Dear Members of the Scottish Parliament's Health, Social Care and Sport Committee,

I am writing in response to the recent submissions by Autism Initiatives and NHS Lothian to the '*ADHD and ASD pathways and support'* inquiry, and to raise critical concerns over the direction these major providers are promoting regarding assessment and diagnostic practices.

Recent submissions to parliamentary inquiries by Autism Initiatives and NHS Lothian propose or advance the expansion of experimental diagnostic pathways as a means of addressing waiting lists. While reducing waiting times is a shared priority, these approaches run directly counter to the standards set out in SIGN 145 and established NICE guidelines, both of which demand rigorous, multidisciplinary, evidence-based procedures led by qualified clinical professionals.

Autism Initiatives' submission references their practice of training staff in 'the administration of recognised gold-standard diagnostic tools' and extending into ADHD assessments by their 'non-prescribing' team, often delivered outside standard clinical settings and through therapeutic models with outcomes not aligned with clinical diagnostic thresholds. This appears to bypass requirements for clinical oversight and multidisciplinary evaluation, risking assessments that may not meet the clinical validity required for formal diagnosis or access to support.

Similarly, NHS Lothian's submission describes a redesign of adult and child neurodevelopmental services, moving away from consultant-led and diagnosis-dependent models, and including workforce redesign to expand the roles of nursing and allied health professionals in assessment. The proposed shift to needs-based models - especially when coupled with proposals for 'abbreviated/truncated pathways' and greater use of digital screening - raises concerns about dilution of clinical standards and the potential for formal misdiagnosis or misclassification, especially in adults and those with complex presentations.

In both cases, these approaches appear to prioritise reducing waiting lists over maintaining clinical standards. If implemented, they risk a surge in invalid or unsafe ASD/ADHD diagnoses, exposing vulnerable individuals to harm, delaying genuine assessment, and undermining trust in neurodevelopmental services.

A further critical issue arises when patients with such locally accepted but non-standard diagnoses relocate to areas where these assessments are not recognised. There is currently no national framework ensuring the portability of neurodevelopmental diagnoses across NHS board boundaries. Some boards accept private or third-sector diagnoses for ADHD under shared care agreements, while others do not, creating a postcode lottery in access to treatment and support. Individuals may be required to undergo full reassessment - often facing waits of 76 weeks or more - during which time they may lose access to medication, employment accommodations, or educational support, exacerbating mental health risks and social instability.

This fragmentation undermines patient rights to continuity of care and equitable treatment under the Scottish Health and Social Care Standards. Without national consistency, individuals are penalised for geographic mobility, and the validity of a diagnosis becomes dependent on location rather than clinical robustness.

Robust diagnosis by qualified clinical personnel is especially critical in adults, particularly those with late diagnoses and in females, due to the complexity of symptom presentation. Adult autism and ADHD often manifest differently than in childhood, with symptoms masked by years of compensatory strategies. In females, traits are frequently internalised - such as anxiety, inattentiveness, or emotional dysregulation - leading to misdiagnosis as depression, personality disorders, or trauma-related conditions. Without a comprehensive, multidisciplinary assessment that includes developmental history and functional impact, these nuances are easily missed, resulting in inappropriate or harmful interventions. A diagnosis has profound implications for identity, mental health, and access to support, and must therefore meet the highest clinical standards to ensure safety and validity.

Remote assessments, mentioned in their submission by Autism Initiatives, are highly controversial and widely criticised within healthcare professional communities because they compromise the depth and reliability of diagnostic evaluation. Observing nonverbal communication, social interaction, and environmental context - key components in identifying autistic traits or ADHD-related executive dysfunction - is significantly limited in virtual settings. The Royal College of Psychiatrists Scotland has expressed concern that over-reliance on remote or abbreviated pathways may lead to diagnostic inflation, particularly in adult ADHD, where symptoms overlap with anxiety, stress, or sleep disorders. NHS Highland, for example, has restricted its adult ADHD service to only those meeting NAIT Level 4 criteria due to resource constraints and the need for clinical safety, highlighting the risks of expanding access without ensuring diagnostic rigour. Professional bodies stress that any use of remote assessment must be part of a broader, clinically supervised pathway, not a standalone or truncated process.

Furthermore, the Autism Diagnostic Observation Schedule-Second Edition (ADOS-2) was not designed for, and is not validated for, online or remote administration due to its reliance on direct, in-person observation of nuanced social and nonverbal behaviours that cannot be reliably captured through video conferencing. The ADOS-2 is a semi-structured, play-based assessment that requires the clinician to observe spontaneous social interaction, eye contact, facial expressions, body language, motor mannerisms, and sensory responses in real time and in a controlled environment. These elements are critical to the scoring algorithm and are often diminished, distorted, or entirely lost in remote settings due to technical limitations such as camera angles, audio delays, internet connectivity issues, and restricted visual fields.

The developers of the ADOS-2, including Dr. Catherine Lord, have consistently emphasised that the tool must be administered in person by a trained clinician who can manipulate materials, adapt activities based on the individual's responses, and observe subtle behavioural cues that are essential for accurate scoring. For example, the assessment includes tasks involving shared attention, joint engagement with toys, and spontaneous

imitation - interactions that depend on physical presence and cannot be replicated virtually. The National Autism Implementation Team (NAIT) in Scotland explicitly states that ADOS-2 should not be used as a standalone diagnostic tool and must be part of a comprehensive evaluation that includes a standardised developmental history interview (ADI-R) and clinical judgement by an experienced professional. Remote administration further compromises this integration by limiting the clinician's ability to observe environmental context and spontaneous behaviour.

Moreover, research has shown that remote assessments can lead to both false positives and false negatives. Individuals with co-occurring conditions such as anxiety, trauma, or ADHD may present differently on camera, potentially inflating or masking autistic traits. The lack of standardisation in remote delivery also introduces variability in administration, undermining the reliability and validity of the results. Professional bodies, including the Royal College of Psychiatrists and NICE, stress that any use of remote tools must be supplementary and never replace in-person, multidisciplinary evaluation for formal diagnosis.

My own experience earlier this year exemplifies the harm caused by an experimental pathway. I received an ASD 'diagnosis' commissioned by NHS Lothian as part of the Edinburgh Integration Joint Board (EIJB) for the Edinburgh Health and Social Care Partnership, delivered by [REDACTED] through a process that in my view lacked clinical oversight, multidisciplinary input, and adherence to SIGN 145. During my assessment, I was explicitly told, 'we only diagnose autism here,' indicating a predetermined outcome with no intention of conducting a differential diagnosis, despite the high comorbidity of autism with other neurodevelopmental and mental health conditions.

The ADOS-2 was administered by an individual who in my opinion seemingly lacked proper understanding of the tool and its limitations. This is particularly concerning as SIGN 145 and NICE guidelines clearly state that ADOS-2 alone is not sufficient for diagnosis and must be used in conjunction with other clinical assessments and developmental history. No diagnostic tools specific to autism masking or female presentation - such as the RAADS-R or AQ-10 with gender-sensitive interpretation - were used, despite established evidence that standard tools can fail to identify autistic women.

To my knowledge, none of the individuals involved in my assessment were qualified clinicians, and there was no oversight from any registered medical or psychological professional. The diagnostic letter I received contained none of the clinical detail required under SIGN 145, including developmental history, functional impact, or evidence of differential diagnosis. Instead, it resembled a generic template listing only a score without clinical interpretation or justification. As a result, the letter is clinically invalid and functionally useless for any purpose beyond accessing Autism Initiatives' own in-house post-diagnostic support services.

Crucially, the letter contains no recommendations - no guidance on reasonable adjustments, support strategies, or accommodations for employment, education, or daily living. This renders it entirely inadequate for use in workplace or educational settings, where employers

and institutions require specific, evidence-based recommendations to implement support under the Equality Act 2010. A diagnosis without recommendations is not a diagnosis in practice - it is a label without utility, failing to enable access to the very support it is meant to unlock.

This case does not seem not isolated. I have been contacted by another individual who reported receiving an ASD diagnosis from [REDACTED], with a diagnostic letter they described as identical in structure and content to mine, which suggests a standardised, template-driven process that bypasses individualised clinical formulation. Given this particular pathway operated between 2019-2025, over 2,000 individuals in Scotland may now hold diagnoses that do not meet national clinical standards.

The scale of this issue is documented by Autism Initiatives themselves. In the summer of 2025, their website stated: 'The amazing work of the autism diagnostic assessment team in Scotland has resulted in over 2,000 people receiving a positive diagnosis of autism (…).'

The financial model underpinning this service further exposes its inherent flaws. NHS Lothian funded these diagnoses through a 2023 contract (MAY478319) awarding £50,000 to Autism Initiatives for 100 assessments - a cost of £500 per diagnosis. This rate is implausibly low for any legitimate multidisciplinary diagnostic process involving qualified clinicians, as it precludes involvement of clinical psychologists, psychiatrists, or allied health professionals whose time and expertise are essential under SIGN 145. The price point appears to guarantee a non-clinical approach prioritising volume and cost-efficiency over diagnostic accuracy and patient safety.

During a medical consultation in 2025, I was informed by the healthcare professional I saw that concerns about the quality and lack of detail in [REDACTED] diagnostic letters had previously been raised within the healthcare system, yet the pathway continued to operate. This raises serious questions about oversight and quality assurance mechanisms.

The following is the full text of the diagnostic letter I received (my personal information and information of the individuals who 'diagnosed' me stripped for privacy reasons and to demonstrate the absurdity of this 'diagnosis'), which exemplifies the failure in clinical validity:

> *[LETTERHEADED PAPER]*
>
> *[Name of Patient's GP Practice]*
> *[Address of the GP Practice]*
>
> *[Dd Mmm YYYY]*
>
> *Re: [Patient's First Name, Last Name], [Patient's Home Address] DOB: [Dd Mmm YYYY]*

An autism assessment was completed with [Patient's First Name] on [Dd Mmm YYYY].

The information we gathered, along with the outcome of the Autism Diagnostic Observation Schedule-2 (ADOS-2) meets the criteria in ICD-11 for Autism Spectrum Disorder (6A02.0 — without disorder of intellectual development and with mild or no impairment of functional language).

Professionals involved

[First Name, Last Name - Assessor 1]

[First Name, Last Name - Assessor 2]

[First Name, Last Name - Decision-Maker]

How the decision was reached

Information gathering meetings were held with [First Name, Last Name - Assessor 1] on [Dd Mmm YYYY], [Dd Mmm YYYY] and [Dd Mmm YYYY].

An ADOS-2 assessment was carried out with [Patient's First Name], by [First Name, Last Name - Assessor 2] on [Dd Mmm YYYY].

[First Name, Last Name - Assessor 1] and [First Name, Last Name - Assessor 2] met with [First Name, Last Name - Decision-Maker] on [Dd Mmm YYYY] to analyse the findings and decide the outcome.

Diagnostic tool scoring

[Patient's First Name] received an ADOS-2 classification of autism (score of 10 achieved: Communication — 2; Social Interaction — 8).

Findings

The experiences [Patient's First Name] has described have been present since childhood and have caused significant difficulties at various points in [Patient's First Name] life, in particular with employment and social relationships.

We can therefore confirm an autism diagnosis. If you require any further information, please don't hesitate to get in touch.

Yours faithfully

Signed p.p. by the Office Manger

[First Name, Last Name - Assessor 2]

This letter lacks any clinical formulation, developmental history, or evidence of differential diagnosis. It does not describe the nature of the 'information gathering meetings,' nor does it reference any standardised developmental history interview such as the ADI-R, which is required under SIGN 145. The 'findings' section is generic and could apply to any neurodivergent or even neurotypical individual experiencing life challenges. The signature by an 'Office Manger' on behalf of the assessor further undermines its legitimacy.

The fundamental question that must be confronted is whether the goal of Scotland's neurodevelopmental services is to genuinely improve health outcomes and support for patients, or whether instead a system that risks mass misdiagnosis, overdiagnosis, and the erosion of diagnostic integrity is being created.

Evidence indicates that while awareness of autism and ADHD has increased, leading to a surge in referrals - over 42,000 children and 23,000 adults were waiting for assessment as of March 2025 - this demand is not being met with proportionate investment in qualified clinical staff or robust diagnostic infrastructure. A 2023 NAIT report found an 86.14% diagnostic rate across neurodevelopmental pathways, raising serious concerns about the specificity of assessments and the potential for overdiagnosis, particularly when tools like ADOS-2 are used in isolation and without clinical oversight.

A more profound risk is that individuals may be misdiagnosed with autism when they actually have another condition - such as complex trauma, anxiety disorders, ADHD, or personality disorders. Without a proper differential diagnosis, the underlying condition remains unidentified and untreated. This results in a double harm: the individual is labelled with a lifelong neurodevelopmental condition they do not have, while being denied access to the appropriate care and support for the condition they actually do have. This is not just a failure of diagnosis - it is a failure of duty of care.

This is not a hypothetical concern. In NHS Aberdeen's Test of Change initiative, holistic assessments revealed that children previously assessed by services had either been missed entirely or had co-occurring neurodevelopmental conditions that were not identified under standard pathways. One 10-year-old had been monitored by Child and Adolescent Mental Health Services (CCH) but was only diagnosed with autism and intellectual disability after a comprehensive review. Another 9-year-old had been referred to LD-CAMHS for suspected intellectual disability, but the referral was refused - only for a holistic assessment to later confirm autism, ADHD, and intellectual disability. This demonstrates how fragmented, non-holistic pathways fail to deliver accurate diagnoses and appropriate care.

Similarly, NHS Tayside suspended all new referrals for ADHD and autism assessments in CAMHS due to overwhelming demand, highlighting a system in crisis where access is denied rather than reformed. When services are so overstretched that they must close their doors, and when alternative pathways respond by lowering diagnostic standards to increase throughput, the result is not improved care - it is a two-tier system of either no diagnosis or a clinically invalid one.

A system that produces thousands of clinically invalid diagnoses under the guise of accessibility does not serve patients - it undermines trust, distorts epidemiological data, and diverts attention from the real need: expanding access to high-quality, multidisciplinary assessment led by qualified professionals. The alternative is not endless waiting, but sustainable investment in clinical capacity, workforce development, and national consistency in diagnostic practice. We must choose: genuine care, or the illusion of it.

The systematic deployment of non-clinical, non-standardised diagnostic procedures - developed in collaboration between a public health board and a third-sector provider - on a vulnerable population without informed consent, independent oversight, or adherence to national guidelines, constitutes a profound ethical failure. It reflects the very real and documented failures seen in systems where cost-cutting, political expediency, and performance targets override clinical integrity and patient safety - such as the closure of NHS Tayside's referral pathway and the widespread failure to identify co-occurring conditions in NHS Aberdeen. When public bodies prioritise throughput over validity, they erode the very foundation of healthcare: trust in diagnosis.

This represents a systemic failure with far-reaching consequences: individuals may be denied appropriate support, misdirected into inappropriate interventions, or left without access to services when their diagnosis is not recognised elsewhere. It also risks eroding public trust in neurodevelopmental services and exposing public bodies to legal and ethical accountability for the misuse of public funds and the delivery of substandard care.

In relation to data protection, it is important to note that under UK GDPR, health information is classified as 'special category data', which requires both a lawful basis and a specific condition under Article 9(2) for processing. Article 9(2)(h) permits processing for purposes such as medical diagnosis, but only when carried out by – or under the responsibility of – professionals who are subject to a legal duty of confidence, such as registered healthcare professionals bound by statutory regulation and professional codes. Where individuals involved in diagnostic assessment are not regulated healthcare professionals, this may raise questions about whether the processing of health data is compatible with the conditions set out in Article 9(2)(h), particularly in relation to transparency, lawful basis, and the expectation of clinical oversight. In my view, these factors warrant further scrutiny as part of any evaluation of diagnostic pathways delivered outside of standard NHS clinical structures.

To uphold quality and safeguard neurodivergent people:

- All diagnostic pathways should adhere strictly to SIGN 145 and NICE statutory guidance, ensuring multidisciplinary, clinically validated procedures led by appropriately qualified professionals.
- Any 'innovations' must first undergo robust independent evaluation for validity and safety before service-wide adoption.
- A national framework for diagnosis recognition should be established to ensure portability and continuity of care across NHS board areas.
- Inter-board agreements and centralised digital health records should be prioritised to prevent service gaps for relocating patients.
- Remote assessments should only be used as a component of a broader clinical pathway, never as a substitute for in-person, multidisciplinary evaluation.

- NHS Lothian and Autism Initiatives should be held accountable for the delivery of non-clinical assessments, and a review of all diagnoses issued under this pathway should be commissioned to identify and rectify invalid cases.

I urge the Committee to scrutinise proposals that circumvent established guidance and to advocate for solutions that expand true clinical capacity, not shortcuts of questionable validity.

Thank you for your continued commitment to safeguarding standards and the rights of autistic and neurodivergent individuals in Scotland.

RESOURCES AND REFERENCES

- SIGN 145: Assessment, Diagnosis and Interventions for Autism Spectrum Disorders https://www.sign.ac.uk/assets/sign145.pdf
- NICE Guidelines: Autism Spectrum Disorder diagnosis https://www.nice.org.uk/guidance/cg142
- NAIT Guide to Using ADOS-2 with Adults (2022) https://www.thirdspace.scot/wp-content/uploads/2022/12/NAIT-Guide-to-Using-ADOS-with-adults-FAQs-2022.pdf
- ADOS-2 training workshop FAQs (Pearson Clinical) https://www.pearsonclinical.co.uk/content/dam/school/global/clinical/uk-clinical/files/ados2-faq.pdf
- NAIT Adult Neurodevelopmental Pathways report (2023) https://www.gov.scot/publications/nait-adult-neurodevelopmental-pathways-report/pages/6/
- Neurodevelopmental Pathways and Waiting Times in Scotland (Scottish Parliament Research Briefing, 2025) https://spice-spotlight.scot/2025/06/27/neurodevelopmental-pathways-and-waiting-times-in-scotland/
- BBC News: 'Thousands on 'hidden' ADHD and autism waiting lists' (2025) https://www.bbc.co.uk/news/articles/cly55rnw5vpo
- NHS Tayside, suspension of new ADHD and autism referrals (CAMHS closure example) https://www.scottishparliament.tv/meeting/scottish-liberal-democrats-debate-addressing-the-inadequate-provision-for-neurodevelopmental-conditions-may-28-2025
- NHS Aberdeen 'Test of Change' (missed/misdiagnosed co-occurring cases) https://communityplanningaberdeen.org.uk/wp-content/uploads/2025/02/NHS-Aberdeen-City-Test-of-Change-Final_.pdf
- Royal College of Psychiatrists Scotland: Professional and pathway guidance https://rightdecisions.scot.nhs.uk/tam-treatments-and-medicines-nhs-highland/adult-therapeutic-guidelines/mental-health/adhd-guidelines/
- Scottish Government Autism Data Protection and Freedom of Information Policy https://www.scottishautism.org/sites/default/files/data_protection_and_freedom_of_information_policy_2018_-_mt_updated_formatted.pdf

- Information Commissioner's Office: UK GDPR and special category data https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/lawful-basis/special-category-data/what-is-special-category-data/
- National Autism Implementation Team (NAIT) Adult Pathway FAQs and practice framework https://www.thirdspace.scot/wp-content/uploads/2023/12/NAIT-Waiting-Times-in-Adult-Neurodevelopmental-Pathways-Report-2023.pdf
- Criteria and tools used in an autism assessment (National Autistic Society) https://www.autism.org.uk/advice-and-guidance/topics/diagnosis/assessment-and-diagnosis/criteria-and-tools-used-in-an-autism-assessment
- Preparing for your assessment (National Autistic Society) https://www.autism.org.uk/what-we-do/autism-know-how/diagnostic-services/your-assessment
- NHS Lothian's RefHelp Adult Autism Service Guidelines https://apps.nhslothian.scot/refhelp/guidelines/mentalhealthadult/autismspectrumdisordersaspergersadults/
- NHS Lothian Health Board's 2023 contract MAY478319 awarding £50,000 to Autism Initiatives for 100 autism assessments - at cost of £500 per diagnosis https://www.publiccontractsscotland.gov.uk/search/show/search_view.aspx?ID=MAY478319
- Autism Initiatives' statement in 2025 related to 2,000 people in Scotland receiving a positive diagnosis of autism https://autisminitiatives.org/news/autism-initiatives-scotland-celebrates-20-years-of-service/