Children in Scotland

Consultation response

# ADHD and ASD pathways and support

August 2025

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## Background

Giving all children in Scotland an equal chance to flourish is at the heart of everything we do.

By bringing together a network of people working with and for children, alongside children and young people themselves, we offer a broad, balanced, and independent voice. We create solutions, provide support, and develop positive change across all areas affecting children in Scotland.

We do this by listening, gathering evidence, and applying and sharing learning, while always working to uphold children's rights. Our range of knowledge and expertise means we can provide trusted support on issues as diverse as the people we work with and the varied lives of children and families in Scotland.

## Why we are responding to this consultation

We are responding to this inquiry launched by the Health, Social Care and Sport Committee into Attention Deficit and Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD) pathways and support as we have a range of evidence on young people's experiences of this issue from those we work with, focusing in particular on young people's experiences in education. Our response will include input from members of Changing our World (our children and young people's advisory group),[1] the Inclusion Ambassadors (a group of secondary school age pupils who are entitled to additional support for learning)[2] and applicants to the Access all Arts Fund (a project to help support children and young people to access creative arts opportunities and support wellbeing).[3]

We will also include data from our services that support children and young people who have additional support needs. Enquire[4] is the Scottish advice

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[1] Changing our World
[2] Inclusion Ambassadors
[3] Access All Arts Fund
[4] Enquire

and information service for additional support for learning, delivered by Children in Scotland. Through this service, we provide advice and information to parents, carers, and professionals on the rights of children and young people to support with their education. Additionally, we provide advice and information for young people through our Reach[5] website and we are partners in the My Rights, My Say service. [6]

## 1. Please tell us your views on the aims of the inquiry, in relation to the people you support, and describe any opportunities for improvement you have identified.

We welcome the aims of the inquiry and throughout our response will identify areas we believe the inquiry could also include in its scope.

### Understanding why waiting times for diagnosis and management of ADHD and ASD are long, including the drivers of increased demand

One factor contributing to increasing demand of seeking a diagnosis and support managing both ADHD and ASD is an increase generally in awareness of both conditions. We have seen that parents and carers, professionals and young people themselves have an ever-increasing understanding of ASD and ADHD in line with society as a whole becoming more aware and accepting of neurodivergence. This is likely to result from increased visibility in media (including social media), easier access to families with shared or similar experiences, and better societal awareness[7], amongst other reasons. Children in Scotland believes strongly that having an earlier and better understanding of a child's needs is a positive and welcome development - as it can help everyone involved (including the child or young person themselves) get the right support in place based on those needs.

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[5] Reach

[6] My Rights, My Say

[7] Scottish Government, *National Neurodevelopmental Specification for Children and Young People: Implementation Review Report* (June 2025), accessed here: https://www.gov.scot/binaries/content/documents/govscot/publications/progress-report/2025/06/national-neurodevelopmental-specification-children-young-people-implementation-review-report/documents/national-neurodevelopmental-specification-children-young-people-implementation-review-report/national-neurodevelopmental-specification-children-young-people-implementation-review-report/govscot%3Adocument/national-neurodevelopmental-specification-children-young-people-implementation-review-report.pdf.

Across a lot of our work, we have heard from children and young people who have experienced substantial waiting times to access a formal diagnosis or support. 24% of the young people who applied to the Access All Arts Fund identified as neurodivergent. Out of these applicants, 20% informed us that they are still awaiting a formal diagnosis of a condition (including ASD, ADHD or both) due to prolonged wait times. One young person stated that:

> "*I am awaiting assessment for ASD and ADHD. Which I have been waiting on since 2021 and been told it will be another 2-3 years wait.*" (Applicant to Access All Arts Fund)

This landscape is reflected in the types of queries that our Enquire team receive. Staff have reported receiving enquiries about children on the waitlist for assessment of both ADHD/ASD for one to two years, and sometimes longer.

We welcome the focus of the inquiry on this issue and advise that this must be coupled with the tangible solutions needed to ensure that children and young people can access timely support.

**Understanding how these conditions are diagnosed and managed**

We agree that it is important for the inquiry to consider this aspect of ADHD and ASD pathways. During our time delivering the Inclusion Ambassadors group, we have heard from members that sometimes a focus on diagnosis can lead to key information that could improve support planning not being considered: "*It shouldn't only focus on my diagnosis*". It is of paramount importance when managing a young person's condition, that their needs as a whole are considered in detail. A diagnosis should not be viewed as the destination, but as part of the journey towards better understanding and related support.

We have also heard from young people about difficulties experienced during the process of obtaining a diagnosis due to the language used not being accessible or easy to understand. One member of the Inclusion Ambassadors shared with us that in their experience of the language used about a young person's needs or diagnosis "*can feel a bit scary and hard – especially when English is not my first language*". Additional support needs can be intersectional. Therefore, there may be other reasons why a child, young person or family could be facing challenges with the process of identifying a young person's needs and accessing the right support. We would welcome an intersectional approach being considered within the scope of this inquiry.

## Understanding the impact of delays on individuals

The impact of waiting for a prolonged period on a diagnosis can be significant both for a child or young person themselves, and for their family. Through our services delivery, we have heard from some parents that they can feel like they are being judged by professionals and other families if their child is struggling in nursery or school, or out of school. We hear how they can worry that people are perceiving them to be a "bad parent" or that their child is choosing to have "bad behaviour" and the toll this can take. We have also heard how this can prevent them from feeling able to work with professionals to address concerns.

A formal diagnosis can be validating and helps parents feel reassured that if their child is in distress at school, it is because their support needs are not yet fully recognised or being fully supported – rather than a "fault" of their child or the support they are receiving from their family. The removal of this actual or perceived barrier can help families feel able to better work with professionals, by knowing everyone is aware of and acknowledges a child or young person's support needs, allowing them to work together to ensure they are getting the adjustments they need.

We have heard from young people across different projects we deliver how delayed access to diagnosis and the support they need can have a detrimental impact on their ability to attend and engage in their education. Among those who applied to the Access All Arts Fund and identified as neurodivergent (including those with ADHD or ASD), 63% reported being unable to attend school due to a lack of support or because the environment was too anxiety-inducing.

The young people told us:

> "*As I am autistic and have struggled with and been excluded from the mainstream education system, many of my interests have gone unpursued as I have no support for them.*" (Applicant to the Access All Arts Fund)
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> "*I have autism ADHD, dyspraxia and dyslexia. I didn't receive any support in school till 3rd year then covid hit so didn't get a chance at a proper education. My parents are also disabled, and we are struggling financially*" (Applicant to the Access All Arts Fund)
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> "*I am autistic and also have dyslexia. I was going to mainstream school, but it is really difficult to be there due to the noise, and I get*

> *confused about where I am meant to be. My anxiety has really affected my mental health and my counsellor thinks it is better for me to stay off school just now, until I feel better.*" (Applicant to the Access All Arts Fund)

We have also heard similar experiences from members of the Inclusion Ambassadors. One member shared that they had to wait until S4 to have accommodations met in some subjects while they were waiting for a diagnosis.

**Case study from this year**: a parent contacted the Enquire helpline about their child who was on the waiting list for an ASD assessment. They were struggling at school, but masking, and it was having a big impact on their school attendance. The school arranged a taxi to help get him to school, but staff felt once they were in school they were "doing great" and, therefore, did not need support. The parent had tried explaining that the child was autistic and masking while at school, but they found it very difficult to help the school understand their needs without being backed up by the likes of a diagnosis. As a result, the child would go into school one day and then be absent for the rest of the week as they were exhausted and filled with anxiety.

Our staff team at Enquire has seen in their work how some children, young people and their families have witnessed the difficulties that can be experienced in accessing support while waiting for a diagnosis. For context, the law gives a right to children who - for whatever reasons - need extra support to benefit from their learning.[8] This means that there is not a legal requirement for a diagnosis of ADHD/ASD (or another condition) to have a right to support. In theory, nurseries and schools should, therefore, put in place supports and adjustments to help children pre-diagnosis when they recognise a child is struggling. Some schools do this well, but the Enquire helpline is regularly contacted for advice relating to children who are on long-waiting lists for diagnosis. These children can face extra barriers to accessing their rights to support. For example, a child who is pre-diagnosis but "masking" while at school can face a situation where the school or local authority do not recognise that they have an additional support need as they 'seem fine' when at school. However, the delay to their needs being formally recognised and understood (and supports being put in place) can then lead to the child experiencing emotional distress at home impacting the child's wellbeing and family life. Over time this can also lead to burnout, school anxiety, and missing school.

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[8] Education (Additional Support for Learning) (Scotland) Act 2004, as amended.

The Enquire service sometimes hears from families who feel like they are falling in the gaps of which service is best placed to support a child who is waiting for an assessment of ASD/ADHD.

To illustrate what this might look like: a situation where parents and school suspect a child is autistic, and the child is on a waitlist for assessment. In the meantime, the child is struggling with high levels of school-related anxiety and their mental health is being impacted significantly and negatively from trying to cope within a mainstream setting that the parents suspect is ultimately not the best setting for their child. The school may put in a referral to the Children and Adolescent Mental Health Service (CAMHS) as they feel the child needs specialist mental health support to help them feel well enough to attend school. However a response that can be received by CAMHS may be that they cannot see the child as it is not an inherent mental health issue, but rather a symptom of needing more support in school. The school may feel unclear on how best to support this child without a better understanding of their needs. They may have tried putting a plan in place based on what has previously worked for other autistic pupils, but these have not been working well for this child who may have quite different experiences and support needs that are not yet fully understood.

We welcome this inquiry considering the impact of delays in children and young people receiving diagnosis and support and hope that this is carried out in depth, includes the contributions of those with lived experience of this issue and is coupled with what solutions are needed to address it.

Another aspect we would recommend the Committee consider and draw attention to in this inquiry is the importance of support and opportunities for young people while they are waiting for a diagnosis. We heard from young people involved in the Access All Arts Fund on how impactful and beneficial access to support and opportunities to explore hobbies has been for their wellbeing whilst they were waiting to access formal support:

> *"I am autistic and have dyslexia. Although my autism has not yet been diagnosed due to huge waiting lists, acting has had a positive effect on my mental health."* (Young person applying to the Access All Arts Fund)
>
> *"I'm on the waiting list for CAMHS [Child and Adolescent Mental Health Services] because we think I might have ADHD or autism, and art really helps me forget about that."* (Young person applying to the Access All Arts Fund)

## Exploring solutions to improve capacity of services, referral pathways and support

We strongly welcome the Committee exploring solutions to improve these issues. We have heard from young people on what they think would improve the support available to those seeking support with ASD or ADHD. It is important to note that a child or young person being diagnosed is not the final solution or a guaranteed way of ensuring support is provided. We have heard from the Inclusion Ambassadors that it is extremely important that the adults around them provide proactive support after a diagnosis is received, especially if that diagnosis may signify how they might process new information:

> "*If someone has autism, they kind of process information differently. So you might have to explain to them sometimes what you mean*" (Inclusion Ambassador)

We have also heard from members of the group how, even with diagnosis, there are significant gaps in implementation of support planning in school. This can negate the "point" of seeking diagnosis for children and young people. They spoke about how some teachers do not look at students' support plans that detail the support and adjustments a young person needs: "*most teachers forget about [support plans] and people can end up struggling or being too shy to say anything to the teacher*".

They have also shared with us how information a school has contained within support plans is sometimes incorrect - one member spoke about the inaccuracies in their support plan and how they had to ask for this to be changed. We have also heard about the detrimental impact on a young person's transition from school when education staff did not share a young person's support needs with other bodies. One member shared how their college was not given information about their additional support needs during transition from secondary school to college. This felt "*annoying*", as the school and social worker had told them that they should expect support upon arrival, which did not happen and was disruptive for them.

Young people who have ASD or ADHD must get the right support and adults must ensure that the relevant information detailing support needs is up to date and implemented. We welcome the inquiry looking at current gaps, but this activity must also be solutions-focused.

Young people have told us that they think support for those with ASD or ADHD would be improved and better implemented through increasing staff capacity and resource and providing training.

Young people have identified limited staff capacity and high workloads as significant issues in implementing effective support for those with additional support needs. One member stated, "extra support should not be at the expense of others" as they felt that staff capacity is so limited, that any support from staff in school feels like they are being taken away from somewhere else. Members shared that, "*Teachers have said [the support plan is] 'too much to read', but it is their job to look after you*" and that this is frustrating to hear this from staff and  may either be indicative of a particular attitude to support planning or lack of time to engage in planning and preparing support.

The Inclusion Ambassadors have also identified training and knowledge building for staff (and the time to attend and engage in this) as an important step. "*They need to teach some teachers a lot more about it*" and "*they don't understand it*". They have spoken about the inconsistency of different teachers' knowledge of additional support needs and how this results in differences in levels of understanding, expectations of pupils and comprehension of students' behaviour: "*Support staff are not always able to help me*".

We have also heard a similar idea from a member of Changing our World who, when asked what they would change about education in Scotland, described not getting enough support with their ADHD and ASD diagnosis in school:

> *"I had a really bad primary school experience as I was given virtually no support with my ADHD and ASD. One of the ways my school handled people struggling with the loud noise was to let them go into the corridor and play chess, which I what I had to do with one of my friends who also has ASD.*
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> *The main thing I would look to improve would be:*
>
> *a.) I would improve teachers' knowledge on ADHD and ASD and what challenges children are faced with if they have ADHD or ASD.*
> *b.) I would make more resources and strategies available for teachers on how to give the same course but in a different way to children with ADHD or ASD."*

## Conclusion

We have valued the opportunity to respond to this consultation on the inquiry on support pathways for ASD and ADHD and share what we have heard from children, young people and families about current high levels of waiting times, the impact of these delays on children, young people and families and how support could be improved.