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



Today's presenter has no conflicts to disclose:

- 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.



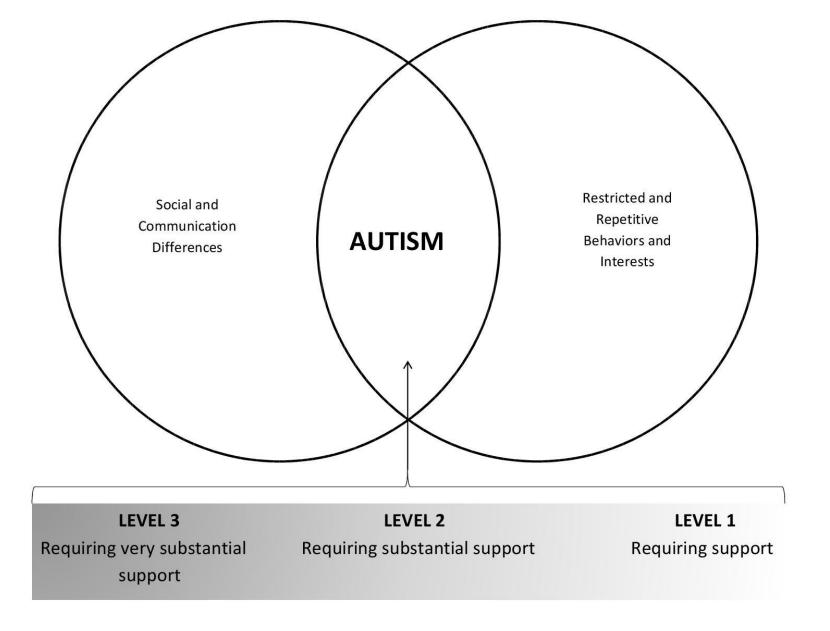


Diagnostic Criteria and Prevalence















Autism is relatively common.

		Currently has ASD	
USA	%	2.9	
	Pop. Est.	1,812,917	
DC	%	2.0	
	Pop. Est.	1,877	
Maryland	%	2.0	
	Pop. Est.	22,126	
Virginia	%	4.6	
	Pop. Est.	73,660	

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**."

Interagency Autism Coordinating Committee (IACC). 2016-2017 Interagency Autism Coordinating Committee Strategic Plan For Autism Spectrum Disorder. October 2017. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: https://iacc.hhs.gov/publications/strategic-plan/2017/.







Developmental Disabilities Systems of Care Framework

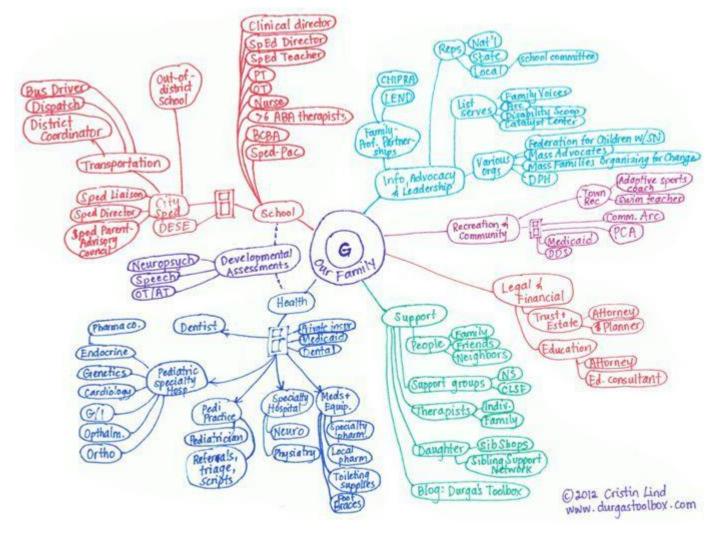






Building this network of supports feels overwhelming at

first...







Main Sources of Funding for Kids with Disabilities

Health Insurance

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





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Early Intervention/ **Public Schools**

- Team classification
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- 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?







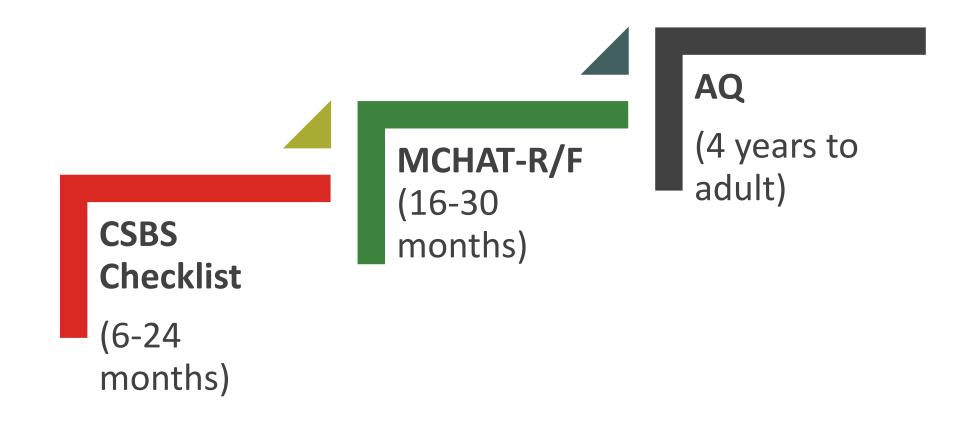
Managing Positive ASD Screen Results







Free Screening Instruments









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.



University Hospital

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

Guthrie W, Wallis K, Bennett A, et al. Accuracy of Autism Screening in a Large Pediatric Network. Pediatrics. 2019;144(4):e20183963







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."





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.







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Although your child's MCHAT was positive, this does not necessarily mean that s/he has autism. I still suggest we refer because s/he probably needs extra help to stay on track.

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

Diagnostic Evaluations for Children with DC Medicaid

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













Select Autism Resources

Autism Screeners

- Open source
 - CSBS Checklist (6-24 months; http://www.autismalert.org/uploads/PDF/SCREENING---
 DEVELOPMENTAL%20DELAY%20&%20AUTISM--CCBS%20DP%20Infant-Toddler%20Checklist.pdf)
 - MCHAT-R/F (16-30 months; https://mchatscreen.com/mchat-rf/)
 - AQ (4 years to adult; https://www.autismresearchcentre.com/arc_tests)
- For purchase
 - SCQ lifetime (age 4+, 5-10 minutes)
 - STAT (requires training)

Autism Assessment Resources

- 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
- Autism Mental Status Examination: http://autismmentalstatusexam.com/
- CDC Autism video glossary https://www.cdc.gov/ncbddd/actearly/autism/video/module1.html
- FSU Autism video glossary
 https://resources.autismnavigator.com/asdglossary/#/section/43/gettingStarted
- Missouri Autism Guidelines Initiative https://autismquidelines.dmh.mo.gov/pdf/Guidelines.pdf

IEP Request Letter







PARENT/CAREGVER ADDRESS
CITY, STATE, ZIP CODE
DATE
NAME OF SCHOOL
ADDRESS OF SCHOOL
CITY, STATE, ZIP CODE
Re: Request and consent for an IEP evaluation for my child
Dear Principal:
I am the parent/guardian of () who is a grader at Grader 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 at to schedule an Individualized Education Program (IEP) meeting.
The best time to reach me is
TIME OF DAY
Sincerely,
PARENT/CAREGIVER SIGNATURE
PARENT/CAREGIVER PRINTED NAME
RECEIVED BY:
SCHOOL OFFICIAL NAME SCHOOL OFFICIAL SIGNATURE DATE School official, please provide a copy of this letter to the parent/caregiver.

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

Szatmari P et al. Prospective Longitudinal Studies of Infant Siblings of Children With Autism: Lessons Learned and Future Directions. J Am Acad Child Adolesc Psychiatry. 2016 Mar;55(3):179-87.







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Social communication signs

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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%)

Szatmari P et al. Prospective Longitudinal Studies of Infant Siblings of Children With Autism: Lessons Learned and Future Directions. J Am Acad Child Adolesc Psychiatry. 2016 Mar;55(3):179-87.







Questions?







Resources for In-Office Diagnosis







Missouri Autism Guidelines Initiative

OVERVIEW OF DIAGNOSTIC EVALUATION TIERS TABLE				
	INDIVIDUAL PRESENTATION	USE OF STANDARDIZED INSTRUMENTS	CONSULTATION WITH OTHER PROFESSIONALS	
TIER 1	Presentation of symptoms that unambiguously indicate an ASD	May be used; not required	None	
TIER 2	Milder or more complex symptoms, difficult differential diagnosis, question about cognitive level	Yes	Possibly; consult with at least one other professional, as indicated	
TIER 3	Very subtle or complex symptoms, some ASD symptoms with multiple co-existing concerns, complex medical or psychosocial history	Yes	Yes; consult with multiple other professionals	







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%





AAP January 2020 Clinical Report

"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."

Hyman SL, Levy SE, Myers SM, AAP COUNCIL ON CHILDREN WITH DISABILITIES, SECTION ON DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS. Identification, Evaluation, and Management of Children With Autism Spectrum Disorder. Pediatrics. 2020;145(1):e20193447.







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

https://www.carautismroadmap.org/elements-of-an-evaluation-for-an-autism-spectrum-disorder/ L Zwaigenbaum and M Penner. Autism spectrum disorder: advances in diagnosis and evaluation. *BMJ* 2018;361:k1674.









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

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

AUTISM MENTAL STATUS EXAM

Date	Rater	Subject # _			
EYE CONTACT (observed)	☐ ≥ 3 seconds	☐ Fleeting		☐ None	
INTEREST IN OTHERS (observed)	Initiates Interaction with Examiner	☐ Only Passively Responds	☐ No Interest		
POINTING SKILLS (observed)	Can Point/ Gesture to Object	Only Follows Point	☐ None		
LANGUAGE (reported and/or observed)	Can Speak About Another Time Or Place	Single Words Phrases (s 3 words) Undeveloped Sentences	☐ Nonverbal		
	☐ Articulation Problem				
PRAGMATICS OF LANGUAGE	☐ Not impaired	Cannot manage turns or topics Unvaried or odd intonation			
	☐ Not applicable			☐ reported ☐ observed	
REPETITIVE BEHAVIORS/ STEREOTYPY (reported and/or observed)	☐ None	Insists on Poutines/ Compulsive-like behaviors	☐ Echok	stereotypy al stereotypy alia otyped speech	
UNUSUAL OR ENCOMPASSING PREOCCUPATIONS	□ None	☐ Present-describe:		reported observed	
UNUSUAL SENSITIVITIES	□ None	Heightened Sensitivity High Pain Threshold			
				☐ reported ☐ observed	





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

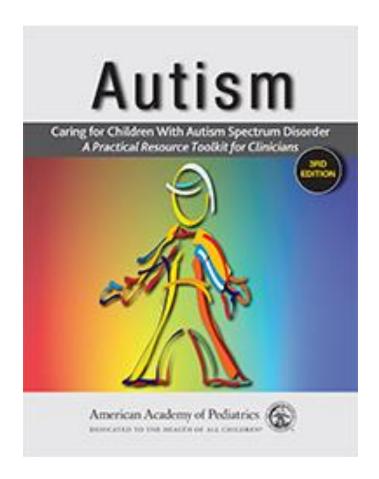
- Find support for yourself, and remember that your child is still
 just as amazing as they were before the diagnosis.
- Read reputable, strength-based, positive sources of information about ASD.
- Don't talk to your child about the diagnosis until you have processed it yourself.
- First stop for educational materials: Autism Speaks 100 Day Kit.







Medical Home



American Academy of Pediatrics

CLINICIAN FACT SHEET

Autism

The Medical Home for Children With Autism Spectrum Disorder



The Need for Coordinated Care

The American Academy of Padiatrics developed the medical home model for delivering primary care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and outurally effective for all children and youths, including those with special health care needs. Children with autism spectrum disorder (ASD) are part of a population that can benefit from having a medical home in which they receive comprehensive, family-centered care and coordination. Children with ASD have limited access to medical homes despite findings that establish a strong correlation between improved access to care and being a part of a medical home. Atthough many parents are untamiliar with the

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







Quick Links Patient Portals International

1-888-884-BEAR (2327)

Make an Appointment

Children's National.

Find a Doctor













Children's National

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?





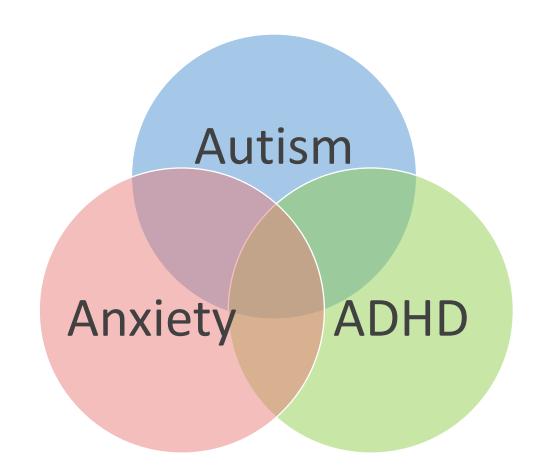


Psychopharmacology





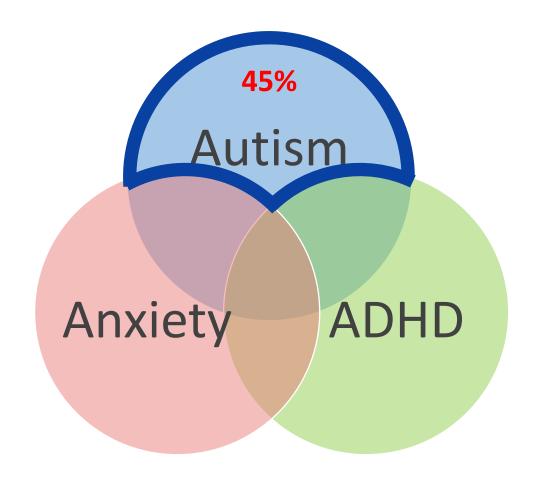








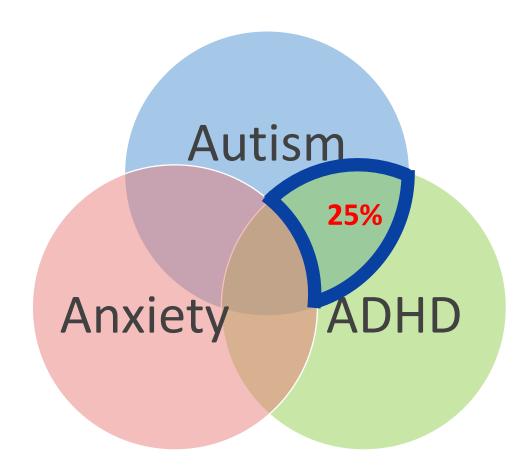








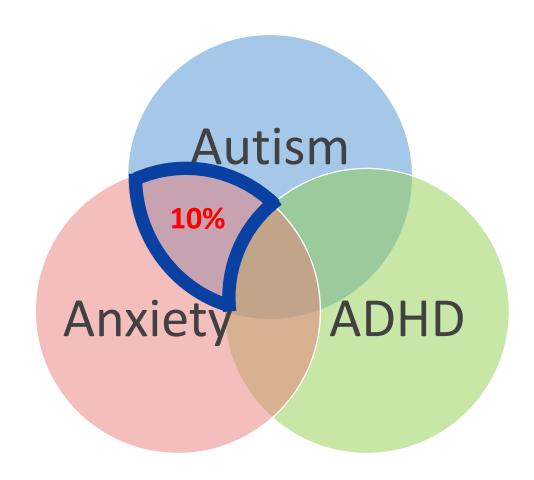








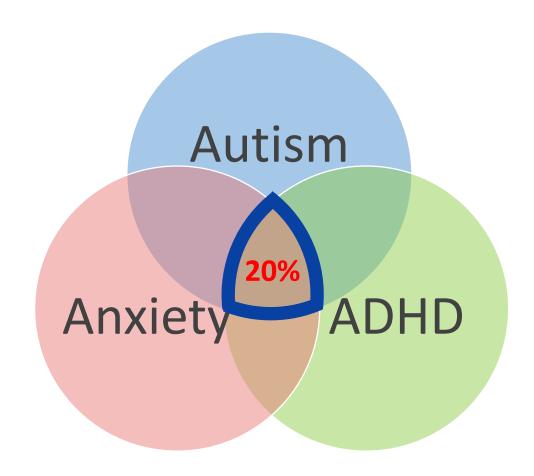


















ASD Psychopharmacology General Principles

- 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)*

Generic (Trade)	S: start dose(mg) T: target dose (mg/day)	Titration Schedule	Formulations (mg)	t 1/2 (hr)	FDA Approved in Youth¹	N: notes; S: side effects; R: risks All: Black Box Warning for SI
Fluoxetine (Prozac)	S: 5-10 T: 20-60 [§]	5-10 mg q 2 weeks	tab: 10, 20, 60 cap: 10, 20, 40 weekly cap: 90 liq: 4mg/mL	96-384	≥7y OCD ≥8y MDD ≥10y Bipolar depression, in combo w/ olanzapine (Puvule capsule only)	N: Long titration / washout = self- tapering N: CYP 2D6 inhibition S: Behaviorally activating
Sertraline (Zoloft)	S: 12.5-25 T: 50-200 [§]		tab: 25, 50, 100 liq: 20mg/mL	26	≥6y OCD	
Escitalopram (Lexapro)	S: 2.5-5 T: 10-30	5-10 mg q 2 weeks	tab: 5, 10, 20 liq: 1mg/mL	27-32	≥12y MDD	N; Few CYP interactions
Fluvoxamine (Luvox)	S: 12.5-25 T: 50-200 [§]	25 mg q 2 weeks	tab: 25, 50, 100	16	≥8y OCD (immediate release only)	N: CYP 2C9 inhibition
Citalopram (Celexa)	S: 5-10 T: 20-40	10 mg q 2 weeks	tab: 10, 20, 40 liq: 2mg/mL	35		N: Few CYP interactions R/S: ↑QTc risk >40mg
Bupropion (Wellbutrin)	S: 37.5-75 T: 150-300	37.5 - 75 mg q 2 weeks	tab: 75, 100 er: 100, 150, 174, 200, 300, 348, 450, 522	21-37		N: Behaviorally activating; used to augment SSRI, treat ADHD R/S: ↑Anxiety, ↑SZ risk
Trazodone (Desyrel)	S: 25 T: 50-100	25 mg weekly	tab : 50, 100, 150, 300 er : 150, 300	10		N: Use for insomnia R/S: Priapism
Mirtazapine (Remeron)	S: 7.5-15 T: 15-30	7.5 mg q 2 weeks	tab : 7.5, 15, 30, 45 dis : 15, 30, 45	20-40		N: Used to augment SSRI, treat insomnia S: Stimulates appetite R: ↑Appetite / wgt gain
Duloxetine (Cymbalta)	S: 20 T: 30-60	20 mg q 2 weeks	dr : 20, 30, 40, 60	12	≥7y GAD	N: Limited evidence supporting use for depression in children

*Some also used for anxiety and chronic pain, *Higher 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.

PDP, 2019





Florida Best Practice Guidelines

http://www.medicaidmentalhealth.o rg/_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,
- Safety concerns related to significant impulsivity (e.g., bolting away, darting across roads, excessive climbing).

Level 1 - Methylphenidate or guanfacine monotherapy.

If child has significant symptoms, consider methylphenidate or quanfacine as a first line medication.

- Use methylphenidate or quanfacine (both immediate-release and extendedrelease) with caution since adverse behavioral effects may be higher in youth with ASD and ID compared to normally developing youth with ADHD. Methylphenidate or quanfacine 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 quanfacine for treatment of inattention without hyperactivity.
 - Obtain resting blood pressure and heart rate at baseline and follow-up.
 - 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 treatmentlimiting 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





