

PART 1: AUTISM SPECTRUM DISORDER (ASD) DIAGNOSTICS – Early Identification

Autism Spectrum Disorders are complex in the way that they manifest, blending any variety of strengths and challenges among several developmental areas (e.g. communication, social interaction, “unusual behaviors”, motor skills, play/imagination/creativity, cognition, social-emotional skills, etc.) but with some core differences in select areas (e.g. communication, social interaction, repetitive, restrictive or unusual behaviors). Because of the variability in how ASD presents, it is difficult for medical providers and families to notice the need for assessment, but early identification is critical for the best prognosis. At Valley Medical Center, there is a specialized and dedicated team of professionals involved in the diagnostics for ASD:

- Neurologists (Dr. Li and Dr. Joseph have over 20 years of experience)
- Speech-language pathologist (SLP) with professional experience since 1999 and specific experience administering the ADOS-2 since 2008

The following information outlines Part 1 of a series of 5, about the importance of early identification, intervention, and support for both patients diagnosed with ASD and their families. All parts within the series are as follows:

Part 1: ASD-Early Identification

Part 2: ASD-Prevalence and Comorbid Issues

Part 3: ASD-Support

Part 4: ASD-Treatment

Part 5: ASD-Communicating with People Diagnosed with ASD

Why is Early Identification of ASD Important?

A significant delay in diagnosis exists between symptom onset (usually between 12-18 months of age) and the average age of diagnosis (usually between 4-6 years of age).

1. To optimize child outcome; intervene before the full syndrome/disorder is manifested and try to alter the trajectory of the child’s development:

- Early diagnosis leads to specialized and effective early intervention which leads to improved social, language, cognitive skills and therefore overall improved outcomes and increased success and independence in the long run
- Two-year-olds have few ingrained habits so it is easy to stop negative behaviors before they become unmanageable; by three-years-of-age, these children were more likely to have motor, communication as well as sensory and emotional problems
- Intervention initiated before 3 years of age has a larger impact than intervention initiated after 5 years of age
- Some insurance companies will not cover some interventions without a diagnosis
- Enhance strengths
- Improve choices and quality of life

- Delays in diagnosis can have significant impact on development and can cause years of prolonged unnecessary training

2. To educate and empower families:

- Alleviate parental stress and uncertainty for the future and empower parents with an early diagnosis and the right tools
- Provide access to resources, intervention, information, and support (e.g. caregiver benefits or disability living allowances)
- Provide strategies for promoting child's development
- Provide opportunities for networking and advocacy
- Clarify genetic implications for family
- Encourage early parent-led behavior intervention as it showed significantly reduced autism symptoms

3. To understand causes and improve treatments:

- Identify core features
- Define etiological subtypes
- Delineate developmental pathways and sequences
- Develop tailored, specific treatments
- Consideration of comorbidities and medical disorders
- Limit mental health problems during adolescence and beyond

General ASD Diagnostics

ASD diagnostics are challenging and complex as they currently consist of observational screenings and tests along with significant interviewing of family members. First, the primary care physician might administer and discuss the patient's development to date as well as administer the M-CHAT-R/F (ages 16-30 months of age). For additional screenings the Centers for Disease Control and Prevention (CDC) website references other tools and also provides a wealth of information on their "Learn the Signs. Act Early." webpage. For children beyond the M-CHAT-R/F screening period, parental concern may be a significant reason to act quickly and refer a child for an evaluation specifically in the area of ASD.

If concerns continue to persist for ASD, referrals to other professionals like speech-language pathology for communication, occupational therapy for sensory integration and processing and play and fine motor development, audiology for an evaluation of hearing, ophthalmology for vision evaluation, and neurology for an evaluation of the patient's neurological system. Besides neurologists, other providers who may make an autism diagnosis include psychiatrists and developmental pediatricians.

Please refrain from indicating a high- versus low-functioning form of ASD. These terms:

- do not relate to formal diagnostic criteria nor is there a consistent or commonly accepted definition of these terms
- are considered to be too stereotypical and simplistic to describe the human development or nature of ASD

- tend to be permanent and do not necessarily reflect a person's behavior or true potential either by minimizing or overestimating a person's abilities
- tend to be dependent upon the person with ASD and their personal performance rather than the environment and supports that are needed

Dr. Barry Prizant's Recommended Top 10 Service Provider Supports for PATIENTS:

1. recommend a collaborative team approach to intervention
2. speak and act respectfully to the person diagnosed with ASD
3. include the person diagnosed with ASD in discussions, activities
4. provide adequate support to help the person with ASD be successful
5. project high, yet realistic, expectations with support
6. help provide creative and flexible options as approaches to intervention or specific situations
7. allow the person with ASD to be your top priority in the moment
8. inquire about and utilize the person with ASD's individual strengths and interests
9. utilize meaningful activities for improved relationship building
10. respect and appreciate the person with ASD

Dr. Barry Prizant's Recommended Top 10 Service Provider Supports for PARENTS:

1. respect and appreciate that parents try their best
2. understand parents' perspective and experience
3. respect the parent expertise regarding their child
4. balance sharing suggestions with active listening
5. be honest in your communication
6. state "I don't know" but that you will help to locate answers to questions/concerns
7. share and celebrate successes, no matter how big or small
8. inquire about parents' goals for their child and family
9. show your interest and concern for the child and family
10. be humble in your role in their lives

Resources:

- VMC process for ASD Diagnostics <https://www.valleymed.org/Our-Services/Childrens-Therapy/Autism-Testing-Checklist/>
- M-CHAT-R/F <https://mchatscreen.com/mchat-rf/>
- Centers for Disease Control and Prevention (CDC) <https://www.cdc.gov/ncbddd/autism/hcp-screening.html>
- Learn the Signs. Act Early https://www.cdc.gov/ncbddd/actearly/index.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Ffactearly%2Findex.html
- Resource on how service providers can support patients and families with ASD: http://barryprizant.com/wp-content/uploads/2015/07/asq16_join_us_on_the_journey_winter_2011.pdf

References:

- adaptions from Laure Swinford's October 13, 2018 WSLHA workshop "Autism Spectrum Disorder: Evidence-Based Assessment and Treatment Recommendations for SLPs
- CDC Screening and Diagnosis of ASD <https://www.cdc.gov/ncbddd/autism/screening.html>
- Why Early Diagnosis of Autism in Children is a Good Thing through posted by Karola Dillenburger, Professor in the School of Education, Queen's University Belfast on The Conversation website <http://theconversation.com/why-early-diagnosis-of-autism-in-children-is-a-good-thing-33290>
- Early Autism Diagnosis: What Parents Need to Know posted by Peg Rosen on Parents website <https://www.parents.com/health/autism/symptoms/importance-of-early-detection-autism/>
- How Early Intervention Can Help Your Child With Autism posted by Lisa Jo Rudy and medically reviewed by Jonathan B. Jassey, DO on very well health website <https://www.verywellhealth.com/early-intervention-for-children-with-autism-260139>
- Early Intervention Makes a Huge Difference for Autistic Children posted on the Autism Spectrum Disorder Foundation website <http://myasdf.org/site/media-center/articles/early-intervention-makes-a-huge-difference-for-autistic-children/>
- Early Diagnosis of Autism and Impact on Prognosis: a narrative review by Elisabeth Fernell, Mats Anders Eriksson, and Christopher Gillberg in Clinical Epidemiology <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3583438/>
- Why is Early Detection and Diagnosis So Important posted on the Lighthouse Autism Center website <https://lighthouseautismcenter.com/infographic-early-detection-diagnosis-autism/>
- Why Timely Diagnosis of Autism is Important posted by Tracy Elliot, Head of Research with Cerebra <https://cerebra.org.uk/research/why-timely-diagnosis-of-autism-is-important/>
- Bringing up a child with disabilities is at least three times as expensive as bringing up other children, a recent study showed parents spend on average greater than \$200 a month out-of-pocket on services <https://pediatrics.aappublications.org/content/143/1/e20180654?download=true>
- High- and Low-Functioning Autism: A False (Harmful?) Dichotomy http://barryprizant.com/wp-content/uploads/2015/07/asq21_high_low_functioning.pdf