
How can standardised assessment tests be adapted to assist in providing a robust diagnosis of Autism Spectrum Disorder in children who are blind or who have visual impairments?
OUTLINE

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What is Autism Spectrum Disorder?

**DSM-V (2013):**

A. *Persistent deficits in social communication and social interaction across multiple contexts.*

B. *Restricted patterns of behaviour, interests, or activities.*

C. *Symptoms must be present in the early developmental period, (but may not become fully manifest until social demands exceed limited capabilities, or may be masked by learned strategies in later life).*

D. *Symptoms cause clinically significant impairment in social, occupational or other important areas of current functioning.*

E. *These disturbances are not better explained by intellectual disability or global developmental delay. Autism Spectrum Disorder and intellectual disability often co-occur; to make a co-morbid diagnosis, social communication should be below that expected for general developmental level.*
A. Deficits in Social Communication and Social Interaction

1. Deficits in social-emotional reciprocity, such as abnormal social approach, or failure of normal back-and-forth conversation; reduced sharing of interests, emotions or affect; failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviours used for social interaction, such as poorly integrated verbal and nonverbal communication; abnormalities in eye contact and body language, or deficits in understanding and use of gestures; total lack of facial expression and nonverbal communication.

3. Deficits in developing, maintaining and understanding relationships; difficulty in adjusting behaviour to suit various social contexts; difficulty sharing imaginative play or making friends; absence of interest in peers.
B. Restricted, Repetitive Patterns of Behaviour, Interests, or Activities

- Stereotyped or repetitive motor movements; use of objects or speech, such as simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic speech.

- Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behaviour, such as extreme distress at small changes, difficulty with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat the same food every day.

- Highly restricted, fixated interests that are abnormal in intensity or focus, such as strong attachment to or preoccupation with unusual objects excessively circumscribed or perseverative interests.

- Hyper-or hypo activity to sensory input or unusual interest in sensory aspects of the environment, such as indifference to pain/temperature, excessive response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement.
Current Incidence of Autism Spectrum Disorder.

- Europe: 1 in 100 (Elsabbagh, 2012)
- Ireland: 1 in 100. (Stynes et al., 2010. DCU).
- UK: > 1 in 100 (Brugha et al. (NHS), 2012).
- US Combined data
  - 2000: 1 in 150
  - 2006: 1 in 110
  - 2012: 1 in 68 (Centers for Disease Control and Prevention)

*We can expect at least the same proportion of children with visual impairments to have co-existing ASD.*
Why Assess Children with Visual Impairments?

- Better understanding of child’s needs. Children at risk of being wrongly diagnosed either way: all unusual behaviour put down to Visual Impairment, or unusual behaviours that are consistent with VI are thought to be indicative of ASD.
- Provide some answers for worried parents.
- Access to additional resources.
- More appropriate interventions, both teaching and therapy.
- Better understanding of behaviour.
- Hopefully, improve happiness and wellbeing of the child.
- Better planning for the child’s future.
How Assess?

- History taking, including medical and ophthalmic history.
- Consultation with parents, teachers and therapists.
- Observation, including play.
- Assessment of specific skills, e.g., communication, adaptive skills.
- Cognitive assessment.
- Measures of behaviour.
- Autism-specific measures: ADI-R
  
  ADOS-2

We focus here on these last two measures.
Autism Diagnostic Interview Revised (ADI-R)
What is the *Autism Diagnostic Interview-Revised (ADI-R)*?

The ADI-R was developed in 2003 by Rutter, Le Couteur and Lord, as a revision of earlier versions and the original 1989 ADI.

It is an extended diagnostic interview, consisting of 93 questions, designed to elicit a full range of information needed to produce a diagnosis of ASD.

It does not provide a clinical diagnosis, which should be based on multiple sources of information, but it does provide a detailed profile of the individual which makes a valuable contribution to the overall diagnosis.
The ADI-R has 93 questions, almost all of which are appropriate to be asked about a child who is blind or who has severe visual impairments. They are grouped as follows:

- **Q1-8:** Early Development
- **Q9-28:** Acquisition and Loss of Language and/or Other Skills
- **Q29-49:** Language and Communication Functioning.
- **Questions 42-45** refer to pointing, nodding, shaking head and waving goodbye.
- **Q50-66:** Social Development and Play
- **Question 50** refers to direct gaze.
- **Q 67-79:** Interests and Behaviours.
- **Q 80-93:** General Behaviours, including isolated skills.
ADI-R and Children with Visual impairments

- It is recommended in the ADI-R Manual that this structured interview may be especially useful for children who have a high risk of ASD, including children with congenital blindness.

- The ADI-R can be said to be almost entirely accessible to discussion of children who are blind or visually impaired.

- Questions of interpretation will be discussed later.
What is **ADOS-2**?

**ADOS-2** was developed by Rutter, Lord et al. and published in 2012. It is a semi-structured, standardised assessment of

- communication,
- social interaction,
- play,
- restricted and repetitive behaviours.

It presents various activities that elicit behaviours directly related to a diagnosis of ASD.

It meets the criteria of the DSM-V and the ICD-10.

*It is available in Czech, Danish, Dutch, English, Finnish, French, German, Italian, Norwegian, & Swedish*
**ADOS-2 Modules**

- **Toddler Module:** for children between 12 and 30 months who do not consistently use phrase speech.

- **Module 1:** for children aged 31 months and older who are at a pre-verbal or single word stage.

- **Module 2:** For children who use phrase speech without being fully fluent.

- **Module 3:** For children and adolescents who can use fluent speech.

- **Module 4:** For adolescents and adults who have fluent speech.
ADOS-2 materials are very visual!
Challenges in using the ADOS-2 with children who are blind or who have visual impairments.

Challenges of **Access**

How can the materials and procedures of the ADOS-2 be made accessible to children with little or no sight?

Challenges of **Interpretation**

How can the scoring and interpretation of the ADOS-2 adequately take account of the differences in development and experiences of this group of children?
Problems of Access: Adaptations

By adaptations we mean changes made in the strict procedures and materials used, without substantially altering the nature of the task.

- Supplying some larger, more easily recognisable toys, including some that had interesting textures and sounds, along with the test items.

- Replacing the cause-and-effect toy from the test kit (jumping bunny rabbit) with one that was less unpredictable in its movements (a vibrating cushion).

- Releasing half-blown-up balloons instead of chasing bubbles.

*In each of these instances, we believe we were able to preserve the integrity of the original tasks.*
Balloon instead of bubbles
Problems of Access: Modifications

By modifications we mean substantial changes to a test task, while endeavouring to maintain its purpose in eliciting verbal or social responses from the child.

One of these is the Construction task at the beginning of the assessment.

For this, the child is asked to reproduce a pattern printed on a card, using soft foam shapes. The examiner give the child some of the required materials, but retains others, in an attempt to elicit a request for more from the child.

This task is accessible to children who have little functional vision, but not to blind children.

We have had a number of attempts at an alternative task, including a Bead construction and one using lollipop sticks. In principle, we think this can be achieved, though our materials are not as yet robust enough.
Same aims as Construction task?
A second modification was with the task known as **Description of a Picture**. A number of alternative pictures are provided in the test kit, and, although they are all ‘busy’, or crowded with detail, they can be used with some children who have a measure of functional vision. The function of the task is to observe the child’s spontaneous language, and to get an idea of what captures his or her interest.

The pictures are not, obviously, accessible to blind children.

Our solution to this was to provide a number of ‘soundscapes.’

As one of the pictures shows a busy beach scene, one of our soundscapes is of a seaside scene, which we will show you now.

Given that not all children have been to the beach, we also created an airport scene, but we were surprised to find that the sounds of the airport are not so easily identifiable.

Our third scene is a supermarket, which we think should be recognizable by all children.
Beach Soundscape
Same aim, different modality
The third modification has been more challenging. This is the task known as Telling a Story from a Book. The test kit contains two picture books, both by the same author/illustrator. The stories are told entirely through the pictures, and there is no text. Both stories are unusual, and the drawings are somewhat surreal and quirky. For children with partial sight, there can be difficulty in recognising what the pictures represent, as there are blurred outlines and some distortion and, in the case of one in particular, no clear distinction between light and shade.

We have not so far come up with a completely satisfactory solution to the book problem, though we consider it too important an element of the assessment to ignore.
The main aims of the story-telling are as follows:

- To obtain a sample of the child’s spontaneous language and communication, as well as a sense of what captures his or her imagination.
- To assess the degree to which the child can convey continuity in a story.
- To assess the extent to which the child can involve another person in telling the story.
Telling a Story From a Book: First Attempt

For this task, it appeared that substantial modifications would be needed. The original ADOS-2 picture books tell the story entirely through pictures, and no text is used. It did not appear possible to tell a story to a blind child entirely without words.

However, we thought a simple story would leave opportunities for the child to expand on the narrative, to take turns, and to comment on any emotional content the story might suggest.

- Our first attempt was a story accompanied by tactile illustrations, called Boo and the Bird, about a bird that flies in the window of a child’s bedroom.

- The plan was to tell the story to the child, guiding him/her through the tactile illustrations, and then to ask the child to re-tell it jointly with the examiner.
BOO AND THE BIRD
THE BIRD FLEW IN THE WINDOW.
DAD PICKED UP A TOWEL AND TIPTOED TOWARDS THE BIRD.
‘GOT YOU! HE’S IN THE TOWEL, BOO!’
Telling a Story From a Book: First Attempt Flaws

The following flaws emerged with *Boo and the Bird*:

- With some justification, the child did not perceive some of the illustrations as we had intended. He rightly insisted, for example, that a feather is not a bird.

- When he did agree with the designation of our illustrations, he sometimes used them differently. For example, we wanted Dad to come up the stairs, but he wanted him to come down.

- Some of our illustrations were not robust enough to stand up to tactile scrutiny.

- The child’s tactile exploration skills were poor, and the task turned out to be more of an exercise in tactile exploration than in story-telling.
Our second attempt was to tell a story using a story box of objects rather than tactile illustrations.

This one was called *Surprise for Boo*, about the arrival of a puppy.

Once again, the plan was to tell the story to the child, using tangible objects rather than illustrations, and then to ask the child to re-tell it jointly with the examiner.
We have tried this one only once so far, and did not manage to engage the child with the story.

His dog liked it, though!

We think we should probably have some kind of paper book as well as the objects, with opportunities for page-turning.
Telling a Story from a Book: Another Solution

In our contacts with a researcher in Los Angeles, we found that they are using a Braille book produced by the American Printing House for the Blind, called *Bumpy Rolls Away.*
APH Braille Books
Problems of Interpretation 1: Eye contact, pointing, gestures and joint attention.

- **ASD criterion: Abnormalities in eye contact and body language.**
  
  *Eye contact not possible for some; difficult for others, e.g. those who have sensitivity to light, or who need to use eccentric looking.*

- **ASD criterion: Deficits in understanding and use of gestures.**
  
  *Few gestures are accessible to this group of children.*

- **ASD criterion: Total lack of facial expression.**
  
  *Facial expressions of blind children or those with VI are often muted.*

- **ASD criterion: Total lack of non-verbal communication.**
  
  *Non-verbal communication not available to some; of reduced meaningfulness to others. Pointing is not usually present in blind children.*
Indicators of Engagement During Conversation: Eye Contact Substitution.

Suggested checklist:

- Direct/alter position to communication partner
- Change in posture
- Head tilt
- Altered facial expression
- Ear tilt/ear contact
- Use of body gesture
- Other.
Problems of Interpretation: Facial Expression and Intonation

Possible ratings:

► Flat
► Muted
► Aware
► Interested
► Animated

Do these expressions appear generally throughout the assessment, or in response to isolated events?
Matthew is aged 8. He was born at 25 weeks, and suffered a brain haemorrhage in the neonatal period. He also developed Retinopathy of Prematurity, and suffered a retinal detachment in his left eye. At age 4 he had surgery for removal of a cataract in his right eye, and now has an artificial lens in that eye. Matthew’s vision is very poor.

During ADOS-2 administration, he made little or no direct eye contact with the examiner. However, he did do the following:

He oriented his face in the direction of the examiner.
He leaned across the table towards her.
He tilted his ear towards her.
He addressed her directly.

Eye contact is considered a significant item for the ADOS-2, with a yes or no rating. Has Matthew done enough to give him a positive rating?
Problems of Interpretation 2: Deficits in Social Communication and Social Interaction

- **ASD criterion: Abnormal social approach**
  
  *Does the child know who is there? What is a normal social approach for a blind child?*

- **ASD criterion: Failure of normal back-and-forth conversation.**
  
  *How does the child learn the rules of turn-taking in conversation?*

- **ASD criterion: Reduced sharing of interests.**
  
  *The blind child will not be able to share all of the interests of peers, and may not know what the other children are talking about.*

- **ASD criterion: Reduced sharing of emotion or affect.**
  
  *Blind child does not have access to facial expressions of others, and may not be fully aware of their emotional reactions.*

- **ASD criterion: Failure to initiate or respond to social interactions.**
  
  *Child needs to know the other person is there.*

- **ASD criterion:** Difficulties adjusting behaviour to suit various social contexts. 
  Limited awareness of what is going on; limited access to social modelling.

- **ASD criterion:** Difficulties in sharing imaginative play.
  Imaginative play later to develop for children who are blind or who have visual impairments.

- **ASD criterion:** Difficulties in making friends.
  May be due to more limited shared interests; to limited opportunities; to limited access to social models.

- **ASD criterion:** Absence of interest in peers.
  Just be sure the child has not become a little prince or princess.
Problems of Interpretation 3: Restricted Patterns of Behaviour, Interests or Activities.

- **ASD criterion: Stereotyped or repetitive motor movements.**

  Very many blind children and adults rock and/or move their heads. Children with certain eye conditions rub or poke their eyes.

- **ASD criterion: Stereotyped or repetitive use of objects.**

  Children may explore or show interest in objects in ways that are unusual but that make sense in the absence of vision (shaking, smelling, scraping, tapping).

- **ASD criterion: Stereotyped or repetitive use of speech, such as echolalia or idiosyncratic phrases.**

  Some children ‘play’ with language and enjoy the sounds of certain phrases. Some use specific phrases to ‘set’ a scene or context. Some use talk to hold onto the communication partner.
Problems of Interpretation 3: Restricted Patterns of Behaviour, Interests or Activities cont.

- **ASD criterion:** Insistence on sameness, inflexible adherence to routines.
  
  *Some children with VI prefer predictable routines, and are averse to surprises, for good reasons.*

- **ASD criterion:** Ritualized patterns of verbal behaviour, such as greeting rituals.
  
  *May sometimes be maintained by family members.*

- **ASD criterion:** Highly restricted, fixated interests that are abnormal in intensity or focus.
  
  *Range of interest of children who are blind or visually impaired may be more restricted that that of peers. May have intense interest in music, for example.*

- **ASD criterion:** Hyper-or hypoactivity to sensory input or unusual interest in sensory aspects of the environment.
  
  *Some children may have strong interest in sounds or textures. Some may use their senses in unusual ways, such as sniffing or smelling. Children with certain conditions gaze at lights.*
So how do we tell?

According to existing research, ASD may not be present if:
- The child shows social curiosity.
- There are indications that the child enjoys social interaction.
- Child seeks sharing of information.
- Signs of empathy.
- Language develops, even if delayed.
- Imitative play develops even if delayed.
- Even if play routines are restricted, the child can be engaged in new toys and activities.
- Child can adapt to changes in routine.
- If child has stereotypic mannerisms, these are VI-specific, and child can learn to control or reduce them. (Pawletko and Rocissano, 2000).
16th International Mobility Conference
‘Transitions; moving on, moving out’

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