Royal College of Psychiatrists in Scotland – the future of provision for neurodevelopmental conditions: our proposal

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Neurodevelopmental conditions

What are neurodevelopmental conditions?

Neurodevelopmental conditions (NDCs) are conditions that affect brain function and disrupt typical neurological development, leading to challenges in social, cognitive, and emotional functioning. Autism spectrum disorder (ASD) and attention-deficit/hyperactivity disorder (ADHD) are the most common examples of NDCs.

ADHD is a neurodevelopmental condition characterised by difficulties with impulsivity, maintaining attention and restlessness. This was historically considered a condition of childhood, but as the understanding of this condition has evolved, there has been an increasing awareness of ADHD in adults. ASD is another neurodevelopmental condition, characterised by deficits in social communication and the presence of restricted interests and repetitive behaviour.

Neurodevelopmental conditions significantly affect many aspects of people's lives – with major emotional, social, and health impacts and risks. It is therefore important that people with NDCs have access to prompt diagnosis and support – and in some cases medication.

It is estimated that NDCs affect 10-15% of the Scottish population.[1] However, NDCs are significantly underdiagnosed in Scotland.

Rising pressure

In recent years, there has been an unprecedented rise in referrals for neurodevelopmental condition assessment and support in Scotland. Referrals for ADHD assessment alone increased by 500%-800% across health boards between 2019 and 2021. This is driven by several factors: increased societal awareness and understanding, unmet historical needs, population growth and social change, and the impact of the COVID-19 pandemic.

However, there is currently no dedicated, national standard NDC referral, treatment or support pathway for adults in Scotland. This is leading to critical issues within the mental health sector.

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[1] Adult Neurodevelopmental Pathways: Report on Actions, Outcomes and Recommendations from Pathfinder Sites in Scotland

Without a nationally agreed pathway in place for NDCs, the rapidly rising scale of need has had a critical impact on service capacity within secondary care mental health services. This has led to unprecedented pressures in the mental health sector and lengthy waits for assessment and treatment across all health board areas in Scotland - which is posing an existential threat to the mental health system.

Impact on services and clinicians

The rising demand for NDC assessment and care is placing immense pressure on Scotland's mental health services, leading to several critical challenges:

- Mental health services are overwhelmed by the volume of referrals for NDC assessment and support.
- This has created lengthy waiting lists – extending to multiple years in some areas. At the same time, the number of people requesting assessments continues to rise, far exceeding the capacity of the staff available to provide these. Projections indicate that, without major systemic change, waiting times could exceed 10 years within the next couple of years.[2]
- The lack of dedicated pathways for NDCs means that general services are absorbing all NDC cases, significantly reducing their capacity to address other cases.
- Because NDC cases are being absorbed by general psychiatry (which is also responsible for managing acute crises and severe and high-risk mental health cases), NDC assessments and treatment are often deprioritised.

General psychiatry staff are struggling to handle the overwhelming demand for NDC assessment and support, while also managing their existing workloads. This dual burden has led to multiple major negative consequences. If staff are diverted away from managing the most severe and high-risk patients, there will ultimately be adverse outcomes. At the same time, requiring clinicians to try and meet unattainable demands leads to an inevitable sense of moral injury, burnout and departure of clinicians from psychiatry. Recent years have seen an exceptional number of psychiatrists leaving general adult psychiatry for just this reason.

Impact on mental illness

Secondary care services are designed for complex mental health conditions such as schizophrenia (which affects about 1 in 100 of the population), and bipolar disorder (which affects 2-3 in 100 of the population). These services were never designed to meet the needs of people with NDC (which affect about 1 in 10 of the population). As a result, services are being overwhelmed with referrals for NDC assessments, which could be handled more appropriately through specialised assessment and care pathways. Without structured pathways, the current

[2] https://www.bbc.co.uk/news/articles/c720r1pxrx5o

approach is fragmented and reactive, straining the system and leading to inefficiencies.

Absorbing NDC cases into general psychiatry is problematic, because NDCs are developmental conditions, not mental illnesses, and require distinct assessment and support approaches. Placing NDC cases on the same waiting lists as those for mental illnesses overwhelms services, delaying care for both groups and deprioritising urgent mental health crises. This lack of separation is unfair as:

1) Individuals with NDCs endure lengthy waits without appropriate support.

2) People with mental illnesses risk worsening outcomes due to delayed access to priority services.

Dedicated pathways for NDC are essential to ensure tailored, timely, and equitable care for all.

Impact on people with NDCs and their families

Prolonged waiting times and a lack of established NDC pathways have severe impacts on individuals waiting for assessment, treatment and care – as well as their families.

Without reasonable support, individuals with NDCs often feel isolated and misunderstood – often struggling with social, educational and workplace challenges which can hinder their development and lead to distress. Often, it is relatively straightforward, practical support that can make a huge difference to the life of someone who experiences a NDC (including their ability to work and support their family rather than relying on the state). However, before such support can be accessed, a diagnosis is usually required. The current situation where a person may have to wait years to undergo a lengthy assessment, in order to access basic support is fundamentally wrong. We need to remove as many barriers as possible between the person and the support they need (including the requirement for a formal diagnosis where possible).

The long delays people with NDCs 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.

The lack of pathways and lengthy diagnosis process is preventing people from receiving effective treatment and outcomes. For example, pharmacological treatment for ADHD is highly effective and can be transformational to people's lives.

Economic impact of undiagnosed NDCs

Undiagnosed NDCs are also having a major impact on our economy: evidence suggests that the economic burden of undiagnosed and untreated ADHD in the

UK could run into billions of pounds each year[3] – which has been concluded to be higher than the cost of diagnosing and treating these cases.[3] Loss of productivity and income, alongside increased healthcare costs of untreated symptoms are major contributing factors to this.

A separate report by the Mental Health Foundation estimated the average lifetime cost of each untreated case of ADHD to be £102,135 per case.[4] The Scottish Government's own estimate of the total value of payments for cases where ADHD has been identified as the primary or secondary condition since the launch of Adult Disability Payment in 2022 to 23 April 2024 is a staggering £31,642,840.[5]

The future of NDC provision in Scotland

The growing demand for NDC services, coupled with insufficient capacity and resources, poses a systemic risk to the sustainability of Scotland's mental health services. Without urgent action to address this, the system risks destabilisation, harming both patients and clinicians.

The National Autism Implementation Team carried out a feasibility study for an adult ADHD pathway in 2020 and published its findings in 2021.[6]

Recommendations from the 2021 report included:

Neurodevelopmental Pathways: There is a need for neurodevelopmental pathways to replace single-condition approaches, with the aim of autism and ADHD assessment and support being accessible in all 14 health board areas.

Stepped Care: There is a need to develop local stepped care pathway models, which will mean forming new teams and partnerships to meet a need not currently met, with leadership from:

1. Third sector and community services, with access to self-help, peer support, psychoeducation and a range of provision before, during and after diagnosis
2. Primary care neurodevelopmental teams, with prescribing and differential diagnosis capability as well as direct access interventions and supports
3. Secondary care neurodevelopmentally informed teams

Other recommendations:

- A neurodevelopmental approach rather than a single condition approach be taken.
- The need for a whole system, cross-sector public health approach delivering proportionate responses identified and in particular

[3] Your-Attention-Please-the-social-and-economic-impact-of-ADHD-.pdf
[4] adhd.pdf
[5] Attention Deficit Hyperactivity Disorder (ADHD) cost of payments: FOI release - gov.scot
[6] NAIT-Feasbility-Study-Report-2021-National-ADHD-Pathway.pdf

resources under the level of secondary care and within third sector specialist providers.
- The need for accountability of a pathway underpinned by a governance framework.
- The need for a competency building framework at all levels of service provision.
- The need for additional funding.

Some components of this pathway could be delivered nationally on a 'Once for Scotland' basis reflecting a stepped approach to developing the building blocks of the overarching pathway.

Our proposal

We envisage a role for national leadership and focus on the delivery of the following 4 levels. It is essential that each level is prioritised equally, to ensure that the whole system functions efficiently. Whilst our 4-level proposal addresses many of the short and medium-term issues, a long-term strategy must be implemented alongside this to address the continual increase in the need for NDC assessment and support.

Level 1: National public health approach

Develop a national public health campaign to promote awareness and understanding of neurodevelopmental conditions, emphasising self-management. Reasonable adaptations to workplaces and educational settings should be described and be made available for those who self-identify as experiencing NDC traits (without the need for a formal diagnosis).

Clear communication should be a priority to manage public expectations, especially given the rising demand for services and the need for their development.

The campaign could follow the model of the realistic medicine initiative,[7] focusing on empowering individuals through self-help, providing accessible educational resources for the public, and engaging employers and education providers to foster inclusivity and understanding.

Level 2: National self-help resources

Create a centralised, national digital platform to provide comprehensive self-help resources for individuals with neurodevelopmental conditions. This platform should include:

- Curated psychoeducation materials about NDCs.

[7] Realistic Medicine | NHS inform

- Access to pre-recorded sessions on key topics such as environmental adaptations and self-management strategies
- Access to individualised, accessible, up-to-date and relevant written or web-based information and signposting to facilitate self-support.
- Resources for employers and educational institutions.

The resources should adopt a strengths-based, non-diagnostic approach, offering practical support for anyone who self-identifies as neurodiverse. This platform would ensure equitable, wide-reaching access to valuable tools and knowledge, empowering individuals to better understand and manage their needs. These resources could be based within the existing NHS Inform platform and would require a relatively modest one-off investment in commissioning and development.

Level 3: Specialist third sector commissioning for a NDC approach

Develop a national approach to commissioning third-sector services for neurodevelopmental conditions, expanding upon the One Stop Shop model to cover a broader neurodevelopmental remit.

This approach should mirror the successful framework used in the Distress Brief Intervention (DBI) programme, focusing on:

- Standardised competency development for staff and services.
- Consistent delivery of care across regions.
- Robust outcome measurement to ensure effectiveness.

Key components of this tier should include:

- Providing support at all stages of the diagnostic journey—before, during, and after diagnosis.
- Support should also be available for those who identify as being neurodiverse, but who either do not meet diagnostic thresholds (or who do not wish to receive the diagnosis).
- Establishing and promoting peer support networks.
- Offering employability support tailored to neurodiverse individuals.
- Facilitating seamless connections with other service providers.

This model would enhance accessibility and consistency in support for neurodiverse individuals, leveraging third-sector expertise to address unmet needs.

Development and implementation of a competency framework and training resources

Development of a tiered competency-based framework that supports wider workforce development and professional learning across the health and social care sector. This could be analogous to the successful approach used in the

development of the National Trauma Training Programme[8] and aligned to a similar overarching vision of developing a neurodiversity-informed and responsive workforce. NHS Education for Scotland (NES) would be a key stakeholder in the development, provision and implementation of a range of up-to-date professional learning resources that are required to build capacity within the workforce and ensure longer term sustainability.

Level 4: Adult neurodevelopmental teams
Prioritise investment in developing Level 3 adult neurodevelopmental teams as part of expanding mental health capacity within primary care. These multidisciplinary teams would include clinicians with the ability to prescribe medication and provide differential diagnoses. They would offer direct-access interventions and support for individuals experiencing significant difficulties in daily functioning due to neurodevelopmental conditions but who do not have a co-existing mental illness requiring specialist secondary care. It is essential that these teams are multi-disciplinary - with the capacity to undertake holistic assessments which consider the entire range of possible conditions that may be present.

Key features of this approach:

- **Collaboration**: Teams would work closely with Level 1-2 services, including specialist third-sector providers, to ensure comprehensive support.
- **Flexible Delivery**: Services could be delivered at the health board level or through regional hubs using a hybrid model of in-person and virtual service delivery.

This structure would address the gap for individuals who need support but do not meet the criteria for secondary care, ensuring timely and accessible interventions.

Services provided by this proposal:
The NDC service will have the capacity to offer a range of interventions including:

- Assessment and diagnosis of ASD and ADHD
- Post-diagnostic needs assessment and care planning
- Post-diagnostic psychoeducation resources
- Supported signposting and care navigation to alternative supports and services based on need
- Environmental modifications including support with education and employment
- Specialist occupational therapy input including both one-to-one and group-based interventions where clinically indicated

[8] The National Trauma Training Programme (NTTP) |

- Safe prescribing of evidence-based pharmacological interventions for ADHD
- Management of stress and distress associated with underlying NDCs and group interventions focussed on sleep and anxiety-related difficulties
- Specialist speech and language therapy input
- Liaison, consultation and joint working with existing adult secondary care MH services
- Transition pathway for young people with ADHD and ASD transitioning to adult services

Modelling of level 4 service proposed: adult neurodevelopmental hubs

Level 4 services be provided through multidisciplinary teams based in regional hubs across the country with the potential to incorporate digital and hybrid approaches to delivering care. Experience from pilot sites such as the ADHD Waiting list initiative in NHS Greater Glasgow demonstrates the feasibility and acceptance of a digital-first approach with significant efficiency savings in delivering this through a centralised team.

These multidisciplinary teams would consist of:

- Consultant psychiatrists
- Non-medical prescribers
- Neurodevelopmental specialists- Nursing, Occupational therapy and Speech and language therapists
- Psychologists
- Social workers
- Peer support workers and health care support workers
- Relevant management and business support functions

<u>Case study: Worked example for one year of a hub</u>

Please note: this is only one proposed way of achieving our desired outcome, and by no means is the definitive/only way forward. This is simply one modelling case study.

- The adult population of Scotland, based on the 2022 Census is around 3.5 million people.
- Each NDC assessment takes an average of 4 hours.
- A whole-time equivalent role makes up 44 weeks of a year for 37 hours per week.
    - 70% of this is for direct clinical care = 25.9 hours per week
    - This time is split 40:60 between assessment and treatment capacity
    - Capacity per clinician for assessment = 10.4 hours per week

    - With a total of 457 hours per year, this equates to **114 new assessments per year.**
    - *Factoring in a 10% rate of missed appointments, this equates to 103 new assessments per year.*

Proposed composition of the hub team:

- Consultant psychiatrist 2 WTE
- Team Lead B8a 1WTE
- NMPs and ANPs B7 4 WTE
- Clinical specialists 16 WTE
- Peer support and health care support workers 8 wte
- Consultant psychologist 1 WTE
- Assistant psychologist 2 WTE
- Social workers 4 WTE
- Business support and management

This team would have the capacity to undertake around 2000 assessments per year and ongoing input to around 8000 patients.

In its initial report, NAIT estimated total demand to be around 4,500 referrals per year national for both ADHD and ASD. Extrapolating local data, post-covid, would suggest around twice that estimate- around 9,000 referrals nationally.

Cases could be stepped down to primary care after 2 years with direct access for advice and return.

Costing

A regional hub-based model for service delivery is likely to require new funding of between £9-£11 million a year depending on whether there are 3 or 4 regional hubs (each hub would cost £2.6-£2.8 million). The cost of replicating this model for each individual board is likely to be substantially higher due to the level of duplication required in each board area and is unlikely to be viable for smaller boards that already have significant workforce challenges.

These proposals ultimately act as short to medium-term solutions, which in itself will not be adequate to address the needs of people with NDC's. The total investment required across all 4 tiers is likely to be around £20 million, spread predominantly across Level's 2 & 3. There is an urgent need for national, cross-sector public health approach – with an overarching strategy to develop a sustainable model of care similar to the work undertaken in England.[9] There is also a need to invest in innovation and research if any solution is likely to be sustainable.

[9] NHS England » NHS to launch cross-sector ADHD taskforce to boost care for patients in England