September 2025

ADHD and Autism Pathways and Support, Health and Social Care Committee Inquiry

National Autism Implementation Team Submission and Consultation Response

Background

The National Autism Implementation Team (NAIT) are a mixed neurotype, cross sector, research practice partnership funded by the Scottish Government since 2019. NAIT support public sector practitioners with the implementation of neuro-affirming, evidence informed and neurodevelopmentally informed practice across the lifespan. Although originally formed with an autism focus, the current NAIT programme of work is now relevant across different neurodivergent groups (including autistic people, those with ADHD, Learning Disability, Fetal Alcohol Spectrum Disorder, Developmental Language Disorder, Developmental Co-ordination Disorder). We are funded through the Mental Health Directorate and our work crosses health, education, justice, employment and social care sectors.

NAIT work includes a focus on neurodevelopmental pathways, assessment, diagnosis and support and professional learning resources underpinning this. Collectively, we often know what should happen, but finding the research that answers our questions, translating research and guidelines into practice or implementing the changes needed across sectors and systems is complex, iterative and can take time. Our team offers ongoing practitioner support to start and persist with changes and to evaluate and share examples of innovation and good practice. Engagement and implementation are supported by NAIT through:

- Practitioner networks
- Neurodivergent partner networks
- Professional learning materials
- Accessible resources shared on our website, newsletters and through networks and events
- The Neuro-affirming Community of Practice Scotland

As well as NAIT work and resources which can be found on our website www.nait.scot , the NAIT team have been part of national work, including:

- SIGN guideline development
- The Autism Toolbox
- The development of national autism resources for Initial Teacher Education
- The Children and Young People's Neurodevelopmental Specification
- Recommendations for Adult Neurodevelopmental Pathways
- The Autism Informed Services resource development and the Autistic Adult Support Fund led by Inspiring Scotland
- NHS Inform updates to autism and ADHD website information
- The Digital Mental Health Innovation Cluster
- The Additional Support for Learning Project Board

Aims of the inquiry and opportunities for improvement identified

The inquiry aims to gather relevant information about questions we focus on as the NAIT team. We welcome the national conversation around the issues in question.

When and why does diagnosis matter?

Although the focus is on provision of pathways and access to assessment, diagnosis and support, there are important questions as context for the inquiry, such as when and why does diagnosis matter to neurodivergent people and should this even be a focus?

Autism and ADHD are not mental health conditions although under-identification and a lack of adjustment in everyday life contribute to the high rates of mental and physical ill health and life expectancy around 16 years below the population average.

We anticipate that the submissions from neurodivergent people will echo what we have heard – that identification or timely and accessible diagnosis really matters for a range of reasons in our current society and should definitely not be offered only after someone is ‘broken’ from living without the self-understanding, support and adjustments they need.

Evidence we reviewed suggest that:

- diagnosis is one important need in a needs-led system.
- the benefits of diagnosis cannot be separated from support to meet needs before, during or after diagnosis.
- the model of providing support only according to need without consideration of diagnosis does not meet needs if it is the only approach on offer.

Neurodivergent people tell us, loud and clear, that diagnosis really matters in many ways. Delayed or missed diagnosis can be harmful. Experiencing differences or

difficulties and even being offered solutions without understanding what is causing the experiences is a significant source of distress. Diagnosis is often therapeutic because it:

- **Validates identity:** helping people understand and celebrate their personal identity.
- **Fosters connection:** enabling people to find a community of peers with shared experiences.
- **Provides clarity:** helping individuals to make sense of their past, present, and future experiences. It provides language for people to use to explain their experiences.
- **Improves access to information:** enabling people to find relevant, meaningful resources.
- **Supports informed decision-making:** helping individuals make choices about which supports and interventions are personally right and a good fit.
- **Increases access to support:** enhancing access to appropriate services, adjustments, and benefits.

Further information about NAIT Key Messages and Why Diagnosis Matters can be found here https://nait.scot/wp-content/uploads/2025/05/NAIT-Key-Messages-for-Neuro-affirming-Health-Practitioners-Adults-2025.pdf

How people in Scotland access assessment and diagnosis for ADHD and/or Autism.

The inquiry seeks to understand a) referral routes, assessment processes, and thresholds for diagnosis, b) the availability and accessibility of diagnostic services across Scotland. These are different for adult and child services because of different contexts, and we will provide responses related to both separately.

Routes to requesting assessment in children's services

- **Neurodevelopmental pathways are recommended as the route to assessment** and diagnosis for autism and ADHD, along with recognition of other neurodevelopmental profiles. Although Scotland and Wales have been leading the way in this area, the autism and ADHD Taskforces in NHS England have also recommended a neurodevelopmental pathway approach.
- Children's pathways have usually been developed in close consultation with children and families and there is a good understanding of the impact of delays and ways to meet a range of needs.
- These are in place in the majority of health boards now for children and young people (9/14).
- There is 40% co-occurrence across autism and ADHD diagnoses and separate pathways are inefficient and ineffective. A recent study in Ireland found that 53% of people with ADHD were also autistic.
- For autism and/ or ADHD support should not be diagnosis dependent and the first line of support should be through the environment and the people and places around the individual.

- Guidance on referral routes and assessment processes for children and young people can be found in the
    - Scottish Government **Neurodevelopmental Specification**
    - **NAIT Neurodevelopmental Pathways Practice Framework (2024**). The latter document was originally shared in 2021 and has been updated in 2024 to reflect implementation underway.

  https://www.gov.scot/publications/national-neurodevelopmental-specification-children-young-people-principles-standards-care/
  https://nait.scot/document/childrens-neurodevelopmental-pathway-practice-framework-2024/
- NAIT link regularly with national neurodevelopmental leads networks to access and share up to date information about routes to assessment and diagnosis.
- The recent SPICe briefing has up to date information from NAIT and local services https://spice-spotlight.scot/2025/06/27/neurodevelopmental-pathways-and-waiting-times-in-scotland/

Referral routes for children can (and we think should) be called 'Requests for Assistance' rather than referrals.

GIRFEC: Neurodevelopmental pathways embed the GIRFEC framework and therefore support according to need should start with the team around the child, in a relevant and proportionate manner.

- Many services use the child planning process as the first step in understanding needs and requesting further assessment to meet needs.
- NHS Fife is a good example of clear information about the pathway and 'routes to referral' for neurodevelopmental assessment.
- Where one health board covers several local authority areas, it can be a more complex job to have a consistent route, so in Glasgow or Edinburgh for example, there may be a range of routes through local GIRFEC processes, that are slightly different in each authority.
- Some areas, for example, NHS Lothian are moving the leadership of neurodevelopmental pathways out of CAMHS and into the Women and Children's directorate to reflect the need for involvement of a broader multi-disciplinary team (MDT) in a GIRFEC based model.

Open referrals or requests for assistance allow families or individuals to self-refer, or schools as well as health professionals to make the request for neurodevelopmental assessment. Where this works well, there is clear guidance and information for those making requests about the information needed to proceed.

- NHS Dumfries and Galloway is a good example of this practice.
- Local areas have been concerned that having an open-referral process will 'open the floodgates' but the evidence from Dumfries and Galloway and in Grampian adult autism team is that this does not happen.

- The demand or need is similar to other areas, but the outcome is better conversations earlier, with the right people and a better 'patient flow'.

Thresholds: In other areas, there are less open referral routes. Referral may require a GP or other health professional to make the referral, following local guidance, which places thresholds or limit to those who can access neurodevelopmental assessment.

'No wrong door' and a single route for 0-18 is recommended, supporting collaboration across Community Child Health, Allied Health Professionals and CAMHS, who worked in separate or overlapping pathways in the past.

- Good examples include NHS Lanarkshire, NHS Dumfries and Galloway, NHS Fife.
- In some other areas, the traditional separate pathways operate. For younger children (e.g., under 6 years) the route is different to that for older children and young people.
- In these areas, the younger children are often seen by a team including a Speech and Language Therapist (SLT) and a Community Paediatrician.
- Older children might be referred for neurodevelopmental assessment through CAMHS and CAMHS thresholds may be applied to requests for neurodevelopmental assessment. This can lead to reactive provision of diagnostic assessment rather than this being an anticipatory support to meet need. There is also a risk that these are more likely to focus on particular conditions or needs and are not staffed to offer a neurodevelopmental approach.

Flexible routes or pathways: Local services are looking for ways to better meet needs for neurodevelopmental assessment which avoid a 'one size fits all' approach. These are summarised here: https://nait.scot/document/nait-identification-and-diagnosis-guide-2025/

- Examples include single practitioner diagnosis, whole school models (NHS Lanarkshire) with the neurodevelopmental service working in a school for a block of time and consensus diagnosis with the team around the child. These are not appropriate for every child but are part of an efficient and effective toolbox when staff have the skills, knowledge, experience and links across the service.
- Many areas use NearMe online appointments to allow families to provide developmental history information without having to attend clinic and without their child having to hear the interview. This is time-saving for clinicians and families.
- NHS Lothian and NHS GGC have used VCreate – a non-synchronous app, to reduce the number of clinic appointments and reduce distress and anxiety for children being assessed. Through this app, parents can share short video clips of positive interactions and play with their child at home, in pre-planned activities. Clinicians can review the data and use it to support the full clinical assessment. It has been time saving and works well for pre-school children or

those at an early developmental stage or who are anxious about going to a new place and unlikely to engage easily with a new person. This has the potential for roll out nationally if it was funded.

Skilled and knowledgeable workforce: It is important to note that there is a skilled and passionate multi-disciplinary workforce across all 14 Children's Health Boards, with a culture of review, development, consultation with families and young people, multi-disciplinary collaboration, data gathering and careful deployment of resources. Where or when diagnostic assessment is accessed, feedback about the staff skill, knowledge, mindsets and family experience is often very positive.

Transition stage: The current wait lists present a particular problem for individuals over 16 who can 'age-out' of children's services before they are seen. Although ARC Scotland have developed helpful guidance, our impression is that this is an area for development across the country.

Transition supports for those who are identified

- The ARC Scotland and COMPASS resources on transitions represent this topic well.
- This is an area which needs focus and listening to a range of neurodivergent young people.
- The term 'care' does not fully represent the range of ways support can be provided. A particular approach might work for people who meet criteria for ongoing care, for example if receiving medication but key elements of support under GIRFEC such as the school, the paediatrician, the educational psychologist don't exist for adults. Often by late teens, SLT, OT or other sources of support for communication and sensory support needs drop off and adult services would need someone to come with a well-formed and specific problem rather than being there to help the individual understand their neurotype and what it means for them in their new contexts.
- The transition is not restricted to mental health services. Support might be best placed within an education or employment setting or with a health professional outwith the local MH services.
- There has been some innovative work in Ireland around doing this better.

Increased capacity: Although there is a still a mismatch between need/ demand and capacity to meet the need, which in turn leads to longer waiting lists, more children and young people are being assessed and diagnosed than ever before.

One way this is evident is that prevalence in Scottish schools in 2022, showed that 2.6% of primary aged children were autistic and 3.9% in secondary schools. This compares with previous prevalence of 1-2%.

- Using data collection and management tools in partnership with Public Health Scotland, most areas are able to show an increase in the number seen. Some areas have made the decision to increase the proportion of existing resources dedicated to neurodevelopmental assessment teams (reflecting the need locally).

- For example, NHS Fife have made successful in-roads into the waiting list through increasing staffing and undergoing a rigorous process of service change in partnership with education services.
- Another example is NHS Lanarkshire where the NDAS service is staffed by between 50-60 team members, including admin and clinical staff and the staff undertaking diagnostic assessment can also take up to 6 sessions with the family to offer support and immediate practical steps instead of referring on to another waiting list.
- NHS Lanarkshire have also spear-headed an innovative approach of the NDAS team working in a primary school for a block of time to see all of the children in the waiting list in that school, meet the parents and staff and offer information and support sessions. This model is well received as a positive experience and provides around 30% more capacity to meet demand for diagnostic assessment than the traditional clinic based model.
- Some local areas also build capacity to meet needs before during or after diagnosis through online information and neurodevelopmental hubs, for example NEST in Ayrshire and Arran https://www.nest.scot/ and many others.

NHS Data

NAIT are working with Public Health Scotland to look at NHS data. Full analysis and publication will follow but early analysis has found:

- Although data recorded is inconsistent, there has been a 300% increase in the number of autistic and ADHD people recorded in adult psychiatric wards in the last 10 years.
- ADHD prescribing data since 2019 shows that in 5 years, double the amount of people are prescribed ADHD medication through the NHS in Scotland. This is to an extent a proxy for those diagnosed, although number diagnosed will be higher because some people diagnosed will not be prescribed medication and a greater number are likely to be paying for private prescriptions compared with 5 years ago.

Assessment processes

The development and implementation of a multi-disciplinary neurodevelopmental pathway is a complex ‘intervention’, with many inter-connected ‘ingredients’. Through NAIT work in Scotland, we have identified that local areas follow a similar process and are at (or between) one of 4 stages:

Stage 1: Understanding and Forming

Stage 2: Development

Stage 3: Implementation

Stage 4: Review

More information can be found here: https://nait.scot/wp-content/uploads/2025/02/Childrens-Neurodevelopmental-Pathway-Practice-Framework-2024.pdf

Health Board	Child ND Pathway Stage	Adult ND Pathway Stage
NHS Ayrshire and Arran	2	2 and 4 ▪ Assessment pathway paused for 'extreme team' review
NHS Borders	3	1
NHS Dumfries and Galloway	3 (and 4)	1
NHS Fife	3 (and 4)	2 ▪ did neurodevelopmental pathway tests of change ▪ business case submitted to the health board and rejected
NHS Forth Valley	3	1
NHS Grampian	2	2 and 4 ▪ autism +ADHD but separate ▪ review ongoing
NHS Greater Glasgow and Clyde	3	2 and 4 ▪ autism +ADHD but separate ▪ review ongoing ▪ business case submitted to the health board and rejected
NHS Highland	4	2 and 4
NHS Lanarkshire	3 (and 4)	2 and 4 ▪ autism +ADHD but separate ▪ review ongoing
NHS Lothian	2-3 (and 4)	2 and 4 ▪ autism +ADHD triaged together but separate assessment processes ▪ neurodevelopmental pathway review ongoing
NHS Orkney	2	1
NHS Shetland	2	1
NHS Tayside	4	3 ▪ a small number of neurodevelopmental specialists offering integrated an approach to

		assessment, diagnosis and support
NHS Western Isles **(also known as NHS Eileanan Siar)**	3	2 ▪ there is an intention to work towards a lifespan pathway

This is an ever evolving situation and this high level summary is not intended to capture the detail and nuance of the range of work previously done, currently underway or planned for the future.

Children and Young People

- All children's services are at least at stage 2, where autism and ADHD pathways operate and the neurodevelopmental pathway is in development.
- 10/14 are at stage 3 and/ or 4 where a neurodevelopmental pathway has been implemented and it is either ongoing or is under review.

Adults

- One health board is at an early stage 3 (Implementation) and has a small team taking an explicit neurodevelopmental approach (NHS Tayside).
- NHS Lothian has implemented a neurodevelopmental approach at the referral point but delivery is usually through two sequential routes for autism or ADHD, rather than a single process.
- At least 9/14 boards have a strategic group and are giving consideration to neurodevelopmental pathway approaches. Within these boards there can be professional groups taking a neurodevelopmental approach although there is not a full pathway in place. These areas often have separate autism and ADHD pathways.
- Areas at stage 1 (and all other stages) offer diagnostic assessment for autism and ADHD for those meeting CMHT thresholds, as part of the clinical formulation. This means that for areas on stage 1, there is a group of adults for whom diagnostic assessment is relevant but who have not route to assessment within their health board.

Routes to requesting assessment in adult services

- Further guidance about the ways neurodevelopmental pathways are implemented can be found here https://nait.scot/document/childrens-neurodevelopmental-pathway-practice-framework-2024/ (children)
- https://nait.scot/document/adult-neurodevelopmental-pathways-reports-on-actions-outcomes-and-recommendations-from-pathfinder-sites-in-scotland-2023/ (adults)
- Some adult services are looking at 'Stepped Care' or flexible pathways where provision is proportionate and relevant to the individual and their needs. We will make reference to routes for adults below.

The adult context

Adult routes differ from children's pathways in a range of ways:

- 'Neurodevelopmental' only really refers to autism and ADHD in the adult context because of the skill mix and current set-up of provision. In the longer term a fuller neurodevelopmental approach will be expected.
- Universal provision is society rather than health visiting, early years establishments and schools and GIRFEC does not apply to most adults.
- Multi-disciplinary teams within mental health services usually do not include paediatricians or education professionals and have fewer Allied Health Professionals and non-medical prescribers than in children's services.
- Provision has often emerged rather than being planned and has landed in Adult Mental Health Services, where there has been a longstanding mental health and trauma informed lens but not a widespread neurodevelopmentally informed lens.
- Along with a broadening of diagnostic criteria to encompass a wider understanding of neurodivergence, intersectionality plays a part, and some groups are even more affected by late or missed diagnosis, such as females, people living in poverty, people from ethnic minority backgrounds or people identified as having mental health conditions or involved with the justice system. Although this also affects children, the impact is often even greater in adult life.

Backlog

- There has been significant historical underdiagnosis of these lifelong conditions (autism and ADHD) and the backlog lies largely with adult services.
- NAIT research found that less than 14% of those likely to have ADHD in Scotland were diagnosed in 2019 and the average age for autism diagnosis in adults is 30 years.
- Recent research outside of Scotland reported 50% of people diagnosed as adults were previously known to CAMHS (and not identified as neurodivergent during that time).
- As well as underdiagnosis, there is also an issue with a need to review people now thought to be mis-diagnosed with mental health conditions, whose needs would be better met by understanding they are autistic or ADHD.

Referral routes and Recommendations: Stepped Care

The NAIT Feasibility study in 2020 and the 2023 NAIT report on neurodevelopmental pathways provide a clear statement that CMHTs and Psychiatric services cannot and will not be the solution to meeting all of the needs for diagnostic assessment of neurodivergent people. Instead, a stepped care approach is required, with new multi-disciplinary specialist teams undertaking diagnosis and offering support and the right conversations at an earlier stage, before crisis hits. These teams should link with CMHTS and use the expertise of psychiatry and psychology services, to ensure smooth links between steps in the pathway.

- Where autism and ADHD assessment can be requested currently, the route in most areas is via the GP, to the Community Mental Health Team (CMHT). Where both are possible or likely, this usually requires two waiting lists and two pathways.
- **To resolve this, Stepped Care neurodevelopmental pathways are recommended as the route to assessment and diagnosis** for autism and ADHD in adults, along with recognition of other neurodevelopmental profiles.
    - Single condition pathways are ineffective and inefficient because co-occurrence is the norm.
    - Reliance on CMHTs, psychology and psychiatry services does not work as these services are set up with a culture and mechanisms to provide a mental health service first and foremost.
    - 70% of autistic people seeking diagnosis have previously been known to the CMHT but were not diagnosed with autism or ADHD during that contact. Practice change within CMHTs is one part of the solution and there are skilled and knowledgeable staff within these services who could work within a stepped care model.
    - Solutions suggested through consultation with service and neurodivergent people include setting up new Allied Health Professional (AHP) and nurse led diagnostic and prescribing teams within primary care, university or employment settings; Partnerships with third sector providers who can share the provision of diagnostic assessment and support.
    - Autism Initiatives longstanding partnership with NHS Lothian was an excellent example of this model, with value for money, robust and effective assessments and high levels of satisfaction from autistic people.
    - Newcastle University is an example of autism and ADHD diagnostic assessment and support being provided in the natural context of university.
    - NHS Fife Occupational Therapy and psychology and Scottish Autism used short term funding to demonstrate the value of cross-sector partnership working.
    - Group diagnosis models have been proposed but not trialled in this population.

Strategy Groups

- The NAIT recommendations included an expectation of Local Strategic Planning in relation to neurodevelopmental pathways. In the last 3 years, most local areas have a set up strategic planning group to plan to understand and meet needs of neurodivergent adults. These groups have supported some of the Tests of Change and newly funded staffing. NES and NAIT have provided a range of professional learning opportunities to support local clinical teams and future planning can now be based on better evidence.
- For example, NHS Lanarkshire set up a new adult autism team in 2024, for adults without a learning disability (building on an excellent autism and LD team model), with the strategic intention to work towards an integrated pathway.
- NHS Greater Glasgow and Clyde used ADHD waiting list initiative funding in 2023-4, to make steps forward in meeting the needs of a large number of people waiting for assessment and understanding the data, the business case and practical clinical solutions. The business case was submitted but not taken forward in 2024.

- NHS Fife also undertook innovative work to understand demand and capacity and tests of change, including AHP and Nurse practitioners as part of the team, working in partnership with existing clinical psychology providers and third sector partners. A business case was proposed but not taken forward in 2024.
- NHS Grampian have set up the Adult Autism Team, with a small number of part time staff including AHPs, Nurses and Psychologists. They work closely with the ADHD team and again have developed data driven proposals for different provision that could happen with different costs. Currently Aberdeen City and Moray HSCPs are continuing to fund the small service but no agreement has been made about developing a service with staffing to meet the demand or integration with ADHD services.

Although the required services are not in place, across Scotland there is a now a growing and larger workforce of staff and leadership and clinical levels who understand local need, who have listened to local neurodivergent people and who have the knowledge, skills and confidence to provide service developments should resource be allocated.

Assessment options

- Most provision is through a fairly medical model and a mental health lens in CMHT, with services structured to respond to the most severe presentations. Most areas undertake ADHD and autism assessment for people who meet CMHT thresholds.
- Actual routes still do not often resemble recommended routes as outlined in the following recommendations, accepted by the Scottish Government: https://nait.scot/wp-content/uploads/2025/02/Adult-Neurodevelopmental-Pathways-Pathfinder-Report-2023.pdf
- Some services provide single condition autism or ADHD assessments to those who do not meet CMHT thresholds. These are usually very well received and valued services, with staff with expert level knowledge. These services would like to (and would be able to) offer an integrated autism and ADHD service but are limited by local commissioning and planning of resources.
- Knowledge, up-to-date understanding, mindsets and attitudes to neurodivergence are changing slowly, with some areas with a strong interest and good levels of knowledge, skill and neuro-affirming mindsets.
- Even when someone meets CMHT thresholds or are in a specialist mental health team, they may be referred out of that team for autism and ADHD assessment, instead of this being part of the holistic differential diagnosis.
- Although many of these individuals could be diagnosed in a fairly straightforward manner, in a stepped care model, by a range of professionals as part of a MDT, the systems offer a one-size complex process, contributing to increased waiting lists.
- Autism and ADHD are not mental health conditions and waiting until someone who is neurodivergent reaches a stage of crisis is not a humane or efficient use of resources.
- There was a time when Mental Health practitioners took the view that diagnosis was not important because they would provide support to meet the need. Some still hold this position. However neurodivergent people have made it clear that

validation of diagnosis is therapeutic in itself, timely diagnosis is an anticipatory and preventative support, which enables people to understand themselves, meet others like them and to advocate for adjustments and supports in everyday life.

Diagnostic rates

- Routes to requesting assessment can be experienced as frustrating. Diagnostic rates are 86% meaning that most adults who think they are neurodivergent probably are and that services spending a lot of time persuading people they don't need a diagnosis, leaves people feeling let down and fails to meet basic needs to be listened to and believed.

Masking

- We now have a better understanding of masking. Many neurodivergent adults mask their difficulties and natural ways of being in order to fit in or manage stigma and shame. Masking is known to have significant negative consequences on mental health and wellbeing in the longer term for many. A very important thing we have learned is that:
  - we do not need to witness certain 'behaviours' to believe people's experiences and thinking or processing style (neurotype).
  - we need to apply the 'functional impairment' aspect of diagnostic criteria in a less literal and more person centred way. People do not need to demonstrate overt functional impairment if they are describing experiences which clearly show how hard they are working to get through everyday and to appear as though everything is fine. This requires a mindset adjustment for many mental health teams.
  - we need to establish that the experience of being neurodivergent has been present since childhood and to understand the different ways this could manifest, given our knowledge of masking and the impact of supportive or non-supportive environments on whether being neurodivergent is experienced as an impairment at all stages in life.
  - timely identification and diagnosis can reduce the risks associated with masking and support people to be their authentic selves.

Support, intervention and medical treatment

- Traditionally, the main offerings of CMHTs would be medication or psychological therapies, like Cognitive Behaviour Therapy (CBT) – which alone do not meet the needs of all neurodivergent people. Although they help some people some of the time, solely offering these misses out other support needs for everyday life.
- Psycho-education, support to the people around the neurodivergent person to understand adjustments and therapies which enable participation in everyday life could be provided with the involvement of Allied Health Professionals as part of the multi-disciplinary team but this tends not to be on offer outwith Learning Disability teams.
- Identity and Connection are the main themes emerging from literature about what works – this means having support to understand your neurotype and neurodivergent identity and support to connect with other people that have had similar life experiences.

Mental Health teams not seeing the autism and ADHD

- Around 70% of people seeking autism and ADHD assessment have been previously known to mental health services but not diagnosed (other than with mental health diagnoses).
- Although at least 35% of people with eating disorders are autistic – this does not reflect the autism diagnoses made in this population. Similar under-diagnosis occurs in forensic/ prison services, substance use, perinatal, Emotionally Unstable Personality Disorder (EUPD) and other specialist services.
- There have been some areas with adult autism assessment teams that operated outwith or parallel to the CMHT – this is problematic because the majority of staff seeing neurodivergent people everyday did not engage with seeing diagnostic assessment as part of their role. This is starting to change.
- Recent data from Public Health Scotland shows an 8 fold increase in the recognition of autistic and ADHD people in mental health in-patient settings in the last 10 years.
- In a recent conversation with a specialist psychiatrist, I asked whether they would routinely diagnose the patients attending the mental health setting with autism or ADHD if it applied. The psychiatrist said, “Absolutely” as this is best clinical practice and really helped with better support and recovery. When I asked them to say this within a training session, they said they could not because they were under criticism from colleagues, who saw this practice as ‘people jumping the waiting list’.
- Clinicians doing good work need to be confident to change outdated mindsets and practices which are contributing to long waiting lists for adults.

Thresholds for diagnosis

- Across Scotland, diagnostic thresholds to access autism and ADHD assessment remain inconsistent and, in some areas, they are being set increasingly high and preventing access to diagnostic assessment for many adults. This results in inequitable access to assessment and creates significant barriers.
- Thresholds are usually applied for access to services rather than to diagnosis itself. They are often a focus for adult mental health teams applying risk and access measures with a mental health lens. They are an applied a way of managing resources within existing models of service rather than because they best meet individual needs.
- We suggest starting with ‘what is this person’s need and how can we meet it, within a stepped care model’ as a better solution.
- Evidence would suggest that the answers to the ever increasing demand on mental health services, will not be solved by increasing thresholds but rather by providing ways to meet needs at earlier stages, through primary care AHP and nurse led teams working in partnership with third sector and with close relationships with areas of the service allocated for people with greater needs.
- In adult services, thresholds are often high because those in lead roles are in the position of protecting their staff and demands on their service which exceed their capacity.
- Referral to CMHTs is commonly required because stepped care options are not in place. CMHTs are designed to support people with severe or enduring mental

health conditions. Many autistic and ADHD adults are excluded from assessment because they do not meet these thresholds, despite clear evidence of lifelong neurodivergence.
- Gatekeeping is widespread: people are told they must show “enough impairment” or reach “crisis point” before assessment is considered. This contradicts evidence that diagnosis itself is therapeutic, preventative, and a protective factor, enabling self-understanding, workplace adjustments, and reduced escalation to crisis.
- Current thresholding practices also create inequity: those with greater advocacy skills, persistence, or financial means are more likely to obtain diagnosis, while others are left without recognition or support.

Are we over-diagnosing and over-medicating?

- There is one narrative that the needs being highlighted are not as high as is suggested and that we are over-diagnosing (and as a consequence over-medicating).
- There is no evidence that this is the case.
- Prevalence in Scotland for autism is at or below the expected international prevalence of 4%.
- Prevalence in Scotland for ADHD is less than half the expected international prevalence of 3-7%.
- It is true that around 20% of the population can identify with ADHD signs but diagnostic standards are very clear and NHS clinicians follow NICE or SIGN guidelines, which require evidence of meeting International Diagnostic Criteria (DSM 5 or ICD11). These are not met by everyone who has some characteristics also found in people with ADHD in terms of significant impact on everyday life, the range and number of presenting characteristics and that these have been present since childhood.

Lived Experience

Many neurodivergent people describe repeated experiences of not being believed, of services minimising their difficulties, or of being told that “a diagnosis won’t change anything”. This is at odds with the consistent message from autistic and ADHD communities that diagnosis is life-changing and provides essential validation and access to support.

Recommendation

- Thresholds for access to diagnostic assessment should be lowered, through the establishment of stepped care service models for adult services, with primary care and community teams working alongside CMHTs, allowing for open referral systems
- Equitable access for children and adults
- Referrals are accepted based on reasonable suspicion of neurodivergence, not on crisis presentation or mental health severity
- Workforce capacity is supported by a stepped care model, where community-based professionals (e.g., AHPs, nurses, psychologists) can lead most

assessments, with medical input when complexity requires different professional perspectives

Availability and accessibility

How long people are waiting for diagnosis and what support is available while they wait.

- **Waiting times, regional disparities, and what (if any) interim support people receive during long waits.**
- **Consider the impact of delays on individuals and families.**

Adults

- Data is not routinely collected or reported nationally. Many local areas have data they can and do share when requested. Wait times are reported in the above SPICe briefing and NAIT wait times review https://nait.scot/document/waiting-times-and-influencing-factors-in-children-and-adults-undergoing-assessment-for-autism-adhd-and-other-neurodevelopmental-differences-2025/
- Demand or need continue to rise sharply because of increased societal awareness of the benefits of identification and diagnosis for people who have for many years been misunderstood and unsupported.
- Many more people are being diagnosed than ever before, through increased NHS activity.
- Even where local areas make changes to better meet needs, these are not on the scale that would be needed for capacity to match demand. The workforce with knowledge, skills and confidence is growing but this development can be hidden by the wait times.
- The 2023 NAIT report recommends a *Stepped Care* approach, so that most neurodivergent adults should in future have their needs met and diagnosis made by AHP and nurse led teams working at a Primary Care or Community Care level. An early focus on this could be part of the immediate solution.
- Some innovative examples include diagnosis made by third sector organisations partnered with the NHS, or by health professionals based in Universities. These all take the pressure off the CMHTs who operate thresholds for access.
- A small number of areas have no wait times because they do not operate an adult autism or ADHD service.
- In other areas adult wait times are interlinked with Adult Mental Health wait times and reflect the ongoing issue that thresholds and criteria for mental health services do not match the needs of neurodivergent people as we now understand them.
- When services report wait times of over 5 years, this is an indication that resource are not allocated to the recommended stepped care model or local business case proposed.
- Private healthcare is known to increase health inequalities and in this context, it often creates more problems than it resolves. Private providers are of variable quality; they are often not integrated with local supports and networks and their use can de-skill local providers no longer building skills or leave public sector providers with less money to support the most complex patients. Our

recommendation is that the long term solution does not lie with commissioning private providers but rather with resourcing public sector providers working in partnership with third sector partners to design provision that can meet the long term needs of this population.

Environment first

Adjustments in naturally occurring physical and social environments are recommended as the first line of approach for autistic people (where medication is not usually a recommended intervention) and for people with ADHD (where medication can offer positive benefits) environmental modifications must be tried and reviewed before medication is considered.

For children and young people: e.g., nursery, school, home, family and community settings.

For adults: e.g., further and higher education, employment and home, family and community settings. It can also mean the need for adjustments in health and social care service settings, when involved with the justice system, interactions with statutory agencies, paying bills, public transport and relationships with friends and neighbours. For reference, this is stated as follows:

NICE (National Institute for Health and Care Excellence) Attention deficit hyperactivity disorder: diagnosis and management: **NG87 (2018)**

Recommendation 1.5.13:

“Offer medication for children aged 5 years and over and young people only if:

their ADHD symptoms are still causing a persistent significant impairment in at least one domain after environmental modifications have been implemented and reviewed …”

Recommendation 1.5.15:

“Offer medication to adults with ADHD if their ADHD symptoms are still causing a significant impairment … after environmental modifications have been implemented and reviewed.”

“The importance of goodness of fit of an individual to their environment is particularly

significant and environmental modifications should precede pharmacotherapy “

RCPsych (Royal College of Psychiatrists in Scotland) ADHD in Adults: Good Practice Guidelines CR235 (2023)

12.2

The revised NICE guideline is clear that environmental modifications need to be addressed first and progress to pharmacological interventions considered only if ongoing impairment in

one domain subsequent to this is present.

12.2.1.

Treatment plans should be devised collaboratively with reference to the patient's goals.

Psychological, behavioural and occupational needs should be addressed.

One example from practice was the SPARKS post-diagnostic psychoeducation group run by OTs in Fife, who received feedback from a psychiatrist about a patient who had been seeing the psychiatrist for several years. The person had tried several medications, which were not very effective and remained unwell. Following the group, they attended the psychiatrist for review and were discharged because the group had made the difference that medication could not. The person had met people with similar experiences and had learned about strategies for their own life. Instead of medication to manage the distress of being ADHD, without strategies for life, the environmental modification helped to reduce the distress at source.

Availability of post-diagnostic and longer-term support.

- **Services and resources available after a diagnosis is made**
- **How well do these services meet the ongoing needs?**

For adults a recent review of HSCP provision for autistic and ADHD adults was published by NAIT: https://nait.scot/document/review-of-post-diagnostic-support-in-health-and-social-care-partnerships-in-scotland-2024/

- Improvements are needed and these should include consideration of public sector and third sector provision and partnerships.
- The Adult Autism Support Fund is making more support available, including national and local provision for autistic adults.
- Scottish Autism are updating their Right Click programmes.
- There is less non-diagnosis specific support for adults and less support with an ADHD focus than there is for autistic adults.
- Ongoing needs can be met in some Primary Care AHP and Nurse led services, such as the Quick Team in East Lothian.
- Historically, support has been from Psychiatry and Psychological therapies, when people meet thresholds for access.
- There is a need for dedicated teams to allow access to neurodivergence focussed or environment focussed supports, such as employment support, FE and HE education supports, psycho-education that is neuro-affirming, supports to understand and advocate for communication and sensory based adjustments, peer supports and connections.

Workforce and funding challenges

- **Availability of trained professionals across health, education, and social care.**

- **Systemic resourcing issues and potential models for improvement.**

Now that we understand that 10-15% of the population are neurodivergent and that they make up at least 50% of people who access mental health services, there is a need for a much broader workforce to be confident and competent to undertake diagnostic assessment as part of routine work with neurodivergent people.

- There are insufficient posts for Speech and Language Therapists, Occupational Therapists and non-medical prescribers in adult services to meet needs both in specialist teams and in teams seeing people for brief or early support, offering drop-ins, phone-lines and information sessions to support people to understand themselves and their way of being.
- The Learning Disability, Autism and Neurodivergence (LDAN) Bill has included consideration of mandatory training which might address this point and the need for a more informed neurodevelopmentally workforce across the board.
- Mindsets are important in making best use of resource, knowledge and skills. Diagnosis can be as or more beneficial to an individual's wellbeing as medication or psychological therapy. If a practitioner knows someone well enough to undertake a block of therapy or to assess their medication need, they could have gathered sufficient evidence anyway, to make diagnosis possible. One model for improvement would be a mindset shift in Mental Health teams about diagnosis and how and when this can happen.
- Digital approaches have a role in reducing the number of face to face contacts needed for assessment and diagnosis and in providing support. Evidence suggests that support options work best when linked to an option for contact with a mentor or support professional, rather than expecting people to use self- help options alone.

Lived experience informing improvements

- **Centre the voices of autistic people, people with ADHD, families, and those who support them.**
- **Learn from examples of good practice and areas where services are working well.**

NAIT host a neurodivergent partner network and have developed co-production guidance to support local services to involve living experience https://nait.scot/document/nait-guide-to-co-production-with-neurodivergent-communities-2024/

Good examples include

Children – in children's services, neurodevelopmental includes the whole umbrella of diagnoses that can overlap and are not restricted to just autism and ADHD. Pathways are also centred on GIRFEC and identifying and meeting needs through the Team Around the Child.

1. **NDAS NHS Lanarkshire**, led by Suzanne Shields, Speech and Language Therapist – the neurodevelopmental pathway team is over 50 staff, with a great MDT representation. Following a long history of working in partnership with schools, this service has led an innovative whole school approach which improves efficiency by at least 30% and improves quality of experience. After this evidence was shared NHS Lanarkshire have provided permanent staffing for the roll out of this part of the service.
2. **NDAS Dumfries and Galloway** also have excellent multi-disciplinary working and offer an Open Referral System – which moves on from the old fashioned 'thresholds' and 'gatekeeping' focussed on keeping people out. Instead, people with the right knowledge and skills have early conversations.
3. **NHS Lothian** are currently taking a very robust, collaborative and neuro-affirming approach to redesigning their children's neurodevelopmental service across the 4 areas of Lothian, with the new service moving out of the Mental Health and into the Women and Children's directorate.
4. **The PHS Neurodevelopmental Trajectory Tool** has been used by many services, including NHS Fife to develop neurodevelopmental pathways that are fit for purpose and recognise need (demand) and capacity planning as central to effective whole systems working.

Adults

- **Greater Glasgow and Clyde ADHD wait list initiative** is an example of good practice, in which they appointed multi-disciplinary teams including non-medical prescribers. When these were hard to recruit, they were flexible in their approach to appointments and included Pharmacists as well as nurse prescribers. They rolled out OT led successful group programmes for ADHD. They made a sizeable increase in their capacity for ADHD assessment and in skills in the workforce. They were in conversation with Glasgow autism services about a more joined up approach. A business case was provided, with strong evidence of both demand and need and ways to meet that need.

1. **Grampian Adult Autism Team** (a very small AHP led team) – also has an open referral system and has worked very closely with autistic people locally to develop services fit for purpose. They have regular newsletter to those waiting and provide consultations and advice to colleagues in the CMHTs to build confidence and capacity. The team have developed a staged business case highlighting what could be done with different levels of resource with the ultimate preference being an adult neurodevelopmental pathway, where ADHD and autism can be assessed in a single process and which includes support before and after the diagnosis.

This is not an exhaustive list. Many other examples of good practice could be shared.

Conclusion

There has been a societal shift in recognition and understanding of neurodivergence in recent years, with a much broader accepted view of the range of people who are neurodivergent and of the range of ways this can impact at different stages of life

and in different contexts. There is a strong need and lots of motivation across the workforce to improve experiences of autistic people and those with ADHD, however we cannot expect to keep doing more of the same and get a different outcome. Evidence informed by and created with neurodivergent people should be at the centre of plans and decisions at all levels. The expectations we set and the data we gather going forward can influence decision making at strategic level about where to focus attention, resource and innovation.