



A Shared Decision Making Tool

For Addressing Concerns about Autism Spectrum Disorder

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About This Decision Aid

This decision aid is for families of young children who may have autism spectrum disorder (ASD). In some cases, caregivers raise concern about autism. In other cases, a score on an autism screening tool may alert a doctor. Regardless, the uncertainty of this time can feel overwhelming. This aid will help you and your doctor discuss next steps for your child.

In this booklet you will:

- Learn the basics of ASD.
- Explore some next steps for your child.
- Compare each option.

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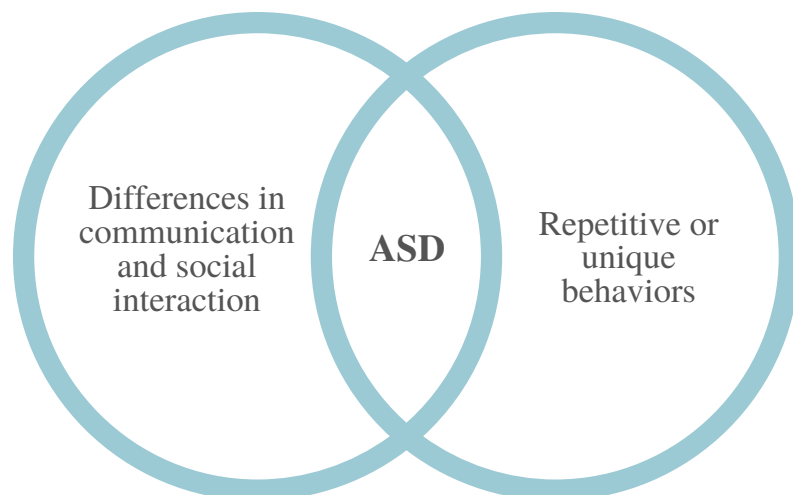
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Autism Overview

What is Autism Spectrum Disorder (ASD)?

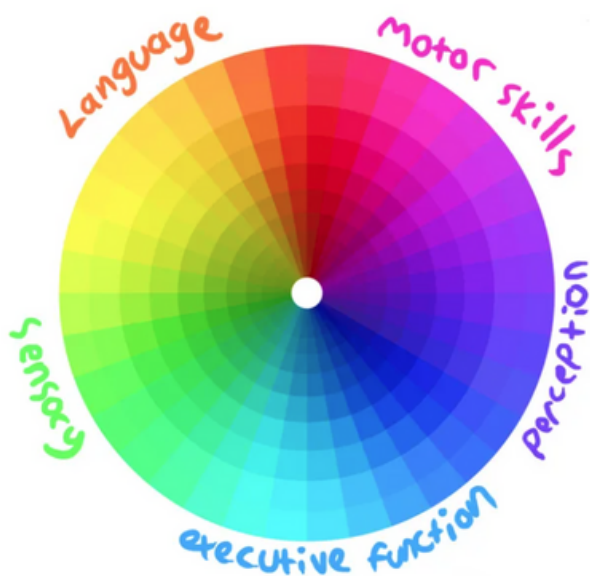
Autism spectrum disorder (ASD) is a disability that impacts development. The two main features of ASD are:

1. Differences in communication and social interaction
2. Repetitive or unique behaviors



What does it mean to be "on the spectrum"?

Some people talk about autistic children as being either "high functioning" or "low functioning." But autistic children have a much broader range of skills and challenges. For example, a child could be "high functioning" in language and motor skills but have some sensory challenges. Because of their broad range of skills and challenges, one child with autism can look quite different from the next.



Courtesy of Rebecca Burgess and The Art of Autism
the-art-of-autism.com

How is ASD diagnosed?

A diagnosis of ASD is made based on the presence or absence of certain behaviors. A specialist will meet with caregivers and ask them about their child's behaviors at home, school, and in other settings. The specialist will also try to see how the child behaves and interacts through a series of guided play activities.

What are some signs of autism?

Every child with autism will have some differences in how they communicate and interact with others, compared to their non-autistic peers. They will also show some repetitive or unique behaviors. But, the exact nature of these differences and behaviors will vary from one autistic child to the next. Below are some examples of behaviors an autistic child might have.

Differences in Communication and Social Interaction

- Differences in nonverbal communication (eye contact, facial expressions, or gestures)
- Trouble relating to others
- Differences in back-and-forth conversations

Repetitive or Unique Behaviors

- Lining up objects
- Flapping hands
- Saying the same word over and over in the exact same way
- Insisting on doing things in a particular way or order
- Very strong and specific interests
- Strong reactions to light, sound, taste, smell, or touch

Write any other behaviors of your child that you would like to tell your doctor:



Expectations about how a child behaves vary from one culture to another. In some cultures, children are expected to point by a certain age. In others, pointing is discouraged because it is seen as rude.

Frequently Asked Questions About ASD

What causes ASD?

Autism is largely a genetic condition. Environmental factors likely play a role as well. We still have a lot to learn about what may contribute to ASD. However, we do know a few things for sure...

Myth: Autism is caused by certain vaccines.

Fact: No studies have found any relationship between vaccines and autism. This myth came from a study that was found to be fraudulent.

Myth: Cold or distant parenting causes ASD.

Fact: There is no relationship between parenting practices and ASD.

Can autism be cured?

We understand autism to be a neurological difference — that is, a life-long difference in one's brain that cannot be changed or "cured." While we cannot change an autistic child's brain, there are a number of therapies that are available that can help autistic children to develop, learn, and function. Here are some examples:

- Speech-language pathology
- Occupational therapy
- Applied Behavioral Analysis (ABA) therapy
- Naturalistic Developmental Behavioral Interventions (NDBI)

NOTE: Learning is easiest when you are young. Studies have shown that therapies for autistic children make the biggest impact when they are started during early childhood.

What does the future look like for a child diagnosed with ASD?

All children develop at their own rate and to their own degree. We cannot ensure an outcome or predict the future for a child. What we can do is provide opportunities. With evidence-based therapies and doing the hard work of parenting at home, we provide our children with the chance to learn and grow.

Next Steps

At this time, your child may not have been given any diagnosis. But, there are a number of things that you can do as next steps.

In the following pages, we will discuss six possible next steps. Each have their pros and cons. You and your provider can discuss which options will work best for your family.

1. Watchful Waiting
2. Autism Diagnostic Evaluation
3. Part C: Early Support for Infants and Toddlers (ESIT)
4. Addressing Co-Occurring Issues
5. Combined Approach



WATCHFUL WAITING



Description

Watchful waiting means you choose to delay starting therapies or the autism diagnosis process. Instead, you and your doctor will keep an eye on how your child is developing.

Benefits ✓

- You do not have to spend money.
- You can always change your mind and get an assessment or start active treatment at any time in the future.

Downsides ✗

- You lose time. Autistic children tend to have better results with early intervention.
- Your child may fall further behind in development as they miss future developmental windows.

AUTISM DIAGNOSTIC EVALUATION



Description

An evaluation will clarify if your child is autistic. If the examiner diagnoses your child with ASD, they will suggest specific next steps.

Benefits ✓

- A diagnosis provides clarity for your family.
- The more you understand your child's particular needs, the better you can help them.
- Certain services for ASD are only accessible with a diagnosis.

Downsides ✗

- There are long wait times to get an autism diagnosis. It is recommended to get on a waitlist as soon as possible.

What if I don't want to label my child?

A diagnosis does not change anything about your child. It only means that they will have more opportunities to get the help they need. A diagnosis is also private. It stays between you and your doctor.

Part C: Early Support for Infants and Toddlers (ESIT)



Description

Part C: ESIT is a publicly funded early intervention program. ESIT aims to help families support their children's health and development. After an assessment, ESIT providers will work with your family. This could include therapies, gaining a support system, or learning skills to support your child. Services are available until your child's third birthday.

The most frequent services are...

Developmental Services and Individual Education	Speech and Motor Therapy
Feeding Therapy and Nutrition Services	Occupational and Physical Therapy

About 1 of every 8 children has a challenge with development that makes them eligible for ESIT.



Benefits ✓

- No medical diagnosis needed
- Short wait time for assessment and services
- Low cost and covered by Medicaid
- Many options for personalized care
- Your family can learn skills to meet your child's needs.

Downsides ✗

- Services may not be offered in preferred language other than English.
- Can be time-intensive

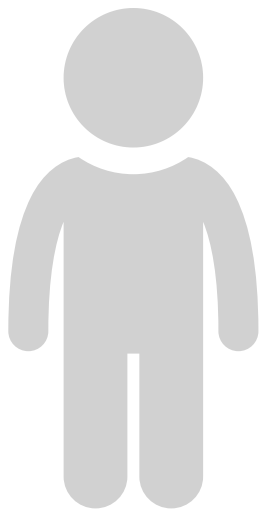
ADDRESSING CO-OCCURRING ISSUES



Description

The possibility of ASD in children is sometimes brought up after caregivers raise concerns about "co-occurring" issues. These are issues that are not symptoms of autism but are more common in autistic children than in the non-autistic children. You may see the co-occurring problem as the most urgent thing to address. Below are some examples of co-occurring issues in autistic children.

Check the boxes if these apply to your child:



- Wandering off
- Difficult sleep patterns
- Stomach issues
- Meltdowns
- Selective eating
- _____



Benefits

- You can work with your primary care provider.
- Treatments for these concerns can lead to meaningful short-term improvement.
- Low cost



Downsides

- Does not directly address concerns with development

COMBINED APPROACH



Description

You can always choose a combination of options for your child. For example, you could seek ESIT services and managing health issues. In the meantime, you could wait for an autism diagnosis for your child.

Benefits ✓

- You maximize potential benefits and minimize downsides.

Downsides ✗

- Pursuing multiple options can be overwhelming.

Sample Plan Using the Combined Approach:

Enroll in ESIT
Services



Address Co-occurring
Issues



Schedule Autism
Evaluation



Compare Options

	Reasons to Choose This Option	Reasons to Avoid This Option
Watchful Waiting	<ul style="list-style-type: none">• Lowest cost	<ul style="list-style-type: none">• You lose time. Child may fall further behind in development.
Autism Diagnostic Evaluation	<ul style="list-style-type: none">• Can access more services• Can better understand child's condition	<ul style="list-style-type: none">• Long wait time
ESIT	<ul style="list-style-type: none">• No diagnosis needed• Offers support for navigating your child's needs	<ul style="list-style-type: none">• May not be offered in your preferred language• Can be time-consuming
Addressing Co-Occurring Issues	<ul style="list-style-type: none">• Addresses immediate concerns• Can work with your primary care provider	<ul style="list-style-type: none">• Does not address the root issue
Combined Approach	<ul style="list-style-type: none">• Maximize benefits and minimize risks	<ul style="list-style-type: none">• Can be overwhelming

1) What are your family's goals for your child for the next year?

2) What are your family's goals for your child for the next ten years?

3) What do you love about your child?

4) What matters to you? (Rank each from 1-5)

Cost	Time requirement	Getting clarity	Managing symptoms and behaviors	Gaining a support system
_____	_____	_____	_____	_____

5) Do you have any questions about the options in this booklet?

6) Do you have any other ideas for your child that you want to discuss with your doctor?

7) Which option(s) are you leaning towards? (Circle all that apply)

Watchful Waiting	Autism Diagnostic Evaluation	ESIT Services	Addressing Co-Occurring Issues	Combined Approach
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8) How sure are you about your decision?

Not Sure at All Somewhat Sure Extremely Sure

9) What would you need to feel confident about the next steps you take?
