



Learning Disabilities, Autism and

Neurodivergence Bill: Consultation

Response from Enquire and My Rights, My Say

April 2024

About Enquire and My Rights, My Say

<u>Enquire</u> is the Scottish advice service for additional support for learning. We provide advice and information to parents, carers and professionals on the rights of children and young people to support with their education. We also provide advice and information and directly to young people through our website, Reach.

The <u>My Rights, My Say</u> service is a partnership between Enquire, Children in Scotland, Partners in Advocacy and Cairn Legal. It is the statutory support service required by Section 31A of the Education (Additional Support for Learning) (Scotland) Act 2004. This includes a Children's Views Service, legal advice and representation service and an advocacy service.

This response has been submitted jointly from Enquire and My Rights, My Say. We will solely be responding to the questions and areas where we have expertise.

Why are we responding to the consultation?

The Enquire and My Rights, My Say services hear every day from children and young people, parents, carers and professionals experiencing the realities of life in and out of school for children and young people with a learning disability, who are autistic and/or neurodivergent.

It's important to highlight that our services support children and young people covered by the definition of additional support needs in the Education (Additional Support for Learning) (Scotland) Act 2004. This is a wider group of children and young people than the scope of this Bill. However, the largest proportion of our helpline enquiries and My Rights, My Say cases involve children and young people with a learning disability, who are autistic and/or neurodivergent.

For example, in 2023/24 Enquire handled 1,634 enquiries from parents or carers of children with additional support needs and the professionals who support them. The table below shows the percentage of these enquires where a child had factors giving rise to additional support needs which could be in the scope of this Bill:Table 1: Enquire helpline enquiries 2023/24 relating to LDAN Bill criteria

Total number of enquiries in 2023/24: 1,634		
Factor(s) giving rise to additional support needs*	%age of all enquiries received	
Autism	57%	
ADHD/ADD	20%	
Dyslexia	10%	
Sensory processing issues	8%	
Learning difficulty	7%	
Learning disability	6%	
Developmental condition**	5%	

*These factors are recorded based on what the enquirer tells us, regardless of if formal diagnosis. For example, where 'autism' is recorded as a factor, this will include some children without formal diagnoses who may be on a waiting list for assessment. It is also important to note that many children will be recorded under more than one of these categories.

** Including dyspraxia, developmental co-ordination disorder, Tourette Syndrome and other developmental conditions not otherwise listed here.

Partners in Advocacy note that for many of the young people referred to their service, there can often be more than one additional support need. For example, in the year 2023/24 for 738 young people, there were 799 identified additional support needs that would be covered by the proposed LDAN Bill.

CONSULTATION QUESTIONS

Part 1: Reach and Definitions: Who should the bill include?

Who should the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill include?

- Proposal 1: People who are Neurodiverse / Neurodiverse People
- Proposal 2: People who are Neurodivergent / Neurodivergent People
- Proposal 3: Including specific conditions only in the bill.

It is not within our area of expertise or remit to advise on which of the three proposals should be taken forward, but we would like to set out some key points that we believe should be considered during the process:

Proposal 2

Should this be the approach favoured, the broad definitions of 'additional support needs' in the Education (Scotland) (Additional Support for Learning) Act 2004 and 'disability' in the Equality Act 2010 may provide helpful learning. These legal definitions do not come with exhaustive lists of what specific types of needs or impairments are included, yet on the whole are functioning well in practice by providing rights and protections to the intended individuals.

Proposal 3

We wonder how including specific conditions only would interact with the wideranging definition in the Education (Scotland) (Additional Support for Learning) Act 2004 and the understanding of which children and young people have 'additional support needs' and who are therefore entitled to additional support with their learning.

We also have concerns that including specific conditions only may be exclusionary and runs the risk that those without a definitive diagnosis, or who are awaiting assessment, would miss out.

This case study from the Enquire helpline demonstrates the long-term and farreaching impact of awaiting a formal diagnosis to secure support:

Parent phoned about a child. Just diagnosed ADHD last week after years of waiting. Child in P3 and struggling. Still can't read or write, isn't taking things in and can't follow instructions. This is affecting the child's mental health, wellbeing and the child is now being bullied. Parent explained had to go through MP to fight for diagnosis as the school not willing to provide support without one. Child is now going on a waiting list of a psychiatrist for medication.

We are concerned that a lack of formal diagnosis is already impacting access to support services in areas such as education where a definitive diagnosis isn't required to be eligible for additional help. Legislation where a diagnosis is required to access rights could further impact the ability of some to access the support they need. In the last year, Enquire received enquiries about 189 children where 'wait time for a diagnosis or lack of diagnosis' was raised as an issue.

We acknowledge it is also important to balance this with how important diagnostic labels are for people. We know, for example, that identifying as dyslexic or as someone with a learning disability can be an important part of their identity and the communities that are created. However, we believe that legal rights should not be contingent upon a formal diagnosis.

Restraint and seclusion

We have committed to exploring options for legislation in this area that would apply equally to all schools. This includes the option of statutory guidance. However, we do not think the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill would be the right to do this as it would need to apply to all young people.

Do you agree with this approach?

Yes, we agree with this approach. Whilst we are aware that this group are disproportionately impacted by the use of restraint and seclusion, and this is an area that would benefit from more clarity in law, it does not feel appropriate to single out any one demographic.

We refer to <u>Enquire and Children in Scotland's previous response to the Proposed</u> <u>Restraint and Seclusion (Prevention in Schools) Scotland Bill.</u> We acknowledge that in this response we suggested there should be consideration given to whether legal guidance on restraint and seclusion could be included in forthcoming legislation, including the LDAN Bill, but on reflection do not believe this is the right place to cover this topic.

Education

What can the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill do?

Proposal 1: Strategies and reporting requirements

We would like to see more consideration and involvement of neurodivergent children and young people in any plans for feedback or reporting, offering the opportunity to share how their needs are being met in school or how they could be better supported. This would also align with commitments in the UNCRC and the UNCRC (Incorporation) (Scotland) Act to adhere to Article 12 that "every child has the right to express their views, feelings and wishes in all matters affecting them."

We also advise that children and young people who are not currently attending school should be considered in plans and reports in order to give a true representation of neurodivergent young people. Inconsistencies and lack of reporting in this area has been acknowledged widely, as well as the disproportionate amount of neurodivergent children out of school, which we will come back to further below.

Proposal 2: Mandatory training for teachers, practitioners and other educators

We hear often about the importance of a tailored and individualised approach to support, and the difference getting the right support in place can make to a child or young person's educational experience. We are also aware that whilst a lack of resources plays a significant role, so can a lack of training and understanding from school staff.

On the Enquire helpline, a lack of understanding of additional support needs is the third most common issue raised by those looking for advice and information relating to a child, raised in 25% of all enquiries in the year 2023/24.

In enquiries related to this issue, the majority concerned children whose additional support needs are within the scope of this Bill::

Total number of children where lack of understanding cited as issue in 2023/24: 403	
Of these:	
Factor(s) giving rise to additional support needs	% of children*
Autism	66%
ADHD/ADD	31%
Dyslexia	16%
Sensory processing issues	16%
Learning difficulty	11%
Learning disability	6%
Developmental condition	4%

Table: Lack of understanding of additional support needs

*Many enquires concern children with multiple factors giving rise to their additional support needs

This case study from the Enquire helpline illustrates how the lack of understanding of a child's additional support needs by school staff can impact the child's learning and wellbeing, as well as their relationship with the school:

Parent called about their child (10) who has always loved school and dreams of being a teacher. Parent explained their child "plays schools every evening with [their] cuddly toys" and "decorating [their] room like a classroom". Since starting P6 child is struggling - teacher "keeps telling [child] work is "not up to p6 standard", that [child] "takes long to write and finish [their] work" and child's "spelling is not good enough"". Parent has requested assessment for dyslexia but has been "told repeatedly" that her child is not trying hard enough. At parents' night, child's teacher, in front of the child, said they will "find p7 difficult, that high school will be impossible and [child] will not be able to be a teacher".

In <u>recent research into provision for pupils with complex additional support</u> needs, commissioned by the Scottish Government and carried out by Humanly, a need for training was highlighted by practitioners, parents and children and young people.

We believe basic training in recognising and supporting pupils with additional support needs should be a key part of any training, including Initial Teacher Education (ITE), as well as an important part of continued professional development for all education professionals, including pupil support staff.

In recognition that for many children and young people, being supported in a way that is right for them is important not just in school but in all areas of their life, we would recommend mandatory training as part of CPD for <u>any</u> professional working with young people, not just at school.

It is also important that any training developed meets the needs identified by young people who have recent and current lived experience of Scottish schools. The Inclusion Ambassadors have produced a significant amount of work in this area, sharing their experiences and recommendations for successful support planning and delivery. The key messages emerging are around the importance of rights-based support, tailored to individual needs and with more training and understanding across school staff. We would encourage their <u>support planning resource</u> to be looked at for more information on the core values they would like to see enforced when supporting pupils with additional support needs, as well as recommendations to improve the process.

Working together with neurodivergent young people to develop, and potentially, deliver, any training will ensure that it takes on board recommendations of where there are improvements in knowledge and awareness needed, based on real and recent lived experience.

Proposal 3: Data

We agree that review of the categories included in the pupil census data would be beneficial as many are now outdated and sometimes unhelpful in giving a true picture of pupils' needs, for example the social, emotional and behavioural needs (SEBN) category. We are also aware numbers and recording practices vary significantly across local authorities which indicates issues around consistency and how recording is communicated. We would support the inclusion of categories to allow accurate and consistent data gathering on the use of part-time timetables, numbers and reasons for children out of school and access to out of school education. We know that, particularly with out of school education, there is an inconsistency in how attendance is recorded.

For example, it may help to consider how this case study from the Enquire helpline would be recorded currently:

Autistic young person has been out of school since lockdown. Multi-agency meeting had recommended an hour a day at the high school a few times a week to support young person to leave house and build some contact with adults. However, funding for staff has been refused, so school are going to remove the support. This will lead to son having no education full-time again and no plan to help him get into school.

At the moment, this young person may be recorded every day as 'attending' as they are attending on an agreed part-time timetable, or they may be marked as 'authorised absence'. Neither would give the true picture of this young person's educational experience or creating meaningful or helpful data for making changes.

We are also aware that the improper and unlawful use of informal exclusions can give a false impression of data collection with this method used but not reported. The 2018 <u>Not Included</u>, <u>Not Engaged</u>, <u>Not Involved</u> report on the experiences of autistic children missing school highlighted some of these issues in detail and included calls for better data and reporting.

Of the enquiries received by the Enquire helpline about children out of school, the majority concern children who would be covered in the scope of this Bill.

Total number of enquiries about children out of school* in 2023/24: 453 Of these:		
Factor(s) giving rise to additional support needs	% of children	
Autism	64%	
ADHD/ADD	23%	
Sensory processing issues	7%	
Dyslexia	6%	
Learning disability	4%	
Learning difficulty	2%	
Developmental condition	2%	

Table: Children out of school 2023/24

*Enquire records children as 'out of school' where they are not attending school full-time for a reason other than formal exclusion.

This suggests that there are particular issues in relation to school attendance for these children, which would be worthy of more detailed data collection on a national scale to help inform the actions required to make improvements.

Ensuring consistent recording of data across all of these areas would also have benefits for all children and young people, not just those who are neurodivergent. We would support the development of clear guidance on a number of these issues, including the use and definition of part-time timetables and planning. Our <u>previous</u> <u>submission on minimum learning hours</u> addresses a number of these issues in more detail.

More reporting however is not the answer alone. The data gathered needs to be accurate, consistent, meaningful and of a high quality. Supported by good guidance, better and more consistent reporting on these areas should lead to improved practice and help gain a fuller understanding of the issues, ensuring any changes implemented are meaningful and impactful.

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

There is a steadily increasing demand for advocacy and support services for children, young people and their families to access their education. There is not only demand for the empowerment offered by direct advocacy services for young people themselves and their families, but also options for professionals to seek children's views in formal adult-led processes like the My Rights, My Say children's views service.

My Rights, My Say partners Partners in Advocacy report that they have seen an increase in referrals from an average 13 referrals per month to currently 17 referrals per month. There are currently 58 young people on the waiting list with a current estimated wait of around 22 weeks. At its peak, there were 64 young people awaiting access to the service with a wait time of almost 6 months.

It is important to note here that My Rights, My Say is operating within some limited parameters given the age restrictions placed on access to the service, as well as capacity within the service itself. Anecdotally, and through evidence gathered from all partners, it is clear the volume of demand on the service and the vitally important role it plays for young people aged 12-15 years old. Our work with these young people also demonstrates the appetite and need for services for those who do fall within the parameters of this service.

We are also mindful of the range of reviews into additional support for learning and education over the last few years, and a number that are planned or underway, such as Angela Morgan's independent ASL Review and subsequent Action Plan, the current ASL Inquiry and ongoing activity focusing on behaviour in schools. We urge careful consideration of how any LDAN Bill would interact and integrate with this and any other policy and legislative developments.

We encourage that consideration is given to the evidence from the ASL Inquiry around the presumption of mainstreaming. Submissions, <u>including our own</u>, highlight that there are multiple neurodivergent children and young people with additional support needs whose needs aren't being met in mainstream school currently. However, what actions are required to tackle this issue must be considered alongside children's rights. We need to consider that children have a right for their local mainstream school to be accessible to them and have appropriate support – which are issues that may be tackled by more training and appropriate resource. However, even with these changes there will still be a limited number of neurodivergent young people where the physical space and environment of our current mainstream school provisions can't meet these needs. For these young people, alternative appropriate provision must be considered.

Children and Young people – Transitions to Adulthood

Transitions is a period of development which can involve changes in every area of life such as housing, employment, social care, education, transport and relationships. We therefore expect some of our overarching and specific consultation proposals, which covers all of these areas and more, to contribute towards improving outcomes for neurodivergent young people and young people with learning disabilities making the transition to adulthood. This also includes our proposals around inclusive communications, mandatory training, independent advocacy, and statutory strategies for learning disabilities and neurodivergence.

Specifically in relation to data, we will consider whether our approach ensures that disaggregated data for neurodivergent young people and young people with learning disabilities is made available to:

- enable us to better understand and measure the extent to which these young people are experiencing a positive and supported transition to young adult life;
- ensure the visibility of these young people;
- help inform the work that will take place under a National Transitions to Adulthood Strategy; and,
- help to inform the development of services to meet the needs of these young people when transitioning to adulthood.

General comments

Transition support is a recurring theme in many parts of our services, including the Enquire helpline, where worries and challenges of moving from children and young people's services to adult services are raised by parents, carers and young people themselves.

Anecdotally, a recurring theme is the 'grey area' when the support from some children and young people's services ceases, but the young person is not yet eligible for support from adult services. Many services designed for children and young people end at age 16, but adult services can often not be accessed until 18 or above. For example, My Rights, My Say is unable to offer advocacy to those post 15, and other advocacy services may only deal with over 18 and not have expertise in school education issues. We also hear of this in social work services where there can be gaps between the remit of different teams. All this can leave young people with very little structured support at a crucial point in their lives.

We urge you to review some of the work conducted by the Inclusion Ambassadors in this area. Their <u>2023 Discussion paper on Transitions</u>, shares the group's experiences and makes some recommendations to help better prepare young people for

transition beyond school. They also contributed to discussions around the development of a Transition to Adulthood Strategy (also 2023), with a key message that any transition planning needs to be person-centred and able to be tailored to individual circumstance. <u>Read more here</u>

More evidence of what has been particularly successful, or not so helpful, during the transition to adulthood can also be found in the <u>Time to Talk Next Steps project</u> <u>evaluation report</u>. The project, delivered by Children in Scotland and partners, provided online 1:1 support for young people aged 16-25 with additional support needs and reported on the year-long pilot in 2023.

Finally, we would also recommend review of our <u>2021 Briefing on Transitions</u> which shares case studies and reflects on how the pandemic has impacted transition planning for young people with additional needs.

The Education (Additional Support for Learning) (Scotland) Act 2004, as amended, outlines transition planning timescales which would apply to children and young people covered by the proposed Bill and which should lead to good practice in this area when considered alongside the Supporting Children's Learning statutory guidance on the ASL Act. However, we are aware that these timescales are often not adhered to, and that some of the good practice principles such as having one key person responsible for transition planning are not always implemented. More work needs to be done to ensure that young people are supported in the transition process to share their views and the pace of change is comfortable and lead by them.

As part of the review of the Supporting Children's Learning guidance that is underway, we believe more clarity is required on transition planning responsibilities. This includes amendments to the section that states that 'the education authority have some discretion about the particular children or young people to whom these duties apply under the Act' (Chapter 6, para 7) which can be a cause for confusion. We also encourage more involvement of other services, such as social work, at an earlier stage in the transition planning process.

For more information, please contact

Jennifer Drummond Senior Communications and Engagement Officer Enquire – the Scottiish Advice Service for Additional Support for Learning jdrummond@childreninscotland.org.uk