NAIT Guidance on Digital Consultation for Neurodevelopmental Assessment and Diagnosis across the Lifespan

Context

This guidance was written in August 2020, in the context of COVID-19, because practitioners across professions sought consensus on whether and how assessment and diagnosis of neurodevelopmental presentations (including autism) can be undertaken with little or no face to face contact.

COVID-19 has led to sudden and unexpected practice changes for those undertaking neurodevelopmental assessment and diagnosis of children and adults.

There are potential opportunities arising as technological solutions are rapidly embraced in clinical practice. However there is limited research to draw on and practitioners are relying on pragmatic decisions about clinical practice. The NAIT team have developed this guidance relevant to local pathways in the current context, through:

- consultation with expert practitioners from a range of professions, working across the lifespan with individuals at different developmental stages
- review of literature evidence
- review of guidance from professional bodies currently available

A timely and accurate diagnostic assessment continues to be an important step for many. Although support for individuals should be available according to need and should not be diagnosis dependent, we know that access to early, person centred and efficient diagnostic assessment increases access to trusted, relevant information and support for autistic individuals and those with related needs, thus improving adaptive functioning and daily life experiences. Receiving a diagnosis can be a key moment, when individuals or families are provided with a construct to begin to interpret their past and future life experiences.

Most NHS health boards, continue to receive referrals for neurodevelopmental assessment but with the pause in direct 'non-urgent' face to face clinical appointments, waiting lists have increased. In some services, there has been an opportunity to redirect resources, with waiting lists being reduced, through use of digital technologies.

A local autism or neurodevelopmental pathway is recommended as a source of guidance and consensus across teams within a locality. Some services are using this time to develop and review existing pathways. See NAIT and Autism Achieve Alliance research and resources to support this process www.thirdspace.scot.

Consultation with autistic individuals and their families, together with evaluation of the experience of those receiving digital consultation for neurodevelopmental assessment is underway in local areas and should inform future guidance.

Key Messages for Practitioners

1. Provide support, information and intervention to those awaiting assessment based on need (not diagnosis)
2. Seek to make timely diagnostic assessment available locally
3. Continue to undertake diagnostic assessment
   a) It is possible to start and complete 'core' (more straightforward) diagnostic assessment for neurodevelopmental disorders through digital consultation, for some individuals
   b) Some 'complex' assessments cannot be completed to adequate standard without face to face contact
   c) Critical background information, such as a developmental history, or information from third parties, can be gathered without face to face contact e.g. questionnaires/ written reports
4. A robust triage team and pathway process for early identification of likely 'core' and 'complex' referrals is fundamental to effective and efficient diagnostic assessment
5. All assessments should follow the same thresholds, key components and standards for diagnostic assessment, regardless of mode
6. Key components for assessment must be gathered through both observation and report. This can start by phone but phone consultation alone is not advised.
7. Diagnosis can be made by a range of professionals from the team, with appropriate skills, experience and knowledge. No single profession is required to sign off diagnosis but it works best with MDT discussion to maintain fidelity and consistency
8. Most assessments can be completed by community teams, with capacity to assess the full range of neurodevelopmental issues, with specialist or broader team involvement where complexity is identified
9. Be prepared – gather as much information and share appropriate information in advance of any appointment
10. For digital consultation provide additional structure and visual supports

Communicating in a virtual world

Digital Health and Care Scotland guidance is as follows:

Virtual Platforms

- "Near Me" should be used by public sector practitioners when in conversations with autistic individuals, and their families
- The use of Microsoft Teams is encouraged as a secure communication and collaboration tool across the public sector in Scotland.
- It allows for *peer to peer* communications i.e. between Allied Health Professionals (AHPs), other health professionals, and with teachers
- There is a capacity within Microsoft Teams for patients to join, when there are more people than Near Me allows to attend the meeting. This requires an additional licence.

Confidential information e-mailed out with NHS Board

- This can be done if there is a data sharing agreement in place between the NHS board and where professionals are sending the information e.g., local authority.
- Professionals need to confirm there is a data sharing agreement in place.
- If a data sharing agreement is not in place, they can ask their line manager to progress this with urgency to comply with legal frameworks.

Sending information from your named e-mail

- Professionals can e-mail about public non-confidential information from their named e-mail account e.g., providing a parent with a link to useful information or setting up an appointment for the individual being assessed
- Professionals should not exchange confidential information about an individual referred to the service using their named e-mail account. In this situation, they should set up a service e-mail address to exchange information. Please encourage referred individuals and their families to set up gmail accounts and ensure they use it in the confidential mode

In other parts of the UK, local digital guidance and platforms may apply.

Autism Assessment – Core Components

The same thresholds and standards for diagnosis according to DSM 5 or ICD criteria apply regardless of the medium of assessment. Diagnosis should not be made by phone call alone or through compromise in terms of key components. SIGN (2016) guidelines and NICE (2011; 2012) guidelines recommend key components to every diagnostic assessment:

1. Multidisciplinary assessment by skilled professionals and more than one practitioner involved
2. Early developmental history and current clinical history
3. Direct observation
4. Contextual assessment
5. Assessment (including assessment of language and communication, adaptive functioning, cognition/ learning and paediatric or other medical examination) which takes account of all possible neurodevelopmental diagnoses. Autism rarely occurs in isolation
6. A formulation that references the definitions of DSM 5 or ICD-11'

Use of standardised autism specific assessment tools (such as ADOS or ADI-r) is recommended for more complex cases

Considerations

The new additional consideration is whether further contact within local physical distancing guidelines is deemed necessary.

The specific approach to assessment will depend on:

- The individual's age and developmental stage
- Access to information/previous reports/ informants for assessment of core components
- Complexity in presentation of the individual and their circumstances
- The skill and experience of diagnosing clinicians in relation to autism at this age/stage and possible underlying reasons or co-occurring presentations
- The means of assessment – different tools lend themselves to different modes of contact

In the COVID context, protocols may need to be updated in preparation for remote or face to face appointments. In advance of the appointment:

- Ensure you have gathered pre-assessment information and consent needed

- Share clear and developmentally relevant information/ instructions about what the individual should expect at the appointment
- State the start and finish time (and stick to them)
- State who will be present/ observing (e.g. it may be possible to involve multi-disciplinary team members or trainees, with limited intrusion providing this is done with consent)
- Provide information about what to expect following the appointment
- Be prepared with a 'technology fail' plan. If the appointment cannot go ahead because of a problem in the moment, it is helpful to be prepared, for example with clarity over how long to persist trying and an agreement to follow up in 24 hours with a telephone call or email

For children and young people with developmental delay, full diagnostic workup requires face to face contact for physical examination by a paediatrician and may require medical investigation.

Factors which may affect remote assessment

A range of factors may introduce complexity to the assessment process, which in turn require adaptations to practice or involvement of specialist practitioners to ensure equal access to robust and timely assessment. The following factors may particularly affect remote assessments:

Preference

- Individuals or families may prefer to wait for face to face assessment
- Previous trusting relationships – whether an individual or family have previously built a rapport with the clinician(s) may affect preference

Practical requirements for individuals

- Requirement for translation of assessment materials and reports or interpretation services
- Disability which limits effective use of phone or video for assessment (e.g. deafness, visual impairments)
- Technology – limited Wi-Fi or access to a suitable device for staff or family

Clinical factors

- A home environment which makes undertaking structured assessment activity difficult
- How easily clinicians can facilitate access to relevant resources at home (e.g. specific toys or games)
- Discrepancies in reports from different aspects of the assessment (e.g. between school and home or clinical history and observation)
- Clinically unclear or subtle presentations (e.g. where symptoms are less manifest in certain environments, are not recognised by some in certain settings, or where individuals have developed coping strategies of covering up signs. This has more recently included reference to 'masking or camouflaging' difficulties experienced)
- The need to take account of possible co-occurring neurodevelopmental diagnoses
- Clinician and patient factors affecting confidence, skill and experience with remote assessment
- High levels of distress (NB. we do not recommend that parents or informants make or share recordings of individuals displaying significant distress)
- Remote assessment alone is not recommended and face to face assessment is recommended when there is significant clinical risk (e.g. a risk of harm to self/others) or where there is complexity in making diagnosis

Factors which may affect face to face assessment

For the foreseeable future, face to face assessment (in clinics, home visits, schools or other community settings) will have to be undertaken under the latest local and national physical distancing and infection control guidance. Professional bodies have provided helpful guidance applicable to clinicians to assist with clinical decision making about when this is indicated and how to carry it out safely (e.g. RCPCH, RCSLT, RCPsych, RCOT, British Medical Association). Where possible, evidence is being gathered about the experience for clinicians and individuals being assessed in an evolving context.

Whatever form the interview takes, the clinician should take account of the guidance to be had from the individual, their family/carers and friends. There is no need to approach an interview blind.

There may be particular considerations for autistic individuals and the following factors may particularly affect face to face assessments:

The environment

- The clinical environment could be modified to allow assessment to take place (e.g. through perspex screens or observation rooms with mirrors and audio-visual communication / recording)
- A clear, uncluttered environment reduces cleaning required following each appointment
- Limit duration of contact and allow for the most effective use of time to observe and assess aspects that could not be assessed in other ways through careful preparation of the session and information gathering prior to face to face contact
- Use of visual supports could support engagement, with clarity over the start and finish of each part of the session (e.g. a visual timetable or list of what will happen, a timer and physical resources required placed in numbered boxes that can be opened/closed in sequence)
- Some individuals could be seen using a 'walking assessment' outside, with appropriate planning and risk assessment

Personal Protective Equipment (PPE)

- PPE worn by staff could be unexpected or frightening. Advanced preparations could help (e.g. photos or videos or practice PPE for home that they can touch)
- Face coverings could limit opportunities for naturalistic assessment of social communication. If face coverings are required, a transparent visor is preferable to a mask which prevents visibility of the full face Take advice from the individual or family about their preference.

Developmental stage

- Some individuals are well able to understand and follow physical distancing rules, providing these are clear (visual supports can act as a prompt)
- Some individuals are not able to follow physical distancing rules. Check in advance if this is a risk and agree with your team how to proceed in accordance with local guidance
- Some individuals require object exchange or sharing of objects in play and communication – two sets of matching objects might be helpful to reduce risk

Remote Assessment

Clinicians are encouraged to maximise use of digital technologies. Different components of assessment lend themselves more or less well to this approach.

For any remote assessment, planning and preparation relevant to the individual(s) attending an appointment are essential.

Effectiveness can be optimised by the following measures:

- Training and information about using NHS platforms is available via NHS Education for Scotland (for example 'Near Me', which can be used for appointments with 'patients or 'Teams', which can be used for meetings with professionals)
- The use of a stand/ holder/ tripod for your device allows free movement during the consultation
- An external microphone can improve sound quality
- Provide clear, easy read and visual guidance prior to appointments or with any written communication. This could include:
    - A contact point for any queries
    - Who will be involved with the phone/ video call from the clinicians' side
    - A statement that sessions will not be recorded from the clinicians' side
    - Clear expectations that consultations will not be recorded from the client's side
    - A statement the clinician will want to know who is present at the consultation from the client's side
    - A list of resources/ toys parents need to gather or delivering a box of resources for parents to use in a particular way during a video call
    - Stating the duration of the appointment (we suggest limiting the duration to an hour or less and stick to planned timing)
- Consider using slides or a white board with pre-prepared illustrations/ schedule during video calls

Considerations for key components of assessment:

1. Multidisciplinary Assessment with more than one practitioner involved

- If not already in place, seek to set up local protocols and a single point of access for requests for neurodevelopmental assessment which follow an appropriate sequence and avoid individuals being passed on via multiple waiting lists or duplication of assessment
- Platforms such as "Near Me hosted by Attend Anywhere" allow up to five different professionals joining a consultation, opening opportunities for more efficient working
- Identify new processes for multi-disciplinary communication, such as video or phone conferencing or email. Ensure staff know about these
- Provide training, mentoring and peer support
- Clarify contacts for peer support and preferred process
- Start assessments with careful review of previous reports and evidence from a range of sources. There may be information from colleagues, with reports of assessment findings relevant to the diagnostic assessment
- If possible, it is helpful to have two screens, one for viewing reports and records and one for the consultation

- Diagnostic assessment does not require any particular professional (see NAIT guidance on who can diagnose autism). It requires clinicians to have skills relevant to the individual presentation
- Review training and skills within community and specialist teams to support increasing capacity (see NAIT resources below)

2. Early Developmental History and Current Clinical History

An autism relevant clinical history includes consideration of early development and family history, together with current presentation.

- This aspect of assessment lends itself well to remote assessment and can be done using standardised or non-standardised tools through:
  a) Verbal interview with the informant(s) (e.g. ADI-r or local proforma)
  b) Questionnaires returned in writing by informant(s)
  c) Online screening tools (e.g. DAWBA)

- It is helpful to gather 'history' information prior to observational assessment
- Families often tell us that they tell people the same story over and over. We now have an opportunity to reduce duplication and to undertake more focussed assessment using digital consultation
- The 'history' can be gathered over time or in a single appointment and could be requested from referrers or individual requesting assessment as a requirement for referral to proceed
- It is possible to send a questionnaire and follow up with a verbal interview to discuss particular aspects of the clinical history which require more in-depth discussion
- Stamped addressed envelopes are recommended to support engagement and equality of access for families, when asking them to return written questionnaires
- Standardised tools are recommended in complex cases (e.g. ADI-r or 3Di)

3. Direct Observation

This component of assessment usually occurs face to face, in a home or clinic setting. It may be the most difficult to achieve remotely, particularly when individuals have come to 'mask' overt signs or where these are subtle. Direct observation can be completed through structured non-standardised observations and in complex cases a standardised assessment tool such as the ADOS is recommended.

Structured non standardised observation

- Make use of reports of direct observation by a clinician prior to COVID-19, which provides adequate evidence that reported behaviours have also been observed
- Direct observation may be possible through short live or recorded video (up to 15 minutes) or in the same room with a perspex screen
- For best results a highly structured and planned session is advised. The BOSA (Brief Obervation of Symptoms of Autism) or assessment videos shared by UCLA Cart(in YouTube clip links below) provide good examples of structured and developmentally relevant ways to elicit conversation, which can include:
  a) Conversation based assessment : for younger children, this involves talking about an object present and in sight/ reach of two people talking and for older children or adults, a game of Jenga with question cards before each turn is an example activity

b) Object based assessment - the clinician can prepare in advance a set of resources in numbered boxes, to be opened, used and 'finished' in sequence, either by a parent or by the individual themselves

- The clinician could offer coaching and advice to a parent with regard to what to do with the objects in each box

Standardised observation assessment

- It is not possible to complete standardised observational assessment remotely and therefore the limitations of a remote assessment may mean that it is not possible to reach a final diagnostic conclusion without a face-to-face interview
- An 'ADOS informed' observation may be possible, so that aspects of the ADOS assessment or related activities could be carried out. This should always be reported descriptively and algorithms or scoring from standardised tools should not be applied

4. Contextual Assessment

It is important to identify how the individual presents in a range of day to day contexts

In children and young people:

- This information can be gathered initially by report through standardised questionnaires (e.g. Social Responsiveness Scale for Home and School)
- You can carry out an in-depth follow up verbal interview with school staff following return of the questionnaire to better understand any discrepancy

Where there is clear <u>consistency between informants</u> using a standardised instrument there is usually no need to undertake direct observation outside of the clinic setting for the purpose of diagnostic assessment (e.g. Social Responsiveness Scale results, from school and home). In such cases, there is a high chance of matching observations in clinic being representative of the child across settings. Teachers know the child or young person well over time and school visits by health professionals may add significant extra time and yet yield little in addition that would change the diagnostic outcome. These may form part of planning for support when possible but should not hinder the diagnostic process.

Where there is <u>discrepancy between informants in different contexts</u>, or where consistency is 'borderline', ADOS informed school observation may be recommended. This is involves:

- specifically noting natural opportunities and 'presses' made by others in the situation, as well as the child's actions
- thinking about the same kinds of things observed in an ADOS assessment. For example, we would not only write down the language used but also, the purpose of communication, the frequency and the quality of nonverbal and verbal communication
- Be aware that you are likely to observe very different behaviours in a routine, familiar and preferred activity compared to a new or less preferred task.
- It is just as important to identify what the situation did <u>not</u> allow you to observe, as it is to report what you saw. For example, in a silent reading activity, you may observe the child does not initiate communication but that might not be unexpected

In the COVID context, there is likely to be reduced opportunity for clinicians to visit schools to make observations of individuals.

- Some visits may be possible with precautions in place
- Where school visits by clinicians are not possible, remote assessment procedures should be agreed with local schools
- **Live video classroom assessment**: the clinician could ask the school staff (with relevant consent) to set up a particular situation or activity, which elicits natural but structured opportunities for the individual to initiate and engage in social interaction and to move and participate within the class.
- Careful planning and clear guidance to all involved are essential to gather relevant and useful information. Protocols may be required to support confidentiality and adherence to guidelines. Do not record these observations.

In adults

- Contextual assessment is not a key component for diagnosis in adults without intellectual disability. It would be rare to observe an individual outside of the clinic context or to ask employers to complete a questionnaire about autism signs
- For assessment of individuals with Intellectual disability, adaptations such as those for schools (above) may be relevant for contextual assessment in daytime or care settings
- For all adults, collateral history (gathering information about the individual in a range of contexts or from family informants) can be gathered via remote assessment Use of this mode of communication may make this easier compared to a face to face interview, requiring less time for the informant to need to set aside and reducing the need to take time of work, source childcare etc.
- Functional impairment rating scales, such as the WHO Disability Assessment Schedule 2.0 (WHODAS), can be sent in advance of teams initiating contact, to assist triage

5. Assessment which takes account of all possible Neurodevelopmental Diagnoses

In acknowledgement that autism rarely occurs in isolation, all comment on 'behaviours' should be made with reference to the context in which they occur and developmental level and expectations. (Including assessment of language and communication, adaptive functioning, cognition/ learning and paediatric or other medical examination).

Accurate diagnosis, which leads to meaningful outcomes for the individual and family requires a good understanding of the individuals' skills across the domains mentioned. Ideally the relevant professionals required to complete the assessment should be part of the team and should be involved following triage of the initial referral.

6. Formulation with Reference to DSM 5 or ICD Diagnostic Criteria

Through formulation, experienced clinicians collate the components of assessment gathered through both report and direct clinical contact/ observation. Consideration is given to:

- Developmental stage and expectations
- All potential explanations for signs observed

- Autism Spectrum Disorder diagnostic criteria
- Co-occurring relevant diagnoses
- Further assessment required
- Functional implications for the individual in relation to appropriate support and information they require

This discussion between clinicians may now need to take place remotely (see communicating in a virtual world section)

Sharing the Diagnosis

The assessment findings and diagnosis are then shared with the individual and/ or their parent carer verbally which could include the use of video conferencing. This is followed up by written report.

- Find out in advance – what method of communication the patient/carer prefers
- Provide information in inclusive and accessible formats
- Ascertain in advance if there someone who can be there with them to help them understand and process the information you share
- Be prepared to share relevant information and signposting, with immediate options in case individuals/ families need this. This could be a number to call or a contact, a link to local information and support or relevant websites
- Make sure you have set aside adequate time for this appointment and communicated the likely time needed to the patient and carers
- Through the assessment the clinicians should have picked up on aspirations and expectations of the diagnostic process and this should inform how news is shared.
- Reactions can vary widely and 'sharing difficult news' is an important clinical skill, doing so remotely adds complexity. This may be helpful training to offer clinicians at this time, through NHS Education for Scotland and/or local NHS training and CPD
- Keep your communication brief and clear and practice active listening
- Often a further follow up appointment is helpful shortly after the diagnosis is shared, to allow the individual/ family to ask questions and discuss what the diagnosis means for them

If services have a website, it may be helpful to post information that previously we would have handed out in printed form, so that we can signpost to one key location.

Sources of Information

Clinical Guidelines

- NICE (2011) Autism: recognition, referral and diagnosis of children and young people on the autism spectrum (NICE clinical guideline 128) https://www.nice.org.uk/guidance/cg128
- NICE (2012) Autism: recognition, referral, diagnosis and management of adults on the autism spectrum (NICE clinical guideline 142) https://www.nice.org.uk/guidance/cg142/chapter/guidance#identification-and-assessment
- NICE (2014) Autism Quality Standard https://www.nice.org.uk/guidance/qs51
- SIGN (2016) SIGN 145 https://www.sign.ac.uk/assets/sign145.pdf

Professional Bodies, Expert clinicians and Government guidance

- 'Assessments in This Time of Social Distancing' Cathy Lord UCLA video https://www.youtube.com/watch?v=sOGv8vbJeeo
- Brief Observation of Symptoms of Autism (BOSA) https://youtu.be/WqzCm8roJy8
- 'RCPCH COVID guidance for Community Settings' https://www.rcpch.ac.uk/sites/default/files/generated-pdf/document/COVID-19---guidance-for-community-settings.pdf
- RCPsych COVID-19 resources https://www.rcpsych.ac.uk/about-us/responding-to-covid-19/responding-to-covid-19-guidance-for-clinicians/covid-19-international-resources
- RCSLT Telehealth guidance https://www.rcslt.org/members/delivering-quality-services/telehealth/telehealth-guidance
- BMA Video Consultations and Home Working https://www.bma.org.uk/advice-and-support/covid-19/adapting-to-covid/covid-19-video-consultations-and-homeworking
- RCOT COVID-19 resources https://www.rcot.co.uk/coronavirus-covid-19-0
- Chartered Society of Physiotherapists Digital Resources https://www.csp.org.uk/professional-clinical/digital-physio
- NHS Education for Scotland Resources for Remote Consulting and Recruitment https://learn.nes.nhs.scot/28943/coronavirus-covid-19/remote-consulting-and-recruitment
- COVID-19 and Near Me https://tec.scot/ or visit https://www.nearme.scot
- Digital Health and Care Scotland Resources Update from the Scottish Government's Digital Directorate, which has established a central point of information in relation to Digital Health & Care. https://mailchi.mp/a7fb8dccccc6/digital-health-and-care-supporting-covid-19-response-update-no-12?e=eecd5a23ba

NAIT resources about assessment and diagnosis and supports and interventions www.thirdspace.scot **including:**

- NAIT Guidance on who can diagnose autism https://www.thirdspace.scot/wp-content/uploads/2020/01/NAIT-Guidance-on-Who-Can-Diagnose-Autism.pdf
- NAIT knowledge and skills survey for practitioners undertaking autism assessment in child services https://www.thirdspace.scot/wp-content/uploads/2020/05/NAIT-Knowledge-and-skills-survey-for-autism-practitioners-undertaking-diagnostic-assessment-in-child-services.pdf and adult services https://www.thirdspace.scot/wp-content/uploads/2020/01/NAIT-ASD-staff-knowledge-and-skills-combined-survey-Adult-services.pdf