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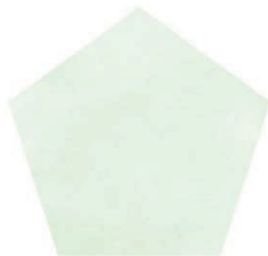
# Early Childhood Diagnosis

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**MEDICAL DIAGNOSIS**

**EARLY DIAGNOSIS IS CRITICAL**

**EARLY DIAGNOSIS RESOURCES AVAILABLE IN THE CAPITAL REGION**





People on the spectrum are not a monolithic population exhibiting a uniform set of symptoms that require unvarying treatment regimens. Likewise, prognoses vary widely.

The broad range of ASD-related symptoms, conditions, and prognoses can leave parents of children with ASD with the impression that their child is, to a significant extent, an experiment of one.



This sentiment was repeatedly expressed by parents, educators, care providers, and advocates interviewed as part of this assessment project.

The wide-ranging nature of ASD challenges our ability to accurately diagnose ASD early in life – the all-important prerequisite to determining and supplying the types and amounts of interventional care required to achieve an optimal outcome. For ASD, as is true for many of our most pervasive medical conditions (diabetes, hypertension, cancer, heart disease, etc.), early diagnosis is the key to efficacious interventions that maximize outcomes.

We interviewed individuals and groups who are involved in the diagnosis and treatment of ASD in the Capital Region. We also spoke with representatives from local, state, and national organizations who had information related to ASD diagnosis and treatment. We also conducted a limited review of expert literature, including information available from the Centers for Disease Control (CDC), the National Institutes of Health Autism Research and Treatment Centers, and other organizations.



**EARLY DIAGNOSIS**

- Referral to physician specialist
- Referral to other medical specialists for comorbidity evaluations (if applicable)
- Referral to early intervention programs

**EARLY INTERVENTION**

- Intensive therapeutic intervention, including ABA therapy and other evidence-based interventions
- Application/referral to state waiver programs (if applicable)

**PRE-K-12 EDUCATION**

- Individual Educational Plan (IEP)
- Continued supplemental intervention and therapy
- Individual Transition Plan (ITP) in high school

**ADULT TRANSITION**

- Post-secondary education
- Career training
- Independent and supported living



# MEDICAL DIAGNOSIS

In the U.S. health care system, a recognized medical diagnosis is the essential door opener for health insurance coverage and the eligibility determinations required to access other financial and service support programs. A medical diagnosis of ASD is made based upon criteria established in the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders Fifth Edition) published in May 2013 by the American Psychiatric Association.



Under the previous version of the DSM (DSM-IV, published 1994), patients could be diagnosed with four separately defined pervasive developmental disorders (PDD): autistic disorder, Asperger's disorder, childhood disintegrative disorder, or the catch-all diagnosis of pervasive developmental disorder – not otherwise specified. Researchers found that these separate diagnoses were not consistently applied across different health care providers and treatment centers.



The revised diagnosis framework represents a new, more accurate, and medically and scientifically useful way of diagnosing individuals with autism-related disorders. Anyone diagnosed with one of the four PDDs from the DSM-IV framework should still meet the criteria for ASD diagnosis in the new DSM-V framework or meet the criteria for another, more accurate DSM-V diagnosis. The DSM Work Group that developed the ASD diagnostic framework believes a single umbrella disorder will improve the diagnosis of ASD without limiting the sensitivity of the criteria or substantially changing the number of children being diagnosed.<sup>21</sup>



The DSM-V criteria were tested in real-life clinical settings as part of DSM-V field trials, and analysis from that testing indicated that there would be no significant changes in the prevalence of the disorder as a result of the change in the diagnosis framework. More recently, the largest and most up-to-date study released in October 2012 issue of *American Journal of Psychiatry* provided the most comprehensive assessment of the DSM-V criteria for ASD based on symptom extraction from previously collected data. The study found that DSM-V criteria identified 91% of children with clinical DSM-IV PDD diagnoses, suggesting that most children with DSM-IV PDD diagnoses will retain their diagnosis of ASD using the new criteria.<sup>22</sup>



The full-text of the DSM-V diagnostic criteria for ASD and the related diagnostic criteria for social communication disorder (SCD) is provided by Autism Speaks on its website.<sup>23</sup> Autism Speaks is an international nonprofit organization focused on ASD advocacy.



21 American Psychiatric Association (American Psychiatric Publishing), "Autism Spectrum Disorder Fact Sheet for DSM-5," available online at <http://www.dsm5.org/Documents/Autism%20Spectrum%20Disorder%20Fact%20Sheet.pdf>  
 22 ibid  
 23 Autism Speaks, "DSM-5 Diagnostic Criteria," available online at [www.autismspeaks.org/what-autism/diagnosis/dsm-5-diagnostic-criteria](http://www.autismspeaks.org/what-autism/diagnosis/dsm-5-diagnostic-criteria).





# EARLY DIAGNOSIS IS CRITICAL

Studies, including randomized ones (randomized clinical trials (RCT)), are showing that early diagnosis and intervention is beneficial and leads to significant improvement in cognition and behavior.<sup>24</sup> Today, research has determined that ASD can be detected as young as 18 months and it is possible to **diagnose ASD correctly when a child is two to three years old**. Efforts are currently underway at the Marcus Autism Center in Atlanta (a NIH Autism Center of Excellence) to reliably detect symptoms in 12-month olds.<sup>25</sup>

Unfortunately, many children with ASD are not diagnosed until the age of 5 or even after they begin elementary school. Minorities are typically diagnosed later than Caucasian children. The **median age of diagnosis in the United States is four years old**.<sup>26</sup> Stakeholder interviews conducted as part of this assessment indicate our Capital Region children are no exception to these statistics. Stakeholders offered a variety of anecdotal rationales for the delay in diagnosis – from lack of access to primary care providers to parental avoidance to limited provider familiarity with ASD.

There is no medical test currently available to diagnose ASD. Diagnosis is based on behavior analysis by trained physicians and psychologists using behavior-based screening tools. Diagnoses are sometimes developed by larger evaluation teams that may also include speech therapists, behavior therapists, language experts, and other therapists.

Prior to medical diagnosis, parents and others who are in close contact with children are ideally positioned to make basic observations that raise “red flags” and warrant a professional evaluation. Autism Speaks offers the following list of “red flags” that may indicate risk for an ASD diagnosis:

- No big smiles or other warm, joyful expressions by six months or thereafter
- No back-and-forth sharing of sounds, smiles or other facial expressions by nine months
- No babbling by 12 months
- No back-and-forth gestures such as pointing, showing, reaching or waving by 12 months
- No words by 16 months
- No meaningful, two-word phrases (not including imitating or repeating) by 24 months
- Any loss of speech, babbling or social skills at any age

24 Dawson et al., “Randomized, Controlled Trial of an Intervention for Toddlers with Autism: The Early Start Denver Model,” 2010.  
25 For more information about the Marcus Autism Center in Atlanta and their research efforts, visit the Marcus Center website at [www.marcus.org](http://www.marcus.org).  
26 Center for Disease Control and Prevention, “Autism Spectrum Disorder, Data and Statistics,” available online at <http://www.cdc.gov/ncbddd/autism/data.html>.

## LOSING VALUABLE TIME

Possible Age of Diagnosis: **between 2 - 3 years**

Current Median Age of Diagnosis: **4 years**

Autism Speaks also offers a basic tool for parents – the Modified Checklist for Autism in Toddlers, Revised (M-CHAT-RTM) – on its website: [www.autismspeaks.org](http://www.autismspeaks.org). Caregivers, including parents and childcare providers, need to be trained to recognize the warning signs or red flags that indicate the need for a professional ASD assessment.



Early diagnosis of ASD by a medical professional is typically accomplished through a two-step process.

1 The first step is a basic developmental screening that can be conducted by a wide range of health care professionals including pediatricians, family practitioners, psychiatrists, psychologists, and other trained professionals. Screening is not the same as diagnosis. It identifies those children who may be at risk and who merit further evaluation. However, if there are concerns, referral for appropriate therapy services is essential even in the absence of a specific diagnosis.

In Louisiana, the EarlySteps program is designed to serve families with a child aged birth to 3 years old who has a developmental delay or a medical condition likely to result in a developmental delay. Eligibility for this state-run program requires either an established medical condition commonly associated with developmental delay or disability, or presence of a developmental delay established through the EarlySteps assessment battery. To access the EarlySteps assessment battery or to get more information about the program, parents/caregivers should call the System Point of Entry Office (SPOE) for their parish of residence.<sup>27</sup> This program, managed by the Office for Citizens with Developmental Disabilities (OCDD) within the Louisiana Department of Health and Hospitals (DHH), also includes the screening of program participants for ASD beginning at 18 months. (*EarlySteps is described in greater detail later in the **State Support Services** section of this report*).

The American Academy of Pediatrics (AAP) specifically recommends that a child be screened for developmental delays and disabilities during well-child doctor visits at 9 months, 18 months, and 24 or 30 months. In addition, all children should be screened specifically for ASD at 18 months and 24 months. Extra screenings are recommended for high-risk children (those with pre-term birth, low birth weight, or with a sibling or parent with ASD) or those who may exhibit symptoms. A copy of the *Surveillance and Screening Algorithm: Autism Spectrum Disorders (ASD)* is provided by AAP on its website.<sup>28</sup> Evidence gathered through our interviews with health care professionals, educators, advocates, and parents of children with an ASD diagnosis in the Capital Region indicates that **the AAP-recommended standards for ASD screening and surveillance are not consistently utilized in the Capital Region – representing a significant opportunity to improve the early diagnosis of ASD in the Capital Region.**

<sup>27</sup> For the System Point of Entry Office contact information or more information about Early Steps, visit the Louisiana Department of Health and Hospitals website at <http://new.dhh.louisiana.gov/index.cfm/page/215>.

<sup>28</sup> American Academy of Pediatrics, "Caring for Children with Autism Spectrum Disorders: A Resource Toolkit for Clinicians", available online at [www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/pages/Caring-for-Children-with-Autism-Spectrum-Disorders-A-Resource-Toolkit-for-Clinicians](http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/pages/Caring-for-Children-with-Autism-Spectrum-Disorders-A-Resource-Toolkit-for-Clinicians).



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The second step in the early diagnosis process is a comprehensive diagnostic evaluation that is typically provided by a much smaller community of specialists including developmental pediatricians, child neurologists, and child psychiatrists and psychologists. Again, evidence gathered through our interviews of stakeholders in the Capital Region indicates that comprehensive diagnostic evaluations for ASD are conducted by only a handful of specialists who are focused on ASD and other developmental disorders. The results from these interviews also suggest lengthy waiting lists to access these specialists, resulting in some families venturing outside the Capital Region to gain access to the qualified specialists they need.

The Louisiana Autism Spectrum and Related Disabilities Project (LASARD), housed in the Human Development Center of LSU Health Sciences Center in New Orleans, offers a number of educational opportunities targeted specifically at Louisiana physicians to increase rates of screening. LASARD has developed a series of webinars that can be viewed by practicing physicians for continuing educational credit. LASARD offers an ASD case trial to teach physicians what to look for in ASD cases and teaches seminars that discuss how to conduct ASD screenings and how to bill third-party insurers for ASD screenings. In addition, LASARD personnel meet regularly with pediatric residents at Tulane Medical School and LSU Medical School in New Orleans to discuss surveillance and screening practices.

An early diagnosis of ASD not only allows the family to access therapeutic and other support structures, but is also invaluable once the child starts schooling. Since most children are not diagnosed until they enter the school system, their access to school support is further delayed. A medical diagnosis is not required for the creation of an Individualized Education Program, but it is required for the school to bill private and commercial insurance and Medicaid for additional services and therapies provided in the classroom, such as speech therapy or ABA therapy. More information on this can be found in the **Pre-K-12 Education** section of this report.

Finally, while obtaining a diagnosis is critically important, comorbid medical conditions associated with ASD can often be a trying experience for parents. These comorbid conditions can include Attention Deficit Disorder (ADD), Attention Deficit/Hyperactivity Disorder (ADHD), gastrointestinal issues, sleep disorders, seizures, intellectual disability, and many others. More detailed information on these conditions and the steps physicians and caregivers need to take to best educate and equip parents can be found in the **Medical Comorbidities** section of this report.



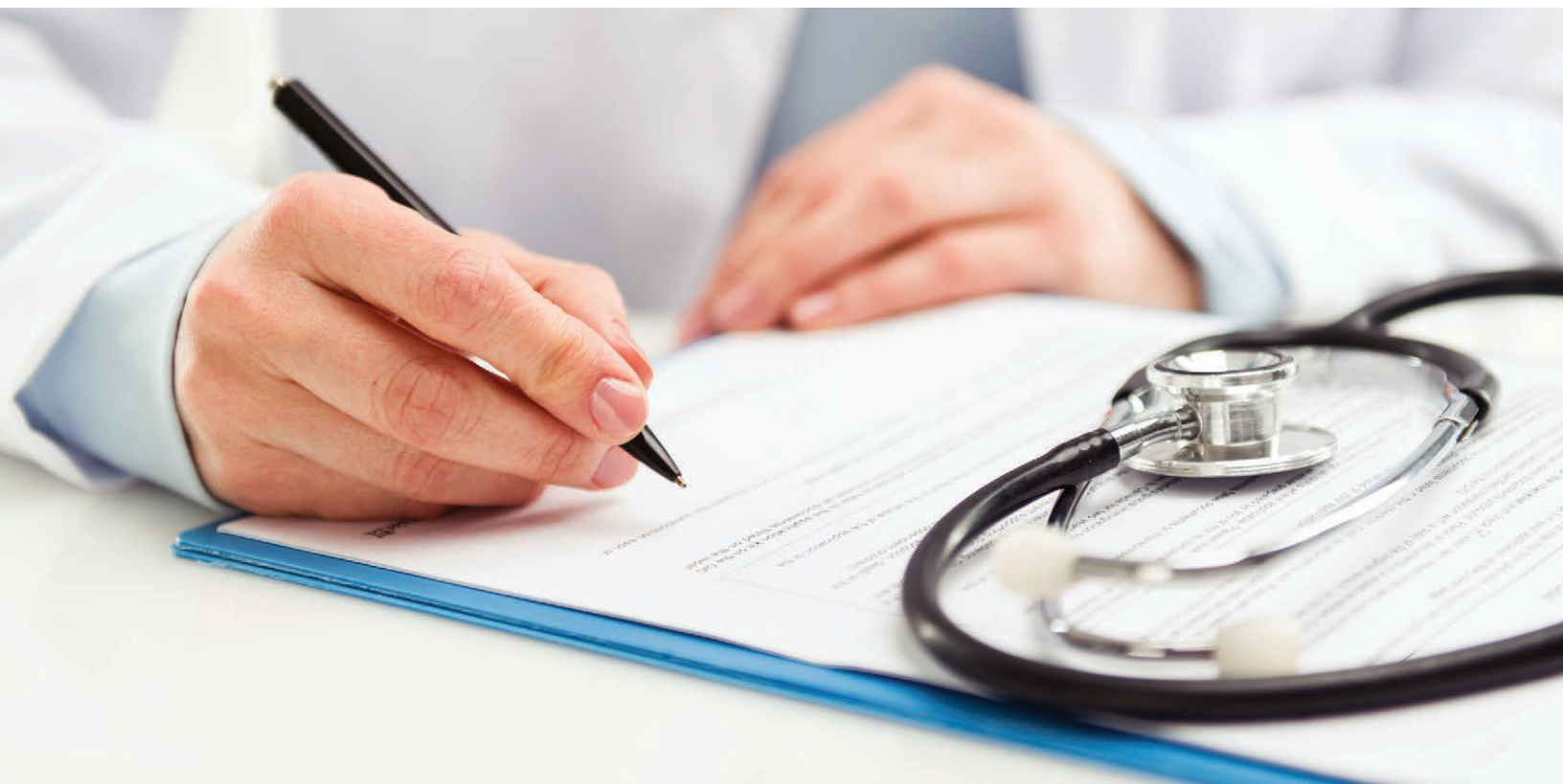


# EARLY DIAGNOSIS RESOURCES AVAILABLE IN THE CAPITAL REGION

The following are significant early diagnosis providers currently available in the Capital Region. This listing is not intended to be an exhaustive list, as we have heard anecdotally that other physicians and psychologists in the region are performing comprehensive diagnostic evaluations. Additionally, screening is available at a variety of service providers as detailed in the [Early Childhood Intervention](#) section. Narrative descriptions for these providers can be found in the [Key Providers and Organizations in the Capital Region](#) section of this report.

- Baton Rouge Clinic Pediatric Neurology (2 pediatric neurologists)
- Our Lady of the Lake Pediatric Development and Therapy Center (1 developmental pediatrician, another joining in summer 2016)
- The Emerge Center for Communication, Behavior and Development (2 psychologists)

Resources are limited for physician specialists in Louisiana. Given the scarcity of these specialists trained to diagnosis in the Capital Region, it is not at all surprising to hear that parents are traveling as far as neighboring states in order to get an ASD diagnosis to access therapies and additional resources.





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## RECOMMENDATIONS

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### **EARLY CHILDHOOD DIAGNOSIS**



Evidence is mounting that shows an early diagnosis of ASD (beginning at 18 months) is possible, reliable, and significantly advantageous to the pursuit of optimal potential outcomes.

1. The Louisiana Chapter of the American Academy of Pediatrics (AAP) should lead an ongoing, focused campaign to endorse and encourage best practices in ASD treatments, particularly related to ASD screening and surveillance best practices and ongoing medical training.
  - a. Promotion and distribution of AAP-developed guidelines, tools, and other collateral resources developed for pediatric health care professionals and new parents.
  - b. Engagement with Louisiana medical schools/pediatric programs to identify and promote any new opportunities to better prepare pediatric residents for early diagnosis of ASD.
  - c. Engagement with Louisiana medical schools/pediatric programs and physician clinics to identify and promote any new opportunities for ongoing training in comorbid conditions and best practices associated with the treatment of ASD.
2. Area providers, including the Baton Rouge Clinic, the Baton Rouge General, Lane Regional Medical Center, Ochsner Health System, Our Lady of the Lake Children's Hospital, and Woman's Hospital should lead an effort to build the cadre of pediatric physician specialists and psychologists needed in the Capital Region to offer all young children with ASD timely, local access to comprehensive diagnostic evaluations and treatment prescriptions. These hospitals should undertake a targeted campaign to recruit these specialists to the Capital Region and expand hospital resources to support and retain them.
3. A comprehensive, robust ASD stakeholder organization<sup>29</sup> based in the Capital Region should design and execute a community education campaign focused on *Learn the Signs of Autism*,<sup>30</sup> a practical guideline that can aid families and other caregivers in identifying early red flags that could warrant a formal evaluation. This campaign should include training sessions, awareness campaigns, and provide informational materials to the following targeted groups:
  - a. Parents/Family caregivers
  - b. Childcare providers
  - c. Educators
  - d. Social service and recreation organizations serving young children
  - e. Churches
  - f. Civic groups
  - g. Other health care professionals (e.g., nurses, physician extenders, technicians)

<sup>29</sup> See Community Recommendation 1 on page 16.

<sup>30</sup> Autism Speaks, "Learn the Signs of Autism," available online at [autismspeaks.org/what-autism/learn-signs](https://autismspeaks.org/what-autism/learn-signs).



4. The Louisiana Department of Health and Hospitals (DHH) should establish developmental screening performance metrics for its Healthy Louisiana (Medicaid managed care, formerly called Bayou Health) contracts that are consistent with Centers for Disease Control and Prevention (CDC) guidance.<sup>31</sup>
  - a. Screening for developmental delays and disabilities during regular well-child doctor visits at:
    - i. 9 months
    - ii. 18 months
    - iii. 24 or 30 months
    - iv. Additional screening as needed if a child is at high risk for developmental problems due to pre-term birth, low birth weight or other reasons
  - b. Screening for ASD during regular well-child doctor visits at:
    - i. 18 months
    - ii. 24 months
    - iii. Additional screening as needed if a child is at high risk for ASD (e.g., having a sister, brother or other family member with ASD) or if behaviors sometimes associated with ASD are present
5. The Louisiana Department of Education (DOE) should establish a requirement, as a condition of state licensure, that all staff of licensed early learning centers be trained as part of the new employee orientation requirements (LA Title 28 Chapter 17.1719) to recognize the “red flags” that may indicate risk for an ASD diagnosis.

The Louisiana Autism Spectrum and Related Disabilities Project (LASARD), a collaborative effort between the Louisiana State University Health Sciences Center Human Development Center and DOE, offers a one-hour training that illustrates “red flags” that may indicate a child has ASD. They also offer 12 hours of DOE approved training for caregivers regarding ASD detection and intervention. DOE may wish to leverage this existing resource to implement this new licensure requirement by allowing early learning center employees to be trained through this program.

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<sup>31</sup> Center for Disease Control and Prevention, “Autism Spectrum Disorder (ASD), Screening and Diagnosis,” <http://www.cdc.gov/ncbddd/autism/screening.html>.