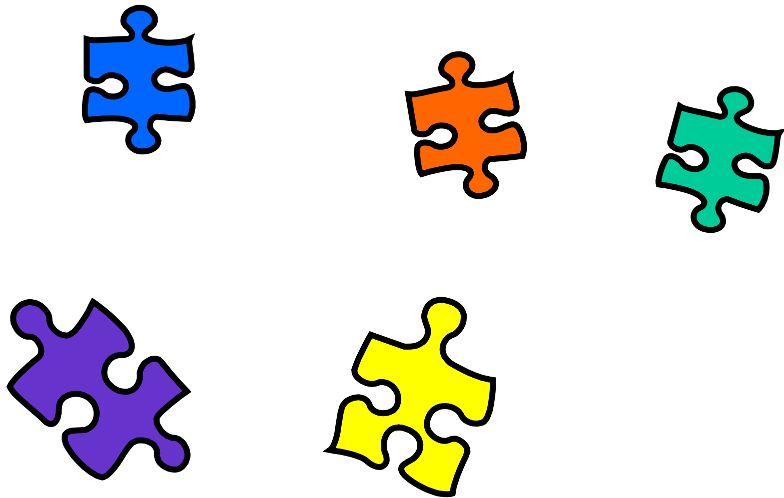
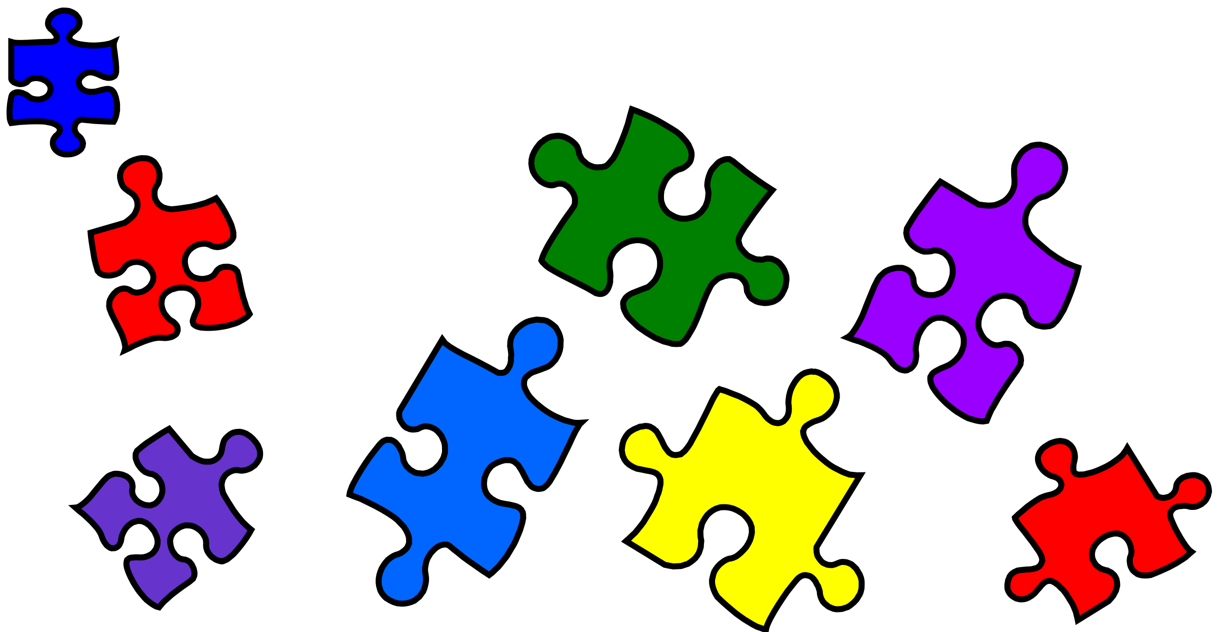


A Parent's Guide to a Diagnostic Evaluation

for a Child With a Possible Autism Spectrum Disorder 2019



Introduction

The Suffolk County Early Intervention Quality Assurance Committee in cooperation with our Preschool Special Education Services Program has developed this ***Parent's Guide to a Diagnostic Evaluation for a Child With a Possible Autism Spectrum Disorder 2019.*** This guide will explain the evaluation process for children who may have an autism spectrum disorder. This guide will help parents or guardians understand what the evaluation process is like, what the evaluator is looking for and what happens after the evaluation. Suffolk County is well known for its long history of outstanding programs serving children with autism spectrum disorders. This reputation is a direct result of Suffolk County's strong commitment to make available an array of services to young children with disabilities as well as to their families.

Effective interventions for young children with autism spectrum disorders emphasize the need for their educational experience to include not only knowledge and skill acquisition, but also concentration on socialization, language and communication, the reduction of problem behaviors and development of adaptive skills. High-quality programs incorporate the family's values, goals and concerns. The role of the service provider is to build on what the family is already doing to support the growth and development of the child.

Developmental research overwhelmingly endorses the key role of parental involvement in treatments for young children. Interventions should support parents and family members as active participants in all aspects of their child's ongoing evaluation and treatments. The providers of service should bring parents timely information about educational philosophies, curriculums and service options.

There are different teaching techniques and environments that will be more effective for some children with autism than for others. It is for this reason that service personnel and families work together to identify and develop quality interventions to address the individual needs of each family. We hope that this ***Parent's Guide to Diagnostic Evaluations for Children with Autism Spectrum Disorders*** will help parents or guardians to understand the diagnostic process for young children who may have an autism spectrum disorder.

Sincerely,

Sheila Ventrice

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Acting Director

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Definitions and Characteristics of Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a condition that impacts an individual's ability to socially communicate with others. It also involves the presence of behaviors that are repetitive in nature. Some children with autism learn to become independent, while others will have significant learning difficulties and will require adult assistance throughout life. This is why it is often viewed as a spectrum of disorders. Some individuals with ASD can speak using many words and complex sentences. Others may present with very limited or no spoken language. The amount of repetitive behavior can also vary greatly.

Below are some of the key features of autism:

Social-Communication Impairment

1. Deficits in social-emotional reciprocity or one's ability to connect with others in a social-emotional manner. This includes failure to initiate and maintain conversation or a back-and-forth social interaction that is expected for an individual's age level.
2. Deficits in nonverbal communication behavior used for social interaction. This can include poorly integrated verbal (spoken language) and nonverbal communication (gestures, facial expression, etc.). There can be abnormalities in eye contact and body language or deficits in the understanding and use of gestures. For those more severely impacted by ASD, there may be a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships. This can include a difficulties adjusting behavior to suit various social situations. It can also include difficulties in sharing imaginative play. At times there could also be the total absence of interest in peers.

Restricted, Repetitive Patterns of Behavior

1. Repetitive motor movements, repetitive use of objects, or repetitive speech. This can also include behaviors such as repetitively lining up objects or toys.
2. Insistence on sameness, inflexible adherence to routines. This includes extreme responses to small changes in schedule or daily routine.
3. Fixated interests or preoccupation in certain topics, objects, or activities.
4. Increased or decreased reaction to sensory input. Examples can include overreacting to certain sounds, smells, or textures. Or not responding to pain in the expected manner.

Additional Diagnostic Information

The symptoms must be present in early development, but the condition may not be fully recognized until the social expectations exceed the individual's limited capacity. The symptoms must cause significant impairment in the child's ability to socialize, engage in leisure activities, or other important areas of life functioning.

Autism Spectrum Disorder will often have accompanying conditions including intellectual impairment, language impairment, and motor impairments. A high percentage of individuals with autism will have accompanying intellectual impairment or what is also referred to as cognitive (intellectual) deficits. The severity of the cognitive deficits is often a strong predictor of a child's

prognosis. In other words, young children with ASD that have average or higher cognitive abilities, often have better outcomes in terms of their future performance at school and other major life functions. Whereas individuals with ASD that have significant cognitive impairments tend to present with more difficulties at school and other life functions.

Table A below reviews typical social responses demonstrated by toddlers and responses (or lack thereof) that are considered “red flags” or symptoms of ASD.

Table A.

Type of Behavior	Example Typical Responses	Example Red Flags for ASD
Eye Contact and Joint Attention	Makes direct eye contact when engaged; will shift eye gaze from item (toy) to the adult in a back and forth manner; responds to name by orienting towards and/or making eye contact with person calling his/her name.	Does not establish natural eye contact or demonstrate shift in eye gaze when engaged with another person. Appears to not hear name being called, although hearing is found to be normal.
Social/Emotional Referencing	When emotions are high the child will reference a familiar person. For example, the toddler falls and gets hurt and immediately looks towards and approaches parent or guardian for comfort.	Even when emotions are high (very excited or upset) the toddler still fails to reference or approach their parent or guardian.
Sharing Interests and Enjoyment	When holding an object of interest such as a toy, the toddler reaches towards the adult as if to give it to them or “share” it. This gesture of sharing occurs in conjunction with eye contact and a shared smile.	Toddler does not reach out to “share” an object of interest. Or the child reaches out but does not make eye contact or share a smile. The toddler may pull parent’s or guardian’s hand toward object for help, but does not make eye contact or share a smile.
Language Directed Towards Others	The toddler directs his/her language towards others by obtaining the other person’s attention and making eye contact. For example, toddler wants a drink, approaches parent or guardian, taps them on leg, looks directly up at parent or guardian, and says “baba”.	Toddler may have very limited to no language. When language is demonstrated it is not directed toward others. For example, the toddler wants a drink, states “baba”, but does not make an attempt to get the parent’s or guardian’s attention.
Play	Toddler plays with toys in an appropriate manner. For example, the child pushes a car as if to make it drive. Toddler pretends to feed a doll.	Toddler spins wheels of the car with his/her finger over and over again. Toddler bangs doll on table in a repetitive manner. Instead of playing with toys, the toddler lines them up.

Diagnostic Evaluations

Early Intervention eligibility and services are established through a comprehensive evaluation process. When a question is raised about a possible Autistic Spectrum Disorder (ASD), the evaluation process becomes more complex.

What is a Diagnostic Evaluation?

A diagnostic evaluation is an assessment to determine if a child has an Autistic Spectrum Disorder. Assessment and diagnosis of a child suspected of having an Autistic Spectrum Disorder (ASD) must include measures of current intellectual, communicative, social and adaptive functioning. The evaluator should present assessment results in a developmental framework detailing the child's abilities, strengths, and current needs. The child's behavior should be observed across a variety of settings and situations. Given the difficulties in social skills and adaptive behavior commonly associated with ASD, detailing a child's behavior among both peers and adults in a variety of situations becomes important for the planning of appropriate intervention.

Who Performs a Diagnostic Evaluation?

Licensed clinical psychologists typically perform diagnostic evaluations for the Early Intervention program. Evaluators should have extensive experience and practice in formal assessment of autism. Other mental health and medical professionals, such as a Licensed Clinical Social Worker (LCSW) are qualified to conduct autism diagnostic evaluations. However, to qualify for specialized services for autism, a child must be diagnosed by an Early Intervention evaluator. Results of outside assessments are reviewed and incorporated into Early Intervention diagnostic evaluation reports.

Who Recommends a Diagnostic Evaluation?

Initial "core" evaluators, service coordinators, Early Intervention Official Designees (EIODs), treatment providers, and parents or guardians can make a recommendation for a diagnostic evaluation.

May a Diagnostic Evaluation be Done Before a "Core" Evaluation?

A diagnostic evaluation should be done only after a general assessment of the child's development has already been completed. The core assessment establishes developmental levels and eligibility for Early Intervention services. A health assessment, often including an audiological examination, is important to identify other conditions that may be associated with autism.

Where Should a Diagnostic Evaluation Take Place?

A diagnostic evaluation may be done in the child's home or in a community setting, such as a special education center or hospital approved as an Early Intervention evaluation site. Evaluations in the home may require preparation, such as arranging for an enclosed space with minimal distractions. These preparations should be requested in advance by the clinician.

Who Attends a Diagnostic Evaluation?
One or both parents or guardians, the child, and the evaluating clinician must be present for the diagnostic evaluation. Other family members (siblings, grandparents) may be incorporated into the evaluation but this should be arranged in advance with the clinician. Other clinicians, the service coordinator, or EIOD may observe the evaluation as well.

What Happens During the Evaluation?
Whether or not a child's age or ability allows for the use of standardized tests, a diagnostic evaluation always contains several *required* components:

- An extended free play observation in a relaxed situation without demands or intrusions, in order to allow the child to adjust to the situation, and to assess the child's spontaneous social engagement with his/her parent, caregiver or guardian and/or examiner.
- Observation of parent/guardian-child interaction patterns.
- Presentation of toys and activities appropriate to the child's developmental level and designed to elicit social, communicative, and play behaviors relevant to the assessment of autism.
- Direct observational assessment of the child's strengths and needs in socialization, functional communication, and play behavior.
- An extensive parent or guardian interview covering the child's socialization, functional communication, and play behavior.
- A diagnostic determination made by the clinician and discussed with parent or guardian post-evaluation.

How Will These Behaviors be Assessed?
The Autism Diagnostic Observational Schedule (ADOS-2) is recommended for children who are ambulatory and who have a mental age above 12 months. Caution must be used in interpreting test scores for children with mental age between 12 and 18 months. The ADOS-2 scoring is based entirely on direct observation of the child during the assessment. Extensive training is needed to learn how to administer the ADOS.

The Child Autism Rating Scale (CARS) or similar rating scale is recommended for use in conjunction with the ADOS-2 for children at least two years of age. Such rating scales provide a structured format for gathering and rating observation and parent or guardian report of the child's behavior on 15 dimensions of autism. If a standardized test cannot be utilized, the evaluator will address all of the required components through parent or guardian interview, clinical observation and interaction with the child.

How is a Diagnosis Determined?
Diagnosis of Autism Spectrum Disorder is based on the criteria in the Diagnostic and Statistical Manual of Mental Disorders: Fifth Edition (DSM-5). Results of formal assessment using the ADOS-2, CARS, or other test instruments and reports adds information to the process of diagnosis, ***but ultimately the decision is based on clinical judgment***, in conjunction with test scores and DSM-5 criteria.

What Happens After the Assessment?
After discussing the results with the evaluator, parents or guardians receive a written report of the diagnostic evaluation. The report is also sent to the EIOD in preparation for the scheduled Individualized Family Service Plan (IFSP) meeting. The report will include the following *required* components:

- Detailed descriptions of data from parent/guardian interview, diagnostic observation, test scores as well as interpretation of all of the above.
- A clearly written diagnostic statement reflecting the results and conclusions of the assessment.
- A statement reflecting that behavioral diagnoses of young children are made with caution and at what point or under what conditions the diagnosis should be reconsidered at a future time.
- Evaluator's and parent's/guardian's perspective on how typical the child's behavior was during the evaluation
- A statement as to the validity of the observational sample as it relates to the diagnostic assessment.
- A statement as to the duration of the assessment.
- A description of the child's strengths and needs in relation to treatment goals, independent of the diagnosis.
- A recommendation for medical follow-up as needed.

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