



Supporting Autism Families: A Framework for Primary Care Providers PHN Lunch and Learn Q&A March 6, 2024

Q: How can they have an "autism diagnosis" at school if they haven't had an autism diagnosis?

A: There are separate processes for recognizing autism in educational settings versus in medical settings: 1) **Educational classification of autism:** Children may be identified within the school system as having one of 13 disabilities that are identified in Part B of IDEA (Individuals with Disabilities Education Act), with one of those disability categories being Autism. Under IDEA Part B, a school-age child with a disability whose disability adversely affects his or her educational performance would be eligible for special education and related services in school through the creation and implementation of an Individualized Education Plan (IEP). 2) **Medical diagnosis of autism:** Children may be identified as having a medical diagnosis of autism by a qualified health care provider (e.g., pediatrician, psychologist, psychiatrist) based on DSM-5 diagnostic criteria for autism. It is important to ensure children receive an evaluation in both the educational and medical setting so that they can access services across systems (e.g., in school, through their health insurance plan). However, often there are gaps in the evaluation process so a child may be identified as having autism in one system before they are evaluated in another system (e.g., child has a medical diagnosis of autism after seeing a health care provider but has not yet been evaluated by the school system or vice versa).

Q: Did you say you do want to see that 16yo? Or do not?

A: The example provided of a 16-year-old child was more complex and therefore one that would be better to refer to a specialty autism diagnostic center than to see within primary care.

Q: Does each county in Virginia have the same starting age for the autism preschool class? 2? 3?

A: We would refer you to the specific counties for this information.

Q: Does Echo Autism discuss or include resources for FMLA / workplace rights for parents? (asking as a staff member of First Shift Justice Project, a non-profit that provides free legal services for people in DC, Maryland, and Virginia (DMV). FSJP offers legal services and information related to medical/caregiving/family job leave benefits; workplace pregnancy and family responsibility-related discrimination; and workplace accommodations for pregnancy, breastfeeding, and domestic violence.)

A: ECHO offers resources such as your program to ECHO participants when relevant to case presentations.



Q: Is Strong Start the same as EI?

A: Yes, Strong Start is the District of Columbia's Early Intervention (EI) program: <https://osse.dc.gov/service/strong-start-dc-early-intervention-program-dc-eip>

Q: My biggest hurdle is locating adult providers with an Autism background for my enrollees 18 and older. My concern is more referencing ongoing support provided by an Adult Provider with an Autism background.

A: Yes, unfortunately this can be challenging. Here are some options that may be helpful, though it is always recommended that patients contact their health insurance provider for additional in-network options:

- <https://www.umms.org/ummc/locations/adults-neurodevelopmental-disorders>
- <https://www.hopkinsmedicine.org/psychiatry/patient-information/bayview/adult/autism-dev-disabilities>
- <https://www.towson.edu/iwb/centers/hussman/>
- <https://www.autismspeaks.org/resource-guide>

Q: Is there an AI-assisted model for diagnosis of Autism that Primary Care Pediatricians can learn and administer to come to an Autism diagnosis?

A: AI-assisted models exist and/or are in development. We are not expert in this area and have no program to endorse at this time.

Q: Why do I feel that the number of kids with an ASD diagnosis has increased over the past 5-10 years? Is that supported by data? Or it is just "over diagnosis" of quirky kids who are high functioning?

A: The CDC's ADDM Network website has very useful information on changes in prevalence over time: <https://www.cdc.gov/ncbddd/autism/data.html>. As noted by the [CDC](#): "It is unclear exactly how much of this increase is due to a broader definition of ASD and better efforts in diagnosis. However, a true increase in the number of people with an ASD cannot be ruled out. We believe the increase in the diagnosis of ASD is likely due to a combination of these factors."

Q: What age can they start ABA therapy?

A: Typically children can begin ABA therapy following a diagnosis of autism (with most children diagnosed after 18-24 months of age). We would refer you to specific ABA providers to better understand their age limits and targets for treatment in toddlers.

Q: Do you have a good list of services in Fairfax County?

A: Because resource lists can quickly go out-of-date, we recommend reviewing guides that are regularly kept up-to-date such as the following:

- <https://www.autismspeaks.org/resource-guide>
- <https://pathfindersforautism.org/providers-services/>



Q: Do you recommend that all kids with a diagnosis of Autism see genetics?

A: Yes, the American Academy of Pediatrics recommends that all children with a new diagnosis of Autism are referred to genetics ([Hyman et al., 2019](#)).

Q: You just mentioned televisit for the first visit. How do you evaluate Spanish or other language only patients?

A: At Children's National, we have bilingual clinicians (English/Spanish) or we use the hospital's interpreter system. Through this system, interpreters can join Zoom telehealth calls with families.

Q: For services such as speech therapy, occupational therapy and executive functioning coach, insurance often does not cover and parents cannot afford to pay out of pocket. How do you assist these families?

A: Access to recommended services will vary by insurance. Additional resources to explore when insurance is limited include the school system (IEP) and federal and state financial assistance waiver programs. Families who require more support around insurance advocacy could benefit from additional assistance from a legal or parent advocacy organization. Please refer to the slides for resources by state and feel free to follow up with us if you have additional specific questions about cases or resource navigation.

Q: I am having more and more parents say they don't want ABA therapy or that they hear bad things about ABA. How do you handle this? What are your thoughts on ABA?

A: A comprehensive discussion of the nuance and controversy in ABA treatment was beyond the scope of this talk. Please see the attached parent handout for parents on ABA therapy. ABA is recommended on an individualized basis by the evaluating clinician. We have also found this resource helpful in addressing family questions and concerns around ABA: <https://depts.washington.edu/uwautism/wp-content/uploads/2020/10/4.-UWAC-Finding-the-Right-ABA-Treatment.pdf>.

Q: In reference to the screens that you've mentioned to quantify symptoms on those kids who fall into the "green" category, I'm wondering how this information would be used practically. Is this used to simply support the diagnosis, or would I need to include this information along with all the other referrals that I'm doing?

A: We recommend joining an ECHO Autism program to work through how to use screeners and diagnostic tools to quantify autism traits. <https://www.childrensnational.org/get-care/departments/center-for-autism-spectrum-disorders/provider-resources>.



Q: I have a 21-year-old with severe autism and it has been hard for family to find support and transition to an adult medical provider. I'm wondering if there are programs for teens/young adults to help the transition and what we can do as PCPs?

A: We acknowledge that this is challenging and that resources are limited. This resource may be a useful starting point in thinking about transition-age issues:

<https://www.autismspeaks.org/tool-kit/transition-tool-kit>. For assistance with service navigation, these resources may be helpful:

- <https://pathfindersforautism.org/providers-services/>
- <https://www.autismspeaks.org/resource-guide>
- For more specific guidance on how to support this young adult and their family, we recommend joining an ECHO Autism program.
<https://www.childrensnational.org/get-care/departments/center-for-autism-spectrum-disorders/provider-resources>

Q: I am confused about a primary care pediatrician diagnosing autism w/ an ADOS. We have not been successful. Is this insurance or school district specific? I'm in Maryland.

A: This is a nuanced question that absolutely will vary by insurance. We would encourage you to join ECHO to learn more about how PCPs can diagnose and document the diagnosis. We would also invite you to email us with specific challenges so that we can learn more and to assist with our advocacy efforts.

Q: Some adults with autism or some families are opposed to ABA. What options do they have for behavioral therapy?

A: Please see the attached parent information handout on evidence-based therapies for autism.