mixed views with those in support feeling that local strategies would be more effective, allowing local services to identify priority issues and areas of the greatest need, and to develop services which support people in their communities. Those who disagreed were mainly concerned about the risk of local variations and a postcode lottery in service provision, as well as a lack of accountability. Respondents tended to prefer local strategies in addition to, and to help deliver, a national strategy.

Similarly, the use of **guidance** received lower levels of support and attracted mixed views. While guidance was seen as helpful and supportive for local services, guidance alone may not be robust enough.

Respondents also wanted to see action and tangible change, not just strategies, and they stressed that funding, resources, suitable staffing, training and education were all required for services, providers and frontline staff to implement any new strategies.

Section 2: Mandatory Training

Overall, 674 respondents provided feedback and there was significant support to establish mandatory training for those working in health and social care and education (from early years to further and higher education). While training for staff in the justice sector was mentioned slightly less often (compared to health, social care and education), this was still very much supported.

Several respondents suggested that mandatory training requirements should be extended to all public services/public sector staff. Respondents also felt that training should not be restricted to public facing staff but should include those at management level and those performing administrative or corporate duties (and should be sector and role specific). Most respondents also advocated for mandatory training rather than voluntary/optional training as they felt this would increase uptake and ensure positive change.

There was also widespread agreement that the design and delivery of this training should involve people with lived experience from a wide range of backgrounds. While there was no overall consensus regarding what the focus and content of the training should be, respondents did stress that training should be neuro-affirming and should cover issues relevant to both children and young people and adults.

Several respondents felt that the development of a national training model would be helpful to ensure consistency across the country and between different public services. There were also calls for training to be accredited, monitored, and updated regularly. Further, it was suggested that refresher training or regularly updated training be offered.

The main concerns were that any training might be too generic, may exacerbate existing “training burnout” faced by public sector staff and may be unrealistic in terms of resources and impact on staff time/capacity.

Section 3: Inclusive Communications

In total, 593 respondents provided feedback at this section. The majority of respondents strongly agreed with proposals for improved **access to alternative means of communication** to allow more people to access services fully. The main perceived limitation was that this proposal placed the onus on people to proactively ask for alternatives, rather than these being made available as standard. Instead, it was suggested that a duty should be placed on public bodies to offer different formats, or for ‘communication passports’ to be used so that services are informed of preferences in advance.

The majority of respondents also supported **better access to Easy Read information** and it was felt that the LDAN Bill should include provisions for a broad duty not only to make Easy Read versions available on request, but also for there to be automatic provision in certain circumstances. Several respondents also stressed that Easy Read must not become the default position for achieving inclusive communications.

While attracting less feedback, there was also strong support for local authority strategies to **consider and report how communication needs have been met** on the basis that it would strengthen awareness, accountability and transparency of provision. It was also felt this would help to ensure consistency of provision.

Feedback on an **Enforceable Accessible Information Standard for Scotland** was also mainly positive with respondents perceiving this as a means of potentially ensuring compliance and action going forwards.

Section 4: Data

Overall, 492 respondents provided feedback at this section and there was widespread support for the collation and use of data generally, regardless of the mechanisms developed to achieve this. It was felt that access to robust and high quality data was essential to identify unmet need and the scale of any issues, for service and resource planning, to identify areas for improvement, and to monitor and assess outcomes. Similar proportions of respondents (roughly half of those who responded at this section) supported each of the proposals including:

- **A Commission(er) Responsible for Data Collation** - respondents were generally supportive of having one central organisation/department/person responsible for co-ordinating and overseeing all data-related issues and which could provide guidance and support to other public bodies; ensure consistency across services/the country; monitor and quality check returns or reporting; collate the data at a national level; ensure meaningful improvements are made as a result of the data; and ensure accountability. Those who disagreed with this proposal typically did so because they disagreed with the creation of a new Commission(er) per se.

- **Duty to Collect Data and to Provide Returns** - this was supported on the basis that there was an identified need and that imposing duties would support public bodies to prioritise this to provide higher quality and more meaningful data. This data would support the development of local services which were best tailored to meet local needs, while returns would allow national datasets to be collated and a national position to be established. Some respondents argued that **all** public bodies should be required to collect data and provide returns, not just “some”.

- **Review the Deaths of People with Learning Disabilities** - respondents generally supported this on the basis that it was important to review experiences and outcomes in order to learn lessons which could improve outcomes going forward and address the early mortality rates for people with learning disabilities. Some wanted these reviews to be expanded to include autistic people, with others suggesting this should include all neurodivergent people. Others were keen to ensure that more could be done to tackle issues while people were still alive rather than only reviewing situations after death.

Many respondents stressed the need for disaggregated and condition-specific data, as well as intersectional data, while many also raised concerns around the collection and possible use of data. Yet others had more practical concerns linked to consistency, data protection, informed consent, and data validity. It was also stressed that data collection needed to be meaningful and used to make real improvements.

Section 5: Independent Advocacy

Overall, 460 respondents commented at this section. Levels of support were similar for each of the proposals presented, with just over half of those who responded offering support to proposals to:

- **Strengthen and Improve Access to Advocacy** - current low levels of awareness and difficulties/barriers faced in trying to access advocacy were highlighted, including long waiting lists and varying provision across the country. As such, there was solid support for the use of and improved access to independent advocacy. There was also strong agreement with a duty for all public bodies to ensure that all people with learning disabilities and neurodivergent people are given information about advocacy and how to appoint their own independent advocate. It was also suggested there was a need for advocacy to support people during **all** challenging life stages and events, and this should not be restricted to limited sectors/services. However, respondents were also concerned about the sector’s ability to increase capacity and meet the needs of those covered by the LDAN Bill.

- **Improve Understanding of Independent Advocacy** - respondents were generally supportive of improving understanding and those who disagreed generally did so because they felt it was suggesting restricted access to advocacy. Respondents argued that the LDAN Bill should provide a legal right to free advocacy in **all** circumstances where it is needed and not just in specific cases for specific people.

Many respondents were keen to stress that any developments related to advocacy should involve and be informed by those with lived experience. Many also argued that the advocacy sector required more funding, resources, staffing (including specialist advocates), and training, both to meet current needs and to accommodate any increase in demand as a result of the proposals. Others called for regulation of the sector. Yet others set out more practical suggestions and recommendations around how advocacy services should operate.

Part 3: Specific Themes

Section 1: Health and Wellbeing

In total, 578 respondents provided feedback, with a little over half expressing support for all five proposals presented. Proposals related to Patient Passports, Annual Health Checks and Mandatory Training were the most popular individual proposals, with similar levels of support expressed for each.

Patient Passports: as one of the most popular proposals, it was felt that patient passports would be highly effective and supportive as long as health and social care staff were properly trained in the existence of, access to, and use of these.

Further clarity was sought from respondents, however, around how these would work (including access, amendments, updating, etc.)

A Legal Duty to Provide Annual Health Checks: Supported by most respondents, however, more information on the practicalities and processes for this proposal were sought. Respondents were also supportive of extending Annual Health Checks to autistic people; however, extending the checks to those with other conditions received mixed feedback. There was also some support for extension to those aged under 16, and unpaid carers. The main concerns, however, were the delays and problems with the current roll out of Annual Health Checks for people with learning disabilities, and whether sufficient capacity and resourcing existed, particularly if checks were rolled out beyond people with learning disabilities.

Mandatory Training for the Health and Social Care Workforce: Again, most respondents supported mandatory training in this sector. Similar to the feedback around training at Part 2 above, respondents preferred condition-specific training, training that could be tailored to job roles and delivered as part of any required qualifications and whilst on the job, and that all staff should be trained.

Inclusive Communications and Accessibility: Again, respondents were largely in favour of the proposals related to inclusive communications and accessibility. Respondents again stressed that alternative communication needed to go beyond Easy Read and services needed to consider more than just written information, by, for example, offering alternative methods of arranging appointments and conducting consultations and responding to individual communication needs in verbal and in-person interactions. Again, it was felt that options needed to be proactively offered to individuals and/or provided as standard.

Neurodivergent and Learning Disabilities Strategies: This was the least supported proposal at this section. While strategies were generally supported as part of a package of measures, many respondents preferred a national strategy instead of (or to help guide and co-ordinate) local level strategies. Others felt that strategies would be ineffective, that local strategies would lead to variation, and that a single strategy for learning disabilities and neurodivergence was inappropriate.

One of the main issues discussed at this section was diagnosis and the current problems and delays in accessing assessments and support. Respondents sought clarity over whether a diagnosis would be required to be eligible for the above proposals. The absence of a dedicated section on diagnosis and pathways to diagnosis within the consultation was seen as a missed opportunity. Problems with public/private shared care arrangements related to diagnosis were also highlighted.

One of the other main concerns at this section was around current staffing, capacity, resourcing and funding of the NHS and healthcare systems. Some were worried that the proposals might raise expectations which could not be delivered, exacerbating the implementation gap, generating increased levels of unmet need/ demand, and potentially worsening outcomes for individuals.

Section 2: Mental Health and Capacity Law

The consultation set out two possible changes the LDAN Bill could make to mental health and capacity legislation in the longer term and subject to more investigation:

1. Specifically remove learning disability and autism from the scope of mental health and incapacity legislation; or
2. Change “mental disorder” to a term that is not stigmatising or offensive.

This section asked a closed question to allow respondents to indicate support for the approach. Of the 361 respondents who answered this, 80% (n=289) said they agreed with the approach. However, the comments provided indicated that there were different points of focus when expressing agreement (or disagreement). Some focused on removing learning disability and autism from mental health and incapacity legislation and/or changing the terminology, while others focused on the need to undertake further work in this area. Comments did not always address or consistently support all elements of the approach set out.

Many agreed with, or stressed the need to **remove learning disability and autism from the current definition of mental illness or disorder.** It was argued that clearer separation of mental health and learning disabilities and autism was needed to reflect the different conditions and needs, and to ensure individuals are referred into appropriate services.

Many also argued that the **terminology and labels used needed to change**. Terminology needed to be more carefully chosen, sensitive, and appropriate. A change in terminology was said to be required more generally, and not only for people with learning disabilities and autistic people, in order to tackle stigma and negative connotations related to mental health.

Many also felt it was sensible to **delay any changes until additional work had been undertaken**. In particular, it would be important to avoid any services being withdrawn to those already using them or in need, and to ensure there were no loss of rights or protections. Respondents did stress the need to avoid any lengthy delays in this area, however, with change being considered a priority.

It was suggested that **more tailored mental health services**, and general support services, were needed for people with learning disabilities and autistic people. It was felt that mental health treatments too often take a neurotypical approach which is unsuitable and ineffective for people with learning disabilities and autistic people. Mental health services were often considered to not be the right setting, but were generally the only route to obtaining support.

Section 3: Social Care

While 437 respondents provided feedback on social care proposals, much of this duplicated or closely mirrored the findings already presented above. That is, **local strategies** may facilitate consistency of high-quality provision across the country while ensuring flexibility for improving service user journeys at the local level, **appropriately designed and delivered mandatory training** would help to raise awareness and skill levels and **improvements to making communication inclusive** would maximise choice and independence.

A large number of respondents indicated that they agreed with all of the social care proposals, mainly on the basis that they would remove barriers to access that currently exist, would protect the interests of people with learning disabilities or neurodivergent people, and contribute to building a fairer and more inclusive society.

Again, the main concern was how the proposals would be funded and resourced, and around workforce capacity and time availability for training. A few also suggested that greater consideration was needed around children's social care needs and carers' needs.

Several respondents also discussed the need for a straightforward and accessible complaints process, with access to independent advocacy being made available when dealing with social care provision issues or complaints.

Section 4: Housing and Independent Living

Overall, 420 respondents provided feedback on five proposals, with nearly two thirds agreeing that all proposals had merit and could be impactful, as follows:

- **Mandatory Training for Housing Professionals** - was the most popular proposal, with views that specialist training regarding both physical and sensory needs would bring significant improvement to the system. There were also calls for training to be extended to other housing related services, for example, inspectors, trades people, letting agents, and landlords.

- **Advice, Advocacy and Guidance** - was supported on the basis that a more regulated/standardised approach in this area would increase accessibility and may also help with navigating other government departments and systems surrounding housing. The need for specialist support, and therefore specialist training for advocates, was regularly cited.

- **Neurodivergence and Learning Disabilities Strategies** - having a strategy and a requirement to evaluate progress against this would help to ensure that policies were inclusive and effective at addressing the specific housing needs of local people with learning disabilities and neurodivergent people.

- **Inclusive communications** - in line with comments elsewhere, it was stressed that alternative formats would be welcomed and should be offered as standard.

- **Data** - while achieving slightly lower levels of support, many respondents agreed with the need to collect, share and use data related to housing and housing needs as it would help the housing system evolve to meet specific needs.

Many respondents also discussed issues in the housing sector more generally and/or identified key areas that needed to be addressed. This included the lack of affordable/low cost and/or social housing, and a lack of suitable accommodation and supported accommodation for those with physical disabilities, learning disabilities and autistic people and other neurodivergent people.

Section 5: Complex Care - Coming Home

This section set out two proposals to tackle delayed discharge from hospital (due to a lack of appropriate community support) and inappropriate out-of-area placement (where people are living away from their home, communities and families when they did not choose to). Two closed questions were asked to identify preferences, and 272 respondents also provided further comments and feedback at this section.

Dynamic Support Registers: Most of those who responded to the closed question (93%, n=224) agreed that there should be a statutory duty upon the relevant public body or bodies (Integration Authority, Health Board, Local Authority) to hold a Dynamic Support Register (DSR). The qualitative comments showed that respondents felt that the data gathered via this were vital in order to identify the number of individuals affected by delayed discharge and out-of-area placements, levels of need, and any issues or patterns which need to be addressed (either locally or nationally). It was also felt this would support strategy and policy development, support early intervention and longer term planning, and to monitor actions and outcomes. Implementing this as a statutory duty would help to strengthen and prioritise the use and impact of the DSR, and provide greater accountability, both locally and nationally. It was suggested that the DSR should also be extended to autistic people and children. Again, concerns related to confidentiality, privacy, and data protection issues, while others felt that the DSR and data reporting would not be sufficient on its own to deliver meaningful change.

National Support Panel: Three options were set out for taking forward a National Support Panel with respondents asked to identify their preferred option at a closed question:

- Over half (59%, n=128) of those who responded, preferred Option B, creating a legislative panel to conduct peer reviews of local processes;
- Around one third (32%, n=68) supported Option A, creating a legislative panel conducting individual reviews within defined parameters; and
- 9% (n=19) preferred Option C, creating a non-legislative panel conducting peer reviews of local processes.

Qualitative comments highlighted that statutory powers were seen as desirable or necessary, to ensure the necessary participation of services, and because statutory powers were required to challenge statutory bodies and statutory decision making, i.e. the Panel needed to have “real teeth” and be able to hold services accountable.

Regardless of preferences, many suggested that the issues in this area were a result of system wide problems, and were therefore not solvable by creating a DSR and/or undertaking case or process reviews alone. Rather, significant investment was said to be required across a wide range of areas, as well as the development of integrated services, for real changes to be felt on the ground.

Section 6: Relationships

This section focused on people with learning disabilities and covered more general relationship issues as well as gender-based violence and children being removed from their parents care. Overall, 360 respondents provided feedback, with most agreeing with all five proposals presented and no clear preference for any one proposal over another.

It was felt that **inclusive communication** and accessible information should be provided for all parents where there was a risk of a child being removed from their care, not only for those covered by the Bill. It was also generally agreed that inclusive communication needed to be appropriate to all groups/needs, should be proactively provided, and must involve advocacy.

Advocacy in the context of relationships was seen as something that should not be restricted to 'reactive' support but was equally important as an early intervention and 'proactive' provision.

There was strong support for **data collection and reporting** with regards to gender-based violence affecting women with learning disabilities as well as for the collection of a broader range of data relating to exploitation and harm affecting people with learning disabilities and neurodivergent people. There were fewer comments regarding data collection on the number of parents with learning disabilities where their children have been removed from their care. Where discussed, however, respondents were broadly supportive. Again, respondents supported the use of condition specific and intersectional data, and stressed that data were only useful if acted upon.

In relation to **national and local strategies**, respondents indicated that there was scope for improvements linked to local authorities setting out how Relationship, Sexual Health and Parenthood (RSHP) education was provided, and the lack of education and support around developing relationships, especially romantic and sexual relationships. It was felt that more education and support was needed in an accessible format, supported by funding for delivery. Only very few respondents commented on Police Scotland setting out how people with learning disabilities are provided with specialist support to report crimes, including gender-based violence and abuse. Where people did give a view, however, this was broadly supportive. Similarly, there was little feedback on the Whole Family Approach and some indication that respondents were unclear what this meant.

In relation to **accountability**, views were split with some supportive of either a new or existing body having the power to investigate both ongoing and historic cases of child removal from parents with learning disabilities, based on their disability, and others not. The main feedback provided here was testimony of the negative experiences families had experienced due to a child being removed and perceptions that there was an urgent need to change or reform current practices.

Other comments suggested expanding the scope of this section to include autistic people and to consider the unique needs with respect to relationships that would be experienced by different individuals covered by the Bill. It was felt the consultation also needed to focus on relationships more generally, as well as bullying, loneliness and isolation, and not just on crisis situations (i.e. the removal of a child or gender-based violence).

Section 7: Access to Technology

The consultation document set out three proposals aimed at improving digital access for people with learning disabilities and neurodivergent people. Overall, 356 respondents provided comments at this section, with over half agreeing with all three proposals, including:

- **Support to directly help people access and use technology** - while this proposal attracted the highest levels of agreement, different interpretations of 'support' were noted. Some respondents assumed this would be financial support (such as increased funding, grants, subsidies or discounts for hardware), others discussed extended training to provide ongoing support related to digital skills, while a few suggested support could be specialist services to help people with learning disabilities and neurodivergent people to purchase, set up and maintain technology and equipment.
- **Training for people with learning disabilities in digital skills and online safety** - the need for individuals to be safe, particularly online was stressed, with people with learning disabilities and neurodivergent people perceived to be particularly vulnerable in this respect. Training in the use of social media was seen as particularly relevant as well as training for children and young people, families and carers. The main caveat, however, related to the current wording of the proposal, with many respondents calling for training to be extended to neurodivergent people.

Data on the number of people accessing and using technology was supported if used in combination with one or all other technology proposals rather than being supported as a standalone option.

Section 8: Employment

Given ongoing work and Scottish Government limitations on changing the law in the area of employment, the consultation did not propose any legislative changes. Instead, the consultation set out three proposals aimed at encouraging more inclusive approaches to employment. Overall, 449 respondents commented at this section, with a broad split between those who supported the ideas set out, those who supported anything new to enhance more opportunities and equality in the workplace, and those who felt that this section did not go far enough, i.e. that more robust plans or legislative changes were needed.

Challenging Recipients of Public Sector Grants: The dominant view was for more action to encourage employers to take proactive steps towards creating a more diverse and inclusive workplace. The promotion of Fair Work First (FWF) and the new proposals to challenge those not upholding the principles of FWF was welcomed on the basis that it would provide an incentive to employers to improve and enhance their practices. The need for more specialist training for line managers was also welcomed as it was felt that managers (and employers more generally) needed better understanding of the wide range of needs and adaptations required to make workplaces accessible and equitable. The proposals could be strengthened, it was felt, by including legal protections and more robust reporting and accountability measures (including measures to enforce compliance).

Training for Job Coaches: a proposal that received considerable support, to equip coaches with the necessary knowledge and skills to support people with learning disabilities and neurodivergent people to access and remain in the workplace. Respondents viewed that job coaches helped to give people with learning disabilities and neurodivergent people confidence in the workplace, as well as giving reciprocal confidence to employers.

Reviewing Language Within Employability Data: also strongly supported, respondents perceived that reviewing the language would help to both remove existing confusion and bias and facilitate data-driven policy making. Such a review would also ensure any outdated or inappropriate language was identified and removed.

While there was very limited explicit disagreement with the ideas set out with regards to employment, a large number of respondents suggested that they found this section disappointing in its scope and ambition.

Section 9: Social Security

The consultation set out three proposals focused on social security. Overall, 365 respondents provided feedback, with many supporting all three proposals.

There was consensus that much needed to change to make the Social Security system easier to navigate and **inclusive communication strategies** were welcomed as a means of helping to improve the service user experience. The main perceived benefits were an increase in accessibility, equality and accountability, as well as reducing missed appointments and inappropriate/inaccurate claims which were felt to occur because of communication barriers. Several respondents also commented that provisions for advocacy in the context of social security communications would be welcomed.

Echoing earlier findings, there was strong support for all public service staff, including Social Security staff, to receive **mandatory training**. Again, it was felt that training must cover a wide range of specific conditions, be co-designed and delivered by those with lived experience, and be delivered to all staff who may interact with communities of interest (rather than just ‘some’ staff).

Further **disaggregation of data reporting** was welcomed primarily on the basis that it would help to facilitate service delivery improvements, and assist workforce and financial planning. It was also felt that data would be helpful in highlighting the numbers of individuals who currently claim for support among those who are eligible (and the number who do not). Further, this would help in making some minority groups more visible in the statistics, it was felt.

There were a number of ‘other’ comments made in relation to social security. Most of these related to perceptions that the current system was not user friendly for people with learning disabilities and neurodivergent people (the focus instead being on physical disabilities). More support was also needed for those without official diagnoses. Several also commented on perceived problems linked to the process of applications/eligibility criteria for various benefits.

Section 10: Justice

This section focused on the adult justice system, with six proposals relevant to both the criminal and civil justice systems. Overall, 343 respondents provided feedback, with over half expressing support for all proposals. While mandatory training was the most popular proposal related to justice, all other proposals elicited similar levels of support. It was also felt that the proposals needed to apply across all justice organisations and partners and should not be restricted to the police, the Crown Office and Procurator Fiscal Service (COPFS), the Scottish Court and Tribunals Service (SCTS), and the Scottish Prison Service (SPS).

Mandatory Training: was considered vital for justice professionals and staff, and was seen as integral to both identification and communication, as well as supporting understanding and interpretation of situations and behaviours to avoid escalation.

Inclusive Communication: was considered vital throughout the justice system, for individuals and their families and carers. It was stressed that serious consequences were experienced when people in the justice system do not understand and cannot access information.

Data and Identification: was considered important to identify individuals with learning disabilities and neurodivergent people at the earliest opportunity and for this information to be shared throughout the system. This would then inform all ongoing contact/interactions and act as a trigger for implementing all other proposals set out in relation to justice. Discussion of data focused on the need for information on the prevalence and over-representation of people with learning disabilities and neurodivergent people in the justice system, to identify levels of unmet need, and for intersectional data to be collected.

Advocacy: was supported in the justice system, however, it was noted that provision was currently “patchy” and needed to be equally accessible across the country. It was also felt that advocacy was not always well understood within the justice sector with respondents supporting more training, awareness raising, and the provision of accessible information in this regard.

Strategies and Co-ordinated Approach: Respondents largely supported the creation of a justice strategy. It was felt that a national strategy would provide an overarching framework, ensuring a joined up system with equal/consistent provision across the country and that it would support the implementation of all the other proposals.

More mixed responses were provided in relation to **Diversion from Prosecution (DfP).** While some felt this would be successful in addressing offending behaviour for accused people with learning disabilities and neurodivergent people (as it could provide better support and education) others felt it might be considered as leniency and not delivering justice and/or could be exploited by neurotypical persons, particularly if a formal diagnosis was not required.

Many respondents discussed the use of the Mental Health Act in the justice sector to determine how a person with learning disabilities or an autistic person will be treated. Almost all respondents who discussed this issue raised concerns in relation to diverting accused persons away from court and into hospital settings. They argued that this was unjust and inappropriate, and needed to be changed.

In addition, it was felt that more preventative work was required to stop people with learning disabilities and neurodivergent people coming into contact with the justice system. Respondents also reported a reluctance or nervousness among people with learning disabilities and neurodivergent people about reporting incidents to the police due to fears that they would not be believed, or because they perceived the system to be too difficult/inaccessible.

Section 11: Restraint and Seclusion

The consultation document set out two areas where the LDAN Bill could focus action to tackle the misuse of restraint, seclusion or other restrictive practices:

- for children: the development of statutory guidance, and to support its implementation and evaluation; and
- for adults: the scoping of a programme of work to further reduce the use of coercion and restrictive practices, and monitoring progress over time.

Of those who provided a response to the closed question, around two thirds (64%, n=202) indicated they supported the approach set out in the consultation document. While 303 respondents also provided qualitative comments at this section, there appeared to be some confusion with regards to what was being asked.

There was strong support for guidance in relation to children and young people and suggestions that this should be comprehensive, broad in scope and appropriate to multiple professional groups. It should also clearly assert that restraint and seclusion should be used only as a ‘last resort’. Several also felt that more or additional guidance relating to the use of restraint and seclusion was also needed in relation to adults/adult institutions. Statutory guidance was particularly welcomed in relation to the grey area of 'last resort' as it was felt that the threshold for this can vary from one person to the next.

As with other areas of the consultation, there was agreement that education and training were required to ensure that all those working with children and adults were aware of appropriate best practice, both to help reduce the use of restraint and seclusion, and to protect staff. Some discussed the importance of de-escalation and felt that more could be done to raise awareness, invest in training and promote this as an alternative and preventative course of action.

There was some debate around **Positive Behavioural Support (PBS)** at this section, with some championing PBS for people with learning disabilities while others (mainly representing neurodivergent communities) viewed PBS in very negative terms.

A large proportion of respondents agreed that this was a complex area of work which they felt was deserving of its own legislation and that it should not be subsumed within the LDAN Bill. Whether included in the LDAN Bill or elsewhere, respondents felt this was an area where change was needed urgently and therefore this should be treated as a priority.

Section 12: Transport

Two specific proposals were presented in relation to transport. In total, 352 respondents commented at this section, with over half agreeing with them both.

The proposal that received most support was for **mandatory training** to be provided to all those who come into contact with the public, including (but not limited to) drivers, conductors, ticketing and booking staff. Training should also cover all transport sectors, including buses, trains, planes and ferries, with some respondents also suggesting that taxi and licensed private hire providers/drivers and the British Transport Police should be required to undertake mandatory training. Those who disagreed with this proposal felt that training would not solve the problems as the biggest issue was accessibility and suitability of the infrastructure.

Most respondents did not express a preference for either **national or local strategies** in relation to transport, instead supporting a combination of both. Where a national strategy was preferred it was felt this would provide a consistent quality of service and a joined up transport system. Others, however, were keen to ensure that local issues (e.g. remote rural and island issues) were recognised and addressed. The main issue raised, however, was the importance of accountability and enforcement to ensure strategies and improvements are delivered on the ground.

Section 13: Education

The consultation document set out three proposals specific to school based education. In total, 499 respondents commented at this section, and just over half indicated that they supported all three proposals.

Mandatory Training for Teachers, Practitioners and Other Educators: Respondents were particularly in favour of mandatory training within the education sector, with this being the most popular proposal at this section. It was felt that training needed to be incorporated into Initial Teacher Education (ITE) and Continued Professional Development (CPD) in a meaningful way, with refresher training provided. It was also felt that training should be included within the Standard for Headship qualification, as well as for Early Learning and Childcare (ELC) practitioners. Most felt that optional training would be far less effective as it could be taken once or avoided entirely, although some education services and local authorities felt CPD should remain voluntary with teachers identifying their own learning needs. In addition to better equipping teachers to deliver lessons that engage and support all pupils with learning disabilities and neurodivergent pupils, many argued that training also needed to support teachers and other educators to recognise and identify potential pupils with learning disabilities and neurodivergent pupils. A few did, however, question how realistic it would be to provide mandatory training across the entire education sector due to the number of different bodies involved, the financial investment that would be required, and capacity to release teachers from classroom duties to undertake training.

Data: Proposals related to data were the next most popular. Disaggregated data were considered important for measuring outcomes and improvements, and for identifying needs, planning services, and identifying challenges, service gaps, or inequalities across schools/ areas. It was felt that any data must be condition specific, intersectional, and record the use and support for part-time timetables. Data were also said to be required for other issues such as the attainment gap, absence and exclusions, the use of restraint, levels of need/unmet need, destinations after school, etc. The need for consistency in data recording between settings was stressed, requiring the provision of clear guidance and parameters.

Strategies and reporting requirements: Respondents felt that this proposal would: make schools and local authorities more aware of needs and make them more accountable; ensure local authorities are aware of how children and young people with learning disabilities and neurodivergent children and young people are being supported; help support future planning, and direct additional funding and resources into the area. Others, however, felt that reporting alone would not provide accountability, and were concerned that this could become more of a tick-box exercise which has little impact on individuals. A series of caveats were also raised around the proposed planning and reporting requirement, including diagnosis issues presenting a significant barrier to accurate reporting; that reporting should take account of children not attending school; and the proposals would require training, and increased capacity, funding and resources, as well as support for pupils with learning disabilities and neurodivergent pupils.

Many used this section to highlight challenges, problems and shortcomings in the current education and school system for children and young people with learning disabilities and neurodivergent children and young people. It was generally felt that the proposals did not go far enough to tackle the fundamental problems, and that more needed to be done to address the implementation gap.

Section 14: Transition to Adulthood

The consultation document did not set out any specific proposals related to transition to adulthood. Rather, it flagged that many of the proposals at other sections would be relevant, particularly in relation to inclusive communications, mandatory training, independent advocacy, and statutory strategies. Four specific aims were, however, outlined in relation to transitions data. Overall, 392 respondents commented at this section.

In many cases, where respondents indicated they agreed with the proposals, it was difficult to identify which proposals they agreed with and why, or if they simply agreed with some of the background information and rationale that had been set out. Several respondents felt that the proposals were “vague” and unactionable, with others indicating that they did not understand what was being proposed. Others perceived that the consultation did not set out any proposals specific to transitions or suggested inaction in this area. The key views were that:

- **Change was Needed** - including more joined up services, more partnership working and a multi-agency approach to transitions, as well as greater and more proactive support. Respondents described a “cliff edge” where support and activities put in place via child and young people’s services stopped when they reached adulthood with nothing to replace them. It was noted that provisions were inconsistent across Scotland with regards to age thresholds and service eligibility.

- **Timescales and Pathways** - more time/longer timescales for transition planning was needed, with respondents suggesting that current transition planning and consideration of options/choices begins too late and should be more phased with a clearer and wider range of pathways available for school leavers.

- **Supporting Transitions** - individuals and their families/carers need to be proactively provided with more information and signposting about transition processes and support, available adult services and how to access them, and their rights and how to ensure these are upheld.

Mixed feedback was provided on whether more legislation was needed in relation to transitions. Some felt that more robust provisions were needed and that the LDAN Bill would have been a good opportunity for this. Others, however, felt that more legislation was not necessary. Again, many respondents felt that the proposals in this section did not go far enough and were not sufficient on their own to tackle the inadequacies in the system and significantly improve transitions.

Part 4: Accountability

The final part of the consultation set out how the LDAN Bill provides an opportunity to ensure that there is improved accountability for the delivery of individual’s rights and presented five options for how this might be achieved. A closed question was used to ask respondents to indicate their preferences:

- 65% (n=291) supported Option 1: Create a new Commission(er);
- 35% (n=159) supported Option 2: Provide better resourcing and additional duties for an existing body;
- 45% (n=202) supported Option 3: Create Champions and Advocates within Scottish Public Bodies;
- 49% (n=220) supported Option 4: Provide better resourcing for existing Disabled Persons Organisations (DPOs); and

- 45% (n=203) supported Option 5: Support good practice through standards, guidance and practical tools and investing in co-production.

Most indicated that they would like to see a combination of different options, but there was no consensus over which combination of options this should be. When considered as standalone options, respondents preferred Option 1 over Option 2. Also, while Options 3, 4 and 5 were supported in principle, respondents typically felt these needed to be implemented in combination with either Option 1 or 2 as they were unclear how these would deliver accountability on their own. In addition to the closed question, 421 respondents provided qualitative comments at this section.

Many respondents supported the **creation of a new Commission(er)** and felt that this was the best way of ensuring that historical failings in supporting the needs of people with learning disabilities and neurodivergent people were addressed (especially if working alongside champions in different sectors). A new Commission(er) was supported on the basis that it would be in a position of authority but would be impartial and independent of the Government; it would be an easily identifiable port of call for any issues; and it could promote good practice and facilitate improvements. It was stressed, however, that it must be permitted to conduct formal investigations and have enforcement powers; have ‘duties’ in the legislation rather than just ‘powers’; be responsible for collating data on outcomes and have a role in promoting and securing rights. Respondents also wanted the Commission(er) to have the necessary expertise, knowledge and capacity, and to work closely with those with lived experience. The main concern was that the creation of another Commission(er) could add more bureaucracy and cost to an already substantial Commission(er) landscape, with risks of overlap/duplication of efforts. Others were concerned about the cost and time required to set up a new Commission(er). The consultation did not ask respondents to indicate a preference for either a Commission or Commissioner, and there was no clear consensus in this regard within the responses.

Respondents felt that, regardless of which accountability mechanism was used, it must be taken forward with, and be representative of, people with diverse lived experience (including their families and carers, as well as children and young people). Respondents also commented that it must be more robust and better enforced than existing measures. Indeed, there was a strong sense that none of the proposed options may make a difference unless there was first a better understanding of why current mechanisms were not working. Respondents also stressed that there was a need for a clear plan with regards to how the Government would monitor and evaluate the success of proposals presented in the Bill. Finally, it was stressed that any ‘new’ accountability measures or strengthening of existing measures must be adequately advertised.

Next Steps

The consultation attracted a large number of responses from a very broad range of respondents, and the feedback given was considerable. The findings from the consultation will be used by the Scottish Government and their partners to refine and finalise the draft LDAN Bill, ensuring that the voices of those who contributed are reflected in any changes made.

Introduction

Background

As part of a national commitment, the Scottish Government is developing a new Bill to be introduced for people with learning disabilities and neurodivergent people in Scotland. The main focus of the Bill is to:

(i) ensure progressive and positive change;

(ii) ensure better protection of people's human and civic rights; and

(iii) ensure greater accountability where examples of discrimination and bias exist.

The Bill is considered to be essential in ensuring that people with learning disabilities and neurodivergent people in Scotland can lead active and fulfilling lives free from marginalisation, stigmatisation, exclusion or disadvantage.

In order to inform the development of the Bill, the Scottish Government conducted a public consultation. The Scottish Government worked extensively with three advisory panels to support the development of the consultation options, including a Lived Experience Advisory Panel (LEAP), a Stakeholder Panel, and a Practitioner Panel.

The consultation was wide ranging and sought feedback on both overarching topics, namely statutory strategies, mandatory training, inclusive communications, data, independent advocacy, and accountability, as well as specific sector and policy linked topics including:

- Health and Wellbeing;
- Mental Health and Capacity Law;
- Social Care;
- Housing and Independent Living;
- Complex Care;
- Relationships;
- Access to Technology;
- Employment;
- Social Security;
- Justice;
- Restraint and Seclusion;
- Transport;
- Education; and
- issues related specifically to children and young people and the transition to adulthood.

The Public Consultation

The consultation was open for four months (one month longer than Scottish Government guidance states for public consultations), from 21 December 2023 to 21 April 2024. It sought feedback from a wide range of respondents. This included, but was not limited to: people with learning disabilities, autistic people and neurodivergent people; their families, friends, carers and supporters; members of the public; and organisations including those which represent, support and advocate for people with learning disabilities and neurodivergent people, as well as those who provide services.

In addition to the main consultation questionnaire available on Citizen Space (the Scottish Government's online consultation portal), a range of alternative formats were also available. This included a Short Guide, Easy Read versions of the various consultation sections, an audio version of the consultation, British Sign Language (BSL) translation of the consultation, and a child friendly version.

Most sections in the consultation document were set out in the same way, as follows:

- what the Scottish Government already knew about the topics and issues;
- what the LEAP had contributed about each topic, their lived experience of it, and suggested changes;
- the ambitions and vision for future outcomes;
- an overview of what happens now in terms of existing rights, duties, and current practice related to each topic;
- what the Scottish Government and their partners are already doing to improve things for people with learning disabilities and neurodivergent people; and
- proposals for what the Bill might be able to do to improve things for people with learning disabilities and neurodivergent people.

Each section generally included three questions to identify which proposals respondents agreed with and why, which they did not agree with and why, and if there was anything else that should be considered in relation to the topic.

To support the written consultation and proactively seek feedback from under-represented and hard to reach groups, the Scottish Government commissioned the Scottish Commission for People with Learning Disabilities (SCLD) to undertake work aimed at promoting, signposting and encouraging groups and organisations to engage with the consultation and provide a response. In addition to providing such support, the SCLD gained significant insight and learning into the various issues relevant to each population group. The results from the SCLD work are provided in their report: Learning Disabilities, Autism and Neurodivergence Bill consultation project: under-represented and under-served individuals.

The remainder of this report sets out the main findings from the written consultation exercise, but the results should be read alongside the SCLD report which provides additional information and highlights significant issues for key groups.

Response Rate and Profile

In total, 877 usable responses were received to the written consultation and included within the analysis. This included 609 (69%) responses from individuals or groups of individuals, and 268 (31%) organisational responses.

Individuals were asked to provide information in relation to their learning disability, autistic and/or neurodivergent status, as well as other demographic information. The table below outlines individual's status or interest in relation to learning disability, autistic and/or neurodivergent status, while tables outlining demographic and geographic characteristics are included at Appendix A.

Respondent Profile - Individuals

Respondent Profile	Number	Percentage of Individuals
Neurodivergent person (i.e. autistic person, person with ADHD, person with a learning difficulty (i.e. dyslexia, dyscalculia))	235	39%
Person with a learning disability	26	4%
Family member or friend of a neurodivergent person or person with a learning disability	326	54%
Carer of a neurodivergent person or person with a learning disability	207	34%
Answering on behalf of a neurodivergent person or person with a learning disability (i.e. parent/guardian, support worker)	76	12%
Answering as a member of the public	84	14%
Prefer not to say / Not answered	18	3%

Base: 609 Individuals
Note: Multiple responses were given at this question

Organisations were asked to identify their type against the following list (with some organisations selecting more than one option):

- Private Sector: n=9, 3%;
- Public Sector: n=81, 30%;
- Third Sector: n=124, 46%;
- Disabled persons/neurodivergent-led/autistic-led organisation: n=32, 12%;
- Other: n=41, 15%; and
- Not answered: n=5; 2%.

Organisations were also assigned to sectors during the data cleaning phase as outlined in the table below.

Respondent Profile - Organisation Sector

Organisation Sector	**Number**	**Percentage of Individuals**
Advocacy Services	7	3%
Carers Groups/Services	10	4%
Children's Organisations/Services	16	6%
Education Services	22	8%
Health Services	29	11%
Housing Organisations/Services	10	4%
Justice Organisations	7	3%
LDAN Representative and Support Services	80	29%
LDAN Organisation: Neurodivergence	(6)	(2%)
LDAN Organisation: Autism	(12)	(4%)
LDAN Organisation: Learning Disabilities	(29)	(11%)
LDAN Organisation: Down's Syndrome	(12)	(4%)
LDAN Organisation: Mixed	(16)	(6%)
LDAN Organisation: Other	(5)	(2%)
Other Disability/Condition Services	11	4%
Local Authorities	14	5%
Mental Health Organisations	16	6%
Other National Public Body/National Agency	6	2%
Speech & Language Therapy	5	2%
Trade Unions & Membership Bodies	5	2%
Other Organisations*	30	11%
Total	**268**	**100%**

* Sectors with less than 5 respondents were grouped under ‘other organisation’.

Organisations were also asked about their geographic location or area of coverage. The results are provided at Appendix A.

Removed Responses

In addition to the 877 usable responses, 28 responses were removed from the final analysis dataset at the data cleaning stage. Of these, 18 were removed because they were blank (i.e. no consultation questions had been answered), while eight represented duplicate responses from the same person/organisation. All such responses were checked to ensure no data were lost, with collated responses created in the dataset where necessary.

Methodology

All responses (across all response types) were collated into an Excel database for analysis. Questions containing quantitative data (i.e. where respondents selected a response from a list of options) were subject to descriptive statistical analysis. This involved generating frequencies and percentages to identify how many people selected each option. Qualitative data (i.e. questions which asked for text based answers) were read and iterative thematic analysis used to identify and extract the key issues and recurring themes both within and between questions/sections. Comparative analysis was also conducted to identify the level of consistency and any differences in feedback by respondent profile (i.e. between individuals from different demographic profiles, between individuals and organisations, and between organisational type and sector).

Caveats and Reporting Conventions

It should be noted that, of the 61 questions asked in the consultation document, only five were closed/quantitative questions (i.e. which required respondents to select options from a list), and therefore supported the presentation of results in the format of firm numbers and percentages. Most questions (n=56) asked for open free-text responses to allow respondents to provide the most important feedback to them. Therefore, it was not possible to consistently and accurately count the number of respondents who agreed or disagreed with the different proposals, or who talked about different issues. Such data does not support quantitative analysis approaches. In order to provide a sense of the scale of support for the different proposals and the prevalence of issues that were discussed, however, descriptive terms have been used throughout this report. Those used most often are outlined below and ranked in order from those representing the highest number of respondents through to the lowest numbers. However, it should be noted that the actual numbers of respondents represented would vary depending upon the size of the relevant sample or sub-sample being discussed (for example, ‘most respondents’ would represent a larger number when used in reference to all respondents who responded to the consultation compared to most of those who discussed a single topic or sub-topic):

- most - generally around or more than two thirds;
- many - more than half;
- some - less than most/many but more than several;
- several - less than some but more than a few;
- a few - a small number of respondents up to around 10; and
- a handful - the smallest number of respondents, up to around five.

Where feedback differed between respondent groups (i.e. between individuals and organisations, between types of individuals, and between organisational sectors) this is identified and outlined in the narrative of the report. However, it should be noted that, at each section/question, there tended to be mixed feedback both within and across groups, and across a wide range of both individuals and organisations of different types. Very few unique or sector-specific issues emerged within the findings. For example, third sector organisations who supported people with learning disabilities and neurodivergent people often gave very similar views to those living with these conditions, and the parents, families and carers of people with such conditions. Similarly, public sector organisations often adopted a broad approach to their responses, discussing both service delivery issues/concerns and the impact issues have on those who use their services, resulting in similar feedback to many individuals and third sector support/representative organisations. Public sector organisations were generally either supportive or neutral towards the proposals and keen to improve their services, but had concerns over implementation - in a very similar way to other respondents of different typologies. The low number of responses from some organisation types/sectors at certain sections/questions also made it difficult to identify common themes and issues at this level. Further, for individual responses, respondents often identified themselves within multiple groups (e.g. they were often a ‘neurodivergent person’, a ‘family member’ and ‘a carer’ for someone with learning disabilities/neurodivergent person, with some also indicating they were ‘responding on behalf of others’ and/or a ‘member of the public’). Therefore, it was difficult to identify clear patterns in the views of individual groups and differences between them. Similarly, some themes only emerged at the aggregate level, i.e. specific issues were discussed by small numbers of respondents within any one group, but added together across the total sample they became common enough to warrant inclusion within the report. As such, in most instances, the views set out in this report represent a wide range of respondent types rather than there being views dominant to or within respondent groups.

While there was no evidence of any typical campaign responses, it should be noted that there was evidence of some co-ordinated responses. Several individuals (often family/friends and carers) repeated some of the content from third sector support services at certain questions. In most instances, the content was not identical, included paraphrasing and/or additional information, or focused on only one part of the organisational response. As such, these were not considered to be campaign responses. In addition, a few individuals and organisations either referred to or expressed support for other organisations’ responses at individual questions/ sections, without repeating the content. All responses were included in the analysis with equal weighting.

More respondents generally answered the earlier questions and sections of the consultation (i.e. Parts 1 and 2), with considerably lower numbers providing feedback at most of the later sector specific and accountability sections (i.e. Parts 3 and 4). While between 50%-80% of all respondents generally answered at least one question at each of the sections covered in Parts 1 and 2, between half and one third of all respondents tended to respond to later sections. Reasons for this were not captured consistently, however, feedback suggested a combination of reasons, including:

- Respondents felt they had provided the relevant feedback at earlier sections, i.e. where sector specific proposals were consistent with those outlined at the overarching themes;
- Respondents had little or no experience in some of the sector specific issues and so felt unable to comment; and
- The overall length of the consultation meant that respondents focused their attention only on sections that had been most important to them, or that respondents had been unable to complete the consultation to the end as it was too time consuming.

Further, due to the size and scale of the consultation, it was noted by a few respondents that various groups had found it difficult to respond, or to respond to all sections/questions. A few organisations noted challenges in engaging with a broad range of service users/members in enough depth and detail to cover all sections/questions, so had chosen to focus on only those considered most important to them. They were concerned that valuable feedback could therefore be missing at other sections of the consultation. Several organisations providing services/support to children and young people also noted that the length of the consultation document and over simplification of the child friendly version meant that feedback from this group was largely lacking. It was suggested that further work was needed in this respect to ensure the views and experiences of children and young people could be captured.

Similarly, a few organisations raised concerns over the lack of consideration and focus on dyslexia in the consultation document, and lack of engagement with people with dyslexia and dyslexia support organisations. One organisation felt the current proposals would not help or support those with dyslexia and, therefore, this group should not be considered within scope for the Bill. Again, it was felt that more work was required here if there was a desire to include those with dyslexia within the scope of the Bill.

Concerns were also raised by respondents throughout the consultation responses that the main focus appeared to be on learning disabilities and autism, and therefore those with other neurodivergent conditions/presentations may not engage with the consultation. Others, however, noted that while autism was specifically named in the Bill’s title and included in detail at the outset of the consultation document, specific reference to this condition was less prevalent throughout the rest of the consultation. It was felt this needed to be consistent, with those in favour of naming autism preferring this to be specifically referenced and considered throughout, while others felt that naming one type of neurodivergent condition was unfair and either other conditions should also be named or autism should fall under the ‘neurodivergent’ heading in the same way as other conditions.

The report used the term ‘people with learning disabilities and neurodivergent people’ throughout in order to maintain consistency with the consultation document and as a shorthand way to refer to all groups and conditions. However, this should be interpreted as including people with learning disabilities, autistic people, and neurodivergent people, covering a wide range of neurodivergent conditions.

There were a few instances of respondents providing information at one question which was more relevant to other questions/sections. The report includes consideration of feedback at the most relevant question/section rather than focusing that feedback at the question/section within which it was provided.

In addition, some issues were raised across the consultation, with respondents highlighting similar preferences, challenges and concerns at many/most of the topics they were asked about. In order for the various sections to be read as stand-alone sections, this repetition has been retained to ensure that key feedback is not omitted from the per-section reporting.

It should also be noted that, while some respondent groups appeared to respond in low numbers (such as individuals with learning disabilities, children and young people, and those in older age groups), it was not possible to identify exactly which conditions or demographics all respondents were experienced in. For example, family and friends, carers, and those responding on behalf of someone else were not required to specify whether they were responding from a learning disability, autism or neurodivergent perspective or about a child, adult or older person. Although some respondents did provide information within their qualitative comments, this was not consistently disclosed. Similarly, many individuals who were neurodivergent were also family or friends of, or carers for, other autistic or neurodivergent people or other people with learning disabilities, but they were not asked and did not always specify the conditions or demographic groups involved. As such, broader experiences were discussed than the basic sample profile suggests, but this cannot be quantified.

In addition, several organisational responses had been developed following engagement with their client group, members or staff. This included focus groups and supported meetings/events and questionnaire surveys. In particular, several third sector organisations who support people with learning disabilities were informed by wider consultation with service users (including both those with lived experience and their families/carers), as were a few responses from organisation representing children and young people. However, not all organisations provided details about the scale of this engagement or the number of people who contributed, therefore it was not possible to quantify how many additional people provided feedback to the consultation overall. It indicates, however, that more people contributed than the respondent numbers noted above.

Despite being boosted by those in other categories or organisational responses that represented wider views, the inability to identify which conditions respondents had experience of means that certain cohorts may remain underrepresented within the results. For example, it is likely that feedback from or regarding people with learning disabilities remains underrepresented compared to autistic and neurodivergent people. Similarly, within the broad ‘labels’, it is not possible to identify individual conditions, for example, the types of individual learning disabilities are not known, while neurodivergent individuals covers autistic people and those with Attention Deficit Hyperactivity Disorder (ADHD), Foetal Alcohol Spectrum Disorder (FASD), and learning difficulties such as dyslexia, and dyscalculia, among others. Again, it is not known which conditions are represented and by how many respondents. Also, as noted above, the consultation results are largely lacking direct input and feedback from children and young people. These limitations should be borne in mind when interpreting the results.

This report focuses on the consultation responses and key themes and issues discussed by respondents, with the introductions at each section/question providing only very brief background information largely focused on outlining the various proposals put forward. For more detailed information on how and why the Scottish Government developed each of the proposals/consultation questions, and the evidence and arguments related to each, please refer to the original consultation documents.

Finally, the findings presented here reflect only the views of those who chose to respond to this consultation. It should be noted that respondents to a consultation are a self-selecting group. The findings should not, therefore, be considered as representative of the views of the wider population.

Summary of Common Findings

Introduction

Throughout the consultation responses several key findings emerged which were common across most of the Parts and Sections covered by the consultation document, and were views shared by a wide range of respondent types.

Common Issues

Involve those with Lived Experience

Respondents were keen to stress the need to include and involve those with lived experience in designing, delivering, reviewing and evaluating any changes. This specifically included, but was not limited to, strategies and guidance; inclusive communication; training; data collection, analysis and reporting; and in the design of any more sector specific and unique proposals.

It was also felt that input needed to be meaningful, with suggestions that changes should be co-designed or led by those with lived experience. Those involved also needed to represent a wide range of learning disabilities, autism and neurodivergent conditions, as well as different demographic backgrounds. It was also suggested that families and carers, and Disabled Persons Organisations (DPOs) should also be involved.

Mandatory Staff Training

The need for mandatory staff training was mentioned repeatedly, both in relation to training on learning disabilities, autism and neurodivergence, and around inclusive communication and other more specific measures. It was argued that training needs to be neuro-affirmative; condition specific; sector and job role specific; and trauma informed. It was felt the need for training was widespread and should be implemented across the public sector, and cover front line practitioners, managers, and reception and other support staff, as well as within relevant regulatory bodies. There were also suggestions that some areas of the private sector would also benefit from such training, including employers and transport providers.

In addition, it was suggested (albeit less often) that greater education and awareness raising was required among the general public in order to tackle stigma, prejudice and negative attitudes often experienced by people with learning disabilities and neurodivergent people.

Accessible Communication

The need for accessible communication and information was widely supported and felt to be vitally important across a wide range of services and sectors. While respondents were highly supportive of the provision of Easy Read information, it was stressed that inclusive communications needed to go beyond that and incorporate a wide range of different formats in order to accommodate differing needs. It was also felt that the availability of alternative information formats needed to be widely advertised and offered proactively rather than requiring people with learning disabilities and neurodivergent people to ask for them.

It was also suggested that the principle of inclusive communication needed to go beyond the provision of written information to include offering different methods for making appointments, conducting consultations/meetings, for the provision of information/data, and understanding how the use of certain methods can be inclusive for some while also being exclusionary for others.

Accountability

Again, in relation to many of the proposals put forward, respondents stressed the need for robust accountability and real consequences for services not delivering on requirements. It was felt that legislating for the development of strategies, the collection of data, reporting, training, etc. would only be useful if these were used to inform changes and implement changes on the ground. Each proposal needed to be meaningful in delivering change, and not be seen as a tick-box exercise or an outcome in itself. As such, respondents wanted to see real accountability, with any accountability body provided with robust oversight responsibilities and “real teeth” to enforce requirements.

Problems and Delays in Diagnosis

Throughout the different consultation sections, respondents highlighted problems with obtaining a diagnosis. This included both difficulties in accessing a diagnostic pathway (particularly for adults who found it difficult to be referred for assessments), and extensive delays in being assessed and diagnosed following a referral. These issues were said to be problematic in themselves, resulting in poor mental health, and in wider problems in terms of accessing support services (again, with the problem being particularly acute for adults as a diagnosis was said to be routinely required to access services).

Issues around diagnosis were also expected to have an impact on the proposals set out in the consultation document, with respondents seeking clarification on whether a diagnosis would be required to access the support set out.

Several respondents also expressed disappointment about the lack of any proposals within the consultation document to tackle diagnosis problems. It was felt that timely and accurate diagnosis was a vital foundation for all other service provision and proposed support measures, and therefore it was a missed opportunity not to address this.

Capacity, Funding and Resources to Deliver

At every section and set of proposals outlined, respondents expressed concern over how each of the proposals would be delivered given the current stretched finances and staffing problems across public sector services. Respondents highlighted and discussed current capacity, funding, resourcing and staffing issues across a range of public sector services and organisational sectors. There was a sense that services were not able to provide an acceptable level of service or reasonable adjustments in line with current legislative requirements, and therefore, they would be unable to fully implement any proposals or changes which may be introduced by the LDAN Bill without adequate funding and increased capacity. Respondents stressed that the proposals needed to be fully funded otherwise it may exacerbate the current implementation gap:

> “There are other areas that must be considered. The most urgent of these is the lack of resources across the system. This is a systemic issue and underlies many of the challenges that young people face in accessing appropriate services and support. We are concerned that the LDAN Bill may focus too heavily on reporting and accountability mechanisms which will be meaningless if statutory agencies and partners do not have the funds available to provide the services in the first place.” (Other Organisation)

Respondents also stressed that, even though they largely agreed with the proposals that had been put forward, they were concerned that they would not be enough on their own to make real tangible changes to service delivery or the experiences of people with learning disabilities and neurodivergent people. Whilst one aspect considered vital for ensuring change was developing additional capacity within existing services (for example, increased diagnosis capacity, increased Additional Support for Learning provision in schools, increased provision of affordable and adapted housing options), it was also felt that greater availability or new tailored services were also required, for example the development of more appropriate mental health services or the provision of adult support, care and activity services. Similarly, it was also suggested that issues around accessibility of services were often structural in nature, for example, existing school and public transport environments were said to be overwhelming and unsuitable for many. As such, greater investment was said to be required to update and redesign certain facilities to be more aware of and inclusive for people with learning disabilities and neurodivergent people.

Uncertainty Around the Need for Legislation

In general, several respondents felt there was a lack of clarity around what the LDAN Bill sought to achieve that was not already covered by existing legislation. Respondents noted that there should already be significant rights and protections conferred on people with learning disabilities and neurodivergent people by the Equality Act, the Human Rights Act, the UN Convention on the Rights of the Child (UNCRC), and the UN Convention on the Rights of Persons with Disabilities (UNCRPD), among others. Rather than introducing further legislation, respondents suggested that efforts should focus on addressing the existing implementation gap and enforcing these current requirements.

Similarly, at various proposals throughout the consultation document, several respondents suggested that legislative changes may not be required. Rather they could be achieved by other means, such as the use of statutory guidance, the introduction of accountability measures and/or reporting requirements.

Common Themes by Respondent Type

As noted above, most findings presented throughout this report represent views that were expressed across a range of different respondent types. Identifying differences in views between different groups of individuals was hampered by the fact that many indicated that multiple respondent categories applied to them, and they provided feedback across different experiences and perspectives. For example, a few individuals had both a learning disability and were neurodivergent, while many with direct lived experience were also family/friends and/or carers of others with learning disabilities or neurodivergent conditions (although the nature of the condition of the person they cared for was not specified). As a result, distinct and reliable differences in the feedback between groups of individuals were difficult to identify and limited. Meanwhile, differences in feedback by organisational sector within consultation sections was also limited, both due to the small numbers of respondents per sector who responded at some sections of the consultation, and due to largely mixed views provided within sectors (and echoed across a range of different sectors and individuals). However, more general and high level differences in organisational feedback and areas of concern are set out below.

Several third sector organisations and DPOs represented minority groups (in the context of this sample), rarer conditions, or particular demographics. As such, these organisations' responses were driven by this perspective and tended to advocate for their specialist issue throughout. This included stressing the need for the consultation document and/or LDAN Bill to take proper account of:

- Different age groups, with more focus needed on children and young people in particular, as well as people in older age/life stages;
- Gender issues;
- Ethnicity and race;
- Intersectionality with LGBTQI+ identities and experiences;
- Intersectionality and co-morbidity of physical disabilities, sensory impairments, and other serious health issues.

LDAN support/representative organisations tended to advocate for the specific group they represented, i.e. either those with learning disabilities, autistic people, or neurodivergent people. Some of these organisations, however, provided wider responses and considered how the proposals would/could impact on others (including service providers) in order to provide a more balanced response.

Carers' organisations tended to advocate for the voice of carers to be heard and taken into account when developing the Bill and any actions that result from it. They also highlighted the crucial role parents/families/carers play in supporting those with learning disabilities and neurodivergent conditions, and the impact this can have on carers (i.e. that they had their own unique support needs which may need to be addressed). As such, they argued for greater support for parents/families/ carers and for such provisions to be added to the Bill.

The health and social care, local authority and justice sectors were largely made up of public sector organisations and other public bodies, although a few third sector organisations were also identified within the sample. Overall, respondents in these sectors were generally supportive of (or neutral towards) the various proposals set out in the consultation document, and were keen to improve their services to be more inclusive and better meet the needs of people with learning disabilities and neurodivergent people. They were, however, concerned about the practicalities of implementing the proposals and commonly flagged funding and resourcing issues, staffing levels, the need to consider and align new and existing requirements and duties, and the potential need for staff training (and increased capacity) and upgrades to IT systems to deliver the desired outcomes. It should be noted, however, that at the section/question level, a common view did **not** often emerge from within each of these sectors, but rather a mix of topics and issues were discussed. Further, the views of respondents in these sectors were often supported by a range of different individual and organisational groups.

Views from mental health organisations were drawn from a mix of public and third sector organisations as well as representative bodies. This was also the case for children and young people's organisations and education based organisations. Within and across these sectors respondents adopted a broad and balanced approach to their responses, highlighting the needs of those with learning disabilities and neurodivergent conditions within their own service sector and more generally, and being keen to support and meet these needs, while also being cognisant of the existing challenges and limitations within the system.

The views of national public bodies and trade unions/representative bodies largely supported the views of the sector they were linked to, e.g. local authorities, health and social care, mental health, etc.

At various points throughout the consultation, advocacy services, speech and language therapy, and sports focused organisations stressed the importance of their services, and the positive impact they can have in supporting people with learning disabilities and neurodivergent people. Again, they largely felt that greater consideration of these services and provisions to support and include these sectors should be made in the Bill. However, these views were also echoed by a wide range of other respondents (both individuals and organisations) who valued and/or had previous positive experiences with such services.

The remainder of this report sets out the findings as they relate to each consultation section.

Part 1: Reach and Definitions: Who Should the Bill Include?

Introduction

This section largely focused on the terminology that should be used in the Bill and who the Bill should include.

Three proposals, and the thinking behind each, were set out:

1. To use and include ‘People who are Neurodiverse’/‘Neurodiverse People’;
2. To use and include ‘People who are Neurodivergent’/‘Neurodivergent People’; and
3. To include specific conditions only in the Bill.

Respondents were asked which proposals they agreed with, which ones they disagreed with, and to outline any other issues which should be considered in relation to this topic.

Main Findings

This section elicited the highest response rate across the whole consultation, with feedback provided by 735 respondents (just over 80% of all respondents).

Proposal 2 (i.e. ‘People who are Neurodivergent’/‘Neurodivergent People’) was the most popular choice, receiving high levels of support overall - just over half of those who provided feedback at this section supported or responded positively about this option. Proposal 3 (i.e. naming/including specific conditions only), was also reasonably well supported, albeit by a lower number/proportion of respondents - just over a third of all those who responded at this section supported this option. Only a very small number of respondents supported the use of the term ‘neurodiverse’ as outlined in Proposal 1.

When considered by respondent type, Proposal 2 and the use of ‘neurodivergent’ remained the most supported option, albeit to differing extents. Around three quarters of neurodivergent individuals and public bodies (who answered this section) supported or responded positively about Proposal 2, while just over half of the individuals with learning disabilities, third sector organisations and DPOs also supported Proposal 2. It should be noted, however, that a few individuals indicated they had both a learning disability and a neurodivergent condition. When third sector organisations and DPOs were disaggregated by learning disabilities or neurodivergent focus, around three quarters of those who supported or represented learning disabilities supported Option 3, while those who supported or represented neurodivergent conditions or a mix of conditions were more split - with slightly less than two thirds supporting Proposal 2 and around a quarter supporting Proposal 3.

Proposal 1 - 'Neurodiverse'

This proposal was widely dismissed by respondents. It was supported by the lowest number of respondents and had the highest number of respondents who explicitly disagreed with it.

While only a very small number supported the use of the term 'neurodiverse', they argued that it would not lead to people being excluded due to technicalities over wording. Individuals also felt this option accommodated self-identification and those without a formal diagnosis, and would not be negatively impacted or limited by delays in this area.

Those who disagreed with use of the term 'neurodiverse' argued that it was inaccurate, too broad, and not the right term to use. Respondents also reiterated concerns from the consultation document that the term 'neurodiverse' referred to a whole population rather than individuals, and therefore it would include neurotypical people within the scope of the Bill, which was considered inappropriate.

Proposal 2 - 'Neurodivergent'

Reasons for Support

The term 'neurodivergent' was considered accurate, clear and precise. Several individuals also noted that this was a term they identified with, or was how they would describe themselves. It was widely felt (by a range of different respondent types) that 'neurodivergent' was a suitably broad term which would include a wide and appropriate range of people, was inclusive of all relevant conditions, capable of covering a spectrum, and adaptable enough to accommodate those with multiple and overlapping conditions/diagnosis. Respondents also liked that it was not too broad/did not include all of society, but also did not exclude individual conditions:

> "I feel proposal 2 is the best option as it encompasses a wide range of people and will not exclude certain conditions. I like that it would cover relatively mild (in some circumstances) conditions such as dyslexia but also the other end of the spectrum too." (Family/Friend)

Respondents also preferred this option as people without a formal diagnosis would still be included and protected by the Bill. This was considered important due to the barriers and difficulties many face in obtaining a diagnosis, the extensive waiting times involved, because some people prefer not to seek a diagnosis or label, and some therefore do not know which specific conditions they have.

Further, a few also felt that this proposal adopted a more human rights and/or social model of disability (rather than a medical model). It was considered to be needs led, focused on the person and common barriers faced in society, rather than being centred on specific labels, conditions, or diagnosis.

Respondents also felt that this proposal incorporated flexibility and future proofing as it could accommodate new conditions and evolving understanding of conditions without the need for updates and revisions to the legislation. It was felt that any requirement to update legislation to include new conditions would take time and incur a delay in people being protected by the Bill.

The order of the terms was also discussed by a few respondents, although there was no general consensus. While a few preferred to place the person ahead of the diagnosis (e.g. person who is neurodivergent/person with autism), others indicated they did not like the person-first language and requested it not be used.

Caveats to Support and Concerns:

Some respondents, who agreed with Proposal 2 in general, also expressed a desire/need to include a clear definition of neurodivergence or specific conditions (and potentially a non-exhaustive list of named conditions). This was particularly the case among organisations, although the reasons provided for this were consistent between different respondent types. It was highlighted that no commonly accepted definition of neurodivergence currently existed, but it was felt that a clear definition would be necessary to ensure understanding around the criteria/boundaries for who is in/out of scope, to ensure the definition does not become too wide and unmanageable, and to ensure that minority groups and those with rare conditions are included within the Bill. It was also felt that further education and awareness raising would be needed around the term ‘neurodivergent’ to ensure common understanding.

Similarly, others questioned exactly what conditions would be included/excluded under this terminology. In particular, it was highlighted that various mental health conditions, dementia and acquired brain injury could be considered to be neurodivergent conditions, but respondents were unsure whether the intention was to included them within the remit of the Bill or not:

> “One thing about proposal 2 to consider is, do mental health conditions (Bipolar for example), personality disorders (borderline personality disorder, Narcissistic personality disorder) count as neurodivergent?” (Neurodivergent Individual and Family/Friend/Carer)

Potential issues identified included difficulties in delivering services around such a definition. While this proposal would be consistent with the Additional Support for Learning Act, where needs rather than diagnosis is the priority, it was noted that, currently, a diagnosis was often required to access specialist support and services.

Several respondents (typically those who preferred Proposal 3) were uncomfortable combining learning disabilities and neurodivergence as there could be unexpected consequences. It was highlighted that the experiences and needs of the two groups are often very different. Some were concerned that people with learning disabilities could become “invisible” and their needs not met if they are subsumed within a broader ‘neurodivergent’ heading or a Bill which tries to tackle both together. Others were concerned that those with neurodivergent conditions would not consider themselves to have a disability and therefore combining these might be inappropriate.

Reasons for Disagreeing

Generally, those who actively disagreed with Proposal 2 felt the terminology may be too vague, open to interpretation and could create “loopholes” or allow “abuse of the system”:

> “…very grey area re what comes under neurodivergent. Need to specifically name to clarify it to people. Definitions are essential, as there is a significant risk that the Bill will become too wide and therefore will not affect any meaningful change.” (Health Service)

Another common source of concern and/or reason for disagreeing with Proposal 2 was the perceived risk that creating too broad a scope would mean a huge number of people would be in scope and could overwhelm services. This could limit the impact of the Bill, with resources and services not being able to cater to all. In particular, respondents were concerned that many individuals, sometimes self-diagnosed, and some high functioning individuals who were most able to advocate for themselves, would monopolize the system/resources, making it harder for those most in need to be supported. Others argued that the use of such a broad label did not accurately reflect the range of identities, needs and experiences of those eligible within the Bill, and were concerned it could result in a ‘one size fits all’ approach and people falling through the gaps.

Both those who supported this proposal and those who did not, argued that some individuals, whom the Bill aims to support, do not consider themselves to be neurodivergent (particularly people with learning disabilities and Down’s Syndrome), and therefore this one umbrella term alone would not accurately reflect all those intended to be within scope. There were concerns that some groups/ individuals would not understand the term or interpret it to mean that they were eligible to the rights conferred in the Bill, and could therefore miss out. As such, it was recommended that if this proposal were to be chosen, the definition and name of the Bill should also specifically mention learning or intellectual disabilities (and potentially Down’s Syndrome - discussed in more detail under Proposal 3), and autism.

Of those who disagreed with Proposal 2 (and Proposal 1), some did so as they felt it did not adequately reflect those with Down’s Syndrome. It was argued that the Down’s Syndrome community would be less visible to services and support, that their needs would not be addressed, and that current levels of support could be diminished due to more generic approaches being developed.

Proposal 3 - Include Specific Conditions Only

Reasons for Support

Respondents who supported Proposal 3, i.e. including only named conditions, felt it was important to be specific, and that this would provide clarity about who would be protected by the Act. These respondents wanted to avoid ambiguity or including too broad a definition or using terminology which could be open to different interpretations:

> “By listing specific conditions, there will be no doubt or confusion from individuals with regards to whether the Bill applies to/includes them… Many people with this so-called 'neurodivergent conditions' require things to be [as] clear and unambiguous as possible. By failing to name their conditions clearly, the risk of them failing to understand that the Bill applies to them is high - therefore defeating the entire purpose of the Bill in the first place. Proposal 3 will create ease for all, by clearly stating who the Bill applies too, thus helping carers, people with these conditions, and/or anyone else supporting them.” (Family/Friend/Carer)

Several respondents felt it was important to name specific conditions to ensure recognition, increase visibility, and improve understanding of different conditions. It was also suggested that this would facilitate the provision of condition specific tailored support. Respondents felt that this would make sure smaller groups and rarer conditions did not get not overlooked or “lost” as they might be if one broad generic term were to be used.

A few preferred this option as it allowed the Bill to focus more on people with learning disabilities rather than learning difficulties or neurodivergent conditions. Respondents had concerns over including specific conditions which were seen as less severe, or less impactful on a person’s daily life/interactions, such as autism, Attention Deficit Hyperactivity Disorder (ADHD) and Foetal Alcohol Spectrum Disorder (FASD), and they wanted to avoid “watering down” the legislation and its impact, which they considered a risk if a “catch all vague description” was implemented.

Concerns over budgets, resources and services’ abilities to develop practices which meet the needs of people with learning disabilities was also highlighted. Again, respondents feared that including too broad a spectrum would reduce the effectiveness of the legislation and services provided, and risked services drawing resources away from learning disability services to accommodate increased demand from neurodivergent people.

Several individuals interpreted Proposal 3 as indicating that the Bill would only apply to autistic people and those with learning disabilities and/or Down’s Syndrome initially, with the option to add more conditions at a later date. Such respondents were generally in favour of this approach, largely because it would allow the targeting of finite resources towards those most in need, at the earliest opportunity.

Equally, the ability to add to the list of specific conditions in the future was seen as a positive. This was considered essential to ensure the list remained up-to-date and reflective of current knowledge and understanding of different conditions and how these may evolve.

Among supporters of Proposal 3, however, there were differences in opinion regarding whether or not the Bill should be targeted at only those with formally diagnosed conditions or should also include undiagnosed individuals. While several respondents felt the provisions within the Bill should only apply to those who have been diagnosed, others felt those without a diagnosis should also be eligible.

Naming Down’s Syndrome

Respondents who discussed whether Down’s Syndrome should be named specifically within the Bill, were generally supportive of this. Many indicated that they supported Proposal 3 because it explicitly named Down’s Syndrome. Others, who either supported Proposal 2 or did not explicitly state a preference for any proposal, also supported the suggestion that Down’s Syndrome should be specifically named, regardless of which proposal was adopted.

While some who expressed support for naming Down’s Syndrome did not provide reasons, others (including several individuals with learning disabilities, family members/carers for people with learning disabilities/Down’s Syndrome, and support organisations) felt it would be important due to the differences between Down’s Syndrome, learning disabilities and neurodivergent conditions. It was argued that people with Down’s Syndrome often have very specific needs which are different to others, and that they/their needs are often overlooked. Respondents were concerned that failing to specifically name and include provisions for Down’s Syndrome would mean these individuals would be “lost”, “overshadowed” or “invisible” within the Bill and be unable to access to the required support.

A smaller number of respondents, however, questioned the need for the separation of Down’s Syndrome within the Bill, or argued against this. These respondents tended to feel that Down’s Syndrome should be included under the wider banner of learning disabilities or neurodivergence and not considered separately. There was a concern that naming Down’s Syndrome specifically would mean that other conditions would also then need to be given the same treatment. Others wanted the legislation to focus on needs rather than conditions.

Concerns and Reasons for Disagreeing

The main concern or reason for disagreeing with Proposal 3 was the perception that this would be too prescriptive and risk missing out or excluding specific conditions:

> “I feel excluding any communities that see themselves as neurodivergent is a failing. This bill is being drafted as current legislation is not clear enough and groups are being excluded from support, so to narrow the scope and still exclude those that need help is counterproductive.” (Neurodivergent Individual and Family/ Friend/Carer)

Others felt this proposal placed a focus on diagnosis and therefore introduced the risk of excluding individuals due to problems and delays with accessing and gaining a diagnosis. This was considered to be a particularly acute problem for women and girls who are often diagnosed later, people from ethnic minority backgrounds and the LGBTQIA+ community, as well as for foreign students who may not receive a diagnosis due to waiting lists being longer than visa allowances.

Issues with misdiagnosis were also highlighted as a risk if eligibility was restricted to only certain named conditions. It was also highlighted that many individuals (presumably undiagnosed individuals) may not know which condition they have, which could result in ambiguity about their inclusion in the Bill and risk them being excluded from support. There were also concerns that this focus on diagnosis and labelling conditions would create a more medical model for the Bill, rather than the desired social model.

There was also some limited concern that creating a list of specific conditions could result in a hierarchy, with some people/conditions being considered more/less worthy of help, support and protection than others.

A few respondents also discussed the practical difficulties with listing specific conditions. Some felt that the list would need to be extensive, and therefore too long to be practical for including in the Bill. Others were concerned that, even though conditions could be added, the list of conditions would require constant updating to remain relevant and up-to-date, and that the time periods involved for such reviews/updates could be lengthy.

The use of labels was discussed, although again with little consensus. A few respondents wanted to avoid being labelled by their specific diagnosis/condition, while others found this “empowering” and preferred to identify their specific condition rather than using a less descriptive and more generic term.

Other Comments and Considerations

Combining Proposals 2 and 3

In addition to those respondents who supported Proposal 2 but wanted to include clear definitions or naming example conditions, several respondents explicitly indicated that they preferred a combined approach of Proposals 2 and 3. These respondents agreed with the use of the term ‘neurodivergent’ but also wanted to name specific conditions so it would be clear who was in and out of scope, making the legislation more workable and closing loopholes. This was particularly relevant for people with learning disabilities and Down’s Syndrome who may not identify with the term neurodivergent.

Title and Reach of the Bill

Regardless of which proposal respondents preferred, there was discussion around the name of the Bill, which conditions should be specifically named and identified, and which conditions would be eligible within the Bill generally.

Name of the Bill: A few respondents objected to the inclusion of autism in the name of the Bill. They felt this was a neurodivergent condition so should sit within that heading. It was argued that to name this one specific condition gave it more prominence and importance than other neurodivergent conditions or types of learning disabilities. Further, respondents felt that naming this condition in the title deviated from the social model desired and indicated the requirement for a diagnosis. However, other respondents felt it was important to retain autism within the title, alongside learning disabilities and neurodivergence, and felt that the condition needed greater mention throughout the consultation document.

Some indicated that the proposed name for the Bill: ‘Learning Disability, Autism and Neurodivergence (LDAN) Bill’, should be retained as it clearly indicated who the Bill was for and who was included. It was also suggested that this name had been circulating for a while and had become recognised, so changing it would lead to confusion.

Again, it was stressed that people with learning disabilities would not identify with the term neurodivergent, while those who are neurodivergent may not consider themselves to be disabled or to have a learning disability. As such, it was considered important to retain different types of conditions within the name and scope of the Bill.

Eligibility: There was much discussion about who was intended to be included within the scope of the Bill, and who respondents felt should/should not be eligible. As noted above, it was felt the term neurodivergent could include a wide range of conditions, including mental health issues, dementia, etc. and so providing clarity would be important.

Respondents queried whether those with learning difficulties were included (or argued that they should be) under the neurodivergent heading. Others argued that Fragile X Syndrome should be considered in the same way as Down’s Syndrome (i.e. if Down’s Syndrome is to be named specifically then so should Fragile X Syndrome). The Scottish Government was also urged to clarify that the Bill would include both mild learning disabilities and profound and multiple learning disabilities (PMLD).

A few respondents also wanted other conditions to be specifically named within the Bill and/or within the title of the Bill. This included people with other genetic syndromes, PMLD and FASD.

Similarly, a wide range of other conditions were also highlighted for consideration, either to be named in the Bill, or for the scope to be extended to include them. This included Global Developmental Delay (GDD), acquired brain injuries, executive function disorder, Developmental Language Delay (DLD), chronic depression and anxiety, obsessive compulsive disorder (OCD), post-traumatic stress disorder (PTSD), complex post-traumatic stress disorder (CPTSD), developmental trauma, and the impact of adverse childhood experiences and attachment disorders.

A few, however, questioned the inclusion of epilepsy within the scope of the Bill when other neurological conditions were not, with others questioning whether this was considered as a neurodivergent condition.

It was also felt important that the Bill acknowledges and reflects the co-morbidity with other conditions which are often prevalent. This included the presence of other physical disabilities, sensory impairments, epilepsy, cerebral palsy, and mental health issues/conditions.

Different Populations in One Bill

Several respondents felt it would be complex and inappropriate to try and cover all conditions and different needs within one Bill, and were concerned that the identity, voice, and needs of some groups would be “lost” when trying to accommodate a broader population. Of these, several were keen to streamline the current Bill and have it focus on only one or more limited populations, although, there was no consensus over which group(s) this should be. Each respondent typically argued for priority to be given to the condition they had, supported, or advocated for. Some wanted a focus on people with learning disabilities only, others wanted a focus on learning disabilities and autism only, while yet others felt it should focus on neurodivergent people only (and exclude people with learning disabilities as it was perceived that they were already protected under different legislation):

> “It is our position that neither people with a learning disability, or autistic people or neurodivergent people, are optimally served by a single legislative Act which conflates their breadth of lived experience and needs. We believe these proposals need further work and do not feel they reflect the best approach for the distinct populations of interest.” (Health Service)

Another option put forward to tackle this by a few respondents (covering a range of different respondent types) was the creation of two separate Bills, one dedicated to learning disabilities (or learning disabilities and Down’s Syndrome) and the other focused on autism and/or neurodivergence. This was also suggested by small numbers of respondents at various sections throughout the consultation where it was felt that it would be difficult or inappropriate to tackle the issues experienced by different groups in the same way. However, as all respondents were not asked about the potential or their preferences for one Bill versus separate dedicated Bills, the true strength of feeling about this scenario is not known.

Greater Clarity Over Purpose of the Bill

A few organisations indicated that the aims, purpose and focus of the LDAN Bill were not obvious, and that there was a lack of clarity over what specific needs were trying to be addressed. These respondents felt that greater clarity was required in this respect to allow informed views to be developed.

In addition, a few respondents felt that new legislation/a dedicated LDAN Bill was not required, or at least questioned the need for it. It was suggested that issues could be dealt with via other avenues, including better enforcement of other legislation (e.g. human rights and equalities law such as the Equality Act, the UN Convention on the Rights of People with Disabilities, and the forthcoming Human Rights Bill for Scotland), and via the better resourcing of existing improvement work (such as the Mental Health Law Review).

Other Comments

A few respondents noted that they did not support or agree with any of the proposals presented. Others provided feedback without specifying their preferred proposal, although most of the comments in this section were consistent with those discussed above.

Other considerations discussed by respondents included:

- General discussion around diagnosis, the problems and lengthy waiting times involved with this, and the lack of appropriate post-diagnosis support - it was suggested that faster and greater diagnosis capacity was required and that both NHS and private diagnosis must have equal recognition;
- The potential for co-presentation of neurodivergent conditions/learning disabilities, physical disabilities, mental health issues and other conditions - while respondents stressed it was not helpful for these to be grouped together, the fact that comorbidities are often present is important to consider;
- That the name of the Bill, definitions and terminology used should be designed in liaison with those with lived experience - it was felt that all work on the Bill should be done/co-produced with those with lived experience and that their voices (and their carers' voices) should be paramount;
- It is important for people to see themselves in the Bill, both in the title and throughout, otherwise they may not recognise that it is about them and will not benefit from it;
- Children's and young people's experiences need to be better considered throughout all sections of the consultation and their views need to be sought directly - in line with the requirements of the UNCRC;
- The Bill needs to address the needs of all age groups, including providing greater information and support for adults living with conditions and consideration of older age needs;
- Consider the provision of support for families, parents, and carers;
- Be mindful of the different presentations of different conditions and differing needs between women/girls and men/boys;
- Be mindful of intersectionality of having a learning disability or neurodivergence and other protected characteristics;
- The Bill should embed a human rights based approach, and align with the United Nations Convention on Rights of Persons with Disabilities (UNCRPD) and the United Nations Convention on the Rights of the Child (UNCRC);
- The Bill provides the opportunity to provide strong, clear guidance and understanding on the term 'neurodivergent';
- Consider funding, resourcing, training and support for services (including workplace managers) to ensure the aims of the Bill can be met; and
- There is a need to tackle the lack of wider societal understanding and inclusion for people with learning disabilities and neurodivergent people, and the stigma, presumptions and prejudices that exist - it was felt that adopting the social model could help to address this.

Part 2: Overarching Themes

Part 2 of the consultation document set out key themes that were of relevance across many areas of life and were central to what the Scottish Government thought should influence policy/practice. Five areas were explored, as follows:

- Section 1: Statutory Strategies for Neurodivergence and Learning Disabilities;
- Section 2: Mandatory Training in the Public Sector;
- Section 3: Inclusive Communications;
- Section 4: Data; and
- Section 5: Independent Advocacy.

Each of these will be considered in turn below.

Section 1: Statutory Strategies for Neurodivergence and Learning Disabilities

Introduction

The Scottish Government sought feedback on options/proposals designed to develop their approach to statutory strategies for neurodivergence and learning disabilities. Six proposals were outlined with respondents asked to indicate which they agreed with, which they disagreed with, and if there was anything else that should be considered in relation to strategies. The six proposals were:

- **Proposal 1:** Introduce a requirement for a **national strategy** on learning disabilities and neurodivergence to be produced by the Scottish Government.
- **Proposal 2:** Introduce a requirement for **local strategies** to be produced by some public bodies, for example health and social care partnerships, local authorities, and other public bodies.
- **Proposal 3:** Introduce **guidance** that could cover a range of topics to be included in national and local strategies.
- **Proposal 4:** Ensure that there is a requirement to **review strategies**, for example every 5 years.
- **Proposal 5:** Ensure that people with **lived experience are involved** in the development of the strategies.
- **Proposal 6:** Consider whether any new accountability mechanism introduced by the Bill should have **a duty to review national and local strategies and their effectiveness**.

Main Findings

Overall, 619 respondents provided feedback at this section. Many (nearly two thirds) indicated support for all six proposals rather than identifying one or a few preferences. These respondents felt that all six proposals were sensible and could/should be implemented together in order to provide the most robust framework:

> “I agree with all of the proposals outlined because, taken together, they will provide a comprehensive strategy which will work both at national and local levels to provide a framework for the lives of neurodivergent people.” (Family/Friend)

The most popular individual proposals were Proposal 5, followed by Proposal 1, then Proposal 4 closely followed by Proposal 6 (with several respondents suggesting Proposals 4 and 6 could be combined) - i.e. that people with lived experience should be involved in developing a national strategy which is reviewed at regular intervals and includes a duty to review/accountability.

Proposal 1: A National Strategy

Where respondents interpreted the proposals as offering an either/or situation, a national strategy was preferred by far more respondents than local strategies.

Those who supported Proposal 1 felt it would be important to develop a national strategy in order to provide leadership “from the very top”, to provide a national standard and consistency across the country, and to avoid the development of regional or sectoral variations. It was argued that a national strategy would help to ensure that a co-ordinated and joined up approach is taken across all geographic areas and across all sectors/types of service provision:

> “Essential that we do not have a "postcode lottery" on what neurodivergence and access to support services means that varies across Scotland. We are a small country, we can have a national strategy with localised deployment tactics - it should not be beyond us to organise this effectively.” (Family/Friend)

It was also suggested that the provision of a national strategy, developed by the Scottish Government, would be helpful in supporting the development of local strategies, plans or actions (to provide some consistency), and would also be necessary to ensure accountability. Some suggested that the national strategy could/should be used in combination with the other proposals, with the national strategy being key in ensuring the model’s success. It was also felt that a national strategy, developed by the Scottish Government would ensure greater status and visibility.

Several respondents who supported the provision of a national strategy to provide leadership, felt that local level delivery or implementation plans should be required (rather than local strategies). These delivery plans would outline how each area/ service will action and contribute towards the national strategy, and how they will achieve the outcomes that have been set by the national strategy.

Although only a very small number of respondents disagreed with Proposal 1, this was generally due to a perception that a national level strategy would be too broad, end up “paying lip-service” to the issues, and would not be impactful. In particular, it was felt that such a strategy would be difficult to implement, both nationally and at local level, in the current financial climate. Meanwhile, others were more generally opposed to combining different populations/conditions (i.e. learning disabilities, autism and neurodivergence) in a single strategy. In addition, a few queried whether, or did not feel that, the Scottish Government would have the necessary knowledge, understanding and front line experience needed to develop an appropriate strategy, and would not have expertise across all the relevant topics/issues. A few also felt it would be difficult for a national strategy to suitably address different local needs and the issues experienced in different geographic locations, with concerns raised about the risk of a national strategy being biased towards the main cities or the central belt.

Proposal 2: Local Strategies for Some Public Bodies

Views on local strategies were more mixed. Those who supported this proposal felt that local strategies would be more effective, allowing local services to identify priority issues and areas of the greatest need, and to develop services which support people in their communities. In particular, it would allow for local situations to be factored into strategies, such as rurality, issues unique to island locations, etc.

Those who disagreed with Proposal 2 were mainly concerned about the risk of different interpretations, local variations and a postcode lottery effect in service provision. There were also concerns about duplication of effort, with all local authorities and public bodies developing strategies in isolation. A few were also concerned that local authorities and other public bodies did not have the resources to develop and take forward local strategies. There was also a sense that local strategies would not be successful, and that there would be a lack of ownership and accountability.

The general preference was for local strategies to be used in combination with a national strategy, rather than instead of a national strategy.

A key issue for some of those who disagreed with this proposal, and a caveat to the support of others, was that respondents wanted this proposal to be more ambitious. Rather than only 'some' public bodies having to produce strategies, it was argued that this requirement should be applicable to **all** public bodies.

Proposal 3: Introduce Guidance

While not discussed by high numbers of respondents, Proposal 3 attracted mixed views, with slightly more respondents in favour of this compared to those against (although comments were often minimal/lacking on both sides).

Common reasons for supporting the provision of guidance which would cover a range of topics included in national and local strategies included that:

- Guidance would help to ensure consistency across the country in the level and type of support people receive;
- Nationally produced guidance could support public bodies to develop their own strategies and/or to implement the necessary policies and procedures to meet a national standard, and ensuring local strategies do not contradict the national strategy;
- Guidance would support service providers and professionals to develop a better understanding of how to help those eligible under the Bill, and provide a point of reference;
- Guidance could/should outline evolving best practice and evidence-based approaches; and
- Guidance can be updated more quickly and easily than legislation to remain up-to-date with research and an evolving evidence base.

The main caveats among supporters and reason given for disagreeing with Proposal 3 was the perception that guidance alone would not be strong enough. Individuals wanted compulsory/legal requirements to be placed on public bodies, rather than guidance. Organisations suggested that statutory guidance was needed to ensure compliance with legislation. There was a perception that guidance would be open to interpretation and potentially seen as optional rather than being a means to deliver meaningful change.

Proposal 4: Reviewing Strategies

Proposal 4 was largely well supported, and of the very small number who disagreed with it, most indicated this was due to the stated timescale for reviews rather than being opposed to the principle of a requirement for regular reviews.

Respondents generally felt that building in regular review periods was a positive step which would help to ensure that strategies remained relevant, up-to-date and reflected the latest research, understanding and developments:

> "I also think with how quickly developments and understandings around neurodivergence, learning disabilities and other categories of disability are developing, continual reviews (e.g. every five years) would be really useful and important." (Neurodivergent Individual and Family/Friend/Carer)

It was also suggested that reviews would allow progress to be evaluated and for strategies to be updated to ensure that service users receive the "optimal support".

As noted above, however, there was some disagreement over how often reviews should happen. While some were content with the five year period proposed, others felt this was too long a time period, with most suggesting reviews should happen every three years. Several respondents preferred even more frequent reviews, at least in the early stages. Such suggestions included yearly or every two years, with a few suggesting strategies should be iterative and constantly monitored and updated as required.

Conversely, a few respondents felt that five years was too short a time period to allow strategies to fully bed in and be impactful. Rather, they felt that longer time periods may be more sensible.

Several respondents suggested that reviews (and accountability, discussed more at Proposal 6 below) should be undertaken independently, and involve those with lived experience directly, support organisations who work with and advocate for the rights of people with learning disabilities and neurodivergent people, or representative bodies established for this specific purpose.

Proposal 5: People with Lived Experience Involved in Development

Ensuring people with lived experience are involved in the development of national and/or local strategies was the most strongly supported proposal, with many suggesting that this was the most important element. It was felt that involving those with lived experience was “vital”/“crucial”/“essential” and something that “must” be done/“needs” to happen, rather than simply being a preference:

> “Proposal 5 is, in my opinion, the most important. Only those who have the types of conditions (and their family/carers) the bill will be supporting know what they need, what is lacking and what can be done better.” (Family/Friend)

It was stressed that engaging people with lived experience (including families and carers) was key to developing relevant, meaningful and impactful strategies and any guidance. It was seen as a way to ensure that strategies reflected and addressed the needs of those it aimed to support, and would help to get the strategy right from the outset. Respondents argued that neurotypical individuals do not have the relevant knowledge, experience and understanding of the needs of people with learning disabilities and neurodivergent people to be able to develop a suitably relevant strategy.

There was also an important ethical and rights based argument that the populations the strategy aims to support should be involved in the development - i.e. “Nothing about us, without us!”. This was a term repeated by those with lived experience and the organisations that support them.

Individuals and organisations also highlighted that securing active involvement from those with lived experience would also be required in order to be compliant with the UNCRPD, and the UNCRC for any areas related to children and young people.

Some respondents, however, suggested that the wording should be tightened up to ensure that this represents meaningful involvement, such as genuine partnerships, co-creation, or having people with lived experience leading the work. A few respondents argued that those with lived experience should be involved from the start of any process and not simply asked for their opinions towards the end of the process, and that they should be involved in the delivery and monitoring of the strategies. It was also stressed that their voices needed to be truly listened to and their views and experiences taken on board and acted upon. Respondents felt it was important to avoid the use of tick-box or tokenistic approaches which resulted in those with lived experience having only minimal or superficial involvement.

Another caveat to support highlighted by several respondents (including both individuals and organisations) was that a wide group of people, covering all conditions, demographic backgrounds, and a range of geographic locations needed to be involved. It was important to include those with a range of intersectional characteristics, and those with multiple and/or profound disabilities, including those who are non-verbal or who will require high levels of support to contribute, those who would be the most vulnerable, have the highest needs, and whose voices would typically be heard least often.

It was also highlighted that ensuring meaningful input from people with learning disabilities and neurodivergent people might require the provision of suitable support, advocacy and/or input from specialist or multi-agency professionals to help them to fully engage. A few organisations also argued that individuals should be paid for their time and input, and should not be expected to contribute for free.

Only a handful of respondents disagreed with this proposal. The only reason given more than once was that strategies would reflect the views and experiences of only a small number of people. Other reasons centred around the current wording of the proposal, with one disagreeing because they wanted those with lived experience to lead the strategy development, not simply be involved, and another disagreed because the involvement of those with lived experience was only a suggestion rather than a requirement.

Proposal 6: Duty to Review Strategies and Effectiveness

This proposal was, again, reasonably well supported, with only a very small number of respondents disagreeing with it. However, those who agreed typically discussed accountability more generally rather than just a duty to review. Respondents expressed strong desires for robust accountability to be built into any strategy model - it was argued that this needed to be a compulsory and integral part of the model which was a legal requirement, and not simply a consideration:

> “The important thing to note here is that we don't want this to only be about strategies. The Scottish Government and Local Authorities have proven that they are very adept at creating strategies but less so when delivering on them. Therefore, accountability has to be a significant element of this Bill. Scottish Government, Local Authorities and Health Boards have to be held accountable to delivering on the strategy.” (Organisation for Other Disability/ Condition)

It was felt that accountability, and a mechanism for guaranteeing this, would be helpful in ensuring progress is made, that standards are being met and upheld, and that the strategy is effective.

It was argued that a lack of accountability, or ineffective accountability mechanisms would lead to services simply paying lip-service to strategies, without any real and meaningful changes for service users.

Accountability was also seen as an important element to ensure that people know what to expect/what they are entitled to, so that there are clear roles and responsibilities so everyone will know who has ownership or overall responsibility, and who to complain to in order to have situations addressed where service provision did not meet the requirements.

As with comments expressed at Proposal 4, several respondents (including both individuals and organisations) indicated a preference for accountability to be managed by service users/those with lived experience, organisations who support those with lived experience, or an independent body, Commission or Commissioner.

While organisations (mostly but not exclusively public sector) were broadly supportive of a duty to review progress and effectiveness, some did caution the need to be mindful of current and anticipated future reporting requirements on public bodies. Resource requirements and the potential impact additional reporting requirements might have on service provision or other duties needed to be considered.

Again, only a very small number of respondents disagreed with this proposal, with a lack of consistency around the reasons why. A few stated they did not understand this proposal or felt it lacked detail and clarity, a few felt proposal 6 could be combined with Proposal 4. Other reasons given by just one respondent each included that such accountability should be the role of parliament; that accountability could end up driving the strategies; that external accountability would be inappropriate for local needs and situations, or that it would not be effective at the local level; and that it would not address wider stigma.

Caveats, Concerns and Reasons for Disagreeing

A very small number of respondents indicated that they disagreed with all proposals related to statutory strategies, with most doing so because they did not feel that strategies would be effective in achieving meaningful change. It was felt these were likely to add bureaucracy and/or become performative and result in very little real or impactful change. It was also suggested that public services were so severely stretched that they would be unable to implement any new strategies.

Others who agreed in principle with the proposals or individual elements also noted that they had little faith in strategies as these had had little/no positive impact in the past, or had led to overlap and duplication. Several examples of problematic strategies were given as having eroded respondents trust, including the National Autism Strategy, Carers Strategies, The Same as You, and The Keys to Life. These were all highlighted as seeming to have little impact, largely due to a lack of funding/resourcing and being output rather than outcome based.

Again, several respondents (typically organisations and a few individuals) also questioned or disagreed with trying to develop a single strategy to cover the full spectrum of neurodivergent conditions and learning disabilities. They generally felt that separate strategies were needed to focus on the needs of distinct groups. In particular, some argued for a dedicated learning disability strategy.

Other Comments and Considerations

The main issue discussed by individuals was the desire to see more than just strategies. Respondents wanted to see action and tangible changes. They wanted to see strategies, practices, and improvements being implemented and delivered to provide effective support for those with lived experience, and their families and carers. A range of respondents (including both individuals and organisations) advised that funding, resources, suitable staffing, training and education were all required for services, providers and frontline staff to implement any new strategies as a result of the LDAN Bill. Further, some respondents (both individuals and organisations) specifically stressed the need for strategies to be fully funded and resourced in order for them to be successful, with several respondents suggesting such funding needed to be sustainable over the long-term and ringfenced.

Other suggestions, comments or areas for consideration which specifically related to the proposals on strategies included:

- Consult with carers and families, as well as a wide range of professionals, service providers and the third sector to inform any strategy development;
- Dedicated Down’s Syndrome strategies should be considered, or for learning disability strategies to explicitly recognise and include Down’s Syndrome;
- Strategies should take a needs based, human right based, person centred, holistic, and outcomes focus approach - they should also be learning disability and neurodivergent-affirming and supportive;
- Ensure strategies are sensible, realistic and deliverable;
- Ensure strategies are clear, concise and understandable for people with learning disabilities and neurodivergent people;
- Strategies need to make provisions for diagnosis and address issues in this area, as well as addressing post-diagnostic support;
- Strategies need to recognise that the needs and experiences of individuals are varied;
- Strategies should consider intersectionality with protected characteristics and the presentation of multiple conditions;
- Any strategies or activities resulting from a LDAN Bill need to be mindful of, and aligned with other legislation, duties, strategies, plans and reporting requirements to avoid duplication and to embed consistent practice; and
- Learn good practice lessons, for example, the co-production of the BSL Act; the ‘Charter for Involvement’; the implementation of the Education (Disability Strategies and Pupils' Educational Records) (Scotland) Act 2002; SCLD guidance on Developing a Learning Disability Strategy; and Scottish Government’s ‘3 Step Improvement Framework for Scotland’s Public Services’.

Some respondents felt that many of the proposals were vague and sought clarity around what these would involve in practice, what topics and issues they would include or seek to tackle, whether and how they could be enforced, who would be involved in monitoring and assessing the implementation and effectiveness, and what funding and resources would be made available. A few individuals noted that they had found some of the proposals complicated and difficult to understand.

Again, a few respondents were not convinced that creating new legislation, statutory strategies and additional reporting requirements were the best/only way to achieve the desired aims. Instead they suggested that existing legislation, policies and strategies, could be strengthened and enforced, and guidance provided to public bodies which required them to explicitly reference people with learning disabilities and neurodivergent people within existing reporting structures.

Section 2: Mandatory Training in the Public Sector

Introduction

The consultation highlighted the need for greater awareness, understanding, and training on learning disabilities and neurodivergence, especially for public facing staff in some public services. Options were presented for placing a mandatory training requirement on health and social care staff as well as, potentially, for those working in the justice system (which could include the police and prison staff), and in the education system (for teachers and other educators). The proposals set out were for such training to be inclusive of neurodivergence more generally, as well as learning disabilities and for mandatory training to involve or include people with lived experience, where possible.

Main Findings

Overall, 674 respondents provided comments at this section. Across responses, there was significant support for proposals to establish mandatory training for those working in health and social care:

> “Absolutely…this training is vital for anyone in the public sector to be able to approach all individuals and provide a safe, supportive and effective service.” (Neurodivergent Individual)

There was also strong support for training in the education sector with some views that this was equally as important, if not more important, than training in the health and social care sectors. All those working in education from early years to tertiary education would benefit from relevant training, it was felt, and training in schools was seen as one of the best means of having a positive impact on improving attitudes and reducing stigma linked to learning disabilities and neurodivergence long term. Including training at university/ undergraduate degree level for relevant professionals was also encouraged as a means of tackling misconceptions and enhancing skills at an early stage.

Support for training was clear among both organisations (including public sector organisations) and individuals. Many cited previous negative experiences of contact with health, care and education professionals which they felt could have been averted if those professionals had been better trained/more aware of learning disabilities and neurodivergence.

While training for staff in the justice sector was mentioned slightly less often across responses (compared to health, social care and education), this was still very much supported where mentioned. Respondents reflected that the experiences of the justice system were likely to be very different for neurotypical people compared to neurodivergent people and agreed that mandatory training was one way to help raise awareness of this and to adapt practices. In addition to police and prison staff, it was suggested that court staff, solicitors, COPFS staff and those involved in the youth justice system would also benefit from mandatory training.

Several other suggestions were made for extending mandatory training to **all** public services/public sector staff as well as organisations receiving funding from the Scottish Government. Specific groups that were mentioned with some frequency included those working in social work services, housing services, residential and care home staff, employability and Social Security Scotland staff as well as emergency services staff. There were also a small number of respondents who felt that training should be extended to some private sector services, (e.g. public transport, banking and finance), as well as third sector providers.

Comments were also made that training should not be restricted to public facing staff but should include those in other roles too (including those at management level and those performing administrative or corporate duties). Some respondents suggested a more focussed approach may be needed rather than targeting such a wide audience from the start (with the initial focus being on health, social care and education) but noted that training for the wider service sector may be valuable in the long term.

Involving People with Lived Experience

There was also widespread agreement with proposals to involve people with lived experience in the training (as well as their families, carers and supporters). This included having people with lived experience input to the content and design of training as well as being involved in the training delivery, where possible. Involving people with lived experience in these ways would help to boost credibility and trust in the training delivered, it was suggested:

> “Training should include all types of neurodivergence and should be developed in conjunction with people with lived experience, and preferably delivered by them.” (Neurodivergent Individual)

Several respondents noted that they would like to see a broad range of people with lived experience being involved, and stressed that it would be important to include people of different genders, ages and personal backgrounds to ensure that training input was representative. It was also suggested that co-production of any training relating to children and young people must involve neurodivergent children and young people in its development.

Respondents also felt that training needed to be tailored to specific public sector areas and thus informed by engagement with people who had lived experience of specific sectors.

Involving people with lived experience was also seen as potentially having the added value of creating new employment opportunities for people with learning disabilities and neurodivergent people.

The main reservations cited by respondents in relation to including people with lived experience were that those who are involved should have relevant skills in ‘training’ or some ‘training experience’ as well as having lived experience.

Overall, however, respondents to the consultation agreed that training would help create a greater understanding and awareness of learning disabilities and neurodivergence across the public sector, and that this, in turn, would help public sector workers have more confidence in their ability to meet people’s needs. It would also allay any fear or misunderstanding that staff may have when dealing with the people covered by the proposed Bill.

Several respondents also noted that such training would hopefully help neurodivergent people feel heard and more likely to access services.

Training Content

There were a range of suggestions on what the training should include, as follows:

- Separate, specific training focussed on learning disabilities, on autism, and on neurodivergence respectively rather than jointly;
- Specific training in relation to Down’s Syndrome, ADHD, FASD and PMLD;
- Exploration of the links between mental health, learning disabilities, neurodivergence and autism, and complexities associated with dual/multiple diagnoses;
- Discussion of the difficulties/challenges of diagnosis and the validity of self-diagnosis;
- Exploration of the needs of those with more severe communication difficulties, including non-verbal communication, and additional mental health problems;
- Discussion of how learning disabilities and neurodivergence can intersect with other identities (e.g. LGBTQ+ status, ethnicity, physical disability, etc.);
- Separate training in relation to both adults and children and young people (including a focus on challenges associated with transition from youth to adult services);
- A focus on the unique experiences of women and girls;
- A focus on the needs of families/carers (including Armed Forces families);
- A specific focus on stigma and discrimination (to encourage reflection of personal attitudes, assumptions and prejudices);
- A focus on managing the impact and functional consequences of individuals’ conditions;
- Training on the adaptation of service environments, e.g. considering sensory triggers/sensitivities; and
- Practical strategies for staff, rather than generic awareness-raising (including such factors as communication and environmental needs):

In the same way that there was no consensus around who should be prioritised for mandatory training, there was also no consensus regarding what the focus and content of the training should be. While some welcomed a very broad approach that covered as many different learning disabilities and neurodivergent conditions as possible, a smaller number suggested that training should initially be limited to autism and learning disabilities (as currently in England), both to minimise confusion during the training, and also because they believed these were the most challenging conditions for people to understand. If training attempted to cover too much too soon it was felt by some that there may be a risk of dilution.

Several respondents also felt that Down's Syndrome should be prioritised within training and felt that this was one disability that was historically often overlooked in training and awareness linked to learning disabilities.

There were calls for training to be neuro-affirming and also agreement that the training needed to cover issues relevant to both children and young people as well as adults. Respondents also urged that all training must be consistent with a Human Rights approach and must be inclusive, diversity and culturally sensitive, person centred and trauma informed.

Similarly, it would be important to ensure that the mandatory training aligned with existing legal requirements related to the inclusion and support of neurodivergent people and to consider ethical considerations in the development and delivery of training.

Training Levels

Some comments were made that the training content and level of detail should vary depending on both the sector being targeted and the specific roles of different staff being trained, with views that training for health staff (including NHS employees) should be at the highest/most advanced level. Other advocates of a tiered approach suggested that a 'learning framework' was needed (rather than just training) which clearly sets out the skills, knowledge and competencies expected of each service and each type of practitioner in the service.

There was consensus that all public services should have a minimum level of training to allow them to respond appropriately to individual needs including for example, reception and administrative staff, especially those who may have public-facing roles.

Overall, respondents wanted training to be delivered flexibly and proportionately with a basic level of understanding for all staff and more enhanced training for staff working in more complex roles or those which would require more regular contact with people with learning disabilities and neurodivergent people.

While a very small number of respondents agreed with the notion of training but were 'unsure' or 'undecided' if it should be offered on a voluntary or mandatory basis, the majority urged for mandatory training, perceiving that this would increase likelihood of uptake and ensure positive change.

Training Delivery Approach

There were several different suggestions for how training should be delivered, with the preference appearing to be for mixed, interactive and blended methods (i.e. face to face training complemented by e-learning or digital options). There were also calls for training to include case studies and videos of people with lived experience where possible, alongside being developed and delivered by those with lived experience:

> “For best results the training should be an immersive, engaging experience with personal testimony from people with lived experience either in person or via videos, as well as practical exercises such as roleplay or problem solving. Training which is just a lecture, or a self-directed online course fails to engage people and risk reinforcing ingrained assumptions.” (LDAN Support/ Representative Organisation - Mixed Conditions)

The main sentiment was that training needed to be delivered in a way that was accessible and a small number of respondents suggested the need for a ‘learning resource’ (alongside training) which could be made widely available and accessible for anyone with an interest in learning (not restricted to public services alone).

There were also several views that training must be consistent across public services, i.e. that the same courses should be offered following a national training model such the NES Trauma Training Programme, for example. This would also make it possible for joint training to be delivered, it was suggested, with multidisciplinary training potentially offering sharing of knowledge, skills, experience and added value e.g. people working in statutory services could train alongside people in mental health, social care, social work or policing. Similarly, a small number of respondents suggested multi-disciplinary input to training development if a national approach was taken.

Comments were made that any core, mandatory, national training must be reviewed on a regular basis to ensure that it remains effective, up to date and reflects current data, research and legislation, and is continuously improved.

There were also calls for training to be accredited and carefully monitored to ensure that it remained fit for purpose and was of a requisite standard (with comments that badly designed training could do more harm than good if they perpetuated negative perceptions, stigmatisation and exclusion). Others suggested that accreditation may also be necessary to make it more robust but also more appealing to staff and to ensure buy in, as well as potentially linking training to existing professional accreditations, CPD and performance indicators.

Several respondents also commented that refresher training or regularly updated training must also be offered (to consolidate the training into practice) and that the approach to training must not be to deliver it as a ‘single event’. One-off or single event training was also described by some as being ‘tokenistic’. While several respondents agreed with the need for refresher training and enhanced training for selected specialists, there was no dominant view on whether any such additional or enhanced training should be mandatory or voluntary.

A request was also made that any development of mandatory training must intersect with and complement other training requirements (including legislative, regulatory and organisational), and national training already underway, especially within specialist contexts such as the justice system.

Concerns

The main concerns were that any training might be too generic and not sufficiently detailed to raise awareness to the extent that was required (with perceptions it may be too autism focussed and may not provide enough focus on valuing neurodivergence). Again, many respondents stressed that training must not cluster together autism and neurodivergence and that the nuances of each must be clearly and separately explored.

Caveats were also raised that the involvement of people with lived experience must be appropriately matched to the training content, i.e. training should be developed by and delivered by those with lived experience of the subject covered (such as autism training being developed and delivered by autistic people). Unless training was delivered by the most relevant persons for each topic, there were fears that false information could be shared which may perpetuate current misunderstanding and stigmas.

Even if training was delivered and attended by relevant staff, some respondents had doubts that staff would implement it correctly in practice, and concerns that putting the training into practice would not be properly monitored. Therefore, regular monitoring of compliance and implementation would be needed, it was felt, to ensure that training was being acted on. It was also suggested that there was a need for combining training with opportunities for active learning and continued growth through mechanisms such as supervision, peer support, reflective practice and wider support, as well as potentially recruiting local training champions to ensure that training was implemented correctly, achieved longevity of success, and could deliver real changes in practice and culture.

Similarly, while a national training programme received much support, some did raise cautions that there had historically been a number of efforts to require/ mandate training in the public sector but that bringing this to fruition had been problematic. Others cautioned that many professionals (especially those in health, education and social care) were already facing 'training burnout' and may find additional training too challenging to take on in addition to existing workloads/ professional demands. A carefully considered strategic approach to implementation and delivery was therefore encouraged.

Others commented that training alone may not be sufficient to tackle the biases that exist in the public sector workforce/more widely in society and that wider public education was required to break down some of the stereotypes and assumptions that exist around neurodivergence, in particular. One way to counter this was to ensure that people with these conditions were more represented among staff in the public sector to enhance inclusivity of services and make them more visible in society.

Several organisations, including Disabled Persons Organisations (DPOs) and other third sector organisations, expressed interest in being involved in the development and delivery of mandatory training in line with the proposals, and felt that they had much to offer in this regard (with several training courses/content already in place). However, there were also some concerns that the burden on learning disability services would be increased to help deliver the training, with a possible lack of capacity to meet future demand.

Overall, the main sentiment in relation to mandatory training was that it was welcomed, but only if it was consistent, regulated and accredited.

Reasons for Disagreeing

The main reasons given for disagreement with the proposal largely aligned with the concerns and caveats to support noted above. Concerns were repeated about training being too generic or attempting to cluster together too many different conditions rather than giving each the attention that they deserve. Similarly, respondents noted that they felt training could become too diluted unless carefully thought through and a reasonable number of respondents noted a preference to restrict training to autism and learning disabilities in the first instance.

On a contrasting note, a small number of comments were made that the proposed training was not fully inclusive, i.e. there were some individuals/conditions not covered within the proposed provisions of the Bill who may perceive it as unfair that mandatory training did not cover their own condition. It was felt that training needed to ensure equality of access and inclusion for all those with disabilities, regardless of the condition.

There was also disagreement on the basis that the ‘mandatory’ nature of the training and the wide reach of the proposal may be disengaging for some staff unless it was tailored specifically to their job/role and was pitched at the appropriate level.

Concerns around targeting too many people/services were also raised again, as well as comments that the training should focus on those working in health, social care, education and justice alone, or as priority areas. A minority view was also put forward that the proposals did not go far enough and that training should be made a requirement for all those entering the health and social care, education and social work professions, for example, before being able to practice.

A small number who disagreed specified that this was because the proposals did not go far enough to include people with lived experience, i.e. the co-production of training was not enough as it should be delivered and monitored alongside people with lived experience too. Families or people who care for people with learning disabilities and neurodivergent people should also be involved in the training, it was suggested.

There were also several concerns around the cost of training and overall cost of implementing this proposal with views that mandatory training on all the specified areas might be unrealistic in terms of resources and impact on staff time/capacity. One suggestion was made for piloting the training in one area or with one service sector and harnessing learning from the experience before widening it too far. A very small number indicated that they felt that the proposed training would be a waste of public money completely. Others again urged the need for a clear plan for financing and implementation of the training before taking this proposal forward (with clear timeframes), including specific details around how those with lived experience would be involved.

Other Comments and Considerations

The main other comments were also related to resourcing, with concerns around the cost of the training and questions about whether sufficient funding would be made available to achieve the proposals. It was suggested that specific budgets would need to be made available to local areas to facilitate the training, and that a ‘train the trainer’ model be used to allow local staff to take on training, rather than relying on centralised or limited training staff. This might include training trainers with lived experience/peer-to-peer training as having trainers with personal experience with learning disabilities and/or neurodivergence may enhance the authenticity and relevance of the training. Others suggested that training be delivered wherever possible by local providers who have capacity to offer high quality lived experience based training as an aspect of community wealth building.

As above, several other comments were made in relation to how the impact of mandatory training would be measured and there were calls for reassurances to be offered that delivery and implementation would be monitored, otherwise training may not result in the outcomes desired. A clear plan setting out accountability mechanisms was needed, it was felt.

Comments were also made about the importance of accompanying training with appropriate promotion and awareness strategies, i.e. to have a comprehensive communication plan to raise awareness about the importance of neurodivergence training and to promote understanding and acceptance across public service sectors.

There were also several suggestions that considerable training content/materials already existed and that there may be benefits in exploring how this could be extended or adapted to help meet this proposal, rather than developing new training from scratch. For example, it was felt that the education sector (spanning early years to tertiary education) may already have resources and materials which work well and which could be adapted for wider use. There were also suggestions that it may be worthwhile exploring if the Oliver McGowan Mandatory Training that is delivered in England could be extended to Scotland in the first instance - although others (both here and at later questions) argued against copying this model. A small number supported exploring models from countries with demonstrably successful training programmes that have a positive impact on the lives of neurodivergent people (e.g. Australia and Canada). Overall respondents agreed that it was important to explore opportunities for integration with existing programmes and build on training programmes where the groundwork has already been established, rather than designing such a programme from scratch.

A few comments were made that more thought needed to be given to how this proposal would sit alongside other developments. For example, with the new National Care Service set to launch, the Scottish Government should consider where this new mandatory training would sit in the new structure and who would have overall responsibility for delivering it.

Finally, some respondents indicated that they felt unable to answer questions regarding this proposal as more detail was required on how training would be delivered in practice and when, in order for them to provide a meaningful response.

Overall, however, the main views in relation to mandatory training were that it was very much supported and, for many, there were views that it should be considered for public sector staff or to extend beyond health and social care to encompass the justice and education sectors as a minimum. A small number of respondents indicated that they viewed this as one of the most important parts of the Bill.

Section 3: Inclusive Communications

Introduction

The consultation set out four proposals for ensuring better and more consistently delivered inclusive communications, these being:

- **Proposal 1:** Provide for neurodivergent people and people with learning disabilities to request access to **alternative means of communication** where the standard means of communication does not work for them and/or for them to be able to request access to a practitioner with specialist training in certain circumstances.
- **Proposal 2:** Better access to **Easy Read** versions of all public facing communications and documents made by public authorities (including a broad duty to make them available on request and an automatic duty to provide them in certain circumstances).
- **Proposal 3:** For local authority **strategies** to be required to include consideration of, and reporting on, how the specific communication needs of people with learning disabilities and neurodivergent people have been met.
- **Proposal 4:** For the Bill to provide for an enforceable **Accessible Information Standard** for Scotland.

Main Findings

In total, 593 respondents provided feedback at this section. There was strong support overall for each of the individual proposals and a large number of respondents indicated that they agreed with all of the proposals set out. Several respondents suggested that inclusive communication was one of the most important aspects of the Bill and felt that improved communication would create a more positive experience of accessing services for people with learning disabilities and neurodivergent people, as well as their family members and carers:

> “The emphasis on inclusive communication within the LDAN Bill is paramount in ensuring equitable access to information and services for neurodivergent individuals and those with learning disabilities. Inclusive communication not only facilitates the exercise of rights and independent living but also fosters meaningful participation in society.” (LDAN Support/Representative Organisation - Neurodivergent Focus)

Several comments were made that a combination of all four proposals was needed to ensure that inclusive communication aspirations were met.

Proposal 1: Alternative Means of Communication

In relation to accessing alternative means of communication, the majority of respondents supported this idea and many noted that they felt this was long overdue. This proposal attracted the most feedback at this section, almost all of which was positive, with several respondents stressing that having easy access to information presented in an accessible format was a basic human right:

> “Everyone with a learning disability should be afforded a means of communication instead of relying on someone else to speak for them.” (Individual with a learning disability)

Respondents who supported this proposal noted that alternative means of communication would allow more people to access services fully. Health settings and justice environments were highlighted most often as places where alternative communications should be made available for individuals and carers who are neurodivergent or have learning disabilities. The importance of providing information in alternative formats in education settings and across multiple local authority services, was also stressed by many. It would be important, however, to ensure that any communication was tailored to the specific needs of individuals/ families and others, and it was recognised that this could make the proposal challenging to implement.

There was particularly strong support for the provision to request access to a practitioner with specialist training, as proposed. This was seen as being highly beneficial, especially where additional support was needed or anxiety existed:

> “…having the option to request a trained expert in certain situations, who has experience of working with neurodivergent people, would greatly reduce stress and anxiety caused by already stressful situations.” (Neurodivergent Individual and Family/Friend/Carer)

There was, however, also some caution that there were potentially significant resource implications in making access to a specialist practitioner an enforceable right across all public services. Caution was also raised that this might not always be practicable in emergency or urgent situations. A small number of respondents also suggested that this proposal could be strengthened further by including provisions to allow individuals to be supported by a preferred family member, carer, advocate or support worker.

There was consensus that different individuals would benefit from different forms of accessible communication (for example, neurodivergent people may prefer a video, whilst people with learning disabilities may benefit from an Easy Read version) and therefore a variety of accessible communication types would be required. Examples of other provisions/specific alternative formats which it was felt should be provided included:

- visual information/communication visuals/symbol charts/photo stories;
- audio communication;
- British Sign Language (BSL);
- Braille;
- Moon;
- Makaton videos and Makaton sign options;

- Picture Exchange Communication Systems (PECS);
- multi-sensory story telling;
- Spelling to Communicate (S2C);
- Talking Mats; and
- clear and large print (including printed options).

A notable number of respondents specifically commented that there needed to be better access to Alternative and Augmentative Communication (AAC) supports and tools for people who would benefit from using them.

Having a wide range of choices available as standard would also embed and reinforce the importance of inclusion and equality, it was suggested.

It is worth noting that several respondents commented on the inaccessibility of routinely used existing communications for autistic people, and specifically the use of verbal communication (either in person, by telephone or online). For this reason, the importance of always having written, email or text chat, or face-to-face with a text-to-speech device was also highlighted.

Several respondents discussed personal challenges that they faced with different communication methods and explained that they found it challenging to speak to strangers, or even familiar people in unfamiliar settings, without some kind of support (usually from a well-known and trusted person, such as a parent or carer).

The main perceived limitation of this proposal (cited by several individuals and organisations) was that it placed an onus on people to proactively ask for alternatives, rather than these being made available as standard. Some suggested this would create a barrier to accessing alternative means of communication, and recommended rewording this to place a duty on public authorities to set out the means and different methods of communication available. Comments were made that a wide variety of alternative formats should be provided more routinely/ proactively:

> "People should not have to request access to alternative means of communication - the request itself is too much of a barrier for so many people. It should be standard to offer options to everyone." (LDAN Support/Representative Organisation - Neurodivergent Focus)

Another solution that was put forward by several respondents was the idea of 'communication passports' which could be shared between services, etc. so that communication preferences were already known by service providers in advance of appointments, etc.

The main caveat to support was that all accessible communication would have to be of a high standard to ensure it fulfils its intended purpose and that the proposal could also be strengthened by adding mandatory timeframes in which to provide/meet accessibility requests. The other main comment in relation to Proposal 1 was that it would need to be accompanied by public awareness to ensure that people are aware of the right to request alternative means of communication.

Proposal 2: Better Access to Easy Read Information

The majority of respondents supported the proposal for better access to Easy Read information with the dominant view being that the LDAN Bill should include provisions for a broad duty not only to make Easy Read versions available on request, but also for there to be automatic provision in certain circumstances.

Comments were made that there would be added value from this proposal as it would support wider groups in society as well, e.g. deaf communities, those with low reading age, and those for whom English is not their first language.

While this was widely supported, several comments were made that Easy Read must not become the default position for achieving inclusive communications as it was not accessible to all. For example, it was noted that it was not widely used by ADHD adults and it may, therefore, be preferable to employ Plain English as a standard instead. There was some fear that the provision of Easy Read may be deemed by some authorities as being an easy solution/adequate to meet their local inclusive communication commitments, but that this was not user focused.

One of the main limitations highlighted with this proposal was that it would be exceptionally resource intensive, with comments that producing Easy Read documents for all published materials may not be a proportionate means of reaching a legitimate aim. A further caveat to support was that this proposal could lead to unnecessary duplication in work between services, unless implemented in a very clear and systemic way.

A small number of respondents raised the possibility of Proposals 1 and 2 being merged and indicated that they were unsure why Easy Read had been singled out.

Again, suggestions were made that people with learning disabilities and neurodivergent people should be involved in both the development and evaluation of Easy Read materials referred to in Proposal 2 (similar to their involvement in any strategy and training developed).

The main caveat to support was again the cost of producing Easy Reads and concerns around lack of expertise, time and resources to facilitate this proposal:

> “Creating Easy Read documents requires training, time and resources. This needs to be considered from a practical and financial point of view.” (Health Service)

Overall, while this proposal was supported as one route to achieving better and more inclusive communications, many respondents felt it should be only part of the wider solution, and should not be the only method prioritised or used.

Proposal 3: Inclusive Communication Strategies

In relation to strategies for meeting and reporting on inclusive communication needs, this was again strongly supported on the basis that it would strengthen awareness, accountability and transparency of provision, and that, without it, it was unlikely that inclusive communications would ever be prioritised in local areas. It was also felt this would help to ensure consistency of provision, and to counter what many described as the current postcode lottery with regards to accessible communication.

Having a nationally agreed standard accompanied by locally implemented strategies was also seen as maintaining some core consistency whilst also allowing for tailored approaches:

> “We recognise the potential benefits of national standards supported by guidance for inclusive communication. This will provide a standard against which training and effectiveness can be benchmarked, and encourage consistent language, communication options, and styles, across public services. Making this guidance adoptable, but easily adaptable for local use, will support more efficient use of public funds and enable public service providers to collectively have more impact on providing effective service delivery, without the expense of each having to develop their own.” (Other National Public Body/National Agency)

In line with comments made in response to Proposal 1, many respondents again stressed that any guidance developed on local strategies should be clear there is a duty to always provide accessible communications, with a move away from an ‘on request’ model.

One of the main caveats to support for Proposal 3 was that it was not clear why legislation was required, with some feeling that national and local ‘guidance’ for strategies may be sufficient.

Proposal 4: Accessible Information Standard for Scotland

Comments linked to the proposal for the Bill to provide for an enforceable Accessible Information Standard for Scotland were all mainly positive and a small number of respondents noted that they felt this proposal would be the most impactful of the four communication proposals overall. Suggestions were made that this could be linked to any new accountability measure that the proposed LDAN Bill might introduce, to ensure compliance.

Several respondents noted that existing guidance and legislation such as the Equality Act (2010) meant that inclusive communication should already be considered best practice and be more widespread, although this was not happening in practice. Similarly, Article 9 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) on the right to accessibility of the physical environment, transportation, information and communication, and services open to the public was also often currently overlooked, it was felt. The Standard in section

250 of the Health and Social Care Act 2012 was also cited as being enforceable only insofar as bodies must pay regard to it. As a result, there was some cynicism regarding the effectiveness of yet more legislation in this regard, and questions around why greater enforcement of existing requirements would not be more effective. Making the Standard enforceable was, nonetheless, welcomed as a means of potentially ensuring compliance and action going forwards.

On a related note, it was again suggested that all of the inclusive communications proposals needed to be considered alongside existing legislation/pending legislation such that a more joined up approach to implementing and enforcing compliance with standards could be found.

Several respondents also suggested that the Accessible Information Standard made under section 250 of the Health and Social Care Act 2012 should be best practice across the whole public sector, not just health and social care services.

A specific point of caution was also noted that it was important to recognise that accessible information was only one part of inclusive communication and that wider/alternative measures were needed alongside this proposal to ensure overall reach and effectiveness of the Bill:

> “Accessible Information is one area of Inclusive Communication. The two terms are not interchangeable. The Accessible Information Standard does not equate to Inclusive Communication good practice. For example, it does not incorporate the need to recognise every community includes people who communicate in different ways or to proactively meet those needs without requiring people to "ask"... It would be better to enforce a National Inclusive Communication Standard (which would incorporate the Accessible Information Standard).” (Other Organisation)

As with many other areas of the Bill, this was one area where the involvement of people with lived experience was again seen as essential.

Again, a small number of respondents set out what they perceived to be the added value of this proposal in terms of addressing literacy barriers within the general population. While there was already good practice established for producing accessible information for people with learning disabilities and associated conditions in some areas, making this mandatory would be beneficial to further increase understanding and access for a range of diverse groups, it was felt, including those for whom English was not their first language.

Some respondents noted a need to recognise that services would need to be given investment to support meeting this standard which they cited as the main risk to implementation. There was also some evidence that a small number of respondents did not understand what was being proposed as well as some concerns that it was not clear specifically which public bodies Proposal 4 would apply to. Overall, however, sentiments reflected support for an enforceable standard as being preferable to guidance which may not be followed.

Reasons for Disagreeing

There were very few respondents who disagreed with the proposals in their entirety. Instead, while some limitations of the proposals were cited, this was often as a caveat to support, rather than being presented as a complete disagreement with the options set out.

As above, the main reason for disagreeing with the proposals (especially Proposal 1) was that respondents perceived them to require individuals to be proactive in asking for information (and a less reactive approach was preferred). It was highlighted that some individuals may face barriers to requesting their preferred/ required format due to language, awareness, knowledge or confidence.

The other main disagreement was related to the proposals being too generic, and therefore not meeting the needs of all those covered by the Bill. Again, it was stressed that the communication needs of those with learning disabilities and autistic and neurodivergent people were too different to be addressed by a single approach.

Others suggested that tackling inclusive communication as part of the LDAN Bill would be less effective than tackling it as part of wider Human Rights legislation if it was to benefit the widest audience possible.

Other reasons for not agreeing with the proposals (mentioned by just a very small number of respondents each) included that:

- Improved advocacy and support would be a better (or additional) way of achieving the intended aims;
- The proposals would not be helpful to those who were undiagnosed and who may therefore find it harder to have their requests/needs met; and
- The proposals currently did not specifically or adequately address the inclusive communication needs of autistic people.

The other main disagreement with any of the specific proposals was with Proposal 3 - a small number of respondents did not agree with 'local strategies' as they felt this left too much room for geographical variation, rather than consistent practice nationwide.

Other Comments and Considerations

Other comments included that:

- Accessible information needed to be high quality and there must be quality checking mechanisms in place to ensure that standards are met (for example, with well-produced Easy Reads);
- Accessible communication strategies should be accompanied by better environments for communication which take account of any sensory adaptations that may be necessary (for example, softer lighting, blinds closed on request, etc.);

- There was a need for wider 'accessible information' in service environments overall, such as clear and concise signage, real-time information displays, etc. as standard;
- Accessible and inclusive communications must also be sensitive to equalities/inclusive of other differences - e.g. ethnic, cultural difference, gender difference, etc. (with production of documents in both a different formats AND in other languages/dual adaptations);
- More focussed strategies/proposals may be needed to cover inclusive communications for children, young people and their families/carers;
- Investment in information technology systems across public services may be required to enable individual's preferences to be easily recorded, updated or shared across organisations;
- The changes covered by the proposals must be enforceable and sanctionable and must not be left to local/organisational choice, as they would otherwise fail;
- The means of complaining about lack of accessibility (and other aspects of service provision) must also be accessible, i.e. it would be important that people with learning disabilities and neurodivergent people were able to make complaints about lack of accessibility/inclusion and further consideration may be needed to assess how far existing complaints systems meet the needs of those covered by the Bill; and
- Training in inclusive communication would be essential to complement the proposals set out (with suggestions made for practitioners with specialist skills and training to be available within all services to assist with communications).

Comments were also made that the Bill should separately consider the inclusive communication support needs of carers/young carers who may be called upon to support communication with their family members when they are trying to access services. In many cases, the preference was for these individuals to speak on someone's behalf, but they too may have communication needs. This was perhaps not sufficiently well covered by the current proposals.

Several respondents again stressed the importance of taking forward these proposals with the inclusion of people with lived experience. Several organisations (including specialist and third sector organisations) also expressed an interest in being involved in the onward shaping and implementation of these proposals.

A number of questions were asked around who would be responsible for funding and facilitating the proposals, and there was particular concern regarding how access to appropriate alternative methods of communication would be met when existing services that facilitate inclusive communication were already struggling with existing demands. Given the relatively small pool of often specialist services/ specialist staff available, it would be important that expectations around access to alternatives were managed so as not to raise expectation that cannot be met.

More general comments were linked to the cost of achieving these proposals as a whole and the time required to embed them, with the need to manage expectations in this regard being a common concern. Some respondents sought greater clarification/assurances around adequate commissioning and planning of services to be able to achieve the proposals.

A number of respondents also asked questions around what quality controls would be in place to ensure that communication standards were being met (other than those set out in Proposals 3 and 4). Clarity was also sought around how both those with clinical and lived experience would be involved in the design and implementation of services. There was a strong preference for co-production in taking forward any strategies and documents related to these proposals, including input from both those with lived experience and communication professionals.

There was consensus that, whatever proposals were implemented, they must also be constantly monitored, reviewed and updated as necessary.

A very small number questioned how these proposals would intersect and/or conflict with Freedom of Information (FOI) legislation and how information regarding communication preferences might be stored and shared.

Several organisations noted that these proposals would be challenging to operationalise given existing workload and budgetary demands, and welcomed further information on how such proposals would be implemented, particularly in primary care, to ensure that the already excessive burdens on services were not exacerbated.

Finally, it should be noted that a small number of respondents used this question to express that they had found the consultation document inaccessible and cited it as an example of where information could have been better communicated. It was suggested that presenting information in alternative formats was not always sufficient in its own right to make the information accessible i.e. the material being presented and the substantive content of the information must avoid overuse of acronyms, be non-jargonistic and be coherent as a starting point.

Section 4: Data

Introduction

The consultation paper set out the importance of high quality and accurate data related to people with learning disabilities and neurodivergent people across Scotland. It also noted the current barriers to achieving this. Feedback was sought in relation to four proposals which were aimed at providing a legal framework to support joined up data collation and sharing. The four proposals were:

- **Proposal 1: Developing a commission(er) with responsibility for data collation** - any accountability model adopted (discussed more at Part 4) could include functions and responsibilities for collecting and analysing data on people with learning disabilities and neurodivergent people, and to make recommendations to other organisations collecting data to disaggregate this to the level of people with learning disabilities and neurodivergent people.
- **Proposal 2: Placing duties on some relevant public bodies to collect data** on people with learning disabilities and neurodivergent people where this would be helpful for better understanding of the needs of these groups and their experiences, informing service design and improvement, and to allow for evaluation of measures to improve outcomes for these groups.
- **Proposal 3: Placing duties on some relevant public bodies to provide returns to the Scottish Government** regarding local data on people with learning disabilities and neurodivergent people, where this would be helpful for a better understanding of the needs of these groups and their experiences, informing service design and improvement, and to allow for evaluation of measures to improve outcomes for these groups.
- **Proposal 4: Consideration of the development of a Scottish version of the LeDeR programme -** Similar to Child Death Reviews, a programme could be established to ensure when someone with a learning disability dies, that a review happens to identify why they died and share the learning on how it could have been prevented.

Main Findings

Overall, 492 respondents provided feedback at this section. Responses were more mixed compared to earlier sections, with feedback often considering data collection, analysis and use more generally rather than always focusing on the proposals set out. Some (often organisations) discussed the types of data they felt were important to collect, or set out their own proposals or models for how they thought data collection and analysis should be undertaken. In particular, public sector organisations discussed what might be possible within existing structures or might be useful to improve service delivery, while third sector organisations outlined the type of data that would be important or desirable to collect generally. Other respondents noted pros and cons of each proposal without indicating whether they supported them or not.

Nevertheless, there was widespread support (among both individuals and organisations) for the collation and use of data generally, regardless of the mechanisms developed to achieve this. It was felt that access to robust and high quality data was essential to identify unmet need and the scale of any issues, for service and resource planning, to identify areas for improvement, to monitor and assess outcomes, etc. Data were also considered important at the national and local level, to assess the national picture and for benchmarking, while also developing local services:

> “Gathering data helps authorities to see who they are providing for and where they need to target further resources. I think this is a very important method to help them allocate funding and training, and further helps them to identify what is needed now or may be needed in the future.” (Family/Friend/Carer)

While not asked about at this question, some respondents also identified sectors where they wanted to see better data in relation to people with learning disabilities and neurodivergent people. This included local authorities, health boards, health and social care, mental health, education, employment, justice, and housing, with some respondents also calling for better data in relation to waiting times for diagnosis/assessment.

Around a quarter of those who responded at this section agreed with all the proposals (lower than the levels of respondents agreeing with all proposals at most other sections). Where respondents agreed with all proposal this was either because each option had merit or because they thought all proposals should be implemented in combination. It was felt this would provide a joined up and consistent approach, which would include accountability and oversight. Similar proportions of respondents (roughly half of those who responded at this section) supported each of the proposals.

Proposal 1: Commission(er) Responsible for Data Collation

Proposal 1, developing a Commission(er) with responsibility for data collation, was largely supported. Respondents were supportive of having one central organisation/department/person responsible for co-ordinating and overseeing all data related issues. It was felt the Commission(er) could provide guidance and support to other public bodies in their data collection efforts to ensure consistency across services/the country. In addition, a Commission(er) could/should monitor and quality check returns or reporting, collate the data at a national level, and ensure meaningful improvements are made as a result of the data:

> “Establishing a Commissioner (or Commission) is the only way to guarantee visibility of learning disabled and neurodivergent people in data collection and ensuring the analysis of that data is used for serving that population rather than for justifying reasons to limit resources and services.” (Neurodivergent Individual and Family/Friend/Carer)

It was also felt that having a named role/designated organisation responsible for this would help ensure accountability - both that the Commission(er) would be accountable, but that the Commission(er) would also hold public authorities to account for data collection, data use, and how it informs service improvements.

However, Proposal 1 also elicited the greatest level of disagreement out of all the proposals presented in this section. Some of these respondents disagreed with the creation of a new Commission(er) because setting up and running a new Commission(er) would be costly, and they felt that resources would be better spent on improving data collection/use and service provision. Several were also concerned that this would build in delays, as time would be needed to set up such a body and establish mechanisms for data collection, while change was felt to be needed more urgently.

Others (including both those who agreed and disagreed with this proposal) felt that setting up a new Commission(er) would not be necessary as existing public bodies could undertake data collection and analysis (or perform a co-ordination and quality control role), and/or would be best placed to do so. A range of examples were provided, with Public Health Scotland (PHS) mentioned by a few organisations. Others felt that the Scottish Government should have responsibility for this rather than a Commission(er). There were also concerns over the resources that would be required to establish a new Commission(er).

Several respondents who were not opposed to the use of a Commission(er) in general felt that they should not be responsible for collecting data themselves. Instead, they should collate returns from public bodies and ensure compliance and quality.

Proposals 2 and 3: Duty to Collect Data and Provide Returns

Of those who discussed Proposals 2 and 3, most considered these jointly. Those who supported these proposals felt they should be implemented together, while those who disagreed with each did so largely for the same reasons.

Those who agreed with Proposals 2 and 3 felt there was a need for local data, information about services being used, experiences of these services, etc. It was felt that imposing a duty for data collection and returns would support public bodies to prioritise this to provide higher quality and more meaningful data. It was also felt that public bodies and local services would be best placed to gather data and provide returns relevant to their services/sector:

> “…public authorities will collect information on different areas relevant to their sector. Requiring public authorities to collect this data and to demonstrate how this data informs policy and practice development will ensure the needs of neurodivergent people have been properly considered.” (Neurodivergent Individual)

In addition, respondents argued that data gathered at this level would support organisations to develop local services which were best tailored to meet local needs, while making returns to the Scottish Government (or a Commission(er)) would allow national datasets to be collated and a national position to be established.

Several respondents also felt that imposing a duty on organisations would ensure data was being gathered, which would address the current lack of data and evidence gaps experienced in certain areas and for particular populations.

It was also felt that Proposals 2 and 3 were “achievable” as many organisations already collect data, and this would not require the establishment of a new Commission(er) or alternative system.

Several respondents suggested that Proposal 2 (or any data system generally) could be enhanced by creating arrangements to allow for data sharing between organisations to ensure vital information is available to all those involved in the delivery of relevant services. This would ensure individuals and their families/carers do not have to repeat information at each contact.

A few respondents also felt that Proposal 3 needed to place a timescale on returns, with most of those who discussed this suggesting returns should be provided and published annually. It was also felt that a duty needed to be imposed on the Scottish Government to ensure annual publication of data/results.

As with previous sections of the consultation, some respondents disagreed with Proposal 2 and 3 due to the wording of the proposal rather than the intention. It was argued that **all** public bodies should be required to collect data and provide returns, not just “some”. Several respondents (typically family/friends and third sector support organisations) also felt that the wording “where this would be helpful” should be removed from the proposals as this could be used as a loophole by public bodies to avoid undertaking these tasks.

Those who disagreed with Proposals 2 and 3 tended to feel that local authorities and local public bodies were already overstretched and would therefore be unable to take on any further responsibilities. It was also felt that the content, nature and quality of data collected and the returns provided would be highly variable.

Disagreement with Proposal 3 specifically was often driven by whether the respondent thought a Commission(er) should be introduced or not, rather than being opposed to a duty to provide returns. Where a Commission(er) was preferred then having public bodies reporting to the Scottish Government was seen as unnecessary - rather, public bodies should be providing data returns to the Commission(er). Should a Commission(er) not be appointed, however, then providing returns to the Scottish Government was desirable.

Views on whether data should be shared with the Scottish Government were also mixed. Most felt that anonymous data should be shared with the Scottish Government because it should have overall responsibility for this and/or to support national policy making decisions, resource planning and budget allocations. Others, however, felt that the Scottish Government did not need access to this level of data, particularly at the local level, and especially if individuals were to be identifiable.

These respondents argued that a Commission(er), if appointed, should have responsibility for the data, otherwise, such data should be retained locally.

Proposal 4: Review the Deaths of People with Learning Disabilities

Overall, respondents were in favour of Proposal 4, i.e. to consider the development of a Scottish version of the Learning from Deaths Review (LeDeR) programme in a similar system to Child Death Reviews. Most of those who supported this felt it was important to review experiences and outcomes in order to learn lessons which could improve outcomes going forward and address the early mortality rates for people with learning disabilities. It was also felt that such a system would mean service providers would be more accountable for their decisions and actions.

Some respondents argued, however, that these reviews should be widened to include autistic people, particularly due to the high rates of suicides and barriers to healthcare. Some also called for the inclusion of neurodivergence more generally, and the inclusion of those with PMLD (both here and in Child Death Reviews). Indeed this was also a key reason for disagreement with the proposal, i.e. respondents felt the stated scope for inclusion in such reviews was too narrow and needed to be widened, rather than these respondents having any real opposition to the use of reviews.

Several respondents were also keen to ensure that more could be done to tackle issues while people were still alive rather than only reviewing situations after death. It was suggested that monitoring quality of life was needed, and/or that the Annual Health Checks could provide a useful forum to inform this:

> “We would suggest that LeDEr is not limited to assessing a person’s life upon their death, but also during regular intervals during their life. This would help to ensure the person is able to provide their own feedback about their life and is an opportunity to highlight issues of concern.” (Organisation for Other Disability/Condition)

However, a few organisations who were supportive of this proposal stressed the need to ensure any learning from these reviews truly resulted in changes and improvements. They noted that the LeDeR system in English had not necessarily resulted in any meaningful improvements in life expectancy or outcomes.

Caveats, Concerns and Reasons for Disagreeing

While only a very small number of people explicitly stated they disagreed with all proposals the reasons provided were consistent with common concerns raised throughout responses generally. The key issues tended to be related to the perception that data collection was not necessary to developing improvements, and a nervousness or suspicion around how the data could be used.

Data Not Required to Progress Improvements

Many respondents who disagreed with all proposals, and several who supported them in principle, noted that a lot was already known about the experiences of people with learning disabilities and autistic people. Therefore, extensive data collection may not be required in order to implement improvements. It was suggested that data collection was not a priority area that needed to be focused on at this stage, but that action and real change was needed.

Inappropriate Use/Used for Negative Purposes

Another major concern for respondents was how data might be used and any negative uses/consequences of developing datasets based on people with learning disabilities and neurodivergent people, i.e. vulnerable groups. Some were deeply concerned about the risks that any such datasets might pose. For example, respondents were worried about data breaches and data being shared inappropriately or sold to third-parties, as well as what any future (typically described as “extreme right wing”) governments might use the data for. They were concerned such data could be used as a list or register to identify vulnerable people for a host of negative purposes:

> “Many of us oppose data collection on us, as the risks outweigh the benefits. Progress has been two steps forward, two steps back. Our legal standing is often compromised with a note of autism or of similar "vulnerability" where we can lose our autonomy in anywhere from custody, divorce or sectioning to name a few.” (Individual with a learning disability)

Several respondents suggested that the use of anonymised or aggregated data may provide a suitable safeguard against these concerns. Others suggested that robust protections were required to ensure data could not be shared inappropriately or sold to third-parties.

Other Comments and Considerations

Disaggregate Data Levels

Many respondents stressed the importance of disaggregated data, and suggested that any data gathering needed to include condition specific data (where known) and co-occurrence of conditions. It was felt highly important that data do not simply attribute everyone under a general LDAN or neurodivergence heading. Some respondents stressed the need to gather data on those with Down’s Syndrome in particular (with PMLD also noted less often), to ensure experiences are not lost within a wider population. A few organisations also noted that disaggregated data was a requirement of the UNCRPD.

Respondents with, or those supporting/representing those with Down’s Syndrome highlighted the comprehensive level of data that was currently collected around Down’s Syndrome in pregnancy compared to the lack of data available about them in the population. They stressed that data should continue to be equally important after people with Down’s Syndrome are born and throughout their lives.

Similarly, respondents called for intersectional data, with a wide range of specific suggestions mentioned. These included: information on other conditions, disabilities or health issues; mental health information; protected characteristics (with several noting the need to identify ethnicity, gender, age or life stage, and LGBTQI+

specifically); socio-economic information and the Scottish Index of Multiple Deprivation (SIMD); unpaid carers; care experienced people; survivors of trauma and/or abuse; victims of crime; and members of the armed forces community.

Data Use

Some respondents also stressed that any data collection needed to be meaningful and used to make real improvements to the lives of people with learning disabilities and neurodivergent people, the data should not become the end result. It was suggested by several organisations (particularly, but not exclusively, in the public sector and representative organisations) however, that greater analytical resources would be required in order to deliver this.

Practical Issues

Issues with data integrity/validity and representativeness were also discussed. Respondents queried how undiagnosed persons and those who do not know they have a condition would be included/counted in the data, or indicated that systems would be needed to take account of this. It was also highlighted that not all relevant individuals are actively engaged with public bodies and some find it difficult to access services, therefore experiences would be missed if only gathering data via services. Conversely, respondents queried how double counting of individuals would be avoided where they are involved with different services and agencies. Further, respondents queried how consistency would/could be ensured between data collectors, with some suggesting that clarity and consistency would be needed around definitions, along with consistency in the language used and interpretation/ coding of data (although others noted this risked adopting a medical model of disability rather than a social model as was preferred at Part 1 of the consultation).

Respondents were also concerned about how informed consent could be ensured, but stressed that this was essential, both for the collection and sharing of data.

Other practical aspects of data collection, analysis and reporting were also flagged as areas for further consideration. These included:

- The need for clarity and transparency about how data will be stored and used, and around any data retention periods;
- Data security, privacy and GDPR compliance would need to be strictly adhered to, although it was noted that GDPR can limit data sharing between agencies; and
- There is a need for joined up systems and data sharing in a secure and data protection compliant way.

Other Issues for Consideration

A range of other issues were also raised by respondents as being areas that required further consideration, as follows:

- Qualitative data is needed, not just quantitative data;

- Involve those with lived experience in determining the scope of data to be collected and in designing any relevant data collection tools;
- A joined up approach, partnership working and collaborative practices are needed to avoid silo working;
- Data could be collected via the Scottish Census, the Scottish Crime and Justice Survey, Scottish Health Survey, and Scottish Household Survey;
- Equivalent data is also required for children and young people with learning disabilities and neurodivergent children and young people;
- The proposals lack reference to autism, and only focus on learning disabilities and neurodivergence. It was suggested that autism needed to be included and named specifically throughout (both here and at other sections of the consultation);
- The third sector also provides services to people with learning disabilities and neurodivergent people, with many either already collecting data or well placed to do so. This sector should be incorporated within any plans;
- A few organisations queried how data from the Annual Health Check would be incorporated within any new system, and felt that greater consideration was needed around how these data are collected and used;
- A few organisations called for the Scottish Learning Disability Observatory to be involved in the analysis of any data given their expertise in the area; and
- A few organisations called for data collection related to the Learning Disability Statistics Scotland (LDSS) to be restarted - although it was stressed that investment was required to ensure data were good quality and fit for purpose, and that statistics for children and young people should be included.

Some organisations set out findings from existing data/research, and/or outlined the scope of data that was already being collected. A few suggested that such sources may provide a useful starting point or could be expanded or rolled out to other sectors. Others (including individuals and organisations, and particularly public bodies) sought clarity or greater levels of information about how data collection would work; how frequently it would be required; what type of data would be collected; whether this would sit alongside or require expansion of currently collected data or represent entirely new requirements; how the data would be used and managed; and how the work would be resourced and funded. In particular, public bodies (amongst others) were keen to stress the additional workload, training and system updates/IT infrastructure that would be required to collect, quality assure, and analyse data and prepare any returns, and were keen to ensure that this would be fully funded and resourced. They were also keen to avoid duplication of effort in relation to data collation, analysis and reporting. Some public bodies were, however, positive about the potential of a formal framework in this regard to provide consistency, to support organisations to formalise developing approaches, and to allow a national picture to be established and appropriate policies to be developed.

Finally, several individuals indicated that they did not understand the proposals set out in this section of the consultation document and so could not comment.

Section 5: Independent Advocacy

Introduction

The consultation document set out the different legislation and approaches related to the provision of free independent advocacy in Scotland. Despite the importance of independent advocacy, with it being one way that people can receive help to understand and access their rights, the difficulties with accessing this support and low levels of use among those who are entitled to it was outlined.

Although the consultation document stated that the proposals for the LDAN Bill would not include a broad right to independent advocacy for people with learning disabilities and neurodivergent people, this was because legislation for advocacy would depend on the outcomes of the proposed changes to other legislation. Rather, feedback was sought on the following two proposals:

- **Strengthen and improve access to existing advocacy** by (a) making regulations around the provision of independent advocacy for people with learning disabilities and neurodivergent people; and (b) placing a duty on all public bodies to ensure that all people with learning disabilities and neurodivergent people are given information about advocacy and how to appoint their own independent advocate to support them.
- **Improve our understanding of Independent Advocacy** by identifying and gathering evidence on specific circumstances where a right to independent advocacy could make a difference, and consider whether the Bill could provide some specific legal rights to free independent advocacy in these circumstances.

Main Findings

Overall, 460 respondents commented at this section. The most popular choice for respondents was for both proposals to be implemented together. It was felt that both were needed to provide a more robust and consistent approach.

Where respondents indicated a preference for a single proposal, Proposal 1 (i.e. to strengthen and improve access to advocacy) was slightly more popular, although roughly similar proportions of respondents supported each (at around half of those who responded).

Proposal 1: Strengthen and Improve Access to Advocacy

Overall there was solid support for the use of independent advocacy generally, and for improving access to this. It was felt that improved access could have an immediate improvement to people’s lives. It will help them to navigate complex systems, understand information and their rights, have their voice heard and choices respected, and result in better outcomes. It was also noted that UNCRDP made provisions for access to advocacy. In addition, it was also noted that this support could aid independence and ease some of the pressure on family members who often need to provide informal advocacy support.

Respondents outlined the current low levels of awareness, as well as the difficulties and barriers they faced in trying to access advocacy and in accessing services without advocacy support. This included long waiting lists for existing advocacy services, and many raised concerns over the different levels of availability in different areas, with some again using the term ‘postcode lottery’ to describe current provision:

> “Overall access to independent advocacy is limited by long waiting lists and individual advocacy is offered mostly at crisis point or in formal process-focused occasions.” (LDAN Support/Representative Organisation - Learning Disabilities)

It was also noted that individuals with the most severe difficulties (either long-term or caused by situational distress) were often the least likely to be aware of, understand, able to access and make good use of advocacy services. It was suggested that the process was currently too onerous for vulnerable people to navigate.

As a result, many respondents suggested that advocacy should be made more accessible and readily available. There was also strong agreement with a duty for all public bodies to ensure that all people with learning disabilities and neurodivergent people are given information about advocacy and how to appoint their own independent advocate. It was felt that such signposting would raise awareness, ensure people understood what this was and how to access it, and would boost uptake.

A few respondents offered practical solutions for signposting, with one mental health focused organisation suggested a ‘No Wrong Door’ approach or single point of entry model whereby the first organisation the person comes into contact with has a responsibility to support them to make contact with the correct service(s), including independent advocacy. A few respondents also called for a central resource or local ‘hub’ for advocacy so that people with learning disabilities and neurodivergent people know who to turn to. Similarly, the success of ‘one stop shops’ was discussed, with respondents suggesting that a similar model could be adopted for advocacy.

Several organisations and a few individuals also suggested there was a need for advocacy to support people during **all** challenging life stages and events, and this should not be restricted to care and mental health (which is the focus of current legislation being reviewed in this respect). Others identified specific systems and sectors where advocacy would be helpful, which included:

- Health;
- Housing;
- Finances;
- Benefits System;
- Child protection;
- Guardianship;

- Education;
- Gender transition;
- Gender based violence;
- Community Inclusion;
- Workplace; and
- Legal system and/or Criminal Justice.

While wider availability of independent advocacy was largely supported, respondents (particularly organisations) raised concerns about the sector’s ability to increase capacity and meet the needs of those covered by the LDAN Bill. It was highlighted that demand for advocacy services already outstripped supply, that some providers are limited in their potential client base by their funding agreements, and that they may not/do not have the necessary skills and experience to support people with learning disabilities, autistic people and neurodivergent people. As such, it was felt that greater funding, staffing levels, training, and resources would be needed to increase current capacity and to provide services suitable for people with learning disabilities and neurodivergent people. A few organisations also suggested that there should be a full financial costing attached to the new Bill.

Some organisations were concerned about relevant bodies being obliged to signpost and offer advocacy services but not having the available funding or resources to deliver this in either the short or long term. Indeed, one organisation noted that the overstretched nature of the advocacy sector might make them reluctant to share information about resources or services they know are underfunded or have long waiting lists.

This concern over resources and funding was echoed by many individual respondents who highlighted how under-funded and under-resourced the services currently are.

Many respondents also agreed with the need for a consistent definition of ‘independent advocacy’, while some organisations suggested that collective advocacy be championed alongside independent advocacy.

Similar to the views expressed elsewhere in the consultation, many respondents also agreed that working with a range of organisations and consulting with those with lived experience would prepare a solid foundation on which to build the LDAN Bill and any developments needed for advocacy. Again, however, respondents were keen to stress that any consultation with and involvement from those with lived experience needed to be meaningful.

Reasons for Disagreeing with Proposal 1

Some respondents caveated their support for Proposal 1 or disagreed with it because it was felt the details in the consultation document were not comprehensive enough. The proposal was felt to lack detail around the aims and scope of the potential legislation or regulations that could be introduced, and required clarity around what the regulations might be and do. It was also felt that the proposal would not have the desired impact unless it was accompanied by additional provision for suitable advocacy services and capacity.

Many respondents were also strongly against the fact that the Bill would **not** make provisions for a broad right to advocacy services for people with learning disabilities and neurodivergent people. Some suggested that the LDAN Bill would be a more appropriate place to include this than mental health legislation (as had been suggested in the consultation document):

> “We are therefore disappointed that a broad right to advocacy for the people covered in this bill has not been proposed and we see it as a huge missed opportunity. It could have the biggest impact in improving outcomes for learning disabled and neurodivergent people.” (Education Services)

A handful of respondents, both individuals and organisations, also voiced concern over people with learning disabilities and neurodivergent people being included under the label of ‘Mental Disorder’ (discussed more at Part 3: Section 2). It was noted that the current situation could lead to differences in service provision where some organisations included learning disabilities, autism or other neurodivergent conditions under the label of mental disorder while others (including some advocacy services) would not provide support as they did not consider the condition as a mental disorder.

Proposal 2: Improve our Understanding of Independent Advocacy

Proposal 2 was interpreted in different ways. Some respondents were supportive as they understood this to mean measures would be implemented to improve individuals’ understanding of independent advocacy, when and how this can be used, how to access it, etc. This was considered to be highly necessary and valuable. A few also preferred proposal 2 as they interpreted this as being more applicable for individuals who did not have a mental health problem.

> “I agree with option 2 to better understand how advocacy can help. I wouldn't know where or how to access an advocate for neurodiversity. Because I am not receiving any support from services I don't know about any help.” (Neurodivergent Individual)

Others thought this proposal meant building the Scottish Government’s understanding of where providing a right to independent advocacy could make a difference. Again, this was a sentiment that was generally supported in order to develop the sector and improve access and provision.

It was suggested that more needed to be done to support the most vulnerable people where and when most required, and that developing an understanding of this to develop specific legal rights to advocacy in these circumstances would be the best use of limited resources.

Reasons for Disagreeing with Proposal 2

Those who disagreed with Proposal 2 generally did so because they felt it was suggesting restricted access to advocacy. One health service organisation referred to this as ‘gatekeeping’. Both organisations and individuals were vocal that the Bill should provide a legal right to free advocacy in **all** circumstances where it is needed and not just in specific cases for specific people. There were concerns this could further exclude vulnerable people/groups and negatively impact those who do not fit the specific criteria:

> “We would not support Proposal 2, which seeks to restrict the areas where independent advocacy might be applied to very niche areas.”
> (LDAN Support/Representative Organisation - Autism)

Proposals Not Ambitious Enough

Both those who agreed in principle with the proposals, and those who opposed both, argued that the proposals were not ambitious or strong enough, and were not sufficient to ensure independent advocacy was supported, promoted and used. These respondents felt that much more needed to be done in this respect, both to strengthen the section itself and improve provision, and to ensure independent advocacy is provided at the right time and when needed to ensure individuals understand and can advocate for their best interests. This would include ensuring they are supported to understand their rights to independent advocacy in order to make an informed decision about its use.

Other Comments and Considerations

A wide range of additional comments were provided or issues highlighted that respondents felt needed to be given further consideration.

Funding, Resources and Training

One of the main issues discussed (and covered above) was the need for more funding and resources for the sector. Many respondents called for ongoing financial commitment should either proposal be taken forward.

Another common issue raised by respondents (including a range of individuals and organisations) was the need for more advocates generally, for more specialist advocates (i.e. those trained and skilled in supporting people with learning disabilities and neurodivergent people), and a need for additional and consistent training. This was all considered necessary in order to provide the best possible service. Some respondents also raised concern about staff turnover and were keen to place emphasis on staff retention within the industry to ensure training budgets were not ‘wasted’.

Several respondents supported the idea of developing advocates within the community, or peer advocates. It was felt these options could be helpful for individuals and support the existing formal services which are unable to meet demand. Others were keen to highlight that family, friends and carers were ready and willing to be trained in advocacy and could provide a valuable additional resource for new or existing services. It was noted that these groups were already advocating for others, that they already knew their needs and had a pre-existing relationship with the person. A few respondents also recommended the recruitment of advocates with learning disabilities or neurodivergence. They felt that this would add significant value to advocacy offered.

Advocacy Should be for Everyone

Some respondents, both individuals and organisations, argued that independent advocacy should be available for anyone who needs it, irrespective of demographics or official diagnosis. It was also suggested that families, siblings and parents/carers should have access to independent advocacy in order to get support.

A few third sector organisations also championed free provision of independent advocacy for the groups they support.

Several respondents also noted support of the recommendation in the Rome Review of Mental Health Law in Scotland which called for anyone with a learning disability to be automatically entitled to support from an independent advocate unless they actively choose to opt out of this. A few did raise concerns over such entitlement however, including capacity issues to cope with increased entitlement, and the potential for discrimination against those who do opt out.

A few organisations were also concerned about, or questioned who should be offered advocacy services. Common with suggestions at Part 1, there were calls to ensure neurodivergence was clearly defined in order to support eligibility for independent advocacy.

Other Issues

It was suggested that there needed to be consistency in the advocate working with an individual (i.e. avoiding turnover of those involved). Respondents stressed that it can take time to build a strong enough relationship to ensure full and successful advocacy, and the potential for turnover in advocacy workers, or being allocated a different advocate for appointments can also act as a barrier for many people with learning disabilities and neurodivergent people taking up advocacy services.

Several respondents called for a person-centric service where advocacy is led by individuals and their need, and not by provision/capacity or influenced by external factors or figures. Respondents also suggested that advocacy should address early, ‘smaller’ or minor issues - providing support to those that need it and at an early stage, before issues become more significant, complex and distressing.

A few respondents stressed the need to ensure that independent advocacy was truly independent, not controlled, funded or incorporated within local authorities, social work, or health and social care providers. Respondents also wanted to ensure that advocacy services were not open to bias or influence from others, and that the system could not be abused or exploited by self-serving advocates.

Several highlighted the need for assessment of systems currently in place, the use of quality assurance mechanisms, and the development of ongoing feedback methods to ensure that those accessing advocacy services can inform quality standards and any future service development. Others, both individuals and organisations, called for regulation in the provision of advocacy and related services in order to ensure quality and suitability of all services. It was unclear, however, how a regulated sector would combine with the above calls for peer and community advocates, as well as greater recognition of parent/carer/family/friends acting as advocates.

Finally, several respondents indicated they did not have enough understanding or experience in this area to comment, while others felt the proposals were unclear and difficult to understand and so they felt they could not offer informed views.

Part 3: Specific Themes

The third part of the consultation document considered 14 different themes, as follows:

- Section 1: Health and Wellbeing
- Section 2: Mental Health and Capacity Law
- Section 3: Social Care
- Section 4: Housing and Independent Living
- Section 5: Complex Care - Coming Home
- Section 6: Relationships
- Section 7: Access to Technology
- Section 8: Employment
- Section 9: Social Security
- Section 10: Justice
- Section 11: Restraint and Seclusion
- Section 12: Transport
- Section 13: Education
- Section 14: Children and Young People - Transitions to Adulthood

The findings for each of these will be set out in turn below.

Section 1: Health and Wellbeing

Introduction

The consultation document highlighted that people with learning disabilities (including those with Profound and Multiple Learning Disabilities (PMLD)) and autistic people experience poorer health outcomes than the general population, are more likely to die earlier and from preventable illnesses. The current legislative landscape related to health was outlined, as well as current and ongoing work in the area - which included the development of the National Care Service Bill, as well as various targeted strategies and plans.

It was suggested that the LDAN Bill could help to create the right conditions for people with learning disabilities and neurodivergent people to access supports and services successfully when they need them, helping to prevent illness and improving overall health and wellbeing. To achieve this, five proposals were set out:

- **Proposal 1: Neurodivergent and Learning Disabilities Strategies** - require Health Boards, Integration Authorities and Local Authorities to set out in their local strategies how workforce and service planning has taken into account the needs of the neurodivergent and learning disability populations.
- **Proposal 2: Mandatory training for the health and social care workforce** - include in legislation a mandatory requirement for health and social care staff to be trained in learning disabilities and neurodivergence.
- **Proposal 3: Inclusive Communications and Accessibility** - (a) to legislate for people with learning disabilities and neurodivergent people to be able to request access to alternative means of communication where the offered means of communication is not suitable; (b) to provide better access to Easy Read versions of public facing communications and documents - this could be via a broad duty to make them available on request as well as an automatic duty to provide them in certain circumstances; (c) to legislate for an Accessible Information Standard for Scotland applicable to NHS Scotland organisations; and (d) to look at how far existing complaints systems meet the needs of people with learning disabilities and neurodivergent people.
- **Proposal 4: Patient Passports -** place a duty on Health Boards, HSCPs and Local Authorities to ensure that a person's "passport" is able to follow them through whichever care pathways they are accessing, such as a hospital or care home admission. These passports would include important information about their needs and preferences, including how to communicate with them in an accessible way.
- **Proposal 5: Annual Health Checks -** consider including the delivery of annual health checks (currently being rolled out for all people with learning disabilities) as a specific legal duty in the Bill, and extending this provision to autistic people. Also consider extending this to those with Attention Deficit Hyperactivity Disorder (ADHD) and Foetal Alcohol Spectrum Disorder (FASD), subject to further evidence gathering.

Main Findings

In total, 578 respondents provided feedback at this section, with over half supporting all five of the proposals. There were calls, however, for the proposals to be implemented consistently across all areas in order to provide equal access and service provision across Scotland.

The most popular individual proposals, or those highlighted as the most important elements of the five options, were the patient passport (Proposal 4), closely followed by the Annual Health Checks (Proposal 5) and mandatory training (Proposal 2). Inclusive communication and accessibility (Proposal 3) was also popular among respondents, While strategies (Proposal 1) received the lowest levels of explicit support and discussion at this section, this was still well supported overall, albeit largely in combination with other proposals rather than as a standalone option.

It should be noted that several respondents simply pointed towards their views at the relevant overarching themes sections in relation to strategies, training and inclusive communication and did not provide any new information or sector specific feedback in this section.

Proposal 1: Strategies

This was the least explicitly supported proposal, with comments and feedback being somewhat limited. While strategies were generally supported as part of the full package of measures proposed, many respondents expressed a preference for a national strategy, either instead of, or to help guide and co-ordinate, local level strategies:

> “There should be a national plan for Scotland and local plans should only add what is needed to make sure everyone gets the same service. Avoid a postcode lottery.” (LDAN Support/Representative Organisation - Learning Disabilities)

Consistent with the caveats and concerns raised at the overarching themes section in relation to strategies, respondents again stressed that strategies needed to be:

- Meaningful and effective, and should not be allowed to become a tick box exercise - it was felt there needed to be appropriate scrutiny and accountability around successful implementation of any strategies;
- Co-designed with people with lived experience; and
- Reviewed and evaluated regularly.

Those who disagreed with the development of neurodivergent and learning disabilities strategies generally did so for the same reasons outlined at the overarching themes sections (i.e. Part 2 Section 1). It was felt that strategies would be ineffective, that local strategies would lead to variation across the country, and that a single strategy for both learning disabilities and neurodivergence was inappropriate. It was also suggested that this proposal was “vague” and that more information was required.

Proposal 2: Mandatory Training

There were considerable levels of support for mandatory training across the health and social care sector. It was felt that training would be useful in its own right, and to support the implementation of various other proposals and measures. This included supporting: the use of appropriate communication options; the identification and treatment of learning disabilities and neurodivergent conditions, as well as other health issues; the delivery and use of patient passports; and in delivering effective Annual Health Checks:

> “Mandatory training is in my opinion, a great way to upskill the workforce and ensure that all actions taken are in support of this target population. Knowledge is the best way to equip staff to deliver the best service to the people scoped within the act.”
> (Neurodivergent Individual)

Respondents mostly agreed that it was important to ensure training was not limited to just learning disabilities and autism, but should cover the range of neurodivergent conditions (with PMLD, FASD, and Down’s Syndrome mentioned specifically). Indeed, it was felt that training needed to be specific about learning disabilities and neurodivergence and treat these separately, as well as provide coverage of different neurodivergent conditions, rather than a more general consideration which could end up diluting the issues or usefulness of the training. This preference was not universal, however, and a few respondents suggested that training should only focus on learning disabilities, or learning disabilities and autism in the first instance.

In addition, it was recommended that training should cover intersectionality, unconscious bias, and be trauma informed. Training should also cover reasonable adjustments so health professionals/settings understand what is appropriate.

There were mixed views, however, related to the Oliver McGowan training used in England. Some supported the use of this or thought this sounded good, while others cautioned against using this training method/content.

It was felt that training needed to be tailored to different job roles and responsibilities rather than a single training course developed for blanket coverage. Further, it was considered important for all staff to receive training, including both primary and secondary care practitioners, managers, front line health practitioners (including dentists, paramedics, etc.), and reception staff. Several also wanted to ensure that education and training on learning disabilities, autism and other neurodivergent conditions was included as part of the university courses and other qualifications required to work in healthcare.

As noted in the overarching theme on mandatory training, respondents were again keen that those with lived experience were involved in designing and delivering this training.

A few were also concerned that better training could result in an increase in people being referred for diagnosis as health related staff will be able to identify possible conditions to a better extent than they did previously.

Proposal 3: Inclusive Communications and Accessibility

Again, respondents were largely in favour of the proposals around inclusive communications and accessibility, with only a handful explicitly stating they disagreed with this. It was felt that developing a greater understanding of communication needs and options, and delivering a more person-centred approach would have positive outcomes.

It was also suggested that clearer signposting to services and support options would be useful.

In terms of accessibility, respondents were in favour of being offered different ways to make appointments and have consultations. Different respondents noted different preferences. Some preferred phone contact while others found this challenging/saw this as a barrier, meanwhile some tended to avoid personal contact and preferred remote mechanisms, such as online, email, electronic forms, etc., while others (particularly people with learning disabilities) preferred in-person approaches/consultations.

A few respondents suggested that services should be required to proactively ask people about their preferred method of contact or communication needs and keep this information on file to ensure future contact is appropriate.

Alternative Communications and Easy Read

While respondents were generally in favour of the proposals, it was stressed that the interpretation of alternative communication needed to go beyond Easy Read, with a wider range of communication options being required to meet different needs. Similar to comments at the Inclusive Communications section in the overarching themes, it was highlighted that Easy Read may be patronising for some individuals, while others may require audio formats, use talking mats, Makaton, BSL, require information in other languages, or would benefit from different coloured paper.

It was also stressed that appropriate communication needed to consider more than just written information, with a need to offer alternative methods of arranging appointments, conducting consultations, the ability for individuals to provide information in a range of formats, and for practitioners to be aware and mindful of verbal and in-person interactions. For example, it was noted that closed and direct questions were often more suitable than open general questions, and that less importance needed to be placed on making eye contact:

> “When thinking about inclusive communication, there needs to be access to a wide range of communication aides beyond verbal communication, e.g. talking mats and “teach me back” processes which offer a flexibility of approach to ensure understanding of information given, and the ability to communicate needs and wants.” (Other National Public Body/National Agency)

Further, it was stressed that any inclusive communication options available needed to be proactively offered to individuals and/or for these to be provided as standard throughout. It was not felt to be appropriate to require individuals to ask for these (again, consistent with comments in the overarching themes section).

Offering appointments via telephone and online were welcomed, with it highlighted that these options were both more suitable for certain conditions/needs, but also helped more generally to address geographical service gaps (e.g. for those in rural areas).

There was also seen to be a need to consider providing suitable information in alternative languages to people with learning disabilities and neurodivergent people where English is not their first language. This included BSL and Makaton, as well as for minority ethnic communities.

Accessible Information Standard and Complaints Systems

There was very little discussion of either the Accessible Information Standard or complaints systems.

Where mentioned specifically by respondents, the concept of an Accessible Information Standard was generally supported, but again, it was felt this should be designed in liaison with those with lived experience.

One Children's Organisation/Service, however, cautioned that the Standard applied in England was too prescriptive, and felt that practitioners should be encouraged to develop and use their skills to identify the best mechanisms for engaging with individuals.

Only a handful of respondents mentioned anything related to complaint systems, although those that did were supportive of reviewing these. Advocacy was also highlighted (by both individuals and a range of different organisation types) as an aspect that would support and enhance inclusive communication generally, and should be implemented throughout any complaints process.

Proposal 4: Patient Passports

Respondents were generally positive about the use of Patient Passports, with this being one of the most popular and well supported proposals. It was felt these would be highly supportive, although it was stressed that health and social care staff would need to be trained on the existence of, access to, and use of these to ensure they were effective:

> “Having a health passport is just simple common sense. Not only will it be better for the patient (as they will not have re-tell their story at every appointment) but it will also benefit healthcare professionals who will be able to know, ahead of appointments, how to deal with patient they are about to see.” (Organisation for Other Disability/ Condition)

A few also suggested that a passport system would also provide people with learning disabilities and neurodivergent people with greater independence and autonomy.

While generally supportive of patient passports in principle, some respondents sought greater information around how these would work in practice. Respondents were keen to understand who would be responsible for the passports; what type of information they would hold; who would be responsible for updating these and how updates would be actioned; who would have ownership or control of these; how the information would be held and shared (e.g. electronically by services, or via an app or hard copy kept by the individual); etc.

There appeared to be confusion among respondents around what type of information would be contained in patient passports, and mixed preferences. Some discussed this in terms of it only containing information related to communication needs and preferences, and issues related to the presentation of some people's conditions (e.g. how to calm them down if they become overwhelmed). Others felt this passport could also contain useful medical, treatment/medication, and care related information.

As such, it was felt that this passport could contain sensitive information, therefore careful consideration would be needed over content and access, and strict data protection protocols would need to be set out. As with training, it was suggested that those with lived experience should be involved in the design of patient passports.

It was stressed that passports (and annual health checks) should be voluntary with no individual forced to have one. Further, it was felt that individuals should either be able to complete this themselves or have input to the content of their own passport and be able to review, amend and remove information if they want. In addition, it was considered important that this remained a living document which could be updated to take account of changes and developing communication preferences.

A few respondents felt it would be important for passports not to be associated with mental health as it could be off-putting for individuals, however, it was suggested that mechanisms should be found to allow passports to be accessed by health, social care and social services. Several respondents also felt the passports could have wider applicability and should be accessible/usable in other sectors beyond health, including employment/workplaces, housing, social security, and the justice system. While a few highlighted IT systems challenges as a possible barrier to such information sharing between different services, others suggested passports held by individuals (either in hard copy or via an app) could be used to overcome this (although it was noted that this would introduce other issues as individuals/carers need to remember to carry and present this each time), or an online system where access can be granted to relevant services/professions.

Several respondents also felt it was important not to create a situation of 'othering' via patient passports. Rather than issuing passports to a small/limited population (which may create stigma or a sense of 'othering'), a few suggesting that passports could be mainstreamed or made available to anyone who might find this useful. An example of another group that may find patient passports useful was children and young people from armed forces families as they may move around frequently.

Respondents who already had experience with a ‘passport’ system (either in healthcare, education or learning disability services, Promoting a More Inclusive Society (PAMIS)’s Digital Passports, or Advance Statements in mental health settings) were generally positive about these and the impact they can make. However, several respondents noted instances where they had been ignored by professionals, as it was either considered to be quicker/easier to ask for the information, or it was noted that passports were often out of date/not updated regularly enough to take account of changing needs and preferences.

In order to develop a more consistent national standard around the use of patient passports, some respondents felt it was important to introduce a statutory requirement rather than make this optional or best practice.

Concerns and Reasons for Disagreeing with Patient Passports

While only a small number of respondents explicitly disagreed with patient passports, the main concerns and reasons for disagreeing were related to these not being effective as they could be (or already were) ignored by health professionals, or would be burdensome or stressful for the individual to manage.

A few were also concerned about how passports would be perceived, i.e. that this might attract stigma. Others were concerned about data protection, particularly if sensitive personal information were to be included.

Several respondents also suggested the name of this product needed further consideration, or recommended that this should be changed. Both ‘patient’ and ‘passport’ were highlighted as potentially problematic terminology.

Proposal 5: Annual Health Checks

Respondents largely supported the use of Annual Health Checks as they perceived these to be more proactive and that they would tackle some of the issues that people with learning disabilities and neurodivergent people face in relation to accessing healthcare. It was suggested that appointments should be made automatically and sent out to individuals to avoid the need for them or their families/carers to take responsibility for this. The standardised nature of these checks also removed some of the stigma around asking for help or feeling like a bother or a burden on GPs/health services:

> “Prompting is one of the primary support needs of ND people, even highly motivated ones, and these checks would go some way to prompting ND people.” (LDAN Support/Representative Organisation - Autism)

It was also suggested that these health checks needed to be conducted by well trained professionals, with a few caveating that this should not be implemented until after the mandatory training has been completed. It was also suggested that, ideally, the Health Check should also be conducted by someone who is familiar to the individual as this will work best when built upon a trusted relationship. Respondents did query, however, the scope of the checks and the nature of the professional(s) who would be responsible for undertaking them, as this could make a big difference to the quality and depth of the check.

It was felt that more information on the practicalities and processes for this proposal was required, including who would deliver this, what would happen in cases of unmet need (i.e. where health concerns are raised that cannot be tackled locally), does such a system rely on a medical rather than social model of disability/need, and how capacity and resource challenges will be addressed to meet demand.

As well as training, it was felt that this proposal also needed to take on board the proposals around accessible communication, and ensure that appointment information was provided in a variety of formats. It was also suggested that easy mechanisms would be needed to allow individuals to rearrange appointments which were unsuitable, for venues to be easily accessible, and for information to be provided in advance about what would happen at the appointment and any tests that would be carried out.

Respondents also indicated a desire for these health checks to cover mental health (mentioned repeatedly by mental health organisations as well as others), dental and oral health, sight and hearing (ophthalmology and audiology). It was noted that all these issues contribute to overall health and were settings that can be difficult for people with learning disabilities and neurodivergent people.

Respondents also generally agreed with the proposals to introduce a legal duty on Health Boards to implement Annual Health Checks, and also called for any new accountability mechanism introduced by the LDAN Bill to seek reports on implementation and impact. A few of those representing people with Down’s Syndrome also sought a full evaluation of the programme, along with a statutory requirement to review and update this every five years.

Extending Annual Health Checks to Others

While many respondents simply expressed support for the proposal without reference to the potential for expansion to specific groups, those who mentioned autism were generally in favour of including this group within the Health Checks. This was considered particularly important due to the lower life expectancy, high instances of mental health problems and high rates of suicide:

> “Please do include autistic people in annual health checks. I face enormous barriers to healthcare as a result of my autism and almost always miss out on accessing care. I would really appreciate this as it takes all the difficulty away and presents a ring-fenced opportunity to speak to a medical professional.” (Neurodivergent Individual and Family/Friend/Carer)

Several respondents argued, however, that if Annual Health Checks are extended to autistic people, then they should also be extended to those with ADHD. This was due to the health challenges faced by those with ADHD and because ADHD and autism are known to frequently co-occur. Others felt it was also important to include those with FASD in the Annual Health Checks, again due to poorer health outcomes. Similarly, cerebral palsy was another condition specifically highlighted for inclusion. Yet others felt that all types of neurodivergence should make a person eligible for an Annual Health Check.

There was a sense among some respondents, however, that not everyone with specific conditions (e.g. autism, ADHD, etc.) would want or need an Annual Health Check. While they generally felt this was a useful and important programme, it may need to be implemented flexibly or on an opt-in basis and based on need rather than solely on condition. These respondents were typically in support of greater evidence gathering ahead of widening the scope of Annual Health Checks.

In addition to neurodivergence, a few respondents suggested that health checks would also be helpful for/should include a much wider range of conditions, including rare conditions and genetic syndromes, those suffering from poor mental health, and people who have addiction issues. Others suggested that annual health checks should also be offered to unpaid carers due to the stress and strain they experience and how difficult they find it to look after their own health needs when there is little respite care available to allow them to attend appointments for themselves.

It was noted by a few respondents that Annual Health Checks are not currently extended to those under the age of 16, with organisations representing children and young people uncertain of the reason for this, and stressing a desire/need for their inclusion.

Concerns and Reasons for Disagreeing with Annual Health Checks

While in support of Annual Health Checks in principle, several respondents highlighted delays and problems with the implementation and current roll out of these for people with learning disabilities. In particular, respondents representing people with Down's Syndrome noted challenges and a lack of access to an Annual Health Check, despite the consultation paper stating that "a health check will be offered to everyone who is eligible by end March 2024":

> "…the roll out of the annual health checks for people with LD has been terrible. Slow, disparate, inconsistent, no urgency, mis-understood, and no accountability from any of the health boards or Scottish government… Hardly anyone with LD has had an annual health check despite the end of March 2024 meant to be the roll out date." (Family/Friend)

Respondents were also concerned about how the Annual Health Checks would be resourced, particularly if rolled out beyond people with learning disabilities. As well as the capacity to deliver this, respondents were worried that wider delivery of Health Checks could put stress on the health system to the detriment of other patients in need.

A range of other concerns were also expressed in relation to Annual Health Checks, as detailed below:

- These could result in added stress for individuals around remembering the appointment and any paperwork, as well as anxiety around the consultation itself;
- That Health Checks may be intrusive and unnecessary;
- That these would not be well attended and could therefore be a waste of resources;
- That the checks would not be detailed or in depth enough to be meaningful;
- Cuts in social care could impact people's ability to attend these checks and other healthcare appointments; and
- Suggestions that the delivery of Annual Health Checks did not require primary legislation.

Other Comments and Considerations

Diagnosis Issues

One of the main issues discussed at this section was diagnosis and the current problems and delays in accessing assessments and support. This included apparent gatekeeping, prioritisation and restrictions currently placed on access to assessment systems in certain areas. Diagnosis delays were discussed at length as posing a significant problem for health and wellbeing in their own right, but were also noted to complicate the proposals set out in this section. As such, respondents sought clarity around whether or not a diagnosis would be required for accessible communication options, to hold a patient passport and to receive an Annual Health Check. It was suggested that the due to the current problems and limitations in the diagnosis system, all provision should be based on need and available to those who self-diagnose.

Respondents noted the absence of a dedicated section on diagnosis and pathways to diagnosis, and saw this as a missed opportunity. It was felt this was an area which required considerable attention and urgent action.

It was also suggested by several respondents that the LDAN Bill should make provisions for the maximum waiting times, not just for an initial assessment by diagnosis teams, but with regards to the time taken to be assessed and to receive effective treatment or support (where appropriate).

Shared Care Arrangements

Linked to difficulties with diagnosis, a few respondents discussed the difficulties that private assessments and diagnosis can create in the provision of healthcare going forward. It was noted that some people, who can afford it, choose to get an assessment and diagnosis privately due to the significant challenges and delays in the NHS system. However, it was highlighted that, while some can then go on to receive appropriate care and medication from the NHS via shared care arrangements, others cannot access this as their GP does not support this arrangement. A "postcode lottery" situation was described, with arrangements said to vary by GP practice. In situations where shared care arrangements are not provided, respondents said they were required to be assessed by the NHS Community Mental Health Team (CMHT), thus sending them back to the long waiting lists and duplicating assessment effort, or they need to fund their own treatment through the private sector.

Specialist Providers

Some respondents called for greater use of **Learning Disability Liaison Nurses**, and for such provision to be expanded to autistic people and neurodivergent people. It was felt these professionals were highly beneficial across a range of different roles, including supporting the individual, assisting both the individual and other professionals with communication needs, and developing learning among other professionals.

Several also suggested that specialist clinics, hubs or healthcare providers who specialise in learning disabilities, autism and neurodivergent conditions would be helpful and supportive of development. Other options discussed included having a main lead professional/service in each local authority, or specialist staff located within each service:

> “We need people who are focused on just treating ND's [neurodivergence] as they will be able to do a much more effective job and this will lead to a step change in support.” (Individual with a learning disability)

Others suggested peer support roles, or promoting the use of a “chaperone” for support in medical appointments and interventions. Again, it was felt that having a trusted person present helped to reduce anxiety, aide communication, and delivered better outcomes. Similarly, a few suggested that having someone who could help with making appointments and reminders about these would be useful.

Capacity, Resources and Funding

One of the main concerns expressed at this section was around the current staffing, capacity, resourcing and funding of the NHS and other public healthcare systems. This was commonly voiced by a wide range of individuals, third sector and public sector organisations. It was stressed that, whilst the proposals were positive in principle, these would need to be fully funded to support successful implementation as the current system was not perceived to have the capacity to deliver them:

> “…many of the rights and removals of barriers outlined here can only be fully implemented if health and social care systems neurodivergent people and people with learning disabilities use are adequately resourced and funded. This is not, to say the least, currently the case.” (Neurodivergent Individual and Family/Friend)

It was noted, however, that funding was not the only issue. Staffing levels would also need to be addressed in order to boost capacity.

There were concerns that the proposals might raise expectations which cannot then be supported or delivered. Without greater capacity in the health and social care system generally, it was felt that service delivery and health outcomes would be unlikely to change. Respondents were concerned that this could exacerbate the implementation gap, generate increased levels of unmet need/demand, and potentially worsen outcomes for individuals.

It was also suggested that healthcare services, and services for people with learning disabilities and neurodivergent people needed greater levels of funding generally in order to deliver significant improvements to health and wellbeing outcomes.

Other Issues/Comments

A wide range of other comments or issues for further consideration were outlined. These are detailed below:

Comments related to service provision:

- A stronger focus is needed on mental health, as well as better access to suitable mental health services;
- Seek to understand and tackle ‘diagnostic overshadowing’ (i.e. the misattribution of symptoms of one illness to an already diagnosed comorbidity) which was said to be common for people with learning disabilities and neurodivergent people;
- Greater access to effective treatment and care is required:

  > “Even if health services can be accessed, the types of services offered are often not neuro-affirming, lack efficacy and a proper evidence base, do not align with human rights and their harms for autistic and other neurodivergent people (regardless of the presence of a learning disability or not) are not understood or dismissed, e.g. therapies offered through a neurotypical lens and Positive Behaviour Support.” (LDAN Support/Representative Organisation - Autism)

- Greater focus is needed on integrated care models, e.g. social care staff trained in the health needs of people with learning disabilities and neurodivergent people. There was said to be a current lack of multidisciplinary and integrated care, particularly related to drug use among young people and adults with learning disabilities and neurodivergent young people and adults; and
- Strengthen early intervention and support.

Comments related to specific communities included:

- Specific consideration was needed for both Down’s Syndrome and PMLD in both the consultation document and the Bill in relation to health and wellbeing; it should not be subsumed within wider labels/communities and their unique needs should be taken into account;
- Issues in older age need to be better understood and supported, including autism in older age, as well as the prevalence/challenges of dementia in people with learning disabilities and neurodivergent people. It was felt

important to provide dedicated training and to develop greater oversight of services for this age group;

- Improve intersectional understanding around differences in presentation/ masking[1], and around barriers to accessing healthcare, for a range of different personal/protected characteristics, including gender, ethnic minorities and the LGBTQIA+ community;
- This section of the consultation was perceived as very adult focused - proposals need to extend to and include children and young people's health and wellbeing, covering both physical and mental health and wellbeing, and be mindful of additional barriers that children and young people face; and
- Greater consideration of, and a more joined up approach was needed to transitions, and moving from children and young people to adult health services.

Other comments:

- The neurodivergent community needs to have trust in the health service, individuals (and their families/carers) need to be believed and understood, and not dismissed or made to feel like a burden;
- Longer appointment times are needed so people with learning disabilities and neurodivergent people are not rushed and communication needs can be accommodated;
- It was noted that health settings were problematic and needed to be designed in liaison with people with learning disabilities and neurodivergent people;
- Implementing a requirement for employers to consider and make reasonable adjustments for the health and wellbeing of their neurodivergent staff;
- Behaviour modification approaches such as Positive Behavioural Support (PBS) and Applied Behavioural Analysis (ABA) should be banned;
- Greater input should be sought from Allied Health Professionals (AHPs) in relation to tackling health and wellbeing. They should also have a role in supporting the proposals set out in the consultation document, particularly speech and language therapists and occupational therapists; and
- It was felt that 'wellbeing' was not addressed in this section and that more focus was needed on this. This included greater consideration and development of other aspects to support health and wellbeing, including:
    - physical activity and access to sports and sports therapy;
    - community based infrastructure changes and creation of high quality green/outdoor spaces (again to involve those with lived experience in the design process);
    - tackling isolation and social inclusion, and offering better access to social activities; and
    - support related to sleep and diet.

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[1] Masking is a strategy used by some autistic people, consciously or unconsciously, to appear non-autistic in order to blend in and be more accepted in society.

Section 2: Mental Health and Capacity Law

Introduction

The consultation document highlighted that current mental health, capacity and adult support and protection legislation in Scotland can, in certain circumstances, apply to people with learning disabilities and autistic people. It set out the various relevant laws and how/when these can apply to people with learning disabilities and autistic people, and the views of LEAP members in relation to this issue. The consultation document also set out previous reports resulting in differing recommendations, and ongoing work in the area.

It was suggested that the LDAN Bill could propose to make changes to mental health and capacity legislation in Scotland as it relates to people with learning disabilities and autistic people. Those changes could be to:

- Specifically remove learning disability and autism from the scope of mental health and incapacity legislation; or,
- Change “mental disorder” to a term that is not stigmatising or offensive.

However, it was also stated that the Scottish Government was not consulting on any proposals for legislative change in this area due to the need for additional work to be carried out first.

Main Findings

Respondents were asked to indicate whether they agreed with this approach (rather than any specific proposals) as a closed question.

Answer	Number	Percent	Valid Percent
Yes	289	33%	80%
No	72	8%	20%
Not Answered	516	59%	-
Total	877	(n=877)	(n=361)

Most of those who provided an answer (80%, n=289) agreed with the proposed approach. Results for individuals closely mirrored the aggregate results above, while organisations and public bodies in particular were more likely to support the proposed approach - 84% of all organisations and 90% of public bodies that responded supported the approach (see Appendix B). However, the small number of public bodies who responded at this question (n=29) should be borne in mind when interpreting the results.

In addition to the closed question, 370 respondents provided qualitative free-text feedback. These qualitative comments, however, often focused agreement on one or both of the options related to removing learning disabilities and autism from mental health law or changing the terminology, or because they supported the need to undertake other work to further consider the issue in detail and to identify potential unintended consequences. Comments did not always address or consistently support all elements of the approach set out.

In terms of those who disagreed, the majority were individuals - only 12 organisations explicitly expressed disagreement with the approach. Some organisations (n=41), however, provided qualitative comments and feedback at this section without answering the closed question, along with 25 individuals. These respondents often acknowledged both pros and cons of the approach, or agreed partially with some elements and disagreed with others. Their comments were generally consistent with those who agreed/disagreed, however, and so are reported together below.

Remove Learning Disability and Autism from Mental Health and Capacity Legislation

Of those who agreed with the approach outlined, many individuals specified the need to remove learning disabilities, autism and neurodivergence from the Mental Health and Capacity legislation. Some argued that including these conditions within the spectrum of mental illness or labelling them as ‘mental disorders’ was offensive, while others noted that the term ‘mental disorder’ was technically incorrect:

> “People with learning disabilities and autism should never have been put in Mental Health Care and Treatment Scotland Act 2003 in the first place… as a person who has learning disabilities it’s very insulting to be called mentally disordered.” (Individual with a learning disability)

Several respondents stressed that learning disabilities and autism are lifelong conditions and cannot be treated or cured in the way that mental ill health can be addressed. Rather, learning disabilities and autism were considered to be neurological differences, and not as there being anything “wrong” or “broken” in these individuals. Respondents argued that having a learning disability or autism was not equivalent to, or the same as, having a mental health issue:

> “My autism and ADHD is not a mental disorder but lack of appropriate health care/support and prejudice means I experience mental health problems such as anxiety, depression, sleep disruption, anger etc.” (Neurodivergent Individual)

Several reasons were provided as to why clearer separation of mental health conditions and learning disabilities and autism was needed. Some felt this would help to better reflect the different types of conditions and the different needs involved. This was important to avoid both misdiagnosis and inappropriate pathways and treatments being applied. For example, respondents were concerned about the inappropriate use of medication and individuals being sectioned when support, adjustments and more accessible communication would be more effective.

Others wanted clearer separation of mental health and learning disabilities/autism as this would be important in ensuring individuals are referred into appropriate support services. It was noted that mental health services were not always well equipped to understand the needs or presentations of people with learning disabilities and/or autistic people (or people with other neurodivergent conditions), or to support or treat these.

Several respondents also felt that separating the issues would help to avoid confusion and conflation, and build/promote greater understanding of each condition.

Respondents (largely individuals and third sector organisations) also discussed the issue of people with learning disabilities and autistic people being detained in hospitals, psychiatric units and forensic settings under the Mental Health Act, solely on the basis of their disability, and not due to mental health issues. In all instances where this was perceived to be the case, it was argued to be inappropriate and a breach of the persons human rights. It was stressed that this practice needed to be halted.

More Tailored Mental Health Services Needed

Even where people with learning disabilities and autistic people experience mental health issues, it was noted that mental health services needed to be better equipped to treat these individuals. It was suggested that treatments too often take a neurotypical approach which is unsuitable and ineffective for people with learning disabilities and autistic people:

> "…often the support or assistance of mental health workers does not help the autistic person as their therapy and coping mechanisms do not take the autism into account so they are not as effective. There needs to be more research and training in this area. Suicidal thoughts are often present in autistic people, teenagers and adults alike. If the assistance they received was designed for them we might be able to save some lives." (Neurodivergent Individual and Family/Friend/Carer)

It was felt that mental health services needed to better understand the characteristics of learning disabilities and neurodivergence, and differentiate these from mental health conditions so they can be treated appropriately. This included ceasing medication and in-patient treatments where these are unnecessary.

It was argued that more training was needed in this area for mental health staff, and that there needed to be better communication and more joint working between learning disability autism and neurodivergence services and mental health services. Several respondents went further and felt that a dedicated service was required to provide support for people with learning disabilities and autistic people (and potentially other neurodivergent conditions), rather than being reliant on the mental health sector. Mental health services were largely considered to not be the right setting, but were said to often be the only route to obtaining support.

Others stressed the need to ensure alternative support, health and treatment services would be available to people with learning disabilities and autistic people in the event that they were removed from mental health provisions. A few respondents also called for the introduction of more appropriate and dedicated legislation for people with learning disabilities and neurodivergent people in order to reflect and acknowledge these as distinct and separate from mental health issues.

Amend the Terminology

Other respondents either made no comment about separating learning disabilities and autism from mental health conditions, or were wary about removing them due to possible impacts on care, support and protections. However, they argued that the terminology and labels used needed to change. Terminology needed to be more carefully chosen, sensitive, and appropriate:

> "…change term mental disorder to words that are not as upsetting or offensive. It is quite a negative word and suggests they have something wrong with them, and labels people." (LDAN Support/Representative Organisation - Learning Disabilities)

The need for a change in terminology was said to be required for all individuals, including people with learning disabilities and autistic/neurodivergent people, and others with mental health issues in order to tackle stigma and negative connotations.

While most respondents did not give suggestions for alternative terminology, a few proposed using terms like mental health 'difference', 'condition', or 'cognitive divergence' rather than 'disorder'. Others suggested that, if people with learning disabilities and autistic people are to continue to be included under Mental Health legislation, then they should be specifically named either under a 'neurodivergent' label or a 'learning disability and neurodivergent' label.

A few suggested that those with lived experience should be involved in determining any new terminology.

Some respondents argued that both proposed changes (i.e. to remove learning disabilities and autism from the scope of mental health and incapacity legislation, and to change "mental disorder" to another term) should be implemented.

Further Work and Consideration Needed

Several individuals agreed that, if enough information was not available currently, then it was sensible to delay any changes until additional work had been undertaken. Similarly, organisations tended to agree that the ongoing work in this area was important and should inform any changes, and that the approach outlined was sensible to avoid any duplication of effort or difference in approach.

Again, respondents stressed the need for those with lived experience to be involved in any reviews or designing any changes.

Unintended Consequences

Other respondents who agreed on the need for more work argued that this was necessary in order to understand any impacts and possible unintended consequences of making changes in this area. It was considered important that support was not withdrawn from those who need it and/or were currently in receipt of services. It was also suggested that removing groups from the Mental Health Act could have implications for other legislation (for example the Assisted Dying for Terminally Ill Adults (Scotland) Bill), and this would also need careful consideration:

> “Caution should always be taken when adjusting wordings in law, to ensure that those who need to seek treatment are not subsequently prevented from doing so because of a linguistic alteration. Thus, a slower and more considered approach to ensure that those who currently access these services are still able to do so, while ensuring that additional people not currently covered are also made able to access these services, is the preferable option.” (Individual with a learning disability)

A few respondents were also concerned about what services individuals would access, if support would be available, and about the risk that they may be more likely to end up in the criminal justice system as a result of being removed from the Mental Health Act and not being able to access services.

Terminology

Respondents felt that more work was required to properly understand and “demystify” neurodivergence, to discuss definitions and the proper language to use, and to look carefully at how learning disabilities and autism are classified and any impacts such classifications or changes to legislation might have on individuals, their legal protections and their rights.

Ensure No Loss of Rights or Protections

It was also considered important to fully understand the potential consequences of removing conditions from the Mental Health Act as this was said to currently provide a number of rights and protections (although a handful of respondents felt the Act does not protect people but rather its interpretation by service providers can disadvantage people). These included (but were not limited to) the right to advocacy and conferring automatic vulnerable adult status. Respondents (across a wide range of different types) were keen to ensure that crucial rights and protections would not be lost.

In relation to advocacy specifically, a few respondents (mostly organisations) stressed the importance for access to this or the provision of advocacy when interacting with the Mental Health (Care and Treatment) (Scotland) Act 2003. It was felt this was vital in helping individuals and their families to understand their rights, to access legal advice and representation for Mental Health Tribunals, and to ensure their voices were heard and respected in decisions around their care and treatment. Respondents suggested that greater signposting and information about independent advocacy needed to be provided to individuals in these circumstances.

Avoid Lengthy Delays

Several respondents who supported the overall approach, however, caveated that it was important for the process not to take too long. Indeed, a few respondents noted that change in this area was overdue, and they felt that previous work and recommendations had not been implemented/impactful and that this issue needed to be treated with urgency.

Reasons for Disagreeing with the Approach

Among the respondents that disagreed with the proposed approach set out for mental health law, a range of different reasons were given.

In many cases, the reasons for disagreeing were the same as those given by respondents who supported the approach, such as the need to separate learning disabilities and autism from mental health, and disagreeing with the terminology used, i.e. ‘mental disorder’. The main issue for these respondents, and the way in which they differed from those who agreed with the approach, was that they wanted to see change happen more quickly and did not countenance any further delays. It was argued that people with learning disabilities and autistic people had been calling for change in this area for a long time, and that views had been clearly expressed in previous reviews. Others highlighted that further delays would result in more individuals and families being subject to the current inappropriate system.

A few also felt that the LDAN Bill should be used to make necessary changes and put appropriate structures and support mechanisms in place rather than waiting any longer. It was felt that not making such provisions was a missed opportunity.

Conversely, a few felt that the current terminology was correct and so there was either no need, or no point in changing it.

A few also felt that changes to terminology or the scope of the Mental Health Act would not result in any changes on the ground, but could result in a range of potential negative consequences, i.e. it could result in individuals becoming ineligible for certain services, support and protections, while not actually changing the risk of being referred into mental health service or being sectioned.

A few respondents (typically family and friends) also disagreed with removing autism in particular from mental health due to the close link between these. Others were concerned about the implications of removing learning disabilities and autism from mental health legislation. Respondents felt there was a risk to individuals being able to access or continue to receive services, or that people may be more likely to ‘fall through the gaps’. A few also indicated that, while in favour of removal, a new or interim system and suitable safeguards needed to be in place to support people with learning disabilities and autistic people so that there would be no gap:

> “Although I agree that autism should not be under the mental health act as it is not a mental health condition, if you want to remove autistic people from the mental health bracket, you need to have a plan already in place that supports autistic people in these areas. It

> would be more detrimental to remove us and then we would have even less support than we do now." (Neurodivergent Individual)

A handful of respondents disagreed because they felt that the consultation document did not outline an approach for mental health and capacity law.

Other Comments and Considerations

Capacity

Several respondents discussed the issue of capacity and the Adults with Incapacity (AWI) Act. It was stressed that assumptions must not be made around capacity simply based on whether a person has a learning disability, is autistic or neurodivergent, and that it needed to be fully and robustly assessed by a qualified professional:

> "…the perpetuation of the belief that all people with learning disabilities, autistic and neurodivergent people might be more vulnerable or lack capacity to make choices for themselves leads to them having their independence and decision-making taken away from them." (Health Service)

It was also noted that autistic people can often lack capacity around decision making during highly stressful moments, but not in a more general sense. Again, this needed to be better understood and taken into account.

However, a few respondents were concerned about proposals to remove learning disabilities and autism from the AWI Act and the possible negative implications it would have on certain individuals who were considered not to have capacity, as well as the impact on their families/carers.

A few respondents (typically organisations) stressed that any changes to the Mental Health Act also needed to be considered in the context of the AWI Act, with a joined up and consistent approach taken.

Guardianship and Supported Decision Making

Concern was also raised about the granting and monitoring of guardianships. In most (but not all) cases where this issue was discussed, respondents were generally negative about this system and either wanted reform or an end to it. A few discussed the granting of inappropriate guardianships, the lack of robust monitoring of guardianships, and the inability to reject or appeal guardianships. A few others complained about the need to reapply for guardianship status at regular intervals when the person has a long-term/life-long condition that will not improve.

Several respondents advocated for supported decision making (SDM), with a few suggesting that SDM may be more appropriate than guardianships. There were calls for more training in this area and greater use of this approach. It was also stressed that those with lived experience should be included in any discussions around the development and use of SDM taking place as part of the Scottish Mental Health Law Review (SMHLR).

Other Comments

A few respondents stressed that more attention was needed on early intervention and support to avoid individuals reaching crisis point.

There was also concern that people with learning disabilities (and their needs, issues, experiences and concerns) may get “lost” within a wider neurodivergent label if they are not clearly identified within mental health law.

Finally, a few mental health organisations noted that some of the comments included in the consultation paper appeared to convey negative perceptions of mental health conditions and could be interpreted as disrespectful and disparaging of this cohort. It was felt that more understanding and respectful consideration was required in relation to mental health and that everything possible should be done to avoid stigmatising conditions/individuals.

Section 3: Social Care

Introduction

The consultation set out three specific proposals linked to improving delivery of social care, social work and community health services for adults with learning disabilities and neurodivergent people, these being:

- **Proposal 1: Neurodivergent and Learning Disabilities Strategies** - for Integration Authorities and local authorities to set out how they and organisations they commission will take into account the needs of people with learning disabilities and neurodivergent people in their workforce planning and workforce training, as well as how they are meeting requirements around inclusive communications and accessibility.
- **Proposal 2: Mandatory Training for the Health and Social Care Workforce** - to legislate for a training requirement for health and social care staff which focusses on both neurodivergence and learning disabilities (rather than just autism and learning disabilities).
- **Proposal 3: Inclusive Communication and Accessibility** - to legislate for people with learning disabilities and neurodivergent people to have better access to inclusive communications.

The consultation also stressed intentions to do more work to look at how far existing **complaints systems** in relation to social care meet the needs of people with learning disabilities and neurodivergent people. However, no specific proposal was set out in relation to this.

Main Findings

Overall, 437 respondents provided feedback at this section. Again, a large number indicated that they agreed with all of the proposals, mainly on the basis that they would remove barriers to access that currently exist, would protect the interests of people with learning disabilities and neurodivergent people and contribute to building a fairer and more inclusive society. Several respondents stressed that the proposals must work in parallel to ensure there is a robust and consistent approach to ensuring the needs of neurodivergent people are met.

It should be noted that a large number of respondents simply cross-referenced their answers to the overarching and other themed areas of the consultation in response to this section, i.e. those on mandatory training, inclusive communications and health and wellbeing (with some respondents noting that there was nothing ‘new’ in this section that had not ready been covered elsewhere and/or that the section did not actually cover anything of detail in relation to Social Care). As such, much of the feedback given at this question duplicated or mirrored closely the main findings already presented above, the main points being that:

- local strategies were seen as helping to facilitate consistency of high-quality provision across the country while ensuring flexibility for improving service user journeys at the local level. By involving individuals with lived experience in the design process, strategies were more likely to be more comprehensive and sensitive to the unique challenges faced by these communities;

- mandatory training was strongly supported as a means of raising awareness and skill levels but must be co-designed and co-delivered by people with lived experience, with sufficient resource put in place to support its development and delivery. It must also be meaningful and relevant to the roles of those who undertake it and should be regularly updated; and
- improvements to making communication inclusive were seen as long overdue and there was strong support for choice to be offered as standard (without the onus being on the individual to ‘request’ alternatives or support).

The main ‘additional’ feedback largely focussed on ways to further strengthen the proposals in relation to strategies, communication and training, as set out below.

Proposal 1: Strategies

Several respondents urged that accountability must be built into local strategies with clear guidelines for action that would be taken if local plans were not sufficiently implemented and/or did not result in tangible improvements. This was also seen as necessary so that their formulation does not become a tick box exercise or become vulnerable to self-evaluation:

> “Without strong accountability processes in place, the needs of neurodivergent people in all sectors can be dismissed or people finding it difficult to access the support they desperately need.” (Neurodivergent Individual)

A very specific point raised by several respondents was the need for this proposal to go further and provide clear guidance and strategies in order that social care planning meets the needs of those with Down’s Syndrome.

Other respondents stressed that local strategies would also need to be flexible, practical and adaptable to ensure they were relevant for a broad range of situations and needs (including meeting the needs of those with PMLD).

A minority suggestion was that there should be separate strategies for neurodivergence and learning disability.

Proposal 2: Mandatory Training

Strong views were again put forward that training must be very specifically tailored to cover the different complexities and challenges faced by different individuals and that learning disabilities, autism and neurodivergence alone were not sufficient as ‘categories’ for training to be structured around (for example, training for health and social care staff must also include topics related to dementia and epilepsy). As with responses to earlier sections of the consultation, however, this view was not unanimous and other respondents expressed a preference for training not to be widened beyond learning disabilities and autism at this time.

Views were also repeated that mandatory training could be broadened out to include all public services and/or all pubic facing staff as well as managerial and strategic staff and that development opportunities for staff must also be embedded to support training.

Widening training to third sector providers (especially those that support local authority social care services in delivery) was also again encouraged.

Making training a measurable objective and having performance indicators linked to uptake of training was again stressed as key, as well as setting out clear plans in the Bill for how training objectives and outcomes would be monitored and evaluated.

Proposal 3: Inclusive Communication

It was suggested that the Bill could be very specific about which groups were in scope for the proposals (i.e. rather than referring to the wider neurodivergent group as a whole, be very specific about the separate needs of, for example, autistic people and those with ADHD and how their communication needs would be separately met).

More attention could also be given, it was suggested, to **how** information was delivered as well as the formats in which it was made available.

Calls were also made for specific provisions to be in place for those who may feel anxious or unable to ‘request’ access to alternative communications, recognising that this can be a barrier to access in its own right.

Other Comments and Considerations

The main additional comments given in relation to these proposals were around how they would be funded, with several respondents again querying if sufficient resource would be available to realise ambitions. This was coupled with equal concern regarding workforce and capacity issues across public services including health, social work, and social care services, and the availability of time for training.

As already raised elsewhere in the consultation, many respondents noted that some local authorities may lack the funds and capacity to deliver, and it was specifically highlighted here that this may be true for remote, rural and island areas, for which other unique accessibility challenges may also exist in delivering social care.

Comments were again made that there should be clear timeframes set out for implementation so that the proposals could come into effect as soon as possible.

As with earlier questions, there were calls here for data to be collected on performance in relation to meeting expectations/standards (not only in relation to training and inclusive communications, but for delivery of inclusive services per se).

A small number of respondents suggested that the Bill overall, including this section, could provide more focus on children’s social care needs as well as adults, with greater consideration of how integration of health and social care work for children:

> “We refer to our previous response to the National Care Service consultation…and in particular the lack of evidence regarding children’s services, with the exception of services for looked after children. We are concerned that this consultation has replicated the approach taken in that consultation and failed to properly take account of children’s needs, views and rights.” (Children's Organisation/Service)

Similarly, several respondents felt that the needs of carers had been overlooked in the current consultation, including in proposals linked to social care.

The only other **new** comments raised here (by just a small number of respondents each) were that proposals must also consider the needs of neurodivergent staff and not just service users, i.e. in relation to such things as accessible training delivery and ensuring a more balanced workforce mix to help embed understanding and respond to the needs of service users.

A final observation was made that it was important to define what was meant by social care and which health and social care professionals were specifically covered by the proposals.

Complaints System

Although no specific proposal was set out, several respondents stressed that they agreed with the need for complaints processes to be straightforward and accessible to all, with many describing the current process in negative terms.

One organisation proposed a multi-stage process (based on research) in relation to complaints handling by public bodies for people with learning disabilities and neurodivergent people, including:

- 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 proactively and regularly inform people who use their services about how they can challenge decisions and 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 provide 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; and
- 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.

Others suggested that people with learning disabilities should have access to independent advocacy when dealing with social care provision issues or complaints as this would make the process more accessible.

More general comments included that the complaints system must allow individuals an opportunity to 'talk' (i.e. either face to face or via video or telephone) rather than relying on written communication.

There were several calls to ensure that any complaints process also allowed for anonymity so that individuals did not feel intimidated or anxious about complaining.

Overall, any action to strengthen complaints processes was welcomed, although making people aware of complaints processes would also be key.

Disagreement with Proposals

Again, where respondents did not agree with the proposals this was mainly due to:

- Views that local strategies could lead to inconsistencies in practice around the country with too much local autonomy, and concerns that strategies would be toothless unless accompanied by clear plans for monitoring and accountability (with a small number of respondents supporting the implementation/delivery of a national strategy over local strategies and some rejecting the principle of 'strategies' per se);
- Concerns that training may become too diluted if the scope was too wide and would be ineffective if its scope was too narrow; and

- Strong views that individuals should not have to ‘request’ information but that it should be provided as standard.

Many respondents detailed other broader concerns linked to social care that were not directly linked to the proposals, and these mainly included comments that:

- The social care system was difficult to access and navigate;
- There was a need for better strategies around transitions in health and social care;
- Criteria for accessing some disability related social work services were inconsistent around the country and this should be addressed;
- Issues around access to services for those without diagnoses should be considered in more detail;
- There was a need for better signposting and awareness of what social care support is currently available;
- More holistic approaches in social care and community health to support people with learning disabilities and neurodivergence people may be needed;
- Better sharing of information between social care and wider services was needed;
- Social care policy should be better integrated and joined up with other policy areas, including education; and
- Social care needed to be more inclusive to meet the needs of those in minority groups.

Broad observations were again made that there was a lack of clarity around what the LDAN Bill sought to achieve that was not (or should already be) covered by the Equality Act and/or the National Care Service Bill. A small number of others again perceived that the LDAN Bill (and individual proposals within it) did not go far enough and should have an even wider reach.

Section 4: Housing and Independent Living

Introduction

The consultation document highlights the need for appropriate housing as an essential requirement for independent living. This in turn, will improve health and wellbeing and consequently save money in the long term from health and social care costs. However, reference is made to the 2018 Equalities and Human Rights Commission report which found that many homes did not meet specific requirements, therefore housing was not fulfilling disabled people's rights to independent living.

The consultation detailed aims to better protect and uphold rights around housing and independent living. Although there are currently a number of measures in place to assist with housing, it was suggested that the LDAN Bill could provide a stronger focus on how public authorities' duties around housing and independent living can be best met for people with learning disabilities and neurodivergent people. Five proposals were put forward:

- **Proposal 1: Advice, Advocacy and Guidance** - consider specialist advocacy services for housing support to enable people with learning disabilities and neurodivergent people to access their rights to housing and independent living.
- **Proposal 2: Neurodivergence and Learning Disabilities Strategies** - require strategies produced by local authorities to set out how independent living principles are embedded into assessment and allocations policies, to ensure real choice and control. Consider whether currently produced Local Housing Strategies must also set out how the needs of people with learning disabilities and neurodivergent people are met, and to evaluate their progress. Consider requiring Integration Authorities neurodivergent and learning disabilities strategies to: set out how housing, care and health services are integrated; describe the supports available to people to help them live independently; and evaluate progress against this.
- **Proposal 3: Mandatory Training for Housing Professionals** - extend the requirement for mandatory training to housing service professionals.
- **Proposal 4: Data** - (a) improve the way data is collected and shared by relevant public bodies (such as local authorities) on the requirements of people with learning disabilities and neurodivergent people, and their housing needs, and (b) collect data on how many people with learning disabilities are considered not to have access to appropriate housing.
- **Proposal 5: Inclusive Communications** - some documents in relation to housing need to be available in Easy Read formats.

Main Findings

Overall, 420 respondents provided feedback at this section. Nearly two thirds of these respondents agreed with all five proposals as each had merit and could be impactful in relation to housing and independent living.

Where respondents did not agree with all proposals, the single most supported option was introducing mandatory training for housing professionals (Proposal 3). This was followed by the provision of advice, advocacy and guidance (Proposal 1), developing strategies and/or incorporating consideration of people with learning disabilities and neurodivergent people into existing strategies (Proposal 2), and providing inclusive communication (Proposal 5). Very similar numbers of respondents supported both Proposals 2 and 5. The proposals related to data (Proposal 4) was the least well supported of all five options, and received the highest levels of explicit disagreement (albeit by a small number of respondents).

The following sections set out the main reasons for support or disagreement with each of the five proposals in turn, however, it should be noted that comments and discussions of each was limited. Rather, many respondents discussed issues in the housing sector more generally and/or identified key areas that needed to be addressed - these issues are discussed after the proposal specific coverage.

Proposal 1: Advice, Advocacy and Guidance

Many respondents agreed with the need for more advice, support and advocacy. The general feeling was that a more regulated/standardised approach in this area would increase accessibility and may also help with navigating other government departments and systems surrounding housing:

> “…this needs to be specialist housing support - the range of conditions covered by LD (learning disabilities) and ND (neurodivergence) is gigantic - and it must not assume that someone who has 'low support needs' would not struggle with housing related issues.” (Neurodivergent Individual and Family/Friend/Carer)

A few also felt that improvements in this area would help to make the housing system more people-centric rather than led by process. The need for specialist support, and therefore specialist training, was regularly cited in response to this proposal.

Although only a handful of respondents disagreed with this proposal, their reasons typically corresponded with caveats and concerns raised by those who supported it. It was felt that advocacy and support should be overarching and not just ringfenced by sector. This echoes sentiments shared in the overarching themes section on advocacy where some respondents felt that individuals would benefit from a one stop shop or single point of contact for a wide range of issues rather than different specialist advocates per sector.

Proposal 2: Neurodivergence and Learning Disabilities Strategies

Many respondents agreed with the proposals set out for the development of neurodivergence and learning disability strategies. It was suggested the current system was inadequate and that improvement in this area would be of great benefit to people with learning disabilities and neurodivergent people. In particular, it was felt that having a strategy and a requirement to evaluate progress against this would ensure that policies were inclusive and effective at addressing the specific housing needs of local populations:

> “We fully support the proposal that legislative requirements should be established for national and local strategies to ensure that the principles of independent living are deeply embedded into the assessment and allocation policies of local authorities. This ensures real choice and control for neurodivergent people and those with learning disabilities.” (Advocacy Service)

There were, however, some caveats alongside support for this proposal. Consistent with concerns raised throughout this consultation, a few respondents were concerned that a lack of resources would inhibit the implementation of any strategies. It was felt that, against the backdrop of public sector budget cuts, it would be difficult to achieve any real changes or improvements.

Another concern, again echoed across the consultation, was that allowing individual authorities to create their own strategies could result in a difference in standards between authorities and a lack of accountability or ambition.

Proposal 3: Mandatory Training

The most popular individual proposal was the requirement for mandatory training for housing service professionals. Respondents were very much in favour of this proposal, with some referring to their own experience of poor service. The general feeling was that specialist training regarding both physical and sensory needs would bring significant improvement to the system. Some stated that improved specialist training would result in a ‘kinder’, more understanding, person-centred approach, with more suitable homes being offered since support staff would be more aware of individual needs.

There was also a common call for such training to be extended to other services and professionals related to housing, for example, inspectors, trades people, letting agents, landlords, etc.:

> “Some of the existing housing legislation, particularly "safety" legislation like gas safety and electrical safety inspections are extremely traumatic and feel like severe invasion of my "safe space" by very unpleasant, poorly trained and unsympathetic people.” (Neurodivergent Individual)

Again, consistent with views expressed elsewhere, it was suggested that training plans be developed in partnership with people with learning disabilities and neurodivergent people.

There was very little disagreement with Proposal 3, however, one individual raised concerns about the efficacy of existing training, with online training seen as ineffective and treated as a tick-box exercise.

Proposal 4: Data

While many respondents agreed with Proposal 4 linked to data, the majority did not offer reasons for their support or provide much discussion of the issues in this respect. Only a few responded with the general notion that the proposal to improve data collection would help the housing system to evolve appropriately to meet specific needs.

As noted above, this proposal elicited the highest levels of specific disagreement, albeit from a very small number of respondents. Consistent with the concerns raised at the overarching theme related to data, a variety of caveats, concerns and queries were raised in relation to housing based data:

- Some questioned what information would be recorded, how and by whom;
- Some were concerned that data collection could lead to discrimination; and
- Some emphasised the need to make good use of the data.

A few also suggested that much more information was needed to develop this proposal.

Proposal 5: Inclusive Communications

Again, many respondents agreed with Proposal 5 and the need for inclusive communications within the housing sector. The main considerations were again consistent with those expressed elsewhere. Namely that, provision of alternative formats should be mandatory and provided as standard so that people with learning disabilities and neurodivergent people and their families/carers do not have to know it is available/ask for this, and that inclusive communication should not be restricted to Easy Read, but rather a wider range of communication/information types were also needed. This included audio and video format, and via advocates:

> “Proposal 5 should make it compulsory for housing authorities to provide Accessible and Inclusive Communication materials.” (Carer)

No respondents disagreed with Proposal 5, although one did suggest that not enough information had been provided in relation to this.

Other Comments and Considerations

A large number of respondents discussed issues related to housing more generally. This included identification of the problems or difficulties in the current system, as well as identification and discussion of the challenges faced by the housing sector in providing appropriate housing to fulfil independent living requirements. Some also outlined other measures that could be helpful in tackling the current issues in this sector. A wide range of additional comments were provided, highlighting other issues that should be given further consideration, as below.

More Suitable and Supported Accommodation Needed

One of the main issues discussed by respondents was the lack of affordable/low cost and/or social housing generally, as well as a lack of suitable accommodation and supported accommodation for people with physical disabilities, people with learning disabilities, autistic people and neurodivergent people. Respondents highlighted the impact this had on both the individuals and their families/carers. The lack of suitable options meant many adults remained in the family home with their parents much longer than their neurotypical peers (thus impacting their independence and autonomy), while families/carers discussed the worry and anxiety they had over the future:

> “Housing and support is one of the main concerns for parents of LDAN adults. This is a concern which is made worse by the lack of housing and suitable supported accommodation caused by a lack of vision and planning by Local Authorities.” (On behalf of a LDAN person, and Family/Friend)

Respondents stressed the importance of increasing supply and ensuring provision happens in a planned and managed way. However, there were differing views and preferences for the types of housing required, with suggestions including fully and partially supported housing, fully independent housing, adapted homes, as well as shared and community living options. Overall, a wider range and choice of options was perceived to be needed, either via local authorities or registered social landlords (RSLs), and supported by the Scottish Government.

Transition and Ongoing Support

Several respondents commented on the need to provide greater education and information to young people, as well as proactive support so that they are able to live independently. It was felt that younger people were given little choice of housing or limited information about what was available to them, and there was a sense that authorities were more inclined to leave young people in their family home wherever possible.

A handful of respondents specifically discussed residential care or schooling for children, as well as the transition from childhood to adulthood and the difficulties faced with housing options at the interface. It was said to be very difficult to accommodate some young people in their local area, but it was argued that providing continuity of care and housing as a person transitions from childhood to adulthood was important.

A few respondents also highlighted the need for ongoing support once people with learning disabilities and neurodivergent people are housed. They said without suitable levels of ongoing contact and consistent support from other services (such as social work/social services), newly housed individuals are “set up to fail” as they are often unable to maintain their tenancy:

> “Checking on people with NDs [neurodivergence] is important. There's numerous cases where social services and housing

> authorities have dumped people into houses and then leave them without any support.” (Neurodivergent Individual)

In addition to supporting young people and adults directly, several respondents also suggested that support be given to their carers or family members. It was thought that supporting carers with training, information and signposting would develop them as effective advocates for their loved ones housing needs.

Investment and Funding Needed

Additional funding and support was said to be needed within the housing sector, both to address issues related to housing stock, and to deliver the aims and proposals set out in this section of the consultation.

It was felt that the current financial situations that public bodies and local authorities are in, budget cuts, financial restraints, and the declared housing crisis in some areas meant tackling the housing stock problem would be difficult without significant investment and increased funding being made available:

> “…recent cuts to the affordable housing supply programme are likely to limit the ability of registered social landlords (RSLs) to achieve their aspirations for the development of new housing. Issues about capital and revenue funding arrangements for supported housing models are a disincentive to develop the specialist models of housing that some people require.” (Housing Sector Organisation)

Several respondents (an equal mix of individuals and organisations) also commented on the need for dedicated government funding to ensure that the aims and proposals set out here could to be turned into reality.

Understanding Needs in Infrastructure, Policy and Housing Allocation

Several respondents felt that people with learning disabilities and neurodivergent people should be considered as high priority on housing lists alongside disabled people, those who are homeless, and asylum seekers. It was mentioned that the points-based system for housing often does not include neurodivergence and respondents felt that this should be corrected to provide a more holistic approach and to ensure such individuals do not become homeless.

Several also highlighted the need for autistic people in particular to have their own space in family homes and/or to live alone upon becoming an adult. They stressed the difficulties and inappropriateness of shared accommodation provisions. However, it was noted that current allocation of social housing for families did not take account of neurodivergence and would often result in room sharing between siblings. Further, it was highlighted that the housing element of Universal Credit did not provide for more than a room in a shared flat until a person reached the age of 35. This meant that housing choices were limited and often unsuitable.

Again, several respondents detailed how sensory issues can result in people being overwhelmed, and therefore noise, light and smells needed to be understood and considered within housing design, adaptations considered, and in relation to housing allocation. Respondents felt that such needs are often dismissed:

> “…the needs of neurodivergent people are every bit as vital as the physical adaptations made for other disabilities. Even something like a grant to cover the cost of adding adequate soundproofing to my home would make an enormous difference to my overall ability to function on a day to day basis.” (Neurodivergent Individual)

A handful of respondents also mentioned that the use of technology could assist people with learning disabilities and neurodivergent people with everyday independent living. This included presence sensors, Artificial Intelligence (AI) central heating controls, and motion-detector systems.

Greater Involvement of Other Professionals

A number of respondents (mostly organisations) mentioned the need to include, or ensure greater involvement from more specialist services. This included involving Speech and Language Therapists in the development of inclusive communication, and Occupational Therapists in the development of training and housing strategy, as well as individual assessments around housing needs and any adaptations required to support independent living:

> “Currently [local authority] works in close partnership… to ensure close cooperation between the services, this include funding a dedicated Housing Occupational Therapist. This has been a successful model and illustrates that partnership working and a degree of service integration can best meet the needs of the wider community and specific groups within it.” (Local Authority)

Home Owners

Finally, a handful of respondents commented that little consideration was given in the consultation document to those who rent privately or own their own homes. They asked that support for buying and owning a home be included in the LDAN Bill.

Section 5: Complex Care - Coming Home

Introduction

This section focused on people with learning disabilities and complex care needs.

The consultation document set out the issues related to delayed discharge from hospital (due to a lack of appropriate community support) and inappropriate out-of-area placement (where people are living away from their home, communities and families even though they did not choose to). It was stated that that was unacceptable, and the Scottish Government indicated its desire to change this.

It was suggested that the LDAN Bill could potentially strengthen some parts of the current Coming Home work to make sure that the vision set out there is achieved. In particular, it was suggested that the legislation could help with two of the key recommendations, including the Dynamic Support Register and the National Support Panel:

- **Proposal 1: Dynamic Support Registers -** to strengthen the existing Dynamic Support Registers and the processes around them so that it becomes law for the relevant local public body (Integration Authority, Local Authority, Health Board) to hold these. Each area would also be required to report data from it to Public Health Scotland (PHS) for it to be published. Consideration should also be given to: (a) who would be included on the Registers; (b) which public bodies would have statutory duties; and (c) the guidance and safeguards to be put in place to ensure that the Registers are used properly.
- **Proposal 2: National Support Panel** - this should work with and support the new Dynamic Support Registers and Peer Support Network[2]. Three options were set out around the scope and remit of this panel:
    - **Option A**: Legislative Panel Conducting Individual Reviews within Defined Parameters;
    - **Option B:** Legislative Panel Conducting Peer Reviews of Local Processes; or
    - **Option C**: Non-legislative Panel Conducting Peer Reviews of Local Processes.

Two closed questions were asked to allow respondents to identify their preferences, and 272 respondents also provided further comments and feedback at this section (the lowest number of respondents to provide qualitative answers of any section in the consultation). Several respondents noted that they either did not understand the proposals enough to comment, or had no experience in this area. A

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[2] The Peer Support Network is for professionals from Health and Social Care Partnerships, clinicians, commissioners, social care providers, housing organisations, local authorities, family members, third sector organisations and other relevant stakeholders to provide an informal group for people to share best practice.

few organisations also noted that this issue was outwith their area and so did not feel qualified to comment.

Proposal 1: Dynamic Support Registers

Respondents were asked to indicate whether there should be a statutory duty upon the relevant public body or bodies (Integration Authority, Health Board, Local Authority) to hold a Dynamic Support Register.

Answer	Number	Percent	Valid Percent
Yes	224	26%	93%
No	18	2%	7%
Not Answered	635	72%	-
Total	877	(n-877)	(n=242)

Most respondents (93%, n=224) who answered the closed element of this question felt there should be a statutory duty related to a Dynamic Support Register (DSR). While the results were fairly consistent between individuals, organisations and public bodies in this respect, organisations and public bodies were slightly more likely to disagree with such a duty (at 11% and 13% respectively) compared to individuals and the aggregate level results (see Appendix B). Again, however, only a small number of public bodies answered this question (n=30) so caution is needed over the robustness of these comparisons.

Overall, 160 respondents also provided qualitative comments at the free-text element of this question. However, responses from some individuals often focused on more general support for the DSR itself and what this aims to achieve, rather than identifying or confirming support for this becoming a statutory duty.

Some respondents felt that the **data** gathered via the DSR was vital in order to identify the number of individuals affected by delayed discharge and out-of-area placements, levels of need, and any issues or patterns which need to be addressed (either locally or nationally). Further, it was felt that analysis of such data would help to support strategy and policy development, support early intervention and longer term planning (e.g. related to housing, care services, staff deployment and training needs, etc.) and to monitor actions and outcomes.

It was also felt that the DSR and associated reporting would provide and maintain visibility of the issue and those who require support. Ensuring that people are not "forgotten about" or allowed to fall through the gaps was seen as key for this intervention.

Support for a Statutory Duty

Across both organisations and individuals that outlined support specifically for introducing a statutory duty related to the DSR, one of the key reasons given was the perception that this would provide greater accountability, both locally and nationally. It was suggested that the reporting requirement would provide oversight and scrutiny, and allow the Scottish Government to identify any issues and intervene when required. A few respondents also suggested that having a statutory duty provided entitlements for individuals as well as a route for redress where service provision falls below what is required.

Some organisations noted that the current implementation of the DSR had been both slow and varied between areas. As such, it was felt that having a statutory duty to hold a DSR would provide greater urgency to develop these across the country, and would provide greater operational clarity and consistency. It was also felt that the legislative footing would ensure the issue was treated as a priority. This would ultimately help to strengthen the use and impact of the DSR. Similarly, individuals tended to want the DSR to be enshrined in legislation due to a level of mistrust and/or a perception that if it is not a legislative requirement then it will either not be implemented at all, that the level of implementation will vary by area, or that it will not be prioritised and kept up to date. It was also felt that establishing this as a statutory duty would help to protect this intervention from any future cost cutting measures.

Some respondents also thought that introducing a statutory duty would help to deliver consistency in the implementation of the DSR across the country, although it was also suggested that national guidance or a national strategy may need to be produced to support this. It was stressed that delivering consistency in this area was necessary and important.

Extend Coverage to Other Groups

Several respondents suggested that the data captured by the DSR should identify the number of autistic people, with a few others suggesting this should also extend to other neurodivergent conditions as well. Others appeared to interpret the proposal and the use of the DSR as already being applicable to autistic people (without any mention of co-occurrences of either learning disabilities or other complex care needs).

A few organisations argued that the DSR should also include children to ensure suitable forward planning takes place. It was stressed this approach was needed due to the lack of inpatient facilities for young people with learning disabilities resulting in them often ending up in unsuitable adult facilities, or in out-of-area placements which risked breaking down. It was noted that authorities should be aware of these individuals while they are children so that longer term planning can happen and to facilitate a more seamless transition into adulthood without the need for lengthy hospital stays or out-of-area placements as local support could be put in place in a more timely manner.

Further, a few respondents suggested that the DSR should capture people in unsuitable or inappropriate settings within their own community, and not just those in out-of-area placements. In addition, it should aim to address delayed transfer between settings, for example being unable to move between hospitals due to a lack of beds, or where people are ‘stuck’ in more high security settings than necessary due to lack of space at lower security facilities.

Caveats, Limitations and Concerns

A few respondents highlighted the need to consider confidentiality, privacy, and data protection issues given the sensitive nature of the data the DSR will contain, as well as the level of data to be published in order to protect anonymity for individuals. It was noted that, within small populations there was a risk that individuals could be identifiable, even using anonymous data.

Some respondents argued that the DSR and data reporting would not be sufficient on its own to deliver meaningful change. It was noted that simply having a register and knowing where people are will not be enough: this information must be gathered and used for the purpose of meaningful change, both for the individual and system improvements. They stressed that more was needed to achieve the aims, including an increase in the supply and availability of suitable housing options, greater social care provisions, and better integration of partner service providers:

> “…there are some significant barriers to delivering the commitment made to people stuck in hospital and inappropriate out of area placements, and this Bill feels like a missed opportunity for action to address those barriers. We cannot achieve our aims without the right accommodation - we need to explore how we better integrate housing planning and provision into Health & Social care strategic planning structures, with the aim of developing measures within this Bill to support that integration. We cannot achieve our aims without the right support provision - we need to explore how this Bill could be used to address the crisis in social care recruitment and retention.” (Justice Organisation)

Consistent with the views at most other consultation sections, funding to support these proposals as well as improvements in this area generally were said to be necessary.

Reasons for Disagreeing

Only a few respondents (n=18) disagreed with a statutory duty related to a DSR, consisting of 10 individuals and eight organisations. There was a general split in the reasons given in their qualitative responses, however, with individuals, third sector and Disabled Persons Organisations (DPOs) typically being opposed to the DSR itself, while health services, local authorities and an Other National Public Body/National Agency representing the public sector were generally supportive or neutral towards the DSR, but were opposed to the need to create a legislative duty.

Those who disagreed with the DSR itself felt the necessary information should be held by the NHS on patient records; that a DSR would be bureaucratic and ineffective; or they were concerned about how such a Register would/could be used. Those who argued that a legal duty was not required noted that Health Boards and Integration Authorities were already operating the DSR, with data being provided to the Scottish Government and Public Health Scotland. They felt the current arrangements were effective without the need for a statutory duty. A couple of these respondents also noted that, as the DSR was a recent development it would need to be reviewed and evaluated to identify any implementation issues, possible improvements required and/or alternative options.

Proposal 2: National Support Panel

A closed question asked respondents to identify which of the three options put forward for the development of a National Support Panel had the most benefits.

Options	Number	Percent	Valid Percent
Option A: Legislative Panel Conducting Individual Reviews within Defined Parameters	68	8%	32%
Option B: Legislative Panel Conducting Peer Reviews of Local Processes	128	15%	59%
Option C: Non-legislative Panel Conducting Peer Reviews of Local Processes	19	2%	9%
Not Answered	662	75%	-
Total	877	(n=877)	(n=215)

Of those who answered, over half (59%) preferred Option B, to create a legislative panel to conduct peer reviews of local processes. Option A, a legislative panel to conduct individual reviews within defined parameters was supported by around a third of those who answered the question, while Option C, creating a non-legislative panel to conduct peer reviews of local processes was the least supported option.

Disaggregated data, however, showed differences in the strength of support by respondent groups (see Appendix B). The results for individuals largely mirrored the aggregate level results above. The order of preference for organisations also followed a similar pattern, however, support for Option 2 was lower (at 47%) and higher for Option 3 (at 18%) compared to the total sample. Meanwhile, public sector organisations showed relatively equal levels of support for all three options (at eight or nine respondents each). However, caution is needed when interpreting these results due to the small number of organisational respondents (n=60) and public sector respondents (n=26) who answered this question.

Option A

Statutory powers were seen as desirable or necessary, both to ensure the necessary participation of services, and because statutory powers were required to challenge statutory bodies and statutory decision making, i.e. the Panel needed to have “real teeth”:

> "Although we challenge this situation in every way we can… it can be impossible to shift statutory decision making… Without statutory support, it is impossible to overcome the hurdles such as finding appropriate accommodation and setting up a suitable care team and package. There is a need for oversight of these situation in order to make progress." (Advocacy Service)

This option was also seen as a person-centred approach, focusing on the individuals and lived experience rather than processes. It was seen as the best way to improve situations for individuals and also to develop broader system changes. It was felt that a review of processes (as suggested at Option B and C) would not be robust enough to understand the lived experience of individuals in the system or any delays/failures, and may be open to manipulation and abuse by services.

A few organisations disagreed with the argument put forward in the consultation document that this option may lack the capacity to tackle the volume of cases required. It was noted that the number of cases which would need to be reviewed were not restrictively high, that findings from early reviews would allow wider improvements to be made for others, and that the numbers of individuals finding themselves in situations that would require a case review should shrink over time as the system improves. A few individuals also suggested that some type of triage system could be established to prioritise cases for review.

It was also noted that this option closely followed the approach taken by the Mental Welfare Commission for expert investigations, patient based enquiries and the dissemination of learning and best practice examples.

A handful of respondents who selected Option A as their preferred option also noted that they would accept Option B instead as this also had merit due to its legislative footing. A few suggested that Options A and B should be implemented together as both reviews of individual cases and reviews of systems and processes would be most effective in driving improvements.

Option B

Again, among both organisations and individuals, the most common reason for supporting Option B, a legislative panel to conduct peer reviews of local processes, was its legislative nature. As with Option A, respondents felt that it was important for the panel to have a legislative footing in order to secure participation and to require recommendations to be adopted and changes to be made.

Heath services who agreed with this option also agreed that there was a need for the panel to have legislative powers to ensure changes can be made. It was felt this would deliver accountability. One also stressed the need for this Panel to be seen as a supportive resource which will help to address complex barriers and issues.

A few respondents perceived Option B to be more practical, realistic and achievable than Option A, while some individuals felt Option B would have a wider reach and make improvements for more people compared to Option A.

Other individuals supported the local approach proposed by Option B. It was felt that local voices would be better heard using this approach, and that involving local knowledge and focusing on local situations would help organisations to better tailor solutions for their own populations. A few individuals also perceived that Option B would bring greater consistency to service delivery and processes across the country, and would help to address the variation that currently exists.

Several respondents suggested that, due to the likely timescales that would be required to set up Option B, they would be supportive of Option C (the non-legislative panel conducting peer reviews of local processes) being used as an interim measure - this view was also echoed by a few respondents that did not indicate a preferred option.

Despite supporting Option B, a few respondents were still keen to ensure that individuals benefited directly from the reviews, whether this be systems for redress in individual cases, or some mechanism to ensure that recommended changes impacted individuals and their outcomes.

A few respondents who supported Option B felt that more detail was needed on any likely sanctions or consequences for services who fail to implement the Panel's recommendations.

Several individuals supported this option as they felt it provided a good middle ground, i.e. it would impact a higher number of people in a shorter timescale than Option A, and although it would take longer to set up than Option C, it would have a legislative footing to ensure cooperation and compliance among services. Again, however, a handful of respondents advocated for a combination of Options A and B as being the best, most comprehensive and effective way forward.

Option C

Option C, to create a non-legislative panel which would conduct peer reviews of local processes, was preferred by the lowest number of respondents. Those who supported this option did so largely because it would be quicker to implement and therefore would have a more immediate impact:

> "Not sure the legal aspect is as important as the requirement to do it sooner and have something in place." (Member of the Public)

Organisations (largely health services, local authorities and an Other National Public Body/National Agency representing the public sector) felt that this option would be more flexible, supportive and collaborative, allowing shared learning and problem solving. It would also allow panels to adapt to local circumstances. Health services also suggested that Option C may be a useful starting point, which could be added to, escalated or tightened up over time if required.

Local authorities and an Other National Public Body/National Agency representing the public sector were also keen not to duplicate the current work or processes already in place, or undermine the role and remit of other organisations (which they felt Options A and B might do), particularly in relation to the Mental Welfare Commission and/or the Care Inspectorate. They noted that there were already a number of governing bodies with oversight in this sector and so felt that a non-legislative peer review panel would provide the additional support required.

Comments from those with No Preference

Several respondents indicated that they did not support any of the options presented. Others either had no preference or could not decide on one single option as they felt all had merit (and/or negative aspects). While some agreed with and stressed the need for any panel to have legislative powers, they either did not have a preference for this to either consider individual cases or local processes, or they did not specify any preference for the structure and remit of the panel.

Other respondents focused on other issues which have been included in the following section.

Other Comments and Considerations

A range of other options or areas for consideration were highlighted and discussed by respondents.

Many respondents offered suggestions around who should have involvement on panels, or who should be invited to contribute views and experiences to the panels, regardless of which option is taken forward. This included:

- People with lived experience;
- Family members and carers;
- DPOs and other third sector support organisations; and
- Expertise from health and social care services and learning disability health services, such as learning disability psychiatry, psychology, nursing and social work.

It was also suggested that peer networks and independent advocacy should be involved and provided to ensure individuals and their families are aware of their rights, are given appropriate support, and in the case of peer networks, it was suggested these can help to identify issues and solutions. Access to advocacy was felt to be particularly important in the event of delays, e.g. delayed discharge from hospital or delays in relocating from out-of-area placements.

As noted above, and throughout the consultation document, several respondents noted that funding and resources would be needed for these proposals to be set up and implemented.

Many also suggested that the issues were a result of system wide problems, and were therefore not solvable by creating a DSR and/or undertaking case or process reviews alone. It was also indicated that in some cases the issues could not be solved by a single organisation or authority. It was noted that there was a systemic lack of alternative accommodation; a lack of communication between professionals/ services and awareness of what each other can provide - it was seen as a disjointed and fragmented system; there was a lack of appropriate accountability;

there are issues around staff recruitment and retention, as well as staff lacking the appropriate skills in social care and community based support; a lack of understanding within the system and/or by individual professionals about different needs; and a lack of information with individuals and families unaware of the processes and their rights. It was stressed that significant investment would be required in all of these areas and the development of greater multi-agency working or integration of services for real changes to be felt on the ground.

A few respondents suggested that consideration should be given to implementing a system to allow a right of appeal (or a Tribunal) for those who are ‘stuck’ in in-patient settings, similar to the provisions set out in the Mental Health (Care and Treatment) (Scotland) Act 2003. Others felt there needed to be change to mental health legislation to stop people with learning disabilities being subject to inappropriate mental health restrictions and hospitalisation.

Consistent with comments noted in relation to the DSR, a few respondents again stressed that autistic people and those with other neurodivergent conditions should be considered and included within this section of the consultation document. Similarly, it was suggested that children and young people needed to be included within any system that may be taken forward.

Should a Commission(er) be established as part of the LDAN Bill, it was felt they should have some role or oversight within the DSR and any Support Panel system that is established.

Other Comments

Only a few other issues or areas for further consideration were raised by more than one respondent, including:

- A few respondents supported the approach set out by New Routes Home, however, they did not repeat any of the detail of this within their responses;
- Any model adopted needs to respect (and potentially consider expanding) the roles and responsibilities of the Mental Welfare Commission, the Care Inspectorate and the Mental Health Tribunal to avoid any duplication of effort;
- Systems should meet the requirements of the UNCRPD;
- A National Strategy should set out further details of the plans for this sector;
- National guidance, best practice, a set of outcomes and a framework for support were suggested as necessary or desirable to support organisations to deliver the proposals and ensure a consistent approach; and
- Ban Applied Behaviour Analysis and Positive Behaviour Support and other behaviourist approaches.

Section 6: Relationships

Introduction

To ensure that children, young people and adults who are neurodivergent or have a learning disability are able to develop and maintain relationships and get the support they need to live a healthy, safe and fulfilling life, the consultation set out a number of proposed actions, including:

- **Proposal 1: Access to Independent Advocacy** where it would assist in matters relating to relationships.
- **Proposal 2: Data Collection and Reporting** specifically on gender-based violence affecting women with learning disabilities **and** on the number of parents with learning disabilities in Scotland, including where their children have been removed from their care.
- **Proposal 3: Inclusive Communications** to assist in situations where a person with learning disabilities is at risk of having their child removed from their care **and** where a neurodivergent person, or person with learning disabilities, has disclosed gender-based violence or abuse and is interacting with the justice system.
- **Proposal 4: National and Local Strategies** to ensure that the Whole Family Approach is being implemented to proactively support neurodivergent parents and parents with learning disabilities **and** that local authorities and Police Scotland are meeting their duties to support people with learning disabilities and neurodivergent people to be involved in their communities and to feel supported in reporting crimes, including gender-based violence and abuse.
- **Proposal 5: Accountability** including the possible creation of a new Commission(er) specifically for people with learning disabilities and neurodivergent people which, among other things, would have the remit to investigate ongoing and historic cases of child removal from parents with learning disabilities, based on their disability.

Main Findings

Overall, 360 respondents provided feedback at this section, with most agreeing with all five proposals.

For some individuals, there was evidence of confusion around the scope of the proposals put forward and also some queries related to how they differed from material covered elsewhere in the consultation. There was also little feedback explicitly in relation to the Whole Family Approach and some indication that respondents were unclear what this meant.

At this section, several respondents also gave feedback which was not specific to any of the proposals but was more overarching. These mainly focussed on the importance of people with learning disabilities and neurodivergent people having better access to relationships, sexual health and parenthood (RSHP) education on a ‘lifelong’ basis (i.e. from early years, primary, secondary and tertiary education and throughout adulthood). Indeed, many respondents highlighted that a right to such education was included in the UNCRC and must be upheld as a fundamental right.

Overall, there was consensus that all individuals, regardless of their disability or neurodivergence were entitled to positive, strong and meaningful relationships and should be facilitated to achieve these. On this basis, all proposals received relatively strong support. Respondents welcomed a human rights-based approach to ensuring people with learning disabilities and neurodivergent people are supported to achieve a wide range of meaningful relationships in their lives as well as mechanisms being in put in place to protect some of the most vulnerable adults and children.

Proposal 1: Access to Independent Advocacy

Several respondents reiterated their feedback given elsewhere in the consultation that access to advocacy was essential in allowing individuals to live lives to their full potential, especially for people with learning disabilities.

Access to independent advocacy was particularly important in relation to the specific scenarios set out in this section (i.e. for those experiencing or disclosing gender based violence or abuse and those facing the threat of their children being taken into care). In both situations respondents noted that people with learning disabilities and neurodivergent people face challenges in navigating complex systems and barriers to effective communication:

> “Independent advocacy is paramount when a neurodivergent individual or someone with learning disabilities discloses gender-based violence or abuse. These individuals often face unique challenges in seeking justice and support due to barriers in communication, comprehension, and navigating complex legal systems. Advocates play a crucial role in ensuring that their voices are heard, their rights are upheld. By providing this service, the advocacy partner can find themselves finally being heard, possibility for the first time, and they realise that they have a say.” (Advocacy Service)

More generally, the right to independent advocacy was something that respondents felt should be prioritised beyond the conditions and circumstances described in this section of the consultation. Most viewed it as a provision that could/would be useful for facilitating relationships (both to maintain existing relationships and to build new ones) at various life stages throughout both childhood and adulthood, however, there were few specific examples given of where respondents felt it would help in terms of relationships.

One of the main things that was raised as being important in relation to advocacy was consistency - i.e. respondents wanted advocacy workers that were known to them (rather than always having changing advocacy workers). It was also stressed that both collective and individual advocacy was needed (i.e. representing groups as well as individuals). Others suggested that a liaison person for individuals, who could build up a relationship and understanding of the individual over time and support professionals to gain a better understanding of the person, would be welcomed. It was felt such a person could also help to provide continuity of care.

Comments were also made, however, about the potential danger of over-professionalising advocacy. Respondents were concerned that this may exclude valuable, cost-effective and accessible sources of community support, peer support and family support, all of which were seen to be equally valuable to individuals and were important to consider, uphold and invest in.

Advocacy in the context of relationships was seen as something that should not be restricted to ‘reactive’ support but was equally important as a ‘proactive’ provision (i.e. support was needed before situations escalated and required resolution). Early intervention was viewed as the best approach to supporting and building relationships for and within neurodivergent and learning-disabled families.

Similarly, some expressed views that advocacy should be offered to parents (where needed) regardless of whether or not they have a diagnosis.

Other common caveats and concerns included that:

- Advocates must be well trained and have lived experience, where appropriate;
- It was important to support children and young people, where they hold differing views from those of their parent or carer, with independent advocacy;
- Women and girls should have the right to same sex carers and, where they have suffered from abuse, same sex Advocates;
- Careful monitoring would be required to ensure that Advocacy does not become an oversubscribed resource;
- Additional funding was needed for advocacy support more generally; and
- There may be some lack of understanding of certain conditions/populations among advocacy providers and, in such cases, advocacy services should work hand-in-hand with third sector providers to ensure that needs are met.

Proposal 2: Data Collection

There was strong support for additional data to be collected with regards to gender-based violence affecting women with learning disabilities (as recommended in Unequal, Unheard, Unjust) as this was seen as a gap in existing evidence which, if filled, would help with improving services and responses to support this vulnerable group.

Some respondents also felt that data collection was required for all gender-based violence and not only that perpetrated against females, with several respondents highlighting male vulnerabilities too. In addition, several respondents supported the collection of a broader range of data relating to exploitation and harm affecting people with learning disabilities and neurodivergent people, and felt that this would be equally useful:

> "We would highlight the need to expand beyond a focus on gender-based violence and abuse, to consider the potential for exploitation of people with learning disabilities in this area. This would include financial exploitation, online sexual exploitation/blackmail, and coercion into criminal activity." (Mental Health Organisation)

Several respondents also stressed that data collection, analysis and reporting must be sufficiently detailed to account for differences within learning disabilities, autistic and neurodivergent communities (including different neurodivergent conditions and different demographic and protected characteristics). Many argued for a more intersectional/nuanced approach to the one proposed (and which also had provisions for data relating to children and young people).

There were fewer comments overall with regards to data collection on the number of parents with learning disabilities in Scotland, including where their children have been removed from their care. Where people did provide feedback this was broadly supportive on the basis that any research in this area would help to fill existing gaps in understanding and inform progressive change in the future. Some respondents suggested that data in this respect should not be restricted to quantitative data collection but might include narrative feedback from parents with lived experience, as well as (potentially) children who had been removed (including when they become adults). In addition to collecting data on such cases, more preventative action and support was needed, it was suggested, to minimise cases of child removal in the future.

Further caveats to support or variable views that were put forward included that:

- Data collection and reporting on gender-based violence should be extended to include autistic and neurodivergent people;
- Existing diagnostics methods for learning disabilities may not be the most reliable and valid form of diagnosing a learning disability and more holistic approaches may be required to ensure that all relevant individuals/cases gender-based violence are accurately reported/recorded;
- There was a need for improved/relevant data sharing across and between services in general; and
- It would be essential to uphold privacy and not cause unnecessary interference to people's lives solely for the purposes of research, i.e. it must inform policy and service planning.

Another common theme was that data collection would only be useful/worthwhile if the data were acted upon.

Proposal 3: Inclusive Communications

Again, people gave very general feedback on this proposal, often consistent with what had been raised elsewhere in the consultation. Some suggested that accessible information (in the format needed by the parent) should be provided for **all** parents where there was a risk of a child being removed from their care, not only those covered by the LDAN Bill:

> “Any parent, whatever their reading ability, literacy and understanding must have information provided in a way they understand when there is a risk of having their child removed from their care. Not only people with LD.” (Health Service)

Several respondents also explicitly agreed that inclusive communications must be made available to all those in the situations described by the consultation document to help them navigate systems which were often complex and confusing, such as the justice system[3]. It was felt this was particularly important given the increased risk of neurodivergent individuals being the victims of crime and their vulnerability to miscarriages of justice.

A specific point of note was raised in relation to social work contact with parents, with suggestions that communications were not always as clear as they could be at present, in part because of a lack of access to assessment of communication support needs.

Echoing comments made in the substantive section of the consultation on inclusive communications, respondents again stressed that it should not be incumbent on individuals to seek information, but that it should be proactively provided. Similarly, awareness of information and rights was also seen as equally as important as ensuring that they were delivered in an accessible way. A small number of respondents also, again, expressed views that inclusive communications must include the provision of advocacy, where appropriate, to ensure that the best ways of communication could be triangulated for the individual.

Comments were also made that this proposal, and others, needed to recognise that women of faith, women in minority ethnic groups, and women with varying sexual and gender identities were all in scope and may be disproportionately at even greater risk of violence, abuse or harm. Respondents suggested that separate provisions may therefore be appropriate to cover their needs.

Other comments included that:

- Inclusive communication should be mainstreamed and offered to parents regardless of whether or not they have a diagnosis of some kind;
- It was not clear who was included in the reference to “support provided by professionals who have specialist training in learning disabilities”; and
- Any information/training/communications must be designed in collaboration with people with lived experience.

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[3] One organisation noted that they were surprised to see the need for legislation to ensure inclusive communication in the context of a child being removed as there is already a requirement to consider advocacy/alternative communication to support a parent’s understanding by the court. They noted that a removal order would not be considered without doing so.

Proposal 4: National and Local Strategies

The majority of comments on this proposal were linked to local authorities setting out how RSHP education was provided. Several respondents cited examples of a lack of assistance, education and support around developing relationships, especially romantic and sexual relationships. Some commented that there was a current lack of understanding of the importance of/barriers to intimate relationships among people with learning disabilities and neurodivergent people and felt that key to this was early and effective RSHP for individuals, supported by well trained professionals:

> “Society also thinks people with learning disabilities should not have sexual relationships. Why not? We are just like everyone else. We want to love and be loved. We have the right to have relationships. We may need support and good information and we might make mistakes but that is also our right.” (LDAN Support/Representative Organisation - Learning Disabilities)

A small number of respondents gave personal testimony (either of their own experiences or of women they were representing) to again highlight that a lack of education around friendships and relationships meant that they were often vulnerable to coercion and harm. Improved education and advice around such things as prevention, protection and safety, as well as support (e.g. advocacy or outreach workers) and someone to provide emotional support was seen as a way of giving these women control over their relationship choices/support with their decisions as well as keeping them safe. This was important more broadly, it was suggested, to protect against harm from relationships as well as abuse from people who should be looking after them, e.g. support workers or family members.

Several others commented that sexual education courses should be more easily accessible, along with more one-to-one support from advocates or learning disability nurses (with suggestions that information on learning disability nurses needed to be more accessible and widespread to ensure that people know what services they can offer or how to access these). While mentioned in the advocacy proposals, and while this was an important area where advocacy support was particularly welcomed, the consensus was that RSHP needed to extend beyond advocacy provision alone.

Broader comments linked to RSHP included that the Scottish Government guidance must be sufficiently clear to enable local authorities or education authorities to deliver the duties under the Bill and that sufficient resourcing must be in place to facilitate delivery (including of RSHP).

Only very few respondents commented on Police Scotland setting out how people with learning disabilities are provided with specialist support to report crimes, including gender-based violence and abuse. Where people did give a view, this was broadly supportive and one suggestion was made that it may be beneficial for Police Scotland to work in a multiagency way to achieve this.

While there was little direct feedback on the other proposals, comments were made that the combination of proposals presented here and elsewhere should help to ensure that public duties/obligations were being met.

Many respondents referenced their earlier responses regarding local strategies, including support for authorities to set out how they provide services to people with learning disabilities and neurodivergent people to enable them to be active and involved in their communities. Most feedback on this proposal was linked to suggestions around what strategies might cover, including:

- Planning and actions linked to education, advocacy, data, and accountability measures;
- An action for the Scottish Government's National Strategy to support more promotion and education of the public;
- Separate sub-strategies for women with learning disabilities and neurodivergent women which would focus exclusively on their unique challenges and needs;
- Clear monitoring and evaluation plans;
- Local RSHP curricular content; and
- Minimum service provision and standards linked to a national strategy.

Comments were also made that the national RSHP resource currently being used by teachers had been updated in recent years and was a useful resource; however, lack of use/delivery in schools may be the bigger issue. As such, they felt that local strategies should/could include a commitment to delivering this education (rather than the focus being on developing anything new). Indeed, one Health Service organisation suggested there should be a requirement for local authorities to provide evidence delivery and monitoring of RSHP, and to ensure that quality assured Continuing Professional Development (CPD) on this is available.

A minority indicated that local authorities already report on the range of services and supports available to their residents, including children and young people. There was also said to be a great deal of work already being undertaken within the education curriculum around RSHP, including consideration of how learners with additional support needs are supported.

Where people did not agree, this was mainly on the basis that strategies were seen as ineffective unless supported by some form of monitoring or accountability to ensure that they were delivered upon. Some concern was also raised that while national and local strategies were welcomed, they could not be implemented by existing teams as they were seen as already overworked/operating beyond capacity.

It was again noted that national and local strategies must be designed and produced by the people they are written for.

Proposal 5: Accountability

Those who touched on this proposal were split. As with the main section on accountability (at Part 4), some were supportive of either a new or existing body having the powers to investigate both ongoing and historic cases of child removal from parents with learning disabilities, based on their disability. Others, however, expressed that a new Commission(er) would add unnecessarily to the already complex accountability landscape and would not be an effective use of resources.

The main feedback given in response to this proposal, however, was testimony of the negative experiences families had due to a child being removed and perceptions that there was an urgent need to change or reform current practices which could be both distressing and frightening (for children and their families in equal measure).

Several other respondents did not comment on accountability directly, but used this section to put forward views that children should not be removed from parents with learning disabilities. Rather they felt parents and families should be better supported.

Some who supported the principle of accountability also suggested that alternative or complementary measures could be taken with regards to the issues discussed in this part of the consultation. This included, for example, both the Children and Young People's Commissioner for Scotland and the Child Health Commissioners Group potentially overseeing issues associated with child health and wellbeing.

Others, however, again stressed that the proposals may potentially introduce another tier in the accountability chain without being able to influence outcomes.

Other Comments and Considerations

Scope

Several comments were made that the proposals here appeared to focus mainly on people with learning disabilities, however, could well be extended to others, including autistic people who may also be disproportionately at risk of abusive relationships, sexual abuse and domestic abuse, victimisation, harassment, assault, and bullying, etc.

Similarly, some commented that the proposals did not go far enough in considering the very unique needs with respect to relationships that would be experienced by different individuals and groups covered by the Bill, for example those with PMLDs.

Wider concerns were linked to the fact that the relationship challenges faced by people with learning disabilities and neurodivergent people went beyond extending provision of RSHP education, as proposed. Similarly, the proposals appeared to focus solely on instances of acute crisis, such as the removal of a child or gender-based violence, rather than relationships more broadly. A separate ‘Relationship Strategy’ may be a more appropriate way to address issues linked to relationships for people with learning disabilities and neurodivergent people, it was suggested.

While this could include intimacy and romantic relationships, it should go beyond this to include friendships and community belonging. This might also include strategies for ensuring that those beyond the public sector also play a part in supporting relationships. In addition, some of the more fundamental ‘relationship’ issues facing these communities, and which could/should usefully be addressed in the Bill were said to include issues with bullying, extreme loneliness and social isolation often experienced by people with learning disabilities and neurodivergent people:

> “Whilst these proposals are in themselves good proposals they will have very limited affects in helping neurodivergent people and people with learning disabilities have healthy and fulfilling relationships and little impact on associated loneliness, social isolation, poor mental health, and trauma.” (On behalf of a LDAN person, and Family/Friend/Carer)

Several respondents suggested that issues linked to relationships were more socially embedded and required to be addressed in a systematic way over the long term and thus questioned if a Bill was the best mechanisms for achieving the wider social and systemic change that was required (especially around reducing stigma and discrimination). In a similar vein, several respondents felt that legislation was not the appropriate mechanism through which to attempt to achieve change.

Children and Young People

There were specific concerns regarding further mechanisms that were needed to support children and young people in particular. Respondents were concerned that the proposals largely focused on adults and therefore may not achieve the scale of change necessary to address the barriers that exist to relationships for children and young people with learning disabilities and neurodivergent children and young people.

Respondents suggested that young people specifically needed more help with such things as how to deal with stigma, harassment and bullying, as well as making friends and socialising with others “like them” or of a similar age in their wider communities.

Suitable Social Spaces

It was felt that relationship barriers were compounded by a lack of suitable social spaces tailored to both children and young people’s specific needs and adults’ needs (including online/virtual spaces). This in turn was also compounded by a lack of awareness of the spaces that were available:

> “There is a diminishing number of LDAN-informed 'third spaces' which would provide social gathering places for our community. Any support of relationships needs to take these deficits into account and counter them by creating more spaces.” (On behalf of a LDAN person, and Family/Friend/Carer)

For children and young people, a lack of community-based day services was mentioned, as well as accounts of young people being actively and/or subtly excluded from more mainstream youth services/clubs/activities, etc. (including as a result of lack of accessibility mechanisms in mainstream provision). More action to support independent social lives of children and young people was perceived to be needed as a priority (especially, but not exclusively, outside of school term times).

Similarly for adults, several respondents mentioned the need to bolster and fund such things as 'Dates-n-Mates' and other groups who provide social opportunities, friendship, relationships support and training/resources for people with learning disabilities and neurodivergent people.

Further, the provision of social spaces was also seen as supportive for the families of people with learning disabilities and neurodivergent people, who themselves often face social isolation and exclusion from mainstream activities.

Ensuring that support workers are fully aware of opportunities for socialising and that they facilitate proper access to such services was also seen as key to widening access and maximising reach.

Respondents stressed that access to social opportunities, friendships and relationships were vital to the wellbeing, confidence and overall life experience of both children, young people and adults alike.

Families and Carers

Many comments were also made with regards to supporting families of people with learning disabilities and neurodivergent people since they too hold a central role in ensuring positive relationships can be established and flourish:

> "…when thinking about relationships for people with mild LD [learning disabilities] who lack capacity to make an informed decision about most things, please be respectful of the family and their role because we have to get involved in our loved one with LD's [learning disabilities] friendships and relationships and talk them through everything…" (Family/Friend/Carer)

Providing more support to families would, in turn, help them to support their loved ones. This included suggestions that training for parents/carers around relationships would be helpful so they can provide greater and more appropriate support in this respect. Support was also needed, it was felt, to help mitigate the stress experienced by families and their relationships with each other when caring for someone with additional support needs. It was noted that carers often experience loneliness, social isolation, poor mental health and trauma, and would therefore benefit from support and greater opportunities to develop and maintain relationships.

Wider Concerns

A broad range of other comments were made at this section, often raised by just a small number of respondents each, including that:

- Proactive relationship support may be needed instead of only focusing on relationships when they go wrong;
- Consideration should be given to the over-representation of neurodivergent people that perpetrate sexual abuse as well as those who are victim to it;
- More consideration was needed of what trauma informed practice might mean in the context of delivering these proposals (i.e. how to support healthy relationships for people who may have been subject to abuse and trauma);
- The proposals do not cover ‘professional’ relationships for people with learning disabilities and neurodivergent people and their families, and how these can be improved, such as relationships with health, social work, Allied Health Practitioners, medical profession and care support staff;
- Consideration should be given to meeting the needs of people who are also transgender and non-binary; and
- Consideration should be given to the needs of the aging population, and how relationships can be maintained in older age for people with learning disabilities and neurodivergent people.

At several of the proposals in this section, respondents flagged the need for, or importance of, better and more consistent training for advocacy workers, support staff, and public service staff around the importance of relationships (especially romantic relationships), sexual health and parenthood for people with learning disabilities and neurodivergent people. It was suggested that such training should be integral to local plans:

> “Training of support staff is vital and people with learning disabilities need to be treated fairly, not infantilised.” (On behalf of a LDAN person, and Family/Friend/Carer)

Reflecting a general emergent theme across the consultation, caution was also raised that, while the proposals were sound in principle, some may have the potential to be risky if not fully researched and consulted on with those with lived experience before implementation.

The development of any new resources for RSHP education or training in this regard should also be co-produced with people with lived experience leading the development of content, it was stressed.

Consistent with views throughout the consultation, the cost of implementing the proposals was also stressed, as well as capacity of services to deliver the proposals:

> “All proposals have workforce time and financial implications that would necessitate the allocation of additional funds. Without additionality, disinvestment from existing services would be required. In the current climate resourcing and funding streams are finite with no flex to redirect funds.” (Local Authority)

Section 7: Access to Technology

Introduction

The need to improve digital access was detailed in the consultation document. Digital inclusion and increasing confidence among people with learning disabilities and neurodivergent people were stated as key aims. Much is already being done to address this and the consultation document identified further ways in which digital access could be improved.

Three proposals were presented for discussion:

- **Proposal 1:** Consider how to ensure that training is available to people with learning disabilities in digital skills and online safety.
- **Proposal 2:** Gather clear data on the number of people with learning disabilities and neurodivergent people accessing and using technology.
- **Proposal 3:** Make more support available to directly help people with learning disabilities and neurodivergent people access and use technology.

Main Findings

In total, 356 respondents provided an answer at this section, with over half agreeing with all three of the proposals. Where respondents did not indicate support for all options, Proposal 3 (providing more support to help people access and use technology) elicited the most support, closely followed by Proposal 1 (to provide training on digital skills and online safety). In addition, most of those who supported Proposal 1 did so in combination with Proposal 3 rather than supporting this as a standalone option. Generally, improvements were welcomed specifically in the online/social use of mobile phones and computers.

Proposal 2 was only supported in isolation by a few respondents, with a general caveat provided by many that data be collected, managed and utilised in a safe and respectful way.

A handful of respondents felt that these proposals would benefit people with learning disabilities and neurodivergent people to find, secure and thrive in employment.

Proposal 1: Training for People with Learning Disabilities

Many respondents championed the idea that access to fit-for-purpose technology and possessing sound digital skills are necessary to live a full and inclusive life. However, the need for individuals to be safe, particularly online, was stressed, with people with learning disabilities (and other neurodivergent conditions) being considered vulnerable in this respect:

> “LDAN people can be very vulnerable when using technology and can so easily get themselves into troubling situations of various kinds. They need extra help with the nuances of communication,

> social behaviour, online safety and even what can get inadvertently get them into criminal behaviour." (Member of the Public)

Social media was mentioned as a key issue by several respondents. It was felt that people with learning disabilities and neurodivergent people needed training in not only how to use various platforms, but also how to do so in a considered and safe way. A few noted how social media (and access to technology generally) can help to reduce isolation, but they also highlighted the mental health risks that can come from the use of social media, and so it was suggested that training which addressed this would be beneficial. It was also suggested by a few individuals that such training would be highly relevant since some people with learning disabilities and neurodivergent people typically spend more time online.

Several respondents felt there was a need to provide training for children and young people specifically. In particular, it was argued that schools and education settings (including special educational needs (SEN) schools) had a role to play and needed to do more to educate young people on this topic, and to provide inclusion to ensure that children with learning disabilities, autistic and neurodivergent children are suitably informed and skilled in digital technology.

Others (including individuals and a wide range of organisation types) highlighted a need to offer training to family members, carers, and support staff so that they can provide ongoing support around digital skills and online safety. It was felt to be important for them to be able to help identify any safety concerns and know what to do if issues arise.

While supportive of Proposal 1, some public sector organisations and representative bodies raised questions about the implementation and delivery of the training. These respondents were keen to understand more about the mechanics of how this would be delivered, such as which organisations would be responsible for providing the training and support, how staff would be trained in this issue, how this would be resourced and paid for, and what quality controls would be in place to ensure the training was suitably targeted to those most in need and did not reinforce existing inequalities or perpetuate negative stereotypes?

Consistent with comments at many other sections of the consultation document, some respondents suggested that those with lived experience should be involved in designing and delivering training programmes in order to ensure relevance and effectiveness.

A few respondents also suggested that different approaches and training content may be required for different conditions or abilities. It was stressed that different learning disabilities and neurodivergent conditions would present different abilities, vulnerabilities and needs in this respect, and therefore a 'one size fits all' approach to this training would not be appropriate.

One of the main concerns, however, and the only common reason given among the handful of respondents who explicitly stated they disagreed with Proposal 1, related to the current wording. Many respondents were concerned that training was only being proposed for people with learning disabilities and called for neurodivergent people to be included. Indeed, much of the feedback provided adopted a broader approach and discussed the need for and provision of training for people with learning disabilities and neurodivergent people more generally, rather than focusing on only people with learning disabilities.

Proposal 2: Data on Numbers Accessing and Using Technology

As noted above, while many respondents agreed with Proposal 2, this was typically in combination with one or all other proposals rather than being supported as a standalone option (only one respondent indicated support for only Proposal 2).

One of the main reason respondents gave for supporting Proposal 2 was the perception that gathering data would inform service delivery, future planning, strategic development and to help direct services, which in turn would improve the lived experiences of many. In particular, a few respondents noted that, as well as improving online/digital services, robust data would help to identify areas where digital and online options are not suitable for individuals/groups of individuals, therefore supporting either maintenance of more traditional methods of information sharing and communication, or the development of other more inclusive mechanisms:

> "[Organisation name] strongly agrees that clear data on the number of LDAN people accessing and using technology is needed to inform strategy and interventions. It is acknowledged that one of the most challenging aspects of tackling digital exclusion is the lack of granular data on who is affected." (LDAN Support/Representative Organisation - Neurodivergent Focus)

It was felt that the collection of such data (including intersectional data) could help to identify the scale and areas of need, help to inform and direct training and support (as offered at Proposals 1 and 3), and identify any gaps, issues or awareness raising that need to be addressed. A few respondents also saw this proposal as a logical starting point or supportive element in designing and implementing Proposals 1 and 3.

Although in favour of Proposal 2, some respondents (often organisations) again sought more information on the implementation and purpose of such data collection, for example, about the type of data to be collected, how this would be gathered, and what it would be used for. Others voiced concern over the collection and collation of data, citing the risk of malicious use and potential discriminatory outcomes:

> "…any data collection should be subject to the necessary checks and balances to prevent abuse of such data, particularly if it may identify specific individuals." (Individual with a learning disability)

Proposal 2 also attracted the highest levels of explicit disagreement at this section. Several respondents felt that collecting data would be futile. They could not "see the point" in collecting more information and they questioned how it would be used to deliver improvements or inform strategic development.

Several respondents said they were unclear of the purpose of the data or how it would be used - they noted that no actions or tangible benefits had been set out for this proposal. Others were concerned that such data collection would be unrealistic and unachievable due to the difficulty of gathering the information and the level of undiagnosed individuals - it was felt that any resulting data would be unreliable, and subject to wide variations. A few also felt that both the money and time that would be needed to establish and conduct this data collection and analysis would be better spent elsewhere, potentially providing technology itself.

Proposal 3: Support to Access and Use Technology

Individuals tended to discuss ‘access’ to technology rather than focusing on the ‘support’ element of Proposal 3. A few indicated that they were not sure what was meant by ‘support’ or what form this would take. Some took this to mean financial support to purchase/rent/access technology, hardware, software, or equipment Others discussed support as being an extension of the training at Proposal 1, suggesting that this should not be a one-off, but should evolve into more ongoing support related to digital skills where required. A few also suggested that support could take the form of specialist services to help people with learning disabilities and neurodivergent people to purchase, set up and maintain technology and equipment.

Having access to technology was considered to help tackle isolation and overcome barriers to information and communication. This was seen as important in most areas of life and when interacting with different organisational sectors. Examples given included: moving away from pen and paper learning in schools/education; being able to access supportive software in the workplace; being able to access supportive methods of communication with GPs and health services; using technology within the prison estate to support communication needs (both internally and for external purposes); and to support independent living.

Many respondents called for increased funding, grants, subsidies or discounts for hardware. It was argued that this would facilitate greater digital access, with respondents noting lower incomes or financial restraints as a key barrier to technology:

> “Neurodivergent people face financial inequalities and low employment rates. Therefore, financial support is necessary to purchase technology, such as a laptop, internet package, etc., for those who can't afford it.” (LDAN Support/Representative Organisation - Neurodivergent Focus)

Only a handful of respondents disagreed with Proposal 3. Generally they were concerned about the risks and potential for people with learning disabilities, and neurodivergent people being exploited through online technologies. One individual suggested that some people within scope had difficulties with reading and following instructions and so focusing on digital access was not a priority, while another individual did not understand how Proposal 3 differed from Proposal 1.

Other Comments and Considerations

A number of other considerations were raised by respondents. These are outlined below.

Development of Training, Systems and Technology

In addition to being involved in designing and delivering training, some respondents also emphasised the need for people with learning disabilities and neurodivergent people to be involved in the development of technology and systems themselves to ensure they are appropriate:

> “Technology and systems must be co-produced with people with learning disabilities, autistic and neurodivergent people. Due to their lived experiences of barriers to access and use technology, they will be able to identify issues that decision makers may not and ensure that systems work effectively. We believe that systems should be designed first and foremost for people with learning disabilities, autistic and neurodivergent people, as this will enable the rest of the population to access and use technology.” (Health Service)

Funding

Many respondents raised questions and concerns about funding, both in relation to the development and delivery of training programmes and administrative systems, and for increased distribution of hardware and software. As noted above, many interpreted Proposal 3 as offering financial support to access technology, or advocated for this approach. However, some respondents were concerned that, should strategies to improve digital access become legislation, then where would the funding and resources come from?

Retain Traditional Access Options

Some respondents raised concerns about losing access to face-to-face and other more traditional mechanisms as systems move more to online and digital. It was stressed that there remained a need to retain a range of different ways to access services as digital methods were not always accessible or preferable for everyone, and particularly for some people with learning disabilities and neurodivergent people. Others went further, calling for active prevention of the risk of discrimination for those who cannot or do not want to use new technologies:

> “We consider it is important that those who are not able to access or use digital technology are not indirectly discriminated against through exclusion from job or learning opportunities, or from opportunities to participate in policy making processes. Consideration ought to be given to requiring non-digital access arrangements to complement digital ones for relevant social goods.” (Justice Organisation)

Some respondents cited a need for proactive opt-in processes to ensure that individuals are not moved to digital, online or paperless services without their consent.

There was also a general feeling among these respondents that some individuals are content to live without unlimited access to technology and that they should not be pressured into learning about and adopting it.

Alternative and Augmentative Communication

Some respondents felt that the proposals did not go far enough and that consideration should also be given to the types of assistive technology available to facilitate digital access. Several mentioned the need for provision and ongoing development of Augmentative Communication Technologies (AAC), and there was concern raised that this had been omitted from the proposals for the LDANBill:

> “The proposals do not discuss augmentative communication technologies and are focused on ‘mainstream’ technology access. Just teaching people about accessing IT and providing Easy Read info will never work for all, especially those with multiple and profound LD [learning disabilities]. There is a need to consider how those with more serve LD [learning disabilities] or those with developmental or mental health co-morbidities may benefit from different types of technological support, and how they may be best enabled to access and use these technologies.” (Children's Organisation/Service)

Populations Included Within the Scope

Finally, a few respondents not only stressed the need for training (at Proposal 1) to be extended to autistic people and those with other neurodivergent conditions, but they also noted that autism was not mentioned specifically at Proposals 2 and 3. It was felt that this condition should be included and specified, in keeping with the naming convention of the Bill and to ensure clarity about who is in and out of scope for this support.

Section 8: Employment

Introduction

Given ongoing work and Scottish Government limitations on changing the law in the area of employment, the consultation did not propose any legislative changes. Instead, the consultation set out plans to explore the following in order to promote and encourage more inclusive approaches to employment:

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

Main Findings

In total, 449 respondents provided feedback at this section. Among these, there was a broad split between those who supported the ideas set out, those who supported anything new to enhance more opportunities and equality in the workplace, and those who felt quite strongly that this section of the consultation did not go far enough, i.e. that more robust plans or legislative changes should have been proposed.

There was, however, consensus that employment was a means of giving people with learning disabilities positive destinations and learning environments where they could develop many social and work-based skills and, as a result, gain in confidence, self-esteem, self-worth and fulfilment. It was also seen as essential for some in providing structure and routine. As such, any proposed changes to improve access to and retention in the workplace were welcomed, as were measures to ensure that the experience at work was equitable and rewarding.

There was also consensus around what was described as a lack of purposeful work opportunities, especially for people with learning disabilities, and barriers faced by people with learning disabilities and neurodivergent people. Most notably, it was felt that employers often did not understand their needs and/or did not meet them.

Challenging Recipients of Public Sector Grants

In relation to this suggestion, the dominant view among respondents was that they would like to see more action to encourage employers to take proactive steps towards creating a more diverse and inclusive workplace. The promotion of Fair Work First (FWF) and the new proposals to challenge those not upholding the principles of FWF was welcomed on the basis that it would provide an incentive to employers to improve and enhance their practices:

> “Fair Work First is already in place and ensuring that best practice as part of this includes disability equality training, including specialist training for line managers on individual impairments, should encourage recipients of public sector grants and those on public sector contracts to adequately train staff to help ensure that any public sector services delivers for all and employs a diverse workforce, with appropriate support for workers that require reasonable adjustments.” (Trade Union & Membership Body)

Several respondents, however, noted that the FWF principles could/should be adopted and upheld more widely across public services and embedded within all public sector contracts rather than being restricted only to the recipients of public sector grants and contracts (and felt that this was a wider challenge). One specific suggestion that was put forward was to incentivise employers with recognition for their compliant practices, where appropriate, with one local authority suggesting this could take the form of recognising or requiring some type of certification (for example the Disability Confident scheme) among grant recipients.

A part of this proposal which attracted considerable feedback was the need for more specialist training for line managers. Several respondents felt that that managers (and employers more generally) needed better understanding of the wide range of needs and adaptations required to make workplaces accessible and equitable. A large cohort stressed that disability training should be mandatory rather than simply ‘best practice’ for any/all employers taking on those with support needs. There were also calls for training around the advantages of employing neurodivergent people in particular, who sometimes have unique skills. Some comments were made that there should be more people with learning disabilities and neurodivergence in leadership roles.

Under this theme, a small number of respondents also discussed the need to further address cultural and organisational barriers around workplace environments. In particular, the growth in 'hybrid' working since the Covid-19 pandemic was something which respondents felt made work environments difficult, specifically where 'hot desking' and open plan office spaces were commonplace. It was suggested that workplace design and layout needed to be considered.

Several respondents noted that places of work (and places such as careers centres/job centres) should/could be better designed to accommodate sensory issues (e.g. having no dress code or uniform, ensuring work spaces do not overload the senses of those with certain neurodivergent conditions in terms of light and sound, etc).

There were also several calls for more flexible and remote working (i.e. working from home) practices to be accepted by employers to help accommodate needs. This would help to support individual’s needs, including anxiety and sensory needs that can be related to busyness, lighting, etc. However, it was felt this would also be mutually beneficial to employers in terms of boosting employee productivity and reducing staff turnover. Indeed, broader support from employers was sought to protect against ‘burnout’ and other anxieties for neurodivergent workers particularly.

Neuro-affirming employment practices were viewed as important tools, both to support people who access services, but also to protect the wellbeing and guard against burnout for neurodivergent staff.

Where people offered tentative or no support for this part of the plan, this was mainly because they felt it did not go far enough. Several respondents suggested that there were existing loopholes which allowed grants and contracts to be used where people with learning disabilities and neurodivergent people were employed but not retained and/or were not being properly treated by colleagues/ management. It was felt that simply highlighting this to employers and challenging poor performance was not enough, and there should instead be legal protection offered to people with learning disabilities and neurodivergent people, as well as more robust reporting and accountability measures in place.

A concern was also raised around the complexities of enforcing the suggested approach in such cases where grant recipients were in receipt of multiple streams of funding from different funders and how evidence and information is requested. Others suggested that more detail was needed on best practice around disability and equality training, including how this would be implemented, what standard employers would be required to reach depending on the size of the organisation, and how this would be different from what is already required and recommended under the Equalities Act:

> “Any influence applied to employers/recipients through funding levers must be proportionate as there is a risk that receiving public sector grants becomes unsustainable for employers, particularly smaller and third sector employers in terms of management of the range of conditions placed on them. It is also true that positive action with those who are willing to be at the table is likely to produce more sustainable, positive outcomes.” (Local Authority)

Similarly, it would be difficult to challenge and enforce compliance among private sector employers, it was felt, and so large gaps in coverage would remain.

In a similar vein, others commented that employers (not only those in receipt of grants and contracts) needed to be made more aware of their responsibilities under the Equality Act and punitive action taken against them if they fail, rather than warnings or challenge alone.

Other minority comments include that:

- People with learning disabilities, including people with Down's Syndrome, should be prioritised within both the Government's Fair Start Scotland programme and within the Fair Work First approach;
- Plans made to improve workplaces through Fair Work First were less likely to be implemented across low-paid workplaces (and thus have less impact on those in such roles);
- It was important to avoid too narrow a view of the employability support for people with learning disabilities and neurodivergent people in any training delivered;
- Policy measures to improve access to Fair Work First for neurodivergent people should include intersectional considerations, as experiences and needs may differ greatly for neurodivergent people in relation to their gender, or whether they are Black, Asian or Minority Ethnic (BAME), LGBT, or disabled, for example;
- Recipients of public grants should be forced to get mandatory training as part of the Fair Work First approach; and
- A duty should be put on all public authorities to report progress in removing barriers to employment for people with learning disabilities, including making reasonable adjustments.

An additional or alternative suggestion was to provide written guidance to employers about the range of adjustments that could be explored, including how flexible working can be better utilised to support employees with learning disabilities (noting the potential cost implications attached). This guidance could be provided to help employers identify when their duty to implement reasonable adjustments arises, in order to prevent delays in support.

Training Job Coaches

There was considerable support for training job coaches, to equip them with the necessary knowledge and skills to support people with learning disabilities and neurodivergent people to access and remain in the workplace. Respondents viewed that job coaches helped to give people with learning disabilities and neurodivergent people confidence in the workplace, as well as giving reciprocal confidence to employers.

Respondents supported appropriate training to allow coaches to understand the specific needs associated with different learning disabilities and neurodivergent conditions (recognising that support needs were highly specific for each individual):

> "Enhancing the skills and knowledge of job coaches who support neurodivergent individuals and those with learning disabilities is crucial. Well-trained coaches are better equipped to provide targeted and effective support, increasing the likelihood of successful employment outcomes." (Family/Friend/Carer)

Coaches could also play an important role in providing continuity, it was felt, both in terms of helping individuals to stay in work once appointed, and to navigate any confusion, disorientation or breakdown in communications and relationships when a person's managers and other senior staff moved on.

A recurring theme was the need for any training being done with job coaches to be kept up to date, and designed and delivered with people with lived experience.

While equipping job coaches with learning disabilities, autism and neurodivergence awareness training was viewed as a positive step, respondents also encouraged this to be extended to all staff supporting people to begin, remain or return to work, including, for example, those working in Human Resources.

Suggestions for what the training should/could include were:

- Understanding environmental and workplace challenges and stressors;
- Better understanding and acceptance of some neurodivergent characteristics and behaviours;
- Understanding about possible adjustments that can be implemented;
- Widening appreciation of lack of confidence among people with learning disabilities and neurodivergent people in requesting such adjustments;
- Understanding of specialist skills/abilities linked with some learning disabilities, autism and neurodivergent conditions; and
- Challenging perceptions that reasonable adjustments constitute preferential treatment.

In addition, it was suggested that intersectional training would help ensure that employers are aware of what they can do to support LGBTQIA+ neurodivergent employees, and how to remove barriers to employment or career advancement.

Other reflections included that:

- There had been a perceived decline in the number of job coaches in recent years;
- Opportunities for neurodivergent people to be coaches should be explored (since they may have a deeper understanding of the barriers and struggles faced); and
- The focus of the Bill in this regard should extend beyond just securing employment to include ongoing support for those already in employment.

Several respondents expressed frustration that the Supported Employment Review recommendations 2021 had not been followed through and felt that the Bill was an opportunity for the Scottish Government to create Supported Employment Quality Standards and develop a learning disability and autism employment plan. Some respondents in this cohort suggested that the LDAN Bill should commit to the expansion of existing Supported Employment services or commission additional services in local areas.

There was also a call for the Scottish Government to consider establishing a National Supported Employment Service in partnership with local authorities, to include a Supported Employment Guarantee in the new Bill and to work with relevant partners to pilot the Quality Standard in Support Employment for Scotland.

Reviewing Language Within Employability Data

There was very strong support for this proposal among both individuals and organisations alike. Respondents perceived that reviewing the language would help to both remove existing confusion and bias and facilitate data-driven policy making:

> “Reviewing the language within impairment level data collected by the Scottish Government on employability is essential to ensure consistency with the language used by individuals and professionals. This will help accurately reflect the experiences and challenges faced by neurodivergent individuals and those with learning disabilities in accessing employment services and support. Additionally, disaggregating data on employability services and employment support will provide valuable insights into the effectiveness of existing initiatives and inform future interventions.” (LDAN Support/Representative Organisation - Neurodivergent Focus)

Such a review was also welcomed as a way of ensuring that any outdated or inappropriate language in relation to people with learning disabilities and neurodivergent people was identified and removed from future use in all domains.

Where people were unsure about this proposal, this was mainly because different words can mean different things to different individuals. Further, it was highlighted that not all people with learning disabilities and neurodivergent people use the same language and some forms of communication (e.g. Makaton) are very unique in their own right.

Several other respondents again noted that neurodivergent people were referred to as a homogenous group within such plans and noted that there should be increased visibility of different neurodivergent conditions (including ADHD) within data measurement frameworks. More nuanced disaggregation was seen as key.

As with other areas of the consultation, there were also concerns that data must not be collected for its own sake, but must be used to inform real change in terms of employability and success within the workplace.

Other comments included that there were other important data gaps in relation to people with learning disabilities, autistic people and neurodivergent people in employment that needed to be filled. They argued that the issue was not simply about language.

Suggestions for additional data or disaggregation included that:

- Data is collected in relation to people with learning disabilities and neurodivergent people who have a clinical diagnosis, as well as from people who identify as having these conditions in the absence of a clinical diagnosis (to prevent possible under-reporting/skewing of prevalence);

- Employers should have a duty to disaggregate their data on the disability pay gap to show the pay gap for people with learning disabilities;
- There is a need to strengthen data collection around reasonable adjustments in order to increase understanding and share practice nationally;
- A duty should be put on all public bodies to publish data on the number of people with learning disabilities employed, including information on pay, gender and hours of work; and
- Data must be disaggregated to show the type of work being carried out by women with learning disabilities and neurodivergent women in particular (and to explore relationships between gender and flexible 'low quality' work with its associated barriers/impacts).

Other comments included that 'data' should not be entirely number based but should/could be complemented with lived experience voices and other data from administrative records.

While welcomed, it was again stressed that the LDAN Bill could be used to make requirements in this area mandatory i.e. data reporting to improve accountability. Some also questioned the likely timescale for such a review and how soon it would be implemented.

Reasons for Disagreeing

While there was very limited explicit disagreement with the ideas set out in the consultation with regards to employment, a large number of respondents did suggest that they found this section disappointing in its scope and ambition. In particular, respondents wanted greater exploration of how current laws, including the Equality Act 2010 and the Human Rights Act 1998, can be used to address the deficit in the right to employment for people with learning disabilities.

While there was some sympathy towards restrictions on legislative change, many disagreed that there was little the Scottish Government could do and felt that more progress could be proposed and made in areas where responsibilities were already devolved/through deploying devolved powers:

> "We note the Equality and Employment law restrictions on action in this sphere, but also that the right of disabled people to work on an equal basis with others and the duty to support this through access to training, public sector employment, reasonable accommodation etc. is an important part of the CRPD (Article 27)…In that context, the approaches discussed appear limited in their impact on ensuring inclusive workplaces and we would urge that a more comprehensive approach be adopted, up to the limits of devolved competence." (Academic)

Others (from a broad range of respondent types) simply expressed disappointment that no legislative changes were proposed in the LDAN Bill, which they felt would have been an ideal mechanism through which to address some of the existing challenges in the employment sphere. It was felt that more could be done within current devolved powers to tackle the employment gap and bring more people with learning disabilities and neurodivergent people into the workplace.

A small number of respondents noted that they felt employment issues should be devolved to the Scottish Government and that, if key decisions were retained by the UK Government, this may hinder progress in this area.

As with other areas of the consultation, respondents again stressed that any proposals would fail unless accompanied by corresponding accountability mechanisms. Some also again stressed that, while new legislation may not be required, more needed to be in place to ensure that existing employment and equalities law was adhered to. Overall, there was a large cohort who felt that this was an area of the Bill that could have been more developed and that the proposed changes, as currently drafted, were likely to be ineffective on the scale required.

Other Comments and Considerations

Several respondents gave feedback that was unrelated to the changes presented in the consultation document and instead focused on employment needs of people with learning disabilities and neurodivergent people more generally. These other observations, some of which were contradictory to one another, focused on:

- The current lack of sufficient job opportunities for people with learning disabilities (and less so those with neurodivergent conditions) and the need for more part-time work opportunities, part-time apprenticeships and community and social enterprise positions (to counter the current skew towards volunteering opportunities only);
- To expand volunteering opportunities for people with learning disabilities and neurodivergent people;
- A need for provision of specialist employability programmes that people with learning disabilities and neurodivergent people would be entitled to access and which are designed with them, for them, their needs and the outcomes they desire (with suggestions that there was currently a patchwork of provision of employability programmes across Scotland);
- More support for families/carers of people with learning disabilities and neurodivergent people to secure and maintain work alongside their caring commitments;
- More action to address the disability pay gap and to tackle indirect and unintentional discrimination (especially for those where additional barriers also exist, e.g. race, gender, age); and
- More general support for to help neurodivergent people feel confident in disclosing their conditions to employers, as well as recognition that certain conditions are often more limiting than others.

Another recurring theme was the need to reduce stigma around learning disabilities, autism and neurodivergence, and address inclusive attitudes, tolerance and understanding in society more generally. It was hoped that this would filter through to more inclusive employment policies and practice. Similarly, there was also said to be a need to challenge stereotypes and stigma linked to being ‘out of work’, recognising that, for some with the most profound learning disabilities and other conditions, gaining and maintaining paid employment was not a realistic ambition (but that meaningful societal contributions could still be made).

Although not specifically covered by the consultation suggestions, several respondents noted that interview and recruitment processes were often not user friendly for people with learning disabilities and neurodivergent people. It was felt that this needed an overhaul (i.e. to make interview methods more flexible, application forms easier to understand, more transparent practices, offering alternative processes, etc.) if employment opportunities were to be maximised.

There were also calls for more training for HR departments and interview panels to make them more aware of the needs of neurodivergent applicants. Similarly, respondents wanted better training around learning disabilities, autism and neurodivergence for Job Centre staff and the Department of Work and Pensions (DWP) staff to prevent bias/discrimination during the job seeking process.

A small number of comments were also made in relation to ‘when things go wrong’ and the need for more support for people with learning disabilities and neurodivergent people around such things as work tribunals, disciplinary hearings, etc. This included the provision of independent advocacy, as well as clear and accessible routes for redress.

Among those representing the interests of children and young people there were calls for any work to increase access to employment to link more clearly with education proposals. The LDAN Bill could, for example, consider employment opportunities throughout education, including creating opportunities for children and young people with learning disabilities and neurodivergent children and young people to access appropriate and supported work experience, support and guidance. A suggestion was also made that the Bill should require the establishment of high quality employability activity in schools for pupils with learning disabilities and neurodivergent pupils, and a Senior Phase School Transition Programmes for Young Disabled People. Further, it was suggested that the Government may wish to consider the development of independent brokerage services for young people in each local authority area, i.e. an advice and information service that young people and their parents and carers can access for employment needs.

While there was support for the Scottish Government’s commitment to at least halve the disability employment gap by 2038, some respondents expressed disappointment at how far distant this deadline had been set.

Finally, as with many other areas of the consultation, respondents again encouraged that the effectiveness of these interventions be monitored, and adapted in response to evidence.

Section 9: Social Security

Introduction

The consultation set out three proposals (linked to other key sections of the document) designed to bring more focus and understanding to the needs of people with learning disabilities and neurodivergent people specifically with regards to social security. These proposals were:

- **Proposal 1: National and Local Strategies** - to consider requiring Social Security Scotland to report on, and evaluate, how its inclusive communication strategies have taken into consideration the needs of people with learning disabilities and neurodivergent people.
- **Proposal 2: Mandatory Training for Social Security Staff** - to explore whether there is a need for training on learning disabilities and neurodivergence to be a statutory requirement for some Social Security Scotland staff.
- **Proposal 3: Data collection** - to disaggregate data reporting from Social Security Scotland to better understand neurodivergent and learning disabilities groups and their needs, including how many people are accessing social security benefits.

Main Findings

Overall, 365 respondents provided feedback at this section. Among those who responded, most expressed support for one or more of the proposals (and many supported a combination of all three). The main reasons given were similar to those given in response to the overarching sections on national and local strategies, mandatory training and data collection, which appeared elsewhere in the consultation document.

Proposal 1: National and Local Communication Strategies

There was consensus that much needed to change with existing processes for Social Security claimants to make the system easier to navigate and this proposal was welcomed as a means of helping to improve the service user experience. Despite recent changes, many perceived that the current system remained complex to navigate and, therefore, welcomed any moves to make information and processes more accessible (discussed more below):

> “Currently application forms and assessments do not meet the needs of autistic and other ND [neurodivergent] people, as well as people with a learning disability. The questions do not take into account the lack of relevance to autistic (other ND) experience. The process does not accept that many will not be in contact with services that would allow them to provide evidence as autism and other ND is not treatable...” (LDAN Support/Representative Organisation - Autism)

Any action taken to improve communications was welcomed, and many respondents reiterated their earlier support for a wide range of accessible communications to be made available routinely. Similarly, Social Security Scotland was urged to ensure that inclusive communication strategies encompassed a broad spectrum of communication needs, ensuring that all individuals, regardless of their neurodivergence or learning disability status, could access information and services effectively.

The main perceived benefits of this proposal were an increase in accessibility, equality and accountability:

> “A national requirement to report on and evaluate inclusive communication strategies would provide the data needed to ensure that individuals, regardless of their location, are treated with parity and equity, receiving information in a way that is fully accessible.” (Advocacy Service)

It was also felt that improved communications would have an impact on reducing such things as missed appointments, inappropriate and inaccurate claims and payments, the need for/use of sanctions, etc. which currently occurred due to communication barriers.

It was felt that any obligation on DWP and Social Security Scotland to ensure that their communication strategies have considered the needs of people with learning disabilities and neurodivergent people should be accompanied by requirements to highlight where needs are not being met, and to act upon any gaps/deficiencies. In addition, it was considered important to include a requirement to ensure that people’s needs are being met within reasonable timeframes.

Respondents who supported this proposal again argued that strategies must be inclusive of all disabilities with an understanding of intersectionality. Respondents also again stressed that strategies must allow for a wide range of communication preferences to be met, including, for example, choice of face-to-face, in person or remote (online or telephone) assessments for Social Security benefits. The need for timely communications was stressed.

Independent Advocacy

Several respondents commented that specific provisions for advocacy in the context of social security communications would be welcomed i.e. someone to advocate for the resources that individuals are entitled to. The provision of advocates to help people navigate what were perceived as often complex processes and systems was seen as potentially empowering people with learning disabilities and neurodivergent people to voice their needs and concerns to ensure they are heard (i.e. supported decision-making).

Access to independent advocacy was seen as especially important for individuals when dealing with benefits provision or complaints. Advocates were also considered to be well-placed to identify systemic gaps or failures in the delivery of

Social Security Scotland’s minimum core obligations (such as inclusive communication).

In relation to the new universal provision set out under the Social Security (Scotland) Act 2018, there was a specific call for data in relation to the take-up of independent advocacy within the social security system in Scotland to be publicly reported through the new accountability mechanism proposed elsewhere in the Bill.

Proposal 2: Mandatory Training

Echoing earlier findings in the consultation, there was strong support for all public service staff, including Social Security staff, to receive mandatory training.

Support was again underpinned by views that the scope and reach of training should be as broad as possible to benefit the wide range of individuals covered by the LDAN Bill. Views were expressed that training must cover a wide range of specific conditions due to the lack of understanding and stigma that currently exists for some. There was a specific emphasis in this section on training for Social Security staff to include a focus on autism (as a hidden disability) and not to focus on neurodivergence more generally, as well as to cover training in relation to multiple, complex and fluctuating needs and the impact of co-morbidities.

Reflecting views on mandatory training more generally, there were again strong calls for lived experience input into the development and delivery of training for Social Security staff, as well as potentially input from the third sector:

> “…training initiatives must be driven by lived experience and co-produced in collaboration with individuals from these communities. Training programmes should not only be led by individuals with lived experience but also provide opportunities for paid involvement, recognising the value of their expertise and contributions.” (LDAN Support/Representative Organisation - Neurodivergent Focus)

Respondents also encouraged training for **all** staff who may interact with communities of interest (rather than being restricted to just ‘some’). There were also calls for Social Security Scotland to employ more people with learning disabilities and neurodivergent people /have a more diverse workforce who better understood the needs of applicants/claimants.

There was less evidence in responses around the need for training to be a statutory (rather than voluntary) requirement, although a small number did emphasise that this would be necessary to achieve the greatest impact.

Several respondents cited experiences of negative interactions with Social Security Scotland staff, especially for those with hidden disabilities or undiagnosed conditions, and felt that better training of staff would help to ensure that all people were treated with dignity and respect in the future. Current misunderstanding and stigma were prevalent, it was felt, for many minority and undiagnosed conditions.

Proposal 3: Data Collection

Further detail/disaggregation of data reporting was welcomed primarily on the basis that it would help to facilitate service delivery improvements, workforce planning and financial planning:

> "Data on extent/type/variations of neurodivergent conditions would be especially helpful to provide a continuous learning loop so that services provided exactly match demand." (Neurodivergent Individual)

It was also felt that data would be helpful in highlighting the numbers of individuals who currently claim for support among those who are eligible (and the number who do not). This would help to monitor and address any awareness issues.

The proposals to disaggregate data would also help in making some minority groups more visible in the statistics, it was felt, which would help with societal awareness more generally. Similarly, a minority of respondents noted that there was a need to further disaggregate the data to provide insights into such things as the gendered experience of the Social Security system and unique issues faced by those living with other protected characteristics.

The main caveats to support were that this proposal, if taken forward, must be done in a way that maximises privacy, choice and anonymity for claimants.

Disagreement with the Proposals

Very few people said that they disagreed with any of the proposals linked to social security and most simply offered caveats to support or raised what they believed to be weaknesses with the proposals.

Some felt that the proposals, as currently worded, could be strengthened. For example, rather that exploring or considering the ideas set out (as was the current wording in the consultation document), the LDAN Bill should legislatively prescribe or make it a duty for Social Security Scotland to deliver on these plans, i.e. they should be made to report on, and evaluate, such things as its inclusive communication strategies, and for there to be a requirement for mandatory training.

The main negative or critical feedback in relation to Social Security Scotland reporting on and evaluating its inclusive **communication strategies** were that:

- The proposals would only be meaningful if accompanied by a clear plan for enforcement/monitoring;
- That any changes in monitoring/reporting requirements should avoid increasing administration burdens for Social Security Scotland (which may in turn have adverse impacts on such things as claims processing times, etc); and
- Lack of clarity (or consensus) around the need for this to be included as a legislative requirement.

The main concerns in relation to **mandatory training** were:

- That the proposals could be specific about who would be trained (with a wide audience being preferred);
- That there must be clarity around which roles training would apply to and what degree of training was required (with a proportionate requirement for training linked to job roles); and
- That time and money invested in training might be better spent on such things as improving access to diagnosis.

The main concerns in relation to **data collection** were:

- Lack of clarity over how data could be used and stored;
- Issues linked to permissions to hold and share data;
- That this would be time and resource intensive (and money may be better spent on other things);
- Uncertainty about how disaggregation would be achieved, for example, for individuals with co-morbidities and dual diagnoses;
- Doubts regarding the accuracy of any disaggregation given the lack of clarity or definition around neurodivergence; and
- Perceptions that individual groups may be conflated, and that the disaggregation would not be sufficiently sophisticated to identify and understand individual (especially minority) populations.

More general comments included that these proposals, singly or combined, would be expensive to implement and may have no material positive impact on individuals' day-to-day lives.

Other Comments and Considerations

There were a number of 'other' comments made in relation to social security. Most of these related to perceptions that the current system was not user friendly for either people with learning disabilities and neurodivergent people (the focus instead being on physical disabilities). More was also needed to support those without official diagnoses, it was felt.

Many commented that the current system (including claiming, adjusting or making appeals in relation to benefits) was too stressful for individuals and their families and was fraught with barriers, mainly linked to inaccessibility of communications (including face to face, online, written and telephone communication). Comments were made that the system was not "compassionate" and that staff at Social Security Scotland sometimes lacked empathy[4].

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[4] In contrast, a small number of respondents gave positive feedback in relation to the new Social Security Scotland compared to previous experiences of the Department for Work and Pensions. This included comments that application processes were easier, staff were friendlier and

Other specific proposals (mentioned by just one or two respondents each), which may be welcomed in the social security sector included:

- Introduction of the Minimum Income Guarantee for disabled people (as currently being explored by Social Security Scotland);
- Reviewing the eligibility criteria for Adult Disability Payment (ADP) to take greater account of neurodivergent conditions and the barriers people with learning disabilities and neurodivergent people face in their daily lives. Linked to this, there needed to be less emphasis on the need for medical evidence, such as diagnoses and medical treatment, and more recognition of informal social support;
- That Social Security Scotland could adopt more inclusive, person centred and flexible responses to service users; and
- That eligibility criteria for certain benefits should be made less “strict”.

Several also commented on perceived problems linked to the process of applications/eligibility criteria for various benefits, the main comments focussing on:

- The complex/onerous application process;
- Assessments being stressful and often inappropriate for people with learning disabilities and for some neurodivergent people. The annual review of lifelong conditions was also seen as outdated, unnecessary and unhelpful;
- Assessment waiting times being too long (which may be compounded for people without formal diagnoses);
- Poor communication including a reliance on digital/telephone communication and over-use of abbreviations and acronyms;
- More sensitivity and flexibility being needed in the system to accommodate fluctuating levels of need over time (especially for children and young people); and
- That the process of transferring benefits from the DWP to Social Security Scotland felt ponderous and slow with many saying that it continues to feel complex and onerous.

There was also a call for the Scottish Government to go beyond the planned independent review of Adult Disability Payments and undertake an independent review of disability and carer payments more widely.

Both here and elsewhere in the consultation, a small number of respondents also called for better systems to be in place to help support people with a learning disability into the workplace.

A number of respondents focused specifically on the challenges faced by family and carers who often apply for assistance on behalf of their loved ones and felt that additional strategies and support should be in place for them. This included the

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applications appeared to be processed more quickly.

suggestion of Digital Passports being used as a tool to help carers applying for Adult or Child Disability Payment.

A small number of respondents also commented on wider social and systemic issues linked to being in receipt of social security, the emphasis being that while access to social security is a human right, ‘being on benefits’ exposed some recipients to feelings of stigma and discrimination. Raising awareness of entitlements to benefits and reducing stigma were seen as wider public education task to be pursued.

Other comments from a small minority hinted that the LDAN Bill's true potential would be limited without full devolution of social security powers to Scotland.

Section 10: Justice

Introduction

The consultation document set out proposals which were relevant to both the criminal and civil justice systems, as follows

- **Proposal 1: Strategies and a Co-ordinated Approach** - to bring together a single national strategy that deals with neurodivergence and learning disabilities in the civil and criminal justice systems.
- **Proposal 2: Data and the Identification** of people with learning disabilities and neurodivergent people in the justice system.
- **Proposal 3: Inclusive Communication** - to support all those in contact with the criminal and civil justice systems to be able to fully understand the information they are being given.
- **Proposal 4: Mandatory Training** - extend the requirement for mandatory training to police, prison, COPFS and relevant courts and tribunals staff.
- **Proposal 5: Advocacy** - develop a consistent approach to advocacy which includes people with learning disabilities and neurodivergent people (to be informed by ongoing work in this area). Also include information in mandatory training about the role and availability of advocacy in the civil and criminal justice systems as well as information about the Appropriate Adults scheme.
- **Proposal 6: Diversion from Prosecution (DfP)** - Better identification within the justice system and training for staff to understand how to do this.

The proposals focused on and sought feedback related to the adult justice system, i.e. on those aged 18 and over. However, the consultation document noted that separate work had and was being done in the child justice sector and highlighted progress in this respect.

Main Findings

Overall, 343 respondents provided feedback in relation to the proposals on justice, with around two thirds of these expressing support for all proposals and/or a preference for them to be implemented together. It was felt that all proposals were needed, and together they would provide the fairest and most accessible system:

> “All of these proposals belong together and should be applied together, if the aim is to ensure that neurodivergent people are treated appropriately within the justice system.” (Neurodivergent Individual)

In addition to covering the police, the Crown Office and Procurator Fiscal Service (COPFS), the Scottish Court and Tribunals Service (SCTS), and the Scottish Prison Service (SPS), a range of other organisations/professionals were identified as needing to be included within the remit of the proposals (particularly those related to accessible communication and training). This included:

- The judiciary;
- Lawyers/solicitors;
- Justice social work teams;
- Community justice providers/professionals;
- Commissioned services including GeoAmey and third sector providers/ partners;
- Police (and any other) call handlers;
- NHS and other health and social care related staff involved within the justice system;
- Forensic medical service clinicians;
- Scottish Legal Aid Board (SLAB);
- Victim Support Service; and
- Victim Information and Advice (VIA).

All individual proposals were also reasonably well supported, either on their own, or more commonly in combination. All proposals elicited more support than disagreement.

Proposal 1: Strategies and Co-ordinated Approach

Those who provided feedback on the creation of a justice strategy to provide a co-ordinated approach were largely supportive. On the whole, respondents felt that a national strategy would provide an overarching framework, ensuring a joined up system with equal/consistent provision across the country. It was also felt that this would support the implementation of all the other proposals and ensure that people’s needs were taken into account:

> “We support this approach, as the creation of a single national strategy that would deal with neurodivergence and learning disabilities in the civil and criminal justice systems, could enable co-ordinated and informed interventions. This approach will stop the fragmented and complex interactions between different parts of the justice system which can reduce heightened levels of risk for this cohort and enable them to receive more co-ordinated communication, support, and fairer access to the civil and justice service provisions.” (Local Authority)

A few also noted that such a strategy would help to reinforce, emphasise and provide a structure to implementing and meeting existing requirements.

Similar caveats and concerns to those outlined at Part 2 regarding statutory strategies were raised, however. In particular, it was said that any justice strategy should be informed by or co-designed with people with lived experience, and that it will be important to learn lessons in relation to the ‘implementation gap’ experienced by other legislation, policies and strategies, and that mechanisms must be implemented to ensure that any strategies would be delivered on the ground.

Proposal 2: Data and Identification

Those who noted support for Proposal 2 tended to discuss the need for identification rather than data. Respondents felt it was important to identify people with learning disabilities and neurodivergent people as this would then inform all ongoing contact/interactions, consideration of the situation, and treatment of the individual (including the ability to avoid situations escalating and incurring additional charges) - i.e. this would act as a trigger for all of the other justice based proposals. It was noted that needs would continue to be unmet if people could not/were not identified. It was highlighted that such identification would ensure that appropriate and accessible communication methods could be provided, that adjustments could be made and appropriate support offered/provided, and that relevant information would be considered by all parties considering the case so that appropriate actions and disposals could be explored:

> "An effective common screening tool utilised across justice agencies would ensure continuity and a streamlined approach. A screening tool would further ensure that front line justice staff are able to seek to identify any communication support needs of people with neurodivergence and learning disabilities at the soonest opportunity, to ensure the correct communication supports are put in place to support that person's understanding to ensure they are aware of their rights and potential outcomes." (Advocacy Service)

A few respondents highlighted that, in many cases families and carers can have an important role to play in ensuring justice organisations and professionals are aware of a person's learning disability or neurodivergence (diagnosed or not) and how this might manifest in their behaviours, understanding, communication needs, masking behaviours, etc. It was stressed that families must be listened to in such circumstances.

It was also suggested that information about an individual's needs and/or learning disability or neurodivergent status should be shared in order to provide a joined up system - although justice organisations noted that changes may be required to current IT systems to facilitate such data sharing.

However, there were caveats to the support for this proposal. A few noted that, while it was important for the police to identify communication issues, learning disabilities and neurodivergence at the earliest opportunity, and for this information to be shared via the Standard Prosecution Reports (SPR), this should not be seen as the only time that these issues could/should be identified. It was highlighted that people with learning disabilities, autistic people and neurodivergent people may not disclose their condition or needs at the first point of contact. Therefore, it was felt that identification should be an ongoing process with ongoing reviews built into the system, and for each agency involved to have a responsibility to identify any potential issues.

A few stressed that any assessments should be voluntary with individuals not subject to these without their consent. Others stressed that any assessment should be about identifying needs rather than seeking to diagnose a person. Indeed, the problem with securing a diagnosis, either once in the justice system or more generally was again highlighted as an issue which would limit the impact of the Bill and any justice based strategy if it required a diagnosis for someone to access support within the justice system.

In addition, several respondents (both individuals and organisations) were concerned about how realistic it would be to create an effective common screening tool due to the considerable number and differences of conditions and the likely level of knowledge and training of the staff administering and interpreting it. It was highlighted that a common screening tool did not currently exist, and that the range of existing screening tools tended to be over-inclusive (resulting in people being wrongly identified as having learning disabilities or neurodivergence). It was stressed that full assessments needed to be conducted to accurately identify and diagnose learning disabilities, autism and neurodivergent conditions, but the current lack of resources and lengthy waiting lists for diagnosis were again highlighted. Others, however, indicated that they were developing screening tools or would welcome involvement in the development of such a tool:

> “I don't agree with 'common screening tool'. There isn't really such a thing that could be used to identify 'neurodivergent' people as a whole, and I don't see how it would work. Simple screening tools are also unreliable, especially when assessed by lay people.” (Neurodivergent Individual)

A few were also concerned about the practicalities and how realistic it would be to try and identify individuals’ needs, particularly those of accused persons at the first point of contact when the person may not be cooperating with the police. Risks of passing on inaccurate information throughout the system were also flagged.

Respondents who did discuss data tended to focus on the need for more research, data and statistics around the prevalence and over-representation of people with learning disabilities and neurodivergent people in the criminal justice system (both as accused persons and as victims). It was also stressed that accurate data needed to be recorded in order to identify levels of unmet need within the system, while others were keen to see intersectional data collected, in order to support the development of targeted and specialist interventions, support and services.

Justice organisations and others involved in the justice system stressed that the need to identify individuals would necessitate significant and ongoing staff training. In addition, the collection and retention of additional data may require updates to IT systems, additional resources, incur additional costs, and would need to be compliant with Data Protection and GDPR laws.

Proposal 3: Inclusive Communication

The provision of inclusive communication was considered vital throughout the justice system, for those accused of crimes and for victims and witnesses, as well as the families and carers of all those involved. It was stressed that inclusive communication needed to extend beyond Easy Read versions of written information, and should also include support to understand verbal information (including via an advocate, social worker, or other support worker), and cover a wide range of different formats, including for those who were non-verbal, those whose first language was not English, those who needed audio or video communication, and those who used alternative languages such as BSL or Makaton, to offer face-to-face, telephone and video meetings or interviews, etc. Accessible communication was said to be necessary to ensure the person understands their rights and can ensure these are upheld, can understand and participate in the process, can be understood and heard within the process, that they understand any court orders or bail conditions, when they need to appear in court appearances, and that they understand any offers of Diversion from Prosecution. It was noted that serious consequences were often experienced when people in the justice system do not understand and cannot access information:

> “We have learned from experience that neurodivergent people and people with learning disabilities are often unfairly disadvantaged because written information is not accessible to them. The inaccessibility of letters means people miss out on opportunities for Diversion from Prosecution (DfP). The inaccessibility of bail conditions and licence conditions, mean people are at increased risk of breaching their Orders and ending up in custody, either on remand or otherwise. All of these outcomes mean an increased cost in terms of court time, prison time, and legal aid.” (LDAN Support/Representative Organisation - Mixed Conditions)

Consistent with comments elsewhere in the consultation, one of the main caveats to support and a key reason among those who disagreed with this proposal, was that some individuals may not identify themselves as having additional communication needs or ask for alternative communication formats or styles. Rather, it was argued that accessible communication should be the norm rather than only being provided on request.

A few respondents also stressed that accessibility needed to go beyond simply communicating information. It was noted that systems needed to be more accessible, particularly to support people with learning disabilities and neurodivergent people to report crimes.

Proposal 4: Training

Training was perhaps seen as the single most important proposal at this section. It was considered vital for justice professionals and staff, and was seen as integral to both identification and communication. Several noted the potential for people with learning disabilities and neurodivergent people to nod or agree due to being overwhelmed, stressed and not understanding the information or questions put to them. Similarly, respondents highlighted that some autistic and neurodivergent people will avoid eye contact or become non-verbal which can lead to officials thinking they are lying, while others can be triggered or experience sensory or emotional overload resulting in them reacting in unexpected ways (sometimes with aggressive outbursts which can then result in additional harm and charges). As such, it was considered important for professionals to be trained to understand and identify these risks, and to deal with them appropriately.

While mandatory training throughout the justice system was welcomed, many respondents specifically highlighted the need for training for the police and call handlers. Several described negative encounters they had had with the police, covering both being an accused person and as victims and witnesses:

> “Definitely better training for police is needed. I got stopped during lockdown for accidentally [speeding] and they managed to make the process as stressful as possible, even though I told them I was autistic… They just looked at me blankly when I said I was autistic, they didn't even acknowledge what I had just said and just ignored it and carried on. There are lots of things they could have done at that point to make it less traumatic for me, but I don't think they understood anything about autism or what they could do differently for me so they just decided not to engage with what I had said.” (Neurodivergent Individual)

Other groups identified as requiring suitable training were jurors and Appropriate Adults.

There was a suggestion that, in addition to training for all staff, it might be sensible to establish ‘champions’ or ‘specialist’ staff to ensure there was always a designated trained and experienced person available, rather than relying on all staff being able to recall their training.

Several respondents were keen that training should be designed/co-designed and delivered by those with lived experience and DPOs. Several also called for training to be both intersectional and trauma informed.

Similar to the argument above that identification should focus on needs rather than diagnosis, respondents also stressed that training should adopt a similar approach. Staff must be taught about hidden disabilities and needs, as well as developing an understanding that not all individuals will have a formal diagnosis or know what specific condition they have.

Proposal 5: Advocacy

Several respondents highlighted their support for the use of advocacy in the justice system, with most discussing the supportive nature of advocacy generally or for this to be provided to all people with learning disabilities and neurodivergent people. It was noted that advocacy can support communication needs and ensures that the person’s voice is heard within the process, with independent advocacy noted to be truly impartial and not influenced by other requirements or parties:

> “Agree with all the proposals but of them all proposal 5 is most important. Unless we can be sure that understanding is taking place, there can be no equality of treatment. Easy read versions of complicated text cannot realistically ensure this. Access to advocacy

> should be essential for those with a learning disability or autism."
> (On behalf of a LDAN person, and Family/Friend/Carer)

It was also stressed that equal provision and access to independent advocacy was needed across the country, and should not vary by area, sheriffdom or court. However, a few respondents highlighted the currently "patchy" provision and the need to improve this going forward.

Some respondents interpreted this proposal as being about training and awareness raising of advocacy services (and the use of Appropriate Adults), rather than about their actual provision or services. This was again largely welcomed, with a few respondents noting that advocacy was not always well understood within the justice sector. It was suggested that mandatory training should seek to include information on this.

It was suggested that independent advocacy should be covered within any mandatory staff training in order to raise awareness and understanding among justice professionals, and that this should be co-designed with independent advocacy organisations and advocacy partners. Similarly, it was suggested that advocates should also receive specialist training (and have access to specialist resources and guidance) in learning disabilities, autism and neurodivergence, to ensure they can suitably and robustly support such individuals through the justice processes. It was also suggested that accessible information about independent advocacy and Appropriate Adults should be made available to increase awareness among individuals themselves.

Only two respondents discussed the proposal to develop a system wide advocacy approach for all individuals (with or without learning disabilities and neurodivergence) which will be informed by wider work. One was keen to see the outcome of the work while the other did not understand why it was necessary to wait.

Feedback about Appropriate Adults was more mixed. Some respondents stressed the need for accused persons to have an Appropriate Adult present, for services to be aware of the need for this and to be proactive in provision. Others, however, were less supportive of the use of Appropriate Adults as they felt this was insufficient and ineffective.

Proposal 6: Diversion from Prosecution (DfP)

Slightly more mixed responses were provided in relation to Diversion from Prosecution (DfP). Some respondents were generally supportive of the consideration and use of DfP for accused people with learning disabilities and neurodivergent people. It was felt this could be used in appropriate circumstances and would be more successful in reducing reoffending rates and addressing offending behaviour as it could provide better support and education:

> "Diversion from prosecution is well placed to contribute to positive outcomes for people at risk of offending, their families/carers and communities. It is also cost effective. The support offered by justice

> social work and their partners is often creative and bespoke, reflecting the unique needs of the person. This support also offers important opportunities to connect people to local sources of support in order to support desistance and reduce the likelihood of further offending." (Other National Public Body/National Agency)

It was also felt that DfP may be a more suitable option for people with learning disabilities and neurodivergent people where their condition had been a factor in their offending.

It was suggested, however, that the typical three months that diversion programmes run for may need to be extended for people with learning disabilities and neurodivergent people, and that greater flexibility and tailored support may need to be provided. Caution was also required to ensure that individuals were suitable for diversion programmes, and could be adequately supported, accommodated and managed within the community. It was stressed that not all people with learning disabilities or neurodivergent people would be suitable for diversion into community programmes, and that where they are, detailed understanding of a person's needs would be required, both to manage risks and to provide the best rehabilitative support.

A few respondents interpreted this proposal as being about training for COPFS and other justice staff to better understand learning disabilities, autism and neurodivergence in order to better inform their decision making and consideration of DfP. Again, this was mostly supported. It was highlighted that both well trained justice professionals and accessible communication were required to ensure that individuals were offered DfP where appropriate and were able to understand and accept such offers. It was suggested that the current information sent to accused persons was inaccessible for those with learning disabilities meaning they cannot take the offer of DfP unless they have support to understand the letter and process.

Some individuals were, however, cautious of the proposals around DfP. A few interpreted this as an intent to divert more, most or all cases with an accused who had learning disabilities or neurodivergence (regardless of the offence or circumstances), which they felt was inappropriate, could be considered as leniency, and would not be considered as delivering justice:

> "I think it would need to take in account all circumstances, not just that the person is neurodivergent or has learning difficulties. Whilst appreciating that some may have more limited capacity to understand the crime committed, this should not be a 'catch all' for DfP - victims of crime already feel the CJS [the criminal justice system] is weighed in favour of the perpetrator of the crime and this could be seen as just another 'excuse' for someone to be excluded due to their neurodiversity or learning difficulties." (Member of the Public)

It was also felt that any policy which increased the potential for diversion for people with learning disabilities and neurodivergent people could be exploited and abused by neurotypical persons, particularly if a formal diagnosis was not required.

A few were also concerned that DfP could be seen as removing responsibility from the accused person, and/or creating a two tier system.

A few individuals indicated that they did not understand the proposals in relation to DfP and sought greater clarity about what this is, when it might be used, etc.

Use of the Mental Health Act in Justice

While the Mental Health Act's use within the justice sector to determine how a person with learning disabilities or autistic person will be treated is not the same as Diversion from Prosecution, several respondents discussed it in relation to diversion, while others considered this as a separate but important issue.

Almost all respondents who discussed this issue raised concerns in relation to diverting accused persons away from court and into hospital settings using provisions in the Mental Health Act. It was noted that they can be found guilty (or are treated as such) without a trial or the evidence being examined, can lose their legal capacity, are detained without a fair hearing in court, and can often be detained in a hospital setting for longer than the sentence they would have received from a conviction in court, and sometimes indefinitely. It was argued that this was unjust and inappropriate, and needed to be changed:

> "Inclusion under the Mental Health Act means that people with a learning disability can be denied the right to a fair trial. The Court can decide that we cannot follow the court proceedings or instruct a solicitor to defend us in court. Instead, there is a 'finding of fact' which simply finds us guilty of the offence without considering evidence. We can then be locked away, detained or restricted in the mental health system for an unlimited time, sometimes for the rest of our lives. How can it be fair that we are detained for longer than someone who is accused of the same crime who does not have a learning disability?" (LDAN Support/Representative Organisation - Learning Disabilities)

Other Comments and Considerations

It was felt that more preventative work was needed to stop people coming into contact with the criminal justice system in the first place. This included earlier diagnosis and post-diagnostic support and more effective early intervention strategies and support. It was also suggested that ongoing support was needed at the end of any sentence to avoid reoffending:

> "Many of the people in prisons are reported neurodivergent. We need to do more before criminality happens." (Neurodivergent Individual and Family/Friend/Carer)

Several respondents with learning disabilities and/or neurodivergent respondents also reported a reluctance or nervousness about reporting incidents to the police. This was due to the risk they would not be believed, because the process was perceived as not being accessible or as too difficult and stressful, and/or due to the lack of support and understanding from justice professionals.

In addition, a wide range of other issues or areas for further consideration were identified by respondents, although each was typically noted by relatively small numbers. Those highlighted by at least a few respondents each included:

- All approaches should be trauma informed throughout;
- Reasonable adjustments need to be made consistently for people with learning disabilities and neurodivergent people throughout the justice system, and costs for these need to be included within legal aid;
- That speech and language therapists and occupational therapists could support the development of any guidance in relation to communications, adjustments to processes, environments and sensory requirements and training;
- Greater consideration of, and measures need to be included for people with learning disabilities and neurodivergent people in specific areas, including civil and family law; youth justice; victims and witnesses; those who work in the justice system; those with PMLD and their families; and families generally;
- Consider the creation and use of specialist courts;
- Consider the introduction or use of a range of different professionals, including intermediaries in court; access to a learning disability nurse at first point of contact; and providing a criminal justice social worker or support worker to provide information and support throughout the justice process; and
- Conduct a review of historical convictions where neurodivergence or learning disability has been a factor in order to identify and overturn miscarriages of justice.

Finally, a few respondents felt that the proposals lacked detail and sought greater information about how each would work in practice, how and who would implement them, how they would be funded and resourced, etc. Others indicated that they did not have enough/any knowledge or experience in this area to comment.

Section 11: Restraint and Seclusion

Introduction

The consultation document indicated that the Scottish Government was considering legislative options to tackle issues related to the use of restraint and seclusion, particularly in relation to children and young people. However, it also stated that the Government “do not think that the LDAN Bill would be the right place to do this because it would need to apply to all children and young people, and not just neurodivergent children and young people and children and young people with learning disabilities.”

Rather, the consultation document set out Scottish Government intentions to take action which would reduce coercion and restrictive practices and prevent the misuse of restraint, seclusion or other restrictive practices. This included:

- For children: the development of statutory guidance in the area, as well as commitments to raise awareness of the new guidance amongst stakeholders, and to support its implementation and evaluation; and
- For adults: the scoping of a programme of work to further reduce the use of coercion and restrictive practices, including seclusion and restraint and monitoring progress with this work over time.

Main Findings

This question attracted less feedback compared to earlier sections of the consultation and many of those who responded also provided less detailed feedback compared to other sections.

Respondents were asked if they agreed with the approach set out.

Answer	Number	Percent	Valid Percent
Yes	202	23%	64%
No	116	13%	36%
Not Answered	559	64%	-
Total	877	(n=877)	(n=318)

Just under two thirds (64%, n=202) of the respondents that answered the closed question indicated they supported the approach set out in the consultation document, compared to just over one third (36%, n=116) who did not. Organisations, and in particular public sector organisations were, however, more likely to agree with the approach compared to individuals or the aggregate level results (see Appendix B). While 61% (n=148) of all individuals agreed, 71% (n=54) of all organisations, and 88% (n=29) of public sector organisations agreed. The small sample size of public sector organisations (n=33) however, needs to be borne in mind when interpreting the results.

Overall, 303 respondents also provided qualitative comments at this section. However, these comments contained considerable overlap between people who ‘agreed’ and those who ‘disagreed’ with the proposals, suggesting perhaps some confusion with regards to what was being asked. Instead of analysing responses by agreement/disagreement, therefore, a more thematic approach was taken which considered all qualitative data separately from the closed question feedback.

Support for a Separate Bill

A very large proportion of respondents (both individuals and organisations) agreed that this was a complex area of work which they felt was deserving of its own legislation and that it should not be subsumed within the LDAN Bill. They noted that control and restraint were issues that affected a diverse mix of populations and was not something confined to people with learning disabilities and neurodivergent people. Indeed, some specifically noted that it would be inappropriate to silo this issue, as to do so would minimise its importance/relevance to alternative populations:

> “Whilst we are aware that this group are disproportionately impacted by the use of restraint and seclusion, and this is an area that would benefit from more clarity in law, it does not feel appropriate to single out any one demographic.” (Education Service)

Reserving this issue for separate attention was also seen as necessary to ensure that it protected those without diagnoses and others who might not automatically or obviously be recognised by the LDAN Bill.

Conversely, a much smaller number of respondents felt it was important to acknowledge that people with a learning disability and neurodivergent people were more likely to experience restraint and seclusion than those within the general population, and so provisions within the LDAN Bill may be appropriate.

Including legislative provisions in the LDAN Bill linked to restraint and seclusion was seen as especially important for those who use behaviour to communicate.

Others argued that a separate Bill may be appropriate but that it could either also be included in the LDAN Bill and/or any alternative Bill could have a separate and focussed section relating to people with learning disabilities and neurodivergent people (to ensure that their unique needs did not get lost or overlooked in wider legislation).

A small number of respondents also referenced the Scottish Government’s consultation on the draft ‘Included, Engaged and Involved: Part 3’ (IEI3) which included updated guidance on restraint and seclusion in schools. It was felt that this was an issue best progressed through that route. For adults, some respondents mentioned the Scottish Mental Health Law Review (SMHLR) and noted that the Bill provided a useful mechanism through which to implement or make the changes that it recommended.

Support for Quick Action

Whether included in the LDAN Bill or elsewhere, several agreed that this was an area of great importance, especially for vulnerable young people, and were keen to see it expedited, rather than being “delayed” (which they perceived may be likely if the issue was reserved for a separate or later Bill). It was felt that any change in this area should be addressed as a priority, that change was needed urgently, and that it needed to be supported by legislation to enforce appropriate practice:

> “If there is to be further legislation or policy on its appropriate use then we support it being omitted from this Bill, however we have concerns over delays which will lead to further harm.” (Health Service)

Separate Provisions for Children and Adults

There was strong support for guidance in relation to children and young people and suggestions that this should be comprehensive, broad in scope and appropriate to multiple professional groups. It should also clearly assert that restraint and seclusion should be used only as a ‘last resort’:

> “[Organisation] supports the publication of non-statutory guidance on physical intervention in schools and recognises the need to provide clarity for all in the school community in relation to this important issue… such guidance, in addition to being clear and accessible, should focus on the promotion of positive relationships, behaviour and wellbeing; on minimising the use of restraint and seclusion as measures of last resort; and on the adoption of a rights-based approach which acknowledges the rights of all in the school setting… Restraint should be a measure of last resort, only used by those who are trained in its use as part of a whole-school approach. The guidance should promote good practice to ensure that all children and young people are safe and protected in a nurturing environment where additional support needs are well understood and provided for.” (Education Service)

While guidance for children and young people was welcomed, several respondents felt that more or additional guidance relating to the use of restraint and seclusion was also needed in relation to adults/adult institutions.

Statutory guidance was particularly welcomed in relation to the grey area of 'last resort', with respondents noting that the threshold for this can vary.

Indeed, if statutory guidance was advanced, this should provide:

- Clear explanations of what constitutes restraint or seclusion;
- A clear definition and explanation of ‘consent’;

- A requirement that restraint or seclusion are only used as a last resort where there is a risk of injury;
- Guidance on de-escalation and alternative approaches;
- A focus on avoidance, as opposed to minimisation or ‘safe’ use;
- Reporting and data gathering requirements; and
- Requirements to report incidents to parents and carers and the timeframe for doing so.

Any guidance must be written in formats accessible to teachers, young people and parents/carers, it was felt, and should also be supported by training (discussed below). It should also include clear guidelines around when teachers, care professionals or others could or should call in the outside help of the police, etc. to ensure that risk of harm to the individual and others is minimised.

If guidance was developed, respondents again urged that this be done in close collaboration with those with lived experience.

A few respondents noted that this section could have made more mention of adult populations generally and felt that the consultation was too skewed towards children and young people on this topic. While many agreed that the LDAN Bill may not be the most appropriate place to incorporate new legislation on this (as it was a matter of basic Human Rights relevant to all regardless of age, diagnosis, setting, etc.), they nonetheless felt that the plethora of existing legislation and guidance could have been bolstered further by the LDAN Bill (noting that any work done to address restrictive practices including restraint and seclusion in Scotland must pay due regard to this existing legislative framework).

Respondents noted that legislation and safeguarding mechanisms already exist within the Adults with Incapacity (Scotland) Act 2000 and the Mental Health Act 1983 to ensure the safety of individuals during restrictive practices. Further, the Mental Welfare Commission, Care Inspectorate and Adult Support and Protection processes also contribute to the implementation of this, as well as the work of the Restraint Reduction Network. Despite this, it was suggested that there was still a lack of consistency in application and that compliance/adherence to good practice needed to be better monitored.

Training

There was agreement that education and training were required to ensure that all those working with children and adults (both with and without learning disabilities or neurodivergent conditions) were aware of appropriate best practice. Several other respondents also urged training around alternatives to restraint and seclusion:

> “We would emphasise that there are effective, evidence based alternatives to restraint available and would advocate for training and provision of these to be prioritised.” (Children's Organisation/ Service)

Several respondents shared personal negative experiences of restraint and seclusion, noting that distressed behaviours from neurodivergent or learning disabled individuals were often a result of communication difficulties, but were misunderstood as indicators of aggression.

Including restraint and seclusion in the mandatory training discussed elsewhere in the consultation was suggested and, overall, respondents noted that better training for health and education staff may help to reduce the use of restraint and seclusion indirectly.

Training (and guidance) for early years staff, teachers, Pupil Support Assistants (PSAs), and other classroom support staff was seen as being particularly important. Training was also considered important to protect staff themselves and to support a safe working environment.

Similarly, it was argued that the legislation should also make it easier for staff to speak up about any misuse of restraint and dangers of injury to patients and staff alike (with a perception that current systems were being under-utilised due to cultural pressures including lack of time, normalisation of violence in daily work and lack of access to reporting systems).

The importance of (and demand for) training for parents and carers was also raised. It was highlighted that restraint and seclusion can also happen in family homes and therefore families, carers and professional workers need support and training to prevent this. A lack of training for families was highlighted as a gap currently, and a source of unmet need which needed to be addressed.

Some respondents felt that, while welcomed, greater clarity was needed around the type of training that would be delivered. A small number also specifically suggested that training in Positive Behaviour Support (PBS) and other preventative measures was necessary to enable the development of ‘capable environments’.

Positive Behavioural Support (PBS)

There was some debate around Positive Behavioural Support (PBS) at this question.

Some championed this as an effective, person centred approach to ensuring needs were understood and met and were disappointed not to see it feature in the consultation:

> “We are missing an opportunity in this Bill, particularly under the overarching theme of mandatory training in the public sector, to embed and promote approaches like Positive Behaviour Support (PBS). PBS is a values-led approach to supporting people with complex support needs; it is not about changing the person’s behaviour but changing the way support is delivered in order to ensure the person is supported in a manner that makes sense for them and to improve their quality of life.” (Justice Organisation)

Proponents viewed that seclusion, segregation and restraint could be delivered within a comprehensive PBS framework. Others argued that PBS approaches should become more mainstream practice and not attached to labelled groups.

Conversely, others, mainly representing neurodivergent communities, viewed PBS in very negative terms and argued that it should be avoided:

> "Positive behaviour support should be banned or at least highly regulated. It is abuse… It is put in place by people who do not understand the harm it does. I have seen firsthand how plans are used in social care settings - restrictive, demonising plans put onto autistic people for so called "challenging behaviour" which is in fact autistic responses to poor care. PBS plans put in place with no consideration of neuro-affirming alternatives." (Neurodivergent Individual)

While some therefore argued for more training and investment in PBS, others argued for it to be banned and there was no real conclusion that could be reached from the feedback around how PBS should be approached.

De-Escalation

A number of respondents discussed the importance of de-escalation and felt that more could be done to raise awareness, invest in training and promote this as an alternative and preventative course of action. It was noted that this may reduce or remove the need for restraint and seclusion:

> "It is also important that any guidance to reduce restraint includes training on/implementation of preventative measures, with capable environments that reduce anxiety and meet people's emotional, communication, physical, mental health and sensory needs."
> (Mental Health Organisation)

Respondents felt that de-escalation should be given greater consideration within the LDAN Bill.

Impacts of Restraint and Seclusion

Some respondents used this question to outline personal testimonies of where restraint and seclusion had been used wrongly or inappropriately in the past, and to highlight the significant negative consequences of such practices.

Several also stressed that early intervention was needed in this regard, as negative experiences of restraint and seclusion in childhood could have long-term impacts that might permeate adult life. Links between restraint and seclusion and trauma were highlighted by many, along with the need to avoid traumatisation and retraumatisation when using such practices.

Several respondents used this question to assert that they did not agree with restraint (and less so seclusion) at all.

Necessary Restraint

A small number of respondents noted that a binary option of ‘support’ or ‘lack of support’ for the proposals did not allow for the nuances/complexities of the issues to be properly discussed, as use of restraint and seclusion should always be on a case-by-case basis.

Several respondents accepted that restraint was sometimes necessary if it was the only means of keeping people safe (either the individual themselves or others), but they stressed that it should always be a last resort.

Other minority views were given that some restraints such as seatbelts in cars, taxis and buses as well as wrist restraints in busy areas may be permissible if they helped to keep vulnerable people (especially children) safe.

Other Comments and Considerations

Other comments included that a consistent, national approach was needed as practices in this regard were currently variable around the country/in different organisations/institutions.

It was also felt that restraint and/or seclusion should be subject to regular data collection, monitoring and review. This would allow oversight of the national and local/sector specific situation, benchmarking, and the identification of any issues and areas of good practice to allow support and improvement measures to be implemented as required.

Support was given to including parents, carers and those with lived experience on a working group to monitor implementation of any changes and ongoing progress in the use of restraint and seclusion as a result of the proposals set out here.

Similarly, robust accountability mechanisms were again urged in this regard. It was felt that guidance alone would not be strong enough to achieve the desired outcomes.

A small number of respondents stressed that further consideration of this issue must acknowledge that restraint and seclusion exists in spheres other than those mentioned in the consultation (schools, hospitals and care settings).

The Scottish Government was also urged to:

- Mandate local authority level data collection, which would provide a much clearer view of the extent to which restraint and seclusion practices are being operated across Scotland;
- Place a duty on public bodies to monitor and report on the use of restrictive interventions;
- Require local services to have local seclusion and long-term segregation policies which include people with learning disabilities and autistic people;

- Require all relevant public sector organisations to produce a regular updated and reviewed workforce development plan in relation to the reduction of the misuse of restrictive practices, including restraint and seclusion;
- Require local services to ensure that individuals have access to independent advocacy for anyone subject to such restrictions;
- Take care that any new legislation and guidance documents do not overlap or misalign with existing legislation and guidance. Respondents were concerned that any misalignment may risk fragmentation of practice approaches and individuals being subject to different rules, guidance and legislation depending upon the setting within which the individual is present;
- Continue funding the Restraint Reduction Scotland Network;
- Have a focus on restraint elimination, not restraint reduction; and
- Carry out more research in this area, including gathering more feedback from people with lived experience and seeking the advice of parents and carers in this regard.

As with many other areas of the consultation, some respondents again queried whether additional funding would be made available for any proposals to be implemented around restraint and seclusion.

Section 12: Transport

Introduction

The consultation document outlined the challenges faced while travelling by people with disabilities, people with learning disabilities and neurodivergent people. There is currently an ambitious and wide-ranging programme of work underway to make improvements, however the consultation document suggested that specific issues for people with learning disabilities and neurodivergent people could be addressed through the LDAN Bill.

Two specific proposals were presented for discussion at this section:

- **Proposal 1: National and Local Strategies** - requiring Regional Transport Partnerships (RTPs) to state how the specific needs of people with learning disabilities and neurodivergent people are being considered and met through travel information systems and accessibility initiatives. Also requiring RTPs to detail how staff across different modes of transport are being trained in disability awareness, how that training incorporates neurodivergence and learning disabilities, and the uptake of this.
- **Proposal 2: Mandatory Training** - extending the requirement for consistent statutory training to transport staff in Scotland.

Main Findings

Overall, 352 respondents provided feedback at this section, with over half agreeing with both of the proposals. Where respondents only supported one proposal, there was greater support for mandatory training compared to developing national and local strategies. Only a few respondents explicitly stated they disagreed with either or both proposals.

Proposal 1: National and Local Strategies

While this proposal was largely supported, comments in relation to the development of national and local strategies were limited. Most respondents did not set out a preference for national or local strategies, instead supporting a combination of both. Where respondents did express a preference however, a national strategy or national guidance received greater support than local strategies alone. As noted at other parts of the consultation, respondents were concerned that local strategies, without any overarching framework, would result in variation across the country. It was felt that a national strategy would help to ensure a consistent quality of service and a more joined up transport system to support cross boundary travel.

A few respondents, however, stressed the need for localised issues to be recognised and addressed, i.e. for remote rural and island areas.

Again, similar caveats and recommendations were made as at other sections:

- Strategies needed to be co-designed with those with lived experience;

- Transport providers must be resourced and funded to implement the strategy;
- The strategy must be effective in delivering change, it should not become a tick-box exercise;
- Statutory requirements/duties are needed and would be a better way of achieving change; and
- Strategies should be reviewed regularly (e.g. every five years).

The main issue raised, however, was the importance of accountability and enforcement to ensure strategies and improvements are delivered on the ground. While respondents supported the use of strategies in principle, it was argued that robust mechanisms needed to be implemented to ensure these are delivered and effective:

> "We need to see actions and feel the benefit of the strategies in daily life. There is a 'enforcement gap' - we believe that enforcement powers for [Proposals] 1 and 2 need to be included on the face of the Bill. Even if actions are mandatory, how do we make actions accountable? We need to remain conscious of the "implementation gap" and produce and use better information and data to evidence that policy outcomes are delivered, driving progress, reducing inequalities and for transport…" (Organisation for Other Disability/ Condition)

Only a handful of respondents explicitly stated that they disagreed with Proposal 1. Most gave no reason for this while one individual felt that strategies would be "costly and do nothing".

Proposal 2: Mandatory Training

Mandatory training was the most supported of the two proposals presented, with several of those who supported both proposals also stating that mandatory training was the most important element.

Many respondents agreed that the transport system would benefit from specialist training regarding learning disabilities and neurodivergence. There were many comments regarding the current lack of awareness, understanding and support, as well as perceived rudeness from transport staff. The majority of these comments were directed towards bus drivers:

> "With respect to mandatory training, this may help. Staff are often unsure how to help people and some are downright rude." (Family/Friend)

It was felt that training should be provided to all those who come into contact with the public, including (but not limited to) drivers, conductors, ticketing staff, and booking staff. It was also suggested training needed to cover all transport sectors, including buses, trains, planes and ferries, with some respondents also suggesting that taxi and licensed private hire providers/drivers and the British Transport Police should be required to undertake mandatory training. Taxis were highlighted as being important for inclusion here due to the problems and barriers that many people with learning disabilities and neurodivergent people experience in accessing and using mainstream public transport options and their increased reliance on taxis. A few also cited examples of poor experiences with taxi providers as justification for this training need.

Again, however, it was stressed that people with lived experience should be actively involved in the development and delivery of training.

Only a few respondents explicitly disagreed with Proposal 2. They typically felt that training would not solve the problems in transport as the biggest issue was accessibility and suitability of the infrastructure (e.g. it was generally too overwhelming to use public transport). Others felt that training for all staff was unnecessary as those who need support will most likely be travelling with someone who can already provide this:

> “Training won’t help. Public transport is just completely inaccessible to autistic people.” (Neurodivergent Individual)

Other Comments and Considerations

Consistent with other sector specific sections, much of the feedback from respondents focused more generally on the difficulties and barriers people with learning disabilities and neurodivergent people face when accessing and using transport services, and the negative impacts that result from inaccessible and unsuitable transport systems, including isolation and difficulties accessing education, work opportunities, and other services. Some also made wider or more practical suggestions around how to improve the system. As such, a wide range of other considerations were raised by respondents, with the most commonly discussed issued outlined below.

More Inclusive Communication

Respondents highlighted difficulties in accessing current information about public transport services and called for greater use of inclusive communication. In particular, it was felt there was a need for improved signage and timetabling information:

> “We would urge that when developing the LDAN Bill there is a commitment to communicate in an accessible manner that considers the principles of Inclusive Communication. This includes awareness of communicating in a manner which matches the strengths and preferences of each individual, as well as the availability of information in a range of accessible formats, including Easy Read, a format that uses simple, jargon-free language, shorter sentences and supporting image. This should be applied across all forms of public transport.” (Organisation for Other Disability/Condition)

Accessibility Initiatives

Accessibility was raised as a primary concern for many respondents. Some mentioned that those using wheelchairs had difficulty with access, ramps and steps. Others raised the issues of noise, space, smell and light as having a direct impact on the experience of travel and public transport use for some individuals. Indeed, some respondents mentioned how distressing it can be to use public services when senses are overloaded by noise, smell, colours and light. Crowded buses and carriages, bright lights and loud spaces were all cited as barriers to travel.

It was suggested that if more trains and buses were available, providing a reliable service and transport in all areas, then individual services would not be so crowded and overwhelming for neurodivergent people. Some also called for quiet carriages and quiet spaces in waiting areas, while a few respondents suggested offering dedicated quiet services/times (similar to those offered by some supermarkets) in order to meet the needs of people with learning disabilities and neurodivergent people.

Much of the remaining discussion around accessibility focused more on physical disabilities, however, rather than being specific to people with learning disabilities and neurodivergent people. This highlights the co-morbidity issues flagged as important throughout the consultation responses, and the need for intersectional data and understanding.

A few respondents mentioned the additional needs of those who are visually impaired. They supported the use of ‘talking bus stops’ and ‘next stop’ announcements on buses.

Several respondents discussed the provision for wheelchairs on buses, and noted that although accessibility had been considered, more could be done in this respect. Respondents said that corridors should be wider and that there should be more adequate space for users of larger wheelchairs. Some also called for better wheelchair restraints on buses, while a few noted that it can still be difficult to access a bus when using a wheelchair.

The provision of toilets was raised by some respondents who suggested that there should be an increased availability of disabled toilets, that some are locked and keys must be obtained, and that some do not have ramps and are therefore inaccessible to wheelchair users. Others discussed the use of ‘standard’ toilets, and suggested that instructions should be made clearer and more accessible.

Travel Training

Some respondents suggested that offering ‘travel training’ to people with learning disabilities and neurodivergent people **and** their carers, friends/family, etc. might help to overcome some of the ‘simpler’ barriers to travel. In particular, it was felt this could provide people with the confidence to use public transport options:

> “Travel training came up in a number of the interviews with parents. There were several examples of a young person receiving intensive travel training, typically provided by a third sector organisation. This had led to the young person having the confidence to negotiate public transport, typically the bus system, and contributed to some level of independence.” (Other Organisation)

Attitudes of the General Public

Abuse from other passengers on public transport services was highlighted by a number of respondents as a significant barrier to use. Respondents noted that fear of discrimination and abuse, and vulnerability to hate crimes resulted in a lack of confidence to travel on their own or on public transport.

As a result, it was felt that more education, awareness raising and training was required for the wider public to tackle stigma, discrimination and harassment (which was again an issue flagged elsewhere in the consultation responses).

Free or Subsidised Travel

Respondents highlighted that people with learning disabilities and neurodivergent people are less likely to hold driving licences or have access to private transport, and that they may also have an increased requirement to attend healthcare and other support based appointments. Therefore, it was argued that free or subsidised transport should be provided for **all** people with learning disabilities and neurodivergent people. This included extending current concessionary bus passes to include people with learning disabilities and neurodivergent people, providing similar concessionary travel options for train travel, and providing a card or travel pass system for taxis.

In relation to trains specifically, it was argued that these were more suited to some people’s needs, were more convenient for some, offered a faster mode of transport, and had destinations that were easier to recognise (i.e. train stations being more obvious than bus stops).

It was also suggested that carers and assisting family members should be offered discounted or free travel, which should be more available and easier to secure.

Review Application Systems for Concessionary Travel/Blue Badge

Both the concessionary bus pass and blue badge schemes were cited as being very beneficial to many. However, some respondents requested that the application systems for each of these be reviewed to be more inclusive of neurodivergent people, and to be awarded indefinitely for life-long, deteriorating conditions, to save pass/badge holders from having to go through the application process for renewals.

In relation to the blue badge scheme specifically, it was felt this focused too much on physical disabilities and needed to be more understanding and inclusive of other needs. Some also felt strongly that many of those who could benefit from this were unaware of **if** and **how** they could apply for it. It was suggested that significant improvements could be made in this area to increase awareness and accessibility.

Funding

Finally, as noted across many sections of the consultation, respondents highlighted the need for funding, both to deliver the proposals around strategies and training, and for any material changes/improvements. Some queried where the money and resources would come from to fund adaptations, training and strategic development in this area.

Section 13: Education

Introduction

The consultation document set out the various legislation, frameworks, plans and guidance that are relevant to schools, including those specific to children and young people with Additional Support Needs (ASN), learning disabilities, autism and neurodivergence, and those relevant to all pupils. Requirements and provisions for Initial Teacher Education (ITE) and Continued Professional Development (CPD) were also outlined. The document also highlighted the difficulties that children and young people with learning disabilities and neurodivergent children and young people continue to have in relation to education. Therefore, it was suggested that the LDAN Bill could consider including the following three proposals:

- **Proposal 1: Strategies and Reporting Requirements -** create a new requirement for education authorities and schools to include information on how the specific needs of pupils with learning disabilities and neurodivergent pupils have been considered and are being met within plans and reports which are already produced to meet the requirements of the Standards in Schools etc. Act 2000. The Scottish Government could also consider whether the Children's Services Plan Annual Reports should include specific consideration of children and young people with learning disabilities and neurodivergent children and young people.
- **Proposal 2: Mandatory Training for Teachers, Practitioners and Other Educators** - feedback was sought on whether the mandatory training requirement for health and social care staff should extended to other public sector areas, and:
    a) Whether there is a need to set out anything in legislation regarding the training requirements for student teachers, given the recently updated Standard for Provisional Registration;
    b) Whether there is a need to set out anything in legislation regarding the training requirements for student Early Learning and Childcare (ELC) practitioners; and
    c) Whether there is a need for a mandatory training requirement for teachers, practitioners and other educators on learning disabilities and neurodivergence as part of their CPD.
- **Proposal 3: Data** - currently there is disaggregated data available on some conditions (i.e. learning disabilities, autism and dyslexia) but not others (i.e. ADHD, FASD, Dyscalculia and other neurodivergent conditions). To better understand the needs of all neurodivergent children and young people and their experiences and outcomes in relation to education, such data could be collected and published. This would allow for reporting on the attainment gap of these groups, school leavers and positive destinations, and to understand the size of these populations and any trends. There may also be a need for data on the use of part-time timetables.

Main Findings

This section attracted a higher response rate than most other sections at Part 3 of the consultation, with 499 respondents providing feedback. Rather than identifying support for, or disagreement with, or commenting specifically on, the proposals set out, however, many individuals used this section to highlight challenges, problems and shortcomings in the current education and school system for children and young people with learning disabilities and neurodivergent children and young people. A wide range of issues were discussed. Some also made suggestions around more practical and more fundamental changes which they thought were necessary.

Where respondents focused on the proposals set out in the consultation document, and identified support or disagreement with these, most indicated that they supported all of the proposals, with mandatory training (i.e. Proposal 2) being identified as the most important/highest priority of the three elements presented. In relation to Proposals 1 and 3, respondents were slightly more supportive of the need for good quality data compared to the need for plans and reporting.

Proposal 1: Strategies and Reporting Requirements

Several respondents felt that a requirement to include specific consideration of learning disabilities and neurodivergent conditions within plans and reports would make schools and local authorities more aware of needs, and ultimately make them more accountable. It was also suggested that this would ensure local authorities are aware of how children and young people with learning disabilities and neurodivergent children and young people are being supported across their area, while also allowing comparison of situations across the country. A few also hoped that by reporting on the scale of needs, this could help support future planning, and direct additional funding and resources into the area:

> “By requiring that each council’s Annual Reports includes specific consideration of neurodivergent children and young people and children and young people with learning disabilities, it ensures that this community is at the centre of decision making. Supporting councils to reflect on what they are doing to support neurodivergent children and children with learning disabilities ensures forward planning and reinforces good practice.” (LDAN Support/ Representative Organisation - Mixed Conditions)

Respondents noted that it is difficult to measure outcomes and improvement without reporting.

Others, however, felt that reporting alone would not provide accountability. There were concerns that this could become more of a tick-box exercise which has little impact on individuals, rather than it delivering meaningful improvements. Even those who supported reporting requirements cautioned that these would only be useful if the information is acted upon to make improvements: reporting alone would not be impactful.

A few individuals interpreted this proposal as being a requirement to develop a report or action plan on each individual child identified as needing support, rather than summary reporting about the situation across a whole school or authority area. In these cases, respondents were generally in favour of an accurate report being developed to inform and guide support for the child throughout their school career, provided schools are held accountable for any delays or failure to deliver.

A few organisations discussed the need for/use of strategies for autistic and neurodivergent pupils and pupils with learning disabilities in education at this proposal rather than planning and reporting. In all cases respondents were supportive of the development of dedicated strategies for the education sector. However, the same caveats as outlined at the overarching strategy section were repeated - i.e. that this needed to avoid local variations and that legislation or statutory requirements may not be required to achieve this.

A series of caveats and concerns were raised around the proposed planning and reporting requirement, including:

- Issues around diagnosis of neurodivergent conditions is a significant barrier to accurate reporting;
- Reporting needs to include information on children not currently attending school (either due to being home schooled, school refusal or exclusion);
- It might be unfair to ask schools to report before they have had widespread training, the necessary injection of funding and resources, and the provision of other support in relation to autistic and neurodivergent pupils and pupils with learning disabilities;
- That such planning and reporting may be impractical as schools/staff will not have the capacity to undertake the necessary data collection, analysis and reporting; and
- Concern that reporting would focus on the plans that have been made rather than detailing whether these have been actioned and how consistently the measures have been implemented - e.g. support not being provided because ASN support staff had to cover staff absences or were diverted to other tasks.

Proposal 2: Mandatory Training

As noted above, respondents were particularly in favour of mandatory training within the education sector, with this often said to be the most important proposal. It was felt this was needed to ensure all staff received appropriate training to give them the knowledge, understanding and skills required. Optional training was felt to be far less effective as it could be undertaken as a one-off or avoided entirely throughout someone’s career.

Several individuals and a range of organisations noted that increasing numbers of children were being identified as neurodivergent or potentially neurodivergent. Therefore teachers and other educators needed to have the training and skills to support/teach them:

> "Given the anticipated levels of neurodivergent and learning disability populations within schools and classes, this is now core business within every classroom, playroom and educational setting. Every professional should have ongoing mandatory training to meet the needs of all learners." (Local Authority)

It was stated that training should be neuro-affirmative, child-centred, informed and/or led by those with lived experience, and specific about different conditions. It should be high quality, have consistency across Scotland, and be built into the standard training provision rather than treated as an optional or "add on" element. Some respondents also suggested that regular refresher training needed to be provided on an ongoing basis to ensure up to date information and practices are shared, and so that teachers do not forget what they have learned. Respondents stressed that training should be meaningful and not simply a tick-box exercise. A few suggested that a robust education/training programme, similar to that used for trauma informed practice, would be welcomed. Those advocating for certain conditions also stressed the need for training to address these specifically, e.g. autism, Down's Syndrome and FASD.

While many individuals and organisations felt that those with lived experience should be involved in developing and/or delivering training, a few organisations identified specific professions that would also be well placed to support training in the education sector. These included educational psychologists, occupational therapists, allied health professionals, and various DPO and other third sector support organisations.

Most respondents who discussed ITE felt that learning disabilities, autism and neurodivergence training needed to form a substantial element of the course or be woven throughout the entire course, and should not simply be covered in a standalone short lesson (noted to be no more than a few hours/half day currently, or optional in some cases). A few respondents who identified themselves as teachers stated that they did not feel the ITE had adequately prepared them for teaching pupils with learning disabilities and neurodivergent pupils and that much more education in this area was required. It was also suggested that trainee ELC practitioners needed mandatory modules/training on supporting children with learning disabilities and neurodivergent children. A few respondents also felt that the Standard for Headship qualification should include training on supporting pupils with learning disabilities and autistic and neurodivergent pupils. Most of those who mentioned CPD tended to agree that training needed to be included as part of such provision. However, there were a handful of education services and local authorities who felt that CPD should remain optional. They suggested that training on this topic should be available but that individual teachers should be allowed to develop their learning via CPD as required and based on need, or that the local authority should identify training needs.

In addition to better equipping teachers to deliver lessons that engage and support all pupils with learning disabilities and neurodivergent pupils, many argued that training also needed to support teachers and other educators to recognise and identify potential pupils with learning disabilities and neurodivergent pupils. Further, it was suggested that teachers and other education staff needed to better understand masking, the impact of masking on mental health, intersectionality, and how conditions may present differently in different groups.

> “ADHD diagnosis in girls is often missed and dismissed. Teachers and public sector staff working with young girls need to be trained on recognising ADHD and supporting individuals for whom neurodivergence may have a disproportionate effect internally versus expressed behaviour and emotions.” (Neurodivergent Individual and Family/Friend)

It was agreed that mandatory training should include pupil facing teaching staff, including pupil support assistants (PSAs) and classroom and learning assistants. Several respondents felt that mandatory training should extend to all staff in education settings, while others named specific roles/settings where mandatory training should be required. This included:

- Head teachers and other management staff;
- Any staff that may have contact with children and young people with learning disabilities and neurodivergent children and young people, such as guidance teachers/staff, administrative, catering, janitorial and other support staff;
- Staff at local authority and private early learning and childcare settings, nurseries and other childcare facilities;
- Staff in local authority education departments;
- Those making decisions about school placements; and
- Those delivering teacher training within ITE.

A few, however, questioned how realistic it would be to provide mandatory training across the entire education sector. Respondents noted the number of different bodies involved and the financial investment that would be required to achieve this.

Several respondents (including both individuals and a wide range of organisations) also stressed that funding and resources would be required in order to deliver mandatory training. It was highlighted that there needed to be budgets and staff cover to allow teachers and other education professionals to be released from classroom duties to attend training. Similarly, high quality evidence based training providers needed to be resourced to deliver increasing levels of training.

While only a handful of respondents explicitly disagreed with the proposal of mandatory training, the reasons were again mixed. One highlighted that some teachers/education professionals are neurodivergent themselves, or have family members who are, and therefore may already be highly effective and not require mandatory training in this area. One simply disagreed with the wording of the proposal rather than the principle, i.e. they wanted **all** staff to receive mandatory training. One wanted a broader and less reactive approach taken to training. And one disagreed specifically with parts (a) to set out training requirement in legislation and (c) a mandatory training requirement as part of staff’s CPD - they felt legislation was not required and that CPD should remain optional and managed by the individual rather than being prescriptive.

Proposal 3: Data

Respondents who discussed this proposal or data generally, tended to agree there was a need for more robust, accurate and disaggregated data. It was felt that any data must be condition specific, with systems also supporting multiple ASN/ disability categories. Those representing Down's Syndrome (including parents/ carers and support/representative organisations) also stressed the need to identify this condition specifically within the data. This level of disaggregation was said to be needed to identify any trends and inequalities, and allow appropriate future planning or identification of measures to support specific conditions.

Disaggregated data was also important for measuring outcomes and improvements. In addition, data was seen as helpful for identifying needs, planning services, and identifying challenges, service gaps, or inequalities across schools/ areas. This applied at the individual school level, local authority and national levels:

> "We would be keen to extend the disaggregated data we currently collect and use this in a meaningful way to support planning for this cohort of the population. This would provide further information around the attainment gap of these groups, school leavers and positive destinations and to understand the size of these populations and any trends." (Local Authority)

As well as condition-specific data, respondents also discussed the use of part-time timetables and the data that should be collected in this respect. As well as basic information on the use of part-time timetables, it was argued that data should include how long these have been in use for individual pupils (with respondents highlighting they are often used as a long-term solution rather than a short-term tool to support adjustment), and identify how many affected families support/do not support the use of the part-time timetable. Others suggested that data also needed to be collected (and reported) on the following aspects:

- What pupils with learning disabilities and neurodivergent pupils are being taught, literacy and numeracy levels, as well as any life skills;
- Any attainment gaps for different groups (although a few noted it was not helpful to measure and compare pupils with learning disabilities and neurodivergent pupils against neurotypical/mainstream attainment);
- Levels of bullying;
- Absences;
- Exclusions;
- The use of restraint;
- The needs of pupils with learning disabilities and neurodivergent pupils and the extent to which pupils who need ASL input receive it and levels of unmet need;

- The provision of specialist staff;
- The provision of appropriate training; and
- Whether positive destinations are achieved after school.

As discussed at previous sections, respondents also felt it was important for data to include intersectional information.

Respondents also stressed the need for consistency in the recording of data between schools/local authorities, with a few organisations noting potential inconsistencies around how attendance is currently recorded. Education services suggested it would be necessary to provide clear guidance and parameters/details of which conditions should be included, as well as around any naming conventions and coding requirements in order to provide consistency.

A few respondents were again concerned that, while data was needed, fulfilling this proposal could become a tick-box routine rather than being effective in monitoring needs and driving change.

Consistent with concerns around planning and reporting above, respondents were also concerned that diagnosis may be necessary for data recording, with some querying or anxious about how those waiting for an assessment or who were undiagnosed but exhibiting additional support needs would be captured in the data. A few, particularly organisations (including a few educational services), stressed the importance of maintaining a social and needs based model, and not requiring medical diagnosis within education - although they were unclear how a social model could be maintained when data would be required on different conditions rather than needs. One education service organisation was also concerned about the ethics of schools ‘labelling’ children and young people who have not been diagnosed and who perhaps do not want a diagnosis or label, while one local authority was concerned that teachers and educational professionals would be required to provide a diagnosis (even informally), which they are not trained to do. There were also concerns that such identification within the education sector could lead to greater demand for assessment and diagnosis services, which were already said to be stretched and oversubscribed:

> “There is also a very practical concern as regards the already considerable pressures experienced by CAMHS and other services in relation to provision of diagnosis. At a time when services are exploring routes for encouraging uptake of support which does not require a diagnosis, introducing another pressure which emphasises the need for diagnosis within education could well be counter-productive.” (Health Service)

Of the education services and local authorities who discussed this proposal, a small number had concerns about how data might be recorded, and noted that current systems/tools made disaggregation difficult. Respondents indicated that these systems would need to be updated to deliver on the proposals. Others, who were more in favour of the data related proposals, sought to avoid duplication, both in terms of double counting individuals and with other data collection requirements.

Caveats, Concerns and Reasons for Disagreeing

One of the main concerns from education services and local authorities, however, was that the proposals were limited to children and young people with learning disabilities and neurodivergent children and young people rather than covering all additional support needs (ASN). There were concerns that an unintended consequence could be a perceived hierarchy of needs, which would not be in keeping with the Additional Support for Learning legislation which promotes inclusion and that no particular disability or additional support need is seen as being prioritised over and above another.

While only a very small number of respondents disagreed with all proposals, their reasons tended to be consistent with concerns expressed by others. Generally this was because they felt the proposals were largely bureaucratic, could not be resourced, and/or because they felt the proposals would not address the main problems or issues in education.

Others, including those who agreed and disagreed with the proposals, sought more information around the practicalities, such as who the reports would be aimed at and how they would be used, what type of data would be required and how this would be used, and how mandatory training would be provided, managed, quality assured and monitored.

More Ambitious Changes Needed

Regardless of respondents views around the proposals, many individuals and organisations argued that more radical and fundamental changes were needed across the education system to better meet the needs of children with learning disabilities and neurodivergent children. Indeed, several organisations (including education services) suggested more needed to be done to address the implementation gap, while others felt that an entire “culture change” was required. Many indicated that the proposals were not ambitious enough/did not go far enough to address the needs of children and young people with learning disabilities and neurodivergent children and young people, or to improve the education system, and that on their own they were unlikely to result in significant changes:

> “As a teacher myself who has experience of supporting ASN pupils, training teachers is NOT enough in order to meet the needs of all children. Only with access to meaningful outside agencies like educational psychologist and Speech and Language, smaller class sizes and an increase in support staff can we actually get it right for all children.” (Carer)

Inclusion and Mainstreaming Issues

One area that elicited much discussion, with respondents often providing lengthy responses, was the principle of mainstreaming. Some individuals argued that the presumption of mainstreaming except in exceptional circumstances was deeply flawed. Several organisations also highlighted that mainstream settings were not always the right environments for children and young people with learning disabilities and neurodivergent children and young people. The lack of appropriate curriculum/classroom support was noted, along with wider and more environmental and structural issues which can make mainstream settings unsuitable for some pupils, meaning they cannot effectively access education or achieve their full potential. It was felt this needed to be recognised from the outset of a child's educational journey rather than an automatic presumption taking precedence:

> "The legal presumption that children with learning disabilities and neurodivergent children will be educated in mainstream schools does not always meet the needs of these children and young people, or help them reach their potential in an education setting. In a growing amount of cases, stipulating that mainstream schooling is the preferred option denies certain children the right learning experience and support, disadvantaging them, their quality of life adversely affected and their aspirations unreached."
> (Neurodivergent Individual)

Respondents highlighted a wide range of negative experiences for some children and young people with learning disabilities and neurodivergent children and young people in mainstream settings. It was suggested that they often:

- Were bullied by their peers;
- Experienced teachers/staff without adequate training and understanding (with some also reporting poor attitudes towards pupils);
- Did not receive the right (or sometimes any) support;
- Were isolated and/or excluded, both from individual lessons and the setting entirely;
- Could not access the curriculum;
- Suffered communication challenges;
- Were overwhelmed by their environment; and
- Experienced negative impacts on their mental health and wellbeing.

It was also noted that academically capable autistic and FASD pupils also struggled in mainstream schools, even where dedicated hubs can be provided. While these pupils may not have difficulty with the curriculum, it was stressed that the environment was problematic and unsuitable, i.e. loud, busy, high volume of people and interactions, size and scale of the buildings, etc.

The high rates of absence, formal and informal exclusion (including perceived illegal instances), and use of part-time timetables were regularly cited as evidence of the failure of the current implementation of the mainstreaming model. Several respondents argued that children and young people should not be forced to 'fail' or to reach crisis point in mainstream schools before being considered for a placement in specialist provision.

However, individuals and support organisations noted that special school provision and capacity was limited, was very difficult to access, and that there was unequal provision across the country. It was also suggested that the ‘exceptional circumstances’ required for eligibility were not clearly defined and that requirements were often set too high. The lack of capacity meant that many children and young people who would benefit/be more suited to a specialist school could not access them and so had no choice but to attend mainstream schools.

The same problems were also noted with ELC settings, where mainstream provision was noted to be busy and noisy with inflexible spaces, making them overwhelming, distressing and unsuitable for some children. Again, there was noted to be a lack of specialist or smaller and more suitable settings available.

Even where individuals and organisations were supportive or neutral about the policy of mainstreaming, many stressed that schools were not currently inclusive enough to support and meet the needs of pupils with learning disabilities and neurodivergent pupils. In particular, it was suggested that teaching methods, systems and infrastructure were not flexible enough to allow pupils to access the curriculum and achieve their full potential. It was argued that mainstream schools/settings needed to be fully updated to support the needs of pupils with learning disabilities and neurodivergent pupils.

A wide range of issues which create barriers were outlined, as well as changes and supports that needed to be implemented across the mainstream education system. Some of the more common aspects are discussed below (i.e. a need for additional staffing, infrastructure issues, and funding/ resourcing). Other aspects identified by more than one respondent included:

- Smaller class sizes were needed and would make a significant difference;
- Bullying needed to be prevented, and tackled quickly and effectively where it occurred;
- Movement breaks and quiet spaces were needed;
- Strict uniform rules were problematic for pupils with sensory issues;
- Augmentative and Alternative Communication (AAC) should be available to all in schools;
- Clear guidance and procedures in relation to reasonable adjustments and accessing specialist equipment was needed;
- Support plans **must** be actioned;
- Greater and more flexible support was needed; and
- Exams were not felt to be the best way to allow pupils with learning disabilities and neurodivergent pupils to evidence their learning or capabilities. Different ways of gaining qualifications needed to be explored, along with greater promotion and recognition of non-academic and vocational programmes and achievements.

It was noted that neurotypical children and young people would also benefit from many of the changes needed to make the education system more accessible.

A few individuals, including a person with Down's Syndrome, as well as several organisations (across a range of sectors) supported the principle of children and young people with learning disabilities and neurodivergent children and young people attending mainstream schools.

Increased Provision of ASN/ASL Staff

Several respondents stressed the need for an overall increase in the numbers of school staff, and in particular, more dedicated and trained Additional Support for Learning (ASL) or Additional Support Needs (ASN) staff to be available within schools. It was felt this sector was "vastly underfunded, under-resourced and under-trained", but crucial in ensuring pupils have access to education.

A few also noted that an increase in educational psychologists was needed, as well as greater access to, and input from, speech and language therapy.

Infrastructure

Some respondents also noted that the design of education settings and the physical infrastructure needed to be considered in order to best support and include pupils with learning disabilities and neurodivergent pupils. It was stressed that open plan environments are not suitable; that lighting and sound needs to be considered; and quiet spaces need to be provided:

> "What is needed, is for planners, architects, HR departments and heads of education to listen to people with lived experience to hear what the need and what works well. For example, open plan schools with hand driers and no doors provides the perfect recipe for over stimulation and massive meltdowns. Teacher and parents have fed this back for decades yet architect's seem to find more ways of reducing the functionality of buildings in order to make them look pretty. Schools are also being 'supersized'. Many autistics struggle with large numbers of people. Supersizing is a sensory hell. GIRFEC fails because the people who plan the schools refuse to listen." (Neurodivergent Individual and Family/Friend/Carer)

Respondents suggested that those with lived experience should be involved in the design of any new facilities or refurbishment of existing settings.

More Funding and Resources Needed

Another common topic discussed by respondents was the need for more funding and resources in the education sector.

Many felt that the current education system was not suitable, and that already existing legislation could not be implemented and delivered due to a lack of funding and resources and the current climate of budget cuts. Increased funding and resources were considered to be necessary to deliver on current requirements, to provide sufficient capacity in specialist schools, and to make mainstream schools more inclusive for pupils with learning disabilities and neurodivergent pupils. Funding was seen as critical to build and staff suitable infrastructure, to design suitable spaces, to increase staffing and facilitate training, to provide smaller class sizes, to develop or purchase additional resources, etc.

Similarly, it was argued that, for the LDAN Bill and associated proposals to be achievable with regards to education, they would need to be fully funded and resourced.

Those who were unsupportive of the proposals tended to argue that this additional burden (for reporting, training and data collection) on schools and teachers was unrealistic and unfair given current resourcing issues. Several of those who supported the proposals in principle also noted that they were unlikely to be effective if funding and resourcing are not addressed.

Other Comments and Considerations

Child Plans and Co-ordinated Support Plans (CSPs)

Both individuals and third sector support/representative organisations suggested that parents and families do not know or are not suitably or accurately informed about their rights in relation to education.

It was also noted that the requirements in the ASL Act meant it was difficult or impossible for children and families to get a Co-ordinated Support Plan (CSP). Respondents suggested that very few parents/carers knew about CSPs and that few were in place, with local authorities opting to use non-statutory Child Plans instead. It was also noted that parents often think CSPs are optional and that schools determine whether they are appropriate or not. Further, a few respondents also highlighted that the need for other services to be involved was difficult to achieve given the stretched nature of these services, and that the terminology used in the Act was vague and can result in “impossibly high” thresholds being applied by individual local authorities:

> “Parents do not seem to know what a CSP is despite it being the primary means of securing enforceable support… No one seems aware that they can bring discrimination claims to the ASN Tribunal… We need to make it easier for parents to access their rights and the rights of their children.” (Neurodivergent Individual and Family/Friend/Carer)

Several individuals also suggested that Child Plans were not effective. They indicated that they were “routinely ignored”, experienced implementation delays and failures, and that review dates were missed. It was felt there was little accountability around the implementation of these plans, and no consequences for failing to deliver the plan or support. As such, respondents wanted to see real consequences where Child Plans are not followed.

Issues with Diagnosis

Waiting times for assessments and diagnosis were again flagged as problematic for education, with earlier access to assessments said to be needed to avoid distress, absence and exclusions among children and young people, and enable earlier access to support. Delays in accessing a diagnosis were also said to be likely to impact on both data recording, planning and reporting. For this reason several respondents stressed the importance of basing all proposals and requirements on need rather than diagnosis.

Again, gender based inequalities in diagnosis were highlighted. It was noted that girls (and women) were typically identified and diagnosed later, which can impact educational experiences, with many girls not receiving the right support across their entire educational career.

Lived Experience and Parent/Carer Involvement

Children and young people with learning disabilities and neurodivergent children and young people, parents/carers/families, and support organisations need to be much more involved in education and their voices heard and listened to. Several respondents felt these groups needed to be involved in the development of educational policies, structures and processes generally. Others stressed the need for greater joint working between parents/carers and schools, with parents/carers being encouraged to be more actively involved in strategies and adjustments for their own child, to receive better communication and more updates about their specific child, and being believed and supported when there are issues at home which do not present in the classroom (due to masking).

Several respondents also felt that more support needed to be provided to parents/ carers and families.

Other Issues

A wide range of other issues were discussed or flagged by respondents as requiring further consideration. These included:

- Greater accountability and consequences needed when schools/local authorities do not meet the required legislative standards, and when tribunal decisions are not implemented in a timely manner;
- Earlier access to independent advocacy is needed;
- Flexi-schooling and virtual classes need to be made more available/ accessible;
- Much more formal support needed for families to home educate their child where the school environment is not suitable. Home schooling also needed to be acknowledged and included in the proposals/LDAN Bill;
- That Positive Behaviour Support (PBS), Cognitive Behavioural Therapy (CBT) and Applied Behaviour Analysis (ABA) should be banned as they can be ableist and harmful;
- Schools were perceived to be using part-time timetables due to a lack of resources, and/or a lack of appropriate knowledge, understanding and support combined with unsuitable infrastructure, rather than being used as a transitional tool or because these are in the best interests of the pupil;

- Greater education and awareness raising is needed for all pupils to ensure understanding, accepting of difference and to reduce stigma;
- Alternative communication skills (e.g. Makaton) should be taught, both for teachers and pupils;
- Greater early years provision, holiday and wrap-around childcare is needed for children with learning disabilities, neurodivergent children, children with ASN, and children with Down’s Syndrome; and
- Any legislation and requirements related to education needs to include private schools and cover further and higher education and lifelong learning - a few respondents also suggested that more lifelong learning opportunities were needed for young people and adults and that this should provide meaningful skills and qualifications.

Section 14: Children and Young People - Transitions to Adulthood

Introduction

The consultation set out the current legislative landscape relevant to young people transitioning to adulthood, as well as a National Transitions to Adulthood Strategy being developed. It was noted, however, that this landscape has been described as ‘cluttered’, ‘complex’ and ‘difficult to navigate’ for young people and their families, as well as professionals working to support them.

It was highlighted that transitions can involve every aspect of life, including housing, employment, social care, education, transport and relationships. As such, it was proposed that many of the overarching and sector specific proposals covered elsewhere in the consultation should also contribute to improved outcomes in this area. This included proposals related to inclusive communications, mandatory training, independent advocacy, and statutory strategies. With specific reference to data, the Scottish Government was keen to develop an approach which will:

- Enable better understanding and measure the extent to which young people with learning disabilities and neurodivergent young people are experiencing a positive and supported transition to adult life;
- Ensure the visibility of young people with learning disabilities and neurodivergent young people;
- Help inform the work that will take place under a National Transitions to Adulthood Strategy; and
- Help to inform the development of services to meet the needs of young people with learning disabilities and neurodivergent young people when transitioning to adulthood.

Main Findings

Overall, 392 respondents provided feedback at this section. Responses showed widely different interpretations of the proposals, with some agreeing and disagreeing for the same reasons - e.g. because they thought the proposal would simplify the current legislation and/or make specific provisions for better planned and supported transitions, while others felt the proposal did not tackle these issues. In many cases, where respondents indicated they agreed with the proposal, it was difficult to identify which element(s) they agreed with and why, or even if they agreed with the proposal or simply some of the background information and rationale that had been set out at this section. Indeed, many of the comments tended to focus on the current problems around transition, the confusing landscape, and the need for better processes or support, rather than linking to the specific elements of the proposal that would deliver this change.

Several respondents felt that the proposal was “vague” and unactionable, with others indicating that they did not fully understand what was being proposed at this section. Others perceived that the consultation document did not set out any proposals specific to transitions, or that what was set out suggested inaction in this area. There was a sense among a few of these respondents that the attitude conveyed was that this issue was too large and too difficult to tackle, which elicited frustration and anger, particularly among individuals:

> “So, the LDAN Bill is not going to add anything here. How long will this take to resolve? This is a huge gap… at every stage my son has gone through regarding his education journey, there is less and less support and the fight gets harder and harder the older he gets, and this to me sums up unfortunately public services not knowing what to do for young people with ASN… Families are always having to fight for everything for their children it just is not right... It simply is not good enough.” (On behalf of a LDAN person)

Change Needed

Whether individuals agreed or disagreed with the proposal, they stressed the need for change in this area. This included the need for more joined up services, more partnership working and a multi-agency approach to transitions, as well as greater and more proactive support. It was argued that support was required in order to prepare for transitions to ensure they are smoother, during transitionary periods themselves, following transitions to monitor progress and ensure longer term success, and also throughout adulthood.

Many respondents suggested that, too often, support would stop at this stage, i.e. transitioning to adulthood. It was described as reaching a “cliff edge”. Respondents highlighted that a lot of support and activities could be put in place via children’s and young people’s services (e.g. via schools and paediatric health services), but this stopped once a person aged out of these services:

> “But perhaps even more critical and not mentioned above is when a neurodivergent adolescent becomes an adult. The care they [received] prior to being 18 suddenly stops and very little explanation as to why is given to them. They and their carers, families and siblings are effectively left to fend for themselves. There is no "bridge" for this transition. We need one urgently.” (Neurodivergent Individual)

Indeed, a few felt that the lack of adult services were often the cause of poor transition experiences, as there was nowhere to transition into. Whilst not making the connection so explicitly, others also flagged cuts to and the lack of adult services, such as day centres which had previously provided purpose, community and care for those unable to work/live independently, as being problematic. As well as isolating the young person, this was also a source of anxiety for families who tried to find other services or activities, although in some cases it was noted that the removal of such services had left them with no alternatives.

Personal Testimony of Difficulties

Personal testimony of difficulties transitioning between children's and adults' services/sectors were provided by a number of respondents, including individuals who had lived experience and from parents/carers. In particular, respondents described poor experiences moving on from school, as well as in healthcare and the transition from CAMHS to adult disability or mental health services. It was noted that poor transitions, and a lack of support and positive destinations after leaving school, or the lack of a clear pathway through adulthood, can lead to significant issues. This included prolonged unemployment, a lack of purposeful activity, isolation, housing issues, and mental health problems for the individual as well as stress and anxiety for family/carers.

Some respondents also noted that the voices of young people with learning disabilities and neurodivergent young people were often not heard or taken into account when planning for transitions, with decisions being based on what is available rather than what the young person and their family wanted, or what would be in their best interests. It was stressed (often by organisations) that young people must be more involved in planning their future, and that services needed to listen to young people and their families during transition planning.

Gaps in Support

Respondents highlighted that gaps in service provision also existed due to different thresholds for children's and adults' services, with it being particularly difficult for those aged 16-18 as they were often between the age limits for services. This was particularly the case for some advocacy services, but was also noted as relevant for other services, such as social work.

In addition, several respondents flagged a gap in support for those who do not have learning disabilities and/or do not require full time care, but who were not fully independent. It was suggested they often still required some support, or support in particular areas, but that this was either difficult to find or did not exist.

Some respondents also suggested that provisions were inconsistent and patchy across Scotland, with some areas/services handling transitions (particularly from school) better than others.

Support Adult Transitions

Another commonly raised issue was that transitions should not be seen as something **only** affecting young people or as children transition to adulthood. Rather, it was stressed that support for transitions is needed throughout life, and particularly throughout adulthood, which respondents felt had not been addressed by the consultation. Various life stages and events were highlighted as transition points where adults required support and potential access to services (for example getting married, having children, housing issues, health issues, bereavement, changing jobs, retirement, and transitioning to senior years). Late diagnosis was also flagged as a key issue around supporting adults and setting up support for adults, and not just young people transitioning from children and young people's services:

> "We would argue that learning disabilities and neurodivergence are lifelong conditions and require a lifelong approach. Whilst it is important to ensure due consideration to the period of transition to adulthood we would advocate a lifelong, seamless, approach where, for example, teams work to support individuals across their lifespan, reducing and increasing that support according to needs and client preferences at different life stages." (LDAN Support/Representative Organisation - Other Conditions)

Support for Parents/Carers

Several respondents stressed that parents/carers also need to be supported through transition periods. This was considered necessary to provide information and a structure which would allow parents/carers to better support their young person to make choices about their future and to access suitable services/their rights. However, a few also noted that parents/carers sometimes needed support to allow the transition to happen, and as they themselves transition from a parent role to that of an unpaid carer.

Key Areas for Improvement

Simplify, Clarify and De-Clutter: A number of respondents, irrespective of whether or not they agreed/disagreed with the proposals, stressed the need to simplify and clarify transition processes, legislation and strategies, and to de-clutter the current landscape. A few felt that the LDAN Bill would be a good opportunity to tackle this.

Information for Individuals and Families: Another key area for improvement was for people with learning disabilities and neurodivergent people and their families/carers to be provided with more information and signposting about transition processes and support, available adult services and how to access them, and their rights and how to ensure these rights are upheld. Similar to concerns raised elsewhere in the consultation (particularly in relation to the provision of inclusive communication), it was important for information to be proactively provided rather than individuals or families having to find this on their own:

> "Transition is such a difficult stage for young adults and also very confusing and stressful for parents/carers that up to date accurate information, positive support and awareness is vital. At present this is an area where a lot of input and change to the present system is necessary." (On behalf of a LDAN person, and Family/Friend)

Timescales and Pathways: Another area commonly flagged for improvement/ seen as necessary to provide good transitions was more time/longer timescales for transition planning. It was felt that preparations needed to start much earlier, with respondents suggesting current transition planning and consideration of options/choices begins too late. A few of those responding as family members, friends and carers suggested this needed to begin at least two years or more before the actual transition point. It was also suggested that the age limit for children’s and young people’s services and the time dedicated to the transition phase could be extended so this occurred in a more phased way. It was generally felt that young people with learning disabilities and neurodivergent young people needed education, support and transition input up to age 25 to allow them to fully reach their potential, (with ongoing input and support from adult services beyond this point if required).

A clearer and wider range of pathways were also said to be needed for young people with learning disabilities and neurodivergent young people when they leave school. This needed to be combined with ongoing support to ensure positive destinations can be maintained over the longer-term. It was suggested that these situations (including further/higher education, housing, employment, etc.) can often break down over time, but that there was currently no review or monitoring of this.

More Services to Transition Into: The creation of more adult services to provide support beyond children and young people’s services was also viewed as crucial to avoid the “cliff edge” situation discussed above (and funding was critical to deliver this). Similarly, more funding was said to be required for services to support transitions, as well as direct funding for individuals/families to allow them to access adult services, support and activities:

> “Where transition planning is done effectively, it remains the case that a plan is only as good as the availability of meaningful destinations. Without addressing the availability of services and support for young people as they move to adult services, a transition plan will have limited effect. While it is right to ensure that planning starts at an appropriate time, and that processes are robust, without meaningful destinations the process will not be complete.” (LDAN Support/Representative Organisation - Autism)

Lead Professional and Peer Support: A few individuals and third sector organisations (who were focused on or advocated for young people) called for a named person, a lead professional, a co-ordinator or a key worker to support individuals and their families/carers through transitions to adulthood (and possibly beyond). Such a professional would take a lead role in managing and co-ordinating transitions, acting as liaison between the individual/family and professional services, maintaining and co-ordinating connections with and referrals into different services, ensuring timely and appropriate communication, etc. It was suggested this would be highly beneficial and remove much of the worry and stress from families trying to do everything on their own.

A few individuals also suggested that a peer support network/model and/or one stop shops would be useful to support and signpost young people with learning disabilities and neurodivergent young people through transition periods.

Eligibility for Adult Services: Some respondents highlighted the disparity in eligibility for accessing children’s versus adults’ services, particularly in relation to diagnosis. While a diagnosis is not required to access or be supported by many children’s services, it was noted that it is generally needed to access adult services/support. Some therefore stressed the need for more diagnoses to occur among children in order to allow them to access adult services later. Others, however, suggested that eligibility for adult services should be brought more in line with the children and young people’s system and be based on need, i.e. not requiring a diagnosis.

Data Specific Proposals

Some respondents (including both individuals and a range of organisation types and sectors) specifically discussed the data aspect of the proposal, with most of these respondents generally supportive of the four aims set out in the consultation document. While many of these respondents generally supported the collection of data to improve learning and understanding, and to help guide future strategy and service development in relation to transitions, several set out caveats and concerns, or were cautious or sceptical of data collection (similar to issues raised in relation to the overarching theme related to data). These caveats/concerns included:

- There being a need to gather disaggregated and intersectional data;
- A need for both quantitative and qualitative data to understand experiences;
- A need to involve those with lived experience in design/co-production of the types of data to be collected as well as data collection methods;
- Any data collection and analysis to be done in line with informed consent, data security measures and anonymity; and
- The practicalities of data collection were questioned, such as how co-morbidities would be classified and whether an official diagnosis would be needed.

Agreement with Overarching Themes on Improving Transitions

Several respondents suggested that national/local strategies in relation to transitions and better education/training and awareness for service providers would be helpful. Accessible information and increased advocacy for transitions was also sought.

While several individuals and organisations agreed that many of the overarching themes would be helpful in tackling and supporting transitions, it was felt that this issue needed greater consideration and specific coverage within the dedicated sections of the Bill to ensure this issue was properly taken into account.

Views Around More Legislation

Support for More Legislation: Some individuals and organisations felt that more robust provisions needed to be made for transitions within the LDAN Bill, and that this issue needed to be addressed specifically in legislation. It was felt that the LDAN Bill provided a good opportunity to support and “bolster” existing legislation, address some of the gaps in this area, and ensure a better and smoother system for transitions. There were also calls for transition planning to become a legally binding process, for there to be mandatory requirements and/or statutory guidance around transitions, and for individuals to have statutory rights in this respect.

A few individuals suggested that the decision to not enact the Disabled Children and Young People (Transitions to Adulthood) (Scotland) Member's Bill should be reviewed as this type of provision was considered highly necessary. Other respondents (including both individuals and a range of organisations) suggested the LDAN Bill should incorporate important elements of the failed Member's Bill. While most respondents did not highlight any specific elements to be adopted, a few organisations felt this should include the use of individual support plans and/or person specific transition plans/strategies, as well as dedicated transition teams and the resources that would be required to support this

No Need for More Legislation: In contrast, other respondents (covering a range of individuals and organisations, but particularly public bodies) felt that more legislation was not necessary in this area. However, respondents largely welcomed the forthcoming National Transitions to Adulthood Strategy.

Rather than new legislation, a few organisations (including a mix of public sector, third sector, and nationally representative bodies) highlighted the 'Principles of Good Transitions' developed by the Scottish Transitions Forum. They wanted to see this further endorsed, widely implemented, and embedded.

Tackle the Implementation Gap

Many respondents, including those who agreed with the proposals in principle and most of those who disagreed with the proposals, felt that they did not go far enough and would not be sufficient on their own to tackle the inadequacies in the system and significantly improve transitions. Together, it was perceived that they would do nothing to tackle the significant implementation gap:

> "The issues for young people with learning disabilities and neurodivergent conditions in transition to adulthood are well-known to those working in this area. As noted, the problem has been the implementation gap, with over-stretched services unable to provide what is promised in policy. [Organisation name] does not feel that this issue is addressed in this Bill." (Mental Health Organisation)

Even those who agreed with the proposals in principle, and were supportive of not introducing more legislation in this area, stressed a desire and need for actions to address the current implementation gap in relation to transitions. Again, increased investment, funding and support from the Scottish Government were said to be needed to deliver this, as well as the development of robust accountability measures (to be delivered by the LDAN Bill) to ensure enforcement of existing legislation and to address any failures to deliver this.

A few individuals only reluctantly supported the proposals on the basis that they were "better than nothing", but again stressed they did not go far enough and did nothing to address the implementation gap.

Sector Specific Transition Issues

Education

There were a few calls for young people to be able to continue with standard education beyond age 16-18. It was noted that young people with learning disabilities and neurodivergent young people often have different developmental timelines and that their achievements cannot always be realised in the same attainment windows as their neurotypical peers. Rather it was suggested that they should have the opportunity to pursue the standard curriculum up to the age of 25.

A more managed and supported transition from school into college and/or university was said to be required, as well as more support for young people once attending further/higher education settings, with providers being required to deliver this. This included the provision of more supported courses, and more support on mainstream courses (including in-class support) to make them more accessible.

It was also felt that more college courses were needed, both in terms of the number of places available for young people with learning disabilities and neurodivergent young people, and a wider range of courses. The lack of choice and low levels of aspiration for people with learning disabilities in particular was highlighted and considered to be an issue that should be addressed.

It was felt that both schools and colleges needed to do more to prepare young people for adult life - e.g. teach skills on building good relationships (discussed elsewhere in the consultation), neuro-affirmative boundaries, financial planning, what and how legislation applies to them, and how to achieve autonomy and control of their own lives. Further, it was suggested that educational settings should do more to support young people into positive destinations, including better preparation for further or higher education, independent living and employment - this included greater provision of work experience (also discussed elsewhere in the consultation). Awareness of, and mechanisms to support the transition to adulthood for those who disengage/refuse to attend school was also said to be needed.

Respondents stressed the need for a dedicated section on post-school education in the consultation/LDAN Bill to address inequalities experienced at college and university - the fact this was not included was seen as a “missed opportunity”. One third sector support organisation also recommended that any mandatory training requirements established for the ELC and school sectors be extended to include further and higher education - which it was noted were not currently in scope at the education based proposals (i.e. Part 3 Section 13).

Employment

It was also felt that the employment section of the consultation/LDAN Bill needed more dedicated coverage and focus on transitions if this issue was to be suitably addressed by those proposals. Other suggestions discussed in relation to employment included:

- Wider education and positive awareness raising of neurodivergence being needed among employers, avoiding the use of a deficit model of explanation;

- Training for workplace supervisors being considered as necessary;
- More organisations and employers needing to offer specific places/ employment for those with additional needs/people with learning disabilities and neurodivergent people, and employers (and education settings) needing to be reminded of their duty to consider reasonable adjustments; and
- Equitable access to employment may require further investigation.

Health

A few organisations highlighted the differences between children's and adults' health services. They noted the single paediatric approach to all health conditions in childhood, but that the adult system often requires the person to be seen by several different specialist and departments. This was said to be difficult for people with learning disabilities and neurodivergent people and their families to manage, and also made transitioning to adult services difficult as multiple services needed to be involved in planning. Again, it was suggested that having a lead service/professional or 'hub' might be helpful to try to align adult health services more with the paediatric approach.

It was also felt that more consideration and detail was needed in the consultation/ Bill for transitions in relation to both health and mental health.

Other Comments and Considerations

Only a few 'other' areas or issues were identified for consideration at this section, including:

- That transition support should be available to all disabled young people, not just young people with learning disabilities and neurodivergent young people;
- That the LDAN Bill should adopt a human rights based approach and be aligned with UNCRDP and UNCRC; and
- That more consideration was needed of issues affecting children, including adverse childhood experiences (ACEs) and childhood inequalities.

Part 4: Accountability

Introduction

The consultation set out how the LDAN Bill provides an opportunity to ensure that there is improved accountability for the delivery of individuals’ rights and presented five options for how this might be achieved, these being:

1. Create a new Commission or Commissioner;
2. Provide better resourcing and additional duties for an existing body;
3. Create Champions and Advocates within Scottish Public Bodies;
4. Provide better resourcing for existing Disabled People’s Organisations (DPOs) who support people with learning disabilities and neurodivergent people in ensuring that their rights are upheld; and
5. Supporting good practice through standards, guidance and practical tools and investing in co-production.

The consultation also set out that these options (either singly or combined) would operate in addition to the existing roles of charities and DPOs and would not replace them.

Main Findings

A closed question was asked to allow respondents to identify which of the 5 options they thought would best protect, respect and champion the rights of people with learning disabilities and neurodivergent people (with the ability to tick multiple options).

Options	Number	Percentage
Option 1: Create a new Commission(er)	291	65%
Option 2: Provide better resourcing and additional duties for an existing body	159	35%
Option 3: Create Champions and Advocates within Scottish Public Bodies	202	45%
Option 4: Provide better resourcing for existing DPOs	220	49%
Option 5: Support good practice through standards, guidance and practical tools and investing in co-production	203	45%

Base: 451 respondents answered this question
Note: Multiple responses were permitted at this question

Most respondents indicated that they would like to see a combination of different options, but there was no clear consensus around which combination of options this should be. There were also similar levels of support for all options with the exception of Option 2 which attracted the least support overall. Option 1 attracted greater support than any of the others as a standalone option.

While supported in principle, a number of respondents indicated that it was unclear how Options 3, 4, and 5 would deliver accountability unless accompanied by either Options 1 or 2:

> "We do not support Models, 3, 4 and 5 as they have no real accountability powers and would struggle to hold public authorities to account." (LDAN Support/Representative Organisation - Down's Syndrome)

The results were also disaggregated by respondent type (see Appendix B). This shows different preferences between individuals (largely represented by the results above), all organisations and public sector organisations.

- Results for individuals was largely consistent with the levels of support outlined in the table above;
- Organisations provided reasonably similar levels of support for Options 1, 2, 4 and 5, with between 52% and 56% of those who responded supporting each of these. Options 3 was slightly less well supported by all organisations (at 44%); and
- Public bodies preferred Option 5, with around three quarters (74%) of those who responded to this question selecting this option. Meanwhile, the least favoured option was Option 1, supported by just over one third (38%). However, the relatively small number of public bodies who responded at this question (n=42) needs to be borne in mind when interpreting the results, along with the fact that nearly half of all public bodies in the sample did not answer this question.

In addition to the closed question, 423 respondents provided qualitative feedback to support their choices and/or to comment on other possible options that should be considered.

Option 1: Create a New Commission or Commissioner

Many respondents supported the creation of a new Commission or Commissioner and felt that this was the best way of ensuring that historical failings in supporting the needs of people with learning disabilities and neurodivergent people were addressed. Many also highlighted that this had been long campaigned for and felt it was long overdue:

> "Despite positive strategies and legislation having been promoted or passed in Scotland over many years, the reality remains that a gulf exists between the aspirations of legislators and the realities of lived experience… We believe that the establishment of a Commission(er) with responsibility to focus on the rights of autistic people and people with learning disabilities can drive the change

> which needs to be realised…" (LDAN Support/Representative Organisation - Autism)

Many specifically supported the idea of a Commission(er) working alongside champions in different sectors, as an approach which they felt would provide the most accountability (ensuring central oversight and local action).

Other frequently given reasons in support of a new Commission(er) were that it:

- Would be a position of authority that was impartial and independent of Government;
- Would be an easily identifiable port of call for people wishing to raise issues linked to accountability;
- Would provide an official point/legal entity with accountability responsibilities;
- Could advocate for good practice/facilitate improvement in areas where practice is identified as being weaker or deficient; and
- Support the dissemination of good practice.

Respondents also commented that they felt the Commission(er) must:

- Have enforcement powers in order to be a credible option;
- Have 'duties' in relation to the legislation rather than 'powers' alone;
- Be able to hold public authorities to account;
- Have responsibility for collating data on outcomes for people with learning disabilities and neurodivergent people, and to monitor and respond to issues of concern;
- Be permitted to conduct formal investigations at both individual and service level;
- Have a role in promoting and securing rights; and
- Have a function to oversee issues of intersectionality, where learning disabilities, autism and neurodivergence overlap with other equality concerns.

Several respondents indicated that they would like reassurances that any Commission(er) would have the necessary expertise, knowledge and the capacity to address the needs of all of the unique communities covered by the LDAN Bill. Some also suggested it may have an even wider remit, for example, to include those with Additional Support Needs (ASN), to serve a wider proportion of the population.

Several comments were also made that it would be very important for the Commission(er) to continue to work closely with or be made up of people with lived experience and to consult with and involve individuals with lived experience in order to prioritise its work (i.e. to be supported, guided and advised by a 'LEAP-like' body which also included families/carers). As with comments throughout the consultation, however, respondents again stressed that such involvement needed to be meaningful and not tokenistic, and that additional preparation, training and support for those with learning disabilities, autism and neurodivergent conditions may be required to allow them to contribute.

Several comments were also made that if a new Commission(er) were developed, there must be robust selection and recruitment procedures in place alongside clear annual reporting mechanisms and a strategic plan in place to guide its/their operation (ideally co-produced with, and scrutinised by, people with learning disabilities and neurodivergent people and their families.) Similarly, making the financial accounts of any new body publicly available was encouraged.

The question did not require respondents to identify whether they had a preference for either a Commission or Commissioner, and there was no clear consensus within the qualitative responses. Most of those who supported this option either repeated the terminology used in the consultation document (i.e. referring to a Commission or Commissioner) or they discussed the issue in more general terms without referencing either a Commission or Commissioner. Only around a third discussed a singular entity, with slightly more referencing a Commissioner rather than a Commission, however, most did not explicitly highlight this was a preference between the two, and should not therefore be interpreted as such.

The main concern in relation to Option 1 was that the creation of another Commission(er) had the potential to add even more bureaucracy and cost to what was described as an already substantial Commission(er) landscape in Scotland, with risks of overlap/duplication of effort. The creation of a new Commission(er) may affect the roles and functions of other Commission(er)s and public bodies, it was felt, including potential transfer of duties and resources from them to the new body, which may cause confusion for both rights holders and duty bearers.

On this basis, some argued for strengthening the powers of existing Commissioners or giving them a broader reach to include people with learning disabilities and neurodivergent people, or putting in place mechanisms to ensure that existing Commissioners were paying due regard to issues that affect people with learning disabilities and neurodivergent people.

For some of those who did not support the ‘new’ body for the above reasons, there was clear evidence that they felt money should instead be used to support existing services or the development of more resources (i.e. the creation of a new body would divert resources from front line services):

> “Better outcomes may be achieved by focusing spending in areas which have a more direct and immediate benefit for those with learning disabilities, autism and neurodivergence.” (Mental Health Organisation)

Another caveat to support for Option 1 was the perception that there was unlikely to be sufficient resource to allow it to operate to its full potential. The time needed to set up a new body was also cited as a reason for marginal support.

As with the Bill overall, a minority view was that the Commission(er) must not conflate autism with learning disabilities. It was suggested that there should be separate Commission(er)s for neurodivergence and learning disabilities, or that dedicated Depute Commissioners or departments (sitting within one Commission or below a single Commissioner) would be required to ensure the two populations were best served. It was also suggested that a pan-disability Commissioner could be created, with specific Depute Commissioners appointed for learning disabilities, autism and neurodivergence.

A small number of respondents indicated that they felt more information on the specific roles and responsibilities of the proposed new Commission(er) was necessary to allow them to comment meaningfully on this option, and hence reserved judgement.

Option 2: Better Resourcing and Additional Duties for an Existing Body

There was less obvious support in the qualitative feedback for Option 2. Where mentioned, however, respondents mainly felt that existing bodies should already be taking more robust action to hold public bodies and public services to account with regard to issues affecting people with learning disabilities and neurodivergent people (and better enforcing equalities legislation more generally).

A small number supported this option on the basis that it would allow for harnessing of existing skills and expertise, as well as pooling of resources and the potential for intersectional learning. Similarly, a small number supported bolstering existing bodies on the basis that this was less divisive and would mean that people with learning disabilities and neurodivergent people were not treated as ‘separate’ i.e. by building on an existing model, individuals would not be segregated/isolated/excluded from the work of other bodies.

A small number also supported this option on the basis that the alternative of a new Commission(er) would not add value to the existing landscape (as above). Given constraints around finite resources, it was considered more resource efficient to better resource an existing Commission than to create a new one:

> “We support Option 2, strengthening existing bodies such as the Mental Welfare Commission to expand their role. It is our view that the accountability landscape is already a complicated one, and that the addition of a Commissioner specific to this Bill would exacerbate that without clear benefit to those most in need.” (Mental Health Organisation)

In contrast, an equal number felt that there were risks of people with learning disabilities and neurodivergent people being overlooked or not receiving the attention that was needed if further accountability responsibilities were allocated to existing bodies. These respondents questioned if any existing Commission(er) would be able to give adequate focus and resources to the issues affecting people with learning disabilities and neurodivergent people and their families.

Similarly, respondents were concerned that the roles of existing bodies may become diluted or compromised if new responsibilities linked to the LDAN Bill were to be subsumed into their existing roles:

> "I do not think that the issue can be subsumed into the brief of an existing Commissioner because the remit is very wide ranging and developing quickly. It's hard to see how an existing Commissioner could take it on without compromising their existing or new brief." (Family/Friend/Carer)

The other main concern linked to Option 2 was that existing bodies potentially did not hold the necessary skills, experience or knowledge required to address the needs of those covered by the LDAN Bill.

There were also views that existing Commission(er)s may lack resources needed to dedicate time specifically to the groups and issues covered by the LDAN Bill.

Option 3: Champions and Advocates within Scottish Public Bodies

As above, many respondents supported the creation of local champions and advocates to work alongside a newly created Commission(er), with the view that this would create the right balance of central oversight and local enforcement. If done in a meaningful way, this was seen as a good method of involving people with lived experience in raising awareness of their rights and promoting respectful cultures in various public bodies (in a more effective way than adoption of Option 1 alone).

Views were put forward that any such champions must be dedicated roles rather than this responsibility being 'added on' to existing roles:

> "The champions and advocates within public bodies should have this as their sole focus to ensure it is done effectively. It would include everything from setting up appropriate systems within each body, to ensuring all staff are trained and kept up-to-date, and support is given to any neurodivergent person taken on." (Family/Friend/Carer)

Suggestions were made that champions could usefully be identified from within existing lived experience communities, with views that DPOs would be well placed to assist with identification of suitable champions.

The main concerns regarding Option 3 were that any outputs or directions from these individuals would potentially be interpreted as 'guidance' or 'advice' which would be more easily ignored than those stemming from a more formal body. The lack of objectivity and independence of any such champions or advocates was also questioned, and it was suggested that their lack of impartiality may mean that they could not be seen as sufficient agents for overseeing accountability.

A handful of respondents made very specific comments that they disliked the use of the word 'champions' which they felt was patronising and off-putting.

Option 4: Better Resourcing for Existing DPOs

Many respondents supported this option, mainly on the basis that there was already significant knowledge, skills and expertise within these organisations which should be harnessed:

> “Existing organisations already have the knowledge and expertise and are led by neurodivergent people, all they need is more visibility and funding to reach a broader audience and create partnerships with public bodies.” (Neurodivergent Individual and Family/Friend/Carer)

There was agreement that DPOs currently lacked the resources required to have maximum impact but that, despite this, they often provided the majority of support and information received by people with learning disabilities and neurodivergent people, and noted that this was often more effective than that provided by statutory services. Giving them greater resource was, therefore, seen as an essential way of better promoting and meeting the needs of people with learning disabilities and neurodivergent people, as well as potentially enabling them to meaningfully participate in statutory services, policy making and training.

If this option was taken forward, the Scottish Government was urged to ensure that national funding for DPOs takes account of the needs of people beyond the central belt (i.e. to include DPOs in remote and rural areas), as well as to consider peer-led organisations and other local or less visible organisations that may not necessarily follow the traditional DPO model.

Again, however, this option overall was not necessarily viewed as an effective solution for accountability. Instead, better resourcing DPOs, and allowing them to work more closely with statutory providers (for example, through advocacy and training) would potentially see a more systemic shift towards neuro-affirming/inclusive outcomes in a more general sense, it was felt.

There was also some resistance to this option (which some described as ‘outsourced support’) on the basis that central and local governments should be the ones providing services and being held to account if they failed. It was argued that the third sector, or individual third sector organisations should not be expected to hold the Government or public bodies to account, that this should be the responsibility of the Government, regulators and/or any identified Commission(er). There were also concerns that third sector organisations or DPOs that receive Government funding cannot be considered as fully independent or impartial.

The other main concern linked to Option 4 was that there may be potential for inadvertent bias, depending on the focus/remit of different organisations, with a risk that some groups may be prioritised over others. Overall, however, there was a strong sense that respondents (especially individuals and third sector partners) supported more investment in DPOs and grass roots community level efforts to ensure that impacts of the legislation were felt directly on the ground.

Option 5: Supporting Good Practice

In line with comments made throughout the consultation, this option was supported by many respondents on the basis that working continuously with people with lived experience (like the LEAP) to produce national standards and guidance was the best way to help people understand the needs and wishes of people with learning disabilities and neurodivergent people and to uphold their rights.

While widely supported, however, this was seen as a fundamental requirement which should underpin all activity resulting from the Bill rather than being an effective mechanism for accountability in its own right. Indeed, some felt that this option did not constitute an accountability mechanism and it was disingenuous to suggest that it did.

Similarly, suggestions were also made that this option should work alongside others. For example, it should be integral to the role of a Commission(er) to work with local people and partners to provide guidance and support.

While largely supported, comments were also made that much already existed to support good practice but that this was not currently recognised or supported by the new Bill. For example, the ‘Charter for Involvement’ was cited as an influential co-produced tool already in existence which could be better promoted and understood through recognition and inclusion in the LDAN Bill and guidance. Instead of ‘more’ guidance, therefore, better use and promotion of existing guidance was urged.

Few respondents gave explicit reasons for not supporting this proposal except to express that it did not appear to constitute an accountability mechanism without additional oversight and enforcement action to complement it.

Overarching Comments

The main overarching comment was that, whichever accountability mechanism was used, it must be taken forward with, and be representative of, people with diverse lived experience (including their families and carers and including children and young people). In essence, respondents felt that any new powers or body created should be co-designed by people with lived experience, drawing on their experience, and must also be accountable to them.

Several respondents also stressed that there was a need for a clear plan with regards to how the Government would monitor and evaluate the success of the proposals presented in the LDAN Bill, (including any accountability measures), providing opportunities for challenge where duties in the LDAN Bill and other relevant legislation were not met. Having regular public reporting and feedback mechanisms would increase transparency and public accountability of how well public bodies uphold the rights of people with learning disabilities and neurodivergent people, it was suggested, as well as robust monitoring and evaluation.

Several respondents stressed that any ‘new’ accountability measures or strengthening of existing measures must be adequately advertised. This would be necessary to ensure people with learning disabilities and neurodivergent people were fully aware of their rights, what should be done to enforce them, and who to contact for accountability concerns.

There were also many comments that whichever option was selected it must be more robust and better enforced than existing measures:

> "There is a real risk here that the Bill will just add another layer onto the complex existing system which is failing without improving matters… Whatever is put in place, it needs to be ensured that there are more teeth, legislative power and with adequate financial and other resources to ensure meaningful change." (Neurodivergent Individual and Family/Friend/Carer)

A small number of respondents indicated that it may be more appropriate to wait for a Bill to be passed and implemented before taking action regarding accountability. Conversely, a small number felt that accountability had not been sufficiently built into the proposals as currently drafted. Others simply noted that they were unclear about if or how any of the current proposals would actually deliver effective change.

Other Options

A number of other options were put forward by respondents, but many were again linked to earlier comments such as the need to better enforce existing legislation or ensure that existing accountability mechanisms/strategies were working rather than introduce new measures. Indeed, there was a strong sense that none of the options may make a difference unless there was first a better understanding of why current mechanisms were not working.

Finally, specific 'Other Options' that were presented included:

- Local (authority) solutions to accountability rather than a single national model that allow measures to be tailored to local needs;
- Individual organisations having flexibility to create their own policies around supporting established rights;
- Having a locus within government which has oversight for specific areas (e.g. one focussed specifically on children, young people and their carers);
- Having a dedicated 'rapporteur' or champion within the Scottish Human Rights Commission to address learning disability, autism and neurodivergence legislation compliance/non-compliance;
- Legal empowerment initiatives to educate and empower people with learning disabilities and neurodivergent people about their legal rights;
- Peer support and mentorship programmes that foster peer networks and provide support, advocacy training, and mentorship (for example, similar to autistic peer support roles currently in place in England); and
- Introducing fines and professional sanctions as a means of enforcement/ penalties for non-compliance with relevant legislation.

Conclusion

Key Findings

Overall the consultation attracted a large number of responses, both from individuals and organisations. While this included a wide range of experiences and backgrounds, the representativeness of respondents is not known and feedback related to certain conditions and/or demographic groups risks being underrepresented.

Respondents were largely positive about most of the proposals outlined across the consultation document, with general support for the implementation of all proposals in combination in order to provide the most robust and accessible set of systems. In particular, respondents stressed the importance of ensuring meaningful involvement from a wide range of people with lived experience in taking forward any changes and designing any new systems or materials. Training for public sector staff (and others), as well as the proactive provision of accessible communication were also seen as key to improving current service provision. The publication of strategies, reporting duties and the development of strong and robust accountability measures were also perceived as vital to ensure change happens on the ground.

Key to the success of the proposals and measures, however, was the need to learn lessons from the current implementation gap which was considered to limit the effectiveness of existing legislation, policies and strategies. It was felt that capacity issues (including funding, staffing and staff retention issues, training, and the general availability of services/facilities) would need to be addressed across the public sector to ensure the proposals can be implemented in a meaningful and transformative way. Some sectors (such as housing, transport and education) would also require more infrastructure-based changes (which were not covered by the proposals) in order to make services more accessible to and suitable for people with learning disabilities and neurodivergent people.

However, it was also suggested that the approaches or proposals outlined for certain sectors did not go far enough and would benefit from more attention or being more robust. This included employment, education, and systems to support transitions. Further, it was suggested that the proposals focused largely on adults, and that greater consideration was needed in relation to children and young people throughout the various sectors and proposals. Barriers to diagnosis were also highlighted as a significant issue which the consultation document did not tackle. Respondents felt this was a missed opportunity and urged the Scottish Government to make provisions for this within the LDAN Bill.

Next Steps

The feedback from the consultation responses will be considered by the Scottish Government and used to support and inform the development of the Draft LDAN Bill.

Appendix A Other Demographic Information

Ethnic Group - Individuals

Ethnic Group	Number	Percentage
White Scottish	371	61%
White British	132	22%
Other White Ethnic Group	30	5%
Mixed or Multiple Ethnic Group	10	1%
Asian, Asian Scottish or Asian British	12	2%
Other Ethnic Group	17	3%
Prefer not to say / Not answered	37	6%

Base: 609 Individuals

Age Group - Individuals

Age Group	Number	Percentage
0 – 15 years old	6	1%
16 – 24 years old	34	5%
25 – 34 years old	78	13%
35 – 44 years old	139	23%
45 – 54 years old	162	27%
55 – 64 years old	108	18%
65 – 74 years old	41	7%
75 – 84 years old	11	2%
Age 85+	2	<1%
Prefer not to say / Not answered	28	4%

Base: 609 Individuals

Sexual Orientation - Individuals

Sexual Orientation	Number	Percentage
Heterosexual/Straight	442	72%
Bisexual	36	6%
Gay/Lesbian	17	3%
Other	25	4%
Prefer not to say / Not answered	89	15%

Base: 609 Individuals

Gender Identity - Individuals

Gender Identity	Number	Percentage
Female	378	62%
Male	154	25%
Non-binary	19	3%
Other	9	2%
Prefer not to say / Not answered	49	8%

Base: 609 Individuals

Local Authority Area - Individuals and Organisations

Local Authority Area	Individuals	%	Organisations	%
	Number	Percentage	Number	Percentage
Aberdeen City	19	3%	12	4%
Aberdeenshire	19	3%	15	6%
Angus	13	2%	13	5%
Argyll and Bute	14	2%	12	4%
City of Edinburgh	95	16%	37	14%
Clackmannanshire	9	2%	11	4%
Comhairle nan Eilean Siar (Western Isles)	3	1%	7	3%
Dumfries and Galloway	27	4%	12	4%
Dundee City	7	1%	11	4%

Local Authority Area	Individuals	%	Organisations	%
	Number	Percentage	Number	Percentage
East Ayrshire	13	2%	13	5%
East Dunbartonshire	7	1%	12	4%
East Lothian	19	3%	15	6%
East Renfrewshire	16	3%	13	5%
Falkirk	21	3%	18	7%
Fife	31	5%	21	8%
Glasgow City	57	9%	39	15%
Highland	23	4%	12	4%
Inverclyde	8	1%	12	4%
Midlothian	14	2%	14	5%
Moray	18	3%	0	0%
North Ayrshire	7	1%	15	6%
North Lanarkshire	21	3%	17	6%
Orkney	1	<1%	3	1%
Perth and Kinross	30	5%	11	4%
Renfrewshire	10	2%	15	6%
Scottish Borders	22	4%	12	4%
Shetland Islands	0	0%	3	1%
South Ayrshire	10	2%	12	4%
South Lanarkshire	17	3%	17	6%
Stirling	13	2%	11	4%
West Dunbartonshire	7	1%	12	4%
West Lothian	33	5%	16	6%
National Organisations	-	-	43	16%
Not Answered	15	2%	68	25%
Base	**609**	**-**	**268**	**-**

Note: Percentages do not add to 100% as multiple responses were provided by some Individuals and Organisations

Appendix B Individual versus Organisation Level Results

Part 3, Section 2: Mental Health and Capacity Law

Agree with the Approach by Respondent Group

Answer	**All Respondents**	**%**	**All Individuals**	**%**	**All Organisations**	**%**	**Public Bodies Only**	**%**
.	**Number**	**Percentage**	**Number**	**Percentage**	**Number**	**Percentage**	**Number**	**Percentage**
Yes	289	80%	227	79%	62	84%	26	90%
No	72	20%	60	21%	12	16%	3	10%
Total (Responded to Question)	**361**	**(41%)**	**287**	**(47%)**	**74***	**(28%)**	**29***	**(36%)**
Total (Responded to Consultation)	877	-	609	-	268	-	81	-

* Please note the small sample sizes of these groups.

Part 3, Section 5: Complex Care - Coming Home

Agree with a Statutory Duty to Hold a Dynamic Support Register by Respondent Group

Answer	**All Respondents**	**%**	**All Individuals**	**%**	**All Organisations**	**%**	**Public Bodies Only**	**%**
.	**Number**	**Percentage**	**Number**	**Percentage**	**Number**	**Percentage**	**Number**	**Percentage**
Yes	224	93%	157	94%	67	89%	26	87%
No	18	7%	10	6%	8	11%	4	13%
Total (Responded to Question)	**242**	**(28%)**	**167**	**(27%)**	**75***	**(28%)**	**30***	**(37%)**
Total (Responded to Consultation)	877	-	609	-	268	-	81	-

* Please note the small sample sizes of these groups.

Part 3, Section 5: Complex Care - Coming Home

Options for the National Support Panel (Proposal 2) - Preferences by Respondent Group

Options	**All Respondents**	**%**	**All Individuals**	**%**	**All Organisations**	**%**	**Public Bodies Only**	**%**
.	**Number**	**Percentage**	**Number**	**Percentage**	**Number**	**Percentage**	**Number**	**Percentage**
Option A: Legislative Panel Conducting Individual Reviews within Defined Parameters	68	32%	47	30%	21	35%	9	35%
Option B: Legislative Panel Conducting Peer Reviews of Local Processes	128	59%	100	65%	28	47%	9	35%
Option C: Non-legislative Panel Conducting Peer Reviews of Local Processes	19	9%	8	5%	11	18%	8	31%
Total (Responded to Question)	**215**	**(25%)**	**155**	**(25%)**	**60***	**(22%)**	**26***	**(32%)**
Total (Responded to Consultation)	877	-	609	-	268	-	81	-

* Please note the small sample sizes of these groups.

Part 3, Section 11: Restraint and Seclusion

Agree with the Approach by Respondent Group

Answer	**All Respondents**	**%**	**All Individuals**	**%**	**All Organisations**	**%**	**Public Bodies Only**	**%**
.	**Number**	**Percentage**	**Number**	**Percentage**	**Number**	**Percentage**	**Number**	**Percentage**
Yes	202	64%	148	61%	54	71%	29	88%
No	116	36%	94	39%	22	29%	4	12%
Total (Responded to Question)	**318**	**(36%)**	**242**	**(40%)**	**76***	**(28%)**	**33***	**(41%)**
Total (Responded to Consultation)	877	-	609	-	268	-	81	-

* Please note the small sample sizes of these groups.

Part 4: Accountability - Preferences by Respondent Group

Options	**All Respondents**	**%**	**All Individuals**	**%**	**All Organisations**	**%**	**Public Bodies Only**	**%**
.	**Number**	**Percentage**	**Number**	**Percentage**	**Number**	**Percentage**	**Number**	**Percentage**
Option 1: New Commission(er)	291	65%	220	68%	71	56%	16	38%
Option 2: Existing Body	159	35%	92	28%	67	53%	23	55%
Option 3: Champions within Public Bodies	202	45%	146	45%	56	44%	19	45%
Option 4: Better Resourcing for DPOs	220	49%	155	48%	65	52%	23	55%
Option 5: Standards, Guidance and Practical Tools	203	45%	135	42%	68	54%	31	74%
Total (Responded to Question)	**451**	**(51%)**	**325**	**(53%)**	**126**	**(47%)**	**42***	**(52%)**
Total (Responded to Consultation)	877	-	609	-	268	-	81	-

* Please note the small sample size of this group.
Note: Multiple responses were permitted at this question

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