

# **Learning Disability, Autism and Neurodiversity Bill: Scoping Analysis 2022**

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Official

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## 1. Introduction

In September 2021, the Scottish Government's Programme for Government stated that we would carry out scoping work on the remit and powers of a Learning Disability, Autism and Neurodiversity Bill. We sought to use this work as an opportunity to understand what this piece of legislation had to do to uphold and protect the rights of autistic people, people with learning disabilities, and other neurodivergent people.

Between May and July 2022, the Autism and Learning Disabilities Team ran 30 events with 18 different organisations. A full list of these organisations is provided in Annex A of this report.

Events consisted of workshops run both online and in-person. During these workshops, we had open discussions around the themes of Human Rights, the Scope of a Bill, Language, and Engagement.

The organisations with whom we conducted this work consisted of a mix of Disabled People-led Organisations (DPOs). We also included national and smaller charities who advocate for and support autistic people, people with learning disabilities, and/or other neurodivergent people.

We used these networks to reach a wide range of people with lived experience, to understand their views on the challenges that they face and potential solutions. We sought to adopt a human rights-based approach to policy design that involved the people whom the legislation would affect from its inception.

We had existing relationships with most of the organisations with whom we worked. This means that our findings should not be taken as representative of all neurodivergent people. Our formal public consultation will seek to extend our reach and include the widest range of views possible.

## 2. Language

We recognise that different disability communities have different preferences in respect of how individual members are described. In this report, we seek to respect these preferences. However we accept that the terminology will not be reflective of the preferences of every member of a given community.

When speaking of autism and neurodivergence, we use identity-first language such as 'autistic person' and 'neurodivergent person', as this formulation was preferred by the majority of such people with whom we interacted during the scoping work.

When speaking of learning disabilities, we use person-first language such as ‘person with a learning disability’, as this was the preference of the majority of such people with whom we worked.

For some communities, ‘neurodivergence’ refers to individuals and groups thereof whose brain processes are different from those of the supposed majority in society. Under this model, ‘neurodivergent people’ would refer generally to people with learning disabilities, autistic people, and a wide variety of people whose neurology is different by virtue of ADHD, dyslexia, dyspraxia, and so on.

Not all individuals or communities identify, or are comfortable, with the terminology of neurodivergence. In an attempt to balance these viewpoints, we refer alternatively within this report to ‘neurodivergent people’ as a whole, and to separate categories of people, such as when we refer to ‘people with learning disabilities, autistic people, and other neurodivergent people’.

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

### 3. Executive Summary

This report does not analyse or make recommendations concerning the policy content of a potential Bill. Instead, it is a factual analysis of comments made during scoping events.

This report is informed by thematic analysis of 986 comments generated during 30 scoping events. Comments were made in response to broad questions that we used to initiate discussions, though were also generated during wider discussion that veered away from these questions.

The majority of comments were made by neurodivergent people, though a small number were made by people who were the family members of, or carers for, neurodivergent people.

Analysis was split between three members of our team to manage the workload, and to dilute the bias that a single analyst might bring to the task. We used mind mapping and link charting techniques to identify and cluster similar responses under shared themes. Based on these comments, we have identified the following:

Our analysis suggests that there is a mix of support for and scepticism towards the creation of a Learning Disability, Autism and Neurodiversity Commissioner amongst the 18 different organisations with whom we worked during the initial scoping of the potential Bill. This division is not determined by neurotype, as a range of mixed neurotype groups have expressed both support for and scepticism towards the Commissioner.

Whilst some of the DPOs with whom we worked were supportive, or were open to exploring the idea, of a Commissioner, the majority of DPOs were more sceptical.

Support for a Commissioner was overall higher in organisations that are not led by disabled people (and which therefore do not qualify as DPOs), though those organisations also represent large numbers of neurodivergent people.

There was consensus amongst participants in the scoping work that a potential Bill should cover people without a formal diagnosis of any of the conditions that this Bill might cover. Participants consistently thought that those waiting for diagnosis should have access to the support they need and expressed the importance of getting a timely diagnosis. Furthermore, many participants supported the notion of a Bill with a wide scope, covering the full range of neurodivergent presentations.

Some participants were less supportive of the scope of a potential Bill being as broad as this. They expressed concern that too broad a scope would not effectively target the needs of any individual or group. Other participants stressed the importance of naming specific conditions within a potential Bill to ensure that the groups associated with these conditions were sufficiently visible and supported.

Participants expressed strong preferences for language associated with the social model of disability, rather than a medical model, to be used throughout a potential Bill.

There was broad support for terms such as ‘neurodiversity’ and ‘neurodivergence’. However, participants stressed that language needed to be as inclusive as possible, and to be adaptable to social changes. Some groups of people with learning disabilities expressed dislike for terms such as ‘neurodiversity’ and ‘neurodivergence’.

The most frequently mentioned topic, measured by number of individual comments, was that all autistic people, people with learning disabilities, and neurodivergent people are likely to be discriminated against. These comments thought people need protection from this discrimination, as well as increased inclusion and recognition of their inherent value. This finding confirms what we already know from previous work on the Towards Transformation Plan. Examining comments made around discrimination in more detail directs us towards specific issues of discrimination, and possible solutions, that a potential Bill could take into account.

The second most frequently mentioned topic was concern that a potential Bill must cover a wide range of neurodivergent people, and questions about whether those with dyslexia, dyspraxia and ADHD would be included in such a Bill’s remit; i.e. what conditions are considered to make a person neurodivergent?

Similarly, a large number of participant comments stated that those without a formal diagnosis must be included in a potential Bill’s remit. Members of several communities thought that it was important to ensure that conditions were specifically named within a potential Bill. These participants agreed that this approach would help reduce the risk of people with those conditions being overlooked by service providers, and would help increase public awareness of those conditions.

The most commonly mentioned means of combating discrimination against neurodivergent people was education and training, both for public bodies and for

neurodivergent people themselves. This included the need for greater awareness, education/training and understanding of people with learning disabilities and autistic people and their needs, particularly for public bodies. A number of people also stated that greater education on and awareness of human rights is needed. Education and training towards this end should be communicated in a clear and accessible way.

Many participants thought that a potential Bill should enforce person-centred support in a range of settings, and across the lifespan. Participants identified a number of ways in which such support could be achieved, and the areas in which it was most needed.

The need for accessible independent advocacy to assist neurodivergent people in enforcing their rights was mentioned often – encouraging self-determination and increasing the accountability of services.

Ensuring provision of support in employment, education, and healthcare settings, including mental healthcare, was also often mentioned. Finally, consistent and high-quality support for transitions between these various settings, and between various life stages, was sometimes identified as desirable.

Many participants stressed that a potential Bill should be constructed to complement existing legislation, services, and the work of public bodies that impact on neurodivergent groups including:

- the Equality Act 2010
- the National Care Service Bill
- existing Commissioners.

A number of comments mentioned a need for alignment with existing or upcoming statutes and enforcement bodies, or else questioned the need for additional legislation that could risk duplicating existing human rights provisions.

One of the key themes for discussion during workshops was how the Scottish Government could improve engagement to reach as many people with lived experience as possible. Discussions around this theme resulted in the following recommendations:

Participants suggested a range of ways in which the Scottish Government can ensure that its work on a potential Bill is inclusive, accessible, and consistent with a human rights-based approach including:

- consulting with people in their own communities through local events
- working with schools
- delivering communications in a range of formats and languages
- issuing regular communications on developments on a potential Bill.

There are some clear key areas where further work will be required with our lived experience, stakeholder and professional panels, and which will be further explored during a formal consultation on a potential Bill in 2023.

- There is no consensus currently on the role of a Commissioner. We will explore this further with stakeholders.
- There does not appear to be consensus regarding definitions of neurodiversity and neurodivergence. This includes who people think should be covered by the remit of a potential Bill.
- Given the limited number of organisations with whom we were able to engage as part of the scoping process. We are unsighted on the views of certain neurodivergent communities, including ADHD, dyslexia, and dyspraxia communities who did not take part in the scoping work. We will seek to recruit members of these communities to the Lived Experience and Stakeholder Advisory Panels as a step towards redressing this gap, and will work with our Panels to ensure that those communities are fully involved in the public consultation on a potential Bill.
- There are some indications throughout the scoping work of areas where people feel that their human rights should be strengthened. However, further work is needed to consider the interactions between this potential Bill and of human rights treaties in Scotland, and whether and how any additional rights should be set out or strengthened here.

## 4. Main Report

### 4.1 Discrimination

The most frequently mentioned topic across discussions was that all autistic people, people with learning disabilities, and neurodivergent people are likely to be discriminated against; they need protection from this, as well as increased inclusion and recognition of their inherent value.

This finding confirms what we already know from previous work on the Towards Transformation plan. Further exploration of the conversations that we had with participants around discrimination direct us towards specific issues of discrimination, and possible solutions, that a potential Bill could take into account.

- There was recognition, particularly from those with learning disabilities, that they have faced extensive abuse and mistreatment in the past, including in care settings and from carers. One participant said: “I needed to get moved to a nicer area as I was being badly bullied. I’d been asking for 3 years. It took someone dying in a similar situation to me to make them act”.
- There were a number of mentions of a need for societal change, particularly attitudinal change. A number of comments focused on the need for positive discussion of autism and learning disabilities and a move away from medicalising and/or pathologising people.
- There was a particular focus from people with learning disabilities on the right to independent living and making their own choices. As one participant put it: they “are classed as vulnerable and needing protection, this can backfire; being vulnerable means that other human rights are taken away and people don’t get a say in things. People can be too protected.”
- These issues broadly reflected outcomes present within the Scottish Government’s plan for people with learning disabilities and autism ‘Towards Transformation’.
- One participant thought that the key outcome from a new Bill and Commissioner would be taking people from the back of the queue, while another described that they would like to see fewer people ‘falling through the cracks’. It was often thought that services were missing people and that existing means of advocacy were inadequate to allow neurodivergent peoples’ needs to be met.
- Both autistic people and people with a learning disability related that there needs to be greater protection from discrimination by increasing inclusion and recognising the inherent value they bring to Scotland.
- The high number of mentions of discrimination against autistic people, people with learning disabilities, and neurodivergent people strongly suggests that this is a very high priority for those surveyed. Running in parallel with this is

the importance, to these groups, of a counter-narrative that focuses on positive portrayals and attitudinal change across society.

## 4.2 Defining Scope and Terminology

The second most frequently mentioned topic was concern that a potential Bill must cover the wide range of neurodivergent people. There were questions about whether those with dyslexia, dyspraxia and ADHD would be included in a potential Bill's remit; i.e. what conditions are considered to make a person neurodivergent?

Similarly, a large number of participant comments stated that those without a formal diagnosis must be included in a potential Bill's remit. However, members of several communities thought that it was important to ensure that conditions were specifically named within a potential Bill.

These participants agreed that this approach would help reduce the risk of people with these conditions being overlooked by service providers, and would help increase public awareness of these conditions.

Generally participants were supportive of other neurodivergent groups being included in the scope of a potential Bill. One participant explained that if a Bill is too narrow in scope, other groups would demand that a separate Bill be created to cover them. Several participants thought that a narrow Bill would be at risk of becoming out-dated as terms and language around neurodiversity and neurodivergence changes and adapts with time and new understandings.

"We also need the dyslexic, dyspraxic, dyscalculic + everyone else in the ND (neurodivergent) community to feel included under the Bill if they're not autistic or learning disability." (autistic person)

One participant noted that it seemed strange to them to have Commissioners or Commissions for such specific conditions and that there should be a Commission not a Commissioner to ensure a diversity of views and experience life.

"If you create a Bill for only a few then a chance others will want their own Bill/Commissioner." (people with learning disabilities workshop, meeting notes)

Participants were split on using the term neurodiversity in the title of a potential Bill. Some valued its broad scope, finding it a term that is positive and inclusive. Others felt it too vague, and so potentially too unfocused to help those who are supposed to be within a potential Bill's remit. Amongst those participants with learning disabilities there was some confusion over the term neurodiversity.

As the Scottish Commission for People with Learning Disabilities (SCLD) event summary put it "neurodiversity was not a term that most attendees were aware of or understood" but that "some see neurodiversity as a term as having the potential to take away the stigma of learning disability".

One participant suggested that there were over 93 different types of neurodiverse conditions and these would each need to be clarified and defined within a potential



Bill. Several groups suggested that agreeing a single glossary of terms would be helpful for both a Bill and Commissioner.

“We can’t future proof, so there should be a commitment to review language continuously” (autistic person)

While definition of terms within a potential Bill was seen as paramount to ensuring that such a Bill is enforceable, some participants spoke about the need for identity-first language. This is language whereby a person’s condition is framed as an integral part of their identity by using it adjectivally rather than possessively, and is contrasted with person-first language. An example of identity-first language can be found in the formulation ‘autistic person’, which would be expressed as ‘person with autism’ in person-first language.

Several autistic participants explained to their groups that a potential Bill needs to take into account that people often use terms that they have been told about through their lives and often have strong ties to the wording used. One participant told their group that many people with diagnoses of Asperger’s for example may prefer to retain the term, despite it being somewhat dated, because that is what they were diagnosed with and have used through their lives.

“I think the nature of terminology and how people identify/describe themselves is wholly independent to them their journey and life experience.” (autistic person)

Our analysis of comments suggests that more work is needed to determine which conditions should be included in the remit of neurodivergence, for the purposes of a potential Bill. Some felt that the term neurodiversity is overly “woolly” or too much of a catch-all, pointing out that neurodiversity covers both neurotypical and neurodivergent people. There were concerns that the term *“risks watering down the reach of the Bill and not targeting those whose human rights are being most abused”* (SCLD participants). Some work will need to be done, pre-consultation, with the panels aiming to reach a consensus on the language that will be used.

It is important to note that the current title of this potential Bill is only a working title – the final title will be largely determined by legal colleagues within the Scottish Government, and will reflect the scope of the Bill.

Groups were asked to tell the facilitators about any terms that they would like used in a potential Bill. Generally these terms were ones that conveyed a sense of difference and capability rather than disability, and largely followed the social model of disability, whereby disability is largely understood to consist of often negative narratives constructed on top of the embodied impairments experienced by disabled people. These terms included:

- impairment/ability
- strengths
- difficulties
- differences
- challenges
- disabled person or person with disabilities

Facilitators also asked about terms that participants would not like to see used in a potential Bill. When asked, the majority of autistic participants provided terms that they felt have medicalised or patronised autistic people. Participants spoke about the history behind some of the terms and stigma attached to them:

- deficit
- disorder
- function labels 'high' or 'low'
- neurodevelopmental
- neuro-atypical
- dysfunctional
- abnormal
- mental illness
- patient

#### 4.3 Risks of Broad and Undifferentiated Definitions

Some autistic participants were critical about widening the remit and were sceptical of how effective a broad neurodiversity or disability Bill would be in providing support for peoples' specific needs. Several of the groups thought that there was a significant risk of a Commissioner's remit becoming too complicated and that it would need to be clear which conditions are included in a potential Bill and which are not. For example, some groups wondered if those with acquired brain injuries or dementia would be covered in the Bill definition of neurodivergent conditions.

"If we were trying to address say both the needs of dyslexic school kids and the needs of elderly people with dementia in the same Bill and my worry...is that autistic specific needs are lost if this tries to span too great an area." (autistic person)

One of the most prevalent risks discussed by the groups was the possibility that having a broad neurodiversity Bill could do a disservice to both autistic people and people with a learning disability. Autistic people spoke about how through their lives many had experienced discrimination because professionals had assumed they had a learning disability and treated them in a way that made them feel disempowered.

Several of the autistic groups shared experience of being sent to special schools without their consent, being locked up in hospitals, being denied access to mental health care, and having their concerns and input ignored by schools. For some, part of this issue was a conflation between learning disability and autism, whilst for others it was a 'layer of special' that professionals assumed.

Similarly, several participants cautioned that adopting terminology that was too broad risked minimising the specific needs and challenges faced by certain groups, even where they share challenges and needs with other neurodivergent communities. For example, family members of, and carers for, members of both the Down Syndrome and FASD communities expressed concern that other neurodivergent groups could be given priority over members of the communities to whom they were close. Family members of, and carers for, members of the Down Syndrome community argued that:

“It is vital that the Bill recognises the diversity of needs within the broad learning disability community and avoids falling into the trap that the learning disability community (and indeed, the autistic community) is a homogenous group.” (family member of a member of the Down Syndrome community)

A member of the autistic community made the same point about singling out certain conditions, arguing that a potential Bill provided an opportunity to increase the visibility of neurodivergent communities that have traditionally been overlooked:

“Singling out and naming certain parts of the population is saying ‘these people are important and matter’.” (autistic person)

#### 4.4 The Need to Cover Undiagnosed People

Whilst the specific conditions that would be included in a potential Bill and Commissioner remit were often discussed and debated, there was a general consensus that not having a formal diagnosis shouldn't be a barrier to inclusion in a Bill or Commission. Many of the participants had experienced or knew of people who had struggled to get their particular conditions diagnosed.

Many people wanted to know what conditions would be included in the definition of neurodivergent. A similar number of participant comments stated that those without a formal diagnosis must be included in the remit of a potential Bill. One comment stated that: “Equality must be ensured when self-identifying.” (neurodivergent participant).

#### 4.5 The Need to Adopt an Intersectional Approach

A related concern was that an intersectional approach is needed both across different diagnoses and other identities that people hold. One autistic participant said “Focusing on the needs of neurologically different people, rather than each specific diagnosis was important, not least because of the overlaps, diagnostic overshadowing and diagnosis accessibility.”

Groups frequently mentioned wider equality groups that should be considered in a potential Bill. General groups discussed wider identities that neurodivergent people have that they felt were not well considered or understood in Scotland.

Participants suggested several different protected groups that additional effort would be required to reach:

- Ethnic Minority Groups BME
- LGBTQIA
- Gender identity
- People with Co-morbid disabilities
- People with Mental health conditions

#### 4.6 Awareness, Education, and Training for Public Bodies

The most commonly-mentioned means of combating discrimination against autistic people, people with learning disabilities, and other neurodivergent people was education and training, both for public bodies and for neurodivergent people themselves. This included the need for greater awareness, education/training and understanding of people with learning disabilities and autistic people, particularly for public bodies. A number of people also stated that greater education and awareness of human rights is needed. This should be communicated in a clear and accessible way.

A very frequently mentioned desire for a potential Bill was a need for greater awareness, training and understanding of people with learning disabilities and autistic people, particularly for public bodies. Access to employment, healthcare, education, and independent living are key areas in which these needs must be recognised.

As one person put it: “many are struggling to get support in school and employment, this is an opportunity to make real progress on that” (autistic participant).

Furthermore, there was a stated need for the recognition of the value of neurodivergent people’s specific skillsets. One participant highlighted this in education, saying “he knows multiple people who can build a PC from scratch but would struggle to fill in a tax form” (NAS participant) and so felt it would be beneficial to have more practical course options in schools. Similarly a participant with learning disabilities stated that assumptions were often made about his capabilities: “People say to me 'you can't do this', but I can” (ARC participants).

#### 4.7 Awareness, Education, and Training across wider society

All of the groups thought that a Bill and Commissioner could have a vital role in raising public awareness and influencing wider societal and attitudinal change. For some, a potential Bill would itself be a statement to local authorities, public bodies, professionals and the general public that neurodivergent people live in Scotland and should be included and accepted in day-to-day life.

One autistic person thought that a potential Bill would be a chance to get the idea of neurodiversity out there and start people thinking that there is not just one way of thinking, seeing the world and doing things. Another autistic person suggested that a key outcome from a potential Bill and Commissioner would be fostering a fairer society that celebrates and accepts neurodivergence, giving people equal voices, where wider society both has awareness and accepts people.

In every workshop the topic of societal awareness and acceptance was discussed. Autistic people in particular stressed the importance of wider societal understanding of autism and the vital role that autistic acceptance amongst professionals has in ensuring that they are able to be understood and have their needs met and interpreted correctly.

Autistic groups frequently mentioned that autistic women and girls are overlooked by diagnostic services, because of a lack of understanding amongst professionals and

the wider public about how autism impacts women and increased likelihood of women masking to appear neurotypical.

“Huge lack of awareness and understanding about autism in general and particularly about autism in girls.” (autistic person)

Workshop participants suggested that raising awareness, either through training courses or wider campaigning should be within the remit of a potential Bill and Commissioner.

For others, the Commissioner represented a chance to upskill professionals across Scotland, particularly in health institutions and teaching professions. Several groups thought that the Commissioner could support the delivery of lived experience led training and resources across Scotland.

“Hire people with lived experience to go and work with different teams. (i.e. human rights, mental health, health care and transport.” (Learning disability workshop, event notes)

Many participants mentioned that they frequently found that public service providers had little direct experience of interacting with neurodivergent people, or had received little to no training on neurodivergence, which led to negative outcomes of stigma of these groups. One participant highlighted this in mental health treatment where those treating them “felt like they made autism the mental health problem” (autistic person). Many people suggested that training on human rights should be given to service providers who work with people with learning disabilities and autism to make sure that they have secure knowledge of human rights.

#### 4.8 Making Neurodivergent People Aware of their Rights

During autism workshops participants often mentioned the need for people to better understand their rights and have these in an accessible format. Similarly people with learning disabilities mentioned the need for accessible information as systems are often complicated and difficult to understand.

Groups often mentioned that a potential Bill has a role in raising awareness and educating neurodivergent people about their human rights in accessible and inclusive ways. One group mentioned that this could be done in a variety of ways including individual support, guidance, and mentoring.

#### 4.9 Person-centred Support

Many participants thought that a potential Bill should enforce person-centred support in a range of settings, and across the lifespan. Person-centred support was a frequently mentioned need. Participants identified a number of ways in which such support could be achieved, and the areas in which it was most needed.

The need for accessible independent advocacy to assist neurodivergent people in enforcing their rights was often mentioned. Ensuring provision of support in

employment, education, and healthcare settings, including mental healthcare, was also mentioned.

Finally, consistent and high-quality support for transitions between these various categories, and between various life stages, was identified as desirable in some comments.

#### 4.10 Independent Advocacy

Groups thought that the biggest barrier to human rights for neurodivergent people is getting relevant legislation upheld. They thought that this can only be made possible if neurodivergent people have equal access to advocacy, legal representation and professionals with training in understanding the intersectionality between different conditions and other factors of advantage and disadvantage that people may have.

Both autistic people and people with a learning disability related that there needs to be greater protection from discrimination by increasing inclusion and recognising the inherent value they bring to Scotland. Frequently participants mentioned that key to achieving this level of inclusion is the widening of accessible advocacy through a potential Bill and Commissioner. It was clear across most workshops that a Bill and Commissioner should have a focus on creating accessible advocacy for neurodivergent people.

“There need to be easier ways of fighting for your rights if they are denied to you.”  
(person with a learning disability)

There was also a particular focus on the need for accessible advocacy, that was clearly signposted and available nationwide, for people with learning disabilities. Some people with learning disabilities wanted a right to advocacy, or guaranteed advocacy for people with learning disabilities.

There were also concerns over guardianship, and its potential removal. A few participants with learning disabilities were worried that people needed guardianship and the support it provided to make decisions. For example, some people aren't able to access self-directed support (SDS) without guardianship, as they need a bank account in order to get SDS.

#### 4.11 Support in Employment, Education, and Healthcare Settings

There was a focus on improving services across the board, with person-centred support a frequently mentioned need for both autistic people and people with learning disabilities.

This was particularly reflected in the discussion on the meaning of human rights for people with learning disabilities which focused on the vital importance of the right to choose: who to live with, where to live, what friends they have and work or activities they do. As one participant from ARC put it, it's about the “opportunity to make mistakes – how on earth do you learn otherwise?”.

Alongside general issues with social and health care services, participants also mentioned more specific challenges faced by people with learning disabilities that a Bill or Commissioner could potentially support.

One of the learning disability groups related that they find gaining employment difficult and that they have found themselves in college in a cycle of 'life courses' without prospects of graduating into a job. A postcard provided by people with down syndrome noted that the writers would like a greater variety of college courses to encourage them to keep learning.

One person also told the group about the struggles they had faced when they got a job and this impacted on the benefits they received and they felt punished for finding work.

"Benefits stop automatically when you go into employment - benefits don't get auto reinstated if it doesn't work out." (person with a learning disability workshop, meeting note)

#### 4.12 Support for Transitions

The importance of provision of services at transition points for people with learning disabilities and autistic people was of concern: "transition from child to adulthood – who oversees things, who can you speak to? People lose support in transitions and with COVID, rights are forgotten about." (ARC participant). SCLD participants echoed this and stated that there need to be "improvements to transitions with clear legal expectations placed on local authorities".

This approach was also supported by family members of, and carers for, people with Down Syndrome, who expressed the hope that a potential Bill:

"will deliver new powers that demand a well-supported and well-resourced transition plan be put in place for every young person leaving school and that the plan remains 'alive and dynamic' through to their 25th birthday."

Other participants sought to highlight the need for transitions to cover the lifespan of an individual, given that any potential Bill is also intended to be whole-lifespan in coverage. These participants highlighted the transition to pension age, as well as from child- to adulthood. One autistic participant noted that:

"getting older is absolutely frightening because it feels like no-one has paid attention to the idea that these autistic children and young people will get older and will at some point need care. And so, in terms of special protective status, there needs to be a lot more thought and investment etc. into care than there has been." (autistic participant)

Participants in one group mentioned that during education is the best time to get the right support in place and that transitions should not be rushed and should instead be tailored to someone's development stage and ability. There was an emphasis that services are best provided at transition points for people with learning disabilities and autistic people.

#### 4.13 Alignment Across Legislation and Services

Participants stressed that a potential Bill should be constructed to complement existing legislation, services, and public bodies that affect neurodivergent groups, including the Equality Act 2010, the National Care Service Bill, and existing Commissioners. Some comments mentioned this need for alignment with existing or upcoming statutes and enforcement bodies, or else questioned the need for additional legislation that could risk duplicating existing human rights provisions.

There were questions over why there might be a need for this specific piece of extra legislation to confer human rights when everyone has them already, and that the legislation should work in conjunction with other pieces of human rights legislation.

The question of how this potential Bill will tie in to other pieces of human rights legislation is a timely one. There will likely be an ongoing discussion amongst those with lived experience as to whether people with neurodivergence need their own specific piece of legislation (in recognition of the specific barriers they face) or if they should be included within broader human rights legislation (resisting further 'othering' of these groups).

For many of the participants, current Scottish legislation, such as the Equality Act, whilst well intended is not visibly enforceable and people would like to see greater enforcement of this type of equality legislation.

To best protect the human rights of neurodivergent people, it was thought that a potential Bill and its resulting legislation can be useful if it's enforceable and resourced. One participant expressed that they had thought that the Autism Act in England had not been effective in changing local authorities practise and is not challenged because of the cost for legal aid.

Participants were emphatic about the need for a potential Bill to be enforceable and have accountability built in to make any meaningful difference. Generally it was agreed that the Commissioner should be able to make sure that local authorities and public bodies are accountable.

Groups that were sceptical about the prospect of a Commissioner largely expressed similar concerns around the enforcement of existing legislation and the need to increase accountability.

#### 4.14 Alternatives to a Commissioner

Given that there is a mixed view on the value of a Commissioner, some groups and participants made suggestions of alternative options that could be put in place instead.

"The Commissioner model is only one possibility and it closes down all sorts of funding for systemic, bottom up approaches" (autistic person workshop)



Groups offered alternative ways that current legislation, strategies and services could be strengthened locally and nationally to better represent the voices of people with lived experience and provide more inclusive and accessible services. Mostly these suggestions proposed 'tooling up' local councils and strengthening existing equality and accessibility interventions in Scotland.

Some participants were concerned that a potential Bill might be duplicating human rights legislation. Similarly some participants wondered if the potential Commissioner would be duplicating what is already in place through bodies such as the Mental Welfare Commission. Groups where these concerns were raised asked if it would be possible to embed a new Commissioner's office into an already existing Commissioner and thought that this could avoid unneeded duplication and provide an existing infrastructure for the Commissioner.

## 5. Engagement Events Details

- Autistic Mutual Aid Society of Edinburgh (AMASE) - 21/06/22 and 14/07/22
- Down Syndrome Scotland (DSS) - 26/04/22, 03/05/22, 04/05/22, 06/05/22, and 11/05/22
- Autism Understanding Scotland (AUS) and Scottish Ethnic Minority Autistics (SEMA) - 14/06/22, 16/06/22, and 30/06/22
- Scottish Commission for Learning Disability (SCLD) - 14/06/22
- Inspiring Scotland - Unknown
- Association for Real Change (ARC) Scotland - 27/06/22 and 04/06/22
- Genetic Alliance UK - 26/07/22
- Fetal Alcohol Spectrum Disorder (FASD) Hub Scotland - 28/06/22
- People First (Scotland) - 09/06/22 and 23/06/22
- Learning Disability Assembly - 17/06/22
- Autistic Knowledge Development - 28/06/22 and 01/07/22
- Scottish Transitions Forum, Divergent Influencers - 11/07/22
- ENABLE Scotland - 21/05/22
- National Autistic Society (NAS) - 18/05/22 and 30/05/22
- Scottish Autism - 10/05/22 and 25/05/22
- Scottish Women's Autism Network (SWAN) - 12/05/22
- Autism Rights Group Highland (ARGH) - 19/05/22
- Autism Initiatives - 21/07/22



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