How to use... an autism assessment tool

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INTRODUCTION

Autism is a neurodevelopmental condition affecting three main areas: social communication, social interaction and restricted patterns of behaviour, interests and activities. The Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM IV) requires six or more clinical manifestations across the three areas.1 In the International Classification of Disease, version 10 (ICD-10) childhood autism is under the umbrella heading of ‘pervasive developmental disorders’. Here the diagnosis includes the same three areas, manifestations of which should be seen by the age of 3 years. However, initial presentation may well consist of what ICD-10 describes as additional non-specific problems such as sleeping and eating disturbances, temper tantrums, aggression and phobias.2 The UK prevalence of autistic spectrum disorder (ASD) is thought to be from 60 per 10 000 to one per 100, although obviously studies vary in the frequency.3 It is important to note that these instruments are most appropriately used as a wider assessment of the child or young person, their current functioning and a detailed developmental history. When scored they provide a diagnostic cut-off within the scoring. They are, however, entirely dependent on parental report. The autism diagnostic interview (ADI-R) and 3di are all structured interviews which may introduce initial screening (including questionnaires), thorough history taking and observation in the clinic. It may also include observation in different settings such as the school or a specific observation group within the health service, including assessments from a range of multidisciplinary team members including speech and language therapists and occupational therapists. There is also the opportunity to use specific diagnostic instruments as part of the assessment (see box 1 for examples).

Both the Scottish Intercollegiate Guideline Network autism guideline number 98 and the recently published National Institute for Health and Clinical Excellence (NICE) guidelines do not support general screening in the population for autism. However, they both emphasise the importance of listening to concerned parents and suggest surveillance tools to use in these cases. Specialist assessment is the key to successful diagnosis, and clinicians performing this should be confident that they have acquired the skills to do so, as they are giving a life-long ‘label’ to individuals. The Scottish Intercollegiate Guideline Network and NICE guidelines support the use of a multidisciplinary team and the importance of history taking and observation. Diagnostic instruments are described as supplements to clinical observation.

When selecting a diagnostic instrument it is useful to consider some basic questions (see box 2).

The diagnostic interview for social communication disorders, the autism diagnostic interview – revised (ADI-R) and 3di are all structured interviews carried out with parents. They enable the clinician to gather very detailed information about the child or young person, their current functioning and a detailed developmental history. When scored they provide a diagnostic cut-off within the scoring. They are, however, entirely based on parental report. The autism diagnostic observation schedule (ADOS) is the only tool that provides a semi-structured direct assessment of the child or young person. It is important to note that these instruments are most appropriately used as a wider assessment of the child and that history and direct observation remain of great importance, particularly in distinguishing other possible...
diagnoses. The instrument will help support the diagnosis and can often be used to demonstrate particular areas of strength and difficulty to those providing further support such as local ASD services, education and the family.

This paper will further explore the use of the ADOS, as it is the only direct observation tool that is in widespread use that has been extensively commented on in the literature. The literature search strategy for this paper is published as an online supplementary appendix.

ADMINISTRATION OF THE ADOS

The ADOS is designed for use by professionals who already have familiarity with autism. It can be used with both adults and children, but for the purpose of this paper the person under assessment is referred to as a child. The ADOS is a semistructured standardised assessment that looks at a child’s social and communication skills and their behaviour. The ADOS provides a way to gather structured information based on observation of a child in a clinical setting in a relatively short period of time, and by using specific tasks that may result in the difficulties seen in autism and ASD becoming more apparent than they may otherwise be within a usual clinic setting. It can be administered in approximately 40 min.

There are four modules, which the professional selects based on a child’s level of expressive language.
- Module 1 for children who do not consistently use phrased speech.
- Module 2 for children who use phrased speech but who are not verbally fluent.
- Module 3 for a child/young person with fluent speech.
- Module 4 for young people/adults with fluent speech.

In the generic ADOS the modules each contain a series of tasks that vary depending on the module used, and notes should be taken during the task. Examples of the tasks are:
- Module 1—bubble play—to see if a child will request more bubbles.
- Module 2—birthday party—to see if a child will engage in symbolic and functional play.
- Module 3—cartoons—observe the way a young person narrates a story possibly using gestures.
- Module 4—create a story—observe creativity in a situation using objects to make up a story.

In 2009 a new module for use with toddlers aged under 30 months (with a non-verbal mental age of at least 12 months) was also developed. Scoring of the ADOS is based on the observations of the child’s behaviour throughout the ADOS only. In younger children ADOS scoring involves the absence of consistent social interaction and communication rather than the presence of an abnormality. There are items scored for communication, social interactions and stereotyped behaviours and restricted interests. Each item is scored from 0 (no abnormality) to 2 or 3 (moderate to severe abnormality) depending on the individual item. The ADOS training suggests that odd behaviours are considered stereotyped behaviours; however, it may be that in an immature child their odd behaviour, for example, frequent requests for information, may be difficult for the clinician to determine if truly a stereotyped behaviour.

These scores are placed into a diagnostic algorithm that provides cut-offs for both autism and autism spectrum disorder. There are no specific scores for a diagnosis of Asperger’s syndrome, but this diagnosis is considered as a clinical diagnosis after exceeding autism thresholds.

While training in the use of the ADOS is recommended, it is not essential for professionals to attend a training course for clinical use of the ADOS material. There is an ADOS training package consisting of DVD demonstrations in the use of the materials, which is suitable for clinical use of the ADOS.

For those who intend to use the ADOS for research purposes, there are approved ADOS training courses available in the UK and USA.
Materials for the ADOS, including training materials, are available from Hogrefe (www.hogrefe.co.uk) or Western Psychological Services (based in the USA).

TECHNOLOGICAL BACKGROUND
The ADOS was originally formulated from an early research version of the ADOS13 and a pre-linguistic ADOS.14 These tools allowed a standard way of observing the social interaction and play of children with suspected autism. They were combined into a single tool to be used in regular clinical practice by trained clinicians.

In preliminary versions of the ADOS15 numerous tasks, or items, which might highlight poor social interaction or particular autistic behaviour, were thought up. The ADOS items were then validated using a large sample of children that were already known to have a diagnosis of autism, ASD or no diagnosis of autism. These items were evaluated to see how well they differentiated between the three groups of children. Those items that did not score differently between the groups were excluded. With the items remaining, a statistical technique called ‘exploratory factor analysis’ was used. This technique looked at which items, when their scores were grouped, signified problems in a particular domain related to the diagnosis of autism, for example, social interaction. Overall, thresholds were set for scores in the domains of social interaction and communication. By looking at the scores for all the children in the validation study, cut-off points in the scores were found for autism and ASD. It was felt that scores for those items grouped in stereotyped behaviours and restricted interests did not distinguish well enough between different clinical groups of children.

As a result of various problems identified with the original ADOS a revision was undertaken.16 The particular issues addressed were the effect of a child’s mental age, verbal ability and chronological age on their scoring within a particular module. Further validation of the items was carried out to try and adjust for these problems and improve the sensitivities and specificities in some of the ADOS modules.

CLINICAL QUESTIONS
In a child referred to a neurodevelopmental clinic can the ADOS assessment determine whether they have autism?
Current guidelines on assessment for autism all indicate that any specific tool used in the assessment of autism should not be used on its own but alongside a full developmental history, examination, and have taken into account developmental concerns expressed by parents, other health professionals and schools.

Certain variables will affect which module of the ADOS is administered, such as age of the child, their verbal abilities and any learning disability. The sensitivity and specificity of the ADOS changes depending on these variables.

Both the original and revised ADOS reports sensitivities and specificities for each module. However, these values, with attempts at replication, have been debated in the literature. The recently published NICE guidelines7 have summarised the ADOS sensitivities and specificities from studies in the literature. The NICE guidelines did, however, emphasise that the evidence came from nine studies, all deemed to be of low quality. They were able to look at subgroup analysis for children under 5 years and children with an intellectual disability. There were not studies of sufficient quality to look at any other subgroup analysis such as age ranges above 5 years. Overall, the accuracy in diagnosing autism compared to the DSM-IV or ICD-10 criteria was 91% sensitivity and 75% specificity. Table 1 gives these figures and includes the subgroup analysis. The likelihood ratios have been calculated from the sensitivities and specificities (likelihood ratio of a positive test = sensitivity/ (1−specificity)).

As a child undergoing an ADOS assessment has already been referred to an autism assessment service and had a full developmental history and other possible assessments, they are in a clinical group much more likely to have autism. This clearly influences the post-test probability. Table 2 gives the positive

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<tr>
<th>Table 1</th>
<th>Sensitivity and specificities direct from NICE guideline7</th>
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<tbody>
<tr>
<td>Accuracy in diagnosing autism compared to DSM-IV or ICD-10 criteria</td>
<td>91</td>
</tr>
<tr>
<td>Children with an intellectual disability (subgroup analysis)</td>
<td>85</td>
</tr>
<tr>
<td>Children 5 years and under (subgroup analysis)</td>
<td>89</td>
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<th>Table 2</th>
<th>Post test probability that ADOS supports autism diagnosis.</th>
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<tr>
<td>Post-test probability that ADOS supports autism diagnosis</td>
<td>General population (autism prevalence 1%)8</td>
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<tr>
<td>Overall (no subgroup analysis)</td>
<td>5</td>
</tr>
<tr>
<td>Children with an intellectual disability</td>
<td>10</td>
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<tr>
<td>Children under the age of 5 years</td>
<td>5</td>
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ADOS, autism diagnostic observation schedule.
post-test probabilities for different clinical scenarios, assuming a general population prevalence of 1%6 and a prevalence in those referred to a neurodevelopmental clinic, in the lower range of that reported in the literature, of 53%.17 18 The positive post-test probabilities have been calculated from the likelihood ratios in table 1.

Therefore, a child being assessed in a neurodevelopmental clinic who has an ADOS assessment has a 80.4% probability of having autism if the ADOS results are positive. The post-test probability is much less, only 5%, if a child from the general population were to undergo an ADOS assessment. This clearly illustrates that an ADOS assessment is only useful when a child, as a result of their neurodevelopmental history, raises the strong suspicion of autism. The post-test probability is highest, 89.7%, in the subgroup of those with an intellectual disability, showing that ADOS is a very useful tool in this group of children who are often referred for an autism assessment.

In a child referred to a neurodevelopmental clinic can an ADOS assessment rule out autism?
The ability to rule out a condition as well as make a diagnosis is always an important part of any type of test. There are other emotional and behavioural conditions that have symptoms in common with autism, for example, attachment disorders and previous severe neglect, in which the child seems to show little affection and interest in those around them. Some children, often with a learning disability, can show quite obsessional behaviours, raising the possibility of autism. Therefore, the ability of a test in autism to rule it out can also be extremely important so children and young people are not given an inaccurate diagnosis that will influence long-term care and provision.

Table 3 gives the post-test probability of autism not being present.

If a child in a neurodevelopmental clinic has an ADOS assessment that does not score significantly, there is only an 11.9% probability that the test is truly negative. Therefore, a negative result on an ADOS assessment does not in itself allow a confident decision to reject an autism diagnosis. This decision will need to be made by considering all the evidence from a comprehensive assessment looking at developmental history, medical history and evidence from different settings that the child spends time in.

Should general paediatricians refer for an ADOS assessment every child whose parents raise concerns about autism?
As has become clear looking at the two scenarios above, an ADOS assessment in itself will not provide a definitive answer to the question ‘does my child have autism?’ What is important and is heavily emphasised by the recent NICE guideline is that there is a clear pathway to refer to for exploring parents’ concerns around autism, gathering all the relevant information and evidence and putting this all together, by a dedicated autism team.

Therefore, if a general paediatrician feels that the parental concerns are significant and valid, fitting in with possible symptoms and signs of autism, then a referral to a local autism team should always be made. If the parental concerns do not fit in with symptoms and signs of autism, either direct consultation to the local autism team for advice, or referral to another service, for example, a local community paediatrician is a possible way forward, as recommended by NICE. There are screening tools, for example, questionnaires, to identify children and young people with an increased likelihood of autism, but these should not be used alone to decide whether to make a referral.

LIMITATIONS
As with many of the neurodevelopmental conditions, for example, attention deficit hyperactivity disorder and dyspraxia, there is no absolute accepted gold standard test for the diagnosis of autism. There are clear diagnostic criteria for autism and Asperger’s syndrome (DSM-IV) and childhood autism (ICD-10), but there will always be a degree of subjective interpretation by professionals of these criteria. Therefore, when calculating the sensitivity and specificity of the test this is always going to be determined by comparing with a clinical diagnosis of autism or ASD, which may be subject to individual clinical bias.

Similarly, there is the risk of subjective differences in how an individual professional scores a child’s behaviour on the ADOS. Interrater reliability has always been reported as very good for the ADOS if clinicians are appropriately trained.11 The ADOS manual recommends that individual clinicians check they are rating the ADOS similarly to experienced colleagues several times a year, to prevent problems with interrater reliability. However, there will always be a concern that the subjective nature of the rating will introduce bias.

The sensitivity and specificity of the ADOS in relation to children with varying degrees of learning disability has been debated in the literature.19 20 A clinical diagnosis of autism can be more difficult in those children with a very low level of functioning, as their learning disability may limit their ability to interact socially and they may only show a limited range of behaviours. The ADOS is difficult to administer to...
children with a profound learning disability. A study in The Netherlands suggested that in a sample of children with a varying range of learning disabilities, the ADOS classifications appeared least valid for those with a mild learning disability.\(^\text{21}\) The revised version of the ADOS has tried to address these concerns, and certainly the most recent analysis of studies done in this area (NICE)\(^\text{7}\) shows that the sensitivity and specificity are now much improved for ADOS in children with learning disabilities.

Autism is sometimes suspected in children with other types of disabilities. However, the ADOS cannot be formally administered and scored for children who are deaf (but can be used informally to provide observations), and in module 1 it cannot be used in children who cannot walk.

A further consideration is that the ADOS was formulated in America and tested on American children. In the original sample the percentage of ethnic minorities was low, with 11% African American, 4% Hispanic, 2% Asian American and 2% mixed ethnic groups. This was slightly increased in the revision with up to 27% African American. Children’s reaction to some of the activities in the ADOS might vary in relation to their country of origin and culture, for example, module 3—talking about friends and marriage.

**FURTHER RESEARCH**

The original ADOS tool has already been refined to try and account for a child or young person’s level of learning disability or language impairment. However, further use in the research setting with different populations will continue to contribute to the validation of ADOS as a useful reliable tool as part of an autism assessment. ADOS is often used in conjunction with the parental interview ADI-R. A further research area would be to look at which other assessment tools in conjunction with ADOS would improve the overall sensitivity and specificity of autism diagnosis. As possible biomarkers become available for autism, for example, specific brain scans, these could be correlated with scores on ADOS again to provide an overall improved specificity and sensitivity.

**CONCLUSIONS**

As yet there is no biomedical marker for autism to enable a rapid diagnosis. ADOS is therefore one of a range of tools that can be used within a comprehensive assessment of a child for autism. It should always be borne in mind that part of the diagnostic criteria in DSM-IV and ICD-10 is the disordered early developmental history and the onset of symptoms and concerns. However, when used in the appropriate way it can be a valuable tool in the assessment process, helping to show autistic behaviour in a structured clinical setting, thereby providing further objective evidence to support a diagnosis. This is particularly the case to aid diagnosis at a much younger age. It also enables a profile of the child’s functioning to be recorded and may be useful to refer back to as the child changes and develops. As a result of its place in the detailed comprehensive assessment of children suspected of autism, it will be of more use by professionals in a specialised autism assessment team rather than when used by a general community or acute paediatrician seeing children with more general behavioural concerns.

**Contributors**

SEC conceived the idea for the article. The literature search was performed jointly between all authors. CB wrote the introduction section, along with regular reviewing of each draft of the article. AH wrote the administration section of the article along with regular reviewing of each draft of the article. SEC wrote the other sections of the article. NAK substantially reviewed the article, rewriting parts of some sections. SEC is the guarantor of the article.

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**Quiz**

**QUESTION 1**

Which of the following describes the three main diagnostic criteria used to diagnose ASD in ICD-10/DSM-IV:

a. Difficulties in social interaction, restricted patterns of behaviour and disturbances in sleeping and eating.
b. Difficulties in social communication, social interaction and restricted patterns of behaviour, interests and activities.
c. Restricted patterns of behaviour, phobias and difficulties in social communication.
d. Difficulties in social interaction, learning disability and language delay.

**QUESTION 2**

Which of the following is true? In diagnosing ASD:

a. Referral to a specialist autism team is unlikely to be needed.
b. A developmental history is essential.
c. It is important only to consider the child’s behaviour and functioning at home.
d. An ADOS assessment can rule out an ASD diagnosis.

**QUESTION 3**

Which of the following is true? An ADOS assessment:

a. Takes a detailed history from a carer to establish autistic behaviours.
b. Can only be used in children and young people who can talk fluently.
c. Can be used in those with a learning disability who need an autism assessment.
d. Can be used in those with hearing impairment who need an autism assessment.


Answers to the quiz can be found on page 63

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**REFERENCES**


**Answers to the questions from page 62**

1. b
2. b
3. c