

# Scrutiny Board (Adults, Health & Active Lifestyles

## Working Group Summary: Children and Adults Neurodiversity Assessments

For consideration: 11th February 2025





# Adults, Health & Active Lifestyles Scrutiny Board

## Children and Adults Neurodiversity Assessments

### Background:

Neurodiversity refers to natural variations in the different ways brains process information. The term neurodivergence describes people whose neurological development and function are different (to a greater or lesser extent) from what is considered to be 'typical'. While the understanding of this is still evolving, the neurodivergent population can be divided into sub-groups of neurodevelopmental conditions, including Attention Deficit Hyperactivity Disorder (ADHD) and autism, which are often given much focus.

Having previously explored the challenges surrounding children's neurodiversity assessments and services in Leeds back in October 2023, the Adults, Health and Active Lifestyles Scrutiny Board committed to revisiting this matter in the following municipal year. Given the challenges that adults are also facing in terms of diagnoses and treatment, the Board agreed to review the position for both children and adults.

The Scrutiny Board held a working group meeting on 25th November 2024 and considered a report by the Leeds Health and Care Partnership which gave an overview of the local position within the context of what is also happening nationally and regionally in relation to children's neurodiversity assessments (ADHD and autism) and adult ADHD and autism diagnosis and treatment services. This summary note presents the main issues arising from the working group's discussion for the consideration of the full Scrutiny Board.

**Attendees:** This working group meeting was attended by the following individuals:

### BOARD MEMBERS

Councillor Andrew Scopes (Chair)	Councillor Kevin Ritchie
Councillor David Blackburn	Councillor Emmie Bromley
Councillor Andy Rontree	Councillor Wyn Kidger
Jane Mischenko (Healthwatch Leeds Co-opted Member)	Councillor Mahalia France-Mir

Apologies: Cllrs C Anderson, L Buckley, J Gibson, C Hart-Brooke and E Taylor. Jonathan Phillips (Healthwatch Leeds Co-opted Member)

### ADDITIONAL ATTENDEES

Helen Lewis, Director of Pathway and System Integration, Leeds Health and Care Partnership (LHCP)
Dr Chris Hosker, Medical Director, Leeds and York Partnership NHS Foundation Trust (LYPFT)
Dr Mike Smith, ADHD Clinical Lead, LYPFT
Sam Prince, Executive Director of Operations/Deputy Chief Executive, Leeds Community Healthcare NHS Trust (LCH)
Sara Clarke, Head of Service, Children and Young People's Mental Health Services, LCH
Janet Addison, General Manager – Children's Business Unit, LCH

**Recommendation:** The Scrutiny Board (Adults, Health and Active Lifestyles) is asked to note the content of this summary.



# Main issues considered by the working group.

## Understanding existing demand pressures.

Members were briefed on the local position surrounding NHS diagnostic assessments for ADHD and autism in relation to children and adults and acknowledged the following headline figures:

*Children (as reported in November 2024):*

- There are 2412 children under 5 awaiting a diagnosis (There are 510 confirmed children waiting for pre-school Autism assessment) with the longest waiting 122.9 weeks. A further 1,902 children are waiting for a Paediatric Neurodisability assessment, which is the start of the assessment process – the majority of these are likely to go onto the autism waiting list.
- There are 4304 children over 5 awaiting a diagnosis (which does not include those who are on waiting list with other providers).

*Adults (as reported in November 2024):*

- The Leeds ADHD Service has a waiting list for diagnostic assessment of around 4,500 people, with the service receiving 160-170 referrals per month on average.
- Demand into the specialist Autism services is lower than into the ADHD service (around 50 per month) and current waiting times are approximately a year to commence the assessment process.

In terms of the position across the region, Members were informed that the West Yorkshire Integrated Care Board (ICB) had commissioned a deep dive into neurodiversity two years ago. The findings from this helped to inform an all-age West Yorkshire Neurodiversity Programme. The current priorities for this programme are:

- To deliver a more consistent approach to “Right to Choose” for Autism and ADHD.
- To deliver improved West Yorkshire wide data on Autism and ADHD.
- To connect places to share learning and good practice in relation to improving assessment pathways and advocate for what places need.
- To deliver specific projects in relation to Autism in Schools (AIS) and Partnership for Inclusion of Neurodiversity in Schools (PINS).
- Work together on a cross-sector approach to offer early support and reasonable adjustments based on need.
- Explore consistency in screening and triage for Autism and/ or ADHD assessment pathways.
- Explore how digital solutions could make the assessment pathway more efficient.

Unmet demand for neurodiversity diagnoses and treatment also remains a national issue. In response to the growing crisis surrounding ADHD assessments in particular, NHS England (NHSE) has established a ADHD task force to investigate the challenges and propose potential solutions. While it is hoped this will result in meaningful support or policy changes, Members were informed that no timetable was given in terms of when to expect the taskforce to report on its findings.

Members acknowledged that while the access to diagnosis issues for children and adults are different and need somewhat different service solutions, there are clear overlaps too. Where there are key themes, these have been reflected in the all-age West Yorkshire Neurodiversity Programme and have been captured as part of this summary note too.



# Main issues considered by the working group.

## The implications of “Right to Choose” for autism and ADHD.

Patients have a statutory right to choose an alternative assessment route with an alternative assessment provider who may have shorter waiting times.

With regard to children, NHS assessments for ADHD and Autism are mainly carried out by the Neurodevelopmental Assessment Team within the Child and Young People's Mental Health Service (CYPMHS) – hosted by Leeds Community Healthcare NHS Trust (LCH). However, children are also accessing private assessments or other providers via the Right to Choose route, or are transferred via the Trust to a subcontractor who is helping to ensure the highest priority children are able to be seen more quickly.

However, Members were informed that the market for this type of provision has grown very rapidly, resulting in a huge variety of provision, pricing and pathways available. It was also acknowledged that any referral made to a qualified private provider under the NHS Right to Choose is paid for by the NHS. This approach therefore still has cost implications locally and Members were advised of the significant cost pressures created by this additional market for diagnostic capacity.

To help address this, Members were informed that one of the priorities of the West Yorkshire Neurodiversity programme is to deliver a more consistent approach to “Right to Choose” for Autism and ADHD. The West Yorkshire Integrated Care Board (ICB) are collectively working on the procurement of all age neurodevelopmental services. In doing so this provides the opportunity for West Yorkshire places to adopt a harmonised approach applicable to accredited providers that will deliver additional good quality, safe and locally integrated capacity in order to achieve the most appropriate and effective autism and ADHD services for the residents of West Yorkshire. It was also highlighted that such mechanisms will help to reduce inequity in access to assessment.

Members were keen to monitor progress surrounding the West Yorkshire Neurodiversity Programme and especially in relation to this particular priority area.



# Main issues considered by the working group.

## **Managing demand for adult ADHD assessments while prioritising those at greatest risk of harm.**

With regard to NHS assessments for ADHD for adults, Members were advised that the Leeds ADHD Service, in conjunction with the Leeds Office of the West Yorkshire Integrated Care Board, identified the need to take action to address the extremely high levels of demand and an unsustainably long waiting list. The service currently has a waiting list of around 4,500 people and receives around 170 referrals per month. It is currently resourced to see and assess around 16 people per month, meaning that the number of referrals it currently receives is over 10 times the number it can realistically see. The service therefore took the decision to temporarily close to new non-urgent referrals from 11th October 2024. Members were informed that this decision was taken following an extensive review and consultation period and supported by a detailed stakeholder communication and engagement plan.

Linked to this, all GPs and other referring clinical services were asked to stop referring non-urgent patients aged over 18 to the ADHD Service at Leeds and York Partnership NHS Foundation Trust (LYPFT) from 11 October 2024 for an initial period of 3 months. While new referrals received on or after this date would not be accepted, Members were informed of the following exceptions:

- Those who have been rejected from other providers due to levels of risk,
- Those currently under acute mental health services (including crisis services) within LYPFT,
- Those from the Child and Young People's Mental Health Service transition pathway where a young person meets the threshold for adult secondary care intervention.

Members were assured that all impacted patients on the waiting list had been contacted regarding the situation and advised of their options and where they can seek further advice and support. As well as providing support information on the LYPFT website, the Trust also liaised closely with its Patient Advice and Liaison Service (PALS) in terms of responding to concerns. Members were also informed of a new partnership set up with the GP Confederation to provide access to the Trust's ADHD Care Navigators. These are trained to provide ADHD informed support and advice as to potentially 're-routing' referrals to alternative providers. It was noted that the Care Navigators were also proactively contacting patients residing in IMD1 areas in Leeds (around 1000 people as defined by GP practice) as importance was placed on ensuring that such approaches are not reinforcing any inequalities linked to deprivation or the ability to seek private options.

Members were advised that extensive and exponentially increasing waiting lists in ADHD services are now unfortunately 'standard' across the country, with other NHS services also closing to new referrals and others considering similar measures. It was explained that this local approach aims to maximise the use of limited resources to provide the highest impact care possible, specifically for complex and high risk cases, until (and if) the national ADHD task force offers practical, implementable support.

Members were advised that this approach would remain under review and that work is also underway with local health and care partners, including the Leeds GP Confederation, to develop a new vision for adult ADHD services in Leeds with the aim of meeting existing demand. The ambition is for this to be developed as a proposal with local partners by the conclusion of 2025/26.



# Main issues considered by the working group.

## Managing demand for children assessments while prioritising those at greatest risk of harm.

With regard to NHS assessments for children, Members were advised that while referrals to the Neurodevelopmental Assessment Team have not been suspended, the current waiting times still remain long. However, compared to the position that was reported to the Scrutiny Board back in October 2023, Members were informed that referral rates for NHS assessments for children in relation to ADHD and Autism appear to have slowed. It was noted that further investigations are being undertaken to help understand the current trend, which will include gathering data from other non-NHS providers in recognition that some families may be opting for a choice assessment in the hope of this route offering a shorter waiting time.

Last year the Scrutiny Board considered the workforce capacity impacts on assessment waiting times in terms of these being exacerbated by a high turnover of clinical staff skilled in delivering assessments (often head hunted by private providers of neurodiverse assessments). Vacancies were also proving hard to fill due to national shortages of key professionals such as psychologists and paediatricians. Work was therefore being undertaken at that point to explore how other key elements of the workforce, such as Advanced Clinical Practitioners (ACPs), could be maximised to help alleviate some of the pressures.

It was reported that while the pre-school (under 5) service had some staffing difficulties last year, it is now back to carrying out diagnostic assessments for 70% of children referred who are more complex and/or can be diagnosed by a sole assessor. The introduction of a sole assessor diagnosis is a new development and provided by a consultant paediatrician. The pre-school pathway also now includes two newly employed trainee ACPs (March 2024) and one qualified ACP (June 2024). This means that the diagnostic pathway has been amended with some children (up to 20%) being seen by an ACP instead of a paediatrician, enabling paediatrician appointment slots to be more efficiently used for children with more complex needs. However, it was acknowledged that the waits for a neurodiversity assessment still remain up to 3 years at longest. All children under 5 are seen and actively supported by practitioners dependent on presenting need and those who will not receive an assessment by LCH will be informed about Right to Choose options.

Members were informed that the service for school age children has a far higher volume of referrals than capacity, but the service is working with other partners to ensure those people with greatest need are seen most rapidly. This includes children known to the criminal justice system and those who are looked after. While those children with a risk factor are seen within 6-9 months, the wait for routine patients is currently up to 4 years for those who are on the CYPMHS waiting list and is longer for those who are entering the pathway through Mind Mate Single Point of Access.

It was reported that the school age pathway has had additional allocation to outsource assessments to an independent provider. This outsourcing is additional to the in-house assessments that are carried out, but Members were assured that both assessment streams have prioritised those children and young people with the most need and with risk factors including children looked after and those living in deprivation as a part of their identification.



# Main issues considered by the working group.

## **Adopting a needs-led and streamlined approach to working with schools, children and families.**

Last year, the Scrutiny Board was informed of a significant piece of work being undertaken by health and education partners in the city to define the strategy for the Neurodiversity Assessment Service for children and young people. This was focusing on a needs-based approach in recognition that whilst diagnosis of ADHD and autism is important, support and reasonable adjustment for children, young people and families should be universally available, with or without a diagnosis.

Figures reported to the working group showed there are 4304 children over 5 awaiting a diagnosis (which does not include those who are on waiting list with other providers). Of these, 2903 are still within the MindMate Spa service without a full referral work up. Importance was therefore placed on a family/carers having access to local support while waiting for a formal assessment, particularly given that the conversion rate between this list and the diagnostic service itself appears to be high. However, caution was applied in terms of interpreting these conversion rates more generally and particularly in relation to adult assessments.

Members were informed that there has been a collective move in Leeds to share and begin to develop a more joined-up way of supporting the needs of children and young people who are neurodiverse and whilst this has not removed the need for diagnostic assessment, it has begun to shift the focus to developing a needs-led offer for children who are neurodiverse. This year the preschool service has been remodelled to provide a needs-led offer alongside enhanced assessments for all children referred with suspected autism. This needs-led offer provides support and advice on things that children with autism often encounter such as communication, continence and behaviour.

It was also recognised by the Scrutiny Board last year that schools have a particular vital role in meeting the educational needs of pupils who are neurodiverse, particularly at vital stages of transition. To achieve this, schools will continue to require access to ongoing workforce support and training. Linked to this, Members were advised that systemwide work is now underway to enhance on schools understanding of neurodiversity and the role that staff within a school setting can play in meeting the needs of this group of children and young people. Several initiatives are being piloted and explored, such as testing out tools and mechanisms for building a thorough understanding of each child, whole school training on neurodiversity and participation in the 'Autism in Schools' project that has been initiated by the West Yorkshire Neurodiversity programme. System leaders are also working in partnership with the Leeds Parent Carer forum as key partners to deliver this project. Additional navigation support has also been provided by Banardos to families as part of the West Yorkshire Neurodiversity Programme, with the impact of this service being evaluated in early 2025.

Importance was also placed on working closely with the Council's Children and Families directorate to help embrace this culture shift. Members learned that a series of workshops with schools, parents and other stakeholders were being planned to help better understand how to meet the needs of children within schools without the need for a diagnostic referral. Members also recognised the value of identifying where good practice already exists within schools in order to proactively share this more broadly, particularly given Ofsted's renewed focus around inclusion and support to vulnerable learners too. In the meantime, it was noted that work will still continue in terms of making referral processes simpler and ensuring there is effective engagement with school staff in the completion of referrals so that the right information can be captured in a more simpler way too.



# Main issues considered by the working group.

## **The prescribing and monitoring of ADHD medication.**

Health care professionals within the ADHD service work across all the areas of assessment, medication pathways and follow-up and once a person has received a positive diagnosis of ADHD, some are advised to commence medication to manage their symptoms. However, it was reported that there are currently over 247 people waiting for medication to be prescribed and then carefully titrated until the correct dose is achieved. Work is therefore being undertaken to increase ADHD prescribing and medication monitoring capacity. In addition to this, Members were also informed about a programme of work looking at the evidence base for non-medication interventions for ADHD and other methods to support people and their families with needs related to neurodiversity.

## **Providing support to adults regardless of diagnostic certainty.**

Members were informed that historically, the Autism Service has had more funding and more capacity than ADHD services. As referenced earlier, the demand into the specialist Autism services is lower than into the ADHD service (around 50 per month). However, the current waiting times are still approximately one year in terms of commencing the assessment process and it can take several months to complete an assessment before obtaining a confirmed diagnosis.

Importance was therefore also placed on developing support offers for adults seeking diagnoses for autism or ADHD, particularly given the long waits for these diagnoses and the need to provide support regardless of diagnostic certainty.

With increasing numbers of autistic people being diagnosed, this will inevitably put pressure on commissioned services linked to autistic people. Members were advised that more city-wide system work is therefore needed to improve understanding, access and the ability of all services to support autistic and neurodivergent people. There are a number of working groups delivering on this, for example the Learning Disability and Autism Employment Task Group and the Neurodiversity and Transforming Community Mental Health Steering Group.

Members were informed that there is a well-established Autism Partnership Board which aims to understand the needs of the local autistic population. Influenced by lived experience, this partnership board has a good understanding of the priorities for Leeds and will be brought together in the review of the Leeds Autism Strategy, which will outline key priorities and actions. Such key areas will include employment, mental health access, health access and pre and post diagnostic support. There will also be a common theme around promoting autism acceptance, work force development, promoting reasonable adjustments and co-production.

The ICB and local authority also commission an autism advocacy provider that works to support autistic people who have little or no funded support, providing advocacy, information, drop-in sessions, autistic-led groups and post-diagnostic support. Members were informed that the ICB and local authority will continue to work with this provider and other third sector providers, to improve the outcomes of the autistic population across the health and care partnership.



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