

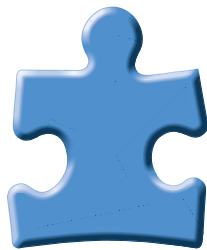


Autism Speaks®

**SCIENCE AND
FAMILY SERVICES**

First Concern to Action Tool Kit





AUTISM SPEAKS®
It's time to listen.

Autism Speaks does not provide medical or legal advice or services. Rather, Autism Speaks provides general information about autism as a service to the community. The information provided in this toolkit is not a recommendation, referral or endorsement of any resource, therapeutic method, or service provider and does not replace the advice of medical, legal or educational professionals. Autism Speaks has not validated and is not responsible for any information or services provided by third parties. You are urged to use independent judgment and request references when considering any resource associated with the provision of services related to autism.





First Concern to Action Tool Kit

If you have a concern about how your child is communicating, interacting, or behaving, you are probably wondering what to do next. The information provided in this tool kit can help you sort that out. The First Concern to Action Tool Kit was developed to provide families of children under the age of five with:

- An overview of early childhood development;
- Guidance on what to do if you have a concern about your child's development;
- Information about obtaining an evaluation for your child's development and treatment options, if needed.

It can be scary to think there might be something different going on with your child's development, but you are not alone. The purpose of this tool kit is to provide you with specific resources and tools to help guide you on the journey from your first concern to action. Not all concerns result in a diagnosis of autism or a specific developmental disability, but being proactive can make a world of difference. It is important to remember that you know your child best. If you are concerned at any time, voice it!

The information here or on any website should not replace a conversation with a health care provider and an observation by an expert in child development. Your child is special, and deserves any help he or she might need to reach his or her full potential.

Here are four things you can do right now if you have a concern:

1. Don't wait. If you ever have concerns, talk to your health care provider. A health care provider can be your pediatrician, family doctor, community health care worker, specialist, or a trusted, knowledgeable, professional in your community.
2. Prepare for your conversation with your health care provider. See what other children the same age are doing and note how your child is different. Take notes about your child's development based on the milestones included in this kit to prepare yourself for a visit with your health care provider.
3. Start the intervention process right away. Your child can receive a free evaluation even without a formal diagnosis by contacting the Early Intervention services through your state. You can find the contact information on the Autism Speaks website.
4. If you need help, contact the Autism Speaks Autism Response Team by calling 1-888-288-4762, (in Spanish: 1-888-772-9050), email familyservices@autismspeaks.org or text ART to 30644.

■ The [blue text](#) indicates a link that you can click on for additional information.





About Autism

Autism Spectrum Disorder (ASD) and autism are both general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by differences in the way a person interacts with other people, or communicates using language or gestures (like eye contact or pointing). People with autism may also behave in unusual ways, such as getting upset when things change, staring at toys, or waving their arms. When a child has challenges in these areas, autism may be considered. Autism appears to have its roots in very early brain development, and the reasons why some children have autism and others do not are not well understood. This kit will also provide you with more information about autism, its signs, and treatment options.

Many strides have been made in understanding autism in recent years. Studies demonstrate that signs of autism emerge as early as six to 12 months. We now have effective tools for screening children for autism risk as early as one year of age. Diagnosis can be made by age two. Despite these strides however, the average age of diagnosis is typically after age four. A later diagnosis may delay the start of the services and supports that can help teach a child better ways of communicating, interacting, playing and learning.

Earlier diagnoses and interventions have been shown to improve outcomes for children with autism. That is why it is so important to learn about child development, so that you are able to recognize areas of concern if they arise, and act on them right away.





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Section I: Understanding Your Child's Development

What should I know about my child's development?

Every child develops differently, particularly in the first five years of his or her life. However, there are certain milestones that a typically developing child is expected to reach by certain ages. The list below will help you determine if your child is achieving these milestones:

By 3-4 months

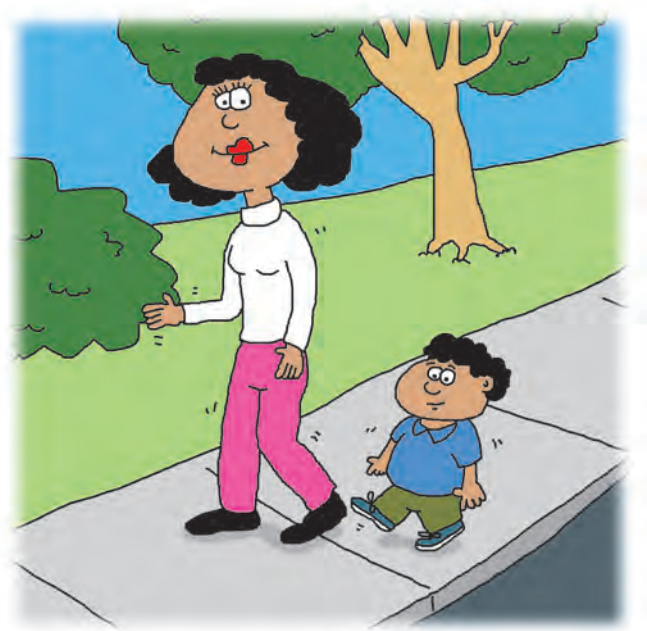
- Watches faces with interest and follows moving objects
- Recognizes familiar objects and people
- Smiles at the sound of your voice
- Turns head toward sounds

By 7 Months

- Responds to other people's emotions
- Enjoys face-to-face play
- Can find partially hidden objects
- Explores with hands and mouth
- Struggles for out of reach objects
- Responds to own name
- Uses voice to express joy and displeasure
- Babbles chains of sounds

By 12 Months/1 Year

- Enjoys imitating people and tries to imitate sounds
- Enjoys simple social games, such as "gonna get you!"
- Explores objects and finds hidden objects
- Responds to "no"
- Uses simple gestures, such as pointing to an object
- Babbles with changes in tone
- May use single words ("dada", "mama", "uh-oh!")
- Turns to person speaking when his/her name is called



**Find developmental milestone checklists
for your child's age at**
www.cdc.gov/milestones.com.





By 24 Months/2 Years

- Imitates behavior of others
- Becomes excited about company of other children
- Understands several words
- Finds deeply hidden objects
- Points to named pictures and objects
- Begins to sort by shapes and colors
- Begins simple make-believe play
- Recognizes names of familiar people and objects
- Follows simple instructions
- Combines two words to communicate with others, such as “more cookie?”



By 3 Years

- Expresses affection openly and has a wide range of emotion
- Makes mechanical toys work
- Plays make-believe
- Sorts objects by shape and color and matches objects to pictures
- Follows a two- or three-part command
- Uses simple phrases to communicate with others, such as “go outside, swing?”
- Uses pronouns (I, you, me) and some plurals (cars, dogs)
- Shows interest in group play



By 4 Years

- Cooperates with other children
- Is increasingly inventive in fantasy play
- Names some colors
- Understands counting
- Speaks in sentences of five to six words
- Tells stories
- Speaks clearly enough for strangers to understand
- Follows 3-part commands
- Understands “same” and “different”



By 5 Years

- Wants to be like his/her friends
- Likes to sing, dance, and act
- Is able to distinguish fantasy from reality
- Shows increased independence
- Can count 10 or more objects and correctly name at least 4 colors
- Speaks in sentences of more than five words and tells longer stories





When should I be concerned?

One of the most important things you can do as a parent or caregiver is to learn the early signs of a developmental disability and become familiar with these milestones.

Here is a list of some "red flags" that may suggest a risk for a developmental delay or possible neurodevelopmental disorder such as autism:

- No big smiles or other warm, joyful expressions by six months or thereafter
- No back-and-forth sharing of sounds, smiles or other facial expressions by nine months
- No babbling by 12 months
- No back-and-forth gestures such as pointing, showing, reaching or waving by 12 months
- No words by 16 months
- No meaningful, two-word phrases (not including imitating or repeating) by 24 months
- Any loss of speech, babbling or social skills at any age
- No response to name by 12 months

If your child is showing any of these, or is not meeting any of the milestones by the age listed, don't panic. Reach out to your pediatrician or family health care provider and let them know about your concern. To prepare for talking with your child's health care provider, note what milestones your child has or has not yet reached compared to other children his or her age.

Before or during the visit, ask for a general developmental screening. If you are worried that it could be autism, you can also fill out an autism screener and bring the results to your health care provider visit.

Another very useful resource is the Autism Speaks Video Glossary, a tool designed to help parents and professionals learn more about the early red flags and symptoms of autism. The glossary contains over one hundred video clips and is available free of charge. If you have access to the internet, please visit www.autismspeaks.org/what-autism/video-glossary to learn more.



From www.cdc.gov/milestones:





Section II: Talking to Your Health Care Provider

How do I talk to my health care provider about my concerns?

Call your health care provider and tell him or her that you would like to make an appointment because you are concerned about your child's development.

Bring the milestones checklist with you and include specific examples. If you or the health care provider thinks there might be a delay, ask for a general developmental screening and an autism-specific screening. If either of you still concerned, ask for a referral to a specialist who can do a more in-depth evaluation. While you wait for the referral, you can also call your state's public Early Intervention office to find out if your child qualifies for services.

You should maintain a trusting relationship with your health care provider. If you have questions, ask them. Bring the MCHAT and any notes with you at the visit so he or she can understand your concerns more.

What typically happens during this visit?

Your health care provider will conduct a developmental screening. The American Academy of Pediatrics has published recommendations on what happens during a typical "well-child" visit. These well child visits, even if your child is not sick, are necessary.

A developmental screening is conducted to see if your child is learning basic skills when he or she should, or if there might be delays. The health care provider might ask you some questions or talk and play with your child during an exam to see how he or she learns, speaks, behaves, and moves. If your child shows delays in a particular area of development, it does not mean that he or she will meet the criteria for a particular diagnosis. This screening simply provides a useful way to identify the potential risk of developing differently.

According to the American Academy of Pediatrics, all children should be formally screened for developmental delays and disabilities during regular well-child health care provider visits at nine months, 18 months, and 24 or 30 months. Additional screening might be needed if a child is at high risk for developmental problems due to preterm birth, low birth weight or other reasons.

There are many types of formal screening tools for developmental delay. Some will be questions for you to answer, and others will be answered based upon what your health care provider observes. Some examples of general developmental screeners are the Communication and Symbolic Behavior Scales (CSBS), the Parents' Evaluation of Developmental Status (PEDS), and the Ages and Stages Questionnaire (ASQ). The Easter Seals has an online ASQ that you can take [online](#).





You may also be asked to have your child's hearing tested with an audiology exam. Hearing loss can affect a child's ability to develop communication and social skills. A hearing test is usually a part of the screening process, and if hearing loss is found, autism may be ruled out.

What is an autism screening?

The American Academy of Pediatrics (AAP) recommends that all children receive autism screening at 18 and 24 months of age, and the Modified Checklist of Autism in Toddlers (M-CHAT) is one of the AAP's recommended tools. The M-CHAT™ is a scientifically validated checklist of questions used for screening children between 16 and 30 months of age to assess their risk for autism spectrum disorder.

The M-CHAT called a "screener" because it is designed to identify those children who need to be referred for a full evaluation. There is a possibility your child may screen positive on the M-CHAT but will not be diagnosed with ASD. This is why it is important to follow up with your health care provider.

How do I prepare for the visit to my child's health care provider?

Before you go to your appointment, fill out the M-CHAT found at the end of this tool kit and bring it to your health care provider. There is also a list of general questions about your concerns that you can complete and bring with you. Your health care provider will ask about these concerns, and it may help determine next steps by thinking specifically about these concerns.

If the M-CHAT screener indicates your child has some signs of autism, it will be important to complete the second step of the screening, the M-CHAT Follow Up interview. The health care provider will need to ask you some additional questions in person to do this. Not all children who show signs of autism after the first step will have autism. For some children, this screener also picks up other developmental delays, like talking late, that also need to be sorted out to see if extra help is needed.



It is important to remember that you know your child best. If you are still concerned after your visit with your health care provider, you may follow-up independently even without a referral and get a second opinion. You can do so by contacting the local birth to three agency listed at the end of the tool kit. If your child is over the age of three, you can contact your local school district and request a formal evaluation.





Section III: Getting a Formal Evaluation

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.



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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](http://www.autismspeaks.org/resource-guide) at 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.

What is **joint attention**?

It is the shared focus by two people on the same object. It can happen when an adult and a child are looking at the same object, and includes a shared interest or back and forth. Research has shown improved joint attention during infancy is an important part of later communication skills

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.





Section IV: What if My Health Care Provider Says “Autism”?

The first time you hear “autism” will likely be a devastating moment. Hopefully the more you read and understand about autism *before* you hear the word, the more you will be prepared for what to do next. In May of 2013, the American Psychiatric Association redefined the criteria for how someone is diagnosed with autism. While the details may have changed, the nature of autism spectrum disorders is still the same. The new definition describes a range of conditions which include problems in social communication and the presence of stereotyped, repetitive behaviors. These behaviors can be hand flapping or “stimming” or lining up objects in an unusual way. For someone to be diagnosed with autism, he or she must show problems in both social communication AND repetitive behaviors. These behaviors may be seen in the past, or may be part of the current symptoms.



Step 1: Act early

If your child has been recently diagnosed with autism, you are probably feeling very overwhelmed. But there are tons of resources out there for you and your family, and those resources and supports are growing every day! The Autism Speaks 100 Day Kit is a good place to start. The 100 Day Kit was created to help you make the best possible use of the 100 days following your child’s diagnosis. It contains information and advice collected from trusted and respected experts on autism and parents like you.

For a free copy of the 100 Day Kit, contact the Autism Speaks Autism Response Team by calling: 1-888-288-4762, (in Spanish: 1-888-772-9050), emailing familyservices@autismspeaks.org, or texting ART to 30644. The Autism Response Team (ART) is specially trained to connect people with autism, their families, and caregivers to information, tools, and resources. ART can connect you with local services and provide tools and resources to help guide you in the right direction. The Autism Response Team is always happy to help!

Why is it important to act early?

Early attention to improving the core behavioral symptoms of autism will give your child – and the rest of your family – several important benefits. Among other benefits, a good early intervention program will:

1. Build on his or her strengths to teach new skills and improve areas of weaknesses. Early intervention is a way to teach your child some things that he or she may need extra help learning. For example, using words to talk, playing with other children, or dealing with changes.
2. Provide you with information that will help you better understand your child’s behavior and needs.
3. Offer resources, support, and training that will enable you to work and play with your child more effectively.
4. Improve the outcome for your child.

If your child receives a diagnosis, reach out for services as soon as you can. It is never too early to act on your concerns or to reach out for help!





Step 2: Access early intervention services

Early intervention services can vary widely from state to state and region to region. However, all services should address your child's unique needs and should not be limited to what is currently available or customary in your region.

Early intensive behavioral intervention involves a child's entire family working closely with a team of professionals. In some early intervention programs, therapists come into the home to deliver services. These services can include parent training with the parent leading therapy sessions under the supervision of the therapist. Other programs deliver therapy in a specialized center, classroom or preschool.

Depending on your child's needs, his or her early intervention services may include, among others:

- Family training, counseling, and home visits
- Speech, occupational, and physical therapy
- Audiology services (hearing impairment services)
- Psychological and medical services
- Social work services
- Assistive technology devices and services
- Adaptive equipment
- Nutrition services
- Health services needed to enable your child to benefit from other services

What early intervention therapies are currently available and do they help?

Scientific studies have demonstrated that early intensive behavioral intervention improves learning, communication and social skills in young children with autism. While the outcomes of early intervention vary, all children benefit.

Researchers have developed a number of effective early intervention models. They vary in details, but all good early intervention programs share certain features. They include:

- Structured therapeutic activities for at least 20 hours per week
- Highly trained therapists and/or teachers delivering the intervention
- Specific and well-defined learning objectives, and regular evaluation and recording of the child's progress in meeting these objectives
- A focus on the core areas affected by autism, including social skills, language and communication, imitation, play skills, daily living, and motor skills
- Opportunities for your child to interact with typically developing peers
- Active engagement of parents, both in decision-making and the delivery of treatment
- Therapists' respect for the unique needs, values, and perspectives of the child and his or her family
- A multidisciplinary team that can include a physician, speech-language pathologist, occupational therapist, physical therapist, and other professionals.

Objective scientific studies have confirmed the benefits of two methods of comprehensive behavioral early intervention: the Lovaas Model based on [Applied Behavior Analysis](#) (ABA) and the [Early Start Denver Model](#). Parents and therapists also report success with other commonly used behavioral therapies, including [Floortime](#), [Pivotal Response Therapy](#), and [Verbal Behavior Therapy](#). For more information, see the "[Treatment and Therapies](#)" chapter of the [100 Day Kit](#), or the treatment section of the [Autism Video Glossary](#).

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Step 3: Monitor progress

Develop a plan with your EI provider focused on skills that your child has, and where you want your child to be in the next month to a year. Determine the best way to track whether or not he or she is moving in the right direction. Intervention for autism needs to be flexible and individualized. Each child with autism is unique and special and should not be treated the same. Some interventions are focused on particular skill sets like joint attention; others cover multiple developmental domains. The important part of early intervention is that it is evidence-based. You can learn more about the latest research on behavioral interventions on the Autism Speaks website.



What can I do when my child is not getting intervention?

Some of the strategies or skills that are taught in the clinic by your child's therapist may be able to be brought home. This time shouldn't be used to replace what is happening by a trained behavioral therapist, speech or occupational therapist, or other expert. However, it is important that skills be taught in natural environments and incorporated into daily activities. Talk to your therapist or early intervention specialist about ways you can work together with your child. Research has shown that this extra time will likely improve the outcome and definitely give you the opportunity to take part in your child's therapy.

Based on researcher recommendations, the Association for Children and Families has put together a guide to help parents facilitate development every day. This guide can be found at www.acf.hhs.gov/ecd/ASD. The major themes include:

1. Engaging your child in play through joint attention
2. Using your child's interests in activities
3. Using a shared agenda in daily routines
4. Using visual cues
5. Sharing objects and books
6. Teaching your child to play with each other
7. Using predictable routines and predictable spaces for your child





Section V: Other Things to Know

Do children or adults diagnosed with autism ever move “off the spectrum”?

Growing evidence suggests that a small minority of people with autism progress to the point where they no longer meet the criteria for a diagnosis. Various theories exist as to why this happens. They include the possibility of an initial misdiagnosis, the possibility that some children mature out of certain forms of autism, and the possibility that successful treatment can, in some instances, produce outcomes that no longer meet the criteria for an autism diagnosis.

We do know that significant improvement in autism symptoms is most often reported with intensive early intervention. We also know that with proper supports in place, all people with autism are able to go on to live fulfilling lives, as independently as possible. As autism awareness continues to grow, the amount of interventions and resources available for individuals on the spectrum is increasing at a rapid rate. Coupled with the great strides being made in autism research, these new resources are allowing people with autism of all ages to see positive outcomes in all areas of life. And you can be sure there is much more to come!

Visit www.autismspeaks.org for more helpful tips, tools and resources for you and your family as you journey down this new road together.





What if it isn't autism? What now?

It is impossible to list all the things it “could be” here. This is why it is important to get a full workup, including an audiology exam. Don't be afraid to keep asking questions and checking back with your health care provider. Don't give up on getting your child help.

You know your child better than anyone. If your health care provider does not respond to your concerns, seek additional help. What you see may not be autism, but if you are concerned, it is probably something.

In May 2013, a new diagnosis emerged from the Diagnostic and Statistical Manual of Mental Disorders or DSM-5. This is the standard set of criteria used to diagnose autism. It is called “Social Communication Disorder.” The goal of this new diagnosis is to more accurately recognize individuals who have significant problems using verbal and nonverbal communication for social purposes, leading to impairments in their ability to effectively communicate, and limits their function in daily life. The main difference between SCD and autism is that individuals with SCD do not exhibit restricted or repetitive behaviors involving his or her body or other objects. The symptoms must be seen early in life, but may not become evident until someone is older.

If your child has problems communicating socially, it may be too soon to tell if your child has autism or SCD. You should talk to your health care provider about the difference and what it means.

Most importantly, continue to keep track of milestones, impairments in functioning, and behaviors that are of concern to you. They will be helpful in obtaining an accurate diagnosis and documenting progress.

Autism Speaks would like to sincerely thank the following people who contributed significantly to this tool kit:

- | | |
|-------------------|--------------------|
| ■ Danielle Gunkel | ■ Reginald Lee |
| ■ Tracey Hellner | ■ Elizabeth Martin |
| ■ Gia Kaleel | ■ Colleen Shin |

The information in this tool kit was partially adapted from the CDC's “Learn the Signs, Act Early” Campaign.

More information can be found at www.cdc.gov/actearly

NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES

Learn the Signs. Act Early.





Information to bring to your health care provider:

Answer the questions below to help you discuss the concerns you have. You should also fill out the M-CHAT so you can discuss the results with your child's health care provider. Bring all of these things with you to the appointment.

What are your concerns?

When do you see these concerns?

Has anyone ever told you they have concerns about your child? If so, what have they said?

Does your child exhibit any unusual behaviors? If so, what are they?

Do you think your child hears well? If not, explain.

How many words does your child have? Do you understand what he/she says?

Does your child have any medical problems? If so, what are they?





Modified Checklist for Autism in Toddlers (M-CHAT)

The M-CHAT is validated for screening toddlers between 16 and 30 months of age, to assess risk for autism spectrum disorders (ASD). This completed form should be brought to your health care provider. The questions can be scored in less than two minutes using instructions found on www.mchatscreen.com. A trained professional can discuss the responses and guide you to find the right resource. These 23 questions should be accompanied by a follow-up interview which will clarify some of the responses.

Please fill out the following about how your child **usually** responds. Please try to answer every question. If the behavior is rare (e.g., you've seen it once or twice), *please answer as if the child does not do it.*

1. Does your child enjoy being swung, bounced on your knee, etc.?	Yes	No
2. Does your child take an interest in other children?	Yes	No
3. Does your child like climbing on things, such as up stairs?	Yes	No
4. Does your child enjoy playing peek-a-boo/hide-and-seek?	Yes	No
5. Does your child ever pretend, for example, to talk on the phone or take care of a doll or pretend other things?	Yes	No
6. Does your child ever use his index finger to point, to ask for something?	Yes	No
7. Does your child ever use his/her index finger to point, to indicate interest in something?	Yes	No
8. Can your child play properly with toys (e.g., cars or bricks) without just mouthing, fiddling, or dropping them?	Yes	No
9. Does your child ever bring objects over to you (parent) to show you something?	Yes	No
10. Does your child look you in the eye for more than a second or two?	Yes	No
11. Does your child ever seem oversensitive to noise? (e.g., plugging ears)	Yes	No
12. Does your child smile in response to your face or your smile?	Yes	No
13. Does your child imitate you? (e.g., you make a face-will your child imitate it?)	Yes	No
14. Does your child respond to his/her name when you call?	Yes	No
15. If you point at a toy across the room, does your child look at it?	Yes	No
16. Does your child walk?	Yes	No
17. Does your child look at things you are looking at?	Yes	No
18. Does your child make unusual finger movements near his/her face?	Yes	No
19. Does your child try to attract your attention to his/her own activity?	Yes	No
20. Have you ever wondered if your child is deaf?	Yes	No
21. Does your child understand what people say?	Yes	No
22. Does your child sometimes stare at nothing or wander with no purpose?	Yes	No
23. Does your child look at your face to check your reaction when faced with something unfamiliar?	Yes	No

How to score the M-Chat. Please score 1 point if you answered "no" to questions 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 12, 13, 14, 15, 16, 17, 19, 21 or 23, or if you answered "yes" to 11, 18, 20 and 22. If the total score was 3 or higher, your child needs a Follow – Up Interview with your provider or a health care professional. Even if you answered "no" to just two or more of questions 2, 7, 9, 13, 14, 15, you should also ask your health care provider to administer the Follow-up Interview. These are considered critical items of the M-CHAT. Even if your scores are below 3 for the total score, and below 2 for the critical questions, and you still have concerns, bring this completed form and your questions to your provider for a more in depth evaluation or referral.

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Sample letter to health care provider

Dear health care provider:

I have concerns about my child's development and have filled out the M-CHAT, or Modified Checklist for Autism in Toddlers. The M-CHAT is a screening tool that has been endorsed by the American Academy of Pediatrics (AAP) to be administered at 18 and 24 months.

The M-CHAT is a screening tool, and because no screening tool is perfect, research recommends that the original 23 questions include a Follow-Up Interview. Because this is a screener, it identifies some indication of autism, and the M-CHAT Follow-Up is an important next step. This interview will help us sort out if we should consider a more in-depth developmental evaluation. Whether my child has autism, another developmental disability, or is considered to be developing typically, I have some concerns and trust you to help me sort them out. My family wants to do all we can to support our child's development.

A guide to administering the Follow-Up Interview can be found at www.mchatscreen.com. I am happy to answer any of the questions that need further discussion. For your convenience, I am bringing the Follow-Up Interview diagram with me to help you clarify the questions that are of concern. Only those questions which indicate a flag for concern need further query.

Thank you for your time with my family.





AUTISM SPEAKS®
It's time to listen.

Have more questions or need assistance?
Please contact the Autism Response Team for
information, resources and tools.

TOLL FREE: 888-AUTISM2 (288-4762)

EN ESPAÑOL: 888-772-9050

Email: FAMILYSERVICES@AUTISMSPEAKS.ORG

WWW.AUTISMSPEAKS.ORG

Text Art to 30644





Our Mission

At Autism Speaks, our goal is to change the future for all who struggle with autism spectrum disorders.

We are dedicated to funding global biomedical research into the causes, prevention, treatments, and cure for autism; to raising public awareness about autism and its effects on individuals, families, and society; and to bringing hope to all who deal with the hardships of this disorder. We are committed to raising the funds necessary to support these goals.

Autism Speaks aims to bring the autism community together as one strong voice to urge the government and private sector to listen to our concerns and take action to address this urgent global health crisis. It is our firm belief that, working together, we will find the missing pieces of the puzzle.



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