1. Introduction

As a result of the Covid-19 lockdown The Retreat had to move all of its clinical activity online – providing video and telephone therapy and assessment as well as taking all meetings and multidisciplinary team discussions online or via phone. Through consultation with experts locally and nationally and within our expert team, we have now developed a solution for our Autism Spectrum Disorder (ASD) pathway for children and young people (CYP). We have developed a new CYP ASD pathway so that we can, with immediate effect, begin offering online assessments for children and young people as well.

The assessment pathway involves adjustments that are different for younger children (4-7 years) and older children (8-18), with regard to gathering clinical information on an individual's social communication.

2. Online Children and Young People ASD assessment pathway

The difficulty we encountered in attempting to offer an online Autism assessment for CYP is that the social communication and interaction assessment, using ADOS-2 assessment tool, must take place in a face-to-face appointment. This is a standardised assessment and it is not possible to complete this assessment via video link because it involves a variety of activities that require specific items (for example a puzzle and a book) and it would not be possible for someone to have access to these items via a video link. NICE guidelines state how a comprehensive assessment should include the carrying out of "direct observation of core autism signs and symptoms especially in social situations". Direct observation is not possible through online assessments. Nevertheless, working with other experts, The Retreat's team have developed an assessment pathway for all age groups that can be offered online and that can lead to a complete diagnosis. The pathway is outlined in **Figure 1** on the next page.

2.1 Referral triaging

We propose that for all referrals that are accepted, a request is made for access to all medical and Allied Health Professionals (AHP) reports to be made available. This would allow the team to identify those referrals where a high amount of previous contact has been had between child and professionals. Where possible, these assessments would be given priority, with a view to speeding assessments up. This could mean, for example, that a child who has a comprehensive assessment report by a community Paediatrician would potentially go on to have an initial consultation, a developmental history where needed, and go straight on to MDT discussion and feedback. This would mean a deviation from working referrals in chronological order of referral date. Therefore we would like to request that commissioners provide a clear decision, in writing, agreeing to this. The potential benefit would be that for some referrals it might be possible to complete specialist assessment quicker.

2.2 Young children

For children aged 4 to 7 we will request that all families whose children have been accepted to the assessment waiting list, submit video footage via the NODA App. This allows clinicians to observe behaviours captured by the family at home, through a secure platform. NODA was developed by Behavior Imaging Solutions with NIH funding in the US. It has been evaluated in a large research study for children in an age range 18months to 7 years. See Appendix 1 for additional information on NODA. Footage will be analysed by the Speech and Language Therapists (SALTs) in our team.

In parallel, information will be gathered from the child's educational setting, as was the case for the pathway pre-pandemic.

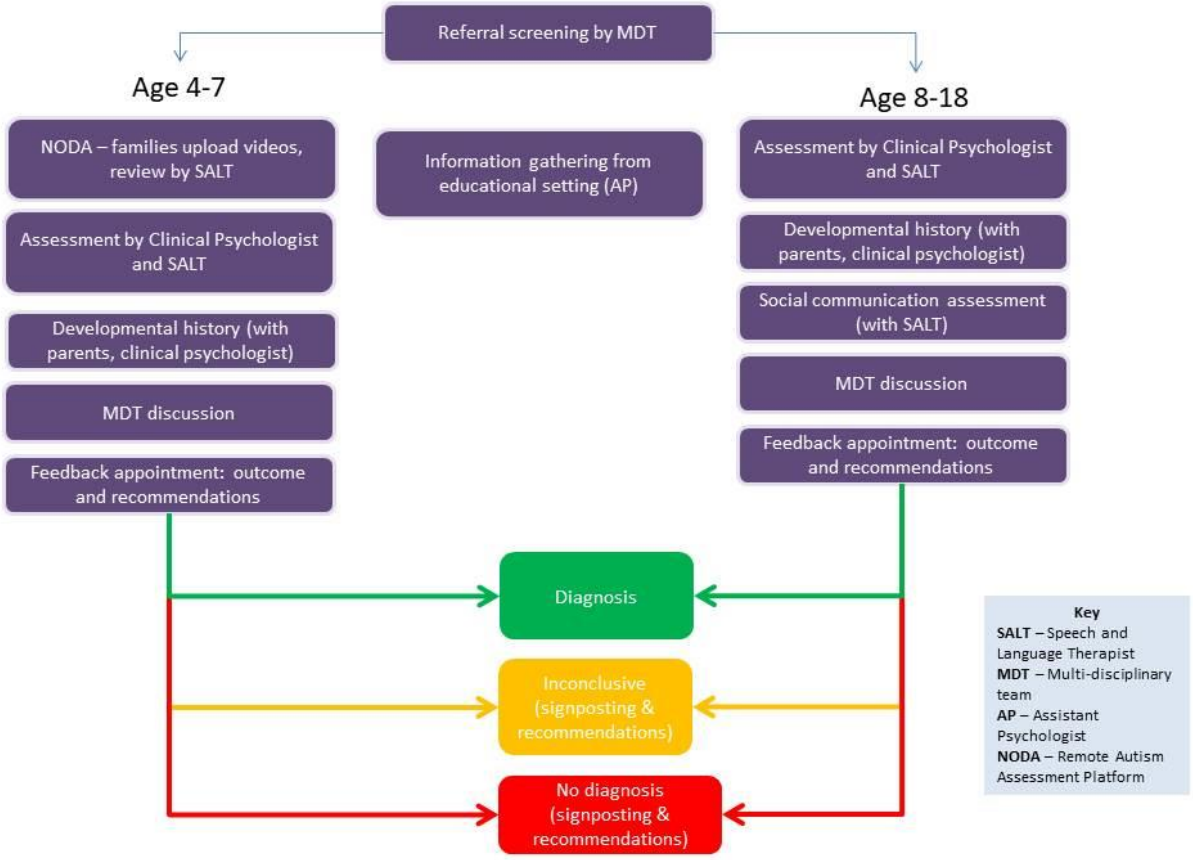
Following this a clinical psychologist and SALT will conduct a clinical interview with parents and child, though video call. It is crucial for this assessment to be carried out by two clinicians with this particular professional background, to ameliorate the loss in direct contact that the online pathway inevitably brings, and to compensate for the loss in clinically relevant information that is inevitable with not being able to have a real life face to face interaction with a child.

Subsequently a developmental history would be gathered by a clinical psychologist with the parent.

Following NICE guidance the multidisciplinary assessment would result in a team diagnostic discussion, followed by an online feedback appointment with the family.

As Figure 1 illustrates, there are three likely outcomes: diagnosis, no diagnosis, and inconclusive assessments. This in itself is no different from the pre-pandemic pathway. However, we anticipate that there might be an increase in the rate of inconclusive assessments. It's difficult to predict the rate in the absence of data. However, we would like to raise this here as a risk. We think that in some cases the team will not be able to come to a conclusion as information on social communication will be clouded or limited as information was not available from an in person assessment by a skilled clinician interacting with the child or young person.

Figure 1: New ASD Pathway for children and young people



2.3 Older children and teens

For older children the assessment pathway we propose only differs in that it will be online and that the previous assessment tool used for the social communication and interaction assessment (ADOS-2) cannot be utilised. However the team has developed procedures to carry out an ADOS informed assessment via video link. This is not dissimilar from what our sub-contractor Healios has been offering.

As for younger children, we think that in some cases the team will not be able to come to a conclusion as information on social communication will be clouded or limited as information was not available from an in person assessment by a skilled clinician interacting with the child or young person. However, given the uncertainty that many children that are due to transition to secondary school (or college) experience, the outcome of an inconclusive assessment might still give valuable information for educational and social care settings with regard to the particular support needs that a child/teens has.

Also, we would like to suggest that the CCG considers an option for families with a child/teen where the autism assessment resulted in an inconclusive outcome, to have another consultation with the specialist team once face to face contact is possible again. This would not entail another full assessment, but gathering of any information (clinical observation) that was not available for the fully online assessment pathway.

Appendix 1: Further information about NODA

NOTE: We are in contact with NODA and we are in the process of undertaking a full Data Protection Impact Analysis to ensure this will be GDPR compliant.

Information about the Naturalistic Observation Diagnostic Assessment for Autism (NODA) can be found here https://www.nodaautismdiagnosis.com/.

NODA is an online assessment platform delivered through an app that families can download onto their smartphone, no laptop or additional computer device is required. Families are asked to record four videos, showing specific scenarios, which they upload via the app for the clinician to access. Each video is approximately 10minutes in length and families are provided with guidance and instructions on how to complete the recording. The scenarios requested are:

1. **Mealtime**. With the child in the centre of the shot the family complete a recording of a typical mealtime. Parents are prompted to: Call their child's name; offer food items; call attention to something and point to it; look at their child and smile at them. Parents are advised to give their child plenty of time to respond.
2. **Play with others**. Ideally this is asked to be with a sibling but can also be with a parent. Parent is asked to set up the recording to capture the play area. Toys that the child plays with are placed in the play area for the child and sibling/parent to access. At least 5 different items are required and can include: dolls and figures; cars; books; puzzles but no electronic devices. Parent or sibling are instructed to play with the child and complete the following instructions: Call the child by their name and wait for a response; offer a toy; draw attention to a toy.
3. **Play alone**. Parent is asked to select toys and place in the play area. Parent briefly plays with/alongside the child to establish the play and follow these instructions: Call the child by their name; point at something saying "Look at that"; Ask the child where something is in the room; See if the parent can get their child to smile. After a few minutes, the parent leaves the area and allows the child time to play with the toys on their own.
4. **Capture any behaviour parents would like assessors to see**. Parents are asked to provide a brief description of the behaviour at the beginning or end of the video and it is essential that the video footage captured is natural and the child has not been asked to do the behaviour beforehand. Parents are asked to capture the best example of behaviour of most concern to the parent. Essential not to use any images in the bathroom/dressing etc.

Clinician analysis of the collected data

Once parents have uploaded their videos, the clinician will be able to access them through the software available to them. When watching the videos, clinicians can place tags at certain points, when they see a particular behaviour. Different tags relating to*, social, behaviour and communication* can be applied and definitions of behaviours relating to each of these areas are provided. The tags are then placed directly into a chart that correlates with the DSM checklist and once the clinician has reviewed all of the available material, they will see a profile of behaviours has been recorded, relating to the DSM - 5 criteria. This profile used in conjunction with a developmental history and any additional information provided, can be used to identify if the child has met the DSM-5 criteria for diagnosis, or not.

If clinicians feel further evidence is required, they can message parents via the app and request additional video evidence. NODA provide a report template and explain how the evidence can be presented to families.

Other details about NODA

- It is a usage-based payment system that The Retreat would pay for – no billing for the CCGs to manage
- The data stored for 7 years, none of video footage is transferred to clinical team, viewing occurs remotely, so The Retreat would not have any issues with storing or handling large data sets.
- NODA build a registration page for us, branded with The Retreat logo
- A registration link is sent to family by NODA and then:-
    - Family registers for NODA
    - The clinician is notified when NODA has been completed.
    - If family registers but then does not complete videos, we don't get charged.
- National Institutes of Health (NIH) funded
- NODA are working on AI system to find key moments of interest – will come along in a few months

Procedures

- Works best to tell families that we are setting this up as first step to any assessment
- Would like to see this done in 7 days or 14 weeks, will only then move forward to next step
- NODA say up to age 7 1/2 (but others have used up to age 8/9)
- Administrator could be the one that sends out links
- Clinician will be notified as soon as first video is uploaded (as sometimes it's only first video you need to see child is clearly autistic)
- Reports come as file and tagging takes 40 to 45 min on average (obvious cases can be more quick, one can