Stronger Together for Autism & Neuro Divergence

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Dear Convener

Scottish Parliament Inquiry - Autism & ADHD Pathways & Support ("Inquiry")

Evidence Session, 30 September 2025 – Follow Up

Thank you for inviting me to give evidence to the Inquiry last Tuesday. It was the first time I have ever done anything like that and I'm very grateful to your Clerks for their proactive efforts to ensure I was prepared and comfortable.

While I am hopeful that I got across to the Committee how important it is to listen to parents and carers of neurodivergent children (in addition to, of course, the children themselves), I feel I had much more to say in relation to each question. I have therefore answered the questions from the evidence session in writing, and have included the answers in an Appendix to this letter. I also recognise that a follow-up question was asked about the presumption of mainstream. Someone from STAND will come back to the Committee on that in writing separately given that it was not one of the predicted questions.

Inclusion

We know that you issued a Call for Evidence for individuals, but in our experience parents and carers have so much life admin to do and are under so much stress, and the ones who are struggling the most are the least likely to have the time or energy to respond. We found it difficult to draft and submit our previous written submission to the Call for Evidence, because it was issued at the beginning of the school summer holidays with the deadline at the end. This was a difficult ask for a charity that is run predominantly by volunteers who are the parents and carers of disabled children.

We are worried that, once again, families with lived experience will be overlooked. To that end, I would like to extend an invitation to you or any of the Committee's members, to attend one of our events and speak to children, parents and carers directly. Please let me know if that would be something you'd find helpful. Alternatively, I could try and arrange an online meeting(s) for you or the other Committee members to speak to parents and carers in a context that works for them. I am doing my best to amplify their voices but equally I do not want to just become another person that speaks **for** them – I want families to have a chance to participate in democracy in a meaningful and inclusive way.

The Minister for Social Care and Wellbeing

On that note, I feel compelled to raise some important points which I hope the Committee can take up with the Minister for Social Care and Wellbeing directly on behalf of our families.

Diagnosis is a need, not a demand

In remarks published last week, the Minister talked about a significant increase in "demand" for assessment and stated that *"diagnosis can be important but should not be a barrier to accessing the help and support that an individual needs."*

I am really concerned here and so are the families that contact us about their struggles. Diagnostic assessment is not a luxury being "demanded" by these children. It is not a separate concept from the "help and support that an individual needs". It's not that it "can be" important - it is vital.

Even when we reach the goal of there being no unnecessary requirements for a child to receive support, it will still be important for children to have access to diagnostic assessment for the reasons we discussed last week and that I mention again in the Appendix to this letter. Also, how can the Scottish Government know what help and support these children need if they don't even know how many of them are autistic or have ADHD in the first place?

Further, even if it is the Minister's view that a diagnosis should not be needed for support, he must caveat this statement each time he says it to **recognise that it is, in fact, currently needed – either formally or in practice – for many types of support.** Not to do so invalidates the experiences of many families and makes them feel as if it's just them that is struggling to access support and therefore it is their fault, when clearly it is not.

The Minister is aware that the Scottish Government itself is contributing to this problem. We have explained in our written submission the issue of "risk in traffic blue badges", which is not yet resolved. The Cabinet Secretary for Transport has, finally (after a great deal of effort from our volunteers which could have been spent on other things), agreed to revisit Transport Scotland's Code of Practice but this has not yet been done and we have been given no timescale for this to be completed.

The Minister stated to Parliament in June that:

"We know that children and families who are seeking support can be left feeling worried or uncertain about what support is available to them and how to access it, fearing that they will be left stranded if they do not have a formal diagnosis. I take the opportunity to reassure parents and carers who may be worried that that is not the case."

However, it **is** the case that they may be stranded – and indeed, for many families right now that is what they are experiencing. I have no doubt that after the evidence that the Committee has already received, members of the Committee will agree. The Minister must recognise the feedback from those with lived experience of the situation rather than invalidate it. We hope that the Committee will ask him to do this.

Waiting Lists and CAMHS

One thing we are really disappointed about is the Minister's statements about CAMHS waiting targets and lists. It is another example of where parents and carers feel that he just "doesn't get it".

The Minister said to Parliament in June:

"Much of the conversation in this chamber around neurodivergence has focused on diagnosis and treatment and on the relationship between neurodivergence and child and adolescent mental health services. Those conversations have included incorrect assertions that young people are being moved off waiting lists to meet the CAMHS waiting times target. I make it crystal clear that that is categorically not the case. CAMHS is a specialist mental health service for children and young people who are experiencing significant mental health problems. Neurodivergence is not a mental health condition and CAMHS is not the appropriate service for children seeking a neurodevelopmental diagnosis."

We were shocked by this statement. Since STAND was established in January 2023, children have been excluded from waiting lists in the context of concerns by Integrated Joint Boards about meeting CAMHS targets. We would be very interested in the Minister's position on why waiting targets are so important for the specialist CAMHS waiting times and not for the neurodevelopmental pathways.

Further, even now children are being referred to CAMHS, having their referrals accepted and then being removed from the waiting lists. This is despite the Minister's statement that CAMHS is not the appropriate service. We are happy to provide further evidence about this, albeit on a confidential basis given it contains children's personal information.

We hope that the Minister will accept that he should revisit his Parliamentary statement about this. He must concede that he cannot be "crystal clear" when attempting to prove a negative, especially in the face of evidence from those who have lived experience.

ADHD, GPs & Shared care

You wrote to the Minister on 23 June 2025 in relation to the Inquiry, asking questions about shared care. However, the Minister's reply on 26 August did not seem to answer the questions in full. For example, his answer on the availability of shared care agreements spoke only of NHS agreements and did not recognise the fact that we have been raising this issue with the Minister's predecessor for almost two years. We flagged specific examples in STAND's Report on ADHD and Shared care in February 2025 which the Minister's predecessor, Ms Todd, said she had read with *"both interest and concern, illustrative as it is of the challenges that so many people face when trying to access the support they need, including medication".*

We look to the Scottish Government for strong leadership here: it is the Scottish Ministers who are responsible for securing the effective provision of services under the National Health Service (Scotland) Act 1978, the Scottish Ministers who introduced the UNCRC (Incorporation) (Scotland) Bill (now Act) to the Scottish Parliament, and the Scottish Ministers who are ultimately accountable if disabled children in Scotland cannot get the ADHD treatment they need.

This a situation which leaves ADHD children (and adults, although that is not our particular focus at STAND) untreated or forced into prohibitive ongoing private prescription and medication costs, while exacerbating the traumatic impact of societal stigma. The families who are affected are already in vulnerable positions, often with parents out of work as a result of the failure of the state to meet children's needs. They are exhausted and lacking in confidence. As you know, one of our "pillars" at STAND is "empowerment", and our projects

seek to empower children and their families to fight for their rights. We would hope that such leadership gives parents and carers more confidence to challenge GP practices' blanket bans on prescribing ADHD medication which has been initiated by a private specialist.

Next steps

Please let me know if you would like to take me up on my offer to arrange for you to meet the families we support.

I am happy to answer any further questions or provide further evidence (although some may have to be provided on a confidential basis given the sensitive nature of the circumstances which families find themselves in).

I want to finish by highlighting the words of one parent which capture what we hear repeatedly:

"It feels like we are in a system designed to break us."

The Committee has the power to shine a light on these failures and to hold the Scottish Government, local authorities and health boards accountable. We urge you to use that power. The children and families we support deserve better. Scotland can do better. We can all do better. We are trying our best at STAND but we need help. We are trying to give support but most of us are also those needing support. That is why we exist in the first place – because when we looked for the support we needed it wasn't there.

Thank you for listening to us.

Yours sincerely

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Appendix - Questions from the Committee to STAND

Contents

Role of Diagnosis

What impact can a diagnosis have for a person with a neurodevelopmental condition such as autism or ADHD?

Diagnosis provides appropriate understanding of needs and supports, not just for the child but for everyone that is part of that child's life including public services. Almost 90% of parents and carers that STAND surveyed earlier this year said diagnosis was "vital" to their child's wellbeing.

Children need the right help before diagnosis, during the assessment process, and after. Every stage matters. When those stages work together, diagnosis becomes the foundation for a life where autistic and ADHD children can thrive.

Diagnosis is key to identifying and meeting needs, but it cannot stand alone. Too often we see children with a diagnosis whose needs still go unmet. This is why diagnosis must work hand-in-hand with a genuine needs-based approach.

It is important to recognise what a diagnosis is and how someone receives one. Diagnostic assessment for autism and ADHD identifies the best ways to address needs and how not to cause harm. To start medication for ADHD, diagnosis is required.

For STAND, diagnosis is not a "label" - it follows thorough assessment and is vital in identifying the nature of the child's needs and how to meet them. It is impossible to know what kind of support a child will need without an assessment which leads to the correct diagnosis.

Two children might look very similar in the classroom but for completely different reasons. Without timely diagnostic services teachers are being asked to guess what's behind the behaviour while also trying to teach 30 other pupils. This is an impossible expectation.

Needs change over time, but whether you're autistic or have ADHD doesn't. Knowing you're autistic or have ADHD helps you plan for future needs before reaching crisis. Access to

support for many services for autism and ADHD often requires a diagnosis or is more easily accessible with a diagnosis, even though it shouldn't be.

If you give support without diagnosis a child may never truly understand themselves. If you give a diagnosis without support, they may know who they are but not get the help they need to thrive. Children need both together - understanding and support - or they are left vulnerable.

One parent told us: *"As a parent I don't benefit from saying my child is autistic but my child does. He's validated, he's seen, he's heard. He's not that naughty child that people may see due to ignorance."*

To what extent are neurodevelopmental conditions being over or underdiagnosed in Scotland?

STAND is surprised that there is any question of overdiagnosis. In our experience, children are facing huge struggles to be assessed, let alone diagnosed. We believe the term "overdiagnosis" is harmful to children and families, fuelling stigma and insecurities. Either children are being diagnosed correctly as per the diagnostic criteria or they are not. We must address the myth about overdiagnosis head on. Even asking the question gives credit to a concern which has no credible or legitimate basis at all, and has its origins in prejudicial and ignorant beliefs.

Even when schools, social workers and the NHS meet a child's needs, that child can still face stigma and misunderstanding in everyday life within the community - like having a meltdown in a supermarket, being unable to speak at a birthday party or needing specific foods and routines. In those moments parents often feel it would be better to disclose that their child is autistic or has ADHD to protect the child from judgement or discrimination. That disclosure becomes meaningless if society dismisses it on the basis that autism and ADHD are reportedly "overdiagnosed."

Claims by prominent politicians which suggest that parents can turn up at their GP and demand diagnoses for benefits are harmful. Many GPs won't even make a referral and will direct families to education authorities. In Scotland, neurodevelopmental conditions such as autism and ADHD are far more likely to be underdiagnosed, especially given the long waits for assessment in most areas and in other areas there being no diagnostic pathways open for children at all.

Parents tell us they are spending their lives taking pictures and videos instead of making memories, purely to prove what they're saying about their child is true. Families are fighting for years just to be heard. This is not what overdiagnosis looks like.

We wish to address the characterisation of increased awareness of need as an “increase in demand”. This is terminology we have even seen used by the Minister for Social Care and Mental Wellbeing himself. The rise in referrals isn't a sudden "flood" of new cases - it's a reflection of unmet need that has always been there. For decades, children, especially those who mask, were missed or mislabelled.

It is extremely frustrating for us to read of the Minister and others, talking of the challenges associated with increased “demand” and insufficient capacity, when we know that the same

multi-disciplinary professionals who already assess children within specialist CAMHS for mental health conditions could assess neurodevelopmental needs too. Health boards must allocate the staff they already have more fairly, based on need and **not on the particular diagnosis that may eventually be given,** so that neurodivergent children aren't inevitably left at the back of the queue.

We often hear concerns about the influence of social media on the number of people seeking assessments for their children to determine if they are autistic or have ADHD. Provided that appropriate referral and diagnostic criteria are consistently and properly applied, we don't understand how increased awareness, acceptance and understanding of these conditions can be a negative thing.

Indeed, in other circumstances the government itself uses social media for public health campaigns to help people identify cancers, sepsis and other conditions at an early stage. For example, it is reported that the work Sir Chris Hoy has done to raise awareness of prostate cancer has resulted in a "spike" in referrals. We believe that this is a good thing.

In the experience of STAND's volunteers and the families they support, the professionals who raise concerns about social media are often the same professionals who show stigma, prejudice and a lack of understanding about autistic and ADHD children and are often the ones creating unnecessary and unlawful barriers to those children getting the support they need. It always seems to be “tiktok” that gets most of the blame here, which suggests to us that it is the lazy repetition of a discriminatory and prejudicial trope by people who have no idea what they are talking about, rather than a genuine evidence-based concern.

We look to the Scottish Government for leadership here. We need Scottish Ministers to lead the way in celebrating the fact that there is more awareness and understanding rather than complain about it. Ministers have committed to introduce the LDAN Bill to better respect and champion the rights of neurodivergent people. These stigmatising attitudes are exactly why this legislation is needed, and we hope that these same attitudes aren’t the cause of the delay in this Bill being introduced.

Are there specific groups more affected by missed or incorrect diagnosis?

Other organisations such as SEMA and SWAN will be better placed to give detail on this to the Committee. On the whole, the children and families we support are so badly affected by the current state of affairs that it is difficult for us to distinguish between the varying degrees of harm and distress and it is not something we would feel comfortable doing. We worry it would be exploited in order to further deprioritise certain subsets of neurodivergent children. In any event there is not enough available data produced by health boards, Public Health Scotland or the Scottish Government for us to meaningfully analyse which groups are more affected. Data isn't produced consistently and even published CAMHS statistics exclude neurodevelopmental waits.

The most obvious group that is likely to have a missed diagnosis in the first place is the huge cohort of children who require assessment for autism or ADHD but are refused access to CAMHS on the basis that they do not have a "co-occurring mental health condition." In some areas in Scotland, these children were removed from waiting lists and and/or have had

referrals rejected by CAMHS despite no other assessment pathway being available, for example in Ayrshire and Tayside.

What we often hear from parents and carers is that their children and/or the parents and carers themselves have experienced incorrect diagnosis of mental health conditions such as bipolar disorder, never having had the opportunity for a proper diagnostic assessment for autism and ADHD. All children should be given the opportunity for a diagnostic assessment if they need it and if that were done then the risk of missed or incorrect diagnosis would be minimised regardless of whether they belong to a specific group.

To be clear, we are not here to say who should have priority over another and we do not think that neurodivergent children should have "priority" over children with mental health conditions. Of course, children with serious mental health needs require urgent care, and we would never dispute that. But the current system is built on thresholds that exclude autistic and ADHD children unless they have a co-occurring mental health condition. This has left thousands of families with no clear pathway at all and does not reflect the significant acute crisis that many autistic and ADHD children find themselves in even without a co-occurring mental health condition.

We do not think that one group's needs should be pitted against another group's needs. It is about fair and proportionate resource allocation, meaning the Scottish Government and health boards planning services in a way that is in alignment with the Public Sector Equality Duty and the UNCRC.

Parents and carers feel that there has been no explanation of why so much resource has been allocated to specialist CAMHS services at the expense of neurodevelopmental assessment pathways. Without that explanation, how can they be expected *not* to think that the reason is that health boards have targets to meet for specialist CAMHS but not for implementation of the neurodevelopmental specification? How can STAND as the charity seeking to raise awareness of the need to respect these children's rights, not demand an explanation as to how this could possibly comply with the Public Sector Equality Duty and UNCRC? If there are good reasons, parents and carers deserve to hear them.

We want to be reassured that the needs of autistic and ADHD children aren't automatically the ones being sacrificed on the basis that society feels that autism and ADHD is being "overdiagnosed", isn't real, is just a character flaw or is a way for parents and carers to attempt to get disability benefits. We hope that decisions can be made by looking across NHS services and resources as a whole, and not by choosing between two vulnerable groups who both need access to assessment and support.

Pathways and Thresholds for Assessment

What is the impact of differing pathways for neurodevelopmental assessment across Scotland? What steps could be taken to address any differences in assessment pathway by area?

We see variation in more than assessment pathways - it is in all aspects of support for and respect for the rights of autistic and ADHD children. This variation creates inconsistency, confusion and inequity.

It is not just that there is variation - the information in each area about assessment pathways and support is often unclear and lacking in transparency. So much of the support that parents and carers rely on is peer support and the variation across Scotland undermines that.

At STAND, we run WhatsApp peer support groups with over 700 members. These groups are divided mainly by age, not geography, to maximise relevance of peer advice. Yet even within these groups, families often cannot support each other effectively because processes differ so widely across Scotland. We group families by age, not by postcode because the challenges of starting school or sitting exams are more alike than the postcode you live in - but even then, families can't share advice because the processes differ so widely across Scotland.

Our volunteers have tried to bridge this gap by running empowerment workshops in several cities across Scotland. However, we find that the lack of consistency and transparency makes it almost impossible to give parents and carers accurate information. In many cases, families themselves end up informing professionals when policies change.

Worse still, when we seek clarity - for example through FOI requests - we are met with obstructive or dismissive replies. For example, we recently asked East Lothian Council to explain their home to school transport policy via an FOI request and. East Lothian Council's Principal Officer for Equity and Inclusion then wrote to our volunteer advising her to seek her own legal advice *"given how this conversation may continue."*

A clear national framework for assessment and support should be established to ensure consistency across Scotland. The existing Scottish Government Neurodevelopmental Specification is rarely implemented as it is but, in any event, it is not clear enough in itself to solve the problem. Further, the Specification is not national medical guidelines like SIGN or NICE guidelines and it has no statutory basis. The specification says support should be consistent across boards but the SPICe briefing confirms there is wide variation. Families describe it as a postcode lottery with very different rules on referral, thresholds and even medication. The Specification says there should be consistency but doesn't say what it should look like, leaving it up to health boards to decide differently. The LDAN Bill might be an opportunity to give this statutory basis. A clear national framework should set out minimum standards that every health board and local authority must deliver, so that families are not at the mercy of postcode lotteries. That could include:

- a consistent and transparent single point of access so families, schools and GPs all know exactly how to refer,
- the implementation of clear maximum waiting times targets for both assessment and treatment so that there is no incentive for health boards to prioritise resources for specialist CAMHS on the basis that they must meet specialist CAMHS targets,
- effective and accessible mechanisms to hold public authorities to account for failure to provide support while waiting for assessment, so children don't lose years of education or development,
- consistent eligibility criteria across Scotland, so a child in East Lothian has the same rights as a child in Glasgow or Highland,

- routine publication of waiting time data for neurodevelopmental assessments so progress is transparent.

Public authorities should commit to openness and transparency, engaging constructively with third-sector organisations that are filling support gaps. Families, carers and third-sector groups should be involved in the design of pathways so they reflect real lived experience.

At the very least, families must be given clear, accessible information about how to navigate support in their area. Without this, inequity will continue and children will be left without the right help at the right time.

What is the view of witnesses about the use of thresholds for accessing neurodevelopmental assessments? Can they give examples of where thresholds are used?

Thresholds already exist for referral to assessments and of course we understand why. Those thresholds are already set out in independently set medical guidelines, for example NICE and SIGN guidelines.

There are also other types of thresholds which services put in place to manage access which are not medical, not independent, inconsistent and often unclear.

We hope that the fact this question has been asked does not mean that there is any suggestion that thresholds need to be even higher. Children struggle enough to access assessment as it is.

Referrals to specialist CAMHS services have their own thresholds - either those set out by the Scottish Government CAMHS Specification or other ones that are mentioned within the specific referral process. For example, in East Lothian the thresholds for direct referral to CAMHS are different from those set out in the Scottish Government CAMHS Specification.

In almost every case we have come across, it is either difficult or even impossible to find out what the thresholds are. Even when we ask professionals who make the referrals, they don't know either - they often just send information and hope for the best. When referrals are rejected, they also don't explain why the relevant threshold wasn't met.

Therefore, our view is that the thresholds need to be consistent across Scotland and across services and people making referrals need training in what these thresholds are. They also need to be transparent and easily understood by everyone involved, including the child and their parents or carers. Right now, even when someone thinks they know the threshold the goalposts are continuously moving often without anyone being told. STAND's volunteers have supported families where referrals were accepted, then later rejected without explanation. In one case, a referral was accepted initially, but months later the assessment team requested more information and asked the referring teacher to complete the forms again. The family was never told why the referral they had accepted was now insufficient or what additional threshold had been introduced.

Those deciding whether to make referrals need the expertise to articulate concerns and explain a child's needs. Too often, this falls to early years staff in private nurseries who lack

time, training and support. Even when training is given, high staff turnover means many leave before they can put it into practice.

The LDAN Bill is a real chance to fix this through training, not just for those making referrals but for all staff contributing evidence. Nursery and school staff must be properly trained and given the time to ensure referrals are based on full accurate information. The LDAN Bill is also a good opportunity for standards to be statutory and therefore consistent across Scotland and transparent.

What is the view of witnesses on self-referral for assessment?

We are not sure exactly what "self-referral" means in this context, especially when it comes to children. However, whatever the referral process is, we believe in creating a "no wrong door" policy where families, GPs and schools all have clear accessible routes into assessment, and are not faced with the possibility that the referral could be blocked by untrained staff involved in the child's care.

Families are often expected to self-refer to services and resources anyway, like Speech and Language Therapy and Occupational Therapy. If they are trusted to do that, then why not trust them to make the referral for assessment?

Teachers, health visitors and GPs are already under huge pressures, and we sometimes witness them essentially being a post-box during the referral process. As mentioned above, one of our volunteers is experiencing this right now – over six months after an initial referral by her daughter's guidance teacher and after CAMHS confirmed it was accepted, the neurodevelopmental assessment team wrote to the teacher and said that they now needed further information and the teacher must make another referral. This means that the teacher is spending time gathering that information from the child and her mother and then sending it back to the team himself, which is time that he could be spending actually teaching. The parents would have been willing to provide that information directly to the assessment team in the first place.

The referral process must be transparent, consistent and well-communicated. Simply allowing self-referrals only to bounce families back later would be counterproductive and harmful. When children courageously open up to teachers about their struggles, only to be told a year later that there wasn't sufficient evidence, it reinforces the damaging feeling that they aren't believed or taken seriously.

Very importantly, parents and carers should not be relied upon as the only route for assessment, or as an excuse to reduce resources for professionals to make the referrals directly. They should not be expected to "project manage" the process either. Depending on the presentation of the child, parents and carers may not identify the need for referral themselves, and we hear of extreme reluctance on the part of teachers and nursery staff to raise the possibility with parents and carers that have not raised it themselves.

Ultimately, it comes down to whether those deciding whether to accept referrals or make them on behalf of children, believe the children and their parents and carers. If they don't believe children and their parents and carers, why not?

Parents and carers will always play a role because they know their child best - but they can't be the gatekeepers or the project managers of the whole system. Too many families are left chasing schools, chasing GPs, chasing CAMHS, just to keep the process moving. That isn't fair, and it isn't safe. Professionals need the time and the resources to do their job properly, so that parents and carers aren't carrying all the responsibility.

We are aware of dangerous narratives which are pervasive in society, for example that parents and carers might seek diagnosis for disingenuous reasons. We trust that it is clear to the Committee that no parent goes through years of waiting lists, assessments and knock-backs just to chase a “label”. Parents and carers want their children to be understood, supported and safe. A diagnosis isn't a prize - it's often the only way to access services that should be needs-based but, in reality, aren't. If anything, families are forced to push for diagnosis because without it, doors stay shut: from Blue Badges, to Section 23 assessments, to school funding.

Parents and carers aren't demanding diagnosis - they're advocating for the children to get the support they deserve. Diagnosis is often the only way to unlock it.

Waiting Times

What can the impact of waiting for a diagnosis be for individuals and their families?

The longer that people wait for a diagnostic assessment, the longer it is before their needs are fully identified and properly understood. The longer it takes to meet those needs, the higher the chance of poorer outcomes for that child. Therefore, the impact of waiting for a diagnosis is huge. Children lose critical years of development, families are left in limbo and support is delayed or withheld.

A child's education, mental health and family relationships can all suffer. Parents describe the process as *"physically and emotionally torturous."* The longer the child waits for a diagnosis, the longer people will assume that those who mask are "getting on fine" when they are actually being traumatised by everyday life. For other children, it increases the chances that they will be excluded from school, stigmatised or mislabelled as disruptive.

The longer the child waits for diagnosis, the longer that parents and carers will be blamed and judged rather than supported and will struggle to go to work, stay in work, maintain relationships and live happy healthy lives. When we talk about waiting for a diagnosis, it's not a neutral "delay" where families feel stranded. It's a period of real harm and can cause trauma which lasts well into adult life.

One parent said: *"I spend my life taking photos and videos to prove what I already know about my child in order to prove that my child needs help. Instead of making memories, I'm gathering evidence."*

Parents and carers are out of work for longer, resulting in huge financial implications. Families tell us they are in survival mode, losing precious time, memories and hope because the system makes them wait for the help their child desperately needs. Meanwhile, the Minister is making statements in Parliament saying that he reassures them they shouldn't

fear that they will be stranded. It's too late - they already are, on a huge and undeniable scale.

For example:

- One parent told us their child will be seven before even reaching diagnosis, meaning two whole years of school without the right support.
- Another family said: *"My daughter self-harms and when her GP referred her to CAMHS they refused it - they said it had to come through school. She was accepted onto the waiting list, then removed again. No explanation. No support."*
- Parents describe being *"in survival mode daily,"* medicating themselves to cope and watching their other children suffer as siblings' needs dominate the home.
- A mother explained: *"My son elopes and in anger puts himself and others at risk. We are still waiting for medication years after diagnosis."*

What can be done to improve people's experiences during the time they are waiting for a neurodevelopmental assessment? What support is available and does this vary by area?

The SPICe briefing shows just how long families are left in limbo. During this time, many children are excluded from school activities, parents reduce or leave work and mental health deteriorates. The waiting period is not neutral; it is actively damaging.

It is difficult to give a view on how to improve children and families' experiences of a process they shouldn't even have to go through. However, there are things we know that are happening that make the experiences even worse.

Transparency and information about referral processes and waiting lists is vital. We often hear that parents should take responsibility for their children, for example last week in the context of the debate in Parliament about behaviour in school. However, parents and carers can't do this if no one will be honest with them about where their children are on a waiting list, whether they're actually likely to ever get an assessment or, in the case of ADHD, medication within a reasonable timescale.

Children, parents and carers need to be believed. If they tell professionals they need help, they must be given that help. Instead, currently, many professionals and those in wider society are sceptical about whether the needs are related to autism or ADHD or not and that then impacts whether the support is offered.

We need leadership from the Scottish Government here. The LDAN Bill is a great opportunity to make a statement that Scotland is a place that actively seeks to support autistic and ADHD people rather than disbelieve them and exclude them.

Further, although assessment and diagnosis is a key way to ensure that needs are properly identified, the more that professionals involved in the care of children are trained on how to accommodate and understand autistic and ADHD children, the less of a negative impact the wait for assessment will have.

Again, this is where the LDAN Bill must step in and ensure that professionals in all areas of a child's life, in the spirit of GIRFEC, are properly trained - early years and childcare services, primary and secondary school, healthcare, social work, transport and justice. A priority is those in early years and school education because it is in those environments where the most evidence is usually gathered and also where needs are so often missed because of the lack of understanding of how autism and ADHD can present.

Improving experiences during the wait must never come at the expense of diagnostic assessment but in the meantime, families should not be left to feel abandoned. The LDAN Bill offers a promising vehicle to ensure that support is guaranteed from first concern, not contingent on diagnosis, while preserving the diagnostic pathway as a right.

Currently, what support is available while waiting varies dramatically across Scotland. Some health boards or local authorities may offer classroom adjustments, speech and language therapy or occupational therapy input; others offer nothing until formal assessment. This postcode lottery breeds despair. One parent was told: *"You'll get a letter when we are able to see him,"* with no indication whether that's weeks or years.

To improve experiences while waiting - and set the basis for a stronger system once the LDAN Bill becomes law - we must:

- **Begin support at first concern:** Let adjustments, therapeutic advice and early interventions start immediately, without requiring a diagnosis or referral. The LDAN Bill should create a statutory duty for that.

- **Transparent communication:** Families must see timelines, know where they are in the process and have clear points of contact. The Bill should mandate that boards provide this information. This is important for any child but **especially** autistic and ADHD children and families.

- **Dedicated liaison/advocacy roles:** Provide ASN or neurodevelopmental support workers for families to call - someone who can advise, reassure and navigate the system.

- **Consistency and legal protections:** Under the LDAN Bill, support during waiting periods and recognition of private diagnoses should be enshrined in law to prevent postcode disparities and ensure accountability.

When the LDAN Bill is introduced, it must mandate that support begins from first concern, continues during assessment, and carries through diagnosis, so that diagnosis is protected, not undermined and families are never left unsupported.

What actions could/should be taken to address long waits for diagnosis?

Long waits are not inevitable. They are the result of how resources are allocated. The same multi-disciplinary staff who assess children in CAMHS for mental health conditions also have the skills to assess for autism and ADHD. Yet autistic and ADHD children are deprioritised.

The answer isn't more rationing or higher thresholds; it's fairer allocation of existing staff and resources.

It is important to remember that this is not the only waiting list families are on. STAND supports families waiting for school placements, for medication, for speech and language therapy, for occupational therapy… for absolutely everything. The cumulative effect of multiple waiting lists is devastating. One STAND volunteer had a mental breakdown while on a waiting list to hear back about a school placement at specialist provision, only to have to immediately start the whole process all over again for their second child.

Actions that would help include:

1. **Fair allocation of staff:** Ensure multi-disciplinary teams already in place assess autistic and ADHD children as well as those with co-occurring mental health conditions.
2. **Interim support:** Support must begin from the first concern, continue during assessment and carry on after diagnosis.
3. **Transparency:** Routinely publish neurodevelopmental waiting times so families aren't hidden from the system.
4. **Consistency across Scotland:** One national framework so children aren't penalised for living in a different postcode.

Availability of Support

How widely is receiving a diagnosis a requirement for accessing support? Can witnesses give examples of cases where a diagnosis?

In theory, absence of a diagnosis should not exclude children from support but in practice, diagnosis acts as a gatekeeper across almost every area of these children's lives.

The Minister for Social Care and Mental Wellbeing stood up in Parliament earlier this year and acknowledged that families fear that they will be left stranded if they do not have a formal diagnosis. Disappointingly, he then stated that this is not the case. However, we have told his officials too many times to count that it absolutely is the case that families are stranded and we have provided evidence of this. The Committee will have seen that public authorities have acknowledged in their written responses to this inquiry that diagnosis has become the primary gateway to support, despite what the Minister says.

Concrete examples from families we support:

- One parent told us: *"School refused to support us unless we had a diagnosis - even the teacher said he was autistic but no one would refer."*

- Teachers tell parents they need diagnostic "evidence" before making referrals, creating circular logic where you can't get assessed without school support but can't get school support without assessment.

- ADHD medication requires diagnosis, but the issue of medication goes further. We have cases where children need melatonin for severe sleep disturbance - health

boards say it should only be prescribed to children with neurodevelopmental conditions, not neurotypical children. Without diagnosis, they can't access it. One parent's autistic 4-year-old was told by a paediatrician that liquid melatonin was "unavailable" and tablets had been "taste-tested" so couldn't be tasted when dissolved. That completely misunderstands sensory processing differences.

- Local authorities apply criteria for access to disability social work services, such as self-directed support, which require a diagnosis for autism or ADHD - in some cases it even requires a diagnosis of autism plus another condition in order to qualify.

- The Scottish Government's own Code of Practice to Local Authorities states you need evidence confirming diagnosis of a mental disorder for risk-in-traffic badges. After a great deal of effort from our empowerment team, the Cabinet Secretary for Transport has finally agreed to review the Code of Practice but we still have no commitment as to what the reviewed guidance will actually say and when it will be reviewed, despite us having been raising this 2022. How many children have missed out on this vital support as a result? Every day goes past and results in even more missing out.

- East Lothian Council's Health and Housing guidance states that, to access housing points for an autistic person you must show that *"you have tried a range of other treatment options"* for autism. It reads like autism is an "illness" that can be "treated." This is factually wrong and forces parents to feel they must pursue interventions - some potentially harmful - just to get safe or suitable housing. If this is their approach, it is extremely unlikely that East Lothian Council would acknowledge or appreciate an undiagnosed autistic child's needs.

The Scottish Government says support should be needs-based but they've created a system where diagnosis is the key that unlocks support, either intentionally or in practice. And then they've made that key almost impossible to obtain.

Autistic and ADHD children have rights under the Equality Act 2010. There is no legal requirement for a diagnosis to have the protected characteristic of “disability. However, to enforce those rights families need confidence they can show their child is disabled. Without a diagnosis or at least the evidence gathered during referral and assessment, that's extremely difficult. If a family were to exercise their rights under the Equality Act, the court or tribunal would have to be satisfied on the balance of probabilities that the child was disabled – if Transport Scotland, schools or social work departments do not even accept that these children are entitled to support without a diagnosis then it does not fill families with confidence that they can prove it in court.

So yes, diagnosis is required. Not in law, but in practice - everywhere, day to day and that matters. In any event, a proper diagnostic assessment is a fundamental part of identifying the support that a child needs. Diagnosis forms part of the support - you can't identify the right support without proper diagnostic assessment.

For families, this isn't about chasing a piece of paper - it's about their children being seen, believed and given the chance to thrive. When diagnosis is treated as an optional extra,

those children are left invisible. No parent or carer should have to fight this hard just for their child to be recognised.

To what extent do witnesses agree with the assertion from Edinburgh CAMHS Team that "support provision must be fundamentally reimagined to prioritise individual needs over diagnostic labels"?

Firstly, diagnosis is not a label, at least if you're doing it properly. It is disappointing that this terminology has been used and it is yet another example of the reinforcement of stigma and prejudice. Would they call other types of diagnosis a “label”? A diagnosis is a clinical determination based on thorough assessment, intended to identify needs and guide support. Calling it a “label” trivialises the process and the lived reality of the children and families we support. Being autistic and ADHD is an integral and fundamental part of who these children are.

Of course support provision must focus on individual needs but a diagnostic assessment forms part of the process of identifying those needs and how to address them.

Needs-based support should begin from the moment of first concern so that children do not spend years in limbo but diagnostic assessment is still crucial as a tool to plan the right help, and predict what further help might be needed in the future.

Further, without diagnosis, children cannot be prescribed ADHD medication. Families often find themselves excluded from Section 23 budgets, housing points and Blue Badges, and find it harder to gather evidence in order to apply for disability benefits.

Diagnosis also provides children with identity and self-understanding, which in itself is a basic human need.

We agree that the way that support is provided should be reimagined: all unnecessary barriers to support should be removed, for example diagnosis requirements for blue badges and Section 23 budgets. However, even if and when this is done, proper diagnostic assessment will still remain a vital part of the process of identifying and meeting many autistic and ADHD children's needs.

This is why it is so important that children do not wait years for diagnostic assessment and so important that the Scottish Government does not think that the negative impact of these waits can be disregarded just because they promise to offer "needs-based" support, especially when they are currently failing to fulfil that promise.

Needs-based support and diagnosis are not alternatives - they work together. Needs-based support is vital while families wait, but diagnosis still matters because it's a recognised, formal framework that can't just be taken away or argued against. A diagnosis enhances the ability of children and families to access and enforce their rights.

Needs-based support helps right now, but diagnosis protects for the long term. Families need both - one without the other leaves them vulnerable.

What wider benefits could result from appropriate supports being made available at the right time?

It shouldn't be necessary to prove wider benefits to justify timely assessment and support - autistic and ADHD children have a right to health care like all other children. But it is true that when support comes at the right time, the benefits extend far beyond the child: stronger families, calmer classrooms and reduced pressure on services because problems are prevented rather than left to escalate.

Children and their families require to be believed, supported, and given the opportunity for diagnostic assessment where a child meets the criteria for that. The right time for support and assessment to begin is as soon as the first concern is raised, whether by a child, their parent or carer or a professional. If that doesn't happen, harm is caused not only to the child but also to their family and wider society. The clearest wider benefit of acting at the right time is simply the prevention of unnecessary harm.

At a recent Stay and Play session, a parent told us that the impact on their mental health, their other children, and even their relationship has been huge, all because they didn't get what they needed at the right time.

Other wider benefits include better education for the child and other children, healthier communities and more efficient and responsible use of public resources and finances.

Ultimately, if every child is supported, nurtured and given the opportunity to thrive, then we, as a society, could get the benefit of what these amazing children have to offer. Instead of these children being seen as, for example, distractible, stubborn and impulsive, they could be seen for who they truly are - curious, determined and creative.

What is so heartbreaking for us at STAND is that many of the parents and carers are in crisis mode, living hour to hour and day to day and have little capacity to think about the wider benefits of their child getting what they need. Parents and carers have told us that their children are barely surviving let alone thriving. One parent told me this weekend that she and her son can't go on.

I attend our events weekly and hear these things first hand, witnessing parents and carers in tears. The truth is, the wider benefits are obvious: better education, healthier families, stronger communities but parents tell us they can't even think about benefits right now because they're just trying to survive today. If we act at the right time, children could thrive and society would gain so much but first we have to stop the harm.

Private Assessment and Shared Care

What role should private providers play in the diagnosis of neurodevelopmental conditions?

It is worth noting that private providers play a role in many aspects of children's lives. For example, specialist provision schools are not always run by local authorities, but the local authorities still place children there. Children entitled to their 1140 hours funded childcare attend private nurseries who are then funded by local authorities directly.

When it comes to assessment for neurodevelopmental conditions, children and families should not be in a position where private providers have to play a role. However, currently they are. Children should be entitled to diagnostic assessment from the NHS but that isn't happening. They are seeking private diagnosis because they feel they have been failed by the NHS.

Worse still, even when children are diagnosed on the NHS for ADHD, they often have to wait years for medication. It is unsurprising that children and families are resorting to assessment from private providers, often with money that they borrow from family and friends, because they don't have any other option.

As with any private health care, the private providers should follow all relevant guidelines and meet the appropriate standards. If they do, then we see no reason for a diagnosis which is made by a private provider to be treated any differently by public authorities to one made by the NHS.

However, in reality it is. For example, GPs and health boards often refuse to accept the validity of any private diagnosis for autism and ADHD, and schools often ignore and dismiss private diagnosis. Some schools have issued direct instructions to teachers to say that they must not cooperate with private assessments in the first place, let alone recognise the diagnosis or take into account the recommendations of the private provider who made the diagnosis. Multiple parents tell us that teachers are being told not to support their child until a public assessment is completed or to ignore private diagnoses. We see this as part of the systemic barriers families face.

We hear a lot from families that GPs and schools criticise private providers but often without any explanation or evidence as to why. This confuses the families given that many of the clinicians who work for the private providers also work for the NHS, for example for CAMHS. Also, they work to the same standards, follow the same guidelines and the clinicians who make the diagnosis are registered with the GMC. In Scotland, private providers are regulated by Healthcare Improvement Scotland.

We conducted a survey of parents and carers earlier this year about private ADHD diagnosis and shared care. As part of that, we asked which providers they used. Two key providers mentioned were Diverse Diagnostics and ADHD Direct. Healthcare Improvement Scotland inspected Diverse Diagnostics in Glasgow in May 2025. The inspection found that assessment consultations were carried out by consultant psychiatrists who used a range of screening tools to assess the patient's medical and psychosocial history (mental, emotional, environmental and cultural factors that can influence an individual's wellbeing and behaviour) to determine if a diagnosis was appropriate. Patients were given a copy of their assessment report and this was also sent to the patient's GP. ADHD Direct was inspected in June 2025 by Healthcare Improvement Scotland - no requirements or recommendations were made at the last inspection in 2023 or in the recent inspection in 2025. The inspection noted that the clinical service manager and chief executive officer delivered training for the University of Wales as part of a postgraduate certified programme in neurodiversity-inclusive healthcare, which was led by the service's clinical lead.

Families don't choose private assessment because they want to; they do it because they feel they have no other option and when that assessment is then dismissed it leaves them paying twice: once with money they can't afford and again with the cost to their child's wellbeing. These children have to undergo yet another assessment on the NHS to eventually get the medication they so desperately need. If the same clinicians, following the same standards, can diagnose in the NHS, then their judgment should be respected wherever it's made.

How confident are witnesses in the standard of assessments provided by private companies? In what ways do these vary from those being provided by NHS Boards?

We are confused as to why there is a persistent narrative emerging that these private providers cannot be trusted. If that is the case, what are Healthcare Improvement Scotland, the GMC, and the Scottish Government doing about it?

We did a survey earlier this year about private ADHD assessment and the overwhelming consensus was that the children and families had faith in the assessments carried out by private providers. We asked specific questions about cases where the NHS had subsequently assessed the child and whether the diagnosis and prescribed medicine was the same as when it had been done via the private assessment - no one who responded to the survey said it wasn't.

We have made FOI requests to a number of GP practices who criticise the quality of private providers because we want to understand why they are concerned. However, we didn't get information about what the concerns are and why they have them. Our Empowerment Champion Project volunteers are now helping families challenge this through complaints, FOIs and subject access requests but so far no GP practice has offered any explanation or evidence for their claims about poor quality private assessments. In fact, some FOI and SAR responses show misinformed and pejorative statements and accusations being levelled against the parents and carers themselves. Private providers should follow NICE or SIGN guidelines, comply with Healthcare Improvement Scotland recommendations and inspections – if they are doing this, and GP practices are still concerned then there is a fundamental issue with the system that the Cabinet Secretary for Health must address as a matter of urgency.

Therefore, we remain as confident as we can be. We are not medical professionals, and therefore all we can do is rely on the relevant regulators such as Healthcare Improvement Scotland to do their job properly. The Cabinet Secretary for Health and Minister for Social Care and Mental Wellbeing must either confirm that they have faith in Healthcare Improvement Scotland, or admit that they do not. If it is the former, they must publicly declare that they disagree with the narrative of the GP practices who are refusing to do shared care on the basis of these apparent concerns. If it is the latter, they must tell us what they are doing about it to protect patients and also explain why some health boards use private providers to deliver their services (e.g. Helios for neurodevelopmental assessment). Why is it ok to trust private providers only when it suits the NHS? Why is it ok to trust them for things other than autism and ADHD?

The fact that concerns are constantly mentioned about private providers for autism and ADHD just makes children and families feel even more stranded. They're told the NHS can't

provide the assessment but then are told that if they go private it can't be trusted and might not be taken seriously by GPs and schools.

Obviously, we would be appalled by any private provider providing a substandard service to vulnerable families. However, unless and until we have proof that this is happening, we will continue to constructively challenge the narrative that private diagnosis should be automatically and routinely ignored or dismissed on a blanket basis, especially when there is no other option.

To what extent would witnesses support the adoption of shared care agreements across Scotland?

One of our main Empowerment workstreams is about shared care agreements between GPs and private providers for ADHD medication. We addressed this in our written submission and shared a STAND report on this with the Scottish Government in February this year.

We support the adoption of shared care agreements for ADHD medication, regardless of whether the secondary care provider is NHS or private. In some cases they already exist but it is totally unfair when practices such as this are inconsistent - not just across Scotland but within health boards.

The impact of the failure of the NHS to properly treat ADHD is huge in itself. The added stress of the gaslighting of parents and carers by some GP practices about this issue makes it even more difficult for them to cope. Some of our case studies have made subject access requests to GP practices about this and had to read the most appalling things written about them. It makes them feel stranded and hopeless.

Ms Todd wrote to us in March saying she had read the STAND research report on shared care for ADHD with *"both interest and concern, illustrative as it is of the challenges that so many people face when trying to access the support they need, including medication."* She also wrote that *"The Scottish Government wants people to get the help they need when they need it and we understand how important a timely ADHD diagnosis and access to appropriate support, including medication, is for individuals."*

We don't seem to be any further forward in October, almost seven months later. The Scottish Government has still not made it clear that blanket bans on shared care by GP practices are inappropriate and discriminatory. They have not clarified that reasons for refusing shared care should not include ongoing grievances about insufficient funding. In fact, the Scottish Government continues to sit on the fence.

The Minister for Social Care and Mental Wellbeing, in his letter to the Convener, repeated the claim made by some GP practices that ADHD shared care agreements are "complex," when we see these agreements and cannot see how they can possibly be described as complex. We don't understand why the Minister is so reluctant to admit this, especially when his predecessor acknowledged the concerns in our report. We are happy to share this with the Committee on a confidential basis.

Obviously, as always, no GP should be expected to do something that is not in the best interests of an individual patient. Also, the shared care agreements should be appropriate

and follow the relevant guidelines. That is the case for all health care. However, the onus should be on the GP practice to explain why they are concerned about the providers, instead of refusing to engage with them at all.

Funding and Workforce

What do witnesses consider are the key funding and resource challenges related to neurodevelopmental assessment?

We find the Scottish Government position on funding for neurodevelopmental services very confusing. For example, we have repeatedly been told by the Scottish Government that the reason that neurodevelopmental assessment waiting times are not included in CAMHS figures is because CAMHS is a "mental health" service and autism and ADHD are not "mental health conditions." However, in statements about funding the Scottish Government and Minister refer to the overall mental health services funding rather than explain the precise funding for neurodevelopmental services.

We are also confused because health boards have the relevant types of staff to conduct neurodevelopmental assessments but they are often ring-fenced to prioritise CAMHS patients only. Without a proper explanation, which we have asked for several times, we are forced to conclude that it is because waiting times for specialist CAMHS services are subject to national and publicised targets, but neurodevelopmental pathways are not.

The Scottish Government says diagnosis isn't important and support should be needs-based but they are telling health boards that access to the assessment teams should depend on the nature potential diagnosis (i.e. whether ultimately they have “only” a neurodevelopmental condition, or whether they have a co-occurring “mental health condition”), not on how significant the child's needs are, not on how much they're struggling, not on urgency. If diagnosis truly didn't matter, access to assessment would be based on the impact of unmet needs, not on which diagnosis the child might end up with.

This suggests children are being deprioritised simply because their needs don't "count" towards a target. If the existing staff who form part of the multi-disciplinary assessment teams who diagnose neurodevelopmental conditions under the Scottish Government CAMHS Specification were to be deployed across both mental health and neurodevelopmental pathways, then this would surely reduce the time that autistic and ADHD children waited for assessment. At the moment it seems that they are waiting years, instead of 18 weeks as per the waiting time targets for CAMHS, simply because of the type of condition which is the source of their particular needs – i.e. that the source is a neurodevelopmental condition rather than a mental health condition.

What role does the multi-disciplinary team play in neurodevelopmental assessment? Could this be further developed or improved?

We see a worrying trend that autistic and ADHD children are getting less and less access to health professionals generally. For example, it is difficult for autistic and ADHD children to access speech and language therapists, with some of those therapists even now being told they're not allowed to come to children's GIRFEC child planning meetings or observe the

child in education settings. This seems to be moving in the opposite direction from multi-disciplinary approaches.

We are worried that some of the responses we have seen to the Inquiry's Call for Evidence are talking about multi-disciplinary teams in the context of a move away from diagnostic assessment, rather than a way to conduct a diagnostic assessment. However, we are reassured that some of the respondents to the Call for Evidence recognise that diagnostic assessments could be streamlined by appropriate use of consensus diagnosis and multi-disciplinary approaches.

What role should the third sector play in supporting neurodivergent people?

STAND started because a group of us met with our local MSP complaining about lack of support. His response was: *"Why don't you do it yourselves?"* We shouldn't have had to, but it was the only option.

STAND's rapid growth shows how vital the third sector is. The third sector is often the only support families get while waiting years for assessment. Charities like STAND give families safe spaces, peer groups, practical help and moral support. We fill gaps when statutory services can't or won't fulfil their obligations and we do it quickly without families jumping through endless hoops.

One family told us: *"STAND has provided us with a safe place to go… helping us with forms, offering advice and giving us friendship. It has become our safe place and the family we now couldn't imagine living without."*

Another said: "*All we can attend is ASN events run by charity groups but these are not often because of the lack of funding."*

The third sector plays a crucial role but isn't funded to do so. We should NOT be filling gaps left by public authorities or compensating for their failure to provide statutory services. There should be no need for us to teach people their rights and how to enforce them - rights should be respected anyway. We should be here to enhance lives, not stop families from drowning.

NHS boards and East Lothian Council already refer families to STAND via their websites. East Lothian even lists us for "advocacy" - which we don't actually provide. We're nowhere near able to help everyone referred - this creates another letdown for families who then lose faith even in us.

If public authorities want to rely on us to fill these gaps, they need to fund us properly to do this work, have meaningful conversations about what we can actually deliver and not signpost families to us for services we can’t provide.

What steps could/should be taken to address reported workforce shortages and training gaps?

Health boards have the relevant types of staff to conduct neurodevelopmental assessments, but they are often ring-fenced to prioritise CAMHS patients only. CAMHS have neurodevelopmental assessment teams but many are deployed only for children who have co-occurring mental health conditions. Without a proper explanation, which we have asked for several times, we are forced to conclude that it is because the waiting times for specialist

CAMHS services are subject to national and publicised targets but neurodevelopmental pathways are not.

If the existing staff who form part of the assessment teams who diagnose neurodevelopmental conditions under the Scottish Government CAMHS Specification were to be deployed across both mental health and neurodevelopmental pathways, then this would surely reduce the time that autistic and ADHD children waited for assessment. At the moment it seems that they are waiting years, instead of 18 weeks as per the waiting time targets for CAMHS, simply because of the type of condition which is the source of their particular set of needs - that it is a neurodevelopmental condition rather than a mental health condition.

We also notice so much duplication of effort and inefficiencies within the processes that children and families go through when trying to access support and assessment. Teachers can spend hours filling in forms only to be asked to do the same forms again a year later when those who are deciding on the next steps for assessment decide to reject the referral they originally accepted.

We also think it's important to recognise that the failure to recognise private diagnosis, forcing children to go through the same assessment processes again on the NHS, seems to be a complete waste of NHS resources.

Regarding training gaps, if health boards and local authorities aren't going to take it upon themselves to provide this voluntarily, then it seems that the LDAN Bill is the best way to ensure that they do.

Data

What data would witnesses like to see routinely published?

We need to see at least the same data that's published for specialist CAMHS services. If they can collect and publish data for one group, they can do it for another.

Without data on diagnosis, we can't properly assess how important diagnosis is. How will we ever know if new approaches are working if we don't have a baseline?

Without diagnosis happening, you can't have this data. The lack of allocation of resources by health boards to neurodevelopmental diagnostic assessment pathwaysundermines their ability to understand and plan services. You can't manage what you don't measure and right now, we're not measuring what matters to autistic and ADHD children and their families.

What could be the impact of routinely publishing data on waiting lists and outcomes?

Publishing data on neurodevelopmental waiting lists would be a first step towards restoring trust in the Scottish Government. Children and families would be more likely to feel that they matter and aren't being erased. It would hold public authorities to be held accountable - we would be able to see whether they're actually meeting children's needs now and planning for those needs.

Children and their parents and carers could make more informed choices. For example, if they knew the waiting time for assessment, and in the case of ADHD the second waiting time

for medication after diagnosis, they could make informed decisions about whether to pursue private assessment.

This also links back to the overdiagnosis question. You wouldn't even need to ask that question if you had data on how many people were actually getting diagnosed in the first place. Without diagnosis happening, you can't have the data to understand what's really going on.

It is important to recognise that there's also a negative impact if you're selective about what you publish. Since 2023, the data published by Public Health Scotland about CAMHS waiting times excludes children referred for neurodevelopmental assessment - on the express instruction of the Scottish Government. This sends a message about the importance of these children, especially in areas which until recently accepted referrals to CAMHS for autistic and ADHD children without a co-occurring mental health condition - they are no longer subject to a national waiting time target when they once were.

We've been in correspondence with the government about this since March 2024 and they're still denying that autistic and ADHD children were removed from waiting lists, despite us providing evidence of this. For example, we have the NHS Ayrshire and Arran integrated joint board papers showing they made the decision to stop accepting neurodevelopmental referrals. These papers stated that they could not meet CAMHS waiting targets if they continued to include these children within CAMHS despite there being no alternative pathway for assessment. On 31st July 2023, 69% of people under NHS Ayrshire & Arran CAMHS for neurodevelopmental assessment **did not have** a co-occurring mental health condition. From 1st August 2023, you could only be assessed by CAMHS if you had a co-occurring condition. Parents weren't told about this until March 2024, despite the referrals still having been made during this time. In other words, the children were referred to CAMHS, were waiting to be seen by CAMHS, and then were told that they were not going to be seen by CAMHS. The Minister for Social Care and Mental Wellbeing stated in Parliament he was "crystal clear" this didn't happen. It was extremely disappointing to hear him say this.

How would access to high quality, up-to-date information on demand for services help witnesses to plan and deliver those services?

STAND doesn't directly plan or deliver NHS or local authority services but we can speak to how lack of data impacts families and creates systemic failures.

What good data would enable:

- **Strategic workforce planning:** If boards knew how many children were waiting, how long they'd been waiting and what the trajectory looked like, they could plan workforce needs. Right now, boards claim they're surprised by demand - but this trajectory was predictable. Data and proper service planning would have shown this coming.

- **Fair resource allocation:** With transparent data, boards would have to justify why resources are ring-fenced for CAMHS but not neurodevelopmental pathways when it's the staff with the same expertise doing both assessments. The current lack of data allows boards to hide discriminatory resource allocation.

- **Identifying which groups are being missed:** Data broken down by age, sex, socioeconomic background would show which children are falling through gaps. We know girls are underdiagnosed. We know socio-economically disadvantaged families face additional barriers. Without data, these inequalities stay hidden.

- **Preventing crisis:** If you could see the gap between first concerns raised and assessment date, you'd see where early intervention is failing. Right now, children deteriorate for years before assessment. Data would show where to target early support to prevent a crisis.

- **Accountability for statutory duties:** Data would show whether boards are meeting their duties under the National Health Service (Scotland) Act 1978 to meet local population needs and plan for future needs. Currently there's no way to hold them accountable.

The Scottish Government position that diagnosis shouldn't matter creates a convenient excuse not to collect data, but you can't manage what you don't measure and right now the deliberate choice not to measure allows systemic discrimination to continue unchallenged. The Minister doesn't seem to have any plans to collect national neurodevelopmental waiting time data; in fact, the health boards state in reports that they are advised by the Scottish Government to exclude such data.

For organisations like STAND, better data would help us:

- know where gaps in statutory provision are greatest,
- target our limited resources effectively,
- provide families with realistic and accurate information about what to expect,
- empower children and families to hold authorities accountable.

Good data would help statutory services do what they're legally required to do - and then we could focus on enhancing lives rather than stopping families from drowning.