Autism: Resources for Diagnosis and Management

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Child and Adolescent Psychiatrist
Medical Director, Children’s National Hospital Center for Autism Spectrum Disorders
Today’s Presenter

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Today’s presenter has no conflicts to disclose:

1. No financial or business interest, arrangement or affiliation that could be perceived as a real or apparent conflict of interest in the subject (content) of their presentation.

2. No unapproved or investigational use of any drugs, commercial products or devices
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Objectives

By the end of this talk, participants will be able to:

• Choose, interpret, and counsel families on suitable ASD screening tools to use in primary care practice
• Prioritize initial management of children newly diagnosed with ASD
• Prescribe psychopharmacologic medications when indicated.
Diagnostic Criteria and Prevalence
AUTISM

Social and Communication Differences

Restricted and Repetitive Behaviors and Interests

LEVEL 3
Requiring very substantial support

LEVEL 2
Requiring substantial support

LEVEL 1
Requiring support
Autism is relatively common.

<table>
<thead>
<tr>
<th>Location</th>
<th>Currently has ASD</th>
<th>Pop. Est.</th>
</tr>
</thead>
<tbody>
<tr>
<td>USA</td>
<td>2.9</td>
<td>1,812,917</td>
</tr>
<tr>
<td>DC</td>
<td>2.0</td>
<td>1,877</td>
</tr>
<tr>
<td>Maryland</td>
<td>2.0</td>
<td>22,126</td>
</tr>
<tr>
<td>Virginia</td>
<td>4.6</td>
<td>73,660</td>
</tr>
</tbody>
</table>

2017-18 National Survey of Children’s Health ASD prevalence, age 3-17
Why is early diagnosis important?

“Given the unprecedented growth and organization of the brain during the first three years of life, behavioral interventions initiated in ASD toddlers within this time period result in a range of positive changes including increases in social attention, language ability, and overall IQ. However, due to the lag in diagnosis, many children miss the opportunity to receive treatment during this critical period of neuroplasticity.”

Developmental Disabilities
Systems of Care Framework
Building this network of supports feels overwhelming at first…
Main Sources of Funding for Kids with Disabilities

Health Insurance

• Individual or team medical diagnosis
• Based on DSM-5 criteria
Main Sources of Funding for Kids with Disabilities

**Health Insurance**

- Individual or team medical diagnosis
- Based on DSM-5 criteria

**Early Intervention/ Public Schools**

- Team classification
- Based on education law
Main Sources of Funding for Kids with Disabilities

**Health Insurance**
- Individual or team medical diagnosis
- Based on DSM-5 criteria

**Early Intervention/ Public Schools**
- Team classification
- Based on education law

**Federal/State**
- DDA determination
- Based on needs, disability, and financial resources

www.autism-society.org/living-with-autism/academic-success

The Ivymount School, Inc. www.ivymount.org
Entry Points

Health Insurance
- Medical autism diagnosis

Early Intervention/Public Schools
- IFSP/IEP evaluation

Federal/State
- DDA and Medicaid waiver applications
Services

Health Insurance
- In-home ABA
- Speech/language
- OT
- Mental health

Early Intervention/Public Schools
- Early intervention/special education supports
- School placement

Federal/State
- Vocational/social/daily living
- Clinical services and therapies
- Respite care
- Case management
Questions?
Managing Positive ASD Screen Results
Free Screening Instruments

- **CSBS Checklist**
  - (6-24 months)

- **MCHAT-R/F**
  - (16-30 months)

- **AQ**
  - (4 years to adult)
What is currently happening after the MCHAT is positive?

• Rates of ASD screening with the Modified Checklist for Autism in Toddlers (M-CHAT) at 18- and 24-month well-child visits were examined among 290 primary care providers within 54 pediatric practices between June 2014 and June 2016.

• Rates of M-CHAT screening were 93% at 18 months and 82% at 24 months.

• 31% of children with scores ≥3 were referred to a specialist for additional evaluation.

MCHAT-R/F

- EHR record examination at CHOP for 4-8 year follow-up period, N = 25,999
- Sensitivity
  - for ASD - 38.8%
  - For any developmental delay including ASD - 11.8%
- Positive predictive value (PPV)
  - for ASD - 14.6%
  - For any developmental delay including ASD – 72%
- Children who screened positive were diagnosed 7 months earlier than those who screened negative

Editorial

“...there is no reason to default to open-ended inquiry. Why not use the **best available measurement tools** to identify developmental concerns with the **highest possible accuracy**? Arguably, the M-CHAT/F remains a strong candidate in that regard.”

Zwaigenbaum L and Maguire J. Autism Screening: Where Do We Go From Here?. Pediatrics. 2019;144(4):e20190925
Surveillance

Take parents’ developmental concerns seriously. Remember, 80% of parents’ developmental concerns are correct and associated with a developmental delay or risk. In particular, consider ASD anytime a parent mentions concerns about language delay, eye contact, social skills, hearing problems, or repetitive behaviors/interests.
Clinical Implications: MCHAT-R/F

Although your child’s MCHAT was negative, this test misses almost 60% of kids with autism. Since we have concerns, I still suggest we refer.
Clinical Implications: MCHAT-R/F

Although your child’s MCHAT was negative, this test misses almost 60% of kids with autism. Since we have concerns, I still suggest we refer.

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Treat the patient, not the test.
Immediate Referrals After Positive Screen

Health Insurance
- Specialist autism evaluation
- Preliminary office diagnosis in clinic
- Speech and audiology

Early Intervention/Public Schools
- Early Intervention (under age 3) OR
- ChildFind (age 3-kindergarten) OR
- IEP evaluation request (school age)

Federal/State
Specialist Autism Evaluation Referral Resources

Services for Children with Suspected Autism Spectrum Disorder Enrolled in Medicaid in Washington, DC

The following clinical information was pulled from DC Collaborative for Mental Health in Pediatric Primary Care’s Child and Adolescent Community Mental Health Resource Guide. Information was collected between September and November 2019 to determine which, if any, of the DC Medicaid plans each clinic accepts. While this list is comprehensive, it is not exhaustive. Clinics that solely accept private plans or do not accept insurance were not included in this list. The information presented below is subject to change, so providers are encouraged to consult the full online Mental Health Resource Guide which is updated on a quarterly basis and is accessible on DC HealthCheck:
https://www.dchealthcheck.net/resources/healthcheck/mental-health-guide.html

<table>
<thead>
<tr>
<th>Clinic Name, Institution, Location</th>
<th>Ages Served</th>
<th>Medicaid Plans Accepted</th>
<th>Medicaid Plans Not Accepted</th>
<th>Wait Times (as of November 2019)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism and Communications Disorders Clinic, Medstar Georgetown Northwest, DC</td>
<td>0-18 yrs</td>
<td>AmeriHealth FFS Medicaid HSCSN</td>
<td>Amerigroup Trusted</td>
<td>6 months</td>
</tr>
<tr>
<td>Autism Spectrum Center, Mt. Washington Pediatric Hospital, Prince George County location (only this location accepts FFS)</td>
<td>0-17 yrs</td>
<td>FFS Medicaid AmeriHealth Amerigroup HSCSN Trusted</td>
<td>Ages 0-3: 6 months Ages 4+: 3-6 months</td>
<td></td>
</tr>
</tbody>
</table>
Select Autism Resources

Autism Screeners
- **Open source**
  - MCHAT-R/F (16-30 months; [https://mchatscreen.com/mchat-rf/](https://mchatscreen.com/mchat-rf/))
  - AQ (4 years to adult; [https://www.autismresearchcentre.com/arc_tests](https://www.autismresearchcentre.com/arc_tests))
- **For purchase**
  - SCQ lifetime (age 4+, 5-10 minutes)
  - STAT (requires training)

Autism Assessment Resources
- Autism Mental Status Examination: [http://autismmentalstatusexam.com/](http://autismmentalstatusexam.com/)
- FSU Autism video glossary [https://resources.autismnavigator.com/asdglossary/#/section/43/gettingStarted](https://resources.autismnavigator.com/asdglossary/#/section/43/gettingStarted)
IEP Request Letter

Dear Principal:

I am the parent/guardian of __________________________ (Name of Student) who is a _______ grade at your school. I am writing to ask for a special education evaluation for my child. My child is not doing well in school, and I believe this may be due to a disability. I believe my child may need special services at school in order to learn. This letter serves as my request and my consent for my child to be evaluated.

Please contact me at _____________________________ (Phone Number) to schedule an Individualized Education Program (IEP) meeting.

The best time to reach me is _____________________________ (Time and Day).

Sincerely,

______________________________
(Parent/Caregiver Name)

______________________________
(Parent/Caregiver Printed Name)
How early is too early to refer?

Social communication signs

• begin to emerge 6-18 months
• not pronounced until after 12 months
• failure to orient to name, reduced eye contact, pointing, and motor abnormalities

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Sibling recurrence risk is 10-20%.

- around 40% of siblings with eventual ASD become symptomatic by 18 months, and in these children, stability of a diagnosis based on a comprehensive assessment is very high (93%)

Questions?
Resources for In-Office Diagnosis
Missouri Autism Guidelines Initiative

<table>
<thead>
<tr>
<th>TIER 1</th>
<th>TIER 2</th>
<th>TIER 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>INDIVIDUAL PRESENTATION</strong></td>
<td>Presentation of symptoms that unambiguously indicate an ASD</td>
<td>Very subtle or complex symptoms, some ASD symptoms with multiple co-existing concerns, complex medical or psychosocial history</td>
</tr>
<tr>
<td><strong>USE OF STANDARDIZED INSTRUMENTS</strong></td>
<td>May be used; not required</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>CONSULTATION WITH OTHER PROFESSIONALS</strong></td>
<td>None</td>
<td>Possibly; consult with at least one other professional, as indicated</td>
</tr>
</tbody>
</table>
Parent report of who first diagnosed child with ASD

- PCP 14%
- Specialist 33%
- Psychologist or counselor (school or non-school) 32%
- Psychiatrist 10%
- Other healthcare provider 11%
“Although most children will need to see a specialist...for a diagnostic evaluation, general pediatricians and child psychologists comfortable with application of the DSM-5 criteria can make an initial clinical diagnosis. Having a clinical diagnosis may facilitate initiation of services.”

Best Practice Components of an ASD Assessment

- **History**: Autism, developmental, psychiatric, and medical history (including verifying that hearing/vision screening has been done)
- “**Physical**”: Observation of child autism traits
  - Adaptive functioning
  - Developmental/cognitive testing
  - Speech/language assessment
  - Audiology assessment

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  - Developmental/cognitive testing
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  - Audiology assessment

History: Parent Interview

ASD PARENT INTERVIEW
(based on DSM-5 criteria)*

Instructions to the interviewer:
A diagnosis of Autism Spectrum Disorder is based on specific criteria outlined in the DSM-5. Below you will find the specific criteria highlighted in bold type. For each criterion, we have provided a number of questions that will help guide you in gathering enough information from parents or other caregivers to make the most accurate decision regarding whether the child being evaluated does or does not meet that criterion. You do not need to ask each question. You can omit questions that are not relevant due to age, developmental level, or cultural or religious factors. You can stop asking questions once you are clear about the child’s skill set for that criterion. You may ask follow up questions that are not listed here, if they will provide you with useful information.

A. **Deficits in use or understanding of social communication and social interaction in multiple contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:**

Introductory questions on communication:
1. How many words, signs &/or gestures does your child use?
2. How does your child usually let you know what s/he wants or needs, e.g., if s/he is hungry or needs help?
3. Can you understand what your child is trying to communicate?
4. Can other people understand what your child is trying to communicate?

*Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) at Oregon Health & Science University, Assuring Comprehensive Care through Enhanced Service Systems for Children with Autism Spectrum Disorders and other Development Disabilities Project. https://www.ohsu.edu/xd/outreach/occyshn/programs-projects/comm-based-asd-identification.cfm*
“Physical”: Autism Mental Status Examination
Questions?
Priorities After Diagnosis

1. Safety
2. Get on Wait Lists
3. Parent Self Care and Education
1. Safety

• Call mental health crisis line rather than 911 when possible for agitation; always mention autism when calling 911

• Consider MedicAlert/GPS device/door alarms if wandering concerns
2. Get on Wait Lists

**Health Insurance**
- Call insurance company about in-network providers and benefits.
- Get on many wait lists for providers.

**Public Schools**
- Call Early Intervention/ChildFind (under 5) OR
- Request in writing an IEP evaluation, and keep a dated copy (school-age).

**Federal/State**
- Get on the Autism Waiver wait list AND the DDA wait list for your state.
3. Parent Self Care and Education

• Find support for yourself, and remember that your child is still just as amazing as they were before the diagnosis.

• Read reputable, strength-based, positive sources of information about ASD.

• Don’t talk to your child about the diagnosis until you have processed it yourself.

• First stop for educational materials: Autism Speaks 100 Day Kit.
Medical Home

Autism

Caring for Children With Autism Spectrum Disorder
A Practical Resource Toolkit for Clinicians

American Academy of Pediatrics

CLINICIAN FACT SHEET

The Medical Home for Children With Autism Spectrum Disorder

The Need for Coordinated Care

Pediatricians recognize that families need support in coordinating care for their child with ASD. Some pediatricians consider themselves to be care coordinators and advocates for children, but few view themselves as comprehensive, direct care providers for children with ASD. Many pediatricians report that they would like more information about caring for children with ASD to support their efforts in providing an effective medical home. They acknowledge that their efforts to link children with ASD with appropriate services can be quite challenging.

Barriers to Coordination

PEDIATRIC HEALTH NETWORK

MedStar Georgetown University Hospital

Mental Health Access in Pediatrics
My IV nurses will use a cold wipe to clean my skin.
My IV nurse may spray something cold on my skin.
This will not hurt me.
Questions?
Psychopharmacology
Comorbidity

Comorbidity

45%

Autism

Anxiety

ADHD

Comorbidity

Comorbidity

Comorbidity

ASD Psychopharmacology General Principles

- Diagnosis is harder due to alexithymia (look for anxiety; find quantifiable treatment targets)
- Medication efficacy rates are often lower
- Side effects are common (e.g. activation with SSRIs, dysphoria with stimulants)
- Atypical side effects and interoception difficulties are common (easy to miss side effects)
- Very rough rule of thumb: start at half the usual starting dose and take twice the amount of time to titrate.
First Line Psychotropic Meds in ASD

• Anxiety/depression: Prozac or Zoloft
• ADHD: Methylphenidate/dexmethylphenidate
• Sleep: Melatonin
• *Reserve Risperdal and Abilify for serious concerns like safety issues (serious aggression or self-injurious behavior) or risk of out of home placement due to risk of metabolic syndrome and movement disorders.*
## Michigan Child Collaborative Care Program Cards

### Antidepressants (1)*

<table>
<thead>
<tr>
<th>Generic (Trade)</th>
<th>S: start dose(mg)</th>
<th>T: target dose (mg/day)</th>
<th>Titration Schedule</th>
<th>Formulations (mg)</th>
<th>t 1/2 (hr)</th>
<th>FDA Approved in Youth</th>
<th>N: notes; S: side effects; R: risks</th>
<th>All: Black Box Warning for S1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fluoxetine (Prozac)</td>
<td>8: 5-10</td>
<td>T: 20-60</td>
<td>5-10 mg q 2 weeks</td>
<td>tab: 10, 20, 60</td>
<td>cap: 10, 20, 40</td>
<td>96-364</td>
<td>27y OCD</td>
<td>N: Long titration / washout = self-tapering</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>weekly cap: 90</td>
<td>liq: 4mg/mL</td>
<td>27y OCD</td>
<td>N: Long titration / washout = self-tapering</td>
<td></td>
</tr>
<tr>
<td>Sertraline (Zoloft)</td>
<td>8: 12.5-25</td>
<td>T: 50-200</td>
<td>25 mg q 2 weeks</td>
<td>tab: 25, 50, 100</td>
<td>liq: 20mg/mL</td>
<td>26</td>
<td>26y OCD</td>
<td>N: Few CYP interactions</td>
</tr>
<tr>
<td>Escitalopram (Lexapro)</td>
<td>8: 2.5-5</td>
<td>T: 10-30</td>
<td>5-10 mg q 2 weeks</td>
<td>tab: 5, 10, 20</td>
<td>liq: 1mg/mL</td>
<td>27-32</td>
<td>212y MDD</td>
<td>N: Few CYP interactions</td>
</tr>
<tr>
<td>Fluvoxamine (Luvox)</td>
<td>8: 12.5-25</td>
<td>T: 50-200</td>
<td>29 mg q 2 weeks</td>
<td>tab: 25, 50, 100</td>
<td>16</td>
<td>26y OCD (immediate release only)</td>
<td>N: CYP 2C9 inhibition</td>
<td></td>
</tr>
<tr>
<td>Citalopram (Celexa)</td>
<td>8: 5-10</td>
<td>T: 20-40</td>
<td>10 mg q 2 weeks</td>
<td>tab: 10, 20, 40</td>
<td>liq: 2mg/mL</td>
<td>35</td>
<td>–</td>
<td>N: Few CYP interactions R/S: 1QTc risk &gt;40mg</td>
</tr>
<tr>
<td>Bupropion (Wellbutrin)</td>
<td>8: 37.5-75</td>
<td>T: 150-300</td>
<td>37.5 – 75 mg q 2 weeks</td>
<td>tab: 75, 100</td>
<td>er: 100, 150, 174, 200, 300, 348, 450, 522</td>
<td>21-37</td>
<td>–</td>
<td>N: Behaviorally activating; used to augment SSRI, treat ADHD R/S: ↑Anxiety, ↑SU risk</td>
</tr>
<tr>
<td>Trazodone (Desyrel)</td>
<td>8: 50</td>
<td>T: 50-100</td>
<td>25 mg weekly</td>
<td>tab: 50, 100, 150, 300</td>
<td>er: 150, 300</td>
<td>10</td>
<td>–</td>
<td>N: Use for insomnia R/S: Priapism</td>
</tr>
<tr>
<td>Mirtazapine (Remeron)</td>
<td>8: 7.5-15</td>
<td>T: 15-30</td>
<td>7.5 mg q 2 weeks</td>
<td>tab: 7.5, 15, 30, 45</td>
<td>dis: 15, 30, 45</td>
<td>20-40</td>
<td>–</td>
<td>N: Used to augment SSRI, treat insomnia R: ↑Stimulates appetite</td>
</tr>
<tr>
<td>Quetiapine (Cymbalta)</td>
<td>8: 20</td>
<td>T: 30-60</td>
<td>20 mg q 2 weeks</td>
<td>dr: 20, 30, 40, 60</td>
<td>12</td>
<td>27y GAD</td>
<td>N: Limited evidence supporting use for depression in children</td>
<td></td>
</tr>
</tbody>
</table>

*Some also used for anxiety and chronic pain, 1Higher doses needed for OCD. CYP = Cytochrome P450 proteins; tab = tablet; cap = capsule; liq = oral liquid, er = extended release, dr = delayed release. Only psychotropic use approvals are listed. Medications may have other approvals in youth.
Florida Best Practice Guidelines

http://www.medicaidmentalhealth.org/_assets/file/Guidelines/2019-ASD%20&%20ID%20Guidelines%20(w%20references)%20%206.5%20x%209.56.pdf

Treatment of Hyperactive, Impulsive, and Inattentive Symptoms in the Context of ASD and ID

Youth with ASD and ID experience symptoms of hyperactivity, impulsivity, and inattention (ADHD) at higher rates than their neurotypical peers. Children and adolescents can benefit from the same evidence-based treatments used to treat ADHD uncomplicated by ASD.

Level 0 - Comprehensive Assessment:
See Principles of Practice. In addition, give special consideration to:
- Developmental history and cognitive assessment (neuropsychological or educational)
- ADHD symptom history
- Parent and teacher rating scales (e.g., Vanderbilt Assessment Scales, Conners Parent and Teacher Rating Scales)*
  Note: Conners Parent and Teacher Rating Scales are not in the public domain.
- Teacher behavior reports
- Involvement in community resources
- Physical examination (e.g., if history of staring spells or focal neurological signs: EEG, MRI)
- Safety concerns related to significant impulsivity (e.g., bolting away, darting across roads, excessive climbing).

Level 1 - Methylenidate or guanfacine monotherapy.
If child has significant symptoms, consider methylphenidate or guanfacine as a first line medication.
- Use methylphenidate or guanfacine (both immediate-release and extended-release) with caution since adverse behavioral effects may be higher in youth with ASD and ID compared to normally developing youth with ADHD.
- Methylphenidate or guanfacine yield benefit in about 50% of children in the ASD and ID population for hyperactivity. Close monitoring is recommended, and lower dosing than expected may be required for tolerability.
- Methylphenidate is favored over guanfacine for treatment of inattention without hyperactivity.
  - Obtain resting blood pressure and heart rate at baseline and follow-up visits.
  - ECG is recommended if the child has evidence of cardiac disease or known family history of sudden death. Consult a pediatric cardiologist before initiating treatment.
  - Continue to increase dose until ADHD symptoms are adequately controlled, maximum recommended dosing is reached, or treatment-limiting side effects emerge.
  
  Refer to Tables 3-7 on pages 23-29 for dosing recommendations.
Troubleshooting Behavioral Issues

- Medical issues [seizures, GI issues (constipation), diet, pain (esp. dental), infection, etc.]
- Changes in environment (BULLYING, substitute teacher, new schedule, recent move)
- Difficulties in communication and resulting frustration
- Inadequate psychoeducational supports
- Psychiatric comorbidity
- Maladaptive reinforcement patterns

Four Main Functions of Behaviors:
- Escape/Avoidance
- Attention Seeking
- Seeking Access to Materials
- Sensory Issues
Questions?

Contact the PHN Quality team if you would like guidance on how to implement the content from today’s talk into your practice workflow or EMR templates.

PHN@childrensnational.org