Learning Disabilities, Autism and Neurodivergence Bill consultation project: under-represented and under-served Individuals

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SCOTTISH COMMISSION
FOR PEOPLE WITH
LEARNING DISABILITIES

Learning Disabilities, Autism and Neurodivergence Bill consultation project: under-represented and under-served Individuals

Executive Summary

This document provides a report to Scottish Government's Learning Disabilities and Neurodivergence Unit on the work commissioned from the Scottish Commission for People with Learning Disabilities to increase the number of responses to the Learning Disabilities, Autism and Neurodivergence Bill from under-served and under-represented communities.

The goal of the project was to inform and give detail of the Bill and the consultation process and to encourage responses. Where needed, and where capacity allowed, those contacted were advised or sign-posted to resources and assistance to support learning disabled, autistic or neurodivergent individuals to make submissions.

The project reached 126 organisation, un-constituted groups and groups on Facebook and WhatsApp; across 15 thematic areas.

70% of organisations reached disclosed that they would, or possibly would, make a submission to the consultation.

20% of the organisations/groups said that they would, or possibly would, support learning disabled, autistic or neurodivergent individuals or groups to respond to the consultation.

Learning points that were shared with the delivery team and that weren't going to be part of a submission to the consultation are captured here.

Reflections on barriers found within the consultation process have also been captured.

Purpose

The purpose of this report is to account to Scottish Government on the work they contracted the Scottish Commission For People with Learning Disabilities to undertake to increase engagement with the consultation for the Learning Disabilities, Autism and Neurodivergence Bill. There was a desire for communities that historically have been under-served and under-represented to be aware of the Bill, and where possible to provide their views.

Introduction

The project was to identify, connect, inform, encourage, advise and support organisations in connection with under-served and under-represented people with learning disabilities, and autistic and neurodivergent people with the aspiration to increase participation in responding to the consultation of the LDAN Bill.

This consultation was a significant opportunity for people with learning disabilities, and autism and neurodivergent people to really speak up for what they need in their lives. This is especially true of those who are most under-represented and under-served.

Project Scope

The diversity of the community that the consultation was trying to reach, and the barriers they face in responding, is vast, and there are many who are historically ‘hard to reach’. Our role in this was to identify key organisations that are already connected with those who are most under-represented and under-served. We engaged with the organisations, informed them of the Bill, its aspirations and processes and, if they were open to further work, advised and supported them in engaging with people with learning disabilities, and autistic and neurodivergent people within their communities to assist them to respond to the consultation. The responses were a blend of organisational responses and responses from people with lived experience.

Not in scope:

- Work with the LDAN sector to develop responses.
- Public (‘Town Hall’) meetings.
- General promotion of consultation.
- Media (social media or press) work to promote the wider consultation.
- Facilitation of events.
- Physically attending events.

The process was delivered by SCLD (governance) and the Project Team (delivery).

Targeted populations

In terms of some of the under-served and under-represented (USUR) populations, the initial ambition was to access and get representation from:

1. Children and young people who SG hadn’t engaged with during development so far.
2. Minority ethnic communities.
3. People in care or hospital settings.
4. People in prison.
5. People that are homeless.
6. Travelling communities.
7. People with Profound and Multiple Learning Disabilities and their families.
8. Families and carers.

Caveats:

In terms of (1), in its widest terms, this is a vast group of individuals. The scope of this project did not include a broad call out to children and young people with Learning Disabilities, Autism and Neurodivergence; nor the school or FE/HE sectors.

Principles:

- Covering all conditions (learning disabilities, autism, ADHD, FASD, dyslexia, Down Syndrome, etc) as far is possible in time available.
- Focus on people's lived experience and their views on proposals in consultation documents.

The initial ambition in the contract was to connect, encourage and support up to 30 organisations within the above streams. This goal was set at a pragmatic level as it was not known what level of appetite and engagement there would be from organisations. That target was exceeded significantly.

The ambition was to see both organisational responses, and responses from individuals with lived experience.

Methodology

There were a series of activities to deliver the project:

- Identification of organisations in contact with those who are most under-represented and under-served.
- Explanation and promotion of consultation process to the above.

- Signposting organisations to Scottish Government materials to support the consultation process. Also signposting to other materials that were available at the start of the consultation, and that were also developed during its progression.
- Informing and signposting organisations to events that their communities may have wished to participate in.
- Delivery of 6 webinars and group sessions to explain the Bill, its processes, and ideas of how to engage well with LDAN individuals.
- Delivery of a small session to help isolated parents respond.
- Development of material to assist communities to submit responses and the provision of a webpage on which these resources were hosted.
- On-going conversations with organisations as they developed their engagement with their communities to support them to be able to respond to the Bill consultation.
- Prompting of organisations to submit adherent and timely responses if they chose to do so.
- Ongoing feedback to the SG Bill Team through regular meetings that fed back data on the progression of the project and relevant findings.
- The provision of a high level summary report on the engagement with organisations and distillation of learning points and any barriers that arose.

The initial contact to organisations stemmed from list provided by Scottish Government and knowledge of the field by the Project Team. Then a ‘snow ball’ technique was used where contacts were asked to suggest others that should be reached. This provided an organic development of contacts which was the fastest way of moving forward in the short window before the close of the consultation.

Governance

SCLD held the project grant from Scottish Government and contracted delivery to the Project Team (Helen Chambers and Kirsty Gilchrist), who then arranged and provided additional freelancers (Fiona Scott, Kate McInnes), project delivery, administration, data capture, project management and reporting.

The Project Team met weekly, and met with SCLD regularly throughout the project.

The PT met regularly with members of the SG Unit.

The project ran from 1 February 2024 - 31 May 2024.

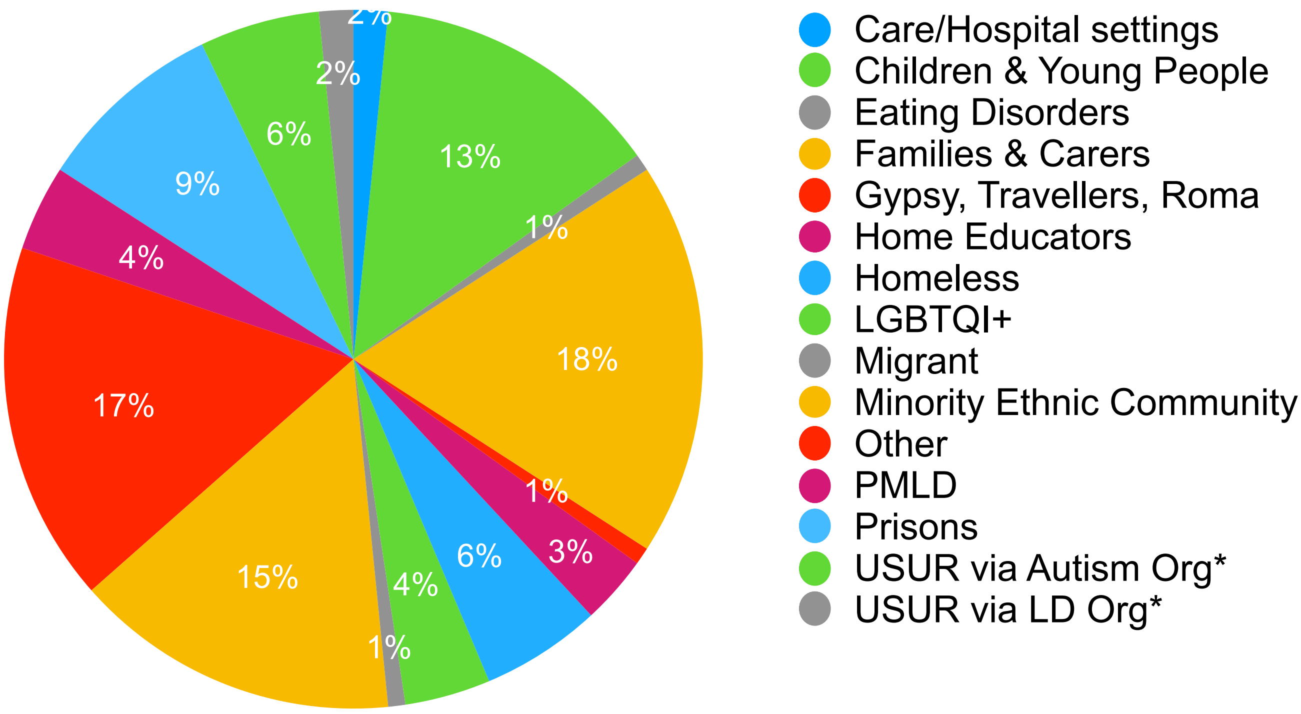
Reach

Due to the nature of the communities that the Project Team were trying to reach there was a lot of contact with small, un-constituted groups, or informal collections of individuals in FaceBook or WhatsApp groups; and occasionally individuals. For the purposes of this report the phrase ‘organisations’ means all those contacted regardless of legal structure.

A list of all organisations/groups contacted is provided in Annex 1.

126 Organisations were reached. A breakdown of various categories of under-served and under-represent communities that were contacted is shown in Chart 1.

Chart 1. Organisations reached, by theme



**An USUR community reached through an Autism, ND or LD organisation*

Chart 2. below shows organisations' likelihood of making a response to the consultation. Two elements are to be noted:

Organisations were approached 3 times to see if they would share if they were likely to make a response. If no answer was given after the 3rd contact we did not chase further as we did not wish to antagonise them or waste their time if they weren't engaging.

It is difficult to know what balance of the organisational responses can be attributed to this project only. Some organisations would have responded with no approach, but we believe this is not the case for a significant and meaningful number due to conversations held during the project.

40% of organisations/groups held a national remit.

20% were based rurally.

Chart 2. Organisations likely to make a consultation submission

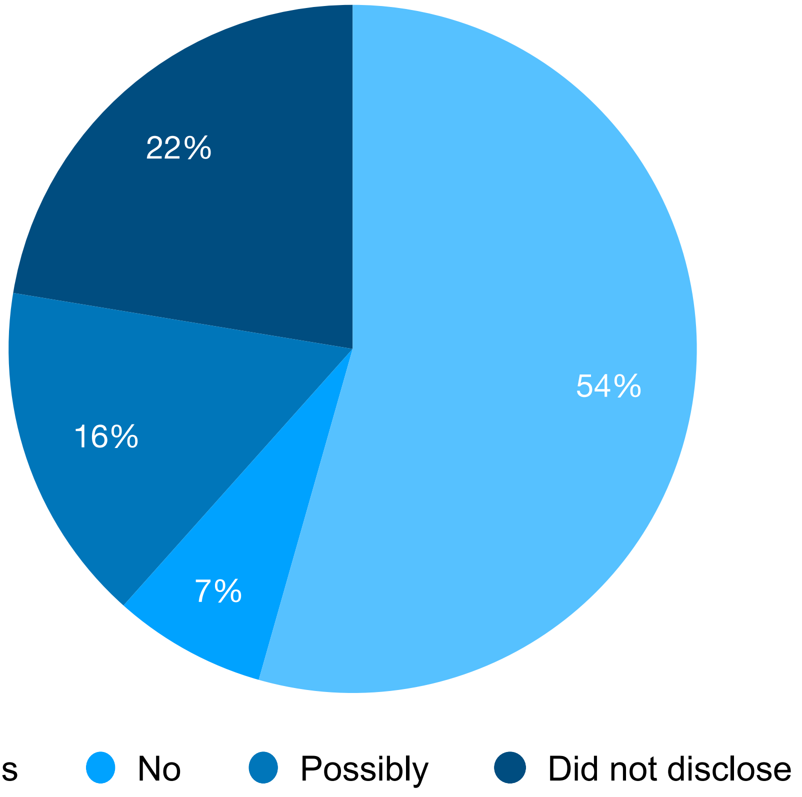
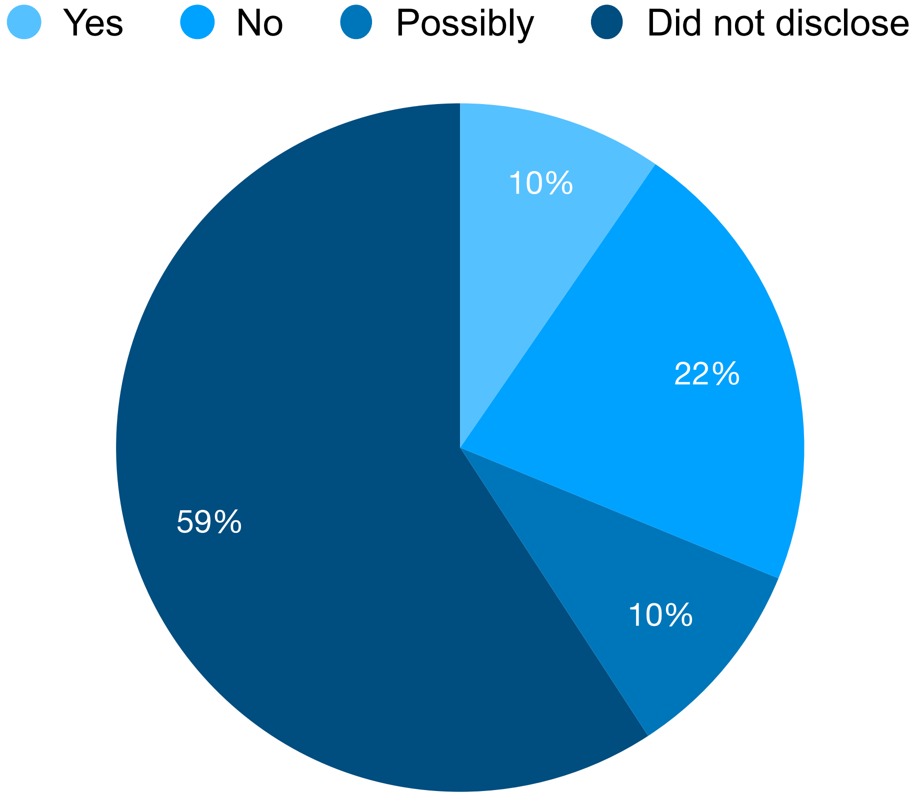


Chart 3. Organisation assisting people with lived experience



We asked organisations, and assisted or sign-posted if they needed more support, whether they would assist people with lived experience of learning disability, autism or neurodivergence to make a response to the consultation. We recorded their answers, again we followed up 3 times. Chart 3. shows their responses.

We are more certain here that replies ‘Yes’ or ‘Possibly’ could be attributed to the project. We had significant conversations with some organisations to support them to work through how they may help their beneficiaries from LDAN communities to respond.

It is worth noting that each ‘Yes’ or ‘possibly’ can represent more than one consultation response. Some organisations held groups where individuals worked to develop their own responses, or helped a number of individuals make responses. We were not able to capture these numbers due to the balance between organisations that we worked with capacity and time to engage with us, and we felt it was more important to release their time to work with people, rather than be chased for data.

As we worked though engaging with organisations it became clear that some additional resources would be useful. These were developed and then placed on a web page so they could be easily accessed.

The resources we developed were:

- Planning to Play Your Part. A resource for families, managers, front-line workers to think and plan a response to the consultation.
- Helpful Questions - A Guide for Support Workers
- A word version of the consultation download (for cognitive dysfunction)
- A Loom* on how to fill the online consultation on behalf of someone else

[*an embedded video that plays in real time to show how the web based submission could be filled in.]

There were 487 hits on the web page, with the peak being in February.

Learning

The following sections reflect on elements of what we heard, and learning from the various thematic communities. To avoid duplication we have strived to not include material that organisations said that they would submit within responses to the consultation. This means that there is more detail in some sections rather than others, and those tend to be the communities that are less resourced, less formally constituted, or with less capacity.

Children & Young People

Reduced capacity to respond was particularly the case for parents, carers and families of children of a school age. Many LDAN children are taken out of formal education because of inadequate support for their mental health struggles. And the more their mental health struggles, the more challenging their behaviour can become. At this point, it seems, services are unable to support them.

This is complex because it is very much dependent on the ability of the parents to support their children through this situation. If the parents are unsupported or unable, then the vulnerability of the children becomes much greater.

Key Learning

Long Transition Processes: Accessing support services requires significant time, knowledge, and effort from parents, who must navigate complex systems to secure necessary assistance for their children. This long "runway" for transition often demands high levels of skill and dedication from parents.

Inadequate Mental Health Services: Children and young people with severe and complex mental health needs are often the least well-served, due to overstretched services. These individuals frequently find themselves at the bottom of the priority list, exacerbating their vulnerabilities and intersectionality.

Parental Isolation: Parents as carers are isolated even if they are linked to groups. At home they may have been missed by the process or the system, and they rely on social media to access the ‘world’. They are not ‘held’ by organisations– and instead feel use organisations for specific, time bound, issues.

Navigational Challenges: Without the necessary orientation, many parents struggle to navigate the systems available to them, resulting in decisions like home schooling when formal educational settings become untenable. In one instance, the local authority was seen as bullying and threatening to home educators.

Dependency on individual parents within Support Groups: The effectiveness of support groups often hinges on the drive and skills of individual parents. If these parents are absent, the support landscape becomes difficult to navigate, and crucial knowledge transfer is lost as these individuals move on.

Middle Tier Vulnerability: Children who are not identified as the most vulnerable often fall through the cracks, described as "not vulnerable enough" to receive adequate support. These children are at heightened risk of isolation, neglect within the educational system, and subsequent issues such as encounters with the justice system or homelessness.

Recognition of Skills in Young People: There is a lack of recognition for the skills and potential contributions of LDAN and neurodivergent young people, particularly those who might excel in non-traditional settings or setting up their own business.

Mental Health - Challenges and Inequalities Faced by Young People of the LDAN community with severe mental health problems.

Because this is a small group of people, there is one network that is purely focused on this across Scotland. We met with some members of this network to encourage them to submit a response, and to understand more about their area of focus.

Young people with learning disabilities in the UK encounter significant disparities and challenges, notably in mental health, that reflect societal attitudes towards this vulnerable population. Children and young people with learning disabilities are over four times more likely to experience mental health issues compared to their peers without disabilities. Notably, one in seven children and young people with mental health difficulties also have a learning disability.

In Scotland there are no dedicated NHS specialist intervention units for these young people and the group we spoke with spoke of a disparity between the services given to those with and without Learning Disabilities or Autism. There was also a concern that these young people are so little supported in practice that their needs are often not prioritised. Therefore, there is a hope that this group is highlighted in the LDAN consultation analysis.

Risk Factors and Early Intervention

These individuals are more vulnerable to mental health problems not directly due to their disabilities, but due to external socio-emotional stressors including poverty, parental mental health issues, and negative life experiences. The risk of developing mental health issues can be identified as early as age 3, underscoring the critical need for timely and effective early intervention strategies to mitigate long-term impacts.

Service Accessibility and Effectiveness

Despite their pronounced needs, there is a stark lack of dedicated mental health services and inpatient units specifically tailored for children and young people with learning disabilities and autism spectrum disorders in Scotland. This group often receives inadequate support due to insufficient research and a general lack of clinical evidence guiding assessment and psychological treatments, particularly for those with severe learning disabilities. The absence of specialised inpatient facilities necessitates reliance on less suitable general adolescent mental health services.

Government and Healthcare System Challenges

According to Dame Lenehan’s review, while these young people are not overlooked by government initiatives, the diffusion of responsibility across various programs leads to a lack of prioritisation for their specific needs. Funding for dedicated learning disability and mental health services has not been effectively allocated or utilised, contributing to ongoing service gaps.

Familial Experiences and Service Gaps

A significant proportion of families in contact with the network have reported a need for more appropriate supports endorsing the utility of an Intensive Intervention Service. Families frequently face challenges with service consistency, needing to repetitively provide the same information to various professionals. This, coupled with delays in service access during crises, highlights systemic inefficiencies. Additionally, there is a notable deficiency in local specialist resources and expertise, which affects the quality and effectiveness of the support available.

Reflections

The persistent challenges and inequalities faced by young people with learning disabilities in accessing and benefiting from mental health services would benefit from urgent attention and improvement. Enhanced funding, specialised services, and a more integrated approach seem imperative to address the needs of this extremely marginalised group effectively.

Home Educated Children

We spoke with three organisations, and visited one group.

There are an increasing number of families who are choosing to home-educate their children, particularly those who are neurodivergent or have learning disabilities. This trend is often attributed to the challenges these children face in conventional school settings, such as sensory overstimulation, inadequate support, the endemic use of restraint and seclusion and bullying.

Given these factors, many parents of neurodivergent or children with learning disabilities see home education not just as a preference but as a necessity, driven by the desire to provide a more accommodating and less stressful learning environment for their child.

The feedback from various stakeholders underscores a significant disconnect between existing educational legislation and its implementation, with a strong call for better enforcement and more informed, empathetic approaches to supporting LDAN children. The need for effective advocacy, both parental and independent, was emphasised as crucial in addressing these challenges.

Children not in school or home educated

We need not to forget about those who aren't in school and are not being home educated. LDAN children are significantly more likely to experience bullying, which can exacerbate depression and anxiety. This group of children are even more at risk as they can be preyed on as vulnerable. This was picked up in the newly published Jay Review of Criminally Exploited Children

> "*Special Educational Needs and Disability (SEND) or learning difficulties. We heard that children with SEND are placed at increased risk if those needs are not recognised or supported. In particular, neurodiversity was cited in nearly all the examples we heard of exploited children, with undiagnosed or untreated ADHD noted as a significant risk factor by multiple witnesses. Victims may be less able to recognise they are being exploited or less able to communicate it or access support, or have limited capacity when making sense of situations or making informed decisions. Children with ADHD are less able to assess risk or control impulsivity. These children are targeted by exploiters as they are perceived to be easier to control*"

Organisation A

A group for parents in the south of Scotland highlighted significant barriers their children face in accessing education. These barriers include refusal of school placements and exclusion due to the children's conditions and the absence of formal diagnoses. During a consultation, these parents expressed concerns that the complexity of the legislative process could overwhelm many, indicating a gap in understanding critical terms like "Bill" and "legislation."

Enforcement of Existing Legislation: The group pointed out that while there are laws intended to support non-verbal and autistic children, these are not adequately enforced, resulting in unmet basic educational needs.

Organisation B

This organisation emphasised the role of parents as primary advocates for home-educated children but noted a deficiency in independent advocacy. They suggested that a significant portion of home-educated children are autistic or have additional support needs (ASN), with many leaving traditional school settings due to unmet needs or bullying. The remarks also touched on a general apathy among home educators towards engaging with local authorities, some of whom they felt exhibit bullying behaviour to try and get children to return to school.

Organisation C

An ASN tutor and home educator, discussed her personal and professional experiences with neurodivergence, including her own recent diagnoses of ADHD and dyslexia. They shared distressing outcomes for their children due to the school environment, including chronic fatigue triggered by school-related trauma. They criticised the frequent, casual use of the term "neurodivergent" in legislative discussions, arguing that it dilutes the seriousness of the issues faced and underscoring the need for empathy and understanding rather than attempts to "fix" neurodivergent children.

People in Care & Hospital Settings

We were initially encouraged when an NHS Board we had approached authorised individual Mental Health staff members to engage with consultation. Information and invites to the H&SC Webinar were circulated across relevant teams but some hesitancy was fed back about engaging with ‘consultants’ (us) rather than directly with the policy team, so we had to rely on individual staff motivations to complete the response rather than being able to spend time directly with staff. As a result we have no direct data about the level of response.

We heard anecdotal evidence of parents being concerned that overly focussing on the Dynamic Support Register and bringing young individuals back into their home region might be at the expense of quality of care in some cases. In particular where the home region was rural and ‘coming home’ meant unnecessary disruption to care or compromise in standards where specialist facilities were not readily available locally. This included the concern that local authorities might feel pressured to meet targets at the expense of what was best for the individual or not be able to reach agreements on funding care out of area. We heard that some parents would rather travel out of area if they felt it was in the best interest of their child for their ‘home’ to be in another region.

Care and hospital settings are notoriously difficult to access to speak with people in the LDAN community. Therefore, we approached People First (Scotland) to see if we could support them in their role of care and hospital settings and the LDAN Bill consultation. They confirmed that they are going in regularly and would submit a response.

Minority Ethnic Communities

We approached ten organisations, of which four responded directly to the consultation. We also engaged with Scottish Ethnic Minorities Autistics (SEMA) to widen the reach of organisations and communities. SEMA achieved this through involving local translators from the LDAN (Learning Disability and Neurodivergence) Alliance community, facilitating broader inclusion of ethnic minority individuals. A detailed account of this engagement will be provided to Scottish Government in a separate report directly from SEMA.

Key Learnings and Challenges

Language and Cultural Barriers: This initiative marked the first extensive inclusion of ethnic minorities in discussions related to neurodivergence and learning disabilities. A significant challenge was the lack of equivalent terminology for concepts like "autism" and "neurodivergence" in many languages, complicating translation efforts and understanding.

Intersectional Challenges: Communities often lack cultural recognition or comfort with learning disabilities and neurodivergent concepts, which complicates representation and acknowledgment within these groups.

Underinvestment: There was a sense that there has been limited investment in community-specific organisations, resulting in a lack of services that individuals feel comfortable accessing.

Organisational Insights

Organisation D

This group focused on health services improvement and empowerment for ethnic minorities, including African, Polish, asylum seekers, and refugees. They noted the silent suffering of members within the LDAN categories and the need for these voices to be heard.

Organisation E

Expressed hesitation in participating due to past negative experiences with governmental engagements and skepticism about the efficacy of proposed legislative changes. They highlighted the community's struggle with cultural and linguistic barriers.

Organisation F

Actively submitted a response focusing on supporting women with mental health issues following gender-based abuse. They emphasised the importance of empowerment and knowledge in accessing support services and addressed the extreme isolation and vulnerability of their service users, especially within Pakistani communities where issues like congenital disabilities from cousin marriages, mental health stigma, and taboos are present.

Cultural and Trauma Considerations

Organisation F underlined the significant trauma experienced by their service users, often related to severe abuse histories including FGM, torture, and rape. The organisation provides support in 34 languages, enhancing accessibility for non-English speakers. However, challenges like mistranslation, stigma, and a lack of specialist support persist, particularly affecting women's ability to engage positively in parenting roles.

Economic Contribution of Refugees

It was noted by organisations that refugees contribute significantly to the economy, reportedly seven times more than they receive in aid, highlighting an important aspect of the economic impact of supporting such communities effectively.

Families & Carers

We noted that families and carers often have very little time to go through this consultation process, and many faced isolation and a lack of support. However, there was a very comprehensive consultation done with National Care Organisations – many of the same elements of learning have been reflected in the Children and Young People section.

People who are Homeless

We engaged with several organisations serving the homeless community or working to prevent homelessness and met with contrasting approaches.

One organisation felt their role was to deal with the acute problem as presented by the service user; and that it was not their place to ask questions about the LDAN status of the individual. They describe identifying someone as learning disabled, autistic or neurodivergent as not within the scope of their remit. As a result they didn't feel able to engage with the consultation process.

In contrast another organisation took the approach that understanding an individual's personal circumstances fully, including any additional challenges they faced such as autism or neurodivergent status, was material to developing an effective holistic service, and to homelessness prevention and reduction. They were already working to understand what their communities' experiences and so were very keen to report their findings directly within the process, and therefore submitted a response.

People in Prisons

Making contact with hard to reach or underrepresented groups was challenging. No more so than when trying to reach LDAN prisoners. This was to be expected, but our experience identified unexpected additional reasons for these challenges.

We spoke to 2 prison governors and developed links to 3 prisons.

During the consultation period, we identified 12 individual contacts linked to the prison service, families of those in prison or organisations supporting former prisoners through the justice system.

Of the main contacts, 4 are national organisations. SACRO provides a wide range of direct, innovative services in Community Justice, Community Safety and Public Protection. SOLD and SISCO work with those going through the Criminal Justice system (CJS). CGL run the Fresh Start Criminal Justice Service. Families Outside work with families of those who are going through the CJS or are already in prison.

All were keen to submit responses to the consultation. Some saw this as an essential opportunity to raise awareness of an issue ‘that did not get the publicity it required’.

Where needed, Family Support Workers and Prison Visitor Centre Managers were encouraged to help families to respond on behalf of their family member in prison.

We attended a national meeting held by SOLD. This came at the end of the consultation period and was useful for us to reflect on our findings compared to the opinions of those who have worked in this sector for many years. 15 attended including representation from Community Justice, University departments of Criminology and of Criminal Psychology, Advocacy, Police Scotland, Employability, Sisco, University of Edinburgh, Fetal Alcohol Spectrum Disorder and SOLD team members including the Chair who is a former prison governor.

Our findings (outlined below), which they found “*sadly familiar”*, broadly reflected their own experiences. They were “*very frustrated and sad there are still continuing problem*s”, “*the SPS (Scottish Prison Service) hasn't moved on*” is a direct quote. It was reported that the SPS are invited to this meeting but do not attend.

Approach

Through existing contacts, we were put in touch with HMP A. The Governor of HMP A is involved with neurodiversity in their role at national level as Chair of SPS E&D Managers Forum. They also works on projects linked to autism training with officers looking at other projects regarding neurodivergence in the prison setting. They are in contact with other governors but to put us in touch with them all would be very onerous, and they did not have time to do so.

Digital safety barriers put in place by the prison service means it is not possible to speak to prisoners other than face to face. Prisoners do not have access to laptops and can only respond in writing. It was decided that a small focus group of a maximum 10 prisoners would be the best option. Unfortunately due to timing constraints the group was unable to go ahead.

HMP A Governor put us in touch with the Governor of HMP B. They were happy to give engage and to arrange an LDAN focus group. 6 questions was the maximum deemed viable for the group to consider. It was decided that to focus on the Justice Section of the LDAN consultation document was the best way to deal with this. The Governor agreed to collect responses after which they would be passed to us for processing a response on the group’s behalf.

We developed the question sets based on the Justice section and tailored it to the requirements set out by the Governor.

A meeting was arranged with an existing group of 10 prisoners, the Recovery Cafe Group.

The focus group agreed with all the proposals in the Justice section and recommended that:

> *Not only the Justice System be responsible for this Bill, but the NHS should be trained in addition. As a whole, the group believed that a strategic and coordinated approach incorporating all 6 proposals would assist not only neurodiverse/learning disabilities but also those with mental health problems. They wanted it noted that if judges, prosecutors, and police had an overall and detailed view of any individual accused of any crime, then a much more informed decision could be considered. Similarly, if prison staff and prison-based services were fully aware of all issues then the individual concerned could be afforded more opportunity to change or adapt. In conclusion the group felt that issues*

> *relating to LDAN should be highlighted long before that individual enters the prison system. If opportunities have consistently been missed by agencies who have early/ formative years' experience, the justice system may always be playing catch up.*

We also spoke to an individual who had been working in HMP C. They found a significant number of autistic people in prison and set up a support group for autistic prisoners that grew & met weekly. They also set up lived experience ambassadors who helped when someone was in need. This work only happened as the individual who led on this was extremely passionate about supporting autistic people, and had identified the high percentage of people whose lives would be improved if there was a greater understanding for their needs. However, after 2 years the prison management decided it did not fit with the prison's vision on wellbeing. HMP C no longer have an autism support group but do have an EDI lead.

Reflections

- There had been difficulty in engaging with women in prison who identify as LDAN. We were told there had been no female voice to date, so we did our best to make sure there were submissions in this process. There is inconsistent support for LDAN prisoners across the prison service.

- It seems that a large number of those who are in prison, or are going through the CJS, have children/ family members who are part of the LDAN community.

- It would seem that there is a lack of support for those in prison with undiagnosed or unrecognised LD, autism, and neurodivergence and this is seen as a problem within some prisons.

- Limited contact between prisons means there is no cohesion or coordination particularly of sharing LDAN related data if a person transfers to another prison. An individual's requirements may be recognised in one prison but not in another as information is not shared.
- There appears to be varying recognition of LDAN within prisons. Some do not believe they have prisoners who are LDAN, others say they deal with issues presented by LDAN individuals on a regular basis.
- Some prisons do not distinguish between LD, autism and neurodivergence, particularly as there is little data or knowledge of the subject and no coherence across the sector.
- There was concern from some organisations about how to submit a response in case it created conflict with prison management. An anonymous approach was suggested.
- There is a need for disability awareness training for prison staff as they have little knowledge of how to support the LDAN community.
- It was reported that there is repeat recidivism because some learning disabled, autistic, or neurodivergent prisoners do not understand their bail or license conditions.

Potential policy developments

There are some interventions that could be considered when developing policy in this area:

- Consistent and coordinated approach in data sharing across prisons.
- An LDAN passport. Not having one for autistic prisoners means reasonable adjustments don't exist. For example, a

prisoner may have been allowed headphones in one prison, but not the new one they were transferred to. Or not having reasonable adjustments may influence visiting times as noise and being surrounded by a lot of people may be a trigger. The concept of an LDAN passport is not new, but was seen by many as an essential requirement for reducing reoffending and assisting rehabilitation.

- An assessment to take place at the point of entry to prison. Issues relating to LDAN should be highlighted long before that individual enters the prison system.
- Mandatory training could reduce trauma experienced at each level of the justice system.
- A greater understanding of neurodivergence and associated factors could promote inclusion whilst reducing reoffending. An example provided described an individual who had sensory issues with being touched, particularly by men. If justice services such as police or prison staff are aware an individual could be triggered, then additional training or even (in this case) only deploying female staff may avert additional charges as well as trauma. If all justice sector staff had the training, then prisoners would be more comfortable disclosing issues.
- Many are intimidated and confused by written documents such as bail conditions. Those who had been subject to WAIS assessments felt their needs had been met much more effectively and alternative communications such as verbal and diluted wording helped. The offer of virtual or telephone meetings alleviated the pressure many felt. They did not want to attend offices or areas that were highly populated. This created an anxiety that could trigger adverse feelings or actions. However, face-to-face meetings could be helpful to

allow them to be fully understood rather than simply being described by their conditions/crime. Whilst the Bill could be helpful, prisoners did not want to be defined by their limitations.

- There could be scope for neurodivergent people to benefit from the use of Diversion from Prosecution, but a level of responsibility should not be dismissed. If information was readily available to police, CJSW and prison staff for example, but they failed to take cognisance, then it could be taken into consideration when deciding to prosecute. Similarly, this could be the case at sentencing or even arrest.
- If certain conditions such as ADHD, Autism and other associated learning difficulties were taken into serious consideration at early stages, the prosecution may not have proceeded with certain cases. Alternatives to custody may also be beneficial if the cases did go ahead.
- With a potentially high percentage of LDAN prisoners, heightened awareness of the needs of this community is likely to reduce challenging behaviour.

Older People

One organisation we spoke with doesn’t collect data on individuals when they engage. In discussions, we learned that the intersectionality of someone who is elderly means that their physical ailments and age were prevalent rather than any neurodiversity issues. Taboos around talking about learning disability or autism and neurodiversity play a role and means that this topic isn’t often discussed. Also many older people who may be autistic or neurodivergent won’t have had this identified.

LGBTQI+ People

Organisations reported an uplift in LGBTQI+ individuals from LDAN communities needing support, putting a strain on the organisations and groups providing that support, as their capacity is not funded sufficiently to pick up on these additional needs. Services are having to change their delivery to accommodate that increase.

An additional issue was trying to get an LDAN cohort to respond to the consultation. It was reported that there is therefore a frustrating combination of a need for more support but also a reluctance to engage from people.

There was significant apathy about the Bill or that anything would change as a result. "*we've been here before*", "*what's the point in this?" "It's just so someone can tick a box isn't it?"* were some of the quotes mentioned by organisations that had been noted when trying to encourage a response to the consultation.

Of the 5 organisations we contacted supporting the LGBTQI+ community, all engaged directly with us. One had already submitted a response and noted the large number of LGBTQI+ people who also identify as neurodivergent. The others were all broadly supportive of the Bill although some noted a high level of consultation exhaustion. They also reinforced the message that their service users did not believe the Bill would have a positive impact.

People with Profound and Multiple Learning Disabilities

The time required to fully consult with people with Profound and Multiple Learning Disabilities was too short in this instance. Instead it was agreed by those organisations who support them, that all previous consultations that have worked with PMLD individuals are used for this consultation, with time given to parents, carers and individuals to comment on the reflections that are drawn out. This meant that parents and carers were not asked again about experiences or about topics which they have already responded to, and currently have consultation fatigue. For any future consultations it would be beneficial to have at least six months in time to develop a story-telling technique to garner the responses authentically.

Gypsy, Traveller & Roma Communities

We are grateful to MECOPP, who undertook to submit a response in addition to the joint National Carers Organisations' response to ensure that the Gypsy, Traveller and Roma communities were represented. Given their organisational and staff time pressures and limitations this was a time consuming undertaking. We had separately been made aware of 'consultation fatigue' cross the NCO cohort.

It could also be noted that a desktop consultation response process does not lend itself particularly well to use by outreach staff.

Other

There was a wide range of organisations that fell into the 'other' category. Below are some key points picked up.

Employment/ modern slavery

There has been some concern on organisations that the Self Directed Support funding system that has been in place for a number of years is now developing an employment gap for people with learning disabilities, autism and neurodivergent people – in some circumstances where they may have previously been employed, they are instead using their Self-Directed Support to pay for work experience. We understand there are now ongoing discussions between Scottish Government teams to address this.

Sex workers

We spoke to an organisation who reported that they did believe they had a number of service users who were from the LDAN Community, including those who may mask symptoms with drug use. They were keen to engage with the consultation process but noted that the absence of existing accurate data would limit their response somewhat.

Veterans

We heard from Organisation G that "*never a week goes by where we don't have to deal with one or other of these issues (LDAN) referencing staff or veteran*s".

A view was that PTSD is generally seen as the only issue veterans must deal with whereas actually LDAN related complexities are more prevalent.

One organisation working in this area had an evaluation report on work with veterans. It focused 'on those who need help most, and reaching the hardest to reach'. However, it only highlighted the support needed by those with PTSD, anger, alcohol, substance use, anxiety and other issues such as homelessness and did not seem to pick up on LDAN related challenges.

Given the close links between veterans and the Criminal Justice System, rather than working in isolation, it would be worth looking more closely at how veterans can be supported by any future LDAN Bill.

Generic Issues

The Project Team collated issues that were common across a number of the thematic areas.

A responding cohort that have a lot of additional support needs need significant time designed into consultation time. This may need to be considered in consultations that are not LDAN specific but where there is a policy intent to include all of Scotland’s citizens.

People reported that it was gratifying to see the level of engagement and support from the policy team and this project. There was a feeling that this underlined and was indicative of level of need, and the frustration with the current situation.

In engaging with thematic areas it was clear that there was a ‘layer cake’ of issues for individuals that sat across a number of the areas within the Bill, and significant elements of intersectionalilty.

There was large spectrum of inclusion (or lack of it) in delivery practice amongst organisations. Often this fell to a lack of identification in early engagement (lack of knowledge, lack of confidence, lack of recognition of these aspects as important underpinning issues) then resulting in a lack of inclusion in practice in service delivery. Other organisations (not LDAN specific) had clearly nailed it; they had thought things through, and workers were confident and positive in supporting individuals from LDAN communities and showed understanding of the nuance needed to help the range of their constituency. The former organisations tended to say ‘it wasn’t possible’, which does not seem the case. The variation in initial identification practice then fed into whether organisations had any sense of whether and how many individuals from LDAN communities were amongst their beneficiaries.

Acute services (older people, homelessness etc.) often don’t include initial screening and their focus and attention lies elsewhere; however potentially inclusion of this in their practice would perhaps help their service delivery and outcomes significantly.

In some instances there was a lack of recognition that acknowledgement of LDAN related needs, and designing responses into service provision, would see delivery improvement to both sides, (provider and individual); not just a one way street with some beneficiaries being seen as getting ‘extra’ or experiencing special treatment.

The support that individuals from LDAN communities experience is very hit and miss, and can vary considerably across time. It is very dependent on individuals within organisations/ delivery ecosystems not systemically designed in.

Any potential need to capture data is likely to initially identify high levels of need and should lead to change in practice, and could domino in increasing training need and costs in the sort to medium term. Over time this has the potential for significant savings as practice (and thus outcomes) improve, e.g. violence reduction, stopping ‘revolving door’ syndrome, and avoiding worse outcomes due to lack of treatment (especially upstream health care and dentistry) or assistance (losing tenancies, sliding into criminal justice territories) etc.

It would appear from conversations that there is significant potential to save money in services with better communication, training and practice. This should be seen as an opportunity to adjust services to improve outcomes at reduced cost and conflict.

We witnessed significant exhaustion, overload and lack of capacity amongst committed and caring practitioners. In a number of engagements this meant that they were unable to give organisational responses, or more often, not able to support lived experience responses.

We were able to encourage some organisations that don’t generally have an LDAN focus to submit and support responses who initially weren’t confident to do so; and they have managed this process. This connection could be nurtured and pursued. This will need time, and resources for capacity if engagement with USUR LDAN communities is to be meaningful. These are often organisations working with are individuals, families and carers that are at the bottom of the pile by the very nature of the overlaying circumstances.

In LDAN communities, there are those that become ‘heard to reach’, by not being identified early enough as requiring additional support. Often because initially their needs are not significant enough to trigger help. They then are at risk of escalating into other risk categories such as becoming victims of crime, homeless, sex workers or sexually exploited, unemployed etc. There could be easy prevention opportunities, thus cost reduction and pull on public services. Our work and conversations have significantly re-enforced, in our view, the potential for a strong prevention agenda, with initial relatively low cost interventions.

Barriers to the consultation process

Feedback was given about the design of the consultation process the various organisations and groups

This included:

- The preparation of the consultation was very well respected.
- The process was seen as terrifying by some, but sheer determination meant people did submit.
- The design of the web content was not accessible to some.
- There was a lack of use of technology within some organisations (both within public and voluntary services) available to assist the submission process for individuals. E.g. no tablets available for home visits so workers trying to work with individuals to submit using phones.

- A sense that the Easy Read documents could have been improved.
- For some parents, families and carers, time was not available to engage with the process when caring support was scarce. A longer consultation time would have helped.
- We encountered cynicism: some people, workers and organisations were fed up. They felt that views fed into previous policy development had not been implemented, and as a consequence respondents were still so exhausted by their daily lives they could not contribute. Some then did go onto engage with us, but others withdrew and did not take anything forward.
- Some expressed views that this is just a repeat of previous activity so the answers were already known.
- Some cynicism was expressed that unless money and resources were committed to deliver the new Act, then no change would be seen.
- Some groups expressed a need to temper the expectations of their beneficiary group to manage exceptions for the amount of change and, a realistic time horizon, for change to be seen.
- There were views that there was not enough time within the process to work with individuals with severe & complex needs to submit responses.

We provide these as helpful reflections for future work, not as criticisms.

Summary

There was a strong desire from the Unit to encourage and see meaningful responses from learning disabled, autistic and neurodivergent individuals from under-served and under-represented communities. This project was able to reach into a wide range of organisations that supported individuals from these communities, and was successful in informing, supporting and encouraging responses. Even with the pressures of fatigue and lack of capacity, whether amongst individuals, parents, carers, families, workers, and organisations; it could be seen that there was a strong and ambitious drive to enable voices to be heard. Many people went the extra mile in difficult circumstances.

It is clear from what we heard that there is a distance between where we are now and the potential positive impact of the final LDAN Act; but with some very clear staging points that could lead to much more positive outcomes for individuals from under-served and under-represented LDAN communities; and there is significant motivation and commitment within individuals, communities and organisations to contribute to moving forward.

We thank the Unit and all those who worked with us on this project; and wish them all the best in taking this very important undertaking forward.

SCLD

The Project Team

May 2024

Acknowledgements

SCLD and the Project Team would particularly like to acknowledge and thank all those who took time to talk to us, often in very strained and constrained circumstances. We hope the opportunity to connect your voices and those of your communities to the consultation will help in seeing a brighter future for all leaning disabled and neurodivergent individuals.

We would like to thank all of those from the Learning Disabilities and Neurodivergence Unit for their collegiate approach to working with us. Their dedication and commitment to ensuring the voices of under-served and under-represented groups from the learning disabled and neurodivergent communities are heard is clear and meaningful.

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Helen Chambers, Director, Helen Chambers Consulting Ltd.

Kirsty Gilchrist, Director, Soloco

Kate McInnes, Soloco

Fiona Scott, Independent Consultant.

Annex 1. List of organisations/groups contacted

Article 12 in Scotland
Aurora Autistic consulting
Blue Triangle
Cannongate Youth
Carers Scotland
Carers Scotland
Carers Trust (Young Carers)
CEMVO
Central Advocacy Partners
Coalition for Racial Equality and Rights
Cyrenians
COCIS
DG Voice
Diversified
Dumfries & Galloway Youth Services
Edinburgh University
Equality Network & Scottish Trans Alliance
Ethnic Minorities Law Centre
Families Like Us
Families Outside
Family Fund
FENIKS
Fun Music Factory Home Education
Grampian REC
Grow & thrive
Healthy Valleys
Highland One Stop Shop
HMP and YOI Stirling
HMP Dumfries
HMP Stirling
Homeless Network Scotland
Intercultural youth Scotland
LGBT Health & Wellbeing
LGBTQPlus
MECOPP
Moray Wellbeing hub
Multi-cultural family base
Networking Key Services
One Stop Shop Highland
PAMIS
Romano Lav
Saheliya
Scottish Autism
Scottish Home Education Forum
Scottish Islands Federation
Scottish Youth Parliament
Shared Care Scotland
SISCO
Skye Autism Support
Smartworks Scotland
Somewhere: for us
STAND Stronger together for autism and neurodivergence
Structure of Intellect
SupportED
Swan Scotland
SWARM Collective Sex Worker Advocacy and Resistance Movement
Team Fostering
The SOLD Network
The Usual Place
Third Sector Dumfries
Venture Trust
Victim Support Scotland
Vox Liminis
West of Scotland Regional Equality Council
Wigtonshire Stuff
Windmills Cafe
Wiston Lodge
Youth Scotland

This list does not equal 126 organisations/ groups. This is because due to the nature of USUR communities, groups and gathering are often un-constituted, or formed of collectives of individuals on FaceBook and WhatsApp. Also in larger organisations one or more areas of the organisation that reach into