

Autism assessment services for children and young people in North Yorkshire Engagement report



July 2022

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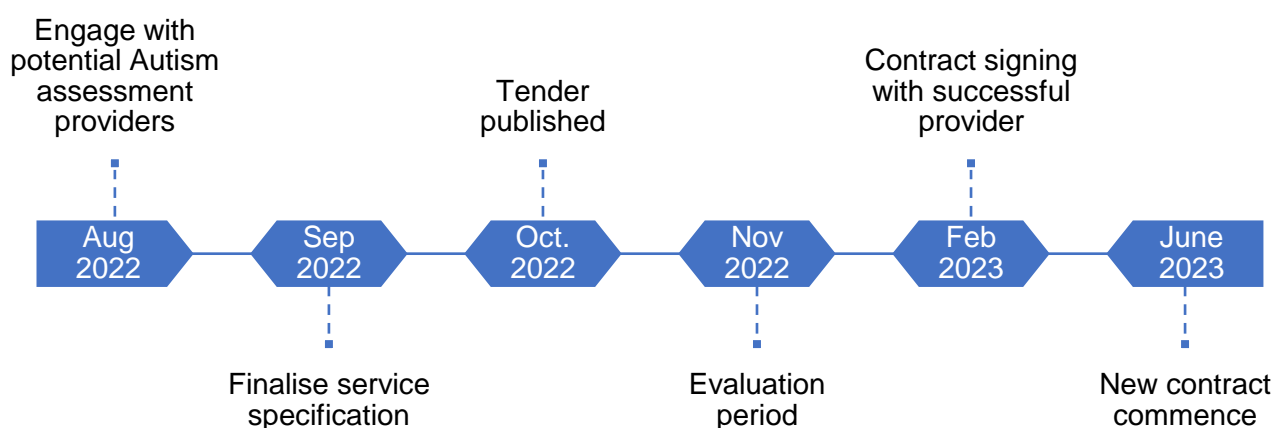
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1. Executive summary

In North Yorkshire the autism assessment service for children and young people is provided by The Retreat and NHS Harrogate and District Foundation Trust - your address will determine where you are referred. One of the contracts is due to come to an end in April 2023. As such a review of these services across the whole of North Yorkshire is taking place.

To support this review in April 2022 we launched an engagement exercise, inviting service users, parents and carers as well as health and education professional across the whole of North Yorkshire to share their feedback and experiences of the existing service. The feedback received will help inform the development of future service specification, so that it can better meet the needs of those who use it.

The existing service is provided to children and young adults from 0 – 18 years of age and covers the identification, assessment, diagnosis of autism and offers a range of support on receiving diagnosis. It is important to note, the engagement exercise focussed on the experiences of the children and young people's autism assessment service. However, the exercise allowed us to gain a greater understanding from those who shared experiences from point of referral through to assessment and diagnosis and after care.



In conducting this review we have been working in partnership with service users, their families, carers, clinicians, health care and education professionals. We used a broad range of methods to ensure we were able to reach as wide a section of our population including online focus groups, telephone calls, surveys and social media.

We received feedback on the engagement via:

- **Surveys** - 3 separate surveys were shared to service users (164), GP/Healthcare professionals (22) and Education professionals (32)
- **Focus Groups** – 3 focus groups were held, 45 registered to take part in the on-line sessions and 22 joined on the day

Key issues raised by service users:

- **Reduce waiting times for assessment**
- **Improved communication and joined up working** - parents would like to have more information about the waiting times and what to expect as part of the referral and assessment process
- **Referral process** - parents welcomed everyone being aware of the referral process in health and education and reducing the form filling
- **Support while waiting for an assessment** - a strong message from parents throughout the engagement exercise stressed the need for health and wellbeing support to be available while waiting for an assessment
- **Streamline the assessment process** - parents would like to see a holistic neurodiversity pathway that recognises the overlapping and often co-occurring nature of different neurotics
- **Support following the assessment** - parents highlighted that post diagnosis they often felt 'alone' and would benefit from support and advice.
- **Training** - Parents welcomed having the opportunity to raise the awareness of autism through this engagement exercise and called for more general awareness amongst health and education professionals

Key issues raised by GPs and healthcare professionals:

- **Referral process** – to streamline and reduce the complexity of the referral process
- **Support** – GPs and healthcare professionals would like more information to be made available to parents detailing at the point of accepting the referral to manage expectations
- **Integrated services** - It was suggested that there needs to be more joined up working when referring patients between services
- **Reduce the waiting times**

Key issues raised by education professionals:

- **Criteria for referral** – Education professionals would like clarification on the referral process and which service to refer to depending on locality – a clear referral pathway that school staff can refer to
- **Support in schools** - Additional resource to be commissioned and follow a more unified national service
- **Support is accessible and available to parents post and pre assessment**
- **Training** - Feedback recommends that all school staff are encouraged to go on Unlocking Autism course
- **Suggestions to improve the current model**

Throughout the focus groups parents who participated shared some very personal experiences and the overwhelming outcome of this exercise has highlighted the need to review the whole of the children and young people's autism pathway. Consistent messages have been received from parents, healthcare and education professionals, highlighting the need that support needs to be made available to service users both pre and post diagnosis as well as looking at ways of reducing the waiting times for accessing an autism assessment. The feedback from this exercise has echoed what was already known from previous patient experience received to the organisation.

The feedback captured gives a greater understanding from the perspective of the service users, families and carers who have accessed the service from the point of referral to assessment and diagnosis. Listening to the experiences from across the wider geography the whole pathway will help us get the service right for the future for all users and feed into broader developments in children and young people's mental health, emotional and wellbeing services as well as provide opportunities for alignment of services in the future.

2. Aim of the engagement

The aim of the engagement was to:

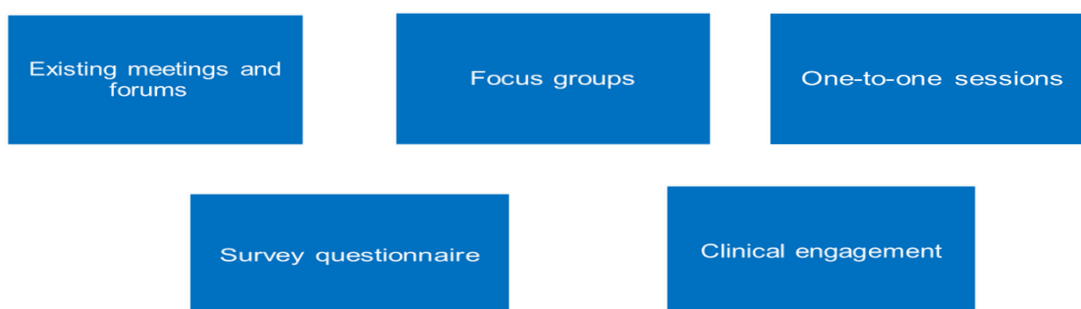
- Work in partnership and listen with service users, their families, carers, clinicians, health care and education professionals to assess:
 - what works well and to understand the positives
 - what could be improved
 - to hear any difficulties in the current assessment service
- Ensure that the voice of children and young people and their parents/carers are central
- Increase awareness and understanding of autism among frontline professionals
- To analyse the feedback from the engagement process to help inform the service specification and ensure that the service meets the needs of the local population
- To provide clear and meaningful feedback on the findings of the engagement process
- To ensure we can demonstrate that the views expressed have been considered and have resulted in improved access for children and young people to the autism assessment service to support their needs

3. Engagement methods

The engagement was launched Tuesday 6 April 2022 and closed Monday 20 May 2022.

A broad range of methods were used to ensure 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 Parent Care Voice Conference/North Yorkshire and York Autism Conference – 31 March 2022. Adapting materials and approaches for engagement as appropriate to ensure we reached our target audience.

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 focus groups were held via Zoom and ran for two hours. We offered a range of dates and times, to ensure that people could attend in the afternoon or early evening and at the weekend. These took place on:

- Wednesday 27 April 2022 at 2pm – 4pm**
 16 registered via Eventbrite, 6 members joined the event.
 Format – A PowerPoint presentation was delivered followed with an open interactive session
 Detailed feedback from this event can be found at **Appendix 1**
- Thursday 28 April 2022 at 6pm – 8pm**
 20 registered via Eventbrite, 8 members joined the event.
 Format – A PowerPoint presentation was delivered followed with an open interactive session.
 Detailed feedback from this event can be found at **Appendix 2**
- Saturday 30 April 2022 at 10am – 12pm**
 9 registered via Eventbrite, 3 members joined the event.
 Format – A PowerPoint presentation was delivered followed with an open interactive session.
 Detailed feedback from this event can be found at **Appendix 3**

4. Feedback

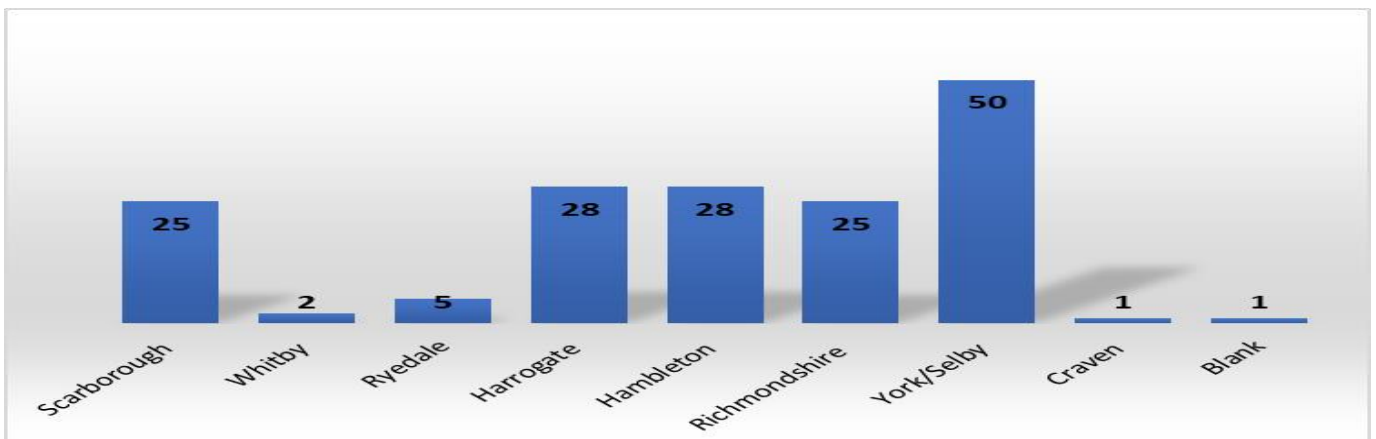
It is important to note, the engagement exercise was focussed on the children and young people's autism assessment service, however, the exercise allowed us to gain a greater understanding from parents, carers who had accessed the service from point of referral through to assessment and diagnosis. The feedback captured will help inform the future delivery of the service model going forward to best suit the needs of the local community.

4a. What did our service users tell us?

A survey was produced which was aimed at service users, parents and carers, who had accessed the service. The survey link was shared via social media, through local stakeholder newsletter, via local support groups, as well focus groups that were held. The service providers, NHS Harrogate and District Foundation Trust and The Retreat shared the survey with a random selection of service users.

164 surveys were completed – 94.51% (155) were parents, 3.66% (6) a child or young person and 1.83% (3) other.

All those completing the survey had accessed the service within the last three years – the table below show the locality of responders



15% (25) Scarborough, 2% (2) Whitby, 3% (5) Ryedale, 17% (28) Harrogate, 17% (28) Hambleton, 15% (25) Richmondshire, 30% (50) York/Selby, 0.5% (1) Craven, 0.5% (1) Blank.

Please see Appendix 4 for the full survey results

Key facts from service users - via the survey and focus groups

- 34.8% (57) responders were very dissatisfied/dissatisfied with **ease of access to referral** and 65.2% 107 responders were neutral/satisfied/very satisfied.
- When asked **what support was offered while waiting for an autism assessment** 71.60% (116) responders replied none.
- When asked **what support would have been helpful** the key themes highlighted were:
 - Access to general support – support groups, parent forums, social media, website (54)
 - Any help and advice would have been useful (30)
 - Greater awareness of the assessment process (28)
 - Directory of resources - social media, support groups, courses (30)
 - Waiting list updates (15)
- Comments received when asked **what worked well during the assessment:**
 - Welcomed the virtual assessment
 - Staff very professional, knowledgeable and caring
 - Seeing parent and child simultaneously
 - Comprehensive holistic assessment
 - Being listened to
 - It was quite stress free as school did all the background work for information for the assessment
 - It was a very calm and stressless experience for me and my child.
 - The friendliness of the staff and their ability to change the assessment to meet my child's needs at the time
 - Being able to stop if you needed a break
 - Both parent assessment and child assessment were thorough and clear.
 - Having support from multi-disciplinary teams, Occupational Therapist, Speech and Language and Paediatrician
 - It was quick once we got the assessment
- Comments received when asked **what did not work well during the assessment**
 - Nothing worked well

- Repetitive after completing a lot of forms prior I had to repeat it all again
- No follow up care after the assessment
- Unable to comment through the assessment
- Felt it was a box ticking exercise
- Having separate pathways for autism and ADHD assessment
- Discharged immediately after diagnosis
- It was very basic - very little probing for extra information
- To be offered a face to face appointment to share diagnosis
- The time that was spent doing the video assessment seemed too short, to represent the child's issues
- Waste of time and it affected the EHCP and what school could offer
- When asked **what would have made the assessment experience better** the key themes highlighted were:
 - Reduce waiting time for assessment (40)
 - Greater awareness of the assessment process (28)
 - Pre and post support available (22)
 - Integrated Service (15)
 - Parents would rather be offered face to face assessment (11)
- 41.4% (67) responders were very dissatisfied/dissatisfied at **how useful the help and advice was they were given** and 43.2% (70) responses were neutral/satisfied/very satisfied. (15.4% (25) did not comment)
- Responders were asked for any additional feedback **based on their experience of the autism assessment service not already detailed** – the feedback was consistent throughout and emphasised the need to:
 - Reduce the waiting times for assessment
 - Ensure help and support is available to families throughout
 - Integrate the service with colleagues from health and education
 - Streamline the assessment process
 - To commission pre and post diagnosis support
 - Introduce a holistic neurodiversity pathway

Feedback suggests that once patients get to the assessment the service they receive is of good quality and the staff are very helpful and supportive throughout. However, there are several areas that were identified as areas for improvements. These were consistent messages that were being received throughout the whole engagement exercise.

<p>Reduce waiting times to assessment Parents reported that once the referral is made, the waits are getting longer and no support is offered or available at that stage.</p>	<p><i>Can children be triaged and referred to other services i.e. speech and language before a diagnosis.</i></p> <p><i>To have a choice whether your assessment is face to face or virtual.</i></p> <p><i>Assessment to be local to families and in a neutral venue rather than hospital environment.</i></p>
<p>Communication and joined up Working Parents said they would like to have more information about the waiting times and what to expect as part of the referral and assessment process.</p> <p>Parents stressed the importance of Paediatricians, schools and Children and Adolescent Mental Health Services to work more closely</p>	<p><i>Information packs to be available to parents upon referral outlining what will happen.</i></p> <p><i>To have a key contact assigned who parents can call on.</i></p> <p><i>To know someone is there to help.</i></p>
<p>Referral process Parents welcomed everyone being aware of the referral process in health and education</p> <p>Some of the parents from the focus groups highlighted the need to reduce the length of the form filling and to tell their story once.</p> <p>Service providers to communicate directly with parents to know what is happening.</p>	<p><i>It would help if professionals understood the referral process and took immediate action.</i></p> <p><i>Due to the long waits, the information provided on the referral form is often out of date by the time you get to the assessment.</i></p> <p><i>Keep parents updated regularly when on the waiting list so you don't think you have been forgotten!</i></p> <p><i>GPs and health care professionals require training and understanding in the referral pathway so parents are not passed around.</i></p>
<p>Support while waiting for an assessment A strong message from parents throughout stressed the need for health and wellbeing support to be available while waiting for an assessment.</p>	<p><i>As a parent you feel lost and isolated, to know there is support and help available would be so helpful.</i></p>

<p>Survey results highlight parents feel unheard and unsupported by a vast majority of therapists.</p>	<p><i>All support services should be led by professionals and available to families at the beginning of this process.</i></p> <p><i>As a parent you are deemed to know everything, you need the professional support.</i></p> <p><i>To be provided with a list of support services and how to access whilst waiting for assessment.</i></p>
<p>Streamline the assessment process Parents would like to see a holistic neurodiversity pathway that recognises the overlapping and often co-occurring nature of different neurotics</p> <p>Parents asked for guidance to outline their role during the assessment, so the assessor can see the qualities the parent believes makes their child autistic.</p>	<p><i>The assessments need to be comprehensive - school involvement, parents/carers input and streamlined, to ensure the child health care needs are met.</i></p> <p><i>To reduce the complexity of trying to manage multiple referrals and pathways, waiting lists etc in order to get the right and most appropriate diagnoses for a child.</i></p> <p><i>ADHD and autism to be part of the same assessment.</i></p>
<p>Support following the assessment Parents highlighted that post diagnosis they often felt 'alone' and would benefit from support and advice. This is when the signposting and help is required rather than been left.</p> <p>Some members of the focus group suggested following diagnosis the healthcare professionals liaised with SENCO to develop a plan.</p> <p>Parents welcomed speaking to other parents and sharing experiences.</p>	<p><i>After the diagnosis you receive a sheet with support groups on and that is it, you are then discharged.</i></p> <p><i>What support is available to those who come out with no diagnosis?</i></p> <p><i>It feels very much that it's assessment and parents are left to get on with it.</i></p> <p><i>It's a massive life changing thing to hear or to have confirmed your thoughts about your child being autistic, but to hear you are being discharged in the same phone call is difficult.</i></p> <p><i>The team were so friendly and welcoming but afterwards it feels isolating and abandoned as you feel grief as a parent</i></p>

	<i>and your child does not want to be autistic which make things difficult.</i>
<p>Training Parents welcomed having the opportunity to raise the awareness of autism through this engagement exercise and called for more general awareness amongst health and education.</p> <p>Specific training to be available in the school session, for teachers to understand how best to manage behaviours and using a consistent approach to support children</p>	<p><i>Some healthcare staff have a lack of understanding of how to manage children with a learning disability and/or autism.</i></p> <p><i>Difficulty in accessing hospital services e.g. A&E departments and phlebotomy due to unsuitable waiting areas and lack of flagging that children have ASD.</i></p> <p><i>To have early intervention before a crisis occurs.</i></p>

4b. What did our clinical colleagues tell us?

A survey was produced which was aimed at GPs and healthcare professionals who refer into the service asking for feedback on their own experiences of referring and how the process could be improved. The survey was distributed to all general practices across North Yorkshire, through the Primary Care Newsletter and via colleagues working in NHS Harrogate and District Foundation Trust.

Please see Appendix 5 for the full survey results

27 surveys were completed – 63% (17) GPs, 25.9% (7) Healthcare professionals and 11.1% (3) other. Responses were received from each of the localities within North Yorkshire.

Key facts from survey:

- 81.5% (22) of responders knew where to refer a child or young person for an autism assessment
- 51.8% (14) were very dissatisfied/dissatisfied **with the overall referral process**, 29.6% (8) Satisfied/very satisfied and 18.5% (5) neutral

<p>Referral process Feedback suggests that the referral process needs to be streamlined and complexity reduced</p>	<p><i>There is too much conflicting advice and clinicians are stuck in the middle and children are losing ground socially and academically.</i></p> <p><i>One system – A mixed picture of ADHD and autism traits can often end up getting bounced between services.</i></p>
<p>Support GPs wanted more information to be made available to parents detailing at the point of</p>	<p><i>Keep the family updated throughout and have access to professional support.</i></p>

accepting the referral to manage expectations.	
Integrated services It was suggested that there needs to be more joined up working when referring patients between services	<i>Single point of access for neuro developmental conditions in general.</i> <i>Improve communication with all health and education teams involved in care of child or young person.</i>
Reduce the waiting times	<i>Triage children in terms of need or academic year at school.</i> <i>Post and pre autism assessment support to be available.</i>
Suggestions to improve the referral process	<i>Online portal for parents to do their own screening questionnaires with signposting to early help or third sector support.</i> <i>System to allow for a second opinion even if the initial assessment missed a lot of relevant information.</i> <i>More information available on 'type' of autism and ways in which living with autism affects their child individually.</i> <i>Melatonin prescribing service commissioned.</i>

4c. What did we hear from education professionals?

A survey was produced aimed at education professionals who refer into the service, asking for feedback on the process of referring and their awareness of what help and advice is available to service users. The survey was distributed to all schools across North Yorkshire via North Yorkshire County Council.

32 surveys were completed – 61.2% (19) SENDCo or SENCO (Special Educational Needs Coordinator), 19.4% (6) Teachers, 19.4% (6) other (Safeguarding/Headteacher/Family Support Manager
Responses were received from, Hambleton, Harrogate, Richmondshire, Ryedale, Scarborough and York.

Please see Appendix 6 for the full survey results

Key facts from survey:

- 77.42% (24) of responders knew where to refer a child or young person for an autism assessment – 22.58% (7) unsure/did not know
- When asked about the overall referring process the results showed:

- 44.83% (13) Very dissatisfied/Dissatisfied
- 34.48% (10) Neutral
- 10.69% (6) Satisfied/Very satisfied

<p>Criteria for referral Teachers would like clarification on the referral process and which service to refer to depending on locality</p> <p>Clear pathway that school staff can make referrals to</p>	<p><i>There needs to be a directory of where to refer children as it is not always apparent which CCG their GP's surgery is in.</i></p> <p><i>Assessment will be declined if young person has a learning disability. In our experience young people can have both a learning disability and autism.</i></p>
<p>Support in schools Feedback suggests that the referral process needs to be streamlined</p> <p>Additional resource to be commissioned and follow a more unified national service</p>	<p><i>While the application is quite short and easily completed, once this has been sent in, the length of time parents wait for further support and assessment is disappointing.</i></p> <p><i>Need to ensure those completing the referrals in schools are trained and experienced to complete.</i></p>
<p>Support is accessible and available to parents post and pre assessment</p>	<p><i>Support parents so that they understand the process, parents feel lost waiting for advice.</i></p> <p><i>Communication to parents needs to be clear and understood and not to use acronyms to describe needs.</i></p>
<p>Training Feedback from teachers recommends that all school staff are encouraged to go on Unlocking Autism course, the course offers useful strategies and the professionals on the course are very knowledgeable.</p>	<p><i>To have a greater awareness of what support services are available so you are able to signpost families.</i></p>
<p>Suggestions to improve the current model</p>	<p><i>A faster diagnosis process and better liaison between all professionals. Sharing referral forms electronically.</i></p>

5. Next steps

We will ensure that those who have given their time and feedback are kept up to date with the engagement process, reports will be shared and we will produce a 'you said, we did' document to illustrate how feedback from our service users, clinicians and colleagues from education has helped to develop the service.

The feedback received from service users, their families, carers, clinicians, healthcare professionals and teachers will be used to help inform the development of future services, so that it can better meet the needs of those who use it.

We would like to thank all those who have taken the time to be part of the

engagement process and shared their thoughts and personal experiences which has allowed us to reach this point.

Appendix 1 Have your say! Children and Young Peoples Autism Assessment Service

Wednesday 27 April 2022

Staff present:	
Suzanne Bennett	Head of Childrens and Young Peoples Services, North Yorkshire CCG
Jacob Gilson	Children & Young Peoples Neurodevelopmental Transformation Project Manager, North Yorkshire CCG
Bridget Read	Engagement Manager, North Yorkshire CCG
Georgina Sayers	Communications and Engagement Manager, North Yorkshire CCG
Alex Flowers	Communications and Engagement Officer, North Yorkshire CCG
Jane Marchant	Engagement and Administration Officer, North Yorkshire CCG
Members present:	
<p>A total of 16 registrations were received via Eventbrite to attend this session. Six patient representatives joined the virtual session held via Zoom.</p> <p>Members who were not able to attend but had expressed an interest in attending, the patient survey was shared giving them the opportunity to share their experience and feedback.</p>	

A presentation was delivered by Bridget Read and Jacob Gilson giving an overview to the session, outlining the aim of the session to carry out effective engagement to help shape the autism assessment service for children and young people in North Yorkshire.

The session was described as being interactive giving everyone the opportunity to share their experiences and also allowing members to share their views anonymously via Mentimeter, an on-line polling which allows you to see the results in real time.

The present autism assessment service for children and young people is delivered by The Retreat and NHS Harrogate and District Foundation Trust. Your address will determine where you are referred.

The challenges the service is faced with were outlined:

- Demand is high for the service
- Waiting lists increasing
- Cases are more complex
- Different models across North Yorkshire

The contract with The Retreat comes to an end March 2023, so there is an opportunity to reach out to service users, parents and carers to gather feedback to help inform the

development of a new service model based on what we are hearing and what best meets the needs of service users.

Following the presentation, the session focussed on an open conversation with the participants. The questions asked to gather individual experiences were:

1. **How did the referral process work for you?**
2. **How would you rate your experience of the autism assessment?**
3. **Overall, how would you rate the help and advice available following the autism assessment?**
4. **What do you think a new service could look like?**

The feedback received:

1. How did the referral process work for you?

Comment 1: The whole experience was very poor, initially referred in 2018, then the process changed, and funding removed. Had no communications throughout. Oct 21 contacted The Retreat to find out what was happening, finally had assessment Nov 21.

Comment 2: Had two experiences at referral stage – one child is on the waiting list but went private with my other child, felt I had no choice, past around from Children and Adolescent Mental Health Service (CAMHS), School and GP. The communication is very poor between healthcare staff and to patients.

Comments 3: Receive no support whilst waiting – there is an awful lot of assumed knowledge – people assume you as parents have the information and know what to do. Massive learning curve for parents/carers whilst on waiting list.

Comment 4: The system is not working for families, the service needs to work closely with schools and education, it is too complex.

Comment 5: Would like to have received acknowledgment that the referral has been received.

Comment 6: The system seems to be overstretched, need to see shorter waiting time.

Comments 7: The schools are failing the children – education and health need to speak to each other.

Comments 8: As a parent feel so isolated no help or support is provided to the family.

Comment 9: Healthcare professionals to have a greater awareness of the services available and you are referred to the right service.

Comment 10: After waiting a year, message to say referral declined because of global delay, entitled to a full assessment but not getting the opportunity to have one.

2. How would you rate your experience of the autism assessment?

Comment 11: The assessment was face to face at Harrogate Hospital and it went well, not given anything useful, it outlined our child had more complex issues. CAMHS very useful.

Comment 12: Had to travel from Scarborough to York for assessment, the assessment did not include a visit to the school environment.

Comment 13: Had a two-hour phone call with a clinical psychologist, a lot of the answers were misinterpreted, nothing matched the assessment and relied on information that was two years old, and it took 14 weeks to get the results.

Comment 14: Difference in assessments – The Retreat does them virtual and HDFT does them face to face.

Comment 15: I cannot see how the online assessments will work.

SB replied: The online assessment came about because of COVID. All face-to-face assessments could not take place, but the organisation wanted the service to continue, so we implemented the virtual assessment. Feedback suggests that it is working well.

Comment 16: We had an online assessment and the process worked ok.

Comment 17: It would be helpful if the assessment process for autism and ADHD ran alongside each other, rather than having to be re-referred for ADHD.

Comment 18: Parents need to be kept informed throughout the assessment process.

Comment 19: The paperwork is too complicated and too long for families to complete. More support should be available.

Comment 20: Why does the assessment have to be done in a hospital – It would be wonderful if this could take place in a more neutral environment, especially as there is no specialist equipment required, like a church hall.

Comments 21: At the assessment I would like to see guidance available for parents and carers to show what our role should be – I want to show my child's qualities which I believe make them autistic, so do I step back from telling them to "sit on the chair properly or you'll fall" because I know they have problems with proprioception or do I let them wobble off, to show the assessor what is really happening?

Comment 22: As part of the assessment, you are asked to have a conversation with your child and be "marked" on it, this is not only intimidating but very hard for both parent and child. Having some prompts or aids would be helpful.

3. Overall, how would you rate the help and advice available following the autism assessment?

Comment 23: After the assessment parents are given a contact list of who to contact – four/five bullet points and that was the final closure with The Retreat, no further contact.

Comment 24: Following the assessment, CAMHS gave us parent training, which was very helpful felt stronger with the advice given. Need to manage expectations when you get the diagnosis.

Comment 25: There is no help and advice available after diagnosis.

Comment 26: It would be helpful for parents to have a clear understanding of what to expect throughout the whole process and to understand what each healthcare professionals/education can do. A clear guide so you know what will happen from referral point and what to do after diagnosis.

What do you think a new service could look like?

Local assessment opportunities. Visits to school setting to help with gathering evidence. Better communication between The Retreat and the patients.

Being listened to, kept informed throughout the assessment process.

Ensuring evidence is up to date. Knowing what happens after assessments whether a diagnosis or not.

Face to face contact with children and young person and ALL the people who are involved in the assessment process/decision making.

Linked with education system better to keep school informed. Better support for parents and children whilst waiting. Identifying issues i.e. violence that needs immediate support. Shorter waiting times.

Joined up working – The Retreat suggested ADHA assessment for my son but that wasn't done alongside the autism assessment so we now have to find out how to get an ADHD assessment.

Better communications to manage expectations and to explain the process upfront.

A greater understanding of the whole process so parents and child know what to expect from the assessment.

Better age related tailored support for young people after diagnosis.

Support for the whole family.

We need a service to provide diagnosis and to offer support whilst waiting and follow up support after diagnosis.

Next steps: The feedback gathered will help shape the autism assessment service for children and young people in North Yorkshire.

CCG colleagues thanked everyone for coming and participating in the meeting.

Key themes:

- Improve communications from point of referral throughout the whole process
- Keep families informed of what is happening
- Support to be available to parents from point of referral through to assessment and after diagnosis
- Reduce the waiting times
- Reduce the lengthy form filling and make it clear and accessible

- Health and education to be more joined up
- Assessment to be local to families and reduce travel
- To have a choice whether your assessment is face to face or virtual
- Clear guidance available to parents so they know what to expect through the whole journey
- Services to be more accessible for parents – parents to have a contact number to call
- Assessment to take place in neutral venue rather than hospital environment
- Guidance for parents to outline their role during the assessment so the assessor can see the qualities the parent believes make the child autistic.
- A directory of support groups to be available - Families who have just received a diagnosis to be signposted to NYCC as parental autism courses now available

Follow up support:

Members were advised at the start of this session, that we were not able to address individual concerns or issues, but we would pick them up outside of this forum. One participant's details were shared with colleagues from the Children and Young Peoples team for further help and advice.

Feedback from each event:

To ensure the events delivered are helpful to those taking part, we ask participants to provide us with their feedback. An example of the comments received:

Thank you for the opportunity to share our experience of autism services in North Yorkshire. I am happy to discuss further any of the issues I raised as I feel it is important to learn from those who have been through the whole process.

The pace was about right, and there was plenty of opportunity to talk. The host wasn't guarded in their responses at the time. It came over as an open and honest platform for discussion.

Appendix 2

Have your say! Children and young peoples autism assessment service

Thursday 28 April 2022

Staff present:	
Suzanne Bennett	Head of Childrens and Young Peoples Services, North Yorkshire CCG
Jacob Gilson	Children & Young Peoples Neurodevelopmental Transformation Project Manager, North Yorkshire CCG
Bridget Read	Engagement Manager, North Yorkshire CCG
Rachael Durrett	Head of Communications and Engagement, North Yorkshire CCG

Alex Flowers	Communications and Engagement Officer, North Yorkshire CCG
Jane Marchant	Engagement and Administration Officer, North Yorkshire CCG
Susan De Val	Commissioning Manager, Vale of York CCG
Members present:	
<p>A total of 20 registrations were received via Eventbrite to attend this session. Eight members joined the virtual session held via Zoom.</p> <p>Members who were not able to attend but had expressed an interest in attending, the patient survey was shared giving them the opportunity to share their experience and feedback.</p>	

A presentation was delivered by Bridget Read and Jacob Gilson giving an overview to the session, outlining the aim of the session to carry out effective engagement to help shape the autism assessment service for children and young people in North Yorkshire.

The session was described as being interactive giving everyone the opportunity to share their experiences and also allowing members to share their views anonymously via Mentimeter, an on-line polling which allows you to see the results in real time.

The present autism assessment service for children and young people is delivered by The Retreat and NHS Harrogate and District Foundation Trust. Your address will determine where you are referred.

The challenges the service is faced with were outlined:

- Demand is high for the service
- Waiting lists increasing
- Cases are more complex
- Different models across North Yorkshire

The contract with The Retreat comes to an end March 2023, so there is an opportunity to reach out to service users, parents and carers to gather feedback to help inform the development of a new service model based on what we are hearing and what best meets the needs of service users.

Following the presentation the session focussed on an open conversation with the participants. The questions asked to gather individual experiences were:

1. How did the referral process work for you?
2. How would you rate your experience of the autism assessment?
3. Overall, how would you rate the help and advice available following the autism assessment?
4. What do you think a new service could look like?

The feedback received:

1. How did the referral process work for you?

Comment 1: The referral process is far too long, had a poor experience. Special Education Needs Coordinator was not keen to progress the referral whilst child at primary. It took for the GP to refer to Paediatrics.

Comment 2: Such a complicated pathway – the GP did not know what to do and where to go, School Health, SENCO, back and forth.

Comment 3: Lengthy waits with repeated knock backs from different services. Paediatrics and CAMHS need to work more closely and make the system seamless for families.

Comment 4: GP had no idea what to do, advised to go to the school SENCO team.

Comments 5: This is a critical time in child years and to have to wait so long without support is very difficult and frustrating for all.

2.How would you rate your experience of the autism assessment?"

Comment 6: Taken two years to get a diagnosis, but no signposting to support networks.

Comment 7: To have a multidisciplinary team involved in the assessment process would be helpful.

Comment 8: As part of the assessment completed the questionnaire, spoke on the phone to speech and language staff, requested to send videos, never been seen face to face.

Comments 9: The experience of speaking to professionals is good, I am confident with the professionals, but we need a child centred approach, the assessment process is alienating. We need to reframe people's perspective.

Comment 10: Once we got the assessment, a good experience.

Comment 11: Why are ADHD and Autism Spectrum Condition (ASC) assessment not undertaken at the same time, these need to be streamlined.

Comment 12: What about children who can't access mainstream school - there is little provision out there.

3.Overall, how would you rate the help and advice available following the autism assessment?

Comment 13: Pre-assessment and post diagnostic support is missing.

Comment 14: Communication hub accessed via North Yorkshire County Council needs to be more accessible and parents made aware.

Comment 15: Parents left to source own self-help groups themselves.

Comment 16: Unlocking autism (a training programme) is available but not accessible if English is not your first language.

Comment 17: Received additional support from Harrogate and District Foundation Trust Team which has helped to keep child in school.

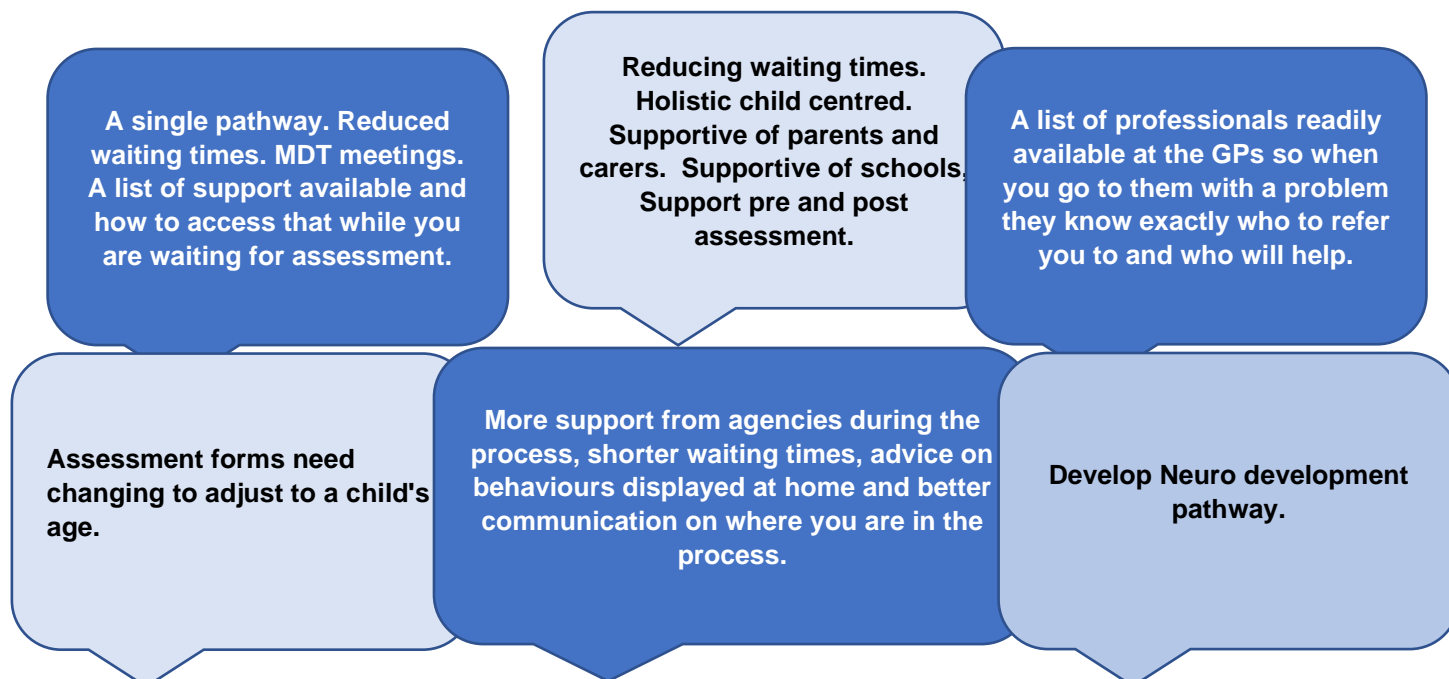
Comment 18: Following assessment (1st daughter) no help or advice, been past to CAMHS, Early Help, Health Child Programme, referred to CAMHS and GP, absolutely no help or support. Where do I go for help?

Comment 19: Had communication with North Yorkshire County Council Hub, a great resource that can be accessed via SENCO.

Response SB: We are working closely with North Yorkshire County Council for both pre and post assessment support to be available. We need the feedback to further develop the service and highlight the need and demand.

Response SDv: There is a lack of community support and we want to work with local authority and voluntary sector.

4. What do you think a new service could look like?



Next steps: The feedback gathered will help shape the autism assessment service for children and young people in North Yorkshire. CCG colleagues thanked everyone for coming and participating in the meeting.

Key themes:

- Complicated pathway
- Paediatrics and Children and Adolescent Mental Health Services to work more closely
- GP and health care professionals to have training and understanding in the referral pathway
- Reduced waiting times to assessment
- Assessment to include a multidisciplinary team
- A child centred approach – a holistic perspective of the child's autism spectrum
- The assessment needs to be comprehensive - school involvement, parents/carers input and streamlined.
- There is a gap in the system to help children with different needs
- Strengthen support to SENCO within school to help children more
- Parents can be left feeling very isolated
- More awareness of autism in primary care
- ADHD and ASC assessment to be streamlined as one

- A process of what to expect when the referral is made to include details of assessment.
- A list of support services available and how to access whilst waiting for assessment

Follow up support:

Members were advised at the start of this session, that we were not able to address individual concerns or issues, but we would pick them up outside of this forum. Three participants details were shared with colleagues from the Children and Young Peoples team for further help and advice.

Feedback from each event:

To ensure the events delivered are helpful to those taking part, we ask participants to provide us with their feedback. An example of the comments received:

I maybe wouldn't have attended had I have known that it wasn't applicable for the area where I live. However, I'm glad I did as the commissioner for my area was also attending & I was informed that my details would be passed onto her.

Really helpful and insightful session. It is encouraging that change to the system and services are set in motion using evidence gathered from our experiences.

Appendix 3

Have your say! Children and young peoples autism assessment service

Focus Group Saturday 30 April 2022

Staff present:	
Suzanne Bennett	Head of Childrens and Young Peoples Services, North Yorkshire CCG
Jacob Gilson	Children & Young Peoples Neurodevelopmental Transformation Project Manager, North Yorkshire CCG
Bridget Read	Engagement Manager, North Yorkshire CCG
Alex Flowers	Communications and Engagement Officer, North Yorkshire CCG
Members present:	
<p>A total of 9 registrations were received via Eventbrite to attend this session. Three members joined the virtual session held via Zoom.</p> <p>The patient survey was shared with members who were not able to attend but had expressed an interest in attending, giving them the opportunity to share their experience and feedback.</p>	

A presentation was delivered by Bridget Read and Jacob Gilson giving an overview to the session, outlining the aim of the session to carry out effective engagement to help shape the autism assessment service for children and young people in North Yorkshire.

The session was described as being interactive giving everyone the opportunity to share their experiences and also allowing members to share their views anonymously via Mentimeter, an on-line polling which allows you to see the results in real time.

The present autism assessment service for children and young people is delivered by The Retreat and NHS Harrogate and District Foundation Trust. Your address will determine where you are referred.

The challenges the service is faced with were outlined:

- Demand is high for the service
- Waiting lists increasing
- Cases are more complex
- Different models across North Yorkshire

The contract with The Retreat comes to an end March 2023, so there is an opportunity to reach out to service users, parents and carers to gather feedback to help inform the development of a new service model based on what we are hearing and what best meets the needs of service users.

Following the presentation, the session focussed on an open conversation with the participants. The questions asked to gather individual experiences were:

1. How did the referral process work for you?

2. How would you rate your experience of the autism assessment?

3. Overall, how would you rate the help and advice available following the autism assessment?

4. What do you think a new service could look like?

The feedback received:

1. How did the referral process work for you?

Comment 1: Referral process shocking, portage and Health Visitor input, excellent, it all fell down going into lockdown, the system is just disjointed from GP to The Retreat.

Comment 2: As a parent you should not have to challenge and chase the system.

Comment 3: Referral got lost several times.

Comment 4: GPs to have a greater awareness of the referral process.

Comment 5: As a parent, have gone through a lot of pain along the journey.

2. How would you rate your experience of the autism assessment?

Comment 5: Difficult to appeal the decision following the assessment, it seems you only have one shot at this.

Comment 6: Sticking point is pre assessment and wider system interview

Comment 6: Why can't Autism Spectrum Condition(ASC) and ADHD assessment be joined up?

Response SB: The ADHD assessment is conducted by CAMHS, the autism assessment by The Retreat, at present there does need to be a separate referral made to CAMHS. It is

helpful during these exercises to gather your views to help shape the future service. We are looking at developing a wider neurodevelopment pathway, looking at the needs of a child and having a central point and your feedback will help inform this pathway.

Comment 8: Person at The Retreat very good.

Comment 9: Parents are not given enough information as to what to expect during the assessment - to have the information you can be more prepared.

Comment 10: Duplication of information asked for, no holistic joined up approach.

3. Overall, how would you rate the help and advice available following the autism assessment?

Comment 11: I would like to see support and advice available led by professionals and to tell me what therapies work.

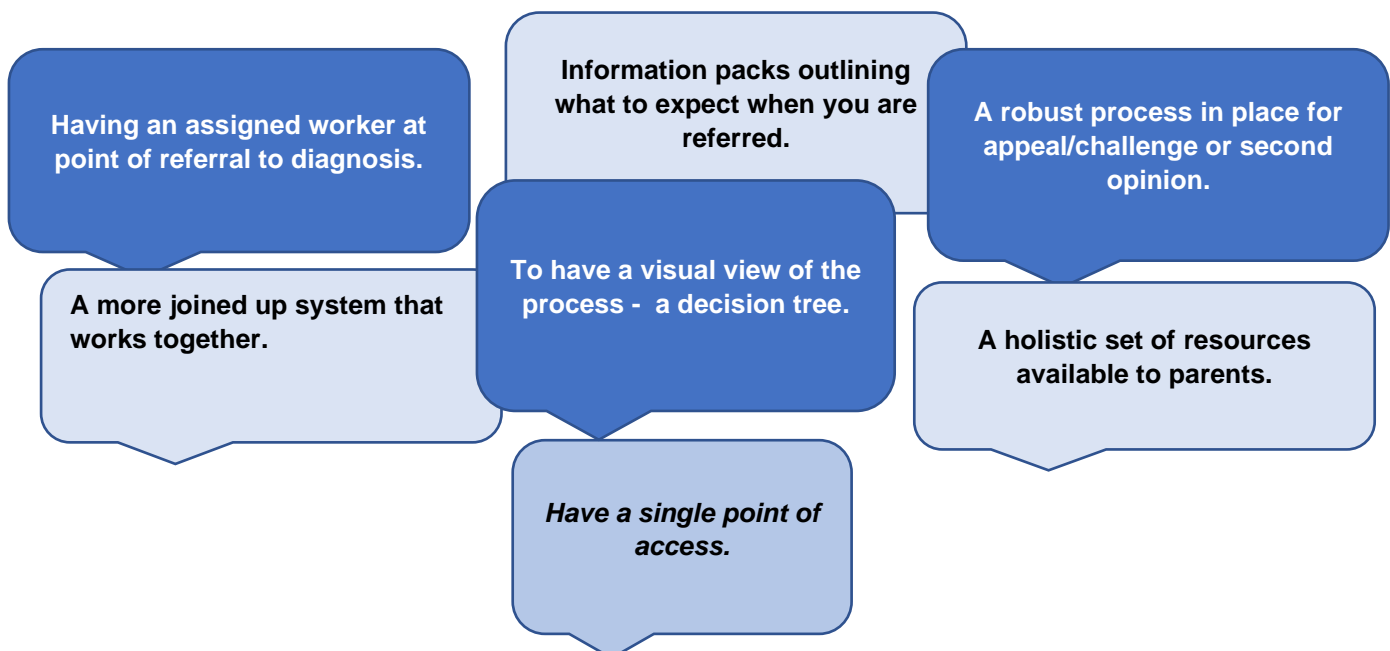
Comment 12: Following the assessment, you may get a diagnosis then you are discharged.

Comment 13: I got in touch with Carers Plus who were helpful and signposted me to parent groups.

Comment 14: It is not just the parents needing help and support the teachers need this as well. Special Educational Needs Coordinator (SENCO) are asking me what would be helpful, they should be advising me what help is available.

Response SB: We are working closely with local authority; you are correct it is not just health we need a more joined up approach.

4. What do you think a new service could look like?



Next steps: The feedback gathered will help shape the autism assessment service for children and young people in North Yorkshire. CCG colleagues thanked everyone for coming and participating in the meeting.

Key themes:

- Families need to know what to expect during the whole process
- Reduce endless form filling
- Joined up working and sharing of information, so that people don't have to keep telling their story again and again
- Support should be available from point of referral
- A single point of contact for people to call; a platform to go to for help and support
- Support services should be led by professionals
- Information packs available upon referral outlining what will happen
- Professionals to liaise with SENCO following a diagnosis
- Joined up ASC and ADHD assessment
- More awareness of autism in primary care
- Greater awareness of the referral process

Follow up support:

Members were advised at the start of this session, that we were not able to address individual concerns or issues, but we would pick these up outside of this forum. Two participants details were shared with colleagues from the Children and Young Peoples team for further help and advice.

Feedback from each event:

To ensure the events delivered are helpful to those taking part, we ask participants to provide us with their feedback. An example of the comments received:

Many thanks for this opportunity to feed back, and I hope you continue to help lots of young people!

Really useful event thank you. It felt positive to be able to share and hear other people's stories.



Appendix 4 - Survey results from service users

Have Your Say – About the Children and Young Peoples' Autism Assessment Service

Section 1. About You

1. Are you completing this survey as: (Please tick box that applies)				
Answer Choices			Response Percent	Response Total
1	A child or young person who has accessed the autism assessment service in North Yorkshire	<input checked="" type="checkbox"/>	3.66%	6





1. Are you completing this survey as: (Please tick box that applies)

2	A parent/family member of a child or young person who has accessed the autism assessment service in North Yorkshire		94.51%	155
3	A carer of a child or young person who has accessed the autism assessment service in North Yorkshire		0.00%	0
4	Other (please specify):		1.83%	3
			answered	164
			skipped	1

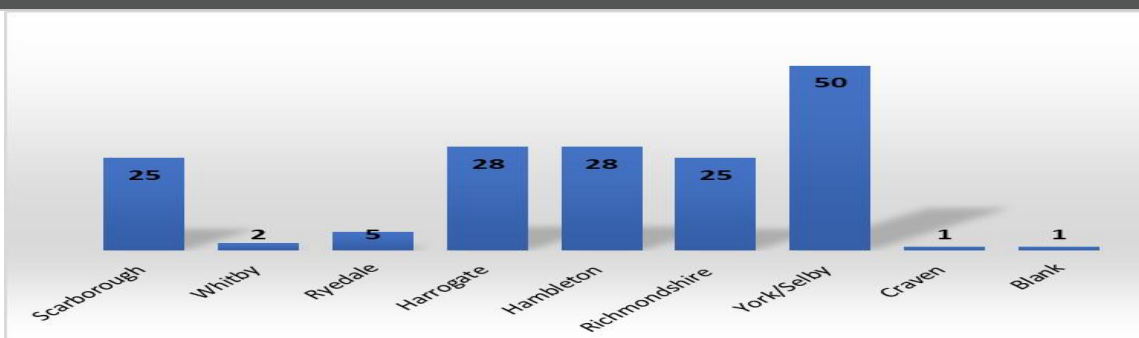
Other (please specify): (3)

- A carer of a child seeking an Autism Assessment.
- Educator who has accessed the service over the past 5+ years
- Parent of child living in North Yorkshire, but accessed West Yorkshires autism service

2. How long ago did you, or the person you are completing this survey on behalf of, access the autism assessment service? (Please tick box that applies)

Answer Choices			Response Percent	Response Total
1	In the past 6 months		26.22%	43
2	In-between 7 months and 1 year		18.90%	31
3	In-between 1 - 2 years		30.49%	50
4	In-between 2 - 3 years		24.39%	40
			answered	164
			skipped	1






3. The table below shows the location of responders



15% (25) Scarborough, 2% (2) Whitby, 3% (5) Ryedale, 17% (28) Harrogate, 17% (28) Hambleton, 15% (25) Richmondshire, 30% (50) York/Selby, 0.5% (1) Craven, 0.5% (1) Blank.

Section 2 - Referral






4. Where did you go to for a referral for an autism assessment? (Please tick the box that applies)

Answer Choices			Response Percent	Response Total
1	General Practitioner (GP)		45.73%	75
2	School		6.71%	11
3	Children and Adolescent Mental Health Services (CAMHS)		18.29%	30
4	Self-referral		4.27%	7
5	Other (please specify):		25.00%	41
			answered	164
			skipped	1

Other (please specify): (41)








- Self referral and G.P.
- Paediatrician referred to CAMHS for ADHD assessment who then referred for ASD assessment. Took a long time!
- Retreat York
- Consultant suggested a referral was needed
- For many years I was asking GP and school and nobody listened, GP was sending us to school, school back to GP, eventually got referral in from GP and learned that I could of referred my child myself, I referred my younger child myself
- Speech and Language Therapist
- Hospital consultant
- Paid privately due to wait list (2)
- Health visitor
- I was referred to CAMHS who couldn't help and eventually my GP. It took 6 years!
- School and GP both
- Occupational Therapist
- HV, GP, Speech and Language
- Paediatrician
- Early Help Practitioner
- School nurse after a meeting we called with the early help service
- Nurse picked it up on hospital visit and referred to early children services for assessment.
- Parent
- Nursery
- Social Services Service

5. Please tick the face that best describes the ease of access for a referral

Answer Choices			Response Percent	Response Total
1	Very dissatisfied		18.90%	31
2	Dissatisfied		15.85%	26
3	Neutral		23.78%	39
4	Satisfied		25.61%	42
5	Very satisfied		15.85%	26
			answered	164
			skipped	1

5. Please tick the face that best describes the ease of access for a referral




6. What support were you, or the person you are completing the survey on behalf of, offered while you waited for the autism assessment? (Please tick all that applies)

Answer Choices			Response Percent	Response Total
1	Early Help Programme		12.35%	20
2	Information about local support groups		13.58%	22
3	Solihull Parenting Programme		1.85%	3
4	North Yorkshire Parent Carer Voice		1.23%	2
5	Unlocking Autism Course		4.94%	8
6	Recovery College		1.85%	3
7	None		71.60%	116
			answered	162
			skipped	3

7. What additional help and advice would have been useful?

Answer Choices		Response Percent	Response Total
1	Open-Ended Question	100.00%	122
<ul style="list-style-type: none"> • Any help would have been useful (30) • Access to general support (54) before, during and after the assessment • Access to regular therapist and mental health staff (5) • Greater awareness of the assessment process (28) <ul style="list-style-type: none"> ○ A waiting list support group ○ Waiting list updates (16) • Access to an earlier assessment (14) • Directory of resources - social media, support groups, courses (30) • Guidance explaining autism (10) • Guidance to parents on how to support child while waiting for assessment • A clear referral pathway for all neuro developmental disorders • Information on SENDIAS • To work with schools (20) <ul style="list-style-type: none"> ○ Guidance to help schools • Early intervention 			
		answered	122
		skipped	43

4. During the assessment

8. Where did you, or the person you are completing this survey on behalf of go for your autism assessment? (Please tick the box that applies)				
Answer Choices			Response Percent	Response Total
1	The Retreat (Scarborough, Whitby, and Ryedale)		14.72%	24
2	Harrogate District Foundation Trust (Harrogate, Hambleton, and Richmond)		37.42%	61
3	Other (please specify):		47.85%	78
			answered	163
			skipped	2
Other (please specify): <ul style="list-style-type: none"> • Limetrees (2) • Phone/Zoom (3) • What was Brompton House, Northallerton • York and Selby CAHMS (2) • Done at ISU at Cygnet Sheffield, on behalf of the retreat • Ebor Psychology (2) • Orca House • Children's development Centre, York Hospital (4) • Home during pandemic • 1st child private / 2nd child online • CAMHS Keighley but we live in North Yorkshire no alternative offered even after complaints • Friarage Northallerton • Pontefract Hospital • Socrates clinical psychology Huddersfield • Scarborough Hospital • It was done by Helios on behalf of the Retreat 				

9. What did you, or the person you are completing the survey on behalf of feel worked well, during the autism assessment?			
Answer Choices		Response Percent	Response Total
1	Open-Ended Question	100.00%	143
Nothing (22)			
The whole process (7)			
The staff - kind, knowledgeable, friendly and supportive practitioners/staff (52) <ul style="list-style-type: none"> • I felt listened to • Allowed child to take their time • Involved all the family in the process • Made to feel at ease • Good connection with all staff 			
The online option worked very well (14) <ul style="list-style-type: none"> • Not having to travel / in home environment • Telephone questionnaire very thorough • First half was phone call based which worked well 			
Integrate team – Health and NYCC - Occupational Therapists, speech and language and paediatrician (2)			

9. What did you, or the person you are completing the survey on behalf of feel worked well, during the autism assessment?

Format of assessment (11)

- Everything was thoroughly explained beforehand
- It was a calm environment
- Well structure
- Being able to stop if you needed a break
- Opportunity to ask questions
- Seeing parent and child simultaneously
- Comprehensive holistic assessment
- Both parent assessment and child assessment were thorough and clear
- Having the parent session first to gather information in preparation for the child assessment
- Parents assessment on MST
- Gathering the information from people involved in child care (nursery, Portage)
- The appointments themselves were good.
- The ability to forward videos to the team
- Initial assessment at Harrogate Hospital very good
- Home visits (2)
- Face to face appointments (8)
- Once we got to assessment it happened reasonably quickly. We were part of fast track pathway so only two assessment visits, one with parents and one with child as assessment centres.
- It was quite stress free as school did all the background work for information for the assessment
- ours was a very exceptional case in terms of being rushed through diagnosis, via CAMHS, because of urgent mental health crisis. The autism diagnosis team moved very fast, referral to assess and to diagnose was c.6 weeks!

Managing expectations (5)

- Prior knowledge of the assessment, an understanding of expectations.
- The sheets explaining what would happen at the assessment were useful to share with our child
- Pre information was good

Timescale (5)

- We were grateful to receive feedback on the day
- It was quick once we got to that point
- Quick verbal diagnosis via telecommunicating

Communication (10)

- Excellent communication skills
- Always knowing the next steps
- Good communication about appointments/ wait times
- Kept us regularly updated with progress

answered	143
skipped	22

10. What did you, or the person you are completing the survey on behalf of feel did not work so well, during the autism assessment?

Answer Choices	Response Percent	Response Total
1 Open-Ended Question	100.00%	140
Nothing it all went well (10) Waiting times (27) <ul style="list-style-type: none"> • No communication advising on timescales • It took too long to wait for assessment • The lack of communication from the service whilst awaiting assessment. 		

10. What did you, or the person you are completing the survey on behalf of feel did not work so well, during the autism assessment?

Communication (15)

- Lack of updates between appointments
- Not listened to as a parent
- Having to keep ringing and chasing the outcome of the assessment
- Information getting lost and misplaced
- Telephone calls not been returned

Referral (1)

- Difficulty in getting a referred

Most of it (4)

Format of assessment (33)

- The phrasing of the questions on the questionnaire
- Parent not in assessment
- Repetition - answering the same questions
- Long process
- Assessment extremely anxiety-provoking for child and parent
- The final assessment being done by professionals who had never met my child
- Doing the parent assessment over the telephone
- Too many people in one room
- Having a further wait for other assessors OT/SALT
- Lots of questions about development of child you may not remember
- Assessor dismissed our concerns about autism
- It was very basic - very little probing for extra information
- It was with a social worker and not a psychologist
- Professionals spent minimal time with my child during assessment
- Child should be involved in feedback session
- Amount of time a child has to spend directly in front of the video – very uncomfortable and distressing
- Child diagnosed based on interviews with parents and feedback from school
- Not considering ADHD as part of same assessment
- It was too clinical and not personal to child

Manage expectations (12)

- Not knowing how long the process will take and what to expect at each stage
- Lack of information shared to understand the process
- Long gaps in between appointments

Information leaflet (2)

- Offers limited information relating to the assessment

Pre and post support (20)

- The lack of support during and after diagnosis
- No information handout
- No time or support to contemplate implications or possibility of a diagnosis
- Lack of support after diagnosis
- Follow up was read off a sheet

Virtual appointment (12)

- A default online meeting option was given - no other choice
- Difficult for child to communicate via Zoom
- Struggled with Zoom assessment
- I do not feel a Zoom call is an ideal or accurate way to assess a child
- The online assessment allowed child to mask the vast majority of feelings / symptoms
- You cannot get a true picture over Zoom
- Would have preferred face to face assessment
- Non face to face contact was impersonal and not appropriate when assessing
- Diagnosis should not take place via Zoom

Telephone consultations (1)

10. What did you, or the person you are completing the survey on behalf of feel did not work so well, during the autism assessment?

- felt unsure of the line of questions and whether we were giving the right information
- long telephone assessment

School (5)

- Lack of school observation
- Support from school
- Not replying with reports in time for the assessment

The environment (5)

- Small room
- Would have preferred face to face appointments

Reduce form filling (9)

- Questionnaires should be available to complete in computer
- More guidance for filling them in to help families collate evidence
- Too many forms to be completed
- Repetition - being asked again and again about the child's traits/behaviours
- The forms are extremely long

Integrate services (3)

- Very little support from other services such as occupational therapy, physiotherapy etc
- Teams to work together to streamline the assessment process.

answered	140
skipped	25

11. Describe what would have made the experience of the assessment better, for you or the person you are completing the survey on behalf of?

Answer Choices		Response Percent	Response Total
1	Open-Ended Question	100.00%	135
<p>Reduce waiting time for assessment (40)</p> <ul style="list-style-type: none"> • Better communication while on waiting list - to be honest about the length of wait • Less waiting time between initial assessment and the remainder appointment <p>Greater awareness of the assessment process (28)</p> <ul style="list-style-type: none"> • Parents would rather be offered face to face assessment (11) • More sensitivity. Parents could do with knowing what the child will be asked. My son (9yrs) was asked about suicide, and I wasn't prepared for that. Timescales can also be very long which for some families can be detrimental. • A video on You Tube to explain the assessment process and children familiar with the venue or through graphics • The person who did the home visits be part of the panel for a decision • Co-assessment for autism and ADHD • To have consistent staff throughout the assessment • Maybe the session split over a week rather than crammed into the whole day • Screening process to improve • To have assessment outside the house and face to face • To fully assess sensory processing difficulties as part of assessment • Having part of the initial assessment with the child not present. • The environment needs to be more homely to put children at ease • Diagnosis to be given face to face • Belief and not judgement • Offered tailored advice to your child rather than generic • More age-appropriate activities for the child to carry out during assessment • A more experienced assessor carrying out the parental assessment 			

11. Describe what would have made the experience of the assessment better, for you or the person you are completing the survey on behalf of?

Integrated Service (15)

- An MDT approach that considers all the elements of my son's life where he has difficulties
- A multi-disciplinary team meeting, within a much closer time frame.
- Access to Occupational Therapist and Speech and Language
- Integrated neurodiversity pathway, rather than individual conditions.
- A comprehensive, person-centred, holistic approach.
- Professionals involved should collaborate more amongst them to avoid repetition.
- Help with urgent issues (such as sleep and problematic stimming)
- Having reasonable access to CAMHS

Schools (7)

- Remove the need for school to decide whether a child needs assessing or not.
- School to be more supportive without diagnosis and to adhere to solid objectives

Pre post support (22)

- Signpost resource for parent and child
- Support following diagnosis on next steps eg DLA, short breaks ...
- Awareness of financial support
- More information on autistic people, best practices. A leaflet to give to family members about it to explain what it is etc.
- After diagnoses, to have a 6 month and 12 month follow-up appointment to discuss issues and sources of support.
- Access to Cygnet course
- Be connected with other neuro divergent children
- Understanding Autism should be available in pre-recorded sessions
- Some after care following diagnosis

Communication (8)

- Being listened to when my child was younger.
- Consistency of personnel
- Reminders (as parents may well be neuro divergent)
- A consistent email address (or a forwarding of old email addresses to new ones)

Greater awareness of autism (7)

- Greater understanding of autism in girls
- Greater empathy by the professionals

Satisfied with the service (14)






answered	135
skipped	30

5. Post Assessment







12. What help and advice were you, or the person you are completing the survey on behalf of offered following the autism assessment? (please tick all that applies)

Answer Choices			Response Percent	Response Total
1	Early Help Programme		7.45%	12
2	Information about local support groups		32.92%	53
3	Solihull Parenting Programme		4.97%	8

12. What help and advice were you, or the person you are completing the survey on behalf of offered following the autism assessment? (please tick all that applies)

4	North Yorkshire Parent Carer Voice		7.45%	12
5	Unlocking Autism Course		31.68%	51
6	Recovery College		6.21%	10
7	None		37.27%	60
8	Other (please specify):		23.60%	38
			answered	161
			skipped	4
<p>Other (please specify):</p> <ul style="list-style-type: none"> Not completed the assessment (7) Speech and Language follow up (2) Referred to Occupational Therapist Lecture by James Koppert with Carers Plus SENDIASS The post diagnosis pack and the online course Found our own help and assistance (5) Beyond diagnosis Specific information about ASD in girls ACCEND Course (2) ADAPT course Private Assessment Understanding autism course Returned to CAMHS An excellent pack full of advice and including a list of recommended books on the subject One group session with other parents - parenting course Cygnets course (5) Parent led CBT course for anxiety and to contact SENDIASS Respite was recommended, safeguarding through social care 				

13. Please tick the face that best describes how useful the help and advice was:

Answer Choices			Response Percent	Response Total
1	Very dissatisfied		23.46%	38
2	Dissatisfied		17.90%	29
3	Neutral		20.99%	34
4	Satisfied		16.67%	27
5	Very satisfied		5.56%	9
6	Not applicable		15.43%	25
			answered	162
			skipped	3

14. What help and advice would have been useful for you, or the person you are completing the survey on behalf of after the autism assessment?

13. Please tick the face that best describes how useful the help and advice was:

Answer Choices		Response Percent	Response Total
1	Open-Ended Question	100.00%	114
<ul style="list-style-type: none"> • Any help would have been useful (30) • Access to general support (54) before, during and after the assessment • Access to regular therapist and mental health staff (5) • Greater awareness of the assessment process (28) <ul style="list-style-type: none"> ○ A waiting list support group ○ Waiting list updates (16) • Access to an earlier assessment (14) • Directory of resources - social media, support groups, courses (30) • Guidance explaining autism (10) • Guidance to parents on how to support child while waiting for assessment • A clear referral pathway for all neuro developmental disorders • Information on SENDIAS • To work with schools (20) <ul style="list-style-type: none"> ○ Guidance to help schools • Early intervention before a crisis 			
		answered	114
		skipped	51



16. Overall experience

15. Is there anything else you or the person you are completing this survey on behalf of would like to share with us regarding the experience of the autism assessment service for children and young people in North Yorkshire?



Answer Choices		Response Percent	Response Total
1	Open-Ended Question	100.00%	104
<ul style="list-style-type: none"> • Reduce the waiting times for assessment • Ensure help and support is available to families throughout • Integrate the service with colleagues from health and education • Streamline the assessment process • To commission pre and post diagnosis support • Introduce a holistic neurodiversity pathway 		answered	104
		skipped	61

5. Demographics







16. What is your gender?

Answer Choices		Response Percent	Response Total
1	Male 	8.02%	13
2	Female 	85.19%	138





16. What is your gender?

3	Transgender		0.62%	1
4	Prefer not to say		6.17%	10
			answered	162
			skipped	3



17. What is your age?

Answer Choices			Response Percent	Response Total
1	19 or under		6.79%	11
2	20 - 34		12.35%	20
3	35 - 49		62.35%	101
4	50 - 64		12.35%	20
5	65 - 79		0.62%	1
6	80 or over		0.00%	0
7	Prefer not to say		5.56%	9
			answered	162
			skipped	3




18. What is your sexuality?

Answer Choices			Response Percent	Response Total
1	Heterosexual/straight		80.75%	130
2	Bi-sexual		5.59%	9
3	Gay/Lesbian		1.24%	2
4	Prefer not to say		12.42%	20
			answered	161
			skipped	4









19. What best describes your ethnicity?

Answer Choices			Response Percent	Response Total
1	White (British)		83.95%	136
2	White (other)		7.41%	12

19. What best describes your ethnicity?

3	Mixed background		1.23%	2
4	Asian or Asian British		0.62%	1
5	Black or Black British		0.62%	1
6	Chinese		0.00%	0
7	Prefer not to say		6.17%	10
			answered	162
			skipped	3

20. Do you consider yourself to have a disability? If so, please indicate the type of disability or illness you have. You may tick more than one:

Answer Choices			Response Percent	Response Total
1	No disability		59.51%	97
2	Physical impairment such as difficulty moving your arms or mobility issues		2.45%	4
3	Wheelchair user		0.00%	0
4	Sensory impairment such as being blind or having a visual impairment		0.00%	0
5	Sensory impairment such as being deaf or having a hearing impairment		0.61%	1
6	Mental health condition such as depression, dementia or schizophrenia		8.59%	14
7	Long-standing illness or health condition such as cancer, HIV, diabetes, chronic heart disease or epilepsy		3.68%	6
8	Learning disability or difficulty (such as Down's syndrome or dyslexia) or cognitive impairment (such as autistic spectrum disorder)		6.75%	11
9	Prefer not to say		7.98%	13
10	Other (please specify):		10.43%	17
			answered	163
			skipped	2

Other (please specify): (17)

Autism and hyper mobility

Recently diagnosed mixed ADHD

Also mental health condition

Fibromyalgia

ADHD (which I do not accept should be put into the same category as chromosome disorders). Also, in answering this question I have discovered that it is not allowed to check more than one box and there may be some people who need to check more than one box and not feel as though they have to choose between illnesses

20. Do you consider yourself to have a disability? If so, please indicate the type of disability or illness you have. You may tick more than one:

Dislike the term 'cognitive impairment' perhaps cognitive difference would be a more positive framing of autism, particularly on a survey where you wish to improve the autism service!

Possible ASD myself

I am autistic

Autistic

Fibromyalgia

Fibromyalgia

Hard of hearing

Chronic health, wheelchair user (system won't let me tick more than one on my phone)

Anxiety, long covid, asthma

**Appendix 5
Survey results from GPs healthcare professionals**

**Have your say – about the children and young peoples' autism assessment service
North Yorkshire**

Section 1: About You

1. Are you completing this survey as: (Please tick box that applies)

Answer Choices		Response Percent	Response Total
1	GP	62.96%	17
2	Health Professional	25.93%	7
3	Other (please specify):	11.11%	3
		answered	27
		skipped	1

2. What area do you work in? (please tick box that applies)

Answer Choices		Response Percent	Response Total
1	Hambleton	18.52%	5
2	Harrogate	29.63%	8
3	Richmondshire	14.81%	4
4	Ryedale	3.70%	1
5	Scarborough	25.93%	7

1. Are you completing this survey as: (Please tick box that applies)

6	Whitby	<input checked="" type="checkbox"/>	7.41%	2
7	York	<input type="checkbox"/>	0.00%	0
			answered	27
			skipped	1

3. Section 2 - Referral

3. Would you know where to refer a child or young person for an autism assessment? (Please tick the box that applies)

Answer Choices			Response Percent	Response Total
1	Yes	<input checked="" type="checkbox"/>	81.48%	22
2	No	<input type="checkbox"/>	3.70%	1
3	Not sure	<input type="checkbox"/>	14.81%	4
			answered	27
			skipped	1

Comments: (6)

1	The Retreat
2	Think its CAMHS?
3	I really have no idea what is going on as get conflicting advice. We are stuck in the middle and children are losing ground socially and academically.
4	It is a joke, it really is. The process of referral is an utter disgrace, truly dreadful its appalling
5	I work in Hambleton and Richmondshire - not a possible answer on previous question
6	The issue is that a mixed picture of ADHD and autism traits can often end up getting bounced between services though.

4. Overall, how would you rate the process for referring a child or young person to the autism assessment service? (Please tick the box that applies)

Answer Choices			Response Percent	Response Total
1	Very dissatisfied	<input type="checkbox"/>	25.93%	7
2	Dissatisfied	<input type="checkbox"/>	25.93%	7
3	Neutral	<input type="checkbox"/>	18.52%	5
4	Satisfied	<input type="checkbox"/>	14.81%	4
5	Very satisfied	<input type="checkbox"/>	14.81%	4
			answered	27
			skipped	1

Comments: (14)

1	Waiting time is too long, process also takes a long time
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3. Would you know where to refer a child or young person for an autism assessment? (Please tick the box that applies)

2	Overly complex forms, especially as clinicians rely on administrative staff to fill and forward and do not see the forms themselves. The level of detail required seems designed to get the referrer to do most of the assessment. GP is often not the best person to refer as the concerns are inevitably raised from family, school, health visitor etc.
3	Timescale for wait is unhelpful
4	We are now having to do the initial assessment for the autism services - yet aren't paid for it nor given the time for it. Initially seeing a patient with their parent and taking a history usually takes 10 mins. Then dictating a further two mins. However now we have to complete the assessment form in order to refer, oh and also print out the questionnaire for parent/guardian to complete, this takes an extra 15 mins. We don't have 25mins. Yet the parent wants you to refer there and then. SO you do it, but then you run late and all your other patients complain and get angry at you for how long you have taken. I dread parents coming in questioning this diagnosis.
5	Seems community paediatrics don't want to see them, even if there are physical impacts of the condition. The waits for assessment are long and limited support for Child and families or the social issues. I feel dreadful for these families
6	It takes ages, there is no help to try and triage these children in terms of need or academic year at school. The waiting lists are huge. They have to see paediatrician first then referred onwards. My understanding is they can't be directly referred but I may be wrong.
7	Such long waiting lists. Families get very little help whilst waiting for the assessment.
8	Lengthy questionnaire, and examples required to proceed with referral.
9	Autism and ADHD should not be referred to different places. Schools have not been adequately informed that they can refer.
10	Waiting list very long, having been assessed there is little or no ongoing support
11	Prompt acceptance - Clear process
12	The referral form is far too long for completion by a GP when have 10-15 min slots. It would work better if the GP referred and a similar system to York where the service contacted the family for an initial screening appointment to see if appropriate to proceed along the pathway. The process takes far too long.
13	It is a long wait and I think we never have referred so many kids
14	Long waits for appointments

5. Thinking about the referral process, can we improve anything for children and young people who have been referred for an autism assessment?

Answer Choices		Response Percent	Response Total
1	Open-Ended Question	100.00%	23
1	An acknowledgement of the referral being made to the referrer so you know that it has been received, although may not be accepted when it is discussed.		
2	The waiting time is long and when asked to complete assessments all agencies take differing times to respond		
3	Reduce time waiting. Allow GPs to refer directly into service if they have sufficient detail and knowledge to do so. Be commissioned to offer ongoing post autism assessment support		
4	Provide a direct access assessment clinic for families. This would speed the process for children and remove an unnecessary link in the chain.		
5	Support offered while waiting as the families are still struggling during the long wait		
6	Referral process involves lots of work and time for GPs		

5. Thinking about the referral process, can we improve anything for children and young people who have been referred for an autism assessment?

7	The waiting times are obviously very long however this is not a problem unique to autism services.
8	As above. We only have 10 mins per appointment, 15mins presently due to PPE requirements and having to clean and wipe everything after EVERY patient ourselves. Doing the form as well as printing out the questionnaires for the parent takes at least 15 mins if not longer. You are using us as the initial assessors yet we aren't given ANY funding for this. THEN if the parent says "I'm not sure they might be both, please can you refer" you have to do further questions and print out a further form, which isn't attached, you have to then google the correct form and printout their labels etc. All this take valuable time.
9	When we refer it would be good to know the physical and social/educational were reviewed in a single collaborative service. We cannot provide melatonin for example - can a paediatrician be involved to review any physical issues and instigate management of issues. Also if you can't see the child for a year then can you offer sign posting or safety netting in the meantime.
10	Yes. Lots. Suggest you act on feedback from parents. Children shouldn't have to see pedestrian first (if that is still the process). I feel strongly there should be a single point of access referral for neurodevelopmental conditions in general ie ADHD and autism. Often children have mixed behavioural symptoms and I feel CAMHS type service is best to triage them then refer on.
11	Much shorter waiting lists. Help and support to be available to all families whilst they wait. Coordination of services - it is very difficult to get support for these children and families due to decimation of the school nursing and health visiting service.
12	It is time consuming, and the waits are long to be seen leaving us with very frustrated parents.
13	Very very long delays and waiting times. Anxious families waiting to be triaged. This leaves a lot of responsibility on the GP who can do nothing but reassure and ask families to wait. I think it is only fair children get assessed as soon as possible to both help the child and the parent who is alone and coping with the anxiety.
14	All of it, start again from scratch, what idiocy when a paediatrician writes to the GP to ask for a referral. The GP refers and it gets bounced.
15	More straightforward referral process.
16	Long waiting time for referrer.
17	See them sooner, co-assessment for ADHD and autism, more support for parents regarding daily issues whilst waiting.
18	Increase capacity.
19	Waiting lists (sadly).
20	Yes - have a more joined up service where the autism and ADHD service is commissioned from the same place allowing for a more holistic assessment of the child rather than bounce between services. Support and resources provided while on the pathway awaiting assessment.
21	Let families know how the process will happen. When they can to expected to be seen, where and what they will need to do. There could be different formats depending on the childs' age and ability.
22	Acknowledgement of referral to patient/parent when it has been received so they do not return to GP to chase up when they have been waiting a long time.
23	Long waiting list is the most obvious thing here but parents and teachers etc are now aware of the lengthy wait and there is some acceptance of this.

answered	23
skipped	5

4. Overall experience

6. Is there anything else you would like to share with us regarding the experience of the autism assessment service for children and young people in North Yorkshire?










Answer Choices		Response Percent	Response Total
1	Open-Ended Question	100.00%	13
1	Positive feedback re-experiences, but the wait is of course very long.		
2	Waiting lists too long.		
3	Having a referral rejected for incomplete information is frustrating. Especially as the information is all there, but in a letter not in separate boxes. And taking NINE months to point it out to the referrer is poor, even allowing for service pressures.		
4	Waiting time is too long. But that's for everything presently. By the time parents come to us they are usually at the end of their tether not knowing how to cope with their child. When a child DNA's please phone the parent before discharging, as re-doing the whole process is such a waste of time.		
5	It feels we are resigned to a slow and limited service that doesn't do our community justice - I feel helpless to offer advice as I have no training in this. The school-based support services often don't feel integrated with us.		
6	It would be great if there was an online portal for parents to do their own screening questionnaires with signposting to early help or third sector support, so they don't need a GP appointment for lower level issues. There are some autistic children who don't need a diagnosis as such, parents just need practical help.		
7	Yes is there anyone who hasn't been diagnosed with autism!! It seems to me that the bar has been lowered. I speak as someone with extensive experience of working with children with autism.		
8	The service is disjointed, difficult to access and extremely slow. If a child is diagnosed with autism, they get very little support. There is no service commissioned for prescribing melatonin. Patients report inadequate assessments particularly when remote. There is no system for a second opinion even if the initial assessment missed a lot of relevant information.		
9	Really helpful response recently when an assessment outcome didn't make sense. Always efficient and considering number of referrals it seems to work really well . Parents often comment that they would like more info on 'type' of autism, and I think by this they mean more of an assessment of the way in which living with autism affects their child individually. Post diagnostic support has increased recently in terms of videos but parents often feel the need of individualised advice for their child - behaviour, worries etc in relation to the ASD which the videos don't address (I think).		
10	The waits are far too long, and families are struggling. There is no service commissioned for melatonin prescribing (if appropriate for select few children) and also kids with autism with extreme behavioural issues at risk to themselves or others that require medication are not supported. The Retreat bounce any prescribing, so these kids are left struggling, families broken and bouncing in and out of school without adequate support in place. Diagnosis is very delayed as services are not joined up and often have dual diagnosis, not to mention the associated anxiety and depression that often goes with neuro disability with no support. If any referrals/bloods or ECGs are requested the GP is asked, which is not appropriate. The service completely needs to be reassessed. It's no use just labelling a child and then discharging them. Families feel lost.		
11	I don't know if you keep the parents and kids informed where they are on the waiting list.		
12	The waits are too long for the families and young people during what can be a stressful time. The referral to the ASD team does not trigger referral to another team such as Occupational Therapy and Speech and Language Therapist and these referrals only get picked up once the children are seen.		
13	The referral proforma is good, easy to use and can direct questioning along the right lines. It can be frustrating if it is sent back if just one section is not completed. The assessment appears comprehensive. It is a bit vague where children get ongoing care and support after diagnosis - previously they have been under paediatric care but no longer. Also why is it that a consultant paediatrician cannot refer for assessment and that it has to go through GP? This is inefficient, causes delays and increases our workload unnecessarily. The paediatrician may know the patient well and could fill in the form but we have to start almost from scratch and make an appointment to get all the history.		
		answered	13
		skipped	15

25 May 2022

Appendix 6 Survey results from education professionals




Have your say – about the children and young peoples' autism assessment service

Section 1. About You

1. Are you completing this survey as a:(Please tick box that applies)				
Answer Choices			Response Percent	Response Total
1	SENDCo or SENCO		61.29%	19
2	Teacher		19.35%	6
3	Teaching Assistant		0.00%	0
4	Other (please specify):		19.35%	6
			answered	31
			skipped	1
Other (please specify): (6)				
Primary School Nurture/Safeguarding				
Safeguarding				
Headteacher				
Family Support Manager				
Headteacher				
Headteacher				
2. What area do you work in? (please tick box that applies)				
Answer Choices			Response Percent	Response Total
1	Hambleton		10.34%	3
2	Harrogate		13.79%	4
3	Richmondshire		3.45%	1
4	Ryedale		27.59%	8
5	Scarborough		41.38%	12
6	Whitby		0.00%	0
7	York		3.45%	1
			answered	29
			skipped	3

Section 2 - Referral

3. Do you know where to refer a child or young person for an autism assessment? (Please tick the box that applies)

Answer Choices			Response Percent	Response Total
1	Yes		77.42%	24
2	No		9.68%	3
3	Not sure		12.90%	4
			answered	31
			skipped	1

Comments: (10)

it is not always easy to find the right person/ route in North Yorkshire.

If children fall into the relevant area for referral to The Retreat then the process is clear. There needs to be a directory of where to refer children as it is not always apparent which CCG their GP's surgery is in.

Send families to GP to initiate assessment.

My understanding, based on the website, is that GPs need to make this referral.






Ask the parents to refer to GP - assuming this is correct?

I would expect this to be done by our SENCO.

Some confusion over children who live outside of Pickering but are registered with Pickering Surgery and being able to refer to The Retreat. Even information from the Retreat has shown confusion [we were told we could and after several referral then told we weren't].

I would normally direct the parents to obtain an appointment with the child development centre via their GP

4. Overall, how would you rate the process for referring a child or young person to the autism assessment service? (Please tick the box that applies)

Answer Choices			Response Percent	Response Total
1	Very dissatisfied		17.24%	5
2	Dissatisfied		27.59%	8
3	Neutral		34.48%	10
4	Satisfied		13.79%	4
5	Very satisfied		6.90%	2
			answered	29
			skipped	3

Comments: (13)

Referrals from school made to The Retreat have initially been declined - this is due to The Retreat requesting an IQ level to establish whether students have a learning disability as opposed to a learning difficulty. Assessment will not be undertaken by The Retreat of young people with a learning disability. In our experience young people can have both a learning disability and autism. The issues leading to a diagnosis of learning disability are frequently interlinked with autism. This situation could lead to young

4. Overall, how would you rate the process for referring a child or young person to the autism assessment service? (Please tick the box that applies)

People being unable to access the support they need due to not having the relevant diagnosis.

The waiting times are extensive and there is little communication either with school or families regarding this. Communication is often lost - school forms have been sent up to three or four times on a number of occasions and then we have been asked for them again.

Many comments heard from parents of the difficulty in the referral and time taken to complete.

I feel the time scale from referral to discussion is too long.

The process of referring a child for an autism diagnosis is a lengthy one. While the application is quite short and easily completed, once this has been sent in, the length of time parents wait for further support and assessment is disappointing.

Would like some clarity as to if GPs will / can still refer for Autism assessments as we have had conflicting messages from local GPs which has caused upset to some parents.

The process takes a long time and we only hear of the results from the parent.

I have spoken to people in the team who say that I cannot refer a child for an autism assessment and that a GP needs to do it. This is what it says on the website. I am however, repeatedly told by other professionals that I need to make this referral.

Takes a long time but good when the child gets seen.

It is very difficult to get a referral. Once the referrals are at the Retreat I am constantly chasing them to find out updates and whether the referral is accepted or not.

As we are on the pilot scheme we are finding it so beneficial to meet with the assistant psychologist to discuss children and then be given screening forms to take to panel. It is a really efficient way for schools to work to get children on the waiting list for assessment more effectively.

Far too slow

Extensive length of time for a child to be initially assessed to go on the waiting list. Schools are given a very, very short period of time to fill out forms and once sent, it takes so long to get the initial forms processed that new forms are sent to us again because they are out of date.

The length of time the whole process takes is very disappointing, it puts parents off referring (when their child might have serious mental health difficulties), it's encouraging parents to go privately which is not what we recommend, and in the case where parents have referred in primary school (by the time they are 'old enough' -7-8 years +) they are not going to get any sort of diagnosis or support until early high school, by which point the foundations of their education will have already potentially suffered.

From a SENCO point of view, I like the weighty forms and the amount of detail it covers, however I feel from a teacher point of view (if I had limited SEN experience) I perhaps wouldn't have enough experience to know what to look for/comment on.

5. Are you aware of the help and advice available to children and young people? (Please tick all that you are aware of)

Answer Choices			Response Total
1	Early Help Programme	<input checked="" type="checkbox"/>	31
2	Local Support Groups	<input type="checkbox"/>	31

5. Are you aware of the help and advice available to children and young people? (Please tick all that you are aware of)

			
3	SENDIASS		28
4	Solihull Parenting Group		28
5	Parent Carer Voice		31
6	Unlocking Autism Course		28
7	Recovery College		26
8	York Inspirational Kids		28

4. Overall

6. Thinking of the current service, how might the children and young peoples autism assessment be improved?(Please detail below)

Answer Choices		Response Percent	Response Total
1	Open-Ended Question	100.00%	29
<p>A requirement for services and parents to share information of the referral on making it - some questionnaires from The Retreat are unexpected.</p> <hr/> <p>Faster process, it currently takes 1-2 years for a diagnosis. Appointments virtually are not good enough. We had a student turned down because they wouldn't engage on the online call, but they wouldn't engage due to their learning needs!</p> <hr/> <p>Quicker process</p> <hr/> <p>There needs to be clearer pathways for schools to help support parents. The process also needs to be speeded up.</p> <hr/> <p>Acceptance of young people with a learning disability. Clarity of where to refer to according to CCG.</p> <hr/> <p>The system with The Retreat seems to be working considerably better than the previous system using CAMHs. Waiting times are reduced and help can be accessed quite quickly.</p> <hr/> <p>Reducing the time taken to process and diagnose. More support for parents as a result</p> <hr/> <p>There needs to be a better way to assess children within the Scarborough area. The travel to York or use of technology is often a significant barrier to our families. The use of online assessments, although it has reduced the waiting time to an extent, is often a source of anxiety and potentially inaccurate assessment as a number of our students who have been referred significantly struggle to communicate with a stranger via an online process. There is little to no support for families following the diagnosis or help in understanding this. Families are often left significantly distressed by the whole process.</p> <hr/> <p>Communication with schools.</p> <hr/> <p>Ease of referral and accessibility.</p> <hr/> <p>To reduce the time scale from referral to decision.</p> <hr/> <p>Supporting schools in supporting children. Currently we do not get assessment reports unless shared by parents. We also are not consulted when this assessment is completed. Often school is the only support network parents and pupils have!</p>			

6. Thinking of the current service, how might the children and young peoples autism assessment be improved?(Please detail below)

The speed in which support, assessment and diagnosis is allocated/ received needs to be improved.

Waiting lists be shorter. Clear guidelines regarding referral and GP's.

The waiting time for assessment is far too long. Assessment needs to happen within weeks not months and years it is taking.

Time awaiting assume that needs to be reviewed as the waiting is far too long
The process is complicated
There is little support available for schools and parents

Shorter waiting times, more dialogue with school

- Clear pathway that school staff can make referrals to
- on referring, being given notice of approximate time scales
- better support for parents so that they understand the process

More resources put into it so the process is quicker and easier, as well as more unified nationally (I am a parent who is going through the process currently and it is different in County Durham). There is lots of information out there but the whole process can seem quite intimidating.

More transparency in relation to progress of assessments.

The teacher questionnaire from the Retreat about the child takes a long time to complete. Would it be possible to gather some of the information by tick box questions rather than needing a full written answer for every question? I realise that descriptive answers give a detailed good view of the child but maybe some balance of workload could be struck.

Better working relationships and updates for schools so that we can work together to provide support for children and their families!

More information on where to refer to and who can refer, shorter waiting times

Which family can refer to which service [CAMHS or The Retreat]. The referral form is comprehensive for both teachers and parents. However, after submitting that it would be great to have some kind of immediate information for parents, if the SENCO is not available to discuss [parent leaflet]. Apologies if this is already provided. It's sometimes quite a long wait and on one occasion, a parent knew it was a long wait and when she contacted the Retreat, was told that they were not going to assess her child but they hadn't informed her, and almost a year had passed.

The waiting time and support for parents could be improved considerably. Parents feel lost waiting for advice and assessment and before we were on the pilot scheme it was almost impossible for school to speak to anyone from CAMHS.

A faster diagnosis process and better liaison between professionals

Having been on the two-day Unlocking Autism course, I would say that all school staff should be encouraged to go on it - especially if they are expected to fill out CAMHS forms. I think whilst teachers wait for their pupils to be assessed, the course offers really useful strategies and the professionals on the course are very knowledgeable.

-I would say from an admin point of view, reduce the lengths of the forms or give longer to schools to get the forms back to CAMHS - returning within two weeks is such a challenge for school staff to meet currently.

- I feel that the forms need updating as they refer to levels or statements at one point and some aspects of the forms I find are repetitive (emotional wellbeing form vs ASD forms).

-Sending the forms through electronically would be much more efficient - I feel personally that you can't fit everything into the small boxes if it's the case that the child displays many tendencies.

-Better communication for parents, the parents we have on the waiting list do not often know where they are in the process and often misunderstand that they are 'on a waiting list to join the autism waiting list' for example.

-Parents also have fed back to me that they don't always understand the communication they do get (misunderstanding the use of acronyms to describe needs) and perhaps don't know what certain pathways mean, how long the waiting lists are and what comes

6. Thinking of the current service, how might the children and young peoples autism assessment be improved?(Please detail below)

As part of the intervention.