Neurodevelopmental pathways inquiry: Summary of call for views submissions

Introduction

The call for views for the Health, Social Care and Sport Committee's inquiry neurodevelopmental pathways ran from 23 June 2025 to 18 August 2025. The call for views was primarily aimed at giving organisations involved in providing support to people with ADHD and ASD an opportunity to contribute their views to the inquiry. This summary of evidence focuses mainly on the organisational responses and a separate analysis has been undertaken which focused on the individual and family responses which were shared sharing via the separate Your Priorities digital platform. This received 1140 submissions.

Respondent characteristics

86 respondents completed the Committee's detailed call for views: 54 organisations and 32 individuals.

Substantive questions

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

The aims of the inquiry were to:

- understand why waiting times for diagnosis and management of ADHD and ASD are reportedly long, including the drivers of increasing demand
- understand how these conditions are diagnosed and managed
- understand the impact of delays on individuals
- explore solutions to improve capacity of services, referral pathways and support.

It is intended that the inquiry will consider the following in relation to neurodevelopmental pathways for ADHD and ASD:

- referral pathways
- assessment, criteria and treatment thresholds
- waiting times
- "waiting well" and support pre-diagnosis
- transitions between services
- funding
- workforce
- the impact on individuals of receiving a diagnosis or waiting for a diagnosis

Key issues raised in the responses

This paper identifies the key themes raised in the submissions, predominantly from organisations, and uses quotes to highlight some of these issues and ideas.

Additionally, over 1000 individual experiences, of people with neurodevelopmental conditions and their family members, were submitted to the Your Priorities digital platform and there were 32 submissions to the detailed call for views. A report, undertaken by Autism Rights Group Highland, Autistic Mutual Aid Society Edinburgh and Scottish Ethnic Minority Autistics in partnership with Scottish Autism, has also been published highlighting the experiences of people going through the autism assessment and diagnosis pathway across Scotland.

Context

Many submissions outlined the current situation in Scotland in relation to the assessment of neurodevelopmental conditions. Many respondents spoke of increased demand. The Royal Pharmaceutical Society argued:

> “prevalence data would suggest that approximately 5% of the population is affected by ADHD and/or ASD, so currently in many areas, it is still currently underdiagnosed. To meet a 5% need would have an enormous impact on capacity of services that are already stretched.”

Child Heads of Psychology Services (CHOPS) (including CAMHS) in Scotland also spoke about increased demand:

> “Requests for assessment and diagnosis of Neurodevelopmental Disorders have increased exponentially and demand currently vastly outstrips capacity. Waiting times for specialist assessment are estimated at 6 years for those under eighteen in some Board areas, with marked geographical differences in terms of service provision.”

It went on to say:

> “Without whole system consideration and radical systemic change, individual’s social, emotional, cognitive and developmental needs are not being adequately met, with associated systemic risks to these individuals, their families and carers, and to wider education, health and social care service provision.”

Many submissions form NHS Boards also highlighted the pressure they are facing. NHS Highland wrote:

> “From our perspective, the current system is under significant strain. Diagnosis has become the primary gateway to support, leading to long waiting times, inequitable access, and growing frustration among individuals and families. This is compounded by chronic under-resourcing and a lack of strategic clarity, particularly in relation to the absence of a national service specification for adults based on the NAIT Stepped Care Neurodevelopmental model.”

North Edinburgh CAMHS Team echoed this saying:

> “A key concern consistently raised by staff is the prolonged waiting times for neurodevelopmental assessments and diagnoses. It is not uncommon for children and young people to remain on waiting lists for several years, with some referrals dating back to 2020.”

Variation in the availability of assessment and services across Scotland was also highlighted by many respondents. The Royal Pharmaceutical Society said:

> “Feedback from our members suggest there is variation across the HBs [Health Boards] on service models, staffing, criteria etc which is often driven by historical service set up, and not fully based on the current needs or addressing service gaps.”

Considering well-documented increases in demand, the National Autistic Society Scotland discussed narratives around overdiagnosis:

> “We would also like to take this opportunity to address any narratives surrounding overdiagnosis, as these discussions are often based on a gross misunderstanding of autism, which is a spectrum condition that affects people in many ways. In particular, media narratives often suggest that diagnosis is predominantly driven by middle class families/parents seeking more support

> for their child in school. In fact, what evidence there is suggests the opposite is true and it is those from more deprived areas who are more likely to be diagnosed."

Theme 1: Pathways

Many submissions discussed the current pathways in place for neurodevelopment assessment and services for both children and young people and adults. NHS Boards provided information on their current pathways, and many gave examples of good practice and made suggestions for improvements. For example, NHS Lothian said that it is working towards establishing "a whole-system, multi-disciplinary model of ND [neurodevelopmental] care". It hoped that this would be a move away from a consultant-led, diagnosis-dependent model towards earlier, function-based interventions that would strengthening transition pathways and embed digital tools to support navigation, self-management, and data visibility.

Variations in pathways and services between Boards were also identified. Royal College of Paediatrics and Child Health (RCPCH) Scotland spoke of:

> "inconsistencies in neurodevelopmental pathways and staff makeup within services". Noting that "these variations contribute to uneven service delivery, exacerbate workforce pressures, and further extend already lengthy waiting lists".

NHS Grampian Speech and Language Therapy Service said:

> "Within NHS Grampian we do not have defined and equitable neurodevelopmental pathways for any age group/client group but as practitioners [we] recognise the need for this."

The National Autistic Society Scotland called for:

> "A nationally consistent approach so that families and autistic adults know what to expect and […] an end to the post-code lottery of access. We are aware that the Scottish Government is considering the merits of stepped approach to support and assessment; we would advise that any new approach should be thoroughly tested and evaluated, involving autistic people, and we would strongly caution against making the threshold for assessment too high. We also want to see integrated pathways commissioned to eliminate current silos and to facilitate the development of strong, multidisciplinary teams."

Many submissions raised concerns about the closure of services and thresholds being placed on access to services. The ADHD coalition said:

> "The recent withdrawal of ADHD assessment and treatment across Scotland will lead to a significant rise in mortality, a reduction in life expectancy, and reduced quality of life in the affected cohort, and increased costs to the NHS and other publicly funded services which will outweigh the cost savings that have driven the decision."

Scottish Autism also raised concerns regarding the closure of pathways:

> “We remain deeply concerned that the closure of pathways will lead to wider unmet need, and that these decisions are being driven by financial considerations. Moreover, we know that unmet need often leads to costlier crisis interventions as people's mental health and wellbeing is negatively impacted.”

In its submission COSLA discussed its joint report, with the Scottish Government, National Neurodevelopmental Specification for Children and Young People Implementation Review Report. This report sets out the review process, findings and recommended next steps.

Broad neurodevelopmental assessment

Some submissions spoke about the advantages of undertaking a broader neurodevelopmental assessment rather than one which is condition specific. Stirling Council said:

> “We feel it may be difficult to separate ASD and ADHD from other neurodevelopmental conditions. The profiles of need that children and young people demonstrate have increased in complexity, and we often find that colleagues in the health service are providing multiple diagnoses following assessment making it difficult to separate neurodevelopmental conditions.”

NHS Grampian Speech and Language Therapy Service noted:

> “Assessment is often single condition and thus children and families are in the system for a long time as may only be assessed for Autism once their assessment for ADHD has been completed”.

Mental health

Scottish Action for Mental Health (SAMH) spoke about the intersection of neurodevelopmental conditions with mental health, noting:

> “It is important that we are clear that neurodivergence (including autism and ADHD) is not a mental health condition and should not be treated as such” […] “Currently, neurodivergence falls under the legal definition of ‘mental health conditions’ and is within the scope of the UK and Scotland’s respective mental health acts. This has been strongly opposed by the neurodivergent community and organisations who support and/or advocate for neurodivergent people across Scotland” […] Autistic adults face significant barriers to accessing mental health support, from an inflexible mental health system which is difficult to navigate, to a perceived lack of autism understanding among health professionals and autism-informed support. Pathways must be put in place so that neurodivergent people can receive appropriate support and treatment for any co-occurring mental health problems”

It goes on to note that National Autism Implementation Team (NAIT) has recommended the Scottish Government “seek to understand the changes needed to effectively meet the mental health needs of neurodivergent people”, including the need for neurodivergence-affirming models of care for mental health.

Gatekeepers

Many submissions discussed the role that gatekeepers can play in accessing services and diagnosis. Salvesen Mindroom Centre argued:

> “Referral pathways often depend on GPs and sometimes teachers, who act as gatekeepers. However, they may lack sufficient understanding of ADHD and autism, especially how these conditions present in girls and women. This can result in missed opportunities for early assessment and diagnosis.”

The Yard agreed saying that some parents/carers reported that “they often need to jump through hoops to simply get a referral to CAMHS for an assessment”. AMASE argued that “many front line practitioners, including diagnosticians, do not have up-to-date understanding of autism and we see out-dated theories and narratives about autism prevailing. Some of the reasons we have heard as to why adults or children have not been referred for an autism assessment or not received a diagnosis despite meeting other criteria are: showing empathy, having friends, making eye contact, being too pretty, having a job”.

ADHD Right Now also argued that everyone should be able to access an assessment when clinically indicated:

> “No one should be denied an assessment because of academic or employment success, or due to misunderstanding of how ADHD presents. Referral thresholds should be based on validated tools. GPs should be supported with clear referral criteria and not expected to make diagnostic judgements. People with ADHD should not be triaged out of services without a clear explanation and opportunity to re-refer”

The University of Glasgow said that in some cases “there are GPs who are generally reluctant to refer, especially once someone is an adult. Sometimes GPs argue that if a person has made it to a certain stage in life, they don’t need to bother with an autism or ADHD assessment. This thinking feels outdated and is out of line with published NHS guidelines.”

Role of the third sector

Many submissions discussed the role of the third sector highlighting the positive role the third sector can play, but raised concerns around short term funding. The North Edinburgh Child and Adolescent Mental Health Service (CAMHS) noted:

> “The closure of community-based services such as Number 6 and Healios has resulted in more referrals to CAMHS, placing further pressure on existing resources.”

Salvesen Mindroom Centre highlighted a need for investment in peer support groups to reduce isolation and foster community among individuals with ADHD and Autism. Referrals to third sector organisations was discussed by Scottish Ethnic Minority Autistics:

> “NHS staff do not understand how to do referrals to third sector partners. This has caused undue stress and waiting times. Lack of believing patients has been a problem for many people.”

Some submissions warned about the approaches of some organisations. AMASE cautioned:

> “Many organisations being funded by public bodies for post diagnostic support use behaviourist approaches, despite evidence that they are not supported by Disabled People’s Organisations, lack a proper evidence base and increasing accounts of harm”.

Private diagnosis

The role of private providers in diagnosis was discussed in many submissions. Some believed the private sector could reducing waiting times (Lanarkshire Carers), others considered that the use of private services created inequality and others noted that the NHS would accept a private diagnosis “when paid for by the NHS but not when sought independently by the patient, even when using the same company”.

Social Work Scotland argued that the use of private providers “raises serious concerns about equity and fairness. Those with the financial means to pursue private assessments are often able to bypass public waiting lists, creating a de facto two-tier system. Once a private diagnosis is obtained, there is often an expectation, sometimes unmet, that statutory services will follow.” This view was also echoed by NHS Highland who spoke about inequity in access.

> “The current delays and limitations within neurodevelopmental services have created a two-tiered system, where those with financial means are increasingly turning to private assessments to bypass long waiting times. This trend raises serious concerns about equity, fairness, and the principle of universal access to healthcare”.

The quality of private diagnosis was also discussed. The Royal Pharmaceutical Society noted “It is important that where private providers are used, that there is assurance that same standard of assessment and standards are met as used in the NHS, and that their use is equitable across Health Boards.” Quarriers argued “there must be a national protocol for recognising private diagnoses to ensure equitable access to treatment and redirecting NHS clinical time away from validation of assessment”. Salvesen Mindroom Centre also considered this point:

> “Unlike the NHS, private assessment providers are not subject to the same regulations or standardised processes, which raises concerns about consistency and quality. Due to long NHS waiting times, more families are

> turning to private assessments. We believe it is essential that these assessments are standardised and regulated to ensure best practice and equitable outcomes".

Other submissions spoke of a need to be able to review private assessments in order to address NHS waiting lists. ADHD Right Now suggested "developing a national standard or checklist (based on UKAAN, NAIT and NICE guidance) that private providers must meet that follows "Gold Standard" recommendations"

Shared care

Following on from the discussion of the use of private providers was a discussion of the use of shared care in Scotland. The Royal College of General Practitioners (RCGP) highlighted issues with the provision of shared care due to "significant concerns regarding the consistency and quality of private assessments, particularly when compared to NHS secondary care standards". It also highlighted concerns that shared care "responsibilities are time-consuming, clinically complex, and currently unfunded under the General Medical Services (GMS) contract".

ADHD Right Now argued for the standardisation of shared care agreements. Noting that "a national framework for Shared Care Agreements should be developed to eliminate the postcode lottery for medication access. This should include:

- Clear national guidance for GPs and health boards with additional support and training where required
- Standard documentation templates and eligibility criteria
- Mechanisms for auditing Shared Care practices to ensure safety and consistency"

Auticon noted that shared care agreements are not consistently supported across Scotland.

Adult pathways

The development of adult neurodevelopmental pathways was also covered in a number of submissions, particularly from NHS Boards. NHS Highland outlined its experience of piloting an adult ADHD pathway:

> "In 2022, as part of the National Autism Implementation Team (NAIT) Pathfinder programme, Highland HSCP piloted an adult ADHD pathway. The pilot was quickly overwhelmed due to the high volume of referrals and the significant time required for assessment, diagnosis, treatment initiation, and follow-up. As a result, the pathway was paused in October 2023. The discontinuation of Scottish Government funding for the pilot further hindered the ability to develop the service as originally intended. At the time of the pause, 745 referrals had been received, with 327 adults awaiting assessment. The pause coincided with a national shortage of ADHD medication, which delayed treatment initiation for 174 adults and caused inconsistent supplies for those already receiving medication. Following a comprehensive review

> and redesign, Highland HSCP has decided to prioritise resources to support individuals with the most critical needs.”

Good practice

Some submission highlighted examples of good practice. NHS Fife was noted for having a pathway of support for ADHD where “children and young people are seen regularly and supported by trained NHS staff throughout their childhood. This is a medical pathway and open only to those who are taking medication”. Dundee and Angus ADHD Support Group was also mentioned as providing third sector support for families and children with ADHD and ASD with or without a diagnosis. The Yard was cited as an example of when services are available without the need for a diagnosis.

Royal College of Speech and Language Therapists highlighted the work of the NDAS service in Lanarkshire:

> “Which has one of the largest core funded teams in Scotland with a single pathway across CCH, CAMHS and AHPs. They provide a comprehensive team approach which involves support before or after diagnosis and have devised the ‘whole school approach’ where an NDAS team goes into a school for 2-3 weeks and works in this setting to complete assessments/ formulation and feedback around individuals; parent information sessions and consultations with school staff. This approach has resulted in around a 30% increase in capacity to meet demand, with the same NDAS resource.”

NHS Lothian spoke of examples that “shift understanding to neuro-affirming culture that respects unique needs and identities” and those that adopt a shared language that focuses on strengths and differences rather than on deficit.

Theme 2: Assessment, criteria and treatment thresholds

Many submissions also discussed how assessments are undertaken, the criteria for diagnosis and the thresholds for treatment. Generally, the assessment procedures used in the NHS were well thought of and cross-discipline, although areas for improvement were identified by some respondents.

Heriot-Watt University argued the:

> “Need to consider an assessment process and tools which better support identification of autism and ADHD which are more accessible and neuroaffirmative (ensuring that neurodivergence is not seen as an abnormality but rather as a normal variation of human experience). We need to consider the impact of diagnosis on the individual and ensure that the process, rather than highlighting deficits with no route to support, offers insights and potential routes to support.”

They went on to say that the “current diagnostic criteria are outdated, deficit-based, and fail to capture the diversity of autistic experience, especially when autism co-occurs with ADHD or other conditions. Older adults, women, and people from marginalised ethnic and LGBTQ+ communities are less likely to receive timely or accurate diagnoses. This is compounded by a tendency to homogenise autistic experiences and overlook intersectional differences".

The Yard spoke of the experience of families that reported that the assessment processes can be lengthy with multiple appointments. They noted that families also report re-referrals before they can achieve diagnosis and that their child is removed from a waiting list, even before anyone has seen them, based purely on what is included in the referral paperwork. They went on to say that this is stressful and frustrating for families.

Other respondents noted that a specialist assessment pathway should be an important part of a service model, but not at the heart of it, with an increased use of consensus diagnosis where appropriate (CHOPS). The Autism Network suggested the use of community-based diagnostic hubs.

Access to support

Many submissions considered that diagnosis acted as a gateway to support, despite this not being Scottish Government policy. Social Work Scotland said:

> "Diagnosis has become the primary gateway to support, leading to long waiting times, inequitable access, and growing frustration among individuals and families. This is compounded by chronic under-resourcing, inconsistent eligibility criteria across areas, and a lack of strategic clarity, particularly in relation to transitions from child to adult services."

Children's Health Scotland agreed:

> "The current system inadvertently incentivises diagnosis as the only route to support. Families pursue diagnosis not out of preference, but necessity. If existing frameworks—such as GIRFEC, SHANARRI, and CSPs—were applied consistently and effectively, the pressure for diagnosis would decrease, and children could receive timely, needs-based support. This would also reduce strain on diagnostic services and allow for more equitable access to care."

Thresholds

A number of submissions spoke on the required criteria in place, in some areas, for referral for a neurodevelopmental assessment. NHS Ayrshire and Arran outlined that in its area "there are no options for assessment and treatment for children, young people and adults in Ayrshire who have a suspected neurodevelopmental profile but do not meet criteria to access a mental health service".

Commenting on the use of criteria to access assessment, Auticon said:

> "By restricting access in this way, many families may be forced to wait until a child's condition deteriorates or meets the tighter criteria before entering the system. This risks delaying early identification and intervention, increasing

> unmet need, and ultimately exacerbating pressure on services in the long term."

The National Autistic Society Scotland outlines its views on a stepped approach which it said is being considered by the Scottish Government.

> "We would advise that any new approach should be thoroughly tested and evaluated, involving autistic people, and we would strongly caution against making the threshold for assessment too high."

Similar concerns were raised by the National Autistic Society Scotland:

> "Since the onset of the current waiting times crisis, we have heard more and more frequently from the Scottish Government about the benefits of a needs-led approach. As such, we want to emphasise that needs-led support should not be used to try and drive down diagnosis waiting times. Indeed, this is a flawed approach, and the recent review of the National Neurodevelopmental Specification for Children and Young People identified that the move to a needs-based model had not reduced the demand for a diagnosis".

Quarriers argued that there should be a national prioritisation criteria in place to "ensure that people approaching the age of 18 or facing other significant life transitions are not disadvantaged by long waits".

The Scottish ADHD Coalition spoke about the possible consequences of under treatment and missed diagnosis:

> "There is a substantial public health cost associated with under-treatment in addition to the personal costs to families affected by ADHD. Treatment has been shown to substantially reduce mortality, hospital admissions, traumatic brain injury, unintentional injury, fractures, and road traffic accidents. No evidence has been presented to support the assertions being made that 'diagnosis is unnecessary' or that untreated individuals fare as well as those who receive treatment. There appears to be no evidence-base for the expectation that patients with non-complex ADHD will receive adequate support in the community as a substitute for treatment. The withdrawal of treatment as an option for those at risk will inevitably lead to increased death and injury in this vulnerable population and marks a significant regression in the provision of healthcare across the nation. Scotland appears to be the first western economy to have taken the decision to withdraw treatment for a widespread chronic treatable condition."

Role of digital

A number of submissions discussed how technology could be used to help with assessment of ADHD and ASD and examples were given of how tools could be used to aid diagnosis.

Rural areas

Issues faced in rural areas were raised in submissions including by COSLA. Auticon said that “rural, island, and under-resourced regions are particularly affected, with some areas lacking any local clinicians trained in specialist diagnostic tools”.

Theme 3: Waiting times

The length of time people wait to be assessed for neurodevelopmental conditions was raised in many submissions. A staff member from NHS Lothian said:

> “A lot of the young people who are on our wait list are waiting over three years for assessment and then if ADHD treatment is required currently it is another two and a half years wait for this, this is not equitable over the Lothians as I am aware the wait lists vary sector to sector, making our service more of a postcode lottery than an equitable accessible service for all who require it.”

Another submission commented that “wait times have grown exponentially. Many reasons were given for the increase including an increased awareness of neurodevelopmental presentations and the impact of lockdown during the COVID-19 pandemic.

Mental health and neurodevelopmental waiting times

Some respondents spoke of the split of the mental health and neurodevelopmental waiting lists. One respondent said:

> “The splitting of waiting lists has hidden the ND [neurodevelopmental] waiting list. This was highlighted very frequently by staff working in teams. Recent publication of improved CAMHS wait times felt contrived and dishonest given the knowledge held by ALL working in CAMHS and government regarding the ND wait times.”

Data

Many submissions spoke of the need for data to be routinely collected and published. Auticon argued there “is no consistent national approach to data collection, service provision, or waiting time reporting. This lack of standardisation makes it difficult to monitor equity, quality, and access across Scotland’s 14 NHS boards”.

Children’s Health Scotland said there was a need to improve data and accountability. Suggesting that health boards should be required to publish waiting time and outcome data. It also suggested that equity of access should be monitored across socioeconomic and geographic lines. This was echoed by the Scottish ADHD Coalition who said that improved data collection could support informed planning in services and thus improved efficiency.

The Royal Pharmaceutical Society called for meaningful, measurable targets that are standard, clear and deliver the desired outcomes. The Royal College of General Practitioners (RCGP) said:

> “The absence of clear and accessible information on waiting times creates uncertainty for both GPs and patients. This lack of transparency undermines trust and can damage the therapeutic relationship, particularly when patients are left to manage their condition for extended periods without specialist input.”

The Royal College of Paediatrics and Child Health (RCPCH Scotland) echoed these concerns saying:

> “It is impossible to gain a complete understanding of current demand for ND services, as there is insufficient data on referrals, assessment processes and outcomes for neurodevelopmental services. Data capture, collation and analysis is imperative to understand the scale of the issue nationally and to develop strategies to address the crisis in services. Without a clear picture of both current needs and future demand, it is challenging to allocate resources appropriately and plan for sustainable service delivery […] This should include data on the number of children referred to services, demographic information, and outcomes.”

SAMH called on the Scottish Government to ensure quarterly collection, collation, analysis, and publication of disaggregated data pertaining to autism and ADHD diagnosis, including data on waiting times for assessment. They went on to suggest that the Scottish Government “should commit to including breakdowns based on the progression and outcomes of referrals, as is the case currently for the regular data published in England”.

Theme 4: "Waiting well" and support pre-diagnosis

Many submissions spoke of the impact of long waits for diagnosis on individuals and their families. NHS Grampian Speech and Language Therapy Service argued “pre and post diagnostic support is hugely needed however current services, defined by their referral criteria, are often not available for the majority of the population”. The Yard said that “the process for assessment and diagnosis is a long process for the family and this can have significant impacts on families as they are left to cope with very little support. This can have an impact on their mental health, parents ability to work due to limited childcare options for children with ASN, family dynamics.” They went on to note:

> “In many areas there is no support available whilst the family are waiting for an assessment, this can be incredibly challenging for families whilst they are left to manage difficult behaviours stemming from their child's additional support needs. In most areas there is very little communication with families whilst they are on the waiting list in terms of wait times and what will happen next.”

The Yard went on to suggest that the “third sector is able to deliver services to families that are flexible to their needs” and suggested that “greater funding to allow the delivery of services pre-diagnosis (such as The Yard) would be invaluable to families”.

The Edinburgh CAMHS Team argued that “support provision must be fundamentally reimagined to prioritise individual needs over diagnostic labels. Investment in community-based initiatives, such as the EDAN Hub and The Yard Scotland, can offer families accessible, sustained support. Furthermore, equipping these community resources with the expertise to support neurodivergent individuals through targeted consultation and training will foster a more inclusive, responsive, and robust support system”.

SAMH raised its concerns that “The extensive delays neurodivergent people are facing in being diagnosed and receiving treatment and support also increases their risk of developing secondary mental health issues – such as anxiety, depression, and substance misuse.” Children’s Health Scotland argued “children’s wellbeing deteriorates during long waits for diagnosis, with increased anxiety, school refusal, and social withdrawal”.

Gatekeeping

Some submissions highlighted a need for “reducing gatekeeping and enabling earlier access to support while people wait for formal diagnosis”. CHOPS highlighted a need for the “provision of tailored needs based support at the earliest stage possible, with no barriers in place to receive this”.

Communication

Issues with communication whilst waiting for assessment was also highlighted. RCPCH Scotland outlined the benefits of providing regular, proactive communication, such as ensuring that children, young people, and their families do not feel abandoned while waiting for assessment. The charity Contact said that “parents have said they don’t receive information and support whilst they wait. Some wait for considerable number of years for an assessment for their child, for some 4 years or more. Parents have described the impact of waiting or not receiving a diagnosis means their young person can’t stay in education and carry out their studies; get therapeutic support or medication and may struggle with relationships, and at work.”

Theme 5: Transitions between services

Many submissions discussed the transition between child and adult services. The Scottish ADHD Coalition argued for improved transition arrangements between child and adolescent and adult services to reduce breaks in treatment and care. Social Work Scotland spoke of the issues that can arise when services are “competing for the same limited funding” along with the “differing legal contexts and expectations/criteria in adult and children's services”. They note that the “disparity creates a situation at point of transition, where young people risk losing support just as they face new and complex challenges in education, employment, and independent living”.

NHS Highland also raised concerns:

> “There is currently no nationally implemented transitional framework for neurodivergent young people moving from child to adult services in Scotland. While the National Neurodevelopmental Specification for Children and Young People (2021) set out clear expectations for early intervention and support, there remains a critical gap in continuity of care into adulthood. Embedding a co-produced, cross-sector transition framework—aligned with the Principles of Good Transitions and supported by dedicated resources—would ensure that neurodivergent individuals experience seamless, person-centred support across the lifespan, reducing the risk of disengagement and unmet need during this pivotal stage.”

Timing out of services

The delay often faced by children and young people waiting to access diagnostic services resulted in some respondents raising concerns regarding the possible transition out of services before a person is seen. Salvesen Mindroom Centre outlined this point:

> “The transition from NHS Child and Adolescent Mental Health Services (CAMHS) to NHS Adult Mental Health Services is widely recognised as a critical point where many young people fall through the gaps. Despite having spent years on CAMHS waiting lists, young people often face the frustrating reality of starting over, joining the bottom of an adult services waiting list for assessment or support. This discontinuity not only delays access to care but can also exacerbate existing mental health challenges during a vulnerable life stage.”

Support post school

A number of submissions also discussed the need for support post school and when young people transition into higher and further education. In its submission the University of Glasgow noted:

> “Neurodivergent students who arrive to HE not having been previously identified as neurodivergent are likely to find themselves at an immediate disadvantage. They will struggle with the social and organisational demands of being in a new environment without the benefit of appropriate one-to-one support (such as specialist mentoring).”

COSLA also highlighted a risk:

> "The lack of structured post-education pathways may leave young people vulnerable to disengagement, and wider more serious impact. Currently a significant percentage of children and young people in school settings are identified as having additional needs. Ensuring these needs are met post school places a significant pressure on the system that requires appropriate consideration, planning and investment."

The University of Glasgow referred to Disabled Students Allowance (DSA) which it noted "is still firmly based on a medical model, where a funding base cannot be reliably established without a medical diagnosis".

Theme 6: Funding and resource

Many submissions discussed the availability of funding and resources. NHS Ayrshire and Arran who spoke of a "lack of national accompanying investment in neurodevelopmental services". Aberdeen City Health and Social Care Partnership said:

> "It is hard to see a way of reducing waits for adults seeking neurodevelopmental assessment besides additional funding for an adequate workforce to meet evidenced demand. This funding does not necessarily have to be targeted only to statutory services but better spread across voluntary and statutory services to allow a stepped care approach to supporting individuals who require support pre and post assessment and to deliver the assessment services themselves."

NHS Lothian spoke of "limited financial resources and fragmented funding arrangements across NHS and HSCPs, reliance on temporary or pilot funding limits sustainability of programmes and progress" and highlighted that "services rely on each other to deliver outcomes without shared resource." North Edinburgh CAMHS Team said that: "Increased funding is essential to expand staffing, enhance training, and improve access to clinic space and resources".

NHS Highland outlined that assessment and diagnostic pathways in Highland Council area have been established through short term pilot funding of specialist psychology and advanced neuro-developmental practitioners.

Funding of statutory and third sector services was raised by Social Work Scotland:

> "The most significant concern raised by our members, impacting both statutory and third-sector provision, is the issue of resourcing. Without adequate staffing and sustainable funding, even the most innovative and effective models of support cannot be maintained. The current reality is that services across the board are operating beyond capacity after many years of constraints in funding […] Without adequate investment in staffing, infrastructure, and service capacity, the system will remain overwhelmed and reactive. Waiting lists will continue to grow, and individuals will continue to experience delays, unmet needs, and avoidable distress."

The RCGP raised concerns about “reductions in funding for third sector organisations that provide vital support to people with mental health challenges. These cuts have further strained general practice, which is already operating under significant pressure.”

Theme 7: Workforce

Joint working

Many submissions spoke of the benefits of interdisciplinary working. CHOPS called for “a move away from the historical medical model of specialist assessment and diagnosis first, followed by support and intervention”. Argyll and Bute Integration Joint Board (IJB) noted that there was limited capacity and availability of professions who can diagnose including no substantive paediatric cover across Argyll and Bute and suggested that increased “whole system” capacity -education, health and social care could maximise assets and address gaps in provision.

The Royal College of Occupational Therapists outlined a view that assessments should be moved “out of CAMHS and into community child health services, creating a dedicated diagnostic service involving Allied Health Professionals and medical staff”. The involvement of AHPs was also highlighted in submissions from the British Association for Music Therapy (BAMT) who outlined the role that music therapy can have when working with children, adults and families of those with ASD or ADHD and the Royal College of Speech and Language Therapists who considered that moving to a MDT model could lead to a more cost-effective and quicker service.

Stirling Council also believed “increased collaboration and partnership working across key services such as health and education is a priority”.

Capacity

The capacity of the current workforce was mentioned in many responses, particularly from NHS Boards. NHS Ayrshire and Arran noted a “national workforce shortage in many areas […] Difficulty in recruiting and retaining professionals in disciplines such as SLT, OT, Psychology and Psychiatry is a significant factor in the service delivery issues faced across Ayrshire”. NHS Lothian outlined concerns that that “we are constantly adding to the wait lists for assessment but do not have the capacity required to assess all the young people who are waiting”.

Aberdeen City Health and Social Care Partnership “Whilst services have many ideas for improvement, we can only work within our current workforce resource and capacity, which is extremely limited […] We are unable to adequately address our waiting times for assessment within this very small workforce resource”

Scottish Ethnic Minority Autistics spoke of the pressure faced by NHS staff “The workload is unreal for NHS staff as well because of the unrealistic demand and not enough staff (for assessments). The burnout of staff will reduce the quality of service.”

Bottlenecks

Submissions also spoke of bottlenecks in the system. For example, the Royal College of Speech and Language Therapists said “our members have reported that referrals in many areas of Scotland often get stuck in a bottleneck situation of professionals around the individual identifying the need, gathering the evidence and sending this off for specialist assessment, but the lack of specialists available means referrals pile up waiting for review”.

Training

A need for additional training was also identified as an issue in many submissions. Particularly for GPs, mental health professionals, health visitors, and early years and education professionals. North Edinburgh CAMHS team argued “providing schools, Social Workers and GPs with enhanced training and guidance on neurodivergence would lead to more accurate and supportive referrals and also resourcing support for young people waiting for diagnosis”. Lanarkshire Carers identified a “need for training for parents, so they can better understand and support their children”.

The Royal Pharmaceutical Society suggested introducing a “neurodiversity friendly pharmacy type model, akin to the dementia friendly pharmacy and Daffodil standards initiatives”.

Theme 8: The impact on individuals of receiving a diagnosis or waiting for a diagnosis

The impact of receiving a diagnosis or waiting for a diagnosis was discussed in many submissions. Children in Scotland spoke of the experience of some parents:

> “They can feel like they are being judged by professionals and other families if their child is struggling in nursery or school, or out of school. We hear how they can worry that people are perceiving them to be a “bad parent” or that their child is choosing to have “bad behaviour” and the toll this can take. We have also heard how this can prevent them from feeling able to work with professionals to address concerns. A formal diagnosis can be validating and helps parents feel reassured that if their child is in distress at school, it is because their support needs are not yet fully recognised or being fully supported – rather than a “fault” of their child or the support they are receiving from their family. The removal of this actual or perceived barrier can help families feel able to better work with professionals, by knowing everyone is aware of and acknowledges a child or young person’s support needs, allowing them to work together to ensure they are getting the adjustments they need.”

Aberdeen City Health and Social Care Partnership argued that “the impact of long waits for assessment is extremely distressing for individuals”. Argyle and Bute IJB outlined that a delay in assessment can result in “pressured family situations impacting on all members” crease impacting on families, services and society”.

The University of Glasgow said “the impact of waiting includes prolonged raised levels of anxiety, often at clinical levels, together with a sense of frustration and anger. For individuals receiving a diagnosis, there are significant benefits to self-knowledge and the potential for more tightly targeted psychoeducation; for students with ADHD, access to medication can be life changing”.

National Autistic Society Scotland considered:

> “Receiving a diagnosis is a validating and life-affirming experience for many and helps autistic people to understand themselves, their identity, as well as their strengths and challenges. The assessment process is much more than a diagnosis; it offers the individual a needs assessment, as well as ruling out or identifying other conditions. Moreover, we know that a diagnosis is, unfortunately, often the gateway to support for individuals. Indeed, the reality is that public services are under pressure and will often prioritise allocation of support based on level of need and/or diagnosis. Autistic people also often struggle to be believed when seeking support due to ongoing stigma and discrimination, which makes a diagnosis important to individual”

North Edinburgh CAMHS Team considered that “delays seen within the assessment process can have a significant impact. Without timely diagnosis, children may face barriers in accessing appropriate educational support and therapeutic interventions. This uncertainty can contribute to emotional distress, identity difficulties, and challenges with mental health. Families often report feelings of frustration and helplessness, and the lack of clarity around a child’s needs can place strain on relationships and parenting approaches”.

Access to services

This summary of written evidence does not provide much detail on the support which respondents would like to see post diagnosis, although a substantial body of evidence was received, as this is likely to be the focus of the forthcoming Equalties, Human Rights and Civil Justice Committee’s inquiry into neurodivergence in Scotland.

Despite the narrative and the National Neurodevelopmental Specification for Children and Young People which states that “understanding of support needs can be enhanced by diagnosis but should not wait for diagnosis” many submissions said that a diagnosis helped people access services. For example, NHS Highland said “with competing demands on local authority resources, diagnosis is often utilised as confirmation for need and additional support or resource allocation where universal services feel under-quipped to provide clear and authoritative information in relation to actual, versus perceived or expressed need”.

The Autism Network gave some examples:

- “Prison inmates denied reasonable adjustments unless they have a diagnosis—yet denied access to clinical assessment unless they are deemed “mentally ill.”
- Teachers refusing to adapt their teaching approaches unless a child has a formal diagnosis, despite clear evidence of need.”

Scottish Autism considered that assessment pathways should be something to which individuals can be guaranteed access:

> “A diagnosis can be vital in supporting a person to better understand themselves and to be better understood and supported by others. While we have heard the Scottish Government argue that a diagnosis is not necessary to receive support, rather that the needs should determine this, we hear on a daily basis that this is not the reality facing people. Moreover, a holistic assessment process should not simply be about confirming or declining a diagnosis, but establishing an individual profile of needs.”

In its submission the Children and Young People's Commissioner Scotland said:

> “Whilst we agree it should not be necessary to have a formal diagnosis of ADHD or Autism to receive support, our view is that access to diagnosis can be an important factor in ensuring children’s right to the highest attainable standard of health. In the context of education, diagnosis can provide important context to ensure that children and young people receive support which is appropriate to their individual needs.”

Theme 9: Suggestions for improvements to pathways?

Many submissions made suggestions in relation to making improvements to the current pathways. This summary outlines some of these suggestions but does not provide a comprehensive list of all recommendations.

ADHD Right Now suggested the introduction of a dedicated neurodevelopmental assessment service at regional/national level to pool clinician expertise and to provide Tier 4 services where cases are either complex or acute. Children’s Health Scotland also called for the implementation of a National Neurodevelopmental Pathway as did Auticon. Auticon also outlined a need for training in neurodiversity, ensuring continuity of care across age transitions. They also called for the diagnostic process to be expediated, a reform of diagnostic criteria and methods and considered that post-diagnostic support, and pre-diagnostic should be strengthened and that a ‘Right to choose’ or shared care model should be established.

ARGH Scotland suggested that “the Scottish Government should Introduce a national neurodevelopmental assessment guarantee, meaning any adult in Scotland can access an assessment pathway should they need to”.

The Autism Network cautioned that “there is no solution here that can be achieved through minor adjustments or ‘tinkering at the edges.’ What’s needed is bold, systemic change. Without it, we risk continuing the cycle of consultation–strategy–review for another decade. This is the systemic change that NAIT (National Autism Implementation Team) have been calling for, but failing to deliver”.

Scottish Autism referred to a number of recommendations from its recent report:

- "The Scottish Government should introduce a national neurodevelopmental assessment guarantee, meaning any adult in Scotland can access an assessment pathway should they need to. This approach could follow the models piloted by NAIT and should also allow for self-referral.
- Waiting times for assessment and diagnosis should be reduced and timely assessment provided.
- Clear information should be provided on what the assessment process will involve, the likely timescales expected and reliable signposting to support services both during the assessment process and afterwards, irrespective of the diagnostic outcome."

RCPCH Scotland noted that it called on the Scottish Government to:

- "Develop and implement a comprehensive public health campaign aimed at raising awareness and understanding of learning disabilities, autism, and neurodivergence. Collaborate with advocacy groups, key stakeholders within the neurodiverse community, education, CAMHS and individuals with lived experiences to ensure the campaign is impactful and authentic.
- Introduce mandatory training programs for the public sector to ensure they are equipped with the knowledge and skills to offer the best support
- Allocate funding and resource to support the implementation of these initiatives. Monitor and evaluate their effectiveness to ensure continuous improvement and sustainability."

Dr Carrie Ballantyne, University of the West of Scotland recommended the introduction of targeted, mandatory training for educators to improve knowledge and reduce stigma, the provision of evidence-based coaching and support models and embedding students and parents in the design of supports to ensure effective, empathetic inclusion strategies that reflect lived experience.

Theme 10: Policy developments

Some submissions made refence to the forthcoming Learning Disabilities, Autism and Neurodivergence (LDAN) Bill. Social Work Scotland spoke of "concern that the lack of clarity about the Bill's content and requirements is preventing them [local authorities] from engaging in meaningful long-term strategic planning. In the absence of clear legislative direction, many strategies are simply being rolled over from previous years, rather than being updated to reflect current needs and emerging best practices".

ADHD Right Now called for a national ADHD Strategy to streamline referral and assessment processes and ensure equity of access across health boards.

COSLA made refence to its recent joint report with the Scottish Government which committed to a series of short, medium and long-term actions to progress improvements in neurodevelopmental support for children and young people.

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