

Beyond the ADOS: An overview of best practices and possible measures for screening and assessment of Autism Spectrum Disorder

Presented by Elizabeth Kryszak, PhD
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Objectives

- Identify necessary components of an Autism evaluation
 - Discuss why multiple assessment pathways are needed to increase access to Autism evaluation services
 - Compare different measures for assessing Autism symptoms and discuss why a particular measure might be chosen for a specific context
 - Discuss differences between Medical Diagnosis and Educational Classification of Autism
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NCH Child Development Center (CDC)

- **Interdisciplinary team**
 - Psychologists, Master's Level Clinicians (Social work, LMFT, Clinical Councilors), & Psychometricians
 - Partner with Developmental Behavioral Pediatricians and NPs, Speech therapists, Genetics
- **Focus on differential diagnosis related to neurodevelopmental disabilities**
 - Assess for Autism, Intellectual Developmental Disorder, Global Developmental Delay
 - Assess for differentials - ADHD, Anxiety, SLD, etc.
 - Help families figure out what is happening and what to do next
- **Treatment for dev. disabilities other than Autism**
 - Those with autism go to NCH Center for Autism Spectrum Disorders (CASD) for treatment

What is Autism Spectrum Disorder (ASD)

Developmental Disability characterized by:

- **Social Communication Difficulties:**
 - Difficulties with social reciprocity
 - Nonverbal communication deficits
 - Difficulties following social norms and building and maintaining relationships
- **Restricted and Repetitive Behaviors:**
 - Stereotyped movements or language; repetitive play and behavior
 - Rigid routines; difficulties with transitions
 - Restricted interests
 - Sensory sensitivities/sensory seeking behavior
- **Symptoms present from young age;
Cause impairment in functioning**

Diagnosing Autism Spectrum Disorder

Symptoms can be assessed starting at 12 months

- Accuracy improves closer to 3 years old
- Early identification is important for early intervention

Many families wait years for initial assessment

- **Average age of ASD diagnosis: ~4.5 years old** (Maenner et al., 2021)
 - First concerns are often as early as 12-18 months
- **Greater delays** for those from (Aylward et al., 2021):
 - Lower SES, Rural areas, Underrepresented ethnic and racial groups

What Makes a Good ASD Evaluation

Goal of ASD Assessment:

- **Identify a pattern** of social communication difficulties and restricted and repetitive behaviors causing impairment

Gold standard models include multiple sources of data (Huerta and Lord 2012; Zwaigenbaum et al., 2009)



Two Key Components of an ASD Evaluation

Comprehensive Interview

- Developmental history
- ASD Symptoms
- Differential diagnosis - Trauma, Anxiety, ADHD, etc.

Behavior Observation

- Direct observation of child
- Includes activities to pull for both social/communication difficulties and unusual behaviors

Additional Components of a Comprehensive Evaluation

Additional Direct Testing

- Cognitive, Academic, Executive Functioning, Developmental,

Rating Forms

- Parent/caregiver, teacher, and self

Previous Assessment

- Evaluation Team Reports (ETR), Other Psychological Evaluation, Speech Evaluation, etc.

Assessing ASD Symptoms: Screeners



Level 1 Screeners

Assess for symptoms in general population
High Sensitivity, Lower Specificity - Goal is to catch any possibility of ASD
Examples: M-CHAT



Level 2 Screeners

Assess for symptoms in at-risk population
High Sensitivity, Better Specificity - Goal is to improve referrals
Examples: ADEC, STAT, RITA

Assessing ASD Symptoms: Diagnostic

- Goal: **aid** in making diagnosis
 - No one measure diagnoses ASD
- Ideally, high specificity and sensitivity (Randell et al., 2018)
 - **Autism Diagnostic Observation Schedule, Second Edition (ADOS-2)**
 - Sensitivity .94; Specificity .80
 - **Autism Diagnostic Interview, Revised (ADI-R)**
 - Sensitivity .52; Specificity .84
 - **Childhood Autism Rating Scale, Second Edition (CARS-2)**
 - Sensitivity .80; Specificity .88
- Need more time and training to administer

One size does not fit all



Children vary in symptom presentation

Mild symptoms/more complex presentation - Need more comprehensive assessment

More straightforward symptoms - Need less



Assessment models with multiple pathways needed to increase access for all

Possibility for secondary screeners to be used as diagnostic measures



Autism Detection in Early Childhood

(ADEC; Young 2007)

- Level 2 Screener
 - Designed for 12-36 months (extended up to 48 months)
 - Quick, easy to administer - 20 minutes
 - Items are straightforward in administration and scoring
 - Requires minimal training and experience to reach reliability
 - Minimal materials are needed
 - Translated into several language
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Initial Support for the ADEC

- **Well-established initial psychometric properties** (Young, 2007)
 - ADEC sensitivity is .86 and specificity is .91
 - Good internal consistency
 - Cronbach's α between .80 and .93 over 5 studies
 - Cronbach's α did not differ significantly with the removal of any specific item
 - Test-retest reliability was consistent over a 12-month period
 - ($r = .90, n = 14, p < .001$)
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Continued Support for the ADEC

- **Works well as a screener** (Young & Nah, 2016)
 - Good sensitivity (.90 to .88) and moderate specificity (.62 to .89) for cutoff score of 11 (Moderate Risk) across 4 studies
 - **Performs similarly to the ADI-R, CARS, & ADOS-2** (particularly the toddler module), in differentiating ASD in toddlers (Nah et al., 2014; Hedley et al., 2015)
 - Improved balance of sensitivity (.85-.87) to specificity (.79-.82) using a higher cutoff score of 14 (High Concern)
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Diagnostic Innovation and the ADEC

- ADEC has diagnostic utility for identifying **CLEAR cases of ASD** in **young children** when the **HIGH RISK** cutoff is used by **EXPERIENCED clinician**
- Utility increased when ADEC is used as an observation tool with other validated assessment tools (e.g., CARS-2, ADI-R)
- Example adaptations with ADEC:
 - Telehealth Assessment (ADEC-Virtual)
 - Enhanced Diagnostic Intake (EDI)



Telehealth Assessment Options

- Telehealth assessment options enhance assessment models
 - **One tool in a comprehensive toolbox**
- Overcome barriers to accessing services including:
 - Transportation and geographical location
 - Time missed from work
 - Need for childcare
 - Family stress
 - Increase agility during times of crisis

Properties of the ADEC- Virtual



Adapted in collaboration with original author



20-25 minutes to administer by telehealth

Same 16 activities
First used as an observation to complete CARS-2



Few materials - all typical household toys and items



Administered by a family member coached by clinician

Scored by clinician
Scores provide a risk level for ASD

Preliminary Validation Study Conclusions

(Kryszak, et al., 2022)

ADEC-V found
to have
acceptable
diagnostic
accuracy

- Best if “High Risk” cutoff is used
- Sensitivity 0.82; Specificity; 0.78 (Clinical Sample)

ADEC-V and
ADI-R
contribute
significantly
and separately

- Best to use combo of interview & observation measures (Huerta and Lord, 2012)

ADEC-V were
slightly
negatively
correlated with
age

- Use caution over 3 years old
- Consider adding other tasks (e.g., pretend play)

Enhanced Diagnostic Intake (EDI) Model

- One 90 min appointment
 - Diagnostic intake clinician completes interview integrated with ADI-R Toddler Algorithm (Kim & Lord; 2012)
 - Psychologist listens to interview and completes ADEC with additional observations needed to complete CARS-2
 - Developmental Profile, 4th edition (DP-4) also completed
 - ASD ruled in or out when presentation is clear
 - Feedback with recommendations given same day
 - Additional assessment appointment scheduled with psych when presentation is less clear

Enhanced Diagnostic Intake Model

291 children seen so far

- Average age: 34 months; 68% male, 32% female

82% completed in one assessment
appointment

- 63% given ASD diagnosis
- 19% ASD ruled out
- 18% needed further evaluation

238 children did not need second 2-3 hour
eval slot

- **Saved families a second trip and several months of wait time**
- **Allowed better use of clinician resources so more kids can be seen**

Considerations for using Secondary Screener in a Diagnostic Model



Need training in ASD assessment

Secondary screeners useful for diagnostics with additional training or expertise in ASD assessment



Make sure assessment measures are acceptable to:

Allow family to access next steps
Meet insurance requirements for eval AND treatment
Be accepted by schools and community partners



Need a pathway for more complex cases

Plan for further evaluation as needed
Lessen pressure to make diagnosis without adequate information

Medical Diagnosis vs. Educational Classification of Autism

Medical Diagnosis of Autism

- Made by doctor, psychologist or other certified provider (varies by state)
- Needed to qualify for medical and behavioral interventions and community resources (e.g., County Board of DD)
- Certain agencies (e.g., Medicaid; County Board) require certain measures (e.g. ADOS or ADI)

Educational Classification of Autism

- Must meet criteria for a disability AND need specialized services to access FAPE (free and appropriate education)
 - **Medical diagnosis does NOT automatically qualify for IEP**
 - Student does NOT need a medical diagnosis to qualify for educational classification
- School completes Evaluation Team Report (ETR)
 - Used to create Individualized Education Program (IEP)
 - Ohio Dept of Ed does not require specific measures

Autism Education Program (AEP)

Autism Scholarship

- Ed choice scholarship through Ohio Department of Ed
- \$32,445 per year (as of FY2025)
- Need IEP under Autism Educational Classification or AEP

Autism Education Program (AEP)

- Law change in October 2024
- For child with medical diagnosis of ASD who:
 - Does not meet criteria for IEP under Autism Classification
 - Wants to use Autism Scholarship

Cautions with Autism Scholarship Program

Using ASP forfeits right to a FAPE (free, appropriate public education)

- Private Schools and providers for ASP are not legally required to provide accommodations like public school for IEP
- No protections for expulsions/suspensions or bullying

Scholarship may not cover full tuition

- School may also not provide transportation

ASP good fit for some but not all

- Schools vary in focus on education vs behavior change
- Need to carefully research school



Thank You!

- **Questions? Referral Discussion?**
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