

Adult Autism & ADHD Assessment & Diagnostic Service Focus Group

Wednesday 28 April 2021 14.00 – 15.30pm

Staff present	
Sheila Fletcher	Commissioning Specialist, Vale of York CCG
Kate Birkett	Contracting and Commissioning Officer, North Yorkshire CCG
Victoria Binks	Head of Engagement, Vale of York CCG
Bridget Read	Engagement Manager, North Yorkshire CCG
Jane Marchant	Engagement and Administration Officer, North Yorkshire CCG
Members present:	
Jo Burrows	Supported Employment Coordinator – Scarborough Whitby & Ryedale
Paula Cooney	Happy Features Training & Development Coordinator
Dr Victoria Gray	Sessional Staff The Retreat
Kate Kennady	Lay Member NY CCG Patient & Public Involvement
Lisa Holden	Patient Rep- Health Creation Alliance

Introductions were given round the group. Sheila Fletcher gave a presentation on the Adult Autism and ADHD Assessment and Diagnostic Service to the group.

The aim of the sessions are to carry out effective engagement on the development of a clear pathway, working in partnership with adults with autism/ADHD and their families/carers.

The present provider for Adult Autism & ADHD Assessment and Diagnostic Service is The Retreat which is based in York. Currently demand is greater than service can allow – current waits 24 months. Waiting lists will be approx. 9 months by April 22.

Additional funding agreed last year, which is non recurrent funding to tackle long waits. We have a high-quality service – the satisfaction and feedback is very good.

There is now a clear commissioning intention for a new service model that would better meet the needs of service users and potentially offer better value for money.

The CCGs will continue the service with the current provider and extend the contract for a further year to 2022. The procurement of a lead provider to deliver an adult autism and ADHD assessment and diagnosis is taking place and the new contract of the will start from 1 April 2022.

Please see slides for full information.

Group Discussion:

Following the PowerPoint slides the session was opened up for group discussion.

Comment 1:

As the contract runs out March 2022 please can you tell me what the time scales are?

Response: Sheila Fletcher stated that there will be an evaluation of all the feedback gathered, drafting of a service specification. The procurement will be advertised and will be signed off by North Yorkshire CCG and the Vale of York CCG before the procurement site becomes 'live' on 7 June 2021 which will finish September 2021. The chosen tender will be awarded the contract and the service will commence on 1 April 2022.

Comment 2: An attendee commented on her own experiences whilst accessing support from Mental Health services and that she felt 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. She now has a very good rapport with her GP and is an active member of a support group promoting wellbeing and mental health.

Comment 3: Another attendee commented on how other mental health conditions can mask autism. It took her over 10 years to get diagnosed, and it was only by chance, and a new GP taking a different approach, that she was given a referral.

Once given a diagnosis, there is a lack of post diagnostic support and needs more sophisticated awareness of the issues that patients are facing. Following her diagnosis, she felt like she had no support and became very unwell. Being left with a diagnosis without support can make people feel alone and can increase suicide risks and affect other health conditions.

Response: S Fletcher replied that post diagnostic support is very important and recognised that it needs to be addressed.

Comment 4: Early detection in children presenting with Autism and ADHD was very important and the current Children's assessment doesn't go deep enough.

Group felt that there should be:

- Greater awareness from Primary Care – GP Training
- Pre-diagnostic Support
- Recognition that patients have complex needs
- There needs to be "case management"
- Dedicated named contact for patients to call on whilst waiting for diagnosis

SF stated that the Retreat does offer patients 1:1s for 2-3 sessions and 1:1s for groups having 5 sessions, and after that they would be referred back to their GP.

Comment 5: Can the public refer themselves directly into the Service?

Response: S Fletcher replied that referral is via their GP. They fill out a questionnaire related to the condition. If the person meets the criteria for referral, the rate of diagnosis is 80%.

Comment 6: When the new contract commences what will be the waiting time to get an assessment?

Response: S Fletcher replied 9 months from April 2022, advising that more work is required to reduce the waiting times. Contract monitoring is in place and the waiting times will be closely monitored.

Comment seven: Who are the Autism Champions?

Response: S Fletcher stated that they can be experienced teachers, support worker, parents and autistic adults who have specialist training (level 1 and sometimes level 2) and/or lived experience of autism in autistic children young people and adults.

Comment 8: Will there be a precedence for using patient within primary care networks to be champions to patients with Autism/ADHD? Peer or lived experience embedded within the PCN or otherwise, e.g autistic people who can feed into the training or awareness raising?

Answer: S Fletcher responded that Patient Participation Groups could also be used as well. Peer support for Mental Health is very important, and currently the City of York has a very good project which could be extended into Mental Health services.

Comment 9: One attendee remarked that she is involved in a face-to-face support group called Scarborough Survivors. She feels like she is going to these sessions to help others, rather than getting help. When giving back you are also gaining as well, which is very important and empowering.

Comment 10: Is any support currently offered or suggested eg peer support groups, while people are waiting for assessment? Any kind of self-help signposting for people would be helpful - such as survivors!

Comment 11: An open drop in service could be useful, as it takes pressure off 'formal' attendance and people can come and go - turn up when they feel able, leave 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.

Next Steps

S Fletcher reported that there is another focus group next week. There will be an evaluation of all the feedback, which will help in drafting the service specification. A report will go to North Yorkshire Clinical Commissioning Group and the Vale of York Clinical Commissioning Group which will include an engagement report. This will be shared with those who have been involved in providing their feedback.

Invitation to tender will go live from 7 June 21 and will close September 21.

Contract will be awarded and the new service commence on 1 April 2022.

S Fletcher thanked everyone for attending today and sharing their experiences.

There is a survey to find out what attendees thought of the session:

<https://www.surveymonkey.co.uk/r/autismADHD2021>

Key themes:

- Lack of post-diagnostic support
- Greater awareness from Primary Care – GP Training would help
- Pre-diagnostic support while waiting for a diagnosis
- Recognition that patients have complex needs, and that Autism can sometimes be masked by other conditions
- There needs to be a 'case management' approach
- Dedicated named contact for patients to call on whilst waiting for diagnosis
- An informal drop-in service for patients
- Signposting to support groups and offering that help while waiting for a diagnosis.
- Use peer or lived experience and embed it within PCNs e.g involve autistic people who can feed into the training or awareness raising



Vale of York
Clinical Commissioning Group



North Yorkshire
Clinical Commissioning Group