

Improving ADHD services for children and young people

Prioritising those most in need

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LARGE PRINT

What is ADHD

Attention Deficit Hyperactivity Disorder (ADHD) is a condition in children and young people that makes it hard for them to focus, sit still, and control their actions or behaviour.

ADHD is part of a group of neurodevelopmental conditions - things that affect how our brain works. Other neurodevelopmental conditions include Autism and speech and language conditions.

Neurodevelopmental conditions are not mental health conditions. Based on national figures, we estimate that there are nearly 30,000 children and young people with ADHD in Greater Manchester.

We are working to improve wider neurodevelopmental support for children and young people, focusing on ADHD and Autism. This paper and our current engagement are looking specifically at how we can improve ADHD services.

Improving ADHD services

Our vision

We want children and young people to have timely access to support that is tailored to helping them to manage their ADHD condition and symptoms, considering their needs as a whole, and not focusing on their diagnosis.

We want more children and young people to be supported early, and to make sure that medication is provided in the right circumstances, where other offers of support/intervention have not met their individual needs.

Most importantly, we want a service that prioritises those children and young people who need it most.

Current issues

From patient, family and service feedback and complaints, we know that the current ADHD service is in many places not supporting children as quickly or effectively as we would like.

The issues include:

- **No prioritisation or triage** with services offered on a first come first served basis, meaning those most in need having long waiting times that could seriously affect their overall health and wellbeing.
- **Long waiting times**, sometimes up to two years for diagnosis and treatment, which can lead to worse symptoms and cause stress for the children and their families. This is because there has been a massive increase in the number of children and young people experiencing symptoms of ADHD, including social anxiety, following the pandemic. The same growth in demand for ADHD services is being seen across the country.
- **Lack of ongoing support**, even after diagnosis, meaning that managing the condition can continue to be very challenging for children and their families.
- **Too much focus on medicine** in treatment plans, without enough consideration for other offers of therapeutic, wellbeing and social support. This can lead a reliance on the medication, problems with side effects, and the children's needs not being met.
- **Variation across Greater Manchester**, with different places having different offers of support.
- **Families turning to private providers** for faster diagnosis for their children (if they have the money), with the private providers sometimes not offering ongoing support after diagnosis, and then difficulties for GPs who may have questions about the diagnosis and recommended prescription.

We want to tackle all these issues by improving the service. Our biggest priority is tackling the lack of prioritisation, and making sure that children and young people who are most in need get help fastest.

As well as the issues for people who use the service, there are issues for teams who manage the service. There are a limited number of doctors and nurses to undertake ADHD diagnosis, and we can't recruit more. We know this because we have tried. Even if there were enough doctors and nurses out there to recruit, we still couldn't afford to recruit enough to catch up with the current waiting list. It will take years to catch up and every week more children and young people are being referred.

So, the service needs to change in order to improve.

Current service

Across many places in Greater Manchester, the current service has long waiting times and it is difficult sometimes for families to get help. Children and young people need to wait for a diagnosis in order to be able to get support.

If a parent or carer has concerns about their child, they go to their GP. If a school has concerns, they can advise the parents to seek help.

The GP then refers the child to the ADHD service (usually in the Children and Adolescent Mental Health Service (CAMHS) and they go on a first-com-first-served waiting list. If they have other needs, they may need a separate referral.

Following a potentially long wait, the child will go for diagnosis and potentially treatment, which is usually medication.

How we would like the service to work

We would like to provide quick access to support through a single service that is able to help children and young people with all their neurodevelopmental needs and prioritises those who need help most.

The service will focus on getting children and young people quicker access to support, with medication only being prescribed as a last resort for those vulnerable children whose needs are not met through other changes and offers of support.

Single point of access

We want it to be as straight forward as possible to get help, so we are bringing in a single point of access for everyone who needs help with a children or young person who may be neurodiverse, including ADHD. This single point of access will be hosted by a specialist neurodevelopmental hub in each locality.

GPs, schools and other professionals can all link into and refer to the hubs if they think a child or young person has symptoms of ADHD that they need help managing.

Locality hubs

There will be one hub in each of the 10 localities in Greater Manchester – Bolton, Bury, Manchester, Oldham, Rochdale, Salford, Stockport, Tameside, Trafford, and Wigan.

Each of the hubs will be slightly different, depending on the locality. Some may be physical buildings, whilst others might be teams of people working together digitally (remotely) or in a different way.

Each hub will have a team of specialists who will work together to support children and their families with ADHD. This may include Psychiatry, Psychology, Speech and language therapists, and others.

Tailored support

When a referral comes in, or a request is made for help, the specialists in hub will offer support based on the needs of the child or young person to help them manage their condition and ADHD symptoms. This will include advice and guidance around diet, exercise, screen time and sleep hygiene, and mental health.

If the right support is given in the right way, this will help children and families to manage the things they are struggling with and reduce symptoms.

As part of the support, the specialists in the hub may refer some children and young people who meet clinical criteria for a specialist ADHD assessment.

Prioritising those most urgent

Referrals for assessment of children and young people that meet the clinical criteria will be triaged to help us prioritise those who need help most urgently.

The triage will consider:

Severity of the symptoms, for example, severe behavioural, emotional, or educational challenges.

Increased risk of harm, for example mental health issues, self-harm risks, risk of exclusion from school, etc.

Vulnerability, for example, children in care, and safeguarding concerns, etc.

Clinical criteria

We believe that to focus the support on those who need help most, we need to introduce clinical referral criteria for NHS-funded specialist ADHD assessments. Referral criteria are very common in the NHS and help us to identify and support people who are most in need.

For children and young people who are experiencing symptoms that may be caused by ADHD, the clinical criteria for an NHS-funded specialist ADHD assessment might include:

- The symptoms severely impact on their ability to live and function daily, and/or
- The child or young person also has severe mental health conditions, and/or
- The child or young person also has co-existing physical or complex conditions.

Children with symptoms of ADHD who meet these clinical criteria will be referred by the hubs for assessment. This will happen alongside any support that they are offered to help them manage their symptoms.

Benefits

By changing children and young people's ADHD services in this way, we believe that we will be able to tackle many of the current issues, including:

- **Prioritising children and young people** who are most at risk and most urgently need help.
- **Reducing the waiting times** for people waiting for support.
- Offer a **range of ongoing and easy to access support**.
- **Reduce the use of serious medications** for treating children and young people ADHD.
- **Reduce the variation** across Greater Manchester, standardising the offer of support.
- **Reduce the need for families to turn to private providers** by providing faster access to support.

Get involved

We have worked closely with professionals from health, schools and social care, as well as families, children and young people to understand the issues with services and how to improve them.

We now want to hear from more families, parents, carers, children and young people and professionals to understand what you think about our plans.

There are several ways in which you can have your say, all options will allow you to share your thoughts and experiences, feel free to use one or more of the options:

- Complete the survey:
<https://healthierwigan.typeform.com/ChildrensADHD>
- You can join a lived experience group, there will be two groups one for parents/carers and professionals and another for children themselves. These two groups will follow the engagement process and contribute along the way (this could be for around 10/12 weeks and will involve attending lived experience meetings) Please contact gmhscp.engagement@nhs.net to register interest.
- Attend one of our focus groups, contact us or visit our website for dates: <https://gmintegratedcare.org.uk/childrens-adhd-services/>
- Contact us by email to share your thoughts/experience on gmhscp.engagement@nhs.net.
- Contact us by phone, text or Whatsapp on 07786 673762.

We look forward to hearing from you.



Greater Manchester

