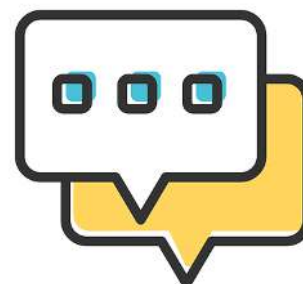


# Adult Autism and ADHD diagnostic pathway

## Involving our community and listening to their experiences



## A summary of what you told us

We are reviewing the Adult Autism and ADHD diagnostic pathway, so that it can better meet the needs of those who use it.

### Who does the service cover?

- All adults from 18 years of age
- Takes account of transition from children and young people to adult services
- It covers the identification, assessment, diagnosis of autism/ADHD and a range of support offered on receiving diagnosis
- A multi-disciplinary agency approach to provision of post diagnostic support

### Listening to our service users, their families, carers and clinicians

We have been working in partnership with adults with autism/ADHD and their families/carers on the development of a clear pathway. We have involved individuals and their families in all stages of the assessment and care planning process

### Aim of the engagement

The aim of the engagement is to:

- Work in partnership with adults with autism and ADHD and their families/carers and healthcare professionals to assess:
  - What works well
  - What could be improved
- Help inform the service specification and ensure that the service meets the needs of the local population
- Increase awareness and understanding of autism and ADHD among frontline professionals
- Develop a clear, consistent pathway for diagnosis in every area
- Improve access for adults with autism and ADHD to the services and support they need

- Enable local partners to plan and develop appropriate services for adults with autism and ADHD

Several methods were used to ensure that we were able to reach as wide a section of our population as possible including online focus groups, telephone calls, surveys and attendance at forums. We raised awareness about the engagement through our networks – including the local authority, health partners, the voluntary sector, our stakeholder newsletter, primary care newsletter, a media release, social media and websites.



The online sessions were held via Zoom and ran for 1.5 hours. We offered a range of dates and times, to ensure that people could attend over a lunchbreak, in the afternoon or early evening. These took place on 27 April 2021 at 12-2pm, 28 April 2021 2-4pm and 5 May 2021 5.30-7pm.

In addition, we held phone conversations with patients who could not access online focus groups, and sent out patient and clinical survey to those who were having an assessment and to clinicians referring in. This feedback has helped to develop the service specification for procurement.

### **What did service users, carers and their families tell us?**

Feedback suggests that the care that people are receiving once they have an adult ADHD or autism assessment is of good quality and that the service users are kept informed and updated as part of the process.

**When you get to The Retreat, they are brilliant.**

However, there are several areas that were identified as areas of improvement.

<p><b>Support while waiting for an assessment</b></p> <p>Patients who were on the current pathway identified that they would like health and wellbeing support while waiting for an assessment.</p>	<p>It was very easy to 'mask' the symptoms whilst trying to get help. If we can diagnose early it would help people, as it impacts on mental health.</p> <p>Any kind of self-help signposting for people would be helpful - such as survivors!</p>
<p><b>Peer support</b></p> <p>Within the focus groups people discussed the idea of peer support and using people with lived experience to help raise awareness and support others going through the process and living with the condition.</p>	<p>Peers or people with lived experience embedded within the primary care or otherwise, e.g. autistic people who can feed into the training or awareness raising?</p>
<p><b>Support post diagnosis</b></p> <p>Patient also highlighted that post diagnosis they often felt 'alone' and would benefit from support and advice. They made suggestions such as having a named contact, or a telephone number to call if they needed to talk to someone about their condition. Carers highlighted their concern for the future and helping the people they care for to live independently.</p>	<p>An open drop-in service could be useful, as it takes pressure off 'formal' attendance and people can come and go when they feel it's too much. It could work well and generate a lot of support which perhaps patients would feel more comfortable with rather than a formal setting</p> <p>After diagnosis there is a void! Help signpost to support groups/services</p>

<p><b>Waiting times</b></p> <p>Once people had been referred for a diagnosis, they highlighted that there is a long wait and that they would like more information about the support that is available.</p>	<p>If more services were available without the long waiting periods it will reduce the delays and provide a better service.</p>
<p><b>Training and awareness</b></p> <p>There was a general recognition that training and awareness could be increased. Suggestions such as a GP training session, autism champions or train the trainer were made. Through the survey, respondents highlighted the need for more general awareness raising across the community to make autism friendly adjustments, and to help people with ADHD and Autism fulfil their potential.</p>	<p>There is such a need for education and training in this area</p> <p>There is no specific training of staff and they are showing blatant ableism in their behaviour over support.</p>
<p><b>Rural communities</b></p> <p>As the service covers North Yorkshire and York, several people commented that it was sometimes difficult to get support in isolated communities. The move to online services via the Retreat has benefited some service users as it reduced the need to travel</p>	<p>I had assessments via zoom and was able to attend all meetings from home.</p>
<p><b>Transition services</b></p> <p>Attendees highlighted that there needed to be more support for those going through transition from child to adult services, as they often slip through the net.</p>	<p>It's difficult when moving from children's services.</p>

<p><b>Communication and joined up working</b></p> <p>Patients said they would have liked to have more information about the waiting times and what to expect as part of the referral and assessment process. Some of the people from the focus groups highlighted the need to make the information available in appropriate formats, less lengthy and no jargon. Service users would like to only tell their story once, and not lose hours repeating the same information to different health professionals.</p>	<p>Once you are referred documents you receive can be so contractual and off putting. Reduce the endless form filling.</p> <p>Hard to know where to go for help and to know what help is on offer and how to deal with the information given.</p>
<p><b>Create autism friendly environments</b></p> <p>Respondents highlighted that the environment of health institutions, such as GP surgeries were not suitable for people with Asperger's. They suggested that the needs to be 'training about the importance of personal space and not touching anyone, as this can be very painful for some people due to heightened senses'.</p>	<p>There needs to be training about the importance of personal space and not touching anyone, as this can be very painful for some people due to heightened senses</p>

## What did our clinical colleagues tell us?

A survey was produced which was aimed at GPs and healthcare professionals who refer into the service. The survey was distributed to all General Practices across Vale of York and North Yorkshire through the GP Stakeholder Newsletter.

<p><b>Criteria for referral</b></p> <p>Practitioners found the referral process forms useful in terms of screen questions, but lengthy. They also wanted patients referred before breaking point.</p>	<p>Diagnosis seems incredibly long winded and hard to achieve</p> <p>There are too many forms to complete and funding to apply for</p>
<p><b>Reduce the waiting list</b></p>	<p>More support needs to be available for patients</p>
<p><b>Ongoing support</b> to be available before and after referrals</p>	<p>Adults with autism and ADHD face multiple barriers getting mental health support as current services won't see them, they need more frequent reviews in the first year.</p>
<p><b>Support to GPs</b></p> <p>GPs wanted a direct link to the service if they have questions – such as an advice and guidance facility. Provide advice to GPs on what to do whilst patient waiting for assessment and update GPs on waiting times, advice available on mediation reviews.</p>	<p>Clinicians need education on treatment and stopping treatment and the resources to cover this.</p>
<p><b>Integrated services</b></p> <p>Clinicians suggested that there needs to be more joined up working when referring patients between services.</p>	<p>Better liaison with the community mental health team and have special therapy teams for ADHD</p>
<p><b>Expectations</b></p> <p>GPs wanted more information to send to patients about what to expect at the point of accepting the referral to manage expectations.</p>	<p>Some patients are 'underwhelmed' by the assessment, and there is difficulty in 'managing expectations'.</p>

## Next steps

The feedback received from service users, their families, carers, clinicians and support organisations will help inform the service specification as part of the procurement process of the new services.

We will ensure that those who have given their time and feedback will be kept up to date with the process, and we will produce a 'you said, we did' document to illustrate how our service users and clinician's feedback has helped to develop the pathway.

We would like to thank all those who have taken the time to be part of the engagement process and share their thoughts and personal experience.

