



The “A-Word” in Early Intervention: To Recommend a Medical Diagnostic or Not

The CDC reports that 1 in 59 children are diagnosed with Autism Spectrum Disorder (ASD). The median age of diagnosis continues to be 2 years or more beyond when families initially develop concerns regarding their child’s development.^{2,3} Specifically, the median age of diagnosis is 4 years of age, despite many parents reporting concerns at around 16 months of age and younger.

Studies have shown that a diagnosis of ASD can be made at 2 years of age, and younger, and that diagnoses of ASD made this early are stable.⁴ Paired with the fact that children aren’t receiving a diagnosis until 4 years of age, this is of great concern because literature shows that *early* and *intensive* intervention provides for the best outcomes for children diagnosed with autism.⁵ Studies also show that children who receive *intensive behavioral intervention* prior to the age of 2 years old make the greatest gains in terms of joint attention, play and language.⁶ In the state of Illinois, children are not able to receive the recommended intensive intervention unless a diagnosis has been made. Therefore, a later diagnosis equates to missed intervention.

So the question remains; if parents and clinicians are concerned about a child’s development prior to 2 years of age, why are so many children being diagnosed up to two years after a concern is noted? Why are two whole years of the most recommended intervention being skipped during one of the most important timeframes of the developing brain?⁹ How can we make sure that all children have access to early *and intensive* intervention? In order to determine barriers to early diagnosis and intervention, the variables affecting this process need to be understood.

The Entry Into a State’s Early Intervention Program

For our kids here in Illinois, the process to a diagnosis of autism often looks like the following:

- 1) the family contacts the primary care physician due to concerns regarding sleep, speech and language development, or other delayed milestones;
- 2) the primary care physician makes a referral to the Illinois Early Intervention (EI) system;
- 3) the family is contacted by an EI representative and assessments are scheduled to evaluate the child;
- 4) two EI therapists representing two disciplines evaluate the child;
- 5) the evaluators, family, and service coordinator meet in order to discuss if the child is eligible to receive EI services and if so,
- 6) an Individualized Family Service Plan (IFSP) is created in order to support the family and child.

It is at this point in time that the ongoing providers are determined and assigned to the case (e.g., a speech therapist and occupational therapist are assigned to the case to assist in speech and motor development). It is also at this point in time that the IFSP team has the ability to recommend a medical diagnostic for the child if they suspect autism or other *medical* conditions that could be influencing development. This point in time is *critical*. With the current waitlist for a medical diagnostic through the state Early Intervention program being 6-8 months, the timing of a medical diagnostic can either assist a family in getting the necessary treatment for their child in the recommended timeframe, or it can interfere with access to recommended and timely treatments. Let’s take a look at two different scenarios that involve differently timed medical diagnostic recommendations:

Scenario 1:

A child comes into the state EI program at 15 months of age and the evaluators note red flags for ASD¹⁰ (i.e., the child does not respond to their name; the child does not point to items to either share information with others or in



response to an adult asking where something is; the child does not engage in purposeful play; the child does not demonstrate joint attention or engagement; the child does not babble or respond to the voice of his caregiver; stereotypy is noted). A medical diagnostic is recommended during the initial IFSP. The IFSP also includes once weekly hour-long sessions to be delivered by a speech, occupational, and developmental therapist. The family is contacted by a medical diagnostic center and the medical diagnostic is scheduled for six months into the future. The child continues to receive three 1-hour sessions per week while waiting to see the developmental pediatrician at the medical diagnostic appointment. At 21 months of age, the child is seen for the medical diagnostic. A diagnosis of ASD is given and the team recommends intensive behavioral intervention which is a service that is not offered via the state Early Intervention program. The family contacts a local provider who requests the necessary paperwork to get started. One full month passes before the paperwork is completed by the medical diagnostic center. The intensive behavioral intervention provider takes an additional 1-2 months to evaluate the child, develop a comprehensive program, hire staff for the child, and train all staff members and the family before treatment can begin. The child begins receiving the recommended treatment at 24 months of age. While this is a great start, this treatment is still occurring 9 months after the red flags were first noticed.

Scenario 2: Avoiding the A-Word to Protect Families’ Feelings

A child comes into EI at 15 months of age and the evaluators note red flags for ASD. The providers note that the family is stressed and struggling with the idea that something could be affecting their child’s development. In order to avoid worrying the family or causing them additional discomfort, the team decides not to recommend a medical diagnostic at this point in time, as they feel that the family is not ready to handle it. They decide that the child will be re-evaluated in six months of time and if at that point in time the red flags are still noted, a medical diagnostic will be discussed. The team feels that the family might be more ready to hear about the “A-Word” after the team has time to develop a rapport. Therefore, the child receives three 1-hour sessions per week of speech, occupational, and developmental therapies respectively until the age of 21 months. At the six-month progress meeting and at 21 months of age, the team discusses the red flags and a medical diagnostic is recommended. Six months pass before the family is seen by the medical diagnostic team and 3 more months pass before the child is able receive the recommended intensive treatment. This child begins intensive services at 30 months of age, or more than one full year after the red flags for autism were noted.

	Scenario 1	Scenario 2
Age of Entry into EI	15 months	15 months
Medical Diagnostic Recommend during Initial IFSP?	Yes	No
Age at medical diagnostic for child A	21 months	NA
Age at 6 month follow-up; medical diagnostic recommended for child B	21 months	21 months
Age at medical diagnostic for child B	NA	27 months
Age that child receives intensive intervention (1 month wait between diagnostic and paperwork and 1-2 months to secure a provider and establish an intensive program)	24 months**	30 months**
***current recommendations are to start intervention as soon as red flags are noted and before age 2^{6,8} Both of these children would be receiving services after the target age.		



Missed Opportunities: We Can Do Better

For some providers and parents, this is not seen as an issue. They believe that as long as the child is receiving Early Intervention services through the state program, the child will be receiving the support they need to develop, as the EI model requires parents to administer ongoing treatment within their everyday routines. However, we know that for our children on the spectrum, the intensity of services matter.^{7,8} Some state run EI programs, such as ours in Illinois, are not equipped to provide for these intensive services and often only provide 1-3 hours of intervention per week with the expectation that families carry over intervention strategies. While families can be trained to implement effective intervention strategies, it is unfair to expect or require families to provide intensive services by themselves, as many families require both parents to work full-time. While some people might point to daycare systems and expect daycares to be able to work with EI providers in order to meet the needs of the child, this is also an unfair expectation as many daycares are not equipped with the appropriate ratio of staff-to-children, as children on the spectrum often require 1:1 intervention during the beginning stages of intervention.⁸ Daycare staff are also unlikely to have the necessary training and education to provide the type of intervention that is consistent with the evidence-based intervention that is recommended.

We know that early diagnosis and intensive intervention is key for these children to develop optimally.^{5,6,7,8,9} So how can we do better? If we see red flags on day one, it is critical to start a discussion about the child's development as soon as possible. While it can be devastating for a family to hear that their child is demonstrating the red flags for autism, imagine how devastating it is for a family to find out that their child missed out on the opportunity for early and intensive intervention and that this early and intensive intervention is linked to the best outcomes noted in scientific literature. By protecting the feelings of a family who we think might not be ready to hear that their child might have autism, we are no longer protecting or providing what's best for the child that we providing services for. We are also setting ourselves up for failure in the long run because eventually, these families will come into contact with someone who will address these concerns and the family will be left with this question: why didn't my provider tell me sooner? Imagine if the medical community took the same approach and avoided telling families that their child has cancer, diabetes, or vision problems?

Tips On Starting the Discussion (for providers):

The fact that Early Intervention providers have been invited into the family's home typically means that the family is already aware that something might be affecting their child's development. While working to establish goals and strategies during the first few visits, *listen* to the family. Listen to their concerns and be with them while looking at the challenges that they are noticing. If the family expresses how hard it is to gain their child's attention, observe this with the family and point out other concerns that you see. One of the first principles of the Illinois Early Intervention program is to facilitate a child's participation in family and community activities. This means that we should be actively looking at the family's routines that they have established with their child. In looking at these routines, we can further understand the strengths and challenges that families are observing and we can use this information to guide a discussion. Perhaps after looking at how the child struggles to attend, we also notice that they are missing other critical foundational skills such as responding to their name, a lack of social referencing, and absent joint attention. Point this out and ask if this is typical for the child. Perhaps this lack of engagement and joint attention has resulted in a lack of imitation and functional play. Point this out. Somewhere during this discussion and observation period, a family will begin to ask questions like, "What can we do?" They might even say something along the lines of, "I'm really scared that it could be something bigger." This is your opportunity to validate their concerns and help them understand the missing foundational skills that you are observing. It will also help you start a discussion about next steps for treatment. Let them know that you see these concerns and that it



could be helpful to bring in a developmental pediatrician to help rule out any other larger or medical concerns. A parent might ask, “What do you mean?” You can simply mention that during the Early Intervention evaluations, the child was not evaluated medically. Therefore, it might be helpful to have a developmental pediatrician also conduct an evaluation in order to determine if any medical conditions could be responsible for these missing foundational skills that are required for further learning. For example, we want to make sure that hearing and vision are developing normally. We want to make sure that the child is taking in information through their senses and responding correctly. Explain the medical diagnostic process, how it can help by furthering our understanding of the child’s development and providing treatment recommendations, the wait-list period, and let the family know that this is a service that is offered through Early Intervention.

Tips On Starting the Discussion (for parents):

If you are parent and you are concerned about your child’s development and whether or not autism is something that should be considered, please do not hesitate to ask your provider directly. They may be relieved to hear you ask about autism directly as this will provide them with the opportunity to discuss the concerns they may have been struggling to mention to you. Mention your concerns during the initial visit with your pediatrician and again during your initial EI evaluation so that providers can discuss whether or not they also see the red flags. Last, contact one of the centers below to schedule an assessment if you’re unable to obtain an assessment through EI or if you’re nervous about the long waitlist. For a free, online autism screening tool, visit <https://m-chat.org/>.

Bypassing The Early Intervention Medical Diagnostic Process If Necessary

Because of the long waitlist for a medical diagnostic through Early Intervention, there are times where we may need to bypass the Early Intervention Medical Diagnostic process all together. For children who come into EI at an older age and won’t make it into the diagnostic center before the age of 3 or for children where intensive services are needed immediately, we can refer families to diagnostic centers that are outside of Early Intervention and that have shorter waitlists. While this will not be feasible for all families who do not have access to commercially available group or private health insurance plans, these centers can be of value to a number of children. Both autism evaluation and treatment are considered an essential health benefit and are covered by both group and private commercial plans or plans that are purchased through the ACA. These centers include:

- Edgewood Clinical Services (<https://www.edgewoodclinicalservices.com/autism-services/>) located in Lisle, IL.
- Caravel Autism Health (<https://caravelautism.com/evaluation-diagnosis/>) located in Naperville, Schaumburg, Deerfield, and Chicago.
- Little Friends’ Center For Autism (<https://www.littlefriendsinc.org/little-friends-center-for-autism/>) located in Naperville, IL.
- Konick & Associates (<https://www.konickandassociates.com/assessments>) located in Naperville, IL.
- Susan Myket, PhD & Associates (<http://www.myketandassociates.com/clinics/the-assessment-clinic/>) located in Naperville, IL.

ASD Intervention

Some readers may cringe every time they read over the words “early and intensive behavioral intervention.” Some might also worry about the idea of labeling such a young child with such a big word such as autism. A quick Google search of autism intervention will often result in a mess of conflicting information that makes it difficult to know *when* we should or shouldn’t intervene and *how* we should or shouldn’t intervene. Stay tuned for another post about intervention where all of



the controversial details will be discussed in detail. For now, please feel free to begin your exploration into early and intensive intervention by accessing the information in the references provided below.

Summary:

- early diagnosis of autism is best so that intervention can be accessed
- diagnosis is required for *intensive behavioral intervention* (i.e., applied behavior analysis AKA ABA) in the state of Illinois
- early and intensive behavioral intervention (ABA) is the best recommended treatment for children diagnosed with ASD
- medical diagnostics should be recommended as early as red flags for ASD are noted
- families should be provided with scientific and evidence-based information regarding ASD and treatments; the National Autism Center provides free information for families and practitioners regarding ASD treatments (<http://www.nationalautismcenter.org/national-standards-project/>)
- families should be provided with additional resources if it is noted that resources outside of EI are warranted

References

²Centers for Disease Control and Prevention; Morbidity and Mortality Weekly Report Retrieved from <https://www.cdc.gov/mmwr/volumes/67/ss/ss6706a1.htm> on 10/7/18.

³Kozlowski AM, Matson JL, Horovitz M. *Parents' first concerns of their child's development in toddlers with autism spectrum disorders*. *Developmental Neurorehabilitation*. 2011;14(2):72–78.

⁴Kleinman JM, Ventola PE, Pandey J, et al. *Diagnostic Stability in Very Young Children with Autism Spectrum Disorders*. *Journal of autism and developmental disorders*. 2008;38(4):606-615.

⁵Eldevik, Sigmund & Hastings, Richard & Hughes, J. Carl & Jahr, Erik & Eikeseth, Svein & Cross, Scott. *Meta-Analysis of Early Intensive Behavioral Intervention for Children With Autism*. *Journal of clinical child and adolescent psychology*, 2009;53(38):439-50.

⁶MacDonald, Rebecca et al. *Assessing progress and outcome of early intensive behavioral intervention for toddlers with autism*. *Research in Developmental Disabilities*. 2014;35(12):3632-3644.

⁷Eldevik, et al. *Using participant data to extend the evidence base for intensive behavioral intervention for children with autism*. *Am J Intellect Dev Disabil*. 2010 Sep;115(5):381-405.

⁸National Research Council (2001) *Educating Children with Autism. Committee on Educational Interventions for Children with Autism*. Catherine Lord and James P.McGee, eds. Division of Behavioral and Social Sciences and Education. Washington, DC: National Academy Press.

⁹Centers for Disease Control and Prevention. Retrieved from <https://www.cdc.gov/ncbddd/childdevelopment/early-brain-development.html> on 10/7/18.



¹⁰Centers For Disease Control and Prevent. Retrieved from <https://www.cdc.gov/ncbddd/autism/signs.html> on 10/7/18.