

## Committee Decision Report

<b>Title of Report:</b>	<i>Adult Autism and ADHD</i>
<b>Date of Decision:</b>	12 <sup>th</sup> September 2024
<b>Report To:</b>	Health Scrutiny Sub Committee
<b>Report Of:</b>	<i>Sheffield Health and Social Care NHS Foundation Trust</i>
<b>Report Author:</b>	

Mark Parker - General Manager  
Adele Rowett - Head of Service  
Robert Verity - Clinical Director  
Greg Hackey - Senior Head of Service  
Holly Johnson - Clinical Psychologist  
Liz Tooke - Transformation and Delivery Manager (ICB)  
Heather Burns - Deputy Director of Mental Health Transformation, Learning Disability, Dementia and Autism and Commissioning Team (MHLDDACT) (ICB)

### Executive Summary:

The purpose of this report is to provide an overview of Sheffield Health and Social Care NHS Foundation Trusts Sheffield Autism and Neurodevelopmental Service and to define the two separate pathways for Attention Deficit Hyperactivity Disorder (ADHD) and Autism. This paper describes the waiting times for these pathways, and the work undertaken to reduce waiting time and provide support to people whilst waiting.



### **Council Plan outcomes:**

The service that is the subject of this report contributes to the wellbeing of our communities (priority 3 below)

[A place where all children belong and all young people can build a successful future](#)

[Great neighbourhoods that people are happy to call home](#)

[People live in caring, engaged communities that value diversity and support wellbeing](#)

[A creative and prosperous city full of culture, learning, and innovation](#)

[A city on the move – growing, connected and sustainable](#)

### **Committee remit:**

This report is to be considered by the Health Scrutiny Sub Committee as its remit includes:

The Adult Health and Social Care Policy Committee is responsible for the review and scrutiny of local health services under the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013. It shall establish a politically proportionate Health Scrutiny Sub-Committee, whose membership comprises members of this Committee and Education, Children and Families Policy Committee, as a standing sub-committee solely for the purpose of exercising the statutory health scrutiny functions described in Article 7 at Part 2 of this Constitution. NHS bodies and health service providers must consult the Health Scrutiny Sub-Committee on any proposals

**Does the report contain confidential or exempt information? No**

**Recommendations:**

The Health Scrutiny Sub-Committee are invited to receive and appraise this report and to support the continued programme of work to improve the experience and quality of service for autistic people and/or people with Attention Deficit Hyperactivity Disorder (ADHD).

**Background Papers:**      None

**Appendices:**            1 - Sheffield Adult Autism Neurodevelopmental Service (SAANS)

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# **Sheffield Health and Social Care NHS Foundation Trust**

## **Sheffield Adult Autism and Neurodevelopmental Service (SAANS)**

## **Background to Sheffield Adult Autism Neurodevelopmental Service (SAANS)**

For information, please note that the Autism and Attention Deficit Hyperactivity Disorder (ADHD) models are 2 distinctly different clinical pathways. However, at present both the Autism and ADHD pathways fall under the SAANS service at Sheffield Health and Social Care NHS FT (SHSC). SAANS was recommissioned in 2013 as an adult Autism diagnostic service. Autistic people who may also have a co-morbidity of ADHD were traditionally seen by SAANS for assessment and post-diagnostic support/medication (ADHD).

As well as serving Sheffield, SAANS receives national referrals on a cost per case basis. The biggest referrer outside of Sheffield is the Derby and Derbyshire Integrated Care Board (DDICB). We have recently given notice to DDICB and this contract will end on the 31<sup>st</sup> October 2024. This will enable us to focus on our local offer.

A note on terminology – while Autistic Spectrum Disorder (ASD) is the medical terminology, first-person, neuro-affirmative language is generally preferred within the autistic community so the term autistic person (rather than person with ASD) will be used in this report.

## **Service Context**

Our Sheffield Adult Autism and Neurodevelopmental Service (SAANS) is commissioned to provide diagnostic assessments and post diagnostic follow up for autism, and ADHD assessment and medication for ADHD where there is a co-occurring diagnosis of autism.

Prior to 2018 the ADHD-only pathway was delivered by our Single Point of Access team with appropriate referrals then being passed onto the Community Mental Health Teams. However, an internal restructure in 2018 transferred referrals directly to the Sheffield Adult Autism and Neurodevelopmental service. This then meant that SAANS received ADHD-only referrals in addition to autism referrals. Some additional Integrated Care Board (ICB) funding was agreed but it has been difficult to retain staff in the ADHD service.

The NICE (National Institute for Clinical Excellence) guidance for ADHD assessment requires diagnosis and medication intervention for people who are moderately to severely impacted by their symptoms. Nationally, there has been an unmanageable increase in demand for ADHD assessment and diagnosis. Consequently, large private providers (eg Psychiatry UK) are being requested by patient choice (which gives service users the legal right to choose their provider at the point of referral) and this is at great cost to the ICB.

## **Autism Service**

### **What is autism**

Autism is a lifelong developmental condition which affects how people communicate and interact with the world.

Autistic people may act in a different way to other people, Autistic people may:

- find it hard to communicate and interact with other people
- find it hard to understand how other people think or feel
- find things like bright lights or loud noises overwhelming, stressful or uncomfortable
- get anxious or upset about unfamiliar situations and social events
- take longer to understand information
- do or think the same things over and over

### **Autism pathway**

The autism service workforce model is multi-disciplinary and psychology led. The team is currently fully staffed for the commissioned clinical establishment.

The service has been successful in attaining the commissioned target for Sheffield which is 600 assessments and 1200 follow ups per annum. There has been a reduction in referrals received from Rotherham, Doncaster and Barnsley due to the introduction of their local autism provision.

The number of people on the wait list for Sheffield autism assessment as at end of July 2024 is 996 with an average wait of 65 weeks. This has halved in the last 12 months as Sheffield patients have been offered 80% of appointments. Our autism service is benchmarked nationally re NICE guidance and assessment criteria. The service is able to offer limited post diagnostic follow up as per stepped care model. Which encourages people to attend our understanding autism group as a first step before considering specialist interventions.

There has been recent investment and development to support waiting well in partnership with Voluntary Action Sheffield (VAS). The service has also recruited Peer Support Workers to provide pre- and post-diagnostic support.

### **Autism assessment process**

All referrals for autism assessment are triaged against the Diagnostic and Statistical Manual-5 (DSM-V) criteria. Information is gathered from individuals at the point of

referral via pre-assessment measures (including information about their developmental history and current difficulties). Support is offered to complete the questionnaires by Peer Support Workers and Assistant Psychologists.

Where the referral is accepted to the waiting list, signposting about voluntary sector support is included in the acceptance to waiting list letter. Where the referral is declined, rationale is explained in the referral outcome letter and recommendations provided about alternative provision.

Assessments are completed by a qualified Autism Assessment Practitioner (Clinical Psychologist, Speech and Language Therapist, Occupational Therapist). MDT discussion will occur to support diagnostic decision making. A 3-hour assessment slot and follow up is offered. Some assessments require multiple appointments with different clinicians where complex (e.g., co-occurring mental health issues or query Learning Disability).

### **How we have addressed autism assessment waiting times**

The service has worked hard to recruit and retain a fully staffed workforce model. Our Specialist Autism Assessment Practitioner posts are recruited based on the skills and experience of the individual rather than relying on recruiting from a specific professional group. This makes it easier to recruit and retain staff and provides the team with a crucial mix of skills. Job descriptions and person specifications are focused on generic skillsets which means that the team can flex to meet gaps in service provision pathways. This helps to mitigate risks of creating single points of failure during periods of staffing gaps.

We operate a one-clinician and one-appointment assessment model as standard (with provision for Multi Disciplinary Team assessment and multiple assessment appointments only for the most complex cases). This ensures we are operating efficiently while retaining compliance with national guidance. Job plans are in place and monitored to ensure we achieve commissioned targets. We have introduced a partial booking process (calling clients from the waiting list to offer options for slots 6-8 weeks in advance) which has significantly reduced the non-attendance (DNA) rate for assessment.

Improvements have been made to the triage process. Triage ensures that the team does not accept people onto the waiting list who may require a different type of service provision. This prevents people having to wait for something that they don't need and ensures that specialist clinical resource is focused on those people who will most benefit from the service. The triage process involves the completion of a detailed pre-assessment pack before the referral is accepted to the waiting list. There is a dedicated consultation mailbox whereby clinicians in other services can discuss potential referrals to ensure these are appropriate.



The service now offers a consultation assessment pathway. This means that clients accessing other SHSC services and requesting autism assessment can be assessed by their worker under supervision from SAANS. This helps to reduce the number of professionals that the person has to deal with, prevents gaps in care, reduces waiting times and decreases the number of referrals for full assessment to the SAANS team.

SAANS has developed a comprehensive offer of specialist training for teams to help them understand autism and autism-friendly ways of working. This further reduces the need for involvement of the specialist autism team and helps the autistic person to make best use of the services they are accessing.

It is acknowledged that waiting times are still long due to the level of demand. The team has worked hard to provide options for information and support while people are waiting to help keep them well.

### **Autism Assessment and Waiting well**

Waiting for a diagnosis of autism should not prevent anyone accessing appropriate support, e.g., reasonable adjustments in the workplace/healthcare. We have a dedicated mailbox for queries which is monitored by peer support workers with lived experience of autism and ADHD who can offer a range of support activities including signposting information to sources of community support and completing the autism pre assessment questionnaire.

The SAANS website includes useful info and video recordings of our 'Understanding Autism' group which people can watch while they are waiting for an assessment. Everyone accepted to the waiting list is sent information about voluntary sector partner agencies they can access while waiting, including SACMHA, Firvale Community Hub, Darnall Well-being, Disability Sheffield, Autism Plus and Percy Street. These services have received specific funding and training to work with autistic adults.

### **SAANS Post-diagnostic support for autism**

Everyone who receives a formal diagnosis of autism by the service is offered a 1 to1 follow-up and provided with information signposting to local support services. People are also offered a place on the 'Understanding Autism' psychoeducation group. This is co-facilitated by the team's Peer Support workers who have lived experience of autism and ADHD. The group offers 8 sessions (virtual/face to face/ pre-recorded videos on website) covering the following topics:

- What is Autism
- Anxiety and Autism

- Sensory issues
- Emotions
- Thinking Styles
- Socialising
- Education and Employment
- Recognising your Strengths
- Individual review on completion of group.
- Focussed and time limited specialist input available for individuals where autism is having a significant impact on functioning and mainstream services are not able to meet needs.
- Psychological intervention
- Speech and Language Therapy
- Occupational Therapy
- Peer Support Worker Interventions

## ADHD service

### What is ADHD?

Attention Deficit Hyperactivity Disorder (ADHD) is a condition that may mean that people can appear restless, have trouble concentrating and may act on impulse.

Symptoms of ADHD tend to be noticed at an early age and may become more noticeable when a child's circumstances change, such as when they start school. Most cases are diagnosed when children are under 12 years old, but sometimes it's diagnosed later in childhood. Sometimes ADHD was not recognised when someone was a child, and they are diagnosed later as an adult.

The symptoms of ADHD may improve with age, but many adults who were diagnosed with the condition at a young age continue to experience problems. People with ADHD may also have additional problems, such as sleep and anxiety disorders.

### Attention Deficit Hyperactivity Disorder referral criteria

Our acceptance criteria is based on NICE guidance:

- Presence of possible ADHD symptoms with onset in childhood

- Persistence in more than one area of life
- Evidence of moderate to severe impact on psychosocial functioning
- A requirement to be assessed by a suitably trained and qualified specialist who is able to diagnose the condition and prescribe appropriate medication

### **ADHD pathway:**

In Sheffield, the current model is such that typically a patient will present to their GP who will send a referral to SAANS for screen, triage, assessment, diagnosis and medication. Some patients may be assessed within the mental health pathway if ADHD is suspected to be part of the presenting symptoms.

In 2021 SHSC trialled a new nurse led model to address the management of the growing waiting list. Unfortunately, the model proved difficult to recruit to and subsequent training and retention issues meant that it did not have the required impact on waiting times. In the absence of appropriately trained resource, the Trust made a decision to focus a staff model of a half time Psychiatry Consultant and 1 whole time Specialty Doctor on prescribing and reviewing the medication needs of those people in receipt of a confirmed diagnosis but who were unable to access the pharmacological interventions and titration requirements that would then allow them to be safely managed through primary care.

Nationally, ADHD demand and waiting times have exponentially increased. We are working as a system to find solutions for meeting need and developing sustainable workforce models. This is in partnership with the South Yorkshire Mental Health Learning Disability and Autism Provider Collaborative. Future direction is about developing a mainstream service that is accessible and responsive. SHSC are developing all our mental health services to be inclusive of people of ADHD (akin to the green light working policy for autism and mild Learning Disabilities).

### **Data and Activity**

Demand nationally for autism and ADHD assessments has risen exponentially.

In 2018 the demand for ADHD referrals was 200 per year. Currently the demand for ADHD assessments is around 200 per month.

Numbers of people waiting as at end of July 2024;

- ADHD: Sheffield 3,616 (2250 on screening and 1,366 on wait list), national referrals 4,298 (2,361 on screening and 1,937 on wait list). 3,832 of these are DDICB service users and will be transferred at the end of October. This will greatly affect the waiting list position.

- National referrals can come as 'Right to Choose' options, or from the DDICB contract – the DDICB contract is due to end in October 2024.

Detailed data and graphs showing trends of referrals and some performance data for autism and ADHD are given in Appendix A.

### **ADHD waiting list**

Our clinical priority within the service between May 2022 and September 2024 was to address those waiting for 1st medication assessment and titration with an existing diagnosis of ADHD. This was felt to offer the best response for patient safety given the very limited clinical resource available.

The service will be offering ADHD diagnostic assessments from September 2024. A clinical structure, offer and workforce model are in development which will see an impact on our waiting list and waiting times for patients. The proposed recruitment includes a Band 7 ADHD Practitioner, Band 6 ADHD Practitioner and a Band 4 AHP Assistant. Job Descriptions are currently being developed and we aim to recruit in October 2024. This new recruitment will be in addition to the existing 1 Specialty Doctor, half time Consultant and Band 6 ADHD Practitioner within the service. The current longest wait for an ADHD assessment is around 6 years.

### **Summary of ADHD related concerns**

- Waiting list – numbers of people and time of waits.
- Capacity to assess, diagnose and start treatment if required.
- NHS financial challenges
- Previous Retention challenges
- To work with GPs in shared care arrangements. These agreements enable GPs to continue to prescribe and manage a service users' medication with the relevant support when required from the specialist provider.

### **How we are addressing ADHD waiting times**

Our plan to address ADHD waiting times and next steps within the service are;

- Reintroduction of assessment appointments. We are in the process of reviewing clinic structures for each role to be able to appropriately monitor the offer of assessments and ensure the appropriate balance of medication appointments to avoid any delays in pathway.
- Recruitment – carry out the proposed staff model to fill vacancies.

- Set up dedicated screening and triage time within clinic structures.
- Development of a pre assessment questionnaire to help assess the appropriateness of referral and avoid long waits when not necessary.
- Wait list review to ensure accuracy by enquiring whether an assessment is still required by the service user, given the length of time on the list.

## **ADHD mitigations**

### **For SHSC:**

- Carry out the plans identified to address the ADHD waiting list (outlined above).
- Reduction of waiting list for medication assessment and titration for those who have previously received an ADHD diagnosis via SHSC who have been waiting protracted lengths of time. This has been completed.
- Work on the waiting well offer and waiting list interventions.
- Mental health transformation developments will include ability to assess and diagnose people with ADHD without need for referral to specialist team. Continued upskilling of a number of SHSC staff with “UKAAN” training (National ADHD training package).
- Working alongside partners to influence system ownership of the problem of high demand and low capacity across the system.

### **For South Yorkshire partners:**

- Working alongside partners to influence system ownership of the problem of high demand and low capacity across the system. This will include collaborating within the Mental Health Learning Disability and Autism Board (which has cross organisational representation and leadership - including NHS, Local Authority and VCSE) to work with experts by experience to develop a shared vision for the wider Sheffield ADHD pathway.
- A tiered service model was proposed and presented by SHSC to Mental Health Learning Disability and Autism Board in June 2023 and was agreed in principle. The clinical model transformation programme is not at a point of progression due to the transformation programmes currently running in PCMHT and SHSC, the new ADHD assessment service has not been delegated to CMHT/PCMHT at this time.
- To work with partners to review the offer of a non- pharmacological / psychoeducation pathway to support people living with ADHD.

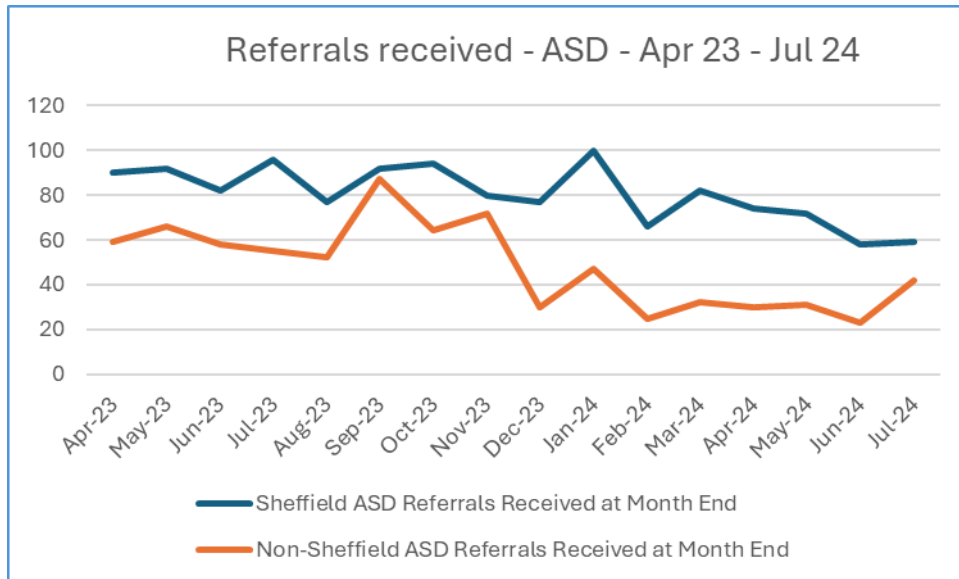
- Working in partnership with the South Yorkshire Mental Health Learning Disability and Autism Provider Collaborative to agree a shared approach to documentation and ensure appropriateness for referral.

## APPENDIX A

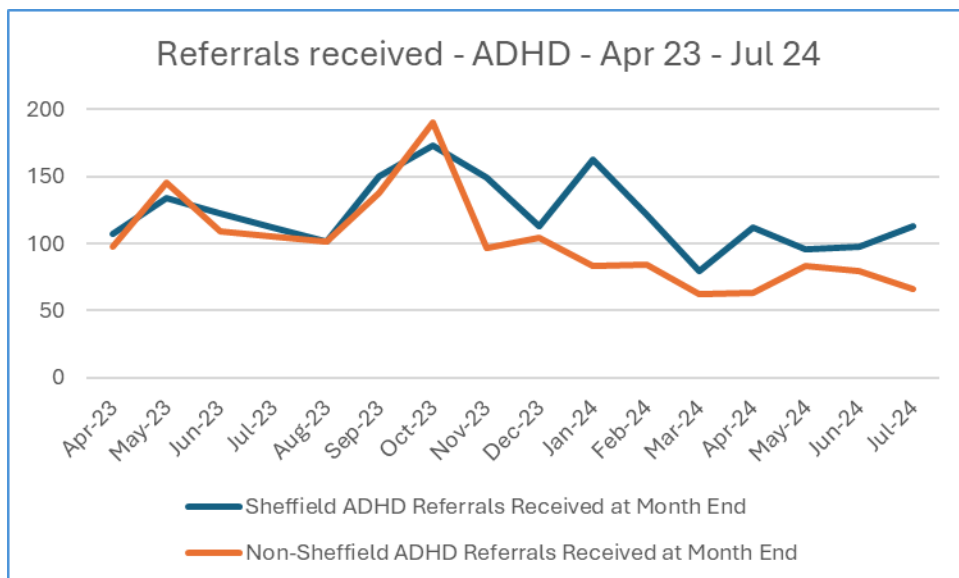
### DATA

#### Referrals

The below graph shows the number of referrals received by SAANS for an autism assessment between the period of April 2023 and July 2024.

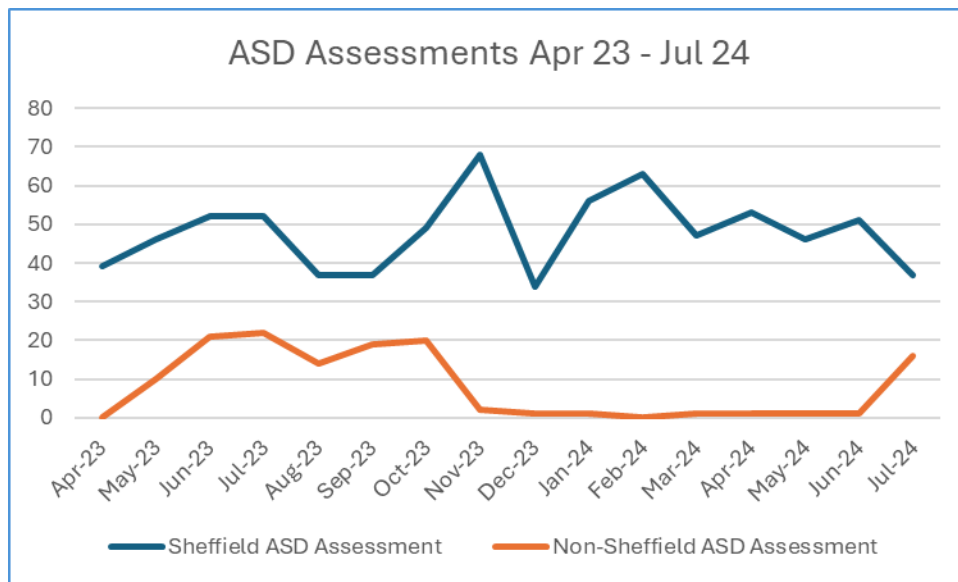


The below graph shows the number of referrals received by SAANS for an ADHD assessment between the period of April 2023 and July 2024.



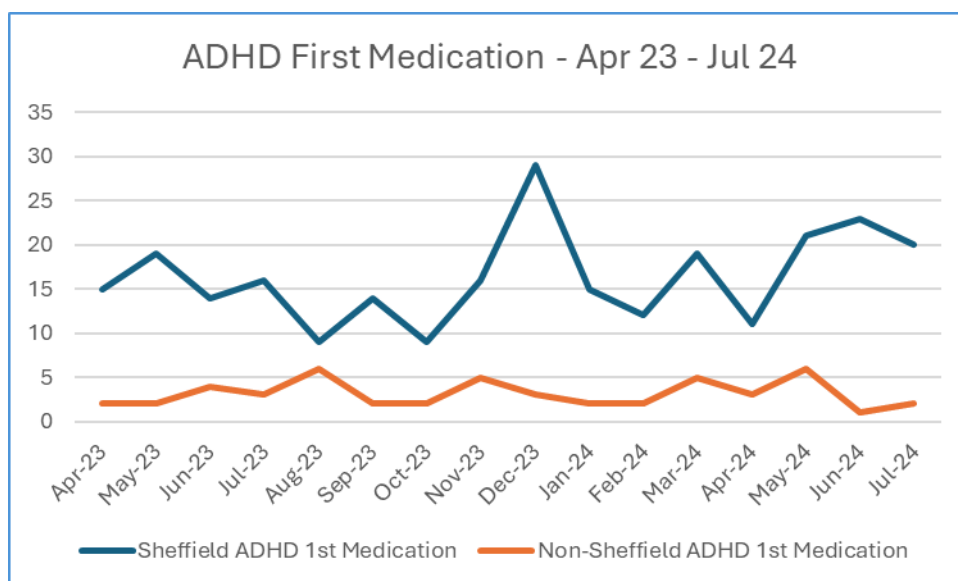
## Autism Assessments

The below graph shows the number of autism Assessments carried out between April 2023 and July 2024.



## ADHD Medication

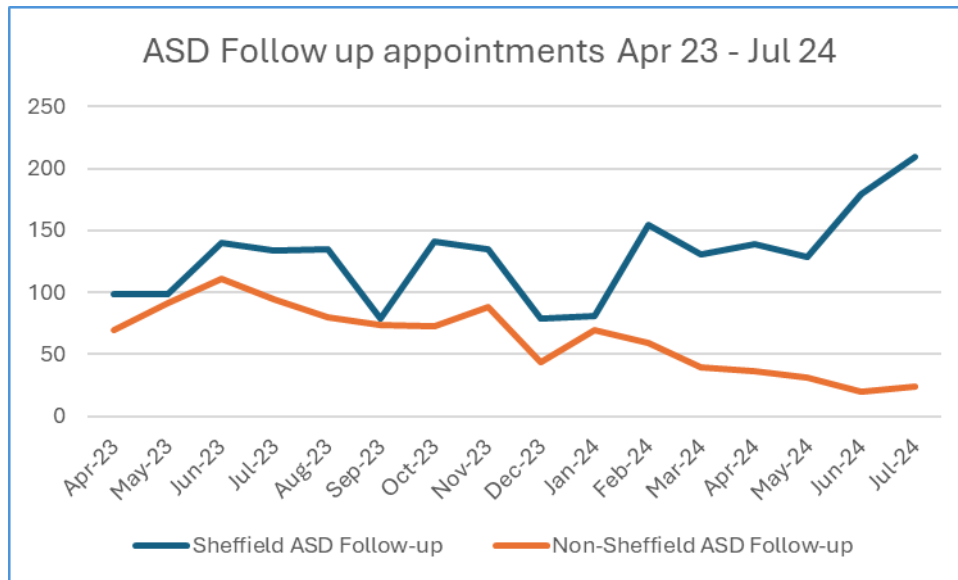
The below graph shows the number of first medication appointment carried out by the service between April 2023 and July 2024.



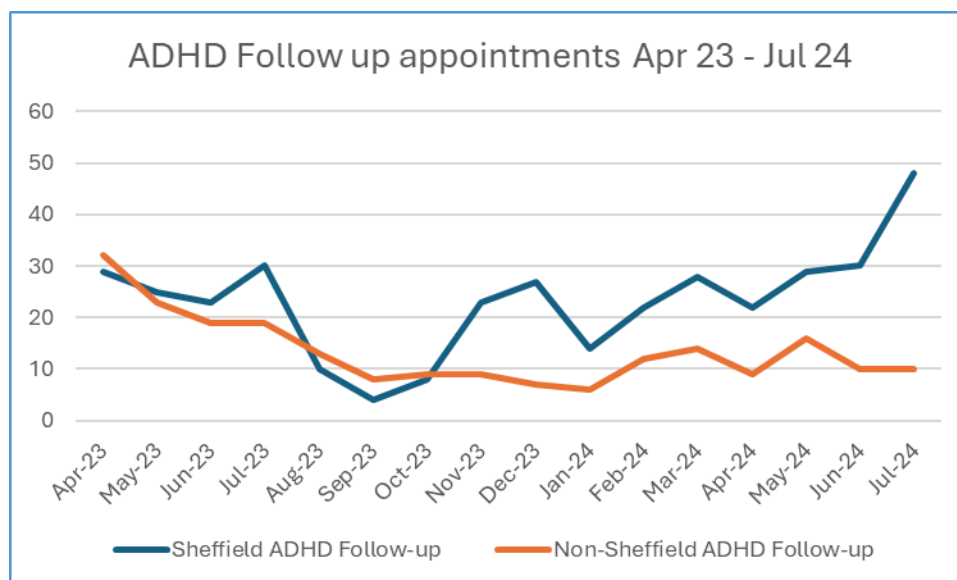


## Follow up appointments

The below graph shows the number of follow up appointments carried out for autistic people following diagnosis between April 2023 and July 2024.



The below graph shows the number of follow up appointments carried out for ADHD between April 2023 and July 2024.



### Autism Diagnosis Rate

The below graph shows the percentage of people assessed for autism that receive a diagnosis between April 2023 and July 2024. The average for this period is 80%.

