

# Evaluation Toolkit

FOR FAMILIES OF CHILDREN AWAITING AUTISM DIAGNOSTIC EVALUATION



## Understand WHAT IS AUTISM?

It can feel alarming to parents to hear a healthcare provider express concerns about their child's development and make a referral for an autism evaluation. These feelings are often accompanied by a host of questions: What is autism? What caused it? What would a diagnosis of autism spectrum disorder (ASD) mean for my child's future? How is it treated? On [page 2](#), we answer these frequently asked questions and provide additional resources to further your understanding of ASD.

## Prepare DIAGNOSIS

Currently, we are not able to use genetic testing, magnetic resonance imaging (MRI), or other medical tests to diagnose ASD. Therefore, we must diagnose autism through the observation of a child's behavior and by gaining an understanding of how the child is developing relative to same-aged peers. On [page 4](#), we explain our evaluation process in detail and provide you with some tips and a checklist so you will come prepared.

## Act SUPPORTING YOUR CHILD

We strive to make the process of evaluation as efficient as possible. However, autism evaluations are in very high demand, so families will typically find themselves having to wait for some period of time before a diagnosis can be made. We understand that waiting can be hard, especially when it pertains to the care of your child. Fortunately, there are a number of things you can do to support your child in the meantime. On [page 5](#), we provide a roadmap for you to follow.



## UNDERSTAND

*“If you’ve met one person with autism, you’ve met one person with autism.”*

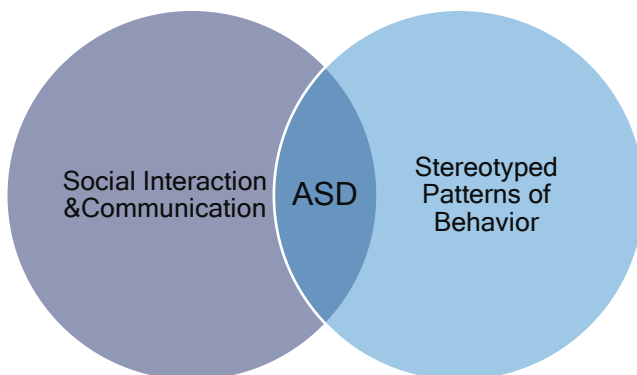
-Dr. Stephen Shore

### WHAT IS AUTISM?

Autism spectrum disorder (ASD) is a neurodevelopmental disorder, marked by deficits in social communication and interaction skills, as well as the presence of repetitive or stereotyped patterns of behavior. ASD symptom presentation and the severity of symptoms varies quite a bit from one individual to the next. A common refrain among members of the autism community is that, “if you have met one person with autism, then you have met one person with autism.” Nevertheless, ASD has some defining features.

### WHAT ARE THE DEFINING FEATURES OF AUTISM?

The American Psychological Association’s *Diagnostic and Statistical Manual of Mental Disorders - Fifth Edition* (DSM-5) specifies that ASD is comprised of two groups of symptoms: (1) deficits in back-and-forth social interaction and communication skills and (2) the presence of restricted, repetitive, or stereotyped patterns of behavior, interests, and activities. ASD is only diagnosed when both sets of symptoms are present.



There are three subcategories of symptoms within the social interaction and communication group. To meet the diagnostic criteria for ASD, an individual must be exhibiting “persistent deficits” in each of the following:

1. Social-emotional reciprocity,
2. Nonverbal communicative behaviors, and
3. Developing and understanding relationships.

To meet the diagnostic criteria for ASD, an individual must also be displaying at least two of the following four subcategories of stereotyped patterns of behavior:

1. Stereotyped or repetitive motor movements (e.g., hand flapping), uses of objects (e.g., lining up toys), or speech (e.g., repeating the same word over and over),
2. Inflexible adherence to routines or ritualized patterns of behavior,
3. Fixated interests (e.g., an all-consuming interest in trains), and/or
4. Sensory sensitivities (e.g., being way over-sensitive to sounds).

### WHAT OTHER FEATURES ARE ASSOCIATED WITH AUTISM?

Though not part of the diagnosis of ASD, there are a number of issues that children with autism may experience.

- Speech delays,
- Balance and motor coordination problems,
- Intellectual disabilities,
- Problems with attention and impulse control,
- Sleep disorders,
- Gastrointestinal problems (e.g., chronic constipation),
- Restrictive eating habits,
- Behavioral problems (e.g., self-harm, tantrums),
- Anxiety or depression, and
- Seizure disorders.

### WHAT ARE THE CAUSES OF AUTISM?

We still have a lot to learn about what causes autism, but there are a few things we know right now. Through identical twin studies, we have learned that genetics are a contributing factor of autism. When one identical twin is known to have autism, the likelihood that the other twin also has ASD is about 77%.

(Continued on page 3)

When compared to the rate of ASD in the general population - which the Center of Disease Control (CDC) currently estimates to be about 1.7% - the above finding clearly indicates that genetics is at play. However, if autism was a purely genetic condition, we would expect the prevalence among identical twins to be 100%. The fact that it is not suggests that other factors in addition to genetics are needed to impact brain development in a manner that results in ASD. Some studies have found correlations between a variety of prenatal and perinatal factors and autism. For instance, the use of certain prescription medications, such as valproic acid and thalidomide, during pregnancy have been associated with increased risk of ASD. Other factors associated with an increased risk of ASD include: certain genetic or chromosomal conditions, such as fragile x syndrome and tuberous sclerosis, and older age of parents. However, it is important to remember that risk factors are not the same thing as causes. We still have more to learn about the causes of autism.

### WHAT WOULD A DIAGNOSIS OF AUTISM MEAN FOR MY CHILD’S FUTURE?

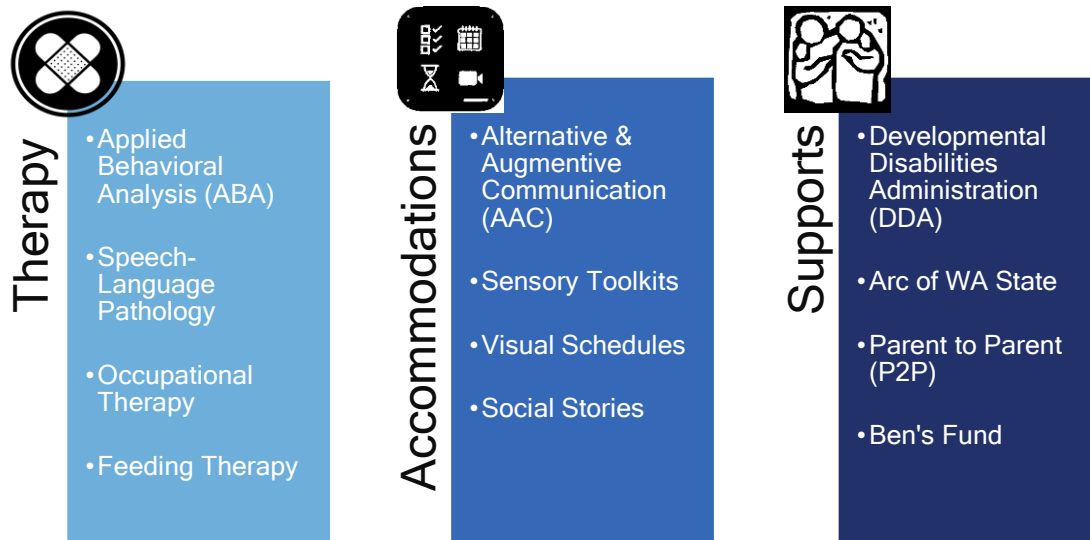
The Americans with Disabilities Act (ADA) defines a disability as “a physical or mental impairment that substantially limits one or more major life activities.” One of the diagnostic criteria for ASD is that “symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning,” (APA, 2013, p. 50). So, by the ADA’s definition, autism is clearly a disability. However Ann Shearer, an international consultant in services to people with developmental disabilities, offers this reminder:

*Just how handicapping the limitation of disability becomes depends either on how well the environment is adapted to the range of people who use it, or on the opportunities they have had to learn to cope with it, or both.*

In other words, with the appropriate services and accommodations, having autism does not preclude a person from developing, learning, gaining independence, or living a happy and fulfilling life.

### HOW IS AUTISM TREATED?

At HopeCentral, we describe care for children with ASD as a three-prong approach. The chart below illustrates this approach and lists examples of care provisions that would fall under each category. Note: This is not a comprehensive list.



### WHERE CAN I FIND OUT MORE INFORMATION ABOUT AUTISM?

Center of Disease Control and Prevention (CDC): Autism Spectrum Disorder  
<https://www.cdc.gov/ncbddd/autism/index.html>

Autism Speaks  
<https://www.autismspeaks.org/>

## PREPARING FOR EVALUATION

Some children are very uncomfortable in unfamiliar environments or are fearful of doctors' offices. Occasionally, we will encounter a child who is so upset that it interferes with our ability to do the evaluation. If you think that your child could potentially react in this way, here are a few things you might try in advance to help:

- **Social Story** - In pictures and words, describe the new experience of an evaluation for your child. Read this story with your child on the days leading up to the appointment. Here is a link to help you with the construction of a social story: <https://www.andnextcomesl.com/2017/03/how-to-write-social-stories.html>
- **Dress Rehearsal** - Schedule a time to come to HopeCentral in advance of your appointment so your child can become familiar with the office and meet our doctors and staff.
- **Positive Reinforcement** - Promise your child a reward for cooperative behavior during the evaluation.



## EVALUATION PROCESS

During the evaluation, our psychologist will collect information about your child's behavior and development through a variety of methods, including: an interview of parents/caregivers, direct observation of your child, review of medical and/or school records, and standardized measures of ASD symptoms and daily living skills. Sometimes, one of our pediatricians will do a physical examination to rule out other genetic syndromes or health issues. In other cases, it may be necessary to do an audiology evaluation to determine whether your child has a hearing impairment. Additionally, we may do a cognitive assessment to determine your child's intellectual abilities.

HopeCentral's diagnostic process starts with a 20-minute phone intake, during which you will be asked a series of questions that will help us with triage. During the phone intake, we will schedule a time for you and your child to come in and meet with either our clinical child psychologist or a psychology intern. The provider will ask you a series of detailed questions and interact with your child. In most cases, further evaluation will be needed and will be scheduled at the conclusion of the first in-person appointment. We will discuss diagnosis and treatment recommendations with you at the conclusion of the evaluation.

## EVALUATION PREP CHECKLIST

- ✓ Complete all questionnaires included with this toolkit.
- ✓ Follow through with referrals (e.g., audiology evaluation).
- ✓ Obtain relevant medical, school, and therapy records.
- ✓ Complete Releases of Information (ROIs).
- ✓ Keep a log of new skills or behaviors.
- ✓ Video record examples of unusual or concerning behaviors.

## SUPPORT ROADMAP:

FOR CHILDREN IN THE EVALUATION QUEUE

