What if my health care provider indicates that I need a follow-up visit with a specialist?

Your health care provider is simply telling you that your child needs a more formal evaluation to learn more about how he or she is learning to talk, interact, act, play, learn, and move. This will be a much longer visit. It is typically done by a specialist in the area of child development, but may involve several different specialists.

What sort of specialist? There are many routes to a formal evaluation.

- You can request an evaluation by public Early Intervention and Education offices. The contact information for these offices changes depending on where you live, but can be found on the Autism Speaks website.

- Another route would be a developmental health assessment by a pediatrician, psychologist, neurologist, or other specialist. This may or may not be covered by insurance, but you should get a referral from your primary care provider to be safe.

- You may also be referred to a private allied health specialist like a speech therapist, occupational therapist, or physical therapist who can evaluate your child.

Many parents choose to follow multiple routes at the same time. For the most part though, information in this tool kit pertains to evaluations that are provided by the public health and education systems.
What are my rights?

Unfortunately, it is common for families to have to wait weeks or months before seeing a specialist. While you are waiting for an appointment with a specialist, there are some things that you may want to know:

The following piece is “time critical” as early intervention services through the public education or health system are only available until age three in most states.

If your child is **under the age of 36 months**:  
- He or she is entitled to an evaluation through your state’s office of Early Intervention, also referred to as “Birth to Three” or “Part C.”
- Federal law requires the local early intervention agency to perform a free assessment to determine if any child has a disability.
- The agency is required to complete an initial evaluation no later than 45 days after receiving written consent from you to assess your child.

If your child is **36 months or older**:  
- He or she can receive an evaluation through the school district.
- Federal law requires the local education agency to perform a free assessment to determine if any child between 36 months and 21 years of age has a disability.
- The initial evaluation must be completed no later than 60 days after receiving written consent from you to assess your child.

What does the typical evaluation through the early intervention system look like?

Once your child is referred, your early intervention office will assign an initial service coordinator to work with you and your family. He or she will talk with you about your concerns about your child’s development. The coordinator will also review your family rights, make sure you understand them, and help you arrange for your child’s evaluation.

If your child’s evaluation shows that he or she is eligible for the state’s early intervention program, your initial service coordinator will set up a meeting to work on your Individualized Family Service Plan (IFSP), a written plan for providing early intervention services to your child. The job of your initial service coordinator is to help you with all the steps leading up to your first IFSP meeting.

The IFSP is a very important document, and you, as parents, are important members of the team that develops it. At your IFSP meeting, you may want to be prepared to discuss how you describe your child to others, what you need help with, and what you’d like more information about.
What are the costs?

Evaluations and assessments by the state early intervention or education department are provided at no cost to parents. They are funded by state and federal funding. In terms of services for your child, whether or not you will have to pay depends on the policies of your state. Services that must be provided at no cost to families include: Child Find services, evaluations and assessments, development and review of the Individualized Family Service Plan (IFSP), as well as service coordination.

Depending on your state’s policies, you may have to pay for certain other services. You may be charged a “sliding-scale” fee, meaning the fees are based on what you earn. Check with the contact person in your area or state. Some services may be covered by your health insurance or by Medicaid. Every effort is made to provide services to all infants and toddlers who need help, regardless of family income. Services cannot be denied to a child just because his or her family is not able to pay for them.

What sort of assessments will my child receive?

Your health care provider may also provide referrals for an evaluation or additional testing, which may or may not be covered by insurance. Here are some important points to remember:

- An audiological assessment (hearing test) referral should be made for all concerns regarding speech, language, or hearing difficulties. This is usually done by an audiologist.
- A cognitive evaluation (or developmental assessment) using standardized tests that measure both verbal and nonverbal abilities should be performed by a psychologist or other professional experienced in testing children.
- A medical and neurological evaluation may need to be conducted to assess such issues as acquired brain injury, seizure disorder, self-injury, and sleep or eating disturbances.
- A speech-language-communication evaluation should be performed on all children who have communication difficulties. This is done by a speech-language pathologist or psychologist.
- An evaluation of sensorimotor skills by a physical or occupational therapist should be considered when a child demonstrates difficulties in how he or she moves or in sensory responses, as part of the diagnostic, cognitive, medical, or speech evaluation.
- If your health care provider sends you to a specialist for a diagnostic assessment of autism, you will receive a written report of the results of your child’s evaluation. This should also include information on your child’s strengths and weaknesses, as well as general level of developmental functioning.

What can I do while I’m waiting?

Fortunately, there are a number of actions you can take while you wait for a formal evaluation or services. Below is a list of suggested activities:

1. **Be persistent.** You may try calling the office or clinic again to see if an appointment opens up sooner. If there is a research study in your area that offers diagnosis and evaluation services, consider participating.

2. **Learn more about developmental delays** and services and treatments available to help your child. This will help you develop a list of questions for the specialist and prepare you to take action if your child is diagnosed with autism or another developmental disability.
3. **Know what to expect.** Your child may have to complete one or more cognitive or “thinking skills” tests, and you will be asked questions about your child’s behavior and development. In addition, you’ll probably fill out one or more “checklists.” In all, the evaluation will take at least several hours and more than one appointment to complete.

4. **Gather information.** It is recommended to put together a folder with your child’s medical records and any previous developmental or behavioral evaluations your child has received. Bring your notes on your own observation of your child’s behavior in different places and with different people.

5. **Arrange to bring someone with you.** Many parents find the process emotional. Rather than go it alone, consider who you can ask to come with you to help you take notes on what was said and help you make sure your questions get answered.

6. **Prepare to get your child’s intervention started.** Even if your child is not diagnosed with autism, the evaluation may reveal developmental delays that would benefit from intervention. The professionals conducting your child’s evaluation can provide you with phone numbers and guidance. You can also find contact information for local services in the Autism Speaks Resource Guide at [www.autismspeaks.org/resource-guide](http://www.autismspeaks.org/resource-guide).

7. **Playtime is important, as all children learn through play.** Playtime is particularly important because it encourages something called **joint attention.** During play time:

   - **Use objects or interests that will motivate your child.** This may be Thomas the Tank Engine, a specific activity, or a topic of interest. Children are more likely to respond if the activity includes something they are interested in.
   - **Face to face is best.** Get down on your child’s level. This encourages communication because it’s easier for him or her to connect with you.
   - **Follow your child’s lead.** Play with what your child is interested in. Notice your child’s cues. Look to see where your child is looking and try playing with that toy. Use your child’s preferences to help motivate him or her to play and interact.
   - **Imitate your child.** Try making sounds after your child does, and playing how your child plays. Most children will also start to imitate you after you spend some time imitating them, which is great for learning!
   - **Take turns with your child.** This back and forth will help your child learn to interact socially. This will also serve as a foundation that will help your child start to watch and learn from you.
   - **Use simple language.** If your child isn’t speaking yet, try speaking to your child using single words to help him or her understand. If your child uses some words, try speaking in short phrases. This will help him or her understand you.
   - **Continuously check to ensure that the routine is motivating to your child.** The more he or she is engaged and motivated, the more rewarding this time will be for both of you.

Don't be discouraged if these strategies don’t work right away! Many children require very specialized treatment in order to maximize their learning. Once you are able to connect with a professional, he or she can provide you with advice specific to your child.