

Diagnosing Autism Spectrum Disorder, Connecting Families to Resources, and ABA Therapy

Available resources, diagnoses by pediatricians and specialists, advice for families following a diagnosis, controversies surrounding ABA therapy

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Increasing Prevalence of Autism

1 in 36
8-year-old children identified with ASD in 2020
*Based on tracking within 11 communities in the United States

Percent of 8-year-old children identified with ASD by ADDM Network Sites

For every girl identified with ASD, Boys were nearly 4 times as likely to be identified

Black, Hispanic, and Asian or Pacific Islander children were more likely to be identified with ASD than White children for the first time in ADDM.

Overall	29.3
Hispanic	31.6
APIA	31.4
White	24.3

Percent identified preschoolers per 1000 children

Approximately 1/3
Of 8-year-old children with ASD also had intellectual disability

Source: National Center on Birth Defects and Developmental Disabilities, CDC

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Why is the prevalence of autism increasing?

- A. Earlier diagnosis
- B. Improved screening
- C. Better differentiation of autism vs. Intellectual disability
- D. All of the above

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Increasing Prevalence of Autism

- Increasing awareness and recognition of ASD
 - Identifying girls with ASD
 - Recognition of ASD among children without developmental delay or intellectual disability
- Improving screening and early identification

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Like It or Not- Our Wheelhouse is Evolving

- We see kids with autism all the time- we know what it looks like!
- In clear-cut cases, we are capable of diagnosing autism spectrum disorder and helping a child get services he/she needs as quickly as possible
- Autism is a CLINICAL diagnosis - it does not require a battery of tests in most cases
- Save referrals for kids with more complex psychosocial problems - this will also free up our specialists to help with those more complex cases

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Takeaway From Today

Let's look at autism spectrum disorder as "bread and butter" pediatrics

Breathe easy!
We are going to give you the tools you need!



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A 3yo Kid Walks Into Your Clinic...

- Only saying a few words, really is just repeating what parents say
- Little to no spontaneous speech
- Does not really engage with other children
- Twirls around a lot, likes to spin things
- Likes to play by himself in a nook in their home
- Throws tantrums when trying to make him do things he doesn't want to do
- Doesn't make eye contact with you or respond to his name when you or parents call him
- Twirls your drawstring on your scrub pants, is very interested in buttons on your laptop
- Takes his parents' hands and tries to drag them to the door when wanting to leave

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What's the Diagnosis?

- Autism spectrum disorder!
- We can all picture this child because we have seen him in our clinic many times
- We can start helping this child and his family connect with support services

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Making a Diagnosis- Checklist

Making a Diagnosis of Autism Spectrum Disorder
© Checkmate

1. **Get a good impression of the child's behavior**
 Interview with parents
 Interview with family
 Interview with school

2. **Rule out other causes**
 Rule out hearing loss
 Rule out intellectual disability
 Rule out anxiety
 Rule out depression
 Rule out trauma
 Rule out other medical conditions

3. **Obtain a good history**
 Obtain a good history
 Obtain a good history
 Obtain a good history

4. **Obtain a good physical exam**
 Obtain a good physical exam
 Obtain a good physical exam
 Obtain a good physical exam

5. **Obtain a good social history**
 Obtain a good social history
 Obtain a good social history
 Obtain a good social history

6. **Obtain a good medical history**
 Obtain a good medical history
 Obtain a good medical history
 Obtain a good medical history

7. **Obtain a good family history**
 Obtain a good family history
 Obtain a good family history
 Obtain a good family history

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How can I help this kiddo?

- Maybe: Take an extra 30 minutes that day to complete the DSM-5 checklist and refer patient for services (might do this if complicated social situation, family unlikely to come back another day, lives far away, etc.)
- Better: discuss with the family that you have concerns the child has autism spectrum disorder
 - Arrange a follow-up visit to complete checklist, write prescriptions and diagnosis letter, and refer to services

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Which of the following is required to make a clinical diagnosis of Autism Spectrum Disorder?

- A. Meeting DSM-5 criteria
- B. ADOS (Autism Diagnostic Observation Schedule)
- C. Evaluation by child psychologist
- D. All of the above

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DSM-5 Checklist

- Takes about 15 minutes to go through with the family
- Give copy to family and scan to the child's record
- For Medicaid, the DSM-5 checklist plus diagnosis letter is all that is needed to start receiving ABA therapy
- For BCBS of AL, they can start ABA therapy with DSM-5 checklist and diagnosis letter, but need full psychology eval within 3 months

DSM-5 Criteria for Autism Spectrum Disorder

Presenting symptoms are required to fulfil A, and B, in addition to documentation for criteria C, D, and E.

A. Deficits in social communication and social interaction (as distinct from symptoms of C, D, and E) must be present in all of the following:

- 1. Deficits in social-emotional reciprocity**
 - Reciprocal social interaction
 - Failure of normal back-and-forth conversation
 - Difficulties initiating or responding to social play or conversation
 - Failure to initiate or respond to social interactions
 - Failure to respond to social interactions
 - Failure to initiate or respond to social interactions
 - Failure to respond to social interactions
 - Failure to initiate or respond to social interactions
 - Failure to respond to social interactions
- 2. Deficits in nonverbal communicative behaviors used for social interaction**
 - Abnormal eye-to-eye contact
 - Abnormal facial expressions
 - Abnormal body posture or gestures
 - Abnormal eye-to-eye contact
 - Abnormal eye-to-eye contact
 - Abnormal eye-to-eye contact
 - Abnormal eye-to-eye contact
 - Abnormal eye-to-eye contact
 - Abnormal eye-to-eye contact
- 3. Deficits in developing, maintaining, and understanding relationships**
 - Failure to develop age-appropriate relationships
 - Failure to develop age-appropriate relationships
 - Failure to develop age-appropriate relationships
 - Failure to develop age-appropriate relationships
 - Failure to develop age-appropriate relationships
 - Failure to develop age-appropriate relationships
 - Failure to develop age-appropriate relationships
 - Failure to develop age-appropriate relationships
 - Failure to develop age-appropriate relationships

B. Restricted, repetitive patterns of behavior, interests, or activities (as distinct from symptoms of A, C, D, and E) must be present in all of the following:

- 1. Stereotyped or restricted motor movements, use of objects, or speech**
 - Stereotyped or restricted motor movements
 - Stereotyped or restricted motor movements
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 - Stereotyped or restricted motor movements
 - Stereotyped or restricted motor movements
 - Stereotyped or restricted motor movements
 - Stereotyped or restricted motor movements
 - Stereotyped or restricted motor movements
 - Stereotyped or restricted motor movements
- 2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior**
 - Insistence on sameness, inflexible adherence to routines
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Refer for Services

- If Medicaid : Give family [DMH Autism Services application](#)
 - Lengthy application, but can provide comprehensive services
- Give list of therapy centers or have patients call 638-PIRC to ask for therapy locations
 - ***Encourage patients to call as many centers as possible and get on wait lists
 - May need to go ahead and make referrals to a handful of centers if there is concern the family may not follow-through
- At minimum:
 - Children under 36 months:
 - Refer to Early Intervention Child Find (1-800-CHILD-FIND)
 - Children 33 months and older:
 - Refer for services through school system/IEP evaluation- can receive speech and OT, unlikely to receive ABA at school (family should call their local elementary school)

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Support the Family

- Give Autism Guide for Parents
 - Regional Autism Network contact information
 - Autism Support of Alabama information
 - Alabama Disabilities Advocacy Program/“Right Not a Favor” booklet link
 - Autism Speaks toolkit link
 - Help Me Grow enrollment info

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Diagnosis Letter

[Name]

is/are the primary care provider(s) caring for patient named [patient name] at [practice name]. [NAME] is a [X] year [X] month old [he/she] who has had a pattern of development concerning for autism spectrum disorder (ASD). [he/she] meets revised developmental screening using the 16-month Ages and Stages Questionnaire (second [month] of ASD) and [he/she] was on the Modified Checklist for Autism in Toddlers (MCHAT) was (MCHAT) screen, which fall in the area of concern.

If applicable: During the [interview] consult visit today, I obtained a focused autism history based on the Diagnostic and Statistical Manual of Mental Disorders (5) criteria for autism and observed [NAME] in play and in interactions with [he/she] (caregiver) and with me.

[OPTIONAL: Summarize history, if not to summarize, say "Please refer to the attached DSM-5 Checklist for details of [NAME]'s developmental history, including written reports."]

[Summarize in clinic observations or other observations from therapy/evaluation visit(s).]

Based on my clinical impression, [NAME]'s developmental profile meets full DSM-5 criteria for a diagnosis of Autism Spectrum Disorder (ASD). Careful consideration was given to other diagnoses, including hearing and vision impairment. As there are not sufficient to rule out [he/she] legal hearing and vision impairment, the child will require sensory developmental services to help [he/she] reach [he/she] full developmental potential.

In addition to speech therapy/occupational therapy/physical therapy(s), I recommend that [NAME] engage in therapy using the principles of Applied Behavior Analysis (ABA) as a medically necessary, evidence based component of [he/she] developmental services given the potential lifelong impact of [he/she] developmental differences on social communication, behavior, and adaptive functioning. ABA engages children through motivational strategies to practice functional behaviors that they may not learn as easily through more traditional social interaction methods or natural environmental exposure. This approach supports self-sufficiency across functional areas, as well as reduces negative behaviors. If appropriate, I suggest medication to help [NAME]'s persistent difficulties with learning developmentally appropriate adaptive behavior due to reduced social engagement further emphasizes the medical necessity of ABA based approaches. Long-term and/or high-intensity medication such as risperidone, aripiprazole, and/or [name] or other [name] [name].

Please contact me at [phone number] if you have any questions.

Sincerely,
 [Physician Name/credentials]
 [Practice Name/Contact Information]

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Autism Guide for Parents

Autism Guide for Parents

We know that receiving a diagnosis of Autism Spectrum Disorder for your child can be overwhelming. While we understand the range of emotions families feel during this time, we as pediatricians remain optimistic about this diagnosis given the successes we see with therapy. We are here to walk with you through this journey with your child. We have compiled this resource guide with the help of the UAB Developmental Pediatrics Clinic to get you started on your journey.

First step: Get connected with therapy
 Research shows that young children with Autism Spectrum Disorder benefit significantly from 20 hours or more per week of one-on-one intervention that is delivered in highly structured settings and with very specific teaching goals. ABA therapy (Applied Behavior Analysis) is the most effective mode of therapy.

- To learn more about ABA therapy, visit: <https://www.autismspeaks.org/applied-behavior-analysis>
- For support and care coordination services:
 - Call the Regional Autism Network
 - 205-934-1112 (for patients in the Birmingham area)
 - Or visit www.autism-alabama.gov/regional-autism-network.html
 - Autism Support of Alabama <http://www.autism-alabama.org/resources/resource-directory>
 - Enroll in Help Me Grow Alabama <https://helpmegrrowalabama.org/>

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Support the Family – Cont.

- Ask how the caregivers are doing, and actually wait for their answer. While you are their child's doctor, you know that this child's skill deficits and challenges greatly impact the family unit.
- Point out what you've noticed the child has done well
 - Often, these families are all too accustomed to hearing how their child is not meeting certain expectations.
- Praise the caregiver. Caregivers are often told what they could be doing better, or they may carry a significant amount of guilt for the challenges their family is facing.

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Support the Family- Cont.

- If you suspect a child may have ASD or another developmental disability, it's important to navigate these conversations *objectively and compassionately*
- To make these conversations most meaningful for families:
 - Have a list of resources for evaluations, ABA, speech, OT, etc. (On the Autism Guide for Parents)
 - Consider the family's insurance as well.
 - Allow the caregiver time to ask questions and prepare for emotional responding.
 - Do not rush this process. You are having a life-changing conversation*
 - Provide encouragement without delivering false hope
 - Avoid statements like, "I'm sure she'll talk one day."
 - Instead, consider, "I've got a list of providers here that I personally recommend to work on her speech development. They'll work closely with you on finding the mode of communication that is right for her."

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What If I'm Not So Sure it's ASD?

- Refer for comprehensive evaluation
 - Cognitive testing, ADOS, etc.
 - Include DSM-5 Checklist if done and relevant clinical records

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Evaluation Clinics/Providers (not exhaustive)

- Birmingham
 - UAB Civitan-Sparks Clinics
 - Mitchell's Place
 - Glenwood
 - United Ability
 - Behavioral Pediatric Institute of Alabama
 - Children's Behavioral Health (limited)
 - Hopebridge
 - Easter Seals
 - Alabama Developmental and Behavioral Specialists
 - Psychology practices
 - Vulcan, Ackerson & Associates, etc.
- Tuscaloosa
 - University of Alabama Autism Clinic
- Huntsville
 - Silver Linings Neurodevelopment
 - Arc of Madison County
- Montgomery
 - Easterseals of Central Alabama
 - Works of Wonder
- Mobile
 - USA Autism Clinic
- Dothan
 - Melanie Cotter, PhD

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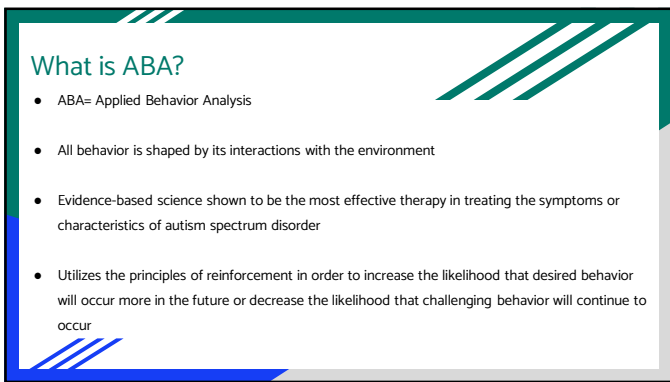
Follow-Up

- 1 month or sooner (if sleep/nutrition/constipation/safety concerns)
- 3-6 months (to ensure family is navigating to services effectively, continued developmental surveillance)

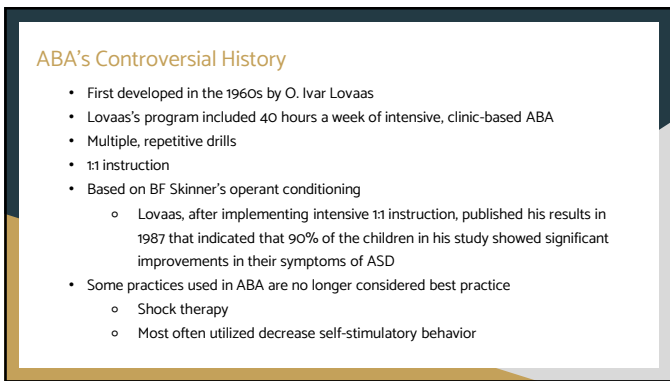
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Controversial Practices Across Healthcare

Fields

- ABA is not unique in being a field that has a history of using procedures that are no longer considered best practice. For example...
 - Lobotomy: Previously used to treat mental illness
 - Electroconvulsive therapy (ECT): History of being used to treat severe depression or bipolar disorder
 - Arsenic: An ingredient in medications until the 1950s
 - Mercury: Previously used to treat syphilis
- Practitioners in any scientific field are tasked with remaining up-to-date with the latest research and modifying practices to reflect advances in their fields. A history of practices once thought to be beneficial does not mean the field is inherently harmful.

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ABA's History of Using Shock Therapy

ABA has a history of using shock therapy, and this history has greatly influenced the way the field is currently viewed. Why was shock therapy predominantly used in the past?

- A. Compliance training
- B. As a punishment procedure for children who engaged in aggressive behaviors
- C. Shocks were delivered if a child did not engage in the appropriate vocalization
- D. Decrease self-stimulatory behavior

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Criticisms of ABA

- Too many hours a week
 - ABA practitioners are not willing to collaborate with other providers
- "One size fits all" model
- Compliance-based
- Not neurodivergence affirming
- Practitioners are too focused on behavior and are not concerned about the emotional or cognitive needs surrounding the behavior.

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Why would we continue to recommend a practice that has been shown to be traumatic?

- We can honor and validate another’s traumatic experiences AND still recognize that when performed with integrity, ABA is still shown to be an effective therapy for those diagnosed with autism spectrum disorder.
- For example...
 - If you had a negative experience with a psychologist, you would not tell someone struggling with mental health that all psychologists are not helpful.
 - If you had a teacher in school who used outdated disciplinary practices for her students, you would not tell someone that he/she/they should not go to school because all teachers harm their students.

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Trauma-Informed ABA

- Trauma-informed ABA can be defined as "recognizing that someone’s history, experiences, mistreatments, or microaggressions all have an impact on how they behave."
 - History of abuse, crisis events, illness or injuries, neglect, mistreatment by other adults, prejudice, misjudgment, or social rejection
- Often, behavioral symptoms of autism align with behaviors related to a trauma-response
 - Repetitive behaviors (objects or speech)
 - Sensitivity to sensory input
 - Lack of social-emotional reciprocity
 - Perseverations
 - Socially avoidant behaviors

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Trauma-Informed ABA

Which of the following is a behavioral symptom closely related to a diagnosis of autism but could also be a trauma-response?

- A. Perseveration
- B. Repetitive behaviors
- C. Sensitivity to sensory input
- D. All of the above

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Social Significance

- When implementing ABA, practitioners are interested in INCREASING desired behaviors and DECREASING challenging behaviors
- These behaviors are also referred to as "socially significant" behaviors or skills
 - Simply put, skills that matter to the learner.
- Communication skills
- Skills that increase independence
- Decreasing aggressive, self-injurious, or disruptive behaviors
- Not every behavior that may be socially significant to the practitioner may be socially significant to the learner
 - Cultural norms
 - Family values

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Socially Significant Behaviors

When we say that ABA practitioners intervene on "socially significant" behaviors, what do we mean?

- Behaviors that are related to a learner's social skills
- Behaviors that matter to the practitioner
- Behaviors that matter to the learner
- Behaviors that will allow the learner to appear more neurotypical

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Discussing Options with Families

- Be mindful that families may have no information regarding autism OR the information they have received is not accurate
 - Social media
- Prior to assigning ABA as the "go-to" for any autism diagnosis, remember that other therapies have been shown to be very beneficial for individuals with an autism diagnosis.
 - Speech therapy
 - Occupational therapy
 - Physical therapy
 - Cognitive behavioral therapy (CBT)

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Recommending ABA to Families

- ABA may be the appropriate recommendation for learners who have delays across developmental domains, are engaging in challenging behaviors, and/or have an autism diagnosis.
 - Remember, in the state of Alabama, ABA therapy is only covered by insurance if the individual has an autism diagnosis.
- It's important to encourage families to find the right ABA center for them, based on the child's needs and the family's needs.
- We have included a handout for questions we recommend that families ask their ABA provider, along with SBH's answers to these questions.

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THANK YOU!

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