Remote autism assessments: Learning from Islington

#3 of the Responding to Covid-19 Series

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Tele-health is not a new development, but one which has suddenly become very important in the context of Covid-19. In Islington, all face-to-face clinics and assessments were cancelled at the beginning of the lockdown, which led to an immediate and unsustainable increase in the assessment waiting list. It became clear that a flexible approach to autism assessments was required during this time and this document will explore the different tools and methods adopted.

Context for virtual assessments and Covid-19

Important information about tele-health approaches:

- The principles of autism assessment, as laid out in NICE guidance and DSM 5 criteria, remain unchanged;
- Autism assessment still required skilled observation;
- Diagnostic tools are not the final word – they are merely tools that provide useful information;
- It is valid to use an abbreviated autism evaluation process to help increase access to autism assessment. ADOS may be the gold standard, but it is not mandatory. ADOS with a face mask is not ADOS and likewise ADOS on video is not really ADOS, however it is absolutely acceptable to use information from an adapted ADOS process in an assessment;
- Virtual autism assessments are the subject of much research and emerging evidence, particularly in the USA, and this includes the Vanderbilt Kennedy Centre's development of Tele-ASD-PEDs which the Islington approach has drawn from;
- Evidence suggests that tele-diagnostic evaluation has around 78% sensitivity (Juarez et al., 2018).

Using TELE-ASD-PEDs

Islington have trialled Vanderbilt Kennedy Center's TELE-ASD-PED assessment. They had previously used Zoom for child observation and gathered history from parents and professionals, but were missing remote versions of ADOS, which is what had been used where diagnosis was not clear cut.

The Vanderbilt Kennedy Center developed the TELE-ASD-PED assessment for use by providers as a tele-health assessment for autism. In the TELE-ASD-PED approach, a professional guides a parent through the process, giving simple instructions on how the parent should play and interact with their child. It is therefore the parent rather

than clinician who leads the activities. These tasks allow the professional to watch for the presence of autism symptoms and the assessment covers general themes found in ADOS – such as requesting, toy play, turn taking etc. Clear parental instructions are given, broken down into what materials are needed, instructions on what to do and exact wording to use (see example below).

The assessment is broken down into the following themes:

1. Toy play (child-directed)
2. Responding to social bids (name, looking at pictures)
3. Toy play (parent-directed)
4. Requesting (parent-led, bubbles & container with snack, sticker, or toy)
5. "Ready-set-go" play (parent-led, bubbles, balloons, balls, cars)
6. Physical-play (parent-led, tossing, chasing, tickling)

There should be an initial conversation with parents about concerns, normal history taking and then an observation of them playing with their child through free and structured play. Please see Figure one for an example of the guidance given to parents. The play based part of the assessment takes 20-30 minutes. In terms of platforms, Vanderbilt uses Zoom but Islington will soon be moving onto Attend Anywhere.

TELE-ASD-PED is recommended for children up to 4 years and Islington are trialling it across this population. It currently covers ADOS module 1 and some of module 2, with the Kennedy Center currently developing module 2.

Parent instruction sheet

Informal Activities Module 2

- **Below are a list of activities to do with your child and instructions of how to carry each part out. Read this instruction sheet in full and do ask your clinician if you have any questions**
- **Introduction to tell your child "We are going to do some games and talking with Min and Nicole today. We will do some games while they watch and then Min will do some games and talking with you too."**

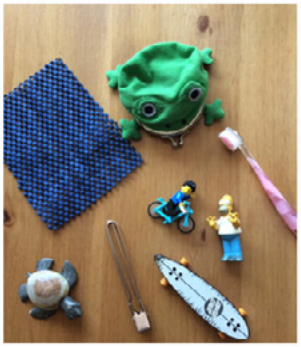
1) Free Play *We want to see how your child plays with a range of different toys*	Some toys you could use.... • Cars/balls • Building blocks • Teddy/doll with cup and plate • Cause and effect toy    	**What to do & What to say** • Show your child the toys you have. Let them explore the toys for about 5 minutes. **Try not to direct their play.** We want to see what they do. • If your child is not interested in the toys after you have left them for a while you can show them some of the toys so we can see what they are interested in e.g. pick up one of the cars or bricks and give it to them to see how they play with it. • If they want to move away, see what they are interested in. It is ok to let them bring different toys over. Try and take a step back from the play and see if your child wants you to join and what they do with the toys.

The scoring system is simple and similar to ADOS. At the end of the process you should have clear idea if they meet DSM 5 criteria.

All the resources are provided for free, as are associated webinars and training available from Vanderbilt Kennedy Center.

Adapted ADOS modules 3 and 4

For over 5s, Islington have used Zoom technology and followed ADOS materials as much as possible, using a similar approach to above but with mixed delivery by the practitioner and the parent.

2) Make believe play *We would like to see how your child plays with 'small world' toys like people, animals, cars etc.*	A range of toys that can be used in make believe play: -Small people/Action figures/Barbie/Play Mobil or Lego people -small animals/stuffed toys/dinosaurs -transport toy like a toy car/plane/boat -Other props such as toy furniture, cleaning cloth, small hair brush, cup, small box ***You don't need all the items above. A small range is ok*** 	**Instructions:** Have all the toys ready in a bag or box and take them out one by one and put them on the table in front of you both. You can talk about what items you are taking out e.g. **"we've got a spiderman, a car, a hair bruish, a small box..."** -Try not to set up the toys in any type of scene. Once the items are on the table encourage your child to play with them in any way they want to. For older children who may not want to play we may say that we want them to make up a movie scene with the toys -Let your child have a go at playing with the toys or making a movie. If they invite you to play you can join. -If your child does not invite you play ask if you can join them after **5 minutes of them playing**. You can ask **"who can I be in the story?"** ***Next step:*** When you join their play try and play in a different way to what they are doing. For example, if their story is about characters fighting you could introduce that your character has a special mission to save the dinosaur. See if they can follow your ideas in play. **What to tell your child (some options):** *"here are lots of different toys. You can play with these now"* *"Can you make a film scene using these toys"* *"Lets try and make a story using these toys. You start first"*
3) Demonstration task	The examiner will lead on this part.	**What to tell your child** ***"Its X's turn to do a game with you now. Lets both look at the screen"***
4) Description of a picture	A picture of a scene with details in We will either email you the photo or	**What to tell your child** "Lets look at the picture with X"

Benefits of virtual assessments

Islington have been able to successful conclude assessments and provide autism diagnosis through these virtual processes. There are a number of key benefits to this method of assessment:

- The child can be seen in an environment which is familiar to them – you do not always see everything in a clinical setting;
- It appoints the parent as co-professionals and partners in the process which was seen as a key benefit;
- Helping the parent to engage in the assessment process gives lots of rich information;
- It was felt that "the joy of this approach is you are more likely to get the best out of the child";
- It is easier to get the professional team together in a virtual way;
- The process is not as rigid as a lot of standardised assessments, you're allowed to repeat things for example. This allows professionals to really see a child's ability to respond to requests;
- The process has had positive feedback. A lot of families are keen to continue with online assessments; they are reluctant to attend health settings and see the process as a tool that is helping them move on with the assessment process.

Issues and challenges:

Whilst there are many benefits, some issues have arisen from this method of delivery:

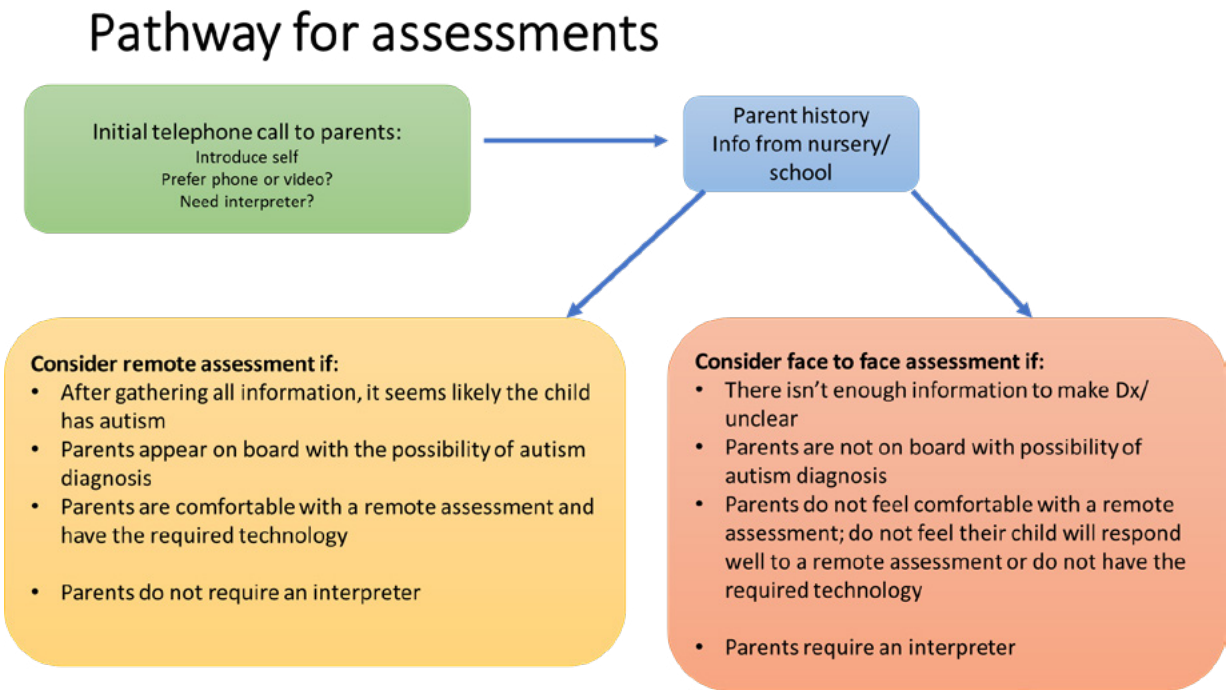
- Evaluating eye contact, integration and facial expressions can be very hard to judge on screen. It is important to remember that the usual rules of eye contact are lost with virtual technologies and practitioners often do not look directly at the camera and therefore are not always looking at the child ourselves.
- Practical issues with the 'demonstration' and 'create a story' tasks, including difficulty placing the camera in a way the activity can be witnessed.
- It can be a more challenging method to use with families who are not sure about wanting an autism diagnosis.
- Some families and children have not engaged well (see key considerations below).
- Virtual assessments were often challenging where there are language barriers, and delivery remained 'clunky' even when using translators.

Key considerations and learning

Selecting children carefully

Not everyone has had positive experiences of virtual ADOS assessment, with some children unable to engage in the process. For it to work well, the child being assessed should be in the right environment; they should be the only child in the room, which also should not have any pets in it room, and they should be free from distractions. Language barriers also reduced the success of virtual assessments, as do parents not being on-board with the possibility of an assessment. Parents must be able to use remote technology, and practitioners should support parents to do this in the ways outlined below. Finally, remote assessments can be particularly valuable where diagnosis or a conclusion seems fairly likely from existing records and information.

The pathway diagram below may be useful to help professionals think through whether a remote assessment is appropriate, though is not intended to be a definitive guide:



Engaging the parent and ensuring they are well prepared

Where virtual assessment worked well, the parent was engaged and prepared, they knew the cues and activities and had set up the camera correctly.

Professionals facilitated this through contact with the parent prior to the sessions to discuss the assessment and what would be needed, including through informal phone calls and trial sessions on Zoom. They also offered pre-assessment family sessions, 'a first family meeting', as an option. Professionals also provided access to all materials in multiple formats, both by email and printed copies that were posted to the family.

Access to technology
There is an issue with lack of IT equipment for some families. However, lots of agencies, charities and schools are currently providing or loaning IT equipment, such as Family Fund and local schools, so this has solved things for some. Direct payments might also be a route to mitigate this, particularly where other children in the household may in receipt.

Similarly many staff have struggled with access to a laptop or iPad. To exacerbate this, Islington found that many of the office computers do not have inbuilt cameras. It may be worthwhile asking local businesses about this, and there have been lots of donations to the NHS. Islington have put in a big capital bid in and hope to have more devices arriving shortly. Also discovered the PCs in their offices don't have video cameras in.

Provide toys if needed
The toys used as part of the assessment are commonly available in most family homes, with a total cost of around £10-15 but this could nevertheless be a barrier to some families participation. Islington are therefore creating a small stock of toys to post out to families who do not have those toys and where cost maybe an issue.

Prioritisation
When rolling out the approach, Islington prioritised children who were about to start primary school, and those who have missed therapy this term. They identified around 40 children who they thought were likely to get diagnosis but needed confirmation. Prioritising this cohort meant they will have the information ready for when they start school in September.

Observers
Observers on the call should decide whether or not to introduce themselves beforehand and should mute and turn their cameras off. Parents should be asked to use speaker view rather than gallery view to hide the observers, and professionals should do the same.

If no conclusion can be reached
Using mixed approaches to assessment can be useful where a final result cannot be reached. This could include families sending videos of their child's usual behaviour and reports from schools and other professionals. Clear Guidance on what to do if a conclusion cannot be met is still lacking however, for example questions over whether it is valid to then conduct a face-to-face ADOS next?_

Other remote assessment option

Gathering clinical information by other methods
This includes parents sending videos of typical behaviour, gathering family history, medical history and school records.

BOSC – Brief Observation of Social Communication

BOSC involves play and conversational tasks, carried out by parents with clinical observation, and should take around 12-14 minutes. There are three versions: for minimally verbal children, phrase speech, and fluent speech:

Healios
Cornwall currently use Healios to deliver online autism assessments on their behalf and Healios also provide feedback through their platform. Cornwall use Helios for straightforward cases, children without complex histories Helios assessment involves observation and interaction, semi-structured play, a developmental interview and a team review process.

Feedback from parents has been largely positive. Helios was regarded as a 'rigorous' and effective process, which also picked up on comorbidities.

However, there is obviously a cost to using the service. Some concerns were expressed about an external organisation doing the assessment as this prevents the assessment becoming part of a developing relationship with the family and therefore reduced continuity of care. The assessment process was felt to be demanding for children, requiring them to sit at the computer for a long time, with some sections taking over 3 hours. Concerns were also expressed that older children had overheard "quite frank and difficult" side conversations between parents and professionals in the developmental interview.

One parent commented: "Helios works well for children willing to engage online. It was module 4 so very demanding, but demanding face to face… It was quite rigorous."

Noda – Naturalistic Observational Diagnostic Assessment
Some areas are using Noda, an app that supports parents to capture behaviour on their mobile phone and which is useful for the second module. It costs £50 per child.

Next steps

Islington are planning to restart face-to-face assessments and are conducting risk assessments. They are prioritising the final part of the autism assessment so they can help families move onto intervention phases.

- Planning has involved procuring visors so the child can see practitioners faces, and in case the child spits;
- Some objects in the ADOS have been changed to things that can be deep cleaned afterwards;
- All changes will apply to everybody so assessments remain standardised;
- Families will be given pre-screening questionnaires to prevent families coming in if infected.

Islington also plan to retain online consultations and reviews and quite a significant part of online assessments. This will allow them to meet social distancing guidelines without reducing the number of children they can assess.