ASD Consultation Across the Lifespan: Getting the most out of an Evaluation

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Conflict of interest

- I receive royalties from diagnostic instruments, including the ADOS, ADI–R, and SCQ.

- I have research funding from NIH, DoD, Clinical Research Associates and the Simons Foundation.
Goal: Getting the most out of an assessment or evaluation

My aim: Talking to parents and caregivers and hoping there are also teachers and therapists and other professionals who do evaluations listening as well

My bias: Love doing evaluations, especially following children and adults and families over years

- Three sub–biases: mixed methods, middle amounts of testing and the links between assessment and treatment are primarily through parents and if we’re lucky teachers/therapists
Outline of talk

- Different goals for different kinds of evaluations
- General issues and strategies
- Organize this talk around some hand-outs
- Purposes of assessment
  - Diagnosis, Cognitive and Domain-specific, Behavior issues
- Age and development related issues
- Using an assessment to step back and consider short-term and longer term goals (don’t think we do this enough)
Purpose of assessment

- Think about it in terms of what you’re trying to accomplish:
  - Get information
  - Get recommendations or referrals
  - Get services

- Think about it in terms of the kinds of information you need:
  - Diagnostic
  - Cognitive
  - Domain-specific (language, motor etc)
  - Behavior and co-morbidities

- Relationship that you will continue
What can an evaluation offer you?

- The person: who has seen, in many cases, hundreds of people with ASD, and people with other kinds of difficulties

- The tests: structure of how to think about how a child or an adult thinks and remembers and organizes information and interacts and plays

- The opportunity for you to watch (does not have to be every time)—most relevant to older children and adolescents
Sources of confusion

- Billing in psychology/neuropsychology and medicine
  - For procedures when you are physically with a patient
    - Not for writing or thinking or making phone calls or scoring (unless you are charging through a private practice)
- Good assessment
  - Based on good preparation and organization – knowing what has been done before and what you’re looking for
- Besides “tickets” into services, a few individualized recommendations may make the most difference
What can you do right at the start?

- Make short lists of what you want from the assessment that you send in with any packets.
- Take them with you to all appointments (don’t count on anyone’s memory).
- Don’t be shy about taking notebooks. Don’t send long videos but take short ones with you.
- Be as polite as you can even if you’re frustrated.
- Stick up for yourself and your child and respectfully keep reiterating how you think the professional might be able to help you (without telling them what to do).
- Practitioners may have a list too (ask them) and also how they may want you to behave.
Any questions?
Getting a Diagnosis of Autism Spectrum Disorder (ASD)

- Social Communication
- Fixated Interests & Repetitive Behaviors
- Expressive Language Level/Cognitive Level
Changes with DSM 5

- Mostly much simpler
- But we still have some frustrating situations
- Circumstances for very young children
  - Very difficult to make diagnoses in very, very young children (children who are not yet walking, children under 12 months of age) but it is not impossible
- Children and adults with very, very limited language or limited mobility
- The requirement that, to have autism, a person has to have an impairment of some sort (this can be self declared)
For social–communication, criteria must be met within EACH subdomain currently or by history

- Deficits in social-emotional reciprocity

- Deficits in nonverbal communicative behaviors used for social interaction

- Deficits in developing and maintaining relationships and adjusting behavior to social contexts, appropriate to developmental level
All individuals must have or have had restricted interests and repetitive behaviors (in at least 2 of 4 domains)

A. Stereotyped or repetitive speech, motor movements or use of objects

B. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior or excessive resistance to change

C. Highly restricted, fixated interests that are abnormal in intensity or focus

D. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment
What do you want the evaluator to know about your child in each of the areas below?

- Parent or caregiver report
  - Structured questionnaires
  - Less structured interviews and packets
  - Structured interviews
- Teachers and therapists
  - Questionnaires and packets
  - Phone calls
- Observation and self-report
  - Interview of the patient or AQ
  - ADOS
    - Ask your evaluator: How will you get this information during this assessment?
## Diagnostic Questions

<table>
<thead>
<tr>
<th>Area</th>
<th>What you want the evaluator to know?</th>
<th>What you want to know or want help with?</th>
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</thead>
<tbody>
<tr>
<td>Social reciprocity</td>
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<tr>
<td>Nonverbal communication</td>
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<td>Peer interaction/adjusting to context</td>
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<td>Repetitive behaviors</td>
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<td>Rituals or resistance to change</td>
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<tr>
<td>Restricted or fixated interests</td>
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<td>Unusual sensory responses</td>
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<tr>
<td>Dimensional Ratings for DSM 5 ASD</td>
<td>Social Communication</td>
<td>Fixated Interests and Repetitive Behaviors</td>
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<tr>
<td>1. Requires very substantial support</td>
<td>Minimal social communication</td>
<td>Marked interference in daily life</td>
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<tr>
<td>2. Requires substantial support</td>
<td>Marked deficits with limited initiations and reduced or atypical responses</td>
<td>Obvious to the casual observer and occur across context</td>
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<td>3. Requires some support</td>
<td>Even with support, noticeable impairments</td>
<td>Significant interference in at least one context</td>
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<td>4. Subclinical symptoms</td>
<td>Some symptoms in this or both domains; no significant impairment</td>
<td>Unusual or excessive but no interference</td>
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<td>5. Normal variation</td>
<td>Maybe awkward or isolated but WNL</td>
<td>WNL for developmental level and no interference</td>
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Most commonly measures: Changes in IQs over time

- Verbal IQ in autism is not stable in young children.
  - Many children with autism will be very delayed in language at age 2, and begin to improve by 3, remain delayed through school age, but have good spoken language by adolescence.

- Nonverbal IQ is more stable, but still may change.
  - In most cases, children who have high nonverbal IQs when they are young (2 or 3), continue to do so into adulthood, unless they do not develop language.

- Children with very low IQs (under 30) even when young, often remain very delayed, but not always.
1. There are many ways to do this. Some tests are much more appropriate to be used with people with ASD. Sometimes examiners are not familiar with these tests or do not have access to them and then parents need to stick for themselves.

2. Verbal skills should be separated from nonverbal skills. Expressive language (e.g., speaking or communicating) should be assessed separately from receptive language (e.g., understanding).

3. In nonverbal skills; nonverbal problem-solving that does not require fine motor skills would be assessed separately from tasks that do, and tasks that are timed.

4. Agreement across tests (whether past and present or present and present) is more important than minor differences across tests. Minor differences within normal ranges in most cases do not mean very much unless they represent very consistent patterns.
# Questions about other domains

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<tr>
<th>Area</th>
<th>What do you want to know?</th>
<th>What do you want the examiner to know?</th>
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<tbody>
<tr>
<td>Expressive Language</td>
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<td>Receptive Language</td>
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<td>Nonverbal Problem Solving</td>
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<td>Fine Motor Skills</td>
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<td>Response to Times</td>
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<td>Nonverbal Activities</td>
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<td>Academic Skills</td>
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<tr>
<td>Vocational Activities</td>
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<td>General Behavior</td>
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Other questions?
Older children and adults: what are our priorities?

Service questions?
  Kinds of classes?
  Academic goals?
  Services?
  Extracurricular goals?

Individualization/quality of life goals? (vocation/avocation)
  Pleasure
  Communication
  Engagement and motivation
  Exercise
  Areas of independence
Contexts in which to get information about these priorities

Academic achievement
  Problem solving
  Focus and independence
  Ways of communicating what he/she knows
Rule out (for information purposes – when someone has prompted, helped, reminds about numerical sign, encourages) though this may be necessary for access to services

Vocational strengths and weaknesses
  Tests like the TTAP; the Vineland, ABAS
Adults

- Recognizing that adults with ASD are in very different circumstances from each other

- How do we give people a maximum amount of input and decision making power

- Use the same steps and logic as with parents advocating – be prepared, stick up for yourself, ask questions (go back through handouts)
Social Impairment & Restricted Interests

Speech/Communication Deficits

ADHD

Aggression

Social Impairment

AUTISM SPECTRUM DISORDERS & Restricted Interests

Intellectual Disabilities

Social Anxiety

OCD

Epilepsy-EEG abnormalities

Immune Dysfunction

Motor problems: Apraxia

Gastro-intestinal Dysfunction

Sleep Disturbance

Depression

Language Disorders

Core Symptom Domains PLUS Associated Medical Features
Psychiatric problems, though not unusual, have to be taken seriously.

- There is an increased risk for different psychiatric problems associated with ASD, which is not surprising.
- These include ADHD, anxiety disorders, depression, OCD and aggression.
- The best way to evaluate these behavior is a combination of observation, parent and teacher report and self report if this is possible, just like everything else.
- Sometimes if there are concerns about these difficulties, additional observations are necessary. It is important not to let these concerns go unaddressed.
Autism Spectrum Disorders

- Repetitive Behaviors & Restricted Interests
- Social Communication Deficits
- Intellectual Disabilities
- Language Disorders

- Sense of humor
- Fine motor skills
- Predictability
- Intelligence
- Visual-spatial skills
- Curiosity
- Attention to detail
- Honesty

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Thank you for listening and thanks to all the patients and parents and clinicians who allowed us to work with them and show you these examples.

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