Minister for Social Care and Mental Wellbeing Ministear airson Cùram Sòisealta is Sunnd Inntinn Tom Arthur MSP/BPA



T: 0300 244 4000

E: MinisterforSCMWS@gov.scot

Clare Haughey MSP Convener Health, Social Care and Sport Committee Scottish Parliament Edinburgh

HSCS.Committee@parliament.scot

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Dear Clare

ADHD and ASD pathways and support

Thank you for your letter on behalf of the Health, Social Care and Sport Committee regarding the inquiry it is undertaking into pathways and support for Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD).

I wish to start by welcoming this inquiry and acknowledging the importance of this work. In recent years, we have seen a significant and continuing increase in the number of people seeking assessment, diagnosis and support for neurodevelopmental conditions, including Autism and ADHD. This is placing significant pressure on services, and I do not underestimate the impact on families who are seeking support. I do however wish to recognise the efforts of health, social care, third sector and education staff who I know are working hard to provide support to those who need it, and continue to address diagnostic assessment waiting lists.

I note that you have presented me with several questions to aid the inquiry, and I have answered each of these in turn, below:

Diagnosis

What does the Scottish Government consider to be the benefits for people with autism and ADHD in receiving a formal diagnosis of their condition?

The Scottish Government recognises that a formal diagnosis can be important for an individual's sense of self and understanding of their own identity. Additionally, in the case of ADHD in particular, medication can be beneficial but can only be accessed following a formal diagnosis. It is also important to acknowledge that non-pharmacological interventions are also available and for children, in accordance with NICE guidelines, should be explored before medication.







However, the Scottish Government is also clear that the absence of a diagnosis should not present as a barrier to support. Support should be made available regardless of whether a person has – or is seeking - a formal diagnosis or not. This is particularly important for those with neurodevelopmental support needs that do not meet diagnostic thresholds.

How does the Scottish Government plan to specifically support groups of neurodivergent people who are under-referred and under-diagnosed, such as ethnic minorities and women/girls?

The Scottish Government has recently announced the next phase of the Autistic Adult Support Fund (AASF), which aims to help adults with an autism diagnosis, self-identified autistic adults, and their families and carers understand what neurodivergence means for them and improve their wellbeing. The next phase of the fund will run from October 2025 until at least March 2028.

Through this, nine organisations will receive £2.5 million of funding, including Scottish Women's Autism Network (SWAN), which is the only Autistic People-led Organisation in Scotland that focuses exclusively on supporting women and girls.

We are also working with Scottish Ethnic Minority Autistics (SEMA), who bring expertise as members of both minority ethnic and autistic communities, to explore the work they could do to support the 9 organisations that will be funded through the AASF, to enhance their practice in supporting minority ethnic autistic people. Through this work, we hope that all funded organisations will be equipped to better engage with minority ethnic autistic people and to provide support that is tailored to their needs.

Additionally, evidence presented to the Education, Children and Young People Committee's Inquiry into Additional Support Needs last year, demonstrated that girls may be more likely to 'mask' traits of ADHD or Autism. The Scottish Government accepted the Committee's recommendation to undertake a literature review in this area to better understand this trend and to provide advice to the education system accordingly. We are working with The National Autism Implementation Team (NAIT) to undertake this work.

What support is available for people and their families/carers when they are waiting for a diagnosis?

As stated above – and in line with the <u>National Neurodevelopmental Specification for Children and Young People</u> – support that meets the child or young person's needs should be put in place as quickly as possible, and this should not be dependent on a formal diagnosis. Such support should be quickly and easily accessible, and is often available in a local community and school.

For example, a formal diagnosis is not required before appropriate support is provided in education. Education authorities have duties under the Additional Support for Learning Act 2004 to identify, provide for and review the additional support needs of their pupils, including those with Autism and ADHD support needs, and this support can be put into place whilst waiting for a diagnosis. Education authorities can ask other agencies (including social work services, health boards and Skills Development Scotland) for help in carrying out their duties under the Act.







We are working closely with local government partners to improve the experience of all children and young people with additional support needs at school through the implementation of the recommendations of the 2020 review of Additional Support for Learning. A range of collaboratively developed information and professional learning continues to help raise awareness of Additional Support Needs; this includes neurodevelopmental support, including for Autism and ADHD.

For adults, as noted above, the Autistic Adult Support Fund (AASF) aims to help adults with an autism diagnosis, self-identified autistic adults and their families and carers understand what neurodivergence means for them and improve their wellbeing.

In 2024–25, 1,800 autistic people and 470 families received support through 16 funded organisations as part of our £1m Autistic Adult Support Fund. Notably, 72% of individuals and 71% of families reported improvements in their wellbeing.

The Scottish Government also funds the charity Scottish Autism to provide an Autism Advice Line which is staffed by advisors who are trained and experienced in working with autistic people and their families. The advice line supports thousands of people every year and have dealt with over 2000 enquiries since January.

Further, the Scottish Government's Communities Mental Health and Wellbeing Fund for Adults provides grants to grassroots community projects supporting people's mental health and wellbeing, with a focus on prevention and early intervention. The Fund prioritises a number of groups with a higher risk of poor mental health and wellbeing, including people with neurological conditions or learning disabilities and from neurodiverse communities. We have invested £81 million in the Fund since 2021, with over 4,700 grants made to local projects across Scotland over the first three years. Year 5 of the Fund will be open for applications through local Third Sector Interfaces by Friday 19th September 2025.

What has the Scottish Government done to support the implementation of multi-disciplinary teams in neurodevelopmental services, in line with the National Autism Implementation Team (NAIT) recommendations?

Following the publication of the Adult Neurodevelopmental Pathways report, the Scottish Government accepted all ten of the report's recommendations, and we are taking work forward to implement these.

The Scottish Government funds the National Autism Implementation Team (NAIT) to work with Health Boards to build a neurodevelopmentally informed workforce in Scotland. They also listen to and work in partnership with neurodivergent people.

NAIT host an Adult Neurodevelopmental Pathway Professional Network to support clinical teams and have hosted a national 'learning from pathfinders event'. These forums highlight developments and innovation in relation to working towards stepped care pathways to meet the needs of autistic adults and those with ADHD, building on learning from 4 pathfinder sites funded by the Scottish Government and supported by NAIT.







NAIT also deliver professional learning and learning conversations through webinars, workshops, in-person training sessions, developing written resources, guidance and key messages.

We have also commissioned NHS Education for Scotland (NES) and the National Autism Implementation Team to provide professional learning about ADHD and neurodevelopmental conditions at informed, enhanced, specialist and expert levels (according to the NES framework). These can be found on the Turas page (NHS Education for Scotland's unified training platform) and accessed by the workforce.

Data collection

What plans does the Scottish Government have to record and report on the number of people seeking an autism and/or ADHD diagnosis through the NHS in Scotland? What plans does the Scottish Government have to record and report on the length of time people are waiting for an autism and/or ADHD diagnosis?

In relation to waiting lists for neurodevelopmental assessment and diagnosis – including the number of people on waiting lists and length of waits - these figures are not currently nationally reported or published. However, individual NHS Boards will hold this information for their local area.

I acknowledge that work is needed to improve the quality of data that we have on neurodevelopmental support and services, including a better understanding of current levels of need and the support that is available. We continue to work with Health Boards and local authorities to improve our understanding of what data is available, and how this could be used to support improvements across the system, so that neurodivergent people receive the support they need, when it is needed.

NAIT has outlined data (p.68-69) that health boards could collect routinely to help understand the demand for neurodevelopmental services. What consideration and/or progress has the Scottish Government made in terms of collecting and publishing this data?

As I have said, data is not nationally reported or published for neurodevelopmental waiting times, and our primary focus is on provision of appropriate support regardless of, and without the requirement for, a diagnosis.

As outlined above, we have begun scoping work to work with Health Boards to better understand what data is available, and how this could be used to support improvements across the system, so that neurodivergent people receive the support they need, when it is needed.

Better data collection and reporting is a key part of the ambitions of the proposed Learning Disabilities, Autism and Neurodivergence (LDAN) Bill. A more strategic approach to data collection and reporting would not only allow us to build evidence on these groups to inform policy and services, but would allow for the implementation of the Bill's policy objectives to be monitored and evaluated to ensure that the right approaches are being taken. Improving data would also support improved service planning and design with the ability to contribute to early intervention, prevention, and more sustainable services.







Adult neurodevelopmental pathways

Does the Scottish Government consider that there is adequate provision for adult diagnosis of neurodevelopmental conditions in all areas of Scotland? If not, what steps are being taken to address areas where there is insufficient provision?

The Scottish Government recognises that there has been a significant increase in adults seeking ADHD and autism assessments across Scotland.

As outlined above, we fund NAIT, which is currently supporting NHS Boards to develop, enhance and redesign existing local neurodevelopmental services. We have also commissioned NES and NAIT to provide professional learning about ADHD and neurodevelopmental conditions.

Earlier this year, my officials wrote to all health boards seeking clarification on the neurodevelopmental assessment and support they currently have in place for adults. This information is currently being collated and considered, along with next steps.

What consideration, if any, has been given to the development of a national neurodevelopmental pathway for adults rather than regional pathways?

We are aware of proposals from the Royal College of Psychiatry and I can confirm I met with representatives from the College in August to discuss their proposals. We will continue to carefully consider these proposals as part of our wider ongoing work to implement and improve Adult Neurodevelopmental Pathways.

What work has the Scottish Government undertaken to produce a National Neurodevelopmental Specification for Adults to complement the existing specification for Children and Young People?

We piloted Adult Neurodevelopmental Pathways in four Health Boards to support a single diagnostic pathway for ADHD and Autism. The results of this work, including a final report, have been published. The Scottish Government has accepted all ten of the report's recommendations, and we are taking forward work to implement these.

We are currently scoping what neurodevelopmental assessment and support is available locally for adults. Understanding current provision across Scotland will provide a starting point for improvement and underpin work going forward to develop a national approach. This will involve key partners, including professional bodies, and is likely to cover a range of issues, including data and support.

Shared care

Has the Scottish Government made an estimate of the number of people seeking private diagnosis for neurodevelopmental conditions?

The Scottish Government has not made an estimate of this number, and does not hold data of this nature. However, we are aware through correspondence and anecdotal evidence of both the significant rise in people seeking a diagnosis for a neurodevelopmental profile and also the number of individuals and families seeking a private diagnosis. As both an MSP and







Minister, I am regularly contacted on this matter and am aware of the varied shared care policies that exist around the country.

Can the Scottish Government provide an overview of the availability of shared care agreements across Scotland?

The Scottish Parliament has produced the following research briefing in to Neurodevelopment pathways (published 24 June) - Neurodevelopmental Pathways and Waiting Times in Scotland. Table 4 (p.57) provides an overview of the shared care agreements across NHS Scotland Health boards.

What is the Scottish Government's position on shared care for ADHD (for both children and adults)?

While the Scottish Government supports the use of shared care agreements where appropriate, decisions remain at the clinical discretion of individual GPs, and they are best placed to decide the best course of action for their patients. This is because shared care agreements are specific and often complex and require an ongoing relationship with either a private or NHS specialist service.

The National Autism Implementation Team (NAIT) has produced guidance on prescribing ADHD medication to adults following private sector diagnosis in Scotland and describes how shared care agreements can work effectively.

Whilst a recommendation from a private specialist does not entitle the patient to NHS prescriptions for that medicine, GPs are contracted to care for patients, as long as it is within their clinical competence to do so. There is no financial mechanism to reimburse patients who seek private diagnosis or treatment while waiting to be seen by an NHS specialist.

It is important to note that private prescriptions are treated and processed differently from NHS prescriptions and therefore subject to a charge. With a private prescription, it is for the community pharmacy to decide what charge to apply for dispensing in addition to the cost of the medication.

What work has been undertaken with the Royal College of General Practitioners Scotland on this issue, as discussed in the debate on neurodevelopmental conditions (28 May 2025)?

My officials are currently considering the suggestions that the Royal College of General Practitioners Scotland have made.

Future plans

What is the Scottish Government's response to the Royal College of Psychiatrists in Scotland (RCPsychiS) proposal for future provision for people with neurodevelopmental conditions?

The Scottish Government recognises the significant increase in requests for neurodevelopmental assessments and supports as outlined by RCPsychiS, the impact on individuals and the pressures that this is placing on our mental health services. RCPsychiS noted the important of taking a needs-based, stepped care approach to neurodevelopmental







support and this is in line with the Scottish Government's view, and the aims of the Neurodevelopmental Specification for Children and Young People. A whole system approach is needed to respond to this challenge and ensure that neurodivergent people receive the support they need, when they need it. As I noted above, I can confirm that I have met with the College to discuss these matters, with a further meeting being planned in due course.

What is the Scottish Government's response to the Child Heads of Psychological Services letter to the HSCS Committee?

I welcome the recommendations from the Child Heads of Psychological services (CHOPs), including the recognition that any approach should support children and young people throughout their whole life. The letter shared the example of Fife, which has received over £200,000 funding from the Scottish Government as a Test of Change area following publication of the National Neurodevelopmental Specification in 2021.

Can the Scottish Government advise on progress and aims of the cross-party summit on neurodevelopmental support needs, as committed to by the then Minister for Social Care, Mental Wellbeing and Sport, Maree Todd MSP, in the chamber debate on neurodevelopmental conditions (28 May 2025)?

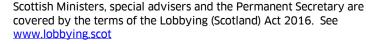
Work is underway to arrange a summit. I would be pleased to keep the Committee sighted on this work as it progresses.

I would also like to bring the Committee's attention to work carried out in partnership with COSLA to review the implementation of the Neurodevelopmental Specification. The <u>report</u> from the review has been published, which sets out the review's findings as well as our next steps to drive forward the implementation of the Specification and improve early support for children and families. This includes the setting up of a Children and Young People's Neurodevelopment Taskforce, co-chaired by Dr Lynne Binnie, City of Edinburgh Council Head of Education, and Fiona Davies, Chief Executive of NHS Highland

To progress this improvement work I have confirmed that the Scottish Government will provide £500,000 additional funding in 2025/26 to support implementation of the Specification, and improve access to support and assessment for children and families. This is in addition to the £123.5m that we have provided to NHS Boards alongside their core allocations to support continued improvements across a range of mental health services and treatments.

I hope the Committee finds my response to their queries helpful and I would be happy to assist with any further questions they may have as the Inquiry progresses.

Yours sincerely









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TOM ARTHUR



